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Exploring the nature of psychological wellness of renal patients on
dialysis under the care of the Waikato Regional Renal Centre

A thesis submitted in fulfilment
of the requirements for the degree

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Abstract

In New Zealand, there has been limited enquiry into the experiences of dialysis patients and the health professionals who work with these patients. The number of people requiring dialysis is increasing every year and the support they require to manage end stage kidney disease is complex. It involves the invasive physical intervention of dialysis, as well as psychological support to cope with the significant life changes and social support to help patients to manage this disease.

The purpose of this research is to explore the nature of psychological well-being of patients under the care of the Waikato Regional Renal Unit. The level of psychological support that the patients have access to is investigated and suggested improvements rationalised against prior research findings are presented. The intent of this research is to create an awareness of the psychological needs of dialysis patients. It aims to give insight into the participants' lived experience as they openly describe their lives as dialysis patients, and endeavours to open up discussion for change.

Two data gathering approaches were used to engage with patients and health professional. I completed interviews with 11 renal patients and 14 health professionals, and administered a mail out questionnaire to 197 patient respondents. Thematic analysis of the interview data identified the following themes; the impacts of end stage kidney disease on the psychological well-being of renal patients, the need for psychological support for patients with end stage kidney disease, and the need for improved communication between and across all parties; the support people, the health professionals and the renal patient.

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Introduction

I came to this research topic as a support person for approximately four years to my friend, a patient with end stage kidney disease. This has allowed me the opportunity to walk alongside a dialysis patient and witness her journey. This experience has given me valuable insight into the complexities of this disease, its management and the very real needs of renal patients. Inspired and encouraged by my friend, other renal patients and staff of the WDHB, I embarked on this thesis research endeavour to better understand the psychological needs of renal patients and of developing services and solutions responsive to them.

This thesis is comprised of five chapters. Chapter one of this thesis reviews the relevant literature regarding end stage kidney disease and the treatment options available. The causes of kidney failure and the impacts of this are then examined. Chapter Two describes the method used for the recruitment of participants, the research tools I developed to complete this research, and the research procedures I used to collect and analyse the data. Chapter Three presents the quantitative results of the findings from my questionnaire. Chapter Four presents an analysis of the transcribed interviews, discusses these findings and the implications of these for patients and the health professionals working with them. Chapter five includes a discussion of the findings and considerations for future research are also included in this chapter.

Chapter One: Literature Review

This chapter begins with a description of kidney failure, and then the treatment options that are available for dialysis patients are explored. The causes of kidney failure are critiqued and finally the impacts of kidney failure are discussed. Christensen and Ehlers (2002) suggest that “end stage kidney disease is a disorder marked by an extreme loss of personal control, an array of acute and chronic stressors, a high degree of emotional distress and psychiatric co-morbidity” (p. 720).

Description of kidney failure

To comprehend what is meant by end stage kidney disease (ESKD) or end stage renal failure (ESRF) an understanding of the illness and a grasp of the terminology is required. The word ‘kidney’ derives from the medieval English word ‘kidenei’ for kidney. The term ‘renal’ comes from the Latin word ‘ren’ meaning kidney or relating to the kidneys. “Nephrology’ is the science of kidney medicine and is derived from the Greek word ‘nephros’ which also means kidney (New Zealand Kidney Foundation, 2007). The kidneys serve important functions including filtration and excretion of waste products, the regulation of necessary electrolytes and fluid, as well as acid-base (pH) balance. They also stimulate the production of red blood cells. The kidneys regulate blood pressure and control reabsorption of water and maintain intravascular volume. The kidneys activate Vitamin D, reabsorb glucose and amino acids and have hormonal functions (Medscape, 2015a).

Chronic kidney disease (CKD) is a general term referring to various disorders that affect the structure and function of the kidney. CKD is a gradual and progressive loss of kidney function. This loss varies dependent upon the cause and pathology, the severity and rate of progression (Levey & Coresh, 2012). A diagnosis of CKD is confirmed by routine laboratory tests to detect the levels of the glomerular filtration rate (GFR) and the levels of albuminuria in the urine (Levey & Coresh, 2012). Albuminuria is a protein that is measured through the urine and high levels of albuminuria are the first signs of kidney disease (National Kidney Foundation Inc, 2015a). GFR is the measurement of the amount of creatinine in

the blood which is a normal waste product removed from the body by the kidneys (Kidney Health New Zealand, 2015; Zhao, 2013). The GFR is the best indicator of kidney function and takes into account the person's age, sex and body size to produce an accurate measure (National Kidney Foundation Inc, 2015b). Once kidney disease has been confirmed further tests are then required. These include imaging tests which could consist of ultrasounds, computerised tomography (CT) scans and X-rays. Often a kidney biopsy is performed to determine what type of kidney disease is present and the extent of the damage (New Zealand Kidney Foundation, 2007).

There are three types of kidney failure. These consist of acute kidney failure (AKF) or acute kidney injury (AKI), chronic kidney failure (CKF) or chronic renal failure (CRF), and ESKD or ESRF (Casey, 2012). AKF is a sudden loss of kidney function, which can be the result of ischemia, which is the reduced blood supply to a bodily organ (Campbell, 2003). This could be the result of a serious accident, a compromised immune system or an infection to the kidney (New Zealand Kidney Foundation, 2007). In New Zealand (NZ) about four percent of patients in intensive care develop AKF, which has a greater than 60% mortality rate. Of the general hospital population in NZ the incidence of AKF is approximately 18% with a mortality rate of 30% to 60%. When recovering from AKF approximately 12% of patients will require ongoing dialysis. Up to 30% will develop CKD (Casey, 2012). In NZ, there has been a rise of CKD patients mainly because of the diabetes epidemic. Most of these patients will eventually require dialysis to survive (Nikolajenko, 2013). There are five stages of CKD; stage one CKD is when there is normal kidney function with normal or increased GFR, stage two CKD is when there is kidney damage with mild decrease in GFR, stage three CKD is when there is a moderately decreased GFR, stage four has a severely decreased GFR, and stage five is termed as ESKD. This latter diagnosis is given when a person's kidney function has stopped. ESKD is fatal because a human body cannot survive more than a few days without kidney function. Therefore, some form of renal replacement therapy (RRT) is necessary for survival. I consider these options in the next section.

Treatment Options

In NZ there were 4368 people receiving RRT as at 31 December 2015 (Kidney Health New Zealand, 2017). Of these 1694 have a functioning kidney transplant and 2674 were receiving dialysis treatment. The mean age of NZ patients requiring RRT is 56 years and the median is 59 years (Kidney Health New Zealand, 2017). The number of patients commencing RRT each year in Australia and NZ increased by 321% between 1990 and 2009. This rise was largely driven by increases in patients with diabetic nephropathy, which is damage to the kidneys caused by diabetes. In 2009 diabetic nephropathy accounted for 35% of patients newly diagnosed with ESKD, 92% of these had type 2 diabetes. By 2015 this number had increased to 47% of all newly diagnosed patients. Furthermore, an increased acceptance for dialysis of older and sicker patients is also contributing to increased numbers receiving RRT (Grace, Clayton, & McDonald, 2012; Kidney Health New Zealand, 2017). There are two types of dialysis treatments available for a person with ESKD. These are haemodialysis (HD) and peritoneal dialysis (PD). Kidney transplants are an option if the patient meets the criteria and a donor kidney is available. However, the only option for some patients is conservative treatment, which is a form of palliative care.

Haemodialysis

Dialysis treatment for renal patients will be a lifetime requirement for survival, or a long-term necessity until a kidney transplant is available. ESKD patients use haemodialysis (HD) to remove the build-up of excess fluid and clean the blood. HD requires the patient to have an intravenous catheter or an arteriovenous fistula (AVF) or an arteriovenous graft (AVG) inserted to create an access site. Intravenous catheters are a soft tube placed in a large vein, usually at the neck, chest or groin area for short to medium term use of between weeks to months (Moss, McLaughlin, Lempert, & Holley, 1988). AVFs join the patient's own artery and vein to create a vascular access or fistula, whereas AVG's use a synthetic material to join an artery and vein. The AVFs have a mean problem free patency period of about three years, and the AVGs last one to two years before indications of failure or thrombosis are noted (Sofocleous & Cho, 2015). AVFs and AVGs can often cause ongoing problems for patients.

The catheters facilitate the connection of the patient to a specialised dialysis machine. The 5008/5008S Therapy System is currently used in the Waikato Regional Renal Centre. This dialysis machine monitors the patient's blood pressure, blood temperature and blood volume. It provides patient safety by using ultrapure dialysis fluid and filters to filter the blood (Fresenius Medical Care Australia Pty Ltd, 2015). Two needles are inserted into the patient's fistula or graft. One draws the blood out of the body and the other returns the cleansed blood to the body. The blood is filtered through a dialyzer or artificial kidney which removes waste products such as urea, creatinine, potassium and excess fluid, and these are washed away. The average person has about five litres of blood which is cleaned through the dialysis machine approximately six to ten times in a dialysis session. Only about 300ml or two cups of blood are out of the body at any time. Dialysis sessions are required on average three times a week with each session lasting four to eight hours (National Kidney Foundation Inc, 2015c). According to Marshall, Byrne, Kerr, and McDonald (2006) the optimal session length is greater than four and a half hours three times a week to ensure the maximum waste products and fluid are removed.

HD is carried out at renal units which are usually attached to a hospital. These units have full-care and self-care facilities depending on the patient's needs. Full-care HD patients are under the care of a renal nurse for the duration of their treatment. Self-care HD patients carry out some of the procedures themselves, but nursing staff are available to assist them. This allows patients to take a more active part in their dialysis treatment and sometimes take full control. HD equipment can also be installed in private homes under the guidance of the renal team and after patient training has been completed. Recently the Kidney Society established four HD community houses in Auckland where up to sixty people can dialyse, and this new initiative is proving very popular for local patients (Kidney Society, 2017). In New Zealand, there were 1752 patients receiving HD treatment as at 31 December 2015 and this has remained static for the past three years. These numbers were made up of 959 patients using hospital based HD, 442 using satellite HD units and 482 using home HD (Kidney Health New Zealand, 2017). Sinclair (2009) states that often patients struggle with home HD because of the lack of explanation regarding techniques, fear of failure and social isolation.

