

'If you don't manage diabetes, it will manage you':
Type two diabetes self-management in rural Australia

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Abstract

The aim of this research was to investigate the barriers to effective type two diabetes self-management faced by people in rural and remote areas of Australia. This research is timely for several reasons including the current rise in the prevalence of type two diabetes across the world (International Diabetes Federation [IDF], 2009), and data supporting the fact that that type two diabetes is poorly managed, especially in rural and remote contexts (Australian Institute of Health and Welfare [AIHW], 2008a). Specifically, the research presented in this thesis aimed to identify barriers to effective self-management in rural and remote areas, to develop a tool for the measurement of these barriers, and to determine the importance of barriers to self-management in diabetes-dependant quality of life in both rural and urban populations.

A mixed methods framework was adopted to address the aims of this research. This approach involved two separate but related data collections and three separate data analyses. Study 1 utilised the methods proposed by Braun and Clarke (2006) in order to conduct a thematic analysis regarding barriers to self-management. Semi-structured interviews with health professionals (n=18) and people with type two diabetes (n=10), and one focus group with people with type two diabetes (n=8) provided the data for this thematic analysis. A socio-ecological framework was used to organise identified themes. Results of Study 1 were subsequently used to inform the development of a survey for collecting quantitative data, which were used in Study 2 and Study 3. Study 2 used Principal Components Analysis to validate an adapted measure of barriers to effective type two diabetes self-management in a mixed rural and urban population (n=326). Study 3 utilised univariate and multivariate analyses to investigate both the demographic predictors of barriers to self-management, and the barrier predictors of diabetes-dependant quality of life in rural and urban populations.

Study 1 identified barriers to effective self-management at intrapersonal, interpersonal, organisational and societal levels of influence. Across all levels of influence, the difficulty of maintaining lifestyle changes was emphasised. Results of Study 2 indicated that the adapted survey was valid in a mixed rural and urban population. Age, number of complications and remoteness were identified as significant predictors of various barriers to self-management in Study 3. Diabetes-dependant quality of life was similar in the rural and urban populations. Psychosocial barriers to management were the only significant predictor of diabetes-dependant quality of life in the rural population, while depression, psychosocial barriers and self-monitoring barriers were significant predictors of diabetes-dependant quality of life in the urban population.

The research presented in this thesis identified barriers to effective type two diabetes self-management in rural and remote areas of Australia, and indicates that, of the barriers identified, psychosocial barriers are the most important in predicting diabetes-dependant quality of life in both rural and urban populations. These results have useful implications for provision of care in that they lend support to the principle that psychological and social factors must be taken into consideration if the goals of type two diabetes self-management, specifically improving quality of life, are to be realised across settings.

Declaration

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution to Laura Jones, and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

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Overview

The research presented in this thesis aimed to identify barriers to effective type two diabetes self-management in rural and remote areas of Australia. This is important considering increased rates of, and complications arising from, type two diabetes in rural and remote areas, compared to urban areas, in both an Australian and global context. Improving quality of life is a central aim of type two diabetes self-management. Therefore, this research also aimed to investigate which barriers to self-management are most important in diabetes-dependant quality of life in rural and urban areas of Australia.

Three independent but related studies were conducted to investigate barriers to self-management in a rural Australian context. The research which forms the basis for this thesis will be presented as three manuscripts which are either accepted for publication (Study 1) or under review (Study 2 and Study 3) in peer reviewed journals. These studies will be linked by chapters which provide a broader context for the research.

Chapter 1 consists of two parts. The first part contextualises the research as a whole by providing an overview of type two diabetes aetiology, descriptive epidemiology, burden, consequences and current management aims and recommendations. The second part of Chapter 1 provides a definition of the concept of 'rural' and a discussion of health and diabetes in rural and remote areas of Australia.

Chapter 2 provides a rationale for the research in this thesis by examining existing literature on type two diabetes self-management. This chapter begins with a definition and discussion of literature relating to adherence to self-management recommendations, followed by literature which investigates factors influencing adherence (barriers and facilitators). Finally, this

chapter provides a rationale for the research presented in this thesis by identifying gaps in the existent literature.

The next chapter, Chapter 3, provides a rationale for the theoretical framework adopted and the mixed methods approach used to conduct this research.

Chapter 4 (Study 1) presents the results of a qualitative investigation of barriers to effective management in rural and remote areas of Australia, as identified by people with type two diabetes and health professionals working with people with type two diabetes. This manuscript has been accepted for publication in the *Journal of Health Psychology*.

Chapter 5 expands on some of the findings of Study 1, and provides the background for the subsequent studies. This chapter outlines the development of a survey to collect quantitative data, which were analysed in Study 2 (Chapter 6) and Study 3 (Chapter 7).

Chapter 6 (Study 2) presents the results of the adaptation of the Diabetes Obstacles Questionnaire (DOQ) (Hearnshaw et al., 2007) to include barriers identified in Study 1, and the validation of this adapted measure in a population of both rural and urban dwelling Australians with type two diabetes. This study is presented in the form of a manuscript which is currently under review for the journal, *Rural and Remote Health*.

Chapter 7 (Study 3) presents the results of an investigation into the predictors of barriers to effective self-management, as measured by the adapted Diabetes Obstacles Questionnaire, and the associations between barriers to effective self-management and diabetes-dependant quality of life. This study is also presented in the form of a manuscript which is currently under review for the journal, *Rural and Remote Health*.

Chapter 8 provides an overall discussion of the three studies. The findings, implications, strengths and limitations are discussed for each study. The findings of the three studies are then integrated and important areas for future research are proposed. Finally, conclusions are drawn in an effort to making a unique contribution to understandings of the experiences of people managing type two diabetes in rural and remote contexts.

Chapter 1: Introduction to Type Two Diabetes and Rural Health

In order to provide a rationale for the importance of the research presented in this thesis, this chapter will provide background information about the problem of type two diabetes in both an Australian and a global context. This chapter will define type two diabetes and discuss its causes, Australian and world-wide prevalence, and common consequences of type two diabetes. Current recommendations for type two diabetes management will also be discussed. This background information is important in understanding the need to conduct research into self-management behaviours, and will thus provide context for Chapter 2 which discusses existing literature focused on type two diabetes self-management.

1.1 Type Two Diabetes

1.1.1 Type Two Diabetes Definition and Aetiology

The term 'diabetes mellitus' refers to the disordered metabolism of carbohydrates, fats and proteins, which arises from inadequate insulin secretion or action, or both. This disordered metabolism results in an increase in blood glucose levels (hyperglycaemia) (World Health Organization [WHO], 1999). Elevated blood glucose levels can cause failure or loss of function of many vital organs, and, in the most severe hyperglycaemic events, coma and death (WHO, 1999). Furthermore, symptoms of diabetes mellitus may be absent or appear insignificant, so diabetes mellitus is often undiagnosed in the early stages; however damage may still occur during these stages (WHO, 1999).

There are two main classes of Diabetes Mellitus; Insulin Dependent Diabetes Mellitus (IDDM), commonly referred to as type one diabetes, and Non Insulin Dependent Diabetes Mellitus

(NIDDM), commonly referred to as type two diabetes. Type one diabetes is characterised by an autoimmune response, which causes the destruction of insulin producing beta-cells in the pancreas. This leads to lower insulin production and a subsequent increase in blood glucose levels. Most commonly, people are diagnosed with type one diabetes early in life (first 25 years), and the origins of type one diabetes appear to be partly genetic and partly environmental, although the exact causes are not known (WHO, 1999). Type two diabetes also results in an increase in blood glucose levels. However, unlike type one diabetes, this is not due to an autoimmune response. Rather, hyperglycaemia occurs due to a decrease in the activity of the beta-cells in the pancreas, which therefore produce less insulin (WHO, 1999), coupled with reduced sensitivity of insulin target cells (Sherwood, 2004). The specific mechanisms through which type two diabetes develop are not fully understood, although it is widely accepted that there are genetic predispositions to type two diabetes (International Diabetes Institute, 2006) and that increased body fat intensifies insulin resistance (WHO, 1999).

Risk factors for developing type two diabetes include a sedentary lifestyle, being overweight, older age, lower socioeconomic status and family history (AIHW, 2010). In 2007-08, over 60% of Australian adults, and 25% of Australian children were reported to be overweight or obese (AIHW, 2010). In conjunction with Australia's ageing population, this increase in the number of people who are overweight and obese has resulted in projections that type two diabetes will become the leading cause of Australian disease burden by the year 2023 (AIHW, 2010). Thus type two diabetes is a National Health Priority Area in Australia (AIHW, 2010). People who are either over 55 years of age, or over 45 years of age and with a first degree relative with type two diabetes, and women who have a history of gestational diabetes, are all at higher risk of developing type two diabetes. Practitioner guidelines recommend that these people be tested for type two diabetes, even if they are asymptomatic (Diabetes Australia, 2011).

Current diagnostic criteria for type two diabetes rely on plasma glucose testing, and a person is diagnosed with diabetes if they have fasting plasma glucose of more than 6.5mmol/L (WHO, 2006). A three-step procedure for diagnosis of type two diabetes, as outlined by Diabetes Australia in 'Diabetes Management in General Practice', recommends that, firstly, an initial risk assessment be conducted, followed by the measurement of fasting plasma glucose, and, thirdly, an oral glucose tolerance test (OGTT) if required. These diagnostic criteria and procedures are consistent with those used other countries, such as the United States (National Institute of Diabetes and Digestive and Kidney Diseases, 2012). Practitioners' guidelines (Diabetes Australia, 2011) recommend that a patient is diagnosed with type two diabetes if they have each of the following indicators, when tested on separate days: symptoms of diabetes (such as sores that do not heal, increased thirst, fatigue and blurred vision) and a random (non-fasting) blood glucose level of greater than 11mmol/L, fasting plasma glucose of greater than or equal to 6.5mmol/L and 2-hour plasma glucose of greater than 11mmol/L during an OGTT.

1.1.2 Descriptive Epidemiology

It is important to discuss the magnitude of the impact of illnesses such as type two diabetes, in order to provide a rationale for research into the management of these illnesses. Prevalence refers to the number of cases of a disease/illness at any one point in time (AIHW, 2008a). It is difficult to measure type two diabetes prevalence due to inaccurate self-reporting and the proportion of people who have type two diabetes but who have not been diagnosed and therefore do not self-report. Specifically, it has been estimated that, in the United States, undiagnosed type two diabetes may affect as many as three percent of the population (Cowie et al., 2006), with suggestions that the onset of type two diabetes may occur between four and seven years before diagnosis (Harris, Klein, Welborn, & Knudman, 1992). However, whilst estimates of

type two diabetes prevalence have limitations, these estimates are important to provide a sense of the magnitude of the problem.

The prevalence of type two diabetes is increasing in both developed and developing countries (Shaw, Sicree, & Zimmet, 2010). This rise has been attributed to increasingly sedentary lifestyles and unhealthy diets, growing numbers of people who are overweight and obese, ageing populations (Shaw et al., 2010; WHO, 1999), and greater longevity of people with type two diabetes arising from improved management and health care (Van Dieren, Beulens, Van Der Schouw, Grobbee, & Neal, 2010). It has been estimated that, across the seven regions of the International Diabetes Federation, comprising 160 countries, 285 million adults had diabetes in 2009 (IDF, 2009). Furthermore, exponential increases in type two diabetes prevalence have been predicted in the future (by the year 2030) due to demographic changes and ageing (Shaw et al., 2010). Based on current trends, specific estimates of a rise to almost 440 million people by the year 2030 have been made by two sources (IDF, 2009; Shaw et al., 2010).

As with global prevalence, the prevalence of type two diabetes in Australia is also increasing (AIHW, 2012a). The most recent Australian data collected, which utilised blood glucose testing, indicated that in 1999-2000, half of type two diabetes cases detected were previously undiagnosed (AIHW, 2008a). The National Health Survey (NHS), which collects self-reported data, and the National Diabetes Services Scheme (NDSS), which relies on doctor or nurse certifications of diagnosis for people registering for the scheme, provide the best current estimates of type two diabetes prevalence in Australia. Estimates from the NHS in 2007-08 which indicated that 4.4% of all Australians had diabetes, at that time, of which 88% were type two, are comparable to the NDSS estimates that 3.9% of the Australian population had diabetes in the same time period (AIHW, 2008a). Estimates also indicate that there are around 40,000 new cases of type two diabetes each year in Australia (AIHW, 2008a). However, it is important to note that

these measures do not account for undiagnosed type two diabetes, and are limited by individuals' awareness and accurate reporting of their diagnosis. Therefore these figures are likely to underestimate substantially the magnitude of the Australian population with type two diabetes (IDF, 2009).

1.1.3 A Focus on Type Two Diabetes

As highlighted above, type two diabetes accounts for most diabetes cases in Australia. Type two diabetes also accounted for four times as many recorded deaths due to diabetes than type one diabetes in Australia in 2005 (AIHW, 2008a), therefore having a greater mortality burden.

Effective self-management is essential to prevent type two diabetes complications and death. Previous research has highlighted the complexity of self-management (Zimmet, Alberti, & Shaw, 2001) and the burden that self-management places on the individual (Gonder-Frederick, Cox, & Ritterband, 2002). Therefore, it is not surprising that there is a large body of research suggesting that type two diabetes is poorly managed. Poor management has been attributed to complex lifestyle changes which need to be maintained over long periods of time (Gonder-Frederick et al., 2002; Lerman, 2005).

Both type one and type two diabetes are commonly researched in health psychology. Given the increased prevalence of type two diabetes, the importance of self-management in preventing disease complications and the complexity of behavioural aspects of self-management, the research in this thesis will focus specifically on type two diabetes. Therefore, the information presented in the remainder of this chapter will focus on type two diabetes.

1.1.4 The Impact of Type Two Diabetes

Health problems have a wide variety of associated costs. Type two diabetes is a major source of economic burden, disability and mortality worldwide (Van Dieren et al., 2010). Costs associated with type two diabetes include, but are not limited to, mortality, development of complications, compromised quality of life, psychological issues and financial costs. The impact of type two diabetes on these factors, at a population level, will be discussed here to provide evidence for the need to manage type two diabetes effectively, and thus a rationale for research into factors which impede self-management.

Mortality

Non-communicable diseases, primarily cardiovascular disease, cancers, chronic respiratory diseases and diabetes, caused an estimated 35 million deaths globally in 2005, which accounted for 60% of all deaths (WHO, 2008). Diabetes alone accounted for 6.8% of global mortality in 2007 (IDF, 2009). In addition, the World Health Organisation has predicted that type two diabetes will be the seventh most common cause of death globally by 2030 (WHO, 2013).

As with prevalence estimates, it is also suggested that the contribution of type two diabetes to overall mortality rates is likely to be significantly underestimated. Diabetes is recorded as a cause of death only when the patient dies from a cause which is exclusively related to diabetes, such as ketoacidosis or hypoglycaemia. However, in the majority of cases, people with diabetes die from consequences which are directly attributable to diabetes, such as macrovascular complications like renal failure or cardiovascular disease, rather than from diabetes itself (Van Dieren et al., 2010). Therefore, diabetes is likely to contribute more to global mortality than is commonly reported.

It is also worth noting that there are large differences in the number of deaths caused by diabetes across different regions, with total deaths in South East Asian and Western Pacific countries almost five times higher than total deaths in North America and South Central Asia (Van Dieren et al., 2010). In addition, it has been reported that gender differences in diabetes-related mortality exist globally, with women having a higher relative risk (3.4) than men (1.9) of dying from diabetes-related causes (Hu, 2011).

In Australia, the leading causes of death are circulatory diseases (37%) and cancers (29%) (AIHW, 2008b). Type two diabetes is one of the top 10 causes of death in Australia (AIHW, 2007a). In 2007, diabetes was associated with 9.5% of all deaths in Australia, whereby diabetes was listed as the underlying cause of 2.8% of all deaths, and as an associated cause of 6.7% of all deaths (causes such as renal failure or cardiovascular disease) (AIHW, 2010).

Complications

In addition to the significant contribution of type two diabetes to premature death, it is widely accepted that type two diabetes is an independent risk factor for microvascular and macrovascular diseases which arise from elevated blood glucose levels. Type two diabetes complications, in addition to their impact on health, are a major contributor to the financial burden of type two diabetes (Hogan, Dall, & Nikolov, 2003). An overview of these complications will be presented here.

Microvascular complications refer to complications affecting the smaller blood vessels. Common microvascular complications of type two diabetes include retinopathy and neuropathy, which are associated with peripheral nerve dysfunction in people with type two diabetes (Fowler, 2008). Poor glycaemic control can lead to eye damage, such as increased refractive errors and

earlier occurrence of cataracts. Type two diabetes is the second most common cause of renal dialysis commencement and most common cause of blindness in people under 60 years old (National Health and Medical Research Council [NH&MRC], 2005), and diabetics in Australia in 2007-08 were nineteen times more likely to have blindness than those without diabetes (AIHW, 2010). Neuropathy (damaged nerves) of the motor and sensory nerves in the lower limbs is also a common complication associated with type two diabetes. Peripheral nerve and blood vessel damage often results in foot problems, such as foot ulcers and ischemic foot disease, reduced pain sensitivity in some areas, and joint damage. Furthermore, type two diabetes is the most common cause of non-traumatic amputations in Australia (NH&MRC, 2005).

Macrovascular complications refer to complications affecting the larger blood vessels. Macrovascular complications of type two diabetes are commonly caused by narrowing of the artery walls throughout the body. Cardiovascular diseases are the most common complication of type two diabetes. These diseases include coronary heart disease, peripheral vascular disease and cerebrovascular disease (stroke) (Fowler, 2008). Type two diabetes leads to approximately double the risk of developing cardiovascular disease for men, and four times the risk of developing cardiovascular disease for women (Resnick & Howard, 2002). Australian 2007-08 National Health Survey (NHS) data indicate that people with diabetes were five times more likely to have a stroke and more than ten times as likely to have a heart attack than those without diabetes (AIHW, 2010). Furthermore, researchers have suggested that as many as half of type two diabetes patients will die of cardiovascular causes such as stroke, myocardial infarction, or congenital heart failure (Lundman & Engstrom, 1998). In addition, hypertension, which is associated with elevated blood glucose levels arising from type two diabetes, affects about 75% of people with type two diabetes, and is known to accelerate the development of both microvascular and macrovascular complications through causing hypertensive damage to vessels (Schutta, 2007).

Importantly, microvascular and macrovascular complications are associated with the duration and severity of hyperglycaemia (Fowler, 2008). Improved glycaemic control reduces the risk of developing macrovascular diseases, such as cardiovascular disease (Diabetes Australia, 2011). Moreover, it is important to note that early diagnosis and management have been shown to reduce the risk of developing complications of the disease (Fowler, 2008). As diabetes is often undiagnosed in the earlier stages (International Diabetes Federation Clinical Guidelines Task Force, 2005), it has been reported that at the time of diagnosis, half of patients have one or more diabetes complications (Manley et al., 1990).

Type two diabetes has serious consequences for both men and women. The condition is associated with impotence in men (around 30% of male diabetes sufferers), and women with type two diabetes are more prone to pregnancy complications. Pregnancy complications are due to the inability to regulate blood glucose levels during the first trimester of pregnancy which can lead to increased spontaneous abortion (AIHW, 2008a).

Quality of Life

In addition to medical complications of type two diabetes, people with type two diabetes may also experience functional and social consequences, such as an impeded ability to drive safely due to problems with vision and lower leg nerves (Diabetes Australia, 2011), and complex lifestyle changes required to self-manage effectively (Gonder-Frederick et al., 2002). Therefore, it is important to consider quality of life when reviewing the impact of type two diabetes.

Changes in the concept of 'health', from merely the absence of illness, to include mental, social and physical well-being, along with increased evidence that psychosocial factors influence physical health outcomes, have led to increased emphasis on quality of life in health research

(Rubin & Peyrot, 1999). It has been previously noted that there is no one definition of the concept of quality of life (S. M. Hunt, 1997). Definitions usually relate to physical and social functioning, and perceptions of physical and mental well-being (Rubin & Peyrot, 1999). The World Health Organisation Quality of Life group has adopted the following definition:

an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment (World Health Organisation Quality of Life Group, 1994, p. 43)

Although quite a broad definition of quality of life, it encompasses the importance of subjective judgement, the individual's own goals, and multiple levels of interaction and facets of health. This definition will be used for the purposes of the current research. Improving quality of life is a central goal of all health interventions, especially those related to chronic disease (Rubin & Peyrot, 1999). Therefore, it is important to investigate factors which influence quality of life in various populations of people with chronic illness.

Health-Related Quality of Life (HRQoL) is a concept which is commonly referred to in literature relating to impacts on quality of life of chronic illnesses such as type two diabetes. Definitions of HRQoL often differ depending on the use of the assessment tools and on the research questions under study (Guyatt, 1997). However HRQoL generally takes into account health status, functional status, and quality of life and 'reflects patients' evaluations of the effects of the disease and treatment on their well-being' (Murdaugh, 1997, p. NS41). There are many ways in which both HRQoL and quality of life can be measured. In the current section, though, HRQoL

and quality of life will be discussed as general constructs. Many issues have been discussed in the literature relating to the measurement of quality of life in health research. These issues and the measurement of quality of life in the current research will be discussed further in section 5.2.2.

Chronic illnesses like diabetes often have no cure. Therefore, patient quality of life is of primary concern (Smith, Avis, & Assmann, 1999). In general, people with chronic illness have poorer well-being and functional status than those without (Rubin & Peyrot, 1999). It is important to recognise that the impact of chronic illness on quality of life varies between conditions (A. L. Stewart et al., 1989). It is widely reported that people with type two diabetes have poorer quality of life than the general population, but better quality of life than people with other chronic illnesses such as chronic hepatitis C, inflammatory bowel disease and depression (Rubin & Peyrot, 1999). People along the diabetes continuum, from impaired fasting glucose to diagnosed diabetes, have poorer health status (Chittleborough, Baldock, Taylor, & Phillips, 2006) and HRQoL (Wee, Cheung, Li, Fong, & Thumboo, 2005) than people with glucose levels within the normal range. Importantly, lower HRQoL is associated with increased mortality in type two diabetes patients, with patients with low HRQoL over twice as likely to have died at 6-year follow-up (Kleefstra et al., 2008).

A multitude of studies have investigated predictors of reduced HRQoL in people with type two diabetes. Previous research has indicated that gender (being female), younger age (Redekop et al., 2002), longer duration of diabetes (De Grauw et al., 1999) and use of insulin therapy (Redekop et al., 2002) are associated with lower HRQoL. In addition, many researchers have reported that the presence of diabetes complications further reduces quality of life (De Grauw et al., 1999; Redekop et al., 2002), as does the presence of additional chronic illnesses (Wee et al., 2005). However, good long-term glycaemic control is associated with improved quality of life (Rubin & Peyrot, 1999). Furthermore, Norris et al. (2011) have suggested that despite many researchers reporting that people with diabetes have poorer health than people without diabetes,

the effect of diabetes on HRQoL has been underestimated, due to a focus on population-level data rather than individual-level data. Thus, the need to investigate HRQoL in specific sub-populations of interest rather than in type two diabetes populations broadly, has been emphasised (Norris et al., 2011). These sub-populations include high-risk populations and populations with specific demographic or clinical characteristics, such as rural and remote dwellers.

Psychological Issues in Type Two Diabetes

In addition to the physical complications and impaired quality of life, which commonly arise as a consequence of type two diabetes, it is important to consider the psychological consequences of the illnesses. Previous research has consistently reported high prevalence of depressive and/or anxiety symptoms in people with type two diabetes (Fisher et al., 2008; Thomas, Jones, Scarinci, & Brantley, 2003). While it is not clear whether poor mental health contributes to type two diabetes, or vice versa, it is well established that people with type two diabetes and mental health issues have poorer glycemic control, health and quality of life outcomes. Therefore, regardless of causal links, it is important to consider psychological problems in type two diabetes. This section will therefore discuss the mental health implications of type two diabetes, predominantly depression, as this is important when considering both the impact of type two diabetes, and factors which impede effective self-management.

Mental health issues in people with diabetes are a global issue. A cross-national survey, utilising face-to-face and telephone interviews of 5104 people with both type one and type two diabetes and 3827 health care providers in Asia, Australia, Europe and North America has indicated that many patients (41%) had poor psychological well-being (Peyrot et al., 2005). Most commonly, research in the area of type two diabetes has focused on affective and anxiety mental

health disorders. For example, a longitudinal study into the prevalence of affective and anxiety disorders including major depressive disorder, generalised anxiety disorder, panic disorder and dysthymia, in people with type two diabetes reported that people with type two diabetes have significantly higher affective and anxiety disorders than the general population (Fisher et al., 2008). In addition, Fisher et al. (2008) reported that anxiety and depression frequently co-occurred in the type two diabetes population. Furthermore, anxiety and depression have been linked to reduced physical and mental functioning in people with type two diabetes (Paschalides et al., 2004). Whilst research has investigated many psychological factors in people with type two diabetes, the role of depression in type two diabetes is most commonly investigated. The prevalence, impact and burden of depression in people with type two diabetes will now be discussed.

Estimates of rates of depression in people with diabetes vary; however, it is widely reported that people with diabetes have higher rates of depression than those without: 17.6% compared to 9.8% was reported in one meta-analysis (Ali, Stone, Peters, Davies, & Khunti, 2006). Another meta-analysis has suggested that people with diabetes are twice as likely to have depression than those without diabetes, with elevated depressive symptoms present in 31% of diabetic patients (R. J. Anderson, Freedland, Clouse, & Lustman, 2001). An Australian population-based survey ($n=3000$) reported that people with diabetes were more likely to have depression (24%) than those who do not have diabetes (17%), a difference which approached statistical significance (Goldney, Phillips, Fisher, & Wilson, 2004). Despite differences in estimates, it has been reported that depression was undiagnosed in 45% of people with diabetes and depression in the United States (Li et al., 2009). Furthermore, it has been noted that the mechanisms by which depression and diabetes are linked are not clear, and need further investigation (Egede & Ellis, 2010).

People with type two diabetes and depression have worse health outcomes in a variety of facets of health. Firstly, depression and anxiety are associated with reduced perception of ability to control diabetes (Paschalides et al., 2004). In addition, the presence of depressive symptoms in people with type two diabetes has been found to significantly predict poorer self-management (Gonzalez et al., 2008) and adherence to medical recommendations around self-management (Ciechanowski, Katon, & Russo, 2000; Lerman et al., 2004). Systematic reviews suggest that co-morbid depression is associated with poorer adherence to both medication and dietary advice (Egede, 2005), as well as self-monitoring and exercise recommendations (Gonzalez et al., 2007). Importantly, health care providers have recognised that psychological issues affected their patients' self-management, and have indicated that they felt they did not have the resources to manage these psychological problems (Peyrot et al., 2005).

Given the evidence that suggests that depression is associated with poorer self-management, it follows naturally that depression is also associated with poorer glycaemic control in people with type two diabetes (Lustman et al., 2000), with effects found to be persistent over a four year time period (Richardson, Egede, Mueller, Echols, & Gebregziabher, 2008). Furthermore, people with both depression and diabetes also have poorer health than those with diabetes and no depression, are more likely to have a Body Mass Index (BMI) of more than 30 (indicating obesity), and have greater non-diabetes related medical co-morbidity (Katon et al., 2005).

Perhaps not surprisingly then, it has also been reported that people with type two diabetes and depression have an increased number of symptoms (Paschalides et al., 2004) and complications of the disease (M. De Groot, Anderson, Freedland, Clouse, & Lustman, 2001), and a significant increase in mortality, which persisted over a three year time period, even when controlling for behavioural mediators (Katon et al., 2005). People with type two diabetes and

depressive symptoms also have significantly poorer quality of life and health status than those without depressive symptoms (Goldney et al., 2004; Sundaram et al., 2007).

Co-morbid type two diabetes and depression also result in higher medical costs than those for type two diabetes or depression alone (Le, Able, & Lage, 2006). Given the high prevalence of co-morbid depression and type two diabetes, and the associations between depression, self-management behaviours and outcomes in this population, it is essential to consider the role of depression when identifying barriers to effective management and predictors of quality of life in diabetic populations.

Financial Burden

Due to the chronic nature of diabetes, effective management requires a variety of health services. Type two diabetes places a huge burden on health systems. It has been reported that diabetes (in general) accounted for an estimated 12% of global health spending in 2010 (Zhang et al., 2011). Specifically, type two diabetes is the third most frequently managed chronic condition by general practitioners, and accounted for 8.5% of hospitalisations in Australia in 2007-08 (AIHW, 2010). The most recent health-spending data indicate that, in Australia, diabetes health care cost AU\$990 million in 2004-2005 (AIHW, 2012a).

The causes of type two diabetes health costs are complex due to the impact of complications. People with type two diabetes have longer average hospital stays than those without (AIHW, 2010). Specifically, the cost of care for type two diabetes patients with macrovascular complications is three times higher than care for those without complications (Van Dieren et al., 2010). Microvascular complications such as retinopathy, neuropathy and vasculopathy also contribute significantly to the economic burden of type two diabetes as they are

a major cause of blindness and vision problems, renal failure and the need for lower limb amputation in people with type two diabetes (AIHW, 2007b). Therefore, effective type two diabetes management is essential not only for prevention of complications and promotion of health and well-being but also for reducing escalating health care costs which are reported both in Australia (AIHW, 2012b) and globally (IDF, 2012).

1.1.5 Type Two Diabetes Management

Given the chronic nature of type two diabetes, effective management is essential in order to lessen the individual and economic impact. This section will overview the aims of type two diabetes management in general. Type two diabetes management at a population level, in relation to national and international health priorities, and at an individual level, in relation to the management behaviours which individuals are recommended to follow, will also be discussed. This section will clarify the term self-management and provide context for the need to investigate type two diabetes self-management.

Aims of Type Two Diabetes Management

Improved management of type two diabetes at a population level, is a global, national and local health priority. Internationally, the World Health Organisation (WHO) has developed an Action Plan for the Global Strategy for the Prevention and Control of Non-Communicable Diseases (2008-2013) (WHO, 2008). This Action Plan stipulates a need to assess existing models of self-care for people with non-communicable diseases, such as cardiovascular diseases and diabetes, and to promote research into the prevention and management of these non-communicable diseases (WHO, 2008). In terms of the management of type two diabetes - a non-communicable,

preventable disease - the Plan stipulates an aim of strengthening health care through the development of evidence-based guidelines, and re-orienting health care systems such that they better account for the chronic nature of the illness (WHO, 2008).

Diabetes has also been targeted as a priority area at a national level by the Australian Institute of Health and Welfare (AIHW, 2012a). Furthermore, improved type two diabetes management is a priority at Australian state levels (for example, by SA Health and the Victorian Department of Health) (Government of South Australia, 2012). The influence of this emphasis is evident in South Australia's 2012 Strategic Plan which aimed to increase by 5%, the number of people living with chronic disease, such as diabetes, who self-report their health status as 'good', 'very good' or 'excellent', on the South Australian Monitoring System (which measures self-assessed health status) (Government of South Australia, 2012).

At an individual level, the aim of type two diabetes management is to improve duration and quality of life for patients (Diabetes Australia, 2011). Management is highly individual as the characteristics of each individual patient's type two diabetes vary considerably (Diabetes Australia, 2011), but, in general, type two diabetes management aims to relieve any acute symptoms of the disease, optimise glycaemic control, control other risk factors for complications, treat existing complications and maintain preventative activities (Diabetes Australia, 2011).

Type Two Diabetes Management Recommendations

Type two diabetes management aims are achieved through medical monitoring and self-management. These will be discussed here. Partnerships between patients and health professionals manage type two diabetes through medical monitoring and annual reviews of management. There is an extensive evidence base for optimal medical management of type two

diabetes (International Diabetes Federation Clinical Guidelines Task Force, 2005). The International Diabetes Federation (IDF) recommendations suggest that type two diabetes care should be collaborative and patient-centred (International Diabetes Federation Clinical Guidelines Task Force, 2005), and the Australian General Practitioner's guide to management suggests a multi-disciplinary team which may include a diabetes educator, dietician, podiatrist, endocrinologist, exercise professional, general practitioner, ophthalmologist, oral health professional, mental health professional and pharmacist (Diabetes Australia, 2011). International Diabetes Federation (IDF) recommendations stipulate specific guidelines for health professionals to deliver optimal care. The IDF recommendations suggest that people with type two diabetes receive ongoing culturally-relevant education from appropriately trained multi-disciplinary health professionals, periodic well-being assessments and appropriate referrals to mental health professionals where needed, clinical monitoring of blood glucose levels, and advice on lifestyle modification, which includes access to relevant health professionals such as dietitians. These guidelines also stipulate that people with type two diabetes should receive advice and assistance regarding self-monitoring of blood glucose levels and taking oral and insulin therapy, regular blood pressure monitoring and annual assessment of cardiovascular risk, eye and foot examination and screening for nerve damage (International Diabetes Federation Clinical Guidelines Task Force, 2005).

Chronic illness management models often aim to increase the involvement of the patient in decision making and goal development processes whilst teaching them the skills needed to adhere to a management plan, thus increasing adherence and promoting positive health outcomes (Lorig, Holman, Laurent, Gonzalez, & Minot, 2000), and reducing the burden on health systems (Newman, Steed, & Mulligan, 2004). Self-management implies that the patient is active in their treatment (Creer, Renne, & Christian, 1976). However chronic illness self-management is a poorly

defined concept (Lorig & Holman, 2003), with no 'gold standard' definition available (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Therefore, there are many definitions used for research purposes. For the purposes of the research in this thesis, the definition proposed by Clark et al. (1991) will be adopted, whereby self-management of chronic conditions is conceptualised as:

day-to-day tasks an individual must undertake to control or reduce the impact of disease on physical health status. At-home management tasks and strategies are undertaken with the collaboration and guidance of the individual's physician and other health care providers (Clark et al., 1991, p. 5).

This research will specifically focus on the self-management of type two diabetes. Type two diabetes self-management requires individuals to partake in many behaviours such as taking medication as prescribed, attending health professional appointments, self-monitoring blood glucose levels, altering diet, exercising and regular foot care (Maddigan, Majumdar, & Johnson, 2005).

Previous psychological research has alluded to the complexity and restrictiveness of type two diabetes self-management as it is influenced by numerous individual, social and environmental factors. It has been noted that diabetes management regimens require lifestyle modification, and treatments which can be intrusive and inconvenient (Lerman, 2005). The magnitude of burden which type two diabetes management places on an individual's life has been highlighted by many researchers, such as Gonder-Frederick and colleagues (2002), who stated:

From a psychobehavioural perspective, it is difficult to imagine any other illness [as diabetes] that places the same level of demand on patients to self-monitor and self-regulate their own health status (Gonder-Frederick et al., 2002, p. 613)

Therefore, it is important to investigate factors that prevent adherence to self-management recommendations.

1.2 Rural Health

So far, this chapter has discussed the causes, diagnosis criteria, complications and management of type two diabetes. Given the rural focus of the research in this thesis, it is now important to consider rural and remote health. In order to provide a background for the investigation of barriers to type two diabetes self-management in rural and remote areas, this section will discuss the measurement and definition of remoteness, rural health in general, and diabetes in rural and remote areas. This discussion will focus on Australian rural and remote health in line with the aims of the current research.

1.2.1 Measurement of Rurality

The measurement of rurality and classifications of rural and remote areas present a challenge for researchers. Given that in 2009, 64% of Australians lived in major cities and 36% of the population lived outside of major cities (AIHW, 2010), a definition of 'rural' is conceptually important in order to define the parameters of the current research. However, a review of rural type two diabetes self-management literature has noted that, although it is conceptually important, often the concept of 'rural' is not defined in research (Williams Utz, 2008). One definition of remoteness, which has been adopted by the Australian Institute of Health and Welfare (AIHW), is:

the remoteness of a location can thus be measured in terms of how far one has to travel to centres of various sizes (Department of Health and Aged Care & GISCA (National Key Centre for Social Applications of Geographic Information Systems), 2001, p. 11).

Several avenues for measuring rurality are available to researchers. These allow researchers to compare health indicators across a range of areas with varying accessibility and remoteness scores (AIHW, 2004). Currently, three main classification systems are utilised for measuring rurality in Australia; the Rural, Remote and Metropolitan Areas (RRMA) classification, the Accessibility/Remoteness Index of Australia (ARIA) classification, and the Australian Standard Geographical Classification (ASGC) Remoteness Areas. Other measures are used internationally, such as The Index of Relative Rurality (Waldorf, 2006), in the United States. These are geographic classifications which have been used to group areas with similar characteristics together for the purpose of describing regional differences (AIHW, 2004). Each of the classifications will be explained below and the strengths and weaknesses of each will be discussed. The classifications are also summarised in the table below (Table 1).

Table 1: Australian rurality classifications

Name	Developer	Data source/rationale	Classifications
RRMA	Department of Primary Industries and Energy Department of Human Services and Health	Categorical measure based on direct distance from Statistical Local Area to centres of varying size	Metropolitan, Rural and Remote (each with sub-categories)
ARIA	Commonwealth Department of Health and Aged Care	Continuous (0 to 12) measure of remoteness based on road distance to each of four service centres of different size	Highly accessible, accessible, moderately accessible, remote, very remote
ASGC	Australian Bureau of Statistics	Continuous (0 to 15) measure of remoteness based on road distance to each of five service centres of different size	Major cities, inner regional, outer regional, remote, very remote

The Rural, Remote and Metropolitan Areas (RRMA) classification was developed by the Department of Primary Industries and Energy and the Department of Human Services and Health in 1994 (AIHW, 2004), as the first widely available Australian remoteness classification. The RRMA

classifies Statistical Local Areas (SLAs), which are a spatial unit used by the Australian Bureau of Statistics (ABS), into one of three classifications; 'metropolitan' (including 'capital cities' or 'other metropolitan centres'), 'rural' (including 'large rural centres', 'small rural centres' or 'other rural areas') and 'remote' (including 'remote centres' and 'other remote areas') (AIHW, 2004).

The Accessibility/Remoteness Index of Australia (ARIA) classification system was developed by the Commonwealth Department of Health and Aged Care in 1997, and is based on a continuous measurement of remoteness developed by the National Key Centre for Social Applications of Geographic Information Systems. ARIA relies on the distance by road to centres of various sizes as a proxy for remoteness. The ARIA classification system provides a continuous measure of remoteness (from 0 to 12), and classifies areas into 'highly accessible', 'accessible', 'moderately accessible', 'remote' and 'very remote'. ARIA scores and classifications can be updated as populations change (AIHW, 2004).

The Australian Standard Geographical Classification (ASGC) Remoteness Areas were developed by the ABS in 2001, and are based on an updated version of the ARIA, the ARIA+, which is determined by road distances to the closest of each of five classes of service centres. The ASGC remoteness categories ('major cities', 'inner regional', 'outer regional', 'remote' and 'very remote') are given to census collection districts based on the average ARIA+ score within the collection district.

It has been suggested that the methodologies underlying the ARIA and ASGC classifications are better than those underlying the RRMA (AIHW, 2004). The RRMA classification system draws upon distance in a straight line from the point of interest to service centres in conjunction with a measure of remoteness from other people (Department of Primary Industries and Energy & Department of Human Services and Health, 1994). The ARIA and ARIA+ classification systems are based on the distance, by road, to service centres, and produce an

index, whereby every square kilometre has an index score, thus providing the flexibility to assign an index score to any area. The use of the centre points of Statistical Local Areas to calculate RRMA scores does not allow this flexibility, and is thus a less precise measure of remoteness than the ARIA and ASGC indexes. However, the ARIA classification system takes a purely geographical approach to measuring remoteness. As a result, very dissimilar locations may sometimes have very similar ARIA index scores (AIHW, 2004). Furthermore, a significant criticism of the ARIA index score is that it assumes equivalent road conditions, and also does not take into account the reduced access to public transport options in rural and remote areas (Australian Institute of Health and Welfare, 2004). However, these limitations are applicable to all three measurement options considered here. Compared with the RRMA, the ARIA is better at differentiating between areas in terms of accessibility/remoteness. The ARIA classification has also been suggested to be quite robust, in that the indexes are based on the distance by road to each of the four urban service centres of different size (based on population size), so classifications change only when there is a large change in the population of one or more of the service centres (AIHW, 2004). The ASGC builds upon the advantages of the ARIA, as it has a scale ranging from 0 to 15, and thus defines the remote areas more precisely. However, the ARIA+ categorisations are more susceptible to change and not as robust as the ARIA due to the additional category added to the ARIA+.

The ARIA and ASGC classifications are predominantly used to provide demographic information about populations in health research. The Australian Population and Migration Research Centre reports the ARIA+ as the most widely used geographical approach to defining remoteness (Australian Population and Migration Research Centre, 2013). The classification of remoteness in the research presented in this thesis was intended to be a robust, continuous measure, rather than a categorical measure; therefore, ARIA index scores were chosen to measure remoteness.

1.2.2 Rural Health

It is important to consider rural health in general in order to provide context for a discussion of type two diabetes in rural and remote areas of Australia. This discussion will subsequently provide support for the need for research into rural and remote type two diabetes.

People living in rural and remote areas of Australia generally have poorer health than those living in major cities (AIHW, 2008b). This is also the case in other countries, both developed, such as America (Hartley, 2004), and developing, such as India (Joshi et al., 2006). People in rural and remote areas are more likely to be of lower socio-economic status, which is associated with poorer health outcomes and greater risk factors for illness. They are more likely to smoke, be physically inactive, eat insufficient amounts of fruit and vegetables, be overweight or obese (National Rural Health Alliance, 2011), and report drinking alcohol in quantities which could produce short term harm (AIHW, 2008b). It has also been noted that people in more remote areas often have more limited access to factors which facilitate health, such as employment opportunities, education, income, and access to goods and services (AIHW, 2008b).

Self-reported rates of depression, anxiety, heart disease and diabetes are similar in rural, remote and metropolitan areas of Australia (AIHW, 2008b); however, it has been noted that people in rural and remote areas are less likely to be diagnosed with these conditions (AIHW, 2008b) and, thus, may be less likely to self-report their presence. Therefore, it is likely that self-reported data in rural and remote areas under-report prevalence (AIHW, 2008b). In addition, people living in rural and remote areas are significantly less likely to self-report having good or excellent health than those living in major cities, and more likely to report fair or poor health (AIHW, 2008b).

Rates of hospitalisation are also higher in people living in remote areas, compared with people living in metropolitan areas (AIHW, 2008b). Hospital separation rates, which act as a proxy for access to health services, and provide a measure of community morbidity when investigating the burden of disease, are also significantly higher for people living in remote areas than for those living in major cities (AIHW, 2008b). Furthermore, life expectancy decreases with remoteness and death rates increase significantly with increased remoteness for both males and females (AIHW, 2008b). In 2002-4, death rates were higher for people in regional (1.1 times higher), remote (1.2 times higher) and very remote areas (1.7 times higher) than for people living in major Australian cities (AIHW, 2007b). Circulatory diseases and injury are significant contributors to this excess death (AIHW, 2007b).

1.2.3 Rural Health Services

In discussing rural and remote health, it is important to discuss rural health services, as poorer rural health is often attributed, in part, to reduced access to services. People living in rural and remote areas have poorer access to preventative health services due to reduced availability of health professionals in allied health fields such as podiatry, dietetics and optometry (AIHW, 2008b). Many challenges to providing comprehensive health and disability services in rural and remote areas have been noted. These include geographical, socioeconomic, cost, transport, access and acceptability issues (National Health Committee, 2010). It has been reported that health services in rural areas globally are inadequate and difficult to access and that health policy makers often lack an understanding of the needs of people in rural areas as different from those in metropolitan areas (Strasser, 2003).

Whilst the per-person supply of general practitioners and nurses across Australian regions in 2005-6 was relatively evenly spread with remoteness, the supply of specialist medical practitioners decreased with remoteness (AIHW, 2008b). Therefore, it follows logically that people living outside of major cities access less specialised services, such as disability support services, than those living in major cities (AIHW, 2008b). In addition, both nurses and medical practitioners in rural and remote areas were reported to have worked longer hours than those in metropolitan areas in 2005 (AIHW, 2008b), and public hospitals in rural and remote areas are less likely to be accredited for compliance with recommended standards (81% and 70% respectively) than those in major cities (99%) (AIHW, 2008b). These data indicate that the available services, on the whole, are not of a comparably high standard, in rural and remote areas.

It has previously been noted that behavioural health research has focused primarily on urban areas, and has, to a certain extent, neglected to consider the factors underlying an increase in need for services, and the inability of current services to meet the needs of people, in rural and remote areas (Heflinger & Chrisrens, 2006). Health care services which are available in rural and remote areas may differ significantly from those in urban areas, as may the barriers preventing people from adhering to treatment and health recommendations. For this reason, it is important to investigate factors which influence the management of chronic illnesses, such as type two diabetes, specifically in rural and remote areas.

1.2.4 Indigenous Australian Health

Although the research presented in this thesis does not focus specifically on Indigenous Australians, in discussing rural health in Australia, it is important to consider this population. Indigenous Australians make up about 2.4% of Australia's population, however, this population is

over-represented in remote (27% of population) and very remote (45% of population) areas (AIHW, 2008b).

It is widely reported that Australians from Aboriginal and Torres Strait Islander backgrounds have poorer health than non-indigenous Australians. Firstly, mortality rates are significantly higher. Age-standardised death rates for indigenous people were 1.8 times higher than those for non-indigenous people between 2004 and 2008 (Thomson et al., 2011). In addition, prevalence of chronic conditions such as type two diabetes in some Australian indigenous communities are among the highest in the world (Australian Institute of Health and Welfare, 2007a). Indigenous Australians are three times more likely to have diabetes reported as the underlying cause of death as non-indigenous Australians (Gajanayake, Hodgson, & Mathur, 2000). Furthermore, prevalence of self-reported diabetes in the indigenous population increases significantly with remoteness, with prevalence rates in remote areas up to 5.5 times those in major cities (AIHW, 2008b), and diabetes death rates for indigenous Australians living in remote areas, in 2002-04, 12.5 times higher than those for indigenous Australians living in major cities (AIHW, 2007b).

