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Diabetic Kidney Disease: Exploring Factors that Impede Early Detection and Intervention in the Primary Care Setting

A thesis presented in partial fulfilment of the
requirements for the degree of
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at Massey University, Wellington, New Zealand.

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ABSTRACT

This thesis describes a study which aimed to identify factors which impede early detection and treatment of diabetic kidney disease (DKD) in primary care.

Diabetic kidney disease is a common, harmful, and costly chronic healthcare condition. Despite long-established and evidence-based guidelines recommending early detection and treatment as the optimal management strategy, significant numbers of people continue to be either undetected or undertreated.

Using a qualitative descriptive methodology, focus groups for primary care healthcare practitioners and semi-structured interviews with patients were conducted. Participants' knowledge about DKD, its risk factors and management, and their perceptions about progression of the disease was collected. Content analysis extracted patterns of ideas from the data and then grouped them into key themes which were then interpreted from the perspective of Wagner's Chronic Care Model. Two themes emerged from patient interviews: locating health within one's lifestyle and motivators to change the priority of that position. Focus groups with health care practitioners revealed four themes: knowledge of best practice, screening and recall, models of primary care delivery, and factors which affect patients' engagement with healthcare services.

This study identified several factors which were found to impede the early detection and treatment of DKD in primary health. This thesis discusses those factors, placing them in the context of current literature on the topic, and from the perspective of effective provision of chronic care. Recommendations for possible improvements are offered, along with suggested directions for future research.

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LIST OF ABBREVIATIONS

ACE	Angiotensin converting enzyme	HbA1c	Glycated haemoglobin
ARB	Angiotensin II receptor blocker	HCP	Healthcare practitioner
CAKS	Council of American Kidney Societies	HQOL	Health-related quality of life
CCM	Chronic Care Model	KDIGO	Kidney Disease: Improving Global Outcomes
CKD	Chronic kidney disease	KDOQI	Kidney Disease Outcomes Quality Initiative
CVD	Cardiovascular disease	QD	Qualitative description
DKD	Diabetic kidney disease	RRT	Renal replacement therapy
eGFR	Estimated glomerular filtration rate	T1DM	Type one diabetes mellitus
ESKD	End stage kidney disease	T2DM	Type two diabetes mellitus
GFR	Glomerular filtration rate	UKPDS	United Kingdom Prospective Diabetes Study
GP	General practitioner		

CHAPTER ONE – INTRODUCTION

Currently, approximately 1500 New Zealanders require dialysis or kidney transplantation for the rest of their lives due to kidney failure as a consequence of diabetes (ANZDATA Registry, 2015b). Approximately 500 more people join them each year, and around half that number exit the dialysis and transplant programmes by dying (on average after between one and five years of treatment), mainly from cardiovascular disease (CVD) (ANZDATA Registry, 2015a, 2015c). These therapies have been developed to treat end stage kidney failure by partially replacing some essential kidney functions. By contrast, early detection and treatment long before kidney function declines can delay the progression to the end stage of the condition, and therefore prevent considerable mortality and morbidity, while reducing healthcare expenditure. Yet the number of patients presenting to nephrology services each year for commencement of renal replacement therapies (RRT) shows no sign of decreasing, suggesting that the benefits promised by early detection and treatment are not being realised.

The purpose of this thesis is to explore what factors interfere with early detection and treatment of DKD. This chapter places the thesis within the context of current knowledge of the topic, and the following brief review of key concepts associated with diabetes will assist the reader to navigate through the subsequent detailed discussion about DKD.

Diabetes mellitus is the term given to a group of chronic conditions which exhibit a common feature of abnormal blood glucose metabolism. There are multiple classifications of diabetes, however in terms of kidney complications, types one and two diabetes are the most relevant. Type one diabetes (T1DM) is an autoimmune-mediated condition, where the insulin-producing islet cells of the pancreas are destroyed by circulating antibodies. This leads to an absolute deficiency of insulin, whose role is normally to facilitate the movement of glucose into cells to be used as a source of energy, or into the liver and fat for storage. Without any insulin circulating, levels of blood glucose rise rapidly and cell metabolism switches from glucose as the primary source of energy, to other forms which produce ketones as a by-product. Acidosis ensues, and if there is no intervention, death occurs as a result of severe ketoacidosis. Replacement of insulin by either subcutaneous or intravenous injection is the universal treatment for T1DM (Wass & Turner, 2009).

In contrast, type two diabetes (T2DM) results from insulin resistance by body cells. Insulin production, at least in the early stages of the disease, is normal if not increased, but because of insulin resistance, glucose remains in the blood rather than moving into the cells. The condition is associated with hyperglycaemia, dyslipidaemia, hypertriglyceridaemia, hypertension, and obesity. Unlike T1DM, the condition takes many years to develop, so the effects of T2DM are insidious and long term complications typically become apparent only after decades of the detrimental effects of insulin resistance and hyperglycaemia (Wass & Turner, 2009). Type two diabetes is much more common than T1DM, with approximately 90% of diabetes falling into the type two category, and while the prevalence of T1DM is increasing by 1% to 2% per year; its prevalence is not increasing at anywhere near the alarming rates of T2DM (Maahs, West, Lawrence, & Mayer-Davis, 2010).

Both types of diabetes can lead to long term complications, which are primarily vascular in nature and are categorised into macrovascular (such as CVD) and microvascular (nephropathy, retinopathy, and peripheral vascular disease). Treatment to prevent long term complications involves managing glycaemic levels so that they remain normal, reduction of insulin resistance (in the case of T2DM) by lifestyle modification and pharmacotherapy, and management of other risk factors such as hypertension and dyslipidaemia (American Diabetes Association, 2015).

Type two diabetes is diagnosed by measurement of glycated haemoglobin (HbA1c). This gives an estimate of the saturation of glucose molecules attached to the red blood cell, thus indicating the average blood glucose concentration over the period of the red blood cell's lifespan of two to three months. Therefore HbA1c provides a useful indicator of long-term glycaemic control. New Zealand guidelines follow international recommendations that diabetes is diagnosed when the HbA1c is higher than or equal to 50 mol/mmol (American Diabetes Association, 2015; New Zealand Society for the Study of Diabetes, 2011).

Prediabetes is a pragmatic term which refers to abnormally high levels of blood glucose which have not reached levels required for the diagnosis of T2DM. Prediabetes is diagnosed when HbA1c is between 40 and 49 mol/mmol, and indicates high risk for progression to T2DM. Treatment for prediabetes is concerned with modifying risk factors such as diet, obesity, exercise, smoking, and hypertension (American Diabetes Association, 2015; New Zealand Society for the Study of Diabetes, 2011).

Diabetic Kidney Disease: Background

Diabetic kidney disease, also known as diabetic nephropathy, is a common microvascular complication of diabetes mellitus. The condition is characterised by structural and functional changes to kidney tissue, including hyperperfusion and hyperfiltration in its early stages, and glomerulosclerosis, thickening of the glomerular basement membrane, and destruction of the microvasculature in the later stages (Sego, 2007). There is gradual and ongoing damage to kidney tissue, leading to a progressive decline in kidney function. The rate of decline depends on a number of variables including ethnicity, hypertension, dyslipidaemia and glycaemic control, and in approximately 40% of people with diabetes, progresses to End Stage Kidney Disease (ESKD), when RRT such as dialysis and transplantation are required to sustain life (Molitch et al., 2004; A. Phillips, 2011).

Glomerular filtration rate (GFR) describes the volume of fluid filtered through the glomerular basement membrane per unit of time, and therefore is used clinically as an indicator of kidney function (L. Stevens, Coresh, Greene, & Levey, 2006). Creatinine is traditionally used clinically to measure GFR, since it is a waste substance which is naturally occurring in the blood, and is wholly filtered by the glomeruli, therefore the amount of creatinine which ends up in the urine, compared to that which remains in the blood, gives an indication of how well the glomeruli are filtering. Historically it was measured by collecting the entire volume of urine over a 24 hour period, in tandem with blood tests for serum creatinine before and at the end of the collection. This method was notoriously imprecise because of multiple opportunities for error during collection of samples, so has been superseded by a method which estimates GFR by using a single serum creatinine level in a formula to calculate 'estimated' GFR (eGFR) (Steffl, Bennett, & Olyaei, 2012). While there has been much debate within the nephrology literature over the last twenty years about the most precise way to measure and interpret eGFR, it remains the simplest and most commonly recommended way to clinically measure kidney function (Bakris, 2011; Levey et al., 2011).

Albuminuria is an early indicator of kidney damage, and can be present for many years before any decline in function (Molitch et al., 2014). Albuminuria is the term used to signify the loss of abnormally large amounts of albumin into the urine. Albumin is the most abundant plasma protein, normally constituting about 50% of protein in the plasma. It is important for maintaining oncotic pressure in the blood and therefore the regulation of blood volume (Farrugia, 2010). It is

normally found in small quantities in the urine of people with normal kidneys, but in larger quantities is a marker of kidney disease (Kidney Disease: Improving Global Outcomes CKD Workgroup, 2013a). The pathogenesis of albuminuria in diabetes is thought to be related to glomerular thickening (after deposition of glucose-protein complexes in the presence of persistent hyperglycaemia), leading to glomerular capillary hypertension, which causes altered permeability in the glomerular filtration system, allowing leakage of albumin across the membrane and into the urine (Yu, 2003). This abnormal loss of albumin into the urine occurs early in the course of DKD, usually long before any reduction in glomerular filtration rate. The significance of albuminuria as a prognostic marker has become increasingly evident in the last decade. In addition to its role as an indicator of presence and progression of the disease, it has been shown to be an important independent risk factor for all-cause mortality and CVD (Bakris, 2011; Hemmelgarn et al., 2010; Ninomiya et al., 2009). For these reasons, degree of albuminuria as well as GFR are required for diagnosis of chronic kidney disease (CKD) in current practice guidelines.

In 2002, a CKD classification system was published by the Kidney Disease Outcomes Quality Initiative (KDOQI), which classified CKD into five stages of pre end-stage kidney disease, based on measurement of kidney function using eGFR (National Kidney Foundation, 2007). Prior to this time, progression to renal failure (as it was known) was generally believed to be an inevitable consequence of chronic renal impairment, and so the nephrology community was mainly concerned with treatments for ESKD. Diagnosis and prognosis for the pre-renal replacement therapy stages of CKD were largely irrelevant (Hallan & Orth, 2010). Therefore publication of this classification system signaled a paradigm shift away from treatment for the end stage of the disease, towards treatment in the early stages to prevent disease progression. The system provided a working definition of CKD for the first time, and it enabled the identification and treatment of people at risk of progressive kidney disease (Eknoyan, 2012). Importantly, for this discussion, it meant that patients at risk of developing later stages of CKD could be identified and treated early in the course of their disease, in order to slow or halt its progression.

The publication of the KDOQI guidelines generated substantial controversy and subsequent research. As a direct result of evidence from international clinical trials which highlighted the adverse outcomes associated with albuminuria, the guidelines were revised and in 2012 a newly modified classification system and guidelines were released, which included albuminuria as well as GFR as a criteria for diagnosis and disease staging (see *Figure 1*). These

guidelines have informed the development internationally of clinical best practice guidelines and quality improvement programmes (J. Collins, 2010a; Eknoyan, 2008; N. Thomas, 2009), including guidelines developed for Australasia (Johnson, 2012).

Prognosis of CKD by GFR and Albuminuria Categories: KDIGO 2012

				Persistent albuminuria categories Description and range		
				A1	A2	A3
				Normal to mildly increased <30 mg/g <3 mg/mmol	Moderately increased 30-300 mg/g 3-30 mg/mmol	Severely increased >300 mg/g >30 mg/mmol
GFR categories (ml/min/1.73 m ²) Description and range	G1	Normal or high	≥90			
	G2	Mildly decreased	60-89			
	G3a	Mildly to moderately decreased	45-59			
	G3b	Moderately to severely decreased	30-44			
	G4	Severely decreased	15-29			
	G5	Kidney failure	<15			

Green: low risk (if no other markers of kidney disease, no CKD); Yellow: moderately increased risk; Orange: high risk; Red, very high risk.

Figure 1: Prognosis of CKD by GFR and albuminuria¹

Diabetic Kidney Disease: A Major Health Concern

Diabetic kidney disease is common, affecting approximately one in every 30 adult New Zealanders.² It is the major cause of ESKD in New Zealand and worldwide. In 2012, 49% of all new patients starting dialysis in New Zealand were due to DKD, and approximately 500 people were receiving maintenance dialysis or living with kidney transplantation as a consequence of diabetes (Clayton, McDonald, & Hurst, 2013). Māori and Pacific people are twice as likely to suffer from DKD as European New Zealanders. Furthermore, high rates of prediabetes and undiagnosed diabetes suggest the prevalence of DKD is likely to double over the next fifteen years (Diabetes Workforce Service Review Team, 2011).

The burden of DKD on mortality, morbidity, and healthcare expenditure is considerable. In addition to the well-established link between diabetes and CVD, CKD and albuminuria each present additional, independent risk factors for CVD, to the extent that people with DKD have the

¹ KDIGO CKD Work Group, 2013a, p. 34. Reprinted with permission from KDIGO.

² Extrapolated data: (Coppell et al., 2013; Kenealy et al., 2012; Ministry of Health, 2014)

same risk for a cardiac event as those who are already diagnosed with CVD (Tonelli et al., 2012). Many more people with DKD die of CVD than progress to dialysis (Adler et al., 2003). According to the New Zealand Ministry of Health (2013), diabetes and CKD respectively were the second and fourth largest causes of premature death, illness, and disability in 2013. Increased hospitalisation rates, frequent specialist medical and nursing interventions, and high pharmaceutical costs contribute to a disproportionately high healthcare expenditure for people with DKD (White & Chadban, 2014). Treatments for ESKD are costly, with reports estimating that they account for between 1% and 3% of health budgets worldwide, and costs for diabetes-related ESKD are up to three times as high as for other causes of kidney failure (White & Chadban, 2014). In addition to CVD, diabetes-related co-morbidities such as peripheral vascular disease and retinopathy increase the risk of adverse events for people with DKD. Amputation, blindness, fatigue, depression, sexual dysfunction, insomnia are all more common in DKD, and contribute to overall reduced quality of life in this population (Wyld, Morton, Hayen, Howard, & Webster, 2012).

Early Detection and Treatment

On a more positive note, early treatment for DKD has been shown to slow, stop, or even reverse the progress of the disease and decline of kidney function. If implemented early and aggressively, interventions to control blood pressure and glycaemic control, along with lifestyle modification to reduce weight, stop smoking, and increase exercise have all been shown to have an impact on the rate of disease progression, with some studies demonstrating that treatment could significantly extend the length of time before dialysis is required (Joss et al., 2004; MacIsaac, Jerums, & Watts, 2010). All the major international clinical guidelines now incorporate these strategies to identify the disease early, and slow the progress of the disease.

These developments over the last 20 years have led to a paradigm shift in thinking about kidney disease and its treatments. Three decades ago, complex technology and high costs meant that treatments for kidney failure were highly specialised, and remained in the realms of secondary or tertiary level hospital care. While there was a recognised role for primary care in treating the sequelae of diabetes, involvement beyond referring patients for renal replacement therapy, was minimal in practice (Eknoyan, 1986; Leonard, 1980).

However, the KDOQI guidelines and their supporting evidence led to a change in focus from the highly specialised and technical application of RRT in secondary care to a generalist

approach to prevention and early detection in primary care. Evidence suggests that this change in focus has been somewhat sluggish, with nephrologists and primary care physicians initially reluctant or unsure how to change the status quo (Khalil & Abdalrahim, 2014). Fears of sudden increases in referrals overwhelming secondary nephrology services led to a flurry of publications debating appropriate referral criteria (de Coster, McLaughlin, & Noseworthy, 2010; Noble et al., 2008; Piccoli et al., 2002). But as research slowly revealed the scale of the at-risk population, it became increasingly evident that specialist nephrology services were not equipped to effectively detect and treat early CKD in terms of workforce, funding, or indeed, skill sets (Coritsidis, Linden, & Stern, 2011). Thus the focus has moved to primary care as the most appropriate provider of healthcare for this population.

Rationale for this Research

Despite the wealth of data supporting early detection and treatment for DKD, there is evidence that a significant proportion of the DKD population is not being identified early, and treatment among those that are detected is frequently substandard. International reports published as recently as 2012 have demonstrated low rates of diagnosis and inadequate intervention (A. Collins et al., 2012). Recent quantitative research from New Zealand reveals similar findings, with one large national cohort study finding that among 22,826 people with T2DM and albuminuria, only 61% were prescribed recommended pharmacotherapy (Kenealy et al., 2012). This data informs us that significant numbers of New Zealanders are not receiving appropriate treatment in primary care, but we have a poor understanding of the reasons behind that outcome. The rationale for this research follows a line of inquiry as illustrated below:

Diabetic kidney disease is currently a major health problem in New Zealand and worldwide, and its magnitude is expected to increase.

Early detection and treatment is the most clinically and cost effective public health strategy to deal with this condition. Key elements of this strategy have been well articulated in the literature.

Yet significant numbers of people with DKD are either not identified early, or are inadequately treated.

Therefore there is a need to discover what factors are interfering with early detection and treatment for DKD.

The researcher comes to this project after working for more than 20 years as a nephrology nurse with patients requiring RRT. Over that time she observed first-hand the increasing frequency with which people required these treatments as a result of diabetes. The difficulties of living with dialysis and transplantation – especially when exacerbated by diabetes – were relentlessly evident, and when combined with the unremitting presentation of new patients in an increasingly constrained healthcare system, a sense of despair grew that the current ‘ambulance at the bottom of the cliff’ approach was short-sighted, inadequate, and unsustainable. Seeing that diabetes was the predominant cause of many patients’ problems, five years ago she moved into a diabetes nursing role, to gain better knowledge and understanding about diabetes and in particular its role in kidney disease. Prevention of the detrimental effects of diabetes on kidney function developed into a special interest and ultimately led to her embarking on this research project.

A qualitative descriptive approach has been selected to address this research question. Numerous studies have demonstrated quantitatively that healthcare provision for DKD is inadequate, but there are few studies exploring the reasons for this phenomena. Research findings have been emerging recently from a group in the United Kingdom and a New Zealand

pilot study, which have taken a qualitative approach to investigate possible explanations (N. Thomas & Loud, 2012; R. Walker, Marshall, & Polaschek, 2014). This research problem seems to merit a qualitative approach, since it is concerned with exploring the reasons behind why and how people receive inadequate treatment. There has been little previous research into this topic, and the possible variables influencing the outcome are poorly understood, but likely to be complex and inter-related, so a qualitative methodology may be useful for elucidating those variables, which are not easily itemised and measured independently. Furthermore, qualitative description is not grounded in any particular theory, and does not require the researcher to interpret the data from any particular philosophical stance, instead presenting a description of the issues in the voice of those who understand it best (Sandelowski, 2000). Coming from a naturalistic paradigm, this approach assumes a complex inter-relationship between factors influencing the reasons for behaviour. Thus it is particularly suited to exploring the experiences and perceptions of those closest to the problem: in this case patients and healthcare practitioners (HCPs) in primary care. Finally, a qualitative approach in this case suits the researcher's worldview of healthcare and research, as well as her professional training and experience, and personal assumptions and beliefs.

Overview of Thesis Structure

This thesis is presented in seven chapters. Following this introduction to the background context, and rationale for the research, chapter two presents a review of the literature relevant to the problem of DKD, and strategies that have been articulated to address it, highlighting gaps where this research might contribute to the knowledge base. Chapter three describes the research approach in more depth, explaining the theoretical positioning of the qualitative descriptive methodology, features of its design, and ethical considerations in detail.

Chapters four and five present the findings from interviews with patients and HCPs. Data from focus groups with HCPs fell into four main themes: knowledge of best practice, detection of DKD, models of care, and factors affecting self-management practices. Patient interviews produced findings which were grouped into two main themes: locating the position of health within one's lifestyle, and factors which motivate relocation of that position. In chapter six, the findings are discussed in relation to each other and organised within the framework of the Chronic Care Model (CCM). Finally, chapter seven summarises the findings, discusses limitations and implications for future research, and concludes the paper with a summary of recommendations.

Conclusion

This research uses a qualitative descriptive methodology to explore the factors which impede early detection and intervention in DKD; a common and harmful, yet treatable complication of diabetes. By analysing the perceptions of patients and HCPs from primary care, the study addresses a gap in current knowledge revealed by poor detection and treatment rates in primary care despite well documented benefits of such an approach. The following chapter reviews relevant literature to provide contextual background to the research problem.

CHAPTER TWO – LITERATURE REVIEW

Introduction

The field of nephrology evolved out of the development of technologies in the second half of last century that could effectively replace the life-sustaining functions of the kidney, thereby prolonging life in cases of end stage kidney failure. For five decades, renal research was focused on dialysis and transplantation, and made significant progress so that patients with kidney failure now live longer, and with better quality of life than ever before. However, the ever-increasing prevalence and burden of kidney failure and catastrophic projections of future prevalence of its most common cause – T2DM – has prompted scientists and clinicians over the last few decades to look towards prevention as the Holy Grail of nephrological research. Early detection and early, aggressive intervention are the goals of optimal treatment.

This chapter seeks to elucidate the relevant literature underpinning DKD and its management. The first section will explain pathophysiology, diagnosis and prognosis, and classification. Evidence of the significance of DKD in terms of health, societal, and economic burden in New Zealand will be reviewed, along with primary prevention and early treatment strategies that are currently recommended according to evidence-based guidelines. The second section will examine various approaches to optimize early detection and treatment, organised into coherent strategies using Wagner's CCM.

The search strategy employed for this literature review began by sourcing original research and reviews published in the English language between 2000 and 2015, using combinations of the following search terms: "diabet* AND nephrol", OR "chronic renal failure" OR "chronic kidney failure" OR "chronic kidney disease" OR "chronic renal disease" OR "CKD" OR "CRF" AND "early detection" OR "early intervention" OR "early management" AND "primary care" OR "multidisciplinary". For specificity to the New Zealand context, the term "New Zealand" was added, and also articles already known to the author were accessed. For the second part of the review, the terms "Chronic Care Model" was added. Databases searched included PubMed, Medline, CINAHL, Scopus, Academic Search Elite and Google Scholar. The reference lists in the retrieved articles were then reviewed to identify further relevant material.

The Significance of Diabetic Kidney Disease

Diabetic kidney disease is a harmful, common, and treatable disease. It carries a high economic burden and there are significant disparities in its prevalence and treatment rates between ethnicities in New Zealand.

Diabetic Kidney Disease is Harmful

*If a cure is not achieved, the kidneys will pass on the disease to the heart.
(Huang Ti Nei Ching Su Wên, 2 BC, as cited in Veith, 1966, p. 181)*

While Huangdi Neijing (an ancient Chinese Emperor whose classic text on internal medicine is considered the doctrinal source for Chinese Medicine) may have understood the links between kidney and heart diseases over 2000 years ago, it is only relatively recently in modern medicine that the link between CKD and CVD has become evident (Anavekar & Pfeffer, 2004; Astor, Hallan, Miller, Yeung, & Coresh, 2008; Coresh et al., 2014; Matsushita et al., 2010). While the link between diabetes and increased rates of mortality from CVD has been well-recognised for some time (G. Li et al.; Morrish et al., 2001; Roglic et al., 2005; Stamler, Vaccaro, Neaton, & Wentworth, 1993; Taylor et al., 2013), research has now also established that kidney disease and diabetes each infer an independent and incremental risk factor for death from CVD. A re-examination of data from the landmark United Kingdom Prospective Diabetes Study (UKPDS) suggested that people with T2DM, who develop kidney disease, were more likely to die from CVD than progress to dialysis (Adler et al., 2003). This finding was supported by a prospective cohort study of 27,998 patients enrolled in a large health maintenance organisation in Oregon, which found that among people with diabetes, those with kidney disease had over 10 times the risk of CVD than those without kidney disease (Keith, Nichols, Gullion, Brown, & Smith, 2004). In a meta-analysis of studies (totalling 1,024,977 participants) assessing the association between markers of kidney disease and mortality, Fox et al. (2012) found that patients with kidney disease and diabetes had a 1.2 to 1.9 time's higher risk of mortality than those without diabetes. An analysis of results from the large 'Action in Diabetes and Vascular disease: preterAx and diamicroN-MR Controlled Evaluation' (ADVANCE) trial, with a sample of over 10,000 patients with diabetes, established a clear and independent association between markers of kidney disease, diabetes and higher mortality risk (Ninomiya et al., 2009). A large population-based survey conducted in

Canada found that hospitalisation for myocardial infarction was twice as common in people with diabetes when compared with non-diabetics, and three times more common in those with diabetes and kidney disease (Tonelli et al., 2012). More recently, a study group based in Seattle analysed data from the Third National Health and Nutrition Examination Survey (NHANES III), with a sample size of over 15,000 adults and children from the general population in the United States. The study group found “an additive interaction between diabetes and kidney disease such that the coexistence of kidney disease and diabetes was associated with a considerably larger excess mortality than the sum of excess risks associated with either risk factor alone” (Afkarian et al., 2013, p. 303). Another study has revealed that those with either diabetes or CKD have an equal risk for a coronary event as people who have already experienced such an event (Tonelli et al., 2012). Local and international guidelines therefore recommend that patients with either diabetes or CKD are treated prophylactically for CVD in the same way as those with established CVD, particularly in terms of hypertension, dyslipidaemia, and anticoagulation (Chadban et al., 2010; KDIGO CKD Work Group, 2013a; New Zealand Guidelines Group, 2012).

For those with DKD who survive to develop ESKD, the statistics are equally grim. Diabetic kidney disease is the leading cause of ESKD in New Zealand and worldwide (White, Chadban, Jan, Chapman, & Cass, 2008). In New Zealand, 49% of new patients starting dialysis in 2012 had DKD as their primary renal disease (Grace, Hurst, McDonald, & Clayton, 2013), and this rate is among the highest recorded internationally, with incidence of ESKD caused by diabetes in New Zealand higher than those in Australia and the United Kingdom, roughly equal to those in the United States, and only exceeded by Mexico, Malaysia, and Singapore (A. Lim, 2014). Since 1990 in New Zealand, there has been a three-fold increase in the number of new patients with DKD starting dialysis each year, and this increase is nearly all accounted for by the increasing prevalence of T2DM (Grace, Clayton, & McDonald, 2012). Mortality on dialysis is high; rates of up to 80% after five years have been reported (Mailloux & Henrich, 2014). Morbidity for people with diabetes on dialysis is also high. In addition to non-fatal coronary events, other co-morbidities including infection, lower limb amputation, loss of dialysis access, eye disease, and depression (Bautovich, Katz, Smith, Loo, & Harvey, 2014; Ndip, Lavery, & Boulton, 2010; Vanholder & Van Biesen, 2002; White & Chadban, 2014; Wuerth, Finkelstein, & Finkelstein, 2005) have all been shown to contribute to reported poor quality of life and increased hospitalisation in dialysis patients with diabetes (Arora et al., 2000; Nissenson, 2014; O'Toole, Fan, Yaqoob, & Chowdhury, 2012; Spiegel, Michelis, Panagopoulos, DeVita, & Schwimmer, 2005).

A recent New Zealand Ministry of Health report places diabetes and CKD at second and fourth place respectively in terms of total health loss (Ministry of Health, 2013). This estimate takes into account the years of life lost through early death, the years lived with disability, and additional burden on health due to risk factors for other disease. Data recording the actual cause of death in diabetes-related mortality are not reported in New Zealand, but Australian data shows that in 2007 kidney disease was the third most common cause of death in people with diabetes, after coronary artery disease and hypertensive diseases (White & Chadban, 2014).