Further issues affecting home HD patients include needle phobias, fear of change, aging and lack of space in the home environment. However, McGregor et al. (2000) report that home HD offers good rehabilitation with good blood pressure control and longer sessions which are on average seven hours of treatment three times a week. Also, home HD has advantages over hospital dialysis due to the lower costs, higher quality of life and longer survival rates.

Peritoneal Dialysis

Peritoneal dialysis (PD) replaces lost kidney function by using the peritoneal membrane in the abdominal cavity as a filter. The peritoneal membrane covers abdominal organs including the stomach, liver, spleen and intestines. These organs are rich in blood vessels which are ideal for the exchange of waste and excess fluid. To access the peritoneal cavity a catheter needs to be surgically inserted. A peritoneal dialysis catheter is composed of a flexible silicone tube with an open-ended port and several side holes to provide optimal drainage and absorption of the dialysate (Ellsworth & Kim, 2015). Dialysate is the fluid used in PD which enters and leaves the peritoneal cavity from bags via the catheter. During PD, the peritoneal cavity is filled with dialysate which draws fluids and toxins out of the blood vessels, and supplies electrolytes and other chemicals to the blood vessels. After a predetermined time, the dialysis fluid is drained into a bag and then discarded along with the removed toxic substances and then replaced with a fresh solution. An adult will hold two to three litres of fluid per exchange depending on their body size and individual conditions (New Zealand Kidney Foundation, 2007).

There are two types of PD, continuous ambulatory peritoneal dialysis (CAPD) and automated peritoneal dialysis (APD). CAPD is continuous and machine free and consists of a daily routine that requires the patient to exchange dialysis fluids every four to six hours. Each exchange takes about forty-five minutes and can be carried out in any clean environment. APD is done overnight with a cycler machine that performs exchanges automatically while patients sleep. The machine controls the movement of fluid in and out of the peritoneal cavity with usually six to eight exchanges every night. The final exchange leaves fluid in the peritoneal cavity so that dialysis can still occur slowly during the day. The APD

machine is portable allowing the user to move freely if required (New Zealand Kidney Foundation, 2007).

PD is the most common form of home dialysis. “The overall proportion of prevalent patients on PD in NZ is 35%, home HD 98%, with the remainder receiving hospital dialysis” (Walker & Marshall, 2014, p. 41). PD is less expensive to set up and maintain than HD (Remuzzi et al., 2013). PD is also associated with reduced mortality when used at dialysis commencement. In Australasia patients starting on PD have approximately 20% reduced adjusted risk of death in the first years of dialysis compared with patients who dialyse in hospital (McDonald, Marshall, Johnson, & Polkinghorne, 2009; Walker & Marshall, 2014). Furthermore, compared with hospital based HD, patients using PD at home report a better quality of life and a more flexible lifestyle, greater independence and more opportunities for employment and social involvement (Kutner, Zhang, Barnhart, & Collins, 2005; Mowatt, Vale, & MacLeod, 2004). There are advantages and disadvantages with both forms of dialysis. The New Zealand Kidney Foundation created this comparison list (Table 1).

Table 1: *Advantages and disadvantages of PD & HD*

Peritoneal Dialysis	Haemodialysis
Performed every day – continuous control of blood chemistry.	Usually performed three times a week – blood chemistries vary from day to day.
Performed every day of the week.	Usually four days off per week.
CAPD is relatively portable – easy to take with you for holidays or travel for work. APD is also portable, as modern machines will fit in the boot of a car.	Haemodialysis has to be done where there is proper plumbing, so if you need to travel you will have to book into a haemodialysis facility close to where you will be.
Peritoneal dialysis is usually done by the patient themselves, and is easy for one person to manage. If required a partner can be trained to assist or perform the treatment.	Some form of assistance is usually required to set up haemodialysis. It can be performed by the patient themselves, or by another person such as a nurse if the patient is unable to do it themselves.
Peritoneal dialysis is always done at home.	Haemodialysis can be done at home, or in a self-care centre near your home, or at a hospital renal unit.
The main complication of peritoneal dialysis is infection – peritonitis. Other risks include blocking or leakage of the peritoneal catheter.	The main complication of haemodialysis is partial or complete blockage of the fistula or graft providing vascular access.
Residual renal function is better preserved in peritoneal dialysis than in haemodialysis.	Residual renal function is lost more rapidly in haemodialysis than in peritoneal dialysis.

Source: (New Zealand Kidney Foundation, 2007, p. 29)

Kidney Transplant

A kidney transplant can be another treatment option for people with ESKD. Kidney transplants are one of the most common and the most successful organ transplantation operations with over an 80% success rate (Youngson, 2000). Donated kidneys can come from two sources, living donors and cadaveric or

recently deceased donors. In NZ, the number of kidney transplants in 2016 was 172. These consisted of 72 live donor transplants and 77 kidneys from 53 cadaveric donors. The median age for NZ transplant recipients in 2015 was fifty and the mean donor age was thirty-six (Kidney Health New Zealand, 2017). Unfortunately, there are more people on the waiting list than there are donors. The average waiting time for a cadaveric kidney in NZ is two to three years (New Zealand Kidney Foundation, 2007).

Another alternative recently carried out in NZ was the establishment of a kidney transplant chain. In 2011 the first two-pair kidney transplant chain operation was performed. This can be utilised when a donor is incompatible with a particular recipient but can be matched with another recipient. This occurred when an ‘emotional donor’, the wife of an ESKD patient, wanted to donate to her husband but was not compatible. Another ‘altruistic donor’ was compatible with her husband so he received this kidney and his wife then donated her kidney to another patient. This transplant chain created the opportunity for two recipients to receive kidneys instead of just using the altruistic donor’s kidney for the husband. This relatively new concept has the potential to increase the amount of living donor transplantations (Voitov, Dittmer, Burton, & Muthu, 2012). As the number of patients requiring kidney transplants is predicted to continue to rise by 4 to 6% annually until at least 2020, the transplant chain model is of significance for NZ patients (Nikolajenko, 2013). It is important to understand that kidney transplants are only available to medically suitable patients. The evaluations of both the recipient and donor involve a rigorous procedure. Regrettably as time passes the health of a recipient will often deteriorate and they may then no longer meet the criteria for a kidney transplant.

The problem of organ shortage has been addressed in Iran by introducing the Iranian model. This model coordinates potential recipients and donors and organises tests to ensure compatibility. A charity known as the Society for Supporting Dialysis and Transplantation Patients was founded in 1978 and by 1990 it had the backing of the Iranian government. The government covers the donor’s full medical care and medical insurance for one year after surgery but only conditions related to the surgery. Donors also receive a gift of about US\$1200 to compensate for lost earnings and absence from work. These

incentives have increased the number of renal donations available to ESKD patients, and in 1999 the waiting list for kidney transplantations fell to almost zero (Einollahi, 2010). The Iranian Model consists of the following characteristics listed in Table 2 below.

Table 2: Iranian Model

Characteristics of ‘Iranian Model’ for living unrelated donor renal transplantation

No coercion
Donors to be true volunteers (altruistic or emotionally related donors)
Donors age > 18 years
Donors given gifts supported by the government
Donors given one year of free health insurance
No commercialism
No matchmaker or broker
No financial benefit for transplant team
No foreign recipients for Iranian donors
No foreign donors for Iranian recipients
Foreigner recipients and donors must be of the same nationality
No waiting list
Rich and poor patients are equally transplanted
Written consent will be obtained from the donor
Written consent will be obtained from the donor’s parents and/or spouse

Source: (Einollahi, 2010, p. 3)

Conservative Treatment

Dialysis or kidney transplantation is not always a suitable option for a patient with renal failure, because it may not be considered in the best interests of the patient’s wellbeing. Brown and Crail (2013) report that in most cases patients for whom treatment is not a viable option are “elderly and have significant co-morbidity, poor functional status, malnutrition or who reside in a nursing home” (p. 401). A conservative treatment pathway is based on realistic discussions about the likely survival of the patient and their quality of life. All decisions regarding these choices involve the patient and family who weigh up the advantages of dialysis versus non-dialysis. With the increased expertise that palliative care specialists can offer, the option of a more holistic approach might be suitable for some patients (Crail, Walker, & Brown, 2013). Treatment options can be reconsidered

at any stage as the patient continues to be under the care of the renal team until death. If a patient is experiencing severe symptoms whilst on dialysis they may change their mind and request conservative treatment and this can then be implemented. For these patients, support can include psychiatric services, counsellors, cultural liaison staff, spiritual care advisers, palliative care and hospice (Egan et al., 2014). The decision to decline treatment will ultimately lead to death within a very short period of time (New Zealand Kidney Foundation, 2007).

In the following section, I turn my attention to the causes of kidney failure.

Causes of Kidney Failure

Diabetes

Diabetic nephropathy or diabetic kidney disease is reported to be the leading cause of renal failure in persons requiring RRT (Ravenscroft, 2005). Diabetic nephropathy affects the ability of your kidneys to do their usual work of removing waste products and extra fluid from your body. The glomeruli are a cluster of capillaries located in the nephron which is the filtering and excretory unit of the kidneys (Gattone, 2009). Diabetic nephropathy causes damage to the capillaries in the kidneys glomeruli, and is characterized by nephrotic syndrome and diffuse scarring of the glomeruli (Mayo Foundation for Medical Education and Research, 2017).