Poorer health in rural and remote areas of Australia is partly, but not fully, explained by a higher proportion of people of indigenous background (AIHW, 2008b). There is a large body of research which investigates the determinants of health in indigenous Australian populations (Thomson et al., 2011) and it is important that research into the disparities in health outcomes and inequities in health resources in this population are investigated in and of themselves. Context-based research is especially important given suggestions that management needs to be investigated in specific cultures and populations in order to design effective interventions for those populations and cultures (Glasgow, Toobert, & Gillette, 2001). Therefore, this research will be focused on aspects of living in rural and remote areas which may influence type two diabetes

management outcomes, rather than focusing on indigenous Australians specifically. Participants in this study were not asked whether they were of indigenous background or not, as it was not the intention of this research to investigate factors specific to indigenous type two diabetes management. However, previous evidence suggests that indigenous Australians are less likely to participate in research than the rest of the population (Donald et al., 2012).

1.2.5 Diabetes in Rural and Remote Areas

Rates of type two diabetes are higher in people living in regional, remote and very remote areas when compared with the general Australia population (AIHW, 2010). Women in rural and remote areas report significantly more diabetes than those in major cities, whilst males in rural and remote areas report slightly (but not significantly) less diabetes than those in major cities (AIHW, 2008b). In addition to the increase in diabetes prevalence, diabetes-related hospitalisations are two and three times higher in rural and remote areas, respectively, than for people in metropolitan areas (AIHW, 2008b), indicating that diabetes has a larger impact on the health of people in rural and remote areas. It has also been reported that diabetes as the underlying cause of death is higher in remote areas (5%) than in rural (2.4%) and urban (2.1%) areas (percentage of deaths caused by diabetes) (AIHW, 2008b). Death rates for people with diabetes in 2002-04 were higher in regional (1.1 times higher), remote (2.1 times as high) and very remote (4.1 times as high) areas than for people with diabetes in major cities (AIHW, 2007b). Furthermore, hospital separation rates indicate higher death rates due to both diabetes and renal failure (a common complication of poorly managed diabetes) in remote areas than urban areas (AIHW, 2008b), suggesting that diabetes self-management is poorer in rural and remote areas than in major cities.

It has also been noted that people in rural and remote areas have reduced access to factors which may facilitate self-management, including factors which promote exercise, such as walking and cycling paths, and reasonably priced foods which are appropriate for people with type two diabetes (AIHW, 2008b). Therefore, given the higher prevalence, hospitalisation, and death rates related to type two diabetes in rural and remote areas of Australia, it is important to investigate the mechanisms by which poorer type two diabetes-related health occurs in these areas.

1.3 Summary

In summary, this chapter has provided a definition of type two diabetes, an overview of type two diabetes diagnosis criteria, prevalence and consequences. Rural and remote health has also been discussed both generally, and more specifically in relation to type two diabetes. This chapter provides the background for Chapter 2 which discusses the literature examining adherence to type two diabetes management recommendations and barriers to adherence.

Chapter 2: Previous Research into Type Two Diabetes Self-Management

The previous chapter defined type two diabetes, introduced the problem of increases in type two diabetes rates both in Australia and globally, and highlighted consequences of poorly managed type two diabetes. Chapter 1 also provided an overview of current recommendations for effective self-management of type two diabetes. The aims of this research are to identify barriers to effective type two diabetes self-management in rural and remote Australia, to adapt and validate a tool for measuring these barriers, and to examine the impact of barriers to self-management on diabetes-dependent quality of life. Therefore it is important to discuss the existing literature related both to adherence to self-management recommendations and to the barriers which prevent patients from managing effectively. This chapter will begin with a definition of the term 'adherence', and discuss adherence to type two diabetes self-management recommendations. The chapter will then discuss previously identified factors which impede effective self-management. By discussing the previous literature in this area, this chapter will provide a background for the research presented in this thesis, which examines barriers to effective self-management Australian contexts.

2.1 Adherence

As discussed in Chapter 1, effective self-management is imperative in slowing the progression of type two diabetes and preventing the development of complications such as microvascular and macrovascular diseases. Self-management recommendations vary between individuals, however, lifestyle changes, which include self-monitoring blood glucose levels, taking medication and changes to diet and exercise, are commonly recommended. Therefore, in exploring self-management of type two diabetes, a key issue is to understand the health

behaviours of patients which are central to these lifestyle changes. Specifically, research has sought to understand why people with type two diabetes follow (or not) self-management recommendations.

2.1.1 Defining Adherence

In describing patient health behaviours, the term 'compliance' has been commonly used in previous medical science research. However, it has been suggested that this term is paternalistic, and focuses too heavily on patient behaviour as the source of non-compliance, while negating the impact of health professionals (Lutfey & Wishner, 1999). Therefore, the term 'adherence' has been more recently used to describe patients' health behaviours. The term 'adherence' is preferable to the term 'compliance', as it has been suggested that it more easily encompasses broader social and personal issues, rather than simply considering the medical goals at hand (Lutfey & Wishner, 1999).

The term 'concordance' has been used most recently in health behaviour research, as it implies that the health professional and patient come to an agreement about the course of action to take (Aronson, 2007). However, it has been noted that use of the term 'concordance', in health literature and by health professionals, has the potential to place responsibility for making management decisions on patients (Aronson, 2007). In addition, researchers have expressed concerns that completely joint decision-making may not be the preference for many patients. This notion is supported by data from the Medical Outcomes Study (MOS), a four year observational study with people with a variety of illnesses, which have indicated that most patients (69%) would prefer their health professionals to make their medical decisions (Arora & McHorney, 2000). The

term 'adherence' has thus been suggested to be an appropriate middle ground between 'compliance' and 'concordance' (Aronson, 2007).

Whilst a definition of adherence is important for self-management research, a review of literature has suggested that there is no simple definition of adherence in relation to diabetes management, primarily due to the changing and multifaceted nature of diabetes management (Hearnshaw & Lindenmeyer, 2005). The World Health Organisation (2003) has adapted definitions of both Haynes (1979) and Rand (1993) to develop a definition of the term 'adherence', in relation to health behaviours in general:

the extent to which a person's behaviour - taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider (World Health Organisation, 2003, p. 3)

This definition will be used from here on.

2.1.2 Adherence to Type Two Diabetes Management Recommendations

Adherence to self-management regimens is poor across chronic conditions. A systematic review has suggested that patient adherence to chronic self-management regimens is an average of 50% in developed countries, and even lower in developing countries (Haynes, McDonald, Garg, & Montague, 2002). In addition, a 30-year review of available adherence literature highlights the considerable financial burden of non-adherence to medical advice and regimens generally (Vermeire, Hearnshaw, Van Royen, & Denekens, 2001).

As highlighted in section 1.1.5, good adherence to type two diabetes treatment recommendations has been shown to be effective in improving patient quality of life and life

expectancy, and in reducing complications associated with the disease (WHO, 2003). However, it has been reported that less than 2% of people in the United States who have diabetes achieve the level of self-care recommended by the American Diabetes Association (Beckles et al., 1998). Specifically, it has been reported that in developed countries, such as the United States (Karter, Ferrara, Darbinian, Ackerson, & Selby, 2000) and in developing countries, such as India (Shobhana, Begum, Snehalatha, Vijay, & Ramachandran, 1999), over two thirds of people with type two diabetes do not self-monitor their blood glucose levels as often as recommended. In addition, whilst initial medication adherence in type two diabetes populations has been reported at between 70 and 80% (Bocuzzi et al., 2001), reports suggest that at 12-month follow up only 15% of patients are taking medications as prescribed (Dailey, Kim, & Lian, 2001), thus indicating difficulties maintaining medication adherence. Reports of adherence to dietary and exercise recommendations have indicated that around half of people in the United States with type two diabetes followed their meal plans, and only about one quarter followed their exercise plans (Shultz, Sprague, Branen, & Lambeth, 2001). In comparing type two diabetes self-management behaviours, authors of a literature review have suggested that patients' adherence to dietary change recommendations were the poorest of the lifestyle change recommendations (Pun, Coates, & Benzie, 2009).

Finally, in light of reports that adherence to recommendations is low for people with type two diabetes, it is important to note that reports suggest that in Europe, only 28% of diabetic patients achieved glycaemic control (Liebl et al., 2001). Practitioners have identified poor patient adherence to recommended lifestyle changes as a major barrier to achieving overall type two diabetes management goals (Brown et al., 2002). Furthermore, it has been reported that health care professionals are aware of poor adherence, and have reported poorer adherence than

patients themselves report in telephone and face to face interviews (Peyrot et al., 2005), thus suggesting discordance between patient and health professional reports.

The World Health Organisation (2003) has identified five interacting dimensions which affect adherence to long term therapies. These have been labelled social/economic, therapy-related, patient-related, condition-related and health system/health care team factors. Social/economic factors include, but are not limited to, socio-economic status, literacy level, education level, living conditions, social networks and cultural beliefs about health and illness. Therapy-related factors include the complexity of the medical regimen, previous experiences with therapies, frequency of changes to the regimen, immediacy of treatment side-effects and benefits and the availability of the health professional team. Patient-related factors relate to the expectations, resources, knowledge, attitudes, and beliefs of the patient. Condition-related factors relate to the demands that the particular illness places on the patient, for example, needing to self-monitor blood glucose levels in type two diabetes management, the rate of progression of the illness, the severity of the symptoms and presence of complications. Health system/health care team factors relate to the development of health systems, patient-provider relationships, medication-distribution systems, models of care for the illness and health insurance plans (WHO, 2003). All of these interacting factors need to be taken into account in the investigation of adherence to chronic illness self-management recommendations. The influence of factors at each of these levels on type two diabetes management have been investigated, and will be discussed in section 2.2.

2.2 Facilitators and Barriers to Effective Self-Management

Self-management of type two diabetes can be quite complex (Maddigan et al., 2005), is highly individual, and can involve modification of a range of health and lifestyle behaviours. Effective self-management is essential for preventing type two diabetes complications. However, as highlighted in the previous section, regimen adherence in people with type two diabetes is poor, especially for lifestyle change recommendations such as diet and exercise (Peyrot et al., 2005). Therefore understanding factors which prevent effective self-management is a vital part of improving type two diabetes outcomes (Pun et al., 2009).

The research in this thesis aims to investigate barriers to adhering to self-management recommendations. Barriers to effective self-management can be conceptualised as factors which impede diabetes self-management, or the improvement of diabetes-dependant quality of life (Glasgow et al., 2001). The literature describing barriers to effective type two diabetes management is broad and complex (Glasgow et al., 2001). For example, literature examines barriers to specific behaviours (for example, to exercise), in specific contexts (for example, in a Hispanic population), different types of barriers (for example, psychosocial barriers), using varied methodologies (for example, focus groups, surveys), barriers identified by different groups (for example, by health professionals, or by families), and barriers in relation to various psychological constructs (for example, locus of control). This section will overview the literature relating to barriers to effective self-management generally in order to contextualise and inform the current research.

Previous literature has emphasised the complexity of multiple interacting influences on type two diabetes management (Simmons, 2001). Reviews of literature about type two diabetes self-management barriers have organised the barriers in a variety of ways. For example, in a 'From Research to Practice' series published in *Diabetes Spectrum* (2001), researchers wrote sections on 'Personal barriers to care' (Simmons, 2001), 'Cultural Barriers to Care' (Tripp-Reimer, Choi,

Kelley, & Enslein, 2001), 'External Barriers to Diabetes Care' (Zgibor & Songer, 2001), 'Overcoming Physical Barriers to Self-Care' (Coonrod, 2001) and 'Psychosocial Barriers to Diabetes Self-Management and Quality of Life' (Glasgow et al., 2001). Due to the variety and complexity of the available literature, and the aims of the current research, a socio-ecological framework will be used to organise the relevant literature into intrapersonal, interpersonal and organisational barriers to self-management. This framework will also be adopted for the identification of barriers in the current research (as discussed in further detail in section 3.1.2). The current chapter will also discuss the need to investigate the opinions of both health professional and patient opinions in identifying barriers, and review previous research which identifies barriers to effective self-management in rural and remote contexts.

2.2.1 Intrapersonal Factors

Intrapersonal barriers primarily relate to the patient's thoughts, emotions and knowledge (Stokols, 1996). Many intrapersonal barriers to effective type two diabetes self-management have been identified. For example, a systematic review into barriers to exercise in people with type two diabetes identified a lack of priority placed on exercise, issues of motivation, mental health, fears and exercise being perceived as uncomfortable (Korkiakangas et al., 2011). In addition, Glasgow and colleagues (2001) conducted a systematic review of psychosocial barriers to effective type two diabetes management and highlighted a wide variety of barriers. These included attitudes to type two diabetes management, depression, health beliefs, locus of control, reduced self-efficacy and self-esteem, lack of social support, high stress levels, lack of knowledge, and reduced motivation (Glasgow et al., 2001).

Self-management barriers relating to attitudes, motivation, education and knowledge, physical factors and psychological factors will be discussed here, and barriers relating to support and stress will be discussed in the next section which focuses on interpersonal barriers.

Attitude

The importance of a positive attitude in type two diabetes self-management has been emphasised in numerous previous studies, and linked to a variety of type two diabetes self-management health outcomes (R. M. Anderson, Donnelly, & Dedrick, 1990). In one study which utilised questionnaire data, a positive attitude towards self-management was identified as the most important predictor of self-management (de Weerd, Visser, Kok, & Van der Veen, 1990). More recently, a correlational study has reported that attitudes measured by the Diabetes Attitudes Scale (DAS-3) (R. M. Anderson et al., 1990), about the severity of type two diabetes and the importance of tight blood glucose control, have been associated with self-care behaviours (Huang, Liu, Zhang, & Yao, 2013). In qualitative research based on interviews, patients have also identified cultivating a positive attitude as conducive to learning more about the disease, and important to effective self-management (Nagelkerk, Reick, & Meengs, 2006). In relation to specific behaviours, self-reported survey data indicate that a belief that medication is beneficial was associated with increased adherence to medication regimens (Farmer, Kinmonth, & Sutton, 2006). In addition, a positive attitude in relation to taking responsibility for type two diabetes has been associated with better glycaemic control, dietary self-management and fewer diabetes-related complications (Masaki, Okada, & Ota, 1990). Importantly, sufficient diabetes specific knowledge has been associated with a positive attitude (de Weerd et al., 1990).

Motivation

High levels of motivation have been proposed to be essential for effective type two diabetes self-management. For example, motivation has been significantly associated with adherence to dietary recommendations (Senecal, Nouwen, & White, 2000). Both health professionals and patients have linked motivation with taking responsibility for health. When describing facilitators of effective management, people with type two diabetes have highlighted the importance of assuming responsibility for their own health as imperative (Nagelkerk et al., 2006). Additionally, family practitioners have identified the ability of a patient to take control of, and assume responsibility for, their disease management as a facilitator of successful diabetes management (Brown et al., 2002).

It is not surprising then, that a lack of motivation has been identified as a hindrance to self-management. Practitioners have expressed frustration about less than optimal management of type two diabetes and suggested that it is very difficult to motivate patients to partake in self-management behaviours (Wens, Vermeire, Van Royen, Sabbe, & Denekens, 2005), identifying a lack of patient motivation as the primary cause of reduced adherence to lifestyle recommendations (Brown et al., 2002). Practitioners have also reported that many patients prefer their doctor to take action, such as prescribing medication, than participate in the ongoing lifestyle changes (such as dietary and exercise changes) required for effective self-management of the disease (Brown et al., 2002). Patients in an Iranian study have also identified a lack of motivation, combined with a lack of self-efficacy, as major barriers to self-management behaviours, with patients reporting that they simply cannot be bothered partaking in self-management behaviours (Shakibazadeh et al., 2011). However, whilst a lack of motivation is readily identified, health professionals have reported that they have not had adequate training in motivating patients to change their lifestyle (Larme & Pugh, 1998).

Health professionals have proposed a range of causes for reduced motivation to self-manage. For example, practitioners have attributed reduced motivation to self-manage type two diabetes to confidence in modern medicine's ability to deal with the illness (Wens et al., 2005). Health professionals have also proposed a lack of acceptance of having diabetes as a cause of reduced motivation, subsequent poor patient self-management and long term complications from the disease (Brown et al., 2002). The nature of the benefit derived from making complex lifestyle changes, whereby the patient does not see any immediate benefit from their effort, has also been suggested to reduce motivation to self-manage (Van den Arend, Stolk, Krans, Grobbee, & Schrijvers, 2000). A lack of motivation has been also attributed to patients' tendency to downplay the consequences of having diabetes and consequent need to self-manage, thus contributing to ineffective self-management (Brown et al., 2002). This tendency for patients to downplay the potential seriousness of the illness, and to dissociate themselves from being 'diabetic' was also identified in qualitative analysis of in-depth patient interviews (Lawton, Peel, Parry, Araoz, & Douglas, 2006). However, in other studies, patients have reported having diabetes as fairly serious for their health (Lerman et al., 2004). These notions of perceived susceptibility and severity of the illness resonate with the central tenets of the Health Belief Model, which explains health behaviours as a product of beliefs about susceptibility, perceived severity, perceived benefits of taking action, perceived costs of taking action, confidence in their ability to successfully perform the action, and cues to action. The use of this model in type two diabetes self-management research will be briefly discussed in section 3.1.1.

Education and Knowledge

Traditionally, knowledge has been seen as essential for effective self-management of health. Therefore, patient education is seen as a fundamental part of management, and essential

for effective self-management (Clement, 1995). In focus groups, people with type two diabetes have identified participating in group education, which encourages discussion with other diabetes sufferers, as important for successful self-management (Nagelkerk et al., 2006). In relation to type two diabetes self-management, having diabetes-specific knowledge has been associated with increased dietary, blood glucose testing and exercise self-management behaviours (Persell et al., 2004) and decreased blood glucose levels (Al-Qazaz et al., 2011), whilst a lack of knowledge has been associated with increased presence of complications (Pace, Ochoa-Vigo, Caliri, & Fernandes, 2006).

Health professionals have suggested that a deficit in patient knowledge about type two diabetes and the requirements of effective management, inhibits self-management (Brown et al., 2002). Furthermore, barriers relating to health beliefs and diabetes knowledge have been shown to significantly predict self-reported self-management for diet, exercise and glucose testing behaviours (Lerman et al., 2004). Patients have also emphasised the importance of knowledge in self-management. For example, in relation to diet, patients have identified a lack of knowledge about choosing and preparing appropriate foods, as leading to poorer dietary adherence (Mathew, Gucciardi, De Melo, & Barata, 2012). Patients have also reported that they receive too much information about medical management, and not enough information about how to self-manage effectively at doctor appointments (Burke, Earley, Dixon, Wilke, & Puczynski, 2006). This echoes the claims of a review of research which states that diabetes education provided by health professionals includes too much detail about the pathophysiology of the disease, and too little information about daily self-management behaviours and recommendations (Tripp-Reimer et al., 2001).

Traditionally, within chronic illness management, there has been an assumption that with the appropriate knowledge, patients will take up effective self-management (Thorne & Robinson,

1988). However, whilst knowledge is important for self-management, it has been noted that good knowledge is not necessarily enough to improve self-management when other barriers exist (Simmons, 2001). Furthermore, a systematic review has both supported this notion, reporting that knowledge alone is not enough to produce adherence to recommendations if other barriers are present, and proposed that the links between knowledge and health outcomes are inconsistent and need further investigation (Nam, Chesla, Stotts, Kroon, & Janson, 2011).

Physical

Physical barriers to self-management relate to factors that are associated with the illness as well as the factors which are not associated with the illness. Factors related to type two diabetes include physical side-effects of diabetes and its management and the long term health effects of the illness. Non-diabetes related factors include other physical difficulties that are independently present. In considering the influence of physical factors on diabetes self-management, it is important to note that people with diabetes are reported to have significantly more physical disabilities than those without diabetes (Gregg et al., 2000).

Physical obstacles to self-management have been identified in a variety of contexts. Participants in an Iranian qualitative study identified faintness, caused by diabetes, as the most important physical barrier to exercise and diet self-management behaviours. Pain and illness resulting from their diabetes were also identified as a major barrier to attending appointments (Shakibazadeh et al., 2011). Issues of physical health have also been identified as important barriers to exercise in a study of both people at risk of developing type two diabetes and people with type two diabetes (Korkiakangas et al., 2011). In addition, considering the inter-related nature of barriers to self-management, physical factors such as reading problems and poor vision, have

been identified as a cause of reduced diabetes knowledge (Rhee et al., 2005), which, as discussed previously, may lead to poorer self-management. Whilst many physical factors cannot be easily fixed, the use of teamwork, services and adaptive devices which lessen the impact of physical barriers have been suggested to present immediate and effective opportunities for self-management improvement as they are not dependant on systematic or attitudinal change like most other self-management interventions (Coonrod, 2001).

Psychological

The importance of mental health issues, particularly depression and anxiety, as psychological barriers to effective self-management is well established in the literature (Lerman et al., 2004), with some studies reporting that almost all participants suggested that they were depressed about their diabetes (Shakibazadeh et al., 2011). However, as highlighted by Glasgow et al (2001), depression can be seen as a psychosocial barrier or as a product of barriers to effective care, depending on the research questions under study (Glasgow et al., 2001). For the purposes of the current research, depression will be included as a covariate and has therefore been discussed as a consequence of type two diabetes in section 1.1.4 (with the psychological impacts of type two diabetes). The measurement of depression in the current research will be discussed in section 5.2.3.

2.2.2 Interpersonal Factors

Interpersonal factors are those which relate to both formal and informal social supports and networks (Gyurcsik, Spink, Bray, Chad, & Kwan, 2006). The impact of interpersonal factors on type two diabetes self-management generally relates to issues of support. The role of support has

been emphasised in numerous studies, including a meta-analysis which has reported consistency in the links between social support and adherence to health recommendations (DiMatteo, 2004). In general, the role of supportive collaborative relationships with people who promote patient accountability are reported to facilitate effective self-management (Nagelkerk et al., 2006).

Social support has been linked with better health outcomes for a variety of conditions. However, the specific mechanisms by which social support promotes health are not clearly understood (Vitaliano et al., 2001). It has been suggested that the link between social support and health may be mediated by improved adherence to health recommendations (Dunbar-Jacob & Schlenk, 2001). Some authors have suggested that this relationship is likely to be complex, highlighting that causality has not been established (DiMatteo, 2004). Social support has been proposed to buffer stress, and influence health behaviours and emotional well being (Cohen, 1998). Regardless of the causal links, it is important to consider the role of social support in type two diabetes self-management adherence. This section will discuss the importance of support from significant others, family and health professionals in order to present a background for the investigation of these barriers in a rural and remote population in Study 1.

Support

The importance of support from a significant other has been emphasised in previous research on type two diabetes self-management adherence. In an investigation into the experiences of men living with diabetes, whilst participants emphasised the importance of assuming responsibility for management, they also emphasised the role of support from their partners in managing effectively (Koch, Kralik, & Taylor, 2000). In relation to specific self-management behaviours, a study exploring healthy eating in people with type two diabetes

proposed that spousal support reinforced the importance of following recommended diet and improved patient self-efficacy. Specifically, spousal support was suggested to improve adherence to a recommended diet through improving dietary competence, helping the patient to have control over what they eat, being committed to support the patient, providing communication and helping the patient to cope with diabetes (Beverly, Miller, & Wray, 2008). Similar results have been reported for exercise adherence in people with type two diabetes, whereby partners' shared similar illness representations, and significant others' ideas about personal control mediated the links between patients' illness representations and adherence to exercise recommendations (Searle, Norman, Thompson, & Vedhara, 2007).

The role of family support in adherence to self-management recommendations has also been investigated. In a population of Mexican-Americans, living with a family group, rather than only a spouse, was associated with better self-management of diet (Wen, Shepherd, & Parchman, 2004). Higher levels of perceived family support were associated with better exercise and diet self-management (Wen et al., 2004). Support from friends and family has been suggested to improve illness management adherence by safeguarding the patient from the stress of the illness, improving self-esteem and giving practical assistance (Shumaker & Hill, 1991). However, in light of other research, it appears that presence of family and their support can be either positive or negative. For example, patients have identified that family members' food preferences sometimes hinder their ability to follow recommended diets (Burke et al., 2006). Also, patients have reported nagging from family regarding following dietary recommendations, which has mixed effects on their self-management (Mathew et al., 2012). In addition, a lack of family and social support has been identified as an important barrier to effective self-management in older people (Choi, Jang, & Nam, 2008). Therefore, it appears that the relationship between family support and adherence to self-management recommendations is dependent on a range of complex factors.

The quality of relationships between health professionals and patients has been shown to predict chronic illness self-management adherence (Kaplan, Greenfield, & Ware Jr, 1989). Patient satisfaction with patient-health professional interactions has been associated with improved adherence to recommendations (Sherbourne, Hays, Ordway, DiMatteo, & Kravitz, 1992). However, whilst the role of health professionals in medical management is well established, the role of health professionals in supporting patient self-management is not well researched (Thorne & Paterson, 2001). Generally, good patient-health professional communication has been shown to predict improved patient self-management and health outcomes (Dunn, 1990). Another way in which health professional relationships have been suggested to facilitate effective self-management is by building upon interactions with the patient and educating and mobilising the patient's social supports such that they are better equipped to give support (Keeling, Price, Jones, & Harding, 1996). Again, these links between health professional relationships and adherence are complex.

2.2.3 External/Systemic Factors

The previous two sections have focused on factors related to the patient that present difficulties for (or facilitators to) effective self-management. However, it is also important to consider factors which are external to the patient. Zgibor and Songer (2001) have reviewed and identified external barriers to diabetes care. These barriers include a lack of transportation, out of pocket expenses, health insurance costs and work arrangements clashing with opening hours of health services. Furthermore, the authors suggested that many barriers may impact an individual's ability to access care, especially for those who are economically disadvantaged. Given the rural focus of this research, section 2.4 will specifically focus on barriers in rural and remote areas, and so the barriers which relate specifically to this context, namely, transportation and health service

access, will be discussed there in order to avoid repetition. Difficulties relating to finances and time will be discussed in this section.

Financial

The costs of following type two diabetes self-management plans have been identified as a barrier to self-management across a number of behaviours. For example, in a systematic review of barriers to regular exercise among both people at risk of developing, and people diagnosed with, type two diabetes, the costs of regular exercise, and the costs of transport to exercise options, have been identified as particularly salient difficulties (Korkiakangas, Alahuhta, & Laitinen, 2009). Furthermore, patients have suggested that financial factors present a barrier to self-monitoring (Zgibor & Simmons, 2002), and physicians have identified the costs of diabetes medications as prohibitive for some people (Brown et al., 2002).

The effects of financial barriers among people of lower socio-economic status are likely to be more pronounced. In people without health insurance in the United States, it has been reported that 60% do not obtain professional diabetes care following diagnosis (Burge, Lucero, Rassam, & Schade, 2000). Furthermore, a lack of health insurance was associated with inconsistent adherence to advice about medication use (Jerant, Von Friederichs-Fitzwater, & Moore, 2005). Health systems vary globally, and research into the role of knowledge in self-management is inconsistent. However, given the importance placed on health professionals' role in patient education and attaining diabetes knowledge in subsequent self-management and health outcomes, financial factors may present major difficulties for patient self-management.

Time

The effect of time constraints in type two diabetes self-management literature is two-fold. On the one hand, poor self-management is attributed to a lack of time and, on the other hand, the constraints of self-management on patient time have also been noted. This section will briefly discuss the effect of busy lifestyles and the burden of type two diabetes self-management on time.

Many people in western societies report that they are short of time (Dean, Smith, Payne, & Weinman, 2005). A lack of time to manage type two diabetes effectively, due to many factors contributing to busy lives, has also been noted. A lack of time is proposed to inhibit exercise (Sluijs, Kok, & van der Zee, 1993), a behaviour which is often recommended as part of type two diabetes self-management plans. Supporting this claim, time constraints were identified as important barriers to exercise in a recent systematic review (Korkiakangas et al., 2009). In addition, patients have suggested that they do not attend diabetes education classes because the times are inconvenient and the sessions are too long (Nagelkerk et al., 2006).

Patients have indicated that type two diabetes self-management places a burden on their time. The need to gather information about diabetes, partake in self-management behaviours such as blood glucose monitoring, exercise and planning and preparing appropriate foods, and the need to attend appointments (and often wait for delayed appointments), have been identified as burdens on patient time (Burke et al., 2006).

Time is an important and rare commodity in the management of type two diabetes. However, in order to compensate for time constraints, rural patients have identified acquiring self-management resources and maintaining routines and regimes which effectively manage diabetes as important to self-management (Nagelkerk et al., 2006). Thus, time management strategies may

be an important avenue for low cost and effective type two diabetes self-management improvements.

2.2.4 Health Professional and Patient Identified Barriers

Existing literature has identified self-management barriers by drawing upon both health professional and patient opinions. Thus there is a wide scope of literature available. However, patients and health professionals have reported different difficulties. Therefore, when identifying obstacles, it is important to consider these differences in opinion. This section will discuss similarities and differences between barriers identified by patients and health professionals and will discuss the importance of taking both opinions into account. This is particularly important for the research presented in this thesis, which considers self-management barriers from both perspectives.

Physicians have described the management of type two diabetes as a compromise between ideal treatment and outcomes and maintaining the current lifestyle of the patient, and have indicated that they often felt that they had little control over which advice the patient acted upon and which they did not (Helseth, Susman, Crabtree, & O'Connor, 1999). Health professionals have identified many barriers to optimal medical care, including unclear diagnoses, late onset of symptoms, ineffective medications which are difficult to regulate, the complexity of treating people who have multiple illnesses or complex needs, and a lack of resources such as time and money. In addition, health professionals have identified challenges to patient self-management behaviours, including the insidious nature of symptoms leading to reduced impetus to self-manage (Larme & Pugh, 1998).

Whilst both health professionals and patients have identified barriers to effective self-management, it has been noted that health professionals and patients have expressed significantly different attitudes towards patient care (R.M. Anderson, Fitzgerald, Gorenflo, & Oh, 1993). Research has identified important differences in patient and practitioner evaluations of the illness and management goals, whereby patients emphasise strategies for management, and practitioners emphasise medical monitoring and control, such as the need to control blood pressure (L. M. Hunt, Arar, Larne, Rankin, & Anderson, 1998). Patient descriptions of management were embedded in a 'life-world context' (L. M. Hunt et al., 1998, p. 656), whereas practitioner descriptions were embedded in a clinical context (L. M. Hunt et al., 1998). In addition, general practitioners have recognised that their efforts do not always meet the expectations of the patients and, furthermore, that this discordance between expectations may lead to a paternalistic relationship, which in turn may induce anxiety in the patient (Wens et al., 2005). Importantly, it has been noted that management is more effective when there is agreement between patients and practitioners about the goals of management (Heisler et al., 2003).

Given the research which suggests that expectations, attitudes and understandings of type two diabetes management differ between patients and health professionals, it is not surprising that patient and health professional perceptions of barriers to management have been investigated simultaneously. Data collected through a postal questionnaire in a population of urban-living New Zealanders reported that most patients (70%) experienced self-management difficulties. However, patients, doctors and other health professionals identified different barriers as most important to effective management (Simmons, Lillis, Swan, & Haar, 2007). The most commonly patient-reported obstacles related to psychological challenges, particularly the strictness of the regimen, followed by system barriers, with knowledge barriers rated as least important. Physicians also indicated that psychological barriers were important, however, system barriers were rated as most

important by other health professionals. Health professionals and physicians also rated difficulties relating to knowledge, as well as the importance of other conditions, more highly than patients (Simmons, Lillis, et al., 2007). This finding echoes earlier research in which practitioners attributed poor self-management to a lack of knowledge, whilst patients expressed difficulties with access to resources required to make behavioural changes, due to poverty and a lack of social power (L. M. Hunt et al., 1998). An existing literature review has identified differences in self-management difficulties identified by patients and health care providers, with patients reporting factors related to psychosocial issues, physical and environmental factors, whilst health professionals perceived the quality of care provided by health professionals as the most important barrier to care (Pun et al., 2009).

Researchers have emphasised the need to place importance on patient perspectives in order to improve patient quality of life (Simmons, 2001). In addition, the discordance between health professionals, physicians and patients regarding perceptions of barriers has been highlighted as an area for future improvement and investigation. It is important that multiple perspectives are taken into account in order to present a well-rounded account of which factors are important when investigating perceptions of barriers in any given population. Therefore simultaneous investigation of patients' and health professionals' opinions is needed to facilitate shared understanding and enhance management (Pun et al., 2009).

2.2.5 Rural and Remote Contexts

As previously highlighted, people in rural and remote areas typically have poorer health than those in urban areas, both in terms of general health, and in relation to type two diabetes outcomes (Simmons, 2001). Therefore, it is important to investigate barriers to effective self-

management in a rural and remote context. This section will review literature which identifies barriers in rural and remote areas, in order to identify gaps in the existent literature and provide a rationale for the research presented in this thesis.

Many of the barriers to self-management identified in urban contexts, discussed above, have also been identified in rural and remote contexts. For example, as discussed in section 2.2.1, patients and health professionals in a variety of contexts have emphasised the importance of attitude. Patients in a rural Australian qualitative study have identified a proactive attitude towards health and exercise as essential for effective self-management (C. Greenfield, Gilles, Porter, Shaw, & Willis, 2011). Again, in relation to psychosocial barriers, patients and health professionals in a variety of contexts have proposed barriers relating to self-efficacy and health beliefs (Glasgow et al., 2001). Similar barriers have been identified in a rural American context, with patients reporting that feelings of helplessness and frustration, due to being unable to achieve glycaemic control despite following recommended management, impede their self-management (Nagelkerk et al., 2006). With regards to the burden of self-management on lifestyle and time, both urban (see section 2.2.3) and rural living patients have highlighted the inconvenience of self-management, with rural patients attributing poor medication adherence to forgetting to take it, not having it with them, inconvenience of taking medication, and cost of medications, along with not understanding the practitioners' reasons for altering their medication regime (Nagelkerk et al., 2006).

However, although similar barriers have been identified in rural and urban populations, researchers have suggested that the impact of such obstacles may be heightened in rural and remote areas. Knowledge about diabetes has been identified as a barrier to early identification of diabetes in a rural-living Appalachian population in America (Tessaro, Smith, & Rye, 2005), and rural-American patients have identified a lack of knowledge about the specific details of recommendations as inhibiting their self-management (Nagelkerk et al., 2006). Furthermore, while

a lack of knowledge has been highlighted in urban populations, a comparison of urban and rural diabetes care in the United States, has reported lower formal diabetes education in rural patients (Moore et al., 2006). Therefore, it is possible that barriers to diabetes knowledge may be exaggerated in a rural population compared with an urban population, as a result of this lower formal diabetes education. The notion of increased impact of obstacles has been emphasised in a review of literature whereby the authors suggest that people in rural and remote areas experience the same difficulties faced in urban contexts - such as difficulties related to the illness, like strains of lifestyle changes - but may face additional difficulties due to geographical location, a lack of services and societal understandings of illness which lead to victim blaming (Zgibor & Songer, 2001).

Despite claims that people in rural and remote areas face heightened barriers to effective self-management, it has been suggested that more research into the difficulties of type two diabetes self-management and health outcomes in rural and remote areas is needed to better understand these associations (Egede, Strom, & Lynch, 2011). The influence of context in self-management behaviours cannot be underestimated. In their review of literature investigating psychosocial barriers to self-management, Glasgow and colleagues (2001) emphasised the need to investigate "which barriers present the greatest obstacles for which types of patients" (Glasgow et al., 2001, p.33). Therefore, whilst many barriers have been identified in urban contexts, it is important to investigate the factors which present additional hurdles in a rural and remote situation.

Access to Health Services

Although many barriers to effective management have been identified in urban contexts, factors such as cultural beliefs about seeking health care, increased costs of care, reduced

availability of specialists, and increased distance to services combined with a lack of transportation have been identified as further increasing the difficulty of managing type two diabetes in rural and remote areas (Williams Utz, 2008).

As discussed in section 1.1.5, people with type two diabetes would ideally have access to a range of health services, including specialist services which include, but are not limited to, mental health workers, exercise professionals and podiatrists. However, people in rural and remote areas often have reduced access to specialist and allied health professionals (see section 1.2.3). Several important differences between health care in rural and urban contexts have been identified. Reduced access to certified diabetes educators (Zulkowski & Coon, 2005) and specialists (Utz et al., 2006) have been reported in rural and remote areas of America. In a study into the use of health care services by people with diabetes living in rural areas of Pennsylvania, USA, significant differences in the availability of health care providers between the rural and the urban areas were identified as an additional barrier to management in rural populations (Dansky & Dirani, 1998).

Although the Australian public health system provides low or no cost health services (Diabetes Australia, 2012a), an investigation into consumer perceptions of rural health issues, with a random sample of 499 Australians living in rural areas, indicated that the cost of goods and services, including health care, is a major concern for people in rural areas (Bourke, 2001). Consumers reported that they would like more direction about how to access locally relevant information as they require it, rather than be overloaded this information at diagnosis (Bourke, 2001). Importantly, it was noted that the distances travelled to reach health services varied greatly (Bourke, 2001). Furthermore, despite the wide range of characteristics of rural areas included in this study, the economic concerns relating to the costs of health care and other goods and services were generally highlighted as a common theme (Bourke, 2001).

The specific aspects of Australian rural living which impact on chronic illness management have previously been investigated through the use of unstructured interviews (M. FitzGerald, Pearson, & McCutcheon, 2001). In this context, patients with chronic illness reported concern about the lack of availability of specialised health services, and the small number of general practitioners (GPs) in the area which bulk billed (whereby health professionals charge the government health system for the full cost of the service, and the patient pays nothing), thus reducing choice of GPs for those on pensions. In addition to a lack of health services, participants reported that excessive road travel to specialist appointments in the nearest major city (when there was not a visiting specialist available locally) presented a major hurdle to self-managing their health. However, the participants also indicated that living in rural areas had advantages such as the close knit community which provided practical and emotional support (M. FitzGerald et al., 2001).

2.2.6 Gaps in the Current Literature

Whilst few Australian studies have focused on the identification of barriers to effective type two diabetes self-management in rural and remote areas, the importance of examining barriers in a rural context has been highlighted by researchers in the United States (Zgibor & Songer, 2001). Nagelkerk and colleagues' (2006) qualitative study specifically investigated barriers to care in a rural context by allowing patients to freely describe barriers that they face. The researchers therefore gained an understanding of the experiences of managing chronic illness in this context. However, this study was conducted in America, where the health systems are very different to those in Australia. In Australia, public services, such as the National Diabetes Services Scheme (NDSS), provide reduced price medications, self-monitoring equipment and access to specialised health and support services (Diabetes Australia, 2012b). Therefore, the barriers encountered in

Australia at a systems level are likely to be far different than those identified in America. In addition, Nagelkerk and colleagues (2006) did not specify where their participants lived in rural America. As with Australia, it could be expected that rural parts of America may differ significantly from each other in their economic, geographical, environmental and socio-demographic characteristics (National Rural Health Alliance, 2011). As the American rural context was not described, it is possible that aspects which may affect diabetes self-management, such as availability of appropriate food options, access to services and road distances to services, have a different impact in an Australian rural and remote context. This research aimed to bridge this gap in the literature by investigating barriers to self-management in a rural and remote Australian context.

One quantitative study which has researched diabetes care in a rural Australian context investigated health risk factors and self-reported barriers to care through the use of a self-report survey. Most participants (84.5%) indicated that they experienced psychological barriers to management; in addition, most participants reported educational barriers to care (82.1%). The most commonly reported barriers included the asymptomatic nature of the disease, a lack of awareness of available services, and the impact of other conditions (M. FitzGerald et al., 2001). However, as these responses were collected via survey, through a pre-determined list of barriers, it was not possible to allow participants to freely indicate barriers that were relevant to their experiences of management. Therefore this survey method may not have captured the breadth of barriers which exist. One qualitative study conducted with patients in rural and remote Australia has investigated psychosocial barriers identified as important to self-management (C. Greenfield et al., 2011). In this context, patients generally reported knowing what was expected of them in their self-management, and that knowledge was not a barrier to self-management. Rather, it was reported that patients managed poorly because they had other things going on in their life at the time, or that type two diabetes management was not a priority for them (C. Greenfield et al., 2011).

However, while this study allowed participants to freely identify barriers, it was focused only on psychosocial barriers and therefore may not capture the range of challenges, including those related to access and services. This research aimed to address these gaps in the literature when identifying barriers to self-management in rural and remote Australia by allowing both health professionals and people with type two diabetes to freely identify barriers to self-management in semi-structured interviews and a focus group discussion.

2.3 Rationale for the Current Research

Type two diabetes is a major cause of death, disability and disease burden in both developed and developing nations (Zimmet et al., 2001) and the effects of type two diabetes in Australia will continue to escalate while obesity, diabetes incidence and longevity increase (Magliano et al., 2009). However, effective type two diabetes management aims to control blood glucose levels (Diabetes Australia, 2011), thus preventing health complications (Fowler, 2008) and going some way to reduce the burden of disease. Therefore, the effective management of type two diabetes is a global, as well as an Australian, health priority. Both the World Health Organisation and the Australian Institute of Health and Welfare have acknowledged type two diabetes management and prevention as priority areas.

Adherence to self-management recommendations, which aim to promote quality of life and reduce complications, is generally poor due to the complexity and difficulty of the lifestyle changes which are required (Gonder-Frederick et al., 2002). The literature reviewed in the first two chapters of this thesis highlights the need to identify factors which impede type two diabetes self-management. Due to the discordance between health professional and patient accounts of barriers to effective self-management, there is a need for research which encompasses both opinions

simultaneously. In addition, it is important that research methods that allow patients and health professionals to freely identify factors which inhibit or facilitate self-management are used. Given the importance of context in self-management it is also important to investigate the presence of barriers to effective self-management in both rural and urban areas to determine whether there are differences in the barriers which are relevant, and to determine whether these barriers affect people in different areas in different ways.

In addition, deaths and complications arising from type two diabetes in Australian rural and remote areas are higher than in urban areas, a difference which is continuing to grow (Dixon & Welch, 2000). Despite literature which suggests that it is important to investigate barriers to effective self-management in specific contexts, relatively few studies have investigated barriers to effective self-management specific to rural and remote areas of Australia. This research represents an attempt to investigate the factors which impede effective self-management in this specific context. The following chapter will describe the theoretical framework and methods used to conduct the research presented in this thesis.

Chapter 3: Theoretical Background and Methodology

This thesis presents three studies in the context of a mixed method framework. The first study aimed to identify barriers to effective type two diabetes self-management in rural and remote areas of Australia. Many barriers to effective type two diabetes self-management have been identified in previous research. However, as previously highlighted, the investigation of barriers to effective care in specific contexts is imperative in improving self-management (Glasgow et al., 2001), and very few studies have investigated barriers specifically in a rural and remote context. By investigating barriers to effective self-management, as identified by people with type two diabetes, and health professionals, in rural and remote areas of Australia, this research makes an important contribution to the literature about type two diabetes self-management.

The second study aimed to adapt an already validated obstacles questionnaire so that it also took rural and remote barriers in to account, and to validate this adapted version. The measurement of barriers to effective type two diabetes management is important in both research and practice. Therefore, it is not surprising that many measures of obstacles and barriers to effective type two diabetes self-management have been developed. Whilst these measures have been shown to have good validity and reliability in a number of contexts, many have not been validated specifically in populations containing people living in rural and remote areas. Given suggestions that experiences of managing chronic illness are different in rural and remote areas than in urban areas, it is important to develop measures that, firstly, encompass barriers which are relevant to these contexts and, secondly, are validated in the contexts for which they are intended. Therefore by adapting and testing an already validated measure, to include barriers identified in a rural and remote context, this research addressed an important gap in the literature.

The third study aimed to identify the demographic predictors of barriers to self-management, and to identify barriers which predict diabetes-dependant quality of life in both rural and urban areas of Australia. Many investigations into the predictors of quality of life of people with chronic conditions, including type two diabetes, exist. However, very little literature investigates diabetes-dependant quality of life specifically in rural populations. Furthermore, there is a lack of research investigating the relationship between barriers to effective self-management of type two diabetes and quality of life. The final study in this thesis began to bridge these gaps in the literature by providing a comparison of diabetes-dependant quality of life between those living in rural and urban populations and, furthermore, investigated the associations between barriers to effective type two diabetes self-management and quality of life.

This chapter will describe the methods and theories used in this thesis. The chapter will begin by discussing dominant theories in health psychology which are commonly applied to self-management of chronic illnesses. The use of a socio-ecological framework in the current research will then be discussed, and the intended use of the Transtheoretical Model of Change (Prochaska & Velicer, 1997) will be explained. A rationale for the use of a mixed methods approach to health research will then be discussed along with a description of the mixed methodology employed in this thesis.

3.1 Theoretical Background and Framework

A theory is a 'systematic way of understanding events or situations. It is a set of concepts, definitions, and propositions that explain or predict these events or situations by illustrating the relationships between variables' (Rimer & Glanz, 2005, p. 4). Explicit health and behaviour related theories have been developed in order to explain the circumstances under which behaviours are

expected to occur (French, Yardley, & Sutton, 2004), and are useful in design and evaluation of health promotion initiatives and disease management programs (Rimer & Glanz, 2005). It is important to review theories which are commonly used to explain type two diabetes self-management in order to provide a background and rationale for the use of the socio-ecological model of health in the research presented in this thesis.

3.1.1 Health Psychology Theories

Researchers in health psychology have developed many theories which attempt to provide a framework to explain health behaviours such as adherence to health professional advice and self-management. An ecological perspective of health proposes that health behaviours are influenced by a range of inter-dependent factors (Rimer & Glanz, 2005). Theories which attempt to explain type two diabetes self-management at individual, interpersonal and community levels will be overviewed here.

