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**IGNITING THE DIABETES SELF-CARE PILOT LIGHT:
UNDERSTANDING INFLUENCES
ON HEALTH ACTIVATION**

A thesis presented in fulfillment of the requirements for the degree of
Doctor of Philosophy

**MASSEY UNIVERSITY
PALMERSTON NORTH
NEW ZEALAND.**

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2011

Acknowledgements

I have been fortunate to have been supported by many people throughout the course of this study and thesis writing. I am greatly appreciative to all of them for putting up with me and for offering encouragement and inspiration. I am especially grateful to the participants in this study who so generously shared their experiences and perceptions in the hope that what they expressed may help others.

Thank you to my three supervisors, Professor Jenny Carryer, Associate Professor Tim Kenealy and Dr. Stephen Neville who so freely offered their expertise and wisdom throughout my course of study. All had complementary skills and qualities which were so readily shared throughout the different stages of the research. As primary supervisor, Professor Jenny Carryer provided exceptional scholarly guidance and unfailing encouragement. Associate Professor Tim Kenealy provided excellent guidance in planning and executing the study, in particular expert advice on statistical testing and reporting. Dr. Stephen Neville provided sound guidance, critique and critical challenge throughout the research and writing processes. I must also acknowledge the Eli Lilly Research scholarship and a grant from NZNO which provided me with the ability to fund aspects of this research.

Thank you to my colleagues and friends at MidCentral Health who contributed support, advice and time. In particular Victoria Perry who kept me focused in amongst the competing demands of my full time employment, local and national professional commitments and doctoral studies; and Sue Wood, Director of Nursing whose brilliance and leadership inspires me to be the best I can be. I am especially grateful to my husband Gary who has endured being second place while sustaining me with a ready supply of love, cups of tea and chocolate. My mother and sisters have all offered unfailing encouragement and nurturing which kept me on track.

Approval to conduct the study was obtained from the Central Region Ethics Committee and Massey University Human Ethics Committee prior to commencing the study (CEN/07/06/036).

Abstract

Diabetes presents a serious health challenge for New Zealand because it is a significant cause of ill health and premature death. It is well recognised that self-care in diabetes, can be demanding and is influenced by numerous factors. Health activation is a composite notion focusing on four major elements believed to influence active engagement in self-care: these are beliefs, knowledge, skills and confidence, and behaviours. In this study I set out to elicit an understanding of influences on diabetes-related health activation in general, and specifically to provide explanations for how diabetes-related distress and/or health professional communication and decision-making styles impact on health activation. An additional aim was to generate new ideas on how diabetes care can be structured to maximise personal resourcefulness and promote health activation.

Mixed methods methodology allowed for a pragmatically structured research approach. In particular the use of both quantitative and qualitative methods ensured that participants' perceptions were comprehensively explored. Two hundred and twenty participants completed a semi-structured questionnaire and eighteen participated in a subsequent interview.

Health activation was found to be dynamic and influenced by many factors. Diabetes-related distress and health professional communication and decision-making styles explored in this study were important contributors to health activation. This information has complemented and expanded knowledge of these constructs and has extended understanding on relationships between them. In particular it has generated knowledge about health activation, diabetes-related distress and health professional communication and decision-making styles specific to the New Zealand context.

Preface

My interest in influences on diabetes-related health activation grew from considering how I, as a nurse, help a person with diabetes to live and care for their diabetes in a way that is not overwhelming, is constructive, and contributes towards positive health outcomes. Some people with diabetes seem able to accommodate the changes to their lifestyle without any disruption to their lives or to those around them, while others live with a constant struggle.

Diabetes is a pathologically complex long term condition, where people with diabetes are burdened with the responsibility for providing the majority of care to manage their condition, and the demands of this can be overwhelming. Juxtaposed with this is the requirement for the contribution of the multidisciplinary team “as co-morbidities interact to produce a complex and challenging clinical dynamic” (Grumbach, 2003, p. 5). No one discipline alone can meet the health needs of people with diabetes. Nurses, doctors, dietitians, podiatrists, obstetricians, paediatricians, psychologists, and others all have a role to play. However, this can create difficulties for the person with diabetes who may be seeing multiple health professionals in a variety of settings.

Over the past 20 odd years I have met and been engaged in therapeutic partnerships with many people with diabetes. I have repeatedly observed people who have had diabetes for many years who have not previously been active participants in their care, suddenly become more active, more interested and focused on improving their situation. Each time I have been unable to determine what has contributed to this change in focus, or more importantly perhaps, what has stopped it from happening before. Those who have been aware of the change in focus have articulated that ‘something’ changed and they ‘woke up’ to the need to be more actively engaged in self-care. A variety of responses have been offered when I have asked, as part of a routine clinical consultation, what precipitated their change? For some it was the diagnosis of a non reversible diabetes related complication; for others it was a similar diagnosis in someone else; some described struggling emotionally with the requirement of the daily self-care demands; and others expressed that

they had seen a different doctor or nurse with whom they ‘clicked’ and it was the way they interacted with them that had made the difference.

Reflecting on these responses led me to consider the ways in which care is provided for people with long term conditions, in particular diabetes and, the vast number of health professionals and ‘helpful others’ encountered by people with diabetes on their health seeking journey. Over the years I have formed impressions about what the focus for the person with diabetes may be when interacting with various health professionals. For the person with diabetes it may not necessarily be on ‘fixing something’, but rather: ‘how can I keep doing what I need to do?’; or ‘what is an approach to this that will help me to sustain my efforts?’; or ‘talk to me in a way that I understand and that respects me?’; or ‘share information with me that my family and I can understand and use in my daily decision-making about how to best care for myself’; or ‘acknowledge that I am a person with life issues and that these issues may be greater than my concerns about my diabetes that doesn’t actually bother me day to day’.

On the other hand, I am acutely aware that health professionals are faced with the challenge of determining what might assist the person with diabetes to effectively self-care in the midst of conducting their assessment, making diagnoses, care planning and evaluating care/treatment effectiveness - all within the limits of consultation timeframes.

As health professionals have limited opportunities to spend any length of time with a person with diabetes, consideration for that person’s world view, their specific beliefs and circumstances influencing their life choices is imperative to make the time effective. Nursing espouses holism - but is it practised? And if it is, does it make a difference to how actively engaged a person is with their diabetes self-care?

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Introduction

Diabetes presents a serious health challenge for New Zealand. It is a significant cause of ill health and premature death. Type 1 diabetes occurs at any age however is more common in young people and New Zealanders of European descent, with approximately 5% prevalence among other ethnic groups (Joshy & Simmons, 2006). With an estimated 15,000 people in New Zealand with type 1 diabetes, it accounts for approximately 10-15% of the known diabetes incidence in New Zealand. Consistent with world wide trends, the prevalence of type 1 diabetes is increasing by 3% annually (Willis, Raizis, Darlow, Scott, & Beaven, 2006) despite there being no association with modifiable risk factors (e.g. obesity, low physical activity levels and smoking) such as is the case for type 2 diabetes.

Prevalence figures estimate the number of people with known type 2 diabetes to be 125,000 and this is predicted to rise by 45% throughout the decade of 2001-2011 to 180,000 (Ministry of Health, 2007). The prevalence of diagnosed type 2 diabetes differs among ethnic groups with Maori (5-10%) and Pacific Island adults (4-8%) compared with New Zealand Europeans (3%), and Asian origin (4%). Of concern, about two thirds of the predicted growth in type 2 diabetes reflects non-modifiable demographic trends (such as age, ethnicity and genetic profile) and only the remaining third reflects projected growth in obesity prevalence (Ministry of Health, 2008).

Overview of Diabetes

Diabetes is complex in nature being a disease of primarily glucose intolerance, due to either an absolute or relative insulin deficiency, thereby impacting on normal metabolic processes essential for glucose homeostasis (Katsilambros & Tentolouris, 2003). Both nerve fibres and small (micro) and large (macro) blood vessels can be damaged by persistently elevated blood glucose levels leading to many other potential complications. Microvascular complications associated with diabetes include retinopathy (eye disease leading to blindness), nephropathy (kidney disease leading to kidney failure and dialysis), peripheral neuropathy (nerve disease leading to anaesthetic and/ or painful extremities), autonomic

neuropathy (nerve disease leading to postural hypotension, erectile dysfunction in men and dry vagina in women, diarrhoea, constipation and/or vomiting, urinary incontinence and more). Macrovascular complications include cardiovascular disease leading to heart disease, peripheral vascular disease leading to poor circulation and cerebrovascular disease leading to stroke. Lipid metabolism is also abnormal and potentially atherogenic, increasing risk of macrovascular complications. Because of this higher risk of macrovascular disease, coexisting cardiovascular risk factors such as hypertension, dyslipidaemia and smoking must always be treated aggressively (Katsilambros & Tentolouris, 2003). As a consequence, maintaining a complex self-care regimen which almost always includes polypharmacy, is commonly required for the multiple co-morbidities, further impacting on the burden of disease.

In type 1 diabetes, insulin producing cells in the pancreas are destroyed by the body's immune system resulting in an absolute deficiency in endogenous insulin. The person with type 1 diabetes therefore requires exogenous (injected) insulin from diagnosis and for the remainder of their life. As type 1 diabetes can present from an early age, a longer duration of disease leads to longer exposure to elevated blood glucose levels with therefore, an increased likelihood of developing micro or macrovascular disease at an earlier age. Furthermore, the duration of living and coping with the demands of diabetes at a younger age presents its own special challenges potentially increasing the burden of disease.

Type 2 diabetes occurs most commonly in people over the age of 40 and accounts for 89% of all known diabetes in New Zealanders of European descent, with a much higher incidence in Maori and Pacific Island people (Joshy & Simmons, 2006). Indeed, according to the Ministry of Health (2008) Maori and Pacific peoples have approximately 2.5 times the risk of developing type 2 diabetes during their lives compared with New Zealand Europeans, and on average develop diabetes 10 years earlier. Furthermore, Maori and Pacific peoples tend to develop complications of diabetes more frequently and at earlier ages than NZ Europeans (Ministry of Health, 2008).

Type 2 diabetes is characterised by disorders of both insulin action and insulin secretion (Katsilambros & Tentolouris, 2003) with several carbohydrate, protein and lipid metabolism changes. In lean older adults, insulin deficiency appears to predominate over insulin resistance. On the other hand, obese older adults with diabetes have significant insulin resistance and relative insulin deficiency (Meneilly, 2001; Roos & Samos, 2002). Initially the management of type 2 diabetes is focused on modifiable risk factors such as diet, smoking cessation, regular physical activity and optimum blood pressure control, in addition to achieving optimum blood glucose levels. However, as type 2 diabetes is known to be a progressive disease, pharmacological therapies are recommended early to achieve target blood glucose levels (United Kingdom Prospective Diabetes Study [UKPDS] Group, 1998; Nathan et al., 2009). With a multifaceted approach, the pharmacological management of diabetes and related conditions is potentially complex, with the goal of treatment to aim towards normoglycaemia, while minimising the risk of hypoglycaemia and avoiding adversely affecting quality of life (Nathan et al., 2009). Other medications required to treat and/or minimise microvascular and macrovascular disease associated with diabetes over time typically include aspirin, statins (and/or other lipid lowering agents), angiotension converting enzyme (ACE) inhibitors or angiotensin receptor blockers (ARBs) and other anti-hypertensive medications.

Glycaemic control is most commonly determined by measuring HbA_{1c} values. The HbA_{1c} value reflects the average blood glucose over the preceding three months and is widely accepted as a reliable and valid index of glycaemic control (MedlinePlus, 2010). Achieving and maintaining an HbA_{1c} of below or around 7% (IFCC HbA_{1c} 53 mmol/mol) (American Diabetes Association, 2010; Diabetes Control & Complications Trial [DCCT] 1993; Nathan et al., 2009) is essential for long term good health and avoidance of complications.

Self-care of Diabetes

Diabetes is considered to be a relatively unique long term condition due to treatment regimens being carried out largely through self-care. Indeed, Anderson et al. (1995)

estimate that 95% of required care is provided by the person with diabetes and/or their family. This is supported by the findings of a large public health survey on people with a long term condition which states that of the potential 8760 hours in one year, on average only three hours is spent with a health professional, leaving the person with 8756 hours to care for themselves (United Kingdom National Health Service, 2007). As such, people with diabetes influence the course of their health and wellness by their level of active engagement in self-care activities.

Self-care or Self-management

The literature surrounding self-care and self-management inconsistently uses the term self-care interchangeably with self-management. Self-monitoring is also a term utilised particularly in diabetes care and is defined by The Joslin Diabetes Clinic as “managing one’s diabetes by checking blood glucose, and being aware of food intake, physical activity and medication and how each of these elements work together in order to keep blood glucose in good control” (The Joslin Diabetes Clinic). According to Curtin, Sitter, Schatell, and Chewning, (2004) self-management is defined as “the positive efforts of patients to oversee and participate in their health care in order to optimise health, prevent complications, control symptoms, marshal medical resources, and minimize the intrusion of the disease into their preferred lifestyles” (p. 379). The New Zealand National Health Committee’s (NHC) (2007) description implies self-management to be an intervention. It states self-management:

provides support for people to have greater control in managing their chronic condition through understanding their condition, being able to monitor and take appropriate action on it, and address areas of their life affected by their condition. Self-management actively involves people with chronic conditions in care planning, forming partnerships between the person, health professionals and the community. (p. 19)

Bycroft and Tracey (2006) refer to self-care as more individualistic in nature as opposed to self-management which occurs in partnership with health care providers. Self-care has been defined by Connelly (1993) as “behaviors to promote health, prevent illness, and treat and cope with health problems” (p. 248) and later by Weinger, Butler, Welch, and La Greca (2005) as “the daily regimen tasks that the individual performs to manage diabetes” (p. 2). Pertaining to heart failure Riegel, Carlson, and Glaser (2004) provide the following description of self-care which includes a management process:

Self-care involves a process of maintaining health through positive health practices, and managing illness and disease. Self-care is performed in both healthy and diseased states, although patients with a chronic illness, such as heart failure, engage in self-care primarily to manage what may be a precarious balance between relative health and symptomatic heart failure. That management process involves cognitive decision making undertaken in response to signs and symptoms. (p. 5)

As well as cognitive decision making processes, self-care also extends to behavioural and emotional responses required to preserve highest quality of life (Schilling, Grey, & Knafl, 2002). While the above description of self-care is more comprehensive and could be applied equally to other long term conditions, for diabetes signs and symptoms may not drive the cognitive decision making to the same degree due to the insidious nature of diabetes, where people are not necessarily symptomatic of hyperglycaemia. The United Kingdom Department of Health (2007) utilise the term 'self-care' to include both self-care and self-management. Within their description of self-care, the individual takes responsibility for their health and well-being in the broadest sense. This includes staying fit and healthy, proactively preventing illness and treating minor and long term conditions. Thus these definitions imply that self-care (or self-management) is about more than adhering to treatment regimens but also requires incorporation of the psychological and social management of living with a chronic illness (Newman, Steed, & Mulligan, 2004). In addition the complexity of living with a disease like diabetes is captured and suggests there

is a need for diabetes to be controlled in the context of an individual's life (Schilling et al., 2002). Patients' views of self-care have been identified by Chambers, Wakely, and Blenkinsopp (2006) as including practical elements and attitudes or beliefs. From the patients' perspective the practical elements included: taking care of your own health; doing your own research; finding alternatives and fine tuning what works for you; entertaining your mind; and relating to others with a similar condition. Attitudes and beliefs included: taking responsibility and making your own decisions; and having confidence.

While it appears that authors frequently utilise the terms self-care and self-management interchangeably, there are also some important distinctions. For example, self-care tends to be characterised by a sociological view of the self focusing on managing and coping with illness whilst acknowledging the complexity of life; whereas self-management implies more of a biomedical view of the self with an emphasis on performing certain tasks and the attainment of goals usually determined by health professionals (Greenhalgh, 2009). Consequently, for this thesis the term 'self-care' will be utilised preferentially as an overarching term to reflect both the notion of an individual taking an active role in their own health care, and the wide range of self-care activities required of people with diabetes to maintain optimal health and wellness. These self-care activities occur both on an individual level and in partnership with health professionals whilst encompassing the full context of their lives.

It is well recognised that self-care in diabetes and other long term conditions, can be demanding and is influenced by numerous factors (Siguroardottir, 2005). Previous research indicates that people with long term conditions experience many different barriers to self-care. These include physical limitations, lack of knowledge, financial difficulties, low self-efficacy, unsatisfactory communication with health professionals, a need for social support, depression and difficulties with multiple medications (Bayliss, Ellis, Steiner, & Main, 2005).

A substantial body of literature is directed towards understanding self-care behaviour. There are a number of theoretical models or approaches for understanding behaviour

change associated with self-care, with some focusing on compliance or adherence, others on empowerment or patient centeredness. These include but are not limited to: the patient empowerment model (Funnell et al., 1991); the self-determination model (Deci & Ryan, 1985); the health belief model (Becker, 1974) ; the social cognitive model (Bandura, 1997); the theory of reasoned action (Fishbein & Ajzen, 1975); and the transtheoretical stages of change (Prochaska & DiClemente, 1983). Many of these theories or models of behaviour change focus on one dimension, such as health beliefs, self-efficacy, knowledge, attitudes, or skills. These one dimensional approaches do not necessarily result in behaviour changes leading to integration of diabetes self-care activities into every day life (Fisher et al., 2005). Rather, it is purported that a critical element of effective self-care is ‘activated’ patients, who have the capability and motivation to participate as effective health care team members (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997).

Health activation is considered to be a multi-dimensional concept incorporating knowledge, skills, health beliefs and behaviours. Patient activation has been a term found in the literature over recent years but until recently a conceptual definition of ‘activation’ was not clearly articulated. Following a rigorous process Hibbard, Stockard, Mahoney, and Tusler (2004) developed the following conceptual definition of ‘health activation’ in patients:

Those who are activated believe patients have important roles to play in self-managing care, collaborating with providers, and maintaining their own health. They know how to manage their condition and maintain functioning and prevent health declines; and they have the skills and behavioural repertoire to manage their condition, collaborate with their health provider, maintain their health functioning, and access appropriate and high quality care. (p.1010)

Hibbard et al. (2004) purport that health activation is developmental in nature with four stages from 1) the patient requiring fundamental knowledge about their condition and possessing a belief that active involvement is important; 2) feeling confident that they can

follow through on treatment recommendations; 3) taking action to maintain lifestyle changes and having confidence they can cope with new problems or situations; and 4) staying on course even when under stress. It is suggested that because health activation is developmental, interventions can be tailored to an individual's stage of activation (Hibbard et al., 2004). Therefore, an 'activated' patient capable of consistently carrying out effective self-care, is considered a critical component of the diabetes care package. A full account of the development of the conceptual definition, the implications of the stages, validity of the Patient Activation Measure and its potential for application will be addressed in the literature chapter to follow.

Failure to achieve biochemical targets increases the risk of complications from diabetes (Diabetes Control & Complications Trial Group [DCCT], 1993; Home, 2005; Nathan et al., 2009; Retnakaran & Zinman, 2008; UKPDS Study Group, 1998). However, achievement of optimal blood glucose levels is often difficult despite active self-care, as many people with diabetes require multiple non-pharmacological and pharmacological interventions, further complicating treatment and challenging a person's self-care capabilities. This was illustrated in the DCCT (1993) where only 5% of a carefully selected and medically well-supported group of people with type 1 diabetes in the nine year multi-site DCCT, maintained an average HbA_{1c} of 6.5% or below through the course of the study.

Because achieving optimal glycaemic control requires multiple interventions, diabetes presents individuals with an "especially daunting array of behavioural challenges" (Heisler, Bouknight, Hayward, Smith, & Kerr, 2002, p. 243). Indeed, several patients in the DCCT who were not successful in achieving glycaemic goals also appeared to have higher levels of diabetes treatment-related frustration and emotional distress associated with lack of success in achieving target blood glucose levels (Weinger & Jacobson, 2001). Emotional and attitudinal barriers may then become insurmountable obstacles to improved blood glucose control and to maintaining a high level of health activation.

Acknowledgement of emotional distress is considered to be important in the development and maintenance of therapeutic relationships (Polonsky et al., 2005). Spencer et al. (2006)

suggest diabetes-related-emotional distress is often considered the ‘elephant in the living room’ by people with diabetes and their family. Instead the focus from health professionals is perceived to be on the physiological aspects of diabetes or the behaviour changes that need to occur to achieve optimal glycaemic control, with the psychological aspects of living and coping with the ongoing demands of self-caring of diabetes often paid little attention. Compounding this, the way health professionals communicate information and involve people with diabetes in decision-making are potentially important influences on active engagement and therefore on health outcomes. The potential for diabetes-related emotional distress is discussed further in the literature review chapter to follow.

Diabetes Care in New Zealand

The New Zealand Health Strategy (Ministry of Health, 2000) provides an overall framework for the health sector and the delivery of care. This includes a framework for national funding, monitoring and supporting the 21 District Health Boards established by the New Zealand Public Health and Disability Act (2000) to deliver high quality diabetes care to the people within their districts. The key goal of the New Zealand Health Strategy is to ensure that inequalities in health status cease to exist and appropriate and accessible services are available to all New Zealanders, especially for Pacific Island and Maori people and people from low socio-economic groups. Therefore, the identification of diabetes as one of the thirteen priority health objectives in the New Zealand Health Strategy was an important impetus for many initiatives and was well received by the diabetes lay and health care communities.

In December 2003 the National Guidelines Group published guidelines on the management of type 2 diabetes to provide an evidence-based summary of best practice. The guidelines aimed to support decision-making by health professionals particularly in primary health care services, i.e. general practice teams. These guidelines were the first comprehensive collection of evidence based care pathways for diabetes care for people with type 2 diabetes and have since provided much needed guidance for primary health care clinicians. They have also provided a tool for people with type 2 diabetes to develop an awareness of the

level of care they should expect and the rationale or evidence behind treatment recommendations, thereby enabling them to participate in their health care decision making more actively.

The “Get Checked Programme” was launched by the Ministry of Health in the year 2000 to provide a mechanism for people with diabetes in New Zealand to improve access to regular review, and to support the provision of a systematic and standardised approach to screening for diabetes-related complications. The programme entitles people who have been diagnosed with type 1 or type 2 diabetes to a free annual health review, carried out by their general practitioner or an appropriately trained registered nurse. The purpose of the annual health review is to ensure completion of assessments and systematic screening for complication risk status or identification, and to assist with care planning. The review comprises measurement of cholesterol/lipids, weight, height, body mass index (BMI), blood pressure, smoking status and microalbuminuria/creatinine ratio measurements, annual foot screening, bi-annual retinal screening and, importantly, HbA_{1c} level. The intention is that a plan of care for the year is then developed and agreed between the patient and the care provider.

In New Zealand, the majority of care for type 2 diabetes is provided by general practice teams supported by guidelines. In some areas, such as the MidCentral District Health Board, a small number of nurses have received additional training in diabetes care and can support the general practice team by providing a medium level of diabetes care. Referrals to specialist nursing and medical services are made for consultation and/or for episodic care as the complexity of their health care needs increases. People with type 1 diabetes generally receive the majority of their diabetes-related care from specialist diabetes teams, in collaboration with the general practice team. Upon referral from their primary health care provider, the person with diabetes receives assessment and care by either a diabetes specialist physician or a diabetes nurse practitioner only, by a diabetes nurse specialist only, or a combination of both. In addition, dietetic and podiatry services are usually available within the specialist multidisciplinary team.

A plethora of literature exists on potential interventions and programme developments focusing on increasing capability for self-care, including increased adherence to prescribed pharmacological and non-pharmacological treatment regimens. However, a recent Cochrane review of twenty one studies aimed at improving adherence to treatment recommendations for people with type 2 diabetes could not conclude whether any intervention is effective (Vermeire et al., 2006). Internationally, there are several ‘chronic care’ programmes or models of care designed with the aim to improve health care for people with long term conditions such as diabetes, respiratory and cardiovascular disease. For further information on the chronic care models and their various and variable implementations, Singh and Ham (2006) provide a useful and comprehensive review of United Kingdom and international frameworks. Some have been implemented to varying degrees in New Zealand with the goal of providing a structured approach to assess and improve care processes and health outcomes. Despite the variances, conceptually this is an important shift in thinking on how diabetes care and other long term conditions should be provided, especially in the primary health care setting which has traditionally responded to acute health needs. Indeed, Bodenheimer, Wagner, and Grumbach (2002) describe this as the “tyranny of the urgent” (p. 1775) where brief and episodic visits occur focusing most often on acute symptoms and the patient’s associated worries. Little time is available for the less pressing need for planning of care to ensure optimal management of the long term condition.

Collaborative Care

Collaborative management of care, as defined by Von Korff et al. (1997), is “care that strengthens and supports self-care in chronic illness while assuring that effective medical, preventative, and health maintenance interventions take place” (p. 1097). Collaborative care emerged in response to a move towards a more active partnership between health professionals and the person with an illness. This was advanced by increased availability to health information and the trends towards consumerism in modern society (Elwyn, Edwards, & Kinnersley, 1999). Potter and McKinlay (2005) provide an informative overview of the 20th century theoretical notions of the patient-doctor relationship in

America, such as: the physician as authority figure; asymmetry; the growth of patient status, and status loss for both physicians and patients as a result of medical reforms and the introduction of managed care programmes. During the 21st century further changes occurred to health professional roles from a focus on acute illness with an emphasis on curing, to a focus on caring for people with long term conditions with an emphasis on surveillance, palliation, or preventing or prolonging decline.

According to May (2005) patients and health professionals in the United Kingdom (UK) began complaining about what they saw as “objectification of experiences of illness” (p. 15). People with long term conditions began to envisage themselves as “alienated not simply from decisions about the trajectories of their treatment, but also from their own bodies and lives” (p. 15). Health care systems were historically designed to treat acutely ill and generally passive patients over the short term and it became clear that health services delivered with a predominantly biophysical focus did not meet the needs of people with long term conditions. Instead, the emphasis changed within the therapeutic relationship to respect both the expert in medicine and the expert in how the disease manifests in daily life (Clark et al., 2008). However, it appears that this may not always be played out in practice and that the “experiential expert remains a largely untapped resource” (Thorne, Paterson, & Russell, 2003, p. 1350).

Increasing evidence suggests individuals who are actively involved in their own health care are likely to achieve better health outcomes (Bodenheimer, Wagner, et al., 2002; Lorig et al., 1999; Von Korff et al., 1997) and measurable cost savings (Glasgow et al., 2002). Improved health outcomes have also been linked to individuals collaborating on care and participating in shared decision making about their care or treatment regimens (Glasgow et al., 2002). Furthermore, Paterson (2001a) concluded that collaborative partnerships between health professionals and individuals with long term conditions were necessary for an individual’s active participation in decision-making about the management of their diabetes.

The delivery of health services encompasses a broad range of disciplines, for example nursing, medicine, public health, professions allied to medicine, health promotion, and many others. In particular, diabetes care most often occurs within the context of the multidisciplinary team and nurses tend to have the most intensive and enduring therapeutic relationships with people with diabetes. According to Muncey (2009), the most prominent “model of disease in the western hemisphere is the biomedical model based on the Cartesian philosophy of the body as a machine” (p. 25) but given the complexity of health and disease and the human response to the challenges of diabetes management, including self-care, a broader approach is required. Indeed, Grumbach (2003) describes the goals of care for long term conditions as follows:

for chronic, incurable conditions, the goals of care are to enhance functional status, minimize distressing symptoms, cope with psychosocial stressors of pain and disability, and prolong life through secondary prevention. In chronic illness, care of the whole person is paramount. (p. 4)

Therefore, health services delivered with a predominant biophysical focus do not meet the needs of people with diabetes (and equally for other long term conditions). Assessment of a person’s capability and willingness to actively engage in health promoting activities is complex and multifaceted. Aside from the proximal to distal influences impacting on their level of health activation as illustrated in Figure 1, a holistic approach is required that encompasses not only the person’s medical status but also attention paid to the dynamic psychosocial and emotional aspects of living with a long term condition.

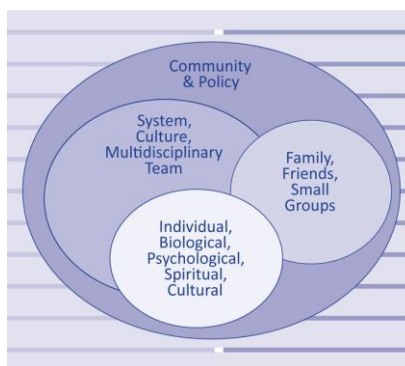


Figure 1. Social epidemiological model of diabetes. (Adapted from Fisher et al., 2005).

Therapeutic relationships between people with long term conditions and health professionals are generally protracted over many months and years. Increased acknowledgement of patient expertise has occurred along with recognition that the challenge of managing diabetes is shared in a partnership between the person with diabetes and the health professional/s. The person with diabetes is considered responsible for their own self-care, and the health professional is considered responsible for providing appropriate advice and optimal pharmacological management (Marshall, Haywood, & Fitzpatrick, 2005).

The Partnership Paradigm

The partnership paradigm is described by Bodenheimer, Lorig, Holman, and Grumbach (2002) as having two components - collaborative care/patient empowerment and self-management education. Collaborative care/patient empowerment is described as a relationship where people with a long term condition/s are seen as experts in their own lives and are encouraged to identify their own problems and define goals, and the health professional is seen as the expert on medical and treatment related issues. Self-management education is described as education that provides the person with problem-solving skills for self-care of a long term condition. According to Marshall et al. (2005), this definition provides a “distinction between patient collaboration in the consultation process and the patient’s ability to undertake self-care activities” (p. 4). Within this model health professionals and people with long term conditions work together to define

problems, set priorities, establish goals, create treatment plans, and solve problems along the way through active and sustained follow up (Von Korff et al., 1997).

Utilising the previous work of: Bodenheimer, Lorig, et al. (2002), Greenhalgh, Long, and Flynn (2005) and Heisler et al. (2003); Marshall et al. (2005) propose a complex pathway between collaborative care and patient and provider outcomes as illustrated in Figure 2.

Within this pathway are a number of interconnected aspects which include improved provider communication, patient decision-making satisfaction, provider attitudes and behaviours, patient attitudes and behaviours leading to patient satisfaction, health status and quality of life.

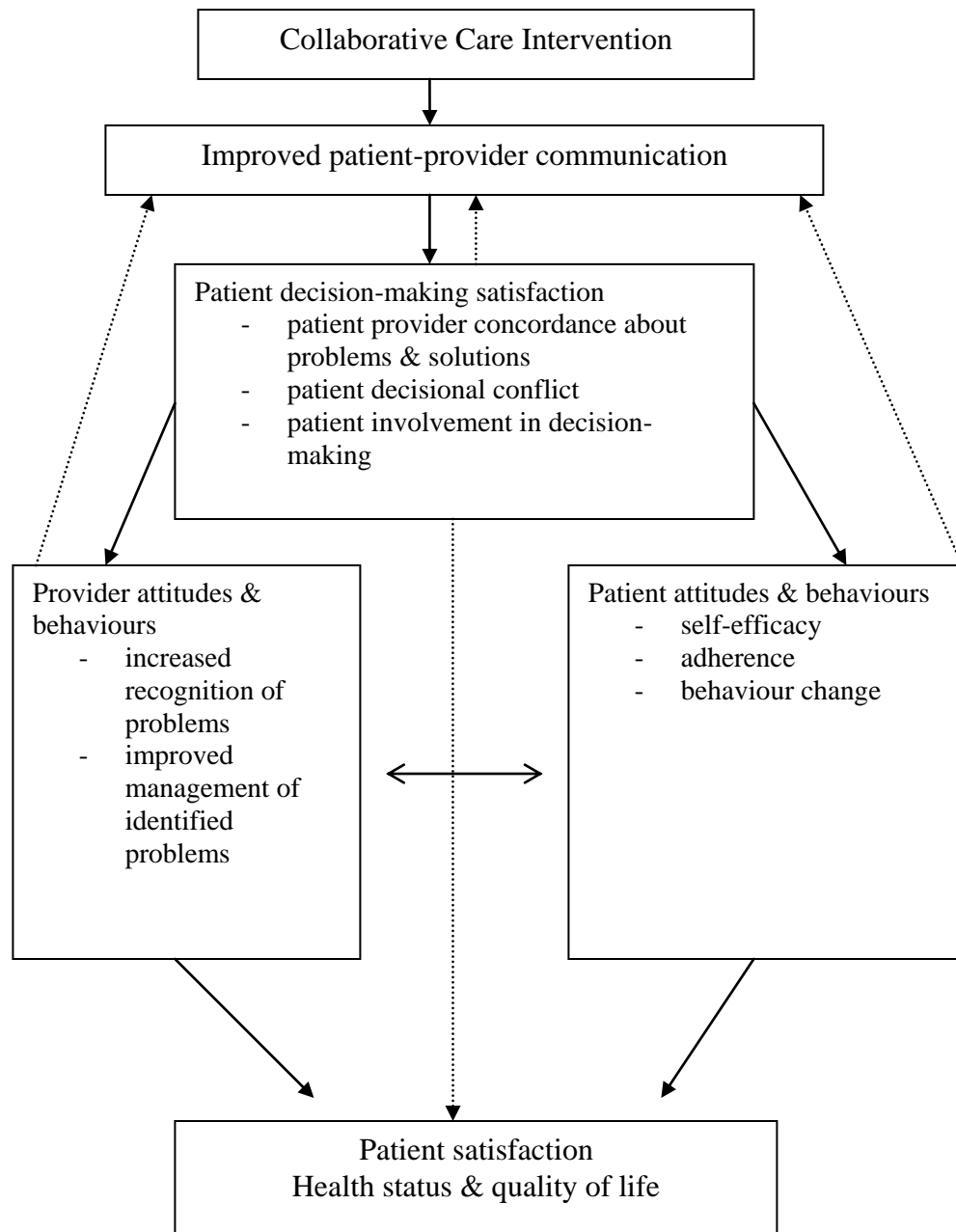


Figure 2. Pathway between collaborative care and patient and provider outcomes. Marshall et al., (2005), p. 16.

This pathway provides a useful framework for organising multiple theoretical perspectives underpinning self-care behaviours for people with diabetes, as discussed earlier in this

chapter. However, the model fails to explicitly acknowledge the potential for distress and the impact this may have on patient attitudes and behaviours. As this work was published around the same time as the work of Hibbard et al. (2004) health activation is also absent and could be usefully added as an intermediate outcome prior to patient satisfaction and health status. Acknowledgement of the social determinants of health and potential impacts on behaviour would also be important.

Study Aims and Research Questions

The purpose of undertaking this cross-sectional, two-phase, sequential mixed methods study was to explore and explain influences on diabetes-related health activation. The conceptual framework below illustrates this study's key constructs of interest in relation to diabetes-related health activation.

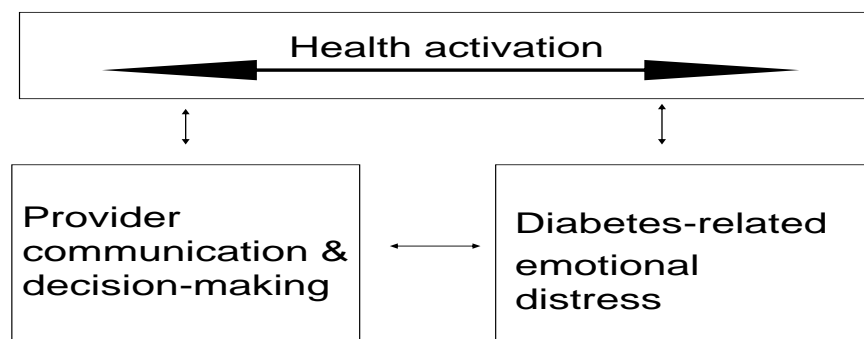


Figure 3. Conceptual framework

Two priority aims have been identified for this study of adults with diabetes: a) to contribute to the understanding of specific factors associated with differences in health activation; and b) to generate new ideas on how diabetes care can be tailored to maximise personal resourcefulness and promote a high level of health activation. With a focus on the proximal, biomedical/psycho-sociological influences on diabetes-related health activation, this study specifically explores and provides possible explanations for the following questions:

- 1) Is diabetes-related distress associated with differences in health activation?
- 2) Are perceived provider communication and decision-making styles associated with differences in health activation?
- 3) Is there a perceived difference between different providers' (i.e. nurses' and doctors') communication and decision-making styles if so, is there an association between perceptions of provider styles and differences in health activation?

Structure of the Thesis to Follow

This introductory chapter has provided the background for the study focusing on potential factors associated with health activation for the person with diabetes. Chapter two provides a review of the literature around the key constructs of interest, that is; health activation; diabetes-related distress; and health professional communication and decision-making styles.

In chapter three a discussion on the mixed methods methodology employed in this study is provided, including the philosophical stances, justifications for utilising this methodology and its fit with research within the multidisciplinary team.

The research methods utilised in this study such as a structured self-administered questionnaire and interviews of a subgroup of participants, are described in chapter four. Ethical requirements are also addressed.

Chapter five presents quantitative analysis of the questionnaire data and focuses enquiry for the interviews. Chapters six through eight present thematic analysis of interview data relating to influences on diabetes-related health activation, a spectrum of control and provider communication and decision-making respectively.

In the discussion and conclusions chapter (chapter nine), the quantitative and qualitative findings are brought together and provide an interpretation of these findings, with consideration of the theoretical perspectives discussed earlier. The literature is revisited as

it pertains to the study's findings. The conclusion and recommendations identify strengths and limitations of this study and provide constructive suggestions for implications for clinical practice and future research in this area of study.

Summary

This chapter introduced literature surrounding factors associated with active engagement in self-care and introduced health activation as it has been recently conceptualised. The potential for diabetes-related distress and tentative ideas on what association may have on differences in health activation were also presented. The provider-patient partnership paradigm was presented as a response to changing health care needs and health care delivery with an increasing emphasis on individuals taking more responsibility for their care.

Introduction

The review of the literature to follow, provides a critical overview of literature pertinent to the provider-patient partnership paradigm as presented in the introduction chapter, and in particular to the constructs of interest within this study, that is health activation, diabetes-related emotional distress and provider communication and decision-making styles. In defining the scope of this review it was determined that as the literature on the four main topics was extensive, only original studies, review articles and systematic reviews would be initially critiqued. Relevant articles were selected and abstracts were therefore studied. Related articles were also checked for other relevant material, the references of the most relevant articles were reviewed and relevant articles were selected. The majority of references are from the year 2000 onwards, although landmark studies predating this were also included. I have read and critiqued literature well beyond what is presented in this review, however due to the sheer volume it is not all presented. Rather, the literature review is organised under four major headings: self-care in diabetes; health activation; diabetes-related distress; and patient - provider relationships. The review of self-management programmes and group diabetes self-management education is deliberately short as there is substantial literature available elsewhere and this is not under direct scrutiny in the thesis.

Search Strategy

The literature presented in this review was sourced from a variety of sources, both within the diabetes literature and the broader long term conditions (or chronic illness) literature. Literature was identified through CINAHL, Medline, PsychLit, Pubmed and other such databases and relevant texts readily available to me. Search terms used in the search are detailed in Table 1. Applicable articles were selected and abstracts were studied. Articles were also checked for other related material, the references of the most pertinent articles were reviewed and relevant articles were selected.

Table 1

Literature Review Search Strategy

Self-care	Provider communication	Decision-making	Diabetes-related emotional distress	Health activation
Self-care	Provider communication	Decision-making styles	Diabetes Distress	Health activation
Self- Management	Nurse communication	Nurse + decision-making	Emotional distress + diabetes	Patient activation
	Doctor/Physician communication	Doctor/Physician + decision-making	Depression + Diabetes	Patient activation measure

Self-care in Diabetes

Despite significant knowledge and technological advancements in diabetes care, outcomes for people with diabetes remain by and large suboptimal. It is well recognized that a fundamental component of achieving and maintaining optimal metabolic control is self-care (Miller, Shewchuk, Elliot, & Richards, 2000). Diabetes is considered to be relatively unique as a long term condition due to treatment regimens being carried out largely through self-care (Anderson et al., 1995; United Kingdom National Health Service, 2007). The person with diabetes is required to make many decisions throughout their day about food choices, physical activity, medication management, monitoring their blood glucose levels and adjusting food and/or medication accordingly. These predominantly lifestyle behaviours can be challenging to maintain over time. In addition, the majority of people with diabetes also have co-morbidities “that interact to produce a complex and challenging clinical dynamic” (Grumbach, 2003, p. 5), further challenging self-care efforts (Bayliss et al., 2005; Bayliss, Steiner, Fernald, Crane, & Main, 2003).

While adequate knowledge is important to assist the person with diabetes to make appropriate decisions, knowledge alone has been found to be poorly related to behaviour change and improved clinical outcomes (Norris, Engelau, & Narayan, 2001; Steed, Cooke,

& Newman, 2003; van Dam, van der Horst, van den Borne, Ryckman, & Crebolder, 2003). With this growing acknowledgement that an individual's behaviour is influenced by multiple factors, Fisher et al. (2005) present a model for a socio-ecological approach to self-care of diabetes. Ecological perspectives can be seen to have emerged through an evolution of views of health and illness (Brownson, Lovegreen, & Fisher, 2006). The socio-ecological approach to self-care model moves beyond the more customary behaviour change models often used in diabetes care and education and the previously held assertions that individuals had the power to control their own behaviour. Rather, it has an appreciation for the multiplicity of influences on behaviour spanning the social environments of the individual, family, friends, workplaces, organisations, cultures and ethnicities, along with the physical and policy environments of neighbourhoods, communities, health systems and government policies. So while an individual remains responsible for their own health care decisions, it is noted that self-care "is dependent on the environmental contexts that surround them" (Fisher et al., 2005, p. 1523).

Previous literature has identified barriers to diabetes self-care. Bayliss et al. (2005) identified the multiple barriers pertaining to people with type 1 diabetes as including physical limitations, lack of knowledge, financial constraints, low self-efficacy, inadequate communication with health professionals, need for social support, depression and multiple problems with managing medications. This is consistent with barriers associated with self-care in type 2 diabetes identified as cost and depression (Daly et al., 2009), low self-efficacy, low family support, fear of hypoglycaemia, diabetes-related distress (Glasgow, Toobert, & Gillette, 2001), and psychological issues relating to strictness of the diabetes treatment regimen (Simmons, Lillis, Swan, & Harr, 2007). More generally, according to the United Kingdom's Department of Health's survey on public attitudes to self-care (2005) comprising 3290 people aged 15 years and older, health care professionals were considered to have a vital role in supporting and encouraging self-care. After knowledge and understanding, participants identified support from health care professionals as the key enabler of self-care however, more than half (55%) of the participants who had been to their primary health care provider in the preceding six months had not been encouraged to do self-care.

Thus, self-care for a person with diabetes will potentially be influenced by many factors such as personal beliefs, family and friends, ethnic and cultural influences, work commitments and relationships with health care professionals. A focus is required that encompasses their broader social contexts and factors influencing their motivation and intention to undertake health promoting self-care activities. These factors may include the individual's own views of the merits or negative consequences and their sense of control over performing these activities.

Self-management Programmes

As presented in the introduction chapter, a plethora of literature exists on potential interventions and structured programmes for the care of people with diabetes and other long term conditions. Aspects of these programmes have been implemented to varying degrees in New Zealand with the goal of providing a structured approach to provide improved care processes and health outcomes.

Possibly one of the best known frameworks for providing care for people with long term conditions is the 'Chronic Care Model' (Glasgow et al., 2005; Wagner, 1998). This model places support for self-care activities into the broad health care delivery system (Walker, 2006). The model focuses on linking informed, active people with long term conditions with pro-active teams of professionals. It acknowledges that a substantial portion of long term condition care takes place outside formal healthcare settings (Bodenheimer, Lorig et al., 2002) and suggests that six elements are of central importance in initiatives to improve long term condition care: community resources; the healthcare system; patient self-management; decision support; delivery system redesign; and clinical information systems (Singh & Ham, 2006). However, a review of the evidence of the impact of the individual elements of the model for improving outcomes found that no single element of the Chronic Care Model was essential for improving outcomes (Tsai, Morton, Mangione, & Keeler, 2005). Therefore it supports the notion that long term condition care is necessarily multifaceted.

Group based diabetes self-management education programmes have been developed and implemented in various forms in response to the increasing burden of long term conditions on the health system and in an attempt to improve an individual's knowledge, understanding and problem solving skills in relation to their disease. One of the better known programmes is the Expert Patient Programme (EPP) (Lorig et al. 1999). The EPP drew on the work of Corbin and Strauss (1988) who identified that three key tasks were involved in managing a long term condition: (1) medical management, (2) behaviour management, and (3) emotional coping. However, in general the majority of evidence for these programmes is weak (Greenhalgh, 2009) with support for short term effects of up to only six months. In a meta-analysis of clinical trials pertaining to group self-management education programmes, Norris et al. (2001) concluded that most studies focusing on changing lifestyle failed to demonstrate improvement in metabolic control when compared to control groups, with increase in knowledge levels inconsistently related to improved glycaemic control. Where interventions were collaborative as compared to didactic, more favourable outcomes were observed. A further meta-analysis by Norris et al. (2002) had similar conclusions. In this study, HbA_{1c} levels improved at immediate follow up but the benefits declined one to three months after the intervention. Of interest, increased contact time with a health professional (predominantly a nurse) increased the effect of improved metabolic control, with a decrease of a 1% absolute reduction of HbA_{1c} evident for every 23 hours (range 13.3 to 105.4 hours) contact time with a nurse. As a 1% absolute reduction confers up to 33% risk reduction in microvascular complications (UKPDS, 1998), this finding is potentially important. Insufficient data was available to enable analysis of effects of psychosocial variables on HbA_{1c}.

Smaldone and Weinger (2005) also report short term benefits of group education for type 2 diabetes but a more recent Cochrane review demonstrated longer term benefits up to 12 months (Deakin, McShane, Cade, & Williams, 2005). Their meta-analysis included only eleven studies of programmes with follow up of six months duration or longer. Benefits were found at four to six months including reduction in HbA_{1c}, fasting blood glucose level, and increased knowledge. At twelve to fourteen months these benefits were maintained with a reduction in requirement for diabetes medications. Their analysis suggested the

programmes under study may also have a positive effect on quality of life, blood pressure, weight and treatment satisfaction. Ongoing care which included education and reinforcement of recommendations was also found to be important in a prospective study in people with diabetes (Rachmani, Levi, Slavachevski, Avin, & Ravid, 2002). In this study, individuals who were motivated and provided with education and ongoing reinforcement, experienced fewer vascular complications long term.

As the evidence is neither consistent nor strong for group based self-management programmes, particularly beyond six months, Taylor and Bury (2007) suggest caution for full scale implementation of these programmes stating that these “lay-led interventions may in fact have little or no unique capacity to promote increased self-efficacy and enhanced chronic illness self-management” (p. 41). Greenhalgh (2009) suggests that self-management education programmes are not successful due to a number of factors: “lack of awareness and engagement among patients and staff; failure to consider low health literacy or cultural norms; lack of attention to the need for family and social support; and a fragmented approach to the provision of health and social care” (p. 630). Thus, unless the fundamental processes of health care delivery are addressed in the planning and implementation of self-management education programmes, their success will continue to be limited.