Health-related quality of life (HQOL) has been reported as poor in dialysis patients, and recently has been the subject of various investigations in the setting of CKD before progression to ESKD. Research conducted in Japan (Okubo et al., 2013), United States (Mujais et al., 2009; Perlman et al., 2005), Sweden (Pagels, Söderkvist, Medin, Hylander, & Heiwe, 2012) and Australia (Chow et al., 2003), and a meta-analysis of relevant literature (Wyld et al., 2012) all conclude that HQOL is significantly reduced in people with DKD, with authors describing HQOL in this population as “distressingly low” (Gorodetskaya et al., 2005, p. 2801) and its effects “profound” (Mujais et al., 2009, p. 1293). The later the stage of disease, the number of co-morbidities, and age were found to be contributing factors. This evidence that quality of life is so detrimentally impacted by DKD, especially in its later stages, further supports a call for improving treatments aimed at slowing progress of the disease.

Diabetic Kidney Disease is Common

Diabetic kidney disease is common, and its prevalence is increasing. It can be a complication of all types of diabetes, however T2DM is the predominant cause of DKD, driven by the increasing prevalence of T2DM, as well as the characteristically insidious development of DKD over many years, in the time before T2DM is diagnosed (A. Lim, 2014).

In a study which extrapolated data on diabetes prevalence to all World Health Organisation member states, it was projected that the total number of people worldwide with diabetes would rise from 171 million in 2000 to 366 million in 2030, representing an increase in prevalence from 2.8% to 4.4% (Wild, Roglic, Green, Sicree, & King, 2004). Data suggests that New Zealand has disproportionately high diabetes prevalence. According to the 2013 New Zealand Health Survey Update, 5.8%, or one in seventeen of the New Zealand adult population has been diagnosed with diabetes (Ministry of Health, 2014). However, other research suggests these

figures are conservative. A study conducted in 2013 by a group from the University of Otago examined HbA1c data from the 2008/09 New Zealand Adult Nutrition Survey to estimate the prevalence of prediabetes, as well as diabetes (Coppell et al., 2013). They found a prevalence of diabetes of 7% in the general adult population. When compared to the New Zealand Health Survey figure of 5.8%, this suggests that there is a 1.2% cohort of people with overt but as yet undiagnosed diabetes. In addition, the prevalence of prediabetes was found to be 18.6%. This represents a large number of New Zealanders (approximately 684,000) who are unaware they are on the pathway towards diabetes, and who may already be developing kidney disease as a result. These findings provided new and alarming evidence about the larger scale of the diabetes problem facing New Zealand than previously thought.

To the author's knowledge, there are no reliable data for current or future prevalence of CKD in New Zealand (J. Collins, 2010a), but reports from other countries including the United States and Australia have found high prevalence in the general population. The Australian Diabetes, Obesity and Lifestyle Study (AusDiab) which began in 1999, and was followed up in 2004, was a nationwide, longitudinal population-based study which looked for the presence of kidney damage in the general population. The study found that approximately 16% of the adult Australian population had one or more indicator of kidney damage (Chadban et al., 2003). In another study which used data from the American National Health and Nutrition Examination Surveys from 1999 and 2004, a CKD prevalence of 13% was found in the general adult United States population (Castro & Coresh, 2009).

With specific regard to kidney disease in people with diabetes, two recent studies have estimated the prevalence of DKD in New Zealand. The first study, a cross sectional survey of 10 primary practices in Rotorua, identified 942 eligible patients with diabetes, and then estimated their GFR using recorded laboratory data. Prevalence of kidney disease in this group was found to be 19.5% (Joshy et al., 2010). The second study looked for the presence of albuminuria in 67,171 New Zealand adults with diabetes in primary care, and found that 50% of Māori, 49% of Pacific people, 31% of Asian, and 28% of European had signs of kidney disease, and concluded that on average, around half of all people diagnosed with T2DM in New Zealand have signs of kidney disease (Kenealy et al., 2012). A previous, smaller study carried out in primary care in Australia had found similar results (M. Thomas, Weekes, Broadley, Cooper, & Mathew, 2006). These estimates are likely to be conservative, since the studies did not include people with undiagnosed

diabetes and prediabetes (19%) who are likely to represent a significant number of people with unrecognised kidney disease (Coppell et al., 2013).

Diabetic Kidney Disease is Costly

The economic cost of DKD in its early stages preceding dialysis are not well studied. Most research into the costs of CKD in general includes the financial cost of RRT, and do not identify the pre-dialysis costs. One such New Zealand study in 2006 estimated that NZ\$90 million per annum was spent on RRT, with NZ\$36 million spent on diabetic ESKD alone (Endre, Beaven, & Buttimore, 2006). Data from Counties Manukau District Health Board (CMDHB) in 2004 showed the average annual cost of dialysis treatment per patient ranged between \$33,585 for home haemodialysis, and \$64,318 for hospital haemodialysis, accounting for 1% of the total health budget (Ashton & Marshall, 2007; National Renal Advisory Board, 2006). A 2009 report from the Australian government estimated that RRT accounted for 85% of costs associated with CKD (Australian Institute of Health and Welfare, 2009). Data from the United States shows that costs associated with diabetes-related ESKD are 30% to 50% higher than those related to other causes of kidney disease (United States Renal Data System, 2013). Considering all of this evidence, it is reasonable to assume that any significant reduction in the rate of progress to kidney failure which translates to extending the pre-dialysis stages of DKD will have major economic benefits.

A comprehensive review of the cost effectiveness of DKD prevention strategies in the United States concluded that current screening tools become less economically effective when applied across large populations, and called for more research to elucidate strategies which will more effectively identify those who are at high risk for the disease. However, they qualified their position by stating “what does remain beyond doubt is that the health and economic burden of diabetic nephropathy is so great that even costly interventions will continue to be worth exploring to protect our patients from the consequences of this devastating condition” (Rippin, Barnett, & Bain, 2004, p. 23). A more recent American study calculated the costs associated with progression of DKD, and found that inpatient, outpatient, and pharmacy costs for those in stages 3 and 4 of the disease were at least double the costs of those patients who were in the earlier stages (Vupputuri et al., 2014). While the transferability of their figures to the New Zealand context is limited due to the differences in healthcare funding, it is fair to assume that some substantial differences in cost depending on how far the disease has progressed would apply in the New Zealand healthcare

system. These results suggest that strategies applied in the early stages of DKD to prevent disease progression are likely to produce economic benefit.

Closer to home, an Australian study examined current costs associated with CKD and RRT and made projections about future costs. The study determined that between 2012 and 2020, expenditure associated with CKD, including inpatient, outpatient, and pharmacologic costs, are predicted to increase by 37%, compared to an overall health expenditure increase of only 26% in that same period (Tucker, Kingsley, Morton, Scanlan, & Dalbo, 2014). The authors proposed that this increase was likely due to increasing prevalence of CKD, although it should be noted that this study included non-RRT related costs for ESKD patients in the CKD-cost total. Therefore, this figure over-represents the expenditure on pre-RRT stages of CKD. However, the authors make the point that lifestyle-modification presents the most cost-effective treatment for CKD, since smoking cessation, weight loss, and increased exercise have been shown to reduce risk of both progression of disease and co-morbidities. While they don't refer directly to DKD, this conclusion is relevant to DKD since these are also recommended for the early treatment of diabetes.

Major Ethnic Disparities in the Prevalence and Treatment of Diabetic Kidney Disease

Significant ethnic disparities exist in the prevalence statistics for diabetes in New Zealand. The higher prevalence of T2DM in Māori has been well-reported, with total New Zealand prevalence of 7.1% compared with 9.7% for Māori (University of Otago and Ministry of Health, 2011). Māori women are twice as likely to have diabetes as non-Māori women, and over the age of 40 Māori of both genders are three times more likely to have diabetes (Joshy, Porter, et al., 2009). In Māori prediabetes prevalence has been estimated as 20.5% compared with 18.1 % in the general population (Coppell et al., 2013). Between 2004 and 2006 diabetes was the third biggest cause of death for Māori men, and the fifth biggest for Māori women, and overall it ranked as the fourth biggest cause of premature death for Māori. In contrast, it did not feature at all in the top five mortality causes for non-Māori (Ministry of Health, 2010). In terms of health loss, diabetes ranked as the second biggest cause of health inequality between Māori and non-Māori, with health loss due to diabetes nearly four times higher in Māori than non-Māori (Ministry of Health, 2013).

Pacific people have the highest prevalence of diabetes in New Zealand (Ministry of Health, 2012b), with prevalence rates higher and climbing more quickly than non-Pacific (Hotu et al., 2010; Joshy, Dunn, Fisher, & Lawrenson, 2009). Pacific women are three times more likely to have diabetes than non-Pacific women (Ministry of Health, 2012a), and in the 40 and over age group, prevalence rates for Pacific people of both genders with diabetes are around three times higher than New Zealand Europeans. Pacific people have the highest prevalence of undiagnosed diabetes, with a rate of 24% compared with 20.5% in Māori and 18.1% in other ethnicities (Joshy, Porter, et al., 2009; Joshy & Simmons, 2006)

In its first comprehensive review of Asian health outcomes and disparities, the Ministry of Health (2006) reported a wide disparity between Chinese and Indian health outcomes, with Chinese ethnicity conferring positive health benefit when compared to the total New Zealand population. Indian ethnic groups experience relatively high rates of obesity, T2DM, and CVD when compared to other Asian ethnic groups and also to the total New Zealand population. After controlling for age, sex, and deprivation level, Indian people in New Zealand are three times more likely to have self-reported diabetes than the total population. Specific complications of diabetes are not reported, however hospitalisation for, and death from, CVD (a major complication of diabetes) are significantly higher for Indian people compared to other Asian New Zealanders as well as to the total New Zealand population (Ministry of Health, 2006). Other New Zealand studies have reported higher prevalence of T2DM (Joshy, Porter, et al., 2009), and albuminuria (Kenealy et al., 2012) in South Asian or Indian ethnicities.

These disparities are reflected in statistics for DKD. Multiple studies show that Māori with T2DM have higher rates of albuminuria than non-Māori (Kenealy et al., 2012; S. Lim, Chellumuthi, Crook, Rush, & Simmons, 2008; McDonald & Russ, 2003; McGrath, Parker, & Dawson, 1999; Metcalf, Scragg, & Dryson, 1997; D. Simmons, Shaw, Scott, Kenealy, & Scragg, 1994), and one study has shown that this occurred even when both groups received appropriate pharmacological treatment at similar rates (Elley et al., 2008). This suggests that strategies aimed at preventing and treating risk factors need to be substantially more intensive for Māori than non-Māori. It also underlines the importance of incorporating lifestyle modification in addition to drug treatment into primary care strategies.

Māori have been found to be predisposed to kidney disease, independently of diabetes, which has not yet been adequately explained but which may be related to familial or

environmental factors (S. Lim et al., 2008; Thompson, Simmons, Collins, & Cecil, 2001). A genetic tendency has been postulated, but it is also possible that environmental factors that occur in familial clusters have some influence. Pre-natal smoking and diet, poverty, reduced access to healthcare services, and low adherence to medication regimens have been implicated (J. Collins, 2010b; Grace et al., 2012; Joshy, Dunn, et al., 2009; Kenealy et al., 2012).

Māori with T2DM are 8½ times more likely to develop kidney disease than non-Māori (Joshy, Dunn, et al., 2009; Kenealy et al., 2012; Ministry of Health, 2010), and the disease progresses faster in Māori (Joshy, Dunn, et al., 2009), suggesting the possibility that the disease is diagnosed at a later stage than in non-Māori, or that Māori with diabetes are treated differently from non-Māori. Māori with T2DM are up to 46 times more likely to develop ESKD, are seven times more likely to be admitted to hospital with a renal-related condition (Joshy, Dunn, et al., 2009), and are 15 times more likely to die of DKD than non-Māori with diabetes (Joshy et al., 2010), while health loss due to kidney disease in Māori is three times higher in Māori than non-Māori (Ministry of Health, 2013).

Rates of albuminuria in Pacific people with diabetes (49%) are similar to Māori (50%), and significantly higher than in NZ Europeans (28%) (Kenealy et al., 2012). Pacific people are more likely to develop ESKD than Māori (Hotu et al., 2010), and the incident rates of Pacific people starting RRT due to DKD strongly reflect the high prevalent rates of diabetes in this population. Between 2000 and 2009, diabetes was the cause of kidney failure for 66% of all Pacific people commencing RRT, compared with 21% of New Zealand Europeans (Grace et al., 2012).

There is no data available for kidney disease in Asian New Zealanders, but studies from overseas reveal similar disparities for Asian ethnicities. A study from Singapore examining prevalence of risk factors for kidney disease in a multi-ethnic Asian population found that despite risk factors being similar in all Asian groups to western populations reported, Indian ethnic groups had a significantly higher rate of kidney disease than other Asian ethnicities (Sabanayagam et al., 2010). Another study in Northern California looking at development of albuminuria in multiple ethnic groups found that incident rates of albuminuria in Asians (which were not further specified) were 35% higher than in white Americans, despite similar medical care (Choi et al., 2011). A United Kingdom study of a multi-ethnic population in primary care with T2DM and early kidney disease found that South Asians (Bangladeshi, Pakistani, Indian and Sri Lankan) had a significantly

faster rate of kidney function decline than white ethnicities (Dreyer, Hull, Mathur, Chesser, & Yaqoob, 2013).

It seems that disparities related to diabetes and its complications between ethnicities in New Zealand are multifactorial, including familial, hereditary and genetic factors, as well as environmental factors such as obesity, smoking, poverty, and access to and utilisation of healthcare. Evidence indicates that particular populations have a higher prevalence of diabetes, along with increased risk, and faster progression of DKD. More New Zealand research is needed to explain the disparities in diabetes-related kidney complications between ethnicities, and in particular for tāngata whenua. In the meantime, this evidence presents a compelling argument for communities, healthcare organisations and policy makers to place a high priority on finding practical and effective strategies for dealing with these inequities.

Diabetic Kidney Disease is Treatable through Early Detection and Intervention

Early detection

It now is evident that to improve dialysis outcomes, it is essential for practitioners to recognize the earlier stages of CKD, not only to retard disease progression, but also to prevent and treat its complications and comorbidities long before the need for dialysis arises. (Eknoyan, 2003, p. 3)

Research generated since the landmark publication of the KDOQI guidelines in 2002 has shown that early detection of albuminuria and hypertension, and their aggressive treatment can reduce, halt, and even reverse the progression of kidney disease, particularly in high risk diabetic populations (Eknoyan et al., 2004; MacIsaac et al., 2010; J. Turner, Bauer, Abramowitz, Melamed, & Hostetter, 2012). Early intervention by modification of risk factors (in particular hypertension and albuminuria) in patients with diabetes has been shown to slow the progression of DKD, thereby prolonging the length of time until commencement of RRT (Chadban et al., 2010; Dreyer et al., 2013; Levin, 2005; Levin & Stevens, 2011; Saweirs & Goddard, 2007). Furthermore, the benefits of early treatment continue after RRT has begun, with fewer adverse outcomes at the time dialysis starts, and reduced morbidity and mortality later in RRT programmes (S. Chen et al., 2010; Hasegawa et al., 2009; Levin & Stevens, 2011).

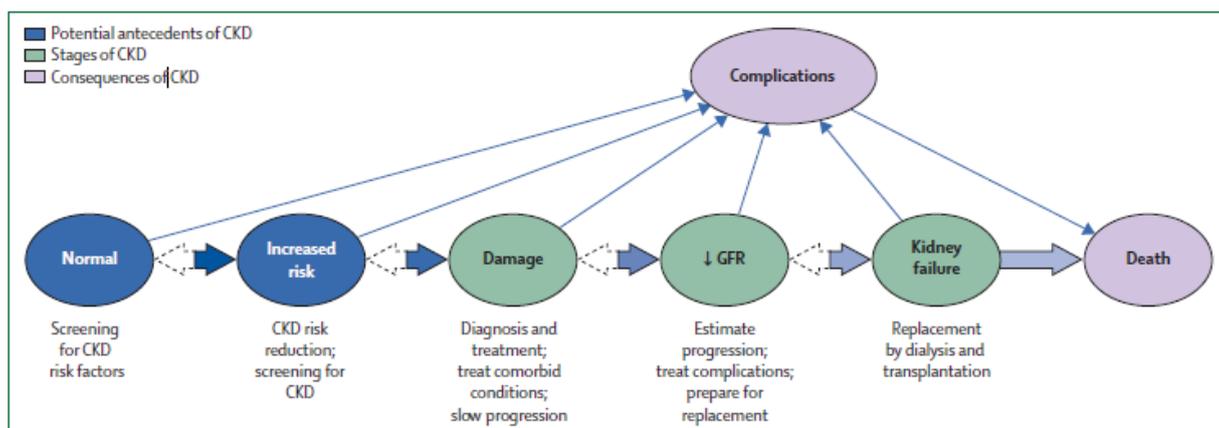


Figure 2: Conceptual model for chronic kidney disease³

Figure 2 illustrates the continuum of progression and complications of CKD, along with management strategies that have been shown to improve outcomes at each of its stages. Horizontal arrows signify progression or, in the case of dashed arrows, remission, which is less common, but is the goal of optimal management.

New Zealand literature supports the international experience. A review commissioned by the National Renal Advisory Board in 2006 reported that nephrology specialist care in the early stages of CKD is associated with decreased morbidity, decreased short-term mortality, improved long-term survival on dialysis, and decreased costs. In addition to higher morbidity, longer hospitalization, higher mortality, and greater cost to the health system, it was reported that late referral also limits treatment options, which in turn can have consequences for long-term outcomes once patients are on dialysis (National Renal Advisory Board, 2006).

As a consequence of this compelling evidence, clinical guidelines now universally recommend at least annual screening for albuminuria to enable earlier and aggressive treatment (Chadban et al., 2010; KDIGO CKD Work Group, 2013b; New Zealand Guidelines Group, 2012).

³ Reprinted from The Lancet, 379(9811), Levey, A., & Coresh, J. Chronic kidney disease, pp 165-180., Copyright (2012), with permission from Elsevier.

Early intervention

The management of nephropathy in diabetes should be multifaceted, advocating a healthy lifestyle and targeting all the individual renal and cardiovascular risk factors. (Thorn & Hägg, 2014, para. 7)

The primary goals of early treatment for DKD are to reduce albuminuria, control hypertension, and optimize glycaemic control. Treatment to reduce albuminuria primarily involves pharmacotherapy with angiotensin converting enzyme (ACE) inhibitors, which have well-recognised reno-protective properties, beyond that which would be expected from their role in lowering hypertension alone (Bakris et al., 2000; de Zeeuw & Raz, 2008; Remuzzi, Perico, Macia, & Ruggenenti, 2005). Another class of antihypertensive therapy, the angiotensin II receptor blockers (ARB), has also been found to have a similar but less potent effect, and is recommended for use in those patients who do not tolerate ACE inhibitors due to side effects (Brenner et al., 2001). While there is recent debate in the international literature about whether ACE inhibitors should be used to treat albuminuria in patients who are normotensive (Rocco & Berns, 2012), in Australasian guidelines the recommendation to treat people with persistent albuminuria with ACE inhibitors whether or not they are also hypertensive, remains current (Chadban et al., 2010; New Zealand Guidelines Group, 2012). Guidelines do not contain specific recommendations for target reduction of albuminuria, although research has shown that aggressive treatment with ACE inhibitors or ARB can reduce albuminuria by up to 50% (Araki et al., 2007; Basi & Lewis, 2007).

In addition to reduction of albuminuria, blood pressure control is important for aggressive treatment of early DKD. There is debate in the current literature about exact treatment targets for blood pressure. The Action to Control Cardiovascular Risk in Diabetes (ACCORD) trial in 2008 was a large, randomised controlled trial which sought to evaluate whether intensive glycaemic control improved outcomes in T2DM. In 2010 data from the trial was analysed to assess the effect of different blood pressure targets on outcomes. Findings suggested that lowering blood pressure below 120 mmHg compared with 140 mmHg systolic had no benefit on outcomes, and may have had deleterious effects (The ACCORD Study Group, 2010). For this reason, guidelines recommend treatment for hypertension to target a blood pressure between the ranges of 120 – 140 mmHg systolic, and below or equal to 80 mmHg diastolic in people with diabetes (Chadban et al., 2010; New Zealand Guidelines Group, 2012).

The third important aspect of treatment for DKD is glycaemic control. The landmark UKPDS and Diabetes Control and Complications Trial (DCCT) studies provided, for the first time, irrefutable evidence that improved glycaemic control can delay the onset, and slow the progression of microvascular complications in T1DM and T2DM, including DKD (Adler et al., 2003; Skyler, 2004). Clinical guidelines therefore recommend target HbA1c between 50 – 55 mmol/mol (New Zealand Guidelines Group, 2012). There is agreement that HbA1c targets should be agreed individually with each patient, and that those who are at particular risk of hypoglycaemia should have a slightly higher target range (KDIGO CKD Work Group, 2013b). An important revelation from the UKPDS study was that for every one percent reduction in mean HbA1c, there was a significant improvement in outcomes, including a 37% reduction in microvascular complications (including DKD), regardless of absolute HbA1c (American Diabetes Association, 2002). On the basis of this finding, guidelines recommend any reduction in HbA1c (but not below 50 mmol/mol) as beneficial for long term outcomes.

Finally, in terms of treatment to prevent or delay the progression of DKD, the importance of lifestyle modification should not be overlooked. A recent observational study found that regular physical activity significantly decreases the risk of kidney disease among people with T2DM (Dunkler et al., 2014). Obesity has been found in multiple studies to be associated with increased risk of CKD, whether or not diabetes is also present (Burton et al., 2012; Eknoyan, 2007; Hill et al., 2013; Maric-Bilkan, 2013). Smoking is thought to have a similar disease-inducing effect on kidney haemodynamics, and therefore is considered an important independent risk factor for CKD, and exacerbating the effects of any co-existing diabetes (Cignarelli, Lamacchia, di Paolo, & Gesualdo, 2008; Phisitkul et al., 2008). The substantial evidence in favour of lifestyle modification for the prevention of DKD, or to delay its progression, underlies the inclusion in clinical guidelines of lifestyle modification as one of the goals of early detection and treatment (Chadban et al., 2010; Johnson et al., 2013; New Zealand Guidelines Group, 2012). Since these modifiable factors are the same as those for T2DM and CVD, it is to be hoped that education and support towards those changes naturally begins early, at the time of diagnosis of diabetes, in primary care.

Diabetic Kidney Disease, Healthcare Delivery and Public Health Policy

Despite the fact that the majority of patients with CKD are managed in primary care, much of the debate until recently centered on comparing outcomes between patients who were

referred late⁴ to secondary care and those who weren't. Multiple studies have concluded that early referral is associated with better outcomes in terms of morbidity, mortality, and cost (Baer, Lameire, & Van Biesen, 2010; M. Chan, Dall, Fletcher, Lu, & Trivedi, 2007; Kinchen et al., 2002). However, there has been a general shift in research and expert opinion over the last ten years away from the notion that CKD is the domain of specialist nephrologists alone, looking instead towards primary care in efforts to attain optimal early intervention for CKD. Primary care offers important advantages over secondary care for early CKD management. In addition to the obvious observation that nephrologists alone would be unable to identify and reach the many thousands of people with early CKD, primary care has developed a skill and knowledge base about identifying and modifying CVD risk, so it makes sense to include CKD (an important risk factor for CVD) in those considerations. Furthermore, primary care already collects and maintains comprehensive population-based databases about the health of a significant portion of the population, and modifying these systems and processes for CKD surveillance would be more clinically and cost effective than starting from scratch. Most importantly, primary care is the main (often the only) health provider for those high risk (diabetic, hypertensive, elderly, and non-European) groups for whom early CKD detection is vital.

Sub-optimal care concerns, combined with the projected volumes of patients with CKD, and the escalating cost of ESKD treatments, led to Adeera Levin's⁵ observation in 2005 that "in an optimally organised system, patients could be identified and managed by primary care physicians and non-nephrology specialists in a collaborative manner, thus offsetting the burden on nephrologists alone" (Levin, 2005, p. S7). The predicament is particularly evident in the United States, where CKD has been described as a public health crisis (Levey & Coresh, 2012; Rettig, Norris, & Nissenson, 2008), and a recent report indicating that among patients with T2DM, albuminuria, and reduced eGFR, only 12% had been identified as having CKD by primary care providers, demonstrates that care is indeed deficient (Szczech et al., 2014). This is despite the introduction of initiatives aiming to improve the quality of care received by those with CKD. In 2006 the Centers for Disease Control and Prevention was funded by the federal government to implement a national surveillance programme (Levey et al., 2009). In response to evidence that

⁴ Defined as those patients who require renal replacement therapy within three months of referral to secondary nephrology services (Grace et al., 2013, p. 2.6).

⁵ Levin is a Canadian nephrologist, researcher, and influential leader of multiple international CKD advisory bodies.

treatments for early CKD were cost effective compared to those for ESKD, the government also charged its national social insurance provider (Medicare) with the task of improving early detection of CKD in order to reduce the financial burden of the disease on the nation. A third initiative was the establishment of the National Kidney Disease Education Programme, whose role is to promote evidence based research aiming to slow the progression of CKD. Convincing evidence of improvement in outcomes in CKD treatment in the United States is eagerly anticipated (Narva et al., 2010).

Meanwhile, in the United Kingdom, the increasingly central role of primary care in optimising early CKD treatment has been most evident, and has been reflected in several key policy innovations within the National Health Service. In 2006, the introduction of CKD registries at primary care level, along with the inclusion of CKD in the National Quality and Outcomes Framework, has raised awareness of CKD in primary health (O'Donoghue, 2009). Under this framework, financial incentives are provided to primary care practices to maintain registries of patients with CKD and to provide evidence-based care (NHS Information Centre, 2015). This requirement to detect, report and treat early CKD has led to a sea-change in CKD awareness and management in the United Kingdom's primary care setting, and although evidence suggests the systems are still embedding, will likely lead to more research into optimisation of care (P. Stevens, De Lusignan, Farmer, & Tomson, 2012). There is some early evidence that suggests these funding changes appear to be having positive effects on improved surveillance (Bennett, 2007; Jameson et al., 2014; McIntyre, Fluck, McIntyre, & Taal, 2012; Radhakrishnan et al., 2014; Schoen et al., 2011).

In New Zealand, emerging local and international evidence of the scale of the CKD problem provided a stimulus for the National Renal Advisory Board to begin a collaboration with the Ministry of Health to sponsor four pilot studies testing the effectiveness of innovative approaches to improving CKD management. The approaches considered were electronic screening and referral for CKD, and nurse-led clinics in primary care focused on intensive management of CKD (R. Walker et al., 2014). The results of these pilot projects and a separate randomised controlled trial undertaken in Auckland in Māori and Pacific patients with DKD (Hotu et al., 2010) led to a National Consensus conference on CKD in 2013. Participants included diabetes and renal specialist nurses and doctors, primary care practitioners, and Ministry of Health personnel. A consensus document summarising the conclusions and recommendations emerging from that meeting is expected imminently (N. Polaschek, personal communication, August 20,

2014). The intended purpose of the proposed consensus statement is to provide the basis for a national strategy for the identification and management of CKD.

Application of Guidelines in Practice

The research described earlier has produced a body of knowledge and guidance which promotes the benefits of early detection and treatment for DKD. However, the application of the evidence in practice has been described in the literature as sub-optimal and uncoordinated (Craig et al., 2003; Joss, Paterson, Deighan, Simpson, & Boulton-Jones, 2002; Levin, 2005; Mathew & Corso, 2009; Nissenson et al., 2001; St Peter, Schoolwerth, McGowan, & McClellan, 2003; Valderrábano, Golper, Muirhead, Ritz, & Levin, 2001). Data from the United States reveals low rates of screening for albuminuria, at 37%, with three times as many serum creatinine tests being performed. Serum creatinine is of no value in the early stages of CKD since it remains normal until the latest stages, suggesting a significant number of care providers are unaware of recommended screening criteria (A. Collins et al., 2012).