At an individual or intrapersonal level, theories focus on factors such as knowledge, attitudes, beliefs, past experience, skills and concepts of self (Rimer & Glanz, 2005). One of the most dominant models of health behaviours, the Common-Sense Model of Illness Representations, proposes that individuals process information related to their perceptions of the reality of a health threat and their emotional reactions to this health threat simultaneously. Specifically, this model suggests that five central attributes of illness representations influence health behaviour decisions; identity (the individual's ideas about the illness), timeline (the expected time frame of the illness progression), the causation of the stimulus, the anticipated consequences of the health threat and the perceived controllability of the outcomes (Diefenbach & Leventhal, 1996). Meta-analysis of research which drew upon the Common Sense Model of Illness

Representations has reported that this theory can be used reliably to make predictions about the relationships between illness representations, coping strategies and health outcomes in people with a variety of illnesses (Hagger & Orbell, 2003). Additionally, this Model has been suggested to be useful for health research among minority populations (Diefenbach & Leventhal, 1996).

Another commonly used theory is the Health Belief Model (HBM) which explains behaviours in terms of six factors. These factors (beliefs about susceptibility, perceived severity, perceived benefits of taking action, perceived costs of taking action, confidence in one's ability to successfully perform the action, and cues to action) are proposed to influence people's decisions about whether they take action (Rosenstock, Strecher, & Becker, 1988). This model is often used to explain prevention and treatment behaviours, and has been found to be useful for addressing health risk behaviours (Rimer & Glanz, 2005). For example, if individuals exhibit signs of reduced belief in the benefits of taking action, the health behaviour may be promoted by emphasising the positive outcomes of the action, along with details about how, where and when to take action (Rimer & Glanz, 2005). The very prescriptive nature of both of these theories thus allows the identification of specific strategies to promote individual behaviour change.

At an interpersonal level, theories recognise the influence of the social environment, and therefore focus on the thoughts and beliefs of other people such as health professionals, friends, family and co-workers. Commonly used theories include Social Cognitive Theory (SCT) (Bandura, 1977). Social Cognitive Theory explains health behaviours through ongoing dynamic processes in which personal, environmental and behavioural factors are interdependent on one another. Like the HBM, SCT proposes several specific concepts which are influential in health behaviours. Behavioural capability - that is, the knowledge and skills to perform the behaviour, expectations about the outcomes of a behaviour and confidence in the ability to perform the behaviour - are concepts which are also considered in the HBM. However, in considering the interplay between

relationships with others, personal factors, and environmental factors, SCT also considers the impact of observational learning (modelling). Observational learning occurs when individuals learn from the experiences of others, and whether the behaviour is more or less likely to produce recurrence of an outcome (Rimer & Glanz, 2005). The SCT's well-defined influences on behaviour allow the design of specific strategies for behaviour change. However, like the HBM, this model is quite prescriptive, and therefore is not as useful when the barriers to adherence are not known.

Community-level initiatives are targeted at whole populations, rather than just at individuals. Communities are groups of people who have shared characteristics, such as geographical location, interests, or similar backgrounds or experiences (Rimer & Glanz, 2005). Therefore, theories at the community level relate to community action, development and planning. Interventions thus seek to influence behaviour at an organisational level. For example, community organisational models aim to identify community problems, and orient resources to assist with these problems through community development, social planning and social action (Rimer & Glanz, 2005). Due to the community-oriented focus of these theories, they draw on concepts such as building community capacity and community empowerment, which are important in improving type two diabetes prevention and management (Satterfield et al., 2003), but do not lend themselves well to self-management, which is the focus of the current research. Therefore, while it is important to mention the usefulness of these theories more broadly, they will not be discussed any further here.

The theories discussed in this section, and many others, have been used to investigate specific behaviours related to type two diabetes self-management. However, a review of literature has reported low correlations between behaviours and psychological constructs, such as those mentioned in the HBM and SCT, in difficult-to-reach and minority populations (Glasgow et al., 2001). Researchers have therefore suggested that these psychological constructs may not be

applicable and have expressed the need to use caution in such populations (Glasgow et al., 2001). Rural and remote living type two diabetic patients can be considered one such hard to reach minority population (Goepfinger, 1993).

Furthermore, the theories discussed above are all quite prescriptive in nature, in that they explain specific actions in terms of a variety of factors. In light of the lack of literature examining barriers to effective type two diabetes self-management specifically in a rural and remote Australian context, the research presented in this thesis is exploratory in nature. Due to the lack of defined variables under study at the outset of the current research, a socio-ecological framework was adopted for Study 1. This framework was chosen as it was important to allow the people experiencing type two diabetes self-management to identify the full range of barriers relevant to them. The use of a socio-ecological framework will be discussed in further detail in section 3.1.2 below.

3.1.2 Socio-ecological Framework

Effective type two diabetes self-management requires many lifestyle changes which can be quite complex (see section 1.1.5). As evident in Chapter 1, effective self-management often requires changes in a variety of behaviours. Barriers to self-management behaviours, as highlighted in Chapter 2, are influenced by an array of obstacles that span many levels of influence. The World Health Organisation (2003) proposed five interacting dimensions which impact on adherence to health recommendations. These dimensions are social/economic, health care team and system-related factors, therapy-related, patient-related and condition-related factors. A focus on the multiple dimensions influencing health behaviour assists in moving away from the notion that patient-factors are solely responsible for adherence. These interacting

dimensions have been discussed in detail in section 2.1.2, and provide a background for the use of a socio-ecological approach in the current research.

Within a socio-ecological approach, health is determined by the biological, behavioural, and socio-cultural needs of an individual and the degree to which these needs are met by the environment and the resources available to them (Stokols, 1996). A socio-ecological approach considers the five interacting dimensions proposed by the WHO (2003). A socio-ecological framework proposes that there are factors at many levels which influence health behaviours, and provides a framework which allows the investigation of these multiple levels of influence, as well as acknowledging the complexities of the interconnected determinants of health (Stokols, 1996). These levels of influence include intrapersonal, interpersonal, organisational/institutional, community and policy levels (Emmons, 2000).

In terms of type two diabetes self-management, intrapersonal factors, which are analogous to the patient-factors proposed by the World health Organisation (2003), relate to knowledge of type two diabetes and its management, skills required to self-manage, attitudes about the importance of self-management and motivation and self-confidence to self-manage. Interpersonal factors relate to the relationships with friends, family and health professionals which mediate stress and provide support for self-management. Organisational/institutional factors related to type two diabetes self-management encompass work-place factors and health services. Type-two diabetes specific community factors may include societal attitudes, the availability of educational and vocational opportunities, and characteristics of neighbourhoods and communities like the presence of both formal and informal supports. At a public policy level, policies relating to provision of health services, pricing and availability of food options, subsidies for medications and community health programs may all influence type two diabetes self-management.

A socio-ecological framework takes into account the interplay between individuals and their social and built environments, along with the interconnections between domains of life (Stokols, 1996). Accounting for these multiple levels of influence contextualises health and allows health promotion strategies to account for influences on health behaviour systematically in order to improve the maintenance of health behaviours. Although major criticisms of the socio-ecological model were not found in the literature, a possible limitation of the application of a socio-ecological model to type two diabetes self-management is the compartmentalising of difficulties. If a socio-ecological model is used to guide research questions, it may not allow for the identification of complex obstacles which span across multiple levels of influence. In order to overcome this possible limitation, the inter-connections between the domains of life need to be fully considered. Whilst the socio-ecological model does describe the inter-dependent nature of the levels of influence, it is not clear how these inter-dependencies should be accounted for in research, and thus may pose limitations for quantitative research using this model.

Many studies into the management of chronic illnesses, including type two diabetes, have been informed by a socio-ecological approach. The socio-ecological approach provides a structure for the understanding of type two diabetes self-management, which assists in the identification of strategies for improved self-management (Whittemore, Melkus, & Grey, 2004). For example, in an investigation of social support and physical activity in people with type two diabetes, a socio-ecological approach was used to describe sources of support for physical activity, and to suggest directions for health professionals to increase physical activity (Gleeson-Kreig, 2008). The socio-ecological framework has been suggested to be a useful framework for the investigation of factors relating the management and prevention of type two diabetes, as it begins to address the complexities and interdependencies between a multitude of factors which play a role in self-management of an illness which encompasses so many facets of life (Whittemore et al., 2004).

The exploratory part of this research (Study 1) utilised a socio-ecological model of health to organise themes which are identified through thematic analysis. Through the use of the multi-levelled framework for thematic analysis of focus group and telephone interview data, barriers were identified at multiple levels of influence, thus providing an in-depth analysis which takes the inter-related nature of these levels of influence into account. These barriers were used to also inform Studies 2 and 3, and recommendations made in the discussion, at the end of this thesis.

3.1.3 Transtheoretical Model of change

Results of Study 1 indicated that maintenance of behaviours is a major concern in type two diabetes self-management (as discussed in detail in Chapter 4; Study 1). The Transtheoretical Model of Change (TTM) (Prochaska & Velicer, 1997) proposes that behaviour change occurs through a process of moving through six stages. The pre-contemplation stage is characterised by no intention of taking action within the foreseeable future (usually the next 6 months). The contemplation stage is characterised by the intention to take action in the foreseeable future. The preparation stage refers to the intention to take action and current planning to do so. The action stage is characterised by people who have made changes within the last six months, and the maintenance stage is used to describe people who have made changes and maintained these changes for more than six months. The termination stage is used to describe people who have made changes in the past, but either these changes are no longer required, or they have not been able to maintain these changes (Prochaska & DiClemente, 1992). This theoretical model has been useful in describing behaviour change across a variety of behaviour changes in general populations, including smoking cessation (DiClemente & Prochaska, 1982), participation in exercise (S. J. Marshall & Biddle, 2001) and dietary change (Kasila, Poskiparta, Karhila, & Kettunen, 2003). In addition, this model has utility in predicting behaviour change in type two

diabetes self-management behaviours (H. Jones et al., 2003), and has been suggested to be useful for the investigation of barriers to self-management in previous reviews of existing research (Simmons, 2001). Therefore, the TTM was identified as useful and appropriate as a guiding theory for the analysis of Study 3. Unfortunately however, due to limited recruitment of study participants in the contemplation, preparation and termination stages, this analysis could not be completed. This is discussed in further detail in the overall discussion (section 8.7) below.

3.2 Methods

This research utilised a mixed methods approach, whereby qualitative and quantitative methods were combined sequentially in three studies, and the results of these studies were integrated at the discussion stage. There is an extensive literature examining the epistemological underpinnings of both quantitative and qualitative literature. There is also considerable debate about what constitutes an acceptable research design in a mixed methods approach (Teddlie & Tashakkori, 2012). Whilst it is not the aim here to engage in depth with these epistemological debates, it is important to provide a summary of the key features of these arguments in order to locate the mixed methods approach taken in this thesis. This section will therefore briefly discuss the qualitative/quantitative dichotomy, mixed methods as an alternative position to this dichotomy, and the use of mixed methods in the current research.

3.2.1 Mixed Methods Research in Health

Health Research in Light of the Qualitative/Quantitative Dichotomy

Epistemological positions are concerned with 'the nature of knowledge, its possibility, scope, general basis, and justification' (Muis, Bendixen, & Haerle, 2006, p. 4). Ontological

positions are concerned with the nature of existence and reality. Epistemological and ontological positions dictate the methods which are deemed as appropriate foundations for the study of phenomena in a given field. The distinction between qualitative and quantitative ontologies, epistemologies and methodologies are routinely drawn upon to justify health research methods (Bryman, 1984). These positions, and examples of qualitative and quantitative research in the field of health, will be briefly discussed here in order to provide context for the qualitative and quantitative dichotomy which will be discussed.

Quantitative and qualitative approaches to research are typically positioned at opposite ends of a continuum when describing core ontological assumptions, epistemological stance, and research methods. Quantitative approaches are generally associated with the ontological assumption that reality is concrete and observable, and are commonly associated with the positivist/empiricist epistemology, whereby research aims for objectivity and replicability. These epistemologies focus on studying systems, process and change, and aim to construct a positivist science (Morgan & Smircich, 1980). A deductive approach is generally taken in quantitative research, whereby a testable hypothesis is developed and data are collected to test the hypothesis. Research adopting a quantitative approach focuses on measuring quantities, rates and relationships between variables, using procedures which are accepted as rigorous. Thus it has been suggested that quantitative approaches to research are appropriate when investigating an area in which there is an already-existing body of knowledge from which to derive hypotheses (Bowling, 2005). In health and social sciences, quantitative research commonly utilises surveys, randomised control trials and population-level epidemiological studies for data collection.

Qualitative approaches to research are very broad and encompass techniques from content analysis, which may be underpinned by positivist/realist ontologies, through to various forms of discourse analysis, which are underpinned by constructionist ontologies and

epistemologies. Qualitative research generally aims to collect in-depth data in order to obtain phenomenological insight and understand how social realities are created (Morgan & Smircich, 1980). Qualitative approaches to research generate non-numerical forms of data, such as textual and narrative sources and are generally exploratory. A diverse range of methods of data collection are used to gather qualitative data. These methods can include interviews, group discussions, collection of media articles, and diaries, to name a few (Carter & Henderson, 2005). One of the main criticisms of qualitative research is the concern about how to ensure the rigour and the thoroughness of the research methods which are the cornerstone of good quality quantitative research (Pope, Ziebland, & Mays, 2000). Techniques such as the reporting of procedures which are accepted as appropriate, explicitly commenting on the representativeness of the findings, the use of inter-rater reliability checks and reflecting on the effect of values and backgrounds of researchers conducting the research (Kitto, Chester, & Grbich, 2008) have been developed to overcome criticisms of qualitative research rigour.

Both qualitative and quantitative approaches have advantages and disadvantages:

“there is a myriad of technical reasons why participant observation is preferable to social surveys in such a sense or vice versa” (Bryman, 1984, p. 81).

However, methodological purists argue that qualitative and quantitative approaches are incompatible and should not be mixed due to epistemological differences which are viewed as fundamental (Johnson & Onwuegbuzie, 2004). According to these purists, the two major paradigms are underpinned by different epistemological and ontological assumptions about the nature of reality and therefore about the purpose and nature of research (Onwuegbuzie & Leech, 2005). The polarization of qualitative and quantitative paradigms has been attributed to

researchers placing emphasis on the differences between the paradigms, rather than the similarities (Porter, 2007).

Mixed Methods as an Alternative Perspective to Qualitative and Quantitative Dichotomy

Within health research, epidemiological and randomised control trial research have traditionally been viewed as the gold standard (Baum, 1995). Such research is typically reductionist in nature and seeks to establish prevalence and aetiology of disease or efficacy of treatments/campaigns. However, as the nature of research questions within health psychology have become more complex, and have sought to take into account social and environmental factors, research methods have diversified to appreciate the value of non-quantitative approaches (Baum, 1995). Therefore, many researchers have challenged the notion that qualitative and quantitative methods are incompatible. These researchers have challenged the polarization of 'quantitative' and 'qualitative' approaches, whereby quantitative approaches are viewed as 'objective', while qualitative approaches are viewed as 'subjective' (Ercikan & Roth, 2006). Many researchers have suggested that qualitative and quantitative approaches are not fundamentally different. Rather, they are dimensionally different, and therefore can be combined to generate useful information (McLafferty & Onwuegbuzie, 2006). For example, Ercikan and Roth (2006) argue that a qualitative/quantitative dichotomy is not helpful in an education setting for three reasons. Firstly, they argue that phenomena under study are simultaneously both qualitative and quantitative; secondly, that qualitative and quantitative data construction processes follow similar interpretative processes; and, thirdly, that data construction processes are based on subjective, defensible judgements. As an alternative to a quantitative/qualitative dichotomy, Ercikan and Roth argue for research methods to be seen as a continuum, and for the research question, rather than the methodology, to be the central focus (Ercikan & Roth, 2006). Furthermore, Ercikan and Roth

(2006) suggest that the research questions should determine the methods which are used to answer them. Similarities between qualitative and quantitative approaches have also been highlighted by other authors (Johnson & Onwuegbuzie, 2004). Given the applied, and often educational, nature of much health and health service research, it can be argued that these principles also apply in a health context.

The notion that research methods should be determined by the questions of interest is central to pragmatism. Pragmatism has been advocated by many researchers in the mixed methods field (Teddlie & Tashakkori, 2012). Johnson et al. (2007) have argued that pragmatism offers researchers an attractive epistemological justification for the use of mixed methodologies, whereby a combination of methods which best allows answers to the research questions is employed. Pragmatism can also assist in determining the ways in which methods should be combined (Hoshmand, 2003). A pragmatic epistemology, whilst currently poorly defined (Teddlie & Tashakkori, 2012), therefore rejects a view that positivist and constructionist epistemologies are incompatible.

It has been argued that mixed methods approaches to research recognise the advantages and disadvantages of both quantitative and qualitative research methods, and have been positioned as a natural complement to these approaches (Johnson & Onwuegbuzie, 2004). Mixed methods research is considered one of the three major "research paradigms", and can be considered a middle ground between qualitative and quantitative perspectives, whereby the perspectives of both approaches are recognised (Johnson, Onwuegbuzie, & Turner, 2007). In their attempts to move towards a definition of mixed methods research, Johnson et al. (2007) utilised expert opinions in the area and came to the tentative conclusion that mixed methods approaches to research recognise the importance of both qualitative and quantitative research, while offering a

third paradigm which provides 'most informative, complete, balanced, and useful research results' (Johnson et al., 2007, p. 129).

The use of mixed methods research is becoming increasingly popular in health research (O'Cathain, 2009) as the mixing of qualitative and quantitative methods allow the researchers to better tailor their methods to the contexts in which they are researching (Johnson et al., 2007). For example, mixed methods allow researchers the flexibility to respond to a range of practical and ethical issues which arise when working with a clinical population (Dures, Rumsey, Morris, & Gleeson, 2011). Mixed methods research is pragmatic in that it allows researchers in health psychology to combine the most appropriate parts of different research methodologies to best answer the research question (Adamson, 2005), thus giving them the flexibility to conduct research in real-world settings, consider time and funding constraints and to investigate complex problems pragmatically (Dures et al., 2011).

Whilst many advantages of mixed methods have been highlighted, researchers have expressed concern about a lack of clear guidelines regarding how to best 'mix' research and a lack of broad agreement to the stages at which methodologies can be 'mixed', and how to interpret conflicting results (Johnson et al., 2007). Through mixing qualitative and quantitative methods, researchers have suggested that some of the limitations of both quantitative approaches (such as a lack of depth and recognition of influences of context and time) and qualitative approaches (such as a perceived lack of rigour, and subjectivism), can be overcome through the use of both methodologies (Johnson & Onwuegbuzie, 2004). However, in contrast to this advantage, other researchers have suggested that the use of both qualitative and quantitative approaches waters down both approaches and provides the advantages of neither (Lowe, 2010). Thus care must be taken to carry out both methodologies correctly, and to consider the ways that mixed methodologies are useful at the research design stage in order to overcome such criticisms.

Triangulation

One commonly highlighted advantage of using mixed methods is the triangulation of results. Triangulation refers to combining methodologies in order to gain multiple perspectives on an area of interest (Johnson & Onwuegbuzie, 2004), such that the accuracy of the research produced is increased (Jick, 1979). This concept was first referred to, in the social sciences, by Campbell and Fiske (1959), who suggested that one method can act as a validation of another, and therefore ensure that the results reflect the underlying phenomena, rather than the methods by which it was studied. This view of triangulation presents epistemological conflict, as the combination of positivist and interpretivist paradigms essentially nullify the usefulness of one methodology as validation of one another, or as cause for rejecting research because results do not converge (Moran-Ellis, Alexander, Cronin, Slaney, & Thomas, 2006). Rather, because researchers cannot be completely impartial in research design, data collection and interpretation of research, it has been suggested that methodologies can be triangulated to add different dimensions and, therefore, enrich understandings of the research questions (Moran-Ellis et al., 2006). Whilst this view does not provide a solution to the aforementioned epistemological problem, viewing the mixing of methods as enriching understandings of a multi-faceted phenomena does not seek to make a claim that the validity of the findings is increased. This is especially important given one major criticism of a mixed methods approach, whereby it is suggested that different methods may have similar flaws, such as bias in the development of research questions and choice of questionnaires, thereby increasing the bias whilst hiding error in claiming that mixed methods have increased validity (Fielding & Fielding, 1986).

3.2.2 The use of Mixed Methods in the Current Research

The current research utilised a mixed methods approach in order to gain a rich and detailed account of the barriers to effective type two diabetes self-management which exist in rural and remote Australia. The importance of embracing the complexity which exists in investigating the specific factors which impact on rural chronic illness management has been highlighted in previous literature (M. FitzGerald et al., 2001), and therefore mixed methods that consider multiple constructions of the phenomena are ideal in investigating such a multifaceted problem.

A wide array of mixed methods typologies exist (Johnson et al., 2007), and it is important to identify the typology which is used in order to consider the ways in which methods are mixed and the gains of mixing methods at different stages (Johnson et al., 2007). Integration, whereby workable relationships between methods are developed, maintains the integrity of each method and allows researchers to investigate the phenomena in greater depth. Within an integration approach to mixed methods, different methods are weighted equally and oriented towards a common goal. The current research adopted an interpretative integration approach, whereby separate methods were used to collect and analyse data, and the results of both the qualitative and quantitative analyses were integrated to discuss the findings of the research as a whole at the discussion stage (Moran-Ellis et al., 2006).

The methods in the current research were mixed sequentially. That is, the results of one methodology informed the next (Lowe, 2010). This rationale for the use of mixed methods has also been labelled a 'development' rationale, where the results from one method help to inform the method of another (Greene, Caracelli, & Graham, 1989). One challenge of the use of sequential methodologies is the need for each of the methods to be able to be reported as stand-alone studies (Lowe, 2010). This challenge is overcome in the current research, as the format of this

thesis allows the integration of results to occur in the overall discussion, rather than in the papers individually.

Given the exploratory nature of Study 1, a qualitative design is ideal because it provides the flexibility to develop hypotheses and identify themes during the data analysis, rather than at the outset of the study (Larmer & Pugh, 1998). Previous researchers have emphasised the sound grounding which qualitative research provides for further quantitative investigation of complex questions (Pope & Mays, 1995). Initial qualitative exploration of an issue allows many perspectives to be taken into account (Carter & Henderson, 2005) and allows for the exploration of experiences of rural type two diabetes self-management, which are central to the research questions, by keeping the initial lines of enquiry open (Rozin, 2001). This is especially important in the current research, where there is a lack of literature identifying barriers to type two diabetes self-management in rural and remote contexts (as discussed in section 2.2.6) upon which to base further quantitative enquiry. Thus the identification of barriers to self-management, through qualitative methods in Study 1, allowed further quantitative exploration of the effect of the barriers on patient quality of life in Study 2 and Study 3.

An understanding of the views of both patients and health professionals allowed a more informed investigation of issues related to self-management in a rural and remote context, especially given that previous researchers have emphasised that the context in which one experiences illness is important in managing that illness (Glasgow et al., 2001). The inclusion of health professionals in this initial exploratory research added further depth to the data, as the health professionals saw a variety of patients within these rural and remote contexts, and could thus report on a wide variety of their patients' experiences and difficulties. This is especially important given discussion in section 2.2.4 about the need to combine both patient and health professional views when identifying barriers to self-management. Through an initial qualitative

approach people were able to describe their barriers to self-management in their own language, therefore ensuring that the depth and complexity of experiences was captured.

The results of Study 1, based on qualitative data, informed the development of hypotheses and the quantitative data collection for Study 2 and Study 3. Thus, the quantitative data collection was informed by the factors which patients and health professionals identified as important to self-management in rural and remote Australia. Study 2, the adaptation of a tool for measuring barriers to effective type two diabetes self-management, was directly informed by the barriers identified in Study 1, adding depth to Study 1 by quantitatively validating the barriers identified. Study 3 utilised the barrier classifications identified in the validation in Study 2 and built on the identification of these barriers by investigating the associations between these barriers, demographic factors and diabetes-dependant quality of life.

3.3 Study 1 Methods

The research in this thesis is presented in the format of three papers written for publication. Given the word limits for the journals to which the manuscripts have been submitted, the method sections in each paper are not explained in lengthy detail. Therefore, more details about the methods used for Study 1 will be discussed here. The methods used for Study 2 and Study 3 will be described in greater detail in Chapter 5, in order to provide a logical background for these studies.

3.3.1 Thematic Analysis

Thematic analysis is one of many possible techniques for analysing qualitative data (Aronson, 1994). Thematic analysis provides researchers with flexibility (Braun & Clarke, 2006)

whilst providing a method for the systematic identification and discussion of recurring themes in the data (French et al., 2004). There are many ways of conducting thematic analysis, however, all forms of thematic analysis involve recognising patterns in the data which are seen to be important in describing the phenomena (Fereday & Muir-Cochrane, 2006) and embracing the complexity of qualitative data by including as many themes as are necessary to reflect the intricacies and nuances of the data (Pope et al., 2000). Identified themes both describe and organise data, and provide a basis for interpreting the aspects of the phenomena which are relevant to the research questions (Boyatzis, 1998).

Thematic analysis is one technique which is compatible with both essentialist and constructionist epistemologies (Braun & Clarke, 2006). Therefore, in light of the tensions between these paradigms and the resultant potential problems for mixed methods research, the use of thematic analysis in a mixed methods approach further overcomes these issues. Whilst thematic analysis is a commonly used qualitative research technique, the methods used to conduct thematic analysis are generally poorly defined (Braun & Clarke, 2006). It is therefore important to be explicit in describing the decisions and processes undertaken in conducting thematic analysis.

3.3.2 Thematic Analysis in Study 1

It is essential that researchers explain exactly how they conduct thematic analysis, so that rigour can be ensured, and so that comparisons with other research can be made accurately (Braun & Clarke, 2006). In describing the processes undertaken, it is important to be explicit about the decisions made by researchers (Braun & Clarke, 2006) so that the agency of the researcher in the process is made clear. This section describes the decisions regarding thematic analysis at the outset of the research, and the processes used to conduct the thematic analysis which forms Study 1.

Decisions

The data used for thematic analysis were semi-structured interviews and a focus group with type two diabetes patients, and semi-structured interviews with health professionals working with people with type two diabetes (see Appendix 1 and 2 for examples of questions). The corpus of data analysed consisted of all interviews and the focus group conducted with both health professionals and patients. All data sources were included as this research sought to obtain a rich description of the data set as a whole, rather than a detailed account of particular aspects of the data. This decision was made in line with the aims of the study to identify a wide variety of barriers and facilitators which have an impact on self-management in rural and remote Australia.

A semantic, explicit-level analysis was undertaken. This analysis involved the identification of themes at a surface level, whereby the analysis focuses on what the participants have said, rather than a focus on the underlying ideas, assumptions or conceptualisations of the participants (Braun & Clarke, 2006). A semantic level approach produces a description whereby the data have been organised in a way that demonstrates the patterns identified. Semantic analysis leads to an interpretation phase that involves a discussion of the patterns and their significance to the research questions (Braun & Clarke, 2006).

Deductive coding occurs when themes and codes are formed prior to analysis, from previous theory or literature. Inductive coding refers to the use of data-driven codes and themes (Boyatzis, 1998) which are developed gradually as a result of the analysis process (French et al., 2004), and are conducted without the use of an initial coding frame. The process of an inductive thematic analysis was chosen for the current research as it complements the aims and specific research questions of the study. An inductive thematic analysis allowed the participants' own

experiences to drive the analysis and was deemed to be the most pragmatic and straightforward way of identifying barriers and facilitators.

Processes

The process undertaken in this analysis is based on recommendations proposed by Braun and Clarke (2006). Firstly the telephone interviews and the focus group were transcribed verbatim. Notes for ideas about initial codes and themes were made at this stage. These initial codes were developed further and refined through careful reading and re-reading of the transcriptions. Extracts of data were then assigned to codes; a process which is also suggested in the method proposed by Boyatzis (1998). Coding and re-coding occurs as a dynamic process until the researcher is satisfied that a theme is an accurate representation of the data (Braun & Clarke, 2006). Through careful reading and analysis of the coded data, initial themes were developed, and extracts were grouped together by theme. Theme development aimed to describe the themes and explore their relationships with the research questions by examining the content of the themes and codes (French et al., 2004). This process focused on the relationships between codes and was important in re-focusing the data. Sub-themes were also developed during this process. Coded extracts were read in detail to review the themes and ensure that all data within a theme fit with the theme and with the other data. Data which did not fit were re-considered for different themes. This process refined the themes. Once the researcher was satisfied that the coded data were organised into themes which accurately represent the data, the themes were defined and labelled. This process aimed to clearly define what the themes included and what they did not.

In reporting the results of thematic analysis, it is recommended that care needs to be taken to avoid repetition as far as possible (Braun & Clarke, 2006). This is often difficult given the

complex nature of the data. In order to reduce repetition in Study 1, the socio-ecological framework (discussed in further depth in section 3.1.2) was used to organise the themes.

A common criticism of qualitative research is that 'anything goes', and that there is a lack of rigour (Mays & Pope, 1995). Corroboration of the themes and codes is regarded as important in establishing rigour in thematic analysis (Fereday & Muir-Cochrane, 2006). The themes identified in this analysis were checked at multiple points with the research team (PhD candidate and three supervisors) to ensure that the data coding and reported themes were not the "unintentional 'seeing' of data that researchers expect to find" (Fereday & Muir-Cochrane, 2006, p. 7).

3.4 Summary

This chapter has discussed the use of theories in health psychology research to provide context for the use of the socio-ecological framework which will be used in Study 1. Chapter 3 has also discussed the use of mixed methodologies in health research. The mixed methods section has outlined the tension between qualitative and quantitative research perspectives, and positioned mixed methods as an alternative to this dichotomy which can be used to produce research of greater depth and relevance than the sole use of qualitative or quantitative methods. This chapter has also provided additional information about the use of thematic analysis in Study 1, which could not be included in the published manuscript which forms Chapter 4, due to word count limits. The next chapter (Chapter 4) presents this manuscript.

Chapter 4: Study 1- Barriers and facilitators to effective type two diabetes management in a rural context: A qualitative study with diabetes patients and health professionals

This paper has been accepted for publication in the Journal of Health Psychology and is presented here in its manuscript format in the same typeset as the rest of the thesis. The published journal format appears as Appendix 3.

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Statement of Authorship:

L. Jones (candidate)

Developed rationale for study, collected data, analysed data, drafted and prepared manuscript for review and responded to reviewer comments.

I hereby certify that the statement of contribution is accurate

Signed

Date: 4/7/2013

S. Crabb

Supervised the development of the work, assisted in analysis and preparation of manuscript.

I hereby certify that the statement of contribution is accurate

Signed:

Date: 4/7/2013

D. Turnbull

Supervised the development of the work, provided guidance on the preparation of manuscript.

I hereby certify that the statement of contribution is accurate

Signed:

Date: 3 July 13 .

M. Oxlad

Supervised the development of the work, provided guidance on the preparation of manuscript.

I hereby certify that the statement of contribution is accurate

Signed:

Date: 3/7/13

4.1 Abstract

Although effective type 2 diabetes management is essential for the prevention of complications, it is rarely carried out. Type 2 diabetes deaths in rural areas are higher than in metropolitan areas. A focus group (n = 8) and telephone interviews with patients (n = 10), and telephone interviews with health professionals (n = 18) in rural areas were conducted to examine this issue in a rural context. Inductive thematic analysis was used to generate 13 themes of barriers and facilitators to type 2 diabetes management at intrapersonal (denial of the illness, motivation, knowledge and skills and lack of time), interpersonal (stress and relationships), organisational (access to recommended foods, transport, health professionals, and exercise options) and societal (engagement and societal attitudes) levels of influence. Across all themes, participants highlighted the difficulty of maintaining management behaviours.

4.2 Introduction

Type 2 diabetes is characterised by disordered metabolism of carbohydrates, fats and proteins, which arises from inadequate insulin action or secretion, or both (Sherwood, 2004). Rates of diabetes have been increasing in Australia, Europe and the United States (Boyle et al., 2001), a trend that is set to continue (Wild, Roglic, Green, Sicree, & King, 2004). Specifically, type 2 diabetes is predicted to become the leading cause of disease burden by 2023 (Australian Institute of Health and Welfare (AIHW), 2010). Therefore, it is becoming more important to understand how to best promote effective diabetes management.

Type 2 diabetes self-management interventions are diverse. These interventions aim to promote patient empowerment (Gonder-Frederick et al., 2002), increase patient involvement and reduce health system burden (Newman et al., 2004). Thus, management often necessitates considerable behavioural and lifestyle changes (H. Jones et al., 2003). However, overall, type 2 diabetes is relatively poorly managed (Maddigan et al., 2005), with both health professionals and patients reporting low levels of patient adherence to recommendations (Peyrot et al., 2005). Factors identified as potentially inhibiting effective management include the cost of diabetes medications, inflexible work conditions and lack of diabetes education (Brown et al., 2002), along with social isolation and a lack of knowledge about diabetes (Wens et al., 2005). However, previous literature suggests a lack of understanding between patients and their practitioners about the requirements of effective management (Freeman & Loewe, 2000). In addition, it has been suggested that health professionals and patients report different barriers when accounting for management difficulties (Simmons, Lillis, et al., 2007).

Although people living in rural areas are reputed to have increased disease risk factors and poorer health than those in metropolitan areas (AIHW, 2010), relatively few studies have investigated the barriers and facilitators of effective type 2 diabetes management among rural

people. Many complex and diverse differences in services, and cultural and geographical circumstances (Bourke, 2001) may make the experience of living with chronic illness in rural and remote areas very different from the same experience in urban areas. In Australia, for example, diabetes rates, and deaths due to diabetes, are twice as high in remote areas as in non-remote areas (AIHW, 2010), a difference that is continuing to grow (Dixon & Welch, 2000). Therefore, holistic research to increase understanding of the experience of chronic illness, specifically in a rural and remote context, is essential (M. FitzGerald et al., 2001).

Only one study that has investigated barriers to type 2 diabetes management in a rural and remote context has been identified. This American study reported barriers identified through a content analysis of three focus groups involving 24 people with type 2 diabetes living in rural America. Barriers included a lack of understanding of the management plan, feelings of frustration due to being unable to achieve glycaemic control, uncoordinated care and limited specialised services such as dieticians (Nagelkerk et al., 2006). A positive attitude, which promotes learning about the illness, and the presence of supportive relationships, which promotes accountability, were proposed to facilitate effective management (Nagelkerk et al., 2006). However, further investigation is required in order to understand how these barriers affect the implementation of models of care in non-urban contexts.

This study aimed to identify factors that prevent and facilitate effective type 2 diabetes management in a rural context, drawing on the perspectives of both patients and health professionals. The study employed a socioecological framework: an approach that proposes that health is determined by the biological, behavioural and sociocultural needs of an individual, and considers the degree to which these needs are met by the environment and the resources available (Stokols, 1996). This framework acknowledges the complexities of the interconnected determinants of

health and provides a structure that allows the investigation of multiple levels of influence, such as intrapersonal, interpersonal, organisational and societal levels (Stokols, 1996).

4.3 Method

Participants

Patients in this study were people who self-identified as having been diagnosed with type 2 diabetes. Ten type 2 diabetic patients living in rural areas of South Australia, aged 33–82 years ($M = 60.4$, standard deviation (SD) = 15.7), participated in semi-structured telephone interviews ranging in length from 10 to 45 minutes. Participants lived in areas with Accessibility Remoteness Index of Australia (ARIA) scores from 1.4 (accessible) to 6.0 (remote). Eight participants with type 2 diabetes, aged 58–73 years ($M = 66.9$, SD = 5.9), participated in a focus group discussion in a large centre with an ARIA of 6.04 (remote). Eighteen health professionals working with people with type 2 diabetes participated in semi-structured telephone interviews, ranging in length from 15 minutes to 1 hour. Health professionals included diabetes educators ($n = 10$), podiatrists ($n = 2$), nurses ($n = 3$) and dieticians ($n = 3$) servicing areas with ARIA scores ranging from 1.4 (accessible) to 11.3 (very remote) and who had been working in type 2 diabetes care for between 1 and 23 years ($M = 8.1$, SD = 6.8).

Data Collection and Analytical Approach

Interview questions were piloted with five health professionals working in rural type 2 diabetes care and six people of various ages and levels of education known to the researcher. Data collection for this study occurred between February and August 2009. This study was approved by the School of Psychology Sub-Committee of the University of Adelaide Human Research Ethics

Committee and by the Government of South Australia Department of Health Human Research Ethics Committee.

Interview prompt questions focussed on the barriers to effective type 2 diabetes management in rural contexts. Data were audio-recorded, transcribed verbatim and then analysed by following thematic analysis framework proposed by Braun and Clarke (2006). Specifically, our thematic analysis took an inductive and semantic approach, and aimed to produce a rich description of the themes in the entire data set.

4.4 Analysis and Discussion

Following a socio-ecological framework, the analysis presented here is structured according to intrapersonal, interpersonal, organisational and societal influences on type 2 diabetes self-management. Thirteen relevant themes are presented in an order allowing minimum repetition given the inter-related nature of levels of influence. Finally, difficulties maintaining management behaviours are discussed. Extracts are identified as health professional (HPI), focus group (FGP) or patient (PI).

4.4.1 Intrapersonal Influences

Denial of illness

Participants in this study reported the experience of being diagnosed with type 2 diabetes to be overwhelming and stressful:

I was frightened, I was, because I knew diabetics, a, a friend of mine lost ah, both of her legs and then she died. (PI 9)

Furthermore, feelings of being overwhelmed were suggested to lead to denial of the need to manage the illness and subsequent avoidance of self-management. Health professionals commonly attributed denial to the insidious nature of the illness (that consequences are not immediately apparent), and to feelings of being unable to cope, whereas patients talked about denial of the illness in more general terms such as avoiding taking responsibility for one's health.

Participants commonly suggested that people who do not 'take ownership of it themselves' (HPI 16) and experience denial of the illness have difficulty carrying out recommended aspects of the self-management of their condition:

if they find it difficult to accept their diabetes in the first place, um, then it is very hard to begin to follow some of the routines that we would like if you are denying that there is even a need or a reason for it. (HPI 4)

The notion that denial causes inaction is strengthened by the suggestion that denial inhibits readiness to change, with several health professionals emphasising that ignorance of the seriousness of complications further prevents effective management via reduced impetus to prevent these complications through self-management; this point is discussed further in the 'Knowledge and skills' section that follows. Such suggestions echo previous reports that practitioners are concerned about patients' lack of acceptance of having diabetes (Brown et al., 2002) and downplaying the seriousness of the illness (Wens et al., 2005), which may lead to poor self-management.

In addition to denial of the illness, some health professionals expressed concern that high incidence of type 2 diabetes and related complications in some remote communities leads to an apathetic attitude that getting the disease is inevitable:

there is a lot of kind of sort of apathy, in that, you know, lots of people have it up here and there's lots of diabetes related complications in our region. (HPI 3)

Previously, both family practitioners (Brown et al., 2002) and people with type 2 diabetes (Nagelkerk et al., 2006) identified the ability of a patient to assume responsibility for their disease management as imperative to successful management. As suggested in this study, such apathy may cause patients to deflect responsibility for management of the illness, therefore leading to poorer management.

Motivation

Previous literature emphasises that a positive attitude towards management is conducive to learning more about the disease (Nagelkerk et al., 2006), and increasing adherence to self-care regimens (Masaki et al., 1990). Furthermore, previous research indicates that more positive evaluations of dietary adherence generate increased sense of control of the illness (Shibayama, Sato, Nishigaki, Ochiai, & Kazuma, 2011) and that positively framed, that is, gain-framed, messages are most effective in promoting exercise behaviours (Ledford, 2012). Both health professionals and patients in this study stressed the importance of motivation and a positive attitude in effective management. Furthermore, health professionals suggested that by discussing the links between effective management and reduced risk of complications, motivation to self-manage could be increased. Motivation was presented as being relatively rare. Most health professionals and patients suggested that motivation facilitates the uptake of information and the translation of information into subsequent behaviour change, thus increasing the patient's ability to self-manage effectively. Decreased levels of motivation were proposed to limit people's ability to manage effectively. Many health professionals suggested that self-management education and

skills are ineffective unless the individual is motivated to change. These findings support previous reports of low levels of patient motivation as an important barrier to management (Zgibor & Simmons, 2002).

Knowledge and Skills

In previous research, patients identified the need to acquire self-management resources in order to manage type 2 diabetes effectively (Nagelkerk et al., 2006). Patients and health professionals in this study commonly suggested that knowledge of type 2 diabetes in general, a good understanding of an individual's specific management plan and the ability to understand information from health professionals, along with the link between effective management and the prevention of complications, facilitate effective management:

when you first get diagnosed, get as much information as you can, cos it can be a bit overwhelming. (P1 2)

As in the above extract, many health professionals and patients noted that patients need to be proactive in seeking information in order to manage effectively. Concurrent with the research of Nagelkerk et al. (2006), the majority of health professionals suggested that patients' lack of knowledge about type 2 diabetes and the requirements for effective management presented major barriers. Moreover, health professionals indicated that a lack of knowledge of specific aspects of management, coupled with a lack of skills required to manage effectively, resulted in sub-optimal management. Most commonly, a lack of meal preparation, exercise, self-monitoring and budgeting skills was reported:

so they don't have the cooking skills and preparation skills to organise all of the meals that they need to, and, like I said before, sometimes it's about budgeting, they may not have budgeting skills to ensure that they have purchased the right types of foods and the right amounts of foods. (HPI 5)

Peel et al. (2004) suggested that newly diagnosed patients would like more information at diagnosis; however, while they agreed that information was facilitative of effective management, the patients in this study did not explicitly report a lack of knowledge as a barrier to their management. In particular, only a few patients who participated in the focus group reported difficulty due to a lack of cooking skills, and those participants discussed alternatives such as finding appropriate ready-made meal options. The following participant, for example, talked about developing skills in choosing the healthiest ready-made options:

you know you would look at all of the products that you can buy and learn to read the labels. (FGP 6)

Health professionals in this study proposed that an understanding of the progression of the illness facilitates the uptake of information and the translation of information into behaviour change. In addition, many health professionals suggested that a lack of understanding about the seriousness of type 2 diabetes and its complications can lead to reduced emphasis on management and subsequent reduced impetus to partake in essential self-care behaviours:

I don't think there has been enough work in linking the concepts ... the community might see a heart attack, see someone go into stroke ... superficially some people get it, but I'm not sure its deeply understood by your average Joe on the street that diabetes is so much more than just pricking your finger. (HPI 3)

As in the above extract, the majority of health professionals in this study stressed the importance of understanding the severity of complications and links between poor management and complications. Many health professionals suggested that patients lack an understanding of the behaviour changes required to manage effectively and therefore reduce the likelihood of complications. This notion is not unique to this population, given previous research indicating that patients' lack of understanding of management plans presents a major barrier to effective management (Nagelkerk et al., 2006).

Lack of Time

Most health professionals and patients indicated that following recommendations for ideal self-management can be time-consuming, with many suggesting that people lack the time required to manage effectively. Time as a barrier to effective management may be more pronounced in a rural context as a farming lifestyle requires a large time commitment. Furthermore, many health professionals proposed that managing a chronic health condition is often not a priority in this context:

I think the time is a big thing, once again, the farming community, it's most important to put your crop in, that's, it's not important to see to your health, um, so I think it's

their attitude ... the farmers, see their time as most important, why would they waste it sitting in a doctor's room. (HPI 14)

It has also been suggested that this lack of time leads to a reduction in the ability to gain skills required to self-manage effectively. Literature regarding adherence to exercise for back pain (Dean et al., 2005) also suggests that time is a commodity in demand, especially so for those managing chronic conditions. In addition, several participants proposed that the insidious nature of type 2 diabetes is a major cause of reduced priority placed on management:

there is a lot of other things going on in their lives, um, I do think there is a relevance problem, in that yeah, if you can't see the damage happening then you don't react to it so yeah, lots of diabetes stuff is on the inside and not visible. (HPI 3)

This 'relevance problem' is suggested to occur as the result of the largely invisible nature of possible complications.

4.4.2 Interpersonal Influences

Stress

It was proposed, predominantly by health professionals, that high levels of stress divert priority away from management:

because we are a farming community and we have got the mines just up the road, people are, people's lives are very busy, very stressful, like we are in a drought, um, people being laid off from the mines, so I think, the, um, environmental stressors as well as the other, the social stressors play a huge part in, in that block to adequate looking after yourself ... your health just goes on the back burner. (HPI 6)

Health professionals reported that patients have many sources of stress such as family situations, financial stress and work-related stress. Additionally, stressors relating specifically to rural living, such as drought and farming issues, were reported as barriers. Interestingly, most health professionals reported some type of stress-related barrier; however, patients in this study did not report such barriers. This effect may be due to the self-selecting nature of the sample, which generally included patients who reported managing relatively well. These participants may have coping skills that enable them to find the time and energy to participate in research.

Relationships

The importance of supportive and encouraging personal relationships with people who promote accountability and provide assistance has been emphasised as important for those managing type 2 diabetes (Nagekerk et al., 2006). Likewise, the absence of supportive relationships with family, friends and health professionals has been suggested as a barrier to effective management in previous research (Korkiakangas et al., 2009). Age-related differences in support from a range of sources, including health professionals, have also been reported in an African American population (Hessler, Fisher, Naranjo, & Masharani, 2011). In accordance with these findings, both health professionals and patients in this study emphasised the importance of

secure and supportive relationships in effective type 2 diabetes management. Such relationships were suggested to facilitate effective management through a buffering effect during difficult times:

my husband's always supportive so, yeah, I think that if a lot of people are supportive around you, and know that you've got it, and, you know, they don't just shove things is your face and say, here, eat this coz they know that you shouldn't. (PI 1)

Here, the participant identified her husband's support, and others' knowledge of her type 2 diabetes, as being important to her ability to carry out the day-to-day requirements of management, a finding that supports previous research that identified spouses as the most frequently reported source of health-related social support across three ethnic groups (August & Sorkin, 2011).

However, previous research also suggests that spouses of people with type 2 diabetes are burdened by attempting to exert control over their spouses dietary behaviour, especially when these spouses showed poor adherence (August, Rook, Parris Stephens, & Franks, 2011). Continued open and supportive relationships with health professionals were also highlighted as facilitators of effective management in this study:

I think the thing is that the support by health professionals ... so knowing, they are not doing this on their own, and um, there is always help there available if they need it. (HPI 10)

Along with the role of health professionals in providing advice and guidance, and the need to be in regular contact with health professionals – factors that were almost always proposed to be essential for effective management – this participant suggests that the security of these continued relationships further facilitated effective management. Interestingly, only a few health professionals

and patients explicitly reported the absence of supportive relationships as presenting a barrier to effective diabetes management. However, those participants heavily emphasised that a lack of supportive relationships was highly detrimental to effective self-management.