Behaviour Change Theories and Models

Over past years multiple theories and models to assist with understanding factors influencing self-care behaviour change have been developed. It is suggested by Butler, Rollnick, and Stott (1996) that use of these theories and models in practice can “help clinicians to see the complexities of decision-making sympathetically, from the patient’s perspective. This change in perception can turn ‘non-compliant cases’ into respected human beings struggling with difficult decisions, often under challenging conditions” (p. 1360). As presented in the introduction chapter, the four prominent theories in the literature on behaviour change are (1) The Health Belief Model; (2) The Social Cognitive/Social Learning Theory; (3) The Theory of Reasoned Action/Theory of Planned

Behaviour; and (4) The Transtheoretical Stages of Change. In addition to these theories identifying specific mediators of behaviour change, there are theories or models that provide a philosophical foundation for behaviour change interventions (Peyrot & Rubin, 2007). One of the more prominent models in this respect is the Empowerment Model.

In brief, the Health Belief Model (HBM) associates adherence with a person's beliefs about their health condition and their prompts and obstacles to participating in health-related activities (Butler et al., 1996; Rosenstock, Stretcher, & Becker, 1988). According to Green (2002) the HBM relates largely to the cognitive factors influencing a person to carry out a particular health behavior, concluding with a person's belief in their ability (or self-efficacy) to successfully carry out the behavior. However, the model does not explain factors that may enable and reinforce the behavior, and these factors become more important to understand when the model is used to explain and predict more complex lifestyle behaviors required over a lifetime (Butler et al., 1996; Green, 2002). Furthermore literature on research in adults and youth with diabetes has repeatedly demonstrated that individuals hold a varied set of beliefs surrounding illness that may not fit the medical view of diabetes and that "these beliefs are robust and proximal determinants of patients' emotional well-being and self-care behavior" (Skinner, Cradock, Arundel, & Graham, 2003, p. 76).

Social Learning Theory focuses on a person's perceived ability to carry out behaviors and follow through on plans of care, referred to as self-efficacy (Bandura, 1986). A person's self-efficacy, that is a person's "beliefs about their capabilities to exercise control over their own level of functioning and other events that affect their lives" (Bandura, 1991, p. 257), has long been posited as a fundamental determinant of successful self-care of long term conditions (Taylor & Bury, 2007). According to Tillotson and Smith (1996) a fundamental principle of social learning theory is that people will participate in health promoting behaviours if they are concerned about their health and believe they have control over it. The locus of control construct had its origin in the social learning theory. Locus of control is an expectancy belief about where control over behavioural outcomes lies. An internal locus of control credits personal control of behavioural outcomes, whereas an

external locus of control credits outcomes to “the control of powerful other people or forces such as luck, fate or chance” (Tillotson & Smith, 1996, p. 133).

According to the Theory of Reasoned Action/Theory of Planned Behaviour behavioural beliefs, normative beliefs and control beliefs guide a person’s action, producing attitudes toward the behaviour, perceived social norms about the behaviour and perceived control over behaviour. According to Ajzen (2002) where there is a more positive attitude and subjective norm, and more perceived control, the person’s intention to perform the particular behavior is stronger. Within this theory therefore, the antecedent of behaviour is assumed to be intention. However, because many self-care behaviors can be challenging to implement and therefore may limit actual control, it is proposed that perceived behavioural control in addition to intention should also be considered.

The Transtheoretical Stages of Change Model (Prochaska & DiClemente, 1982, 1983) consists of different stages through which an individual progresses before deciding to change a behaviour. Motivational interviewing, where the person is encouraged to examine the positive or negative aspects of change and then come to a decision for themselves, has been incorporated into this model and together can be directly applied in many different health care contexts (Butler et al., 1996). In practice, utilisation of the Transtheoretical Stages of Change Model enables the health professional to identify what stage a person is at in terms of changing behaviour and therefore apply targeted interventions to support change. According to this model a person may be pre-contemplative, contemplative, or ready/ preparing to be ready. If a person is considered to be pre-contemplative, the likelihood of changing a behaviour is remote, but the health professional can raise the possibility and encourage the person to consider change more positively. If a person is considered to be contemplative, they are usually aware of the need for changing a behaviour but remain ambivalent about changing. Exploring this ambivalence through motivational interviewing may lead to discomfort and provide impetus for making a decision to change behaviour. When a person is ready or preparing to change, the health professional may support them by assisting with realistic goal setting or other practical aspects that will support implementation of their decision to act.

The concept of empowerment in diabetes care emerged in the 1990s with the emphasis on self-care and in recognition that the person with diabetes was in control and therefore responsible for their diabetes care (Anderson, 1995; Asimakopoulou, 2007). The empowerment model grew out of an awareness that the provision of diabetes care within an acute care/ traditional medical model of care, where the health professional is in control of decision making and implementation of care, diminished the adequacy of care for people with diabetes as it attempted to do the impossible, that is to be responsible for the individual's self-care activities (Anderson & Funnell, 2005). According to Anderson (1995), a core value underpinning the philosophy of empowerment is "to provide care that meets the needs and expectations of people with diabetes" (p. 414). It opposes the traditional medical model where the physician is considered the final authority in the treatment of the diabetes, and argues that the person with diabetes is in control of their own diabetes care on a daily basis. Anderson and Funnell proposed that care using an empowerment approach requires a "change from feeling responsible *for* patients to feeling responsible *to* patients" (p. 155). This means health professionals need to act collaboratively to assist people to make the best possible diabetes self-care decisions based on their own health priorities and goals. This model is aligned with the belief that the majority of health care for people with diabetes is "interwoven into the fabric of their daily lives" (Anderson & Funnell, p.154), therefore this model has the person at the centre of the behaviour change process with health care providers fostering patient autonomy (Peyrot & Rubin, 2007).

These five major theoretical approaches for influencing self-care behaviour provide important insights into cognitive and behavioural factors influencing self-care decision-making and behaviour (Jack, 2003). They focus on specific behaviour change based on a person's beliefs about the illness and their perception of their ability, confidence or responsibility to achieve desired outcomes. The empowerment model specifically focuses on power relationships advocating a sharing of power and responsibility with recognition of the person with the long term condition having specific expertise. However, they all tend to focus on one dimension of behaviour change and one self-care behaviour thereby not accounting for the different behaviours associated with different self-care activities

(Daly et al., 2009). Individually the theories or models do not encompass the multiplicity of influences on self-care behaviours, in particular the emotional cognitions and responses to living with a long term condition. As a result these one dimensional approaches do not necessarily result in desired behaviour change (Fisher et al., 2005). Von Korff et al. (1997) purport that a critical element of effective self-care is ‘activated’ patients, who have the capability and motivation to participate as effective health care team members. Consistent with this Rachmani et al., (2002) suggest that when patients are motivated, inquisitive and actively involved in their self-care, health professionals are more likely to be more proactive with their care.

Health Activation

The term ‘patient activation’ has been used predominantly in diabetes literature to represent interventions to encourage people to be more involved with their self-care (Williams et al., 2005). As presented in the introduction chapter, a conceptual definition of ‘activation’ had not been clearly articulated, and therefore could not be consistently measured in research or practice. Following a rigorous process Hibbard et al. (2004) developed a conceptual definition of ‘health activation’ as presented in chapter one. Consequently health activation is considered to be a multi dimensional concept incorporating knowledge, skills, health beliefs, confidence and self-efficacy. It brings together the previously described theories on behaviour change acknowledging that active engagement in self-care is a complex undertaking across many self-care activities. This conceptual definition thus represents a state of being rather than an intervention. The literature on health activation as conceptualised by Hibbard et al. (2004) is currently limited and focuses around assessing the application of health activation to different age groups, ethnicities and its impact on supporting health care behaviour changes.

In a large study involving a sample of 1515 people aged between 45 to 97 years of age with over half under the age of 65 years, the ‘Patient Activation Measure’ (PAM) was developed (Hibbard et al. 2004). This was later refined by Hibbard, Mahoney, Stockard, and Tusler (2005) with 1469 people with long term conditions. Eighty-eight percent of their sample

was white, 63% were female and half the sample had high school education or less. Seventy-nine percent of the sample reported at least one long term condition, and among those 73% reported two or more long term conditions. The PAM has been found to be stable across differing levels of health status, sex, age groups and several chronic illnesses, and its high reliability estimates indicate the measure is appropriate for individual level use, such as designing a care plan for an individual patient. The PAM assesses patients' health beliefs, knowledge, skill and confidence for self-care and determines an individual to be in one of four stages: 1) belief that an active role is important, 2) confidence and knowledge to take action, 3) taking action, and 4) staying the course under stress. Because health activation has been shown to be developmental, Hibbard et al. (2005) suggest that interventions can be tailored to an individual's stage of activation.

The development of a conceptual definition of health activation and early testing of the PAM led to an interest in the relationship between health literacy and health activation in older adults. In 2005, Greene, Hibbard, and Tusler were commissioned by the American Association for Retired Persons (AARP) to conduct a study to examine this relationship with respect to older adults' ability to manage their own health. Specifically, the study examined how health activation impacted on a number of different health outcomes relating to confidence to make decisions, and increased engagement in health-care related behaviours, healthy behaviours and self-care behaviours. The study involved 293 participants 65 years of age or older who were living independently. The main thrust behind the commissioning of the research was that older adults were increasingly being required to make health care decisions of increasing complexity and to be more responsible for their own health, but it was considered questionable that all have the capability to undertake the tasks related to this level of responsibility. The majority of participants in the study were women (69%) and just over half rated their health as good or very good (52%). Half had three or more chronic conditions and 40% had one to two chronic conditions. Sixty-two percent had an education level beyond high school. Ethnicity was not reported. According to Greene et al. the study sample was older, in better health and had more education than compared with a national sample of non-institutionalised Medicare beneficiaries. The mean health activation score was 61.1 (range 0-100) which is

higher than other national samples. The mean health literacy score was 60.1 with only 14% with an inadequate or marginal health literacy score, lower than samples from other cities with rates ranging between 31% to 36 %.

In this study, health literacy and health activation were found to impact differently on decision-making, health-care related behaviours, healthy behaviours and self-care behaviours. Health literacy was more strongly associated with decision-making than health activation. This related to both confidence to make decisions and the ability to use information to effectively make decisions. An individual's level of health activation had a greater influence on increased engagement with outcomes related to health care behaviours. These differences have potential implications for care planning and delivery and policy decision-making, as health professionals will need to consider health literacy levels of older adults in order for them to actively and effectively participate in making decisions about their own care. From a health activation perspective, health professionals will need to assess the person's capability and commitment to follow through on decisions made. Despite the limitations of the study which include an atypical sample, outcome measures based on self-report and therefore subject to response bias, and the cross-sectional nature of the study not enabling causal inferences, this study provides valuable new information for the American older adult and may have relevance to practice in the New Zealand context. It has also contributed to knowledge of the application of the PAM in older adults.

As all studies on health activation to date had been cross sectional and therefore not able to measure health activation over time, Hibbard, Mahoney, Stock and Tusler (2006) undertook a study to assess whether health activation was a dynamic or changeable characteristic and whether changes in health activation were accompanied by changes in health care behaviours. They conducted a randomized controlled trial with 479 participants aged between 50-70 years of age. Participants were divided into a control group and an intervention group. Participants in the intervention group underwent a chronic disease self-management programme consisting of two and a half hour sessions each week over six weeks. Demographic details for participants in both the control and intervention groups respectively, were comparable with the majority of participants on

average 60 and 59.6 years, 69% were female in both groups, the majority were white (95.6% & 97.5%), had three chronic conditions, and their average activation scores were 60.2 and 60.1 respectively. Eighteen health related variables were included as outcome variables including self-management behaviours, disease specific behaviours, health related quality of life, depression and social desirability.

Overall the study found that a positive change in health activation related to a positive change in a variety of self-care behaviours but the impact of the intervention (the six week chronic disease self-management programme) was unclear. While significant differences were present at six weeks between the control and the intervention group (increased depression was associated with decreased activation; increased health related quality of life was associated with increased activation; and increased depression was associated with reduced health related quality of life), these differences were not present between groups at six months with both groups demonstrating an increase in their health activation levels. This study provided further insight into the utility of health activation by demonstrating that when health activation is increased, self-care behaviours follow. It also highlights the importance of screening for depression, for as long as depression persists activation is less likely to occur. The authors concluded that health activation levels do change over time and that individuals “exhibit different change trajectories” (Hibbard et al., 2006, p.1460). Furthermore, they suggested that health activation is a useful intermediate outcome but as there were no significant differences remaining after six months between groups, it is unclear what factors stimulate spontaneous activation. Further research is suggested to explore what leads to spontaneous activation and what interventions may be more effective for different health activation levels.

In order to provide further confirmation and increase understanding of the utility of the PAM beyond the previous studies, Mosen et al. (2007) examined the PAM’s association with both process and health outcomes. Their study was based on the premise that “not only are chronic conditions different in their time course and severity, they also require the patient to make nearly continuous decision-making owing to constantly changing circumstances” (p. 21). This cross sectional study involved 4108 participants with one or

more of six different long term conditions who completed a self-administered survey. The mean age was 62 years, half were males, 64% were white and three quarters had education levels beyond high school. The PAM was the primary independent variable and there were five dependent variables: the process outcome variables included: use of self-care services, performance of self-care behaviours, and medication adherence. The health related outcome variables were: overall satisfaction with care, self-reported quality of life, and functional status. The mean PAM score for this sample was 56.8 with a third of participants in stages three or four.

Overall, this study found that with each increased stage of PAM scores, a significant association was found with improved outcomes for both process and health outcomes. The PAM appeared to be more sensitive in its ability to detect differences in participants at health activation stages two to three. Specifically, this study found that participants with high PAM scores were significantly more likely to perform self-care behaviours, use services supporting self-care, and report high medication adherence. Furthermore, those with a high PAM score were ten times more likely to report high satisfaction, five times more likely to report good quality of life and had higher physical and mental functional status scores. This study provides further support for the association between patient activation and both process and health related outcomes. Moreover, it appears to be the first study to specifically demonstrate an independent association between patient activation and health related outcomes. However, as this was a cross sectional study and it was not possible to determine causality, further research is required to assess the PAM's effect on process level measures over time.

Thus far, studies involving the PAM were predominantly based on participants who were 50 years or older and of white ethnicity. Therefore the usefulness of utilising patient activation in practice with indigent populations had not been established. Rask et al. (2009) explored the validity of the health activation construct as measured by the PAM by correlating PAM scores with diabetes knowledge, attitudes and self-care behaviours in a predominantly minority and uninsured population in the United States. They hypothesized that health activation was associated with a higher degree of compliance with healthy

diabetes behaviours and use of preventative services. Secondary analyses explored the stability of activation scores over time and the correlation between activation and socio-demographic characteristics. Participants who were over the age of 18 years with type 2 diabetes on either oral diabetes medication and/or insulin were invited to participate. Interviews were conducted with 287 predominantly African American participants (90%), over half of whom were female (59%) with a mean age of 51.5 utilising the PAM and the SF-12 Health Survey to measure physical and mental health status. The SF-12 Health survey is a shortened version of the SF-36 Health Survey (Ware, Kosinski, & Keller, 1996). Participants were followed up by telephone six months later. Co-morbid conditions were common and nearly 30% of participants reported depression. Sixty-two percent of the participants scored the highest PAM stage, stage four, corresponding with both higher physical health and mental health composite scores from the SF-12 compared to those in lower health activation stages. In addition, stage four activated patients were more likely to report having good health (68%).

Overall, this study's findings supported the validity of the PAM in this group of African Americans, with higher levels of health activation associated with higher levels of healthy behaviours and less difficulty managing their diabetes care. However, the numbers of participants self-rating at stage four is of interest as previous national samples report between 14% and 22% will report this high level of health activation. As participants' demographics in this study are different from previous studies, in that they are younger, had a higher rate of chronic disease and reported significantly worse health status than other studies, this level of health activation is surprising. Rask et al. (2009) suggest this may be due to different ways of responding and disadvantaged groups may feel the need to present themselves in a positive light in order to increase their likelihood of ongoing care. However, despite this anomaly, differences in health activation in this sample did correlate with the adoption of positive self-care behaviours.

The studies described provide an understanding of the utility of the PAM across a wide age range, sex, ethnicities and its impact on self-care behaviours. While identifying that health activation as a state of being is dynamic in nature and that health activation trajectories

differ by individual and across self-care behaviours, none of the studies investigated psychosocial issues that may potentially influence health activation. Due to diabetes potentially impacting on every facet of life; adjustment to changes in every day life and to living with a long term condition can result in considerable depressive symptomology and/or diabetes related emotional distress. Emotional and attitudinal barriers may then become insurmountable obstacles to improved blood glucose control and a high level of health activation.

Diabetes-related Emotional Distress

Diabetes is well recognised as one of the more behaviourally and psychologically challenging of the long term conditions (Delamater et al., 2001; Sultan & Heurtier-Hartemann, 2001). Literature suggests that the impact of long term conditions, especially diabetes, results in a disruption to life and is potentially a continual source of stress impacting on health (Karlsen, Idsoe, Dirdal, Hanestad, & Bru, 2004; Snoek, Pouwer, Welch, & Polonsky, 2000). Willoughby, Kee, Demi, and Parker (2000) describe the diagnosis of a long term condition as “initiating a process of continuous appraisal and re-appraisal through which the individual adapts or adjusts to the requirements and limitations imposed by the illness” (p. 106). Paterson (2001b) challenges the traditional view of living with a long term condition as a predictable trajectory describing it as “misguided and incomplete” (p. 22). Paterson suggests that the long term condition trajectory is dynamic and will change as the person’s perspective is altered as they experience life with a long term condition amidst their personal and social contexts also changing. She states “the perception of the reality, not the reality itself, is the essence of how people with chronic illness interpret and respond to their illness” (p. 23).

Empirical studies strongly suggest that the presence of diabetes in adults doubles the odds of comorbid depression when compared with the general population (Anderson, Freedland, Clouse, & Lustman, 2001; Egede & Zheng, 2003; Fisher, Glasgow, Mullan, Skaff, & Polonsky, 2008; Nichols & Brown, 2003; Talbot & Nouwen, 2000). This is particularly so for people with diabetes as they develop co-morbidities (Engum, Mykletun, Midthjell,

Holen, & Dahl, 2005). Both major and minor depressive illness in people with diabetes have been found to be associated with poorer self-care (Gonzalez et al., 2008) and increased cardiac risk factors such as smoking and less physical activity, along with a significantly higher mortality in people with type 2 diabetes (Katon et al., 2005). The higher prevalence of depression is purported to result from the greater burden of having a long term medical condition rather than directly from the disease itself (Jacobson, 1993). It is suggested that the perceived disability associated with having a long term condition or being aware of having a long term condition may have more of an impact on one's life than the actual disease itself (Talbot & Nouwen, 2000) further impacting on emotional well-being and motivation for diabetes self-care. Fisher et al. (2008) reported that while depression prevalence was double that of people without diabetes, many more people with diabetes were experiencing emotional distress and worry about their diabetes rather than depression per se. This finding is supported by Pibernik-Okanovic, Grgurevic, Begic, Szabo, and Metelko (2008) as two thirds of the clinically depressed participants in their study also reported high diabetes-related distress. Diabetes-related distress is defined by Fisher et al. (2008) as "patient concerns about disease management, support, emotional burden, and access to care" (p. 246). Furthermore, Fisher et al. state it is a common condition, often including high levels of negative affect and is linked to "poor biobehavioural disease management and can easily be confused with major depressive disorder or minor depression" (p. 250). Distinguishing between these conditions is considered to be important as they will respond to different interventions (Fisher et al., 2007). More demanding self-care behaviour has been found to increase distress (Polonsky et al., 1995; Herschbach et al., 1997; Aalto, Uutela, & Aro, 2000) and diabetes related distress is an independent and major contributor to poor adherence or neglect of self-care (Sigurdardottir, 2005), thereby impacting on metabolic control and short and long term complications.

Studies assessing diabetes distress in people with diabetes demonstrate varying levels of distress. Cross cultural differences in distress levels are apparent with people in the United States of America (U.S.A) reporting higher levels of distress (Snoek et al., 2000). In a multinational study comprising 13 countries and examining diabetes attitudes, needs,

wishes and needs (The DAWN Study), reported outcomes were generally significantly better for participants in Germany, Spain, and the Netherlands than for U.S.A participants (Rubin, Peyrot, & Siminerio, 2006a). Aalto et al.'s (2000) cross sectional study examining disease-related distress among people treated with insulin, found that most respondents (40%) reported moderate levels of distress. Severe distress was found in 29% of participants and was significantly associated with a number of diabetes-related cognitions including lack of perceived reward for self-care effort, poorer perceived health and higher perceived threat of complications.

Fisher et al. (2008) found 25% of 496 people with type 2 diabetes experienced moderate or higher distress levels defined as a score of equal to or greater than 3 (from a range of 1-6). In this participant group, higher distress was associated with higher HbA_{1c} levels, less healthy diet, non-HDL cholesterol levels and lower physical activity levels. In other studies higher levels of diabetes-related distress have been found to be associated with being female, of younger age, lower education, the requirement for blood glucose monitoring, having suboptimal metabolic control, being more depressed and being treated with insulin therapy (Aalto et al. 2000; Anderson, Fitzgerald, Gorenflo, & Oh, 1993; Delahunty et al., 2007; Paddison, Alpass, & Stephens, 2008; Pibernik-Okanovic et al., 2008; Polonksy et al., 2005; Rubin et al., 2006a; Rutherford, Wright, Hussain, & Colagiuri, 2004). Anderson et al. (1993) found that health professionals underestimated the perceived negative impact diabetes has on the lives of people who are required to take insulin. Davis, Clifford, and Davis (2001) explored diabetes-related quality of life in people with type 2 diabetes. They argue for a “biphasic model of changes in diabetes-specific quality of life” (p. 69) after commencing insulin therapy as quality of life initially improved, possibly due to increased intervention, support and symptomatic well-being but then decreased after one to two years.

Weinger and Jacobson (2001) found people with type 1 diabetes experienced high levels of frustration related to their treatment, and emotional distress associated with lack of success in achieving target blood glucose levels. They concluded that treatment-related frustration may at first help motivate people with type 1 diabetes, however, without care focused on

addressing the underlying challenges to organise and structure their diabetes care, people with diabetes may be unable to incorporate newly learned self-care behaviours into their lifestyle.

Major deficiencies in health professional attention to psychological issues have been identified in the literature (Rubin, Peyrot, & Siminerio, 2006b; Simmons et al., 2007). Spencer et al. (2006) suggest diabetes related emotional distress is often considered the elephant in the living room by people with diabetes and their family. Instead the focus from health professionals is perceived to be on the physiological aspects of diabetes or the behaviour changes that need to occur to achieve optimal glycaemic control, with the psychological aspects of living and coping with the ongoing demands of self-managing diabetes often paid little attention. This focus on disease rather than life or living can act as a barrier to learning about diabetes and developing problem-solving skills as the person with diabetes perceives the health professional as not interested in their emotional needs nor willing to value their experiential expertise (Cooper, Booth, & Gill, 2003; Zoffman & Kirkevold, 2005).

Differences in attention to psychosocial issues were apparent in the multinational Diabetes, Attitudes, Wishes and Needs (DAWN) study (Rubin et al., 2006b) between health professionals in primary care and specialist services, with health professionals in diabetes specialist services (in particular specialist nurses), more likely to perceive psychological issues to be present more frequently, and to recognise them as having a greater impact on a person's life (Rubin et al., 2006b). In this study both specialist doctors and nurses perceived psychosocial problems as more common and/or more severe, offered more support than generalists, and were more likely to seek the psychological expertise of others. One of the suggested reasons for these findings was that diabetes specialist doctors and nurses are more likely to care for more people with diabetes, and these people tend to have greater complexity. Therefore, specialist doctors and nurses may be more aware of the impact of the difficulties in living with the disease and the impact of these problems for the person with diabetes.

Nurse case management has also been found to have a positive impact on a number of outcomes including diabetes-related distress (Gabbay et al., 2006). Rubin et al. (2006a) reported that better collaboration between health professionals and people with diabetes was associated with better well being and improved regimen adherence. Fuertes et al. (2006) promote the importance of relational factors, in particular human connection and trust, where the merits of the therapeutic alliance focusing on the cognitive and emotional dimensions of the relationship between patient and health professional are emphasised. Thorne (1993) concludes that:

for the chronically ill, life can be a bitter struggle, a struggle endowed with the potential either to destroy or to enhance quality in living. Understanding the social world in which that struggle is enacted is therefore as important for health professionals and policy makers as it is for patients and families.
(p. 55)

Patient-provider Relationships

The literature on patient and health professional relationship, including communication and decision-making, is vast. Indeed Clark et al. (2008) comment that “few areas at the intersection of the behavioral science and medicine have spawned more articles” (p. 54). Central to the literature on provider relationships is person-centredness where health professionals are required to adopt a more holistic approach recognising the centrality of individuals as partners in care with a multidisciplinary collaborative approach (Walker, 2006). Person-centred care is a commonly used concept in nursing and health care more generally however, despite its popularity as a concept person-centredness has multiple interpretations (McCormack & McCance, 2006; Mead & Bower, 2000).

McCormack and McCance summarise the existing literature surrounding person-centredness. They describe it as requiring the “formation of therapeutic relationships between professionals, patients and their significant others, and that these relationships are

built on mutual trust, understanding and sharing collective knowledge” (p. 473). Roter and Hall (2004) present four main communication groupings consistent with the literature on patient-centredness and functions of the medical visit: data gathering and facilitating of patient disclosure; patient education and counselling; emotional responsiveness; and partnership building. These are all consistent with many nursing theories on therapeutic caring where the ‘person’ is considered central to the therapeutic relationship (Henderson, 1966; Peplau, 1991; Watson, 1999, 2008).

Following a comprehensive review of the literature on patient-centredness within medical practice, Mead and Bower (2000) proposed that patient-centred medicine differed from the ‘biomedical model’ often used to describe medicine, in terms of five key dimensions, each of which represented a particular aspect of the doctor–patient relationship. Again, reflecting the complexity of providing person-centred care, these dimensions include: the bio-psychosocial perspective; the ‘patient-as-a-person’; sharing power and responsibility; the therapeutic alliance; and the ‘doctor-as-person’. However, the evidence associated with physical and psychological health benefits and a patient centred-approach in either nursing or medicine is considered to be inconsistent (McCormack & McCance, 2006; Michie, Miles, & Weinman, 2003). Despite the relative absence of robust evidence surrounding the effectiveness of person-centred care, individuals seeking health desire a therapeutic relationship in which they are central and this is especially so for those with long term conditions.

Patient Preference For Participation

Effective provider communication and shared decision making has been identified as resulting in greater patient satisfaction, adherence to treatment plans, and improved health outcomes (Heisler et al., 2002). However, the literature on patient preference for participation in the consultation and involvement in decision making is inconclusive. McPherson (2009) suggests that “preference effects will remain the elephant in the room and widely held to be fanciful” (p. 59). Clark et al. (2008) suggest that both experience and literature provide good evidence that individuals prefer to take a lead role in determining a

course of action. Robinson and Thomson (2001) concluded that despite previous research demonstrating that patient preference for involvement in decision-making varied according to age, socioeconomic status, illness experience and gravity of decision, it was more important to participants to be able to talk about the treatment rather than make the decisions. Bowling and Ebrahim (2001) concur purporting that while people do want to be involved in consultations, they want to be less involved in decision-making. Arora and Mc Horney (2000) found in a study involving 2197 people with long term conditions that the majority of patients preferred to leave their decision-making to health professionals, but those more likely to be more active were younger, female and with a higher education status. Heisler, Cole, Weir, Kerr, and Haywood (2007) demonstrated support for a participatory style in which older adults are actively encouraged to participate contrary to previous research demonstrating that older adults do not want to be involved.

Keisler and Auerbach (2006) conducted a comprehensive review on the literature surrounding the match of patient preference for participation with actual physician behaviour. Their review focused on aspects of the consultations such as information sharing, decision-making, interpersonal behaviours and patient and doctors' beliefs and orientations. Their findings demonstrated variable levels of support for the positive effects of matching an individual's preference for information, control over decision-making and interpersonal behaviour during the consultation. Despite this, mismatches between an individual's preference and physician behaviour could lead to a negative impact on effective treatment, patient satisfaction and patient emotional well-being.

According to Heisler et al. (2002) medical practitioners vary widely in their provision of recommendations for self-care, and many patients do not receive assistance with self-care. Indeed, DiMatteo (1998) asserts that at least 50% of patients leave a consultation not knowing what they are supposed to do to take care of themselves. Parkin and Skinner (2003) also found a discrepancy between health professionals' and patients' recall of key issues relating to diabetes care discussed in consultations. According to their study results, both groups failed to agree on the diabetes related issue that had been discussed about 20% of the time and there was disagreement on the general self-care goals that had been agreed

just under 50% of the time. In a study designed to determine the frequency of physicians' assessment of people with diabetes' recall and comprehension of new concepts, Schillinger et al., (2003) found that few did this. Where assessment of recall and comprehension did occur, people with diabetes had a lower HbA_{1c} suggesting that within many health encounters an important opportunity is missed which may have far reaching consequences for the person with diabetes. Indeed, Heisler et al. (2002) concluded the influence of communication and provider decision making style on self-care seemed to be at least in part mediated by understanding, therefore "care should be structured to maximise the exchange of information to facilitate patient's self-management" (Heisler et al., 2002, p.250).

Piette, Schillenger, Potter, and Heisler (2003) investigated how general health related communication and diabetes-specific communication was associated with active self-care in a sample of ethnically diverse adults with diabetes. Their cross sectional study demonstrated that general communication was associated with mental and physical function and diabetes specific communication was associated with self-care activities although this varied across the spectrum of self-care activities. They concluded that joint goal setting improved satisfaction and adherence to treatment regimens, and that it was important to provide emotional support to avoid patient burnout.

Epstein et al. (2005) conducted a review on patient centred communication. They differentiated patient centred communication from patient centred care in that patient centred communication is "to help practitioners provide care that is concordant with patients values, needs and preferences and allows patients to provide input and participate actively in discussions regarding their health and health care" (p. 1516). Conversely patient centred care refers to "actions in the service of patient centredness including interpersonal behaviours, technical interventions, and a health system's innovations" (p. 1517). They concluded there is a lack of theoretical and conceptual clarity of terms and therefore problems with measuring patient centred communication. Golin, DiMatteo, Leake, Duan, and Gelberg (2001) conducted a study to determine how to assess who wanted to participate in decision-making. Their study revealed that people with diabetes

with more education about diabetes had more desire to participate, and preferred the final decision to be made by the both them and health professional on an equal basis. Schattner, Bronstein, and Jellin (2006) also found that patients wanted more information from health professionals and to take part in decision-making.

Contexts and Conditions Supporting Participation

Participation in decision-making occurs in potentially differing contexts ranging from the medical context, that is the reason for the consultation (acute or long term); the patient – health professional relational context, that is the person has seen the same health professionals for years or an episodic encounter with a limited history; and the patient’s personal context, that is the systems in which their life is embedded – friends, family, ethnicity and culture (Bylund & Imes, 2005).

Self-care decision making has been described as a complex developmental process taking place within “the context of a disease trajectory, a health care culture, and a uniquely meaningful life” (Thorne et al., 2003, p. 1349). Thorne et al. (2003) examined decision-making in relation to self-care in 21 people with either type 2 diabetes (7), HIV/AIDS (7), or multiple sclerosis (7) who had each had several years of making decisions relating to their self-care. They concluded that self-care has different meanings both to and between individuals and health professionals. Thus they state that self-care “is so intricately bound to the living of a life in all of its complexity and fullness that there might be few truly universal or generalizable features within it” (p. 1349).

Koch, Jenkin, and Kralik (2004) concur following their qualitative study exploring self-management in 24 older adults over the age of 60 years with asthma. Consistent with Greenhalgh’s (2009) view that conventional self-management programmes take a biomedical view of the self characterized by “capacity and motivation to perform certain goal orientated tasks expected by doctors and nurses” (p. 630), Koch et al. commented on the rise of the self-management movement in the literature. They concluded that a “medical prescriptive approach to self-management is widespread, emphasising adherence

to direction given by health care professionals. The self in self-management has been ignored and the person has been objectified as the ‘patient’” (p. 485). Through in-depth interviews, an open-ended questionnaire and two action groups, three models of self-management were identified; the medical model, the collaborative model and the self-agency model. Participants most commonly identified with the medical model which predominantly involved taking medications and following instructions as given. The collaborative model involved a participatory process where both the medical and aspects relating to the ‘self’ could be considered with the person central to the encounter. This model has also been referred to as the partnership paradigm (Bodenheimer, Wagner, et al., 2002). The self-agency model differed in that participants considered themselves to be experts on their own health and their illness response was informed by their experiences of living with and managing their condition. Being in control of their own lives was of central importance to those who claimed to manage the ‘self’. Koch et al. (2004) offer a recommendation “not to assume we know what they want to learn, but rather to offer a participatory partnership that facilitates their control of ‘what’ and how it is offered” (p. 491). Greenhalgh (2009) concurs suggesting an alternate framing of self-management support towards “a sociological self focused on coping with illness rather than managing it” (p. 630).

In one of the few nursing studies found on this topic, Zoffman, Harder, and Kirkeveld (2008) conducted a study with eleven people with poorly managed diabetes and eight nurses. Their qualitative grounded theory study aimed to develop a theory entailing how patient-provider communication and reflection in diabetes care may or may not lead to effective shared decision-making. Their study provides an important re-orientation of perspectives in the literature on communication and shared decision-making. Their findings included difficulties in achieving focused communication in that, patients seldom told professionals what was particularly difficult for them and health professionals seldom shared with the patient what they thought may be particularly difficult for them. In their study most activities with nurses involved disease orientated activities focusing on symptoms, test results and planning treatment as opposed to considering the person’s response to their diabetes in daily life. Zoffman et al. (2008) noted that shared decision-

making is mostly described in the literature as patients being involved in professionals' decision-making, and the finding from their study suggest this is of limited value in the care of people with long term conditions. They state that "shared insight into each patient's decision-making is more valuable than shared insight into professional's decision-making, as it improves the opportunities for supporting each patient in developing self-management of the illness" (p. 680). Furthermore, consistent with recommendations from nursing theorists for many years (Benner, Tanner, & Chelsa, 1996; King, 1981,1997, 2001; Orlando, 1972; Peplau, 1988, 1991; Wiedenbach, 1964) Zoffman et al. (2008) recommend a life-orientated approach as more helpful than a disease-orientated perspective when considering shared decision-making.

A continuum of involvement of nurses in decision-making has been described by Millard, Hallett, and Luker (2006). Unable to find consensus in the literature on a definition for patient participation, nor what it encompasses, Millard et al. identified patient participation as a complex concept, suggesting it incorporates multiple notions such as patient collaboration, patient involvement, patient partnership, shared decision-making and person-centred planning. Furthermore, it is acknowledged that participation as a concept may have multiple culturally defined meanings. Following an ethnographic study involving 22 community nurses and 107 patients, they made 137 observations of interactions examining the extent to which nurses involved patients in decision-making about their care and the manner in which this was conducted. Their study revealed an 'involving-non-involving continuum' to represent the degree to which patients participated in making decisions about their nursing care. The degree of involvement was found to be due in part to the attitudes and behaviours of nurses within individual nurse-patient relationships. In relationships where nurses were more involving, nurses related to patients across both professional (task) and social dimensions (interest in the person), while nurses less likely to involve patients in decision-making restricted their interaction to the professional dimension (i.e. the task to be performed). Millard et al. (2006) suggest that the social dimension of the relationship served a particular purpose in that it "established the nurse and patient as equal actors in the interaction" (p. 148). Indeed, Saba et al. (2006) concluded from their study of people with diabetes, hypertension or both, that it was important for effective decision-making that

attention was paid to both the communication style used and affective relationship dynamics.

Health Care Characteristics Influencing Quality Of Care

Time spent with individuals with a long term condition has previously been identified as the only significant predictor of reduction in HbA_{1c} suggesting that interventions must include adequate time (Norris et al., 2002). In an interpretive study exploring self-care decision-making in diabetes Paterson (2001a) also found that time was one of the key resources required. Time was found to be “significant in interactions with clients who have chronic illness because their illness presents complex medical, psychological and social needs that cannot be addressed in the time-efficient medical model of health care in which only the pathology is addressed” (p. 579).

Continuity of care, length of visit and type of relationship (acute versus ongoing) has also been found to influencing quality of life and positive health outcomes (Adams, Smith, & Ruffin, 2001). Overland, Yue, and Mira (2001) concluded that as people with diabetes age and their health needs become more complex they seek better continuity of care.

Furthermore, exposure to a higher volume of people with a similar health condition as a primary diagnosis, has been demonstrated to be a factor improving quality of care (Adams et al., 2001; Halm, Lee, & Chassin, 2002). When people with asthma experienced increased participatory decision making, an association with increased health-related quality of life was found. Both higher health-related quality of life and higher rating of quality of care was associated with specialist services (Adams et al., 2001).

Summary

The literature is potentially exhaustive on issues pertaining to caring for people with long term conditions, self-care, psychosocial issues and collaborative relationships between health professionals and people with health conditions. A consistent view exists

surrounding the need for care that has at its centre the person and that they are encouraged and supported to actively participate in their care. Evidence is strong that self-care is essential and that those who actively participate have better outcomes. Depression and distress are well recognised in the literature also. However, the links between these three major constructs is not clear. Questions remain surrounding the extent to which diabetes-related emotional distress is associated with differences in health activation and, if so, how is this related to clinically important outcomes. In addition, is the interpersonal relationship between a person with diabetes and health professional associated with either emotional distress or health activation and if so how is this related to clinically important health outcomes?

The following chapter describes the mixed methods methodology employed in this study. It presents an overview of mixed methods methodology and the philosophical stances, justifications for utilising this methodology and its fit with research within the multidisciplinary team.

Introduction

The review of the literature presented in the previous chapter provided an overview of the multiple factors influencing health activation and therefore, active engagement in self-care activities. In this chapter the philosophical and theoretical underpinnings of mixed methods methodology, and its relevance to research for multidisciplinary health care teams and in particular nursing are explored, providing justification for this methodological choice. The study design and sampling strategies are then discussed, including the identification of potential challenges associated with mixed method research designs and how these have been minimised in this study. Research methods, including ethical considerations and expectations considered to protect participants, are presented in the research methods chapter.

Methodology

The “needs-based or contingency approach” (Johnson & Onwuegbuzie, 2004, p. 17) was used to determine the appropriate methodology for this study. According to Greene and Caracelli (1997) the contingency approach is formed on the basis that one method of inquiry is unlikely to provide multiple explanations, instead, “a method’s usefulness depends on the contextual circumstances” (p. 63) surrounding the specific topic of interest. Thus, this cross-sectional two-phase explanatory study utilised mixed methods methodology with a “pragmatic approach” (Morgan, 2007, p. 48) to meet the stated aims and research questions.

The term mixed methods methodology is broadly defined as “research designs using qualitative and quantitative data collection and analysis techniques in either parallel or sequential phases” (Tashakkori & Teddlie, 2003, p. 11). A fundamental principle of mixed methods research is that multiple data is collected using a mixture of different strategies, approaches and methods to produce a research process where strengths are balanced and weaknesses are minimized (Johnson & Onwuegbuzie, 2004). According to Johnson and Onwuegbuzie effective use of this principle is a major source of justification for mixed methods research because the study will have greater strength than if conducted with a

single method. Moreover, Twinn (2003) asserts that this methodology has particular relevance when there is a need to expand our understanding of complex health behaviours and that "the research question rather than a particular research paradigm, determines the approach and methods used to explicate the problem" (p. 544). In particular, a mixed methods methodological approach employing the use of both quantitative and qualitative methods ensures that perceptions of participants are comprehensively honoured.

Mixed methods methodology is an approach to knowledge derived from theory and practice, is commonly partnered with a pragmatic approach, and attempts to take into account multiple stances, perspectives, positions and research approaches (Johnson, 2008). According to Johnson and Onwuegbuzie (2004) a key feature of mixed methods research is "methodological pluralism or eclecticism" (p. 14). It is the explicit framing of two or more paradigms or worldviews (Sandelowski, 2002) with each remaining distinct from the other providing "an axiomatic bridge between epistemological tensions" (Carrier, personal communication, April, 2007). Moreover, Johnson (2008) states that "dichotomizing the world is not going to solve our difficulties; yet listening and learning from the tensions produced by poles can advance our thinking" (p. 204). Paradigms present philosophical assumptions by describing a preference for a "trilogy of concepts from the philosophy of knowledge" (Morgan, 2007, p. 57). As described by Holloway and Wheeler (2010) these concepts relate to distinctions between ontology (the nature of being, the reality or existence), epistemology (the theory of knowledge), methodology (the framework of theories and principles guiding inquiry purposes, questions and logic) and axiomaticology (value laden or value free). Based on the work of Kuhn (1962, 1977), Morgan (2007) refers to four versions of paradigms emphasising that they are not necessarily mutually exclusive: 1) paradigms as world views, 2) paradigms as epistemological stances, 3) paradigms as shared research beliefs among members of a specialty area, and 4) paradigms as model examples of research. Paradigms as world views is considered to be the broadest version, however, paradigms as epistemological stances appears to be the most widespread version utilised in social science research methodology.

Greene and Caracelli (2003) assert that “paradigms are social constructions, historically and culturally embedded discourse practices, and therefore neither inviolate nor unchanging” (p. 95). Within social sciences research literature, three major paradigms as epistemological stances have been identified – positivism, subjectivism and constructivism - from which research methodologies and methods emerge. For the following discussion I have identified two major competing epistemologies – positivism and constructivism - acknowledging subjectivity as a critical element of constructivism.

Competing Paradigms: Positivism and Constructivism

Positivism and constructivism have key assumptive ontological, epistemological, methodological and axiomatic differences and thereby competing dualisms exist. In brief, positivism values realism, deduction, objectivity, reductionism, and generality; while constructivism values relativism, induction, subjectivity, holism and context. Central to positivism is deductive logic, the aim to discover and confirm causal relationships (Davidson & Tolich, 1999). Underlying the positivist approach is reductionism, the assumption that the world may be understood by studying the parts of a bigger picture in isolation of the social context. The constructivist paradigm in contrast is underpinned by an analysis of socially meaningful behaviour in a systematic way to understand how individuals interact with their social world (Davidson & Tolich, 1999). In other words, constructivism attempts to provide an understanding of the world within its context. From these two competing paradigms emerge related methodological approaches and quantitative and qualitative methods.

Quantitative methods are generally grounded by positivist beliefs including that researchers are able to be objective and that variables can be precisely measured (Holloway & Wheeler, 2010). As quantitative methods are traditionally underpinned by deductive logic, they seek consensus and norms or patterns that can be generalised to predict behaviours. In contrast, qualitative methods value personal involvement and subjectivity and are said to encompass the comprehensiveness of people and focus on their experience in every day settings (Holloway & Wheeler, 2010; LoBiondo-Wood & Haber 1994). Through

disciplined inquiry qualitative research can comprehensively explore the unique social and cultural aspects of an individual's experiences and actions (Holloway & Wheeler, 2010; Polgar & Thomas, 1995). Qualitative research can be particularly relevant in nursing as it can assist to define personal and social frameworks in which health care is delivered. The concern is not so much with generating new knowledge but with understanding a particular practice within its wider professional practice context (Holloway & Wheeler, 2010). Qualitative methods are therefore considered more appropriate when the researcher is not seeking to generalise, but rather is seeking "complexity and pluralism" (Davidson & Tolich 1999, p. 115).

An Alternative Approach: Pragmatism

With consideration for the complexity of humans, health, illness and health care services, Morgan (2007) presents an argument for Khun's (1977) third and preferred version of paradigm to be more appropriate within the social science research field, that is, paradigms as shared research beliefs among members of a specialty area. Johnson, Onwuegbuzie, and Turner (2007) concur by describing a research paradigm as a "set of beliefs, values and assumptions that a community of researchers has in common regarding the nature and conduct of research" (p. 24). This idea is further supported by Denscombe (2008) who argues for the use of "communities of practice" (p. 270) as the basis for a research paradigm that allows for diversity while being consistent with the philosophical underpinnings of pragmatism.

As previously mentioned mixed methods methodology connects with the philosophy of pragmatism (Denscombe, 2008; Maxcy, 2003; Teddlie & Tashakkori, 2003). The primary philosophy of pragmatism is that "knowledge is viewed as both constructed and based on the reality of the worlds we experience and live in" (Johnson & Onwuegbuzie, 2004, p. 18). Pragmatism is considered to offer an outcome focused and practical method of inquiry (Johnson & Onwuegbuzie, 2004) and is often presented as the "third methodological movement" (Tashakkori & Teddlie, 2003, p. ix) or more commonly as the third research paradigm (Johnson & Onwuegbuzie, 2004; Johnson, 2008).

The expansion in research approaches has led to conflicts about ontological, epistemological and methodological validity¹. As reported in Cresswell and Tashakkori (2007), Howe (1988) posited the ‘incompatibility thesis’, stating that quantitative and qualitative research approaches and their methods, cannot and should not be used together as they are traditionally associated with two distinct paradigms that are not compatible with each other. According to Symonds and Gorard (2008), theorists utilising quantitative and qualitative research approaches as mono-methods were not convinced that different types of data could support each other or “that methods other than their own could provide a coherent version of reality” (p. 2). However, along with many others in the mixed methods research community, Johnson and Onwuegbuzie (2004) advocate for the “rejection of the incompatibilist, either/or approach to paradigm selection and recommend a more pluralistic or compatibilist approach” (p. 17). In support of this stance, Feilzer (2010) states that when pragmatism is considered as an alternative paradigm or approach it “sidesteps the contentious issues of truth and reality, accepts philosophically, that there are singular and multiple realities that are open to empirical inquiry and orients itself towards solving practical problems in the real world” (p. 8).

Pragmatism differs from the traditional paradigms of positivism and constructivism in that “it is not the abstract pursuit of knowledge through ‘inquiry’ that is central to pragmatic approach, but rather the attempt to gain knowledge in the pursuit of desired ends” (Morgan, 2007, p. 69). Feizler (2010) states that pragmatism “focuses on the problem to be researched and consequences of research” (p. 7). However, with the view that a paradigm consists of shared research beliefs among members of a specialty area Morgan (2007) recommends the term “pragmatic approach” be used, as opposed to pragmatic paradigm, refocusing on “methodological rather than metaphysical concerns” (p. 48). That is, the methodology (driven by the research question) is the “primary determinant of both epistemology and methods” (Bazeley, 2009, p. 88). To summarise the key points, pragmatism and mixed methods research reject the incompatibility thesis, consider the research question as the primary determinant of methods and methodology, embrace both

¹ For a detailed historical account of the emergence of mixed methods refer to Teddlie and Tashakkori in chapter one of the Hand Book of Mixed Methods (2003).

points of view from constructivism and positivism, avoid the use of metaphysical concepts (e.g. ontology) and present a “very practical and applied research philosophy” (Teddlie & Tashakkori, 2003, p. 21).