In 2003 the Council of American Kidney Societies (CAKS) met to address perceived problems and identify barriers to attaining the best outcomes for patients with CKD. The meeting and its outcomes were reported the following year (Parker III et al., 2004). Nineteen barriers to effective early detection and management of CKD were identified. Several of the barriers were concerned with poor quality or unavailability of evidence regarding efficacy and cost-benefit of treatment, and have been subsequently addressed by research which has occurred in the years since. The remaining barriers were concerned with funding difficulties within the United States health system, inadequate workforce, unresponsive healthcare delivery models, and poor general awareness about CKD among HCPs and the public. Awareness about CKD among HCPs was the predominant concern, constituting six of the nineteen barriers. Aspects of this issue included poor understanding among primary care teams about the definition of CKD, its significance in terms of poor outcomes, and best practices in its treatment. It is interesting to note that the preferred action plan developed by the working group to address these problems was primarily concerned with increasing the specialist nephrologist workforce, as demonstrated in the following excerpt:

The problem and barrier is compounded by the observation that the involvement of nephrologists early in the care of CKD patients will lead to improved outcomes, yet severe limitations exist on the availability of nephrologists to participate in

CKD care. Unless there are substantial alterations in the nephrology human resources workforce in the future, nephrologists will not be able to provide principal care to the entire CKD population and collaborative care models will need to be used. (Parker III et al., 2004, p. 713)

The authors also noted that “patient provider attitudes and behaviours may limit the effectiveness of collaborative approaches” (Parker III et al., 2004, p. 714), and posited that enhanced communication between nephrologists and primary care providers would be required to ameliorate those issues. These comments expose an underlying assumption that the role of primary care in treating CKD is limited to early referral to a nephrologist and then acting as a supporter of specialist intervention thereafter. This specialist nephrology-oriented perspective is probably reflective of the composition of the working group; 34 of the 43 members were specialist nephrologists (membership also included one nurse, one patient advocate, three primary care physicians, and seven representatives from the pharmaceutical and medical equipment industries). While this report provides a useful starting point for identifying potential barriers to optimal treatment for CKD, its specialty-centric focus poses limitations for its usefulness in finding ways to deal with those barriers.

In the United Kingdom, investigators have noted inconsistencies in prevalence rates between national quality indicator data and epidemiological studies, which suggest a portion of the population with early kidney disease are not being identified by screening practices (Crimson, Gallagher, Thomas, & de Lusignan, 2010; de Lusignan et al., 2009; N. Thomas & Loud, 2012). Research studies show that up to a third of CKD patients seen by nephrologists are referred too late, with inadequate treatment prior to referral (Craig et al., 2003; Joss et al., 2002; L. Phillips, Donovan, & Phillips, 2009), and in New Zealand these findings are supported by ESKD registry data (Grace et al., 2013). Thus there is evidence that although there are well established recommendations for early screening and intervention, their application in practice is inconsistent.

This evidence poses a challenge for clinicians and researchers alike: when there are such well-established evidence-based recommendations to guide practice concerning CKD management, why is a significant proportion of CKD patients not achieving the targets set by those guidelines? A number of studies have investigated this question, and have proposed a variety of barriers which interfere with the application of best practice. This evidence will be considered in the following section, using the CCM as a framework for organising the discussion.

The Chronic Care Model: a Template for Optimal Management of Diabetic Kidney Disease

As discussed previously, it is argued that the traditional healthcare model delivers care that is suboptimal for people with chronic conditions, including those with CKD (Bodenheimer, Wagner, & Grumbach, 2002a; Valderrábano et al., 2001). The CCM offers an alternative paradigm for chronic care, focusing on tailoring various aspects of healthcare delivery to people with long term health needs. The model has been widely adopted and validated (Coleman, Austin, Brach, & Wagner, 2009; National Institutes of Health, 2014), and its applicability in the early CKD context has been noted in the literature (de Lusignan et al., 2013; Greer & Boulware, 2015). Because of its relevance to this setting, the following discussion will use the model's components as a framework to review the barriers to optimal CKD management evident in the literature.

Developed by Edward Wagner and his colleagues based in Seattle in the mid-1990s, the CCM responded to evidence of increasingly poor outcomes for chronic care management in the western-style health system, which had evolved historically to deal very effectively, albeit reactively, with acute illness or injury. Under the traditional model, care comprised episodic and immediate medical intervention aimed at cure, and was inadequate to address the increasing need for proactive, patient-centered and life-long care for chronic conditions (Wagner, Austin, & Von Korff, 1996). The CCM derived from evaluation of the characteristics of successful chronic care interventions and programmes, and distilled those features into four interrelated elements which influence health outcomes: increasing providers' skill and knowledge about the patient (Decision Support), improving care delivery by utilising the healthcare team better and planning care more effectively (Delivery System Design), empowering and supporting patients to effectively manage their own health (Self-Management Support), and making better use of information systems (Clinical Information Systems). Community (in terms of Resources and Policies) and Health System Organisation are overarching features which support well-prepared healthcare provision (Wagner et al., 2001). Improvements in these elements support "productive interactions between informed activated patients and prepared proactive practice teams" (Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004, p. 301), and have been conceptualised in a diagram which has been reproduced in *Figure 3*.

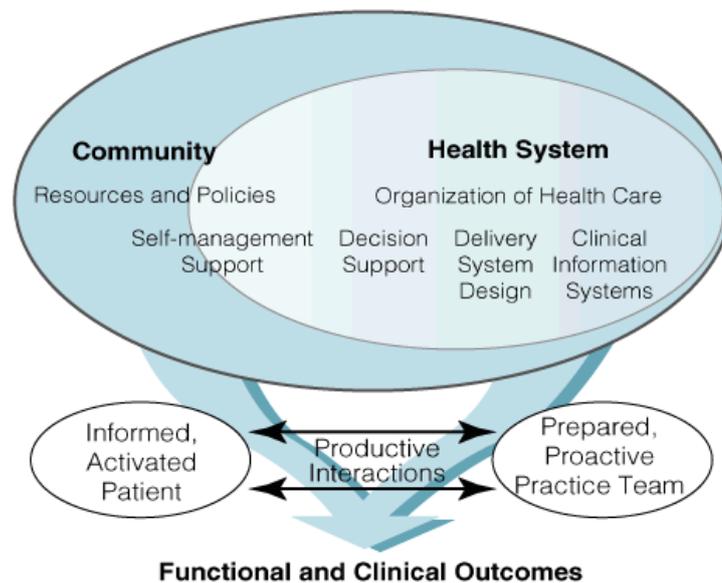


Figure 3: The Chronic Care Model ⁶

Healthcare Delivery System Design

Delivery system design refers to the way in which practices are organised to deliver care. System design includes the way in which team members work, and the tasks they perform, as well as the way in which interaction with patients occurs. It has been shown that effective team co-ordination, role definition and communication are key features of successful chronic care programmes, and that they must be explicitly planned in a systematic way to meet the needs of people with chronic health problems (Dean, 2012; Wagner et al., 1996).

In the years since the publication of the CAKS report, multiple articles have set out to identify barriers to optimal early CKD treatment associated with various models of healthcare delivery. Various endpoints have been measured to assess the effectiveness of healthcare delivery in primary care for people with early DKD. Herget-Rosenthal et al. (2006) measured multiple endpoints in 174 primary care patients with stage 3 to 5 CKD in Germany. This study found that only 39% of patients met blood pressure targets, 42% had adequate bone disease management, and 59% of patients with diabetes or proteinuria were on ACE inhibitors or ARB. Altogether, only 35% of patients achieved targets in all indicators, suggesting overall care was sub optimal. Manns et al.

⁶ Developed by The MacColl Institute, © ACP-ASIM Journals and Books, reprinted with permission from ACP-ASIM Journals and Books.

(2012) discovered that despite an electronic prompt, elderly patients with diabetes and microalbuminuria were undertreated with ACE inhibitors or ARBs. Fraser et al. (2013) found in a large sample of patients with stage 3 CKD attending primary care practices in the United Kingdom, that only 35% of hypertensive patients reached KDOQI targets. And in a recent study by Jain Calvert, Cockwell, and McManus (2014), a significant discrepancy was revealed between the prevalence of biochemical markers of kidney damage and reported prevalence according to the Quality and Outcomes Framework, suggesting under-reporting by primary care.

A recent New Zealand study provides evidence that screening and DKD detection practices in primary care are producing suboptimal results. This study, a cross sectional analysis of the New Zealand 'Get Checked' national diabetes data in 2012, found that in the study population of 75,529 people with T2DM, 9.3% had not been screened for albuminuria. Of those who had been screened, 35% had albuminuria. Māori and Pacific people were over-represented in that group: 49.8% and 48%, respectively, had positive albuminuria tests. Furthermore, only 61% of those with albuminuria had been treated according to local and international recommendations (Kenealy et al., 2012).

In a New Zealand study, Hotu et al. (2010), recognising that traditional models of primary and secondary healthcare delivery were not achieving blood pressure targets in patients with CKD, proposed an alternative model outside of the primary versus secondary debate. The study's aim was to assess the efficacy of a so-called 'community-based' model in a RCT comparing conventional care to a novel, community based care for blood pressure management. Patients assigned to the community-based group received monthly visits from a culturally-appropriate healthcare assistant, under the supervision of a registered nurse. During the visit, blood pressure was monitored and antihypertensive therapy adjusted using an algorithm. At 12 months, the community-based group had achieved a significant improvement in blood pressure in comparison to the conventional group, along with reduced albuminuria. The authors proposed that these improvements were due to the removal of financial and language barriers, more frequent and longer follow-up visits, and greater adherence to guidelines by healthcare assistants and nurses. Other similar studies have reported comparable results (Mugarza, Wilding, Woodward, Hayden, & Gill, 2008; A. Williams, Manias, & Walker, 2010; Woodward, Wallymahmed, Wilding, & Gill, 2006). This approach seems to offer clinical as well as cost advantages and further evaluation may be warranted.

A recent New Zealand study investigated the efficacy of collaboration between primary and secondary care in reducing progression of DKD (R. Walker et al., 2014). Pre- and post-intervention outcomes were compared in a group of 36 patients at high risk for CKD progression. The intervention used the services of a nephrology nurse practitioner, who, with the assistance of a practice nurse, organised and led a series of sessions with each patient every fortnight for twelve weeks. The group was then monitored for twelve months. The content of each visit included self-management support, along with planned treatment and lifestyle modifications. The outcomes measured showed significant improvements in albuminuria, 5-year absolute cardiovascular risk, cholesterol, blood pressure and HbA1c. Although there was no change in mean body mass index, there were significant improvements in other areas of self-management including smoking cessation, HbA1c, and self-management score. Furthermore, these improvements in self-management persisted through and possibly beyond the twelve month follow-up period. Due to the study's design (a quality improvement pilot study), it is not possible to say with certainty that the improvements were directly related to the intervention. Other confounding factors (notably the fact that the study was funded by the Ministry of Health, so visits were free of charge for patients), may have influenced the outcomes. It could also be argued that the improvements were more related to the intensive attention the patient received, rather than the HCP collaboration. Nevertheless, this study shows that collaboration between specialists and primary care can have significant positive effects on patient outcome, and at relatively low-cost.

In terms of secondary care, collaboration between renal and diabetes specialist care has received attention in the literature, as has intensive versus conventional treatment. In a retrospective review of patient data from 130 patients attending a joint renal-diabetes clinic, one study found that the rate of decline of eGFR was significantly reduced between the first and third years (Jayapaul, Messersmith, Bennett-Jones, Mead, & Large, 2006). These results have been subsequently supported by similar studies (Graham, Magee, Hunter, & Atkinson, 2010; McKay, Patel, & Shilliday, 2009), and in 2011 by a study from New Zealand (Slade, Williams, Manning, & Walker, 2011). These results all point to there being a benefit for patients to be treated early by a combined specialist nephrology-diabetes approach in secondary care – however common sense dictates that the number of patients who could benefit from healthcare provided according to this model would be small compared to the total prevalence of DKD in the community, and probably not favourable in terms of population or cost-benefit.

A United Kingdom study provides compelling evidence that intensive, multidisciplinary treatment may delay the need to start dialysis by up to 20 years (Joss et al., 2004), and while other studies have failed to replicate such dramatic outcomes, they nevertheless support the proposal that intensive intervention with a multidisciplinary approach achieves better outcomes than current, conventional treatment (J. Chan et al., 2009; Holman, Paul, Bethel, Matthews, & Neil, 2008; A. Patel et al., 2008). In his editorial review of this evidence, Marshall (2009, p. 1132) states “whether care is provided as primary or secondary care is probably not important. What is vital is that care is delivered by a multidisciplinary team of diabetes specialists that is fully trained and has appropriate skills to provide all aspects of diabetes management.” He goes on to point out that the research shows that factors that contribute to poor care include “clinical inertia, patient and professional reluctance to intensify management, and, on occasion, lack of appropriate tools and knowledge” (2009, p. 1132). This evidence and commentary put forward a view that the design of the healthcare delivery system per se is not the key factor contributing to quality of outcomes, but is underpinned by the two fundamental factors which are labelled in the CCM as decision support and self-management support.

Self-Management Support

People living with mild to moderate CKD must, by virtue of the chronicity of the illness and its complexity become self-managers. (Costantini et al., 2008, p. 148)

A central premise of the CCM is that informed, activated patients working in partnership with prepared, proactive teams of health practitioners will lead to improved outcomes. The successful partnership will exhibit two key characteristics; collaboration between the patient and the HCP, and self-management education (Bodenheimer, Lorig, Holman, & Grumbach, 2002). Bodenheimer and colleagues suggest the latter differs from traditional patient education because rather than imparting technical knowledge and skill, it helps the patient to develop problem-solving and decision-making skills which can be usefully applied to social and emotional, as well as medical problems. Theoretical underpinnings of self-management include self-efficacy – the confidence a person has that they can carry out behaviour necessary to reach an identified goal, and self-determination – the natural human orientation towards health when basic psychological

needs such as autonomy, competence and relatedness are supported (Krichbaum, Aarestad, & Buethe, 2003; G. Williams et al., 2009).

There is a wealth of research giving evidence that improved self-management leads to better diabetes management (Tomky, 2013), and self-management education is well entrenched in clinical guidelines for good diabetes management (Funnell et al., 2011). However, until recently, there was relatively little research dealing with CKD (T. Li et al., 2011). Most studies dealing with this topic are focused on self-management of RRT, such as dialysis and transplantation (Curtin, Mapes, Schatell, & Burrows-Hudson, 2005; Richard, 2005; Tsay, 2003), however in the last five years there has been increased attention in the literature to self-management in the pre-RRT stages of CKD. The quantitative research in this area is primarily concerned with the effect of self-management on clinical indicators of CKD progression such as albuminuria and blood pressure, whereas qualitative studies are interested in patient or HCP perceptions of self-management.

To investigate whether a structured self-management programme could influence clinical outcomes in early CKD, S. Chen et al. (2011) conducted a randomised controlled study to investigate the effects of standardised self-management programme on the number of hospitalisations and change in GFR over a twelve month follow up period. The self-management programme included structured group patient education, peer support, and telephone support, and was provided by a multidisciplinary team mainly comprising nurses, dietitians, pharmacists, and volunteers. The study found a significant reduction in decline of GFR, and significantly fewer hospitalisations in the intervention group compared to the group which received conventional care. In another study with a similar aim, Lin, Tsai, Lin, and Chen (2013) conducted a single group longitudinal study on a group of 33 people in Taiwan with stages 1 to 3 CKD. The intervention was a five week structured self-management programme, where participants attended weekly group sessions, the content of which were based on learning self-regulation activities and processes. Participants were tested before the intervention, and at one, two, and three months after the intervention. While no significant change in GFR was detected in the post-testing, there were significant improvements in self-efficacy over the study period. The study's ability to make statistical inferences was compromised by its small sample and single-group design.

A similar study conducted in the United Kingdom articulated difficulty isolating the 'active ingredient' in self-management support (N. Thomas & Bryar, 2013). This study examined the effect of a structured self-management programme on achievement of blood pressure targets in

primary care. It found that patients who had received self-management support achieved a mean blood pressure that was much closer to recommended targets than those who had not. However, this was not found to be a statistically significant difference, and the authors concluded that this was most likely because the study was underpowered, and that future studies would need to replicate these results with a larger sample. However, the authors noted that 58% of participants in this study achieved target blood pressure, compared to 26% in a national audit, and so concluded that it was likely that the change in blood pressure occurred as a result of the intervention, rather than external influences. Possible reasons for these changes were postulated. Increased concordance with medication (presumably as a result of self-management education and support) was one possible reason; another was more diligent monitoring as an effect of the research and associated awareness among HCPs. Increased confidence to treat patients more aggressively as the study progressed, resulting from increased HCP knowledge, was also a possible reason.

In a quantitative sub-study of the New Zealand study by Walker, Marshall and Polaschek (2013) previously discussed, the authors investigated whether the intervention (a structured self-management programme implemented in primary care by a nephrology Nurse Practitioner in collaboration with a practice nurse) influenced a range of self-management outcomes, measured by a validated assessment of self-management capability. At the end of the twelve month study period, all but two of the twelve self-management indicators had improved, suggesting that a structured self-management programme conducted collaboratively in primary care is an effective way to improve CKD patients' engagement with effective self-management behaviours. A similar study design involving 'coaching' from a specialist nephrology Nurse Practitioner in the Netherlands had previously found that blood pressure, lipids and medication use was improved in a group of patients who had received more intensive attention from the Nurse Practitioner, namely motivational interviewing and coaching for self-efficacy, regarding risk factor modification (van Zuilen et al., 2011). These studies provide evidence that risk factors and self-management capacity can be enhanced by intensive attention from specialist nephrology nurses.

The connection between self-efficacy and self-management in CKD was studied in a cross sectional survey in 2008. In this study, 174 patients with CKD completed questionnaires which measured self-efficacy, physical and mental functioning, and self-management. The study found that self-efficacy correlated more consistently with self-management behaviour than any of the

other demographic or health characteristics (Curtin et al., 2008). Recently a Taiwanese group developed and validated an instrument to measure self-efficacy in CKD patients (Lin et al., 2012). Further local research is required to evaluate whether this could be a useful tool to enhance the implementation of CKD self-management support in the New Zealand primary care setting.

Family support is a feature of instruments designed to measure self-management capacity (Flinders Human Behaviour & Health Research Unit, 2012; Lin, Wu, Wu, Chen, & Chang, 2013), and may be a factor in depression and poor self-reported quality of life for people with CKD (Palmer et al., 2013). Studies have found level of family support has an effect on self-management in other chronic conditions (Denham, Ware, Raffle, & Leach, 2011; Dunbar et al., 2013), but to date there is no published literature examining its effect in CKD. In her evaluation of a self-management package for CKD patients in New Zealand, R. Walker et al. (2013) note that perceived level family support was one of only two self-management domains which were not affected by a self-management intervention. This may have been because family support was already adequate, or may reflect a need for more research to investigate the implications of family support on self-management.

In a qualitative study of people with CKD stages 1 to 3, Constantini et al. (2008) found that patients' experience of self-managing CKD was a process of renegotiating life with CKD, involving iterative stages of firstly learning about kidney disease and its implications, and then integrating this new information into their lifestyle. The study found several barriers to self-management. An important finding was an unmet need for comprehensible disease-specific information that was relevant to the patient's personal context. The absence of signs or symptoms in the early stages of the disease were perceived by participants as an obstacle to accepting that there was any need to manage the disease. Care provided solely by a physician alone was also seen as a barrier, with participants perceiving the physician as 'too busy' or not able to give advice about all aspects of their condition, especially those involving learning to live with the disease. Participants also perceived that clinicians withheld information, especially that which was concerned with prognosis and chronicity. The author speculated that there could be multiple reasons why information might be perceived as being withheld, including reluctance on the part of the clinician to disclose what could be perceived as bad news about the long term nature of the disease. This issue of failure to disclose information to the patient is one which has been the subject of several recent papers, discussed below. These findings are supported by qualitative evidence from a study in

Sydney, Australia that patients desire “early, comprehensive and practical information to enable them to regain a sense of control over their condition” (Lopez-Vargas et al., 2014, p. 241). Other authors have emphasized the importance of contextually relevant, patient-centered knowledge as a cornerstone for effective self-management (Burckhardt, 2005; Pickard & Rogers, 2012; N. Thomas, Bryar, & Makanjuola, 2008). These studies underline the importance of meeting patients’ need for clear and relevant information, shared in the context of a collaborative decision-making partnership with their HCP.

The disclosure of CKD to patients were further investigated by two succeeding studies. In a large observational study, McIntyre et al. (2012) found that 41% of patients with CKD stage 3, were unaware of their diagnosis, even though their general practitioner (GP) had enrolled them in the United Kingdom CKD register. Similar findings have been reported elsewhere (Szczech et al., 2014; Tuot et al., 2013; Waterman, Browne, Waterman, Gladstone, & Hostetter, 2008). Reasons for this unawareness are unclear, but may be linked to factors related to social class or health literacy, HCP knowledge, or discomfort on the part of HCPs discussing the diagnosis or its prognosis. In another qualitative study exploring how United Kingdom primary care teams manage early CKD, GPs and practice nurses who took part in focus group interviews expressed similar anxiety about discussing a CKD diagnosis with patients (Blakeman, Protheroe, Chew-Graham, Rogers, & Kennedy, 2012). This was the predominant theme, and was a relatively new problem, becoming evident only since the compulsory coding of people with evidence of kidney disease on the CKD register. Three tensions arising from this activity emerged from the data. The first was related to HCP anxiety about how and when to discuss the CKD diagnosis with patients, particularly the elderly, or those with mild impairment. Secondly, a reluctance to ‘label’ the patient with the term ‘CKD’ was expressed, with GPs stating that they were concerned it might create panic or undue anxiety, and preferring instead to ‘skim over’ the term. Healthcare practitioners were more likely to ‘lump’ the condition in with discussions about CVD risk and overall wellbeing, thus missing opportunities to point out specific CKD management strategies. Finally, the way in which work was distributed among the primary care team had an influence on whether, or how well, the CKD diagnosis was disclosed to patients, with some practitioners more proactive than others.

In a study with similar design but conducted in the United States, Greer, Crews and Boulware (2012) carried out focus group interviews with primary care physicians and nurses, to

identify their perceived barriers to educating patients about CKD. Six main themes emerged: low priority of CKD for the patient, CKD not being treated as a distinct diagnosis, HCP's inadequate knowledge or skill, fear of overwhelming the patient, insufficient educational resources, and health system limitations including time and funding constraints. The author's concluded that in addition to infrastructural improvements, there was a need for HCPs to recognise CKD as a distinct medical issue in order to appreciate the value of educating patients specifically about CKD management.

To summarise, there is limited research available specifically targeting self-management in CKD, however studies suggest that there is an unmet need for improved disease-specific and relevant information which patients can access easily. Patients with CKD are frequently unaware of their diagnosis, or of self-management practices which may slow disease progression. The reasons for this unawareness are not yet clear, and more research is warranted, but may include issues related to HCPs being unprepared for the task of educating their CKD patients, possibly because of their own lack of knowledge, anxiety, or discomfort with the topic. There is evidence that successful self-management support can improve CKD risk factors as well as patient self-efficacy. Collaboration between specialised renal nurses and primary care may offer opportunities for improving self-management support for patients, as well as enhancing knowledge-sharing among HCPs.

Decision Support

In the CCM, decision support refers to the capacity of the healthcare organisation to assure its clinicians are adequately qualified and skilled to deliver effective and efficient care (Coleman et al., 2009). In the case of primary care, this may mean adequate access to appropriately qualified specialists. The availability of current clinical practice guidelines is crucial for expert decision-making, and HCPs' understanding of, and familiarity with guidelines is also an important aspect of effective decision support. However, simple understanding of the guidelines is not adequate in itself; studies consistently show that in order to improve clinical outcomes, guideline recommendations must be routinely embedded into daily practice (J. Fox, Patkar, Chronakis, & Begent, 2009; Wagner et al., 2001). Computer technology is extensively used to support application of recommended practice, through reminders, alerts, and other applications which help HCPs make more informed decisions about patient management (Bryan & Boren, 2008; Jamal, McKenzie, & Clark, 2009). However deficiencies in care for people with CKD in primary care

are evident (Taal, 2013), and multiple studies have attributed this at least in part to inadequacies in HCP specialty knowledge or attitudes towards CKD management.

Access to specialist expertise is an essential element of adequate decision support for CKD management in primary care. Collaboration between primary care and nephrology and/or diabetes specialists has been proposed as an effective way to address the need for expertise in primary care (Bowman, Kleiner, & Bolton, 2013; Campbell & Bolton, 2011; Dean, 2012; Pellegrino & Schmidt, 2011; Tuot & Powe, 2011; Wright Nunes, 2013). Various collaborative approaches have been the subject of multiple research studies. A meta-analysis of studies examining the effects of interactive communication between primary care and specialists in multiple chronic conditions found that there were clinical benefits from such interaction (Foy et al., 2010). General practitioners and nephrologists have been found to be generally supportive of collaboration, although the exact preferred content of that collaboration differed (Diamantidis et al., 2011). Reports from the United Kingdom and also New Zealand suggest that collaboration between specialist nephrology nurses and primary care can produce promising results (N. Thomas & Loud, 2012; R. Walker et al., 2014). The use of the internet to facilitate consultations between primary care and nephrologists (so-called ‘telenephrology’) has been shown to improve HCP knowledge, meeting the need for immediate expert assistance (Gordon, Fink, & Fischer, 2013; Lee & Forbes, 2009), and has been effectively implemented in Northland to address rural isolation (Sawiers, 2013). Electronic reminders or prompts have been shown to improve decision support in other chronic conditions, but evidence in CKD is scarce and inconclusive (Abdel-Kader et al., 2011; Samal, Linder, Bates, & Wright, 2014).

Another approach to developing expertise within primary care has been the establishment of local practitioners with a special clinical interest, who is mandated by the practice to be the key resource for that specific condition. These roles (termed “resource nurses”, “link nurses”, or champions”) may be performed by nurses or doctors in primary care, and have been promoted as effective in the management of other chronic conditions such as diabetes (Mash, Levitt, Van Vuuren, & Martel, 2008; Peterson et al., 2008; Spollett, 1993), palliative care (Byron, Moriarty, & O'Hara, 2007), asthma (Ragazzi, Keller, Ehrensberger, & Irani, 2011), and wound care (Everitt, 2008). Literature supporting their use in CKD is yet to be produced; it is presumed that as awareness of CKD develops, research examining this approach’s usefulness for CKD management in primary care will be forthcoming.

Practitioners' knowledge about CKD has recently been investigated by a group in the United Kingdom. The Quality Improvement in CKD (QICKD) trial is a multifaceted approach to improving quality in CKD management in primary care. It has included several phases: initially a review of interventions for improving outcomes (Gallagher, de Lusignan, Harris, & Cates, 2010), followed in 2010 by a qualitative diagnostic analysis to elicit the views of GPs and practice nurses regarding the management of CKD. The investigators conducted focus group interviews, and distributed a questionnaire to GPs and practice nurses (Crinson et al., 2010). Thematic analysis of focus group interviews revealed that HCP's attitudes towards CKD management fell into the following main themes: concerns with the usefulness of eGFR as tool for assigning a diagnosis, skepticism about whether CKD should really be considered a disease at all (especially in the elderly), reluctance to pursue what were perceived to be over-complicated medication regimens, uncertainty when to refer to secondary care, the need for more professional education about CKD management, the stigmatising effect of the 'CKD' label, and discomfort explaining the concept of CKD to patients. Overall, the investigators concluded that there were gaps in the knowledge base of practitioners, gaps in their understanding of the benefits of early and aggressive treatment, and doubt about best practice.

The group developed and subsequently validated a questionnaire to evaluate confidence in management of early CKD (Tahir et al., 2014). The questionnaire was aimed at individual GPs and practice nurses, acknowledging findings from the preliminary review that successful interventions were often led by nurses rather than doctors. It uses numeric scales to assess 7 key knowledge areas: hypertension management in CKD, interpretation of eGFR, identifying proteinuria, medications for reducing progression of CKD, CVD risk management, referral to secondary care, and diabetes management. The questionnaire was found to be a valid tool for measuring clinician confidence and knowledge, and the authors recommended it be used to assess CKD knowledge gaps in primary care.