4.4.3 Organisational Influences

The themes described here all relate to issues of access, a salient issue for individuals living in rural communities.

Recommended Foods

In addition to the barriers relating to knowledge of and skills to prepare appropriate skills identified in the 'Knowledge and skills' section, health professionals and patients suggested that effective type 2 diabetes management is facilitated by the availability of good-quality recommended foods at reasonable cost. Some patients suggested that they find the recommended diet restrictive, especially when they eat out in rural areas. Most health professionals suggested that reduced availability of fresh food in rural areas was a major barrier to effective management. Furthermore, the costs of recommended foods were suggested to be prohibitive to some patients:

the biggest restriction there is probably the cost of food, and the availability of good quality fresh food is appalling here it really is, it's much cheaper to buy a bag of hot chips from the supermarket than it is to buy a bag of apples. (HPI 9)

Here, the prohibitive costs of healthy foods are suggested to encourage people to take up less healthy options. Some health professionals also emphasised the importance of patients receiving

specific, locally relevant advice around healthy food choices to assist in preparing appropriate meals:

Um, when I was able to give them advice that was local, like specific to their local area ... products that I have actually bought at the local store, I think that really helped. (HPI 2)

Exercise Options

Some health professionals indicated that exercise options are limited for rural dwellers and that a lack of diversity in options for exercise contributed to difficulty in managing type 2 diabetes:

we didn't have a swimming pool dedicated to rehab and aqua types of sports, where people, you know with joint problems or really overweight or obese people could perhaps get in the water and do some kind of exercise. (HPI 5)

Both health professionals and patients commonly suggested that the lack of diversity in exercise facilities presents a barrier to effective management.

Transport

Although not a dominant theme, a lack of transport, both public and private, was suggested by both health professionals and patients to inhibit effective type 2 diabetes management. It was suggested that a lack of public transport in rural areas made it difficult for patients to attend required appointments and shop efficiently and, therefore, to self-manage well if they did not have private transport:

if you don't have transportation to get to [rural region of South Australia] it makes it a lot difficult, so people in the rural areas, um like further rural, would be a lot more disadvantaged by not having everything there at hand and some places don't have the internet, so you don't have the information. (PI 1)

This lack of transport for attendance at appointments, coupled with the lack of Internet in rural areas was proposed to contribute to an inability to gain information required to manage effectively.

Health Professionals

Regular access to a range of health professionals was reported as essential in gaining the help and information required for effective management. Previous research indicates that patient-practitioner relationships directly predict adherence to dietary and exercise recommendations (Maddigan et al., 2005). Importantly, participants in this study indicated that limited specialised health professional services, such as dietician, podiatrist and endocrinologist appointments, impede effective management by preventing rural patients from receiving adequate information. Furthermore, health professionals reported giving specialised information outside of their qualifications due to shortages of specialist services in rural and remote areas:

we would often have periods of three and six months without having an dietitian here um, so that meant that somebody like myself is giving dietary information ... I can give basic dietary advice but I'm not a dietician. (HPI 4)

Many health professionals suggested that the lack of readily available multidisciplinary care, combined with reduced training opportunities to update skills, resulted in sub-optimal patient care. These reports support previous patients' suggestions that uncoordinated care between hospitals and other health-care professionals, as well as limited resources, presented difficulties in their management (Nagelkerk et al., 2006). Health professionals in this study also noted that improved support systems and more readily available professional development opportunities would help to retain health professionals in rural areas, promoting continuity of specialised care and therefore improved quality of patient care. Additionally, it was noted that where there was access to specialised health professionals in rural and remote areas, long waiting periods for appointments presented difficulty:

if I have just been to that clinic area, um, last week, um, they [patients] are going to have to wait until I get back there next month. (HPI 11)

A lack of appointments, combined with long waiting periods, was suggested to result in reduced flexibility in appointment times, making the ongoing care that is needed to manage effectively unavailable to rural patients. Additionally, when patients do get appointments to see specialised health professionals, they reported waiting for long periods:

I go to doctor (name) and if you think you got a ten o'clock appointment and you think you are going to see her at ten o'clock you've got a second thought, you take a big book with you. (PI 10)

Furthermore, appointments are reported to be too short to develop rapport with clients, thus reducing the quality of patient care. Participants reported that a shortage of health professional availability in rural areas also leads to services that lack a focus on prevention:

physio services were more about like treating problems people already have, rather than preventative, so like mobility issues. (HPI 2)

It is emphasised here that health professional services have a focus on existing problems, rather than the prevention of future health issues, primarily due to a lack of time. Both a majority of health professionals and some patients suggested that better coordinated care, focussing on prevention within the services that health professionals provide, could improve future management.

Continuity of care is important in both effective type 2 diabetes management and in improving patient Health-Related Quality of Life (HRQoL) and treatment satisfaction (Hanninen, Takala, & Keinanen-Kiukaanniemi, 2001). However, continuity of care is often compromised in rural locations, where there is a tendency, confirmed by participants in this study, for health professionals not to stay in one job for extended periods of time. Furthermore, rural areas often lack health professionals with the experience to manage patients with complex needs and multiple illnesses effectively.

Despite the reported disadvantages of living in rural areas, some participants highlighted advantages, which included more integrated health systems in some centres, allowing consistent advice across health professionals and information about a client's management to be easily sourced. Health professionals also noted improved quality of care in areas serviced by a consistent group of health professionals due to their specific knowledge of the community, its services and

facilities. Some patients also reported that they benefited greatly from services in their area, which provide diabetes educator home visits.

4.4.4 Societal Influences

Engagement

Participants emphasised the role of employment and meaningful roles in the community as an indicator of 'getting their lives together' (HPI 3) and the ability to manage type 2 diabetes effectively. Physicians have previously suggested that social isolation presents a barrier to effective management (Wens et al., 2005). This study supports this finding, as social circumstances such as disengagement from the community, unemployment, lack of meaningful roles in society and isolation were reported to present barriers to effective management of type 2 diabetes:

people may not turn up, because um, other problems, you know like unemployment, and there was a lot of single mums and housing trust. (HPI 5)

Here, the lack of support for single parents, lack of financial resources and unemployment are proposed as barriers to effective management by reducing the ease with which people can attend appointments. The general stress that isolation and social circumstance place on the patient, along with a lack of encouragement and support, is also reported to contribute to the inability to manage effectively.

Societal Attitudes

Both participant groups commonly reported that patients felt that societal values and attitudes impacted their ability to manage effectively. Societal perceptions that type 2 diabetes is caused by poor lifestyle were suggested to elicit victim blaming for the illness. It was also suggested that community values that lack emphasis on prevention of chronic illness, along with perceptions that health services are primarily for the treatment of illness and injury, rather than for the promotion of future health, are detrimental to effective management. This supports previous research, which suggests that rural societal attitudes, such as stoicism, play an important role in the management of back pain (Dean, Hudson, Hay-Smith, Jean, & Milosavljevic, 2011).

Feelings of embarrassment, both in terms of the social stigma around having type 2 diabetes, and partaking in conspicuous behaviours essential to management, such as self-monitoring, exercising and taking insulin in public places, were proposed to prevent people from managing effectively:

I mean I had somebody tell me here last week, 'oh there is no way I am walking down the street, I wouldn't want anyone to see me'. (HPI 9)

The above extract is reflective of health professional reports that social embarrassment results in the reduction of self-management behaviours such as exercise, self-monitoring and taking medication. This finding mirrors Korkeakangas et al.'s (2009) review, which suggests that shame and feeling uncomfortable prevent patients from exercising.

4.4.5 Maintaining Lifestyle Changes

Participants identified many barriers to adherence to behavioural changes required for effective type 2 diabetes management at the interpersonal, organisational and societal levels. Perhaps most interestingly, study participants suggested that maintaining changes in lifestyle, previously noted to be essential to managing effectively in the long term (Nagelkerk et al., 2006), presents a major challenge. That is, people can make changes initially, and carry out required behaviours in the short term, but in the long term, these behaviours are not maintained. Both patients and health professionals emphasised the need to maintain behaviours from medium to long term in order to manage effectively:

I sort of get all, a bit razzed up when I come out of the hospital and diabetes educators, and that wears off after about a day and I just go back to doing what I normally always do. (PI 2)

This participant suggested that while in hospital for diabetes-related health problems, they are temporarily motivated ('razzed up') to change. However, this motivation is short lived as they soon return to their old ways. Health professionals have also suggested that people get 'tired' (HPI 17) of managing diabetes:

adhering to advice and maintaining adherence, because, yeah, often patients will adhere for a while, they will say that things are going good and then go back to their old ways. (HPI 16)

Such statements reflect a general perception among participants that while many people have the ability to make necessary lifestyle changes, effective management entails long-term adherence to advice and recommendations, and in many cases, these changes are not maintained. This finding is important in light of previous research that has suggested that as type 2 diabetic patients move through stages of change, from pre-action to maintenance, their self-determined motivation to exercise increases (Fortier et al., 2012).

The picture that emerges from this study is one whereby health promotion strategies are initially effective in providing people with the information to manage effectively, and people are able to acquire the understanding and skills to manage effectively, but barriers other than knowledge and skill acquisition then prevent individuals from maintaining these changes. This finding may have been somewhat pronounced in this study, as the self-selecting participants may already have been well-informed and highly invested in their management of type 2 diabetes. For other patients, knowledge and skill acquisition may present major barriers.

4.5 Conclusion

Prevention and management of chronic illness requires attention at multiple levels of influence, along with community engagement (Whittemore et al., 2004). This research drew upon both patients and health professionals in rural communities in order to identify facilitators and barriers to effective management across multiple levels of influence. While many of the barriers suggested in the study, such as lack of motivation, social expectations and unsupportive relationships may be applicable to both rural and urban contexts, factors that came under the theme of access, as well as specific issues around rural time management, may be more applicable to rural contexts. Unlike patterns evidenced in previous studies (Simmons, Lillis, et al., 2007), for the most part, both health professionals and patients broadly agreed in identifying barriers and facilitators to

effective management. This is possibly due to the self-selecting nature of the sample, which included patients who were more likely to be managing better than average, more informed and proactive with their management.

Current findings emphasise the need for more interdisciplinary and collaborative services, particularly in rural areas, while highlighting the need to retain health professionals in rural communities in order to achieve greater continuity of care and better rapport with patients, thus improving the quality of care and facilitating more effective management. It is also clear that potential barriers, specific to a patient's own context, should be taken into account when providing information and guidance about management, with advice and services tailored specifically to rural aspects of management. The need for increased focus on prevention of type 2 diabetes and associated complications in rural areas is further emphasised.

While this study adds valuable information about managing type 2 diabetes in a rural context, it must be considered in light of its limitations. Recruitment of individuals with type 2 diabetes living in rural areas was challenging. Due to the voluntary, opt-in nature of this recruitment, patients in this study were likely to be healthier, more highly educated and managing better than the general type 2 diabetes population. However, the inclusion of health professionals may have reduced this bias. Health professionals worked in a variety of roles in a number of rural settings, therefore providing a rich and varied account of type 2 diabetes management. However, it should be noted that rural communities are certainly not homogenous, and there may be environmental, geographic and other factors influencing the experience of people with type 2 diabetes in rural communities. This research was conducted with participants living and working in rural areas of South Australia, an area strongly affected by drought. Barriers affected by this issue may not be generalisable to other rural areas, and similarly, other areas may experience barriers not identified

here. Our findings, however, do resonate with those of Nagelkerk et al. (2006), whose research was conducted in rural America.

Data for this study were generated through telephone interviews and one focus group discussion, as these provided convenience and flexibility for participants. It has been suggested that factors affecting management at multiple levels of influence must be taken into account in order to promote the maintenance of behaviour changes (Emmons, 2000). Although focus group discussions have been reported to be useful in gaining information in health research (Wilkinson, 1998), more naturalistic settings, such as health professional–patient and patient–family interactions, may allow the intrapersonal and interpersonal themes identified in this analysis to be investigated in further depth. Consulting with already established community groups may have allowed the barriers at organisational and societal levels to be investigated further.

In light of the current findings, which highlight the complexity of effective type 2 diabetes management in rural areas, and previous literature suggesting that 'diabetes self-management is an enormously complex, multifactorial process influenced by a broad range of reciprocally interacting individual, social and environmental variables' (pg 613, Gonder-Frederick et al., 2002), future research should focus on the effect of management barriers on patient quality of life, and the ways in which these barriers, specific to a rural and remote environment, can be minimised to improve management and reduce incidence of complications. Consideration of factors that impede the maintenance of effective management behaviours might also be given special attention.

Chapter 5: Justification of Second Data Collection

The aim of the research presented in this thesis, as discussed in Chapters 1 and 2, is to investigate the barriers which impact on type two diabetes self-management in rural and remote living Australians. Study 1 identified many barriers to effective type two diabetes self-management for people living in rural and remote areas of South Australia. The barriers identified fit into themes relating to denial of the illness, motivation, knowledge and skills, lack of time, stress, relationships, access to recommended foods, transport and health professionals, social engagement, social attitudes and difficulties maintaining lifestyle changes. This chapter will provide a rationale for the second stage of data collection which formed the basis of Study 2 and Study 3, through examining some extra data from Study 1 and literature relevant to the variables measured.

The second stage of data collection was used to expand on the findings of Study 1 by adapting and validating a tool for measuring barriers to self-management in rural and urban contexts (Study 2), identifying demographic predictors of barriers to self-management and identifying barrier predictors of diabetes dependent quality of life in both rural and urban populations (Study 3). This chapter will discuss the development of the questionnaire used to collect the data that forms the basis of both Study 2 and Study 3.

5.1 Rationale for Second Data Collection

5.1.1 Participant Descriptions of Type Two Diabetes Self-Management

When asked about the aim of type two diabetes management in Study 1, both health professionals and people with type two diabetes commonly reported that it was to promote future

health and quality of life through the prevention of complications. Responses such as the following were common:

To prevent major at risk or high risk complications later in life (HPI 16)

Participants also emphasised that effective type two diabetes management could prevent premature death, reporting that it was so that they 'don't die' (P12). Furthermore, participants expanded on this notion, through statements like the following, which emphasised that quality of life could be improved through effective self-management:

Um, from my perspective, um, probably just, I look at it as if you don't manage diabetes it will manage you- so it kind of takes over people's lives, like especially up here¹ if they start getting bad complications so I guess just trying to avoid the serious complications so that people can have um- you know you don't have to have disability you know, and it sort of impacts on your lifestyle, with diabetes you can be totally on top of it, but there's kind of two paths people can go down, and I kind of try to steer them on the kind of like path that's going to stop all of that negative consequences (HPI 3)

Here, the respondent emphasised the need to control diabetes, as otherwise it 'takes over people's lives' through the manifestation of complications. Furthermore, these complications were presented as being avoidable through the description that 'you can be totally on top of it', with

¹ Participants have used the term 'up here' to talk about rural and remote areas in which they live. In South Australia, where this data was collected, more remote areas are mostly north of the urban centre of Adelaide, hence, the term 'up here'.

effective self-management. Therefore, the role of self-management was reported to be to avoid the disease having a large negative and controlling impact on an individual's life through 'stop[ping] all of that negative consequences'.

When asked about what it meant to manage type two diabetes effectively, both health professionals and people with type two diabetes in Study 1 reported that effective self-management involved people playing an active role in their diabetes management. It was reported that people with type two diabetes could do this through following the advice of health professionals, attending appointments, and independently seeking out information about their illness. In addition, effective management was also reported to be 'getting educated' and acquiring the knowledge and skills to manage the illness effectively. Behaviours which participants reported in Study 1 as being important in managing type two diabetes effectively, such as following a healthy, 'sensible' diet in line with healthy eating guidelines, exercising moderately and regularly, self-monitoring blood glucose levels, and taking medication as prescribed, mirror the current health promotion messages around type two diabetes self-management (Diabetes Australia, 2012a).

5.1.2 Informing Subsequent Studies

As discussed in section 1.1.5, promoting quality of life is a central aim of type two diabetes management. In addition, both health professionals and patients in Study 1 highlighted the importance of patient quality of life as a central goal of type two diabetes self-management. Furthermore, as concluded in Study 1 (L. Jones, Crabb, Turnbull, & Oxlad, Published online ahead of print 16/03/2013), research into the impact of barriers to type two diabetes self-management is needed, specifically in rural and remote areas. Therefore, it is important to briefly overview the

research into quality of life in people with type two diabetes, in order to provide context for the discussion of the rationale for development of the survey used in studies 2 and 3.

Previous researchers have indicated that it is essential to consider quality of life in health for three main reasons (Polonsky, 2002). Firstly, it is widely reported that people with type two diabetes have significantly impaired quality of life compared to people without type two diabetes (Glasgow, Ruggiero, Eakin, Dryfoos, & Chobanian, 1997). Secondly, patient perceptions of quality of life are recognised as the most important clinical and research outcome (Glasgow et al., 2001), due to the notion that successful management and interventions should reflect the positive impact of the treatment or management on patient well-being (Polonsky, 2002). Finally, investigation of quality of life is important in light of evidence which suggests that distress and poor quality of life impact on patients' ability to carry out self-management recommendations (Delamater et al., 2001, as cited in Polonsky, 2002). Thus, reduced quality of life is associated with poorer glycemic control (Rubin & Peyrot, 1999), which leads to long-term complications (Fowler, 2008). Furthermore, quality of life has been identified as the most appropriate outcome measure of barriers to self-management (Glasgow et al., 2001). Therefore, diabetes dependent quality of life was chosen as the outcome variable for Study 3.

5.2 Survey Design

Studies 2 and 3 were informed by the results of Study 1, which identified barriers to effective type two diabetes self-management in rural and remote areas of Australia. Study 2 built upon the results of Study 1 by adapting an already validated measure of barriers to self-management to include factors identified in Study 1 as relevant to rural and remote diabetics. This adapted measure was validated to assess its usefulness in a population of mixed rural and urban

type two diabetes patients. Study 3 built upon Study 1, Study 2 and the previous literature by assessing the importance of barriers to type two diabetes self-management on diabetes dependent quality of life.

Both Study 2 and Study 3 drew upon quantitative data collected through a self-report survey completed by people diagnosed with type two diabetes by a health professional. This section will describe the development of the self-report survey. Barriers to effective self-management and diabetes dependent quality of life were the key variables under study in Study 2 and Study 3. Firstly, the measurement of barriers to effective self-management will be discussed. Specifically, the choice and adaptation of the Diabetes Obstacles Questionnaire (DOQ) will be explained. Next, the measurement of quality of life will be discussed and the choice of the Audit of Diabetes Dependent Quality of Life (ADDQoL) will be outlined. The measurement of covariates - depression, anxiety, stress, type two diabetes complications, additional illnesses, and demographic variables - will also be discussed. The piloting process used for this survey, participant recruitment and a rationale for the use of paper and online surveys will be explained.

5.2.1 Measurement of Barriers to Effective Management

The Diabetes Obstacles Questionnaire (DOQ)

Many questionnaires have been designed to investigate obstacles to type two diabetes management. These questionnaires vary greatly in the types of barriers that they measure, and the length of the measures. In order to justify the use of the Diabetes Obstacles Questionnaire (DOQ) in this research, it is important briefly to discuss other measures which were considered.

The Problem Areas In Diabetes (PAID) scale (Polonsky et al., 1995), a 20-item questionnaire which investigates emotional problems reported by people with diabetes, was

considered; however this scale focused on emotional factors and so did not take into account issues of knowledge, access and services. The Diabetes Care Profile (J. T. Fitzgerald et al., 1996) was also considered for the current research. The Diabetes Care Profile is a 234-item scale which investigates social and psychosocial factors related to care in great depth. This scale investigates the importance of a variety of barriers to self-management, many of which are similar to the Diabetes Obstacles Questionnaire, such as attitudes, abilities, social and personal problems, importance placed on self-management, knowledge barriers and barriers to specific self-management behaviours. However, this scale was considered too long for use in the current study where it would be combined with other measures.

The Diabetes Obstacles Questionnaire (DOQ) was developed with the aim of providing a valid, meaningful and reliable tool for measuring obstacles to effective type two diabetes management. A literature review and focus groups in 6 European countries provided the basis for the development of the DOQ (Vermeire et al., 2007). The DOQ contains 78 items in 8 sub-scales, which are rated from 'Strongly Disagree' to 'Strongly Agree' on a five-point Likert scale. For the purposes of this research, the DOQ was scored from 'Strongly Disagree' (1) to 'Strongly Agree' (5) such that higher barrier scores indicate greater impact of barriers. The sub-scales relate to medication, self-monitoring, knowledge and beliefs, diagnosis, relationships with health care professionals, lifestyle changes, coping with diabetes, and advice and support. The DOQ has been validated in European countries including Belgium (Vandekerckhove, Vermeire, Weeren, & Van Royen, 2009), but not in Australia. Previous validations have indicated that the DOQ has good face validity, construct validity and internal reliability (Hearnshaw et al., 2007). The DOQ was chosen as a measure of barriers to effective type two diabetes management in the current research (Studies 2 and 3) due to the similarity between the barriers identified in the previous thematic analysis

(Study 1) and the individual items in the DOQ. The items in the DOQ which correspond well with barriers identified in Study 1 are shown in Table 2.

Table 2: Examples of barriers identified in the thematic analysis (Study 1) and related single items in the DOQ

Thematic Analysis barrier	DOQ sub-scale and item
Denial of the seriousness of the potential complications	Knowledge and Belief sub-scale 10. I don't believe the consequences of type 2 diabetes are serious
Lack of motivation to manage the illness	Diagnosis sub-scale 4. The way I was told that I had diabetes did not motivate me to manage my diabetes well Lifestyle Changes sub-scale 11. I lack the motivation to exercise Coping with Diabetes sub-scale 6. I feel that I would like to take a holiday from my diabetes
Lack of knowledge about management requirements	Knowledge and Belief sub-scale 1. I do not know as much as I need to know to manage my diabetes 4. I have difficulty understanding the information from health care professionals 6. I do not know as much as I need to know about the consequences of having diabetes
Lack of time to manage	Lifestyle Changes sub-scale 9. I am unable to fit exercise into my lifestyle Coping with Diabetes sub-scale 3. I find it difficult to get into a suitable routine to cope with my treatment plan Self-monitoring sub-scale 1. I find it especially hard to test when I'm busy
Lack of family/friend support	Lifestyle Changes sub-scale 3. My diabetes has put a strain on my personal

	relationships
	Coping with Diabetes sub-scale
	8. I feel that my family would like to take a holiday from my diabetes
	Advice and Support sub-scale
	7. I feel I get little support from my family
	8. I feel I get little support from my friends
Lack of health professional support	Relationships with Health Care Professionals sub-scale
	1. I feel my questions about diabetes are not answered
	2. I feel I am not listened to
	12. Talking about my diabetes with members of the diabetes team does not make me feel better
Social isolation and a lack of social support	Advice and Support sub-scale
	5. I would manage my diabetes better if I had more encouragement socially
	6. I feel very alone with my diabetes
Embarrassment	Coping with Diabetes sub-scale
	7. I eat something I should not rather than say I have diabetes
Services available	Relationships with Health care Professionals sub-scale
	17. Clinic times are inconvenient for me
	18. I have to spend too much time waiting in clinics

Adapting the Diabetes Obstacles Questionnaire

Barriers to effective self-management were identified in the thematic analysis in Study 1. As shown in Table 2, these barriers mostly fit well with the individual items presented in the DOQ. However, barriers identified in Study 1 relating to the difficulties of maintaining behaviour changes, and access to services, appropriate foods, exercise options and transport, which may be more relevant to rural and remote dwellers, were not accounted for in the original DOQ. Therefore, 10

items encompassing these barriers were developed in consultation with other health psychology researchers (the supervisors of this project). These barriers were written into the same format as existing DOQ items, and were then included in the whole survey. These items were added to the self-monitoring (n=2), lifestyle changes (n=2) and advice and support (n=1) sub-scales. A new sub-scale, labelled 'access' was also added to include barriers relating to access to appropriate foods, transport, exercise options and health professional services (n=5). These items are detailed in Study 2, Chapter 6, so will not be discussed in detail here. The adapted version of the DOQ was later piloted (as described in section 5.2.7).

5.2.2 Measurement of Quality of Life

As indicated earlier in this chapter, it is important to investigate quality of life in research into type two diabetes management and outcomes. Therefore, it is essential to consider the measurement of quality of life, both in general, and specifically related to type two diabetes.

A Cochrane review has highlighted the lack of clear definition of the concept of quality of life (Norris et al., 2011). This lack of definition makes accurate quality of life measurement difficult. However, as discussed in Chapter 1, The World Health Organisation Quality of Life Group has proposed the following definition of Quality of Life:

an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment (World Health Organisation Quality of Life Group, 1994, p. 43)

This definition has been used to conceptualise the term 'Quality of Life' in this thesis.

Quality of life has also been conceptualised as being related to an individual's health status. The impact of health status on quality of life is often referred to as Health Related Quality of Life (HRQoL). It is important to measure HRQoL as separate to health status (Bradley, 2001) because although two people may have the same illness characteristics and health status, they may have dramatically different quality of life (Guyatt, Feeny, & Patrick, 1993). For example, two people with type two diabetes may have the same blood glucose levels, or similar complications, but have very different psychosocial functioning; that is, the impact of the illness affects them differently. The concept of HRQoL has been discussed in further detail in Chapter 1 (1.1.4). This section will now focus on the measurement of HRQoL.

Many generic and specific measures of HRQoL exist (Luscombe, 2000). Generic measures of HRQoL assess the impact of health on quality of life in the areas of physical, social and psychological functioning (Polonsky, 2000). Generic measures of HRQoL allow comparisons between the quality of life of people with different illnesses (Rubin & Peyrot, 1999), and may be easier to administer due to having fewer questions (Guyatt et al., 1993), than illness-specific measures of HRQoL. However, they contain generic domains such as mobility which do not always have relevance to people with chronic illnesses such as type two diabetes, and do not cover important domains unique to specific illnesses, such as diet, which are relevant for these specific illness populations (Bradley et al., 1999). Illness specific measures of HRQoL assess domains affected by the illness, such as symptoms, self-care, functional ability and sexual functioning (Luscombe, 2000). It is important to recognise that, as there is conjecture about a definition of quality of life, there is also disagreement about what should be measured by illness-specific HRQoL measures. For example, some researchers have argued that illness specific HRQoL should only assess the subjective impact of the illness on physical, psychological and

social well-being (Polonsky, 2000), whilst others have suggested that almost all research investigating quality of life should use multidimensional assessments which also consider physical, psychological and psychosocial dimensions of life (Rubin & Peyrot, 1999).

Both generic and illness specific measures of HRQoL have advantages and disadvantages (Guyatt et al., 1993). Previous researchers have highlighted the importance of taking disease-specific characteristics of quality of life into account in the measurement of HRQoL, in order to investigate and address the impact of the illness properly (Polonsky, 2002). Illness-specific HRQoL assesses how the illness in question affects many aspects of the person's life, such as freedom, income and the quality of their environment (Polonsky, 2002) and allows the effect of an illness on a specific life function (for example, psychological functioning) to be determined (Rubin & Peyrot, 1999). In addition, specific measures have been suggested to be more responsive to change than generic measures because they include only the facets of HRQoL which are relevant to a clinical population (Guyatt et al., 1993). Therefore, in the current research, diabetes-dependant quality of life was used as an outcome measure to assess the impact of barriers to self-management.

Whilst many tools have been developed to measure HRQoL, it is important to recognise the multivariate nature of HRQoL (Polonsky, 2002). In a review of HRQoL measures, Gill and Feinstein (1994) suggested that a lack of emphasis on patient opinions can lead to suboptimal face validity. Gill and Feinstein (1994) have identified several important characteristics for effective measures of HRQoL. Firstly, it has been suggested that the inclusion of global ratings, in which respondents rate their overall quality of life, be coupled with global ratings of health related quality of life, in which patients rate their quality of life as determined by their health. The inclusion of two global ratings is suggested to allow differentiation between health-related factors and non-health related factors (Gill & Feinstein, 1994). This notion has also been supported by more recent

investigation into the measurement of HRQoL (Polonsky, 2002). Secondly, a good measure of HRQoL should allow respondents to rate the severity and importance of the domains of life represented in HRQoL measures. By rating the importance of the domain and severity of the impact of the illness, the measures will better capture the impact of illness on an individual's quality of life (Gill & Feinstein, 1994). Finally, it has been suggested that HRQoL measures should provide scope for respondents to elaborate on certain factors which have not been included in the measure, through the use of open response questions, thus increasing the comprehensiveness of the measure (Gill & Feinstein, 1994).

The Audit of Diabetes Dependent Quality of Life (ADDQoL) (Bradley et al., 1999) was chosen to measure illness specific HRQoL in the current research. The ADDQoL takes into account the multi-dimensional nature of health through the use of 19 domain-specific questions. Participants rate the importance to their life and the severity of diabetes impact, for each of the 19 domains. Two global rating scales, one relating to overall quality of life, and one relating to diabetes-dependent quality of life, are also included. Thus the ADDQoL overcomes HRQoL measurement issues suggested in previous literature (Polonsky, 2002).

The Audit of Diabetes-Dependant Quality of Life (ADDQoL)

The ADDQoL was designed with the aim of producing a measure of quality of life which takes into account the perceived impact of diabetes on an individual's life, while allowing individuals to indicate which aspects are relevant to them and to indicate subjective importance of these aspects of life (Bradley et al., 1999). Diabetes-specific measures, such as the ADDQoL, have been suggested to be more sensitive to change than generic measures such as the Short Form (SF) questionnaires (Bradley et al., 1999). In addition, the ADDQoL-19 has been shown to

have satisfactory reliability and validity (Polonsky, 2002) , with excellent internal reliability and construct validity (Bradley et al., 1999). Importantly, the reliability and validity of this measure has been demonstrated in an Australian population (Ostini, Dower, & Donald, 2011), further assuring its suitability for use in the current research. Despite its complexity, the ADDQoL-19 has been suggested to be appropriate for large-scale population based research (Bradley et al., 1999).

The ADDQoL-19 contains 19 domain-specific items, which contain two parts: part one asks the participant to rate the impact of diabetes on a specific aspect of life on Likert-type scales ranging from very much more/better/greater (-3) to less/worse (1), and part two asks the participant to rate the subjective importance of that aspect of life on Likert-type scales as above from very important (3) to not at all important (0). For example, for the question relating to freedom to eat as they wish, participants answer the question relating to how their life would be if they did not have diabetes:

(a) If I did not have diabetes, my freedom to eat as I wish would be:

○	○	○	○	○
Very much greater	Much greater	A little greater	The same	Less

Then, participants rate the importance of the domain to their life:

(b) My freedom to eat as I wish is:

○	○	○	○
Very Important	Important	Somewhat Important	Not at all important

Scores are then multiplied to produce a weighted score for each domain. The average of all weighted domains is then calculated to produce an overall score of diabetes-dependant quality of life. The ADDQoL-19 also contains two overview questions which ask about the participants' quality of life (in general), from excellent (3) to extremely bad (-3), and their quality of life (in

general) if they did not have diabetes, from very much better (-3) to worse (1) in order to provide global ratings, as discussed above.

5.2.3 Measurement of Depression, Anxiety and Stress

Given the aforementioned importance of depression in quality of life, adherence to recommendations, and presence of complications (section 1.4.1), a measure of depression was included in the second stage of data collection in order to investigate the effect of depression on quality of life and to account for this when investigating the barrier predictors of diabetes-dependant quality of life. As highlighted in a review produced by Glasgow and colleagues (2001; see section 1.1.4), depression can be conceptualised as a barrier (an independent variable), or as an outcome (dependant variable) in type two diabetes management research, depending on the research questions. In this research, depression was included as a covariate, in order to account for the effect of depression on both barriers to effective self-management and on diabetes-dependant quality of life.

Depression, Anxiety and Stress Scale- 21 (DASS-21)

Many depression, anxiety and stress measures exist (Sharp & Lipsky, 2002). The Depression, Anxiety and Stress Scale (DASS-21) was included in this survey as it is a quantitative measure of distress along the axes of depression, anxiety and stress. The DASS-21 is relatively short, which was seen as an advantage given the length of the survey and participant time considerations. Additionally, normative data derived from a large sample are available for comparison (Henry & Crawford, 2005; Lovibond & Lovibond, 1995). The DASS-21 is a shortened version of the DASS-42, which has been shown to have acceptable to excellent internal

consistency and concurrent validity (Antony, Cox, Enns, Bieling, & Swinson, 1998). The DASS-21 contains 21 questions, 7 relating to each of depression, anxiety and stress. Participants are asked to rate the relevance of each statement to them over the past week on a 4 point Likert-type scale ranging from 0 (did not apply to me at all) to 3 (applied to me very much, or most of the time). In scoring the DASS-21, scores for each of the domains (depression, anxiety and stress) are summed separately and multiplied by two to establish a score for each domain. It is important to note that the DASS is not a measure which is disease-specific, and it is used to measure Depression, Anxiety and Stress in a variety of clinical and research settings.

5.2.4 Measurement of Diabetes Complications

The presence of type two diabetes complications and additional illnesses have been found to impact significantly on quality of life in people with diabetes (De Grauw et al., 1999; Redekop et al., 2002; Wee et al., 2005). Therefore, it is essential to account for complications and co-morbidity in health research (S. Greenfield, 1989). Complications and additional illnesses were used as a covariate in the current research, such that their influence on diabetes-dependant quality of life was accounted for. Medical records are typically utilised to account for complications and co-morbidity, through indexes such as the Charlson Index (Charlson, Pompei, Ales, & MacKenzie, 1987); however, previous researchers have highlighted that this is an expensive process, and is often impractical in research contexts (Katz, Chang, Sangha, Fossel, & Bates, 1996). Therefore, survey alternatives, which ask about the presence of the condition in question, have been investigated. Evidence suggests that, for more serious and well-defined illnesses and conditions, self-report is likely to be valid (Katz et al., 1996).

It has been noted that there is a lack of consensus in the literature about what constitutes 'co-morbidity' (V. De Groot, Beckerman, Lankhorst, & Bouter, 2003). For clarity, the current study will use the term co-morbidity to describe other illnesses (in addition to type two diabetes) which are self-reported from a list. The list was compiled from literature about type two diabetes complications (Fowler, 2008), combined with suggestions from health professionals (who participated in Study 1) about illnesses which are common in the population under study. The response option 'other' was also included so that participants could nominate illnesses other than those included on the list.

5.2.5 Demographic and Management Variables

The questionnaire collected demographic information which included date of birth (day/month/year), gender, post code of place of residence and time since type two diabetes diagnosis (in years and months). Information relating to type two diabetes management was also collected, such as the type(s) of management used (that is; diet, exercise, medication, self-monitoring).

5.2.6 Stage of Change

As discussed in Chapter 3, data collection included a measure of Stage of Change, as defined in the Transtheoretical Model of change (TTM). Although these data were not used in final analyses due to a lack of participants in the Termination and Pre-action stages, a description of the questions will be provided here.

A variety of stage of change questionnaires were investigated. In the interests of keeping the measure as brief as possible, four multiple choice questions were developed, one for each of

the following self-management behaviours; taking medication, self-monitoring blood glucose levels, following a recommended diet, and following exercise recommendations. The response options for each item were:

Pre-contemplation- I have not made any changes to my (behaviour) and do not intend to in the next 6 months

Contemplation- I have not made any changes to my (behaviour) but I do intend to in the next 6 months

Preparation- I intend to make changes to my (behaviour) and am currently preparing to make these changes

Action- I have made changes to my (behaviour) in the last 6 months

Maintenance- I have made changes to my (behaviour) and have maintained these for MORE than six months

Termination- I have previously made changes to my (behaviour), but have not been able to maintain these changes.

These questions were adapted from one diabetes-specific stage of change study (H. Jones et al., 2003) and the format of the questions was adapted from a previously used bowel cancer screening questionnaire (Duncan et al., 2012).

5.2.7 Piloting the Survey

The draft questionnaire was piloted on a sample of health professionals including doctors (n=2), diabetes educators (n=3) and one dietician, and people known to the researcher (n=6), to

ensure readability and coherence. Supervisors of this project (n=3) also gave feedback about the content, relevance and readability of the questionnaire. It was suggested that the survey was quite long and time consuming, especially for a clinical population. Therefore, the Problem Areas In Diabetes (PAID) scale, which was used in the original validations of the DOQ (Vandekerckhove et al., 2009) to assess criterion validity, was not included in the final survey for use in establishing criterion validity. As discussed earlier in this chapter, the PAID was also not chosen to measure barriers to effective self-management as it focused primarily on psychosocial barriers, and it was decided that a broader measure be used to encompass a greater range of barriers in rural and remote and urban populations.

5.2.8 Ethical Approval

This study was considered to be low-risk, and therefore, ethical approval was granted by the School of Psychology sub-committee of the University of Adelaide Human Research Ethics Committee for the use of the questionnaire, recruitment avenues and participant incentives.

5.3 Data Collection

5.3.1 Sampling Strategy

The recruitment of participants for Study 1 was found to be difficult, probably due to a lack of contacts within the rural communities and health services as avenues for recruitment. Consequently, data collection took longer than expected. Given these difficulties it was decided that a convenience sample, containing anyone who had been told by a health professional that they had type two diabetes, would be utilised for the subsequent data collection. The limitations of convenience sampling—primarily, a lack of rigour due to selection bias—are widely noted in the

literature (M. N. Marshall, 1996). Despite these limitations, it was decided that convenience sampling was the best way to achieve the required recruitment of participants in a timely fashion. Also, given the long period of time which it took to recruit participants from a clinical population in rural and remote populations for Study 1, it was decided that data collection for the subsequent studies would occur simultaneously. Furthermore, both urban and rural participants were encouraged to participate, in order to provide greater numbers for the validation of the DOQ, and also to allow the comparison of rural and urban groups, which is insightful for both a contribution to the current literature around effective management and rural health, and for development of policy and models of care. As this project aimed to encompass a wide range of experiences, the only inclusion criteria applied to the sample was a diagnosis of type two diabetes by a 'health professional'.

5.3.2 Participant Recruitment

A variety of recruitment strategies were employed in this round of data collection. Firstly, participants from Study 1 who indicated that they would be interested in participating in future research were re-contacted and sent a paper copy of the survey (and information to access the online version if they preferred). Secondly, a media release was produced by The University of Adelaide (see Appendix 4), and released during Diabetes Week in July, 2011. Diabetes Week is an annual campaign week coordinated by Diabetes Australia whereby diabetes prevention and management are the focus of media releases and campaigns across Australia. The media release relating to the current study was sent to radio, print and online media sources Australia-wide. As initial data were collected, it became apparent, as expected, that most participants were from urban areas. Therefore, posters were created (see Appendix 5) and placed in post offices, on community noticeboards, and in health clinics in rural locations in South Australia, Western

Australia and Victoria. Finally, health professionals who participated in Study 1 were re-contacted and asked to give information about the survey to their clients at consultations. This recruitment strategy, while allowing greater participation, did not allow the researchers to gain any information about the people who chose not to participate.

5.3.3 Survey Format

Data for Studies 2 and 3 were collected both online, through Survey Monkey (<http://www.surveymonkey.com>), and via paper surveys. Previous research has indicated that online and paper-based health surveys are generally equivalent in the results that they produce (Vallejo, Jordan, Daaz, Comeche, & Ortega, 2007); although, in an adolescent population, it has been reported that an online version is favoured (Mangunkusumo et al., 2005). However, participants in both the studies by Vallejo et al. (2007) and Mangunkusumo et al. (2005) were adolescents or university students. In a study of older respondents, significantly less people participated in an internet-based survey when given the option of a hard copy (Bech & Kristensen, 2009). Furthermore, the people who did choose the online version were significantly younger, with higher income, health status and education levels than those who participated in the paper survey (Bech & Kristensen, 2009). Importantly for the current study, though, internet-based data collection has been suggested to allow researchers to access difficult-to-reach participant groups, such as rural populations and people with illnesses (Mann & Stewart, 2000). In addition, the use of internet-based survey in the current study is supported by previous literature which suggests that, in Australians aged between 50 and 74 years, over eighty percent have some form of internet access, and, furthermore, that over sixty percent seek health information via the internet (Zajac et al., 2012). However, this Australian study did not breakdown internet access by remoteness, and

the under-utilisation of computers and online forms of rural data collection has been highlighted in a review of rural American type two diabetes research (Williams Utz, 2008).

Online data collection in the current study allowed data to be collected quickly and at little cost (an important feature given the lack of funding for the project). This format also allowed participants to complete the survey in their own time, and to take breaks and come back to the survey if they wished, which was especially important with an older clinical population. Online data collection also allowed participants to respond to the media release advertising the study, the posters, or to information provided by health professionals about the study, anonymously and in their own time, by following the link provided. Furthermore, online surveys reduce the likelihood of missing data, due to the reminders to complete questions, reduce the chance of error in entering the data, and have thus been suggested to improve data quality (Bech & Kristensen, 2009).

However, a review of literature has documented many concerns with the use of internet-based data collection, such as the impact on the construct validity of the measures used and ethical issues regarding uncontrolled access to surveys (Whitehead, 2007). In addition, although internet surveys have been reported to gain better response rates than paper surveys from Americans assessing the quality of the health system, neither method yields a representative proportion of minority populations (Bethell, Fiorillo, Lansky, Hendryx, & Knickman, 2004). These ethical and sampling issues may present a potential problem in the type two diabetes population, as incidence of type two diabetes increases with age (AIHW, 2007a). In relation to consent with the online survey, a consent form was included in the online version as well as with the paper version.

Paper surveys identical to the online version were produced and provided to participants who indicated, when they contacted the researcher either in response to the media release or a poster, that they would prefer to complete in paper format (see Appendix 6 for survey). This

approach allowed people with type two diabetes who did not have computer or internet access to participate. Paper surveys were also given directly to patients by health professionals in rural and remote areas of South Australia who indicated that they would be willing to provide their clients with information about the study, to increase the participation in rural and remote areas. These health professionals gave participants a pack containing the information sheet, consent forms and survey for the participant to take away and consider their participation.

As an incentive to complete the survey, participants had the opportunity to provide contact details to be placed in a draw to win one of three vouchers for a store of their choice. This incentive was approved by the School of Psychology Sub-committee of the University of Adelaide Human Research Ethics Committee. Participants were also given the opportunity to provide contact details if they wished to receive a summary of the results of the study. These contact details were separated from the responses provided in order to maintain participant confidentiality and anonymity.

5.4 Summary

This chapter has provided background information about the development of the survey used to collect data for studies 2 and 3. Additional information about the recruitment strategies and survey piloting has also been provided, as the following two chapters, in the form of manuscripts submitted for publication, could not include detailed information due to word count limits. The following chapter will discuss the adaptation and validation of the DOQ in a mixed rural and urban population (Study 2). Chapter 7 will then discuss the predictors of barriers to effective diabetes self-management and the impact of barriers to self-management on diabetes-dependent quality of life (Study 3).

Chapter 6: Study 2- The adaptation and validation of a tool to measure barriers to effective type 2 diabetes self-management in rural and urban Australians

This chapter has been prepared in manuscript form and has been submitted to the Australian Journal of Rural and Remote Health.

Author Contributions

L. Jones (candidate)

Designed study, collected data, analysed data, wrote manuscript, edited manuscript.

I hereby certify that the statement of contribution is accurate

Signed:

Date:

4/7/2013

D. Turnbull

Conceptual input in design, provided advice on data collection, provided advice on writing of manuscript, edited manuscript.

I hereby certify that the statement of contribution is accurate

Signed:

Date:

3 July 13

S. Crabb

Conceptual input in design, provided advice on data collection, provided advice on writing of manuscript, edited manuscript.

I hereby certify that the statement of contribution is accurate

Signed: .

Date: 9/7/13

M. Oxlad

Conceptual input in design, provided advice on data collection, provided advice on data analysis,
provided advice on writing of manuscript.

I hereby certify that the statement of contribution is accurate

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Date: 3/7/13

6.1 Abstract

Introduction

The measurement of barriers to effective type 2 diabetes self-management is important for both research and practice, and many valid and reliable measurement tools exist. Previous reviews of literature have highlighted the importance of context-specific measures. However, current measures do not specifically encompass barriers relevant to people living in rural and remote contexts. The adaptation and validation of previously-validated tools which take into account barriers in rural and urban contexts is therefore important. This study aimed to investigate the factor structure of an adapted version of the Diabetes Obstacles Questionnaire (DOQ) in an Australian population, of both urban and rural dwellers with type 2 diabetes, thus bridging the gap in the barriers to type 2 diabetes management literature which has previously been identified.

Methods

The DOQ was adapted to include factors relating to rural and remote type 2 diabetes management identified by both patients and health professionals in a previous thematic analysis. Self-report questionnaires investigating the management of type 2 diabetes were completed by a non-purposive sample of 326 Australians living in rural and remote (n=110) and urban (n=216) contexts, with type 2 diabetes. This data was collected in both online (n=270) and paper (n=56) format. Principal Components Analysis (PCA) was conducted to determine the factor structure of the resultant questionnaire in a mixed rural and urban dwelling population. Separate PCA on the rural dwelling sample data was also conducted.

Results

Analysis resulted in 81 of the 88 items in the adapted version of the DOQ producing 7 sub-scales with Cronbach's α scores of >0.86 . These sub-scales represented barriers related to medication (10 items), self-monitoring (8 items), knowledge (6 items), relationships with health care professionals (24 items), psychosocial aspects (18 items), lifestyle changes (9 items) and access (6 items). Preliminary PCA of the useable rural participant data resulted in a similar factor structure.

Conclusion

The adapted version of the DOQ is valid in an Australian type 2 diabetes population, of people living in both rural and urban areas, and adds a new valid sub-scale which investigates issues of access, relevant to rural and remote dwellers. This adapted measure provides a tool for investigating the barriers to effective type 2 diabetes management in both rural and urban contexts, and thus allows for the comparison of barriers between these contexts, in order to inform the development of models of care which specifically target the barriers relevant in each context. Further investigation into the sub-scale structure of the adapted questionnaire in a rural and remote-only sample is needed for further validation.