A great strength of the pragmatic approach to social science research methodology therefore, is its emphasis on “the connection between epistemological concerns about the nature of knowledge that we produce and technical concerns about the methods that we use to generate that knowledge” (Morgan, 2007, p. 73). It would appear logical that the method for a study is not determined by a limited view of science, but on a comprehensive appreciation for all forms of inquiry, with reasoning based on contemporary knowledge about how best to answer research questions. Therefore, when operationalised through the third version of a paradigm, pragmatism avoids the top down approach of ontological assumptions about the nature of reality (Guba & Lincoln, 2005; Morgan, 2007), but rather holds a position of the world as it can be measured, as relating “more closely to an “existential reality” – different elements or layers – some objective, some subjective and some a mixture of the two” (Morgan, 2007, p. 8).

Greene, Caracelli, and Graham (1989) inductively identified five broad purposes of mixed methodological studies which still stand in contemporary mixed methods literature. These are: triangulation (where the purpose is seeking convergence and corroboration); complementarity (where the purpose is seeking elaboration, enhancement, illustration & clarification); development (where the purpose is utilising results from one method to help inform another method); initiation (where the purpose is discovering paradoxes and contradictions in order to reframe the research question); and expansion (where the purpose is seeking to expand the breadth and range of inquiry by using different inquiry methods for different inquiry components). The purpose of undertaking this study was to explore and explain influences on diabetes-related health activation. A two-phase, sequential mixed methodological approach was utilised specifically to provide a fuller understanding through complementarity and expansion.

Methodological Mapping

As previously discussed, mixed methods methodology underpinned by the pragmatic approach concentrates on “methodology as the area that connects issues at the abstract level of epistemology and the mechanical level of actual methods rather than separating our thoughts about the nature of knowledge from our efforts to produce it” (Morgan, 2007, p. 8). Moreover, Morgan suggests a framework for three major methodological choices that are central to the kinds of research purposes researchers pursue and the procedures utilised in that pursuit. These are: the connection of theory and data; the relationship to the research process; and inferences to be obtained from the data. These are displayed in Table 2 aligned with the qualitative, quantitative and pragmatic approach.

Table 2

A Pragmatic Alternative to the Key Issues in Social Science Research Methodology. (Morgan, 2007, p. 71).

	Qualitative approach	Quantitative approach	Pragmatic approach
Connection of theory & data	Induction	Deduction	Abduction
Relationship to research process	Subjectivity	Objectivity	Intersubjectivity
Inference from data	Context	Generality	Transferability

Connection of Theory and Data

Morgan argues that the distinction between induction (discovery of patterns) and deduction (testing of theories and hypotheses) (Johnson & Onwuegbuzie, 2004) as a means of connecting theory and data is virtually impossible in reality to operationalise as the “actual process of moving between theory and data never operates in only one direction” (p. 70). Rather he proposes abductive reasoning that “moves back and forth between induction and deduction by first converting observations into theories and assessing those theories through action” (p. 71). According to Feilzer (2010), abductive reasoning refers to the

“logical connection made by researchers between data and theory, often used for theorising about surprising findings” (p. 10). As such the logic of inquiry with mixed methodology includes the use of induction, deduction, and “abduction (uncovering and relying on the best set of explanations for understanding one’s results” (Johnson & Onwuegbuzie, 2004, p. 17). One of the most common uses of abduction is within sequential designs, as used in this current study, where the results of one study inform the inquiry in the second study. The use of abduction facilitates the interpretation of the data from “a multidimensional perspective, each data set informed, questioned, and enhanced by the others” (Feilzer, 2010, p. 12).

Relationship to Research Process

The second methodological choice is determining the relationship between the researcher and the research process. Morgan argues that the “usual forced dichotomy between subjective and objective is an equally artificial summary of the relationship between the researcher and the research process” (p. 71). Furthermore, Muncey (2009) states that the “false dichotomy between subjectivity and objectivity may not provide the best evidence” (p. 23). Instead, the emphasis on an intersubjective approach pragmatically captures the duality of working between the objective and subjective. Intersubjectivity represents the pragmatic response to incommensurability, or divergence, of ontological stances – in the pragmatic approach the researcher is comfortable with understanding both a single reality and one that is determined by multiple interpretations.

Inference from Data

The final methodological choice is to rise above the distinction between qualitative research findings which are considered to be “specific and context-dependent” (Morgan, 2007, p. 72), and quantitative research findings which are considered to be “universal and generalised” (Morgan, p. 72). According to Morgan, pragmatism rejects the need to choose between the extremes of context or generality but rather advocates transferability. Morgan borrowed the concept of transferability from Lincoln and Guba (1985) who considered the

question of whether what is learned in one context can be relevant in another context as an empirical issue. However, in his use of transferability, Morgan has a subtle but important point of difference by stating that it cannot be simply assumed “that our methods and our approach to research make our results either context bound or generalisable: instead, we need to investigate the factors that affect whether the knowledge we gain can be transferred to other settings” (Morgan, 2007, p. 72). In this context, transferability requires a process of working back and forth between specific results and their more general implications. This approach pragmatically focuses on the degree to which the application of learnings from one type of method in one particular setting can be made with the best utilisation of that knowledge in other settings.

Nonetheless, while promoting a more flexible pragmatic approach to research, Morgan does not advocate total abandon from conducting research using solely qualitative or quantitative research methodological approaches, but rather suggests that problems occur when these two methodological choices are treated as absolute and defining characteristics for these two different research approaches. These problems are exacerbated when we deny the possibility of working back and forth between the two positions. Therefore, the pragmatic approach offers an alternative methodological approach with a pluralistic view on the abductive, intersubjective and transferable aspects of research.

Mixed Methods Methodology and Health Care Teams

The delivery of health services and the research communities within health, encompass a broad range of disciplines for example; nursing, medicine, public health, health promoters, and other professions allied to health. The majority of health professionals function within multidisciplinary teams each with their different “history, value set, and preference for addressing different types of research questions” (O’Cathain, 2009, p. 3). Drawing on their own set of beliefs, values and specific paradigmatic assumptions, each discipline has a frame for what kinds of knowledge are valued and their relevance to application in practice. According to Muncey (2009) the most prominent “model of disease in the western hemisphere is the biomedical model based on the Cartesian philosophy of the body as a

machine” (p. 25). Therefore, scientific methods have dominated in health care research but given the complexity of health and disease and the human response, it would seem that utilising and mixing methods appropriately would provide “the sophisticated range of evidence on which to base practice” (p. 25). Indeed, Leddy and Pepper (1998) state “the notion of one paradigm is not acceptable to sciences, particularly nursing, which deals with human beings, and complex health/illness situations” (p. 74). Monti and Tingen (2006) concur stating “the challenges confronting practitioners of nursing art and science are too numerous and pressing to permit disenchantment for change or challenge to occur by the unqualified acceptance of a single paradigm” (p. 37). Furthermore, Johnson and Onwuegbuzie (2004) suggest that when a “pragmatic and balanced or pluralist position” (p.16) is taken, communication between researchers from different paradigms will be improved as they collectively work towards improving knowledge.

Nursing has frequently been described as both a science and an art and as such has drawn on an eclectic range of knowledge sources such as natural sciences, human sciences, arts and humanities (Bunker, 2006; Rose & Parker, 1994). Meleis (2007) describes the nursing perspective as consisting of four defining characteristics: 1) nature of nursing science as a human science; 2) a practice-orientated discipline; 3) a health-orientated discipline; and 4) a caring discipline (synonymous with the art of nursing). Johnson (2006) undertook a philosophic study to examine the discourse surrounding the art of nursing. Johnson concluded that there were five separate senses of nursing art, described as the nurse’s ability to: “1) grasp meaning in patient encounters; 2) establish a meaningful connection with the patient; 3) skillfully perform nursing activities; 4) rationally determine an appropriate course of nursing action; and 5) morally conduct his or her nursing practice” (p. 133). Peplau (1988) espoused that both nursing science and nursing art are essential and that they can each enlighten and cultivate the other. Hence, as nursing care is focused on promoting health and preventing disease, to promoting functional health and ameliorating suffering and to maximising well being in all aspects of peoples lives, we need “both numbers and words if we are to understand” (Miles & Huberman, 1994, p. 41) and develop nursing theory and practice.

A mixed methods methodological approach holds high regard for the acceptance of difference and the diversity of perspectives. Greene and Caracelli, (2003) state that “the complexity and the pluralism of our contemporary world demands such a commitment” (p. 95). This commitment is compatible with the holistic view of the discipline of nursing which deals with “wholeness, perceptions, experiences, multiple realities, appearances of phenomena, and the existence of phenomena” (Meleis, 1998, p. 88). It is also compatible with Johnson’s (2008) view as previously presented, that rather than dichotomising the world, we should listen and learn from tensions produced from opposing poles. Therefore the mixed method methodological approach, with its methodological pluralism (Johnson & Onwuegbuzie, 2004), fits comfortably within the philosophy of the discipline of nursing and other disciplines within health and is considered to be justified in this study on “pragmatic rather than ideological grounds, to help researchers to engage with the complexity of health, health care, and the environment in which studies take place” (O’Cathain, 2009, p. 4).

As previously presented Greene et al. (1989) inductively identified five broad purposes of mixed methodological studies which still stand in contemporary mixed methods literature. These are: triangulation; complementarity; development; initiation; and expansion. Mixed methods methodology has been utilised in this study to seek complementarity (to provide elaboration, enhancement, illustration and clarification); and expansion (to expand breadth and range of inquiry by using different inquiry methods for different inquiry components). Complementarity and expansion appropriately serve the overall research aims and questions, provide sound justification for the use of mixed methods methodology and guide the selection of an appropriate study design.

Study design

This study was conducted utilising a Sequential (two-phase) Mixed Explanatory Design (Creswell, Plano Clark, Gutmann, & Hanson, 2003). The overall purpose of this design is that qualitative data helps explain or build upon quantitative findings (Creswell & Plano Clark, 2007). Within this design, two phases of the study occur chronologically with

questions for the second phase of the study emerging from the findings from the first phase of the study with data analysis always beginning before all the data are collected (Onwuebugzie & Leech, 2004). Priority can be given to either quantitative or qualitative data or equal status to both, and the two methods are integrated during the interpretation phase (Creswell, 2009; Creswell & Plano Clark, 2007). According to Creswell and Plano Clark, the Explanatory Mixed Sequential design has two variants: the follow up explanations model and the participant selection model. Both of these models have an initial quantitative data collection phase, but they differ in the connection of the two phases and the relative priority placed on the two phases. The follow up explanations model places priority on the quantitative component, whereas the participant selection model prioritises the qualitative component.

As depicted in Figure 4, in this study the participant selection model was employed with priority placed on the qualitative data. The purpose of the quantitative data was to provide an understanding of participant characteristics and factors associated with health activation, diabetes-related emotional distress and provider communication and decision-making styles.

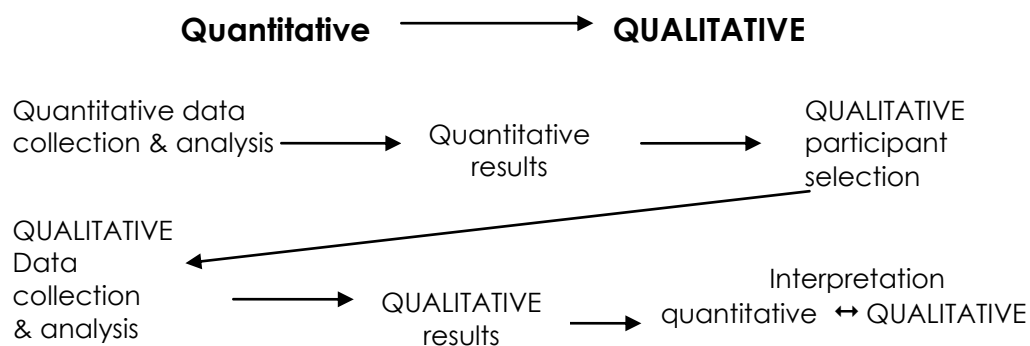


Figure 4. The participant selection model. Adapted from Creswell and Plano Clark (2007, p. 73).

Inter-relationships between constructs were then explored utilising statistical testing. That data was then utilised to guide purposeful sampling, to focus information seeking and suggest analytical paths for the qualitative phase of the study (Sandelowski, 2002). In the

second phase, qualitative interviews were used to probe statistically and non-statistically, but clinically significant, quantitative results by exploring aspects of health activation with a subset of participants who took part in the quantitative phase.

One of the main strengths of the sequential design is its straightforward nature with clear stages, providing ease of implementation and reporting. The design's main weakness can be the length of time involved in collecting data (Creswell, 2009). The sequential design is considered to have particular relevance when there is a need to expand our understanding of complex health behaviours with the purpose of developing appropriate interventions to meet identified health needs (Twinn, 2003).

Challenges to Mixed Method Study Designs

According to Collins, Onwuegbuzie and Jiao (2007) at least four challenges to mixed methods research should be considered when determining the study design. They are representation, legitimization, integration and politics. An ideal study design is one that addresses the research aims and research questions and enables the researcher to concurrently attend to these four challenges as effectively as possible (Onwuegbuzie & Collins, 2007). Each of these challenges is briefly discussed with explanations of how they have been met in this study.

Representation refers to the difficulty in capturing (representing) the lived experiences using text in general, words and numbers. The challenge of representation is often increased in mixed methods research because the elements of both quantitative and qualitative methods bring to the study their unique challenges. The challenge of representation was minimised in this study by employing a sequential mixed explanatory design enabling the data to be collected and analysed separately and in a way that a full, accurate and representative description of the variables of interest could be presented and rigour for each type of data analysis could be assured. Meta-inferences have not been made as participants were not identical in both parts of the study, but rather findings from

both parts of the study have been analysed separately and then integrated during the interpretation phase.

Legitimation or validation is considered to be one of the biggest challenges for using a mixed methods methodology (Onwuegbuzie & Collins, 2007). It refers to the difficulty in obtaining findings and for making inferences that are deemed credible, trustworthy, dependable, transferable and/or confirmable by all consumers of the research (Giddings & Grant, 2009). Readers of purely quantitative research will assess for reliability, and validity (internal, external, construct, content, predictive), whereas readers of qualitative research will seek credibility, relevance, applicability, fairness and trustworthiness (Buetow, 2007). Because the utilisation of quantitative and qualitative methods in the same study aims to combine strengths of each method and minimise weaknesses, the assessment of validity of study findings can be complex (Onwuegbuzie & Johnson, 2006). Furthermore, as the consumers of this research may be diverse, their assessment of the quality or validity will be determined according to different criteria.

Maintaining Rigour

Many qualitative researchers strongly object to the use of the term validity in qualitative research as it is considered to deny the view of multiple truths. Indeed, Onwuegbuzie and Johnson (2006) state “some qualitative researchers view the concept of validity (and the word) as representing a debunked modernist perspective that champions universal rationality, rules, order, logic, and the like” (p. 55). Thus, it is considered counterproductive to use the word validity in mixed methods research. To this end Teddlie and Tashakkori (2003), and Tashakkori and Teddlie (2006) have proposed an alternative framework for assessing the overall quality of mixed methods studies recommending ‘legitimation’ to be used as a more inclusive and descriptive term. Legitimation is described as a process, rather than an outcome, that is “analytical, social, aesthetic, emic, etic, political, and ethical” (Onwuegbuzie & Johnson, 2006, p. 60), with regular checks occurring at each stage of the mixed method research process.

Building on these conceptualisations, Onwuegbuzie and Johnson, (2006) have described a typology of legitimation in mixed methods research where they offer legitimation as a “conceptual framework for mixed methods validity” (Greene, 2006, p. 96). This framework consists of nine types of legitimation, each referring to a separate aspect of methodology (e.g. sampling) or to a different type of mixed methods design (e.g. sequential or concurrent). In this study, the data from both quantitative and qualitative phases of the study were collected and analysed in ways that satisfied quality assurance criteria for each type of method and in a way that a full and accurate description of the variables of interest could be presented. In addition, the typology of legitimation as described above was applied as an overall assessment of quality and is presented at the end of the methods chapter.

The mixed methods methodology was chosen in this study to fulfill the research aims and questions by providing complementarity and expansion of findings. The use of a sequential mixed explanatory design enabled the collection of different types of data, with the quantitative findings utilised to inform the focus for data collection and analytical probing during qualitative data collection and analytical phases. The data from both quantitative and qualitative analyses have been integrated appropriately in the interpretation/discussion phase consistent with the sequential mixed explanatory design.

The challenge of politics as described by Onwuegbuzie and Johnson (2006) relates to the contradictions and inconsistencies that present when quantitative and qualitative data are compared and contrasted. A major barrier to applying mixed-methods can be that quantitative and qualitative methods are centred on divergent assumptions and beliefs about social occurrences and knowledge (Greene & Caracelli, 1997), therefore potential tensions and conflicts may arise when using them together. While it is not always easy to do so because of axiomatic differences, these tensions and conflicts have been minimised by conducting the study in a way that the assumptions and beliefs inherent in both methods have been explicit and honoured. The research questions guided the data collection and the subsequent quantitative and qualitative data have been utilised conscientiously to seek complementarity and expansion of understandings of the constructs of interest.

Summary

In conclusion, this study utilised a mixed methods methodology, incorporating a sequential mixed explanatory design to satisfy the overarching goals of this study: a) to contribute to the understanding of specific influences on health activation; and b) to generate new ideas on how diabetes care can be tailored to maximise personal resourcefulness and promote a high level of health activation. A mixed methods methodology with a pragmatic approach was chosen for this study as it connects philosophically with the discipline of nursing which pays attention to all influences on a person's life from the biological, social, spiritual, cultural, family and to the broader community and socio-political influences. As the broader research community within health and social sciences has become progressively more multidisciplinary, multifaceted and dynamic it has become more important for researchers to be familiar with various research methods and where possible to utilise a complementary approach. As stated by Johnson and Onwuegbuzie (2004) a mixed methods approach has the potential to "facilitate communication, to promote collaboration and to provide superior research" (p. 15). In addition, as this study is likely to be of interest to people with diabetes and multidisciplinary diabetes health care teams, it was important to consider that consumers of research, and in particular different disciplines, attach greater credence to different types of data collection and analytic techniques (i.e. quantitative data versus qualitative data) depending on their disciplinary philosophical background.

The sequential mixed explanatory design was efficient as each study was conducted in a sequential order enabling adequate planning of resource utilisation. This design was compatible with my capabilities as a researcher and has met all ethical requirements as judged by the Central Regions Ethics Committee.

While the utilisation of mixed methods methodology is not always easy to implement because of axiomatic differences, it has been successful in this study as both quantitative and qualitative analyses together have produced more insight than either analysis individually, thus achieving complementarity and expansion and satisfying likely

consumers of this study's findings. Methods utilised in this study are described in the following chapter.

Introduction

The previous chapter presented the research methodology and study design. As discussed this cross-sectional study was conducted with a sequential mixed explanatory design to explore and explain influences on health activation. The quantitative data provided valuable broad contextual information about the population group of adults (over the age of 25 years) with insulin-treated diabetes for the study and provided rationale for participant selection for the priority qualitative component. The qualitative data contributed perspectives and experiences in more detail, providing depth, complementarity and an expanded understanding of the constructs under study.

A research proposal was prepared and approval obtained from the Central Region Ethics Committee and Massey University Human Ethics Committee prior to commencing the study (CEN/07/06/036). The standard ethical requirements to protect participants from harm, respect their right to autonomy, self determination, confidentiality and anonymity formed the basis of planning and conducting the study. The methods utilised in this study for sampling data collection, data analysis, ethical considerations and quality assurance assessments will be discussed.

Participants

All people with type 1 or type 2 diabetes in the MidCentral District Health Board (DHB) area who were over 25 years of age, treated with insulin and able to read and write English were eligible for selection. The majority of people accessing health care services with type 1 and type 2 diabetes are adults, and children and youth have particular age and stage related challenges influencing self-care and adherence to treatment regimens. Therefore this study purposely focused on adults with diabetes, excluding youth as defined by the international definition of youth as less than 25 years of age (Ministry of Youth Affairs, 2002).

Two data collection methods were used in this study – the quantitative phase utilised a survey approach and the qualitative phase utilised face to face or telephone interviews. Sampling strategies, data collection, development of questions and analysis techniques will be discussed separately for each phase of study.

Sampling Strategies

The two-dimensional sampling model (Onwuegbuzie & Collins, 2007) was utilised to determine a rigorous sampling design for this study. The two-dimensional sampling model provides categories in which mixed method sampling designs can be grouped according to a) the time orientation of the components, i.e. sequential or concurrent, and b) the relationship of the quantitative and qualitative samples i.e. identical (exactly the same participants in both the qualitative and quantitative phases of the study); or parallel (samples for the qualitative and quantitative phases are different but drawn from same underlying population; or nested (sample members selected for one component of the study represent a subset of those participants chosen for the other phase of the study); or multilevel (the use of two or more samples that are drawn from different levels of the study). According to Collins et al., (2007) this model provides a framework for “making the decisions explicit and promotes interpretive consistency” (p. 290) between interpretations made and the sampling design used, as well as other stages of the development, planning and implementation of the study.

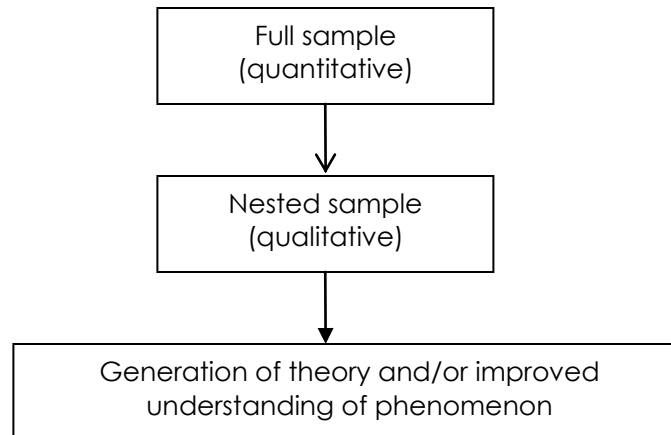


Figure 5. The flow of nested sampling designs. (Onwuegbuzie & Leech, 2007, p. 247).

As depicted in Figure 5, the current study employed a sequential time orientation with a nested relationship between quantitative and qualitative data collection processes, that is the quantitative data was collected first with a large sample, followed by the qualitative data collected with a nested sample.

Quantitative Study Sampling Strategy

A survey approach was taken with the quantitative phase of the study utilising a simple sampling scheme. Simple sampling is defined by Collins et al. (2007) as “every individual in the sampling frame (i.e. desired population) has an equal and independent chance of being chosen” (p. 272). Green (2008) contends that conducting a survey in this way contributes population based sampling frames that are broad, thereby enabling the participants to be situated within an overall population. Therefore, this sampling strategy was chosen because an overall impression of the study’s population group was desired to provide a frame of reference when interpreting qualitative data. The nature of sampling from the full population enabled the quantitative drawing of statistical significances (Collins et al., 2007), and generalisability of results to the broader population of interest. It is important to note however, that a major limitation of this form of data collection and

analysis can be that data not displaying significance is neglected and therefore ‘deviant’ cases are not reported (Carr, 1994).

Sample size is determined by the research aims and questions, followed by the research design (Onwuegbuzie & Collins, 2007). After conducting statistical power analyses on quantitative research designs, Onwuegbuzie and Collins provide minimum sample size recommendations for many of the common research designs. For designs aiming to make correlations between variables, a sample size of 64 participants is recommended for one-tailed hypotheses; or 82 participants for two tailed hypotheses. These sample sizes will enable detection of “moderate effect sizes with 0.80 statistical power at the 5% ($p = < 0.05$) level of significance” (p. 288). Therefore, at least 82 participants would provide a sufficient sample size for the quantitative phase of this current study.

Qualitative Study Sampling Strategy

Findings from the quantitative data analysis were utilised to guide the purposeful sampling for the qualitative phase of the study. The qualitative part of the study consisted of an in-depth exploration through a semi-structured interview with a purposely selected nested sample of participants who indicated their willingness to participate in an interview on their study questionnaire. Purposeful sampling was utilised in this study as the goal was to obtain insights into a phenomenon, individuals or events (Onwuegbuzie & Collins, 2007) as opposed to making broad generalisations about a population. Purposeful sampling selects participants who are most relevant to answering the research question/s and is deliberately biased (Buetow, 2007).

Interviews were chosen for data collection for this part of the study in order to gain the subjective view of participants in depth and to expand on findings from the quantitative results. One of the advantages of interviews is the flexibility to respond to differences that may be individual and situational (Buetow, 2007). It is acknowledged nonetheless, that interview data may be a shifting target, that is both socially and culturally constructed data “combining memory, learned conventions, and narrative models for telling one’s story with

selected life events and conscious or unconscious motivations” (Sandelowski, 2002, p. 106).

Data Collection

Development of study questionnaire.

A survey approach was taken for the quantitative part of the study with data collected by completion of a self-administered questionnaire. Relevant literature was reviewed to determine the most appropriate measures to be utilised in the study. A plethora of measures were found assessing many different aspects considered to impact on a person’s active engagement in diabetes-related self-care, in particular psychological impacts (Polonsky et al., 2005; Snoek et al., 2000), knowledge, empowerment (Anderson, 1995; Anderson & Funnell, 2005), problem solving (Glasgow, Toobert, Barrera, & Strycker, 2004) self-efficacy and locus of control (Auerbach et al., 2002; Bandura, 1991; Cvengros, Christensen, & Lawton, 2004) and readiness to change (Prochaska & DiClemente, 1982). Each of these concepts are important contributors to active self-care although the measure associated with each of them tended to focus on the prediction of a single behaviour. Conversely, the Patient Activation Measure (PAM) (Hibbard, et al., 2004), was found to assess the broad range of elements believed to be involved in ‘health activation’, that is: 1) knowledge, 2) beliefs, 3) skills and 4) behaviours that underpin active engagement in self-care, and was therefore considered to be the most appropriate measure for inclusion this study. The Diabetes Distress Scale (DDS) (Polonsky et al., 2005) was determined to be the most appropriate questionnaire to utilise in this study to assess emotional distress as the DDS and its predecessor (Problem Areas In Diabetes) has been the most widely used tool in the literature focusing on diabetes-related distress. In addition there is evidence of reliability and validity from studies in a variety of countries and with cultural groups as previously discussed in the literature review chapter. The Provider Communication and Decision-Making Style measures (Heisler et al., 2002) were determined to be the most effective measures of provider communication and decision-making respectively, as they were specifically and directly relevant to issues pertaining to the research questions. Additionally, the measures

were relatively brief allowing for focused and efficient data collection and had proven reliability and validity in adults with long term conditions. To my knowledge none of the tools have been previously utilised in New Zealand research so using them in this study provided valuable information as to their utility in adults with diabetes on insulin within the New Zealand context.

The questionnaire.

The study's self-administered questionnaire (Appendix A) consisted of five sections. The first section asked participants to indicate if they wanted assistance from me or a nurse known to them to complete the questionnaire, as it was acknowledged from the consultation process with Maori and Pacific colleagues that participants may prefer the option for face to face, or verbal responding.

The second section was used to collect demographic and health related details for participants. This section asked about age, sex, ethnicity, type of diabetes, duration of diabetes and its treatment, general health, how often they access medical and nursing services for help with self-management of their diabetes, education, location, living arrangements, and other health conditions.

The third section contained the short form of the PAM (Hibbard et al., 2004), a thirteen item scale to measure patient activation. The PAM assesses patient knowledge, skill and confidence for self-care and measures health activation across four stages: 1) belief that an active role is important, 2) confidence and knowledge to take action, 3) taking action, and 4) staying the course under stress. Participants were presented with 13 statements relating to statements about their health (e.g. "When all is said and done, I am the person who is responsible for managing my health condition") and they were asked to indicate their level of agreement on a four point Likert scale ranging from disagree strongly, through disagree, agree, agree strongly and an option of not applicable.

The measure was developed using Rasch analyses and is an interval, unidimensional, Guttman-like measure (Hibbard et al., 2004). The PAM has been found to be stable across differing levels of health status, gender, age groups and several chronic illnesses. Its high reliability estimates indicate the measure is appropriate for individual level use and to assess activation across a variety of subgroups in the population. Reliability assessments were conducted during the development and testing of the PAM by Hibbard et al. (2004, 2005) in a population sample of 1469 aged between 45 to 97 years of age, with 66 percent of the sample under the age of 65 years. Eighty-eight percent of their sample was white, 63% were female and half the sample had high school education or less. Seventy-nine percent of the sample reported at least one long term condition, and among those 73 % reported two or more long term conditions. Internal consistency of the PAM was found to be satisfactory with a Cronbach's alpha coefficient 0.91 for the 13 items. A license was obtained from Insignia Health to include the PAM.

The fourth section contained the "Diabetes Distress Scale" (Polonsky et al., 2005). The scale is a 17 item scale to measure diabetes-related emotional distress. The Diabetes Distress Scale is an updated version of the Problem Areas in Diabetes Scale but is more conceptually driven based on items from four previously established domains of diabetes-related distress. These formed the four subscales within the tool: 1) emotional burden (EB); 2) physician-related distress (PD); 3) regimen-related distress (RD); and 4) diabetes-related interpersonal distress (ID). Participants were presented with 17 statements relating to the potential emotional burden of living with diabetes. They were asked to consider the degree to which each item may have been a problem for them during the past month (e.g. feeling that diabetes is taking up too much of my mental and physical energy every day) and to indicate their level of agreement on a six point Likert scale ranging from not a problem (1) to a serious problem (6).

The Diabetes Distress Scale's structure, reliability and validity was assessed across four clinical sites in two different countries in adults 18 years or older, with a diagnosis of either type 1 or type 2 diabetes, with no severe cognitive or visual limitations (Polonsky et al., 2005). Participants were of different cultural and ethnic groups. Those assessments

provided data to indicate this tool has a consistent, generalisable factor structure and good internal reliability and validity. Specifically Cronbach's alpha was adequate for the total 17 items = 0.93; and for the four subscales EB = 0.88; PD = 0.88; RD = 0.90; and ID = 0.88. Permission was granted by Dr. Bill Polonsky to replicate and use the scale in this study.

The fifth section was an assessment of provider communication and decision-making style utilising a modified version of the validated 10 item scale developed by Heisler et al., (2002). Informed by the work of Kaplan, Gandek, Greenfield, Rogers, and Ware (1995), the items were part of a larger questionnaire created for the Veteran Affairs (VA) Diabetes Quality Improvement Project in the year 2000, and focused on the evaluation of the level of patient involvement in medical decision making and their satisfaction with patient-provider communication. Participants were asked to respond to questions about their doctor/s' and nurse/s' decision-making style (e.g. "How often does your doctor/ nurse offer choices in medical care?") on a four point Likert scale ranging from none of the time, through some of the time, most of the time and all of the time. The questions on communication with their doctor/s and nurse/s measured patient satisfaction with provider communication about their illness and treatment (e.g. "How good is your doctor/nurse at telling you everything?"). In the original measure the questions only asked about physician and patient interaction. For this current study, the same questions were also asked for each medical practitioner and/or nurse participants had seen.

For each statement, participants were also asked to rate how important this was to them on a four point Likert scale ranging from not important, slightly important, somewhat important or very important. Participants were asked to answer these questions on separate pages for each nurse they had seen (e.g. Practice Nurse at their General Practice Surgery, Diabetes Nurse Specialist at the specialist diabetes service, Diabetes Nurse from their Primary Health Organisation, Maori Disease State Management Nurse, or Mobile Community Nurse). Participants were also asked to answer these questions on separate pages for their General Practitioner and Diabetes Specialist Physician. I was instructed by the Ethics Committee to present the two types of medical practitioner roles separately,

although this was not my intention as the diabetes specialist physician would have been easily identifiable. Although no clear rationale was given by the ethics committee for this, I can only assume it was in the interests of consistency of approach between nursing and medicine. If participants had not seen a particular type of doctor or nurse, they were asked to leave those pages blank.

The provider communication and decision-making scales reliability and validity were assessed in a study in which 1314 participants from 25 Veteran Association medical centres were surveyed (Heisler et al., 2002). The sample had a mean age of 67 years and a mean duration of diabetes of 12 years. Almost all were males and 81% were white. Both communication and decision-making scales were found to have adequate reliability with a Cronbach's alpha of 0.93 for all 6 PCOM questions; and 0.94 for all four Decision-making Style questions. Permission was granted by both Dr. Michele Heisler and Dr. Sheree Kaplan separately to utilise the measure in this study.

Piloting of the questionnaire.

Piloting of the initial questionnaire occurred with eight willing adults with diabetes who were attending the local diabetes clinic for routine appointments. As they were waiting to be seen, individuals were approached by the researcher and explanations were given about the study. They were asked if they were willing to provide feed back on study materials, in particular the information sheet and the study questionnaire. Specifically feed back was sought on the clarity of explanations of the study in the information sheet and ease of understanding the questionnaire instructions, appropriateness of the questions and general formatting and appearance of the questionnaire. The questionnaires were completed anonymously and they were offered the choice of taking the questionnaire home with them. Following feed back, no changes were required to the information sheet and minor changes were made to the instructions for completing the questionnaire, as some pilot participants did not know the difference between the different types of nurses, so this was made more explicit in the final questionnaire.

Data collection – Quantitative Study

Survey.

A survey approach, utilising a structured questionnaire, is a typical non-experimental data collection method which allows for the collection of views from large numbers of people across a broad geographical spread. This method of data collection enables the reduction of responses to numbers that can be statistically analysed. Data is then collated and statistically significant findings can be reported and generalised. Participants were recruited utilising the simple sampling method, whereby all people meeting study criteria who were on the Manawatu, Horowhenua, Tararua Diabetes Trust Get Checked data base were mailed out the study materials. It is possible the participants in the pilot were included in the mail out but this was not considered to be problematic as there were only eight. In fact, some of the pilot participants expressed a keenness to be involved. The Manawatu Horowhenua Tararua (MHT) Diabetes Trust mailed out the study materials independent of the researcher to ensure privacy requirements relating to the database were not breached.

Study materials.

The study package contained a covering letter from the MHT Diabetes Trust (Appendix B), the information sheet outlining the study (Appendix C), study questionnaire (Appendix A) and a return slip for participants to indicate their willingness to take part in an interview (Appendix A). A prepaid, addressed envelope was also included for the return of the questionnaire within two weeks of receiving it to the MHT Diabetes Trust. Participants who did not wish to participate were asked to complete the demographics section only so information on non-responders could be obtained.

Participants were mailed study materials in two batches, one month apart, due to resources within the MHT Diabetes Trust. The Dilman 'Total Design Method' (1978) was utilised to maximise response rates. A follow up letter was sent out two weeks after the study

materials were sent thanking those who had returned their questionnaire and serving as a polite reminder for those who were still considering taking part. When using this method, normally two follow up letters would be sent however, only one letter was sent on the instruction of the Ethics Committee.

Upon the request of the Ethics Committee, all primary health care providers were mailed a letter informing them of the study and that their patients would potentially be recruited to take part in the study (Appendix D). The diabetes physician was aware of the study as he was a close colleague and the study had been discussed with him on many occasions. An invitation was issued to contact the researcher for further information should this be required, however none did.

Ethical Considerations

As previously stated, a research proposal was prepared and approved by the Central Region Ethics Committee and Massey University Human Ethics Committee prior to commencing the study. The standard ethical requirements to protect participants from harm, respect their right to autonomy, self determination, confidentiality and anonymity formed the basis of planning and conducting the study.

Protection from harm.

The data collection methods utilised in this study did not present any physical risks to participants and psychological risks were not expected. The potential for anxiety or distress was minimised by participants determining their own level of participation and participants were able to contact the researcher for assistance should distress occur during or after data collection. As some participants were known to the researcher in my clinical role, participants were assured that participation or non-participation would not adversely impact on their health care. Interviews were scheduled at a time and location mutually convenient to the participant and the researcher.

Respect their right to autonomy and self determination.

The study required participants to be adults (over the age of twenty five years of age), English speaking, and able to give informed consent. Participants were recruited through the Manawatu Horowhenua Tararua Diabetes Trust as a third party. All potential participants were provided with a written information sheet Appendix C about the nature and content of the study and were able to self determine their level of participation. Participants were made aware that returning the questionnaire implied consent and were offered assistance from either the researcher or a nurse of their choice to complete the questionnaire if they wished. Those who participated in an interview provided further written consent at the time of the interview. The risk of exploitation was minimised by ensuring the study was scientifically sound prior to commencing and that the study was carried out in a way that was relevant and respectful to potential participants and health care providers. In addition, the questionnaires were mailed out and introduced by a third party. The data collection methods were chosen for this study as it allowed for the collection of views from large numbers of adults with diabetes, and offered the option of both written and verbal responses.

Confidentiality and anonymity.

With consideration for the need for confidentiality and anonymity, participants for the quantitative part of the study were recruited from a third party. Anonymity and confidentiality was assured and maintained throughout the study. The study questionnaires did not contain the name or address of participants and no information identifying a participant was included in any publication of results. Participants interested in taking part in an interview completed their details on a separate sheet to the study questionnaire and were consequently contacted. Audiotapes and transcripts of the interviews and journal notes were stored in a locked filing cabinet. The tapes were labeled with a code and the information linking these codes to participants' names was secured separately. Participants were offered the opportunity to review their interview transcripts and to edit or delete any statements. Electronic storage of the transcripts was password protected known only to

me. Audiotapes were erased on the conclusion of the study and all other research data (rendered anonymous) have been securely stored at my place of work for the mandatory period of five years after which time they will be destroyed.

Cultural appropriateness

This study is not about ‘things Maori’ or specific to Pacific Island people but about an experience pertinent to having diabetes, however it is acknowledged that the experience will be strongly culturally moderated. Maori and Pacific Island participants were encouraged to determine their own level of participation and support. For advice about effective and appropriate recruitment of Maori and to ensure cultural safety, consultation occurred with the Kaumatua and Kuia from the Maori Health Care Team at MidCentral District Health Board (Te Whare Rapuora) in the first instance, prior to submission to the Ethics Committee and the commencement of the study. Advice was sought on the planned study, the questionnaire and recruitment plans. Advice was also sought about the individual nature of the survey questions and the appropriateness for Maori and other cultural groups given the whanau approach to health and well being. However, advice from Kuia and Kaumatua was that it was appropriate to utilise the questionnaire, especially as there was the opportunity for verbal responding and interview as well.

Following this consultation the study was formally approved by the Manager of the Maori Health Unit, MidCentral Health. A further meeting was held with the MidCentral District Health Board Nursing Practice Development Team’s Kaiwhakarite to ascertain and discuss cultural safety issues pertaining to Maori participants and nurses, and to explore the possibility and appropriate manner in which to involve Maori nurses with assisting the recruitment of participants into the study. A meeting was also held with a Pacific Island Nurse Educator at MidCentral Health to ascertain and discuss cultural safety issues specific to Pacific Island people and to explore the possibility and appropriate manner in which to involve Pacific Island nurses with assisting the recruitment of participants into the study. A hui was held with nurses working for the four local Maori Health Care Organisations to explain and discuss the study and to confirm their availability to assist participants with

completing the questionnaire should this be requested (Appendix H). Importantly, advice was obtained from Dr Denise Wilson, then in the School of Health and Social Services, Massey University, who is an expert on Kaupapa Maori Research, on study procedures and analysis of Maori participant data. A commitment was made to consider the Maori participant data as an important subset of data to be independently and jointly reported, with special attention given to reporting issues specific to Maori.

Data Analysis

Quantitative data analysis.

Initially, univariate statistics were utilised to generate data for range of responses, means, and standard deviations for demographic and health related data and for each measure. In addition, the Likert scale response format generated data for bivariate and multivariate statistics utilising all four scales. Responses were analysed for potential differences or relationships between demographic data and other variables, and between variables and across subscales. In particular, *t*-tests and correlations were conducted. The *t*-test is a hypothesis-testing procedure that is used to evaluate differences in mean scores on the dependent variable between two populations or independent variables (Gravetter & Wallnau, 2004). Correlational techniques have been used to determine if relationships exist between groups of participants or specific variables (Munro, 2005). Preliminary analyses were performed on each of the continuous variables to ensure there was no violation of the assumptions of normality, linearity and homoscedasticity (Spicer, 2005).

The *t*-tests and correlations were followed by multiple linear regression analyses utilising standardised beta coefficients. Multiple regression is described by Spicer (2005) as “a data analysis technique that enables the analyst to examine patterns of relationships between multiple independent variables and a single dependent variable” (p.91). Standard multiple regression is when this analysis is conducted in one step. Regression diagnostic procedures yielded no evidence of substantive multicollinearity (highly correlated independent

variables), heteroscedasticity (wide variance of the differences between the obtained and the predicted dependent variable scores) or overly influential outliers in any of the models.

Patient activation measure (Health activation).

All 13 question scores of the PAM were combined into a single '0 to 100' interval scale according to the PAM License Package instructions (May, 2007) to obtain a total PAM score. The PAM divides into one of four progressively higher activation levels: stage one (PAM score of 47.0 or lower) indicates that the participant may not yet believe that the patient role is important. Stage two (PAM score of 47.1 to 55.1) indicates that the participant lacks confidence and knowledge to take action; stage three (PAM score of 55.2 to 67.0) indicates the participant is beginning to take action; and stage four (PAM score of 67.1 or above) indicates that the participant may have difficulty maintaining behaviours over time.

Diabetes-related distress scale.

The DRD was scored by giving the six response options available for each DDS item a value from 1 – 6. Then the total of all 17 items were added together to obtain the total score, then it was divided by 17.

The four subscales scores were obtained by the following process:

- emotional burden - by adding the total scores on items 1, 3, 8, 11 and 14, then dividing the score by 5.
- physician related distress - by adding the total score on items 2, 4, 9, and 15, then divided by 4.
- regimen-related distress - by adding the total score of items 5, 6, 10, 12 and 16, then dividing by 5.
- interpersonal distress - by adding the total score of items 7, 13 and 17, then dividing by 3.

Provider Communication and Decision-making Styles.

The total score for the PCOM measure was obtained by adding the total score of all six questions then dividing that score by six (the total number of items). The same was repeated for PDM except the score was divided by four as there were four items.

Data Collection - Qualitative Study

Interviews.

Participants identified their willingness to participate in an interview when they returned the study questionnaire. However, as there was a time delay between mail outs of the questionnaire, participants returning their questionnaires and the interviews occurring, a letter (Appendix E) was sent informing participants on the status of the study and checking if they still wanted to participate in an interview.

As the primary aim of this study was to understand influences on health activation, the 96 potential interview participants who indicated their willingness to take part in an interview were divided into two groups representing low and high health activation based on their health activation scores. Ten participants from each of the two groups were selected to provide a range of diabetes-related distress scores, sex and other demographic variables shown to be of importance from the quantitative analysis. All six Maori participants who agreed to participate in an interview were included. An attempt was made to ensure an even representation of the Maori participants in each group to reflect the local demographic profile. This provided a possible 20 participants to interview as a starting point with the plan to interview more or less as required for data saturation. Participants were then contacted by telephone to check they were still willing to take part in an interview and as some time had lapsed since participants had returned their questionnaires, questions were invited about the study and an offer was made to resend the information sheet.

Participants were given the option of either an interview in person at a location convenient to the participant, or over the telephone. Conducting interviews over the telephone can have potential disadvantages as they may be less personal and body language cues are unable to be seen and interpreted. Conversely however, it may be more convenient for the participant, participants may feel freer to express themselves, and the participant's story may be told without any researcher interpretation of body cues or potential bias (Buetow, 2007). A consent form (Appendix F) was sent in the post for the participant to read, sign and return to the researcher prior to the interview taking place in keeping with standard ethical requirements.

Interviews lasted between half an hour and an hour. Interviews were semi-structured with a set of open-ended questions (Appendix G) to focus the exploration and obtain in-depth responses to phenomena of specific interest. While the semi-structured approach may reduce flexibility in making the interview relevant to the participant and their context, it maximises the comparability of responses, minimises interviewer effects and facilitates analysis when considering responses across sub-groups (Buetow, 2007).

An interview question guide was developed with content areas defined on theoretical grounds and based on the quantitative findings. The interview question guide contained 10 core questions addressing four topics including: 1) expectation for self-care, 2) health activation, 3) diabetes-related emotional distress, and 4) health professional communication and decision-making style. The interview questions were modified as the interviews were conducted due to participants not understanding the questions and/or as new areas of interest arose during the interviews warranting further investigation. The actual number of questions asked of participants varied depending on whether these issues were relevant to them. Eighteen interviews were conducted with the majority of participants (14) opting for a telephone interview. A decision was made to stop interviewing at this point as data saturation had occurred. Interviews were transcribed by a person paid by the researcher and a confidentiality form was signed. The researcher then listened to a sample of three of the 18 interviews to confirm the transcriber had recorded interview data correctly and

captured verbal cues appropriately. All interviews were subsequently listened to by the researcher in addition to reading the transcripts.

Qualitative Data Analysis

Through interviews, participants' responses were explored to gain an expanded understanding of their experiences and viewpoints. In an attempt to gain insights, qualitative researchers extract meaning from data and develop themes to describe the phenomena under study. De Santis and Ugarriza (2000) define a theme as "an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole" (p. 362). Therefore, data collected from the interviews were subjected to thematic analysis to identify and explore common themes. Morse and Field (1995) describe thematic analysis as involving "the search for and identification of common threads" (p. 139) that extend throughout the data. Boyatzis (1998) characterises thematic analysis as a tool to be used across different methods and asserts that it is not tied to theory or epistemology, thus it provides a flexible and useful research tool. Thematic analysis fits well within this mixed methods study as a method that "works both to reflect reality and to unpick or unravel the surface of reality" (Braun & Clark, 2006, p. 81).

Thematic analysis was conducted using the framework presented by Braun and Clarke (2006). This framework has six phases consisting of:

- 1) the researcher becoming familiar with the data,
- 2) generating initial codes,
- 3) searching for themes,
- 4) reviewing themes,
- 5) defining and naming themes, and
- 6) producing the report.

1) Becoming familiar with the data:

The transcripts were initially read through to gain an impression of ideas and potential patterns. Interviewed participants were assigned a number from 1 to 18 for the purpose of identifying transcripts and gathering relevant excerpts. The transcripts for participants with low health activation scores were then read through again more carefully, with notes taken on initial ideas on 'post it' stickers with the participant identification number and transcript page number recorded. This generated a large number of 'sticky notes' which were then arranged in broad groupings in the style of an affinity chart. The same process was repeated for participants with high activation scores.

2) Generating initial codes:

The affinity chart groupings made with the 'sticky notes' enabled the initial identification of broad codes. The research questions then guided the refocusing of codes. Simultaneously, the transcripts were emailed to one of the research supervisors who independently read the transcripts and identified general codes and potential themes. The researcher and supervisor then met to compare initial analyses.

3) Searching for themes:

The initial broad codes were then arranged around the study constructs of interest (general influences on health activation, diabetes-related emotional distress and how this influences health activation and provider communication and decision-making styles and how these influence health activation), and potential themes began to emerge. However, these themes were still broad and connections were yet to be made between constructs of interest. Specifically, the researcher searched for any similarities or differences in potential themes between those with low and high health activation for both diabetes-related distress and provider communication and decision-making styles. Extracts from the data were collated and grouped according to each code. The intention was to identify themes with common

meaning but also to identify divergent themes that may shed some additional light and offer a different perspective to the complex phenomena under study.