In NZ 49 % of all new patients have diabetic nephropathy as the cause of their ESKD (Kidney Health New Zealand, 2015). In Australia and NZ males are more likely to commence RRT due to diabetes than females, except among Australian Aborigines where females are more at risk (Grace et al., 2012). Māori and Pacific Islanders are three times more likely to get diabetes. Joshy, Dunn, Fisher, and Lawrenson (2009) report that Māori with diabetes are up to forty-six times more likely to have renal failure, much higher than the current official estimate which is three times more likelihood of renal failure for Māori. Also, Māori with type 2 diabetes are fifteen times more likely to die from diabetic nephropathy than NZ Europeans with type 2 diabetes. Māori diabetes patients have significantly higher incidence of dialysis or transplantation (46-fold), rates of renal admission (7-fold) and renal death (4-fold). Māori patients progressed to ESKD at a faster rate from

initial hospital admission for CKD. This huge ethnic disparity highlights the need for Māori diabetes patients to be screened regularly for kidney disease, and the monitoring and management of risk factors (Collins, 2010; Joshy et al., 2009).

Patients with diabetes are susceptible to the thickening of the walls of the small arterioles and capillaries which can affect the kidneys, retina, brain and peripheral nerves. This arteriole damage can cause diabetic nephropathy which leads to ESKD (Medscape, 2015b). The number of people with type 1 and type 2 diabetes is rising, however due to obesity rates increasing type 2 diabetes is now an epidemic (Ministry of Health New Zealand, 2013). According to Ravenscroft (2005) the “incidence and onset of diabetic nephropathy for type 1 diabetes is 33-45%, type 2 diabetes 15-25%. The incidence of kidney failure after 15-20 years of diabetes for type 1 diabetes is 30-50% and for type 2 diabetes it is 5-10%” (p. 503).

Type 1 diabetes is a chronic illness where the pancreas can no longer produce insulin. Onset is often in childhood but it can also develop as an adult. Approximately 5% of diabetics are type 1 and they will need to inject insulin to stay alive. Type 2 diabetes is when there is a resistance to insulin, or the production of insulin is not enough to keep a person healthy (Ravenscroft, 2005). The treatment for type 2 diabetes consists of diet, exercise, medication and education pertaining to blood glucose control. ESKD patients who have type 1 diabetes and meet the requirements for a kidney transplant may also be suitable for a pancreas transplant. This can be done simultaneously or separately depending on the availability of the organs. The benefit of this is that the transplanted pancreas can produce insulin which cures diabetes, improving the overall health of the patient. The prevalence of co-morbid conditions is markedly higher for patients with diabetes and survival rates significantly poorer (National Kidney Foundation Inc, 2015d).

Glomerulonephritis

The second most common cause of ESKD is Glomerulonephritis (GN). GN is a kidney disease affecting the capillaries of the glomeruli. GN is characterised by the presence of albuminuria and edema which is a build-up of fluid in the cells of tissue or in body cavities. Hypertension, the elevation of blood pressure, is also

present (Medscape, 2015a). Very little is known about the cause of GN however it is understood that the patient's own immune system attacks the nephron and causes inflammation, damage and scarring. The onset of GN can be slow or rapid. While some people recover without treatment and some respond to immunosuppressive medication, others progress to ESKD (New Zealand Kidney Foundation, 2007). In NZ 20% of new patients present with this condition (Kidney Health New Zealand, 2015).

Hypertension

In NZ the cause of ESKD in 11% of all new patients is attributed to Hypertension (HTN) or high blood pressure (Kidney Health New Zealand, 2015). HTN can contribute to or cause CKD and vice-versa in a cyclic relationship. HTN damages the blood vessels within the kidney and throughout the body. When this damage occurs in the kidney the function is impaired and the kidney cannot efficiently filter fluid and waste from the blood. This leads to an increase of fluid volume in the blood which causes an increase in HTN (Buffet & Riccheitti, 2015). The importance of lowering blood pressure through effective treatment can reduce the risk of kidney damage by half and the risk of kidney failure by a third (New Zealand Kidney Foundation, 2007).

Analgesic Nephropathy

Analgesic Nephropathy is a term used by nephrologists to describe how some drugs cause kidney damage. The most prevalent of these to cause kidney damage was the drug phenacetin, which was used for pain relief (van der Woude et al., 2007). Phenacetin was mixed with aspirin and codeine and sold as a head-ache powder, but in the early 1980s phenacetin was banned because it was found to be causing kidney damage (New Zealand Kidney Foundation, 2007). Phenacetin has also been listed as a risk factor in kidney cancer if a person has a past history of long term use (National kidney Foundation Inc, 2015e). Other non-phenacetin combinations are also under constant review especially those containing paracetamol, aspirin and caffeine, to ensure they are safe from causing kidney damage (van der Woude et al., 2007).

Vascular Risks

Vascular risks occur when there is a compromised blood flow to the kidney. This can involve the large blood vessels leading to the kidney or the smaller blood vessels within the kidney. When these vessels become blocked it can result in kidney damage and renal failure. The vascular system is put at risk if a person is a smoker, if they have a diet high in fatty foods, high cholesterol, do not regularly exercise or are obese. The consequences of these lifestyle choices can cause heart attacks, strokes and kidney failure (New Zealand Kidney Foundation, 2007).

Obesity is a strong risk factor for developing CKD and ESKD. The kidneys must work harder in obese people to meet the demands of the increased body weight more blood must be filtered which can damage the kidneys. The World Health Organisation (2017b) estimates that by 2025 “obesity will affect 18% of men and over 21% of women worldwide, and that severe obesity will affect 6% of all men and 9% of all women, people who are overweight or obese have 2 to 7 times more chance of developing ESKD compared to those of normal weight” (p. 1).

Furthermore, acute kidney injury (AKI) occurs more frequently in obese people. By reducing obesity CKD can be reversed or the progression slowed down (World Health Organisation, 2017a).

Screening

In NZ regular screening for CKD in the Primary Health Organisations has been recommended by the Ministry of Health, however there is currently no systematic process for screening apart from those who have diabetes (Nikolajenko, 2013). According to Walker, Abel, and Meyer (2010) early detection of renal failure is important so that the patient can receive pre-dialysis care, which is effective in extending the time before going on dialysis is necessary. Pre-dialysis education also improves patient acceptance of their diagnosis and the treatment choices available. One research project in NZ analysed the historical abnormal glomerular filtration rates (GFR) of a community over five years to gain a baseline of how prevalent CKD was in this community. The results showed that

2130 people had results consistent with stage 1 CKD (normal kidney function with normal or increased Glomerular Filtration Rate (GFR)); 5390 were consistent with stage 2 CKD (kidney damage with mild decrease in

GFR); 1201 were consistent with stage 3 CKD (moderately decreased GFR); 69 were consistent with stage 4 CKD (severely decreased GFR); and eight with stage 5 CKD (end stage kidney failure). While the eight people with stage 5 CKD knew their diagnosis, a significant number of those at stage 3 and 4 did not” (Nikolajenko, 2013, p. 16).

In total 8798 people had results consistent with different stages of CKD. Of these 1270 were diagnosed as stages 3 and 4 CKD, when pre-dialysis care should be in place. Pre-dialysis education is effective in reducing the requirement to start dialysis urgently, and for improving patient and clinical outcomes.

In the next section, I move on to explore the impacts of kidney failure for end stage kidney patients, which are many and complex.

The impacts of kidney failure

Nutrition

Nutrition management is complex for renal patients because everything that is ingested produces waste which builds up in the bloodstream. In particular the levels of sodium, potassium, phosphate and fluids need to be closely monitored. Elevated levels of any of these will cause the renal patient to experience negative side effects and even death (Beto & Bansal, 2004). The recommendation is that HD patients gain no more than 500 grams per day measuring from their dry weight which is “the weight when all extra fluid is removed, ideally post-dialysis weight as a goal” (Beto & Bansal, 2004, p. 407). The recommended fluid intake is no more than 1.0 – 1.5L of fluid including fluid in food over 24 hours, because prolonged fluid overload is related to “congestive heart failure, hypertension, pulmonary edema and shortened patient survival” (Christensen & Ehlers, 2002, p. 713). PD patients have fewer problems regarding fluid retention than HD patients. A further problem for renal patients can be malnutrition and between thirty and fifty percent suffer from this (Fouque, Pelletier, Mafra, & Chauveau, 2011). However, it is common for renal patients to have a high body mass index (BMI). A BMI of between twenty-five and twenty-eight has been correlated with higher survival rates. Renal patients who are under the care of a dietician have a 19% lower mortality rate which confirms that nutrition care is vital (Steiber, 2014).

Medication

People with chronic kidney failure (CKD) have complex medical needs likely to involve the need to take medication. Medication for patients with CKD and ESKD requires special consideration because the kidneys metabolize or filter a large proportion of all medications. Due to the reduced glomerular filtration rate (GFR) the clearance of these medicines needs to be strictly monitored (Weir & Fink, 2014). Caution is required with over the counter medications as there is a significant risk associated with certain medications such as non-steroidal anti-inflammatory drugs which need to be avoided (University of Maryland, 2011). As CKD patients have high co-morbidities such as diabetes and hypertension requiring medication there is a risk of polypharmacy, creating an opportunity for negative drug interactions. Commonly prescribed medications for a person with renal failure are erythropoietin which is used to treat anaemia; blood pressure medication to lower the patient's blood pressure; phosphate binders to help control the level of phosphate and calcium in the body; vitamins and minerals in particular vitamin D which is normally activated by the kidneys; lipid lowering agents to help lower cholesterol; diuretics which increase the flow of urine and antibiotics to treat infections (New Zealand Kidney Foundation, 2007).

Pain

Pain is particularly common in patients with renal failure, with a reported 80% of those on haemodialysis experiencing pain. Although pain is a frequent symptom for most patients with ESKD, it remains ineffectively managed (White & McDonnell, 2014). Salisbury et al. (2009) discuss key reasons for this including the lack of recognition that there is a problem because of poor communication with patients, the pathology of the pain is poorly understood and it is often chronic and complex. The pain could be a result of ESKD or from a co-morbid condition such as vascular disease or diabetic neuropathy. In patients with ESKD the pharmacokinetics or the movement of drugs within the body, and the pharmacodynamics or the biochemical and physiologic effects of drugs and how these are altered is a concern. This can lead to reluctance to prescribe effective doses of analgesic drugs that offer relief from pain (Salisbury et al., 2009). The World Health Organization developed a pain management approach known as the analgesic ladder. However, this ladder was inappropriate for ESKD patients

because it contains non-steroidal anti-inflammatory drugs, in particular morphine which is not recommended for renal patients as it is not removed by dialysis and accumulates in the body. The analgesic ladder has been modified for renal patients and includes three steps which are designed to provide increased pain relief (Figure 1).