6.2 Introduction

Type 2 diabetes is a major health problem in both developed (Boyle, Thompson, Gregg, Barker, & Williamson, 2010) and, increasingly, developing countries (Yoon et al., 2006). Furthermore, type 2 diabetes is expected to become the leading cause of disease burden by 2023 (Australian Institute of Health and Welfare, 2010). Adherence to health professional advice is considered to be essential to effective management, but it has been noted that adherence is rare (E. Lin et al., 2004) and difficult to achieve and sustain, due to the significant complex changes to lifestyle required (Gonder-Frederick et al., 2002), and the maintenance of these changes over time (L. Jones et al., Published online ahead of print 16/03/2013). Non-adherence is considered problematic, and many challenges to effective self-management have been proposed by both patients and practitioners (Nam, Chesla, Stotts, Kroon, & Janson, 2011), including the difficulty of making changes to lifestyle.

Furthermore, it has been reported that type 2 diabetes incidence and complications are twice as high in remote populations as in non-remote populations (AIHW, 2008a). In addition, systematic review and meta-analysis has indicated that the proportion of people in rural and remote areas with type 2 diabetes has increased dramatically over a twenty five year time period (Hwang, Han, Zabetian, Ali, & Venkat Narayan, 2012). The contexts in which people manage chronic illness are important factors in the barriers which they face in their self-management, an aspect which is particularly important in an illness such as type 2 diabetes, where effective management often requires modification of behaviours spanning multiple aspects of life simultaneously (Gonder-Frederick et al., 2002). Therefore, it is important to develop psychometrically valid and reliable measures of barriers to adherence which account for factors which are specific to these contexts, such as in rural and remote areas.

Thematic analysis (L. Jones et al., Published online ahead of print 16/03/2013) has investigated the barriers to, and facilitators of, effective type 2 diabetes self-management, and identified barriers at several levels of influence in rural and remote areas of Australia. It has previously been suggested that in order to maintain behaviour changes, it is important to take into account factors at different levels of influence on health behaviours (Emmons, 2000). Barriers at an intrapersonal level included a lack of motivation, denial of the seriousness of the illness and the consequences of poor management, a lack of time and type 2 diabetes management being a low priority for the use of this limited time. Barriers identified at the interpersonal level included high stress levels and a lack of supportive relationships, while at the organisational level barriers included a lack of access to appropriate food and exercise options and a lack of access to health professional services. Societal level barriers included factors such as unemployment, social isolation and embarrassment when exercising, taking medication and self-monitoring in public (L. Jones et al., Published online ahead of print 16/03/2013).

The DOQ was developed with the aim of producing a valid, reliable and meaningful tool for assessing obstacles to type 2 diabetes self-management which is easy to administer to a clinical population, while providing the ability to identify and focus on specific areas of management (Hearnshaw et al., 2007). The DOQ was developed from a review of both academic and lay (health promotion) literature about obstacles, and focus groups conducted across the United Kingdom and six other European countries, which identified barriers relating to the themes of the course of diabetes, information, person and context, body awareness and relationships with health care providers (Vermeire et al., 2007). Detailed information about the development and validation of the English version of the DOQ has been described elsewhere (Hearnshaw et al., 2007). However, as yet, this questionnaire has not been validated in an Australian population. As noted by Hearnshaw et al. (2007), the obstacles to effective management in specific populations may differ; it is

therefore important to validate this questionnaire specifically in a rural population as well as an urban population in Australia.

On the whole, barriers identified in the previous thematic analysis fit well with the barriers measured by the DOQ; however, barriers which may be more relevant to rural and remote management, such as the lack of access to health professionals and appropriate food options, are not prominent in this questionnaire. Factors which were suggested to span across many of the levels of influence, such as a lack of ability to maintain behaviours required for effective management, and a lack of focus on prevention of both the illness itself and associated complications were not encompassed by the DOQ.

The DOQ's ease of use has been emphasised (Hearnshaw et al., 2007). However, as the authors noted, the DOQ was not validated through exploratory factor analysis of the questionnaire as a whole to determine a factor structure in either the development of the questionnaire (Hearnshaw et al., 2007), or subsequent validations in European populations (Vandekerckhove et al., 2009). Rather, the eight sub-scales were generated through a review of literature and general face validity. Items remaining in each sub-scale after correlational analyses were factor analysed, however, this method does not allow the factor structure of the set of items as a whole to be determined.

The current study aims to build on previous validations of the DOQ by establishing its' validity in an Australian population. In order to address the aforementioned shortcoming of previous DOQ validations, this research will investigate the sub-scale structure of the DOQ through PCA of the whole questionnaire, as recommended by the original authors (Hearnshaw et al., 2007). Further, this study will adapt the existing DOQ to include barriers identified in previous research, as being relevant to rural and remote dwellers (L. Jones et al., Published online ahead of

print 16/03/2013), by including items which encompass these previously identified barriers. In addition, this study will utilise data from both rural and remote dwelling patients with type 2 diabetes, thus allowing the validity of the adapted DOQ to be established in a rural and urban dwelling population. Therefore, the current study will respond to calls for the development of practical assessments of barriers to type 2 diabetes self-management for use in specific contexts (Glasgow et al., 2001).

6.3 Methods

Development of DOQ

The DOQ is a 77 item questionnaire with 8 sub-scales: Medication (n=10), Self-monitoring (n=5), Knowledge and Beliefs (n=9), Diagnosis (n=6), Relationships with Health-Care Professionals (n=18), Lifestyle Changes (n=13), Coping (n=8) and Advice and Support (n=8). Each item is rated on a five-point likert scale (from 1= strongly agree to 5= strongly disagree), and represents one obstacle to effective management, with all items being weighted equally.

Instrument Adaptation

The adapted DOQ questionnaire contained 88 items; the original 77 from the previously validated DOQ and an additional 11 items reflecting barriers relevant to an Australian rural population as identified in a previous thematic analysis (6) of responses of 18 health professionals and 18 people with type 2 diabetes, using the methodology described by Braun & Clarke (Braun & Clarke, 2006). An additional sub-scale, 'Access', was created to reflect barriers relating to the lack of availability of health professional services, transport, and appropriate and affordable food and

exercise options. All additional items were presented in the same format as the original DOQ questionnaire. The changes arising from this analysis are as follows (Table 3).

Table 3: Items added to the adapted version of the DOQ following previous thematic analysis

Sub-scale	Questions added following thematic analysis
Self-monitoring	I don't know how to self-monitor properly Self-monitoring in public makes me feel embarrassed or uncomfortable
Lifestyle Changes	I find it hard to maintain the changes suggested to me It is too hard for me to prepare and cook meals that are recommended to me
Advice and Support	The health professionals available in my area do not have the experience to give me the advice I need, especially for multiple illnesses
Access (new sub-scale)	It is hard for me to make appointments with the health care professionals I need to see The health care professionals that I need to see are not available where I live It is too difficult for me to travel to appointments with health care professionals Health care professionals do not stay in my area long enough to give me continued support I do not have access to the foods which are recommended to me

Validation Design/ Procedure

Results of the initial DOQ validation indicated correlations between variables within each sub-scale. Therefore, when participants completed more than 50% of a given sub-scale, missing values for that sub-scale were estimated using responses present in that sub-scale. These values were estimated using Expectation-Maximisation (EM) algorithm (Dempster, Laird, & Rubin, 1977) which uses two steps (expectation, maximisation) in an iterative process until differences between

the two are trivial. Cases were then excluded pair-wise to remove cases which had completed less than 50% of each sub-scale from the analysis.

Kaiser-Meyer-Olkin (KMO) test was used to establish the appropriateness of the sample for factor analysis. Internal consistency of the scale was established using Cronbach's alpha both within sub-scales and for the survey as a whole, with values of 0.8 desirable (Kline, 1999). The Audit of Diabetes Dependant Quality of Life (ADDQoL) (Bradley et al., 1999) was included in this survey to assess construct validity, due to its' use in previous DOQ validations, its' demonstrable psychometric properties, and its' validation in an Australian population (Ostini et al., 2011). Content validity was assessed through literature review and consultation with health professionals and people with type 2 diabetes. Criterion validity of the DOQ has previously been assessed through correlation with the Problem Areas In Diabetes (PAID) scale (Welch, Jacobson, & Polonsky, 1997). However, following feedback from health professionals and people who piloted the current survey, it was suggested that the PAID not be included in the current study due to survey length, especially given the clinical target population. This is further vindicated by the attrition rate of participants who started the survey (13.5%).

Participants

Participants in this study were 326 Australians with type 2 diabetes. Participants were recruited through media release advertisements produced by the University of Adelaide, and posters on community notice boards. Participants had the option of doing the study online (n=270) or being sent a paper copy (n=56).

Participants were aged between 40.1 and 91.6 years (m= 67.5, SD=10.3), and came from areas with Accessibility Remoteness Index of Australia (ARIA) scores ranging from 0 (very

accessible) to 10.64 (very remote) ($m=1.69$, $SD=2.25$). The sample contained 60.8% males and 39.2% females. Time since diagnosis ranged from 0.1 to 50 years ($m=8.68$, $SD=7.59$). Participants also indicated which other illnesses and complications they had experienced, with high blood pressure being the most common ($n=199$), followed by arthritis ($n=87$) and heart disease and respiratory problems (both $n=46$). Participants in this study were managing their diabetes with diet ($n=118$), diet and exercise ($n=191$), medication ($n=242$) and no current management ($n=11$). An ARIA of greater than 1.84, in accordance with an 'accessible' classification (De Grauw et al., 1999) was selected for splitting the participants into 'rural' ($n=110$) and 'urban' ($n=216$) categories for further analyses.

This study was approved by the School of Psychology sub-committee of the University of Adelaide Human Research Ethics Committee.

6.4 Results

Missing Data

Little's MCAR test was insignificant ($p=.65$) and therefore it can be assumed that data were missing completely at random. Cases missing more than 50% of a given sub-scale were excluded. Excluded cases from each subscale were: medication ($n=9$), self-monitoring ($n=15$), knowledge ($n=14$), diagnosis ($n=15$), relationships with health professionals ($n=20$), lifestyle ($n=19$), coping ($n=20$), advice ($n=20$), access ($n=21$). Less than 7% of responses were missing across all original DOQ sub-scales.

Cases which had less than 50% missing on a given sub-scale were estimated using Expectation Maximisation method algorithm. This was used to estimate medication ($n=5$), self-

monitoring (n=4), knowledge (n=1), diagnosis (n=1), health professional relationships (n=3), lifestyle (n=4), coping (n=3), advice (n=3), access (n=0) responses.

Principle Components Analysis

Kaiser-Meyer-Olkin test of sampling adequacy was .94, indicating that the data are suitable for factor analysis. PCA with a varimax rotation was used to derive sub-scales from the 88-item adapted questionnaire. Seven factors were extracted, each with a minimum of 4 items with loadings of greater than .35, resulting in an 81-item scale. For the most part, the sub-scales proposed by Hearnshaw et al. (2007), were retained. Questionnaire items (n=13) which had loadings of greater than 0.35 in more than one factor were placed in the sub-scale (factor) on which they loaded highest.

A summary of the items in each of the original DOQ sub-scales and their relationship with the adapted questionnaire is presented in Table 4. A summary of the resultant sub-scales of the adapted version of the DOQ can be seen in Table 5. These sub-scales will be discussed in turn.

Table 4: Characteristics of items in each sub-scale in the adapted DOQ

Original Sub-scale	Original Items	Items in adapted DOQ	Other items included	Items loading on another sub-scale	Items loading on no sub-scale
Medication	10	10	0	0	0
Relationships with HPs	18	24	8	0	2
Diagnosis	6	Not retained	n/a	3	3
Lifestyle Changes	15	9	1	7	0
Coping	8	Not retained	n/a	8	0
Advice and Support	9	Not retained	n/a	9	0
Self-monitoring	7	8	1	0	0

Knowledge and beliefs	10	6	0	2	2
Access	5	6	1	0	0

Table 5: Adapted DOQ sub-scale characteristics: mean factor loadings, mean factor scores (SD), Cronbach's α (alpha) and correlations with Audit of Diabetes Dependant Quality of Life (ADDQoL) scores.

Sub-scale	Items (n)	Mean loading	Mean score (SD)	Cronbach's α	Correlation with ADDQoL
Medication	10	.66	3.85 (.90)	.90	.43*
Self-monitoring	8	.55	3.51 (.86)	.87	.45*
Knowledge	6	.60	3.61 (.91)	.86	.24*
Relationships with health care professionals	24	.61	3.49 (.84)	.96	.40*
Psychosocial	18	.49	3.27 (.87)	.95	.67*
Lifestyle changes	9	.61	3.12 (.89)	.90	.39*
Access	6	.61	3.70 (.92)	.89	.37*

*significant at $p < .01$ (2-tailed)

All items from the originally proposed medication sub-scale remained valid in the current study. The 10-item medication sub-scale showed excellent internal reliability with a Cronbach's α (alpha) of .90. Item loadings on this factor ranged from .55 to .75.

The originally proposed self-monitoring sub-scale was retained in this analysis. Three additional items also loaded on this factor; one from the 'coping' sub-scale, and two items added to

this scale by the researchers based upon previous thematic analysis. The resulting 8-item sub-scale had a Cronbach's α (alpha) of .87. Item loadings for this factor ranged from .36 to .70.

Six of the ten originally proposed 'knowledge and beliefs' sub-scale items were retained in this analysis. Two items loaded on the same factor which did not have enough item loadings to be considered a sub-scale and two items loaded on the 'relationships with health care professionals' sub-scale. The resulting 6-item sub-scale had a Cronbach's α (alpha) of .89, with items in this factor loading between .37 to .75.

The originally proposed 'diagnosis' sub-scale was not retained in this analysis. Three items loaded on the 'relationships with health professionals' sub-scale, while the remaining three items loaded on factors which did not have enough items to constitute sub-scales.

All but two of the originally proposed items from the 'relationships with health care professionals' scale were retained in this analysis. These items loaded on a factor which did not have sufficient items to constitute a sub-scale (both relating to clinic times). In addition, three items from the originally proposed 'diagnosis' sub-scale loaded on this factor, along with two items from the originally proposed 'coping' sub-scale and one item from the originally proposed 'advice and support' scale. The resultant 24-item sub-scale had a Cronbach's α (alpha) of .96. The item loadings on this factor ranged from .37 to .80.

The originally proposed 'lifestyle changes' sub-scale was split into two factors in this analysis. The first seven items relating to diet and social aspects were combined with items from the originally proposed 'coping' sub-scale (n=4) and the originally proposed 'advice and support' sub-scale (n=7) which also related to psychosocial aspects of management and social expectations. The resulting 18-item 'psychosocial' sub-scale had a Cronbach's α (alpha) of .95, and items had loadings on this factor ranging from .43 to .73. The remaining six items from the

originally proposed 'lifestyle changes' sub-scale loaded on one factor, along with one item from the original 'coping' sub-scale and two items added by the researcher following previous thematic analysis, which all related to exercise and making lifestyle changes. The resultant 9-item 'lifestyle changes' sub-scale had a Cronbach's α (alpha) of .90. The item loadings on this factor ranged from .37 to .83.

The original 'coping' subscale was not retained in this analysis as the items in this sub-scale loaded on the 'psychosocial' sub-scale (n=4), the 'lifestyle changes' sub-scale (n=1), the 'self-monitoring' sub scale (n=1) and the 'relationships with health care professionals' sub-scale (n=2).

Items from the original 'advice and support' sub-scale loaded on the 'relationships with health care professionals' sub-scale (n=1), the 'psychosocial' sub-scale (n=7), and the item added by the researchers loaded on the 'access' sub-scale. Thus the originally proposed 'advice and support' sub-scale was not retained in this analysis.

All five of the items in the 'access' sub-scale proposed to take into account barriers affecting rural and remote dwellers from previous thematic analysis were retained, along with one item added by the researchers to the 'advice and support' scale. The resultant 6-item sub-scale had a Cronbach's α (alpha) of .89. Items loadings for this factor ranged from .40 to .79.

Construct validity of the adapted DOQ was determined by correlations between each of the sub-scales with a measure of diabetes-dependant quality of life (ADDQoL). Moderate-high significant correlations with all sub-scales indicate good construct validity (Table 4). Face validity of this scale was established through consultation with both a range of health professionals (n=6), and a pilot study with a range of lay persons (n=6) of a variety of ages and backgrounds.

The usefulness of the resultant questionnaire in a rural and remote population was established through PCA of the questionnaire responses in rural and remote participants in this study (n=110). The medication sub-scale from the initial questionnaire requires only people taking medication to complete this section. Therefore this sub-scale caused a 'not positive definitive' result due to an insufficient sample size on those questions. When these items were removed, PCA produced a factor structure similar to that of the mixed population for the remainder of the items within the questionnaire. However some items had higher and more frequent cross-loadings in the rural sample than in the mixed sample and items within the self-monitoring and knowledge sub-scales did not load as cohesively. Whilst the sample size (n=110) for this population is deemed in the appropriate range (Tabachnick & Fidell, 2007), it is recommended that these analyses be repeated with a larger sample and that these findings be interpreted with caution, especially given the lower KMO of 0.61. We therefore recommend that this questionnaire, as validated in the mixed population, is appropriate for use within both a rural and remote and an urban population; however it is advisable to test the factor structure further within a larger rural and remote population in order to make stronger claims about the factor structure in this population.

6.5 Discussion

Recruitment of 326 participants who completed this questionnaire is considered adequate for Principle Components Analysis (Tabachnick & Fidell, 2007). However, the opt-in approach to recruitment may have led to some bias in the sample, in that the participants may be more educated, healthier and from higher socio-economic status backgrounds and therefore have greater interest in participating (Del Boca & Noll, 2000). Therefore, it is likely that the data for this study were drawn from a sample which has greater interest in their self-management and give self-management behaviours greater priority.

As can be seen in the mean scores for each barrier, which are relatively high (with higher scores indicating barriers are less pertinent to them), participants in this study experienced relatively low levels of barriers to effective management. The recruitment avenues of the study also meant that the researchers did not have access to individuals' medical records, as the previous two validations of the DOQ obtained to assess validity. Furthermore, due to nature of recruitment for this study, no information about the characteristics of non-participants, who may have seen advertisements or received a survey, is available for comparison. However, it has previously been noted that people who do not participate in research are likely to be less educated and have poorer health than those who do participate (De Grauw et al., 1999).

Most of the originally defined sub-scales (Vermeire et al., 2007) and 81 of the 88 items proposed in the adapted version of this scale were retained. The originally proposed 'coping' and 'advice and support' sub-scales were not retained, as could be expected from the emergence of a sub-scale focused on psychosocial aspects. The additionally proposed sub-scale relating to access and availability retained six items as expected.

Two items from the 'knowledge and beliefs' sub-scale, relating to a belief that the consequences are not serious and that type 2 diabetes is mild compared to type 1 diabetes loaded on one factor which did not have enough items to be considered a sub-scale. The remaining items in this sub-scale relate to knowledge and the individual's ability to access information. Given the similarity between the items which did not load on this factor, it is possible that participants in this study have responded differently to these items as they have differentiated between knowledge and belief about the seriousness of the illness. Interestingly, two items from this sub-scale which loaded on the 'relationships with health care providers' were both related to knowledge of the consequences of diabetes and benefits of treatment, therefore it is possible that these items are linked to perceptions of the role of a health professional. The 'relationships with health care

professionals' sub-scale retained most of the original items, whilst gaining some items which loaded from other sub-scales. Items in the resultant sub-scale related to communication, information provision, being included in decision making and patients' feelings at consultations. Two items relating to clinic times being inconvenient and waiting times in clinics, which loaded on a factor which did not form a sub-scale, may have been perceived as practical aspects and therefore separate to health professional relationships. However, these items both loaded quite strongly, and it may therefore be useful to add items in the future which may better investigate convenience as a barrier to effective management.

It has previously been suggested that the sub-scales of this questionnaire have the potential to be used separately (Hearnshaw et al., 2007), thus allowing relatively short and convenient assessment of barriers to specific aspects of management in both clinical and research settings. The high Cronbach's α scores from the current analysis lend support to this suggestion. However, given the high Cronbach's α of the questionnaire as a whole, which indicates that all items in the questionnaire are measuring a general 'management' construct, it may be useful for all sub-scales in the questionnaire to be administered.

The adapted version of the DOQ may have application in helping to develop and maintain a patient-centred approach, which has previously been noted as beneficial for reduction of complications (Susman & Helseth, 1997), in clinical settings. The adapted DOQ allows the identification of barriers specific to an individual's management, and therefore provides the opportunity for health professionals to better understand the circumstances of individuals' management and to tailor care and advice accordingly. This is especially pertinent given previous research which suggests that patients' health beliefs are not well understood by practitioners (Street Jr & Haidet, 2011) and that patients and practitioners perceive different barriers to the effective management of Type Two Diabetes (Simmons, Lillis, et al., 2007). The DOQ therefore

provides the opportunity to improve communication such that the barriers relevant to individuals are the driver of conversation and decisions around best management, thus promoting a patient-centred approach (M. Stewart, 2001). In addition, the facilitation of a patient centred approach, through using a tool such as the adapted DOQ, may help to inform patient-centred interventions, which have previously been suggested to have increased effectiveness (Renders et al., 2001) compared with non patient-centred interventions.

6.6 Conclusions

By investigating the usefulness of an adapted version of the DOQ in assessing barriers to effective type 2 diabetes self-management in both urban and rural and remote areas of Australia, this study provides an important contribution to both rural type 2 diabetes research and practice. The results indicate that the adapted DOQ is valid and reliable in an Australian population. Furthermore, preliminary analyses indicate that the adapted DOQ is appropriate for use in a rural and remote population. However, it is recommended that further analyses with larger samples be conducted to make stronger claims about the underlying factor structure in this population.

In addition to the applications of the DOQ for use for individual assessment of barriers, the adapted version of the DOQ, with the inclusion of the access sub-scale, may allow the assessment of barriers common to patient settings, with a view to informing the review or development of models of care for specific health care settings. This is especially important given the complex and multidisciplinary nature of the illness (Gonder-Frederick et al., 2002). Furthermore, research into the barriers which are faced in specific settings, using a psychometrically valid tool, may serve to better inform policy around the best management, allocation of services and needs of people such

that patients can better overcome barriers, manage more effectively and thus prevent complications.

Chapter 7: Study 3- Barriers to diabetes management as predictors of Diabetes

Dependant Quality of Life in Rural and Urban living Australians

This chapter has been prepared in manuscript form and has been submitted to the Australian Journal of Rural and Remote Health.

Author Contributions

L. Jones (candidate)

Designed study, collected data, analysed data, wrote manuscript, edited manuscript.

I hereby certify that the statement of contribution is accurate

Signed:

Date: 4/7/2013

D. Turnbull

Conceptual input in design, provided advice on data collection, provided advice on writing of manuscript, edited manuscript.

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Date:

3 July 13.

S. Crabb

Conceptual input in design, provided advice on data collection, provided advice on writing of manuscript, edited manuscript.

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I hereby certify that the statement of contribution is accurate

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Date: 3/7/13

7.1 Abstract

Background

Increased incidence of, and complications arising from, type 2 diabetes have been widely reported in rural and remote areas of Australia. Previous research has identified both barriers to effective type 2 diabetes management, and predictors of quality of life among people with type 2 diabetes. However, there is a paucity of research into the predictors of these barriers to management. Furthermore, as improving quality of life is the primary aim of type 2 diabetes management, it is important to investigate the barriers which best predict quality of life in both rural and urban populations. This study aimed to investigate demographic and psychological predictors of barriers to management, as well as the barriers which significantly predict diabetes dependant quality of life in Australians living in rural and urban areas.

Method

A non-purposive sample of 326 Australians with type 2 diabetes and living in rural (n=110) and urban (n=216) settings completed a self-report questionnaire containing demographic information, the Audit of Diabetes Dependand Quality of Life (19), the Depression, Anxiety and Stress Scale (21), and the adapted Diabetes Obstacles Questionnaire (DOQ). This questionnaire was completed in paper (n=56) or online (n=270) format.

Results

Depression, illness complications, age and remoteness were statistically significant predictors of various barriers to management. The demographic variables explained between 7% and 30% of variance in scores of various barriers. Quality of life in the rural and urban groups was similar. The only statistically significant predictor of quality of life in the rural population was

psychosocial barriers, whilst depression, psychosocial barriers and self-monitoring barriers statistically significantly predicted diabetes dependant quality of life in the urban population.

Conclusion

The current study supports previous research highlighting the importance of depression as a barrier to effective type 2 diabetes management. Unexpectedly, the rural and urban populations were similar in diabetes-dependant quality of life. Whilst barriers to management predicted diabetes dependant quality of life in both the rural and urban populations, they only explained 31% (rural) 36% (urban) of the variance, and therefore much variance is left unexplained. Importantly, this study highlights the different barriers which predict diabetes-dependant quality of life in rural and urban populations, and thus has important implications for the management of type 2 diabetes in these populations and the design of interventions to improve quality of life for in these populations.

7.2 Introduction

Type 2 diabetes accounts for 90% of diabetes worldwide (Cefalu, 2012), with diabetes and related complications having a significant economic impact on individuals, families, and health systems. It has been reported that diabetes rates are twice as high in remote areas as in non-remote areas (AIHW, 2008a). In addition, diabetes-related hospitalisation rates are two and three times higher for rural and remote populations respectively, than for people in urban areas (AIHW, 2008a). Moreover, deaths due to diabetes are two and four times as high in rural and remote areas respectively, than in urban areas (AIHW, 2008a). It is therefore important to investigate the management of type 2 diabetes specifically in rural and remote contexts.

In general, type 2 diabetes is poorly managed (C. C. Lin, Anderson, Hagerty, & Lee, 2008), thus many barriers to effective type 2 diabetes management have been identified (Nam et al., 2011). Given the higher incidence of both diabetes and associated complications in rural and remote areas (Australian Institute of Health and Welfare, 2008a), barriers relating to a rural context have also been investigated (Nageikerk et al., 2006). People with type 2 diabetes living in rural and remote areas not only experience the same strains of managing their illness as people in urban areas experience (Gonder-Frederick et al., 2002), but may also experience additional strain and barriers such as the need to travel for specialist treatment, a lack of locally-available services, and limited access to recommended foods in further remote areas (L. Jones et al., Published online ahead of print 16/03/2013). Although many barriers to effective care have been identified in both rural and urban areas, the demographic predictors of these barriers have not been examined. Knowledge of factors which predict barriers to effective management is essential in identifying which barriers may be most relevant to an individual, and in developing plans to overcome such barriers.

It is widely reported that people with chronic illness have poorer quality of life than those without (A. L. Stewart et al., 1989; Wee et al., 2005). People along the diabetes continuum have poorer health status (Chittleborough et al., 2006) and health-related quality of life (Wee et al., 2005) than people with blood glucose levels within the normal range. Importantly, lower health-related quality of life is associated with increased mortality in type two diabetes patients, with patients scoring poorly on a Health Related Quality of Life (HRQoL) measure over twice as likely to have died at 6-year follow-up, compared to those with higher scores (Kleefstra et al., 2008).

Improving quality of life is the ultimate goal of health interventions and management of chronic conditions (Rubin & Peyrot, 1999). A multitude of studies have investigated predictors of reduced health-related quality of life in people with type 2 diabetes. Demographic variables such as female gender (Rubin & Peyrot, 1999) and younger age (Redekop et al., 2002) have previously been associated with poorer quality of life in people with type 2 diabetes. However, inconsistencies in literature about the predictors of health-related quality of life exist. In a review of the effect of duration of diabetes on quality of life, Rubin and Peyrot (1999) reported mixed findings, with some studies finding a significant impact of duration of illness on reduced quality of life, while other papers reported no significant relationship. In addition, it has been widely reported that the presence of additional chronic illnesses (Wee et al., 2005) and diabetes complications further reduces quality of life (De Grauw et al., 1999) (Redekop et al., 2002), with suggestions that complications are a major disease-specific indicator of quality of life. Furthermore, Rubin and Peyrot (1999) have suggested that this association between complications and quality of life is so strong that it may mediate the effects found between other variables and quality of life, thus highlighting the need to account for complications when investigating predictors of quality of life in people with type 2 diabetes.

Meta-analysis of research investigating the prevalence of co-morbid depression reported that people with diabetes were twice as likely to have depression than non-diabetics, with elevated depressive symptoms present in 31% of diabetic patients (R. J. Anderson et al., 2001). People with type 2 diabetes and co-morbid depressive symptoms have been shown to have significantly reduced quality of life and health status (Sundaram et al., 2007). Importantly, depression and anxiety were associated with an increased number of symptoms (Paschalides et al., 2004) and the presence of complications (Peyrot & Rubin, 1997). After 3 years, depression remained a significant predictor of mortality for people with diabetes (Katon et al., 2005) thus it is important to include depression in the study of quality of life in people with diabetes (Rubin & Peyrot, 1999).

Whilst many predictors of quality of life have been identified in people with type 2 diabetes, and many barriers to effective management have been identified, there is a lack of research which investigates the associations between barriers to effective management and quality of life in this population. Furthermore, it has been suggested that, when investigating barriers to effective management, quality of life is one of the best criterion variables to use (Glasgow et al., 2001). Previous literature highlighted the need to identify similarities and differences between barriers impacting on effective management in different contexts (Glasgow et al., 2001), and that people living with type 2 diabetes in rural and remote areas experience different additional barriers to management (L. Jones et al., Published online ahead of print 16/03/2013) and have worse health outcomes than those in urban areas (AIHW, 2008b). It is therefore important to investigate which barriers to care significantly predict diabetes dependant quality of life in both rural and urban contexts.

The current study aims to address two gaps in the type 2 diabetes management literature. Firstly, this study will investigate the demographic and psychological predictors of barriers to effective management in a mixed rural and urban sample. It is hoped that investigating predictors

of barriers to effective management can help to inform models of care which may overcome such barriers, and help to identify individuals who may experience greater barriers to management. Secondly, this study will aim to investigate the barriers which are important in predicting diabetes dependant quality of life in rural and urban contexts separately. Investigations of the effect of barriers to care on diabetes dependant quality of life can help to better inform interventions which aim to improve diabetes dependant quality of life in people with type 2 diabetes in both rural and urban contexts.

7.3 Methods

Participants

Participants in this study were a non-purposive sample of 326 Australians who self-identified as having been diagnosed with type 2 diabetes. One hundred and sixteen females (39.2%) and 180 males (60.8%) participated. Participants were aged between 40.1 and 91.6 years ($m= 67.5$, $SD=10.32$), and lived in areas with Accessibility Remoteness Index of Australia (ARIA) scores ranging from 0 (highly accessible) to 10.6 (very remote) ($m= 1.68$, $SD= 2.25$). Participants had been diagnosed with type 2 diabetes between 0.1 and 50 years ago ($m=8.7$, $SD= 7.6$). Full descriptive statistics are provided in Table 1.

Participants were recruited through a media release produced by the University of Adelaide, posters advertising the study, and through information about the study provided by health professionals.

Materials

Participants completed a survey anonymously either online or in paper format. The survey contained demographic questions including age, gender, time since diagnosis, current diabetes management and any current complications and other illnesses. The adapted Diabetes Obstacles Questionnaire (DOQ) (Hearnshaw et al., 2007; L. Jones, Turnbull, Crabb, & Oxlad, Under Review) was included as a measure of barriers to effective management. Health related quality of life was assessed through the use of the Audit of Diabetes Dependant Quality of Life (ADDQoL-19) (Bradley et al., 1999) due to its demonstrable validity in an Australian population (Ostini et al., 2011) and ability to encompass the multi-dimensional subjective nature of quality of life, thus overcoming difficulties with quality of life measurement suggested in previous literature (Polonsky, 2002). Depression, anxiety and stress were assessed using the short form Depression Anxiety and Stress Scale (DASS-21) (Lovibond & Lovibond, 1995).

The adapted DOQ encompasses 7 barrier categories as follows; Health Professional Relationship barriers refer to the assistance, advice and information provided by health professionals and interpersonal relationships with the health professionals and management team. Psychosocial barriers relate to support from friends and family, feelings associated with management, and the impact of diabetes on social life and relationships. Lifestyle barriers relate to ability to make and maintain lifestyle changes and routine. Medication barriers relate to feelings about medication type, dose, side-effects and the physical act of taking medication. Self-monitoring barriers relate to feelings about self-monitoring and practical factors such as convenience and time. Knowledge barriers relate to knowledge of consequences and treatments, and information which is available to the patients. Access barriers relate to difficulties accessing health services and appropriate foods. Validation of the adapted DOQ in an Australian population of rural and urban dwelling people with type 2 diabetes indicated that the scale has high internal validity

(cronbach's $\alpha > .86$ for each sub-scale). The DASS-21 scales have also been shown to have high internal reliability (Henry & Crawford, 2005). The ADDQoL has been shown to have good discriminant validity and high internal reliability in an Australian population (Ostini et al., 2011).

Procedure

The survey was piloted with health professionals (n=6) and people of a variety of ages (n=6) to ensure face validity. Participants opted-in to this survey voluntarily through response to advertisements or anonymously completing a survey given to them by their health professional, and 82.8% (n=270) completed the survey online while 17.2% (n=56) were sent a paper copy.

This study was approved by the School of Psychology sub-committee of the University of Adelaide Human Research Ethics Committee.

Analysis

Preliminary analyses were carried out to identify statistically significant associations between variables. Correlations were conducted to identify statistically significant associations between continuous demographic variables, barriers to effective management and diabetes-dependant quality of life. Independent samples t-tests were conducted to determine whether there were statistically significant differences between categorical demographic variables in barriers to effective management and diabetes-dependant quality of life. Variables with statistically significant associations were then used in multivariate analyses.

Multivariate analyses were conducted to determine the most important predictors of barriers to effective management and diabetes-dependant quality of life in both the rural and urban

populations. Variables which were found to be statistically significantly related to barriers to effective management in the preliminary analyses were entered into multiple regressions to identify important predictors of each type of barrier to effective management. Demographic variables which were found to be statistically significantly related to diabetes-dependant quality of life were entered at Step 1 of a linear regression, and barriers which were found to be statistically significant were entered at Step 2. Linear regressions were conducted for both the rural and urban data.

7.4 Results

7.4.1 Descriptive Statistics

As shown in Table 6, participants reported managing their diabetes with diet (n=118, 36.2%), diet and exercise (n=191, 58.6%), medication (n=242, 74.2%); some participants reported no current management (n=11, 0.3%). Among other illnesses and complications participants had experienced, high blood pressure was the most common (n=199, 61%), followed by arthritis (n=87, 26.7%), heart disease (n=46, 14.1%) and respiratory problems (n=46, 14.1%).

Table 6: Descriptive statistics (demographics, QoL, barriers, depression, anxiety, stress scores)

Variable	n	Mean	Min	Max	SD
Age (years)	284	67.5	40.1	91.6	10.32
Time since Diagnosis (years)	283	8.69	.1	50	7.60
Complications (number)	326	1.51	0	8	1.43
ARIA score (index)	293	1.69	.00	10.64	2.25
ADDQoL(19) score	298	-1.91	-9	6.21	2.16
Anxiety	301	8.51	.00	42	8.71
Depression	300	10.6	.00	42	11.28

Stress	300	12.02	.00	42	10.84
Access barrier	304	2.30	1	5	.92
Lifestyle barrier	305	2.89	1	5	.90
Psychosocial barrier	301	2.73	1	5	.87
Health professional relationship barrier	298	2.51	1	5	.83
Knowledge barrier	311	2.39	1	5	.91
Self-monitoring barrier	300	2.48	1	5	.86
Medication barrier	311	2.15	1	5	.89

7.4.2 Predictors of Barriers to Effective Management

Preliminary Analyses

Preliminary analyses were conducted to determine which relationships between demographic variables and barriers to management were statistically significant. Of the barrier scores, age was statistically significantly positively correlated with lifestyle barriers ($r=.197, p<.01$), psychosocial barriers ($r=.144, p<.05$), and self-monitoring barriers ($r=.176, p<.01$).

A statistically significant difference between gender means for psychosocial barriers was observed, with females scoring higher ($n=113, M= 2.85, SD=.89$) than for males ($n=177, M=2.64, SD=.85$), $t(288)=-2.05, p<.05$, effect size (d)= -0.25, thus indicating that females experienced statistically significantly more psychosocial barriers than males. No other statistically significant differences between genders on barrier scores were evident.

With regards to relationships between remoteness and barriers to care, correlational analyses indicated that remoteness (ARIA score) as a continuous variable was statistically significantly related to barrier scores on knowledge ($r=.15, p<.05$) and access ($r=.33, p<.01$), but no other barriers. An ARIA of greater than 1.84, in accordance with an 'accessible' classification

(Australian Institute of Health and Welfare, 2004) was selected for splitting the participants into 'rural' (n=110) and 'urban' (n=216) categories for further analyses. Access barrier scores were statistically significantly different for rural (n=104, M=3.34, SD=1.0) and urban (n=185, M=3.99, SD=.77) participants, $t(288)=-5.15$, $p<.01$, effect size (d)= -.63. Knowledge barrier scores were statistically significantly higher in the rural (n=105, M=2.58, SD=.85) than in the urban population (n=185, M= 2.23, SD=.89), $t(286)=3.31$, $p<.01$, effect size (d)= .40. No other statistically significant differences between rural and urban groups were present in barrier scores.

Time since diagnosis was only statistically significantly related to barriers relating to medication ($r=.164$, $p<.01$), while stress, anxiety and depression were statistically significantly related to all barrier scores, and number of complications was statistically significantly related to all barriers except for access (see Table 7).

Table 7: Correlations between Depression, Anxiety and Stress scores and barriers to management scores

	Depression	Anxiety	Stress	Complications
Access	.36**	.33**	.35*	.11
Lifestyle	.46**	.37**	.40**	.17**
Psychosocial	.53**	.43**	.49**	.21**
Health Professional Relationships	.40**	.34**	.34**	.21**
Knowledge	.23**	.20**	.24**	.12*
Self-monitoring	.42**	.36**	.36**	.15*
Medication	.32**	.33**	.30**	.18**

*Statistically significant at $p<.05$, **Statistically significant at $p<.01$.

Multivariate Analyses

Demographic variables statistically significantly related to each barrier were entered into linear regression analyses, in order of highest to lowest correlation coefficient, to determine the most important predictors of these barriers. Variables which did not statistically significantly predict the barrier scores were subsequently removed from the model. A summary of statistically significant predictors for each barrier category is presented in Table 8 (below), and statistically significant predictors of each barrier category will be discussed in turn.

Access

Depression, anxiety, stress and remoteness (ARIA score) were found to be statistically significantly related to access barriers, and were entered into a regression model which explained 21% ($F(5, 281) = 14.8, p < .001$) of variance in access barrier scores. Remoteness and depression were the only two statistically significant predictors of barriers related to access.

Lifestyle

Depression, anxiety, stress, complications and age were found to be statistically significantly related to lifestyle barriers and were thus entered into a regression model which predicted 22% of variance in lifestyle barrier scores ($F(5, 272) = 15.33, p < .001$). Age, depression and complications were statistically significant predictors of lifestyle barriers.

Psychosocial

Depression, anxiety, stress, complications and age were statistically significantly related to psychosocial barrier scores. This regression model accounted for 29.6% of variation in psychosocial barrier scores ($F(5, 270) = 22.7, p < .001$). Age, depression and complications were statistically significant predictors of psychosocial barriers.

Health Professional Relationships

Depression, anxiety, stress and complications were found to be statistically significantly related to health professional relationship barriers and were thus entered into a linear regression which accounted for 18% of the variance in health professional relationship barrier scores ($F(4, 288)=15.6, p<.001$). Depression and complications were the only two statistically significant predictors of health professional barriers.

Knowledge

Depression, anxiety, stress and complications were entered into a linear regression which predicted 6.9% of variance in knowledge barrier scores ($F(4, 290)= 5.4, p<.001$). However, none of the demographic variables entered statistically significantly predicted knowledge barrier scores.

Self-monitoring

Depression, anxiety, stress, complications and age were found to be statistically significantly related to self-monitoring barriers and were entered into a regression model which predicted 19% of variance in scores for self-monitoring barriers ($F(5, 267)= 12.2, p<.001$). The only statistically significant predictors of self-monitoring scores were age and depression.

Medication

Depression, anxiety, stress, complications and diagnosis length were statistically significantly related to medication barriers, and were thus entered into a linear regression which predicted 12% of variance in medication scores ($F(5, 271)=7.5, p<.001$). None of the demographic variables statistically significantly predicted variance in medication barrier scores.

Table 8: Variables statistically significantly predicting barriers to effective management

Barrier	Predictor Variable	Standardised coefficients B (95% CI)	Significance
Access	Remoteness	.30 (.08, .16)	<.05
	Depression	.24 (.00, .04)	<.001
Lifestyle	Age	.17 (.01, .02)	<.05
	Depression	.29 (.01, .04)	<.01
	Complications	.10 (-.01, .137)	<.01
Psychosocial	Depression	.41 (.02, .05)	<.001
	Complications	.14 (.02, .15)	<.05
	Age	.11 (.00, .02)	<.05
Health professional Relationships	Depression	.37 (.01, .04)	<.01
	Complications	.13 (.01, .14)	<.05
Knowledge	No statistically significant predictors	n/a	n/a
Self-monitoring	Depression	.4 (.01, .05)	<.001
	Age	.17 (.01, .02)	<.01
Medication	No statistically significant predictors	n/a	n/a

7.4.3 Predictors of Diabetes Dependant Quality of Life

Preliminary Analyses

Preliminary analyses indicated that age and time since diagnosis were not statistically significantly correlated with Diabetes Dependant Quality of Life scores and no statistically significant differences between male and female quality of life scores were observed.

Urban dwellers had poorer diabetes-dependant quality of life ($n= 185$, $M=-2.01$, $SD=2.05$) than the rural dwellers ($n=107$, $M=-1.80$, $SD= 2.23$), a difference which was not statistically significant ($t(290)=0.83$, $p>.05$). Additionally, remoteness as a continuous variable was not statistically significantly related to Diabetes Dependand Quality of Life ($r=.07$, $p>.05$).

Depression ($r=-.250$, $p<.01$), anxiety ($r=-.154$, $p<.01$) and stress ($r=-.234$, $p<.01$), were all statistically significantly related to Diabetes Dependand Quality of Life, along with total number of complications ($r=-.134$, $p<.05$). Number of complications was also statistically significantly related to stress ($r=.203$, $p<.01$), anxiety ($r=.276$, $p<.01$) and depression ($r=.227$, $p<.01$).

All barrier categories were statistically significantly related to diabetes dependant quality of life in both rural and urban populations (see Table 9).

Table 9: Correlations between barrier categories and diabetes dependant quality of life for urban and rural populations.

Barrier	Correlation (Urban)	Correlation (Rural)
Access	-.40**	-.31**
Lifestyle	-.38**	-.30**
Psychosocial	-.58**	-.46**
Health Professional Relationships	-.36**	-.25*
Knowledge	-.24**	-.16
Self-monitoring	-.34**	-.27**
Medication	-.31**	-.35**

*Statistically significant at $P<.05$, **Statistically significant at $p<.01$.

Multivariate Analyses

In order to investigate the contribution of various barriers to diabetes dependant quality of life in both urban and rural populations in this sample, two linear regressions were carried out as previously indicated. Demographic and psychological variables found to be associated with either barriers to management or to diabetes dependant quality of life, and hence considered covariates, were entered at the first step. Barriers were then entered at the second step to determine their relative importance in accounting for diabetes dependant quality of life.

Rural Participants

Variables entered at Step 1 were depression, anxiety, stress, age and complications. The 7 barrier categories were entered at Step 2. The resultant model indicated that demographic and psychological variables accounted for 8.7% of the variance in diabetes dependant quality of life scores in the rural population, which was not statistically significant ($F(5, 102)= 1.95, p=.09$). When barriers to management were added, the resultant model, predicted 31.3% of the variance in diabetes dependant quality of life scores ($F(12, 95)= 3.6, p<.001$). However, the only statistically significant predictor was psychosocial barriers, although stress did approach significance ($p=.057$) (see Table 10).

Urban Participants

Linear regression to identify predictors of diabetes dependant quality of life was carried out in the urban population with the same method as the rural population. Demographic and psychological variables in the urban sample explained 15.6% of variance in diabetes dependant quality of life scores ($F(5, 167)=6.17, p<.001$). When barriers to effective management were entered at step 2, the total variance explained increased to 36.3%, ($F(12, 160)= 7.6, p<.001$). Depression, psychosocial barriers and self-monitoring barriers were statistically significant predictors of diabetes dependant quality of life in the urban population (see Table 10).

Table 10: Statistically significant predictors of diabetes dependant quality of life scores for rural and urban participants

Rural/Urban	Predictor	Standardised coefficients B (95% CI)	Significance
Rural	Psychosocial	-.64 (-.26, -.71)	<.01
Urban	Depression	-.36 (-.12, -.02)	<.01
	Psychosocial	.25 (.11, 1.1)	<.001
	Self-monitoring	-.65 (-2.1, -.96)	<.05

7.5 Discussion

The results of this study indicate that depression is a statistically significant predictor of most barriers to effective management. Given the importance of depression and psychosocial barriers in predicting quality of life, in both this study and previous research (Sundaram et al., 2007), it is important to emphasise the role of psychological services in the care of people with type 2 diabetes both in urban areas, and in rural areas, where a lack of psychological services has been reported (McGovern & Hodgins, 2007). Furthermore, the current study further highlights the need to investigate mental health more extensively in studies of barriers to effective care.