4) Reviewing themes:

Two further meetings were held with study supervisors where initial codes and themes were discussed and potential thematic directions were explored. An assessment was made to ensure the themes ‘worked’ in relation to the general codes generated from the initial read through and across the entire data set. Then a further meeting was held with two research supervisors and local nursing experts to assist the researcher to review and further develop thematic interpretation. Some qualitative research texts recommend ‘member checking’ of data, that is, asking participants to review developing themes as a measure of trustworthiness of the researcher’s interpretations. However, Sandelowski (2002) suggests “such member validation exercises are themselves the ambiguous results of particular social interactions in which members are not always the best judge of what a valid research account is” (p. 108). In justifying this position Sandelowski purports that participants may “forget what they have said, regret what they have said, feel compelled to agree with researchers, or as we all do, have the need to present themselves in different ways at different times” (p. 108). Therefore, while those participants who requested a copy of their transcripts were provided with one, participants were not asked to review the developing themes. General themes however, were discussed informally and opportunistically with adults with diabetes who had not participated in the study to test their general fittingness.

5) Defining and naming themes:

The initial themes were considered and final themes were named by the researcher with descriptions of meaning provided. Initially as many codes as possible were made to ensure broad coverage. Next the codes were compared and contrasted and then grouped into categories, making sure that the categories contained similar codes. This generated a number of categories that were increasingly complex and inclusive leading to the

development and naming of themes. Themes were grouped around the study's main constructs that is, health activation, diabetes-related emotional distress and provider communication and decision-making styles. Relationships between themes were also considered as some codes and categories fitted into more than one theme.

6) Producing the report:

Consistent with the sequential mixed explanatory design the results from the thematic analysis are reported separately in chapters 6, 7 and 8.

Legitimation

Strengths of each approach have been maximised to complement each other and minimise the weaknesses. Strategies to ensure legitimation (or validation) criteria according to the Typology of Legitimation (Onwuegbuzie & Johnson, 2006, p. 57) were met for the study as outlined below. As can be seen all the legitimation types were accounted for with the exception of conversion legitimation as it was not relevant due to data not being converted (i.e. quantitative to qualitative and vice versa).

Typology of legitimation.

Sample integration legitimation.

The extent to which the relationship between the quantitative and qualitative sampling designs yields quality meta-inferences:

- A sequential mixed design with priority on qualitative component was utilised appropriately
- An appropriate two dimensional sampling design was utilised to promote theoretical validity and audit trails
- Meta inferences were not made, however quantitative and qualitative data sets were subjected to abductive reasoning during the interpretation phase.

Inside-outside legitimisation.

The extent to which the researcher accurately presents and appropriately utilises the insider's view and the observer's views for purposes such as description and explanation:

- Independent review of transcripts by supervisor with comparison drawn of themes generated by researcher and supervisor
- Themes reviewed by third party nurse experts to confirm credibility and fittingness of interpretation
- Emerging themes were discussed with adults with diabetes for confirmation of fittingness
- Sequential design consistent with explanatory studies – with both quantitative and qualitative data analysis
- An intersubjective approach was maintained with both the objective and subjective roles played simultaneously.

Weakness minimisation legitimisation.

The extent to which the weakness from one approach is compensated for by the strengths from the other approach:

- Collection of quantitative data provided broad population base information about study participants. Adequate power enabled the objective data to be generalised and the subjective qualitative data provided context. Together, quantitative and qualitative findings can be applied to enable transferability of findings to other settings
- Consideration was given to non-statistically significant findings for relevance to clinical practice.

Sequential legitimisation.

The extent to which one has minimised the potential problem wherein the meta-inferences could be affected by reversing the sequence of the quantitative and qualitative phases:

- Constructs of interest were chosen for the study based on clinical experience and anecdotal accounts from adults with diabetes
- Meta-inferences were not made as participants were not identical in each study
- It is possible different results would have been obtained if the sequence of phases were reversed, however, it is expected that the results would not have differed conceptually.

Conversion legitimization.

The extent to which converting qualitative data to quantitative data, and qualitative data to quantitative data yields quality meta-inferences:

- Not applicable as conversion of quantitative data to qualitative data, or qualitative data to quantitative data did not occur in this study. Rather the two data sets were considered together during the analysis and interpretation phase.

Paradigmatic mixing legitimization.

The extent to which the researcher's epistemological, ontological, axiological, methodological, and rhetorical beliefs that underlie the quantitative and qualitative approaches are successfully (a) combined or (b) blended into a useable package:

- Pragmatic approach was utilised which focused on methodological issues rather than metaphysical issues
- Pragmatism provided an axiomatic bridge between epistemological tensions and promoted utilisation of appropriate tools to meet ends
- Approaches are blended by utilisation of findings from quantitative study informing qualitative and vice versa.

Commensurability legitimization.

The extent to which the meta-inferences made reflect a mixed worldview based on the cognitive process of Gestalt switching and integration:

- This study was not ontology driven but based on methodology as the primary determinant of the study framework, therefore honouring multiple perspectives
- Meta-inferences were not made as the participants were not the same in both studies, however findings from both studies have been integrated and considered abductively and intersubjectively during the interpretation phase to reflect multiple realities.

Multiple validities legitimization.

The extent to which addressing legitimization of the quantitative and qualitative components of the study results from the use of quantitative and qualitative, and mixed validity types, yielding high quality meta-inferences:

- Appropriate assessments of quality for quantitative and qualitative methods have been employed, thus achieving internal and external validity and reliability for the quantitative phase; and credibility, fittingness, auditability and confirmability for the qualitative phase as detailed below:

Quantitative.

- Internal validity:
 - Questionnaire was pilot tested prior to data collection
 - The same questionnaire administered to all participants
 - Appropriate design to answer study questions
- External validity:
 - Simple sampling
 - Adequate power
 - Appropriate sampling strategies

- Reliability:
 - Internal consistency assessments of all measures were conducted and found to be satisfactory

Qualitative.

Credibility:

- Rich, thick description of qualitative data was provided to convey the findings
- Different data sources were utilised to build a coherent justification for themes
- Negative and discrepant data running counter to themes identified have been acknowledged and discussed
- Researcher bias identified through self-reflection of my background (e.g. being female, NZ European, a nurse, daughter, wife, sister and middle class socioeconomic status) and how this may have shaped my interpretation of data was acknowledged

Fittingness:

- Results resonate with other contexts outside the study settings

Auditability:

- A clear audit trail of data analysis and decision-making procedures were described
- Expert critique and peer debriefing occurred to enhance the accuracy of my interpretations

Confirmability:

- Credibility, fittingness and auditability have been demonstrated.

Political legitimization.

The extent to which the consumers of mixed methods research value the meta-inferences stemming from both the quantitative and qualitative components of a study:

- Different consumers of this research will appreciate findings from each part of the study as they relate to their paradigmatic beliefs.

Summary

This study used a mixed methodological approach with a two-phase sequential mixed explanatory design, with the purpose of minimising the weaknesses and complementing the strengths of each method of data collection and analysis. Combining methods in this study was important for fulfilling the study's goals and has produced superior results. If quantitative methods alone were employed the data would be relatively devoid of contextual richness. However, if only qualitative methods were utilised, in-depth information on a small cohort would have been obtained but the insights, while true and real for them, may or may not be representative of the broader population of interest. It is important to note that as the variables being explored are dynamic, the potential for bias of results is real due to participants responding 'on the day' depending on how they felt and this applies equally for both the quantitative and qualitative data collection methods.

It was important to use methods that would appeal to as many potential consumers of the research. In particular, people with diabetes will have a high level of interest in the findings and it is important that their stories are heard as their stories assist to ground the findings in their reality. Furthermore, from a cultural perspective, consultation with Maori and Pacific leaders during the development of the study confirmed the requirement to approach data collection in a varied way.

The next four chapters present the quantitative and qualitative results respectively. They are followed by a discussion and conclusions chapter where the results of both studies are integrated, interpreted and discussed.

Introduction

A sequential mixed methods design has been used in this study to explore and explain factors associated with differences in health activation (HA), in particular relationships between diabetes-related distress and provider communication and decision-making styles on HA. The quantitative data collection involved a self-administered questionnaire comprised of four measures: the Patient Activation Measure (PAM), the Diabetes-related Distress Scale (DDS), the Provider Communication style (PCOM) scale and the Provider Decision-making style (PDM) scale. In this chapter, the results from the quantitative analysis - range of responses, means, standard deviations, and univariate statistics - will be presented individually for each scale. This is followed by bivariate and multivariate statistics utilising all four scales. For multiple regression analyses, an evaluation of the standard multivariate assumptions was performed through examination of the residuals for all relevant variables. Assumptions of normality, linearity and homoscedasticity of demographic variables were adequately met, so there were no transformations of variables or exclusion of outliers. Since no *a priori* hypotheses had been made to determine the order of entry of the independent variables, all variables indicated in the model were entered simultaneously. All tests are two-tailed and statistical significance is cited at $p < 0.05$.

Sample Description

Of the 982 people with diabetes on insulin over the age of 25 years invited to participate, 220 returned a completed questionnaire. This represents a response rate of 22%. Participants had a mean age of 62 years ($SD = 13.69$) with a range of 26 to 90 years and just over half were males. Full demographic details for participants are summarised in Table 3. Participants had a mean duration of diabetes of nearly twenty years (mean = 19.8, $SD = 12.50$) and a HbA_{1c} range of 5.5 – 12.3% (mean = 7.9%, $SD = 1.23$). The number of Maori participants (6%) was insufficient to fulfill the commitment made in the methods chapter to consider the Maori participant data as an important subset of data to be independently and jointly reported. Subsequent advice from Dr. Wilson confirmed that the

Maori participant data could not be meaningfully considered separate from other participant data.

Table 3

Participant Demographics, N = 220 (% = percent of valid data)

Characteristic	N	%
Sex	N = 220	
Male	119	(54.3)
Female	101	(45.7)
Ethnicity	N = 220	
NZ European/Other	207	(94.1)
Maori	13	(5.9)
Highest education	N = 216	
Primary schooling	8	(3.7)
1-3 years secondary schooling	79	(36.6)
4 or more years of secondary schooling	35	(16.2)
Trade or professional certificate or diploma	69	(31.9)
University degree	25	(11.6)
Geographical location	N = 217	
City population $\geq 30,000$	90	(41.5)
City population $>10,000-29,000$	64	(29.5)
City population $1000-10,000$	41	(18.9)
City population $300-1000$	8	(3.7)
Rural outside city boundaries	14	(6.5)
Living with	N = 218	
Spouse/partner	127	(58.3)
Spouse/partner and children	34	(15.6)
Children only	8	(3.7)
Other relatives or unrelated adults/Other	6	(2.8)
Alone	37	(17.0)
Residential Care	4	(1.8)
Other	2	(0.9)

Health related characteristics are presented in Table 4 where it can be seen that three quarters of participants were treated with insulin only and over half had type 2 diabetes. While participants had between one and 11 co-morbidities (median = 2.00, $SD = 2.17$) not necessarily related to their diabetes, most rated their health as good, very good or excellent.

Table 4

Participant Health Related Characteristics, N = 220 (% = percent of valid data)

Health related demographics	<i>N</i>	<i>n</i>	%
Type of diabetes	<i>N</i> = 218		
Type 1 diabetes		85	(39.0)
Type 2 diabetes		133	(61.0)
Diabetes treatment	<i>N</i> = 215		
Insulin only		163	(75.8)
Insulin and diabetes tablets		52	(24.2)
General health	<i>N</i> = 214		
Excellent		26	(12.1)
Very good		66	(30.8)
Good		73	(34.1)
Fair		36	(16.8)
Poor		10	(4.7)
Very poor		3	(1.6)
How often see General Practitioner for self- management help	<i>N</i> = 213		
Once a month		13	(6.1)
Once every 3 months		105	(49.3)
Once every 6 months		42	(19.7)
Once a year		40	(18.8)
Never		0	(0)
Other		13	(6.1)

Table 4 (continued)

Participant's Health Related Characteristics, N = 220 (% = percentage of valid data)

Health related demographics	<i>N</i>	<i>n</i>	%
How often see a nurse for self-management help	<i>N</i> = 198		
Once month		22	(11.1)
Once every 3 months		31	(15.7)
Once every 6 months		28	(14.1)
Once year		54	(27.3)
Never		14	(7.1)
Other		49	(24.7)
Has other health conditions (each participant may have more than one condition)			
Arthritis or rheumatism		73	(33.8)
Asthma / chronic bronchitis / emphysema		28	(13.0)
Bowel disorders, e.g. colitis or polyps		25	(11.6)
Cancer		17	(7.9)
Chronic kidney or urinary tract conditions		28	(12.9)
Chronic liver trouble, e.g. cirrhosis/hepatitis		5	(2.3)
Chronic skin conditions, e.g. dermatitis or psoriasis		15	(6.9)
Depression, anxiety, other mental health problems		30	(13.9)
Epilepsy		1	(0.5)
Hearing impairment or loss		67	(30.9)
Heart trouble/stroke/ high blood pressure or hypertension		196	(82.7)
Hernia or rupture/ stomach ulcer or duodenal ulcer		14	(6.9)
Sight impairment or loss		89	(41.0)

The relationships between participant demographics and health related characteristics were then investigated using Pearson product-moment correlation co-efficients and are displayed in Appendix I. General health was reverse coded to enable a more logical interpretation of analyses. As displayed in Appendix I, type 1 diabetes had small associations with a higher level of education, having a longer duration of diabetes, better general health but a higher HbA_{1c}. Moderate associations were found between type 1 diabetes and being younger and having fewer co-morbidities. Having type 2 diabetes was moderately associated with older

age, poorer general health and more co-morbidities. Higher HbA_{1c} was found to have a small association with being younger, having type 1 diabetes and being of Maori ethnicity.

Patient Activation Measure (Health Activation)

The Patient Activation Measure (PAM) measured the participants' knowledge, skills and confidence for self-care. It consisted of 13 items each with a Likert scale response format with four options: disagree strongly, disagree, agree, agree strongly, and an additional option was provided for not applicable. As discussed in the methods chapter, the PAM provides a score equating to one of four progressively higher activation levels where stage one is low health activation and stage four is high health activation.

Health activation scores are calculated based on the number of items answered by each participant according to the PAM scoring instructions. Internal consistency of the PAM was found to be satisfactory with a Cronbach's alpha coefficient of 0.91 for the 13 items. Participants were initially stratified into the four groups to provide an understanding of where participants self rated their level of health activation, however all statistical tests utilised the total PAM score as a continuous variable to ensure assumptions for tests were not violated. Of the 220 participants 2 did not provide sufficient items to generate a valid score and were therefore dropped from this analysis providing a total of 218 participants with a health activation score. The mean health activation score for the 218 participants was 63.44 ($SD = 18.1$), ranging from 13.3 to 100 from a possible 0-100. The full details of the number and distribution of responses to individual items of the PAM is included in Appendix J. Examination of mean scores' histograms show a relatively normal distribution although as can be seen in Table 5, nearly three quarters of participants (73.6%) in the current study are grouped into either health activation stages three or four.

Table 5

Health Activation Stages, N = 218.

Health Activation level	n	%
Stage 1: Believes active role is important	31	(14.2)
Stage 2: Has confidence and knowledge to take action	25	(11.5)
Stage 3: Takes action	79	(36.2)
Stage 4: Maintains action under stress	83	(38.1)

Correlations.

The relationship between health activation (HA) and participant demographic characteristics was investigated using Pearson product-moment correlation coefficients. Preliminary analyses were performed on each of the variables to ensure no violation of the assumptions of normality, linearity and homoscedasticity. On examination of the histogram, number of co-morbidities was found to be moderately negatively skewed therefore a square root transformation was performed. Square root transformation is most commonly used to transform ‘count’ data as opposed to a logarithm transformation used to transform ‘size’ data (McDonald, 2009). Subsequent analyses were conducted using both the non-transformed and transformed scores and this was not found to make any differences to the results obtained. Thus, for simplicity, only the non-transformed scores are reported and only correlations between health activation and participant demographics are presented in Table 6. Appendix K contains correlations between health activation and health-related characteristics. A small, negative association suggests that higher HA is associated with younger age. A small, positive association correlation was found between HA and general health, and HA and educational achievement, suggesting higher health activation is associated with better general health and higher educational achievement.

Table 6

Correlations between health activation (HA) and participant demographics, N = 218

	HA	Health	Age	Sex	Ethnicity	Education	Location
HA	-	.274***	-.302***	.131	.040	.319***	-.079
Health		-	-.004	-.153*	.026	-.139*	.008
Age			-	-.213**	.056	-.268***	.050
Sex				-	-.088	.005	.011
Ethnicity					-	.121	-.023
Education						-	-.058
Location							-

* $p < .05$, ** $p < .01$, *** $p < .001$ **Multiple linear regression.**

A multiple regression analysis was performed in order to determine which of the demographic variables or health related characteristics with theoretical interest or a previously reported significant relationship, made the greatest unique contribution to health activation. All regression analyses are reported with standardised β . Based on the multiple linear regression analysis, as illustrated in Table 7, the adjusted R^2 for model one was .21. The significant variables in model one therefore explain 21% of the variance in health activation ($p = < .001$). Of the nine variables entered, better general health contributed the largest unique contribution ($\beta = .255$) to higher activation levels. Higher educational achievement also made a significant contribution ($\beta = .234$) to health activation. Younger age made the next largest contribution ($\beta = -.209$), with being female also making a contribution to the variance ($\beta = .135$). As can be seen, HbA_{1c} level, number of co-morbidities, type of diabetes, and frequency of visits to either a nurse or medical practitioner did not make a significant contribution to the variance in health activation.

Based on model one, a further multiple linear regression analysis was performed with only the independent variables making a significant contribution to health activation. As illustrated in Table 7, the adjusted R^2 for model two was .21 therefore the significant variables in model two explain 21% of the variance in health activation. Of the four variables entered, better general health contributed the largest unique contribution ($\beta = .261$) to higher activation levels. Higher education made the next largest contribution ($\beta = .225$), and younger age made also made a significant contribution ($\beta = -.214$) to health activation. Being female did not quite reach statistical significance.

Table 7
Predictors of Health Activation

Variable	Health Activation		
	Model 1 β	Model 2 β	95% CI
Constant			
Age	-.209	-.214**	[-.447, -.112]
Female	.135***	.124	[-.036, 9.015]
Highest education	.234*	.225**	[1.562, 5.589]
General Health	.255**	.261***	[2.243, 6.276]
Number of co-morbidities	.028***		
Type 2 diabetes	-.046		
HbA _{1c}	-.071		
Frequency of Medical visits	-.112		
Frequency of nurse visits	-.013		
Adjusted R^2	.21	.21	
F	6.572***	14.937***	

Note. $N = 218$. CI = Confidence interval. * $p < .05$, ** $p < .01$, *** $p < .001$

Health activation overview.

Small but significant relationships between a number of demographic variables, health related characteristics and health activation were presented demonstrating that, for

participants in this study, higher health activation levels were seen in those with better general health, more highly educated, and younger age. Health activation does not seem to be associated with duration of diabetes, geographical location, ethnicity, glycaemic control as measured by HbA_{1c} or by frequency of visits with nurses or medical practitioners. Of particular interest, while most participants scored a health activation stage of three and four, suggesting a reasonably high level of engagement in diabetes self-care, this did not necessarily translate into lower HbA_{1c} levels, that is, more optimal glycaemic control. This is of interest as it could be expected that higher health activation would have a positive effect on HbA_{1c} levels. It is also of interest that frequency of visits with a health professional did not appear to contribute to the variance on health activation possibly suggesting that what occurs at the visits that may be more important than frequency, or indeed that health activation is not related to health services at all.

Diabetes-related Distress

The Diabetes-related Distress Scale (DDS) is a measure of diabetes specific emotional distress. It consisted of 17 items with a six point Likert scale response format ranging from 1 = not a problem to 6 = a serious problem. Of the 220 participants who returned a completed study questionnaire, 201 completed the DDS. Consistent with reliability assessments conducted by Polonsky et al. (2005), in this study, the Diabetes-related Distress (DRD) Scale had good internal consistency with a Cronbach's alpha coefficient of 0.93 for the 17 items. For each of the subscales Cronbach's alpha is 0.86 for Emotional Burden (EB); 0.88 for Physician-related Distress (PD); 0.86 for Regimen-related Distress (RD); and 0.88 for Interpersonal Distress (ID).

As previously mentioned in the methods chapter, individual item scores were converted into total scores according to scoring instructions accompanying the scale (Polonsky et al., 2005). On examination of the histogram, the total DRD mean scores were found to be moderately negatively skewed. A square root transformation was performed to normalise the data. Subsequent analyses were conducted using both the non transformed and transformed scores and this was not found to make any substantive differences to the results obtained. Thus, for simplicity, only the non transformed scores are reported.

Overall, a relatively low level of diabetes-related distress (DRD) was reported with a mean score of 2.00, $SD = 0.92$ (range = 1.00 to 5.47). Responses to individual items are presented in Appendix L. The items where 30% or more participants rated three or more on the DRD questionnaire included ‘feeling that I am often failing with my diabetes regimen’ (35%), ‘feeling that diabetes controls my life’ (39%); ‘feeling that long term complications are inevitable no matter what I do’ (47%); ‘feeling that family and friends don’t appreciate how difficult living with diabetes can be’ (40%), ‘feeling that I am not sticking closely to a good meal plan’ (35%) and ‘feeling that diabetes is taking up too much of my mental and physical energy ever day’ (30%). As presented in Table 8, the total scale mean score was relatively low, as were subscale mean scores with the emotional subscale providing the highest mean score of 2.25 ($SD = 1.19$).

Table 8

Mean Total Diabetes-related Distress Scores and Subscales Scores

Diabetes Distress Scale	Mean	(SD)
Total scale	2.00	(0.92)
Subscales		
Emotional burden	2.25	(1.19)
Physician-related distress	1.63	(1.02)
Regimen-related distress	2.06	(1.02)
Interpersonal distress	2.04	(1.28)

Correlations.

Relationships between diabetes-related distress (DRD) and participant demographic characteristics were investigated using Pearson product-moment correlation coefficients. Preliminary analyses were performed on each of the variables to ensure no violation of the assumptions of normality, linearity and homoscedasticity. As can be seen in Table 9 age and general health were found to be moderately correlated with DRD, with younger age and poorer health associated with higher DRD scores. Being female and having and

higher HbA_{1c} levels had a small correlation with higher DRD scores. There were no significant correlations with other demographic variables.

Table 9

Correlations between Diabetes-related Distress and sample demographics

(Ns = 184 – 201)

DRD	<i>r</i>
Age	-.365***
Female	.177*
Ethnicity	-.013
Education	.033
Size of geographical location	.022
General health over past 4 weeks	-.439***
Type of diabetes	-.086
Years with diabetes	-.006
HbA _{1c}	.252***
Number of co-morbidities	.035
Frequency of nurse visits	.046
Frequency of doctor visit	.101

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

Correlations were then performed for variables found to have significant relationships with DRD total score, for each subscale within the Diabetes-Distress Scale. It can be seen in Table 10 that younger age and higher HbA_{1c} was associated with increased distress relating to emotional burden, regimen related issues and interpersonal distress subscales. General health had small to moderate associations with all subscales suggesting that poorer health impacts across the spectrum of diabetes-related distress.

Table 10

Correlation of Demographic and Health-related Characteristics with Diabetes-related Distress subscales

	Diabetes-Related Distress Subscales			
	Emotional burden	Physician related distress	Regimen-related distress	Interpersonal distress
Age	-.349***	-.129	-.389***	-.236***
Female	.144*	.120	.091	.159*
HbA _{1c}	.195**	.084	.390***	.201**
General health	-.436***	-.242***	-.295***	-.449**

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

Multiple linear regression.

To further explore the contribution of demographic and health-related characteristics with significant associations with DRD, a multiple regression analysis was performed and is reported with standardized β . Preliminary regression analyses were performed with other variables of theoretical interest such as who the participant lived with, geographical location and frequency of visits with a health professional, however they did not yield any statistically significant results, therefore only the final model below is presented in Table 11. Based on this analysis, the adjusted R^2 for the model of .333 indicates that the model explain 33% of the variance in diabetes-related distress. As presented in Table 11, of the four variables entered, general health makes the largest unique contribution ($\beta = -.422$) with the negative beta demonstrating participants with poorer health experienced more diabetes-related distress. Age makes the next largest contribution ($\beta = -.312$) suggesting younger participants experience higher DRD. Higher HbA_{1c} levels made the third largest contribution ($\beta = .174$).

Table 11

Predictors of Diabetes-related Distress

Variable	Diabetes-related distress	
	β	95% CI
Constant		[2.460, 4.832]
Age	-.312***	[-.029, -.013]
Female	.049	[-.130, .311]
HbA _{1c}	.174**	[.041, .219]
General health	-.422***	[-.450, -.256]
Adjusted R^2		.33
F		25.626***

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

Diabetes-related distress overview.

Overall, it appears from analysis of demographic characteristics that diabetes-related distress was more likely to occur in adults who were younger, or who had poorer general health. Not surprisingly, higher HbA_{1c} levels were associated with more diabetes-related distress. Analysis of the DRD subscales shows that younger age and higher HbA_{1c} was associated with increased distress relating to emotional burden, regimen related issues and interpersonal distress subscales. General health had small to moderate correlations with across all subscales suggesting that poorer health impacts across the spectrum of diabetes-related distress. A multiple regression analysis showed that general health made the largest unique contribution with poorer health associated with more diabetes-related distress.

Provider Communication and Decision-Making Styles

The Provider Communication (PCOM) style and Decision-Making (PDM) style measures assessed participant's perceptions of how health professionals communicate information about their condition and treatment options to them, and the degree to which they are involved in decisions relating to treatment of their condition. The measures consisted of

six items in relation to communication and four items in relation to decision-making, each with a four point Likert scale response format with options 'poor', 'fair', 'good' or 'excellent'. In addition, participants were asked to rate how important each of the items was to them, also with a four point Likert scale response format ranging from 'not', 'slightly', 'somewhat' to 'very'. Questions were repeated for each of the different types of doctors (General Practitioner and Diabetes Specialist Physician) and Nurses (Practice Nurses, Diabetes Specialist Nurses, Primary Health Organisation Diabetes Nurses, Maori Disease State Nurses or Mobile Community Nurses) from whom participants had received care for their diabetes. Internal consistency of the Provider Communication (PCOM) and Decision-making Style (PDM) measures was assessed. Both were found to have adequate reliability with a Cronbach's alpha of 0.93 for all 6 PCOM questions; and 0.94 for all four Decision-making Style questions.

Response rates to questions about each of the different types of doctors and nurses varied and the response rate between ratings of 'how good' they were at communicating and decision-making and 'how important' it was to them also varied. Response rates and responses to individual items for each type of doctor and nurse are presented in Appendices M and N. As the numbers of responses was low for Primary Health Organisation Diabetes Nurses ($n = 37 - 45$), Maori Disease State Nurses ($n = 2$) and Mobile Community Nurses ($n = 5$), their data has not been included in the analyses to follow.

Mean scores.

As previously mentioned in the methods chapter, individual item scores were converted into total scores. Mean PCOM scores ranged from 2.88 to 3.51 for the four health professional groups and mean PDM scores ranged from 2.30 to 3.05 from a possible range of 1- 4. Paired sample *t*-tests were performed to compare total mean scores between each of the health professional groups in order to determine how well participants perceived the performance of health professionals providing care, and if there was a difference between different types of medical and nursing roles. However, as some participants rated more than one health professional, these are reported descriptively rather than statistically due to dependence issues.

Provider Communication (PCOM) and Provider Decision-making (PDM) styles mean scores for each type of doctor or nurse are presented in Figures 6 and 7 for each item.

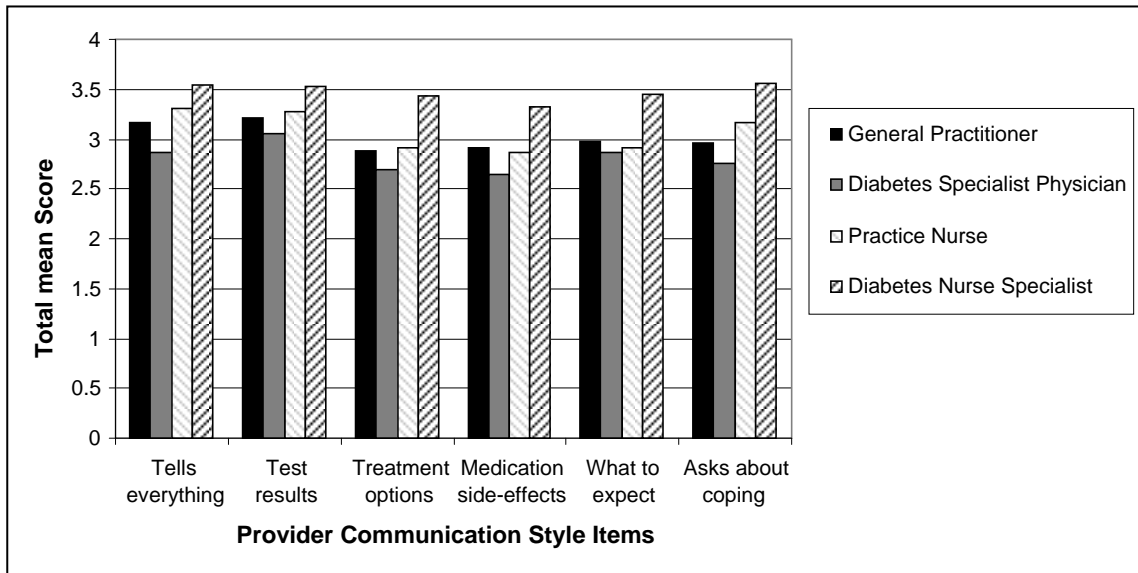


Figure 6. Provider Communication style – ‘How good is your doctor or nurse at...?’ mean scores by provider group

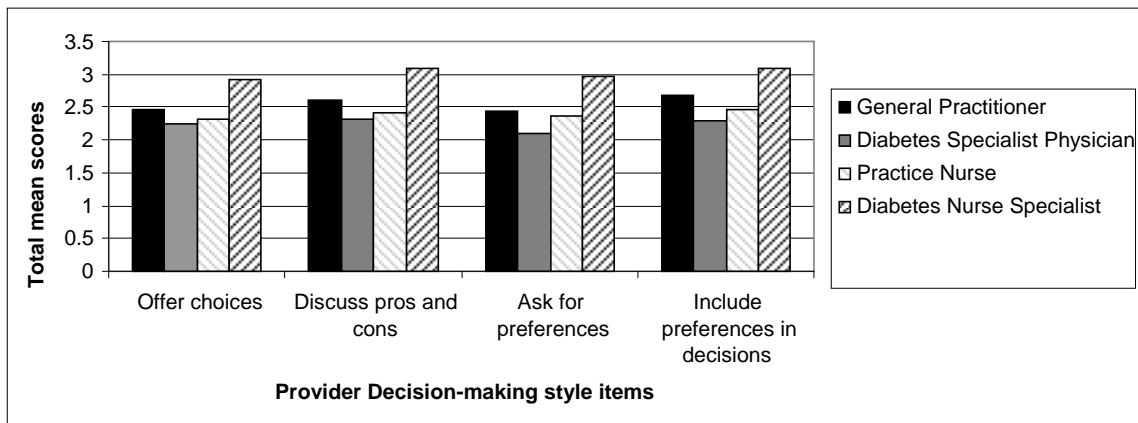


Figure 7. Provider Decision-making - ‘How good is your doctor or nurse at...?’ mean scores by provider group

It can be seen that Diabetes Specialist Nurses are rated the highest across all items with mean scores consistently above 3.33 and 2.92 respectively.

Paired samples *t*-tests were then conducted to evaluate the difference between total scale mean scores for ‘how good?’ and ‘how important?’ for both PCOM and PDM for each type of doctor and nurse. As illustrated in Figures 8 and 9, all groups showed differences in ‘how good?’ versus ‘how important?’ suggesting that participants’ rating of how good their doctor or nurses were with communication and decision-making did not meet their rated level of importance. These differences were all statistically significant and are detailed in Appendix O.

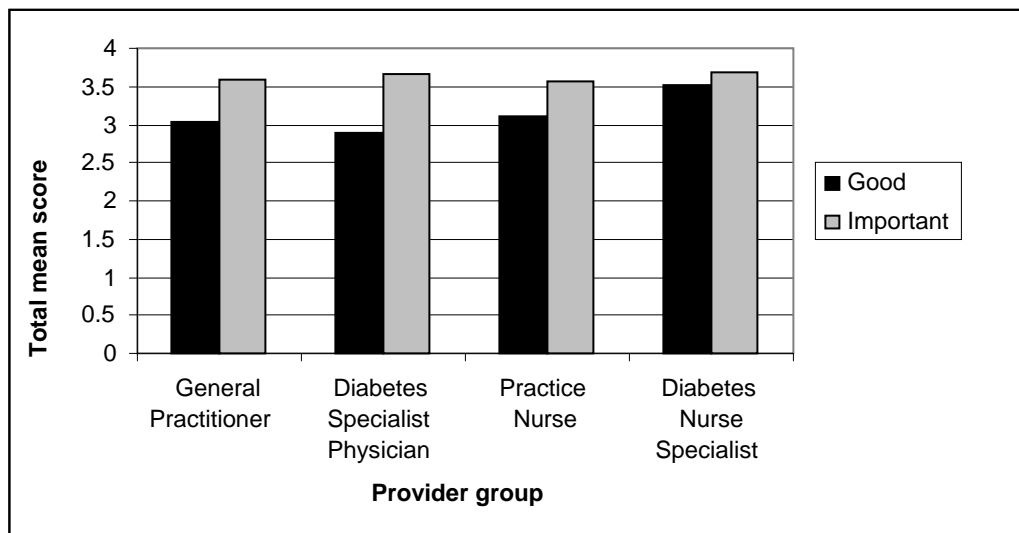


Figure 8. Provider Communication total mean scores – ‘good’ versus ‘important’

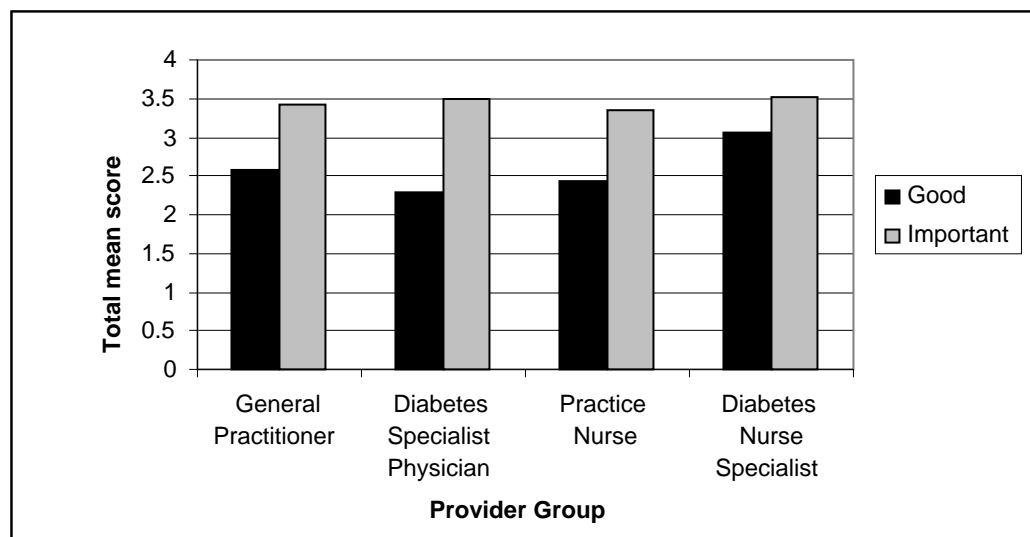


Figure 9. Provider Decision-making total mean scores – ‘good’ versus ‘important’

Correlations.

The relationship between PCOM and PDM and demographic characteristics was investigated using Pearson product-moment correlation coefficients. Preliminary analyses were performed on each of the variables to ensure no violation of the assumptions of normality, linearity and homoscedasticity. As shown in Table 12, there was a small positive correlation between HbA_{1c} and practice nurse communication suggesting that those with poorer glycaemic control rated practice nurses' communication style higher.

Table 12

Correlations between Provider Communication (PCOM) 'good' and Participant Demographics and Health-related Characteristics.

Demographic characteristics	PCOM	PCOM	PCOM	PCOM
	GP	DSP	PN	DSN
	Ns = 176 - 192	Ns = 112-124	Ns = 92 - 99	Ns = 110-115
	<i>r</i>	<i>r</i>	<i>r</i>	<i>r</i>
Age	.002	.150	-.143	-.003
Co-morbidities	-.124	-.170	-.143	-.092
HbA _{1c}	.107	.083	.232*	.091
Years with diabetes	.038	-.165	.051	.067
Female	-.104	-.369***	-.123	.006
Ethnicity	-.011	-.067	.168	.079
Highest educational achievement	-.043	.020	.006	.033
Size of geographical location	-.087	-.047	-.044	-.070
Type 1 diabetes	-.045	-.027	-.119	-.041
Years with diabetes	.038	-.165	.051	.067
General health over past 4 weeks	.198**	.345***	.104	.143
Frequency of nurse visits	.014	-.109	-.011	-.009
Frequency of medical practitioner visits	-.273***	-.095	-.080	.024

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

Higher ratings of GPs' communication style were associated with better general health and less frequent visits. Higher satisfaction with diabetes specialist physicians' communication style was associated with males and those with better general health. There were no significant relationships between diabetes specialist nurses' communication style and participant demographics. Correlations for decision-making style are displayed in Table 13. As can be seen, for decision-making style, a significant moderate positive correlation was present between higher HbA_{1c}, being Maori and having type 1 diabetes for practice nurses, although as the number of Maori and participants with type 1 diabetes was low, this correlation may in part reflect an outlier effect.

Table 13

Correlations between Provider Decision-Making (PDM) 'good' and Participant Demographics and Health-related Characteristics.

Demographic Characteristics	PDM GP	PDM DSP	PDM PN	PDM DSN
	<i>Ns</i> = 176 - 192	<i>Ns</i> = 112-124	<i>Ns</i> = 92 - 99	<i>Ns</i> = 110-115
	<i>r</i>	<i>r</i>	<i>r</i>	<i>r</i>
Age	-.045	.042	-.139	-.045
Co-morbidities	-.087	-.147	-.134	-.065
HbA _{1c}	.121	-.002	.309**	.095
Years with diabetes	.043	.039	.047	.138
Female	-.068	-.084	-.125	.126
Ethnicity	.063	.045	.228*	.151
Highest educational achievement	-.015	.028	-.084	.115
Size of geographical location	-.240**	-.190*	.026	-.058
Type of diabetes	-.050	-.131	-.210*	-.141
Years with diabetes	.043	.039	.047	.138
General health over past 4 weeks	.163*	.206*	.086	.042
Frequency of nurse visits	.047	.002	-.005	.070
Frequency of medical practitioner visits	-.194**	-.111	-.127	.071

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

Higher ratings of GPs' decision-making style were associated with better general health, less frequent visits and those living in smaller geographical locations. Higher satisfaction with diabetes specialist physicians' decision-making style was also associated with better general health and living in smaller geographical locations. There were no significant correlations for diabetes specialist nurses and participant demographic or health related characteristics.

Provider communication and decision-making overview.

Provider communication and decision-making mean scores ranged from 2.8 – 3.5 and 2.3 – 3.5 respectively from a possible range of 1-4. Diabetes specialist nurses were consistently rated higher across all items which is not unexpected as diabetes specialist nurses have as their primary focus diabetes care and education. However, diabetes specialist nurses' communication and decision-making style was not associated with any participant demographic characteristic. Universally, participants rated a high level of importance for each of the questions on communication and decision-making and a significant difference was present between their perceived ratings of 'how good' their doctor or nurse was versus 'how important' it was to them.

Participants in this current study clearly indicated that being informed and being involved with decision-making about the management of their diabetes was very important, however some provided additional information regarding differing expectations according to provider roles.

Health Activation, Diabetes-Related Distress, Provider Communication and Provider Decision-making

This study was designed to explain the influences on health activation (HA), in particular exploring the influence of diabetes-related distress (DRD) and provider communication and decision-making styles on HA; and the relationship, if any, between DRD and provider communication and decision-making styles. Thus far, the results from the quantitative

analysis - range of responses, means, standard deviations, and univariate statistics – have been presented individually for each scale, followed by bivariate and multivariate statistics utilising all four scales. In this next section, relationships will be explored by use of Pearson-product moment coefficient analyses between HA and each of the independent variables – DRD, PCOM and PDM; and then between each of the independent variables. This is followed by multiple linear regression to determine unique contributions to HA by each health professional group. Preliminary analyses were performed on each of the variables to ensure no violation of the assumptions of normality, linearity and homoscedasticity.

Correlations.

Initially, relationships between health activation, diabetes-related distress and the highest score a participant gave for communication and decision-making, regardless of which provider it was for, were analysed. It can be seen in Table 14, small significant relationships were present between health activation and both communication and decision-making. While these correlations are small, they suggest that HA is positively associated with greater satisfaction with communication and decision-making.

Table 14

Correlations between Health Activation, Diabetes-related Distress, Overall Provider Communication and Overall Decision-making styles

	Health activation	Diabetes-related distress	Communication	Decision-making
Health activation	-	-.119	.172*	.160*
Diabetes-related distress		-	-.118	-.124
Communication			-	.168*
Decision-making				-

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

As significant relationships were present, the same analyses were performed for each provider group to determine if the relationships were present across all provider groups.

As can be seen in Table 15, there were small positive correlations between HA and PCOM for all health professional groups except for Diabetes Specialist Physician. Small positive correlations were also found between PDM and all provider groups except Practice Nurses indicating that overall, positive experiences with provider communication and decision-making is associated with higher health activation.

Table 15

Correlations between Health Activation (HA), Diabetes-related Distress (DRD) and Provider Communication and Decision-Making style for each health professional group

	HA	DRD
	<i>r</i>	<i>r</i>
Communication GP	.194**	-.262***
Communication DSP	.155	-.401***
Communication PN	.245*	-.044
Communication DSN	.291**	-.235*
Decision-making GP	.172*	-.152*
Decision-making DSP	.207**	-.324***
Decision-making PN	.141	.034
Decision-making DSN	.242**	-.139

Note. * $p < .05$, ** $p < .01$, *** $p < .001$. GP = General Practitioner, DSP = Diabetes Specialist Physician, PN = Practice Nurse, DSN = Diabetes Specialist Nurse

For diabetes-related distress (DRD), small to moderate negative correlations between diabetes-related Distress (DRD) and communication for General Practitioners, Diabetes

Specialist Nurses, and Diabetes Specialist Physician suggests that higher DRD is associated with less satisfaction with communication for most provider groups. Similarly, for decision-making, higher DRD was associated with less satisfaction with decision-making, particularly for General Practitioners and Diabetes Specialist Physician.

Higher health activation was found to be associated with higher satisfaction with both provider communication and decision-making, especially for diabetes specialist physician and diabetes specialist nurses. Less satisfaction with provider communication and decision-making was found to be associated with higher levels of diabetes-related distress for nearly all provider groups, but especially for medical practitioner groups.

Multiple Linear Regression.

To determine which of the independent variables - diabetes-related distress, communication or decision-making styles - plus relevant demographic and health-related characteristics determined from prior analyses, contributed the greatest effect on health activation, further analyses were required. Therefore, a series of multiple regression analyses were performed. Using total scale scores, the contribution of DRD and relevant demographic characteristics to HA was initially analysed. Further regression analyses were repeated using the same variables but by each provider group and are reported using standardised β throughout.

As reported earlier in this chapter, correlations between demographic variables and health activation were all small or moderate indicating that the data is suitably correlated with HA (the dependent variable) for examination through multiple regression to be undertaken. Initially the correlations amongst the demographic variables were examined. As previously presented all correlations were small to medium indicating that multicollinearity is unlikely to be a problem.

In the first model (Table 16) the adjusted R^2 of .210 indicated that the model explains 21% of the variance in health activation. As presented in Table 16 age (being younger) makes the largest contribution to health activation ($\beta = -.311$), with education (being more highly

educated) providing the second largest contribution ($\beta = .215$), and better general health providing third greatest contribution ($\beta = .179$). The same regression analysis was repeated for each health professional group. The results of the analyses presented in Tables 17 through 20 demonstrate that the combination of DRD, age, HbA_{1c}, general health, education, communication and decision-making styles have a range of adjusted R^2 from .212 to .314, explaining between 21 and 31 % of the variance in HA across health professional groups.

Table 16

Predictors of Health Activation

Variable	Health Activation	
	β	95% CI
Constant		[50.778, 104.629]
Diabetes-related distress	-.149	[-5.933, .095]
Age	-.311***	[-.593, -.219]
HbA _{1c}	-.052	[-2.695, 1.173]
General health	.179*	[.588, 5.251]
Education	.215**	[1.333, 5.513]
Adjusted R^2		.210
F		11.462***

Note. N = 218. * $p < .05$, ** $p < .01$, *** $p < .001$.

Table 17

Predictors of Health Activation for General Practitioner

Variable	Health Activation	
	β	95% CI
Constant		[41.453, 102.977]
Diabetes-related distress	-.101	[-5.292, 1.359]
Age	-.297***	[-.598, -.186]
HbA _{1c}	-.107	[-3.585, .545]
General health	.168*	[.203, 5.191]
Education	.200**	[.920, 5.490]
GP DM	.059	[-2.302, 4.550]
GP COM	.116	[-1.552, 6.841]
Adjusted R^2		.212
F		7.578***

Note. N = 192. * $p < .05$, ** $p < .01$, *** $p < .001$.

Table 18

Predictors of Health Activation for Diabetes Specialist Physician

Variable	Health Activation	
	β	95% CI
Constant		[42.988, 114.409]
Diabetes-related distress	-.141	[-7.261, 1.766]
Age	-.350***	[-.690, -.208]
HbA _{1c}	-.075	[-3.664, 1.473]
General health	.188	[-.329, 6.584]
Education	.186*	[.193, 5.729]
DSP DM	.138	[-2.019, 6.987]
DSP COM	-.014	[-5.993, 5.387]
Adjusted R^2		.299
F		6.464***

Note. N = 124. * $p < .05$, ** $p < .01$, *** $p < .001$.

Table 19

Predictors of Health Activation for Practice Nurse

Variable	Health Activation	
	β	95% CI
Constant		[41.702, 125.117]
Diabetes-related distress	-.302*	[-10.521, -1.268]
Age	-.425***	[-.885, -.302]
HbA _{1c}	-.048	[-3.626, 2.239]
General health	.123	[-1.596, 5.669]
Education	.249*	[.957, 7.643]
PN DM	.050	[-4.064, 5.755]
PN COM	.130	[-3.571, 9.658]
Adjusted R^2		.314
F		6.488***

Note. N = 99. * $p < .05$, ** $p < .01$, *** $p < .001$.