A final study built on the findings from this preliminary work, by testing whether audit-based education for HCPs improved clinical outcomes in CKD (de Lusignan et al., 2013). Audit based education is an educational intervention which uses computer information systems to compare data across organisations against evidence-based guidelines, followed by feedback and action plans. In a meta-analysis it was found to have some merit as an educational intervention in medicine although any theoretical basis for this is unclear (Jamtvedt, Young, Kristoffersen,

O'Brien, & Oxman, 2006). In this study, 93 British primary care practices were randomised to three groups: one group received guidelines and prompts documenting the gap between recommended and actual outcomes (generated from their medical records) sent to them, 32 practices received the guidelines and prompts, along with audit based education to provide peer support and feedback for improvement, and 31 practices continued with usual practice (i.e. no intervention). After a two year study period, it was found that patients in the audit based education group of practices were more likely to achieve reduction in their blood pressure than the other two groups. This group also had a higher proportion of patients who were changed to ACE inhibitor medication from other less appropriate antihypertensive, experienced fewer cardiovascular events, and had lower mortality. The authors note that statistically, the confidence intervals were wide and so the outcomes should be interpreted with caution. However, the implications of this study seem important enough to warrant further research to investigate whether they can be confirmed in other populations, and other aspects of the provision of education in primary care, such as the cost effectiveness, should be evaluated.

Another United Kingdom initiative has responded to deficits in knowledge and confidence in primary care with regard to CKD management. A collaborative quality improvement project was commenced in Greater Manchester in 2009, involving 19 primary care practices, and supported by the National Institute for Health Research Collaboration (Humphreys et al., 2012). Over a twelve month period, four group learning sessions were held, with activities run by local teams in between to apply and test practice changes. Overall improvements were noted by the end of the study period: the number of patients enrolled on the CKD register had increased by 31%, and the percentage of those enrolled patients, with blood pressure within target range had increased from 34% to 74%. Average cost per practice was estimated to have been £20,632. Challenges included variations in the rate of change across the 19 practices (highlighting that complex interventions must be tailored to local needs and characteristics), and some practices struggled to gain engagement from their practice teams, making their efforts much more onerous. While project funding covered some of the costs incurred by practices, financial restraints would be likely to have an impact on any on-going implementation of this kind of intervention. The report noted that feedback from HCPs found the joint learning events to be most valuable, providing opportunities for learning, seeking advice, and gaining motivation for change. While this was a complex undertaking, requiring buy-in at multiple levels of the healthcare system, it demonstrated

that elements of collaborative learning and quality improvement can have positive effects on outcomes in CKD management.

An Italian study examined awareness of GPs about CKD by conducting a survey of 320 GPs over 12 months (Minutolo et al., 2008). Results showed that only 15% of patients with evidence of CKD were correctly coded as such in disease registers. The authors concluded that this suggested low awareness of diagnostic criteria by GPs, however it could also indicate the other barriers that have been found in other studies such as inertia, reluctance to label patients, skepticism about the value of treatment, fear of causing undue anxiety, lack of time for administration, or unclear role responsibilities regarding reporting within the practice team. Two other studies have also looked at awareness about CKD in primary health: the first evaluated a set of variables generated from a survey of 1550 primary care physicians in the United States. Analysis revealed that there was significant variations between physicians' ability to recognise CKD stages 2 to 4, with a 26% reduction in recognition with every ten years of advancing age (Israni, Shea, Joffe, & Feldman). The second study investigated characteristics of primary care practices, rather than individual physicians, in 230 primary care practices in the United Kingdom (N. Walker, Bankart, Brunskill, & Baker, 2011). In a cross sectional analysis of demographic and quality outcomes data, the investigators found that characteristics most often associated with lower rates of disease recognition were socioeconomic deprivation and which primary care trust that the practice belonged to. Training status (meaning whether the practice engaged in medical teaching), patient volumes, and previous concordance with reporting requirements was not associated with variations in rates of reporting of CKD. The authors did not attempt to offer any explanation for these findings, other than to point to evidence in the primary care literature that poor socioeconomic status is also associated with poor health outcomes that may be related to organisation or accessibility and engagement with healthcare providers. The influence of the primary care trust (the equivalent of Primary Health Organisations in New Zealand) suggests there may be an opportunity to influence reporting rates by working with these organisations to promote awareness of CKD and its management. To this author's knowledge, there is no published literature which has examined this aspect of primary care delivery for CKD.

In response to this evidence of poor HCP awareness of CKD and its early management, numerous internet-based tools and resources have become available over the last five years, aiming to increase knowledge and understanding among primary care and other non-nephrology

HCPs. In the United States, the National Kidney Disease Education Programme have developed a series of web-based education modules, with one specifically targeting early identification and management of DKD (National Kidney Disease Education Program, 2014). British Medical Journal Learning offers a similar series of modules, which are endorsed by the New Zealand College of General Practitioners (Cockwell & Arnold, 2014). And in Australia, the Kidney Check Australia Taskforce provides free workshops and online modules specifically targeting HCPs in primary care (Kidney Check Australia Taskforce, 2014).

Research reveals barriers to optimal early CKD management include lack of CKD knowledge among HCPs in primary care, along with attitudes towards the condition which obstruct best practice. Attitudes such as doubt or skepticism about the disease and its management, fear of stigmatising patients by assigning them a CKD label, or discomfort discussing its life-long implications may play a role. Educational interventions in primary care have shown promising results, but have proven to be complex undertakings with multiple challenges and the effects of interventions are difficult to measure.

Clinical Information Systems

It is likely that both provider education and system redesign will be required to fully realize the benefits of new information technologies. (Drawz, Miller, Singh, Watts, & Kern, 2012, p. 6)

Wagner et al. (1996) state that the collection and organisation of patient information is an essential ingredient of the CCM, affording 3 important functions: 1) for comprehensively planning and conducting individual as well as population-based care; 2) for reminder systems to help HCPs attend to patient needs according to guidelines; and 3) for providing feedback to HCPs about their performance and the effectiveness of care. While information systems can be paper-based, electronic technologies offer multiple opportunities not possible with manual systems. There is evidence that electronic health records (EHR) have proved useful in primary care organisations for facilitating the identification and management of CKD in primary care settings (Abdel-Kader et al., 2011; T. Patel, Pogach, & Barth, 2009; Shirazian et al., 2013). We have seen in the previous section that electronic information systems are increasingly used as tools for decision support. Two areas where information systems have had a significant impact on improving renal care are the implementation of disease registers, and the automation of reporting of kidney function.

Disease registers

It is thought that the first modern disease register was Norway's National Leprosy Register set up in 1856 (Newton & Garner, 2002). There are now many hundreds of disease registries operating in different countries around the world (Rankin & Best, 2014). Healthcare can benefit from disease registers in three main areas: patient care (for example enabling risk assessment and monitoring of high risk groups); public health (for example, for surveillance and provision planning, monitoring the burden of disease and the effectiveness of treatments); and research (Newton & Garner, 2002). There are reports in the literature describing the processes for establishing and maintaining various regional CKD registers, and outlining their benefits and limitations (McBride, Dohan, Handley, Powe, & Tuot, 2014; Navaneethan et al., 2011). Two studies highlight that implementation of information systems as part of a quality improvement strategy requires modification of multiple elements of healthcare delivery including system design, funding, education, and collaboration, and that reliance on information technology alone will be inadequate (Drawz et al., 2012; McBride et al., 2014).

National CKD registers are beginning to be established in several countries. In the United Kingdom, the national CKD register was introduced with the CKD Quality Outcomes Framework Indicators in 2006. Data relating to eGFR, albuminuria, blood pressure, and medication, and is collected in primary care. Its impact was evident almost immediately, with 1.9 million people being newly registered as having CKD stages 3 to 5 during 2006 (Radhakrishnan et al., 2014). Two years after its introduction, an analysis showed the number of referrals to secondary care had doubled, and late referrals had reduced by 7% (O'Donoghue, 2009). However a recent study uncovered significant misclassification, with patients either wrongly classified or not classified at all. The authors suggest that this may justify automation of the classification process (based on laboratory reports), rather than relying on manual classification by HCPs (Jain et al., 2014).

The United States CKD Surveillance System (Centers for Disease Control and Prevention) was launched in the United States by the Centres for Disease Control in 2006, and assembles data from 20 different sources, including large healthcare providers and cohort studies such as the National Health and Nutrition Examination Survey. A search of the literature did not find any articles reporting on the impact of this surveillance.

The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) collects data about ESKD in Australia and New Zealand (ANZDATA Registry, 2014). Established in 1975, and

collecting data from every nephrology service in Australasia, it is one of the world's oldest and most comprehensive ESKD registries (Radhakrishnan et al., 2014). However it does not collect any data regarding CKD, and, to the author's best knowledge there is no plan to add this functionality. The only CKD surveillance in Australasia occurs in Queensland, with the CKD Queensland Registry (Queensland Health, 2012). A joint venture between Queensland Health and the University of Queensland's Centre for Chronic Disease, the registry began in 2009 and consolidates data from multiple healthcare organisations into one repository (Venuthurupalli, Hoy, Healy, Salisbury, & Fassett, 2012). Currently in New Zealand, there is no national CKD surveillance system, although the Ministry of Health and National Renal Advisory Board are currently looking at ways in which data may be effectively collected for that purpose (N. Polaschek, personal communication, August 20, 2014). While New Zealand has been at the forefront of innovation in other areas of CKD management, this is an aspect which is lagging behind other jurisdictions, and based on evidence of positive benefits found from CKD registries in other countries as well as long, local experience with the ANZDATA registry, needs urgent attention.

Automated reporting of estimated glomerular filtration rate

Automated reporting of estimated glomerular filtration rate (eGFR) has had a significant impact on early recognition of CKD. The new CKD classification system, introduced in 2002, depended on determining the eGFR in order to define the stage of the disease. Laboratories around the world therefore began automatically reporting eGFR alongside serum creatinine, including New Zealand which was one of the first to implement this innovation (Saleem & Florkowski, 2006). Various studies have investigated whether this change has improved early detection rates in primary care, as measured by the number and timing of referrals to nephrology services. A recent review of 22 studies from five countries concluded that the introduction of automated eGFR reporting has resulted in greater identification of CKD, particularly in the elderly and females (Kagoma et al., 2011). There is no evidence yet that automated reporting of eGFR has improved clinical outcomes, but it seems reasonable to conclude that this use of information systems will help primary care detect the disease earlier.

Conclusion

Kidney disease is a common, harmful, and costly complication of diabetes, with particularly high prevalence and poor outcomes in Māori and Pacific people. If untreated, it can lead to ESKD, requiring dialysis or kidney transplantation to sustain life. If detected early, by

measurement of GFR as an indicator of kidney function, and albuminuria as a marker of kidney damage, treatment can slow, or reverse the progress of the disease. Early treatment aims to control hypertension and glycaemia, and reduce albuminuria, through pharmacologic intervention and lifestyle modification. Evidence-based treatment guidelines based on a prognostic classification system have been widely adopted, yet there is evidence that early detection and treatment is sub-optimal.

Research has explored various strategies to improve early management of DKD. Multidisciplinary health delivery systems utilising collaboration between primary and secondary care, as well as between nephrology and diabetes specialists seem to offer advantages over other systems. There is room for improvement in self-management support practices, with a need for more relevant patient education and a re-shaping of HCP attitudes to increase patients' awareness of their condition and thereby regain control over it. Inadequate knowledge about CKD in primary care, along with feelings of discomfort or anxiety discussing the disease with patients, undermine clinical decision-making in primary care. Educational strategies to address this have shown some promise, and clinical information systems are developing which also strengthen decision support. Finally, the research confirms that the four aspects of optimal chronic care: delivery system design, self-management support, decision support, and information systems, are inter-related and co-dependent. Change in one aspect is likely to have an impact on the other three, and so any interventions to remove barriers to optimal early CKD care should consider the implications on all four aspects as an integrated whole.

CHAPTER THREE - RESEARCH DESIGN

Introduction

This chapter sets out the theoretical and methodological basis for the research undertaken for this thesis. The philosophical basis for the selection of the qualitative descriptive research methodology is explained, and its congruence with this study's context clarified. Methods used for participant recruitment, data collection and analysis are elucidated, followed by an outline of how trustworthiness and rigour were promoted. Finally, steps to address the relevant ethical issues arising from the research are considered.

Research Aim

This research aims to explore the perceptions of patients and primary HCPs about what factors impede early detection and intervention for DKD in the primary care setting.

Research Methodology: Qualitative Description

Qualitative description is a relatively recently-coined term used to describe a commonly-used research methodology which is not wholly committed to any particular theoretical foundation (Annells, 2007). There is a lack of agreement in the literature about how to label this type of research. Various terms have been used, including '*basic qualitative*' (Merriam, 2009), '*interpretive descriptive*' (Smythe, 2012; Thorne, Kirkham, & MacDonald-Emes, 1997), '*generic qualitative*' (Caelli, Ray, & Mill, 2008), and '*fundamental qualitative description*' (Sandelowski, 2010). For the purposes of the following discussion, this methodology will be referred to as simply "qualitative description" (QD).

Unlike other qualitative methodologies that have been embraced by nursing researchers in the last two decades such as phenomenology, grounded theory, and ethnology, QD research is typically characterised by a stance which does not necessarily view the subject matter through the lens of a traditional philosophical position (Chenail, 2011). Often there is no specific theoretical foundation, or alternatively it may draw from multiple theoretical perspectives (Caelli et al., 2008). Purposeful sampling techniques obtain rich information, across a broad range of variations of responses to the phenomenon being studied. Data generation is directed at finding the '*who*',

'*what*', and '*where*' of the phenomenon in question, usually using open-ended, moderately structured interviews amongst individuals or groups. During data analysis, participants' perceptions are summarised, with the assumption that they are closest to the phenomena being studied and are therefore 'expert'; their own words are used with minimal interpretive or explanatory transformation by the researcher (Sandelowski, 2000). Content analysis techniques are usually utilised to extract and sort commonalities or differences among the data, without re-presenting the data in any other terms than their own (Sandelowski, 1995). The product of such research is a straight descriptive summary of the phenomenon viewed through the words or actions of those who understand it best (Neergaard, Olesen, Andersen, & Sondergaard, 2009).

Chenail (2011) describes QD as one of the major useful qualitative methodologies for patient-focussed studies, and defines it as "a type of qualitative research which uses "generic" qualitative methods to produce conceptual categories and themes" (Chenail, 2011, p. 1180). Sandelowski (2000), was among the first to distinguish QD from other qualitative methodologies which are characterised by the use of concepts drawn from theoretical frameworks. She argues that there are three distinct features of this type of research which separate it from other qualitative methods. Firstly, she refutes the notion put forward previously by Thorne et al. (1997) that this is a distinctively new methodology adapted by and for the nursing discipline from grounded theory, phenomenology and ethnography. Instead, she argues that this method has a long tradition in nursing research, but has not until recently been acknowledged in its own right, and is often in fact mis-represented by authors as being one of the other qualitative methodologies. Nor does she agree with other authors that it merely provides a useful starting point from which to develop into one of the other qualitative methodologies. Secondly, she contends that this method is less interpretive, meaning that the researcher is not required to attach meaning to the data, but should instead present the data at 'face value' in order to accurately describe the experience from the participant's viewpoint within the context in which it occurs. Thirdly, she concludes that qualitative descriptive researchers are not required to construe the meaning of the data in order to conceptualise or produce abstract theories, as they are with other qualitative methodologies such as phenomenology or grounded theory (Sandelowski, 2000).

One view is that a slavish allegiance to methodologies derived from the social sciences, such as phenomenology and ground theory, undermines nursing's unique position as an applied

healthcare discipline to make a meaningful and lasting contribution to knowledge about healthcare. Thorne (2011) argues that nursing has reached a professional maturity where it now has a mandate to establish its own research methodology based on epistemological assumptions specifically oriented to the discipline of nursing. Neergarde, Olsen, Andersen and Sondergaard (2009) support this view, and emphasise that by taking care to acknowledge and utilise it accurately, health researchers can promote QD as a valid methodology for nursing research.

Theoretical Positioning

While QD has been described as a methodology that is not necessarily underpinned by any one specific theoretical framework or set of philosophical assumptions (Chenail, 2011; Neergaard et al., 2009; Smythe, 2012; Thorne et al., 1997), this study is underpinned by Sandalowski's (2000) view of QD as being grounded firmly within the naturalist paradigm of inquiry. Sandalowski has described naturalism in this context as "entailing a commitment to studying a phenomenon in a manner as free of artifice as possible in the artifice-laden enterprise known as conducting research" (Sandelowski, 2010, p. 79). Naturalistic inquiry is sometimes cited as meaning simply that research is carried out in the phenomena's natural setting (Chang, Wallis, Tiralongo, & Wang, 2012; Coventry et al., 2012). While this is not untrue, according to Lincoln and Guba in their seminal text on the subject (Lincoln & Guba, 1985), it is a somewhat limited view of the paradigm as a basis for rigorous research. In addition to the aspect of the setting of the study, other important characteristics are evident when one considers the selection of appropriate methods, the theoretical basis for study, the type of knowledge underpinning the study, the instruments used, and the nature of the study design. However, before those matters concerning method and design can be described, a brief discussion regarding the basic assumptions underlying the naturalistic paradigm is warranted.

The naturalist paradigm of inquiry stands in contrast to the traditional rationalist (sometimes termed 'scientific') view of inquiry (Guba & Lincoln, 1982; Lincoln & Guba, 1994; Sechrest, Babcock, & Smith, 1993). In the rationalist paradigm, the researcher views reality as being a single and tangible truth which can be split into discreet fragments and each studied independently of the other. The rationalist would expect that a truth can only be deemed valid if it can be generalised across contexts independent of variables (Creswell, 2009). In order to maintain scientific rigour, the researcher and the subject of the study should be kept apart so that

one cannot influence the other, and inquiry should be guaranteed to be free of influence by the values of the researcher (by virtue of the objectivity of the methodology) (Sechrest et al., 1993).

The naturalist, on the other hand, would propose that there are multiple realities which cannot be split into their component fragments, since each component is dependent upon the other for its existence. The naturalist would expect to develop knowledge which is specific to the individual case being studied, and which should not therefore be generalised to other situations (Guba & Lincoln, 1982). The naturalist would support the view that mutual interaction between the researcher and the 'subject' (especially when the subject is a human) is inevitable, and would argue that events or phenomena occur as a result of a multiplicity of factors which may or may not be interrelated, therefore to observe these factors in action they must be studied in their naturally-occurring context (Lincoln & Guba, 1985). The naturalist view is that inquiry is always value-bound, and that values are influenced from a number of directions, including those of the researcher, the assumptions which underpin the methodology, the methods used, and the social context in which the study occurs (Lincoln & Guba, 1994).

Methodological Congruence

The way in which the researcher thinks about the nature of knowledge and its construction influences the way in which the researcher approaches their research. In his "interactive model" of research design Maxwell (2013), includes the researcher's background, beliefs, education and experience as factors which influence the conceptual framework component of a qualitative study's design. In addition to identifying theories and concepts that have been published about the phenomenon being studied, Maxwell asserts that the researcher's own assumptions, expectations, and beliefs about the phenomenon are important aspects that inevitably position the researcher within a paradigm which influences the methodological design of the study. Furthermore, the integrity of the research may be judged by the congruence between the selected methodology (which is influenced by the researcher's worldview), and the research question, aims, and techniques of data collection and analysis. In good quality research, each of these aspects of the design must be congruent with the others (Morse & Richards, 2002).

As a novice researcher, with 25 years of experience working as a nurse specialist in the secondary care setting with people with diabetes and kidney disease, the researcher approached this study with her own set of assumptions and beliefs, which are set out in Table 1:

Table 1
Researcher's Assumptions and Beliefs

1. Many people with DKD do not receive appropriate treatment in the early stages of the disease but the reasons for this are not known. While there are known estimates of how many people are not receiving appropriate treatment, there is little understanding of *why* people do not receive treatment, *how* they come to be missed by current public health strategies, or *what* factors influence their likelihood to seek and receive treatment
2. The researcher's position as a novice, non-Māori, undertaking a Master's degree, locates this research as an academic enterprise, within Aotearoa New Zealand's dominant post-colonial pakeha context
3. People's perceptions of their health needs are influenced by multiple factors, including their own view of how and where they fit in the world, their previous experience of health and healthcare systems, their expectations, and their belief systems. These perspectives (or 'realities') are interpreted subjectively, and therefore can be presented in different ways
4. People learn new ways of responding to the world around them through social interaction and experience. Thus people also construct their own reality in relation to their health through social interaction. The quality and outcome of interaction with HCPs can have an impact on their view of health and self-management
5. Healthcare practitioners generally want to achieve the best outcomes for their patients; however various factors can interfere with or even undermine attainment of these goals, including healthcare delivery systems and processes, level of knowledge, professional role ambiguities, and the nature of patient interaction
6. This research presents an opportunity for mutual benefit for all parties involved: for patient participants, through increased understanding of their health and self-management; for HCP participants, through the opportunity to learn how to better manage DKD, and for the researcher, to develop greater insight into the complexities of primary care
7. This research will contribute to what is known about *how* and *why* some people do not receive appropriate treatment in the early stages of DKD. As this body of knowledge expands, it may be useful for healthcare policy-makers as well as individual HCPs who are caring for people with DKD

Thus the selection of the QD methodology for this research is entirely congruent with its aims and the researcher's worldview and experience. The following section explains how the study's design and methods fit with this methodology.

Research Method and Design

Participants

This study collected data from patients and primary HCPs from two primary care practices in the Wellington Region. These practices were pragmatically selected because they were seen as ‘typical’ metropolitan medical centres, and pre-existing collaborative relationships with the researcher facilitated the study. After a period of preparatory consultation, where relationships with key staff were built and the purpose of the research explained, and ethical approval was obtained, patients and HCPs were invited to participate in the study. Recruitment took place over a ten week period, with data collection overlapping in the final 4 weeks.

Patient participants:

Patients were purposefully identified through discussions with primary care nurses, aiming to recruit patients who were willing to engage in the research, and who also met the criteria outlined in Table 2. Patients who met any of the criteria in Table 3 were not selected.

Table 2
Patient Selection Criteria

- Diagnosis of T2DM for at least 12 months
- Evidence of kidney disease shown by albuminuria within last 12 months
- Awareness of diabetes and kidney disease diagnoses
- Aged older than 18 years.

Table 3
Patient Non-Selection Criteria

- Diagnosis of kidney disease from cause other than diabetes
- Evidence of CKD later than stage 3 (eGFR < 30)
- Current diagnosis of mental illness or serious mental disability
- Aged under 18
- Not proficient in English language
- Anyone personally known to the researcher

Identified patients were then approached by their Practice Nurse to elicit whether they were prepared to be interviewed for the research. The five patients who agreed were then contacted by the researcher by phone, to explain the research, answer questions, ascertain their willingness to participate, and arrange an interview. One of the five patients interviewed was

male, the rest were female. The average age of participants was 53 years, with a range from 31 to 70 years of age. Three out of the five were of Pacific ethnicity, and two were European New Zealanders. The location of the interview was determined by each patient, and all but one elected to conduct the interview in their homes, with the remaining interview conducted at the hospital diabetes clinic. One participant preferred to have his spouse present for the interview; the others all had family members present in the home but not actively engaged in the interview. Written consent was sought immediately prior to the interview.

The final number of patients who participated was based on practicalities as well as the principles underpinning qualitative sampling approaches. Time constraints, researcher inexperience, patient reluctance to be involved, and workload issues at the practice were logistical issues which precluded the selection of a large group of patient participants. On the positive side, a small number of cases with a range of well-articulated responses is more likely to produce the rich information required to illuminate the research question (Patton, 2002). One of the goals of purposeful sampling in this study was to select a small number of typical patients who were representative of this population in this setting. Deliberately selecting patients, on the basis of the expert knowledge provided by the practice's HCPs as well as the researcher provided confidence that the sample did not contain accidental random variation (Maxwell, 2013).

Healthcare practitioner participants:

Two primary care practices were approached and invited to participate in focus group sessions through advertisements placed at the practice, as well as by personal approaches by the researcher to practice managers, GPs or practice nurses. Groups were mixed in composition – one focus group was relatively small, with three GPs, and four practice nurses, two of whom had a special interest role in diabetes. The other focus group was larger, comprising four GPs, seven practice nurses (one of whom had a special interest diabetes role), a clinical pharmacist and a nurse manager.

Data Collection

Two methods of qualitative data collection were used in combination for this study: individual semi-structured interviews with patients, and focus group interviews with HCPs. While these methods are frequently used in combination for qualitative research, they are more commonly used sequentially to obtain information from the same group of participants, thus

providing a triangulation strategy, than used each on a different group (Lambert & Loiselle, 2008; Morgan & Bottorff, 2010; Murdoch, Poland, & Salter, 2010). However, as used in this study, the combination of these two methods used in parallel on the two different groups of participants offers more opportunity to obtain views about the same topic from different perspectives (Lambert & Loiselle, 2008). With the emphasis on eliciting deep, rich, subjective description from the participant's perspective, these methods are compatible with the naturalistic philosophy behind the QD methodology (Clark, Maben, & Jones, 1996; Freeman, 2006).

Interviews

Semi-structured interviewing is a common form of qualitative data collection (Donalek, 2005; D. Turner, 2010). The purpose of this type of interview is to collect detailed and richly illustrated information from the participant's perspective (Minichiello, Madison, Hays, & Parmenter, 2003). Using a conversational style, relevant data is revealed by the participant. Because it is assumed that what *has* been said will influence what *will* be said, pre-prepared questions should be avoided in favour of a set of broad topic areas that will steer the conversation towards relevant information. The underlying assumption of qualitative interviewing is that the participant is expertly informing the researcher about a topic which the researcher knows little about (Minichiello et al., 2003).

Patient participants were individually interviewed using a semi-structured interview protocol based on the structural stages and process techniques proposed by Rubin and Rubin (2005), and Legard, Keegan and Ward (2003). After establishing rapport, introducing the research, and determining contextual background information, the researcher posed three main questions, each followed up by further probing questions to obtain richer and deeper detail. Each of the main questions addressed one of the three topic areas suggested by the research question, based on the researcher's prior knowledge and understanding of early detection and intervention in DKD. Open-ended, they sought broad descriptions about the component parts of the research topic. Using this broad component approach elicits a wide range of possible responses straight from the participant's experience and perceptions. It also reduces the risk of boxing the participant into a particular response, or restricting the participant to answering questions about what the researcher thinks is important (Rubin & Rubin, 2005). Using a combination of careful listening and sensitive probing, issues which were pertinent to the research topic were then taken up and explored in follow up questioning. Specific techniques were used to elicit meaningful and

rich data, such as avoiding the use of the word “why”, and instead asking for descriptions of experiences, and avoiding asking about opinions, which can limit the depth of information gained (Rubin & Rubin, 2005). Any incidental requests for health information made by the participant were noted and set aside, and were then addressed after data collection for the research had finished. At the end of each interview the researcher checked that there wasn’t any unfinished business before thanking the participant and reiterating how the interview data will contribute to the research, and answering any final questions (Legard et al., 2003). One of the interviews was 90 minutes in duration; the others lasted 60 minutes (see Appendix 1).

Focus groups

The use of focus groups as a qualitative data collection method has increased in popularity over a wide range of disciplines in the last 30 years (Morgan, 1996; Parker & Tritter, 2006), and has latterly become common in nursing research (Clark et al., 1996; McLafferty, 2004). Focus groups allow generation of data about a topic determined by the researcher through purposeful use of group interaction (Morgan, 1996). It is the group interaction element that distinguishes it from other types of group interviews (McLafferty, 2004). To obtain its full benefit, the researcher studies how group members collectively make sense of the topic and construct meanings around it (Doody, Slevin, & Taggart, 2013a). In this way, focus groups are useful for revealing *why* group members think and act as they do, rather than simply *what* they think and do, and it is often the nature of the social interactions among the group which is informative (Barbour, 2005). While often cited as being a cost-effective way to get maximum data from a group of people in a relatively short time (Lambert & Loiselle, 2008; Morgan, 1996; Parker & Tritter, 2006), others caution that it should not be used as an inexpensive alternative to individual interviews and must be analysed for the group interaction rather than individual input from participants (Barbour, 2005; St John, 2003).