Given previous research which suggests that the effect of barriers to effective management on quality of life should be investigated in unique populations (Glasgow et al., 2001), barrier predictors of diabetes dependant quality of life were investigated in rural and urban populations separately. Diabetes-dependant quality of life was similar in the urban and rural populations. Psychosocial barriers were the only statistically significant predictor of diabetes-dependant quality of life in the rural population, while depression, psychosocial barriers and self-

monitoring barriers were statistically significant predictors in the urban population. The lack of predictive ability of depression in the rural population may be a reflection of notions of self-reliance in rural and remote populations which are highlighted in previous research (Dean et al., 2011). Therefore, it may be useful to consider attitudinal and self-reliance factors in future investigations of quality of life in these populations. The strong emphasis on psychological barriers to quality of life of people with type two diabetes in both rural and urban populations indicates a need for these barriers (such as lack of support from friends and family, and feelings of embarrassment, resentment and being overwhelmed), to be addressed in the treatment plans of people with type 2 diabetes.

Overall, barrier scores and diabetes-dependant quality of life in the rural and urban populations in this study were similar. Remoteness was a statistically significant predictor of access barriers. However, somewhat unexpectedly, remoteness was not a statistically significant contributor to variance in other barrier scores, indicating that scores on other barriers were not statistically significantly impacted by remoteness. In addition, access barrier scores were not predictive of diabetes dependant quality of life in the rural population. Therefore, further investigation is needed to determine predictors of previously identified worse health outcomes in rural and remote populations (Australian Institute of Health and Welfare, 2008a). In addition, it is important to recognise that rural populations are by no means homogenous. In fact, it has been highlighted previously that rural areas vary greatly in geographical, social and cultural factors, and also in the services available to people living within these areas (Bourke, 2001). Therefore, further research should build upon the current research and investigate the barriers relevant to specific rural areas, rather than using 'rural' as a category for investigation. Furthermore, the results of this study highlight the need to investigate protective factors which may have reduced the impact of

type two diabetes on quality of life in these populations which are seemingly coping better than average.

Limitations

Whilst providing further insight into demographic and mental health variables which predict barriers to effective management, and into which barriers predict diabetes dependant quality of life in rural and urban populations, the current study must be considered in light of its' limitations. Firstly, recruitment through health professionals, as was partly utilised in this study, may lead to the participation of more frequent attendees to health services than is typical in the general diabetes population. In addition, due to the self-reported and self-administered nature of this study, as previously highlighted, the likelihood of completing the questionnaire fully and properly is reduced (Guyatt et al., 1993).

Barriers investigated in this study came from a varied sample of people living in both rural and urban populations, and not specific isolated communities or cultural groups. Therefore, caution should be taken in generalising the results of the study to such populations, which need investigation in and of themselves. Furthermore, the data collected for this study were cross-sectional, which does not allow causation to be established. Future longitudinal research should investigate the relationships between barriers to effective management and the demographic and mental health variables, in order to begin to establish causation. Such longitudinal research could also shed light on the discrepancies in previous literature around the effect of length of diagnosis on quality of life in this population (Rubin & Peyrot, 1999).

The current study utilised a convenience sample, whereby participants volunteered to participate in response to advertisements. It is therefore likely that these participants were healthier and more invested in their management (De Grauw et al., 1999), and possibly experiencing

greater quality of life and fewer barriers to management and than non-participants. Previously reported rates of diabetes complications (AIHW, 2008a) indicate that this study population is in similar, or slightly better, health than average. Australian norms for coronary heart disease were 10% in the general type 2 diabetic population, and 10.4% (n=34) in the current sample. Stroke rates in the Australian type 2 diabetes population have been reported at 10.2% for females and 7.7% for males, whilst in the current sample, 3.4% (n=11) of participants reported having had a stroke. Self-reported Australian rates of kidney disease have been reported to be 6.3%, which is very similar to the current study (6.1%, n=20). However, the average weighted impact ADDQoL score for the current study population is -1.91 (SD= 2.16), which is lower than previously reported data of -1.66 (Ostini et al., 2011). From these comparisons, it is evident that the current study participants were similar in health outcomes to the general Australian type 2 diabetes population. Therefore, it is unlikely that the study was affected by a healthy-responder effect.

One possible reason for the lack of predictive ability of some of the barrier categories is the breadth of specific barriers which were encompassed by each category of barrier. Due to sample size restrictions and a lack of power given the number of significant correlations between individual DOQ items and diabetes-dependant quality of life in both the rural and urban populations, the current study could not assess the ability of individual barrier items to predict diabetes dependant quality of life. However, it may be useful for future larger-scale research to investigate the individual items within the adapted DOQ and their ability to predict diabetes dependant quality of life in both populations.

Whilst it is important to investigate the demographic predictors of barriers to effective management such that the barriers which a patient may face can be better understood and overcome, these do not predict a great amount of variance in the barriers. Thus, future research should build upon this and investigate other predictors of barriers to effective management,

especially in specific health contexts. It is also evident that relationships between barriers to effective management and diabetes dependant quality of life need further investigation.

7.6 Conclusion

This study further highlights the importance of depression as a major predictor of self-management and quality of life, supporting previous literature which suggests that depressive symptoms are a significant predictor of diabetes dependant quality of life (Sundaram et al., 2007). Importantly, barriers to effective care, specifically psychosocial barriers and self-monitoring barriers, account for diabetes dependant quality of life variance over and above what is explained by depression and demographic variables alone. Therefore, the current study has highlighted the need for barriers to effective management to be considered in practice, so that diabetes-dependant quality of life can be improved. Specifically, this study highlights the need for health professionals to attend to the psychosocial aspects of type two diabetes management in both rural and urban areas, as these provide the greatest opportunities for improved diabetes-dependant quality of life.

Chapter 8: Overall Discussion

8.1 Introduction and Overview of Thesis

The premise for the research in the current thesis arose from published reports that people in rural and remote areas of Australia have higher prevalence of type two diabetes and worse type two diabetes outcomes than those who live in urban areas. Effective self-management has been shown to promote health of people with type two diabetes, however, it has been noted that it is complex, and thus rare. Therefore, it is important to identify factors which impact on self-management. Whilst barriers to self-management have been investigated in a variety of contexts, there is a lack of literature which examined this problem in rural and remote Australian contexts. Thus the overall aim of this thesis was to contribute to knowledge in the area of type two diabetes self-management in Australian rural and remote contexts.

Specifically, this research aimed to:

- Identify barriers to effective type two diabetes self-management in rural and remote areas of Australia,
- Adapt an existing tool for the measurement of barriers to type two diabetes self-management such that it encompasses the barriers identified as relevant to people in rural and remote areas, and establish the validity of this measure in a mixed rural and urban sample, and
- Investigate predictors of barriers to effective self-management, and examine which specific barriers predict diabetes-dependant quality of life in rural and urban populations.

The aims of this thesis were addressed through a mixed methods approach, whereby three studies were carried out; one qualitative and two quantitative. Two phases of data collection were conducted. The first phase involved conducting interviews and one focus group with health

professionals and people with type two diabetes in rural and remote areas of Australia. This qualitative data provided the basis for a thematic analysis which identified barriers to self-management in rural and remote Australia (Study 1). The second phase of data collection involved gathering self-report survey responses from people with type two diabetes living in Australia (this sample included urban and rural and remote participants). This quantitative data provided the basis for the validation of the adapted Diabetes Obstacles Questionnaire (DOQ) in a mixed rural and urban population (Study 2). The quantitative data were also used to investigate the demographic factors which are important in predicting barriers to type two diabetes self-management and investigating the barriers to self-management which impact on diabetes dependent quality of life in rural and urban populations (Study 3).

This chapter will discuss the findings of the research presented in this thesis. Firstly, the chapter will provide an overview of the three studies conducted; the aims of the studies, rationale for the research, findings and significance of each study will be presented. Following the presentation of findings, a meta-inference will draw the three studies together and discuss the findings overall. The limitations of the research as a whole will be discussed in order to contextualise the research and provide some reasoning for unexpected results. Implications of the current research are then discussed in relation to practice and policy and service provision. Finally, recommendations for future research in type two diabetes self-management and in rural and remote populations are made, and conclusions are drawn.

8.2 Summary of Findings

Study 1

Whilst there is a large body of research investigating self-management of type two diabetes in urban populations, there is a lack of research into the barriers to self-management which affect people living in rural and remote contexts, especially in Australia. Study 1 aimed to identify barriers to type two diabetes self-management in rural and remote areas of Australia. By focusing on rural and remote settings, this research responds to calls for context-specific identification of barriers to type two diabetes self-management (Glasgow et al., 2001).

The research presented in this thesis identified barriers at intrapersonal, interpersonal, organisational and societal levels of influence. At the intrapersonal level, denial of the illness and the seriousness of associated complications, reduced motivation, a lack of knowledge and skills required to manage, and a lack of time were identified as barriers to self-management. Whilst many of these barriers have been identified in other contexts, it was important to confirm the presence of these barriers in a rural and remote context in order to inform future rural-specific models of care. For example, practitioners have previously identified denial of the illness and the seriousness of type two diabetes consequences as important barriers to effective self-management (Wens et al., 2005). A lack of motivation has also been ranked as one of the most important barriers to effective self-management by practitioners (Simmons, Lillis, et al., 2007) and lack of knowledge and skills have been identified as barriers by patients and practitioners in New Zealand (Simmons, Lillis, et al., 2007) and rural patients in America (Nagelkerk et al., 2006). Previous research has also reported a lack of priority placed on diabetes self-management in general (C. Greenfield et al., 2011), and for specific behaviours such as exercise (Donahue, Mielenz, Callahan, Sloane, & Devellis, 2006) and following recommended diet (Shultz et al., 2001) as barriers to effective self-management. A lack of time has been previously identified as a barrier

to self-management behaviours such as exercise, in a systematic review of research in a variety of contexts (Korkiakangas et al., 2009), however this barrier may be heightened in rural and remote areas due to aspects of rural-living such as farming lifestyles.

At the interpersonal level of influence, increased stress levels, due to unemployment, work-related stress, and a dependence on factors such as weather for agriculture, were identified as barriers to self-management. The presence of supportive relationships was identified as a facilitator of self-management, thus building upon a large body of research which emphasises the importance of supportive relationships with spouses (August & Sorkin, 2011), health professionals (Nam et al., 2011) and family (Jerant et al., 2005), by confirming the importance of support in a rural context as well.

At an organisational level, barriers were specifically related to the theme of 'access'. Emphasis was placed on the impact of reduced access to recommended foods, appropriate exercise options, and public transport to attend appointments. Limited health professional availability and experience highlighted in this study echo previous research in a Canadian context suggesting a lack of health professional skills (Brown et al., 2002), therefore suggesting that these problems may occur across a variety of contexts. In addition, a lack of transport to attend appointments and the availability of health care professionals in rural areas have been identified as barriers to self-management by rural Americans (Nagelkerk et al., 2006) and in a review of external barriers to care in the United States (Zgibor & Songer, 2001). The identification of these important barriers to type two diabetes self-management in a rural Australian context is novel, but not unexpected in light of reports highlighting limited access to general health services in rural Australia (M. FitzGerald et al., 2001). Furthermore, identification of barriers at an organisational level responds to calls from the World Health Organisation to identify and address systemic barriers such as access to care, allocation of resources, continuity of care and information

provision in order to improve adherence to illness self-management recommendations in general (WHO, 2003).

At the societal level, barriers were identified in relation to community attitudes. A systematic review of barriers to effective care has emphasised the importance of cultural beliefs and attitudes in type two diabetes self-management (Nam et al., 2011). The importance of context in attitudes and beliefs, especially in high-risk sub groups, has been highlighted (Department of Health Victoria, 2007). Therefore the identification of these barriers in a rural and remote context provides an important avenue to inform interventions aimed at improving self-management. Participants identified a community attitude that type two diabetes is the fault of the individual - therefore, linked with victim-blaming for the illness - as detrimental to self-management. Social embarrassment associated with having type two diabetes was suggested to prevent people from exercising as recommended. A lack of importance placed on preventative health was also suggested to impede self-management. These findings support previous research in other populations which has suggested that shame prevents Mexican Americans from exercising (Mier, Medina, & Ory, 2007). In addition to attitudes, a lack of engagement in employment and reduced social connectedness were also identified as barriers to self-management in the current research.

An important original finding of this study, identified across socio-ecological levels of influence, was the difficulty of maintaining recommended lifestyle changes. Whilst many participants indicated that patients were able to make changes to their lifestyle initially, the difficulty of maintaining these changes in the long term was emphasised. This finding echoes previous commentary: "It seems to take a long time for newly acquired health behaviours to become established in a person's lifestyle" (Vallis, 2009, p. 7). However, difficulty maintaining lifestyle changes are not surprising, given previous patient reports of adherence to self-management recommendations are significantly lower for lifestyle modification behaviours than for other

behaviours such as taking medication and attending appointments (Peyrot et al., 2005). The difficulties maintaining self-management behaviours, which were reported in the current research, are important in light of the emphasis placed on patient education and skill attainment, in recommendations for type two diabetes management (Diabetes Australia, 2011). Although the importance of patients gaining the skills and knowledge required for management cannot be underestimated, the current findings highlight the need for a specific focus on the ways in which self-management behaviours can be maintained.

One major strength of Study 1 is the utilisation of both patient and health professional opinions, which provided a wider range of experiences upon which to draw. This feature is especially important given previous evidence that identification of barriers to self-management can differ markedly between patients and their health professionals (Simmons, Lillis, et al., 2007). Health professionals had the perspective of observing a wide range of individuals' experiences of self-management, and their inclusion in this research may therefore go some way to reducing the sampling bias discussed in section 8.4. In addition, some rural health professionals worked in multiple locations, thus broadening the perspectives encompassed and adding to the breadth of the barriers identified. Importantly, the qualitative approach to this research has given people in rural and remote areas a voice and allowed them to identify freely the barriers that are most relevant to them. This ensured that the barriers identified were not generated through the researchers' previous assumptions.

Additionally, a socio-ecological framework has been usefully applied to many health behaviours, including physical activity (Elder et al., 2007) and nutrition education (Gregson et al., 2001). However, this study is unique in applying this framework to the self-management of type two diabetes in rural and remote contexts. A socio-ecological framework was useful in identifying barriers to type two diabetes self-management because it takes into account the multi-levelled

nature of factors influencing self-management. Furthermore, a socio-ecological framework is of particular use in rural and remote areas as it can inform health promotion programs which take health contexts into account (Stokols, 1996). Previous research has suggested that changes at an individual level are insufficient for people with and without diabetes to adopt a healthy lifestyle. Rather, it has been suggested that changes also need to be made at the level of built and social environments, and to public policies and health systems (Hu, 2011). Therefore it is important to consider barriers to self-management at many levels of influence.

Study 2

Self-management barriers identified in Study 1 were used to adapt an already-existing questionnaire, the Diabetes Obstacles Questionnaire (DOQ) (Hearnshaw et al., 2007), such that it included barriers relevant to rural and remote dwellers. The DOQ was adapted by adding ten items identified as relevant to rural and remote self-management in Study 1, but which were not already covered by the DOQ. These items related to access barriers and difficulties maintaining lifestyle changes (as identified in Study 1).

The original DOQ validation was conducted through the identification of initial sub-scale structure based upon expert opinion and literature review, and refined through further statistical analyses (Hearnshaw et al., 2007). The current study built upon previous validations by using Principal Components Analysis (PCA) to determine an underlying factor structure, as recommended by the authors of the initial validation (Hearnshaw et al., 2007). The current validation indicated that a seven factor solution containing 81 of the 88 original items showed good to excellent internal reliability. This validation confirmed the presence of most of the initial barrier categories except for the 'coping with diabetes' and the 'diagnosis' sub-scales. Sub-scales in the

adapted DOQ represented barriers related to medication, self-monitoring, knowledge, relationships with health care professionals, psychosocial aspects, lifestyle changes and access.

Study 2 established the validity of the adapted version of the DOQ in a mixed rural and urban population, so that the barriers identified in Study 1 could be quantitatively measured. Most items added to the DOQ from the thematic analysis remained in the adapted version after PCA was conducted, confirming their relevance for the measurement of barriers to effective type two diabetes self-management. In addition, the 'access' scale, added to capture rural and remote issues of access to services, appropriate foods and exercise options, was retained in the analysis, indicating that these barriers sit together to represent one underlying latent variable, and thus one issue related to self-management. When the rural and remote data were analysed separately from those collected from urban participants, the factor structure was similar to that of the mixed sample; however, due to sample size restrictions (n=110 in the current rural sample), this investigation was limited to preliminary analysis and needs further research. In order to confirm the identified factor structure in a rural and remote population, a sample of at least 330 people is needed to obtain enough statistical power given the large number of items (n=88) in the questionnaire.

The adaptation of this questionnaire to incorporate factors specific to rural and remote areas provides an important contribution to the type two diabetes self-management literature, and responds to calls for the need to "develop practical assessment and intervention approaches that can be implemented in primary care or similar settings and are capable of reaching large representative segments of the population" (Glasgow et al., 2001, p. 40). In addition, the development of a measure which encompasses barriers relevant to rural and remote dwellers can allow the mediating and moderating effects of different barriers to self-management to be investigated; an area which has been previously highlighted as important for type two diabetes

self-management research (Nam et al., 2011). Furthermore, whilst the DOQ has been validated in several European countries, this is the first attempt to validate it in an Australian population, and in a sample which purposively includes people living in rural and remote areas.

Study 3

Many barriers to type two diabetes self-management have previously been identified, including those reported by the analysis presented in Study 1. However, there is a lack of research identifying the predictors of such barriers. Study 3 addressed this gap in understanding by identifying important demographic and psychological predictors of barriers to effective self-management in a mixed rural and urban population.

In identifying predictors of barriers to self-management, regression analysis indicated that none of the demographic variables significantly predicted medication or knowledge barriers. Depression was a significant predictor of all other barriers, and age was an additional significant predictor of self-monitoring, psychosocial and lifestyle barriers. The number of complications of diabetes an individual experienced was a significant predictor of whether they also experienced lifestyle, psychosocial and health professional relationship barriers. Remoteness was a significant predictor of access barriers only.

In addition to identifying predictors to self-management barriers, Study 3 identified self-management barriers important in predicting diabetes dependent quality of life. The rationale for this investigation was threefold. Firstly, participants in Study 1 reported that improving quality of life was the most important outcome of type two diabetes self-management. Secondly, the importance of using quality of life as an outcome measure for barriers to effective type two diabetes has been highlighted in previous literature (Glasgow et al., 2001). Finally, prior to the current research, there was lack of literature which specifically investigated the relationships between specific barriers to

self-management and diabetes-dependant quality of life. In addition, a previous review of literature has highlighted the importance of identifying similarities and differences between the barriers which are important across different cultural groups, and has highlighted the paucity of such research (Glasgow et al., 2001). The current research has begun to bridge this gap by investigating the barrier predictors of diabetes-dependant quality of life in both rural and urban populations separately.

Regression analyses indicated that psychosocial barriers had the most significant impact on diabetes-dependant quality of life in the rural population; predicting an additional 22% of variance above that predicted by demographic and psychological variables. Depression, psychosocial barriers and self-monitoring barriers were significant predictors of diabetes-dependant quality of life in the urban population, with the two barrier categories predicting an additional 20.7% of variance above what was explained by demographic and psychological factors. Unexpectedly, in this study there was no significant difference between the quality of life of the rural and urban populations.

Psychosocial barriers have previously been defined as 'psychological and interpersonal factors that impede diabetes management or diabetes-related quality of life' (Glasgow et al., 2001, p. 33). The psychosocial barriers in this questionnaire included factors relating to interpersonal relationships, support and feelings of being overwhelmed and alone. The importance of psychosocial barriers in diabetes-dependant quality of life in the rural population, while a novel finding, is not surprising in light of previous reports that psychological and educational barriers to self-management are the most frequently reported barriers in rural Australians (Simmons, Bourke, Yau, & Hoodless, 2007). Psychosocial barriers also predicted diabetes-dependant quality of life in the urban population, reflecting patient and practitioners' previous suggestions that there is a major unmet need for psychological and social services in all areas, (Simmons, Lillis, et al., 2007).

One unexpected finding was that self-monitoring barriers were predictive of diabetes-dependent quality of life in the urban population, but not the rural population. Self-monitoring barriers in the adapted DOQ relate to knowledge about how to self-monitor, feelings about self-monitoring, and the difficulty of self-monitoring. Therefore, this unexpected finding may have arisen as a result of the research design, whereby the factor structure of the adapted DOQ in the mixed populations was not confirmed in a large enough rural-only sample. For example, items relating to self-monitoring knowledge may have had a better fit with knowledge barriers, and items relating to feelings about self-monitoring may have had a better fit with the psychosocial barriers, if a larger rural sample was available to confirm the factor structure of the DOQ. The use of the mixed rural and urban factor structure to predict the importance of barriers to diabetes-dependent quality of life in the rural population may therefore have contributed to the lack of importance of self-monitoring barriers in the rural population.

Depression was a significant predictor of diabetes-dependant quality of life in the urban population, but not the rural population. This finding is surprising given the reports that mental health issues and psychological distress are higher in rural and remote areas than in urban areas (AIHW, 2010). In light of the importance of depression in diabetes-dependant quality of life, it is important to note that previous researchers have suggested that depression and stress may play a role in diabetes self-management not only indirectly, through influence on behavioural self-management, but on the underlying metabolic processes (Glasgow et al., 2001). Regardless of the mechanism by which depression influences type two diabetes self-management, this study provides further support for the need to address depression in models of care for self-management (National Health and Medical Research Council, 2005).

The importance placed on psychosocial barriers to self-management and depression in diabetes-dependant quality of life in both rural and urban populations in this study extends upon

previous findings that psychosocial factors such as anxiety, depression, social support and stress are important predictors of dietary, medication-taking, exercise and glucose testing self-care behaviours in an urban population (Wilson et al., 1986). This research also responds to the identified need to compare barriers to self-management and diabetes-dependent quality of life in different populations and to investigate quality of life as an outcome measure in self-management research (Glasgow et al., 2001). Furthermore, through the use of a measure (the Audit of Diabetes Dependent Quality of Life) which includes domain-specific questions and allows participants to rate the importance of each of the domains to their life (Bradley et al., 1999), Study 3 has overcome previous criticisms that many measures do not allow patients to make judgements about their overall sense of well-being which are based on many facets of their life (Arnold et al., 2004). The investigation of factors which predict barriers to self-management is also a novel contribution to the literature. This investigation was strengthened by the use of the adapted DOQ which takes into account barriers relevant to people in rural and remote areas, thus ensuring that the measures used were relevant to the population under study.

8.3 Meta-inference/Triangulation

Triangulation refers to combining one or more data sources or methods which investigate the same phenomena, in order to establish internal consistency within the findings (Jick, 1979, see section 3.2.1). The use of triangulation in the current study was not primarily aimed at confirming the findings of one study with the findings of another, but, rather, at investigating the phenomena from multiple angles in order to gain a greater depth of knowledge and, secondly, to establish some consistency in the findings (Moran-Ellis et al., 2006). Due to the sequential nature in which the studies in this thesis were conducted, this section will discuss the ways in which the studies

built upon each other and will integrate the findings of the three studies presented in this thesis in order to provide a concise discussion of the findings as a whole.

Previous research investigating rural and remote barriers to effective self-management has focused solely on patient responses (Nagelkerk et al., 2006) and there is evidence to suggest that patients and health professionals report different barriers to self-management (Simmons, Lillis, et al., 2007). Therefore, Study 1 integrated responses from both health professionals and patients. This integration increased the breadth of responses gathered in the qualitative data collection, and allowed a wider range of self-management experiences to be captured. Most of the barriers identified in the thematic analysis of the qualitative data were supported in the Principle Components Analysis (PCA) of the quantitative data. However, of barrier categories identified in Study 2, only the psychosocial barriers in the rural/remote population, and the psychosocial and self-monitoring barriers in the urban population significantly predicted diabetes-dependant quality of life in regression analyses (Study 3).

In addition to supporting the presence of barriers to effective self-management identified in Study 1, Study 3 added depth to these findings by confirming the impact of these barriers on diabetes-dependent quality of life. The inclusion of barriers to self-management in a regression model which already included demographic and psychological factors, increased the predictive ability of the model by around 20%. Thus, Study 3 confirmed the importance of barriers in quality of life which was suggested by health professionals and people with type two diabetes in Study 1 and by previous researchers in the area (Glasgow et al., 2001).

The most consistent finding to come out of this research as a whole was the importance of psychosocial barriers to self-management. In the current research, many psychosocial barriers were identified in the areas of knowledge, skills, motivation, stress and relationships in Study 1.

These barriers formed one cohesive sub-scale in Study 2, indicating that they are all part of the same underlying construct. Importantly, in Study 3, psychosocial barriers were the only significant predictor of diabetes-dependent quality of life in the rural population, and one of three significant predictors of diabetes dependent quality of life in the urban population.

Most of the unexpected findings in the current research related to the impact of remoteness and access barriers. Whilst remoteness was an important factor in predicting the level of access barriers a person experienced in Study 3, access barriers were not a significant predictor of diabetes-dependant quality of life in the rural and remote population. The lack of importance of access barriers in quality of life were unexpected in light of the barriers identified in Study 1, where health professionals and people with type two diabetes both identified access to services, transport and food and exercise options as important factors in managing type two diabetes effectively in rural and remote areas.

Another important unexpected finding was the impact of remoteness on quality of life. Given previous reports that people with type two diabetes in rural and remote areas have poorer health outcomes than people in urban areas, and that poorer health outcomes are strongly associated with reduced diabetes-dependant quality of life (Kleefstra et al., 2008), it was expected that remoteness would significantly predict diabetes-dependant quality of life. However, the results of Study 3 indicated that there was no significant difference between diabetes-dependant quality of life in the rural and urban participants. This finding was unexpected, and may be a reflection of a tendency of rural participants to downplay difficulties, possibly as a result of societal attitudes which foster stoicism (Dean et al., 2011). This notion of stoicism may also go some way to explaining the lack of importance of depression in diabetes dependent quality of life in the rural population.

Furthermore, access barriers were the only barrier category significantly predicted by remoteness. Issues of access to services were emphasised strongly in Study 1, however the lack of importance of access barriers to diabetes-dependant quality of life in Study 3 was unexpected. Whilst this is clearly an area which needs further investigation in light of the importance placed on access barriers in Study 1, this research highlights the need to investigate issues of access at a more local level, such that the services available in each rural and remote area are investigated, rather than investigating 'rural' access as a whole. All of the unexpected findings in relation to the importance of barriers in rural and urban populations, however, should be interpreted cautiously in light of sampling limitations and the classification of 'rural', and sampling bias which are discussed in the next section (section 8.4).

8.4 Limitations

This section will discuss limitations as a result of the design of the research, recruitment and sampling frame, and the use of rural classifications.

Research Design

Firstly, all three studies utilised data which were self-reported by patients or health professionals. Self-report data are suggested to be biased by many factors including respondent characteristics, motivation and cognitions (Del Boca & Noll, 2000). The qualitative data collected may be influenced by patient or health professional perceptions of an imbalance of power or authority with the researcher, and, therefore, participants may have given responses which they thought the researchers wanted to obtain. Social desirability bias, whereby participants report what is socially desirable (Paulhus, 1984), may have influenced the responses of both qualitative and

quantitative data collection, despite assurances of patient confidentiality and anonymity. Limitations posed by the self-report nature of the data could be overcome in future research utilising biological indicators of effective self-management such as blood glucose levels over time, medical self-management records, or linking reports of health professionals to their patients to triangulate patient self-reports, as suggested by previous researchers to validate self-report data (Tisnado et al., 2006).

An important consideration for the development of the quantitative survey was reducing patient burden, thus limiting the time it took to complete the survey. Health professionals in Study 1 emphasised the importance of considering the length of surveys which are used with people with type two diabetes. In order to limit patient time, the demographic variables were limited to date of birth, post code, diabetes complications, other illnesses and gender. Education level, income and health literacy were not investigated in this study. The future inclusion of these education characteristics may identify significant predictors of various barriers to self-management including knowledge barriers. In addition, the inclusion of an objective measure of diabetic control, such as blood glucose level, may be used to predict medication barriers in future research. As well as omitting some demographic characteristics, the questionnaire did not include the Problem Areas In Diabetes Scale (PAID) (Polonsky et al., 1995; Welch et al., 1997). The PAID was used in the initial validation of the DOQ to establish criterion validity (Hearnshaw et al., 2007) but was not included in the current research due to considerations of participant burden. Therefore, a major limitation of the adapted DOQ validation is the lack of established criterion validity.

Whilst it was not the intention for the current research to provide a longitudinal investigation of barriers to self-management, it is vital to consider briefly the impact of the cross-sectional research design on the parameters of the research. It is important to investigate the sensitivity to change of a measure. This usually requires longitudinal or repeated measures

research designs. Therefore, whilst Study 2 has extended previous DOQ validations by using Principle Components Analysis and validated the questionnaire in a novel population, the cross sectional design of this study did not allow the sensitivity of the DOQ to change over time to be investigated.

In addition to limitations in Study 2, the cross-sectional design also limited the information gained about the relationship between barriers to self-management and quality of life and depression. While the results that depression is important in both predicting barriers and predicting diabetes dependent quality of life in rural and urban populations are important, the cross sectional nature of the research does not allow causation or directionality to be established. Thus, these findings do not shed any light on whether depression causes people to be more likely to have diabetes, or whether having diabetes makes people prone to depression.

Sampling

Previous research has highlighted many difficulties in doing research with people in rural and remote areas. For example, in their summary of the literature, and through drawing on researchers' reports, Anderson-Loftin, Barnett, Bunn, and Sullivan (2005) have suggested that it is difficult to recruit participants in a clinical population, especially in rural and remote areas (Anderson-Loftin et al., 2005). Thus, issues of sampling posed the most significant limitations in the current research.

Firstly, non-purposive sampling strategies were used for both data collections. In Study 1, patients responded to a media release advertising the study, and to recruitment letters given to them by their health professionals. For Study 2 and Study 3, participants responded to a media release, invitations given out by their health professionals, or to posters advertising the study which

were placed on community notice boards and in rural medical practices. Due to the voluntary opt-in recruitment of the convenience sample in the current research, it is likely that the patients in the current research were not representative of the type two diabetes population in a number of ways. Firstly, it is likely that participants were more frequent attendees at health services where they received information about the study. Secondly, participants who responded to the media release are likely to be more invested in their own self-management than those who did not respond. Recruitment avenues aside, the participants in this study are likely to be healthier than non-participants, as previous research has suggested that people who were invited to participate, but declined were significantly older and had significantly more incidence of illness than those who did participate (De Grauw et al., 1999). Therefore, it is possible that the people who participated in the current study were less affected by barriers to self-management, and may have placed their diabetes self-management as a higher priority than those who did not, hence their decision to participate. These factors compromise the generalisability of the results of this study.

A previous literature review of research into type two diabetes management in rural America noted that such research tends to use convenience samples, which are prone to sampling bias (Williams Utz, 2008). Whilst these limitations are difficult to overcome, it has been highlighted that accurate descriptions of the populations from which the samples were drawn, along with descriptions of geographic factors, can allow the representativeness of the samples to be better determined (Williams Utz, 2008). However, in addition, to the nature of recruitment for the current study, the recruitment strategy for both data collections means that there is no way of determining whether participants were healthier than those who did not participate as no information about non-participants is available.

The recruitment issues experienced in the current research could be somewhat reduced in future research through a purposive sampling strategy. Such strategies could utilise registers such

as the National Diabetes Services Scheme (NDSS) to target people who have been diagnosed with diabetes. This method was not used in the current research, as the researcher did not have affiliations with the Scheme, and so could not access their mailing lists. Advertising in NDSS brochures was also investigated; however the costs of this were prohibitive for the current research. The use of a Health Omnibus study, such as the South Australian Health Omnibus Survey (SAHOS) or the Health Monitor (HM) survey, to collect data which are representative of the general population, was also investigated. Through consultation with researchers who use the SAHOS to track diabetes prevalence, it was decided that including a limited number of questions in the SAHOS which ask about a diabetes diagnosis and willingness to be contacted for the current research was not cost-effective because the study surveyed the general population and not a diabetic population, and would be unlikely to yield a sufficient number of responses from the population of interest. However, either of these recruitment avenues, in research which is connected to a program such as the NDSS, or which has funding to include questions in a Health Omnibus study, is likely to gain a more representative sample of the type two diabetes population. In addition, such a recruitment strategy could provide some data about non-responders.

Further to the limitations to generalisability posed by the sampling frame used in the research, the analyses used in the quantitative studies were limited by the sample size. Whilst the sample size was adequate for PCA using rural and urban data in Study 2, the analysis of the structure of the DOQ in a rural-only population was limited to a preliminary analysis, due to the rural sample size ($n=110$). In addition, whilst data were adequate for the regression analyses presented in Study 3, a larger sample would have allowed further analysis of the impact of individual barrier items, as opposed to barrier classifications.

Rural Classifications

The use of a classification such as the ARIA system (explained in detail in 1.2.1) provides a relatively gross geographical indication of remoteness. The use of this classification to group people into 'rural' and 'urban' categories may have impacted on the findings of this research. The lack of difference in quality of life between the rural and urban populations in Study 3 was unexpected, and may be explained by the definitions of 'rural' that were used. Participants were assigned to 'rural' and 'urban' groups based on their post code (as explained in section 1.2.1). Thus, geographical distance from centres of varying sizes determined 'remoteness'. As previously highlighted, rural communities are very diverse in their economic, geographical, environmental and socio-demographic characteristics (National Rural Health Alliance, 2011) and rural Australians are diverse in their levels of rurality and in demographic characteristics (Bourke, 2001). It is important to note that 'rural' or 'remote' areas by no means represent homogenous groups, and that rural areas may be very different from one another. For example, in looking at differences between rural areas, the AIHW have reported that death rates are slightly, but significantly, lower for coastal rural and remote areas than for inland rural and remote areas. This difference may be due to aspects other than purely geographical features, such as migration at retirement (AIHW, 2007b). Therefore, a limitation of this analysis is the use of 'rural' as a homogenous group, which in reality may be very heterogeneous in nature. This limitation could be somewhat overcome through larger-scale research with the statistical power to differentiate between more tightly defined rural and remote populations.

8.5 Implications for Practice

The results of this research as a whole can provide health professionals with an increased understanding of the barriers faced by people managing type two diabetes in rural and urban areas

of Australia. Thus the findings can inform the advice and support that they give people with type two diabetes.

Guidelines for diabetes self-management service delivery state that services should be “targeted at high risk clients who experience poorer health and have difficulty accessing services” (Department of Health Victoria, 2007, p. 9), and emphasise the importance of “interrelationships among individuals and the social, cultural, environmental, behavioural and biological factors that influence their health” (Department of Health Victoria, 2007, p. 7). Therefore, by identifying barriers to rural and remote self-management at many levels of influence, this research can inform the development of models of care by targeting difficulties faced in rural and remote contexts. For example, recommendations for supporting effective self-management highlight the importance of incorporating knowledge-based education (Department of Health Victoria, 2007). Addressing the barriers identified in the current study, such the lack of community-specific information about services and facilities identified in Study 1, can inform the development of such knowledge-based education. Online information services which integrate community-specific knowledge about resources and services could begin to address issues of knowledge and limited access to services by increasing awareness of the services that are available.

Guidelines for supporting self-management of type two diabetes suggest initial assessment of the coping skills of the patient, lifestyle risks and knowledge of diabetes (Department of Health Victoria, 2007). The current research suggests that barriers such as social isolation, a lack of supportive relationships and increased stress need to be considered in initial assessment phases as they may influence a patient's coping skills and lifestyle risks. In addition, Australian diabetes self-management guidelines recommend ongoing education, annual testing of blood glucose levels and fat profiles, twice-yearly assessment of feet, eyes, blood pressure and BMI, and reviews of diet, exercise, medication and smoking status (Department of Health Victoria,

2007). The results of Study 1 suggest that a lack of public transportation in rural and remote areas needs to be considered when formulating appointments for ongoing monitoring such that participation is increased and the available health services are utilised.

The initial DOQ validation paper suggests that the DOQ has application for identifying specific issues within a clinical setting (Hearnshaw et al., 2007). Developing individual self-management plans needs to be a dynamic process whereby health professionals evaluate and change plans as the needs of the patient change (Department of Health Victoria, 2007). Therefore, the validation of the adapted DOQ provides a tool to identify barriers which are relevant to individuals in rural and urban areas of Australia which can be used to better tailor individual self-management plans to meet patient needs. In addition, by identifying barriers relevant to individuals, and helping to orient advice and services to the needs of the patient, the use of a tool such as the adapted DOQ might promote a patient centred approach in clinical settings. This is important given previous literature which highlights the importance of patient-centred practice (Renders et al., 2001) in improving health outcomes for people with type two diabetes (Susman & Helseth, 1997).

The identification of predictors of barriers to self-management in this research can be used to inform clinicians of the barriers which may be relevant to individuals and specific populations, based on their demographic characteristics. For example, older people with type two diabetes may need greater assistance in overcoming lifestyle challenges, and people who experience more diabetes complications may need increased support in their relationships with health professionals.

Specifically, the finding of the importance of depression in barriers to self-management highlights the need to continue attempts to address mental health issues in the self-management of type two diabetes in both rural and urban populations. These findings are especially important

considering the higher prevalence of depression in people with type two diabetes than without (Li et al., 2009). Furthermore, people with type two diabetes and mental health issues have poorer health outcomes than those without mental health issues (Paschalides et al., 2004). The current research suggests that people with depression may be affected by barriers to self-management to a greater extent than people without depression. Therefore, these findings may go some way to explaining the link between depression and poorer health outcomes; people with depression experience greater obstacles to the self-management behaviours which promote positive health outcomes. Whilst further research is needed to investigate the causal aspects of this relationship, these findings have important implications for practice, and suggest that special attention should be given to reducing the barriers for people who are known to have depression and type two diabetes, as well as treatment for depression, where possible. Therefore, routine screening for mental health issues, specifically depression, should be incorporated into initial screening and yearly monitoring for people with type two diabetes so that mental health problems can be identified and, therefore, proactive steps can be taken to lessen the impact of self-management difficulties. Proactive measures may include identifying social supports, supportive relationships and mental health services in order to lessen the impact of psychosocial barriers. In addition, the promotion of widely-available online services, such as the Beyond Blue website (www.beyondblue.org.au), which aim to provide people with access to psychological services (Beyond Blue, 2011), should be promoted routinely as a source of information for people in rural and remote areas where psychological services may be limited.

8.6 Implications for Service Provision and Policy

In addition to providing a greater knowledge of barriers to self-management for health professionals, understandings from this research can be extended to service providers and policy

makers in order to better inform systemic factors which aim to improve type two diabetes management.

The identification of access barriers to self-management can be aligned with the aims of the National Health Priority Areas. National Health Priority Areas, were formed through collaboration between Commonwealth, State and Territory governments. These Priority Areas direct the focus of health improvement towards reducing inequities in health, reducing the burden of illness and improving access to quality health care (Parliament of Australia, 2000). One of the mechanisms by which this initiative is said to work is through "identifying appropriate points of intervention" (Australian Institute of Health and Welfare & Commonwealth Department of Health and Family Services, 1997, p. 153). Diabetes Mellitus is one National Health Priority Area (Department of Health and Ageing, 2012b). Thus, by identifying barriers to type two diabetes self-management, the current research can inform identification of the most effective points of intervention. Specifically, the barriers identified at organisational and societal levels in Study 1, such as issues of access, can contribute to understandings about the best ways to intervene for people in rural and remote areas with type two diabetes – understandings that can in turn inform guidelines and policies in this area.

Furthermore, the identification of access barriers in rural and remote contexts supports the already highlighted need to address "social, economic and environmental issues, such as access to fresh food and improving access to primary health care services" (Department of Health Victoria, 2007, p. 19). Policy responses that would work to address these barriers and needs might include subsidising the costs of exercise options and fresh foods in rural and remote communities, as emphasised by the National Rural Health Alliance's recommendations for the development of a National Food Plan in Australia (National Rural Health Alliance, 2012). Such subsidies have been effective in increasing fresh food consumption and physical activity in countries such as Canada.

These subsidies have been funded by removing sales tax on healthy foods, providing 'tax credits' for using exercise facilities and subsidising recreational activity (Madore, 2007).

A lack of specialists and experienced health professionals in rural and remote areas was emphasised as important in type two diabetes self-management in Study 1. These results indicate that it is important to consider ways in which more specialist services can be provided to rural and remote areas. Existing Australian schemes, such as the Nursing and Allied Health Rural Locum Scheme (Department of Health and Ageing, 2012a), promote working in rural areas to health professionals and students, thus attempting to address a shortage of health professionals in these areas. The Rural Health Workforce (Rural Health Workforce Australia, 2013) is involved in recruiting and supporting health professionals to work in rural and remote areas. The results of this research can be used to build upon these schemes. Improvements to these schemes, and others, may include incentives for continued service in rural areas to increase health professional retention, and greater professional development opportunities to improve diabetes specific health care skills.

Current recommendations for type two diabetes management emphasise the importance of access to multi-disciplinary care teams, which ideally include psychologists and social workers (Diabetes Australia, 2011). By identifying psychosocial barriers as important factors in diabetes-dependant quality of life, this research highlights the importance of this emphasis. Specific psychosocial self-management barriers included the strain placed on family and personal relationships, resentment of the need to make lifestyle changes, feeling overwhelmed, feelings of being alone and having little support from friends, family and socially. By identifying these barriers, the current research presents the opportunity for policy makers to specifically target models of care so that they address social problems. For example, efforts to further develop, promote and assess the efficacy of resources, such as diabetes counselling websites and telephone lines like Diabetes

Counselling Online (2013), may be useful in beginning to address psychosocial barriers such as feelings of being alone and having little support from family and friends. These services could also be developed or modified to address the psychosocial barriers listed above by connecting people with psychological and social services in their area, organising support groups with others who can promote accountability and understand similar experiences and reduce strain placed on family and relationships.

The adaptation of a measure which reliably assesses barriers to diabetes self-management in rural and urban areas is complementary to the implications of the research discussed thus far. The adapted DOQ provides the opportunity to assess barriers which are relevant to people living in specific populations, such as rural and remote areas. Thus, the DOQ is an ideal tool for policy makers to use when gathering data to inform the service provisions of a defined area.

8.7 Future Directions

The importance of access barriers was emphasised throughout this research. The significant associations between remoteness and access barriers in Study 3 support the identification of these barriers in Study 1, and suggest that these access problems are, in fact, increased in rural and remote areas. The investigation of this association is novel in the type two diabetes self-management literature and is important as it lends further evidence to previous calls for increased services in rural and remote areas where shortages of psychological and social services, and difficulties with uptake of psychological services have been emphasised (Roufeil & Lipzker, 2007). It is important to investigate factors which influence uptake and awareness of services in rural areas (Collins, Winefield, Ward, & Turnbull, 2009), so that they can be specifically targeted to the needs of the communities which they service. Thus future research may focus on

ways in which these barriers may be reduced, for example, by connecting people to services more effectively.

As discussed earlier, the adaptation of the DOQ provides a measure which reliably identifies barriers to self-management. The adapted DOQ thus provides a measure which is useful for future investigations into barriers to type two diabetes self-management in a variety of contexts, and for measuring the outcomes of interventions. Future research in this area should focus on validating the DOQ in a rural-only population in order to address the limitations discussed earlier in this chapter. It would also be insightful for community-based research using the DOQ in rural and remote areas to investigate the similarities and differences between barriers to self-management in different rural areas, especially in light of the potential limitations in this study related to the use of homogenous 'rural' and 'urban' classifications.

One of the novel findings of the current research is that people were generally able to gain the knowledge and skills and make lifestyle changes required to self-manage effectively, but had difficulty maintaining these changes. The maintenance of behaviour changes is required for long term glycaemic control (NH&MRC, 2005). Therefore, it is important to investigate the factors which prevent people from maintaining lifestyle changes. The Transtheoretical Model of Change (Prochaska & DiClemente, 1983) posits that people move through a series of stages of behaviour change, from pre-contemplation to maintenance, and possibly termination, depending on the behaviour. This model has formed the basis of many interventions for behaviours specifically relating to type two diabetes self-management (H. Jones et al., 2002). The second round of data collection, which produced quantitative data for both Study 2 and Study 3, included an assessment of stage of change (discussed in section 5.2.6) with the aim of determining which barriers were most relevant at each stage of change. It was hoped that this could provide information relating to the barriers that inhibit people from maintaining behaviour changes. However, in line with earlier

discussions about the sampling bias in the current research, most participants were in the action and maintenance stages (50% combined), with few in the earlier stages of pre-contemplation (11%), contemplation (3%), preparation (3%) or in the termination (31%) stage. Therefore it was not possible to address this aim in the current study. This is an important area for future research which should ensure that there are enough people in each stage of change by adopting a purposive sampling strategy. Although resource intensive, recruitment through health professionals at the time of diagnosis and whilst managing the illness would ensure that people in various stages were recruited. However, in order to recruit people in the termination stage (people who have made changes and have not maintained them), it may be appropriate to advertise through media sources and community settings, explicitly stating that they are needed for research even though they are not currently active in self-management.

While existing psychological research into type two diabetes self-management is somewhat broad, few attempts have been made to integrate qualitative and quantitative approaches. It is evident that there is a need for research which integrates these methods and ties together specific foci in order to develop a more holistic view of self-management. The current research, through the use of mixed methods, can provide a starting point. In order to build on these findings, future research would ideally integrate many forms of data, such as biological indicators of health and effective self-management, self-report and observational data pertaining to self-management behaviours, and self-reported qualitative and quantitative data investigating quality of life. For example, given the importance of psychosocial barriers to effective self-management identified here, future research should investigate the opinions of health professionals, people with the illness, as well as the wider community and the experiences of friends and family/spouses. Collection of data from more varied sources would allow further triangulation of the results and could begin to explore issues of community attitudes in further depth. Furthermore, in rural and

remote areas, where a lack of services have been reported, future research should focus on pairing barriers and quality of life data with an investigation of service availability and utilisation to determine the significance of access barriers in specific regions.