Table 20

Predictors of Health Activation for Diabetes Specialist Nurse

Variable	Health Activation	
	β	95% CI
Constant		[29.761, 111.490]
Diabetes-related distress	-.153	[-7.375, 1.435]
Age	-.291**	[-.622, -.123]
HbA _{1c}	-.171	[-5.202, .216]
General health	.085	[-2.075, 4.799]
Education	.271**	[1.531, 7.550]
DSN DM	.015	[-4.615, 5.167]
DSN COM	.237	[-780, 12.679]
Adjusted R^2		.266
F		6.229***

Note. N = 115. * $p < .05$, ** $p < .01$, *** $p < .001$.

Based on these analyses, being younger made the largest unique significant contribution to HA for all health professional groups. As can be seen in Table 17 the General Practitioner model has an adjusted R^2 of .212 explaining 21% of the variance in health activation (HA). Of the seven variables, age made the largest unique contribution ($\beta = -.297$) with education level making the second largest contribution ($\beta = .200$). The negative beta for age demonstrates that younger participants are likely to be more health activated, and the positive beta for education demonstrates that those with higher education qualifications are more likely to be more health activated. With an adjusted R^2 of .299, the Diabetes Specialist Physician model (Table 18), explains 30% of variance in HA with age making the largest contribution ($\beta = -.350$) followed by education ($\beta = .186$) suggesting that those who are younger and are more educated, have higher health activation. The Practice Nurse model (Table 19) explains 31% of the variance in HA ($R^2 = .314$) with age again making the largest unique contribution ($\beta = -.425$) followed by DRD ($\beta = -.302$) suggesting that those who were older or with higher DRD scores had lower HA. Lastly, with an adjusted R^2 of .266, the Diabetes Nurse Specialist model (Table 20) explains 27% of the variance in health activation with age making the strongest unique contribution ($\beta = -.291$) followed by education ($\beta = .271$). This model demonstrates that being younger and more educated was associated with being more health activated. Overall the four models suggest that, other factors being held at their mean, that in no case is there an additional effect from decision-making or communication styles.

Overall Summary

Overall participants rated themselves to have relatively high levels of health activation and relatively low levels of diabetes-related distress (DRD). Satisfaction with provider communication and decision-making styles was moderate across all provider groups. Analyses presented thus far provide an indication that significant relationships are present between higher health activation, better general health, younger age, higher education, fewer co-morbidities, type 1 diabetes and communication styles. Multiple regression analyses indicate that age (being younger) made the largest unique contribution to health activation for all provider groups. Across the four provider models level of education,

general health and diabetes-related distress also contributed significantly to health activation.

Factors associated with active engagement in self-care appear to be multifaceted and complex. As people with diabetes do not live and manage their diabetes in a vacuum from the multiple influences and demands on their life, further exploration to tease out these complexities is warranted. Therefore, supplementary explanations were sought through interview with willing and relevant participants and are presented in the following chapter.

Introduction

To provide an introduction to the next two chapters, this chapter presents themes relating to the more general factors participants perceived as influencing their health activation and diabetes self-care. As discussed in the literature review health activation is a multidimensional concept comprising the following components: health beliefs, knowledge and confidence to take action, possessing skills to modify actions according to differing circumstances and behaviours to maintain active self-care activities even when under stress (Hibbard et al., 2004). Health activation can be measured and is represented by four stages: 1) the individual believes an active role is important; 2) the individual has confidence and knowledge to take action; 3) the individual is taking action; and 4) the individual is able to maintain action even when under stress. Health activation is considered to be a dynamic state of being potentially influenced by numerous factors. It has also been suggested to be a useful intermediate outcome measure and that when health activation levels increase, self-care behaviours follow. Although, as the findings from the analysis will demonstrate, the individual nature of a person's diabetes drives "different change trajectories" (Hibbard et al., 2006, p. 146) in relation to self-care behaviours and activities. Furthermore, a high health activation level did not necessarily translate into active self-care for some participants in this study.

The previously reported quantitative analysis of diabetes-related distress indicated that overall, participants in this study did not report high levels of distress. This relatively low level of reported distress is incongruent with my years of experience in clinical practice with people with diabetes and with literature on diabetes-related distress. Therefore, this was an area of particular interest to explore qualitatively with participants while keeping in mind potential reasons for this incongruence such as response bias, social awareness of preferred responses, quality of local services and previous studies being imbalanced or not pertinent in the context of the New Zealand culture.

The four themes presented in this chapter are: **solitary self-care; uncertainty for future health; the relentlessness of self-care; and she'll be right**. Chapter seven presents a spectrum of control from personal to interpersonal perspectives, and chapter eight focuses

on the impact of health professional communication and decision-making styles as determined by thematic analysis of participant interview data.

Solitary Self-Care

Overall participants identified with the need to be responsible for their self-care but some described a sense of isolation in relation to this. In the quantitative analysis 40% of participants felt that family and friends didn't appreciate how difficult living with diabetes could be. Similarly, the majority of those interviewed believed that no-one truly understood their diabetes or how they felt about or struggled with their self-care demands, as illustrated by these participants' quotes:

Oh, they've got no clue. No, no clue at all. People just don't understand. Unless you live with it you can't because, you know people make comments, fly-away comments like oh that's a high blood sugar, and you're sitting there and you've had like the worst day ever, like you know your cat's at the vet or you like, you know you fell over on your way to class or something, and you feel like smacking them on the side of the head because you're like, well you know what, you just don't know do you? You just don't have a clue (18, p. 24).

Yeah, people don't get it – because they can't see anything – you know it's not like an illness you can see it – they don't get it at all (10, p. 13).

Unless you've got it yourself it's damned hard to put yourself in the position of here. I mean can you imagine going home and stabbing yourself three times a day and things like that (7, p. 9).

Almost universally no matter what their level of self-rated health activation, participants voiced a clear stance that self-care of their diabetes was their own responsibility and no-one else could, or should do it for them. This belief of having an active role is consistent with

Stage one of health activation. The expectation of self-care by health professionals and others was considered a necessity but participants repeatedly expressed this with a caveat that ‘back-up’ was needed should they run into trouble or need advice. For example:

The professional world can only help you, they can't do it for you (9, p.3).

Well in the long run it is up to yourself really anyway so I guess you've got to take some kind of responsibility for it. It's nice to have back-up and support and information and things like that, but still on a day-to-day basis you've sort of got to deal with it on your own (15, p. 2).

Well it's [self-care] realistic because if you don't, you can't have somebody else watching over you 24-7, you've got to be able to cope with it yourself, know the ins and outs, the ups and downs, and what to expect, and if you get stuck you scream for help (11, p. 2).

As well as being aware of their own responsibility to pay attention to their diabetes, others around them also made comments or suggestions with regards to their diabetes giving the impression that self-care was simple. These observations or comments from others were described as a source of irritation and resentment as they felt judged by people who knew very little about the intricacies of living and managing the demands of diabetes:

My parents are keen to see me get good control, my partner is pretty much the same but nothing they say affects me because I find it really is a, it's quite an isolating disease – it's yours. And I think unless you live it you can't, well I think you don't tend to listen to other people. It's a very, very independent disease – it's kind of like your own, I know myself I get a bit grumpy when people say things about it because it's mine and I take responsibility for it, so I push myself.....I don't want to die young (18, p. 11).

I don't think people who don't live with it can really get it. It's like a lot of things isn't it, you can read it out of a book but if you don't have it, how do you really get it? I don't know (10, p. 15).

You've got to have it to really know what you've got to do, you know what I mean eh? You can do all the studies and all the qualifications in the world, but I mean when you've got it it's a different story (13, p. 14).

It was acknowledged by many participants that it was not unreasonable for others to lack appreciation of the difficulties associated with self-care as true understanding was considered to only occur through personally living with it. However, while it appeared a greater appreciation from others would be helpful there was a reluctance to burden them with their difficulties, thereby increasing isolation further. This is vividly described by this participant:

Even my own children have no idea what I go through. What my regime is in the morning to be at a 9 o'clock meeting. They have no idea. And I've tried just in passing just to say little things but their space, their head, their thinking and space is in a different time. They're in a different world and so I'd rather not put what I suffer from into their life. I just keep that back (3, p. 17).

Diabetes has been under the media spotlight over recent years in an attempt to raise awareness of the need to reduce risk factors relating to type 2 diabetes and once diagnosed, the need to maintain a healthy lifestyle has been emphasised. Based on this brief media information other people's attitudes about what people should or shouldn't do on an individual level interfered at times with participants responses to managing their diabetes, sometimes resulting in rebellion as captured by this participant:

I think when it comes down to like managing living with diabetes people are a real pain in the arse. You pick up anything, you know it could be a

biscuit, it could be like – are you allowed that? That gets in the way because sometimes you almost will go and overeat or overdo something because you're annoyed. You're like – shut up don't tell me what I can and can't do, and sometimes you'll end up making yourself unwell or high or low because you are trying to sort of, I don't know trying to prove something to other people and then you just end up going the other way (18, pp. 11-13).

Rebellion has been identified by Paterson and Thorne (2000) as a phase in a trajectory towards developing expertise in diabetes self-care. This rebellion phase is characterised by denial of diabetes, in particular in the presence of others and took a form of ignoring diet, alcohol restrictions, hiding the need for insulin and falsifying or not doing blood glucose monitoring. While the rebellion phase as described by Paterson and Thorne is relevant, the rebellion described by participant 18 reflected more 'a moment in time rebellion' in response to others, as opposed to a phase of ignoring or rebelling against her diabetes over time. This moment in time rebellion was a spontaneous response and may be a reflection of the individual's state of mind at that moment in time and a mechanism of ensuring a perception of control. The solitary nature of self-care and the uncertainty of reward for self-care efforts may exacerbate the potential for rebellion.

Uncertainty For Future Health

Distress associated with uncertainty is reported in the literature particularly in those treated with insulin. For example, Aalto et al. (2000) reported severe distress in 29% of their study's participants with distress significantly associated with a number of diabetes-related cognitions including lack of perceived reward for self-care efforts and threat of complications. In this current study 35% of participants rated a distress level of three or more (from range of 1-6) in relation to feeling they were often failing with their diabetes regimen, and 47% rated a distress level of three or more with respect to believing they would get complications no matter what they did. A strong thread throughout most interviews was participants' awareness of the risk for short term complications of diabetes

(hypoglycaemia and hyperglycaemia) and the potential long term complications of poorly controlled diabetes (micro-vascular and macro-vascular disease). Many talked about the uncertainty of reward for their effort, both in the short term for achieving goals e.g. blood glucose levels or target HbA_{1c}, and for long term complications of diabetes. One participant eloquently described this:

I mean I know for me I don't want the complications of this disease. I can't think of anything worse, because you know if we think about it, diabetes is a crap disease, it's something that it is horrendously not understood. It's like this huge disease that people don't seem to understand. A lot of it is not definite, so like they can say, you can have great blood sugars [and avoid complications] but then people get complications, and people with bad blood sugars don't get complications. I mean I'm not the best controlled diabetic and at 26 I have no complications, but I know other diabetics who have been really, really careful and at my age have got some deterioration in their sight, or have got a wound or something, and it's, it's kind of hard to know what motivates you to keep control because there's no, there's no 100% statistic that says you maintain an HbA_{1c} of 6% or something, you're going to be fine (18, pp. 16-17).

Despite the uncertainty described above, the knowledge of potential complications (consistent with stage two health activation) acted for some participants as an activator for self-care as they strove to have a healthy and long life with their limbs and body intact. So while for some concern for future health related to complications may threaten health activation and lead to neglect of self-care activities, for others a degree of concern (and sometimes distress) provided the necessary motivation to sustain self-care efforts. For example:

Well if you don't take care of yourself you're going to get very, very sick and you're going to get really severe complications, yeah (11, p. 8).

I've seen people that have had amputations and I thought you know how terrible, because one joker I knew he used to cut his little hedge from the wheelchair and I thought I don't want that (6, p. 24).

First of all I don't want to let it rule my life, that's probably the main one, because it's, it can't be a thing that will – it can't be because it'll kill me and I don't want to let it kill me, and the other thing is the complications. I mean nobody wants to go blind, nobody wants to lose a foot, you know and as far as I'm aware heart problems are really common with Type 1s later on in life, and that terrifies the crap out of me..... and yeah just think that maybe my life could be cut short because of a disease that I don't control or don't look after myself (18, p. 9).

It was apparent that concern for the risk of developing complications and uncertainty for future health was a strong driver for many to actively engage in self-care behaviours. This driver though was ever present and uncomfortable as it pervaded nearly every aspect of a person's life on a day to day basis.

Relentlessness Of Self-Care

The burden of living with a long term condition is well described in the literature with the awareness of having a long term condition perceived to have more of an impact on life than the actual disease itself (Talbot & Nouwen, 2000). In this current study, the ongoing and everydayness of self-care of diabetes was a common issue raised by many interviewed participants. Having to consider and plan for unexpected events in a day was always in the back of their mind and at times 'life' got in the way. For example:

Life is a huge problem. You know a lot of things affect diabetes heaps. Like everything in life does, I tried to explain it to someone once – every single minute of every single day I know I have diabetes – every second. So when I see a nurse and, or anybody, and they say oh you've got diabetes and think

about it for 30 seconds that's 30 seconds out of their life, but every second of every day I know and that has a huge impact on how you live because you know it's there and it never goes away. There's never a moment where you don't know, or when you don't think, and I mean that's pretty full-on. It can be quite stressful because it's – well I mean yeah that's your whole life, you know that's pretty full-on to have something that's there all the time. I mean I'm not saying that I you know I walk down the street and I'm like "I'm a diabetic, I'm a diabetic" like repetitively in my head, but for instance something like walking down the street I know that if I walk you know for too long and I get stuck somewhere and I might go low, you know there's always something in the back of your mind. Always, always there (18, pp. 11-13).

I think it's more just the relentless quality to it. I've found that if you have a friend that has the flu and you bring them chicken soup and they feel better, you as a friend feel better for it, but if your friend has diabetes and you help them on a bad day that they're struggling or whatever, the next day may be just the same or worse. So I think that's the relentless quality to it (17, p .4).

The quantitative analysis of diabetes-related distress found that 30% of participants scored three or more on the distress scale to the item asking if diabetes was taking up too much of their mental and physical energy everyday. The relentless nature of diabetes self-care demands for many participants challenged reaching stage three or four health activation. Participants described they had “just not into it days” when it was hard to maintain their self-care efforts despite having the knowledge and skills to do so. On these days they felt worn down and did not have the energy nor the inclination to focus on their diabetes regimen requirements, as expressed by these participants:

And if you're having trouble controlling and you can't get things under control then you quite easily can slip into a pattern of well I just can't do it and so I'm just not going to try anymore. And I actually, I'm speaking for

myself but in speaking to other diabetics, a lot of them have said they have “just not into it” days...or weeks (laughs) when they just can’t go there anymore or when it’s just become too much, and unfortunately we are damaging ourselves when we do that, but I think that it’s, it’s a reality of the disease that sometimes you just have to, you just have to stop and you just can’t – yeah you just have to stop and carry on and then get back on track (18, p. 15).

Because it’s an ongoing problem. Well, I find with myself anyway I have days when I feel really, really down actually. Yesterday was one of them, and whether it’s just the diabetes or my other problems as well I don’t know, but there are days when you do feel really down and you wish you didn’t have to worry about your diet and sometimes you think oh I wish I could go and eat a piece of chocolate cake or, occasionally you might do that but then because I don’t have it in the house I can’t do it (laughs) (2, p. 7).

Consistent with Paterson’s (2002b) stance that a person’s response to a long term condition is dynamic and changing according to living their life amidst changing personal and social contexts, participants in this study described a change in priorities as life progressed leading to more active self-care. Relentlessness became more or less of an issue as priorities changed following a significant life event, such as a new partner, a pregnancy or with lifestyle changes. These changes provided renewed interest and motivation to self-care as described by these participants:

I went through a marriage break-up and that wasn’t great for your health, sort of probably ate the wrong things, did the wrong things, but since [new partner] has come along it’s much better because she sort of keeps me on the straight and narrow. Yeah. Because without that you don’t really worry too much you just sort of party. Yep. Now I’ve got an incentive to take better care of my health. Ah, yeah probably mostly she’s the reason, the incentive to live a bit longer I guess (5, p. 5).

I think the thing that most gets in the way is just the sick and tired of it, you know, I need a holiday, I need a break and there's just not that factor there. It's more of I need to stay committed and focused to, like for my pregnancies there was a real reason outside of myself to do that. And I just had to try to figure out a way to get that feeling back which is important enough for me to maintain good health and this is the way to do it. But, that is a day to day thing, I still struggle but it's like when people are dieting or any other kind of thing, yeah, get stressed, yeah don't want to write everything down, don't want to test, don't want to ... (17, p. 7).

This raises consideration of the interpretation of quantitative measurement of health activation, self-care or any health related issue on one occasion, as they are at best a static measure of that individual's perception at that moment in time. While the same could be said for qualitative data collection techniques, the opportunities for free exchange of dialogue increases the likelihood of a less time bound or 'of the moment' response. These participant excerpts illustrate this well:

There's a lot of other factors there that, yeah all of a sudden, things change, stress is a big thing as well too that influences it a lot there. Just your state of mind as well too, so I think there's a lot of factors that can, can actually change, change the course in how well you manage your diabetes (16, p. 5).

Sometimes you feel like it wears you down, you know, and I go through periods that I just can't be bothered, I'm just over it, I don't want it anymore, you know. Every now and then you'll get a poor-me period. Yeah, and you'll think I just I'm over this whole thing and I don't want it and I don't want to inject anymore and ... mmmm... yeah but it's more like a block of things so maybe that's you know at a time that something's happening or whatever, you know (10, p. 17).

Participants frequently described how personal issues competed for and often overrode the energy and/or time they had to pay attention to their own health care needs. As an example, in the quantitative analysis, 35% of participants rated three or more on the distress scale that they did not stick closely enough to a good meal plan. This fluctuation in self-care energy levels illustrated the dynamic nature of health activation and why people don't always actively engage in self-care activities. For example:

Yeah I think for me if I'm having like a – I personally suffer from depression and if I am in a low and having a bad crappy week or whatever – diabetes is like the last thing on my mind. It's like I have to get my mood up to cope with life and diabetes is just way down there. It's like I don't even care, diabetes can change on your priority list quite easily. If you've got a lot going on it tends to move further and further back and then your motivation is like oh well, it's not going to get any better so I may as well just focus on what I can make better or what I can do because sometimes it does – it feels like you just can't get anywhere with it (18, p. 14).

I'm pretty full on with day to day and it just seems to me that I've got another thing that I've got to stop. I can swing back and forth like a yo-yo, like in the morning I could be 5 and I can be 28 in the afternoon, or I can be higher than that, so I swing quite quickly and, which means to really get a good handle on it I need to test throughout the day quite a bit.....Yeah, but I'm always too busy and it's just stopping and doing it, I don't particularly like to do it. I mean I do at work, I'm not worried about people – obviously everyone knows I've got diabetes – but I don't like it to be seen as something I'm doing when I should be working, you know what I mean (10, pp. 10-11).

Yeah, just the amount of times that I've just sort of broken down into tears for no apparent reason, I just seem to lose it, and that's when yeah all of a sudden diabetes wasn't so important – I didn't really care. And, so yeah

just trying to get around it now, just trying to juggle life in general really, just trying to find that balance and it's easier said than done (16, p. 24).

In addition to life events more broadly, living with a long term condition incurs particular expenses such as: more frequent visits to a health professional, prescription charges, particular food choices, and many find it difficult to manage. Indeed Carryer, Budge, Hansen and Gibbs (2010) identified in their study of 341 people with long term conditions in a provincial district health board, that nearly 60% exist on an income of \$20,000 or less. In this current study financial difficulties presented a barrier for many participants making access to services challenging, as was making the right food choices. This barrier was most clearly described by this participant who lived in a rural community and found barriers to making appropriate choices due to the cost of every-day living:

But you can't afford to. You can't afford to do what you are supposed to do. Well the problem is I'm a pensioner, I'm on a fixed income, and there's only so much I can do with the money I'm given, you know. I'm 21 kms from a supermarket, I'm 35 kms from a doctor, I'm 26 kms from the WINZ office, and when your car does 10 -12 kms to a litre, and a litre of petrol is \$1.40, you know it's costing you about \$7 just to go to the supermarket. So when you start adding all that together and you're only getting the pension, you know, you tend to buy all the cheap stuff, and the cheap stuff usually has all the fat in it (4, p. 6).

Knowledge and confidence about their diabetes and how to undertake the self-care requirements was greatly influential on participants' levels of distress and engagement in self-care activities. Despite receiving advice from health professionals some still didn't understand what they needed to do. This is not necessarily unusual as it has been previously reported in the literature that medical practitioners vary widely in their provision of recommendations for self-care (Heisler et al., 2002), 50% of people with diabetes leave consultations not knowing what to do to (DiMatteo, 1998), and 50% have not been told about treatment options nor do they have a self-care plan (Colin-Thomé, 2006). In this

current study where participants did not feel knowledgeable or confident to implement treatment recommendations, health activation was likely to be lower and self-care was more of a struggle. For example, one participant stated the following:

In spite of going to the doctor and things like that I always had trouble getting a handle on it, getting to know what I should and should not be doing. You get told but when it's sort of, when you get back to the real world it sort of doesn't quite workAnd it's great in theory but in practice it's not quite so easy (5, pp. 2-3).

When participants felt as if they were in control of their diabetes and its management, the potential for distress was reduced. For these participants, both knowledge and their capability to interpret and integrate this in terms of their own life context reduced distress, contributed to a higher health activation level and influenced their self-care:

I think education, I think feeling that you're in charge of your own life and what you - yeah having some effect over potential outcomes I guess and realising that, it's a sports analogy, but it's the long game it's not the short game that's the whole idea (17, p. 16).

As previously stated, the quantitative results for diabetes-related distress in this study did not demonstrate a high level of distress overall but participant responses during interviews clearly demonstrated otherwise. This again highlights the value of both quantitative and qualitative exploration of the phenomenon under study. During the interviews participants were directly questioned about this and why they thought this could be. Responses from participants about this phenomenon varied. As the data will show, the stoical nature of the New Zealand culture in respect to expressing emotions and/or distress appeared to influence the way in which participants responded to interview questions surrounding distress and admitting to experiencing distress.

She'll Be Right

The 'kiwi can do' attitude was suggested by some participants as a barrier to acknowledging or disclosing distress and that in keeping with the New Zealand 'she'll be right' motto, New Zealand people with diabetes just got on with it. Participants did not want to appear as victims and admission of distress was expressed as self pitying, for example:

I don't like to make a big thing out of it [feeling distressed] so that you know, I don't like to be a victim (15, p. 14).

No I don't believe in being self-pitying and all that nonsense. You've got to face up to reality and that's it (8, p. 5).

Well you just take it in your stride and get on with life (9, p. 9).

Well I can understand the Americans [admitting to distress] because they're paranoid. I mean everyone's got a psychologist – I mean even with little kids – it's just ridiculous. If it ain't broke you don't fix it.... We just get in and get things done and we don't complain. Yeah that's what we do (7, p. 18).

Non-disclosure was suggested by participants as a way of avoiding facing the source of distress and the potential judgment of others:

The diabetics I've talked to here in New Zealand talk about a lot of stress. I think it's more about non-disclosure rather than mentally pull yourself up by your bootstraps kind of thinking, I think it's more of I don't really want to say that. Saying is becoming and also well then I have to deal with it and oh what will people think of me (17, p. 13).

Just as a nation we're more laid-back where kiwis are more like oh away you go. Maybe that or maybe it's because we're too ashamed of saying yes I'm feeling a bit stressed out here (14, p. 17).

The stigma attached to admitting to emotional distress may serve as a preventive to disclosure. This participant's quote illustrates this cultural attitude eloquently:

I think the particular culture in New Zealand I've noticed, it's the mental health stigma where you can't just be unwell mentally, it's a real black and white situation, you're fine or you're crazy, you just can't be just a little bit unwell or stressed and maybe need some help, or have issues (17, p. 12).

It was therefore apparent that New Zealand cultural attitudes towards the expression of emotional distress (and depression) altered perceptions of distress and was a barrier to participants admitting to feeling distressed. The 'kiwi can do' attitude promoted nondisclosure but nondisclosure was also described as an avoidance tactic to facing up to and dealing with the cause of distress.

Summary

This chapter presented four themes relating to the factors impacting on participants' level of health activation and engagement in diabetes self-care: **solitary self-care; the relentlessness of self-care; uncertainty for future health; and she'll be right**. Self-care was identified as a solitary endeavour, often perceived by outsiders as simple. The relentless self-monitoring involved with self-care, and being monitored by others created distress for some. It is clear that in general participants accept responsibility for self-care of their diabetes and try hard to maintain well health, both in the short and long term. For many of the participants interviewed, self-care of diabetes was challenging as competing demands made it difficult to focus thereby impacting on health activation. It is apparent that a variety of factors promoted health activation such as concern for complications, life priorities changing and level of perceived knowledge and confidence to manage different

situations. Affirming Thorne et al.'s (2003) position that self-care is intricately connected to “the living of life in all of its complexity and fullness” (p. 1349), participants in this study perceived and responded to challenges to life with diabetes in different ways and at different times.

The influence of diabetes-related distress on health activation and self-care, appeared to exist on a continuum from distress as de-activator to distress as an activator. Coping with hypoglycaemia and the day to day swings in blood glucose levels on a daily basis created distress, as did the knowledge of the risk for long term complications as a result of unstable blood glucose control. New Zealand cultural attitudes influenced participants' perceptions about distress and their likelihood to disclose it to others.

The next chapter will describe themes pertaining to a spectrum of control as described by participants and chapter eight focuses on the impact of health professional communication and decision-making styles.

Introduction

Chapter six presented participants' perceptions of the relentless and solitary nature of diabetes self-care and introduced the impact of distress on health activation. This chapter builds on and provides further understanding of diabetes-related distress and its impact on health activation with a specific focus on 'control'. Many participants mentioned the word control when referring to their diabetes and their ability to actively engage in self-care. As the data to follow will show, a spectrum of control in relation to life with diabetes was described. Some described distress related to not feeling in control of their body, especially when their self-care efforts did not lead to expected or desired outcomes. Some felt as if their life was being controlled by their diabetes, and at the other end of the spectrum other participants felt in control of their diabetes and described diabetes to be comfortably integrated into their daily life. Interestingly though this did not necessarily translate into high health activation, positive self-care action or optimal HbA_{1c} levels. Overall the spectrum of control was dynamic with participants at times feeling in control and at other times feeling their lives were being controlled.

Control as a construct features in at least two major health behaviour theories or models, such as the Social Learning Theory within which the locus of control construct had its origin, and the Empowerment Model. Locus of control is an expectancy belief about where control over behavioural outcomes lies. A distinction is made between the loci of control as they have "different motivational, affective, and behavioural effects and indicate whether personal or social remedies are required" (Bandura, 1997, p. 27). An internal locus of control credits personal control of behavioural outcomes, whereas an external locus of control credits outcomes to "the control of powerful other people or forces such as luck, fate or chance" (Tillotson & Smith, 1996, p. 133). The concept of empowerment in diabetes care emerged in the 1990s with the emphasis on self-care and in recognition that the person with diabetes was in control and therefore responsible for their diabetes care (Anderson, 1995; Asimakopoulou, 2007). The empowerment model grew out of an awareness that the provision of diabetes care within an acute care/ traditional medical model of care, where the health professional is in control of decision making and

implementation of care, diminished the adequacy of care for people with diabetes as it attempted to do the impossible that is, to be responsible for the individual's self-care activities (Anderson & Funnell, 2005).

In this chapter control will be discussed from participants' perspectives of personal control within the context of their life with diabetes expressed within three themes: **frustration; longing for normality; and in control**. Participants' perspectives within the context of the interpersonal relationships with health professionals are also presented under the theme: **self-determination**.

Personal Control

Frustration

A lack of perceived control of their body and not achieving desired results led to extreme frustration and low motivation for self-care activities for many participants. Participants described ongoing frustration that their body would not respond to their attempts to maintain blood glucose levels within target ranges and at not achieving the expected reward for their self-care efforts, such as improved blood glucose control. This was especially so when the body responded inconsistently to activity, insulin dosing and food intake, as described by this participant:

Oh it can go anywhere from just down with low blood sugars and high blood sugars and that to absolute frustration that my body does not do what it wants to do. Which is often times things people face when they're older but not things people face when they're younger. At 20 you shouldn't have to say well I have to control what my body's doing every time I eat something, my body doesn't react the way it should (17, p. 11).

Frustration due to a lack of perceived control over their body could lead to distress and avoidance of self-care activities. This often manifested as a deliberate avoidance of blood glucose monitoring as a way of exerting control and reducing distress. For example:

When I do comply with what I'm supposed to be doing, and that's like taking my blood, I get really distressed because when I see that I've got high blood sugar levels, I don't want to take them anymore, and that distresses me, because I keep to a good sugar-free regime. Now when I don't take my bloods and there are days, more days than not, then I feel really good. I feel really good and so I just don't want to know about diabetes and I just get on with life.....So yes I do get distressed about it and my way of coping with it is to not even take a blood, yeah I just won't look at it because if I see how high it is it distresses me because I'm thinking, I can't find a balance, what am I doing, and when I do get distressed I can go straight into a hypo (3, p. 11).

When the body did not behave as predicted and hypoglycaemia eventuated, some participants expressed feelings of embarrassment and shame after having a hypoglycaemic episode in the presence of others, in particular at their place of work. Their embarrassment and shame was due to either behaviour changes associated with reduced cognitive function as a result of hypoglycaemia (e.g. confusion, aggression, lack of co-ordination), or unconsciousness requiring emergency medical attention. Whilst embarrassment was expressed, participants also expressed frustration with what was considered an over-reaction from others as they tried to show concern or support. For example this participant stated:

Another scenario, I was at work here, it was at a morning meeting and I had a hypo during the meeting, and then I just felt totally ashamed, after the admin staff had come and just think oh what an egg I am, and that makes yourself a little bit embarrassed because you know you've got to turn up and face those people the following day ... and its like oh yeah you've got this

problem. My manager at work she sat down and talked to me all about it and did the whole touchy-feely thing, I was like harden up, it happens (14, p. 16).

Despite relentless attention to self-care issues, life events occurred and sabotaged their efforts despite best intentions. As has been discussed in the previous chapter, frustration ensues and exacerbates the need for constant vigilance which is not perceived to be normal.

Longing For Normality

Participants expressed a longing for normality in their life, defined as the absence of the daily requirements of diabetes self-care. The quest to function on a daily basis with the maximum degree of normalcy has been eloquently described by Thorne (1993) as having a major influence on the way in which people with diabetes may define themselves, organise their lives, and cope with the complexity of self-care. In this study, participants described resentment towards the daily requirement for structure imposed by diabetes as it exacerbated their sense of abnormality, for example:

I'm just struggling dealing with the stress and the emotional side of having diabetes. It's yeah at the end of the day I just want to be normal. Like I've said to people time and time again I'd be in debt for the rest my life if, if it meant being cured or not having to do the old injections and not being so reliant on having to check my blood glucose all the time. That's the thing you get sick of doing it and you've always got to be prepared and have something on you and a couple of times where I've been caught out (16, p.30).

I think that the nature of my life each day is different. Some people are very routine and that's their personality and I think they'd be the perfect diabetics, people that thrive on routine and order and sameness, like you know accountants. Accountants should be the ones that are diabetics, but I think that's a different personality, whereas I think for me I like the change

in the routine but it makes it harder to manage in a consistent way, managing diabetes (17, p. 8).

It sort of overtakes your world you know, your life a little bit and sometimes it just peeves you off and it's like oh, I'll just inject and not worry about it, do you know what I mean to get me through the day. (10, p. 12).

Participants attempted to accommodate the self-care demands and manage the requirements of their diabetes regimen to fit in, but the constant flexing and adapting to accommodate competing demands took precious energy and time and was not always sustainable. Even when going on holiday the need for forward planning led to frustration and presented challenges as participants and their family and friends desired spontaneity:

Well, there's the blood tests, always having to make sure that you remember to take your insulin with you when you go out, which sometimes doesn't happen, and then you've got to make a trip back or else finish off early (1, p. 15).

It is – oh absolutely a drag yeah. Even though sometimes I've got to eat because I'm going to inject, sometimes I don't even want to eat, not even hungry. And probably one of the biggest inconvenience I think is I hypo quite quickly and so if I don't basically have an idea of what I'm going to be doing for the morning, and people try to wing it with me, like we went away on holiday and you know trying to plan for the next morning – what are we going to do are we going to do something quite energetic or are just going to be lazing around for the day. They're like oh we'll just wing and we'll see what happens tomorrow morning. Well it don't work for me so I wouldn't inject (10, pp. 12-13).

So normality was perceived by participants as the ability to be carefree and careless. The opportunities for spontaneity, seizing the opportunities and being relaxed were not possible

hence normality seemed unachievable. Perhaps as a result some participants acted defiantly towards their diabetes presenting interesting contradictions as this defiance produced both positive or negative impacts on health activation, self-care and diabetes-related distress. For example, when a participant described being in control of their diabetes, this did not necessarily translate into a high health activation level or achievement of ideal glycaemic targets. For these participants the belief of being in control of their diabetes and deciding when to pay attention to their self-care requirements was enacted in order to reclaim control over their life, thereby reducing diabetes-related distress and restoring a perception of normality:

Well living with diabetes like I said before, it can control your life, it can, but I don't allow it to control my life. And whether that's right or wrong, I'm still around, I'm still here, I'm doing things that I like to do (3, p. 21).

Yep it does control my life, (laughs), or tries to and I try to ignore it. Put it that way. Well it wants a lot more attention than it's getting (laughs). So, if it could talk it would (10, p. 17).

I think it probably should control my life more than I let it. I think that's the problem we've just been discussing. Like when I've been single over the last five or six years, it should have been controlling my life and I haven't let it. I've just led a pretty normal life eating anything, probably drank too much (5, p. 7).

Thus participants described a range of ways in which diabetes potentially controlled their lives, or aspects of it. As a consequence some behaviours were not always conducive to achieving optimal blood glucose levels, but rather aimed at maintaining a degree of normality and achieving a sense of being in control.

In Control

A defining distinction between participants with lower health activation and higher health activation scores in the quantitative analysis was that those with higher health activation scores expressed characteristics of positive internal locus of control. Those with higher health activation had incorporated diabetes into their lives in a way that it had its place, they paid it attention and felt in control. Diabetes was not controlling their life or defined as something they were wrestling with. Diabetes was not external to them but rather had become part of who they were and part of their life rather than their whole life, for example:

I think all diabetics are personally affected, we can't separate it because it is our life. And if we don't do the things that we have to do then, you know, there's only one way, you just got to exit don't you, and so if you just want to stay here a bit longer you've got to control it. So I don't think you can separate your medical condition with your personal. No you can't because it's like half of your being alive (3, pp. 17-18).

I wouldn't let it control my life, wouldn't let it (laughs). No like I said earlier you know, if I've got sports I don't mind missing a meal until after the sports and then doing my insulin after the sport, so I'll control it when I'm ready (laughs) (14, p. 18).

I think if you let it control your life well you don't have a life really. No, and I would never let it. That sounds really, really harsh but no, I do not let it control my life and I will never let it control my life, although it is, you know it's a massive part of my life, it is not my life (18, p. 19).

This sense of being in control was expressed by participants most commonly with respect to their belief in their capability to modify their treatment requirements to accommodate daily life events. These participants acknowledged their life stressors and competing

demands but had developed the ability and confidence to apply their diabetes knowledge to work around problems that arose and thereby integrate their diabetes and the self-care activities into their lives and various life events. They described being in control so that diabetes did not rule their life:

It's OK to say oh this chocolate cake is coming out – I'm going to eat it anyway – OK well don't beat yourself up over it, eat that and account for it and the worst thing I think is to eat the chocolate cake and then feel like you're sneaking so you don't take extra insulin and you don't account for it, it's knowledge that OK yeah I've done this, no point beating myself up over it, or my body by not accounting for it and not dealing with it (17, p. 23).

Oh, well I mean you don't want to let diabetes rule your life do you? So, if you want to lead a normal life you've got to learn how to control it. Oh, yes I went through that. I was just, well I was testing and testing and testing, and if I had a low I wanted to hide, now I know how to cure that low with the glucose tablets and a sandwich, so I'm more confident with that (12, p. 4).

Not saying manipulation is always that great but if I can get my blood sugars down or up I know that I can, if I'm home sick and I have high blood sugars I can maintain highish blood sugars without making myself go low. If I'm, you know if I'm going out or doing something I know how to maintain that so that I don't go high (18, p. 32).

But I have learnt over the years that if I forget my insulin it's not going to make that much difference. Your glucose levels will go up, but if you get home at a reasonable time and make an adjustment (laughs) then you can handle it. In other words you learn to cope. But even so, you've got to be aware that you've made an error and you've got to take the appropriate action (1, p. 15).

So it is apparent that adequate knowledge of diabetes management and how to apply this on a day to day basis supported people to achieve and maintain a higher level of health activation. With increased knowledge came confidence and with confidence these participants felt more able to adapt to day to day challenges. This ability to adapt provided a greater sense of, or possibility for, feeling in control. Control has thus far been described in the context of the individual and their expressions of frustrations with lack of control over their body, longing for normality and being in control of their diabetes amidst life events. Themes pertaining to control were also evident within interpersonal relationships, in particular within the therapeutic relationship.

Interpersonal Control – Control Within The Therapeutic Relationship

Health professionals involved in diabetes care encourage active self-care and teach people how to adjust their insulin dose according to blood glucose levels, food intake, planned physical activity, inter-current illnesses and other such events. Participants with more ‘diabetes know how’ and/ or who had had diabetes for many years, described both active and passive resistance to health professional advice. This was often in response to the way in which health professionals interacted with them. For many participants, control over their diabetes and its management was important and any threats to this control by a health professional they had not connected with or believed to be not credible, led to descriptions of active resistance. Those with more diabetes ‘know how’ preferred to be more self-determining and in control of diabetes management and pharmacological treatment options.

Self-Determination

Self-determination of best pharmacological therapies and doses was a key element of maintaining control for most participants who self-rated as more highly activated. They actively sought advice and then considered it for best fit with their circumstance. They took responsibility for determining the appropriate response to varying challenges as it pertained to them as an individual and their own life context, and this may have at times diverged from health professional advice, for example:

Well all they can do is make suggestions. It is up to you as to what you do with the suggestions that they make isn't it. If your personality is such that you can cope with health professionals (laughing) then that's OK, but of course some people would follow everything slavishly and then not say anything if it upset them or upset their body. Because the health professional told them to do it (1, p. 7).

The empowerment model posits health professionals need to act collaboratively to assist people to make the best possible decisions based on their own health priorities and goals. Consistent with that approach, 'getting along' together with mutual respect and understanding was of critical importance to participants in this study. The development of self-care capability to manage their diabetes on a daily basis in a collaborative fashion was essential. For example this participant describes the importance of feeling listened to, understood and supported to develop the skills needed for effective self-care:

If you don't have a person that's willing to listen to you and understand where you're coming from you can't, you can't talk to them. Then you associate really negative feelings with diabetes, and then when you see that person you become sort of angry about the whole situation, and if they don't work with you, you're just either going to fight against them or you're not going to help yourself at all, and so you have to be able to get along to understand, well to learn, and you have to get along to have the support because diabetes you can't, you can't manage diabetes alone. But yeah you can't manage diabetes 100% alone, you have to have the input of professionals (18, p. 5-6).

There were times when participants had no intention of following the advice of health professionals, as they had their own tried and true methods of managing their diabetes. Some participants were reluctant to disclose their self-care decision making, particularly around insulin dosing, as they felt they might get told off as they perceived at times that the health professional would not determine their decisions as appropriate in terms of

maintaining physical health. This participant's description of his non-disclosure of his self dosing illustrates this well:

Because I'm pretty stubborn, I like to do things myself, even when it comes to changing the dosage of my insulin, I hate going to the doctor (laughs). Simply because I feel like, I'm answering to someone else but I feel like what I tell them is wrong, and that it's going to be a negative for me, because I'm going to get told off type stuff, and you know no-one likes being told off, but it's just like trying to think what he wants to hear, and then you say that's what I'm doing. But all the time (laughs) I've actually cut back on my Actrapid but I'm not going to tell the doctor that because he might tell me off (14, p. 3).

Self-determination was sometimes manifest through resistance. Participants described attending appointments but not openly sharing relevant information, presenting fabricated information based on their expectation of what the health professional may want to hear, or not admitting to certain things if they didn't think the health professional understood their perspective. This participant expressed this very vividly:

Well one thing that I do totally different, and I'll probably get slapped over the hand, is the whole testing of the blood, the blood sugar count. I haven't probably done that for ten years, simply because I feel that I know where I'm at, and can diagnose myself based on how I'm feeling. And yet, when I go to the doctor it's like, oh have you got your blood glucose machine. It's like oh no, I forgot that (laughs). All well knowing that there's no results on the tester anyway so But I do feel that over time people do get to know themselves and can identify situations and know how to deal with them appropriately (14, p. 11).

So decisions were being made by participants based on their own judgement about what the right thing to do was based on their own personal circumstances and their past experience.

Some participants described a sense of apathy as they had given up trying to meet health professionals' expectations of how their diabetes should be controlled. Apathy usually developed over years and as a result of not achieving desired targets despite considerable effort. Participants who described going through the motions anticipated likely questions and recommendations and endured the consultation, providing the health professional with 'acceptable' responses and then left. A participant described this eloquently:

I've been trying for many years to fit what a model of how it should be but in reality that's not how it is really. Well I suppose I've got to the point where I don't say anything really. I just really just come and get my appointment really over and done with and then I go home.....Well, like for example if I see the doctor it's more of well I just have to sort of say to him when he does ask me, that I've got to more or less sit there and say well, yes well I will take more notice of my bloods, and hmmm get my weight down and, so I'm really telling him what he wants to hear rather than in discussion about how I can improve on anything. And I know that that's what he wants to hear so I say it. Rather than getting to any discussion because there is really no discussion (3, p. 20).

While these participants understood they were not gaining benefits to their health from these behaviours, they felt defeated by the system and this was their only available option in the absence of effective or useful health professional input. The data suggests that if the health professional is prepared to get to know them and discuss treatment options in an open manner then they may be less likely to go through the motions and/or fabricate information.

Summary

In this chapter control was discussed from participants' perspectives of personal control within the context of their life with diabetes under three themes: **frustration; longing for normality; and in control**. Personal control was characterised by being in control or being

controlled. A spectrum of control in relation to life with diabetes was described. Some described distress related to not feeling in control of their body, especially when their self-care efforts did not lead to expected or desired outcomes. Some felt as if their life was being controlled by their diabetes, others felt in control of their diabetes. At the other end of the spectrum participants described diabetes to be comfortably integrated into their daily life. Overall the spectrum of control was dynamic with participants at times feeling in control and at other times feeling their lives were being controlled.

Participants' perspectives within the context of the interpersonal relationships with health professionals were also presented under the theme: **self-determination**. It appears that the relationship with health professionals plays an important role in supporting high health activation and effective self-care. Chapter eight explores this in more detail and describes themes pertaining to the impact of health professional communication and decision-making styles on health activation and self-care.

Introduction

In the previous chapters I explored the themes pertaining to the solitary and relentless nature of diabetes self-care and how this impacted on health activation, active self-care and contributed to diabetes-related distress. A spectrum of personal and interpersonal control was identified spanning both internal and external loci of control. Health professional attitudes were described by participants as impacting on their self-care either positively or negatively. This chapter will focus on participants' perceptions of health professional decision-making and communication styles.

As previously reported this study's quantitative results suggested that overall, participants were satisfied with communication and decision-making from nurses and medical practitioners, with diabetes nurse specialists being rated the highest overall. In particular positive significant relationships were found between higher health activation and higher satisfaction with communication and decision-making especially for diabetes specialist nurses and diabetes specialist physicians. Participants rated a high level of importance for communication and decision-making for all of the health professional groups, however satisfaction levels did not reach equivalence with level of importance for any of the health professional groups. Keisler and Auerbach (2006) reported that a mismatch between patient preferences for physician communication and decision-making behaviours and actual behaviours may lead to a negative effect on treatment effectiveness, patient satisfaction and emotional well being. The discrepancy between level of importance and participant satisfaction suggests that participants' preferences for communication and decision-making were not consistently being met in this study and further inquiry was warranted to understand this more fully.

This chapter presents themes pertaining to health professional communication and decision-making styles as they impact on health activation and self-care. Initially three themes are presented pertaining to participants' descriptions of essential elements of effective therapeutic partnerships and factors determining a therapeutic connection with health professionals. These are: **proficient practitioner; mutual commitment; and therapeutic connection.** These are followed by themes relating to participants' perceptions of how

nurses' and medical practitioners' communication and decision-making styles differ. These are: **therapeutic dialogue; nurse as translator; nurse with diabetes 'know how'; doctor as decision-maker; and the person-practitioner disconnection.**

The Proficient Practitioner

Where participants described a positive therapeutic relationship with health professionals a key element appeared to be mutual respect developed over time. Participants also described the importance of the health professional possessing an adequate level of knowledge and skill in diabetes care both so they could impart knowledge to them and to ensure they would receive high quality care. Some described feeling dubious when it was obvious to them the health professional did not know a lot about the intricacies of diabetes therapies and their applications to individuals, for example:

You can't let such a huge part of your life be interfered with by someone you don't trust and don't have a relationship with. Like if you don't have a good relationship with somebody you're not going to listen to them about something that you've lived for so many years, and something that's sort of all about you (18, p. 7).

I find that the GPs that I've seen are not particularly knowledgeable. One incident I asked for, it wasn't my typical GP it was just a walk-in, I'll give him that, and I said I need some test strips and he wrote out a prescription for three months for 50 test strips, and I said oh I use more test strips than that, and he said you don't test more than once a week do you? I said well yeah I probably test six times a day, and he said, oh you don't have to test that much, and at that point I really lost all faith in anything he said after that because here he was telling somebody that's an insulin dependant diabetic that they should test their blood once a week, and I find that atrocious, I mean what an idiot. So, regular care but it has to be somebody that their area of expertise was diabetes or endocrinology or something, because this was a GP and you

know it seemed very very basic you know telling an insulin-dependant diabetic to test their blood once a week (17, p. 19).

As well as the health professional having expertise in and understanding the nuances of diabetes, getting to know each other was described by participants as an important element in forming the therapeutic relationship. Taking a personal interest in the individual and their life, knowing their medical and social history, what interventions had been tried before and what was or wasn't effective for them, was described by many as critical to developing faith in their recommendations. As these participants noted:

So it's not just regularly seeing someone, it's having faith in that person that they can provide appropriately for you. And understands not only nuances of diabetes but particularly have an interest in you as a patient and your history and what's effective for you and what's not (17, p. 21).

If someone just comes in and starts talking to me about diabetes I'm like – hello who are you? Yeah, and that comes back to that relationship between health professionals and us. It's really important (18, p. 28).

Thus health professionals need to have expertise in diabetes but no matter how expert they are this can be wasted without attention to the person, mutuality and respect.