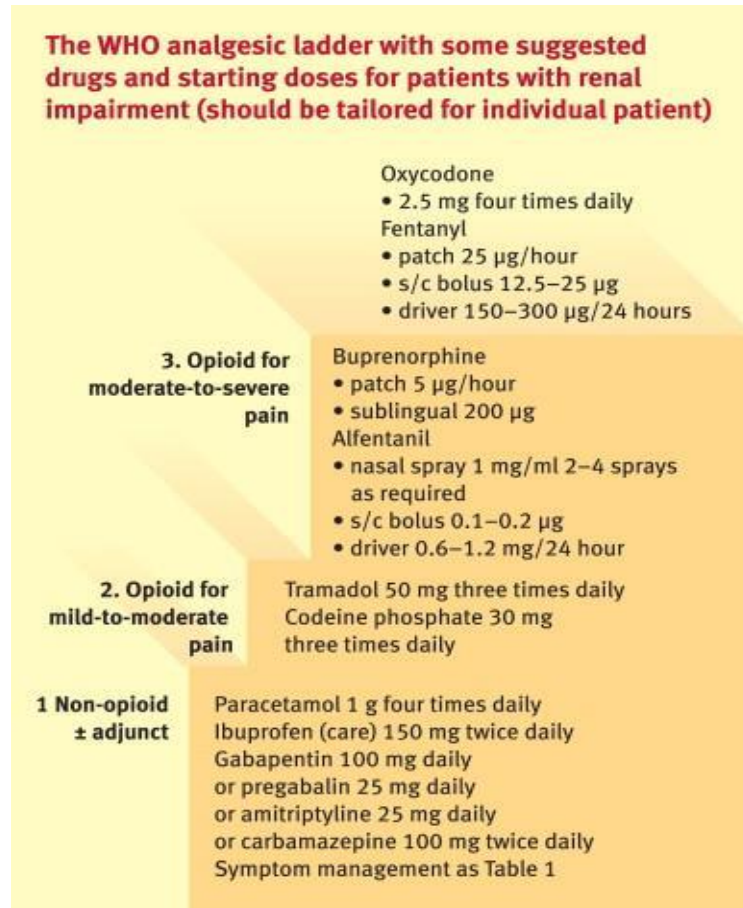


Figure 1: *The WHO analgesic ladder*

Source: (Brown, 2015, p. 494)

The undertreatment of pain has a significant impact on the quality of life of renal patients and “may induce depression, anxiety, insomnia, and decreased functional capacity and interfere with ability to interact socially” (Barakzoy & Moss, 2006, p. 3202).

The financial cost of kidney failure

The cost for a person requiring renal replacement therapy ranges from \$65,000 per patient annually for hospital-based dialysis, or home-based dialysis costs around

\$35,000 annually. “Expenditure on RRT accounts for between 1 to 2% of the total public health expenditure. Dialysis currently costs NZ over \$150 million each year” (Henderson, 2014, p. 4). If the patient is a NZ resident the public health system covers these costs. Renal patients in NZ consist of 68% using HD and 31% using PD (Kidney Health New Zealand, 2015). Karopadi, Mason, Rettore, and Ronco (2013) reported that in 2008 the prevalence of ESKD worldwide meant that 1.75 million patients were receiving dialysis treatments. 89% or 1.55 million were using HD and 11% or 197,000 were using PD. They further established that HD was used more in developed countries and PD in developing countries. The cost of a kidney transplant in NZ is estimated at \$90,000 in its first year (Henderson, 2014). The survival rate for the first year after a kidney transplant now exceeds 90%, however at ten years it is less than 40% (Levey & Coresh, 2012).

There are financial factors for a renal patient that must also be taken into consideration which include the loss of regular income. This can be due to treatment times clashing with work commitments and hospitalisations due to illness. The renal patient has high travelling expenses because they have regular hospital and clinic visits as well as hospital based treatments for some HD patients. Most renal patients take a cocktail of medications which have an associated cost, however this is minimal for the individual patient in NZ because of government subsidies. A mobile phone is also essential for a patient who is on the transplant list so they can be contacted if a kidney becomes available.

Psychological effects of kidney failure

People with renal disease will usually experience grief and loss associated with their diagnosis and illness. Grief is “prolonged or abnormal levels of bereavement or sense of abandonment following a loss” (Brown & Barlow, 2011, p. 128). The psychological effects for people diagnosed with kidney failure usually include the grief cycle. This consists of the emotional stages of denial, anger, bargaining, depression and finally acceptance. These stages have no particular order or any specific time frame that these emotions will affect individual patients (New Zealand Kidney Foundation, 2007).

The psychological challenges for people with CKD may include the change in their identity from being healthy to being sick and the fear of dialysis treatment. Some patients may feel acceptance about dialysis treatment as it keeps them alive, but many resent and dislike this invasive treatment. They may worry about the uncertainty of the disease outcome and the risk of death. They may experience disruptions to daily life and financial struggles because of the rigid treatment programme. Patients' self-concept and self-esteem will often be altered due to changes in their physical ability, lifestyle and social roles and they may feel like a burden to family and friends (Schick Makaroff, 2012).

Schick Makaroff (2012) raises issues regarding the impact of a lack of freedom for a CKD patient. This is due to the time spent in treatment, restricted diet and fluids, limited options for travel especially for HD patients, work constraints, medical costs, reduced income and increased dependence on others. De Sousa (2008) concurs that these restrictions impede on the person who is living with kidney failure so they struggle to pursue a normal life. CKD patients can rarely return to full time work and as a result their income and the associated sense of accomplishment, self-esteem and identity are affected. They may encounter negative experiences with the healthcare service and feel a lack of autonomy when decisions are made about care. This is common among people suffering with chronic illness (Schick Makaroff, 2012).

Living with a kidney transplant also requires psychological adjustment. These patients worry about their future health and finances, and they must also cope with the side effects of immunosuppressive medications. Transplant patients must follow a strict medication regimen and continue to go to clinic and laboratory appointments. Non-adherence to these factors is believed to be an important contributor to renal graft rejection and failure (Christensen & Ehlers, 2002). Furthermore, if the kidney came from a cadaveric donor, the recipient may need to mourn the death of the unknown person and also feel guilt about receiving the organ. Live donor recipients may fear organ failure, and struggle with how to show their gratitude to the donor. If the organ does fail and dialysis is re-initiated this can be a major crisis point for the patient, with an estimated 60% experiencing symptoms of depression (Zalai, Szeifert, & Novak, 2012).

Depression

The psychological distress imposed on patients with CKD contributes to at least one in four suffering from depression (Zalai et al., 2012). It is estimated that the prevalence of depressive disorders in patients with chronic medical illnesses is one and a half to four times higher than the general population. ESKD patients are reported to have the highest incidence with four times higher rates of depressive disorders. This is associated with adverse dialysis outcomes. Contributing to this are biological, psychological, spiritual and socio-economic factors as presented in Table 3 below.

Table 3: *Factors contributing to depression in patients with CKD*

Psychological Distress and Depression in Patients with Chronic Kidney Disease

Biological factors: Uremic toxins; chronic inflammation; disturbance of glucose-insulin homeostasis; deregulation of hypothalamic–pituitary–adrenal axis; other biological mechanism → Changes in neuro-hormonal activity → Somatic symptoms, sickness behaviour; sleep disturbance; pain; fatigue; reduced appetite; decreased sexual drive.

Psychological, spiritual factors: Changes in social roles and self-image; decreased autonomy and control; loss of freedom; hopelessness; limited capacity for self-expression, productivity and social involvement; negative body image; low self-esteem; fear of uncertain future, ill health, death and dying, existential questions, meaning of life.

Socio-economic factors: Younger age; female gender; low perceived social support; unemployment; low income.

=Depression

Source: (American Psychiatric Association, 2013, p. 160)

Depressive disorders are diagnosed by severity, duration and the number of symptoms. Table 4 provides a description of Major Depressive Disorder,

Persistent Depressive Disorder (Dysthymia) and examples of Other Specified Depressive Disorder. Table 4: Symptoms of depressive disorders (DSM 5)

Major Depressive Disorder

Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.

1. Depressed mood
2. Markedly diminished interest or pleasure in all, or almost all activities
3. Significant weight loss or gain or decrease or increase in appetite
4. Insomnia or hypersomnia
5. Psychomotor agitation or retardation
6. Fatigue or loss of energy
7. Feelings of worthlessness or excessive or inappropriate guilt
8. Diminished ability to think or concentrate, or indecisiveness
9. Recurrent thoughts of death, recurrent suicidal ideation, or a suicide attempt

The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning

Persistent Depressive Disorder (Dysthymia)

Depressed mood for at least 2 years

Presence, while depressed, of two (or more) of the following:

1. Poor appetite or overeating
2. Insomnia or hypersomnia
3. Low energy or fatigue
4. Low self-esteem
5. Poor concentration or difficulty making decisions
6. Feelings of hopelessness

Examples of Other Specified Depressive Disorder

Recurrent brief depression: depressive episodes lasting from 2 – 13 days at least once per month

Short-duration depressive episode (4-13 days): Depressed affect and at least four of the eight symptoms of a major depressive episode

Depressive episode with insufficient symptoms: Depressed affect and at least one of the eight symptoms of a major depressive episode

Source: (Zalai et al., 2012, p. 430)

It should be noted that diagnosis of depression in ESKD patients is problematic due to similarities between the somatic symptoms of depression and the physical symptoms associated with the side effects of ESKD treatment. Neurovegetative signs of depression comprising of “fatigability, cognitive deficits, decreased appetite, insomnia and loss of libido can occur secondary to chronic renal failure and in the absence of a depressive syndrome” (Christensen & Ehlers, 2002, p. 717). ESKD is associated with conditions such as “anaemia, electrolyte disturbances, and underlying systemic disease (e.g., diabetes) which may mimic depressive symptoms. In addition, ESKD patients may take medications such as antihypertensive and corticosteroids which can produce mood-altering effects” (Christensen & Ehlers, 2002, p. 717). Antihypertensive drugs are a class of drug used to treat hypertension and prevent the complications of high blood pressure such as stroke or myocardial infarction. Myocardial infarction or heart attack is the irreversible death of heart muscle secondary to prolonged lack of oxygen supply (Medscape, 2017). Corticosteroids, often referred to as steroids, are man-made drugs that closely resemble cortisol, a hormone that your adrenal glands produce naturally (Cleveland Clinic, 2017).