The focus group method was selected for this study as a pragmatic way to obtain rich data from the HCP participants while maintaining the group context. The selection of this method recognised the collegial nature of primary care practice, acknowledging the influence that individuals have on the group dynamic. Participants were invited to attend two focus group sessions which were held during a pre-existing weekly group meeting time at each practice. The venue and time were chosen to enable maximum attendance and minimal disruption to work schedules. One focus group was held in each of the practices, with seven and 20 participants in

each group, respectively. Doody et al (2013a) recommends that while groups can range from between four and 12 participants, it is important for the size to be workable within the complexity of the topic, experience of the moderator, and depth of information sought. For the second focus group in this study, the number of expected participants was unknown until the time of the meeting, and it would have been impractical and discourteous to exclude some of them. In the end, nine of the total number actually contributed to the discussion. Morgan (1996) suggests that ideally there should be four to six focus groups to achieve saturation of information, however in this study more than two would have been unfeasible given practical constraints such as time and workload. The sessions were one hour in duration, most of which time was spent exploring the topic rather than in introductions and ice-breakers, since participants already knew each other and felt comfortable divulging information within the group.

A discussion guide was prepared before the sessions. Using a semi-structured approach, the guide included eight open-ended questions designed to stimulate discussion, while encouraging a natural progression from the general to the specific (Doody, Slevin, & Taggart, 2013b). Within the structure of the discussion guide, there was room for the moderator to probe for more detail as seemed appropriate at the time (see Appendix 2).

An independent facilitator, experienced in focus group moderation, conducted the sessions. The role and skills of the moderator are crucial for collecting rich and useful data from focus groups (Clark et al., 1996; Doody et al., 2013b; Morgan, 1996; St John, 2003). Prior to the sessions, the moderator prepared for the focus groups by familiarising with the research topic and the participants. During the sessions, the moderator began by introducing herself and the topic (no participant introductions were unnecessary since they already were familiar with each other) before progressing on to the questions in the discussion guide. Moderator involvement was kept as much as possible to a minimum, allowing participants maximum opportunity to express their interests (Morgan, 1996), intervening only where necessary to ensure that all participants were given an opportunity to contribute, and occasionally to focus the conversation back to the topic.

Individual and focus group interviews were recorded using a portable digital recorder (Fernandez & Griffiths, 2007). A copy was made of each recording and stored in a locked cupboard until it was destroyed at the end of the study. Each recording was transcribed verbatim by the researcher into a written record of each interview. Care was taken to include non-verbal content such as pauses, facial expressions, and gestures, as these essential elements of the

conversation add crucial meaning and add to the accuracy of the interpretation during analysis (Sandelowski, 1994; Wellard & McKenna, 2001). Supplementary notes were made during each interview by the researcher, and these were used to aid the transcribing of this non-verbal content, including contextual and environmental influences. Each recording was reviewed once more by the researcher following transcription, to ensure that nothing had been overlooked and any previously unnoticed features could be recorded (Wellard & McKenna, 2001).

Data Analysis

Qualitative content analysis is widely used and accepted as the analytic method of choice in QD studies (Sandelowski, 2000). Developing out of quantitative research traditions in the 20th century, this method of analysing textual or visual data has moved away from simple quantification of words or phrases towards the classification of large amounts of verbal communication into chunks of information with common themes, patterns, or content in order to identify core meanings (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005; Patton, 2002). It is concerned with developing increased understanding of a particular phenomenon by learning through the eyes of those experiencing it (Vaismoradi, Turunen, & Bondas, 2013), and is therefore congruent with this study's aim to make sense of why some people in the early stages of DKD do not receive appropriate treatment, by listening to the experience of people with DKD as well as those treating them.

The aim of content analysis is to reduce a volume of data in verbal or textual form into smaller groups of categorised concepts in order to make sense of it. There is some discussion in the literature about variations in how qualitative content analysis may be conducted (Braun & Clarke, 2006; Hsieh & Shannon, 2005; Vaismoradi et al., 2013); the model of content analysis informed by Patton (2002) and Graneheim and Lundman (2004) has been adopted for the analysis of data in this research. Patton's model includes the identification of themes as a component of content analysis, and distinguishes between *patterns* and *themes* in the data. A pattern becomes evident where participants describe experiencing similar events or occurrences, whereas identification of a theme makes the underlying belief, feeling, or idea apparent. An example of a pattern from the context of this study could be that all participants said they understood that the presence of protein in their urine was a sign that diabetes was affecting their kidneys. The underlying theme here could be termed "understanding of DKD".

Graneheim and Lundman (2004) characterise qualitative content analysis as focusing on the participant's perspective, elucidating differences as well as similarities, and as dealing with "manifest" (what the text says) as well as "latent" (what the text means) content. These characteristics are congruent with naturalistic foundations of QD as a research methodology.

An inductive process of content analysis, as described by Elo and Kyngas (2008) has been employed for this study. Inductive inquiry discovers the patterns and themes as they emerge from the data, as opposed to deductive inquiry, where patterns and themes (theories) that are already known are applied to the data. While a deductive approach is useful when a body of knowledge about the study topic already exists, an inductive approach is suited to topics about which little is already known (Braun & Clarke, 2006). In this study, there has been little research exploring why or how some people are not treated appropriately in the early stages of DKD, and therefore an inductive approach is appropriate.

Elo and Kyngas (2008) describe three stages in the process of content analysis. During the first stage ("Preparation"), the researcher reads and re-reads the data to become immersed and completely familiar with its content. During this stage, the researcher will select a "unit of analysis" (Elo & Kyngäs, 2008, p. 109), the choice of which depends on the research aim and question, and the nature of the data. Graneheim and Lundman term this as a "meaning unit" and consider it as "words, sentences, or paragraphs containing aspects related to each other through their content and context" (Graneheim & Lundman, 2004, p. 106). The next stage involves organising the data into patterns or themes, and then progressively grouping them into categories based on similarity. In this research, a unit of analysis, for example, was words or phrases to do with interpretation of health information. "He broke everything down to the point where I could understand it"; "I find it hard getting information from her"; "looking up information on the internet" and "they tell me I've got blood sugar" are examples of this unit of analysis. These examples were eventually all grouped into a single theme of "Making sense of health information". Participants were then coded to maintain anonymity, using letters and numbers. Patient participants were coded as 'P' followed by a sequentially assigned numeral: P1, P2 and so on. Healthcare practitioner participants were given letter coding related to their role (see Table 4), followed by a sequential number and another letter to denote which focus group they were in. For example, GP1A denotes the first GP to speak, from focus group A. The final stage of content

analysis is the detailed and accurate reporting of the process and results of the analysis, so that its rigour and trustworthiness can be scrutinised.

Table 4
Letter Coding System for HCPs

GP	General practitioner
PN	Practice nurse
DPN	Practice nurse with diabetes role
CP	Clinical pharmacist
NM	Nurse manager

Rigour and Trustworthiness

This research has been designed with the requirement in mind to establish its authenticity and trustworthiness. Lincoln and Guba (2000) illuminate the paradigmatic controversies apparent in the concept of qualitative research validity, stating the case for the use of an entirely different set of criteria for judging the validity of qualitative versus quantitative research.

The concept of trustworthiness in qualitative research was proposed and developed by several authors during the 1980s and 1990s when the debate between the worth of qualitative versus quantitative research seems to have been at its highest (Guba, 1981; Guba & Lincoln, 1982; Lincoln & Guba, 1994, 2000; Sandelowski, 1986, 1993; Sechrest et al., 1993). Out of that debate, a general agreement has developed that while qualitative research has a mandate to produce findings with the same degree of validity and methodological rigour as its quantitative counterparts, the traditional criteria used to assess the worthiness of quantitative research are either irrelevant, or not applicable in the qualitative paradigm (Cutcliffe & McKenna, 1999; Krefting, 1991; Maxwell, 2002; Morse, Barrett, Mayan, Olson, & Spiers, 2002; Tobin & Begley, 2004). There is some disagreement about whether concepts or terms such as *reliability* and *validity* can or should be borrowed from the quantitative paradigm to describe the quality of qualitative research (Morse et al., 2002; Rolfe, 2006; Sandelowski, 1993; Tobin & Begley, 2004). However, regardless of this historical and on-going debate, there is universal acknowledgement that all research must be subject to assessment of its rigour in order to evaluate its merit (Ignacio

& Taylor, 2013; Krefting, 1991; Lincoln & Guba, 2000; Maxwell, 2002; Morse et al., 2002; Morse & Richards, 2002; Patton, 2002).

Various models have been proposed for the conceptualisation and assessment of the trustworthiness of qualitative research (Altheide & Johnson, 1994; Cohen & Crabtree, 2008; Lincoln, 1995; Maxwell, 2013; Sandelowski, 1986, 1993; Tracy, 2010; Whittemore, Chase, & Mandle, 2001). This study has utilised the model proposed by Guba (1981) and subsequently expanded by Lincoln and Guba (1985, 2000) which, three decades on, is well articulated and continues to be frequently cited by qualitative nursing researchers (Bradway et al., 2012; Kalb, O'Conner-Von, Schipper, Watkins, & Yetter, 2012; Krefting, 1991; Weimand, Sällström, Hall-Lord, & Hedelin, 2013; Whittemore et al., 2001). This model is based on four aspects of trustworthiness: *credibility*, *transferability*, *dependability*, and *confirmability* (Lincoln & Guba, 1985, 2000).

Credibility refers to whether the research adequately and accurately represents the multiple realities revealed by the participants. In this study, credibility was addressed in three ways. During interviews, selected questions were reframed to ensure the same respondent gave the same answer consistently (Tobin & Begley, 2004). Triangulation, where data is collected from multiple sources and then compared to ensure consistency, was used to compare data collected from each set of participants (Maxwell, 2013; Sandelowski, 1993). Finally, a series of member checks were carried out: participants were asked to check transcripts of interviews to ensure that they were accurate reflections of what was intended, and impartial peer checking was conducted by the researcher's supervisor, who checked data analysis, encouraged reflexivity, and critiqued the design and methods (Krefting, 1991).

Transferability is the degree to which the findings of a study can be applied to contexts that are outside, yet similar, to the study conditions. In this research, the data has been deliberately described in enough detail to enable the reader to assess the transferability of the findings.

Dependability is concerned with minimising the degree to which data, or decisions about data analysis, change over time (Graneheim & Lundman, 2004). The short timeframe afforded for data analysis was advantageous for dependability, and checking by the researcher's supervisor highlighted potential issues where dependability was threatened. Data collection and analysis

processes were carefully documented into an auditable format, and subsequently followed, as suggested by Tobin and Begley to enhance dependability (2004).

Confirmability refers to the research findings being derived objectively from the data, rather than through the researcher's interpretation. Throughout the project, the researcher's own assumptions and beliefs were challenged at each stage, ensuring a high degree of reflexivity which supports confirmability of the findings.

Ethical Considerations

An application for ethics approval was made to the Massey University Human Ethics Committee, and approval was granted on 5 November 2013 (reference number 13/69) (Appendices 3 and 4).

Patton's Ethical Issues Checklist (2002, p. 408) has been used as a basis to structure the examination of this study's ethical issues.

Explaining Purpose

Maxwell notes that any research project, no matter how beneficent its intentions, is always an intrusion for the participants to some extent, and that a primary ethical obligation is to understand how the participants view the researcher's actions. The process of learning how participants perceive the researcher and the research then becomes an opportunity to develop ethically appropriate relationships with participants (Maxwell, 2013).

Selected patients were initially approached by their usual Practice Nurse if they were prepared to be interviewed for the research. Those who agreed were then visited by the researcher for a meeting to discuss the purposes of the research and the nature of participation. Questions were encouraged. Written information was left for the patient to consider. That visit was followed by a phone call from the researcher to answer any questions and ascertain willingness to participate.

The researcher used the study's preliminary consultation phase to build up rapport and establish trusting working relationships within the practices in order to ensure that HCPs understood the purpose of the research and did not feel professionally threatened by it. The researcher shared information about treatment recommendations for DKD in general and the

aims/benefits of this research in particular. Potential barriers to recruitment were identified and mitigated during this phase. Consultation preceded participant recruitment, and was ongoing throughout the study. A mutual positive benefit was derived through the opportunity to share knowledge and expertise between the HCPs and the researcher.

Reciprocity

The researcher's self-awareness of what he or she brings to the relationship with participants can negatively influence the research project if not adequately explored and understood (Maxwell, 2013). To mitigate this, the researcher explored her own assumptions and purposes in the project's early stages to become more aware of these issues and deal with them prior to involvement with participants (see Table 1, p. 51).

The researcher approached participants with an alertness for issues of misunderstanding about the purposes of the research or the nature of their involvement. It was made clear that participation was entirely voluntary, with no expectation of compensation for participants' time and inconvenience (Appendices 5 and 6). With this in mind, interviews and focus groups were conducted with every effort to reduce inconvenience to participants.

It was acknowledged that any healthcare issues which participants identified during interviews as needing to be addressed would be brought to the attention of their healthcare team. Written and verbal information explained the relationship between the researcher and the participants, and made it clear that the research is part of Master's study and is not related professionally with the researcher's employment.

Participants were given the opportunity to review and/or keep a copy of their transcript as acknowledgement of their ownership of their story. The research findings were communicated to patient participants in easy-to-understand language, including any recommendations relating to their personal healthcare.

Participating HCPs were sent a summary of the research findings. During the research period HCPs reported professional benefit from information-sharing with the researcher.

Risk to Participants and Researcher

During risk assessment, it was recognised that there was potential for patient participants to feel that either they or their HCPs carried the blame for their kidney disease. To avoid this risk, the researcher emphasised in verbal and written information that DKD is a common disease which is at least theoretically preventable to some extent, and that the purpose of this study is to find ways to increase the implementation of that knowledge in practice.

The potential for HCPs to feel their expertise being threatened was identified as a risk. New information about CKD management offered by the researcher could carry the implication that primary care professionals were lacking in knowledge. This would have negative consequences for participation in the study, and would also potentially threaten their relationship with their patients by feelings of blame and mistrust. By acknowledging this risk openly at the start of the study, the researcher was able to incorporate early efforts to reduce it. Strenuous efforts were made at the beginning of the project to build strong, collaborative working/learning relationships with practices based on mutual professional trust. Written and verbal information emphasised this research as addressing the prevalence statistics of diagnosis and treatment of early DKD. In addition, the researcher worked with practices to identify and accept practice limitations as well as celebrate the special expertise of the primary healthcare team. The research has benefited from the expert knowledge and advice given by the primary healthcare team.

Self-risks identified by the researcher included lack of confidence with primary healthcare as well as research due to inexperience, which could lead to personal loss of self-esteem, and potentially threaten the study's validity. To deal with this, the researcher identified and disclosed her inexperience to participants, but also recognised that she offered different areas of expertise for the benefit of participants.

Confidentiality and Anonymity

Participants were assured of confidentiality on at least three occasions: verbally when seeking participation, in written information given out prior to participation, and in the consent form obtained immediately prior to interviews. Participants were reminded that their anonymity to the researcher could not be obtained; however their data would not be available to their healthcare team or any other individuals or organisations. Any participants who were personally

known to the researcher were excluded from the study. The researcher signed a confidentiality agreement with each participant.

Participant names were not used during data collection, with data identified solely by the use of labels ('A', 'B' etc). The key explaining which label belongs to which patient was kept secure and separate from the data by the researcher for the duration of the study and destroyed at the end of the data collection period. Maintaining anonymity of each primary care practice was challenging, due to issues such as geographical location, relatively small population base and other features which could identify the practice to anyone with any experience in the local primary care field. While patient participants' identity was protected by their small number in comparison to the practice's total number of patients, there was a risk in particular to the HCPs working in those practices. These risks were disclosed during the preparatory stages of the study. Particular attention was paid to ensuring on-going of anonymity of patient participants, and where possible, HCPs, after the study was completed and during reporting of the findings.

Recordings and transcripts were kept securely with access only available to the researcher and her supervisor. Consent forms were kept secure and separate from the data. At the end of the study, data was securely archived before destruction according to University protocols.

Informed Consent

Care was taken to ensure full disclosure of information to participants throughout the research process. Verbal and written information provided to potential participants during the recruitment process assured them the right to ask questions prior to or during the study, as well as to withdraw from the study at any stage prior to data analysis. Written informed consent was obtained prior to commencing data collection, which included a summary of the rights of participants and responsibilities of the researcher.

Māori Participation

A discussion of Māori epistemological and ontological research principles is outside of the scope of this paper; however as the conduct and findings of this study involve, and have implications for Māori; its ethical reasoning as regards Māori must be considered. The underlying principles of qualitative inquiry sit well with traditional kaupapa Māori, defined by Royal (2012, p. 30) as "values and plans of action decided by Māori (emphasis upon who decides what the values

and action plans should be), ... which express a set of deeper cultural values and world view (emphasis upon ... traditional knowledge — mātauranga Māori)". In particular, the central Māori concept of interdependent relationships between the individual, the immediate group, wider society and the spiritual element is reflected in QD's notions of multiple truths, and the role of the researcher as a participant. Additionally, methods such as interviewing and discussion fit well with the traditionally oral basis of Māori knowledge and interaction (Cunningham, 2000). However, the researcher is very clear that as a non-Māori novice researcher, this research is not kaupapa Māori research, and therefore the study's findings in terms of their benefits, representation, legitimacy, and validity are addressed in terms of the researchers' own cultural agendas, concerns, and interests (Bishop, 2005; S. Walker, Eketone, & Gibbs, 2006). The researcher acknowledges that the research topic, in terms of Māori health, has come about as a product of the history of colonisation (Mahuika, 2008). However, given the significance of the research problem for Māori health, it is essential that the findings be meaningful to Māori.

During the consultation phase the researcher focussed specifically on learning ways in which Māori can be optimally involved and engaged in the research process. The researcher undertook training in the application of tikanga Māori in the context of health research, and guidelines provided by the Health Research Council regarding health research involving Māori were studied (Māori Health Committee, 2010). Advice and approval for the research was sought from the Capital and Coast District Health Board Research Advisory Group – Māori (see Appendix 5). It is hoped that this study may provide insights into how qualitative nursing research can complement kaupapa Māori research, for mutual benefit and without compromise or misappropriation of tikanga principles.

Conclusion

The aim of this research was to explore the perceptions of patients and primary HCPs about what factors enable or impede early detection of, and appropriate intervention for DKD in the primary care setting. To achieve this aim, the design used a QD methodology, founded on a naturalistic inquiry paradigm. Individual interviews with patients, and focus group interviews with primary HCPs were the data collection methods used. Data was analysed using a method of qualitative content analysis to elucidate patterns and themes from the interviews. Techniques such as question reframing, triangulation, member checking, and auditing, were incorporated into the design to enhance credibility, dependability and confirmability, and thus promote

trustworthiness of the findings. Measures were implemented to attend to the ethical matters considered relevant to this study, which included explanation of purpose, reciprocity, risk, confidentiality, informed consent, and Māori participation.

CHAPTER FOUR – HEALTH PROFESSIONALS’ PERSPECTIVES

Introduction

Four main themes were identified through analysis of the data from two HCP focus groups. These themes were: knowledge of best practice, screening and recall, models of primary care delivery, and factors which affect engagement with healthcare services. Three of these themes have been divided further into sub-themes, set out in the diagram below. The following discussion will show how and where these themes were evident in the data generated by the HCP focus groups.

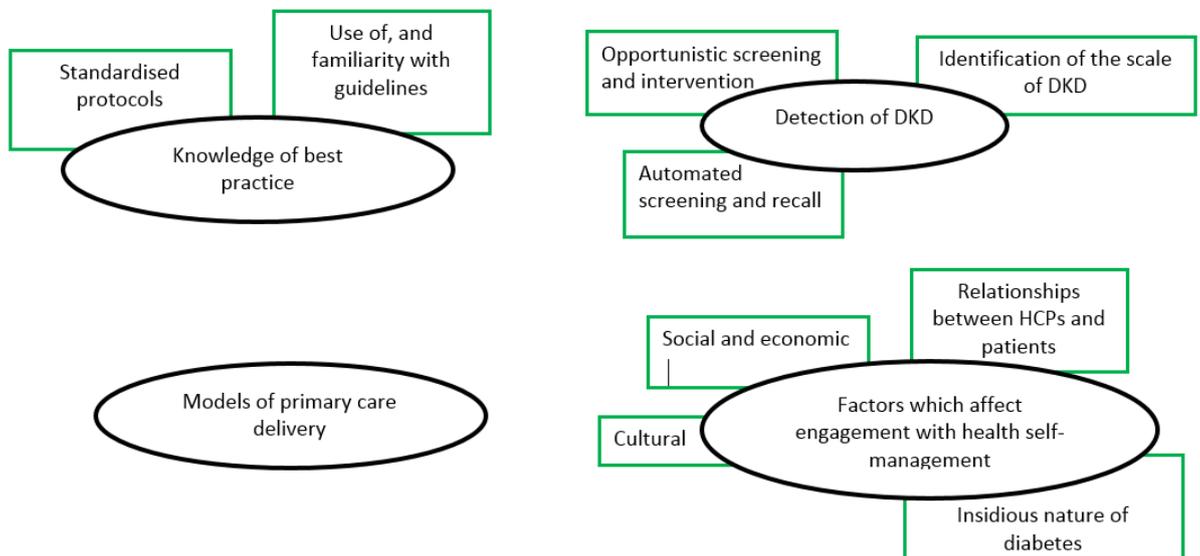


Figure 4: Themes and sub-themes evident after analysis of data from focus groups

Theme One - Knowledge of Best Practice

Understanding of DKD and how to identify and manage it were topics that arose frequently in both focus groups. Participants’ comments revealed varying levels of familiarity with best practice guidelines and in some cases, uncertainty about their application in clinical practice. These sub themes are discussed in the following section.

Use of, and Familiarity with Best Practice Guidelines

“... give them ACE, straight away... as soon as microalbuminuria...” (GP1B)

Familiarity with, and understanding of, best practice clinical guidelines came up in both focus groups. Members of both groups made comments which showed they were aware of such guidelines, as demonstrated by one respondent's comment; “and if [microalbuminuria is] positive then they go on an ACE inhibitor and you monitor their blood pressure and their creatinine and ... make sure it's not deteriorating” (GP3A). While these comments demonstrated general awareness of guidelines, others showed varying degrees of familiarity with them. In one case, when asked by the moderator which guideline she had been quoting, the speaker replied “I guess whatever, you know, what's on hand, but both...” (DPNA).

In both groups there was evidence of uncertainty about interpretation of the detail of guidelines, although there was a good grasp of general principles. This uncertainty was in terms of how DKD should be identified, as well as how the stage of the disease should be classified and documented. One GP asked how we were classifying the disease for the purposes of the interview: “How do you classify renal? Is that from microalbuminuria onwards?” (GP3B). Another GP stated:

I have no idea when to start labelling things 'Chronic Kidney Disease'. If they've got a positive microalbuminuria then you should be doing it, but, you know... it's not clearly defined anywhere that I can work out, you know, so, I think from our point of view, we're monitoring people and making sure they're stable, and if they've got some protein in their urine then we're doubly checking their blood pressure and their creatinine and that sort of thing. (GP3A)

General practitioners in one focus group recognised that they do not necessarily classify a patient's stage of DKD according to the guidelines.

One thing I did think about before I came into this meeting, [is] us doctors being better at actually classifying it, you know, as the different stages, depending on the GFR or the microalbuminuria. (GP1A)

We could label that as diabetic kidney disease, and we could be doing that better than we are. (GP3A)

Feelings of discomfort were expressed about using the label “Chronic Renal Failure”, demonstrating misunderstanding that this label has been removed from guidelines for exactly the same reasons:

You know, the problem with the label Chronic Renal Failure is that it's quite a big deal label which doesn't... really have a lot of meaning in terms of how you would manage somebody... because with the new criteria lots of people get labelled chronic renal failure. (GP3A)

But I wouldn't put a 'Chronic Renal Failure' label in for somebody... without... really thinking it through and talking to them about that, because it's kind of a label that doesn't necessarily add that much and it can be a real negative for people. (GP3A)

Another comment showed uncertainty about how or whether to classify a patient's disease which is successfully regressing due to early and appropriate treatment:

And the other thing about the microalbumin is that we have quite a lot of people where it reverses... it's virtually back to normal, but they've had it in the past ... it might have started at 13 or something and it's down to 2, or 1... they should probably have the label, but clinically it's not always an issue. (GP3A)

This comment showed a misunderstanding of the purpose of the classifications associated with CKD, as discussed earlier. While most comments demonstrated a good grasp of general principles of current best practice for DKD intervention and treatment, there was evidence of areas of uncertainty or misunderstanding which suggests some need for revision or reinforcement of key concepts associated with practice guidelines. This could include strengthening of understanding of expected minimum standards of care.

Standardised Protocols

“I think standardising and saying here is a baseline to work from is really important.” (GP1B)

Both focus groups commented that they had developed standardised care or treatment plans for people with diabetes in their practice, based on recommended guidelines, and the protocols from both practices included blood testing at regular intervals for people with diabetes to screen for developing kidney disease. Staff from one practice described how they had formalized these protocols into a booklet:

All the doctors got together about three or four years ago and just standardised the blood tests and urine tests we were doing and that went into a little green book which everyone's got. It's a little green book everyone carries around with them, so that's just standardised. So there's a list of bloods that we do including ... microalbuminuria and HbA1c. (GP1B)

The need and benefit of these standardised treatment plans was well understood and readily explained in terms of ensuring consistency in a busy Practice with a large staff, so that “everyone does the same thing rather than different people doing different things” (GP2B). Also there was benefit in terms of the high numbers of people at risk of DKD, so protocols ensured widespread application of best practice, regardless of individual staff members' expertise.

Theme Two – Detection of Diabetic Kidney Disease

While there was universal acceptance of the benefit of early detection of DKD, comments in both focus groups indicated that clinical processes to enable consistently earlier detection were variable in their efficacy, and that general awareness of the scale of the problem was sub optimal.

Identification of Patients with Diabetic Kidney Disease

Healthcare practitioners in both groups were able to immediately quote the number of patients with diabetes in their practice; however neither group was able to quantify those with DKD on-the-spot. There was a general acceptance that they are very busy screening for this subset, and there were dedicated diabetes nurses in both groups. In one case, there was an interchange between HCPs to come to a consensus:

Moderator: So how many of those 420 [with diabetes] do you think might have renal disease?

GP1B: Fifty per cent maybe.

GP2B: I would say more than 50 per cent.

GP3B: Around 65.

GP1B: Sixty-five and climbing [Laughs]

In theory, identification of people with DKD through routine urinalysis should be reasonably straightforward, yet neither Practice could accurately quantify the numbers during the focus groups. It was unclear whether this was simply because of unfamiliarity with this cohort, or whether it reflected a general unawareness about the importance of early identification.

Automated Screening and Recall

“Well, they have a proteinuria done every annual review.” (GP3A)

Both focus groups described their use of Practice-wide systems and processes to ensure that patients are screened and recalled according to recommended guidelines. Methods included either manual or computerised routines for monitoring results from blood tests. Both focus groups relied heavily on computerized systems to automatically trigger reminders or flags for screening and recall activities. An example is a trigger system based on a patient’s age and ethnicity which alerts the nurse or doctor that the patients should be screened for diabetes if they are “...35 for Pacific and Māori and South East Asians; 45 other groups especially the healthy population...” (GP3B).

There were numerous comments reflecting the extensive use of computers as helpful tools to remind practitioners of various recall activities: “when a patient is due for a cardiovascular assessment; up comes the red light...” (PN1B); “that's within the system - within our patient management system, it’s just a process where you can set recall.... you can set them recurring...” (GP1A). Computers were also used by both practices to generate lists of patients who met high-risk criteria for DKD, such as elevated HbA1c or albuminuria, so they could be recalled for further intervention:

Once every three months [the Diabetes Specialist] comes, and so we do a query builder of all our patients with a HbA1c over 64 and then I go around all the doctors and we sit down and we discuss their list of people and we talk about what the management plan is, and how we're going to follow it up or whether we're going to discuss it at the meeting, yeah, so people get picked up there too.