8.8 Conclusion

The research presented in this thesis identified barriers to effective type two diabetes self-management in rural and remote areas of Australia, adapted and validated an instrument to measure barriers to self-management in rural and urban areas, investigated demographic determinants of barriers to self-management, and investigated associations between barriers to self-management and diabetes-dependent quality of life in both rural and urban living Australians. Relatively little research exists in the area of rural type two diabetes self-management, thus the research presented represents a valuable contribution to the field. The use of mixed methods and a socio-ecological framework has produced an in-depth investigation of a complex problem, and allowed the identification of barriers to type two diabetes self-management. By investigating barriers to self-management, this research can help to inform a systematic approach to improving self-management and therefore reducing the consistently reported growing burden of the disease. Through the adaption and validation of the Diabetes Obstacles Questionnaire, this research also provides a starting point for the future investigation of barriers in specific rural and remote areas, such that planning can begin to overcome these barriers and improve self-management. It is hoped that increased research into rural and remote type two diabetes management can improve the quality of life of this population.

Appendices

Appendix 1: Examples of questions which were asked in telephone interviews and focus groups with people with type two diabetes

How long ago were you diagnosed with type two diabetes?

What effect has type two diabetes had on your life?

What was your initial reaction when you were told that you have type two diabetes?

What role does your doctor play in your type two diabetes treatment?

How do you feel about your type two diabetes treatment?

What do you think the aim of your diabetes management is?

What effect do you think that type two diabetes has on your health?

What makes type two diabetes management difficult for you?

Are there any things which help you to manage type two diabetes?

Do you have any strategies that help you to manage your type two diabetes?

Do you think there are any things that make your type two diabetes management different from if you were living in the city?

Do you have any advice for other people living in the country about controlling their type two diabetes successfully?

Do you think that there are any things which could make type two diabetes management easier or more effective in rural and remote Australia?

Appendix 2: Examples of questions which were asked in telephone interviews with health professionals

What is your role at your workplace? What does this involve?

How long have you been in this role/involved with patients with type two diabetes?

How do people typically react when they are told that they have type two diabetes?

What effect do you think that being diagnosed with type two diabetes has on people's lives?

What do you usually tell people do to manage their type two diabetes?

How do you think people find following the advice of Health Professionals?

What is the aim of type two diabetes management?

Who do you think is responsible for managing type two diabetes?

What do you think is the patient's role in managing their type two diabetes?

Ideally, who do you think should be involved with managing type two diabetes?(In your experience, is this what usually happens in rural South Australia?)

Are you involved in any diabetes education services in your area?

What is your role in these?

What is the aim of these services?

Do you think that patients find these useful?

What is good about them/ Why not?

Do you think that there are things that your patients could do to help to manage their type two diabetes more effectively that they don't do? (What are they)

Why do you think that they don't do these things?

What kinds of things may make it hard for them to do these things?

From your experiences, what effect do you think that type two diabetes has on the patient's health?

What is your idea of managing type two diabetes well?

What do you think helps people to manage their diabetes well?

Are there any things that make managing type two diabetes difficult for patients? (What are they)

From experiences of patients that you see, what do you think is the most difficult part of living with diabetes?

Do you think there are any things that make type two diabetes management different from if patients were living in the city?

What advice do you give to patients with type two diabetes that help them manage their diabetes more effectively?

Are there any things that you think could be done to make diabetes management in rural areas easier or more effective?

Do you have any other comments about the effect of type two diabetes on your patient's lives, or about managing type two diabetes?

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Barriers and facilitators to effective type two diabetes management in a rural context: A qualitative study with diabetes patients and health professionals

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NOTE:

This publication is included on pages 209-224 in the print copy of the thesis held in the University of Adelaide Library.

It is also available online to authorised users at:

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Appendix 4: Media Release for second data collection

Study to examine impact of diabetes on lifestyle

People living with Type 2 diabetes are being recruited for a national online survey to understand how it affects their quality of life.

The University of Adelaide study hopes to pinpoint the difficulties that diabetes sufferers face in different areas of the country and how they can be overcome.

Study co-ordinator Psychology PhD student Laura Jones says Type 2 diabetes is one of the top 10 causes of death in Australia and is increasing across all age groups – particularly children.

"Diabetes affects approximately 7.4% of the Australian population – about 1.6 million people – with 90% of these cases being Type 2 diabetes. More worrying is that an estimated 50% of diabetes sufferers are undiagnosed and not aware they are at risk."

Type 2 diabetes is associated with lifestyle – too much fatty food and too little exercise – and occurs when pancreatic cells become resistant to insulin, leading to high blood sugar levels.

The SA Health-funded study will reveal the differences in managing diabetes in both urban and rural areas, helping health authorities to identify gaps in services and professional expertise.

"There is some evidence to suggest diabetes is more difficult to manage in remote and rural areas and this is backed up by the statistics which show diabetes rates are twice as high in remote areas."

At least 200 people will be recruited for the online survey and there is also an option to complete a paper survey.

"Type 2 Diabetes is Australia's fastest growing chronic disease, with one person diagnosed every seven minutes. The tragedy is that most people can avoid it by choosing a sensible diet and lifestyle. Once you are diagnosed there is no cure so prevention is the answer."

National Diabetes Week runs from 10-16 July. For more information go to www.diabetesaustralia.com.au

To take part in the survey go to xxxxxxxxxxxxxxxx or phone Laura Jones on

Media Contact:

Candy Gibson

Media Officer

Marketing and Strategic Communications

The University of Adelaide

Phone: +61 8 8303 3173

Mobile:

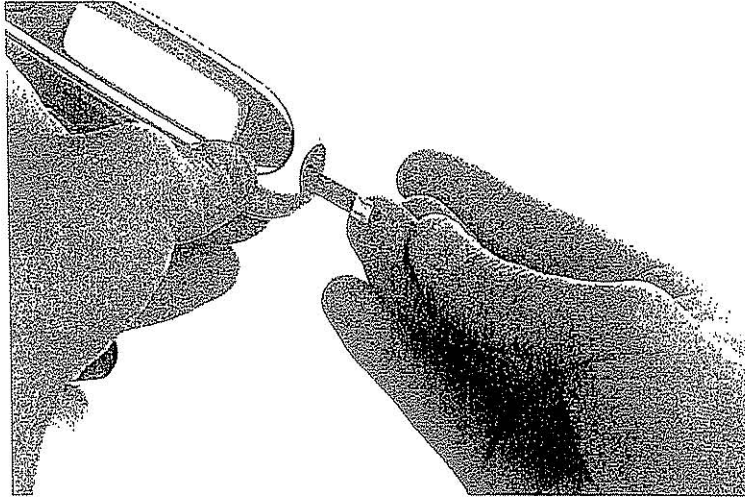
Email :

Appendix 5: Poster for second data collection



THE UNIVERSITY
OF ADELAIDE
AUSTRALIA

Do you have Type 2 Diabetes?



Seeking Volunteers for Research Survey

Volunteers are being sought to participate in a survey run through the University of Adelaide, looking into the management of Type 2 Diabetes, and the effect of Type 2 Diabetes on your life. The survey takes approximately 45 minutes to complete, is anonymous and all results are kept private and confidential. Participants go into the draw to win one of three \$100 vouchers for a store of their choice.

People with Type 2 Diabetes who are interested in participating in this study can access the online survey at:

<http://j.mp/t2diabetes>

Or receive a paper copy of the survey by contacting Laura Jones, PhD Candidate, on:

Laura Jones
C/- School of Psychology
University of Adelaide
Adelaide, 5005

If you would like to be involved, or enquire further about this study, please take one of the tear off tickets below:

Appendix 6: Questionnaire used for second data collection

1. Type 2 Diabetes Management: Participant Information

Dear Participant,

Thank you for considering participating in this study. This research is open to people who have been diagnosed with Type 2 Diabetes, and aims to find out more about barriers preventing people from controlling their Type 2 Diabetes effectively. This study would involve you completing an online questionnaire. The questionnaire includes questions about your current Type 2 Diabetes management, barriers which may make it difficult for you to manage your Type 2 Diabetes effectively, symptoms of anxiety and depression which you may have had, and questions about your quality of life. Through participating in this study, your responses will contribute to gaining a better understanding of the needs and experiences of people living with Type 2 Diabetes, with the aim of making Type 2 Diabetes management easier and more effective in the future. This study is for research purposes only, so please answer questions as honestly as possible, there are no right or wrong answers, we are aiming to find out more about your personal experiences of managing Type 2 Diabetes.

As a small token of appreciation for your time and effort in participating in this study, you may enter a raffle draw to win one of three \$100 vouchers for a store of your choice. The final page of this questionnaire provides you with the opportunity to enter the raffle, and to request a summary of the results of the study. Please note that all contact information which you provide here will be kept private and confidential and will be separated from your questionnaire responses, so that your anonymity is maintained.

Ethical Considerations:

Due to the questions in this study asking about your feelings towards your diabetes management, it is possible that you may feel distressed. If you experience any discomfort or distress, please do not hesitate to contact Lifeline on 13 11 14. A list of help and information services which you may find useful are also provided on the next page.

All information that you provide will be kept private and confidential. Furthermore, your responses are anonymous, so when the results of this data are analysed, nothing will link you to your responses and your identity will be protected in any publication of this data. If, at any time, you feel that you would like to decline to answer questions, or to withdraw your consent to participating in this study, you are free to do so.

This study has been approved by the School of Psychology Sub Committee of the University of Adelaide Human Ethics Committee. The convener of this committee, Associate Professor Paul Delfabbro, can be contacted on (08) 8303 5744 or paul.delfabbro@psychology.adelaide.edu.au if you have any questions regarding ethical approval.

It is anticipated that this questionnaire will take approximately one hour to complete. If you have any questions about the study, or would prefer to receive a paper copy of this questionnaire, please do not hesitate to contact Laura Jones either by phone, on (08) 8303 3850, by email at laura.jones@adelaide.edu.au, or by mail at:

Laura Jones
c/- School of Psychology
The University of Adelaide
Adelaide, 5005

Thank you for your time and for considering participating in this study.

2. Help and Information Services

The following services are help and information services which you may find useful.

Lifeline

Phone: 13 11 44

Website: <http://www.lifeline.org.au/Find-Help/Crisis-Support/24-Hour-Crisis-Support/Lifeline-s-24-Hr-Telephone-Crisis-Support-Service---13-11-14/default.aspx>

Lifeline is a free, confidential, 24 hour crisis support service where you can speak to trained telephone volunteers. These volunteers are also able to provide you with referral information for other services in your local area.

Diabetes Counseling Online

Website: <http://www.diabetescounselling.com.au/>

Diabetes Counseling Online is a free online counseling service, specifically for people with diabetes, where you can chat with trained counselors who also have diabetes, or who live with people who have diabetes. This website provides information and counseling via email, discussion groups, chat rooms.

Australian Psychological Society

Website: <http://www.psychology.org.au/FindaPsychologist/>

The Australia Psychological Society is the largest Australian professional association for psychologists. The link above provides details of psychologists in your local area.

Diabetes Australia

Website: <http://www.diabetesaustralia.com.au/>

Phone: 1300 136 588

Diabetes Australia provides information about managing your diabetes, support groups and the National Diabetes Services Scheme (NDSS).

3. Consent

Please read the following information carefully and provide your consent to this study by clicking on the 'yes' button, below.

I consent to taking part in the research entitled 'Type 2 Diabetes Management'.

I acknowledge that I have read the Participant Information page entitled 'Type 2 Diabetes Management: Participant Information'

I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is freely given.

Although I understand that the purpose of this research project is to improve the quality of medical care, it has also been explained to me that my involvement may not be of any benefit to me.

I have been informed that, whilst information gained during the study may be published, I will not be identified and my personal results will not be divulged.

I am aware that I may provide identifying information such as an email address, or postal address if I wish to receive feedback about the results of the study as a whole, or to enter the raffle draw, and that this information will be kept separately from survey responses, and not used for any other purpose.

I understand that I am free to withdraw from the study at any time and that this will not affect medical advice in the management of my health, now or in the future.

I am aware that a copy of this information sheet/consent form will be available on this website until the study has been concluded.

I am over 18 years of age.

I consent to participating in this study.

Yes

No

4. Your current Type Two Diabetes Management

*** Please click on one of the following statements that best describes the changes you have made to manage your Type 2 Diabetes:**

- I have not made any changes to my lifestyle and do not intend to in the next year or two.
- I have not made any changes to my lifestyle, but I intend to in the next year or so.
- I intend to make changes to my lifestyle, and am currently preparing to make these changes.
- I have made changes to my lifestyle in the last 6 months.
- I have made changes to my lifestyle, and I have maintained these for MORE than six months.
- I have previously made changes to my lifestyle, but have not been able to maintain these changes.

*** How are you currently managing your Type 2 Diabetes (please click on all relevant responses)?**

- Diet
- Diet and Exercise
- Medication
- I am not currently doing anything to manage my Type 2 Diabetes
- Other (please specify)

5. Other Illnesses and Health Conditions

Please indicate which of the following Type 2 Diabetes complications you have experienced:

- Eye problems
- Foot problems
- Heart disease
- Stroke
- High blood pressure
- Kidney disease
- Neuropathy (nerve damage)
- Tooth and gum problems

Please indicate which of the following illnesses you have been diagnosed with:

- High blood pressure
- Heart disease
- Respiratory problems (such as Asthma, Emphysema)
- Osteoporosis
- Arthritis
- Cancer
- Stroke

6. Medication

Are you currently managing your Type 2 Diabetes with medication (tablets or insulin)?

Yes

No

7. Medication

Please click on the response which indicates how much you agree or disagree with each statement in relation to your diabetes medicine (tablets or insulin), not other medication that you may be taking.

I do not feel I am being prescribed the medication (type) that is right for me

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I do not feel I am being prescribed the medication dose that is right for me

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I don't know what to do about taking my medication when I am feeling unwell

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Taking insulin makes life too complicated

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Taking insulin means my diabetes is getting worse

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

People treat insulin users differently

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I am not in a convenient place when it is time to take my medication

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I forget to take my medication

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

My medication causes unwanted side effects

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I feel resentful that I have to take my medication

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

8. Self-Monitoring

Please click on the response which indicates how much you agree or disagree with each statement in relation to self-monitoring your blood glucose levels.

I find it especially hard to test when I'm busy

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Self-monitoring makes me feel frustrated

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Self-monitoring makes me feel fearful of a high reading

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I don't feel that self-monitoring is helping me to control my diabetes

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I find it too uncomfortable to self-monitor

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Self-monitoring in public places makes me feel embarrassed or uncomfortable

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I don't know how to self-monitor properly

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

9. Knowledge and Beliefs

Please click one response which indicates how much you agree or disagree with each statement in relation to your experiences of accessing knowledge about diabetes.

I do not know as much as I need to know to manage my diabetes

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I have difficulty accessing information that is relevant to me personally

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I have difficulty understanding the information from literature (for example, pamphlets and websites about Type 2 Diabetes)

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I have difficulty understanding information from health care professionals

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I think that the information on diabetes is not consistent

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I do not know as much as I need to know about the consequences of having diabetes

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I do not know enough about the treatment for diabetes

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I believe type 2 diabetes is mild compared with type 1

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I do not know enough about the benefits of diabetes treatment for me

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I don't believe the consequences of type 2 diabetes are serious

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

10. Diagnosis

Please click on the response which indicates how much you agree or disagree with each statement in relation to when you were first diagnosed with diabetes.

The way that I was told that I had diabetes made me feel confused

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

The way that I was told that I had diabetes made me feel afraid

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

The way that I was told that I had diabetes made me feel that it was not a serious condition

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

The way that I was told that I had diabetes did not motivate me to manage my diabetes well

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I was not given as much information as I needed about the consequences of having diabetes

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

The way that I was told that I had diabetes made me feel guilty

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

11. Relationships with Health Care Professionals

Please click on the response which indicates how much you agree or disagree with each statement in relation to when you were first diagnosed with diabetes.

I feel my questions about diabetes are not answered

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I feel I am not listened to

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I feel my judgment is not trusted in managing my diabetes

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I am not advised at all on what to do about my diabetes

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I am not assisted in setting realistic targets for changing my lifestyle

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Treatment alternatives are not explained to me

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I have not been told what to expect from my diabetes

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I have not been told what to expect from my treatment

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I do not feel I am part of the diabetes team

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

The good and bad aspects of each choice have not been discussed with me

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I am not asked at all which choice I would prefer (in managing my type 2 diabetes)

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Talking about my diabetes with members of the diabetes team does not make me feel better

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Adjustments to my diabetes plan cannot be discussed

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I feel threatened when I go for a check up

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I feel a sense of powerlessness when consulting with nurses

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I feel a sense of powerlessness when consulting with doctors

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Clinic times are inconvenient for me

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I have to spend too much time waiting in clinics

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

12. Lifestyle Changes

Please click on the response which indicates how much you agree or disagree with each statement in relation to changes in your lifestyle.

My diabetic diet spoils my social life

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I generally still feel hungry after finishing a meal

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

My diabetes has placed strain on my personal relationships

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

There is little hope of leading a normal life when you have diabetes

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Changes in my diet have put a strain on my family

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I have difficulty sticking to my diet when I am away from home

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I feel resentful that I am obliged to change my eating habits

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I am unable to fit exercise into my lifestyle

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I am unable to afford the cost of exercising on a regular basis

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I haven't found an exercise I enjoy

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I lack the motivation to exercise

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Weight control is a real problem for me

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I am not able to change my lifestyle to fit with advice from health care professional(s)

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I find it hard to maintain the changes suggested to me (even though I can make the changes for a short period of time)

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

It is too hard for me to prepare and cook meals that are recommended to me

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

13. Coping with Diabetes

Please click on the response which indicates how much you agree or disagree with each statement in relation to problems with sticking to your diabetes plan

Self-management of diabetes is difficult to maintain because diabetes complications are not immediate

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Good control of diabetes involves a lot of sacrifice

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I find it difficult to get into a suitable routine to cope with my treatment plan

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I am not convinced that the treatment I receive for my diabetes is effective

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I feel overwhelmed by the responsibility of having to take my medication

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I feel that I would like to take a holiday from my diabetes

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I eat something that I should not rather than say I have diabetes

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I feel that my family would like to take a holiday from my diabetes

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

14. Advice and Support

Please click on the response which indicates how much you agree or disagree with each statement in relation to receiving advice and support about your diabetes.

I am not convinced health care professionals believe the treatment I receive for my diabetes will work

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I am too often told what I should and should not be doing to manage my diabetes

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Constantly repeating what I should be doing to manage my diabetes makes me do it less

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I am criticized too often about the way I manage my diabetes

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I would manage my diabetes much better if I had more encouragement socially

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I feel very alone with my diabetes

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I feel I get little support from my family

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I feel I get little support from my friends

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

The health professionals available in my area do not have the experience to give me the advice I need, especially for multiple illnesses

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

15. Access and Availability

Please click on the response which indicates how much you agree or disagree with each statement in relation to your access to the services you need to manage your diabetes.

It is hard for me to make appointments with the health care professionals (doctors, diabetes educators, dietitians, specialists etc) I need to see

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

The health care professionals that I need to see are not available where I live

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

It is too difficult for me to travel to appointments with health care professionals

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Health care professionals do not stay in my local area long enough to give me continued support

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

I do not have access to the foods which are recommended to me

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

16. Anxiety and Depression

Please read each statement and click the appropriate response which indicates how much the statement applied to you over the last week. There are no right or wrong answers. Do not spend too much time on any one statement.

	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of the time	Applied to me very much, or most of the time
I found it hard to wind down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was aware of dryness of my mouth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I couldn't seem to experience any positive feeling at all	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it difficult to work up the initiative to do things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I tended to over-react to situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I experienced trembling (eg, in the hands)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I was using a lot of nervous energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried about situations in which I might panic and make a fool of myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I had nothing to look forward to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found myself getting agitated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it difficult to relax	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt down-hearted and blue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was intolerant of anything that kept me from getting on with what I was doing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt I was close to panic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was unable to become enthusiastic about anything	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt I wasn't worth much as a person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I was rather touchy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt scared without any	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

good reason

I felt that life was

meaningless



17. Your Management

Please select the options which best describe how you have followed your diabetes treatment plan in the last 1-2 months.

In the past 1-2 months, how well have you followed recommendations for:

	Never	Rarely	About half of the time	Usually (occasional lapses)	Always	Not Applicable
Checking blood glucose with monitor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recording blood glucose results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking the correct dose of diabetes pills or insulin	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking diabetes pills or insulin at the right time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eating the correct food portions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eating meals/snacks on time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keeping food records	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reading food labels	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Treating low blood glucose with just the recommended amount of carbohydrate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Carrying quick acting sugar to treat low blood glucose	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Coming in for clinic appointments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exercising	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

What was your most recent Blood Glucose Test (either self-tested or when you were tested by a health care professional) reading?

18. Quality of Life

This questionnaire asks about your quality of life- in other words how good or bad you feel your life to be. Please click on the circle that best indicates your response for each item.

This Questionnaire is the Audit of Diabetes Dependant Quality of Life (ADDQoL). Copyright Prof Claire Bradley: 24.2.94

What we would like to know is how you feel about your life now.

In general, my present quality of life is:

- excellent
- very good
- good
- neither good nor bad
- bad
- very bad
- extremely bad

Now we would like to know how your quality of life is affected by your diabetes, its management and any complications you may have.

If I did not have diabetes, my quality of life would be:

- very much better
- much better
- a little better
- the same
- worse

19. Quality of Life

Please respond to the more specific statements on the following pages. For each aspect of life described, you will find two parts:

For Part (a): click to show how diabetes affects this aspect of your life;

For Part (b): click to show how important this aspect of your life is to your quality of life.

1 (a) If I did not have diabetes, i would enjoy my leisure activities:

- very much more
- much more
- a little more
- the same
- less

(b) My leisure activities are:

- very important
- important
- somewhat important
- not at all important

2 Are you currently working, looking for work or would you like to work?

- Yes- If yes, complete (a) and (b)
- No- If no, go straight to 3(a)

(a) If I did not have diabetes, my working life would be:

- very much better
- much better
- a little better
- the same
- worse

(b) For me, having a working life is:

- very important
- important
- somewhat important
- not at all important

3 (a) If I did not have diabetes, local or long distance journeys would be:

- very much easier
- much easier
- a little easier
- the same
- more difficult

(b) For me, local or long distance journeys are:

- very important
- important
- somewhat important
- not at all important

4 Do you ever go on holiday or want to go on holiday?

- Yes- If yes, complete (a) and (b)
- No- If no, go straight to 5 (a)

(a) If I did not have diabetes, my holidays would be:

- very much better
- much better
- a little better
- the same
- worse

(b) For me, holidays are:

- very important
- important
- somewhat important
- not at all important

5 (a) If I did not have diabetes, physically I could do:

- very much more
- much more
- a little more
- the same
- less

(b) For me, how much I can do physically is:

- very important
- important
- somewhat important
- not at all important

6 Do you have any family/relatives?

- Yes- If yes, complete (a) and (b)
- No- If no, go straight to 7 (a)

(a) If I did not have diabetes, my family life would be:

- very much better
- much better
- a little better
- the same
- worse

(b) My family life is:

- very important
- important
- somewhat important
- not at all important

7 (a) If I did not have diabetes, my friendships and social life would be:

- very much better
- much better
- a little better
- the same
- worse

(b) My friendships and social life are:

- very important
- important
- somewhat important
- not at all important

8 Do you have or would you like to have a close personal relationship (e.g. husband/wife, partner)?

- Yes- If yes, complete (a) and (b)
- No- If no, go straight to 9

(a) If I did not have diabetes, my closest personal relationship would be:

- very much better
- much better
- a little better
- the same
- worse

(b) For me, having a close personal relationship is:

- very important
- important
- somewhat important
- not at all important

9 Do you have or would you like to have a sex life?

- Yes- If yes, complete (a) and (b)
- No- If no, go straight to 10 (a)

(a) If I did not have diabetes, my sex life would be:

- very much better
- much better
- a little better
- the same
- worse

(b) For me, having a sex life is:

- very important
- important
- somewhat important
- not at all important

10 (a) If I did not have diabetes, my physical appearance would be:

- very much better
- much better
- a little better
- the same
- worse

(b) My physical appearance is:

- very important
- important
- somewhat important
- not at all important

11 (a) If I did not have diabetes, my self-confidence would be:

- very much better
- much better
- a little better
- the same
- worse

(b) My self-confidence is:

- very important
- important
- somewhat important
- not at all important

12 (a) If I did not have diabetes, my motivation would be:

- very much better
- much better
- a little better
- the same
- worse

(b) My motivation is:

- very important
- important
- somewhat important
- not at all important

13 (a) If I did not have diabetes, the way people in general react to me would be:

- very much better
- much better
- a little better
- the same
- worse

(b) The way people in general react to me is:

- very important
- important
- somewhat important
- not at all important

14 (a) If I did not have diabetes, my feelings about the future (e.g. worries, hopes) would be:

- very much better
- much better
- a little better
- the same
- worse

(b) My feelings about the future are:

- very important
- important
- somewhat important
- not at all important

15 (a) If I did not have diabetes, my financial situation would be:

- very much better
- much better
- a little better
- the same
- worse

(b) My financial situation is:

- very important
- important
- somewhat important
- not at all important

16 (a) If I did not have diabetes, my living conditions would be:

- very much better
- much better
- a little better
- the same
- worse

(b) My living conditions are:

- very important
- important
- somewhat important
- not at all important

17 (a) If I did not have diabetes, I would have to depend on others when I do not want to:

- very much less
- much less
- a little less
- the same
- more

(b) For me, not having to depend on others is:

- very important
- important
- somewhat important
- not at all important

18 (a) If I did not have diabetes, my freedom to eat as I wish would be:

- very much greater
- much greater
- a little greater
- the same
- less

(b) My freedom to eat as I wish is:

- very important
- important
- somewhat important
- not at all important

19 (a) If I did not have Diabetes, my freedom to drink as I wish (eg: fruit juice, alcohol, sweetened hot and cold drinks) would be:

- very much greater
- much greater
- a little greater
- the same
- less

(b) My freedom to drink as I wish is:

- very important
- important
- somewhat important
- not at all important

20. Demographics

What is your date of birth?

	Date	Month	Year
Date of birth	<input type="text"/>	<input type="text"/>	<input type="text"/>

What is your gender?

- Male
- Female

* What is the post code of your place of residence?

How long ago were you diagnosed with Type 2 Diabetes (In years and months)?

21. Thank you

Thank you for completing this survey. Your time and effort is greatly appreciated.

If you wish to be entered into the draw to win one of three \$100 vouchers for a store of your choice, please provide your contact details here:

If you wish to receive a summary of the results of this study, please provide your contact details below:

References

- Adamson, J. (2005). Combined qualitative and quantitative designs. In S. Bowling & S. Ebrahim (Eds.), *Handbook of health and research methods*. Maidenhead, UK: Open University Press.
- Al-Qazaz, H. K., Sulaiman, S. A., Hassali, M. A., Shafie, A. A., Sundram, S., Al-Nuri, R., & Saleem, F. (2011). Diabetes knowledge, medication adherence and glycemic control among patients with type 2 diabetes. *International journal of clinical pharmacy*, 33(6), 1028-1035.
- Ali, S., Stone, M. A., Peters, J. L., Davies, M. J., & Khunti, K. (2006). The prevalence of co-morbid depression in adults with Type 2 diabetes: A systematic review and meta-analysis. *Diabetic Medicine*, 23(11), 1165-1173.
- Anderson-Loftin, W., Barnett, S., Bunn, P., & Sullivan, P. (2005). Recruitment and retention of rural African Americans in diabetes research: Lessons learned. *The Diabetes Educator*, 31(2), 251-259.
- Anderson, R. J., Freedland, K. E., Clouse, R. E., & Lustman, P. J. (2001). The prevalence of comorbid depression in adults with diabetes: A meta-analysis. *Diabetes Care*, 24(6), 1069-1078.
- Anderson, R. M., Donnelly, M. B., & Dedrick, R. F. (1990). Measuring the attitudes of patients towards diabetes and its treatment. *Patient Education and Counseling*, 16(3), 231-245.
- Anderson, R. M., Fitzgerald, J. T., Gorenflo, D. W., & Oh, M. S. (1993). A comparison of the diabetes-related attitudes of health care professionals and patients. *Patient education and counseling*, 21(1), 41-50.
- Antony, M. M., Cox, B. J., Enns, M. W., Bieling, P. J., & Swinson, R. P. (1998). Psychometric properties of the 42-item and 21-item versions of the Depression Anxiety Stress Scales in clinical groups and a community sample. *Psychological Assessment*, 10(2), 176-181.
- Arnold, R., Ranchor, A., Sanderman, R., Kempen, G., Ormel, J., & Suurmeijer, T. (2004). The relative contribution of domains of quality of life to overall quality of life for different chronic diseases. *Quality of Life Research*, 13(5), 883-896.
- Aronson, J. K. (1994). A pragmatic view of thematic analysis. *The qualitative report*, 2(1), 1-3.
- Aronson, J. K. (2007). Compliance, concordance, adherence. *British journal of clinical pharmacology*, 63(4), 383-384.
- Arora, N. K., & McHorney, C. A. (2000). Patient preferences for medical decision making: who really wants to participate? *Medical care*, 38(3), 335-341.
- August, K. J., Rook, K. S., Parris Stephens, M. A., & Franks, M. M. (2011). Are spouses of chronically ill partners burdened by exerting health-related social control? *Journal of Health Psychology*, 16(7), 1109-1119.
- August, K. J., & Sorkin, D. H. (2011). Support and influence in the context of diabetes management: Do racial/ethnic differences exist? *Journal of Health Psychology*, 16(5), 711-721.
- Australian Institute of Health and Welfare. (2004). Rural, regional and remote health: a guide to remoteness classifications *Rural Health Series*. Canberra: Australian Institute Health and Welfare.
- Australian Institute of Health and Welfare. (2007a). Diabetes: The facts Retrieved 28/12/2007 from <http://www.aihw.gov.au/diabetes/index.cfm>
- Australian Institute of Health and Welfare. (2007b). Rural, regional and remote health: a study on mortality *Rural health series* (2nd Edition ed., Vol. 8). Canberra: Australian Institute of Health and Welfare.

- Australian Institute of Health and Welfare. (2008a). Diabetes: Australian facts 2008 *Diabetes series* (Vol. no. 8). Canberra: Australian Institute of Health and Welfare.
- Australian Institute of Health and Welfare. (2008b). Rural, regional and remote health: indicators of health status and determinants of health *Rural Health Series* (Vol. 9). Canberra: Australian Institute of Health and Welfare.
- Australian Institute of Health and Welfare. (2010). Australia's health 2010. *Australia's health series* no. 12. Cat. no. AUS 122. Retrieved 16/01/2012, 2012
- Australian Institute of Health and Welfare. (2012a). Diabetes Mellitus Retrieved 11th October, 2012, from <http://www.aihw.gov.au/diabetes-mellitus-health-priority-area/>
- Australian Institute of Health and Welfare. (2012b). Health expenditure Australia 2010-11 *Health and welfare expenditure series* Canberra: AIHW
- Australian Institute of Health and Welfare, & Commonwealth Department of Health and Family Services. (1997). First report on National Health Priority Areas 1996. Canberra
- Australian Population and Migration Research Centre. (2013, 14/03/2013). Australian Population and Migration Research Centre Summary Retrieved 15/03/2013, from <http://www.adelaide.edu.au/apmrc/research/projects/category/aria.html>
- Bandura, A. (1977). *Social Learning Theory*. Englewood Cliffs, New Jersey: Prentice-Hall.
- Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling*, 48(2), 177-187.
- Baum, F. (1995). Researching public health: behind the qualitative-quantitative methodological debate. *Social Science & Medicine*, 40(4), 459-468.
- Bech, M., & Kristensen, M. B. (2009). *Differential response rates in postal and web-based surveys among older respondents*. Paper presented at the Survey Research Methods, Bremen.
- Beckles, G. L. A., Engelgau, M. M., Venkat Narayan, K. M., Herman, W. H., Aubert, R. E., & Williamson, D. F. (1998). Population-based assessment of the level of care among adults with diabetes in the U.S. *Diabetes Care*, 21(9), 1432-1438.
- Bethell, C., Fiorillo, J., Lansky, D., Hendryx, M., & Knickman, J. (2004). Online consumer surveys as a methodology for assessing the quality of the United States health care system. *Journal of Medical Internet Research*, 6(1), 13-24.
- Beverly, E. A., Miller, C. K., & Wray, L. A. (2008). Spousal support and food-related behavior change in middle-aged and older adults living with type 2 diabetes. *Health Education & Behavior*, 35(5), 707-720.
- Beyond Blue. (2011). Beyond Blue Retrieved 15/06/2013, from http://www.beyondblue.org.au/index.aspx?link_id=2.896
- Boccuzzi, S. J., Wogen, J., Fox, J., Sung, J. C. Y., Shah, A. B., & Kim, J. (2001). Utilization of oral hypoglycemic agents in a drug-insured US population. *Diabetes Care*, 24(8), 1411-1415. doi: 10.2337/diacare.24.8.1411
- Bourke, L. (2001). Australian rural consumers' perceptions of health issues. *The Australian journal of rural health*, 9(1), 1-6.
- Bowling, A. (2005). Quantitative social science: the survey. In A. Bowling & S. Ebrahim (Eds.), *Handbook of health and research methods*. Mainhead, UK: Open University Press.
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage Publications, Incorporated.

- Boyle, J. P., Honeycutt, A. A., Narayan, K. M. V., Hoerger, T. J., Geiss, L. S., Chen, H., & Thompson, T. J. (2001). Projection of diabetes burden through 2050 impact of changing demography and disease prevalence in the US. *Diabetes care*, *24*(11), 1936-1940.
- Boyle, J. P., Thompson, T. J., Gregg, E. W., Barker, L. E., & Williamson, D. F. (2010). Projection of the year 2050 burden of diabetes in the US adult population: Dynamic modeling of incidence, mortality, and prediabetes prevalence. *Population Health Metrics*, *8*.
- Bradley, C. (2001). Importance of differentiating health status from quality of life. *The Lancet*, *357*(9249), 7-8. doi: 10.1016/s0140-6736(00)03562-5
- Bradley, C., Todd, C., Gorton, T., Symonds, E., Martin, A., & Plowright, R. (1999). The development of an individualized questionnaire measure of perceived impact of diabetes on quality of life: The ADDQoL. *Quality of Life Research*, *8*(1-2), 79-91.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101.
- Brown, J. B., Harris, S. B., Webster-Bogaert, S., Wetmore, S., Faulds, C., & Stewart, M. (2002). The role of patient, physician and systemic factors in the management of type 2 diabetes mellitus. *Family Practice*, *19*(4), 344-349. doi: 10.1093/fampra/19.4.344
- Bryman, A. (1984). The debate about quantitative and qualitative research: a question of method or epistemology? *British Journal of Sociology*, 75-92.
- Burge, M., Lucero, S., Rassam, A., & Schade, D. (2000). What are the barriers to medical care for patients with newly diagnosed diabetes mellitus? *Diabetes, Obesity and Metabolism*, *2*(6), 351-354.
- Burke, J. A., Earley, M., Dixon, L. D., Wilke, A., & Puczynski, S. (2006). Patients with diabetes speak: Exploring the implications of patients' perspectives for their diabetes appointments. *Health communication*, *19*(2), 103-114.
- Campbell, D. T., & Fiske, D. W. (1959). Convergent and discriminant validation by the multitrait-multimethod matrix. *Psychological Bulletin*, *56*, 81-105.
- Carter, S., & Henderson, L. (2005). Approaches to qualitative data collection in social science In A. Bowling & S. Ebrahim (Eds.), *Handbook of health and research methods*. Maidenhead, UK: Open University Press
- Cefalu, W. T. (2012). Evolving treatment strategies for the management of type 2 diabetes. *American Journal of the Medical Sciences*, *343*(1), 21-26.
- Charlson, M. E., Pompei, P., Ales, K. A., & MacKenzie, C. R. (1987). A new method of classifying prognostic comorbidity in longitudinal studies: Development and validation. *Journal of Chronic Diseases*, *40*(5), 373-383.
- Chittleborough, C. R., Baldock, K. L., Taylor, A. W., & Phillips, P. J. (2006). Health status assessed by the SF-36 along the diabetes continuum in an Australian population. *Quality of Life Research*, *15*(4), 687-694.
- Choi, G., Jang, S. M., & Nam, H. W. (2008). Current Status of Self-management and Barriers in Elderly Diabetic Patient. *Korean Diabetes Journal*, *32*(3), 280-289.
- Ciechanowski, P. S., Katon, W. J., & Russo, J. E. (2000). Depression and diabetes: Impact of depressive symptoms on adherence, function, and costs. *Archives of Internal Medicine*, *160*(21), 3278-3285.
- Clark, N. M., Becker, M. H., Janz, N. K., Lorig, K., Rakowski, W., & Anderson, L. (1991). Self-Management of Chronic Disease by Older Adults: A Review and Questions for Research. *Journal of Aging and Health*, *3*(1), 3-27.
- Clement, S. (1995). Diabetes self-management education. *Diabetes care*, *18*(8), 1204-1214.
- Cohen, S. (1998). Psychosocial models of the role of social support in the etiology of physical disease. *Health Psychology*, *7*, 269-297.

- Collins, J. E., Winefield, H., Ward, L., & Turnbull, D. (2009). Understanding help seeking for mental health in rural South Australia: thematic analytical study. *Australian Journal of Primary Health, 15*(2), 159-165.
- Coonrod, B. A. (2001). Overcoming physical barriers to diabetes self-care: reframing disability as an opportunity for ingenuity. *Diabetes Spectrum, 14*(1), 28-32.
- Cowie, C., Rust, K., Byrd-Holt, D., Eberhardt, M., Flegal, K., Engelgau, M. M., . . . Gregg, E. W. (2006). Prevalence of Diabetes and Impaired Fasting Glucose in Adults in the U.S. Population: National Health and Nutrition Examination Survey 1999–2002. *Diabetes Care 29*(6), 1263-1268.
- Creer, T. L., Renne, C. M., & Christian, W. P. (1976). Behavioral contributions to rehabilitation and childhood asthma. *Rehabilitation Literature, 37*, 226-232.
- Dailey, G., Kim, M. S., & Lian, J. F. (2001). Patient compliance and persistence with antihyperglycemic drug regimens: Evaluation of a Medicaid patient population with type 2 diabetes mellitus. *Clinical Therapeutics, 23*(8), 1311-1320. doi: 10.1016/s0149-2918(01)80110-7
- Dansky, K. H., & Dirani, R. (1998). The use of health care services by people with diabetes in rural areas. *Journal of Rural Health, 14*(2), 129-137.
- De Grauw, W. J. C., Van De Lisdonk, E. H., Behr, R. R. A., Van Gerwen, W. H., Van Den Hoogen, H. J. M., & Van Weel, C. (1999). The impact of type 2 diabetes mellitus on daily functioning. *Family Practice, 16*(2), 133-139.
- De Groot, M., Anderson, R., Freedland, K. E., Clouse, R. E., & Lustman, P. J. (2001). Association of depression and diabetes complications: A meta-analysis. *Psychosomatic Medicine, 63*(4), 619-630.
- De Groot, V., Beckerman, H., Lankhorst, G. J., & Bouter, L. M. (2003). How to measure comorbidity: A critical review of available methods. *Journal of Clinical Epidemiology, 56*(3), 221-229.
- de Weerd, I., Visser, A. P., Kok, G., & Van der Veen, E. A. (1990). Determinants of active self-care behaviour of insulin treated patients with diabetes: implications for diabetes education. *Social Science & Medicine, 30*(5), 605-615.
- Dean, S. G., Hudson, S., Hay-Smith, E., Jean, C., & Milosavljevic, S. (2011). Rural Workers' Experience of Low Back Pain: Exploring Why They Continue to Work. *Journal of Occupational Rehabilitation, 21*(3), 395-409. doi: 10.1007/s10926-010-9275-z
- Dean, S. G., Smith, J. A., Payne, S., & Weinman, J. (2005). Managing time: An interpretative phenomenological analysis of patients' and physiotherapists' perceptions of adherence to therapeutic exercise for low back pain. *Disability and Rehabilitation, 27*(11), 625-636. doi: 10.1080/0963820500030449
- Del Boca, F. K., & Noll, J. A. (2000). Truth or consequences: The validity of self-report data in health services research on addictions. *Addiction, 95*(SUPPL. 3), S347-S360.
- Delamater, A. M., Jacobson, A. M., Anderson, B., Cox, D., Fisher, L., Lustman, P., . . . Wysocki, T. (2001). Psychosocial Therapies in Diabetes Report of the Psychosocial Therapies Working Group. *Diabetes Care, 24*(7), 1286-1292.
- Dempster, A. P., Laird, N. M., & Rubin, D. B. (1977). Maximum Likelihood from Incomplete Data via the EM Algorithm. *Journal of the Royal Statistical Society. Series B (Methodological), 39*(1), 1-38.
- Department of Health and Aged Care & GISCA (National Key Centre for Social Applications of Geographic Information Systems). (2001). Measuring remoteness: Accessibility/Remoteness Index of Australia (ARIA). Canberra Department of Health and Aged Care
- Department of Health and Ageing. (2012a). Rural and Regional Health Australia Retrieved 9/01/2013, from <http://www.ruralhealthaustralia.gov.au/>

- Department of Health and Ageing. (2012b). Work of the Australian Government on diabetes Retrieved 12/12/2012, from <https://www.health.gov.au/internet/main/publishing.nsf/Content/pq-diabetes-gov>
- Department of Health Victoria. (2007). Diabetes self-management: Guidelines for providing services to people newly diagnosed with Type 2 diabetes. Melbourne, Australia: Department of Health Victoria.
- Department of Primary Industries and Energy, & Department of Human Services and Health. (1994). Rural, Remote and Metropolitan Areas classification. 1991 Census edition. Canberra
- Diabetes Australia. (2011). Diabetes Management in General Practice: Guidelines for Type 2 Diabetes 2011/12 (17 ed.).
- Diabetes Australia. (2012a). Managing Type 2 Diabetes Retrieved 22/8/2012, from <http://www.diabetesaustralia.com.au/Living-with-Diabetes/Type-2-Diabetes/Managing-Type-2-Diabetes/>
- Diabetes Australia. (2012b, 16/08/2012). National Diabetes Services Scheme Retrieved 17/10/2012, from <http://www.ndss.com.au/>
- Diabetes Counselling Online. (2013). Retrieved 9/1/2013, from <http://www.diabetescounselling.com.au/>
- DiClemente, C. C., & Prochaska, J. O. (1982). Self-change and therapy change of smoking behavior: A comparison of processes of change in cessation and maintenance. *Addictive behaviors, 7*(2), 133-142.
- Diefenbach, M. A., & Leventhal, H. (1996). The common-sense model of illness representation: Theoretical and practical considerations. *Journal of social distress and the homeless, 5*(1), 11-38.
- DiMatteo, M. R. (2004). Social support and patient adherence to medical treatment: a meta-analysis. *Health psychology, 23*(2), 207-218.
- Dixon, J., & Welch, N. (2000). Researching the rural-metropolitan health differential using the 'social determinants of health'. *The Australian journal of rural health, 8*(5), 254-260.
- Donahue, K. E., Mielenz, T. J., Callahan, L. F., Sloane, P. D., & Devellis, R. F. (2006). Identifying Supports and Barriers to Physical Activity in Patients at Risk for Diabetes. *Preventing Chronic Disease, 3*(4), 3-12.
- Donald, M., Dower, J., Ware, R., Mukandi, B., Parekh, S., & Bain, C. (2012). Living with diabetes: Rationale, study design and baseline characteristics for an Australian prospective cohort study. *BMC Public Health, 12*(1).
- Dunbar-Jacob, J., & Schlenk, E. (2001). Patient adherence to treatment regimen. In A. Baum, Revenson T. A. & Singler J. E. (Eds.), *Handbook of Health Psychology* (pp. 571-580). Mahwah, NJ: Erlbaum.
- Duncan, A., Turnbull, D., Gregory, T., Cole, S. R., Young, G. P., Flight, I., & Wilson, C. (2012). Using the Transtheoretical Model of Behaviour Change to describe readiness to rescreen for colorectal cancer with faecal occult blood testing. *Health Promotion Journal of Australia, 23*(2), 122-128.
- Dunn, S. M. (1990). Rethinking the models and modes of diabetes education. *Patient Education and Counseling, 16*(3), 281-286.
- Dures, E., Rumsey, N., Morris, M., & Gleeson, K. (2011). Mixed methods in health psychology: Theoretical and practical considerations of the third paradigm. *Journal of Health Psychology, 16*(2), 332-341.
- Egede, L. E. (2005). Effect of depression on self-management behaviors and health outcomes in adults with type 2 diabetes. *Current diabetes reviews, 1*(3), 235-243.
- Egede, L. E., & Ellis, C. (2010). Diabetes and depression: Global perspectives. *Diabetes Research and Clinical Practice, 87*(3), 302-312.