De Sousa (2008) states that depression, anxiety, suicide and delirium are common complications for ESKD patients. Repeated observational studies about depression have reported that ESKD patients have higher suicide rates than the normal healthy population. To cause death these patients simply miss dialysis treatment or consume high potassium foods, or voluntarily withdraw from dialysis altogether (De Sousa, 2008). ESKD patients are also more likely to be noncompliant regarding diabetes treatment and hypertension and have alcoholic tendencies. ESKD patients are noted as the biggest deniers of psychiatric illness because they already feel over-medicalised. According to Gurkan, Pakyuz, and Demir (2015) they may “practise dysfunctional coping strategies including behavioural disengagement, mental disengagement, focusing on and venting of emotions, denial and substance abuse” (p. 1394). Increased mortality and hospitalisation rates and less treatment compliance are associated with depression in CKD leading to poorer quality of life for these patients (Bautovich, Katz, Smith, Loo, & Harvey, 2014).

Health related quality of life

White and McDonnell (2014) refer to the growing body of literature reporting that impaired health relates to quality of life. Health related quality of life (HRQOL) is defined as “the state of one’s well-being in the areas of physical health, mental health, social health and a global sense of one’s health. It is the subjective impact that a disease process has in a patient” (White & McDonnell, 2014, p. 76). The health-related quality of life (HRQOL) for patients with ESKD is identified as poorer when compared to patients with other chronic illnesses and has been likened to cancer patients receiving palliative care. Patients can become resentful of the enduring nature of the disease and the high symptom burden of ESKD impacts on HRQOL. As routine psychosocial screening is not included in treatment patients with ESKD, depression is often unrecognised and undertreated by healthcare professionals. A more vigorous management of depression has the potential to dramatically improve HRQOL (White & McDonnell, 2014).

Bhowmik and Kumar (2014) also note that because of the multiple co-morbidities that occur in ESKD patients, they need a more specialised treatment programme. They suggest that to improve the quality of life for these patients the nephrology teams work in tandem with palliative care practitioners and with patients and their families.

Treatment

Bautovich et al. (2014) stress that there is an urgent need for well-conducted randomised trials of intervention for depression in CKD, to provide more knowledge around the safety and efficacy of treatments. Schick Makaroff (2012) note that research is required to explore the role of lay caregivers and children of parents living with CKD in the treatment of depression. Avşar et al. (2015); Zalai et al. (2012) highlight the importance of intervening early when treating major depression to obtain the best results. Routine screening is suggested for depression at either clinic appointments or dialysis treatment to identify people in psychological distress using a screening tool such as the Beck Depression Inventory (BDI) which takes approximately five minutes to complete (Zalai et al., 2012). The BDI is used to detect the presence of depression and to determine a baseline level of severity. This baseline can then be used to determine the effectiveness of interventions (Groth-Marnat, 2009).

According to De Sousa (2008) antidepressant therapy combined with psychotherapy is the recommended treatment for depression. Zalai et al. (2012) also recommend psychotherapy and pharmacotherapy, but suggest that these can be complemented with other therapies including “light therapy; different stress reduction methods; music, or art therapy, and physical activity” (p. 434). Cognitive behavioural therapy (CBT) is a goal oriented, time limited, and evidence based therapy which treats depression. Significant reductions in depressive symptoms have been recorded when CBT was used with CKD patients and they also maintained better emotional, behavioural, interpersonal and cognitive adjustment. Group and individual sessions were both successful in reducing the symptoms of depression. An advantage of CBT is that it does not involve medication. If antidepressant medication is required for CKD patient’s careful attention must be paid to the possibility of drug interactions and side effects (Zalai et al., 2012).

Gabbard (2001) states that the therapeutic alliance is especially important in depressed patients. Also, that the patient therapist match is just as important between patients and their pharmacotherapy healthcare providers and their psychotherapy providers. Positive psychology which focuses on resilience and protective psychosocial factors can also help patients and their families cope with CKD. Furthermore, Zalai et al. (2012) suggest that “narrative medicine, whole person care, integrative and holistic medicine” (p. 435) could be helpful for staff caring for these patients. For CKD patients who have home based treatments the option for telephone or computer-based telecommunication has been recommended. It is suggested that future studies should focus on the promotion of self-management through telemedicine and the internet (Taal, 2013; Zalai et al., 2012).

Non-compliance

According to Christensen and Ehlers (2002) ESKD is unique among medical conditions because of the extreme dependence on artificial means for survival, as well as the considerable behavioural demands on the patient. The psychological factors for ESKD patients include “patient non-adherence with the medical treatment regimen, patient emotional distress, and psychosocial influences on morbidity and mortality” (p. 713). I present these factors in Table 5 below.

Table 5: *Nonmedical factors for chronic diseases*

Nonmedical factors influencing morbidity for people with chronic diseases

Cognitive, emotional and behavioural factors

- Depression due to loss of role function
- Persistent or chronic intermittent pain resulting in avoidance behaviours
- Poor psychological adjustment due to fear, anxiety, low self-esteem
- Lack of confidence in prevailing abilities
- Poor pain coping skills
- Mood fluctuations
- Stress and fatigue
- Helplessness
- Affective distress
- Health distress

Physical factors

- Muscle weakness
- Poor or reduced aerobic capacity
- Poor flexibility
- Obesity or malnourishment
- Sleep disturbances

Other factors

- Marital status and stability
- Poor patient-health provider communication skills
- Problem of poor adherence to long-term maintenance of treatment regimes
- Extent and quality of social support
- Access to quality health care
- Age, race, gender, education level, culture, socioeconomic status

Source: (Marks, Allegrante, & Lorig, 2005, p. 39)

The most significant behavioural impediment for ESKD patients is non-adherence to the medical treatment regimen. Non-adherence among renal patients has been

estimated at between 30% and 60%. This includes not adhering to diet, fluid intake and medication recommendations. The restrictions regarding the recommended amount of fluid intake is the most common non-adherence (Christensen & Ehlers, 2002). Non-adherence by missing dialysis treatment sessions is relatively rare and is estimated to occur in approximately 2% of patients. However, this does not include the shortening of treatment sessions because of problems or negative symptoms.

Self-efficacy

Favourable outcomes for ESKD patients have been attributed to the concept of self-efficacy. Bandura (1995) defined self-efficacy as ones' belief in ones' ability to succeed in specific situations or in accomplishing a task. One's sense of self-efficacy can play a major role in how one approaches goals, tasks, and challenges. High self-efficacy is related to positive behaviours patients can sustain for longer, whereas low self-efficacy has the opposite effect (Wierdsma, Van Zuilen, & Van Der Bijl, 2011). The tasks associated with chronic disease are displayed in Table 6.

Table 6: *Chronic disease tasks*

Tasks a patient with chronic disease may have to be able to perform
Correct medication usage
Exercise
Weight loss
Appropriate food selection
Stress management strategies
Pain and other management strategies
Behaviours that improve or slow down disease progression, for example, testing for blood glucose
Accurate self-diagnoses, data analysis, and decisions such as adjusting insulin levels
Modified personal care, household and community mobility activities
Adjustments to new social and economic circumstances
Pertinent communications with physicians, family members, and other caregivers
Modification of his or her living and work environment as well as valued activities

Source: (Marks et al., 2005, p. 151)

There are many factors that are potentially modifiable when self-efficacy improves and focusing on self-efficacy perceptions can influence morbidity in chronic illness (Marks et al., 2005). Hence a focus on self-efficacy can improve the long-term maintenance which is required for ESKD patients to successfully manage this chronic disease, therefore improving quality of life significantly. Conversely, having low self-efficacy may create changes in health-related self-management behaviours which worsens health outcomes especially pain levels and mental health status (Marks et al., 2005, p. 40). Self-efficacy in patients with chronic illness such as ESKD is facilitated when awareness and training about self-efficacy are implemented (Fu et al., 2003; Lorig et al., 2001; Tsay, 2003; Wu, Hsieh, Lin, & Tsai, 2016).

One of these programmes is the Chronic Disease Self-Management Program which consists of a 17-hour course delivered over seven weeks to patients with a variety of chronic illnesses. It focuses on the day-to-day self-management of symptoms common in patients with a chronic illness. Other self-efficacy programs implemented with ESKD patients involve topics such as “pathophysiology of renal failure and haemodialysis, medications, complications, nutrition, fluid restrictions, control of thirst and urge to drink, and stress management” (Tsay, 2003, p. 372). Participants in these reported improved health behaviour, self-efficacy, and health status. A list of self-efficacies enhancing strategies pertinent to managing chronic disease such as ESKD is displayed in Table 7.