Mutual Commitment

Participants described an approach to care that involved both the health professional and the person with diabetes as needing to be committed to diabetes care. The commitment extended across the spectrum of turning up to appointments, contributing to the consultation and following through on agreed recommendations. As this participant noted:

Well I mean, the apathy can be on both sides can't it. I mean the apathy can be from the caregiver who is just saying oh it's just an appointment that I have

and I'm not really sure I know what I'm doing but I'm just gonna turn up. Particularly I think it is helpful to make subtle changes, subtle but effective changes and adjustments of insulin and things like that, it's really based on communication between the patient and the health care professional. So that's a trust relationship and then the patient's committed, the caregiver's committed (17, p.24).

Participants acknowledged that the person with diabetes has to want to be helped and participate in their diabetes care, otherwise health professionals' efforts will be futile. The requirement for the individual to want to be helped has been commented on by Mol (2008) who states that "professionals in a consulting room can do no more than attend to people who define themselves as being in need of care...health practitioners depend on active patients" (p.72). For example, these participants described the need for the person with diabetes to be committed to their own care:

For me I believe it's totally up to the individual, and if the health professional was to say oh we're going to help everyone, I think that they'll be totally missing the boat, because you can really only help those that want to help themselves (14, p.23).

Yeah well that's it, but yeah like I said you've got to be willing to help yourself first and if you're not going to follow-up on that then you can't hold the health professional accountable for it (16, p.39).

Some participants felt that they themselves were the greatest barrier to their own active self-care as they were reluctant to seek advice from health professionals either due to not wanting to face up to not having tested their blood glucose levels, or thinking they knew all the answers when in reality they didn't. For example:

You know, go in and know that we haven't really been monitoring ourselves properly and now we have to tell somebody (laughs). Because from day to

day you just, me specifically, you know people ask how I am and I always say I'm fine, I'm fine, oh how's your diabetes, fine, fine, everything's fine, fine (10, pp.23).

Yeah basically the biggest barrier to my self-care is myself. At times thinking yeah I know it all (laughs), I've had diabetes now for 25 years and I know it all (laughs) when in fact maybe I don't and that's why I get into trouble sometimes. And just thinking that I can fix it myself rather than seeking advice. Yeah (14, p. 14).

Furthermore, relationships with health professionals and the degree of perceived understanding of the challenges of living with and managing diabetes influenced help seeking behaviours. This participant stated:

Yeah I don't normally fess up to people even when things aren't fine, so yeah, when you have to.....Cos um, what are they gonna do? (laughs). I don't know, I don't know, just never have. I just think well what are they gonna do and they don't get it anyway, even if I said I felt like crap they wouldn't get it anyway, you know, because probably looking at me I look fine, even if I feel like crap (10, p. 25).

So, openness and mutual commitment to care and self-care have been identified by participants as important to supporting active participation in their care. An important question is how can the health professional make a difference to the level of mutual focus? One approach may be through the development of a personal connection whilst maintaining therapeutic boundaries.

Therapeutic Connection

Participants described the personal nature of the therapeutic relationship to be of critical importance to support them to develop a high level of health activation and to support them

in their self-care endeavors. A health professional who made the effort to know and understand their health beliefs and them as a person, and who understood the nuances of diabetes was highly valued by participants. In addition, acceptance of them as they were in a non-judgmental manner was important:

And I think for me that rings really true because you live with it every single day and if you don't have a person that's willing to listen to you and understand where you're coming from you can't, you can't talk to them – they have to have an in-depth understanding of what it's like. And be willing to accept what you're going through because it's not an easy disease to manage and I think if you, if you have a health professional that say judges you or is not kind to you, which I have experienced myself, it makes it impossible (18, pp. 5-6).

Oh because I've been under a lot of different care I've experienced good and bad, as far as kind of empowerment of you're in charge of it yourself and you can make changes and you can do things appropriately and manage things better by doing these things, rather than well that wasn't very good, you're not handling this well or some kind of judgement (17, p.6).

As described in the previous chapter, a sense of control within the therapeutic relationship was important for many participants. Participants described more positive experiences when the health professional was open, responsive to questions and shared decision-making. This supports McCormack and McCance's (2006) summary of the literature surrounding person-centredness in care as requiring the "formation of therapeutic relationships between health professionals, patients and their significant others, and that these relationships are built on mutual trust, understanding and sharing collective knowledge" (p. 473). It is also pertinent to consider the dynamic nature of life whilst living with a long term condition and the influence this may have on an individual's behaviour and their response to advice each time they meet with a health professional. In this current study participants described the importance of having their personal expertise

acknowledged and utilised in the decision-making process with different options discussed and considered. This is likely to influence the attainment and maintenance of health activation stages three and four as the individual develops skill and confidence to self-care. For example:

If I feel like I'm more in control of changes that are being made, or have at least some say in what I feel is effective, particularly from being diagnosed such a long time ago, I feel like I know my body and what's happening and what affects it more than just reading a chart I think, that works best for me (17, p. 2).

Yeah, yeah options, well because we're the ones that have got to live with it from day-to-day. It's all fair and good to say OK I want you to do this, this and this, but hey it might not suit some people, but you're not going to know unless they either a) say something to you or b) you actually ask them. Yep. You've always need the options there (16, pp. 37-38).

Due to the long standing nature of diabetes care the therapeutic relationship generally exists over many years and people with diabetes and health professionals get to know each other well. The delicate balance between professional and personal relationships raised an interesting issue. While there was a strong desire for the health professional to relate on a personal level this participant demonstrated insight about the requirement for professional distance in order to maintain therapeutic boundaries:

Like I know I fiddle with my doses. I do that because I know my body and if a health professional comes in and just says do this, I'm going to be like whoa – no because that doesn't work. And if they say well I'm the health professional I know, it's going to be like – no, no, that's not how it works. So you have to have that personal relationship but you kind of can't as well. It's interesting (18, p. 30).

For some participants, regular contact with a health care professional and perception of greater vigilance from others provided motivation to maintain their self-care efforts, thereby potentially contributing to stage three health activation. Knowing they had an appointment coming up inspired some participants to make a greater effort to carry out the required monitoring and self-care activities. For example:

I think knowing what's happening helps. I think meeting with [the specialist nurse] helps because I feel much more in charge of things. By just reporting in and knowing that the time is coming up to report in motivates me, not in a kind of student/principal kind of way or a student/teacher kind of way, but in a way of oh I want to make sure I can have as much information as I can and that's helpful to visualise at the end of the tunnel kind of thing rather than just feeling like I'm on my own in this and getting feedback (17, p. 9).

But for some this increased self-care activity was episodic in nature and focused around the up coming appointment only. Because self-care is a largely solitary exercise, life pressures and the quest for normalcy overrode their energy or inclination for active diabetes self-care in between appointments illuminating the dynamic nature of health activation, for example:

Yeah, because I know for that three months prior to it I don't have to talk about it to anyone, nobody's asking me about it, I can just carry on, you know what I mean. It's not until I have to report to somebody that I know it's coming up, my appointment, and I'll start doing my bloods and all that regularly leading up to it. And I don't know if other people do that but I'm picking probably (10, p.8).

Participants described the importance of duration of relationship with health professionals and that time was needed to build a relationship in which they felt they could build trust and therefore feel comfortable to disclose feelings of distress related to their diabetes. Reluctance to disclose personal information has been described in the literature, in

particular by Zoffman et al. (2008), who found that patients seldom told health professionals what they thought was particularly difficult for them. In this current study many participants described it as hard to express their feelings particularly with a health professional they did not know, did not trust or felt they did not know or understand how diabetes impacted on their life. This participant drew particular attention to the importance of developing trust over time:

No, well it's really a matter of the person being comfortable with the health professional, and that's the thing like a lot of people, I know I used to just sweep it [my distress] under the mat and carry on, so unless you're completely comfortable you know enough with them, then you can sit there till you're blue in the face but they're not going to tell you what you want to hear. Yep, and that comes with time. So you're not going to go and see somebody and then all of a sudden open up and tell them everything (16, p. 25).

Thus, it can be seen that self-determination of diabetes care and its management was important to many participants, as was recognition of their expertise in diabetes care as it related to them and their life. The capability and desire to be in control was a common characteristic of those with a higher level of health activation and difficulties within the health professional – patient relationship arose when self-determination was denied. The desire for control over determining treatment regimens was important for many participants, particularly those with long standing (greater than 15 years) type 1 diabetes. Control manifested in a variety of ways, consistent with literature on patient preferences for decision-making, with participants desiring at the very least discussions on potential options and some involvement in decision-making.

Participants described a range of experiences of how nurses and medical practitioners related to them and how this impacted on their attitude towards health activation and self-care. Moreover, the way in which health professionals interacted with participants also contributed to diabetes-related distress.

The data to follow will show consistent differences between participants' responses about role expectations of nurses and medical practitioners. As an introduction, nurses were generally perceived as someone to whom they could talk about their health concerns, someone who could translate treatment instructions into everyday language and for diabetes specialist nurses, someone who assisted them to navigate their way through the complexities of the required multiple diabetes self-care activities. Medical practitioners' roles were perceived by participants to be focused on making a diagnosis, treating and prescribing medications, and to be the ultimate decision maker about care. Medical practitioners in general however, were not considered to be in touch with the person's reality and therefore participants perceived that treatment recommendations were not always realistic.

Therapeutic Dialogue

Participants consistently described the nurse as someone who would take time to talk to them about their diabetes, was receptive to questions and would freely give information. The relevance of the social dimension of the nurse's practice was described by Millard et al. (2006) as serving the particular purpose of establishing equality between the nurse and the patient within the interaction. In this current study, the more personal approach taken by nurses was highly valued because they attempted to get to know the person as an individual and to understand the support structures or barriers to maintaining self-care:

Nurse doesn't sound as threatening as a doctor. Even if we took away the sexist if the doctor was female, I still feel that it would be easier to talk to the nurse simply because nurses aren't seen as the "bad people" (laughs). If you put them in like cowboys and Indians (laughs), you know good people/bad people. Yeah, so talking to a nurse is like, they're like your friend. Talking to the doctor is like talking to the principal (14, p. 4).

Yeah, I think because you see, well for me I see the nurse more, I only really see the doctor when I need a prescription, you know for after six months if he

hasn't seen me, he'll request that I go and see him and he'll ask how I was and I'll just say fine and he'll get me to go do bloods and he'll give me my prescription. Whereas with the nurse we tend to chat a bit more about things and she does ask me a lot more questions and stuff. Well she takes a lot more personal interest and she does give me good information. I will ask her questions whereas most doctors I don't, I just say oh I need some insulin, they'll say how's it going and I'll say great, and we'll move on. Whereas she will push me more for questions and stuff like that so she does I think get a bit more and then she'll feed me more information based on that. Yeah, and she does try and chase me down and get me in to see her more regularly (10, pp. 15-16).

The value of time was frequently mentioned by participants and was a major differentiating factor between the experience of seeing a nurse and a medical practitioner. Nurses were perceived to take more time with participants and to make extra effort to help participants with their diabetes self-care requirements. One participant noted:

Oh nurses are a bit more considerate I think. Yeah, it's not very nice but, yeah doctors are pretty rushed so you know they've got to see a certain amount of people all the time you know, they haven't got the time to really explain things to you in simple English. With the nurses it's entirely different you know I find them much more helpful. They take the time to explain things to you, you know and if you've got questions they'll answer them if they know and if they don't they find out for you (7, p. 10).

Many participants described feeling that treatment recommendations given to them by medical practitioners were often not realistic for them. Nurses were perceived to have a greater appreciation for the complexities of people's lives and how those might impact on their diabetes self-care. The nurse focused more broadly on the "big picture" and they worked with individuals to develop strategies that considered their life context.

Individualised recommendations or treatment plans that were based on and constructed with more than data or laboratory results were highly important. For example:

I think, in my personal experience, doctors tend to be more focused on numbers rather than a holistic approach to diabetes care and management. I find that the nurses in general look at the big picture (17, p. 4).

Sometimes he [the doctor] doesn't understand. It can be difficult at times but he just sort of gives you the facts and figures and don't do this, don't do that and you think well yeah, you try and do that. But your lifestyle has got to come into the facts and figures to make them work right. ...The nurses have got the hands-on approach about how to do things and the best way to do things. One's theory [the doctor], the other's practical [the nurse] (11, pp. 11-13).

I think they [nurses] have a bit more empathy and have got that, and they give you a bit more time, and appear to be more understanding. More empathetic and show more caring, and care more about you know what is actually happening to you and maybe has a better understanding of why we do the things that we do. It's you know it's not about well you must do this, this and this, but really overall you have to live, and there's a part in your regime that you must live (3, pp. 18-19).

Nurse As Translator

Many participants frequently described feeling confused or unsure about recommendations given to them by their medical practitioner. This was described as being due to the way in which information was provided, and the language used to communicate messages. Nurses were perceived as being able to translate the medical practitioner's recommendations into language they could understand and to provide practical interventions the participants could manage. As noted by one participant:

Nurses tend to be more down to earth or more basic, or more simple, easier to understand. They use language that you can understand. For example, when I saw [the specialist diabetes nurse], well it was simple. She told me what the problem was and how to sort out what to eat, what I could expect, in layman's terms. So more communication in simple layman's terms, not medical terms (5, p. 14).

Typically diabetes specialist nurses and diabetes physicians care for more people specifically with diabetes, and people seen by specialist services tend to have greater complexity (Rubin et al., 2006b). Therefore the expertise of diabetes specialist nurses and diabetes physicians in treating diabetes and understanding its impact on life is generally more advanced than most primary health care providers. Nurse specialist case management resulting in better collaboration of care has been found to have a positive impact on diabetes-related distress, better well being and improved regimen adherence (Gabbay et al., 2006; Rubin et al., 2006a). The themes that follow highlight these differences from participants' perspectives within this current study.

The Nurse With Diabetes 'Know How'

Participants described diabetes specialist nurses as having a similar level of knowledge and skill as medical practitioners with respect to their diabetes care but described specialist nurses as 'seeing' things differently from doctors. In addition, specialist nurses were perceived to be able to provide alternative explanations and options that may offer a more individualised approach which took into account their capabilities and their life context. Participants described specialist nurses as spending time getting to know the person as a basis for understanding what might work for them. The specialist diabetes nurse was also considered to have more diabetes knowledge and skill than other nurses and therefore more effective with supporting problem solving and decision-making. This participant describes it well:

I knew basically from all my research and from knowing my body through years of this, kind of what to do, but there's still a lot of fine-tuning and that, I find it is extremely helpful to have the support of somebody that's knowledgeable, somebody that can actually help with, even like the high blood pressure medication, I would never have thought that, would never have dreamed that that would be something that I'd need, but there you have it, and that [a nurse practitioner] can not only diagnose but prescribe and that's really helpful (17, p. 19).

Participants described the relationship with the specialist nurse as one where they were able to 'bounce ideas off' one another in an open and mutually respectful way. Receiving positive feed back supported and encouraged participants, reduced their sense of isolation and supported development of skill and confidence. Overall they felt more in control and that by working with a specialist nurse they would be able to navigate an easier path to get the same or a better result. This is captured well in the following excerpts:

Usually they [specialist nurses] perceive things differently from what the doctors do and tell you say an easier way or some other solution that gets the same result (11, pp. 12-13).

It comes down to communication again. You've got to try and, you've really got to push the conversation with [the doctor], whereas I find with [the specialist nurse] she'll listen to what you have to say, she actually works through the whole process with you so you work hand in hand together. So it's not like OK we're going to do this, we're going to do that, it's just like ah we'll what about if we try this and try that, and then you come back to me with this then we'll have a look at it from there, we might need to change this here and this there and so forth there, so you actually work through the whole process with her. And yeah you can just bounce off each other (16, p. 36).

Diabetes specialist nurses were also commonly perceived to have greater appreciation of the dynamic nature of the difficulties of living with and self caring for diabetes, and for making appropriate adjustments in treatment recommendations relevant for that moment in time. This is consistent with the DAWN (Rubin et al., 2006b) study where specialist nurses in particular were more likely to perceive psychological issues and recognise them as having a greater impact on peoples lives. This participant's quote illustrates how the specialist nurse in this instance supported his self-care by being available for regular contact, being able to ask or answer questions, discuss concerns, and acknowledging his level of self-care effort:

Like with [the specialist nurse] she was she was excellent for me. What I found like she was always in contact with me there and I could discuss anything with her and yeah she had a good understanding of how I felt and she knew the effort I was putting in (16, p. 11).

As described earlier in this chapter, in contrast to the nurses' role being perceived as someone to whom they could talk about their health concerns and who could translate treatment instructions into everyday language, participants described the expected roles of medical practitioners to be focused on making a diagnosis, treating and prescribing medications, and to be the ultimate decision maker about care. Two themes have been identified in relation to participants' perceptions and experiences: **doctor as decision maker** and **the person-practitioner disconnection**.

Doctor As Decision Maker

Overall, medical practitioners were highly valued for their knowledge and skill. Medical practitioners were perceived as the ultimate decision-maker and some participants trusted their advice with the belief that they had no reason to question it. For example:

The doctor and that, they're trained to do their job and they know what they're talking about and I'm just the Truck Driver or something like that, you

know I don't know anything about being a doctor you know. I'm quite happy with the advice. I don't think they'd give you the wrong advice, put you crook or anything like that. Well I hope not. They're a person that most people trust. You know, people go to them for advice and take that advice because you're there to seek it (7, p. 14).

I always liked him because he's straight up, he just tells it straight out, no ifs, buts or nothing. Yeah, but it's not a negotiable thing because it's doing damage whether you like it or not, Yeah, well I would say health professionals are not there to annoy you. Well, the idea is they've got the knowledge that the person who has got the complaint hasn't, so if you don't listen you're not going to progress for a start (9, p. 20).

In contrast to generalist and specialist nurses, lack of time and rushed appointments with medical practitioners was frequently described. Participants perceived limited opportunities with the medical practitioner for explanations, learning how to adjust medications, and for participation in decision-making about treatment changes. As these participants noted:

I feel like the nurse has time to talk to you, and with the doctor is yep signed, yep done. Where the nurse takes a little bit extra time, and with my experience the nurses always ask extra questions, like I might be going to see them for my diabetes but they'll also ask about my sport or what else is happening in my life. Whereas the doctor you're in, you're out (14, p. 5).

Oh, I suppose if I ask them they'll take the time, but you know, I don't know I just sort of got so used to just going in there and saying well right I'm here, blood pressure's OK, that's OK, got any pills, that's OK and then pay your bill (7, p. 13).

However, some participants were confident enough to question decisions or treatment plans despite the awareness of time constraints:

Yes I am involved with decision making if I put my foot down (laughs). Why aren't you doing this or why aren't you doing that then he will explain to me. Well, I suppose because they're inclined to be busy and your appointment time is restricted, there is that feeling that if you're not pushy enough you will miss out and you'll go home and you'll say well now why didn't I ask that? (1, p. 11).

The Person-Practitioner Disconnection

Medical practitioners in general were not considered by participants to be in touch with the person's reality (health beliefs and commitments of everyday life) and therefore treatment recommendations were not always perceived to be realistic. Participants frequently described a disconnection between theory and how this could be applied to their reality. In some instances participants believed recommendations were based on an agenda determined by the medical practitioner which was not congruent with that of the participant. For example:

In spite of going to the doctor and things like that I, you know I never really, always had trouble getting a handle on it, getting to know what I should and should not be doing. You get told what to do but when you get back to the real world it sort of doesn't quite work as youAnd it's great in theory but in practice it's not quite so easy (5, pp. 2-3).

I think because when we do come along to see either the specialist or the doctor, we know ourselves, well I can only just talk for myself, I know myself what I am supposed to do, it doesn't work, it doesn't work, the theories don't work, not for me anyway. And so I sit there and I hear what they are

saying but I know inside deep down that that's not how it is. It's what the books may say but for me it's not really how it is (3, p. 3).

Another example of disconnection was surrounding communication within consultations with medical practitioners. Some participants described attending appointments but leaving feeling as if they had not achieved anything. This was described by participants at times as due to lack of confidence and/or knowledge to ask questions, and at other times limited opportunity to ask questions or discuss options as medical practitioners were perceived by some participants to predominantly write in the clinical notes and ignore them. As described by these participants:

I'm not real good with medical situations, or I'm out of my depth with medicine, health and those sorts of things and I don't know the correct questions to ask. And I found that the doctor I was using was not forthcoming. So you sort of went along and when you left you sort of thought well that was a bit of a waste of time, I didn't learn anything there, and I sort of went away none the wiser. It seemed like a sort of a bit of a waste of time even going (5, pp. 11-12).

I don't feel that there's a real doctor/patient relationship because he doesn't really look at you when he's talking to you, just puts his head down and just writes and there's silence and he just keeps writing and then there's silence and sometimes I feel like saying hey, you know, tapping him on the shoulder and going hey, you know I'm here, I've come today because I want to hear what I should be doing and you are busy writing and then you're saying well and the doctor, this is a classic example, well you know what you should be doing don't you. And I'm sitting there and I'm thinking, what the hell am I doing here? I may as well not come. You may as well just tell me over the telephone (3, p.5).

Rather than supporting the development of self-care capability and considering an individual's life context, the focus of the medical practitioner was frequently perceived by participants to be on clinical data and results and not on them as an individual. Many participants described feeling unfairly judged for not meeting clinical targets without consideration for their life context. Some expressed feeling 'naughty' and having to 'fess up' to a medical practitioner whom they felt was acting as judge and jury. For example:

It's like going to trial with a bad reading or a bad HbA_{1c} or, and it's not even about bad record keeping or whatever it's just a pure HbA_{1c} number that comes up and it's seen as poor management rather than looking at circumstances. I think doctors look at it as this person's not being very good with their management, rather than OK what are the facts that are affecting this? (17, p. 4).

I know that I should monitor a lot more carefully and I don't, and so then you feel like a little bit like the kid going to the Principal. Yeah. (laughs) It's probably the best way to describe it. Yep, and confess (laughs). Sit there like the yeah naughty school kid. Yeah, some of them do treat you like that and others, at other times it's just because you know you really haven't got yourself together and you should be doing it better and so now you can go and tell somebody that, you know. Stare them in the face and tell them how pathetic you've been (10, p. 23).

It is evident that participants have different expectations of nurses and medical practitioners. Communication and decision-making needs were not always met by both nurses and medical practitioners, and participants described with great clarity differences in the approaches utilised by nurses and medical practitioners. Participants demonstrated an awareness of differing levels of knowledge and expertise and how helpful this was when that knowledge and expertise was utilised in a way that accounted for their life context. A number of participants recognised the value of accessing both the complementary attributes

of nurses and medical practitioners in order to support development of health activation through improved knowledge and confidence to carry out self-care activities. For example:

...and I think that you actually do need the nurses perhaps to do more of the holistic side and the doctors to do more of the diagnosing, treating, fixing as such. I think maybe that is quite true to a certain degree (18, p. 29).

Well doctors have got a good deal of the knowledge but the nurses have got the hands-on approach about how to do things and the best way to do things. Yeah, so if they're a good team they complement each other (11, p. 12).

Summary

The themes pertaining to nurse and medical practitioner communication and decision-making styles as they impacted on a person's capability and inclination towards active self-care of their diabetes have been presented. Overall, participants clearly described differences in how nurses and medical practitioners relate to them both in terms of communication and decision-making processes. Participants identified the importance of health professionals recognising their expertise in self-caring for their diabetes, although at times their self-care strategies may not be considered effective for maintaining physical health by health professionals. Being involved in decision-making was important for many participants and for those with more expertise maintaining a sense of control in the therapeutic relationship was essential.

Participants described a requirement for mutual commitment to diabetes care and suggested that therapeutic relationships most effectively supported development of health activation and active self-care when founded on the following characteristics: a genuine interest in, and consideration for, the person and their life context; open communication; adequate consultation time; responsiveness to questions; and mutual respect for expertise between

both person with diabetes and the health professional. The importance of duration of relationship and continuity of care was also highlighted thus, the three thematic analysis data chapters have illuminated Thorne et al.'s description of self-care decision making as a complex developmental process taking place within “the context of a disease trajectory, a health culture, and a uniquely meaningful life” (2003, p. 1349).

Chapter nine will provide an interpretation and discussion of both the quantitative and qualitative findings with links to relevant literature or theoretical positions. The value of utilising mixed methods methodology in this study will be critiqued and limitations to the study will be presented. The significance and implications for nursing, the broader multidisciplinary diabetes team and service delivery will be discussed and suggestions for future research will be identified.

Introduction

Diabetes presents a serious health challenge for New Zealand because it is a significant cause of ill health and premature death. Diabetes is considered to be relatively unique as a long term condition due to treatment regimens being carried out largely through self-care. As such, people with diabetes influence the course of their health and wellness by their level of active engagement in self-care activities. It is well recognised that self-care in diabetes, can be demanding and is influenced by numerous factors (Siguroardottir, 2005).

Health activation is a composite notion focusing on four major elements believed to influence active engagement in self-care: beliefs, knowledge, skills and confidence, and behaviours (Hibbard et al., 2004). In this study I set out to elicit an understanding of factors associated with differences in diabetes-related health activation in general, and specifically to provide explanations for how diabetes-related distress and/or health professional communication and decision-making styles contribute to health activation. This has been accomplished in the data chapters through the representation of participants' perceptions as they responded to quantitative and qualitative enquiry. The additional aim of generating new ideas on how diabetes care can be delivered to maximise personal resourcefulness and promote health activation is attended to in concluding the study.

The literature review provided an overview of existing theories or models on behaviour change related to research topic. It also provided a synopsis of relevant literature on self-care, emotional distress and health professional communication and decision-making which supported the process of enquiry. The study began with a practice based hunch consistent with abductive reasoning. The research questions based on this hunch influenced the choice of mixed methods as a methodology that could support the inquiry. Mixed methods methodology allowed for a pragmatically structured research approach, utilising abduction, intersubjectivity and transferability within its methodological approach. In particular, the use of both quantitative and qualitative methods ensured that perceptions of participants were comprehensively honoured.

The description and interpretation presented in this thesis is inevitably limited. The multiple influences on health activation, and the complexities of maintaining diabetes self-care makes a definitive analysis elusive. It is important to acknowledge that the experience of others with diabetes as they live their life with the challenges of diabetes self-care may diverge from the description of perceptions of participants in this study principally because everyone is unique, although similar perceptions may be held.

Overview of findings

In this study health activation was found to be dynamic and associated with many factors. Diabetes-related distress and health professional communication and decision-making styles explored in this study were important contributors to health activation in either a positive or negative way. This was more evident in the qualitative data and subsequent thematic analysis than in the statistical analysis of the quantitative data. Overall participants rated themselves as having a high level of health activation suggesting they believed in the need to be actively participating in their diabetes care and perceived themselves to have the necessary knowledge and skills to do so. However, this was not always borne out in the qualitative data where interesting contradictions were present depending on an individual's perception. Health activation was found to be likely to change with duration of disease, in response to life events, development of complications, others around them, life pressures, self-care fatigue, and interactions with health professionals. It is acknowledged this study's findings may be influenced by response bias as potentially those who were more health activated were more likely to participate in the study. Thematic analysis revealed overarching influences on health activation encapsulated in three inter-related themes: **solitary self-care, uncertainty for future health, and the relentlessness of self-care.**

Contradictory findings were apparent for diabetes-related emotional distress between the quantitative and qualitative findings. Participants reported low distress overall in the questionnaire (mean 2.0 from possible response range of 1-6) but the thematic analysis of qualitative data revealed considerable distress across a range of life issues. Thematic analysis of qualitative data revealed divergent and context rich perspectives. Participants

described a reluctance to express distress, influenced by what was described as the New Zealand ‘stiff upper lip’ culture. Participants’ response to distress manifested in a variety of ways from stimulating self-care action to avoiding self-care activities in order to reduce distress. The theme **she’ll be right** addressed possible explanations from participants’ perspectives for the difference between quantitative findings of relatively low levels of distress and experiences in clinical practice, with particular relevance for the New Zealand context from the participant’s perspective.

A spectrum of control was described in four themes encompassing both personal and interpersonal perspectives of control: **frustration, longing for normality, in control and self-determination**. It is evident that adults with diabetes have health needs that are socially and emotionally complex in addition to having medical complexity associated with this disease of multi-pathology. Consequently attention must be paid to all dimensions of health and illness.

A complex interplay of behaviours occurred in interactions with health professionals. Many participants described wanting control over their diabetes management to varying degrees, but at the same time wanted access to advice from a health professional who understood the nuances of diabetes care when they needed help. People behaved in different ways in order to exert control and this at times included withholding or fabricating information. The ongoing management of diabetes amidst the complexity of life is personal and challenging and there were times when participants needed to save face by saying what they thought the health professional wanted to hear in order to not be seen as pathetic or a failure.

A number of themes pertaining to health professional communication and decision-making styles were identified and were structured under two sections, the first focuses on essential elements of effective therapeutic partnerships. These are: **proficient practitioner, mutual commitment, and therapeutic connection**. The second section presents themes relating to participants perceptions of how nurses’ and medical practitioners’ communication and decision-making styles differ. These are: **therapeutic dialogue, nurse as translator,**

nurse with diabetes ‘know how’, doctor as decision maker, and the person-practitioner disconnection. These will be described in more detail throughout the chapter.

Effective interpersonal relationships with health professionals were critical to the development of self-care skills and the confidence to carry them out. Participants clearly described the different professional orientations, roles and communication styles of medical practitioners and nurses. Participants described medical practitioners as responding to the diagnosis, treatment and ongoing management of the disease, whereas nurses responded in a more contextual manner focusing on managing life with the disease. These differences have been previously described in the literature (Collins, 2005; Seale, Anderson, & Kinnersley, 2005) and reflect the professional orientation and body of knowledge of these different but related disciplines. The ongoing challenge in practice appears to be the synergistic utilisation of health care professionals with different but complementary knowledge, skills and interpersonal styles to ensure people with diabetes receive a comprehensive package of care that is responsive to all of their needs.

In this discussion and conclusion chapter the study findings are reviewed and considered alongside relevant literature and theoretical positions. Comment is made on the chosen research methodology, the research process, the limitations, and significance of the study. Finally, suggestions for further research are made.

Health activation

The demographic profile of the 220 participants who completed the Patient Activation Measure (PAM) was presented in chapter five where it described that three quarters of participants (73.6%) rated themselves using the PAM as having a health activation level corresponding to stages three or four (Appendix J). This means those in stage three felt they could take action to maintain lifestyle changes, and had confidence to cope with new problems or situations. For those in stage four, they believed they stayed on course with their diabetes self-care even when under stress. This is higher than reported in a previous study with 1469 participants in which only 58.8% were in stages three and four (Hibbard et

al., 2005). To add a visual comparison, the percentage of health activation stage groupings from this current study and the Hibbard et al. study are presented in Table 21.

Table 21

Health Activation Stages for Current Study and Hibbard et al. (2005).

Health Activation	Current study %	Hibbard et al. %
Stage 1	15.0	11.8
Stage 2	11.4	29.3
Stage 3	35.9	36.5
Stage 4	37.7	22.3

The difference in participants' rating of their health activation level could be explained in a number of ways. Hibbard et al.'s study included people with a variety of long term conditions, whereas this study included only people with diabetes. People with diabetes are required to undertake a wide array of self-care activities imposing on multiple aspects of life, arguably more than most other long term conditions, therefore their responses may differ. The number of participants in this study is comparatively small in relation to Hibbard et al.'s study and it is possible that a response bias exists as participants who were more activated may have been more inclined to participate in the study.

From the quantitative data analysis it would appear that the demographic and health-related characteristics significantly associated with higher health activation were having type 1 diabetes, being younger, having better general health, less co-morbidities and a higher level of education (Table 6). Younger participants with type 1 diabetes who rated themselves as more highly activated, did not necessarily have lower (better) HbA_{1c} levels (Appendix K). While being Maori was significantly associated with a higher HbA_{1c}, there was no significant association between being Maori and health activation level although, the numbers of Maori in this study were low and it is therefore not possible to draw any conclusions. There could be value in further testing and exploring interactions in the quantitative data in future research.

While the quantitative data showed that being older, having type 2 diabetes, having poorer general health, more co-morbidities, and being less educated was significantly associated with lower health activation, this was not necessarily borne out in the qualitative analysis. From the qualitative data analysis those with a low health activation generally had limited knowledge about diabetes and/or lacked the skills and confidence to attempt adjusting aspects of their treatment regimen (insulin, food, physical activity) to accommodate changing circumstances or planned activities. While consistent with stages one and two health activation, these characteristics were the same for participants with both type 1 and type 2 diabetes, and for varying ages and health status. Thus, for this study's participants it appears that understanding the nuances of diabetes and having confidence to make adjustments to their treatment regimens was more influential on health activation than type of diabetes, health status or age.

While a higher health activation is purported to be desirable, low health activation was not necessarily negative for some participants. They welcomed health professionals making decisions for them about their treatment recommendations as they perceived health professionals to possess superior knowledge. As a positive form of autonomy, the deference to others with perceived expertise to make an informed decision on their behalf has been previously described as welcomed paternalism (Moser, Houtepen, van der Bruggen, Spreeuwenberg, & Widdershoven, 2009). According to Moser et al. these people “freely transfer or delegate” (p. 211) an element of their decision making to another person. Paradoxically, these people are not necessarily passive recipients of care, but rather they are choosing to assume a passive role (Millard et al., 2006). In a study focusing on people with cancer, Brown et al., (2002) suggested that non-involvement in decision-making may be also due to low energy levels in response to the “emotional onslaught of a diagnosis” (p. 237). This could equally be applied to diabetes both at the time of diagnosis and throughout their extended disease trajectory as the impact of the disease advances and new complications develop. A relationship between health activation and diabetes-related distress did not reach statistical significance in either correlational or regression analyses (Table 14 & Table 16). However, in the interview participant group those with lower health activation described negative emotions associated with their diabetes more so than

those with higher health activation. This difference reflects the ability for interview data to reveal individual variability whereas the quantitative data averages participants' responses. The negative emotions were associated with their frustration at having diabetes in the first place, the relentless nature of diabetes self-care, life events presenting challenges to their self-care and at times experiences with health professionals. As presented in chapter six, 40% of participants felt as if family and friends didn't appreciate how difficult living with diabetes was. This was reiterated in the theme **solitary self-care** where the participants felt alone in their self-care endeavours. This supports the call for caution in some of the literature surrounding self-care. While on the one hand self-care is purported to be empowering, on the other hand there is the potential for it to be "excessively individualistic and victim blaming" as it focuses on individual responsibility (Chapple & Rogers, 1999, p. 445; Kim & Kollak, 2006).

Universally participants considered self-care to be very important to avoid complications although, those with low health activation often described feeling overwhelmed with diabetes and its self-care requirements. Thorne et al. (2003) described an individual's assumptions about their future health as powerfully influencing self-care decision making in diabetes. They stated "the envisioned future became intricately interwoven with fine tuning the bases for self-care decision-making" (p. 1347). In this study the theme **uncertainty for future health** encompassed the uncertainty of reward for effort both for short and long term complications. For some uncertainty was an activator and for others a deactivator. Participants with lower health activation were more likely to express difficulties with figuring out what to do when their body didn't respond how they thought it should or expected it to. Although many participants with lower health activation were well versed in diabetes management, strategies they had tried in the past did not always seem to work and this sense of puzzlement quickly led to frustration and at times distress, resulting in lack of action. This lack of action as a result of failed attempts has been described in Vroom's Expectancy theory (Vroom, 1964). Expectancy theory defines motivation to act as a process governing different choices and a process that is controlled by the individual. The individual makes choices based on an assessment of how likely it is that a given behaviour will lead to a desired result and what value the individual places on

the result. If the individual either does not perceive a high likelihood that they will be successful or the result is not highly valued, then little effort will be invested. This is more likely to occur when the individual does not have effective support structures to provide encouragement during more challenging times.

The theme **the relentlessness of self-care** captured the felt burden of living with diabetes and its required self-care activities. The quantitative analysis of diabetes-related distress found that 30% of participants rated three or more (from a range of 1-6) for the question in the diabetes distress scale asking how much of a problem it was that diabetes was taking up too much of their mental and physical energy everyday. The relentless nature of diabetes self-care demands for many participants challenged reaching stage three or four health activation. Participants described they had “just not into it days” when it was hard to maintain their self-care efforts despite having the knowledge and skills to do so.

The measurement of health activation using the PAM provided an insight into how participants rated their beliefs about active participation in care and their capability to manage aspects of their disease treatment. Previous literature found that a positive change in health activation related to a positive change in a variety of self-care behaviours (Hibbard et al., 2006). In this study however, the PAM did not appear to be sensitive to the differing perspectives on health, social, cultural and political perspectives, what being highly activated actually meant to individuals or the relationship with distress on different components of health activation such as confidence and ability to stay on track. This may reflect differing perspectives on what self-care is and what it is trying to achieve. Thorne et al. (2003) discuss individualised standards influencing self-care decision-making. That is, standards that were contextually unique to that individual, such as the ability to play golf or avoiding hypoglycaemia, defined what self-care activities were important for that individual. Interviews with participants in this current study provided further insight on what health activation meant to individuals. As previously mentioned participants universally agreed that they had a major role and responsibility for self-care of their diabetes and many perceived they were highly activated in this respect. Nonetheless, it appears that preserving health and well-being and functioning on a daily basis with the

maximum degree of normalcy had primacy of purpose. The quest for normalcy has been described as having a major influence on the way in which people with diabetes may define themselves, organise their lives, and cope with the complexity of self-care (Thorne, 1993).

Consistent with the conceptual definition of health activation (Hibbard et al., 2004) the defining characteristics of participants with high health activation in this study were diabetes know-how and confidence. I have defined diabetes know-how as an individual possessing a higher level of knowledge and skill about diabetes and the confidence to manipulate their insulin regimen to fit their lifestyle or daily challenges as they presented. Participants with diabetes know-how had the confidence to try different things and to maintain their efforts in search for optimal blood glucose control even if their first attempt was unsuccessful. Within this group however, were contradictions pointing to an awareness of differing participant perceptions of what being highly health activated was. Some self rated as highly health activated but did not engage in what would be considered as health promoting self-care activities by health professionals; for example not regularly monitoring their blood glucose level, not taking their medication regularly as prescribed nor adjusting insulin based on blood glucose results or planned activity or food excursions. The incongruence between participants' self rating of high health activation and actual behaviour may reflect the absence of the social, cultural and political influences from Hibbard et al.'s conceptual definition of health activation. An individual's social and cultural contextual factors will differentially determine the meaning of what it is to be highly health activated. The political context, that is the unequal social conditions and relationships within which people interact, the financial difficulties people face, differing access to health services and unequal power status within health care relationships, will also be influential on health activation and an individual's participation in active self-care. It would appear that while being highly activated may be perceived by some to be focused on controlling blood glucose levels, for others it was more about actively working to control their life and making an appropriate fit in their life for their diabetes, thereby maintaining a sense of normalcy. This meant at times that diabetes itself and health professional advice was ignored or not heeded as they strove to maintain a sense of

normality or to minimise potential distress when strategies did not produce desired outcomes.

Diabetes-related distress

Diabetes-related distress (DRD) was present in this study sample at levels consistent with the literature with a mean score of 2.00, $SD = 0.92$ (range = 1.00 to 5.47). Higher distress levels were reported with significant associations by those who were younger, female, and had higher HbA_{1c} levels. From studies to date distress scores range from 1.00 - 5.76, from a possible 1 – 6, with a mean score of 2.27 ($SD = 1.03$) (Polonsky et al., 2005). As presented in Table 22, total scale mean scores and subscale mean scores in the current study are similar to those in other studies using the Diabetes Distress Scale (Polonsky et al. 2005). Mean scores in this study were higher for the emotional burden subscale rather than regimen related as in Polonsky et al. (2005) however, this may be due to all participants in this study being on insulin.

Table 22

Mean Total Diabetes Distress Scores and Subscales Scores for the Current Study and for Polonsky et al. (2005). 1=no problem – 6 = serious problem.

Diabetes Distress Scale	Current study		Polonsky et al.	
	Mean	(SD)	(2005) Mean	(SD)
Total scale	2.00	(0.92)	2.27	(1.03)
<i>Subscales:</i>				
Emotional burden	2.25	(1.19)	2.58	(1.35)
Physician-related distress	1.63	(1.02)	1.74	(1.08)
Regimen-related distress	2.06	(1.02)	2.63	(1.37)
Interpersonal distress	2.04	(1.28)	1.82	(1.16)

Overall, diabetes-related distress levels reported by participants using the diabetes distress scale appeared relatively low and this is consistent with the literature. However, data from the 18 participants who participated in interviews revealed a divergent picture. Thematic analysis of the interview data revealed a range of negative emotions impacting on participants' lives such as feeling down, feeling pathetic and experiencing just not into it days. Interestingly, many participants appeared reluctant to classify these negative emotions as distress and were reluctant in general to admit to feeling distressed.

While acknowledging the qualitative data is based on a smaller subset of this study's participants, the marked discrepancy between quantitative and qualitative findings raises questions about the Diabetes Distress Scale as an appropriate scale to use in the context of NZ culture. Based on participants' responses in this study, people with diabetes in New Zealand may be reluctant to admit to distress and this potentially would likely apply to those with other long term conditions. Participants offered suggestions for the discrepancies such as the stigma associated with emotional distress, with a pervading perception that those admitting to experiencing emotional difficulties were weak. The theme **she'll be right** captured the 'stiff upper lip' attitude often held in New Zealand and was remarked on by many as a potential barrier to disclosing distress. The lack of an established relationship with a health professional whom they trusted was also described as a potential barrier to disclosing distress. Furthermore for some, admitting distress would mean having to face up to their problems and dealing with them.

It is possible the self-report nature of the distress scale in the context of a research project was less conducive to revealing distress and that participants felt freer to express their feelings in a more personalised way through interview. Although it is known that people seldom tell professionals what is difficult for them (Zoffman et al., 2008), universally participants agreed that health professionals should enquire about distress. Therefore it is possible that in a clinical practice context where the information was to be utilised to inform a package of care, participants may respond differently again.

The thematic analysis in chapter seven described a **spectrum of control** spanning personal and interpersonal characteristics. On the personal level three themes were identified: **frustration, longing for normality and in control**. These themes capture the essence of how participants struggled with the unpredictable nature of diabetes while they sought to achieve control of it. Frustration occurred as the body did not respond in the way they expected or wanted it to resulting at times in rebellion. Rebellion was directed at either the diabetes itself by not blood glucose monitoring or proactively adjusting insulin doses, or to others around them including health professionals. Rebellion was not necessarily a phase in a trajectory towards developing expertise in diabetes self-care as described by Paterson and Thorne (2000) but rather reflected more ‘a moment in time rebellion’ in response to others’ criticism or challenging life events.

Quantitative data analysis showed a significant positive association between higher distress and higher (worse) HbA_{1c} levels (Table 9). In response to frustration, longing for normality and wanting to be in control, a counterstrategy for some was to completely ignore their diabetes. Of interest some of these participants rated themselves as highly activated. These participants were acting consciously and knowledgably and were aware they were putting their physical health at risk, however, maintaining emotional well-being was more important to them as was the ability to function on a day to day basis. Indeed, this wrestling for control has been expressed by Townsend, Wyke, and Hunt (2006) as a “moral dimension to the chronic illness experience” (p. 186) where the impacts of a long term illness are voiced as “something to be struggled against, and to be controlled” (p.186).

Chapple and Rogers (1999) report a diversity of control behaviours, with those with a long term condition more likely to want to be in control of their own care in contrast to those in an acute care situation preferring others to take control. Control beliefs have been previously described by Bandura (1997) as “whether one can produce desired events or avoid undesired ones independent of any means.....Lack of control may arise from personal incapacities or the social structure of outcome contingencies” (p. 27). Social cognitive theory comprises internal and external locus of control. A distinction is made between the loci of control as they have “different motivational, affective, and behavioural

effects and indicate whether personal or social remedies are required” (Bandura, 1997, p. 27). Therefore it is possible that people experiencing more distress had low perceived internal locus of control as they felt less able to personally maintain control of their diabetes and felt less control within clinical encounters with health professionals. In this study control and distress appeared to be inextricably linked on a dynamic continuum where at times distress acted as an activator or as a de-activator. In Thorne et al.’s (2003) study on self-care decision-making participants described the decision to take control as including heightened vigilance and monitoring and goal setting. Being ‘in control’ also meant being able to mediate the effects of diabetes. While this description will be congruent with some of this current study’s participants, for others being in control of their diabetes meant putting it to the back of their mind and not letting it interfere with their day to day activities.

Interpersonal control was represented by the theme: **self-determination**. Control of their diabetes and its management was highly important for many participants and any threats to this were met with both overt and covert resistance. When participants felt able to self-determine their treatment options they were more positive about their diabetes and less distressed as they felt more in control of its management. Having options presented and the opportunity to discuss these options and how they may fit their personal circumstances was empowering. Indeed, as stated by Townsend et al. (2006) “people express their desire to be perceived as credible patients in the medical encounter, and as medication users” (p. 186). Where participants perceived they did not have the opportunity to contribute, or felt they had their own ways of managing their diabetes, they would just go through the motions when they attended appointments. This may manifest in behaviours such as not disclosing accurate blood glucose results or insulin doses. Others who had tried to fit what they called ‘a model’ for years but had not achieved it, attended appointments and passively agreed with all recommendations knowing full well they had no intention of applying them. This behaviour may be explained by Goffman’s theory of face work “whereby individuals interpret and act in order to maintain face of self and other” (Shattell, 2004, p. 715). Goffman (1959) surmised that when an individual “appears before another

he will have many motives for trying to control the impression they receive of the situation” (p. 26).

To summarise diabetes-related distress, adults with diabetes treated with insulin in this study experienced distress at similar levels to that described in the literature when responding to the Diabetes Distress Scale (Polonsky et al., 2005). More distress was described in the interviews than was evident in the quantitative analysis and for many was a part of life with diabetes. While many participants described a reluctance to disclose distress, diabetes was frequently referred to as a difficult disease to have as it impacted on every facet of daily life. For some managing their diabetes occupied a significant amount of time and energy. Maintaining a balance between day to day life pressures and diabetes self-care activities was challenging for many and appeared to negatively impact on health activation. For some it was easier to ignore their diabetes self-care in order to preserve emotional wellbeing. A spectrum of control was described characterising personal control where participants sought control over their diabetes and their lives, and interpersonal control within therapeutic relationships where participation in decision-making to varying degrees was important. In the literature review I presented a variety of perspectives on control over decision-making which concluded that eliciting preferences for participation in or control over decision-making is important, as joint goal setting improved satisfaction and adherence to treatment regimens. Interpersonal control within the therapeutic relationship will be discussed further in the section to follow.

Health professional communication and decision-making styles

Quantitative data analysis of health professional communication and decision-making did not reveal a significant contribution via regression analysis to health activation across all health professional groups (Tables 17-20). However, health professional communication and decision-making styles was associated with health activation as demonstrated by small but significant positive correlations for some of the health professional groups (Table 15). Quantitative data analysis demonstrated that participants placed a high level of importance on both communication and decision-making and that satisfaction overall with all health

professional groups was relatively high (Figure 6 & Figure 7). However, participants' ratings of 'how good' health professionals were did not match the level of importance suggesting that their needs were not consistently met (Figure 8 & Figure 9). Significant relationships were evident between health professional communication and decision-making styles and diabetes-related emotional distress (Table 15). Increased satisfaction with both general practitioner and diabetes specialist physician communication and decision-making styles was significantly associated with lower levels of diabetes-related distress. Higher satisfaction with diabetes specialist nurse communication was significantly associated with lower diabetes-related distress (Table 15). The significant relationships between health professional communication and decision-making styles and diabetes-related emotional distress suggests that while either on their own may not directly be associated with health activation, it is possible they may have an indirect, moderating effect on health activation.