- Egede, L. E., Strom, J. L., & Lynch, C. P. (2011). Disparities in diabetes self-management and quality of care in rural versus urban veterans. *Journal of diabetes and its complications*, 25(6), 387-392.
- Elder, J. P., Lytle, L., Sallis, J. F., Young, D. R., Steckler, A., Simons-Morton, D., . . . Lohman, T. (2007). A description of the social-ecological framework used in the trial of activity for adolescent girls (TAAG). *Health Education Research*, 22(2), 155-165.
- Emmons, K. M. (2000). Health behaviors in a social context. In L. F. Berkman, Kawachi, I. (Ed.), *Social Epidemiology*. New York: Oxford University Press.
- Ercikan, K., & Roth, W.-M. (2006). What Good Is Polarizing Research Into Qualitative and Quantitative? *Educational Researcher*, 35(5), 14-23.
- Farmer, A., Kinmonth, A. L., & Sutton, S. (2006). Measuring beliefs about taking hypoglycaemic medication among people with Type 2 diabetes. *Diabetic medicine*, 23(3), 265-270.
- Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, 5(1), 80-92.
- Fielding, N. G., & Fielding, J. L. (1986). *Linking Data: The Articulation of Qualitative And Quantitative Methods In Social Research*. . Beverly Hills, CA: Sage.
- Fisher, L., Skaff, M., Mullan, J., Arean, P., Glasgow, R., & Masharani, U. (2008): A longitudinal study of affective and anxiety disorders, depressive affect and diabetes distress in adults with type 2 diabetes. *Diabetic Medicine*, 25(9), 1096-1101.
- Fitzgerald, J. T., Davis, W. K., Connell, C. M., Hess, G. E., Funnell, M. M., & Hiss, R. G. (1996). Development and validation of the Diabetes Care Profile. *Evaluation & the Health Professions*, 19(2), 208-230.
- FitzGerald, M., Pearson, A., & McCutcheon, H. (2001). Impact of rural living on the experience of chronic illness. *The Australian journal of rural health*, 9(5), 235-240.
- Fortier, M. S., Sweet, S. N., Tulloch, H., Blanchard, C. M., Sigal, R. J., Kenny, G. P., & Reid, R. D. (2012). Self-determination and Exercise Stages of Change: Results from the Diabetes Aerobic and Resistance Exercise Trial. *Journal of Health Psychology*, 17(1), 87-99. doi: 10.1177/1359105311408948
- Fowler, M. J. (2008). Microvascular and macrovascular complications of diabetes. *Clinical Diabetes*, 26(2), 77-82.
- Freeman, J., & Loewe, R. (2000). Barriers to communication about diabetes mellitus - Patients' and physicians' different views of the disease. *Journal of Family Practice*, 49(6), 507-512.
- French, D., Yardley, L., & Sutton, S. (2004). Research Methods in Health Psychology. In M. Johnston, S. Sutton & A. Baum (Eds.), *The Sage handbook of health psychology*: SAGE Publications Limited.
- Gajanayake, I., Hodgson, G., & Mathur, S. (2000). Diabetes as a cause of death, Australia, 1997 and 1998 *Diabetes series no. 1*. Canberra: Australian Institute of Health and Welfare.
- Gill, T. M., & Feinstein, A. R. (1994). A critical appraisal of the quality of quality-of-life measurements. *Journal of the American Medical Association*, 272(8), 619-626.
- Glasgow, R. E., Ruggiero, L., Eakin, E. G., Dryfoos, J., & Chobanian, L. (1997). Quality of life and associated characteristics in a large national sample of adults with diabetes. *Diabetes Care*, 20(4), 562-567.
- Glasgow, R. E., Toobert, D. J., & Gillette, C. D. (2001). Psychosocial Barriers to Diabetes Self-Management and Quality of Life. *Diabetes Spectrum*, 14(1), 33-41.
- Gleeson-Kreig, J. (2008). Social support and physical activity in type 2 diabetes a social-ecologic approach. *Diabetes Educator*, 34(6), 1037-1044.
- Goeppinger, J. (1993). Health promotion for rural populations: Partnership interventions. *Family & Community Health*, 16(1), 1-10.

- Goldney, R. D., Phillips, P. J., Fisher, L. J., & Wilson, D. H. (2004). Diabetes, Depression, and Quality of Life: A population study. *Diabetes Care*, 27(5), 1066-1070. doi: 10.2337/diacare.27.5.1066
- Gonder-Frederick, L. A., Cox, D. J., & Ritterband, L. M. (2002). Diabetes and behavioral medicine: The second decade. *Journal of Consulting and Clinical Psychology*, 70(3), 611-625. doi: 10.1037//0022-006x.70.3.611
- Gonzalez, J. S., Safren, S. A., Cagliero, E., Wexler, D. J., Delahanty, L., Wittenberg, E., . . . Grant, R. W. (2007). Depression, self-care, and medication adherence in type 2 diabetes: Relationships across the full range of symptom severity. *Diabetes Care*, 30(9), 2222-2227.
- Gonzalez, J. S., Safren, S. A., Delahanty, L. M., Cagliero, E., Wexler, D. J., Meigs, J. B., & Grant, R. W. (2008). Symptoms of depression prospectively predict poorer self-care in patients with type 2 diabetes. *Diabetic Medicine*, 25(9), 1102-1107.
- Government of South Australia. (2012). South Australia's Strategic Plan: Health Retrieved 29/06/13, from <http://saplan.org.au/targets/85-chronic-diseases>
- Greene, J. C., Caracelli, V. J., & Graham, W. F. (1989). Toward a conceptual framework for mixed-method evaluation designs. *Educational evaluation and policy analysis*, 11(3), 255-274.
- Greenfield, C., Gilles, M., Porter, C., Shaw, P., & Willis, K. (2011). It's not just about the HbA1c, Doc! Understanding the psychosocial is also important in managing diabetes? *Australian Journal of Rural Health*, 19(1), 15-19.
- Greenfield, S. (1989). The state of outcome research: Are we on target? *New England Journal of Medicine*, 320(17), 1142-1143.
- Gregg, E., Beckles, G., Williamson, D., Leveille, S., Langlois, J., Engelgau, M., & Narayan, K. (2000). Diabetes and physical disability among older US adults. *Diabetes care*, 23(9), 1272-1277.
- Gregson, J., Foerster, S. B., Orr, R., Jones, L., Benedict, J., Clarke, B., . . . Zotz, K. (2001). System, environmental, and policy changes: using the social-ecological model as a framework for evaluating nutrition education and social marketing programs with low-income audiences. *Journal of nutrition education*, 33, S4-S15.
- Guyatt, G. H. (1997). Measuring health-related quality of life: General issues. *Canadian Respiratory Journal*, 4(3), 123-130.
- Guyatt, G. H., Feeny, D. H., & Patrick, D. L. (1993). Measuring health-related quality of life. *Annals of Internal Medicine*, 118(8), 622-629.
- Gyurcsik, N. C., Spink, K. S., Bray, S. R., Chad, K., & Kwan, M. (2006). An ecologically based examination of barriers to physical activity in students from grade seven through first-year university. *Journal of Adolescent Health*, 38(6), 704-711.
- Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and Health*, 18(2), 141-184.
- Hanninen, J., Takala, J., & Keinanen-Kiukaanniemi, S. (2001). Good continuity of care may improve quality of life in Type 2 diabetes. *Diabetes Research and Clinical Practice*, 51(1), 21-27. doi: 10.1016/s0168-8227(00)00198-4
- Harris, M. I., Klein, R., Welborn, T. A., & Knudman, M. W. (1992). Onset of NIDDM occurs at least 4-7 years before clinical diagnosis *Diabetes Care*, 15(7), 815-819. doi: 10.2337/diacare.15.7.815
- Hartley, D. (2004). Rural health disparities, population health, and rural culture. *American Journal of Public Health*, 94(10), 1675-1678.
- Haynes, R. B. (1979). *Determinants of compliance: The disease and the mechanics of treatment*. Baltimore, MD: Johns Hopkins University Press.

- Haynes, R. B., McDonald, H., Garg, A. X., & Montague, P. (2002). Interventions for helping patients to follow prescriptions for medications. *Cochrane database of systematic reviews (Online)*(2), CD000011-CD000011.
- Hearnshaw, H., & Lindenmeyer, A. (2005). What do we mean by adherence to treatment and advice for living with diabetes? A review of the literature on definitions and measurements. *Diabetic Medicine*, 23, 720-728.
- Hearnshaw, H., Wright, K., Dale, J., Sturt, J., Vermeire, E., & Van Royen, P. (2007). Development and validation of the Diabetes Obstacles Questionnaire (DOQ) to assess obstacles in living with Type 2 diabetes. *Diabetic Medicine*, 24(8), 878-882.
- Heflinger, C. A., & Chrisrens, B. (2006). Rural behavioral health services for children and adolescents: An ecological and community psychology analysis. *Journal of Community Psychology*, 34(4), 379-400. doi: 10.1002/jcop.20105
- Heisler, M., Vijan, S., Anderson, R. M., Ubel, P. A., Bernstein, S. J., & Hofer, T. P. (2003). When do patients and their physicians agree on diabetes treatment goals and strategies, and what difference does it make? *Journal of General Internal Medicine*, 18(11), 893-902.
- Helseth, L. D., Susman, J. L., Crabtree, B. F., & O'Connor, P. J. (1999). Primary care physicians' perceptions of diabetes management - A balancing act. *Journal of Family Practice*, 48(1), 37-42.
- Henry, J. D., & Crawford, J. R. (2005). The short-form version of the Depression anxiety stress scales (DASS-21): Construct validity and normative data in a large non-clinical sample. *British Journal of Clinical Psychology*, 44(2), 227-239.
- Hessler, D. M., Fisher, L., Naranjo, D., & Masharani, U. (2011). Young adult African American patients with type 2 diabetes: A high risk patient sub-group with few supports for good diabetes management. *Journal of Health Psychology*, 17(4), 535-544.
- Hogan, P., Dall, T., & Nikolov, P. (2003). Economic costs of diabetes in the US in 2002. *Diabetes Care*, 26(3), 917-932.
- Hoshmand, L. T. (2003). Can lessons of history and logical analysis ensure progress in psychological science? *Theory & Psychology*, 13(1), 39-44.
- Hu, F. B. (2011). Globalization of diabetes: The role of diet, lifestyle, and genes. *Diabetes Care*, 34(6), 1249-1257.
- Huang, J., Liu, Y., Zhang, Y., & Yao, H. (2013). Correlation between self-management and knowledge of and attitude to diabetes in type 2 diabetic patients in Changsha. *Journal of Central South University (Medical Sciences)*, 38(2), 176-181.
- Hunt, L. M., Arar, N. H., Larme, A. C., Rankin, S. H., & Anderson, R. M. (1998). Contrasting patient and practitioner perspectives in type 2 diabetes management. *Western Journal of Nursing Research*, 20(6), 656-682.
- Hunt, S. M. (1997). The problem of quality of life. *Quality of Life Research*, 6(3), 205-212. doi: 10.1023/a:1026402519847
- Hwang, C. K., Han, P. V., Zabetian, A., Ali, M. K., & Venkat Narayan, K. M. (2012). Rural diabetes prevalence quintuples over twenty-five years in low- and middle-income countries: A systematic review and meta-analysis. *Diabetes Research and Clinical Practice*, 96(3), 271-285.
- International Diabetes Federation. (2009). *Diabetes Atlas*
- International Diabetes Federation. (2012). *Healthcare expenditures IDF Diabetes Atlas 5th Ed.* Retrieved 19/04/2013, from <http://www.idf.org/diabetesatlas/5e/healthcare-expenditures>
- International Diabetes Federation Clinical Guidelines Task Force. (2005). *Global guideline for Type 2 diabetes*. Brussels: International Diabetes Federation.

- International Diabetes Institute. (2006). Type 2 Diabetes Fact Sheet Retrieved 29/7/2008, from <http://www.diabetes.com.au/diabetes.php?regionID=237>
- Jerant, A. F., Von Friederichs-Fitzwater, M. M., & Moore, M. (2005). Patients' perceived barriers to active self-management of chronic conditions. *Patient Education and Counseling*, 57(3), 300-307.
- Jick, T. D. (1979). Mixing Qualitative and Quantitative Methods: Triangulation in Action. *Administrative Science Quarterly*, 24(4), 602-611.
- Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher*, 33, 14-26.
- Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a Definition of Mixed Methods Research. *Journal of Mixed Methods Research*, 1(2), 112-133.
- Jones, H., Edwards, L., Greene, G., Rossi, J., Ruggiero, L., Prochaska, J., . . . Zimman, B. (2002). Impact of multiple self-management interventions on stage of change in the Diabetes Stages of Change (DiSC) study. *Diabetes*, 51, A213-A213.
- Jones, H., Edwards, L., Vallis, T. M., Ruggiero, L., Rossi, S. R., Rossi, J., . . . Zinman, B. (2003). Changes in diabetes self-care behaviors make a difference in glycemic control - The diabetes stages of change (DiSC) study. *Diabetes Care*, 26(3), 732-737. doi: 10.2337/diacare.26.3.732
- Jones, L., Crabb, S., Turnbull, D., & Oxlad, M. (Published online ahead of print 16/03/2013). Barriers and facilitators to effective type two diabetes management in a rural context: A qualitative study with diabetes patients and health professionals. *J Health Psychol*. doi: 10.1177/1359105312473786
- Jones, L., Turnbull, D., Crabb, S., & Oxlad, M. (Under Review). The adaptation and validation of a tool to measure barriers to effective type 2 diabetes self-management in rural and urban Australians.
- Joshi, R., Cardona, M., Iyengar, S., Sukumar, A., Raju, C. R., Raju, K. R., . . . Neal, B. (2006). Chronic diseases now a leading cause of death in rural India—mortality data from the Andhra Pradesh Rural Health Initiative. *International journal of epidemiology*, 35(6), 1522-1529.
- Kaplan, S. H., Greenfield, S., & Ware Jr, J. E. (1989). Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Medical care*, 27(3), S110.
- Karter, A. J., Ferrara, A., Darbinian, J. A., Ackerson, L. M., & Selby, J. V. (2000). Self-monitoring of blood glucose: Language and financial barriers in a managed care population with diabetes. *Diabetes Care*, 23(4), 477-483.
- Kasila, K., Poskiparta, M., Karhila, P., & Kettunen, T. (2003). Patients' readiness for dietary change at the beginning of counselling: a transtheoretical model-based assessment. *Journal of Human Nutrition and Dietetics*, 16(3), 159-166.
- Katon, W. J., Rutter, C., Simon, G., Lin, E. H. B., Ludman, E., Ciechanowski, P., . . . Von Korff, M. (2005). The association of comorbid depression with mortality in patients with type 2 diabetes. *Diabetes Care*, 28(11), 2668-2672. doi: 10.2337/diacare.28.11.2668
- Katz, J. N., Chang, L. C., Sangha, O., Fossel, A. H., & Bates, D. W. (1996). Can Comorbidity Be Measured by Questionnaire Rather than Medical Record Review? *Medical Care*, 34(1), 73-84.
- Keeling, D. I., Price, P. E., Jones, E., & Harding, K. G. (1996). Social support: some pragmatic implications for health care professionals. *Journal of advanced nursing*, 23(1), 76-81.
- Kitto, S., Chester, J., & Grbich, C. (2008). Quality in qualitative research. *The Medical Journal of Australia*, 18(94), 243-246.
- Kleefstra, N., Landman, G. W., Houweling, S. T., Ubink-Veltmaat, L. J., Logtenberg, S. J., Jong, B. M., . . . Henk, J. G. (2008). Prediction of mortality in type 2 diabetes from health-related quality of life (ZODIAC-4). *Diabetes Care*, 31(5), 932-933.

- Kline, P. (1999). *The handbook of psychological testing (2nd Ed)* (2 ed.). London: Routledge
- Koch, T., Kralik, D., & Taylor, J. (2000). Men living with diabetes: minimizing the intrusiveness of the disease. *Journal of Clinical Nursing*, *9*(2), 247-254.
- Korkiakangas, E. E., Alahuhta, M. A., Husman, P. M., Keinänen-Kiukaanniemi, S., Taanila, A. M., & Laitinen, J. H. (2011). Motivators and barriers to exercise among adults with a high risk of type 2 diabetes - a qualitative study. *Scandinavian Journal of Caring Sciences*, *25*(1), 62-69. doi: 10.1111/j.1471-6712.2010.00791.x
- Korkiakangas, E. E., Alahuhta, M. A., & Laitinen, J. H. (2009). Barriers to regular exercise among adults at high risk or diagnosed with type 2 diabetes: A systematic review. *Health Promotion International*, *24*(4), 416-427.
- Larme, A. C., & Pugh, J. A. (1998). Attitudes of primary care providers toward diabetes: barriers to guideline implementation. *Diabetes Care*, *21*(9), 1391-1396.
- Lawton, J., Peel, E., Parry, O., Araoz, G., & Douglas, M. (2006). Lay perceptions of type 2 diabetes in Scotland: bringing health services back in. *Social Science & Medicine*, *60*(7), 1423-1435.
- Le, T. K., Able, S. L., & Lage, M. J. (2006). Resource use among patients with diabetes, diabetic neuropathy, or diabetes with depression. *Cost Effectiveness and Resource Allocation*, *4*.
- Ledford, C. J. W. (2012). Exploring the interaction of patient activation and message design variables: Message frame and presentation mode influence on the walking behavior of patients with type 2 diabetes. *Journal of Health Psychology*, *17*(7), 989-1000.
- Lerman, I. (2005). Adherence to treatment: The key for avoiding long-term complications of diabetes. *Archives of Medical Research*, *36*(3), 300-306.
- Lerman, I., Lozano, L., Villa, A. R., Hernandez-Jimenez, S., Weinger, K., Caballero, A. E., . . . Rull, J. A. (2004). Psychosocial factors associated with poor diabetes self-care management in a specialized Center in Mexico City. *Biomedicine & Pharmacotherapy*, *58*(10), 566-570. doi: 10.1016/j.biopha.2004.09.003
- Li, C., Ford, E. S., Zhao, G., Ahluwalia, I. B., Pearson, W. S., & Mokdad, A. H. (2009). Prevalence and correlates of undiagnosed depression among US adults with diabetes: The Behavioral Risk Factor Surveillance System, 2006. *Diabetes Research and Clinical Practice*, *83*(2), 268-279. doi: 10.1016/j.diabres.2008.11.006
- Liebl, A., Neiyay, A., Spannheimer, A., Reitberger, U., Wagner, T., & Gartz, A. (2001). Costs of type 2 diabetes in Germany - Results of the CODE-2a study. *Dtsch Med Wochenschr.*, *126*(20), 585-589.
- Lin, C. C., Anderson, R. M., Hagerty, B. M., & Lee, B.-O. (2008). Diabetes self-management experience: a focus group study of Taiwanese patients with type 2 diabetes. *Journal of Clinical Nursing*, *17*(5A), 34-42. doi: 10.1111/j.1365-2702.2007.01962.x
- Lin, E., Katon, W., Von Korff, M., Rutter, C., Simon, G. E., Oliver, M., . . . Young, B. (2004). Relationship of depression and diabetes self-care, medication adherence, and preventive care. *Diabetes Care*, *27*(9), 2154-2160.
- Lorig, K., Holman, H., Laurent, D., Gonzalez, V., & Minot, M. (2000). *Living a Healthy Life With Chronic Conditions: Self-Management of heart Disease, Arthritis, Stroke, Diabetes, Asthma, Bronchitis, Emphysema and Others*. (2nd ed.). Boulder, Colorado: Bull.
- Lorig, K., & Holman, H. R. (2003). Self-management education: history, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine*, *26*(1), 1-7.
- Lovibond, S. H., & Lovibond, P. F. (1995). *Manual for the Depression Anxiety Stress Scales* (2 ed.). Sydney Psychological Foundation.
- Lowe, J. (2010). Clear as mud: results and the use of mixed methods. *Australian and New Zealand journal of public health*, *34*(4), 344-345.
- Lundman, B., & Engstrom, L. (1998). Diabetes and its complications in a Swedish county. *Diabetes Research and Clinical Practice*, *39*(2), 157-164.

- Luscombe, F. A. (2000). Health-Related Quality of Life Measurement in Type 2 Diabetes. *Value in Health (Wiley-Blackwell)*, 3, S15-S28.
- Lustman, P. J., Anderson, R. J., Freedland, K. E., De Groot, M., Carney, R. M., & Clouse, R. E. (2000). Depression and poor glycemic control: A meta-analytic review of the literature. *Diabetes Care*, 23(7), 934-942.
- Lutfey, K. E., & Wishner, W. J. (1999). Beyond "compliance" is "adherence". Improving the prospect of diabetes care. *Diabetes Care*, 22(4), 635-639.
- Maddigan, S. L., Majumdar, S. R., & Johnson, J. A. (2005). Understanding the complex associations between patient-provider relationships, self-care behaviours, and health-related quality of life in type 2 diabetes: A structural equation modeling approach. *Quality of Life Research*, 14(6), 1489-1500. doi: 10.1007/s11136-005-0586-z
- Madore, O. (2007). *The impact of economic instruments that promote healthy eating, encourage physical activity and combat obesity: literature review*. Canada Parliamentary Information and Research Service, parliament of Canada.
- Magliano, D. J., Peeters, A., Vos, T., Sicree, R., Shaw, J., Sindall, C., . . . Zimmet, P. Z. (2009). Projecting the burden of diabetes in Australia—what is the size of the matter? *Australian and New Zealand journal of public health*, 33(6), 540-543.
- Mangunkusumo, R. T., Moorman, P. W., Van Den Berg-De Ruiters, A. E., Van Der Lei, J., De Koning, H. J., & Raat, H. (2005). Internet-administered adolescent health questionnaires compared with a paper version in a randomized study. *Journal of Adolescent Health*, 36(1), 70.e71-70.e76.
- Manley, S., Meyer, L., Neil, H., Ross, I., Turner, R., & Holman, R. (1990). UK Prospective Diabetes Study 6. Complications in newly diagnosed type 2 diabetic patients and their association with different clinical and biochemical risk factors. *Diabetes Research*, 13(1), 1-11.
- Mann, C., & Stewart, F. (2000). *Internet communication and qualitative research*. Thousand Oaks, London: Sage.
- Marshall, M. N. (1996). Sampling for qualitative research. *Family Practice*, 13(6), 522-526.
- Marshall, S. J., & Biddle, S. J. (2001). The transtheoretical model of behavior change: a meta-analysis of applications to physical activity and exercise. *Annals of Behavioral Medicine*, 23(4), 229-246.
- Masaki, Y., Okada, S., & Ota, Z. (1990). Importance of attitude evaluation in diabetes patient education. *Diabetes Research and Clinical Practice*, 8(1), 37-44. doi: 10.1016/0168-8227(90)90094-a
- Mathew, R., Gucciardi, E., De Melo, M., & Barata, P. (2012). Self-management experiences among men and women with type 2 diabetes mellitus: a qualitative analysis. *BMC Family Practice*, 13(1), 122.
- Mays, N., & Pope, C. (1995). Rigour and qualitative research. *BMJ: British Medical Journal*, 311(6997), 109.
- McGovern, A., & Hodgins, G. (2007). Responding to the local context: Psychology services in south-western NSW. *In Psych: The Bulletin of the Australian Psychological Society Ltd*, October 12-13.
- McLafferty, C., & Onwuegbuzie, A. (2006). *A dimensional resolution of the qualitative-quantitative dichotomy: Implications for theory, praxis, and national research policy*. Paper presented at the annual meeting of the Mid-South Educational Research Association, Birmingham, AL.
- Mier, N., Medina, A. A., & Ory, M. G. (2007). Mexican Americans With Type 2 Diabetes: Perspectives on Definitions, Motivators, and Programs of Physical Activity. *Preventing Chronic Disease*, 4(2), 1-8.

- Moore, K., Roubideaux, Y., Noonan, C., Goldberg, J., Shields, R., & Acton, K. (2006). Quality of diabetes care for urban & rural Indian Health Programs. *Ethnicity and Disease, 16*, 772-777.
- Moran-Ellis, J., Alexander, V., Cronin, A., Sleney, J., & Thomas, H. (2006). Triangulation and integration: processes, claims and implications. *Qualitative Research 6*(1), 45-49.
- Morgan, G., & Smircich, L. (1980). The case for qualitative research. *Academy of management review, 5*, 491-500.
- Muis, K. R., Bendixen, L. D., & Haerle, F. C. (2006). Domain-generality and domain-specificity in personal epistemology research: Philosophical and empirical reflections in the development of a theoretical framework. *Educational Psychology Review, 18*(1), 3-54.
- Murdaugh, C. (1997). Health-related quality of life as an outcome in organizational research. *Medical care, 35*(11), NS41-NS48.
- Nagelkerk, J., Reick, K., & Meengs, L. (2006). Perceived barriers and effective strategies to diabetes self-management. *Journal of Advanced Nursing, 54*(2), 151-158.
- Nam, S., Chesla, C., Stotts, N. A., Kroon, L., & Janson, S. L. (2011). Barriers to diabetes management: Patient and provider factors. *Diabetes Research and Clinical Practice, 93*(1), 1-9.
- National Health and Medical Research Council. (2005). National Evidence Based Guidelines for the Management of Type 2 Diabetes Mellitus. Sydney: Australian Government.
- National Health Committee. (2010). Rural Health: Challenges of Distance Opportunities for Innovation. Wellington, New Zealand.
- National Institute of Diabetes and Digestive and Kidney Diseases. (2012, 29/08/2012). Diagnosis of Diabetes and Prediabetes. Retrieved 10/02/2013, from <http://diabetes.niddk.nih.gov/dm/pubs/diagnosis/>
- National Rural Health Alliance. (2011). Diabetes in Rural Australia. Canberra, Australia.
- National Rural Health Alliance. (2012). Submission on Development of a National Food Plan. Canberra: National Rural Health Alliance.
- Newman, S., Steed, L., & Mulligan, K. (2004). Self-management interventions for chronic illness. *Lancet, 364*(9444), 1523-1537.
- Norris, S. L., McNally, T. K., Zhang, X., Burda, B., Chan, B., Chowdhury, F. M., . . . Patrick, D. (2011). Published norms underestimate the health-related quality of life among persons with type 2 diabetes. *Journal of Clinical Epidemiology, 64*(4), 358-365. doi: 10.1016/j.jclinepi.2010.04.016
- O'Cathain, A. (2009). Editorial: Mixed methods research in the health sciences: A quiet revolution. *Journal of Mixed Methods Research, 3*(1), 3-6.
- Onwuegbuzie, A. J., & Leech, N. L. (2005). Taking the "Q" out of research: Teaching research methodology courses without the divide between quantitative and qualitative paradigms. *Quality & Quantity, 39*(3), 267-295.
- Ostini, R., Dower, J., & Donald, M. (2011). The Audit of Diabetes-Dependent Quality of Life 19 (ADDQoL): feasibility, reliability and validity in a population-based sample of Australian adults. *Quality of Life Research, 21*, 1-7.
- Pace, A. E., Ochoa-Vigo, K., Caliri, M. H. L., & Fernandes, A. P. M. (2006). Knowledge on diabetes mellitus in the self care process. *Revista latino-americana de enfermagem, 14*(5), 728-734.
- Parliament of Australia. (2000). The National Health Priority Areas Initiative. *About Parliament: Current Issues Brief 18 1999-2000* Retrieved 12/12/2012, 2012, from http://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/Publications_Archive/CIB/cib9900/2000CIB18
- Paschalides, C., Wearden, A. J., Dunkerley, R., Bundy, C., Davies, R., & Dickens, C. M. (2004). The associations of anxiety, depression and personal illness representations with glycaemic

- control and health-related quality of life in patients with type 2 diabetes mellitus. *Journal of Psychosomatic Research*, 57(6), 557-564. doi: 10.1016/j.jpsychores.2004.03.006
- Paulhus, D. L. (1984). Two-component models of socially desirable responding. *Journal of personality and social psychology*, 46(3), 598-609.
- Persell, S. D., Keating, N. L., Landrum, M. B., Landon, B. E., Ayanian, J. Z., Borbas, C., & Guadagnoli, E. (2004). Relationship of diabetes-specific knowledge to self-management activities, ambulatory preventive care, and metabolic outcomes. *Preventive Medicine*, 39(4), 746-752.
- Peyrot, M., & Rubin, R. R. (1997). Levels and risks of depression and anxiety symptomatology among diabetic adults. *Diabetes Care*, 20(4), 585-590.
- Peyrot, M., Rubin, R. R., Lauritzen, T., Snoek, F. J., Matthews, D. R., & Skovlund, S. E. (2005). Psychosocial problems and barriers to improved diabetes management: Results of the Cross-National Diabetes Attitudes, Wishes and Needs (DAWN) Study. *Diabetic Medicine*, 22(10), 1379-1385.
- Polonsky, W. H. (2000). Understanding and Assessing Diabetes-Specific Quality of Life. *Diabetes Spectrum*, 13, 36-41.
- Polonsky, W. H. (2002). Emotional and quality-of-life aspects of diabetes management. *Curr Diab Rep*, 2(2), 153-159.
- Polonsky, W. H., Anderson, B. J., Lohrer, P. A., Welch, G., Jacobson, A. M., Aponte, J. E., & Schwartz, C. E. (1995). Assessment of diabetes-related distress. *Diabetes Care*, 18(6), 754-760.
- Pope, C., & Mays, N. (1995). Qualitative research: reaching parts other methods cannot reach: an introduction to qualitative methods in health and health service research. *British Medical Journal*, 311, 42-45.
- Pope, C., Ziebland, S., & Mays, N. (2000). Analysing qualitative data. *British Medical Journal*, 320(7227), 114-116.
- Porter, E. J. (2007). The Qualitative-Quantitative Dualism. *Journal of Nursing Scholarship*, 21(2), 98-102.
- Prochaska, J. O., & DiClemente, C. C. (1983). Stages and processes of self-change of smoking: toward an integrative model of change. *Journal of Consulting and Clinical Psychology*, 51(3), 390-395.
- Prochaska, J. O., & DiClemente, C. C. (1992). Stages of change in the modification of problem behaviors. *Progress in behavior modification*, 28, 183-218.
- Prochaska, J. O., & Velicer, W. F. (1997). The transtheoretical model of health behavior change. *American Journal of Health Promotion*, 12(1), 38-48.
- Pun, S., Coates, V., & Benzie, I. (2009). Barriers to the self-care of type 2 diabetes from both patients' and providers' perspectives: literature review. *Journal of nursing and healthcare of chronic illness* 1(1), 4-19.
- Rand, C. S. (1993). Measuring adherence with therapy for chronic diseases: implications for the treatment of heterozygous familial hypercholesterolemia. *The American journal of cardiology*, 72(10), D68-D74.
- Redekop, W. K., Koopmanschap, M. A., Stolk, R. P., Rutten, G. E., Wolffenbuttel, B. H., & Niessen, L. W. (2002). Health-related quality of life and treatment satisfaction in Dutch patients with type 2 diabetes. *Diabetes Care*, 25(3), 458-463.
- Renders, C. M., Valk, G. D., Griffin, S. J., Wagner, E. H., Van Eijk, J. T., & Assendelft, W. J. (2001). Interventions to improve the management of diabetes in primary care, outpatient, and community settings: A systematic review. *Diabetes Care*, 24(10), 1821-1833.
- Resnick, H., & Howard, B. (2002). Diabetes and cardiovascular disease. *Annual Review of Medicine*, 53, 245-267.

- Rhee, M. K., Cook, C. B., El-Kebbi, I., Lyles, R. H., Dunbar, V. G., Panayioto, R. M., . . . George, C. D. (2005). Barriers to Diabetes Education in Urban Patients Perceptions, Patterns, and Associated Factors. *The Diabetes Educator*, 31(3), 410-417.
- Richardson, L. K., Egede, L. E., Mueller, M., Echols, C. L., & Gebregziabher, M. (2008). Longitudinal effects of depression on glycemic control in veterans with Type 2 diabetes. *General Hospital Psychiatry*, 30(6), 509-514.
- Rimer, B. K., & Glanz, K. (2005). *Theory at a glance: a guide for health promotion practice* (2nd ed.): US Department of Health and Human Services, National Institutes of Health, National Cancer Institute.
- Rosenstock, I. M., Strecher, V. J., & Becker, M. H. (1988). Social learning theory and the health belief model. *Health Education & Behavior*, 15(2), 175-183.
- Roufeil, L., & Lipzker, A. (2007). Psychology services in rural and remote Australia. *In Psych: The Bulletin of the Australian Psychological Society Ltd*, 29(5), 8.
- Rozin, P. (2001). Social psychology and science: Some lessons from solomon asch. *Personality and Social Psychology Review*, 5(1), 2-14.
- Rubin, R. R., & Peyrot, M. (1999). Quality of life and diabetes. *Diabetes-Metabolism Research and Reviews*, 15(3), 205-218. doi: 10.1002/(sici)1520-7560(199905/06)15:3<205::aid-dmrr29>3.0.co;2-o
- Rural Health Workforce Australia. (2013). Rural Health Workforce Australia Retrieved 9/1/2013, from <http://www.rhwa.org.au/site/index.cfm?display=288847>
- Satterfield, D. W., Volansky, M., Caspersen, C. J., Engelgau, M. M., Bowman, B. A., Gregg, E. W., . . . Vinicor, F. (2003). Community-based lifestyle interventions to prevent type 2 diabetes. *Diabetes Care*, 26(9), 2643-2652.
- Schutta, M. H. (2007). Diabetes and hypertension: epidemiology of the relationship and pathophysiology of factors associated with these comorbid conditions. *Journal of the cardiometabolic syndrome*, 2(2), 124-130.
- Searle, A., Norman, P., Thompson, R., & Vedhara, K. (2007). Illness representations among patients with type 2 diabetes and their partners: relationships with self-management behaviors. *Journal of psychosomatic research*, 63(2), 175-184.
- Senecal, C., Nouwen, A., & White, D. (2000). Motivation and dietary self-care in adults with diabetes: Are self-efficacy and autonomous self-regulation complementary or competing constructs? *Health Psychology*, 19(5), 452-457.
- Shakibazadeh, E., Larijani, B., Shojaeezadeh, D., Rashidian, A., Forouzanfar, M., & Bartholomew, L. (2011). Patients' Perspectives on Factors that Influence Diabetes Self-Care. *Iranian J Publ Health*, 40(4), 146-158.
- Sharp, L. K., & Lipsky, M. S. (2002). Screening for depression across the lifespan: A review of measures for use in primary care settings. *American Family Physician*, 66(6), 1001-1008.
- Shaw, J., Sicree, R., & Zimmet, P. (2010). Global estimates of the prevalence of diabetes for 2010 and 2030. *Diabetes research and clinical practice*, 87(1), 4-14.
- Sherbourne, C. D., Hays, R. D., Ordway, L., DiMatteo, M. R., & Kravitz, R. L. (1992). Antecedents of adherence to medical recommendations: results from the Medical Outcomes Study. *Journal of behavioral medicine*, 15(5), 447-468.
- Sherwood, L. (2004). *Human Physiology: from cells to systems* (5th ed.). Belmont, USA: Thompson Brooks/Cole.
- Shibayama, T., Sato, E., Nishigaki, M., Ochiai, R., & Kazuma, K. (2011). Influence of dietary therapy appraisal on future perceived control of type 2 diabetes. *Journal of Health Psychology*, 16(8), 1141-1150.
- Shobhana, R., Begum, R., Snehalatha, C., Vijay, V., & Ramachandran, A. (1999). Patients' Adherence to Diabetes Treatment. *Journal of Association of Physicians of India*, 47(12), 1173-1175.

- Shultz, J. A., Sprague, M. A., Branen, L. J., & Lambeth, S. (2001). A comparison of views of individuals with type 2 diabetes mellitus and diabetes educators about barriers to diet and exercise. *Journal of Health Communication, 6*(2), 99-115. doi: 10.1080/108107301750254457
- Shumaker, S. A., & Hill, D. R. (1991). Gender differences in social support and physical health. *Health psychology, 10*(2), 102.
- Simmons, D. (2001). Personal Barriers to Diabetes Care: Is It me, Them, or Us? *Diabetes Spectrum, 14*(1), 10-12.
- Simmons, D., Bourke, L., Yau, E., & Hoodless, M. (2007). Diabetes risk factors, diabetes and diabetes care in a rural Australian community. *Australian Journal of Rural Health, 15*(5), 296-303. doi: 10.1111/j.1440-1584.2007.00903.x
- Simmons, D., Lillis, S., Swan, J., & Haar, J. (2007). Discordance in perceptions of barriers to diabetes care between patients and primary care and secondary care. *Diabetes Care, 30*(3), 490-495.
- Sluijs, E. M., Kok, G. J., & van der Zee, J. (1993). Correlates of exercise compliance in physical therapy. *Physical therapy, 73*(11), 771-782.
- Smith, K. W., Avis, N. E., & Assmann, S. F. (1999). Distinguishing between quality of life and health status in quality of life research: a meta-analysis. *Quality of Life Research, 8*(5), 447-459.
- Stewart, A. L., Greenfield, S., Hays, R. D., Wells, K., Rogers, W. H., Berry, S. D., . . . Ware Jr, J. E. (1989). Functional status and well-being of patients with chronic study. Results from the medical outcomes study. *Journal of the American Medical Association, 262*(7), 907-913.
- Stewart, M. (2001). Towards a global definition of patient centred care: The patient should be the judge of patient centred care. *British Medical Journal, 322*(7284), 444-445.
- Stokols, D. (1996). Translating social ecological theory into guidelines for community health promotion. *American Journal of Health Promotion, 10*(4), 282-298.
- Strasser, R. (2003). Rural health around the world: challenges and solutions. *Family practice, 20*(4), 457-463.
- Street Jr, R. L., & Haidet, P. (2011). How well do doctors know their patients? Factors affecting physician understanding of patients' health beliefs. *Journal of General Internal Medicine, 26*(1), 21-27.
- Sundaram, M., Kavookjian, J., Patrick, J. H., Miller, L.-A., Suresh Madhavan, S., & Scott, V. (2007). Quality of life, health status and clinical outcomes in Type 2 diabetes patients. *Quality of Life Research, 16*(2), 165-177. doi: 10.1007/s11136-006-9105-0
- Susman, J. L., & Helseth, L. D. (1997). Reducing the complications of type II diabetes: A patient-centered approach. *American Family Physician, 56*(2), 471-478.
- Tabachnick, B. G., & Fidell, L. S. (2007). *Using multivariate statistics* (5th ed.). Boston: Allyn and Bacon.
- Teddlie, C., & Tashakkori, A. (2012). Common "Core" Characteristics of Mixed Methods Research A Review of Critical Issues and Call for Greater Convergence. *American Behavioral Scientist, 56*(6), 774-788.
- Tessaro, I., Smith, S., & Rye, S. (2005). Knowledge & perceptions of diabetes in an Appalachian population. *Public Health Research, 2*(2), 1-9.
- Thomas, J., Jones, G., Scarinci, I., & Brantley, P. (2003). A descriptive and comparative study of the prevalence of depressive and anxiety disorders in low-income adults with type 2 diabetes and other chronic illnesses. *Diabetes care, 26*(8), 2311-2317.
- Thomson, N., MacRae, A., Brankovich, J., Burns, J., Catto, M., Gray, C., . . . Urquhart, B. (2011). Overview of Australian Indigenous health status Retrieved 18/10, 2012, from http://www.healthinonet.ecu.edu.au/overview_2012.pdf

- Thorne, S. E., & Paterson, B. L. (2001). Health care professional support for self-care management in chronic illness: insights from diabetes research. *Patient Education and Counseling, 42*(1), 81-90.
- Thorne, S. E., & Robinson, C. A. (1988). Health care relationships: the chronic illness perspective. *Research in Nursing & Health, 11*(5), 293-300.
- Tisnado, D. M., Adams, J. L., Liu, H., Damberg, C. L., Chen, W. P., Hu, F. A., . . . Kahn, K. L. (2006). What is the concordance between the medical record and patient self-report as data sources for ambulatory care? *Medical Care, 44*(2), 132-140.
- Tripp-Reimer, T., Choi, E., Kelley, L. S., & Enslein, J. C. (2001). Cultural barriers to care: inverting the problem. *Diabetes Spectrum, 14*(1), 13-22.
- Utz, S., Steeves, R., Wenzel, J., Hinton, I., Jones, R., & Andrews, D. (2006). "Working hard with it": Self-management of type 2 diabetes by rural African Americans. *Family and Community Health, 29*(3), 195-205.
- Vallejo, M. A., Jordan, C. M., Daaz, M. I., Comeche, M. I., & Ortega, J. (2007). Psychological assessment via the internet: a reliability and validity study of online (vs paper-and-pencil) versions of the General Health Questionnaire-28 (GHQ-28) and the Symptoms Check-List-90-Revised (SCL-90-R). *Journal of Medical Internet Research, 9*(1), e2.
- Vallis, M. (2009). Barriers to self-management in people affected by chronic disease *Diabetes Voice* (Vol. 54, pp. 5-8): International Diabetes Federation.
- Van den Arend, I., Stolk, R., Krans, H., Grobbee, D., & Schrijvers, A. (2000). Management of type 2 diabetes: a challenge for patient and physician. *Patient education and counseling, 40*(2), 187.
- Van Dieren, S., Beulens, J. W. J., Van Der Schouw, Y. T., Grobbee, D. E., & Neal, B. (2010). The global burden of diabetes and its complications: An emerging pandemic. *European Journal of Cardiovascular Prevention and Rehabilitation, 17*(SUPPL. 1), S3-S8.
- Vandekerckhove, M., Vermeire, E., Weeren, A., & Van Royen, P. (2009). Validation of the Diabetes Obstacles Questionnaire (DOQ) to assess obstacles in living with type 2 diabetes in a Belgian population. *Primary Care Diabetes, 3*(1), 43-47.
- Vermeire, E., Hearnshaw, H., Rätsep, A., Levasseur, G., Petek, D., van Dam, H., . . . Van Royen, P. (2007). Obstacles to adherence in living with type-2 diabetes: An international qualitative study using meta-ethnography (EUROBSTACLE). *Primary Care Diabetes, 1*(1), 25-33.
- Vermeire, E., Hearnshaw, H., Van Royen, P., & Denekens, J. (2001). Patient adherence to treatment: three decades of research. A comprehensive review. *Journal of Clinical Pharmacy and Therapeutics, 26*(5), 331-342. doi: 10.1046/j.1365-2710.2001.00363.x
- Vitaliano, P. P., Scanlan, J. M., Zhang, J., Savage, M. V., Brummett, B., Barefoot, J., & Siegler, I. C. (2001). Are the salutogenic effects of social supports modified by income? A test of an "added value hypothesis". *Health Psychology, 20*(3), 155-165.
- Waldorf, B. (2006). *A continuous multi-dimensional measure of rurality: moving beyond threshold measures*. Paper presented at the Annual Meetings of the Association of Agricultural Economics, Long Beach, CA, July.
- Wee, H. L., Cheung, Y. B., Li, S. C., Fong, K. Y., & Thumboo, J. (2005). The impact of diabetes mellitus and other chronic medical conditions on health-related quality of life: Is the whole greater than the sum of its parts? *Health and Quality of Life Outcomes, 3*(1-11).
- Welch, G. W., Jacobson, A. M., & Polonsky, W. H. (1997). The problem areas in diabetes scale: An evaluation of its clinical utility. *Diabetes Care, 20*(5), 760-766.
- Wen, L. K., Shepherd, M. D., & Parchman, M. L. (2004). Family support, diet, and exercise among older Mexican Americans with type 2 diabetes. *The Diabetes Educator, 30*(6), 980.

- Wens, J., Vermeire, E., Van Royen, P., Sabbe, B., & Denekens, J. (2005). GPs' perspectives of type 2 diabetes patients' adherence to treatment: A qualitative analysis of barriers and solutions. *BMC Family Practice*, *6*, 1-10.
- Whitehead, L. C. (2007). Methodological and ethical issues in Internet-mediated research in the field of health: an integrated review of the literature. *Social Science & Medicine*, *65*(4), 782-791.
- Whittemore, R., Melkus, G. D., & Grey, M. (2004). Applying the social ecological theory to Type 2 diabetes prevention and management. *Journal of Community Health Nursing*, *21*(2), 87-99.
- WHO. (1999). Definition, Diagnosis and Classification of Diabetes Mellitus and its Complications. Part 1: Diagnosis and Classification of Diabetes Mellitus. Geneva: World Health Organisation (Department of Noncommunicable Disease Surveillance).
- Wild, S., Roglic, G., Green, A., Sicree, R., & King, H. (2004). Global prevalence of diabetes - Estimates for the year 2000 and projections for 2030. *Diabetes Care*, *27*(5), 1047-1053. doi: 10.2337/diacare.27.5.1047
- Wilkinson, S. (1998). Focus groups in health research. Exploring the meanings of health and illness. *Journal of Health Psychology*, *3*(3), 329-348.
- Williams Utz, S. (2008). Diabetes care among rural Americans. *Annual Review of Nursing Research*, *26*(1), 3-39.
- Wilson, W., Ary, D. V., Biglan, A., Glasgow, R. E., Toobert, D. J., & Campbell, D. R. (1986). Psychosocial predictors of self-care behaviors (compliance) and glycemic control in non-insulin-dependent diabetes mellitus. *Diabetes Care*, *9*(6), 614-622.
- World Health Organisation. (2003). Adherence to long-term therapies: Evidence for action. Geneva World Health Organisation.
- World Health Organisation. (2006). Definition and Diagnosis of Diabetes Mellitus and Intermediate Hyperglycemia. Geneva: World Health Organisation.
- World Health Organisation. (2008). 2008-2013 action plan for the global strategy for the prevention and control of noncommunicable diseases : prevent and control cardiovascular diseases, cancers, chronic respiratory diseases and diabetes. Geneva: World Health Organisation.
- World Health Organisation. (2013). Diabetes Fact Sheet Retrieved 15/03/2013, from <http://www.who.int/mediacentre/factsheets/fs312/en/>
- World Health Organisation Quality of Life Group (Ed.). (1994). *The development of the World Health Organization Quality of Life Assessment Instrument (the WHOQoL)*. Heidelberg: Springer-Verlag.
- Yoon, K. H., Lee, J. H., Kim, J. W., Cho, J. H., Choi, Y. H., Ko, S. H., . . . Son, H. Y. (2006). Epidemic obesity and type 2 diabetes in Asia. *Lancet*, *368*(9548), 1681-1688.
- Zajac, I. T., Flight, I. H., Wilson, C., Turnbull, D., Cole, S., & Young, G. (2012). Internet usage and openness to internet-delivered health information among Australian adults aged over 50 years. *The Australasian medical journal*, *5*(5), 262-267.
- Zgibor, J. C., & Simmons, D. (2002). Barriers to blood glucose monitoring in a multiethnic community. *Diabetes Care*, *25*(10), 1772-1777.
- Zgibor, J. C., & Songer, T. J. (2001). External Barriers to Diabetes Care: Addressing Personal and Health Systems Issues. *Diabetes Spectrum*, *14*(1), 23-28.
- Zhang, P., Zhang, X., Brown, J., Vistisen, D., Sicree, R., Shaw, J., & Nichols, G. (2011). Global healthcare expenditure on diabetes for 2010 and 2030. *Diabetes Research and Clinical Practice*, *87*(3), 293-301.
- Zimmet, P., Alberti, K., & Shaw, J. (2001). Global and societal implications of the diabetes epidemic. *Nature*, *414*(6865), 782-787.
- Zulkowski, K., & Coon, P. (2005). Patient perceptions & provider documentation of diabetes

care in rural areas. *Ostomy Wound Management*, 51(3), 50-58.