Table 7: *Self-efficacy enhancing strategies*

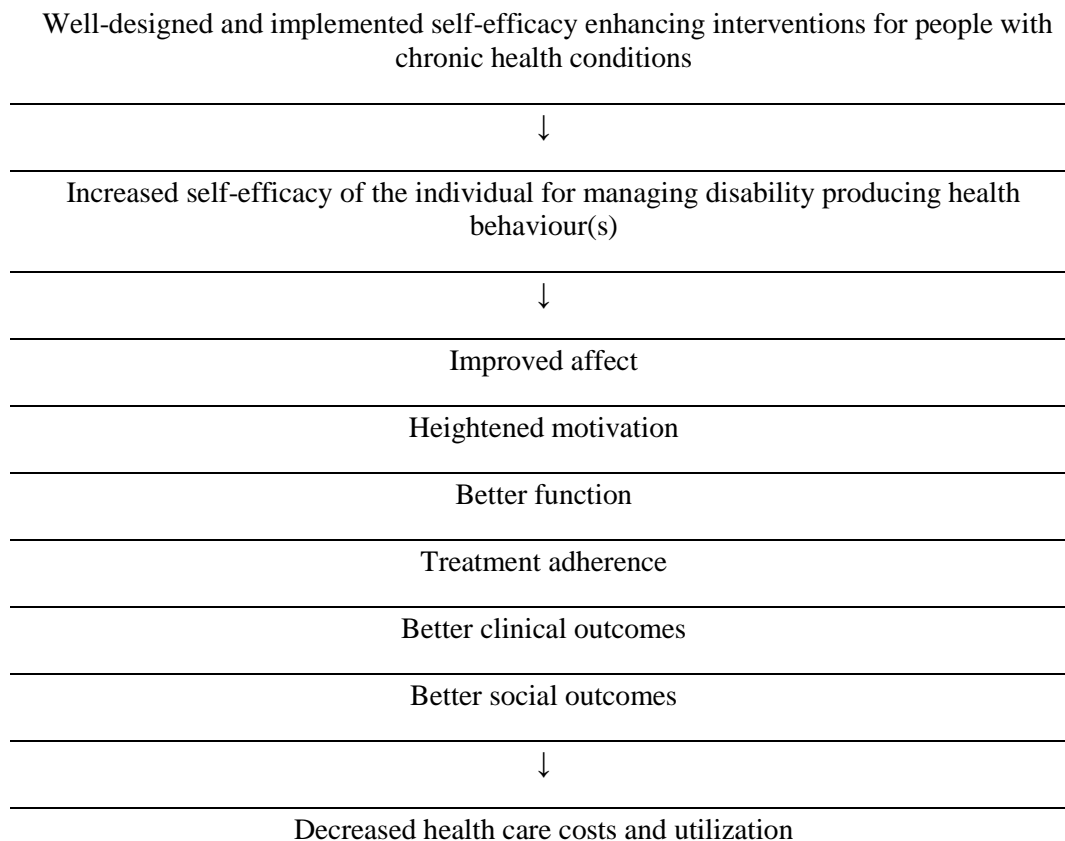
**Summary of primary characteristics of successful self-efficacy enhancing strategies
for people with chronic disease**

1. Use a variety of learning strategies including lectures, discussions, brainstorming, demonstrations, goal setting, contracting, modelling, mental practice, homework, recall-enhancing methods, workbooks, texts, and videotapes, and provide mutual aid and support.
2. Involve significant others, such as spouse or family members, and encourage collaboration with other health care providers and self-efficacy of caregivers.
3. Foster self-management of exercise, food selection, weight control, fear, pain, depression and anxiety, and related self-monitoring strategies in small steps.
4. Apply encouragement, persuasion, and direct or indirect support for the desired changes.
5. Foster self-appraisal of emotional and physiological responses, decision making, and the necessary knowledge, skills, and problem-solving ability to deal with disease-related issues across different domains.
6. Use trained educators, a detailed manual, and multicomponent teaching strategies with content drawn from both patients and practitioners.
7. Use both individual and small-group intervention approaches especially collaborative and active participation strategies.

Source: (Marks et al., 2005, p. 152)

There is growing evidence that suggests self-management programs that include self-efficacy can be valuable regarding the management of chronic disease. These outcomes are hypothesized in Table 8.

Table 8: *Self-efficacy enhancing interventions*



Source: (Marks et al., 2005, p. 153)

Locus of control

The construct of locus of control (LOC) is related to self-efficacy. LOC is a

“cognitive style or personality trait characterized by a generalized expectancy about the relationship between behaviour and the subsequent occurrence of reinforcement in the form of reward and punishment. People with internal locus of control tend to expect reinforcements to be the consequences of their own efforts or behaviour, whereas people with external locus of control expect them to be the consequences of chance, luck, fate, or the actions of powerful others” (Colman, 2017, p. 1).

Christensen and Ehlers (2002) posit that HD patients with internal locus of control exhibit more favourable treatment adherence. However other research suggests that internal LOC expectancies is not related to HD regimen adherence (Brown & Fitzpatrick, 1988; Schneider, Friend, Whitaker, & Wadhwa, 1991). This controversy according to Christensen, Turner, Smith, Holman, and Gregory (1991) is because most of the previous research does not differentiate between internal LOC, powerful others, and external LOC beliefs which may factor into

the apparent inconsistency of these findings. Furthermore, LOC can change as the illness progresses and becomes life threatening, especially among patients who experience rapid illness progression. One technique is to suggest patients' focus move from the uncontrollable factors such as the necessity to dialyse, to the more controllable factors such as self-care activities. Self-care activities are controllable and improve internal LOC. Whilst coping with a largely uncontrollable illness such as ESKD this change can impact positively on patients' health status (Cvengros, Christensen, & Lawton, 2005).

Social support

Isolation for the renal patient can include the feelings of disconnection within established relationships, and a view that they are being left behind and that no one cares. They often feel as though they are a burden on family members who may have to help support them financially and emotionally (Schick Makaroff, 2012). Social support is very important for renal patients and this can be received from family members, friends and medical personnel. According to Hoth, Christensen, Ehlers, Raichle, and Lawton (2007) social support is associated with reduced depressive symptoms. Patients who are severely ill and have a less supportive family environment reportedly had higher levels of depression and anxiety than patients with a more supportive family environment. However, in patients with low illness impairment it was reported that the effect of family support was not significant (Christensen & Ehlers, 2002). Kimmel (2001) recognise social support as an important factor for patients adjusting to chronic and acute illness and its link to improved health outcomes. It has been associated with better compliance in ESKD patients, lower levels of interdialytic weight gain and better biochemical compliance measures. Quality social support also correlates positively with adherence in ESKD patients to their fluid and treatment regimens. If a patient has a supportive family environment and little intra-familial conflict they are more likely to cope better with all the restrictions. Interestingly, Christensen and Ehlers (2002) suggest that the perceived level of social support is more important for males than females.

Anxiety

Research pertaining to anxiety in patients with ESKD has not received as much attention as depression. "Anxiety is a physiological and psychological state

characterised by cognitive, somatic, emotional, and behavioural components” (Kohli, Batra, & Aggarwal, 2011, p. 177). Anxiety is typically recognised as uneasiness, apprehension or worry. Anxiety is a normal response to stress but extreme or prolonged anxiety can lead to mental health problems and reduced quality of life. The symptoms of Generalized Anxiety Disorder are presented in Table 9 as follows.

Table 9: *Symptoms of Generalized Anxiety Disorder*

Generalized Anxiety Disorder

Excessive anxiety and worry occurring more days than not for at least six months	
The individual finds it difficult to control worry	
The anxiety and worry are associated with three (or more) of the follow	
1.	Restlessness or feeling keyed up for on edge
2.	Being easily fatigued
3.	Difficulty concentrating or mind going blank
4.	Irritability
5.	Muscle tension
6.	Sleep disturbance (difficulty falling or staying asleep, or restless unsatisfying sleep)

Source: (American Psychiatric Association, 2013, p. 222)

HD patients with cardiac disease are more likely to have higher anxiety and reduced general health, and generally females on HD have higher anxiety with lower quality of life (Alavi, Aliakbarzadeh, & Sharifi, 2009). House (1987) conducted a study with HD patients and reported that 17.1% suffered from depression and 8.7% from anxiety which were the most common diagnoses. However, Öyekçin, Gülpek, Sahin, and Mete (2012) report depression at 11.1% and anxiety at 2.8%. Numerous other studies have reported a significant correlation between depression and anxiety in ESKD patients (Alavi et al., 2009; Hmwe, Subramanian, Tan, & Chong, 2015; Kohli et al., 2011)

ESKD patients with internal LOC generally show less anxiety and cope better with solution management (Kohli et al., 2011). Coping strategies for ESKD

patients experiencing anxiety or depression include problem focused coping strategies such as “active coping, planning, restraint coping, seeking of instrumental social support, suppression of competing activities” (Gurkan et al., 2015, p. 1394). Emotion focused coping strategies include “positive reinterpretation, humour, seeking emotional social support and turning to religion” (Gurkan et al., 2015, p. 1394). Religion is used as a coping strategy because praying can evoke the feelings of serenity, rest and acceptance. Gurkan et al. (2015) found that non-Western patients who practice traditional philosophies such as Chinese-Confucianism, Buddhism and Taoism manage life stressors differently from patients with Western philosophies who turn to religion for comfort.

Summary

It cannot be denied that the psychological effects for patients with ESKD are many. They must manage the enduring treatments of HD or PD as well as changes regarding occupational, marital, familial, societal and personal aspects of their lives. Furthermore, normal life is impeded by dietary constraints, time restrictions, feelings of handicap, financial burdens and an awareness of impending death (Kohli et al., 2011). It is essential that these patients be equipped to formulate a ‘new normal’ whilst surviving amid uncertainty (Schick Makaroff, 2012).

This chapter provides a guide into understanding the complexities of ESKD. It highlighted what the issues are for renal patients and the resources required to support these patients. The physical, emotional, social and financial factors were considered in this review. The research reviewed in this chapter provides a starting point to explore the nature of psychological wellness of renal patients on dialysis under the care of the Waikato Regional Renal Centre, which is the focus of this study.

Chapter Two: Method

The primary focus of this research was to explore the nature of psychological wellness of renal patients on dialysis. This research used both qualitative and quantitative methods to obtain data. The qualitative data was made up of semi-structured interviews with dialysis patients and renal health professionals. The quantitative data was derived from a questionnaire designed for PD and HD patients. The questionnaire also gathered short qualitative responses.