Thematic analysis of interview data extended the representation of participants' perceptions by revealing a number of ways in which health professional communication and decision-making styles either promoted or hindered health activation and increased or decreased diabetes-related distress. Within any clinical consultation many dynamic processes are occurring with both the patient and the health professional entering the consultation with their own agendas. At times unspoken and unseen power struggles exist as either or both of the players vie for control of decision-making either consciously or unconsciously.

Essential elements of effective therapeutic partnerships and factors determining a therapeutic connection were captured in the themes **proficient practitioner**, **mutual commitment** and **therapeutic connection**. Behaviour within clinical consultations varied with those with high health activation in particular behaving differently in nurse consultations and medical practitioner consultations. This appeared to be driven by role expectations and/or in response to perceived positive or negative health professional interpersonal behaviours. Participants' perceptions and expectations of the different roles of nurses and medical practitioners were identified in the themes **therapeutic dialogue**,

nurse as translator and nurse with diabetes ‘know-how’, doctor as decision-maker and the person-practitioner disconnection.

The proficient practitioner incorporated the desire for clinical expertise combined with openness, mutual respect and responsiveness. Many of the participants with high health activation had experiences of a specialist nurse or specialist medical practitioner whom the participant recognised as having expert knowledge of diabetes and its management. They also were perceived by the participant to function as collaborators in problem solving and decision-making, to develop plans that were perceived to be realistic and based on comprehensive knowledge and, most importantly, had an understanding of the person and their life context. Health professional expertise in diabetes care was highly regarded by participants, especially those who were more health activated, and they were acutely aware when this was lacking. Nurse specialist case management resulting in better collaboration of care has been found to have a positive impact on diabetes-related distress, better well being and improved regimen adherence (Gabbay et al., 2006; Rubin et al., 2006a). Likewise for participants in this study receiving care from the same health professional who had developed an understanding of them, their life context, and their history of diabetes and previous clinical management was of critical importance to many participants.

Mutual commitment described participants’ view that both the health professional and the person with diabetes was committed to diabetes care. The commitment from the person with diabetes extended across the spectrum of turning up to appointments, contributing to the consultation and following through on agreed recommendations, and for the health professional as taking time and applying their expertise to ensure the most appropriate care was prescribed. Whilst describing a desire for mutual commitment, some participants felt that they themselves were the greatest barrier to their own active self-care as they were reluctant to seek advice from health professionals either due to not wanting to face up to not having tested their blood glucose levels, or thinking they knew all the answers when in reality they didn’t. Indeed, the requirement for the individual to want to be helped has been commented on by Mol (2008). Mol states that “professionals in a consulting room can do

no more than attend to people who define themselves as being in need of care...health practitioners depend on active patients” (p.72).

Participants described the personal nature of the therapeutic relationship and the ability to make a positive **therapeutic connection** to be of critical importance to support them to develop a high level of health activation and in their self-care endeavors. A health professional who made the effort to know and understand their health beliefs and them as a person, and who understood the nuances of diabetes was highly valued by participants. In addition, acceptance of them as they were in a non-judgmental manner was important. These characteristics are consistent with a review of the literature of nurse-patient interaction where Shattell (2004) revealed that patients believed relationships were the most important aspect of their care. Patients wanted nurses to take their time, be genuine, and valued being listened to. From a personal perspective they wanted to be valued and respected as individuals. Shattell concluded that “nurse-patient interaction can have a major influence on patient care experience and should be vigilantly considered” (p. 720). In this study participants described the importance of having their personal expertise acknowledged and utilised in the decision-making process with different options discussed and considered. This is likely to shape the attainment and maintenance of health activation stages three and four as the individual develops skill and confidence to self-care.

The therapeutic connection was enhanced when participants had the opportunity to develop a relationship with a health professional over time during which they could build trust and confidence. Knowing the health professional and feeling connected was more likely to result in disclosure of negative thoughts or feelings related to their diabetes. Self-determination of diabetes care and its management was also important to many participants, as was recognition of their expertise in diabetes care as it related to them and their life. The capability and desire to be in control was a common characteristic of those with a higher level of health activation and difficulties within the health professional – patient relationship arose when self-determination was denied. The desire for control over determining treatment regimens was important for many participants, particularly those with long standing type 1 diabetes. Control however manifested in a variety of ways,

consistent with literature on patient preferences for decision-making, with participants desiring at the very least discussions on potential options and some involvement in decision-making.

Conversations with nurses were described by participants as more likely to be open than with medical practitioners, with increased discussion, sharing of knowledge and collaborative decision-making. The theme **therapeutic dialogue** captured how participants consistently described the nurse as someone who would take time to talk to them about their diabetes, was receptive to questions and would freely give information. The relevance of the social dimension of the nurse's practice has been described by Millard et al. (2006) as serving the particular purpose of establishing equality between the nurse and the patient within the interaction. In this current study, the more personal approach nurses took was highly valued as they attempted to get to know the person as an individual and to understand the support structures or barriers to developing self-efficacy and maintaining self-care.

The value of time where treatment plans were discussed, and improved understanding was achieved, was frequently mentioned by participants in this study and was a major differentiating factor between the experience of seeing a nurse and a medical practitioner. Nurses were perceived to take more time with participants and to make an extra effort to help participants with their diabetes self-care requirements. This is important as time spent has been found to be the only significant predictor of reduction in HbA_{1c} (Norris et al., 2002). Participants described differences in the style and emphasis within consultations between nurses and medical practitioners. Talking with a nurse was more frequently described as if they were talking with a friend and that the nurse would often seek more information pertaining to their wider social context. This is consistent with literature on nurse and medical practitioner styles within consultations and reflects the different disciplinary approaches. Collins (2005) video and audio-recorded consultations of both nurses and medical practitioners. Consistently nurses talked in a way that enabled "wider ranging illumination and explanation of problems" (p. 792) whereas in medical practitioner consultations conversations were focused on general explanations or "strategic talk towards

particular consultation goals that transcended what the patient was saying” (p. 792). These findings are congruent with participant descriptions in this study and highlight the differences in approaches and the value of utilising the expertise of both disciplines to maximise the resources available to the patient.

The theme **nurse as translator** captured the essence of nurses’ practice where they were described as translating poorly understood recommendations into language and interventions that were understandable and realistic for that specific individual. Many participants frequently described feeling confused or unsure about recommendations given to them by their medical practitioner. This was described as being due to the way in which information was provided, and the language used to communicate messages. Participants highly valued consultations where the nurses took time to explain treatment plans, freely provided information to support their self-care and had a more personal approach. Shattell (2004) described the nurse-patient interaction as being central to clinical nursing practice and identified three key issues shown to be important in the quality of interactions. These are issues such as: power; the social and cultural context; and interpersonal competence. Interpersonal competence was described by Fosbinder (1994) following a qualitative study involving forty patients and twelve nurses in a private acute care hospital. Four major themes were identified including translating, getting to know you, establishing trust and going the extra mile and these themes were suggested to provide a framework for an emerging theory of interpersonal competence. Of interest, 16 years later this current study’s participants, who were accessing predominantly outpatient or primary health care services, expressed very similar interpersonal skills that promoted effective self-care. I would concur with Fosbinder who stated that “because nursing care is provided through interpersonal skills, and it is these skills that patients value the most, educators must equate interpersonal skillfulness with technical competence” (p. 1091).

Based on the quantitative data analysis in this study, diabetes specialist nurses (DSN) were consistently rated highest for communication and decision-making for all items in the two scales (Figure 6 & Figure 7). Diabetes specialist nurses’ communication and decision-making had small positive significant associations with health activation (Table 15). In

addition, diabetes nurse specialists' communication had a small but significant negative association with diabetes-related distress suggesting that as communication was perceived as better, distress was lower. However, in the multiple regression analysis diabetes nurse specialists' communication or decision-making styles did not significantly contribute to health activation.

While regression analysis did not demonstrate DSN communication or decision-making to contribute to higher health activation or reduced distress, thematic analysis of interview data suggested otherwise. As previously discussed, a number of health professional behaviours were identified through interviews and subsequent thematic analysis as having an association with self-care in particular and health activation in general. These comprised clinical expertise, credibility usually developed over time, responsiveness, respect for personal expertise, and realistic care planning. While medical practitioners were described by some participants as possessing these attributes at times nurses in general, but especially diabetes specialist nurses, were perceived by participants as more consistently displaying these qualities in practice.

The theme **nurses with diabetes 'know-how'** described how diabetes specialist nurses who had more experience working in diabetes care facilitated higher health activation and lower distress. Diabetes care is necessarily delivered within the context of the multidisciplinary team. Typically diabetes specialist nurses and diabetes physicians care for more people specifically with diabetes, and people seen by specialist services tend to have greater complexity (Rubin et al., 2006b). For that reason their expertise in treating diabetes and understanding its impact on life is generally greater than most primary health care providers. Diabetes specialist nurses constitute the greatest number within the multidisciplinary teams as the majority of work related to a long term condition is carried out by nurses who have expertise in diabetes care and in supporting self-care (Carey & Courtney, 2007; Moser et al., 2009; Vrijhoef, Diederiks, & Spreeuwenberg, 2000).

In this study diabetes specialist nurses were perceived to be more knowledgeable than other nurses about diabetes and more skillful with the nuances of diabetes care, were able to

problem solve more effectively, and had a greater appreciation for the difficulties experienced from living with and self-caring for diabetes. In addition, they responded to questions, freely gave pertinent information and advice that was practical and relevant to their life, and were more likely than the other health professional groups to recognise personal expertise and be willing to work together. Participants identified these nurses with diabetes 'know-how' as reducing distress levels as they felt acknowledged as a person, listened to and their personal expertise was acknowledged and utilised in care planning. Furthermore, participants perceived DSNs to practise in a way that recognised their individuality and supported self-determination whilst providing care with a high level of diabetes knowledge and skill. Nearly twenty years ago Benner (1984) recognised and acknowledged the differences in nurses' practice in a continuum from novice to expert. Benner describes the expert nurse as one who "with an enormous background experience, now has an intuitive grasp of each situation and 'zeroes in' on the accurate region of the problem without wasteful consideration of a large range of unfruitful, alternative diagnoses and solutions" (p. 32). While this description is still often utilised today, this study's findings enable an extended understanding of expert practice in diabetes care.

Health professionals in general and DSNs in particular, are most often involved with people with diabetes over prolonged periods of time due to the long term and ongoing nature of diabetes. DSNs in particular will have exposure to greater numbers of people with diabetes experiencing challenging situations, clinically and emotionally. Diabetes specialist nurses appear to engage in therapeutic relationships in a way that is consistent with Millard et al.'s, (2006) observation that where patients feel more able to participate in decision-making, nurses' behaviour spanned two dimensions - professional and social. The social function maintained therapeutic boundaries but established the nurse and patient as equals in the therapeutic encounter. When this was established it facilitated open dialogue and increased participation. These attributes also reflect moral capacities identified by Moser et al. (2009) in order to support people with diabetes in autonomous decision-making processes. These are: commitment, sensitivity and flexibility, self-determination, shared decision-making and welcomed paternalism.

Participants have described nurses, and especially DNS, as a vehicle for experimenting with ideas and developing expertise. As identified by Zoffman et al., (2008) there is tremendous value in understanding the insight into patients' decision-making rather than professionals' decision-making as this will facilitate opportunities for individualising treatment recommendations and care planning. Thus the diabetes specialist nurse role has the potential to be a powerful promoter of health activation when it is practised in a responsive and skillful way, combining effective interpersonal and communication skills with diabetes expertise to provide proactive clinical management and advice on optimal pharmacological management.

As previously discussed participants had clear views on the different roles of nurses and medical practitioners. The theme **doctor as decision maker** captured participants' perceptions of medical practitioners as the ultimate decision-maker with a focus on diagnosing problems and prescribing medications. Some participants valued the direct approach medical practitioners took as they liked to hear the facts and then be told what was going to happen. These participants preferred decisions to be made for them as they perceived the medical practitioner to have superior knowledge. Individualised recommendations or treatment plans that were based on and constructed with more than data or laboratory results were highly important. However, in contrast to visits with nurses, medical practitioner visits were generally described as hurried, with limited opportunity for discussion or sharing of information and minimal collaborative decision-making. Time is a commodity in short supply, especially in general practice as they struggle with the competing demands of providing acute first point of contact and long term condition care. Rushed appointments was also described by Carryer, Snell, Perry, Hunt, and Blakey (2008) in their study exploring experiences of people with long term illnesses when accessing general practice services. Participants' comments in their study suggested they had few opportunities to increase their self-care skills through a partnership with a health professional, nursing or medical, who had time to focus on their individual circumstances.

The theme **the person-practitioner disconnection** captured participants' views that medical practitioners in general were usually not in touch with the person's reality (health

beliefs and commitments of everyday life) and individuality, and therefore treatment recommendations were not always perceived to be realistic. This view was held particularly by those who rated themselves as more highly health activated and had more diabetes ‘know-how’. Some participants lacked confidence to ask questions, and at other times perceived limited opportunities to ask questions or discuss options. Rather than a focus on the individual, their life context and their self-care capability, the focus of the medical practitioner was frequently perceived by participants to be on clinical data and results and not on them as an individual. Many participants described feeling unfairly judged for not meeting clinical targets without consideration for their life context.

Participants demonstrated an awareness of differing levels of health professional knowledge and expertise and how helpful this was when that knowledge and expertise was utilised in a way that accounted for their life context. A number of participants recognised the value of accessing both the complementary attributes of nurses and medical practitioners in order to support development of health activation through improved knowledge and confidence to carry out self-care activities. While medical practitioners focused predominantly on clinical problems and solutions, nurses were perceived to have a greater appreciation for the complexities of people’s lives and how those might impact on their diabetes self-care. The nurses focused more broadly on the “big picture” and they worked with individuals to develop strategies that considered their life context. These descriptions are congruent with the findings from Collins’s (2005) study where nurses and medical practitioners were found to have different starting points for consultations. Nurses tended to focus on behaviour and the likelihood of undertaking those behaviours at the start, then progressed to clinical issues. Medical practitioners started with a medical point of view, addressing clinical solutions and interventions first, with discussion about behavioural issues on the periphery. These differences may be explained by socio-political perceptions where the role of medical practitioner may be considered as more prestigious in wider society than nurses, thereby creating a social distance in medical practitioner consultations (Seale et al., 2005). That is patients may feel less relaxed and more concerned about time constraints with medical practitioners and therefore less likely to enter into discussion unless invited. This once again highlights the differences in styles,

distinguished by different disciplinary approaches, for how nurses and medical practitioners provide explanations and invite different types of contributions from patients. Both are important and add immense value to patient care especially when practised in a complementary way. From the patient's perspective the potential for socio-political perceptions to influence their behaviour is an important consideration.

In summary, health activation is dynamic and associations were multi-factorial. Diabetes-related distress and health professional communication and decision-making styles were important contributors to health activation. While participants' characteristics were in general consistent with health activation stages, some interesting contradictions were illuminated around health beliefs and priority setting. While interviewed participants resoundingly considered self-care to be their responsibility and many had the knowledge and confidence to take action and maintain this under stress, the action they took was not always congruent with preserving physical health but instead preserving emotional well-being in order to function on a daily basis. Therefore, the application and interpretation of the Patient Activation Measure is not simplistic and requires consideration of people's shifting priorities and multidimensional decision-making in the context of their unique life issues and problems.

Diabetes-related distress was dynamic and responsive to immediate life pressures and experiences and also to perceived long term threats. Sense of control was influential for many on distress levels. Control pertained to control of their blood glucose levels in particular, but also control over the management of their self-care activities and treatment decisions. While not necessarily responsible for the source of distress, nurses' and medical practitioners' approach to diabetes care, and the way in which they interacted with participants, had the potential to heighten or ameliorate distress. Diabetes-related distress is often the elephant in the room and it is important that it is identified and addressed. Therefore, nurses and medical practitioners have a moral responsibility to understand and consider how, through our clinical interactions, we may contribute to distress for the particular individual and how we might operate differently in practice to minimise or ameliorate their distress.

Positive interpersonal relationships between health professionals and patients are very important in diabetes care. It is interesting that overall participants rated a similar level of satisfaction for nurses and medical practitioners' communication and decision-making styles in the questionnaire but the thematic analysis clearly provided a distinction between participants' perceptions of the differences in roles and styles between nurses and medical practitioners. Nurses, especially diabetes specialist nurses, were perceived by participants to be more effective in general at supporting decision-making and in communicating in a way that the person felt acknowledged as a person, information was shared freely, and time was spent discussing pertinent diabetes or life issues. Continuity of care from the same provider, or team of providers who were knowledgeable about diabetes, appeared to support the development of positive relationships and more active self-care. The package of care that the diabetes specialist nurse brought to the clinical encounter appeared to be more advanced diabetes specific knowledge and expertise combined with a collaborative style of practice. It is probable that a combination of increased autonomy of specialist nurses and the structure of specialist outpatient services allowing more time facilitates this type of package to flourish.

Reflections on Methodology

Mixed methods methodology is an approach to knowledge derived from theory and practice, is commonly partnered with a pragmatic approach, and attempts to take into account multiple stances, perspectives, positions and research approaches (Johnson, 2008). Mixed methods methodology has been utilised in this study to seek complementarity (to provide elaboration, enhancement, illustration and clarification); and expansion (to expand breadth and range of inquiry by using different inquiry methods for different inquiry components).

This study evinces the value of a mixed methods methodological approach when exploring the complexities of health behaviours. It has broadened my repertoire of methodologies as a researcher and increased my capability and enthusiasm for methods of understanding health behaviours in ways that account for its inherent subjectivity (Brannen, 2005; Thorne, 1993). The data obtained from the structured questionnaire provided data for statistical

analyses to assist with answering the research questions. Through the utilisation of the simple sampling technique, that is every person in the desired population, had an equal and independent chance of being chosen (Collins et al., 2007), an adequate sample was obtained allowing statistical generalisations to be made. This information has complemented and added to what is currently known about health activation, diabetes-related emotional distress and provider communication and decision-making styles, and has extended knowledge on relationships between these. In particular it has generated knowledge about these constructs specifically in relation to the New Zealand context. Qualitative data obtained through interviews of a smaller number of purposely selected participants enabled the collection of rich context-laden data. A strength of using mixed methods is enhanced understanding of multiple contextual factors influencing participants' responses. Its use in this study has revealed "potentially silenced voices or perspectives" (Boyatzis, 1998, p. 30) to be brought forward and acknowledged. Furthermore, the collection of qualitative data has added to understandings by providing a rich description of participants' experiences enabling analytical generalisations.

Participants were given the opportunity to choose between a face to face or telephone interview. I was initially concerned that telephone interviews would compromise the quality of interview and the ensuing data as I would be unable to see verbal cues or body language. However, if anything participants appeared to feel more at ease in expressing themselves over the telephone. Care has been taken to consider what was shared by participants in interviews and to represent this in a way that honours their perspectives.

Throughout the research process, data and the evolving analysis has been shared in scholarly dialogue with my supervisors, expert colleagues and patients in practice. The diverse ways the data has been analysed was described in chapter four. Throughout the research process I have attempted to acknowledge and take into account the inherent subjectivity in how the data has been analysed, interpreted and reported. I was also cognisant of my position as a senior clinician in the local specialist diabetes service and how this may influence participants' responses. Developing explanations for influences on health activation, specifically diabetes-related emotional distress and health professional

communication and decision-making styles, has been the main aim of this thesis. Both the quantitative and qualitative data contribute to the explanations I have presented.

As any clinician or patient knows, individual experiences are rather more “unique and mysterious than statistical norms suggest” (Thorne, 1993, p. 5). The level of understanding about individual perspectives gained in this study would not have been possible without a mixed methods approach to research. Given only the quantitative data I would have concluded that health activation is not associated with diabetes-related distress, nor with interactions with health professionals. I would not have uncovered the different perceptions participants had about how nurses and medical practitioners relate to them. But given the mixing of quantitative and qualitative findings I can explain much more than this and why these findings were obtained. As exemplified by this study, the collection and analysis of qualitative data relevant to influences on diabetes-related health activation can “illuminate important nuances that might otherwise remain hidden” (Igo, Kiewra, & Bruning, 2008, p. 166).

Rigour in Mixed Methods Methodology

Onwuegbuzie and Johnson (2006) provided a typology of legitimation for studies utilising mixed methods methodology. This typology included a number of strategies to ensure legitimation (or validation) criteria were met for the study. Consistency with the methodology was discussed in chapter four and evidenced in the research process and the findings and descriptions of perceptions in the quantitative data and the three qualitative data chapters. In describing the study participants’ perceptions I have used their own words as exemplars that demonstrate the individuality of their experiences while also illuminating the universal meanings of their perceptions in the thematic description. Quotations were selected to communicate diverse representations and include a selection of participants. Individual participant’s transcripts informed my understanding of the individual’s experiences, their priorities in life and with diabetes, continuing engagement in their social world, and together as a body of data the overall analysis was informed by all participants’ transcripts.

The validity, reliability and credibility of the description and interpretation was checked with adults with diabetes, my supervisors and colleagues practising in diabetes and respiratory care. The potential for my professional status as a nurse practitioner in diabetes care to influence participants' responses and subsequent analysis and interpretation was considered. I have also considered my emotional responses to participants' descriptions and how this may have shaped my interpretation of their accounts. Furthermore, the influence of my supervisors' work and schools of thought were considered. Discussion with colleagues working as clinicians and researchers in diabetes care and other long term conditions has verified my interpretation.

In chapter four detail regarding the process of statistical analysis of quantitative data and thematic analysis of qualitative data and writing has been provided for the purposes of auditability. For the quantitative data, this involved ensuring appropriate validity of measures utilised, an appropriate study design and sampling strategies and assessments of internal consistency of measures utilised. In addition it required becoming familiar with statistical analytical processes in general and in particular, utilisation and interpretation of the appropriate statistical tests relevant to this study. For the qualitative data analysis, this involved engaging with the data as words on a tape, text on paper, clusters of data on post-its and sheets of paper, and journal notions. Working with the data meant becoming immersed, excited, overwhelmed and distracted. It also inevitably resulted in dwelling, re-reading, rewriting, revisiting and ongoing discourse.

Final interpretations have been made on the basis of findings from both the quantitative and qualitative data analyses thereby meeting inquiry purposes of providing complementarity and expansion. The quantitative and qualitative analyses have complemented each other, with the quantitative data providing breadth and the qualitative data providing depth. Together they have provided more data than either analysis alone. Strengths of each approach have been maximised to complement each other and the weaknesses of each approach minimised for example, where quantitative data provided averages of responses, qualitative data provided individual responses.

In writing this thesis I have endeavoured to provide adequate detail so that others interested in diabetes care can consider the significance of this study and the contribution it may make to their own areas of interest and practice. This is characteristic of fittingness with the final criterion for qualitative research of confirmability being met when the research meets the standards of credibility, auditability and fittingness.

Limitations of the Study

Every study should be open to critique and the nature of that critique will be informed by their ontological and epistemological assumptions and how they relate to the study. The most obvious critique would be from traditional researchers regarding the utilisation of mixed methods methodology. However, as discussed in the methodology chapter, rather than dichotomising the world, we should listen and learn from tensions produced from opposing poles. The mixed method methodological approach, with its methodological pluralism (Johnson & Onwuegbuzie, 2004), fits comfortably within the philosophy of the discipline of nursing and other disciplines within health and is considered to be justified in this study on “pragmatic rather than ideological grounds, to help researchers to engage with the complexity of health, health care, and the environment in which studies take place” (O’Cathain, 2009, p. 4). It is possible the focus on methodology as the primary determinant of the study framework as opposed to ontology may also draw critique but it is argued that a great strength of the pragmatic approach to social science research methodology is its emphasis on “the connection between epistemological concerns about the nature of knowledge that we produce and technical concerns about the methods that we use to generate that knowledge” (Morgan, 2007, p. 73). Furthermore, it is logical that the method for a study is not determined by a limited view of science, but on a comprehensive appreciation for all forms of inquiry, with reasoning based on contemporary knowledge about how best to answer research questions.

Researchers more familiar with quantitative methods may critically assess bias, sample selection and size and generalisability of the findings. Selection bias was minimised by the utilisation of a third party to distribute the invitation to participate in the study. It is acknowledged that the response rate at 22% was relatively low. This may have been

influenced by the ethics committee instructions to only send one reminder to participants. This instruction was unfortunate as repeat mailing strategies and telephone reminders have been shown to be highly important in maximising response rates (Buetow, 2007). In addition, people with long term conditions (diabetes, respiratory and cardiac care conditions) had been targeted for other studies in the same district within a similar time period this study's invitation and questionnaire was sent out. It is possible they had been saturated with research questionnaires and only those with a high level of interest and/or energy were inclined to participate in yet another study. Non-response bias was not tested for significant differences in demographic and health characteristics between non-respondents (those who did not return a questionnaire) and respondents (those who did return a questionnaire) as demographic data was not available to the researcher due to confidentiality issues with the Manawatu, Horowhenua, Tararua Diabetes Trust database.

Over many years, a survey's response rate was considered to be an important indicator of survey quality due to possible non-response bias, and a higher response rate was considered to assure more accuracy (LoBiondo-Wood & Haber, 1994). Although there is no scientifically determined measure for what an appropriate response rate is for studies utilising quantitative methods, in general 50% is considered adequate, 60% is considered good and 70% very good (Babbie, 1992). On the contrary a number of studies more recently demonstrate that a low response rate gives rise to minimally less accurate results (American Association for Public Opinion Research, 2008; Curtin, Presser, & Singer, 2000; Holbrook, Krosnick, & Pfent, 2008; Keeter, Kennedy, Dimock, Best, & Craighill, 2007) and that "consumers of survey results should treat all response rates with skepticism, since these rates do not necessarily differentiate reliably between accurate and inaccurate data" (American Association for Public Opinion Research, 2008, para. 7). Nevertheless, due to the low response rate in this study, it must be acknowledged that the conclusions drawn from the findings may not be representative of all and that those who did reply may have been more highly activated.

Although considerable effort was made to recruit Maori or Pacific Island people to participate, this study was not able to make any claims about significance for Maori or

Pacific Island peoples due to the low number of participants. As Maori and Pacific Island people are over represented in diabetes from an epidemiological perspective and their health outcomes tend to be worse, understanding their unique perspectives on influences of health activation is a lost opportunity. It is important to acknowledge that the research questions themselves are not unbiased. With consideration for this, the research questions were crafted to avoid words and phrases that may have caused distress or concern and indeed advice was provided by the ethics committee on the title of the study in order to reduce emotiveness.

As this study was conducted within one provincial district health board in New Zealand, it is possible the participants who responded may not be typical and that local services may not be representative of others in New Zealand. Inevitably the nature of the self-report measures introduces perception bias but this risk was countered by utilising mixed methods. It is also important to question the reliability of participants consistently distinguishing between types of health professional roles or knowing or remembering who they have seen. Moreover, recall bias may be present due to time lapsed since their last clinical encounter, their past or last experience and changes in their health status.

In the questionnaire, participants were asked ‘how good’ the nurse or medical practitioner was at communicating and making treatment related decisions. ‘Good’ is a very subjective term with different meaning and standards specific to the individual, therefore in hindsight it may have been better to ask questions pertaining to these constructs in a different or more specific way. For example, the questions did not afford participants the option of rating or commenting on the way in which health professionals acted which led them to rate ‘how good’. Alternatively there may be limited value in assessing satisfaction in this way as participants’ perceptions of experiences are inherently subjective therefore qualitative assessment enabling participants’ voices to be expressed in the fullest sense may be more appropriate and enlightening.

Significance and Implications for Nursing Practice and Service Delivery

It is clear from participants' descriptions that living with and self-managing their diabetes can be extremely challenging. The relentless nature of self-care demands can be overwhelming and negatively impact on health activation. It is also evident that diabetes-related distress and/or the way in which nurses and medical practitioners interact with people with diabetes has a degree of influence on health activation and active self-care. I believe this study can make a significant contribution to understanding how health professionals can maximise the limited time they have with people with diabetes who are left to self-care 95% of the time (Anderson et al., 1995). There is already a substantial body of knowledge on the multiple barriers to self-care, spanning the social determinants of health. There is a considerable body of knowledge on communication within the health care context, patient centredness, patient participation and collaborative care. Multiple theories abound on behaviour change, all with a particular focus. This study shows that in addition to diabetes specific expertise, the things that supported participants the most were relatively simple based on humanistic principles of caring, mutuality, respectfulness and reciprocity. One has to ask the question why is that so hard to implement in practice?

Patient participation is a complex concept. It encompasses notions of "patient collaboration, involvement, partnership, shared decision-making and person-centred planning" (Millard et al., 2006, p. 143). It is notable that understanding the individual's personal expertise and how they apply this to their daily decision-making is important to many. Negotiating and sharing decisional control can enhance participation for those who want to participate. Supporting decision-making that leads to both emotional, physical and functional health will most likely result in greater participation and the most health gain. Each person enters the clinical encounter with a unique constellation of aspirations, problems, fears, knowledge, and capability. Furthermore, the social context within which people conduct their lives will influence choices available and their response to the challenges of self-care. The challenge to health professionals therefore is to provide services that are responsive to each individual's specific needs and encourages active mutual participation where this is desired and appropriate.

This study has demonstrated that the orientation of care supporting high health activation needs to be on positive therapeutic relationships and careful assessment encompassing physical, social, emotional psychological, cultural and spiritual domains. Physical assessment comes naturally to most health professionals but the psychosocial elements of assessment can be more challenging and require effective interpersonal skills, time, confidence and trust. Realistic planning of care and treatment regimens, care and follow up can be both achieved through comprehensive assessment and acknowledgment of personal expertise.

In the introduction chapter, a complex pathway between collaborative care and patient and provider outcomes in long term condition care (Marshall et al., 2005) was introduced. Within this pathway are a number of interconnected aspects which include improved provider communication, patient decision-making satisfaction, provider attitudes and behaviours, patient attitudes and behaviours leading to patient satisfaction, health status and quality of life. This study has explored the majority of these aspects and found them to be relevant but also identified the importance of emotional distress and the potential for health activation as an intermediate health outcome indicator. Furthermore, I suggest the pathways are far more dynamic and bi-directional than first proposed, as now illustrated with circles indicating my changes in Figure 10.

This thesis provides insightful examples of the importance of positive therapeutic relationships where both people with diabetes and health professionals are encouraged to participate openly and fully. Diabetes services and those who work within them need to practise in a way that is responsive and sensitive to the unique and sometimes mysterious health behaviours of those they serve. If the care of people with diabetes and its related conditions focuses on maximising physical, functional and emotional well-being, there is a greater possibility people with diabetes will more consistently undertake self-care activities. This will require a change to care delivery models, particularly in primary health care where a large proportion of diabetes care occurs. Despite moves towards chronic care models, the pervasive model of care in primary care does not support appropriate care delivery for long term conditions as it continues to suffer from the tyranny of the urgent Bodenheimer, Wagner, et al., (2002). Furthermore, it does not support practice nurses'

autonomy to practise to their full potential. As nurses are philosophically committed to functional well-being in the context of illness and are the largest primary health care workforce, this is a major lost opportunity. This study has illuminated differences in the way nurses and medical practitioners relate to patients in consultations through providing different types of explanations, inviting different levels and types of contribution from patients, and focusing on differing aspects of patients' understanding. These respective and complementary styles should consciously and synergistically be utilised in the delivery of diabetes care.

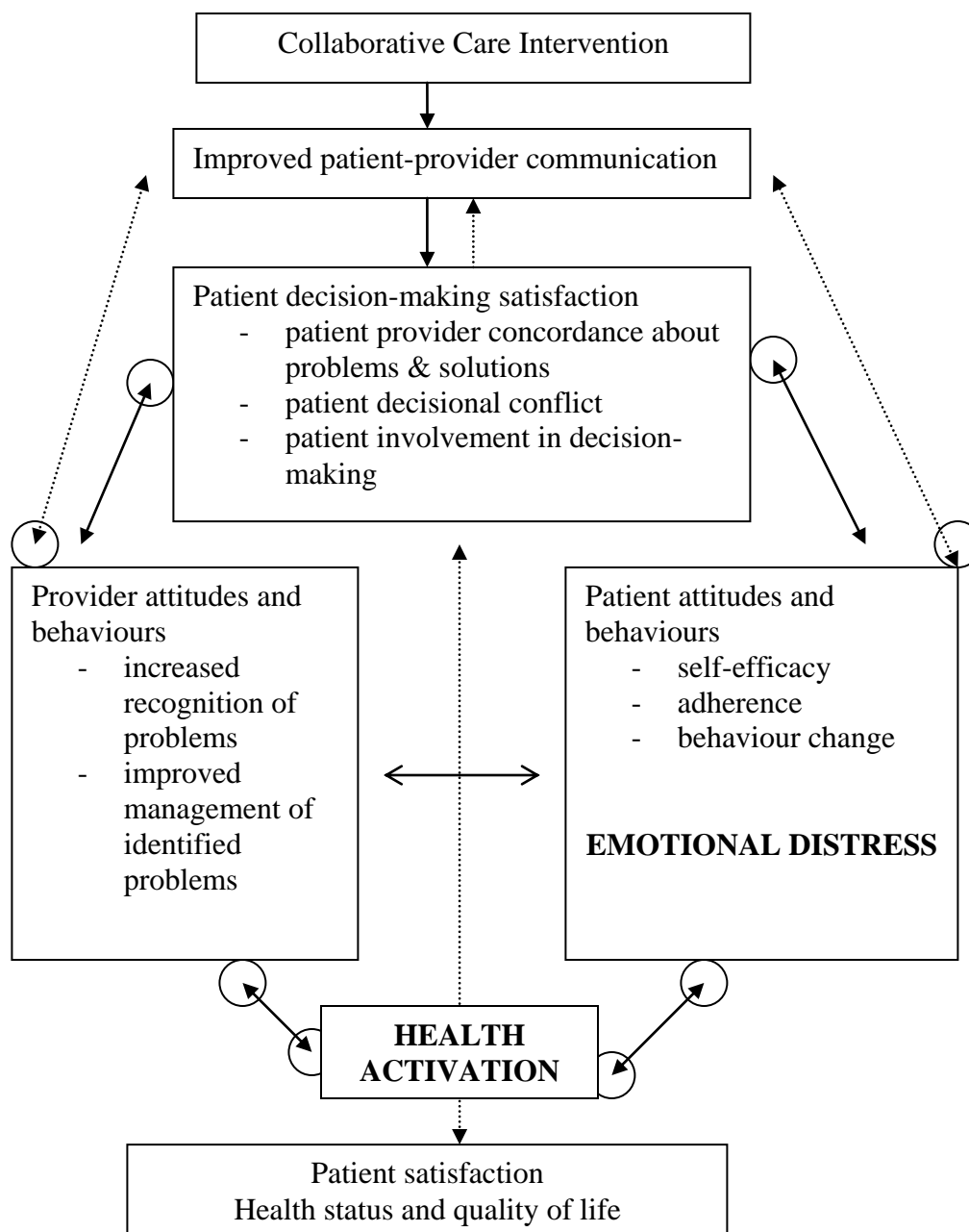


Figure 10. Pathway between collaborative care and patient and provider outcomes with emotional distress and health activation

Suggestions for Future Research

Mixed methods methodology was well suited to examining factors associated with differences in health activation. It revealed a variety of health behaviours employed by adults with diabetes treated with insulin. The quantitative data provided insights into the presence of relationships and differences between the constructs of interest. The qualitative data expanded this by providing rich and full descriptions which were at times at odds with the quantitative findings. Some questions were raised in this study about the sensitivity of the health activation tool to individual health beliefs beyond self-responsibility and locus of control. It appears that for this study's participants, health activation is constructed around personal decision-making and that at the heart of this is the person's beliefs about what is important in their life as well as their belief in their own ability to change their circumstance. Maintaining normalcy and being in control was also important. Further research on the utilisation of this tool in the New Zealand context and with ethnicities other than New Zealand European would extend our understanding of usefulness in practice more broadly. This study was not able to make any claims about significance for Maori or Pacific Island peoples due to the low number of participants. Appropriately conducted research with these ethnic groups may identify important characteristics useful in practice as they are epidemiologically over represented in diabetes estimates and future projections.

Diabetes-related distress was present in similar amounts when compared to the international literature utilising the Diabetes Distress Scale. While participants generally rated a low level of distress in the diabetes distress scale, the interviews with the 18 participants revealed a range of negative emotions and cognitions relating to control. Furthermore, participants described a reluctance to disclose distress but conversely they all agreed it was important and should be asked about. Therefore an assessment of diabetes distress, negative emotions and control cognitions could be useful in practice. After the commencement of this study Fisher et al., (2008) developed and tested a two item diabetes distress screening instrument. An investigation applying this two item instrument in New Zealand diabetes services would provide valuable information about its utility in practice. In addition, further research into the negative emotional effects of diabetes is warranted

given the range of negative emotions expressed by participants in the qualitative analysis. As these expressions were only illuminated through the use of qualitative methods in this study, it is reasonable to suggest that this may be a superior approach to investigate the true extent of distress or negative emotions. Exploring the contradictions revealed in this study between the quantitative and qualitative findings and between participants' rating of high health activation and actual behaviour would be of particular interest.

Participants with a higher self-rated level of health activation were defined by possessing more diabetes know-how and confidence to experiment with and implement changes to their treatment regimens. They also felt more empowered to actively participate in consultations and challenge or debate recommendations. An investigation on how health professionals could cultivate and support the development of diabetes know-how could be instrumental in improving health activation and health outcomes overall. Participants described diabetes specialist nurses as working differently with them in combination with having expert diabetes knowledge and skills. Further exploration of these attributes would be helpful to enable them to be developed, shared and taught.

Concluding Statements

This study set out to contribute to the understanding of factors associated with differences in health activation for adults with diabetes treated with insulin. An additional aim of the study was to then generate new ideas on how diabetes care could be tailored to maximise personal resourcefulness and promote health activation. In undertaking this study I believed the interpretation and understanding that developed could inform the practice of nurses, and others in the multidisciplinary team caring for people with diabetes.

Considering the potential influence of diabetes-related distress and health professional communication and decision-making styles on health activation through both structured questionnaire and interviews, acknowledged the complexity of health care behaviours and health care delivery. Understanding the complex and dynamic nature of individuals' responses to the challenges of self-care of a long term condition such as diabetes can

expand the compassion of those providing diabetes care and also has relevance for the care of individuals with other long term conditions.

If the care of people with diabetes and its related conditions focuses on maximising physical, functional and emotional well-being, there is a greater possibility people with diabetes will more consistently undertake self-care activities. This will require both attitudinal changes and changes to care delivery models, particularly in primary health care where a large proportion of diabetes care occurs. Despite moves towards models of care more suited to support long term condition care, the pervasive model of care in primary care does not support appropriate care delivery for long term conditions as it continues to suffer from the 'tyranny of the acute'. Furthermore, it does not reliably support practice nurses' autonomy to practice to their full potential. As nurses are philosophically committed to functional well-being in the context of illness, and are the largest primary health care workforce, this is a major lost opportunity. Time pressures within the general practice setting in particular continue to constrain the ability to pay the required attention to the complex health needs of those with diabetes and their related conditions.

The extended autonomy experienced by nurses practising as specialist diabetes nurses in dedicated specialist multidisciplinary teams enables the application of a package of expert nursing skills, expert diabetes knowledge and skills, and time to more ably meet the complex and dynamic health needs experienced by adults with diabetes. While diabetes care is most often provided within the context of the multidisciplinary team, I conclude that nurses in particular can be powerful promoters of health activation when nursing is practised in a responsive and skillful way, combining communication skills with diabetes expertise to provide proactive clinical management and pharmacological management.

All members of the multidisciplinary team contribute an important aspect of care to the person with diabetes. Some of our current professional boundaries have already shifted and nurses are undertaking more of what was traditionally considered to be in the medical domain. These boundaries will continue to shift and some will disappear. Therefore some of the professionally constrained themes in this study are both time and place bound.

The growth in diabetes incidence continues to challenge our health care system and we need a skilled multidisciplinary workforce. Additionally we need to recognise and celebrate the diversity of the multiple disciplines within the diabetes health care team and ensure that our unique skills are practised in concert to provide the best possible package of care. As health professional disciplinary groups come from different philosophical backgrounds, so do the patients who are accessing services. It is clear from this study that people are all very different and their desire to participate in care varies. No one communication or decision-making style will be effective with all patients. What is important is that health professionals are sensitive to these differences and respond to them in a meaningful and genuine way. Moreover, the orientation of care supporting high health activation needs to be on positive therapeutic relationships, careful assessment encompassing physical, social, emotional psychological, cultural and spiritual domains. As presented earlier this study showed that in addition to diabetes specific expertise, the things that supported participants the most were relatively simple, based on humanistic principles of caring, mutuality, respectfulness and reciprocity. These should not be hard to implement in practice.

Studies like this will continue to extend our knowledge on how best to serve and support adults with diabetes in their relentless quest for optimal blood glucose, cholesterol and blood pressure control while maintaining a sense of normalcy and functionality. This study can inform caring for people in a way that will maximise personal resourcefulness, reduce diabetes-related distress and promote effective self-care.

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Appendix A: Questionnaire

Appendix A: Questionnaire



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Diabetes: Understanding influences on health activation



This project has been reviewed and approved by the Massey University Human Ethics Committee, and the Central Region Ethics Committee, PN Protocol CEN /07/06/036

Helen Snell

Nurse Practitioner – Diabetes and related conditions
Principal Investigator/Doctoral Student
Massey University, Palmerston North

Appendix A: Questionnaire

Diabetes: Understanding influences on health activation

We are interested in your experience as an adult who lives with and takes care of your diabetes. The information you provide will be used to help improve the care provided to people with diabetes in the future.

To take part all you need to do is:

- a) Fill in the questionnaire by ticking or circling your response to each statement.
- b) Indicate on the sheet at the back if you would like to be interviewed.
- c) Return the completed questionnaire to me within two weeks.

An envelope is provided, please note that you do not need to use a stamp.

Please note that filling in this questionnaire and returning it to me means that you agree to take part in the study.

You may be assured of complete confidentiality. You will see that the questionnaire has a space on the bottom right hand corner of the cover sheet for your national health index (NHI) number. This number is there so that the Principal Investigator can look up your latest HbA_{1c} result to put with your other answers. Your NHI will not be linked with your name on this questionnaire and no other information will be recorded.

If you would like to complete the questionnaire with the Principal Investigator or another nurse who you know, please write your name and contact details on the sheet enclosed.

If you **do not wish to participate** in this study, please tick here ☐ and we would be grateful if you could complete just the 'About you' questions at the front of the questionnaire, and then return the questionnaire in the prepaid envelope. This information is very important to help us understand the groups of people who prefer not to take part in the study. This information will not be used for any other purpose.

Thank you in anticipation

Helen Snell

Nurse Practitioner – Diabetes and related conditions

Principal Investigator/Doctoral Student-Massey University

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Appendix A: Questionnaire

Diabetes: Understanding influences on health activation

If you **would like help to complete the questionnaire** from the Principal Investigator or a nurse you know, please fill in your contact details here and return this with the questionnaire in the prepaid envelope.

The Principal Investigator will contact you to make the arrangements for this to happen:

Name: _____

Address: _____

Telephone: _____

Email: _____

(optional)



Thank you in anticipation

About you

The questions about you will help us better understand and interpret the results.

In what year were you born? _____

Are you ☐ Male ☐ Female

Which ethnic group do you most strongly identify with?

- | | |
|---|--|
| <input type="checkbox"/> New Zealand European | <input type="checkbox"/> Niuean |
| <input type="checkbox"/> Maori | <input type="checkbox"/> Chinese |
| <input type="checkbox"/> Samoan | <input type="checkbox"/> Indian |
| <input type="checkbox"/> Cook Island Maori | <input type="checkbox"/> Other, please state |

.....

What type of diabetes do you have:

- ☐ Type 1 ☐ Type 2
(treated with tablets first and then insulin)

How long have you had diabetes?

Years _____ Months _____

How is your diabetes treated now?

- ☐ Diabetes tablets & insulin ☐ Insulin

How would you describe your general health over the past 4 weeks?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Very poor

When and where did you have your last Free Diabetes Get Checked Review?

Date_____ Provider_____

How often do you see a medical practitioner to help you with your self-management and diabetes care?

- ☐ Once a month
- ☐ Once every 3 months
- ☐ Once every 6 months
- ☐ Once a year
- ☐ Other? Please specify_____

How often do you see a nurse to help you with you diabetes self-management and care?

- ☐ Once a month
- ☐ Once every 3 months
- ☐ Once every 6 months
- ☐ Once a year
- ☐ Other? Please specify_____

What educational experiences have you had?

(Please tick as many as apply)

- ☐ Primary schooling
- ☐ Between one to three years of secondary schooling
- ☐ Completed four or more years of secondary schooling
- ☐ Trade certificate or professional certificate or diploma
- ☐ University degree

About you (continued)

Which of the following best describes where you live?

- ☐ A city with population of 30,000 or more, e.g. Palmerston North
- ☐ A town/city with a population of between 10,000 & 29,999, e.g. Feilding, Levin
- ☐ A small town with a population of between 1000 & 10,000, e.g. Ashhurst, Dannevirke, Foxton, Otaki, Pahiatua, Shannon?
- ☐ A rural centre with a population of between 300 & 1000, e.g. Bunnythorpe, Colyton, Eketahuna, Rongotea, Tokomaru?
- ☐ A rural area outside a town/city boundaries?

Do you live with.....(please tick more than one circle, if necessary)

- ☐ With your spouse/partner?
- ☐ With your spouse/partner and child or children?
- ☐ With relatives other than spouse/partner/children?
- ☐ Alone?
- ☐ With other adults who are not related?
- ☐ In a rest home/nursing home?
- ☐ Other? Please specify_____

About you (continued) Do you have any other health conditions?