(DPN1A)

This comment also reflects the human intervention element that was evident in screening or recall activities in both practices. While computerised systems sped up the identification of certain at-risk groups, comments showed that a significant amount of activity was then undertaken by the practitioners themselves. In the example above, this involved discussion and consultation between practitioners, and other examples involve communication with patients to remind them to attend the practice for follow up. Many of the comments made reference to the amount of effort and time these activities required. Some were fairly straightforward: “We routinely recall people...and if they don't present then we follow that up by letter or phone.” (DPN1A), while others showed the extent of negotiation and skilled communication required.

...so we become experts in being undercover investigators in all these areas - seriously, haven't we? And so we know when to be a little bit more aggressive with this patient and this patient we know to just back off and let them do whatever... (PN3B)

So ... I get a message and I will follow that up and I will keep following that up until they finally show up [laughs]. [Everyone laughs]. It can be quite time consuming, but eventually most of them do, yeah, even if they get a bit annoyed with us [laughs]. (DPN2A)

Planned screening and recall activities were clearly identified as important aspects of DKD management, consuming a significant amount of resource in terms of infrastructure and staff. However, both focus groups also emphasised the importance of unplanned, opportunistic screening.

Opportunistic Screening and Intervention

“... a lot of our work here ends up being opportunistic.” (GP1B)

This theme was a common feature of both group discussions. General practitioners and nurses consistently agreed that opportunistic screening and intervention made up a significant part of their work in diabetes generally. There was consensus that automatic screening systems do not adequately identify all people with DKD, since they rely on patients to actively engage in screening practices, which is not always the case: “Mostly it's through the opportunistic screening” (GP2B). The discussions above about the amount of time required to follow up patients following automatic triggering for screening highlighted this problem.

There were generally two groups of patients for whom opportunistic screening was required: those who had forgotten or overlooked screening requests (often due to busy lives with other priorities) but who engaged happily when reminded; and those who were difficult to engage despite many attempts. The latter group will be discussed under the theme of barriers to intervention, while the former group generated a lot of discussion in both groups:

And people find that really easy, I've done that twice this morning, [laughs], microalbumins, just to say 'look, I, you know, you need it', you know, for whatever reason it hasn't been done, and there'll be some good reasons, so I just said 'look if it's helpful we can just send it off now, this morning', and they just said 'great', so... I've sent two off this morning in that manner. (DPN1A)

People come in acutely and then I can see that they haven't been seen for ages – ‘wait a minute, let's talk about your diabetes’... (GP1A)

The sentiments expressed in these comments were mirrored when discussing the need to spend more time to explore more than simply the acute issue that the patient presents with. This highlighted shortcomings in the current care delivery model, and is discussed as a separate theme below.

Theme Three – Models of Primary Care Delivery

“...the model is absolutely insane...” (GP1B)

A discussion in one of the groups about the inadequacies of the current primary care model for meeting the needs of people with chronic conditions was initiated and led by one particular GP, with general assent from the nurses and GPs present. It was felt that the usual fifteen minute appointment time was insufficient to adequately address all of the issues that people with chronic disease face, and that patients “don't want to come to a GP practice and sit there and tell someone their problems or whatever in 15 minutes” (PN6). One GP commented: “we've got a fatally flawed model. I mean 15 minute appointments are a joke” (GP1B).

If you've got 15 minutes to be opportunistic as well as a problem that's in front of you... if we had half hour appointments for instance I think we'd be a lot more effective... I don't know whether people agree, but it seems to me a lot of what we deal with is compromised by the time constraints we've got often with people.
(GP1B)

As well as the difficulties of working within the allocated 15 minute time slot, there was unanimous agreement that repeated visits for frequent reviews are unrealistic: “every time they come back it takes three hours out of their day and if they're working and haven't got much money it's just a disaster” (GP1B). This statement summed up the frustrations of working with patients to manage long term conditions in the current model: “Sitting with these fifteen minute appointments, with a list of patients to see a mile long... it doesn't work at all” (GP1B). Alternative models were debated, each with their own drawbacks. “Maybe the model that we use is wrong. Maybe we should do it a different way” (PN6B).

Community and church-based delivery of health services seemed promising: “That's where things should be happening” (GP1B), but a model based on a ‘drop-in’ system was quickly discounted as a previous attempt had been “a disaster because everything was acute. There was no continuity in anything” (GP1B). More intensive intervention for those at high risk (an approach which has received some attention in recent literature) was regarded as simply more of the same flawed approach, pointlessly creating “more visits to the doctor and the clinic – waste of time” (GP3B). In the end, the exchange finished with a sense of disheartenment “I don't know what the

answer is to be honest. I'm not sure 100 per cent. I still haven't worked it out" (GP1B), and the conversation moved on.

Theme Four – Factors Which Affect Engagement with Health Self-Management

Factors which prevented or interfered with optimal self-management were specifically sought during both focus groups, and were elucidated by HCPs in some depth. This was the most common theme in both focus groups. Participants' frustration was evident and in some instances expressed helplessness or even hopelessness that there would ever be a solution to some of these issues.

Social and Economic Factors

"...money is a big issue for them." (GP2B) "...the whole focus has gone somewhere else, so health drops right down the list." (GP1B)

Both focus groups pinpointed the cost of attending appointments and obtaining medications as an obstacle to optimal care. It was evident that practitioners were aware of this issue with numerous comments such as "a prescription of five dollars is actually a lot of money for people" (PN1A), and "they choose which [medication]... maybe these two, my Warfarin and my insulin... because they haven't got the money..." (PN1B). Other comments from HCPs showed that they tried wherever possible to minimize costs: "we've got one of our people on PHO funded prescriptions⁷ because of that very reason; she can't afford it" (GP3A).

They prefer to use money more for other things, for family rather than medications and if it is for diabetes and they will just get only the one they want but leave the rest of the medications with the pharmacist. (DPNB)

One participant noted that some patients attend free hospital clinics in preference to primary care because of their cost, leading to inconsistency and disintegrated care:

I've seen several patients... who used the ED and the hospital and not the GP practice that they were enrolled in. So they go to the renal unit for their kidney

⁷ Situations where funding for prescription costs has been specially negotiated between the practice and the Primary Health Organisation (PHO).

failure and that's not talking to the diabetic unit, so each one is sort of independently unaware of what the other part of the hospital's actually doing. So you know, people can fall through the cracks like that too so it is a problem. (CPB)

However, while the cost of primary care and prescriptions was seen as an obvious barrier, there was general agreement that it was just one of many inter-related social factors which were difficult to conceptualise, but which had major impacts on patients' ability to effectively manage their health:

[Diabetes is] the least of their problems, isn't it, well as far as they see it, anyway... they're busy at work? Or it's not a priority, or they're sitting at home on the computer and won't leave the house... sick kids to look after, or... a family member is unwell and their health takes priority. (GP1A)

Priorities were mentioned numerous times by both GPs and nurses: "health is not their priority. There are other social things going on in their life" (PN2B); "the social factors are major, so, we're not the top of their priority list, they'll just get by day-to-day, no worrying about diabetic kidney disease, like that's the least of their priorities" (PN1A).

Healthcare practitioners from both practices made comments recognising that health is prioritised differently according to what else is going on in people's lives, so the same patient might manage their health differently at different times depending on other social influences:

It's often hard for us to see clearly those reasons and you try and make them understand their own health but in their life sphere at that time then, it's not something that's a priority. (GP1A)

I've noticed a lot of the diabetes; it typically goes up and down like that. When they're ... getting on top of it, the HbA1c's are coming down which is fine. And then you'll see them six months later and it's back up where it was. Invariably there's a whole lot of social issues that have happened, like the house has changed or their son or daughter's been in police thing - the whole focus has gone somewhere else, so health drops right down the list because there are a whole lot of other factors. I see it as a bit of a see-saw with a lot of people. (GP1B)

Some HCPs accepted that this is to be expected as a normal part of everyday life, especially for people with chronic disease: “It is problem for the people... and as everybody said we just have to grab them and test them opportunistically” (GP3A). A more common feature was frustration at what they perceived as a lack of self-efficacy in some patients. A sense of bafflement was expressed by some HCPs that they could neither understand nor control how patients prioritised and managed their health: “We are trying to do our best, but it's so difficult because what is beyond our walls here... is quite difficult”, “unless the patient is one of those patients that doesn't want to come in but they're a whole different kettle of fish anyway” (GP3B).

They don't take the insulin... and they've had their disease described to them by doctors and nurses and even me. And I see them in six months' time and... their HbA1c is through the roof. Why do people do that? It's got to be something to do with their society and their social environment. (CPB)

Sometimes they come in with so much that you actually never, you know, you do your best but there are times when you don't get to engage what it is that we want to. (DPN1A)

So it's not that we're not doing the tests or tracking the kidneys or anything. It's actually a whole lot of other factors that come into play in a practice like this, which is actually very difficult in a low socio economic area. (GP1A)

These comments indicated that the challenges of managing a chronic illness within a busy and changing lifestyle, as well as healthcare costs were influential forces affecting how patients engaged with healthcare services. The next sub-theme explores the effects of cultural influence on that engagement.

Cultural Factors

“They've always been brought up that way and sometimes you just can't interfere with that... So it's very community oriented and we only really reach to the doctors when we're at the end of the street...” (PN3B)

Of the two focus groups, one explored cultural issues in some depth, while the other didn't at all. This probably reflects the different cultural make-up of each practice's patient

population. One discussion explored a generalisation that Pacific patients didn't seem to engage in self-management practices effectively. The discussion was led by Pacific nurses, one of whom succinctly presented the fundamental differences in belief systems about health that creates discord about self-management. Differences in beliefs about 'prevention' of illness, family and community involvement in health management, and the importance of a collective approach to health maintenance were put forward as issues influencing how Pacific people respond to advice given by healthcare practitioners about managing their diabetes. Because of this discord, a solution to a health problem put forward by doctors may not make sense within the Pacific health belief context, and therefore will not be followed. So, it was argued, by weighing up the options and choosing the option that follows a path which is familiar and makes sense in their worldview, these patients are in fact exercising self-efficacy. It is only from the HCPs' perspective that this behaviour appears to be irresponsible and even negligent.

[Prevention] is not a common practice in most Pacific Islands. It's not a service provided by their governments as well so yeah, we don't get that at all. So preventative cares is - falls on your own traditional way of caring for your own people, mainly the younger looking after the older and the old caring for the new families... they all respect the doctor encouraging them with medication and so on and so forth. But there's also the other belief that [they] don't always have to rely on medication. They've always been brought up that way and sometimes you just can't interfere with that... So it's very community oriented and we only really reach to the doctors when we're at the end of the street... Sometimes, with the perspective that we have as nurses, I have to put that away and just talk to them as a daughter or just as a normal person out there in the community. I don't always have to put on my nursing hat when I'm with them... it's how we develop a trustworthy sort of relationship. (PN3B)

The church was seen as an important opportunity to influence lifestyle behaviours in Pacific communities, with some nurses already involved in initiatives such as an exercise programme run by the church. When asked by the moderator why she thought the exercise programme was so well attended, the nurse replied that it was "because it doesn't cost anything... but also because it's... done by the church." (DPNB)

Insidious Nature of the Disease

“... diabetes doesn't make them feel unwell specifically, so... easy for them to ignore.” (GP2B)

Healthcare practitioners noted how difficult it can be to convince patients that they should follow the prescribed treatment for diabetes and DKD. There are no outward signs of disease or illness to signal the development of DKD: “patients feel that they're well” (NMB). The presence of microscopic amounts of protein in the urine (unnoticeable to the patient) is the indication that treatment with additional daily medication should begin. This is on top of a pre-existing medication regimen for diabetes. The diabetes itself does not make the patient feel unwell, but the medication prescribed for it often does, especially if it causes hypoglycaemia.

For diabetes, if you swallow a tablet... there is no benefit, because ... your HbA1c is the same whether you take the tablet or whether you don't, you know? And if you do take some of the tablets you finish up with a hypo and that they recognise, so that is something to stay away from. (CPB)

Healthcare practitioners acknowledged that they cannot promise that the treatment will make their patients feel any better (they feel fine anyway); they can only cite empiric science to try to convince patients that they may benefit some long way in the future. When faced with a treatment which causes inconvenience, unpleasant side effects, extra expense, is possibly at variance with one's own health beliefs and worldview, and has no immediate gain, it is easier to understand why patients may choose to ignore it at worst, or at best to only adhere to it when convenient.

Relationships between Healthcare Practitioners and Patients

“... I think [if] people don't engage with their health provider, they won't come back.” (GP1B)

Healthcare practitioners didn't specifically raise the nature of their relationship with patients as a factor which influenced the course of disease or treatment. However, they did discuss specific interventions which, to be successful, implicitly relied on a solid foundation of trust

and respect. Healthcare practitioners from one Practice described how discussing recent blood results and their significance was a positive motivator for some patients to make changes to their lifestyle. Nurses explained the importance of reviewing blood results with patients because “it gives them an evidence base. [They say] ‘well this is what I’m doing and it’s working’” (DPN2A); and “they are interested in their results and they like to return and see how they’ve done” (DPN1A). While these nurses did not explicitly categorise these interactions as a product of the relationship they had with these patients, it seems reasonable to assume that this kind of interchange could not be effective if that relationship were not existing. Some of the nurses made comments which showed their respect and admiration for those patients who did manage to incorporate their complex disease management into busy lifestyles: “A lot of people... get their diagnosis of diabetes and they go... ‘I’m going to get this under control’ and they do. There’s a lot of people that get stuff sorted out” (DPN2A).

Relationship-building was also alluded to when discussing two systemic factors which impacted on their ability to build effective therapeutic relationships. Staff turnover was raised by a nurse who was aware that she (as a new nurse) had to work harder with patients to build trust that the more established nurses she observed working around her: “frequent turn-over of staff, that, I’d say that’s a major contributing factor to [late presentation and non-adherence]” (PN3A). Her comment showed her implicit understanding that a trusting partnership-type relationship with patients improves outcomes. She was also making the point that in where there is high staff turnover, there will always be a proportion of newer staff who are learning their role, who may not yet have acquired understanding and expertise about the importance of early detection and treatment of DKD. In these circumstances, opportunities to screen or intervene early may be missed. The group expressed widespread agreement that this is an inherent problem in situations of frequent staff turnover.

The other systemic factor which was reported to have a negative effect on HCPs’ ability to build effective relationships with patients was the fifteen minute appointment time which has already been discussed within the theme of the primary care model.

Conclusion

The focus groups revealed four key themes concerning early detection and management of DKD. While the existence of clinical guidelines was recognised, there was evidence of areas of uncertainty of their application in practice. Overall, there was low awareness of the scale of the DKD problem within the practice population, and although computerised automation tools were acknowledged to be helpful for screening, they generated significant amounts of follow up work for HCPs. Despite these tools, HCPs explained that a number of cases were identified opportunistically rather than through any planned screening programme, and these cases were often inadequately addressed because of logistical issues related to the design of primary care model, which was seen as incompatible with optimal management of chronic conditions such as diabetes and its complications. Finally, multiple factors which influence self-management behaviour were identified. These include social, economic and cultural factors, as well as the insidiousness of diabetes, and most importantly, the nature of the relationship between HCPs and patients.

CHAPTER FIVE – PATIENTS’ PERSPECTIVES

Introduction

Two main themes were extracted from the data generated by patient participant interviews. These were the factors which influenced where health was positioned within their lifestyle, and the factors which motivated participants to change the priority of that position. Within each theme were subthemes which are outlined in green in the diagram below, and will be discussed in the following section.

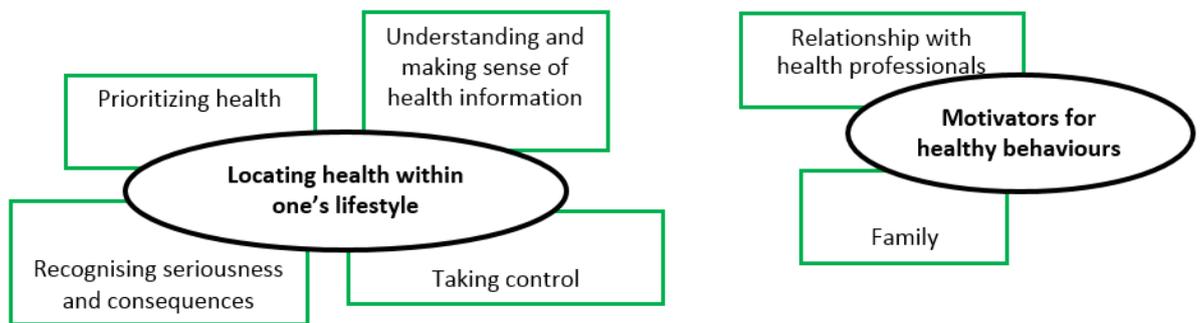


Figure 5: Themes and sub-themes evident after analysis of data from interviews

Theme One – Locating Health within One’s Lifestyle.

All participants described aspects of the difficulty of living with diabetes and its consequences. They described how other aspects of lifestyle such as family, employment, and the church competed with health in terms of importance, and how health was frequently re-prioritised in order to satisfy those competing interests. The level of understanding about diabetes, and its seriousness and consequences had an impact on how health was prioritised. The need to take control of the condition was commonly expressed. A discussion of each of these sub themes follows.

Understanding and Making Sense of Health Information

"...I think there's a lot of information out there, and you know I just don't think a lot of people are really getting the message." (P1)

All participants were able to describe in one way or another their understanding of DKD and its treatments. The presence of proteinuria was universally recognised as a sign that their diabetes was affecting their kidneys. "Protein leakage" was a term used by all the participants to describe the manifestation of the disease process, and all of them credited this understanding as coming from either their GP or practice nurse. One participant said that he got information from "a mixture of GP and looking up on the internet..." (P2), and added that he thought some information from the internet could be "a bit dodgy" (P2).

Although they had a clear idea that proteinuria was a sign of diabetic kidney complications, knowledge gaps or misinformation were evident in four participants' comments. "I don't know whether [the kidney damage has] got any worse or not" (P5); "I don't know if I am type 2 or type 1" (P3); "isn't metformin taken by the type 1 and type 2?" (P3); and "I thought insulin is worse than having tablets" (P3). Three participants asked directly for more information about treatment for the condition; "I don't know whether I can ...prevent it getting...is there anything that can help to protect [the kidneys]?" (P5); "...you kind of hope it goes away by itself but it looks like it's not going to happen. I'd be interested if you could tell me a bit more about that" (P2); and "I don't really know much about how the medication - whether it works long term... I need to find out about that..." (P1).

Importantly, participants' comments showed that they understood that their kidneys had been affected by the diabetes. Where there were knowledge gaps, these were mostly inconsequential – pieces of information that in practical terms are not important for effective self-management practices. However, these comments did indicate that one crucial message had not been comprehensively understood: that something can be done in the early stages of DKD to slow or reverse the progression of the disease. This represents an important area of self-management education which did not seem to have been adequately addressed in the case of these participants. Had they been aware that their lifestyle choices can affect the rate of progression of the disease, they may have made different choices.

One participant explored how she made sense of the information she received from primary care nurses and doctors. She discussed how she took more in from some (HCPs) than others. She had found one HCP in particular whom she thought was better at giving her the information she needed because “he broke everything down, to the point where I could retain that information in my head” (P1), whereas another had the opposite effect, because “she kept going on and on to the point where I just got so bored, I didn't want to listen to her anymore, and I refused to see her, I didn't want her coming over, because it was the same old thing” (P1). She also described a language barrier she had experienced with one particular nurse, which arose out of the nurse’s assumption that she would understand a Pacific language better than English:

...but I kind of find it hard getting information from her only because I think English is her second language, and so, because I do have Samoan blood in me, she kind of speaks to me in, you know, that language. And I can understand some of it but not all of it, and I don't have the heart to say to her "Can you please just tell me, give me that information all in English because I don't understand you properly!! [Laughs]. (P1)

This participant made an important observation about how she builds up her understanding of her health by saying: “I take in what I already know” (P1). When asked to elaborate, she explained that she has a bank of knowledge about her health and in particular her diabetes, and anything she hears from HCPs which fits in with that bank of knowledge is the information she ‘takes in’ first. For any new information that does not fit with something she already knows, she will do some research on to understand it better: “with the new information that I've just found out, I'll do a little bit of research on it, and it's what they have said is what's out there” (P1). Another participant echoed this notion in reference to information from the internet: “most of the better stuff just confirms what they've told me at the clinic” (P2). This process of ‘making sense’ of health information incrementally builds up a body of knowledge which can then be used to make choices about how to manage one’s health. It also shows a degree of discernment about selecting which knowledge to focus on – only taking in what one believes to be true, based on what one already knows. Therefore information which is provided by HCPs without contextual reference to what is already known, is unlikely to be retained or accommodated.

Another important point noted by this participant was that she sometimes feels confused because information is presented to her by different HCPs in different ways, so that in the end she has to do her own research to make sense of it:

...the doctor will explain what diabetes is, and the things that he's mentioning to me I already know, so that's OK, I've still got that in my head, but the information that's new to me; I believe the doctor, you know, he knows what he's talking about, but I will still - because the nurse is telling me something which is probably the same, but in a different way, so I get a bit confused as to who's - which one is actually right. And so I'll just go and do a little bit of research then and just "Yeah, they're both right but, I like the information I got from this person versus that person. (P1)

This was the only participant who explicitly critiqued the way in which health information was presented to her. All the other participants universally praised their HCPs for their care and attention. The question arises as to whether the communication difficulties experienced by P1 were also experienced by the other participants. It is possible that the knowledge gaps exhibited by the other participants may be related to similar difficulties.

One final important observation made by P1 was in relation to written health information provided in the form of pamphlets in English as well as other languages. She made the point that although there is a lot of written information available in a variety of places, she doesn't notice this written information being taken up and used, and observes people around her who are in denial about their condition.

...I could be sitting in the room with some Islander people, or Asians, whatever, and there's information there and sometimes they do have pamphlets in other languages, but people would just - because they got so many other things on their mind, they're worried about why they're there at the doctors and whatever's going on and they have, like, severe, like their diabetes is out of control, and there's all this information there but they're not utilising it ...I felt like I was like in that position before I learnt what diabetes was, and had a proper insight about it. Yeah, I think there's a lot of information out there, and you know I just don't think a lot of people are really getting the message, and then they don't take it seriously

until they've been told like me ...you notice that no one's really taking those pamphlets home, just curious people, or people who want to know a little bit more, but, I just feel like the people are not really understanding it too well. (P1)

This participant articulated her strong feeling that in order to take in the information that they need to be better self-managers, people with DKD must first take the condition seriously. In her experience, written information did not grab the attention in the same way that an interaction with a HCP who explained the seriousness and consequences could.

In summary, participants understood that their kidneys were being affected by diabetes, but they did not realise that they could affect the progress and outcomes of that by modifying their health behaviour. The relevance and usefulness of health information from HCPs was generally seen as variable, depending on the individual style of communication and the nature of their relationship with that HCP. The way in which HCPs impart health information is an important factor on how well that information is assimilated by patients, and may influence the degree of importance the patient places on health compared to other competing aspects of life. The level of seriousness assigned to one's health affects the priority it assumes within the lifestyle.

Taking it Seriously

"...I know that if I'm not going to take this seriously... why bother doing anything about my diabetes. You know, I'm just going to go downhill..." (P1)

Four out of the five participants spoke of DKD as a "serious" complication of diabetes, and explained its seriousness in terms of its consequences: "if I do not start on that medication it's going to get worse, and I'll eventually end up on the dialysis" (P1); "an early warning sign that there could be kidney failure on the way"(P2); "I was kind of scared of it affecting my kidneys [because] my dad was in dialysis"(P3); "I knew that ... when it gets bad you have to have dialysis" (P4). They also expressed a common feeling of shock when they were told of the kidney involvement, summed up by P1 in this comment: "I didn't expect to hear that, it was a shock for me to learn that I've got protein leaking out of my kidneys... I never thought it would get to that stage, so it was a bit of a surprise" (P1). Two participants explained that the discovery of kidney disease for them was a "wake up call" (P1), indicating that they saw this development as a sign

that they needed to pay additional, or renewed attention to their health; “kind of like a shift from denial to 'maybe I'd better take this a bit more seriously'” (P2).

I had a really good think about it, and I decided that it's time for me to get on track and do something about it. Especially now that there's a bit of protein leaking in my kidneys, I've got to take it seriously. (P1)

One participant expressed a sense of regret and guilt about not having taken it more seriously earlier. She talked about having “neglected” her health, feeling “responsible” for having developed proteinuria:

...had I taken my medications in the past like she told me to, I may not have the protein, you know, I wouldn't be in this position right now, but because I left it for so long, and my diabetes got much worse, I might have to go on insulin. (P1)

The participants who expressed their ‘shock’ to learn that they were developing this ‘serious’ complication expanded this into a new theme about reprioritization of health within their lifestyle as a way to deal with this progression.

Reprioritising Health

“...whether it's worth it - drinking, you know, having fun, is that worth more than seeing my children grow up...” (P1)

In taking the disease and its self-management more seriously, three participants made the point that they had re-prioritised their health in relation to other aspects of their life. One explained how her health had slipped down her priority list while she was studying: “and then while I was studying, I couldn't manage my diabetes... I just felt like I couldn't maintain my health and study at the same time.” (P1). Another described how her own health had been a lower priority to her than that of her spouse: “you focus on the... other person's needs rather than your own really. Your own needs... come last...” (P5). Both of these participants went on to describe how the discovery of proteinuria had challenged them to reprioritize their health, and their comments implied a sense of satisfaction that they are now managing their health more successfully as a result. “I thought no, this time it's going to be about me” (P5).

I'm mellowed out now; I don't have that stress I used to have before where I didn't have time for myself. I've got more time for myself and the doctor... I've got a busy life, but I can still manage to take my medications. I never forget to take my medications, not like before, you know with all that stress. I couldn't cope - it was like I didn't have time to take those meds... I'm actually putting my medications before - it's a priority now. I think I took my schoolwork - that was my priority at the time, but right now it's my health. My kids and my health. (P1)

Meanwhile another participant explained that his invalid wife's health took priority over his own, and while he acknowledged that reprioritizing his own health in relation to his wife's was probably necessary, his comments showed this was something he was not yet ready to consider.

One thing that has changed in the last couple of years is that [my wife] had a stroke, so I'm not getting out walking as much as I used to, and I kind of miss getting exercise a bit, and that's one of the main things that I could [do to] help get fit... the main [barrier to self-managing health better] is making sure that [my wife's] comfortable with what I'm going and doing. (P2)

Adherence to medication was an indicator of where health was positioned in relation to other aspects of lifestyle. Two participants openly explained how difficult they found taking diabetes medications reliably long term. One explained how "when I felt like I was really going downhill, then I'll start taking it for a week and then I feel better and then I'm not taking it anymore. It was on and off" (P1). Another described how her busy lifestyle resulted in her forgetting to take the tablets:

Mostly I'm missing my tablets. My metformin, sometime I miss it. Because I have to take it in the morning and at night, so if I forgot in the morning then I take it in the afternoon so then I forget sometimes at night - just busy. But I have to eat food with it and I'm not really a morning breakfast person. I'm up early and then run out the door. (P3)

Another participant said she had no difficulty at all remembering to take her tablets. She placed great importance on taking her medications regularly, and so had worked out a method of dispensing all her medications for the day into a container which she carried with her to make sure she would not forget them. The same participant expressed frustration that other people seemed

to have difficulty fitting their medications into their lifestyle, indicating to her they weren't taking their health seriously enough, and gave it too low a priority:

Maybe they don't even think about it ...some people, I don't know why, some of our people too, when they travel they forget about their tablets and I said to my family "Oh I don't know why these people forget", but that is their life, if they can't carry them around, well something will happen, they will just drop there and die. (P4)

Together, these comments indicate that participants had a notion of the importance of their health within the context of the rest of their lifestyle. Those who had made a decision to reprioritise their health were implicitly making a stand to establish or regain more control over their health.