Recruitment of participants

Recruitment procedures

A meeting was held at the Waikato Renal Unit attended by Mr P. Sizeland the clinical director, Mrs H. O'Connell the associate charge nurse of the unit and myself. It was decided that I would not be allowed access to the names and addresses of patients because I was not employed by the District Health Board (DHB). However, Mr Sizeland advised me that the staff were prepared to label the envelopes and post out the questionnaires on my behalf. I agreed to supply them with the sealed envelopes and they facilitated their distribution. I provided the Regional Renal Centre in Hamilton, and the satellite units in Gisborne, Rotorua, Tauranga and Whakatane with a total of five hundred and thirty-one envelopes. The envelopes contained the questionnaire, interview recruitment poster, and a letter from the Renal Centre supporting my research. Also included was a self-addressed envelope and a complementary ballpoint pen. A total of four hundred and seventy-five questionnaires were either handed out or posted to renal patients, and the fifty-six that were not required were destroyed. Three hundred and fifty-five envelopes required outgoing and return postage, and 176 required only return postage because they were handed out at the renal centres to the in-care haemodialysis patients. Staff confirmed these numbers by completing and returning to me a confirmation sheet (Appendix A).

Recruitment of questionnaire participants

An envelope containing the questionnaire was either posted or handed out as arranged by the renal staff. The questionnaire included a brief synopsis about the research and about myself, and informed participants about their rights if they decided to participate. The questionnaire included background questions and

asked about social support using the Social Provisions Scale–Short Version (SPS). Also included was the Beck Depression Inventory-Second Edition (BDI) and the Beck Anxiety Inventory (BAI), as well as questions pertaining to psychological well-being (Appendix B).

Recruitment of Peritoneal dialysis and haemodialysis patients for interview

Patients on dialysis were recruited for an interview using a flyer. This flyer was included with the questionnaire. The flyer included the title of the research, researchers name and a brief description of what the research entailed.

Recruitment of health professionals for interview

Health professionals were recruited for interviews using a flyer distributed at the renal unit. However, some health professionals were contacted directly for an interview including the clinical director of the renal unit and staff who work at the Kidney Society. Unfortunately, the clinical director did not respond to my requests and no interview was obtained.

Participants

The following demographic information was collected from section one in the questionnaire. The patient sample who responded to my questionnaire was comprised of 114 males and 82 females, one participant withheld this information. They were aged between 29 to 91 years old (Mean = 60.73 years, Median = 62 years). Four participants did not verify their age. Twenty-seven participants were never married, 115 were married or de facto, 25 widowed and 29 separated / divorced. One participant did not answer this question.

The self-identified ethnicity of the participants included 99 Māori (50.5%), 77 NZ European (39.3%), 8 Other European (4.1%), 7 Pacific Islander (3.6%), and 5 of some 'other' ethnicity (2.6%). The high representation of Māori participants was expected due to the considerably higher rates of ESKD among indigenous people (McDonald & Russ, 2003). One participant did not answer this question.

However, 14 participants listed more than one ethnicity or ticked the box labelled 'Other', highlighting the diversity of the sample which included Dutch, New Zealander, Middle Eastern, Indian Nepalese, South African, Malay, Scottish, Irish, Chinese, African, Pakeha, Kiwi and English.

Just over a third of participants indicated a household income of less than \$20,000 (N=71, 38.6%), there were 45 in the 20,001-30,000 range (24.5%), 28 in the 30,001-50,000 range (15.2%), 19 in the 50,001-70,000 range (10.3%), 12 in the 70,001-100,000 range (6.5%), and 9 whose house-hold income was 100,001 or more (4.9%). A low income of less than \$30,000 was reported by 63.1% of the participants, with only 36.9% above this figure.

Development of research tools

Research flyer

Two separate research flyers were developed, one for dialysis patients and one for health professionals. They included the title of the study and a brief description about what the research entailed (Appendices C & D). I provided my contact details (phone and email) so that they could arrange a time to meet with me and share their personal stories. Ethical approval details were also provided to reassure potential participants that the study had been ethically approved.

Participant information sheet

Two information sheets were developed to inform participants about the research, one for renal patients and another for health professionals. The information sheets explained the objective of the research, and the rights of the participants (Appendices E & F). The information sheets listed the contact details for myself, my supervisor and the Chair of the Ethics Committee. This was to ensure that interested people or participants could contact the appropriate person if they needed to.

Participant consent form

Two consent forms were developed for either patients or health professionals to ensure the participants understood their rights and what was required of them. I asked each participant to read and complete the form. Each participant received a copy of this form which included the contact details for the Ethics Committee (Appendices G & H). They were given adequate time to ask questions of me as

the researcher and to have their questions answered to their satisfaction, or to discuss their participation with others if they wanted to.

Interview questions for dialysis patients

The interview questions for the renal patients consisted of nineteen different questions (Appendix I). An interview checklist and reflexive notes were taken at every interview. The interview schedule included items to gather patient background information and treatment modalities which were followed by items to invoke conversation about psychological help, well-being, social support and the roles whanau/family/significant others play in their lives. The items in the dialysis patients' interview schedule were aligned with items in the survey questionnaire and interview schedule for health professionals to allow for the emergence and examination of parallel and related perspectives.

Interview question for health professionals

The health professional schedule included 18 items (Appendix J) and included items that enquired of their training in mental health and their strategies for determining depression and anxiety amongst renal patients. Items about the lack of psychological services and the impact access to these services could have for these patients were also included. Further items related to their perspective on how whanau / family / significant others impact on their care of the patient.

Mail-out Questionnaire

The questionnaire included a cover letter introducing myself and why the research was being conducted. It also included confirmation of ethics approvals and contact details. The questions were arranged in sections and the first section consisted of background questions such as age, gender, ethnicity and income. The next section asked about the type of dialysis treatment the patient was using and the length of time they had been in treatment. It also asked whether or not they were on the transplant list. Then three self-report measures were used: a) the SPS, b) the BDI and the c) BAI. Participants were then asked questions pertaining to aspects of renal services being provided and their individual coping mechanisms used during treatment, followed by social support questions. Finally, different therapies and holistic techniques were presented to gauge the patient's amount of interest in these.

The Social Provisions Scale – Short Version

The SPS was completed by the questionnaire participants. This scale was used to assess the way in which participants perceived their social relationships, and rated various dimensions of social support and interactions available to them. There were ten questions in total. Each question was answered by choosing a word that best described how the participants felt about the question; ‘strongly disagree’ = 1, ‘disagree’ = 2, ‘agree’ = 3 and ‘strongly agree’ = 4’. Each answer had a score ranging from 1 – 4. The negatively worded items were reversed such as (4=1, 1=4). This self-report scale had a possible minimum score of 10 and a maximum score of 40. The higher the score indicated that the more supported the participant felt. Social provisions theory considers the functions of social relationships across specific social roles including “romantic partner, spouse, family members, friends, colleagues etc., especially when individuals face critical life-changing events” (Chiu et al., 2016, p. 298). There are five subscales which include, Guidance, Reassurance of Worth, Social Integration, Attachment and Reliable Alliance.

Guidance refers to having people available who can provide suggestions, solutions, and advice when needed; reassurance of worth refers to having others validate one’s competence and value; social integration denotes sense of belonging to a group with whom one shares common interests and social activities; attachment refers to feelings of intimacy, peace, and security (similar to emotional support); reliable alliance has to do with perceived access to assistance in times of need from others (Chiu et al., 2016, p. 298).

It is suggested that people need all five types of social provisions as listed in the subscales. If one is deficient an individual is at risk of experiencing social and or emotional loneliness. Each subscale had two questions the total minimum score for each subscale is two and the maximum is eight.

The SPS is a self-report scale used “to examine the degree to which participants’ social relationship provide various dimensions of social support” (Cutrona & Russell, 1987, p. 472). The validity of the SPS is recognised by Caron (2013) who states that

the SPS items are highly correlated with total scores and its internal consistency is excellent. The alpha for the global scale is 0.880 and the alphas for the five subscales ranged from 0.528 to 0.690. The analyses suggest that the SPS is a reliable and valid instrument for measuring the availability of social support” (p. 297).

Further studies concur with these findings and state that the SPS scale is one of the most widely used measures of perceived social support in psychological literature (Chiu, Motl, & Ditchman, 2016; Perera, 2016).

The Beck Depression Inventory

The BDI is an indicator of the presence and degree of depressive symptoms. The 21 item self-report scale was analysed using overall results, as well as looking at cognitive affective symptom scores and somatic symptom scores (Beck, Steer, & Brown, 1996). The cognitive affective symptoms include sadness, pessimism, past failure, loss of pleasure, guilty feelings, punishment feelings, self-dislike, self-criticalness, suicidal thoughts or wishes, crying, loss of interest, indecisiveness and worthlessness. The somatic symptoms include agitation, loss of energy, changes in sleeping pattern, irritability, changes in appetite, concentration difficulty, tiredness or fatigue and loss of interest in sex (Delisle et al., 2012).

The minimum score achievable in this test is 0 and the maximum is 63, a higher score indicating increasing symptom severity (Delisle et al., 2012). The scores have four categories which ranged from 0-13 being minimal, 14-19 being mild, 20-28 being moderate and 29-63 being severe depressive symptoms. Kimmel (2001) recommends a BDI score of >15 for a diagnosis of depressive disorder in patients with end stage kidney disease, while Hedayati, Bosworth, Kuchibhatla, Kimmel, and Szczech (2006) suggested a score of >14 for a diagnosis. Nineteen of the items are rated from 0 to 3, two items 0 to 6.

The BDI was used to assess each participant's level of depression. The BDI on average has a “Cronbach’s alpha coefficient of approximately 0.85, and reliability of the BDI among medical samples was satisfactory, with an alpha of approximately 0.90, ranging between 0.84 and 0.94” (Wang & Gorenstein, 2013b, p. 1279). Wang and Gorenstein (2013a) investigated self-assessment measures to

evaluate depression, and found the BDI outnumbers the other measures in the amount of published research, and that the BDI is increasingly used in the medically ill to evaluate depressive symptoms. Adult renal haemodialysis patients were represented in this finding.

The Beck Anxiety Inventory

The BAI is a twenty-one item self-report scale. The minimum score achievable is 0 and the maximum is 63, with a higher score indicating increased symptom severity. The participants choose from four options; not at all, mildly (it did not bother me much), moderately, (it was very unpleasant, but I could stand it) and severely (I could barely stand it). The score ranges for interpreting the intensity of self-reported anxiety were total score 0-7 points indicating minimal anxiety, 8-15 indicating mild anxiety, 16-25 indicating moderate anxiety and 26-63 indicating severe anxiety (Beck & Steer, 1993).