	Please tick <u>one</u> circle on <u>each</u> line	Yes	No
1	Arthritis or rheumatism?	<input type="radio"/>	<input type="radio"/>
2	Asthma / chronic bronchitis / emphysema?	<input type="radio"/>	<input type="radio"/>
3	Bowel disorders, e.g., colitis or polyps?	<input type="radio"/>	<input type="radio"/>
4	Cancer?	<input type="radio"/>	<input type="radio"/>
5	Chronic kidney or urinary tract conditions?	<input type="radio"/>	<input type="radio"/>
6	Chronic liver trouble, e.g. cirrhosis?	<input type="radio"/>	<input type="radio"/>
7	Chronic skin conditions, e.g. dermatitis or psoriasis?	<input type="radio"/>	<input type="radio"/>
8	Depression, anxiety or any other mental health problems?	<input type="radio"/>	<input type="radio"/>
9	Epilepsy?	<input type="radio"/>	<input type="radio"/>
10	Hearing impairment or loss?	<input type="radio"/>	<input type="radio"/>
11	Heart trouble, e.g., angina or heart attack or heart failure?	<input type="radio"/>	<input type="radio"/>
12	Hepatitis?	<input type="radio"/>	<input type="radio"/>
13	Hernia or rupture?	<input type="radio"/>	<input type="radio"/>
14	High blood pressure or hypertension?	<input type="radio"/>	<input type="radio"/>
15	Sight impairment or loss?	<input type="radio"/>	<input type="radio"/>
16	Stomach ulcer or duodenal ulcer?	<input type="radio"/>	<input type="radio"/>
17	Stroke?	<input type="radio"/>	<input type="radio"/>

Appendix A: Questionnaire

<p>Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by <u>ticking the box</u> . If the statement does not apply to you, tick NA</p>						
		Disagree Strongly	Disagree	Agree	Agree Strongly	NA
1	When all is said and done, I am the person who is responsible for managing my health condition.					
2	Taking an active role in my own health care is the most important factor in determining my health and ability to function.					
3	I am confident that I can take actions that will help prevent or minimise some symptoms or problems associated with my health condition.					
4	I know what each of my prescribed medications does.					
5	I am confident that I can tell when I need to get medical care and when I can handle a health problem myself.					
6	I am confident I can tell a doctor or nurse concerns I have even when he or she does not ask.					
7	I am confident that I can follow through on medical treatments I need to do at home.					
8	I understand the nature and causes of my health condition (s).					

Appendix A: Questionnaire

		Disagree Strongly	Disagree	Agree	Agree Strongly	NA
9	I know the different medical treatment options available for my health condition(s).					
10	I have been able to maintain the lifestyle changes for my health condition that I have made.					
11	I know how to prevent further problems with my health condition(s).					
12	I am confident I can figure out solutions when new situations or problems arise with my health condition(s).					
13	I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress.					

Appendix A: Questionnaire

Living with diabetes can sometimes be tough. There may be numerous problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 17 potential problem areas which people with diabetes may experience.

Consider the degree to which each of the items may have been a problem for you **DURING THE PAST MONTH** and circle the appropriate number.

Please note that we are asking you to indicate **the degree to which each item may be a problem for you in your life**, NOT whether the item is merely true for you. If you feel that a particular item is not a problem for you, you would circle "0". If it is very problematic to you, you might circle "5".

	Item	1	2	3	4	5	6
1	Feeling that diabetes is taking up too much of my mental and physical energy every day.						
2	Feeling that my doctor or nurse doesn't know enough about diabetes and diabetes care.						
3	Feeling angry, scared and/or depressed when I think about living with diabetes.						
4	Feeling that my doctor or nurse doesn't give me clear enough directions on how to manage my diabetes.						
5	Feeling that I am not testing my blood sugars frequently enough.						
6	Feeling that I am often failing with my diabetes regimen.						

Appendix A: Questionnaire

	Item	1	2	3	4	5	6
7	Feeling that friends or family are not supportive enough of my self-care efforts (e.g. planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods).						
8	Feeling that diabetes controls my life.						
9	Feeling that my doctor doesn't take my concerns seriously enough.						
10	Not feeling confident in my day-to-day ability to manage diabetes.						
11	Feeling that I will end up with serious long term complications, no matter what I do.						
12	Feeling that I am not sticking closely enough to a good meal plan.						
13	Feeling that friends or family don't appreciate how difficult living with diabetes can be.						
14	Feeling overwhelmed by the demands of living with diabetes.						
15	Feeling that I don't have a doctor Who I can see regularly about my diabetes.						
16	Not feeling motivated to keep up my diabetes self-management.						
17	Feeling that friends or family don't Give me the emotional support that I would like.						

This next section asks questions about what you think about how your doctor or nurse communicates with you and makes decisions with you about your diabetes care.

As there are different types of doctors and nurses providing diabetes care in our community, there are separate pages for these different types doctors and nurses.

Please complete a separate page for each type of doctor and each type of nurse you have seen for your diabetes care.

If you have not seen a particular type of doctor or nurse, then leave those pages blank.

Thank you

General Practitioner

If you have not seen this type of doctor for your diabetes then leave this page blank.
For each item, tick the box that indicates your experience **and** how important this is to you.

Communication					How important is this to you?			
How good is your <u>doctor</u> at:	Poor	Fair	Good	Excellent	Not	Slightly	Some what	Very
Telling you everything?								
Letting you know test results when promised?								
Explaining treatment alternatives?								
Explaining side-effects of medications?								
Telling you what to expect from your disease or treatment?								
Asking you how you are coping with your diabetes?								
Decision-making style					How important is this to you?			
How often does your <u>doctor</u> :	None of the time	Some of the time	Most of the time	All of the time	Not	Slightly	Some what	Very
Offer choices in medical care?								
Discuss pros and cons of each choice with you?								
Get you to state which option you prefer?								
Take your preferences into account when making treatment decisions?								

Diabetes Specialist Physician

If you have not seen this type of doctor for your diabetes then leave this page blank

For each item, <u>tick the box</u> that indicates your experience and how important this is to you.								
Communication					How important is this to you?			
How good is your <u>doctor</u> at:	Poor	Fair	Good	Excellent	Not	Slightly	Some what	Very
Telling you everything?								
Letting you know test results when promised?								
Explaining treatment alternatives?								
Explaining side-effects of medications?								
Telling you what to expect from your disease or treatment?								
Asking you how you are coping with your diabetes?								
Decision-making style					How important is this to you?			
How often does your <u>doctor</u>:	None of the time	Some of the time	Most of the time	All of the time	Not	Slightly	Some what	Very
Offer choices in medical care?								
Discuss pros and cons of each choice with you?								
Get you to state which option you prefer?								
Take your preferences into account when making treatment decisions?								

Practice Nurse at your General Practice surgery								
If you have not seen this type of nurse for your diabetes then leave this page blank.								
For each item, <u>tick the box</u> that best indicates your experience and how important this is to you.								
Communication					How important is this to you?			
How good is your <u>nurse</u> at:	Poor	Fair	Good	Excellent	Not	Slightly	Some what	Very
Telling you everything?								
Letting you know test results when promised?								
Explaining treatment alternatives?								
Explaining side-effects of medications?								
Telling you what to expect from your disease or treatment?								
Asking you how you are coping with your diabetes?								
Decision-making style					How important is this to you?			
How often does your <u>nurse</u> :	None of the time	Some of the time	Most of the time	All of the time	Not	Slightly	Some what	Very
Offer choices in medical care?								
Discuss pros and cons of each choice with you?								
Get you to state which option you prefer?								
Take your preferences into account when making treatment decisions?								

Diabetes Nurse Specialist from the Diabetes Lifestyle Centre

If you have not seen this type of nurse for your diabetes then leave this page blank.

For each item, tick the box that best indicates your experience **and** how important this is to you.

Communication					How important is this to you?			
How good is your nurse at:	Poor	Fair	Good	Excellent	Not	Slightly	Some what	Very
Telling you everything?								
Letting you know test results when promised?								
Explaining treatment alternatives?								
Explaining side-effects of medications?								
Telling you what to expect from your disease or treatment?								
Asking you how you are coping with your diabetes?								
Decision-making style					How important is this to you?			
How often does your nurse:	None of the time	Some of the time	Most of the time	All of the time	Not	Slightly	Some what	Very
Offer choices in medical care?								
Discuss pros and cons of each choice with you?								
Get you to state which option you prefer?								
Take your preferences into account when making treatment decisions?								

Diabetes Nurse from your Primary Health Organisation

If you have not seen this type of nurse for your diabetes then leave this page blank.

For each item, tick the box that best indicates your experience **and** how important this is to you.

Communication					How important is this to you?			
How good is your nurse at:	Poor	Fair	Good	Excellent	Not	Slightly	Some what	Very
Telling you everything?								
Letting you know test results when promised?								
Explaining treatment alternatives?								
Explaining side-effects of medications?								
Telling you what to expect from your disease or treatment?								
Asking you how you are coping with your diabetes?								
Decision-making style					How important is this to you?			
How often does your nurse:	None of the time	Some of the time	Most of the time	All of the time	Not	Slightly	Some what	Very
Offer choices in medical care?								
Discuss pros and cons of each choice with you?								
Get you to state which option you prefer?								
Take your preferences into account when making treatment decisions?								

Maori Disease State Management Nurse								
If you have not seen this type of nurse for your diabetes then leave this page blank.								
For each item, <u>tick the box</u> that best indicates your experience and how important this is to you.								
Communication					How important is this to you?			
How good is your <u>nurse</u> at:	Poor	Fair	Good	Excellent	Not	Slightly	Some what	Very
Telling you everything?								
Letting you know test results when promised?								
Explaining treatment alternatives?								
Explaining side-effects of medications?								
Telling you what to expect from your disease or treatment?								
Asking you how you are coping with your diabetes?								
Decision-making style					How important is this to you?			
How often does your <u>nurse</u> :	None of the time	Some of the time	Most of the time	All of the time	Not	Slightly	Some what	Very
Offer choices in medical care?								
Discuss pros and cons of each choice with you?								
Get you to state which option you prefer?								
Take your preferences into account when making treatment decisions?								

Mobile Community Nurse								
<p>If you have not seen this type of nurse for your diabetes then leave this page blank.</p> <p>For each item, <u>tick the box</u> that best indicates your experience and how important this is to you.</p>								
Communication					How important is this to you?			
How good is your nurse at:	Poor	Fair	Good	Excellent	Not	Slightly	Some what	Very
Telling you everything?								
Letting you know test results when promised?								
Explaining treatment alternatives?								
Explaining side-effects of medications?								
Telling you what to expect from your disease or treatment?								
Asking you how you are coping with your diabetes?								
Decision-making style					How important is this to you?			
How often does your nurse:	None of the time	Some of the time	Most of the time	All of the time	Not	Slightly	Some what	Very
Offer choices in medical care?								
Discuss pros and cons of each choice with you?								
Get you to state which option you prefer?								
Take your preferences into account when making treatment decisions?								

Thank you for completing this questionnaire



If there is anything else you would like to add regarding your condition, care or any concern you might have, please use the space below.

Your contribution to my research is very greatly appreciated. If you would like a summary of results, please print your name and address on the back of the return envelope. I will see that you get it.

Diabetes: Understanding influences on health activation



Would you like to participate in an interview?

If yes, please fill in your contact details here and return this with the questionnaire in the prepaid envelope:

Name: _____

Address: _____

Telephone: _____

Email: _____

Appendix B: Letter from MHT Diabetes Trust

Appendix B: *Letter from MHT Diabetes Trust*

February 2008

Dear potential participant

You will find enclosed an information sheet and a questionnaire inviting you to participate in a study being conducted by Helen Snell, Nurse Practitioner – Diabetes and related conditions. This has been sent to you by the Manawatu, Horowhenua, Tararua (MHT) Diabetes Trust on her behalf. This letter is to reassure you that Helen has not had access to any details about you held by the MHT Diabetes Trust.

I hope that you will take the time to read the information sheet and consider taking part in this study. The results will form the basis of her doctoral degree in Nursing (specialising in diabetes). The information from the study will be shared with the diabetes community locally, nationally and internationally, with the intention of improving diabetes care.

Yours sincerely

Ken Morton

Manager, Manawatu, Horowhenua, Tararua (MHT) Diabetes Trust

Appendix C: Information sheet

Appendix C: Information sheet



Massey University
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Diabetes: Understanding influences on health activation

Information Sheet for Participants

Principal Investigator

Helen Snell, MN, MPhil (Nursing), FCNA(NZ)
Nurse Practitioner – Diabetes and related conditions
MidCentral Health
Ph: (06) 350 8114
Doctoral Student – Massey University

You are invited to take part in a study. We are interested in your experience as an adult who lives with and self-manages diabetes. This study has grown out of our interest in the many things that can either help or get in the way of people to taking care of their diabetes as recommended by health professionals.

Research tells us that people are more or less successful with their diabetes self-management depending on how actively they take part with their own health care. We also know from patient experiences and research that living with diabetes can be positive and rewarding, but many people with diabetes find it difficult to keep up the healthy activities required of them all of the time. As a result, some people with diabetes experience emotional distress. Other studies suggest that the way health professionals communicate and share the decision-making about treatment options with people with diabetes, impacts on motivation and participation in self-management of their diabetes.

Therefore, we are interested to find out how actively you take part in your diabetes care, and whether diabetes-related emotional distress and/or the way nurses and/or doctors communicate with you impact on this. This information will help health professionals to know how we can provide care differently to meet your needs better and the only way we can find out these things is to ask



Appendix C: Information sheet

you. The information you provide will be used to help improve the care provided to people with diabetes in the future.

There are two parts to this study: a questionnaire which will take you about 20 minutes to complete and an optional interview to talk about your experiences in more detail. You are free to complete just the questionnaire if you wish, but if you would like to be interviewed, please complete your contact details on the letter with the questionnaire.

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 that decision will in no way affect you or your diabetes care. If you would like to take part in this study all you need to do is complete the enclosed questionnaire and return it to the Principal Investigator in the prepaid envelope provided within the next two weeks. Please note that returning the completed questionnaire means that you agree to take part in the study.

However, if you do not wish to participate in the study, could you please indicate this by ticking the box on the front of the questionnaire and return it to the Principal Investigator in the prepaid envelope. That will ensure that you can be taken off the mailing list for reminder letters. We also ask you to take a few moments to complete only the 'about you' questions at the back of the questionnaire, as this information is very important to help us understand the groups of people who prefer not to take part in the study. This information will not be used for any other purpose and you will not be contacted again.

What are the aims of the study?

The aims of this study are to find out what affects adults with diabetes to actively take part in their diabetes care, and to identify if there are better ways for nurses and/or doctors to work with people with diabetes. It is hoped that the information you provide will improve the quality of care provided to people with diabetes in the future.

Who will the study involve?

We hope to include at least 350 people with diabetes who are treated with insulin (with or without diabetes tablets) from the MidCentral District Health Board region, over the age of 25 years from different ethnic backgrounds and age groups.

Appendix C: Information sheet

Am I eligible to take part?

You are able to take part if you are 25 years of age or older, have either type 1 or type 2 diabetes, have had diabetes for more than one year, are taking insulin (with or without diabetes tablets) and you are able to read and write English.

What would I have to do?

If you choose to take part you will need to fill in the questionnaire and return it to the researcher in the prepaid envelope provided within the next two weeks. A follow up letter will be sent to you after two weeks as a thank you for those who have returned the questionnaire, or a reminder if we still haven't heard from you.

How do I take part?

Once you are happy with the information you have received about this study, just fill in the questionnaire. Put the questionnaire into the envelope provided and return it to the Principal Investigator. Remember that you can receive more information about the study from the Principal Investigator whose contact details appear at the top of this information sheet.

What are the benefits in my taking part?

By taking part you are assisting us to learn about how the way health professionals communicate and make decisions with you impacts on helping you to actively look after your diabetes. It is hoped this information will help health professionals, in particular nurses, improve the care you are offered. If you would like to receive a summary of the study findings please indicate this by writing a postal address on the back of the prepaid envelope. No name is required.

What are the risks in my taking part?

It is not anticipated that there will be any risks resulting from your participation in this study. However, if you are concerned at any stage throughout the study please contact a health professional or the Principal Investigator who is a Nurse Practitioner – Diabetes and related conditions.

Appendix C: Information sheet

What will happen to the information I provide?

You are assured of complete confidentiality. The information you provide will be used to find out how actively you take part in your diabetes care, your level of diabetes-related emotional distress and what you think about health professional communication and decision-making style. Your individual information will not be made available to your health professionals. As this study forms part of a University degree a thesis will be submitted to Massey University. It may also be published in nursing/medical journals. No material which could personally identify you will be used in any reports on this study. Results of the study will be sent to all participants who requested them once the study has been completed. If you would like to discuss the outcomes the Principal Investigator is happy to talk to you.

You will see that the questionnaire has a space for your national health index (NHI) number. This is only there so we can look up your latest HaemoglobinA1c result (a single blood test that tells you what your blood sugar levels have been on average over the past 3 months) to go with your other answers. **Your name will never be placed on the questionnaire** and no other information will be looked at or recorded.

Only the Principal Investigator or her Supervisors (3) will have access to the questionnaires which will be kept in a locked filing cabinet for the duration of the study and for 5 years thereafter.

Where can I get more information about this study?

You are welcome to contact the Principal Investigator Helen Snell by phoning 350 8114, or one of the supervisors, if you have any questions, or would like to discuss your participation in this study.

If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Advocate, telephone 0800 11 22 33.

This project has been reviewed and approved by the Massey University Human Ethics Committee, and the Central Region Ethics Committee PN Protocol CEN/07/06/036.

Appendix C: Information sheet

Please feel free to contact the Principal Investigator or her supervisors if you have any questions about this study.

Principal Investigator

Helen Snell, MN, MPhil (Nursing), FCNA(NZ)
Nurse Practitioner – Diabetes and related conditions
MidCentral Health
Ph: (06) 350 8114
Doctoral Student – Massey University

Research Supervisors

Professor Jenny Carryer, PhD, RN, FCNA(NZ)
Clinical Chair of Nursing
School of Health Sciences
Massey University/ MidCentral District Health Board
Ph: (06) 3569099

Dr. Tim Kenealy, PhD, MBChB, FRNZCGP
Associate Professor of Integrated Care
University of Auckland
(09) 2760044

Dr. Stephen Neville, R.N; PhD; FCNA(NZ)
Senior Lecturer, Massey University
(09) 4140800

Appendix D: Letter to Primary Health Care providers

Appendix D: Letter to Primary Health Care providers



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11 February 2008

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Dear Colleague

Diabetes: Understanding influences on health activation

This letter is to inform you that I am commencing a study exploring the influences on health activation in people with diabetes in the MidCentral Health District. This study forms the basis of my doctoral studies at Massey University towards a PhD in Nursing. The study consists of a self administered questionnaire, followed by interviews for interested participants. The questionnaire asks participants to complete the 'patient activation measure' to obtain information about their level of health activation, then specifically explores diabetes related emotional distress and the patients perspective on provider (nurse and doctor) communication and decision making styles.

This study has been discussed with and has the support of the MidCentral District Health Board's Diabetes District Management Team, MidCentral Health's Te Whare Rapauro, MidCentral District Health Board Nursing Practice Development Team's Kaiwhakarite, Maori Health Service Providers (via Te Puna o Te Ora), the Manawatu, Horowhenua, Taranua Diabetes Trust, and MidCentral Health. Ethical approval has been granted by the Central Region Ethics Committee and the Massey University Human Ethics Committee.

Questionnaires will be mailed to potential participants in coming weeks. If you have any questions about the study, please do not hesitate to contact me.

Yours sincerely

Helen Snell

Nurse Practitioner – Diabetes and related conditions

M.N., M.Phil(Nursing), FCNA(NZ), PhD Candidate

Email: helen.snell@midcentraldhd.govt.nz

Te Kōwhiri
ki Pākehā

Appendix E: Follow up letter about interviews

Appendix E: *Follow up letter about interviews*



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3 September 2008

Dear

You will recall completing a questionnaire for my study within the past few months and you kindly indicated your willingness to participate in an interview.

I have been continuing to recruit participants into the study and have only just closed off that section of the study. I will be starting to analyse the data from the questionnaires which will help me determine what the next steps are for my study.


I have had a fantastic response overall and especially from people indicating their willingness to take part in an interview, thank you to you all. However, it does mean that I will not be able to interview everyone who has said they are willing. For those who will be interviewed, I hope to be in contact with you in the next month to arrange a time that is mutually convenient.

If you indicated your willingness but have changed your mind or your circumstances have changed, that is not problem, just please let me know on 3508114 as soon as is convenient to you.

Yours sincerely

Helen Snell, Nurse Practitioner – Diabetes
Principal Investigator

Appendix F: Consent form for interview



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Consent Form - Interview

Diabetes: Understanding influences on health activation

Principal Investigator:
Helen Snell, Nurse Practitioner – Diabetes and related conditions, MidCentral Health District Health Board, Ph: (06) 350 8114, *Doctoral Student – Massey University*

Co-Investigators:

- Professor Jenny Carryer, Clinical Chair of Nursing, School of Health Sciences, Massey University/ MidCentral District Health Board, Ph: (06) 3569099 or (06) 3509143.
- Dr. Tim Kenealy, Associate Professor of Integrated Care, University of Auckland 09 2760044.
- Dr. Stephen Neville, Senior Lecturer, Massey University, 094140800

STATEMENT BY THE PARTICIPANT


- I have read and I understand the information sheet dated May 2007 for volunteers taking part in the study designed to explore factors influencing self-management with diabetes care activities. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my continuing health care or future health care.
- I understand I am free to decline to answer any question in the interview.
- I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.
- I have had time to consider whether to take part.
- I know who to contact if I have any concerns or questions about the study.
- I consent to my interview being audio-taped/video-taped YES/NO
- I understand the tape can be turned off at any time YES/NO
- I wish to receive a copy of the results YES/NO
- I understand this study has been approved by the National Health Committee (Central region).

I _____ (full name) hereby consent to take part in this study under the conditions set out on the information sheet, of which I have a copy.

Signed (Participant)_____ Date _____

Signed (Researcher)_____ Date _____

If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Services Consumer Advocate on 0800 11 22 33.



Appendix G: Interview Guide

Appendix G: Interview question guide

General

There is a big emphasis in health care on self-management, that is you taking an active role in the self-care of your diabetes.

Can you tell me how you feel when you hear this?

And/or maybe (Is this something you place importance on?)

Health activation

Some people have said that they know what they need to do to take care of their diabetes but choose not to. What do you think about that?

Other possible questions

-Are there any barriers in your life for taking action/maintaining action?

-What/who helps you in your life to take action/maintain action or effort?

Emotional distress

Do you currently feel that diabetes is causing you to feel distressed? In what way?

Previous research tells us that living with diabetes can lead to high levels of diabetes-related distress, but most people in this study had relatively low levels. Why do you think this might be?

Some participants in this study felt that diabetes controls their life. Is this an issue for you?

-In what way?

-Why not?

Some participants have said they feel that complications from diabetes are inevitable. Do you feel like this? Why?

Some participants have said that family and friends don't appreciate how difficult living with diabetes can be. Tell me what your experience has been?

-Is this the same for health professionals?

-Is this different for nurses and doctors? (and different nurses and doctors) Tell me how? (Try to tease out if any difference between Practice nurse, Diabetes Specialist Nurse, GP, Diabetes Specialist Physician)

Appendix G: Interview Guide

Health provider decision-making and communication style

Research tells us that health professionals spend on average about 3 hours per year helping people with their health conditions. How would your experience compare with this?

-Is this enough to help you with your diabetes self-care strategies?

-Is this different for nurses and doctors? (and different nurses and doctors) Tell me how?

(Try to tease out if any difference between Practice nurse, Diabetes Specialist Nurse, GP, Diabetes Specialist Physician)

There was an interesting range of comments from participants in this study about what they thought doctors and nurses are meant to help you with. I am interested to know your perspective.

(Try to tease out if any differences between Practice nurse, Diabetes Specialist Nurse, GP, Diabetes Specialist Physician)

Appendix H: Panui



PANUI

*Te Wakahuia, Pembroke Street, Highbury, Palmerston North
November 2007, 10.30–11.30am*

“Understanding influences on diabetes-related health activation”
Helen Snell, Nurse Practitioner–Diabetes & related conditions



Helen would like to invite you to hear about and discuss her planned research exploring influences on diabetes-related health activation. This research forms the basis of her doctoral degree at Massey University and hopes to provide a contribution to our knowledge about to help people with diabetes to take an active role in their diabetes health care activities. Importantly, Helen would like your help to encourage all eligible people with diabetes to participate.

To confirm your attendance, please contact:
Judy Kitchen, Diabetes Lifestyle Centre
Phone: 06 3508114
or
email Helen Snell, Diabetes Lifestyle Centre
helen.snell@midcentraldhb.govt.nz

Appendix I: Correlations between participant demographics and health related characteristics

	Health	Age	Sex	Ethnicity	Education	Geographical location	Type of diabetes	Yrs with diabetes	HbA1c	Frequency of doctor visits	Frequency of nurse visits	Co-morbidities
Health	-	-.004	-.153**	.049	-.139*	.008	-.184**	-.034	.000	-.072	.029	-.360***
Age		-	-.213**	-.083	-.268**	.050	.478**	.075	-.254	.034	.095	.319***
Sex			-	-.036	.005	.011	-.042	.155*	-.012	.120	.069	.018
Ethnicity				-	-.006	-.026	.082	.086	.179**	-.028	-.105	.082
Education					-	-.058	-.214**	.017	-.011	.077	.090	-.278***
Geographical location						-	.062	-.080	.019	-.012	-.088	.068
Type of diabetes							-	-.192**	-.151	-.072	.016	.416***
Yrs with diabetes								-	.013	-.016	.083	.041
HbA1c									-	-.033	-.128	-.106
Frequency of doctor visits										-	.099	.025
Frequency of nurse visits											-	.097
Co-morbidities												-

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

Appendix J: Patient activation measure - response to individual items

Appendix J: *Patient Activation Measure: Response to Individual Items, with Percentage of Not Applicable (NA), Disagree strongly (DS), Disagree (D), Agree (A), Agree Strongly (AS).*

	Questionnaire items	NA %	DS %	D %	A %	AS %
1.	When all is said and done, I am the person who is responsible for managing my health condition.	1.4	0.9	0.9	47.3	49.5
2.	Taking an active role in my own health care is the most important factor in determining my health and ability to function.	1.8	0.5	0.5	53.2	44.1
3.	I am confident that I can take actions that will help prevent or minimise some symptoms or problems associated with my health condition.	2.7	0.5	3.2	60.0	33.6
4.	I know what each of my prescribed medications does.	3.6	1.8	9.1	52.3	33.2
5.	I am confident that I can tell when I need to get medical care and when I can handle a health problem myself.	1.8	1.4	6.8	56.4	33.6
6.	I am confident I can tell a doctor or nurse concerns I have even when he or she does not ask.	2.3	0.9	5.9	55.5	35.5
7.	I am confident that I can follow through on medical treatments I need to do at home.	1.8	0.5	2.3	55.0	40.5
8.	I understand the nature and causes of my health condition (s).	3.2	0.9	6.4	55.9	33.6
9.	I know the different medical treatment options available for my health condition(s).	8.2	1.4	15.0	54.1	21.4
10.	I have been able to maintain the lifestyle changes for my health condition that I have made.	2.3	1.8	9.1	63.2	23.6
11.	I know how to prevent further problems with my health condition(s).	2.7	1.4	11.8	57.3	26.8
12.	I am confident I can figure out solutions when new situations or problems arise with my health condition(s).	3.2	1.4	22.7	52.7	20.0
13.	I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress.	1.8	3.2	19.5	59.1	16.4

Appendix K: Health activation correlations

Appendix K: *Correlations of Health Activation with demographics and health related characteristics*

	HA	Type of diabetes	Yrs with diabetes	HbA _{1c}	Frequency of doctor visits	Frequency of nurse visits	Co-morbidities
HA	-	-.218**	.089	-.013	-.098	.005	-.209**
Type of Diabetes		-	-.192**	-.151*	-.072	.016	.416***
Yrs with Diabetes			-	.013	-.016	.083	.041
HbA_{1c}				-	-.033	-.128	-.106
Frequency of doctor visits					-	.099	.025
Frequency of nurse visits						-	.097
Co-Morbidities							-

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

Appendix L: Responses to diabetes-distress scale

Appendix L: *Diabetes-related distress. Response to Individual Items, Response to each question with Percentage of not a problem =1 to serious problem = 6*

		not a problem				serious problem		
	Item	Missing %	1 %	2 %	3 %	4 %	5 %	6 %
1	Feeling that diabetes is taking up too much of my mental and physical energy every day.	2.7	45.5	22.3	13.2	11.8	4.1	0.5
2	Feeling that my doctor or nurse doesn't know enough about diabetes and diabetes care.	2.7	65.0	14.5	9.1	3.6	1.8	3.2
3	Feeling angry, scared and/or depressed when I think about living with diabetes.	1.8	50.0	23.6	10.0	8.6	4.1	1.8
4	Feeling that my doctor or nurse doesn't give me clear enough directions on how to manage my diabetes.	2.3	66.8	15.9	5.9	5.5	2.7	0.9
5	Feeling that I am not testing my blood sugars frequently enough.	2.7	55.9	13.2	13.3	7.7	5.0	2.3
6	Feeling that I am often failing with my diabetes regimen.	2.7	34.1	29.1	15.5	10.9	5.0	3.2
7	Feeling that friends or family are not supportive enough of my self-care efforts (e.g. planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods).	1.8	54.1	21.4	10.0	7.7	1.8	3.2
8	Feeling that diabetes controls my life.	1.8	32.3	26.8	18.2	10.9	4.5	5.5
9	Feeling that my doctor doesn't take my concerns seriously enough.	3.2	65.9	15.0	6.8	4.5	1.4	3.2

Appendix L: Responses to diabetes-distress scale

10	Not feeling confident in my day-to-day ability to manage diabetes.	2.7	53.2	22.7	11.4	5.9	3.6	0.5
11	Feeling that I will end up with serious long term complications, no matter what I do.	1.8	32.7	18.2	15.9	12.7	11.4	7.4
12	Feeling that I am not sticking closely enough to a good meal plan.	2.3	29.5	33.6	18.2	9.5	4.1	2.7
13	Feeling that friends or family don't appreciate how difficult living with diabetes can be.	1.8	43.2	19.1	12.7	9.5	7.3	6.4
14	Feeling overwhelmed by the demands of living with diabetes.	2.3	49.1	21.8	10.0	10.0	4.1	2.7
15	Feeling that I don't have a doctor Who I can see regularly about my diabetes.	2.8	7.0	9.1	8.2	5.5	1.8	2.7
16	Not feeling motivated to keep up my diabetes self-management.	1.8	52.7	19.5	10.9	8.6	3.6	2.7
17	Feeling that friends or family don't Give me the emotional support that I would like.	2.3	59.1	17.7	6.8	6.8	4.5	2.7

Appendix M: Responses to Communication & decision-making style - good

Appendix M: *Communication and decision- making – ‘How good’*

General Practitioner - Good

	Questionnaire items	n	Poor %	Fair %	Good %	Excellent %
	Communication: How good is your GP at:					
1.	Telling you everything	202	4.5	14.4	41.1	40.1
2.	Letting you know test results when promised?	202	5.9	10.9	38.1	45.0
3.	Explaining treatment alternatives?	200	10.5	21.0	39.0	29.5
4.	Explaining side-effects of medications?	203	11.3	19.2	36.9	32.5
5.	Telling you what to expect from your disease or treatment?	201	9.0	15.0	43.3	31.8
6.	Asking you how you are coping?	204	9.3	19.6	37.3	33.8
	Decision-making style How often does your GP:		None of time %	Some of the time %	Most of the time %	All of the time %
1.	Offer choices in medical care?	201	18.4	32.8	32.8	15.9
2.	Discuss pros and cons of each choice with you?	199	16.6	28.6	32.2	22.6
3.	Get you to state which option you prefer?	197	26.9	24.4	26.4	22.3
4.	Take your preferences into account when making treatment decisions?	196	17.3	21.9	35.2	25.5

Appendix M: Responses to Communication & decision-making style - good

Diabetes Specialist Physician – Good

	Questionnaire items	n	Poor %	Fair %	Good %	Excellent %
	Communication: How good is your Diabetes Specialist Physician at:					
1.	Telling you everything	130	11.5	19.2	40.8	28.5
2.	Letting you know test results when promised?	126	7.1	17.5	38.9	36.5
3.	Explaining treatment alternatives?	130	13.8	25.4	37.7	23.1
4.	Explaining side-effects of medications?	130	18.5	23.8	33.1	24.6
5.	Telling you what to expect from your disease or treatment?	130	10.0	22.3	39.2	28.5
6.	Asking you how you are coping?	130	13.8	23.1	36.2	26.9
	Decision-making style: How often does your Diabetes Specialist Physician:		None of the time %	Some of the time %	Most the time %	All of the time %
1.	Offer choices in medical care?	127	30.7	28.3	27.6	13.4
2.	Discuss pros and cons of each choice with you?	127	26.8	29.1	29.1	15.0
3.	Get you to state which option you prefer?	126	41.3	20.6	26.2	11.9
4.	Take your preferences into account when making treatment decisions?	126	34.9	19.8	27.0	18.3

Appendix M: Responses to Communication & decision-making style - good

Practice Nurse - Good

	Questionnaire items	n	Poor %	Fair %	Good %	Excellent %
	Communication: How good is your Practice Nurse at:					
1.	Telling you everything	109	1.8	11.9	39.4	46.8
2.	Letting you know test results when promised?	108	6.5	10.2	32.4	50.9
3.	Explaining treatment alternatives?	104	11.5	19.2	34.6	34.6
4.	Explaining side-effects of medications?	103	12.6	19.4	36.9	31.1
5.	Telling you what to expect from your disease or treatment?	105	9.5	22.9	34.3	33.3
6.	Asking you how you are coping?	107	5.6	15.9	34.6	43.9
	Decision-making style: How often does your Practice Nurse:		None of the time %	Some of the time %	Most of the time %	All of the time %
1.	Offer choices in medical care?	98	33.7	23.5	20.4	22.4
2.	Discuss pros and cons of each choice with you?	99	28.3	25.3	22.2	24.2
3.	Get you to state which option you prefer?	98	32.7	21.4	23.5	22.4
4.	Take your preferences into account when making treatment decisions?	98	29.6	21.4	22.4	26.5

Appendix M: Responses to Communication & decision-making style - good

Diabetes Specialist Nurse - Good

	Questionnaire items	n	Poor %	Fair %	Good %	Excellent %
	Communication: How good is your Practice Nurse at:					
1.	Telling you everything	109	1.8	11.9	39.4	46.8
2.	Letting you know test results when promised?	108	6.5	10.2	32.4	50.9
3.	Explaining treatment alternatives?	104	11.5	19.2	34.6	34.6
4.	Explaining side-effects of medications?	103	12.6	19.4	36.9	31.1
5.	Telling you what to expect from your disease or treatment?	105	9.5	22.9	34.3	33.3
6.	Asking you how you are coping?	107	5.6	15.9	34.6	43.9
	Decision-making style: How often does your Practice Nurse:		None of the time %	Some of the time %	Most of the time %	All of the time %
1.	Offer choices in medical care?	98	33.7	23.5	20.4	22.4
2.	Discuss pros and cons of each choice with you?	99	28.3	25.3	22.2	24.2
3.	Get you to state which option you prefer?	98	32.7	21.4	23.5	22.4
4.	Take your preferences into account when making treatment decisions?	98	29.6	21.4	22.4	26.5

Appendix M: Responses to Communication & decision-making style - good

Primary Health Organisation Diabetes Nurse - Good

	Questionnaire items	n	Poor %	Fair %	Good %	Excellent %
	Communication: How good is your Primary Health Diabetes Nurse at:					
1.	Telling you everything	45	4.4	6.7	20	68.9
2.	Letting you know test results when promised?	42	7.1	4.8	21.4	66.7
3.	Explaining treatment alternatives?	42	7.1	11.9	14.3	66.7
4.	Explaining side-effects of medications?	42	14.3	4.8	26.2	54.8
5.	Telling you what to expect from your disease or treatment?	41	7.3	4.9	31.7	56.1
6.	Asking you how you are coping?	42	7.1	7.1	16.7	69
	Decision-making style: How often does your Primary Health Diabetes Nurse:		None of the time %	Some of the time %	Most of the time %	All of the time %
1.	Offer choices in medical care?	37	18.9	13.5	32.4	35.1
2.	Discuss pros and cons of each choice with you?	39	15.4	15.4	30.8	38.5
3.	Get you to state which option you prefer?	39	25.6	12.8	28.2	33.3
4.	Take your preferences into account when making treatment decisions?	39	20.5	12.8	30.8	35.9

Appendix M: Responses to Communication & decision-making style - good

Maori Disease State Nurse – Good

	Questionnaire items	n	Poor %	Fair %	Good %	Excellent %
	Communication: How good is your Maori disease state Nurse at:					
1.	Telling you everything	2	0	0	0	0.9
2.	Letting you know test results when promised?	2	0	0	0	0.9
3.	Explaining treatment alternatives?	2	0	0	0	0.9
4.	Explaining side-effects of medications?	2	0	0	0	0.9
5.	Telling you what to expect from your disease or treatment?	2	0	0	0	0.9
6.	Asking you how you are coping?	2	0	0	0	0.9
	Decision-making style: How often does your Maori disease state Nurse:		None of the time %	Some of the time %	Most of the time %	All of the time %
1.	Offer choices in medical care?	2	0	0	0	0.9
2.	Discuss pros and cons of each choice with you?	2	0	0	0	0.9
3.	Get you to state which option you prefer?	2	0	0	0	0.9
4.	Take your preferences into account when making treatment decisions?	2	0	0	0	0.9

Appendix M: Responses to Communication & decision-making style - good

Mobile Community Nurse – Good

	Questionnaire items	n	Poor %	Fair %	Good %	Excellent %
	Communication: How good is your Mobile community Nurse at:					
1.	Telling you everything	5	0	0	40	60
2.	Letting you know test results when promised?	5	0	0	20	80
3.	Explaining treatment alternatives?	5	0	0	20	80
4.	Explaining side-effects of medications?	5	0	0	40	60
5.	Telling you what to expect from your disease or treatment?	5	0	0	20	80
6.	Asking you how you are coping?	5	0	0	20	80
	Decision-making style: How often does your Mobile Community Nurse:		None of the time %	Some of the time %	Most of the time %	All of the time %
1.	Offer choices in medical care?	5	0	20	60	20
2.	Discuss pros and cons of each choice with you?	5	0	20	40	40
3.	Get you to state which option you prefer?	5	0	20	40	40
4.	Take your preferences into account when making treatment decisions?	5	0	20	20	60

Appendix N: Responses to communication & decision-making style - important

Appendix N: Responses to communication & decision-making style - important

General Practitioner – Important

	Questionnaire items	n	Not %	Slightly %	Somewhat %	Very %
	Communication: How important is it to you that your GP is good at:					
1.	Telling you everything	195	1.5	5.6	17.4	75.4
2.	Letting you know test results when promised?	191	1.6	4.2	20.9	73.3
3.	Explaining treatment alternatives?	191	2.1	6.8	29.8	61.3
4.	Explaining side-effects of medications?	193	2.6	5.2	24.4	67.9
5.	Telling you what to expect from your disease or treatment?	191	2.1	4.7	24.6	68.6
6.	Asking you how you are coping?	190	4.2	7.9	26.8	61.1
	Decision-making style: How important is it to you that your GP:		Not %	Slightly %	Somewhat %	Very %
1.	Offers choices in medical care?	189	5.3	7.9	31.7	55.0
2.	Discusses pros and cons of each choice with you?	189	5.3	4.2	29.6	60.8
3.	Gets you to state which option you prefer?	187	7.0	4.8	31.6	56.7
4.	Takes your preferences into account when making treatment decisions?	186	3.8	6.5	30.1	59.7

Appendix N: Responses to communication & decision-making style - important

Diabetes Specialist Physician – Important

	Questionnaire items	n	Not %	Slightly %	Somewhat %	Very %
	Communication: How important is it to you that your Diabetes Specialist Physician is good at:					
1.	Telling you everything	124	0.8	2.4	16.9	79.8
2.	Letting you know test results when promised?	119	0.8	5.0	22.7	71.4
3.	Explaining treatment alternatives?	124	1.6	5.6	23.4	69.4
4.	Explaining side-effects of medications?	124	2.4	4.8	25.8	66.9
5.	Telling you what to expect from your disease or treatment?	124	1.6	5.6	21.8	71.0
6.	Asking you how you are coping?	123	1.6	4.9	21.1	72.4
	Decision-making style: How important is it to you that your Diabetes Specialist Physician:		Not %	Slightly %	Somewhat %	Very %
1.	Offer choices in medical care?	117	1.7	6.8	29.9	61.5
2.	Discuss pros and cons of each choice with you?	117	1.7	6.0	30.8	61.5
3.	Get you to state which option you prefer?	117	4.3	4.3	30.8	60.7
4.	Take your preferences into account when making treatment decisions?	116	4.3	4.3	25.0	66.4

Appendix N: Responses to communication & decision-making style - important

Practice Nurse - Important

	Questionnaire items	n	Not %	Slightly %	Somewhat %	Very %
	Communication: How important is it to you that your Practice Nurse is good at:					
1.	Telling you everything	107	0.9	7.5	20.6	71.0
2.	Letting you know test results when promised?	105	1.9	5.7	20.0	72.4
3.	Explaining treatment alternatives?	103	2.9	12.6	23.3	61.2
4.	Explaining side-effects of medications?	100	1.0	10.0	27.0	62.0
5.	Telling you what to expect from your disease or treatment?	104	2.9	10.6	21.2	65.4
6.	Asking you how you are coping?	104	2.9	5.8	25.0	66.3
	Decision-making style: How important is it to you that your Practice Nurse:		Not %	Slightly %	Somewhat %	Very %
1.	Offers choices in medical care?	94	5.3	11.7	24.5	58.5
2.	Discusses pros and cons of each choice with you?	95	6.3	9.5	24.2	60.0
3.	Gets you to state which option you prefer?	93	7.5	10.8	24.7	57.0
4.	Takes your preferences into account when making treatment decisions?	94	7.4	9.6	23.4	59.6

Appendix N: Responses to communication & decision-making style - important

Diabetes Specialist Nurse - Important

	Questionnaire items	n	Not %	Slightly %	Somewhat %	Very %
	Communication: How important is it to you that your Diabetes Specialist Nurse is good at:					
1.	Telling you everything	120	0	3.3	17.5	79.2
2.	Letting you know test results when promised?	116	0	5.2	20.7	74.1
3.	Explaining treatment alternatives?	118	0.8	5.9	19.5	73.7
4.	Explaining side-effects of medications?	116	0.9	5.2	24.1	69.8
5.	Telling you what to expect from your disease or treatment?	118	0	4.2	20.3	75.4
6.	Asking you how you are coping?	119	0.8	3.4	19.3	76.5
	Decision-making style: How important is it to you that your Diabetes Specialist Nurse:		Not %	Slightly %	Somewhat %	Very %
1.	Offer choices in medical care?	112	3.6	6.2	26.8	63.4
2.	Discuss pros and cons of each choice with you?	112	11.8	14.3	27.7	46.2
3.	Get you to state which option you prefer?	111	3.6	6.3	25.2	64.9
4.	Take your preferences into account when making treatment decisions?	110	3.6	6.4	22.7	67.3

Appendix N: Responses to communication & decision-making style - important

PHO Diabetes Nurse - Important

	Questionnaire items	n	Not %	Slightly %	Somewhat %	Very %
	Communication: How important is it to you that your PHO Diabetes Nurse is good at:					
1.	Telling you everything	41	2.4	2.4	17.7	78.0
2.	Letting you know test results when promised?	40	5.0	2.5	7.5	85.0
3.	Explaining treatment alternatives?	40	2.5	7.5	15.0	75.0
4.	Explaining side-effects of medications?	41	4.9	4.9	12.2	78.0
5.	Telling you what to expect from your disease or treatment?	36	5.0	0	15.0	80.0
6.	Asking you how you are coping?	41	4.9	0	17.1	78.0
	Decision-making style: How important is it to you that your PHO Diabetes Nurse:		Not %	Slightly %	Somewhat %	Very %
1.	Offers choices in medical care?	36	5.6	2.8	13.9	77.8
2.	Discusses pros and cons of each choice with you?	38	5.3	2.6	15.8	76.3
3.	Gets you to state which option you prefer?	38	7.9	5.3	10.5	76.3
4.	Takes your preferences into account when making treatment decisions?	37	8.1	2.7	16.2	73.0

Appendix N: Responses to communication & decision-making style - important

Maori Disease State Nurse – Important

	Questionnaire items	n	Not %	Slightly %	Somewhat %	Very %
	Communication: How important is it to you that your Maori disease state Nurse is good at:					
1.	Telling you everything	2	0	0	0	100
2.	Letting you know test results when promised?	2	0	0	0	100
3.	Explaining treatment alternatives?	2	0	0	0	100
4.	Explaining side-effects of medications?	2	0	0	0	100
5.	Telling you what to expect from your disease or treatment?	2	0	0	0	100
6.	Asking you how you are coping?	2	0	0	0	100
	Decision-making style: How important is it to you that your Maori disease state Nurse:		Not %	Slightly %	Somewhat %	Very %
1.	Offers choices in medical care?	2	0	0	50	50
2.	Discusses pros and cons of each choice with you?	2	0	0	0	100
3.	Gets you to state which option you prefer?	2	0	0	0	100
4.	Takes your preferences into account when making treatment decisions?	2	0	0	0	100

Appendix N: Responses to communication & decision-making style - important

Mobile Community Nurse - Important

	Questionnaire items	n	Not %	Slightly %	Somewhat %	Very %
	Communication: How important is it to you that your Mobile Community Nurse is good at:					
1.	Telling you everything	5	0	0	20	80
2.	Letting you know test results when promised?	5	0	0	0	100
3.	Explaining treatment alternatives?	5	0	0	0	100
4.	Explaining side-effects of medications?	5	0	0	20	80
5.	Telling you what to expect from your disease or treatment?	5	0	0	0	100
6.	Asking you how you are coping?	5	0	0	0	100
	Decision-making style: How important is it to you that your Mobile Community Nurse:		Not %	Slightly %	Somewhat %	Very %
1.	Offers choices in medical care?	5	0	0	20	80
2.	Discusses pros and cons of each choice with you?	5	0	0	0	100
3.	Gets you to state which option you prefer?	5	0	0	0	100
4.	Takes your preferences into account when making treatment decisions?	5	0	0	0	100

Appendix O: Mean scores – good versus important

Appendix O: *Provider Communication and Decision-making total mean scores ‘Good’ versus ‘Important’*

<i>General Practitioner:</i>	<i>N</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>
Communication ‘good’	181	3.04	.78		
Communication ‘important’	181	3.58	.57	(180) = -9.45	<.001
Decision making ‘good’	185	2.57	.94		
Decision making ‘important’	185	3.42	.77	(184) = -12.27	<.001
<i>Diabetes Specialist Physician:</i>					
Communication ‘good’	115	2.88	.81		
Communication ‘important’	115	3.66	.67	(114) = -12.91	<.001
Decision making ‘good’	115	2.30	.98		
Decision making ‘important’	115	3.50	.67	(114) = -12.918	<.001
<i>Practice Nurse:</i>					
Communication ‘good’	94	3.12	.79		
Communication ‘important’	94	3.56	.65	(93) = -5.31	<.001
Decision making ‘good’	90	2.44	1.09		
Decision making ‘important’	90	3.34	.88	(89) = - 7.81	<.001
<i>Diabetes Specialist Nurse:</i>					
Communication ‘good’	108	3.51	.71		
Communication ‘important’	108	3.69	.52	(107) = -3.34	<.001
Decision making ‘good’	109	3.05	1.05		
Decision making ‘important’	109	3.52	.73	(108) = -5.65	<.001