Taking Control

"You can't expect people to be coming to you all the time and telling you what to ...do. You've just got to take the bull by the horns and get on with it really."
(P5)

Self-determination was a common theme running through the interviews. As discussed above, participants expressed varying stages and methods of exercising control (or not) over their health. None of the participants expressed any sentiments that suggested they believed that anyone else should be responsible for their health, in fact their comments showed their desire to take full responsibility: "I want to stay on top of my health" (P1); "I've got to take responsibility for my own health" (P2); "the doctors only to give me the treatment and for me, I have to look after myself" (P3); and "you've got to do it yourself, you know, you've got to want to do it yourself" (P5). In the case of two participants, this 'taking control' was manifested by setting rules about healthy food choices, which impacted on the whole family:

I'll change the way of the food I eat... I know I try and keep my family away from the fizzy drinks. I know chocolate, ice cream, not really in my house most of the time. I only buy it sometimes. Not every day. But the fizzy drinks, they can go and buy their own fizzy drinks. (P3)

I just want to do my own food. I never rely on them to cook for me. So I just tell them to do your own cooking. Do your own food, I'll come and fix my own food to eat. Because they know that I'm just being very careful with my diabetes. (P4)

Three participants talked about the importance of one's attitude towards self-management. The point was that knowledge and understanding of the condition alone is not adequate: "it's the attitude, it's the attitude as well, so it's not only that they don't understand, like, they do have an understanding, some understanding, anyway, but it's the attitude as well" (P1); "you've got to get on with life and I think if you have a good attitude about yourself, I think it plays a big part really" (P5). One participant explained in reference to her father: "He knows all that, but he's stubborn, and chooses - we choose what we want to do and sometimes I think he just can't be bothered." The concept that one can choose how to manage one's health is an important element of self-determination. One participant articulated the internal dialogue she had with herself while choosing to regain control:

Oh my god, what am I going to do about this, am I going to try and cut down on my drinking, give it up, just change the lifestyle that I'm living, or am I going to just feel depressed and go and get me a six-pack or something and drink. (P1)

This statement showed that while she understood she had to take control and do something 'about this', she was also acknowledging that it was not going to be an easy road to follow, and that although the alternative would be easier, it would be associated with feeling 'depressed' and so was an even less attractive option. This participant had already explained that the discovery of proteinuria had made her think about her long term future, and she had realised that if she didn't make a change, she may not live to see her children grow up. This raises the second common theme evident in the interviews; that of motivators for change.

Theme Two – Motivators for Change

Participants' comments indicate that they are all at different stages along the process of changing their health behaviours. One participant in particular had moved through the process to achieve health behaviour change, so during the interview she and the interviewer were interested in exploring this further. Therefore her thoughtful insights are the predominate voice in this theme. Factors which acted as motivators toward change fell into two categories: relationships in families and loved-ones, and relationships with HCPs.

Relationships with Families and Loved-Ones

"I've got to deal with this otherwise I won't be around to see my grandchildren or my children grow up." (P1)

Two participants cited their relationship with family members as their main motivation to maintain their health; in particular their children and spouses; "we've got to remind ourselves, you know, you want to be around, I want to be around, we love each other, so you gotta do the right thing by taking your medications" (P2). One participant (P1) repeated on several different occasions that she wanted to be around to see my grandchildren", "see my kids [grow up]." Both participants felt a sense of responsibility for their loved ones – P1 as a parent of small children, and P2 as a carer for his wife with a chronic condition. Perhaps not surprisingly, their concern was mainly about who would care for their loved ones if they were gone, and this reflected the seriousness with which they were treating their health issues.

Relationships with Healthcare Practitioners

"...I think it's knowing that the doctor really does care about me..." (P1)

Three participants discussed aspects of their relationship with their HCP which were relevant to their level of motivation to adhere to healthy behaviours. Broadly, these aspects fell into two contrasting categories: feeling obligated to follow advice because that is what is expected contrasted with a climate of mutual respect and trust which influences behaviour through a sense of partnership. Two participants made comments indicating a belief that adherence behaviour comes from a sense of obligation due to external expectations, rather than any internalised sense of compulsion. They described how their doctor offered advice, and they followed it, because both parties believed this is what is generally expected; they are acting out the roles they believe to be the norm in this type of relationship. When asked what the doctor could do to encourage adherence to medication, for example, one participant stated: "only to give me more advice. I know they have to do that. They have to tell us what to do, to take tablets... I think I have to follow those treatments. Since my last visit to the doctor I took my tablets every day" (P3). However, this statement contradicts a previous comment ("mostly I'm missing my tablets" P3), and so underscores the limitation of this approach: her motivation is high soon after seeing her

doctor, but diminishes as time passes before her next visit. While both participants suggested system or process-based interventions such as blister packed medications and text reminders about appointments might help adherence, neither referred to their relationship with their HCP at any time in the interview, and made no reference to it influencing their likelihood to adhere to treatment.

Another perspective came from two other participants, who spoke of a deeper relationship with their HCP. In their cases, adherence behaviour was an outcome of a sense of belonging to, and having invested in, a partnership with their HCP which was based on mutual trust and respect. A sense that their HCP genuinely cared about their welfare was central to this construct; "I knew that [my doctor] really does care, that's how I could just really sense that she really does care; she's worried" (P1). In this case, the relationship had been built over two generations of her family, so she felt an even greater sense of belonging in a partnership:

She was also Mum's doctor as well and Mum died of a heart attack, and she was the one who was dealing with Mum at the time; she doesn't want to see me go down that road. So she's just really worried and concerned. (P1)

'Support' was a term used by two of the participants when referring to this relationship, and they expressed a notion that they were receiving that support as a 'gift' from their HCP, rather than as a standard part of treatment. Their comments conveyed their sense of gratitude that the HCP was going beyond the purely professional relationship to offer something more personal: "the support that I've been given, and shown by the doctor and the nurse..." (P1); "...I think just knowing that support [from my doctor and nurse] is there, that network, is good..." (P5); "Just to know that they're there to help you... I've just always found... them to be a great support..." (P5). Thus there is a sense that the participants saw the support offered by their HCP as coming from a genuine sense of caring about their welfare.

One participant in particular expanded on the caring nature of the relationship with her HCP in more depth. She explained that her doctor was sometimes "... a little bit hard on me. She's always telling me off...", yet because this approach came from a position of genuine care and concern, she found this tactic helpful as a motivator, rather than being offended or repelled by it. She believed "she's just being real, she's just open... and what she said to me was right: stop wasting her time, you know. So that's another thing that kind of motivated me to attend these

appointments" (P1). By contrast, she found a similar approach from another HCP with whom she had no prior relationship to be unhelpful:

I was too scared to go back to her because she's the type who would tell you how you would ...um..., she doesn't realise that what she's saying to me is actually - she's giving me that information in a scary - that's scaring me. (P1)

Similarly, she found the more 'gentle' approach from her nurse unhelpful also:

The nurse is telling me a lot of good things as well, advice, but the way she gives me the information is not as - it's like a discipline kind of thing - she's too soft; the way she says it, like 'ohhh, you know you're OK'; the doctor's saying 'YOU ARE NOT OK! This is NOT OK!' And then you've got the nurse saying 'you're going to be OK. As long as you do this, change that and then it's going to be OK'. And I'm like ohh - I'm not really going to listen to you because what you're saying it doesn't really make me feel ... like I can't discipline myself if you're going to keep making things so easy for me. (P1)

This participant had insight into the fact that the difference in outcome was related to the nature of the relationship rather than the HCP's approach per se: "It's got to be someone that you trust, someone that you've known for a very long time, that just really pushes you and just tells you how it is. I reckon that would change a lot of people's attitudes" (P1). She went on to apply this idea to her father's case, suggesting that he would also be more motivated towards healthy behaviour if "there was someone there to push him and motivate him and talk to him the way that the doctor spoke to me that day"; "it's not until they get that real hard talk, you know; "You're going to die if you don't do this". That's when they take action..." (P1).

Thus, participants described two main sources of motivation to adhere to treatment: their desire to stay well so they could look after their family, and also their sense of obligation to their HCP to look after themselves. This latter source of motivation came from either an externally generated idea about what was expected or a more internally driven feeling of commitment to a partnership based on mutual trust and respect.

Conclusion

Two main themes were evident after content analysis of the data. These were positioning health within one's lifestyle, and motivators for changing the priority of that position. Within each of those themes, there were several sub-themes. The position of health compared to other aspects of lifestyle is influenced by the level of seriousness assigned to specific health behaviour and risk, which in turn is affected by the how patients make sense of health information, largely influenced by the way in which that information has been imparted by the HCP. Reprioritisation of health often occurred after learning of the degree of seriousness the condition or its consequences posed, and often led to a desire to regain control over the condition. Motivators which helped change the level of priority include concern about who would look after family members (specifically children or spouse) if they were unable to do so, and a feeling of obligation to their HCP to keep themselves well. This motivating factor was stronger if the relationship with their HCP was built on mutual trust and respect, with the patient feeling that their HCP came to the partnership with a genuine sense of caring for the patient.

CHAPTER SIX - DISCUSSION

Introduction

The findings of this study have identified various factors which may impede early detection of, and intervention for, DKD in the Primary Care setting. The combined themes that were extracted from both datasets fall broadly into two categories: provider-oriented themes (those that were concerned with healthcare systems, processes and were 'external' to the patient), and patient-oriented themes (beliefs, feelings, or values that were 'internal' to the patient). In order to explain and interpret these findings, this discussion is organised within a conceptual model which comprehensively encompasses both those perspectives, and offers strategies for addressing and improving health providers' preparedness to intervene effectively.

The following discussion uses the four elements of the CCM (Wagner et al., 1996), as a framework for interpreting the findings and relating them to the research topic.

Decision Support

Decision support refers to systems and processes which promote HCP's capacity to deliver clinical care that is consistent with recommended guidelines. Expert and qualified practitioners, with access to best practice guidelines and specialist advice, are essential elements of good decision support in the CCM (Wagner et al., 1996).

Use of, and Familiarity with, Guidelines

The issue of practitioner expertise did not come up at all in any of the patient interviews, suggesting that this is a provider-oriented issue, and that patients assume their nurses and doctors are knowledgeable about best practice. However, patient awareness of evidence-based treatment has been shown to be a significant factor in successful self-management (Jacob & Serrano-Gil, 2010; N. Thomas & Bryar, 2013), and according to Wagner et al. (2005) "making patients aware of evidence-based guidelines for the care of their illness, and urging that they demand it, may be an important strategy" (Wagner et al., 2005, p. 12). Other than knowledge of proteinuria as an indicator of disease progression, patients did not show they had knowledge of any treatment targets, including blood pressure or HbA1c. This suggests a need to incorporate information about

treatment parameters and targets into self-management education. Self-management as a whole will be discussed later in this chapter.

The practices interviewed for this research had established roles for Practice Nurses with a special interest in diabetes – often termed as “champions” or “resource nurses” in the literature (Bodenheimer, Wagner, et al., 2002a; Spollett, 1993; Uplinger, Turkel, Adams, Nelson-Slemmer, & Pierce, 2009), as well as regular case review meetings with diabetes medical specialists. These are strategies which are widely practised, and have been shown to distribute expertise across Primary Care in clinically and economically effective ways (Foy et al., 2010; Ladden et al., 2013; Renders et al., 2000).

Healthcare practitioners’ comments showed they were aware of the existence of clinical guidelines, and were mostly aware of the principles they contained, if not the detail. Comments showed a shared understanding that the presence of microalbuminuria indicates early DKD, and that this can be effectively treated with ACE inhibitors. There was variability in familiarity with clinical guidelines, with comments showing participants weren’t certain exactly which guidelines contained direction regarding DKD, and some not clear about specific aspects of screening and treatment. This suggests a need for regular review and revision of the content of relevant guidelines.

There was also evidence of uncertainty regarding the classification of CKD. This uncertainty was in terms of the rationale for classifying the stage of disease progression, as well as how and when to apply the classification system. This finding is supported by numerous studies in the literature, which have found that HCP attitudes towards classifying CKD influences rates of detection and treatment (Khalil & Abdalrahim, 2014; Minutolo et al., 2008; Szczech et al., 2014). As discussed earlier, the introduction of the Kidney Disease Outcomes Quality Initiative classification system in 2002 enabled a clinically useful “prognosis ... based on the clinical diagnosis, stage, and other key factors relevant to specific outcomes” (Levey et al., 2011, p. 17) rather than previous diagnostic systems based on histopathology, which did not help direct clinical management. Definition of the stage of disease is important for this discussion because it enables identification of those at risk, and initiation of early treatment to prevent disease progression. The classification of patients by their stage of disease progression gives clear direction to HCPs about optimal management, preventing patchy or haphazard clinical management.

Reluctance to classify the stage of disease for fear of ‘labelling’ patients shows misunderstanding of the purpose and content of the classification system. The term ‘Chronic Kidney Disease’ is now used universally in guidelines, and encompasses the progressive nature of the disease, while avoiding judgment values associated with the term ‘failure’. This term has replaced the outdated term ‘Chronic Renal Failure’, which defined the disease by only its end-stage, implying ‘failure’ is inevitable and unavoidable. The newer term can and should be used to clarify for HCPs and patients alike the stage their disease has reached, how it should be treated at each stage, and how its progression to the next stage can be slowed or prevented (Eknoyan, 2003). Reluctance to define the stage of disease in this way because of fear of branding patients is therefore misguided. In contrast, the use of the classification to demonstrate to patients that their disease is in its earliest stages and is therefore eminently treatable, may promote patient engagement in self-management practices and lifestyle modification.

These issues highlight a possible gap in understanding among HCPs about the usefulness and application of the classification system and its relationship to clinical practice. For successful early detection and treatment, HCPs must recognise that a crucial first step is to identify (by classification) the subset of patients in their practice who are likely to benefit from early intervention. If HCPs do not identify those patients, then no amount of well-planned systems and well-implemented processes beyond that first step will be of benefit. The scope of this research did not ascertain whether HCPs were accurately identifying this group of patients, so no conclusions can be drawn, but focus group comments indicate that reluctance to ‘label’ patients may be a factor contributing to any missed cases. Future research determining the extent to which these patients are correctly identified by HCPs would be of benefit. In the meantime, a revision programme explaining to HCPs the purpose, content, and benefit of the classification system, and its application in clinical practice is likely to be at the very least helpful, and may increase the rate of identification of those patients who would benefit from early treatment.

Standardised Protocols to Ensure Widespread Application of Best Practice

Each practice had a protocol to manage early detection and treatment for those with DKD, and comments indicated that HCPs generally knew key concepts associated with screening and treatment. In one case the protocols were printed and contained in “the little green book”, whereas in the other, the actual format of the protocols was not specified.

This research did not seek to assess the quality of practice protocols or their compliance with recommended guidelines, and to the author's best knowledge, this is not measured at a regional or national level, so there is no evidence to support, challenge, or compare the effectiveness of individual practice protocols. An audit of DKD detection and treatment protocols, led by PHOs or perhaps commissioned by a national body such as the National Renal Advisory Board, would provide useful data to help elucidate the extent to which recommended guidelines for detection and treatment of DKD are embedded into Primary Care protocols.

Delivery System Design

Doctors expressed frustration at the constraints imposed by the traditional 15 minute appointment time on their ability to treat patients effectively. Wagner et al. (2005, p. 12) maintain that longer and more structured visits enable more effective chronic care delivery by allowing more time for planning, collaboration, patient interaction and self-management support. In addition, HCPs in this study commented that shorter visits restrict opportunities to uncover unexpected issues that may have a significant impact on patient prognosis and progress. The current Primary Care model, which is built around acute episodes of medical intervention aimed at cure, is not compatible with care delivery fashioned along the lines of the CCM, and so there is a direct conflict between that which HCPs know should be delivered, and that which is possible to deliver within the current delivery system design.

Nurses spend significant amounts of time outside of consultations, following up patients who have been identified by screening activities, to ensure they receive appropriate treatment and self-management support. This more intensive approach is an accepted and expected aspect of effective chronic care delivery that supports self-management and results in improved outcomes (J. Chan et al., 2009; Joss et al., 2004; Wagner et al., 2005). However, rather than happening as a result of a planned, purposeful strategy to improve care, it happens on an ad hoc basis as and when necessary. As such, these activities are not resourced adequately in terms funding or time, and nurses perceive them as frustrating distractions from other aspects of their work, rather than essential and effective interventions.

Healthcare practitioners asserted that the cost of GP visits and pharmacy charges are a barrier to early detection and intervention in DKD. Both practices alluded to ways in which they have manipulated their funding to enable reduced costs for a few patients for whom this is a

particular problem, and this was supported by the comments of one such patient. While this is not the only factor, it was highlighted as the most significant of the 'simple' reasons that people might be missed in the early stages of disease.

These findings support the notion that the current design of the Primary Healthcare delivery system is neither meeting the needs of patients at risk of DKD, nor the HCPs who should be involved with them. The roles HCPs perform within the healthcare team, the way in which patients interact with HCPs, and how those interactions are funded, are aspects of the design of our current primary care delivery system that these findings suggest should be reviewed and brought more into alignment with current concepts supporting successful care for chronic conditions.

Self-Management Support

As discussed earlier, a central paradigm to the CCM is the notion that patients are their own principal carers, not HCPs (L. Simmons, Baker, Schaefer, Miller, & Anders, 2009). The role of the HCP is therefore to provide information and support necessary to empower patients to perform this role effectively.

These findings showed that patients and HCPs were grappling with where and how to locate health within one's lifestyle, in order to successfully self-manage. For patients, this was the over-arching theme. They described how the priority their health took within their lifestyle varied according to what else was going on in their busy lives, and so their health priorities were fluid and likely to change according to a number of external factors. They all recognised that at those times when their health was positioned higher up the priority list, they felt better about themselves, and felt good about being 'in control'. This was echoed in the HCP focus groups, with doctors and nurses acknowledging that it was not realistic to expect self-management to consistently be placed as top priority. However, comments from HCPs and patients indicated that both groups accepted that optimal self-management is reliant on health issues being given high priority. Therefore the challenge for patients is to find ways to keep health at the top of their priority list, and for HCPs it is to find the best ways to support that.

Patients thought that for health issues to be more consistently prioritised highly, there must be a sense of being 'in control', and for this to happen, health issues must first be well understood and then taken seriously, with a good understanding of the consequences of poor self-

management. Research has shown that patients who are in control of their health issues have better outcomes (Juul, Maindal, Zoffmann, Frydenberg, & Sandbaek, 2011; Krichbaum et al., 2003; G. Williams, McGregor, Zeldman, Freedman, & Deci, 2004; G. Williams et al., 2009). Every patient interviewed for this study made the point that they know they should be in control, they want to be in control, and they feel better when they are in control. This contradicted the HCPs' perception that patients do not care, or even want to relinquish control, based on the observation that they do not adhere to the advice they are given by HCPs. It is here that a dichotomy becomes apparent: both parties want the same outcome – for the patient to be in control – but as each party is only viewing the issue from their own perspective, each party becomes frustrated; the HCP is frustrated at the patient's apparent self-neglect, and the patient is frustrated because they don't know how to regain control, or where to get help. Again, this has important implication for how HCPs in primary care are prepared for their roles as 'coaches' for people with chronic conditions. Working alongside people to help them regain control is a skill which HCPs in primary care need to have, yet it is not a feature of the current system which is based on treating acute medical problems as efficiently as possible.

The findings showed that patients do not necessarily understand the key message that DKD, if detected and treated early, can be slowed or reversed. An important finding from the patient interviews, which is supported by the self-management literature (Burckhardt, 2005; Pickard & Rogers, 2012; N. Thomas & Loud, 2012), was that health information that has no contextual reference to what is already known and understood is less likely to be retained and acted upon. Most patients interviewed stated that they had no trouble understanding health information from their HCPs, and yet they had noticeable knowledge gaps and requested extra information from the interviewer. They all knew that proteinuria is a sign of kidney damage, yet they were not able to attach this piece of information to any meaningful understanding that fitted within their personal world. This could be interpreted as an example of how well-intentioned HCPs pass on information that they believe (and the guidelines agree) is important for self-management, yet without any consideration that for it to be meaningful (and therefore produce positive health behaviour) there must be some prior assessment of how that information will fit with what is already understood. If it is a piece of information that has no relevance to the patient's world (based on what they already know), then it will remain an interesting but irrelevant piece of trivia to them. Healthcare practitioners who are armed with an appreciation of this might approach a teaching opportunity differently; more conscious of the importance of

immersing oneself for a moment in the patient's world and seeing how he or she perceives his or her health issues in the context of his or her lifestyle. There may be important implications here for future planning of primary care workforce development, to ensure that HCPs who work in primary care are cognisant of, and competent to deliver, healthcare education about chronic conditions that interlaces the key message within an existing, meaningful understanding of how health fits within the lifestyle or indeed the entire worldview.

Other aspects of communication which had an impact on how patients made sense of health information included the language used, and the consistency of the message. In terms of language, one patient found that when HCPs assumed her preferred language was Samoan, she found it more difficult to understand the message than when it was given in English. This underlines the importance of HCPs assessing what language patients prefer to hear health information in. Consistency between different HCPs was also highlighted by patients, and has been found in other studies to be a barrier to patient autonomy (Costantini et al., 2008; N. Thomas et al., 2008). This consistency applies not only to the actual message being transmitted, but also to the level of importance or seriousness it is assigned by the way in which it is communicated. If a piece of information is given by one HCP in a way which portrays it as being of minor importance, but by another as being of major importance, then the patient is left confused and likely to revert back to their default position of 'what they already know'. Therefore it is imperative that HCPs have a common understanding about health information – not only the content of what they deliver, but also how important each piece of information is, on a scale of 'nice to have' as least important, up to 'have to have' as crucial. This again has implications for the way in which HCPs are prepared for practice, and also for the way primary care teams work together to plan their approach to health education for chronic care self-management.

This research found that the nature of the relationship between patients and HCPs was an important factor influencing the way in which patients self-managed. The findings support the position put forward by Bodenheimer, Lorig, Holman and Grumbach (2002); that a partnership-type relationship, built on mutual respect and a sense of personal commitment to that relationship was determined to be more likely to lead to long-term adherence to healthy behaviours. In contrast, it is proposed that a relationship based on feelings of externally-generated expectations and obligations resulted in variable adherence behaviours, more likely to lapse in the long term. Furthermore, issues related to the design of the delivery system discussed

earlier, such as healthcare costs and high staff turnover, are likely to undermine any developing sense of partnership.

A notable feature which was revealed by the focus group discussions was that HCPs did not specifically articulate this process of relationship-building as an aspect of self-management support, suggesting they do not consider it to be as important as patients did. Time is not specifically set aside or funded to allow effective relationship-building to take place in primary care, and so nurses and doctors who do recognise its importance must fit it into their schedule opportunistically. Thus there is a paradox; the current primary health delivery system is not designed for this most important feature of self-management, while there is universal agreement among patients, HCPs, and in the literature that attention to this aspect of effective self-management produces the most successful outcomes for patients (Bodenheimer, Wagner, & Grumbach, 2002b; Costantini, 2006; Hudon et al., 2013; Novak, Costantini, Schneider, & Beanlands, 2013; Pickard & Rogers, 2012).

Finally, patients cited their families as a major motivator for patients to manage their health well. This is perhaps not surprising, and, if asked, most HCPs would probably agree on the importance of incorporating family members into chronic care in a positive way. However, this level of importance was not reflected in the HCP findings. Patient comments indicated they found lifestyle modification difficult when the rest of the household was not engaged in making the same changes. For a chronic disease with such evident familial links, health education and lifestyle modification coaching for the whole family would seem to have a two-pronged benefit: in addition to enabling and supporting the patient with early DKD to make healthy lifestyle changes, those same changes may reduce the risk of the disease for other individuals within the family. With the exception of Pacific Nurses, none of the HCPs interviewed discussed the need to provide health education for the wider family, and to the author's knowledge this is not conducted in any planned or purposeful way. As previously discussed, family involvement in self-management education and support interventions may offer improved outcomes for patients with other chronic conditions (Denham et al., 2011; Dunbar et al., 2013), but this study's findings suggest it is a somewhat neglected aspect of effective CKD self-management support which could be incorporated into planned programmes of health education in the primary care setting in the future.

In summary, the findings suggest there could be more effective delivery of self-management support for patients with CKD in primary care, and that there is room for improvement in self-management support in primary care from the perspectives of health system design, local organizational management, and workforce development.

Clinical Information Systems

The scope of this research did not extend to an evaluation of the application or effectiveness of clinical information systems in each of the practices. A separate study or review, examining how clinical information is collected and utilised in primary care would provide valuable information about how this aspect of chronic primary care could be optimised. With this limitation in mind, the focus group discussions did shed some light on ways in which information systems were incorporated into care delivery.

There is no nationally mandated register⁸ for CKD in New Zealand, and the focus group discussions did not reveal whether either practice used their computerised system to maintain local patient registries either for DKD, or diabetes in general. According to the literature, such registries are a critical feature of successful chronic care, and their value has been demonstrated in the setting of DKD in primary care (Bu et al., 2007; Dean, 2012; Kleophas et al., 2013; Magee et al., 2010; Snow, Caulin-Glaser, Arnette, Mochan, & Shubrook, 2012). The uncertainty evident in both focus groups about how many patients were in the practice with DKD, suggests that quantification of this cohort was not a routine practice. Future research could investigate whether DKD registries are routinely maintained in primary care, and if so, how they are utilised to improve early detection and treatment.

It was clear that both practices relied on their computer systems to generate alerts and reminders, and to automate screening and recall activities. Comments showed that screening for microalbuminuria in particular had become routine as a result of computerised reminders. Healthcare practitioners felt that this was an important aspect of effective treatment, and this is supported by evidence in the literature (Renders et al., 2000). However, it was not clear whether those who did not attend the practice for these routine tests were identified and followed up, or whether there was any system to prevent them being 'lost'. This group, if not actively identified

⁸ Defined by Bodenheimer, Wagner, et al. as "list of all patients with a particular chronic condition" (2002b, p. 1766)

and followed, will not benefit from early detection and treatment, and their non-engagement suggests they are an important group to reach early.

Effective clinical information systems are an indispensable feature of successful chronic care programmes, and have been shown to benefit early detection and management of DKD. This research did not seek to evaluate information systems in the primary care practices participating, but does provide a platform of background evidence to support future research addressing that purpose.

Conclusion

This study sought to explore what factors impede early detection and treatment for DKD in primary care. The findings have shown that the participating primary care practices had an appreciation of elements of clinical decision support that were available to them. Overall, there was adequate and timely access to expert advice, and awareness of the availability of best practice guidelines. However there was evidence of room for improvement in how well-supported clinical decision making was in practice. In particular, unfamiliarity with the content of recommended guidelines, and uncertainty with a degree of skepticism regarding the classification of CKD, demonstrated a gap in knowledge about the utility and benefits of CKD classification and guidelines.

Findings clearly highlighted the incompatibility between the current primary care healthcare delivery system, and provision of effective chronic care. In addition to the expenses incurred by patients visiting the primary care clinic, the findings confirmed that the traditional focus on episodic interventions for acute illness does not meet the needs of patients with chronic conditions. Barriers to early detection and treatment for DKD resulting from inadequacy of the healthcare delivery system were evident in the findings. These included time constraints imposed by the appointment system, and also no expectation that planned and systematic identification and follow up for high risk patients should be an intrinsic and essential feature of HCP workload in primary care.

Perhaps the most glaring anomaly when analyzing the findings alongside the CCM is poor overall provision of self-management support. The patient participants confirmed their need for self-management support, and individual HCPs' comments showed they instinctively recognised its value. But there was no evidence in the findings that self-management support is routinely

incorporated into patient care in a planned and consistent way. Lip service to the importance of self-management support in chronic care is not adequate – its key elements need to be embedded into routine practice, and given the same importance as other aspects of care such as the evaluation of risk factors and medication management.

The integration of information systems into clinical practice was not evaluated as part of this study, however the findings confirm that both primary care practices routinely use electronic and paper systems to support clinical practice. A focus for future research could be to evaluate the validity, quality and utility of various clinical information systems in the context of CKD, and DKD in particular.

CHAPTER SEVEN – CONCLUSION AND RECOMMENDATIONS

This study set out to investigate possible reasons for why approximately one in every two people with DKD are still presenting for RRT, even though there are well-established guidelines for prevention of the progression to ESKD through early detection and treatment. The burden of DKD and its therapy are considerable, in terms of mortality, morbidity, and healthcare expense. On further investigation, it became evident that detection and treatment in primary care appears to be suboptimal. Therefore, this research explored the factors which impede early detection and treatment of DKD in primary care.

Using qualitative descriptive methods, the content of interviews with patients and HCPs was analysed to extract common or key themes. This approach was selected in order to build up a rich picture, from a diverse range of experience, in the words of those who are closest to the issues. Evidence in the findings supported the hypothesis that there are various factors inhibiting early detection and treatment for DKD in primary care. It is noteworthy that while patient and HCP participants identified similar areas of concern, the factors inhibiting detection and treatment which emerged are all provider-oriented, i.e. within the realm of HCP practice in primary care, or the structures supporting that practice. Those factors have been discussed in detail in the previous chapter, and are summarised below.

Summary of Factors Impeding Early Detection and Treatment of Diabetic Kidney Disease

1. Patients' lack of knowledge about diabetes treatment targets and positive outcomes associated with early treatment.
2. Healthcare practitioners' lack of working familiarity with current clinical guidelines.
3. Healthcare practitioners' reluctance to formally diagnose patients with early DKD.
4. Poor understanding about how well clinical guidelines are embedded into everyday practice in primary care.
5. Conflict between the objectives and implementation strategies of good chronic care, and current primary care delivery system design.

6. The cost of primary care for patients.
7. Healthcare practitioners are not necessarily prepared well, with the required skills or knowledge to deliver care for people with chronic conditions.
8. Healthcare practitioners neglecting to actively promote family engagement in self-management support practices.

Previous studies which have looked at this subject have approached it from a specialist nephrology (or diabetes) nursing or medical perspective. To the best knowledge of the researcher, this is the first study to explore the processes at work in primary care alone, and to propose ways in which the current primary care system could be adjusted for improvement, without the additional involvement of specialist nephrology or diabetes services.

Limitations of this Research

This research found several factors which impede early detection and treatment of DKD in primary care. However, the research has certain limitations which should be noted when considering the findings. Firstly, the professional role of the researcher, coming from a specialist nephrology/diabetes nursing background, may have influenced the responses of both patient and HCP participants. In the case of HCPs, they may have felt inhibited or conflicted by the researcher's association with their local specialist diabetes service, with which they had a previous relationship. In the case of patients, while the researcher made efforts to explain that she was interviewing them for research and was independent of their healthcare team, participants' responses may nevertheless have been tailored to suit what they believed would be expected by a HCP. All of the participants asked for information and advice from the researcher during interviews, indicating that they considered her role to be primarily that of diabetes nurse (rather than independent researcher). This was partially overcome in focus groups by the presence of a moderator, and could have been overcome by the use of an independent interviewer for patient interviews (which was unfeasible due to fiscal and time constraints). However it could be argued that the researcher's background enriched the patient interviews, allowing patients to get right to the crux of the matter without having to explain themselves first, and providing them with an opportunity to seek more information about their health and its self-management.

Another implication related to the researcher's role is her lack of professional experience in primary care. This could be seen as a strength, as the researcher had no pre-conceived ideas about what factors might be important or how processes should be altered. Indeed, with no pre-existing knowledge of how primary care works (other than that of a lay-person), the researcher approached data collection and interpretation as a complete novice with no agenda other than to draw out participants' key ideas. However this lack of experience may also have led to the researcher missing or misunderstanding important points because of incorrect assumptions or missing knowledge. The researcher was acutely aware of her inexperience while conducting the focus groups, and for this reason took care to summarise and seek clarification both during and at the end of the focus groups, to ensure that no key data was omitted.

The participant samples were small, and therefore, it could be argued, inadequate. The researcher proposed to interview ten patients but in the end only five agreed to participate. There could be multiple reasons for this, including inertia on the part of patients as well as the practice nurses who were recruiting them. Time constraints prevented actively seeking more patients. However, those who did agree comprised a range of demographic, cultural and socioeconomic backgrounds, and from the perspective of qualitative data collection, this small but diverse group provided a variety of well-articulated ideas which, while perhaps not generalizable to the larger population, nevertheless represent reality for those patients, and are therefore valid to include in the findings.

Finally, during analysis it became evident that specific topics had not received enough attention during interviews, leading to inadequate data collection in some aspects of the topic. For example, the issue of whether practices kept local registers of people with CKD is an important question which was not covered. Future research should ensure that all aspects are given adequate attention during data collection.

Future Research

In the process of identifying factors which impede early detection and treatment in primary care for DKD, this study highlighted other aspects of care that could be further explored in future research. The primary care practices interviewed for this research demonstrated difficulty articulating exactly how many patients in their practice had DKD. Many countries maintain CKD registers to help identify and organise those at risk of disease progression, support evidence-based

care for individuals and populations, and to provide feedback to primary care practices about their performance. This research revealed that there may be a need for a national CKD register in New Zealand, and future research examining the utility, cost effectiveness, and implementation of such a register may be warranted.

While HCPs confirmed during interviews that their practices maintained up to date protocols for guiding care, based on evidence-based recommendations, this research did not set out to assess the quality or application of these protocols in practice. Uncertainty regarding CKD classification and unfamiliarity with guidelines indicated there may be inconsistency between recommended best practice and local protocols, or patchy application of local protocols in practice, or both. The existence, quality, and application of local practice protocols could therefore be a useful topic for future research.

Finally, this study explored early detection and intervention in primary care, and although concerned with DKD, most of the findings could be applied equally to other chronic conditions such as CVD, cancer, diabetes and stroke. The findings from this study could therefore be used as a platform for future research looking at factors influencing prevention and early intervention for other chronic diseases in primary care.

Recommendations

This research found various factors which impede early detection and treatment of DKD in primary care. Taking into account the limitations of the study, and areas for possible future research, the findings support the following recommendations for policy and practice changes in primary care.

Decision Support

1. Self-management support in primary care should incorporate patient education about treatment parameters and targets, so that patients may be more actively engaged in their treatment.
2. There is a need for an on-going revision programme explaining to primary care teams the purpose, content, and benefit of the classification system, and its application in clinical practice.

3. Primary care teams and professional organisations should incorporate regular review of DKD clinical guidelines into on-going professional education, along with methods to embed recommended practice into everyday use.
4. An audit of early DKD detection and treatment protocols, led by PHOs or perhaps commissioned by a national body such as the National Renal Advisory Board, to help elucidate the extent to which recommended guidelines for detection and treatment of DKD are embedded into Primary Care practice.

Delivery System Design

1. The roles HCPs perform within the healthcare team, the way in which patients interact with HCPs, and how those interactions are funded, should be reviewed and brought more into alignment with current concepts supporting successful care for chronic conditions.
2. The cost of primary care for people with chronic conditions should be reviewed and alternate funding models investigated.

Self-Management Support

1. Professional development programmes for primary care must prepare HCPs to deliver appropriate care for people with chronic conditions. This includes:
 - a. learning methods for motivational support,
 - b. coaching patients and families in a partnership arrangement,
 - c. learning concepts and methods of delivering healthcare education which embeds the key message within existing experiential or contextual knowledge.
2. Primary care teams must focus on self-management support as a key goal of care for people with DKD. This includes:
 - a. delivering self-management support in a way which is consistent in both content and emphasis,

- b. recognising relationship-building as a legitimate and important aspect of self-management support, and ensuring time, funding, and training is provided to enable it to happen in a planned and purposeful way,
- c. incorporating family engagement into planning for self-management education programmes.

Clinical Information Systems

1. The feasibility and utility of a national CKD register should be undertaken, to inform future development of local and/or national registers aiming to improve individual and population-based care for CKD.

Conclusion

The negative impact of DKD on wellbeing, lifespan, and healthcare expenditure is well understood, and early detection and treatment are recommended as optimal management. Yet despite a wealth of evidence-based direction for early detection and intervention for DKD in primary care, patient outcomes remain suboptimal. This research has identified various factors which impede early recognition of DKD in primary care, or interfere with optimal treatment. These findings may be useful for future investigations into strategies to improve early DKD management, as well as primary care policy development, workforce planning, self-management support programme design, and application of best practice. In this relatively young field of healthcare research, this study offers a possible direction for future research aiming to ultimately improve health and wellbeing for a significant number of New Zealanders.

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APPENDICES

Appendix 1

Patient Participant Interview Schedule

Research aim: to explore the perceptions of patients and primary healthcare practitioners about what factors enable or impede early detection of, and appropriate intervention for DKD in the primary care setting.

Stage One: Arrival

- *Aiming to establishing the relationship, rapport, participant has control, interviewer responsible for putting at ease*
 - confirm participant wants to proceed with interview
 - avoid research topic until interview begins, start interview when participant comfortable

Stage Two: Introducing the research

- nature and purpose of the research
- seek permission to record the interview
- reaffirm confidentiality
- explain and seek written consent

Stage Three: Begin

- *aiming to get a feel for how interviewee will respond to being interviewed and adapt approach accordingly*
 - ask for background information (informal manner) e.g. age, who they live with, whether they work etc
- *follow-up questions to implicitly set the scene for the level of detail and levels of questioning, probing etc*

Topic area: Demographic data

- What ethnicity do you identify with?
- How old are you?
- Were you born in NZ? If not, how long have you been in NZ?

Stage Four: The interview

Topic area: Understanding of DKD: risk, progression, long term consequences

- Tell me about your diabetes.
- Can you describe to me how it affects your day to day lifestyle?
- Do you think it will affect you differently in the future?
- One of the complications of diabetes is kidney disease. What do you know about whether your diabetes has affected how your kidneys work?
- How did you find out what you know about kidney disease?

Topic area: Engagement with screening practices

- Describe to me how you get information about your health.
- Who is the health professional that you get most of your health information from?
- How well do you understand the written/verbal health information given to you?
- How do you get help to understand what your health professional has told you?
- How did you find out you had kidney disease?
- How often do you attend your GP? Why is that?

Topic area: Engagement with early treatment

- After you found out you had kidney disease, did anything change? Did the doctor or nurse do anything differently as a result of knowing you had kidney disease? Did you?
- What factors do you think assist you to follow the treatment suggested by your doctor?
- What factors do you think prevent you from following the treatment suggested by your doctor?

Stage Five: Ending

- *Aiming to signal approaching end to allow interviewee to return to the level of everyday social interaction*
 - check participant has no unfinished business
 - would you like a copy of the recording?
 - explain opportunity will come for reviewing transcript
 - any final questions

Appendix 2

Focus Group Interview Schedule

Research aim: to explore the perceptions of patients and primary healthcare practitioners about what factors enable or impede early detection of, and appropriate intervention for DKD in the primary care setting.

Stage One: Setting scene/ground rules

- Welcome & thanks for coming, personal introduction, outline of the research topic, & purpose of the study
- confidentiality reaffirmed, what will happen to the data and reporting, treat what other people say as confidential and not to be repeated outside the session
- beneficial outcomes expected
- discussion format, so no right or wrong answers, everyone's views are of interest, aim is to hear as many different thoughts as possible
- need to record the discussion, don't talk over each other etc

Stage Two: Introductions

- *Brief introductions for transcription purposes (and to put everyone at ease)*

Stage Three: Opening the topic

- *Aiming to move from responding only to moderator to more group interaction, responding to each other rather than moderator*
- *engage as many of the participants as possible, ask further questions (or rephrase same question) to open out the response, get quiet ones involved*
 - Can you give me a general idea of how many people with diabetes you have here and what are their characteristics (demo, comorbidities etc)?
 - What kind of care 'package' is there for people with diabetes here?
 - How are people with DKD identified? (may need to summarise guidelines here)
 - Once identified, how do you treat them?
 - Do you know how many people get missed (i.e. have DKD that isn't picked up)? Of those picked up, do you know how many don't receive appropriate treatment? (What's your sense of how many?)

Stage Four: Discussion

- *Aiming to balance group interaction against individual detail; free-flowing debate against coverage of specified topics. Probe the group as a whole and individual members, direct discussion over any missed topic areas, keep the discussion focused on subject.*
 - What factors do you think enable DKD to be picked up early? (→explore processes or systems that currently work well; tease out why they work well; what successful features may be transferable?)
 - What do you think are the reasons behind why some people with DKD are missed? (→explore each reason)
 - Why do you think some patients don't receive appropriate treatment even though you're aware of their DKD? (→explore each reason)
 - What do you think could be done/changed/started/removed to identify and treat those people that are missed? (→explore each idea)

Stage Five: Ending the discussion

- *Aiming to signal the end approaching, finish on a positive note*
 - Finally, does anyone have anything else to say before we finish? Where would you like to go from here (plan future discussion if necessary about any specific ideas that came up)
 - Summarise key points of discussion
 - That's the end of this session. Thanks for coming. Discussion has been really helpful.
- *be prepared to stay awhile after the tape recorder has been switched off in case of questions, reluctance to leave etc*

Appendix 3a

Initial Email from Massey University Human Ethics Committee

Miranda Walker

From: Broad, Patsy <P.L.Broad@massey.ac.nz>
Sent: Tuesday, 15 October 2013 9:07 a.m.
To: Miranda.walker@paradise.net.nz
Cc: Gilmour, Jean
Subject: HEC: Southern A Application 13/69 - Application Outcome

13/69 **Diabetic kidney disease: Exploring factors that enable or impede early detection and intervention in the primary care setting**
Miranda Walker (HEC: Southern A Application 13/69)
Department: School of Nursing
Supervisor: Dr Jean Gilmour

The Massey University Human Ethics Committee: Southern A considered the above application at their meeting held on Tuesday 8 October 2013.

The application was provisionally approved, subject to the fulfilment of the conditions below to the satisfaction of Dr Brian Finch (Chair).

Please note that the Committee is always willing to enter into dialogue with applicants over the points made. There may be information that has not been made available to the Committee, or aspects of the research may not have been fully understood.

- The committee would like to thank the applicant for a well-prepared and thorough application that included information sheets of a high standard.

SECTION A

Q4/INFORMATION SHEETS

- Paragraph 1, last sentence states "... late identification ..."; however elsewhere in the application "early" identification is referred to. Please ensure consistency.

SECTION B

Q11

- For information: A correction was made recently to the NZ Health Survey results – the correct figure for the NZ adult population estimated to have pre-diabetes is 25% (rather than 18%). In addition, please note that Maori and Pacific people have a higher prevalence of risk factors (not "greater" risk factors).

Q12/17/19/22/INFORMATION SHEETS

- The committee noted that there are privacy issues with the current recruitment process (through the primary care nurses). In order to ensure the researcher does not have access to identifiable patient information prior to consent, the committee suggests that the researcher discusses the study with the practice nurse in general terms; the practice nurse is provided with information sheets to distribute to potential participants, who are asked to contact the researcher directly if they wish for further information, or would like to volunteer to take part in the study. Please reconsider the current process and make relevant changes – include detail in the information sheets.

Q19

- As above – potential participants should be provided with information sheets and then asked to contact the researcher if they wish to volunteer. This process would be less coercive and make the voluntary basis of participation much clearer than the current procedure.
- How will prioritisation of Maori and Pacific people take place in the recruitment process?

Q19/23/INFORMATION SHEETS

- The committee would recommend defining early DKD, e.g. stages 1-3; or eGFR range 30-60.
- Exclusion criteria should be stages 4-6 (i.e. not later than Stage 3 as phrased in Q19).
- How will the researcher check inclusion/exclusion criteria are appropriate for each participant? Suggest the researcher has a form/checklist that is worked through when each potential participant contacts the researcher by phone.

Q21

- Please provide a copy of the permission letters, when received.

SECTION C

Q35

- Please provide further detail regarding the “additional opportunities to access information about their health”. Is the researcher intending to provide advice/education to participants during the interview; or at a later date? Please comment.
- PHO/practice benefits: Is the researcher intending to provide advice/education during the focus group; or will this occur at a later date? Please comment.

SECTION I

Q61/63

- Please provide detail of consultation undertaken with the groups listed and supporting documentation.

ADVERTISEMENT

- Should be printed on the relevant Massey University departmental letterhead.
- The advertisement currently states that lunch will be provided; however, this may not be the best time of the day to conduct a focus group. The committee suggests the researcher negotiates the time with the practice.
- Statement in bold after “When/Where” – will the researcher need to know how many people wish to attend, in advance? If so, suggest rephrasing of the statement.
- Please ensure inclusion of the correct approval statement: *“This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 13/69. If you have any concerns about the conduct of this research, please contact Dr Brian Finch, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 350 5799 x 84459, email humanethicsoutha@massey.ac.nz.”*
- Please provide a copy of the revised advertisement.

INFORMATION SHEETS

- Specify groups the information sheets are for, e.g. focus group and individual interview.
- Refer Qs 4, 12 and 19 above – include relevant details.
- Note: Information sheet for focus group states “late” identification – please ensure consistency in detail.
- Information Sheet (Interview), paragraph 6, sentence 2 – committee suggests removal as the applicant is conducting the study in her capacity as a researcher; rather than a diabetes and kidney nurse.
- Use of personal cell phone – suggest using separate cell number for the research. Note: The Committee noted that the researcher is an experienced professional in this area and therefore voiced slight concern that participants may continue contact after the study for professional advice in this capacity.
- Please ensure inclusion of the following statement: *“This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 13/69. If you have any concerns about the conduct of this research, please contact Dr Brian Finch, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 350 5799 x 84459, email humanethicsoutha@massey.ac.nz.”*
- Please provide a copy of the revised information sheets.

QUESTIONS FOR FOCUS GROUP

- Stage Four – the committee noted that the questions appear to focus on the barriers/negatives – does the researcher also wish to identify what works well?

Please supply to the Secretary, one (1) copy of this email with the reply inserted under each point, plus any amended documents which should clearly identify changes made, e.g. using track changes, italics or bold

font. Please ensure that your Supervisor has checked your response before you submit your reply. Do not begin your research until you receive your final letter of approval.

Yours sincerely
Dr Brian Finch, Chair
Massey University Human Ethics Committee: Southern A

*Patsy Broad
PA/Research Ethics Administrator
Research Ethics Office
Courtyard Complex, Room 1.25
Tūritea Campus
Massey University/Te Kunenga ki Pūrehuroa
Private Bag 11222
Palmerston North 4442
NEW ZEALAND*

*Extension: 81082
Phone (DDI): 06 350 5573
Email: p.l.broad@massey.ac.nz
Fax 06 350 5622*

Appendix 3b

Final Approval Letter from Massey University Human Ethics Committee



MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

5 November 2013

Miranda Walker
74 Overton Terrace
Rataitai
WELLINGTON

Dear Miranda

Re: HEC: Southern A Application – 13/69
Diabetic kidney disease: Exploring factors that enable or impede early detection and intervention in the primary care setting

Thank you for your letter dated 4 November 2013.

On behalf of the Massey University Human Ethics Committee: Southern A I am pleased to advise you that the ethics of your application are now approved. Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Dr Brian Finch, Chair
Massey University Human Ethics Committee: Southern A

cc Dr Jean Gilmour
School of Nursing
WELLINGTON

A/Prof Annette Huntington, HoS
School of Nursing
WELLINGTON

Massey University Human Ethics Committee
Accredited by the Health Research Council
Research Ethics Office

Massey University, Private Bag 11222, Palmerston North 4640, New Zealand T +61 6 330 1113 F +61 6 330 1122
E humanethics@massey.ac.nz researchethics@massey.ac.nz jean.gilmour@massey.ac.nz www.massey.ac.nz

Appendix 4

Letter of Endorsement from CCDHB Research Advisory Group – Māori



Research Advisory Group – Māori
Māori Partnership Board, Capital & Coast DHB

RESEARCH ADVISORY GROUP MĀORI (RAG-M)

18 September 2013

Miranda Walker
74 Overtoun Terrace
Hataitai

Tēnā koe Miranda

RAG-M 2013/274 - Letter of Endorsement

On behalf of the Research Advisory Group Māori I write in relation to your study titled: *Diabetic Kidney Disease: what factors enable or impede early detection and intervention in the primary care setting*

You have supplied RAG-M the following documentation on which to base our assessment:

- RAG-M Cover sheet
- Research Proposal
- Ethics Application
- Information sheet for practices
- Information sheet for participants

Our reading of your proposal characterises the research as: a qualitative descriptive study, using semi structured interviews and focus groups with patients who have early diabetic kidney disease, and with primary care practitioners and practice nurses to identify factors that enable or impede early detection and intervention of the disease

Diabetes is a considerable health issue for Māori, as highlighted by the literature review and statistical data presented in the background for your study. This study has the potential to contribute to a greater understanding of the disease and its management.

We commend your use of appropriate protocols to collect ethnicity data from patients. We acknowledge the opportunity for whānau to attend interviews allowing guidance from participant and whānau as to the appropriate inclusion of tikanga Māori within the research setting.

We also acknowledge your intention to consult with local organisations that have a specific focus on Māori health and diabetes, and to seek a cultural supervisor. Your

commitment to attending the Tikanga Māori Research-specific Training later this month is appreciated.

One of our aims is to improve whānau health literacy, therefore we trust that you allow time to respectfully explain the terms, meanings and commitments of the study in plain language, and provide an opportunity for whānau members to discuss the implications of the project on request.

The committee makes the following requests prior to agreeing to endorse the research:

1. We request one small amendment to the information sheet for participants: that the option for whānau to attend interviews is stated on the sheet.
2. The committee requests a 'local report' of the numbers of Māori patients recruited, and any specific issues/ concerns recruiting or retaining Māori be submitted at the completion of local involvement in the study
3. The committee looks forward to receiving a copy of the final study report upon completion of the study at the end of 2014.

On confirmation that the expectations specified above are understood and accepted by you we will be able to endorse your research proposal. Please confirm these details by signing the section below and returning a copy to ragm@ccdhb.org.ac. We thank you for consulting RAG-M and wish you well in your study.

Nāku noa nā,



Jack Rikihana
Chair RAG-M

.....
I agree to all of the above requests from the RAG-M committee.

PI Signature M Walker Date: 2 October 2013

Appendix 5

Patient Participant Information Sheet



Diabetic Kidney Disease: what factors enable or impede early detection and intervention in the primary care setting

INFORMATION SHEET FOR INDIVIDUAL INTERVIEWS

My name is Miranda Walker, and I am a Masters student in Nursing at Massey University. As part of this degree I am conducting a research project. The project is looking at the experiences of people who have type 2 diabetes and early signs of kidney complications.

I am inviting you to participate in this study.

Diabetes is the most common cause of kidney disease in New Zealand. Medical treatment can slow down or even stop the progress of diabetic kidney disease, but only if it starts early. The aim of this research is to find out what factors help or delay early treatment for diabetic kidney disease.

In order to obtain this information I would like to speak to you about your experiences and knowledge of diabetes, its complications, and its treatments. I expect that this would take about an hour of your time, and would happen at a time and place that is convenient to you. Your whanau or family is welcome to be present if you wish. I would record our conversation for typing up later, and then I would offer you the typed version so you can check and edit it if necessary to make sure it is accurate. The written record of the conversation will be anonymous so you will not be identified personally.

I am asking if you would participate because by telling your stories about your health, we may learn ways of improving treatment for you and for others in the future. A small koha (information about how to live a healthy lifestyle, and a \$20 petrol voucher) will be offered to you as a way of thanking you for your time and effort.

Whether you agree to an interview or not, your usual treatment from your GP and Practice nurse will continue.

If you would like to volunteer for an interview, please contact the researcher directly by cell phone 0223631907, or by leaving the attached slip with your Practice Nurse so the researcher can contact you.

All information collected for this project will be kept confidential. No one except me and my supervisor (Dr Jean Gilmour) will hear the recordings or see the typed versions of the conversations. During the project, the tapes and written information will be stored in a locked cupboard. At the end of the project, you would be sent a summary of the research findings. The finished thesis will be submitted for marking to the School of Nursing and then deposited in the University Library. It is intended that one or more articles will be submitted for publication in scholarly journals. Tape recordings and written information will be stored

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Wellington Campus, Private Box 756, Wellington 6140, New Zealand T +644 801 5799 www.massey.ac.nz

for ten years in the Massey University School of Nursing archive and then destroyed, according to University protocols.

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study at any time before the data is analyzed;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- ask for the recorder to be turned off at any time during the interview.
- be given access to a summary of the project findings when it is concluded.

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 13/69. If you have any concerns about the conduct of this research, please contact Dr Brian Finch, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 350 5799 x 84459, email humanethicsoutha@massey.ac.nz

If you have any questions or would like to receive further information about the project, please contact me:

Miranda Walker
Email: miranda.walker.1@uni.massey.ac.nz
Cell: 0223631907

or my supervisor:

Dr Jean Gilmour
School of Nursing
College of Health
Massey University, Wellington
Private Box 756
Email: J.A.Gilmour@massey.ac.nz
Phone: 04 8015799 Extn 62487

Kind regards

Miranda Walker

✂

YES: I would like to volunteer to tell my story for this research. Please contact me:

give contact details eg phone number:

Appendix 6

Healthcare Practitioner Participant Information Sheet



Diabetic Kidney Disease: what factors enable or impede early detection and intervention in the primary care setting

INFORMATION SHEET FOR FOCUS GROUP PARTICIPANTS

My name is Miranda Walker, and I am conducting a research project as part of a thesis towards a Masters degree in Nursing at Massey University. The research aim is to explore what factors impede or enable early detection and treatment for diabetic kidney disease.

Early detection and intervention in the Primary Care setting is promoted as the most cost effective and clinically successful way to prevent or slow the progression of diabetic kidney disease. Yet its prevalence seems to be increasing, and there is evidence to suggest that some people either miss out on screening, or do not receive appropriate treatment early. This project will explore what factors enable or impede early identification and treatment of diabetic kidney disease.

I am inviting you to participate in a focus group session with other medical and nursing staff at your primary care practice to explore knowledge and perceptions about DKD, its risk factors and management, progression of the disease, screening practices, and factors that impact on early detection and treatment. This would take about an hour, and would take place at the Practice during work time. The meeting will be facilitated by an independent moderator, and I will be present to take notes and summarise. The session will be recorded for later transcription and key themes extracted. A summary of the key themes will be reported back. The written record of the meeting will be anonymous so no one will be identified personally.

All information collected for this project will be kept confidential. No one except me, my supervisor (Dr Jean Gilmour), the moderator and a transcriber will hear the recordings or see the typed versions of the meetings. During the project, the tapes and written information will be stored in a locked cupboard. At the end of the project, you would be sent a summary of the research findings. The finished thesis will be submitted for marking to the School of Nursing and then deposited in the University Library. It is intended that one or more articles will be submitted for publication in scholarly journals. Tape recordings and written information will be stored for ten years in the Massey University School of Nursing archive and then destroyed, according to University protocols.

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study at any time before the data is analyzed;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the project findings when it is concluded.

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 13/89. If you have any concerns about the conduct of this research, please contact Dr Brian Finch, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 350 5799 x 84459, email humanethicssoutha@massey.ac.nz

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ki Pūrehuroa

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Wellington Campus, Private Box 755, Wellington 6140, New Zealand T +644 801 5799 www.massey.ac.nz

If you have any questions or would like to receive further information about the project, please contact me:

Miranda Walker
Email: miranda.walker.1@uni.massey.ac.nz
Phone: 04 8082485
Cell: 0223631907

or my supervisor:

Dr Jean Gilmour
School of Nursing
College of Health
Massey University, Wellington
Private Box 756
Email: J.A.Gilmour@massey.ac.nz
Phone: 04 8015799 Extn 62487

Kind regards

Miranda Walker