The four subscales included neurophysiological, subjective, panic and autonomic symptoms. The neurophysiological symptoms of anxiety include seven items: wobbliness in legs, unsteady, dizzy or lightheaded, numbness or tingling, shaky, hands trembling and feeling faint. The subjective aspects of anxiety include six items: unable to relax, fear of the worst happening, nervousness, fear of losing control, feeling scared and feeling terrified. The panic symptoms of anxiety include four items: heart pounding or racing, difficulty breathing, fear of dying and a feeling of choking. The autonomic aspects of anxiety include four items: indigestion or discomfort in the abdomen, feeling hot, sweating (not due to heat) and flushed face (Beck & Steer, 1993).

The BAI was used to measure the severity of anxiety each participant was experiencing. The BAI “was constructed to measure the symptoms of anxiety, and the BAI showed high internal consistency $\alpha = .92$ (Beck, Epstein, Brown, & Steer, 1988).

Ethical Approval

Ethical approval for this research was granted from the University of Waikato’s School of Psychology Ethics Committee, approval number 16:18. The DHB research committee, and the Te Puna Oranga Māori Consultation Research Review Committee, approval number: RD016048. Furthermore, I based my

research approach using the Code of Ethics for Psychologists working in Aotearoa / New Zealand. The Code of Ethics has four key principles; respect for the dignity of persons and people; responsible caring; integrity in relationships; social justice and responsibility to society (The New Zealand Psychological Society, 2012).

Obtaining ethics from three different agencies was a challenge and very time consuming. It took one month to get ethics approval from the University of Waikato and the feedback offered was very helpful and the recommendations were implemented. The Waikato DHB took four months to complete my ethics approval which was unexpected, and required a lot of follow-up on my behalf. However, communications were very helpful and pleasant whilst working on the approval. Te Puna Oranga Māori Consultation Research Review Committee took one month to approve my research.

Research procedures

Semi structured interviews

One-on-one interviews were a part of this research, and there were no time restrictions. It was at the participant's discretion to advise me when and where would be suitable for them to participate. Interviews were carried out in the dialysis patients' private homes and at the in-care centre in Hamilton. The health professional interviews were all conducted within a workplace environment.

At the start of every interview I thanked the participant for their time and participation, and I introduced myself and discussed with them my background and my connection to the research. I then asked if they had any questions regarding the research that I could answer and clarify. I explained how a semi-structured interview was implemented whilst encouraging free discussion. I asked them to read the information sheet and read and sign a consent form. A copy of the information sheet and consent form were left with each participant, and I retained a signed consent form for my records. Once this paperwork was completed I asked permission to record the interview and I turned on two recording devices to ensure no loss of data. The interviews then commenced.

However, after completing a couple of patient interviews I realised that one of my questions was too complex: Do you feel factors such as depression, anxiety,

stress, family, financial issues are taken into consideration within your treatment programme? Which ones have you been affected by? I decided to remove stress, family, financial issues and only ask about depression and anxiety. Another patient question that was recorded differently than expected was: How would you rate your health in general now? This became a Likert Scale answer with 1 being poor and 10 being excellent, which was proposed by a participant at an interview. At every interview, I tried to use open and probing questions because it “helps create a climate of attentiveness and listening where people feel able to respond in any way they like. Probing questions like ‘tell me more about that’ encouraged the participant to respond with a deeper level of understanding” (Breakwell, Hammond, Fife-Schaw, & Smith, 2006, p. 331).

In total twenty-five interviews were completed which consisted of eleven dialysis patients and fourteen health professionals. The demographics for the dialysis patient participants included five females and six males. There were four participants who identified as Māori and seven as European. The ages ranged from 30-50 years old for five of the participants and 51-75 years old for six participants. The health professionals included 12 females and 2 males. All participants were given a pseudonym to protect their identity and keep their participation confidential.

The average time for the dialysis patients’ interviews was fifty-three minutes, and the average time for health professionals was sixty-one minutes, this does not include pre-and post-interview discussions or travel. In total seven of the participants lived out of Hamilton and four participants required the travel time of over two hundred kilometres to conduct the interviews. At the end of each interview I thanked them for their participation and presented each participant with a box of chocolates as a thank you gift. All the interviews were recorded and then transcribed verbatim, because total transcription is regarded as good practice (Breakwell et al., 2006). If requested on the consent form by the participant the transcript was sent to them for verification. I posted out eight transcripts to dialysis patients, and nine to the health professionals. No participants have contacted me with any issues or problems. The transcribed interviews were then analysed using thematic analysis.

Thematic analysis

Thematic analysis “involves analysing and interpreting texts and interviews in order to discover meaningful patterns descriptive of a particular phenomenon” (Auerbach, 2003, p. 13). A thematic analysis is an “empirically driven approach for detecting the most salient of content in interviews” (Harper & Thompson, 2012, p. 220). The patient and health professional interviews were analysed using thematic analysis to “emphasize both the commonalities and differences between participants concerning the dominant themes” (Breakwell et al., 2006, p. 270).

An appropriate method of analysis is important when completing qualitative research, and a thematic analysis is a widely used qualitative analytic method within psychology research. It is similar to grounded theory which allows for theories to evolve or be grounded in the data (Braun & Clarke, 2006). In this research, an inductive analysis was chosen to analyse the data, because this approach means “the themes identified are strongly linked to the data themselves” (Braun & Clarke, 2006, p. 83). Inductive analysis “is therefore a process of coding the data without trying to fit it into a pre-existing coding frame, or the researcher’s analytic preconceptions. In this sense, this form of thematic analysis is data driven” (Braun & Clarke, 2006, p. 83). The semi-structured interview format encouraged free discussion from the participants producing rich narrative data, and each participant expressed very personal views about their journey. Thus, a collection of narrative data rich in depth of knowledge and experience was presented to analyse and interpret. An analysis of the interview data was completed using guidelines by (Braun & Clarke, 2006) (Table 10).

Table 10: *Phases of thematic analysis*

Phase		Description of the process
1.	Familiarizing yourself with the data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2.	Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3.	Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4.	Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5.	Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and overall story the analysis tells, generating clear definitions and names for each theme.
6.	Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back to the analysis to the research question and literature, producing a scholarly report of the analysis.

Source: (Braun & Clarke, 2006, p. 87)

Three main themes were created and fifteen subthemes which have been defined as;

- Impacts on psychological well-being
- Need for psychological support for patients
- Need for improved communication

These themes will be the structure for the findings in the next chapter. The next chapter provides a detailed presentation of the findings from the completed questionnaires and interviews with dialysis patients, and health professionals working in renal care.

Chapter three: Questionnaire Findings

The questionnaire I administered comprised of five sections the first of which contained items that gathered demographic information about the respondents. This information has already been presented in chapter two. The second section asked about the type of treatment respondents were on and the length of time they had been in treatment. It also asked about aspects of renal services being provided and the individual coping mechanisms respondents used during treatment. The third, fourth and fifth sections contained the three self-report scales the SPS, the BDI and the BAI.

In this chapter, I report the results of the questionnaire survey. While mostly quantitative, there were also items in the questionnaire that sought an explanatory or expanded comment from the participant. I present these comments progressively and as appropriate to the quantitative results found and conclude with a summary of the results from the completed analysis.

One hundred and ninety-seven dialysis patients completed the questionnaire. The sample is comprised of 113 (57.7%) respondents on HD and 83 (42.3%) using PD. The four types of treatments the respondents are currently using are presented in Table 11.

Table 11: *Types of dialysis treatment*

		Treatment option			
		N	Percent	Valid Percent	Cumulative Percent
Valid	In care Haemodialysis	82	41.6	44.8	44.8
	Home Haemodialysis	31	15.7	16.9	61.7
	Continuous Ambulatory Peritoneal Dialysis	25	12.7	13.7	75.4
	Automated Peritoneal Dialysis	45	22.8	24.6	100.0
	Total	183	92.9	100.0	

Missing	14	7.1		
Total	197	100.0		

When asked if they had used both haemodialysis and peritoneal dialysis treatment options 101 respondents (52.1%) stated ‘yes’ and 93 (47.9%) stated ‘no.’ The amount of time respondents had been a dialysis patient ranged from 1 month to 360 months or 30 years. The mean was 56.92 months or 4 years 9 months. The majority (N=130, 68.4%) of the respondents have been dialyzing for up to 5 years. Forty-two (22.1%) respondents have been dialyzing from 5 to 10 years, 9 (4.8%) from 10 to 15 years, 7 (3.6%) from 15 to 20 years, one (0.6%) from 20 to 25 years and one (0.5%) from 25 to 30 years.

Transplant list

Most of the questionnaire respondents 135 (73%) reported that they were not on the transplant list. Several added extra information, “not sure,” “no I am a Jehovah’s Witness,” “I have a live donor,” and “suspended until I have had an operation.” Of the 11 patients I interviewed, 9 reported they were not on the transplant list. *Amy* expressed that for her “the biggest problem is the transplant list, I had two donors over three years ago and no one followed them up.” *Zoe* noted “I have been on the list for a year now,” and *Ned* commented that he is “15kg overweight, if I lose it then I can go onto the transplant list.”

Coping mechanisms

The questionnaire respondents were asked ‘do you have any coping mechanisms you use whilst in treatment?’ Fifty respondents (26.9%) answered ‘yes’ and 136 (73.1%) answered ‘no’. Out of the 50 who answered ‘yes’, many gave qualitative responses about their coping mechanisms such as; “squidgy ball to strengthen and open up the fistula.” “I stand up while draining out; this makes me feel I am helping to get all the extra fluid out.” “I make sure I have everything I need, phone, drink, emergency numbers.” “Humor.” “Relaxation.” “I think a lot about the past.” “Private sessions, only immediate family come in, I’m on home haemodialysis.” “Prayers, worship, singing.”

Requests during treatment

The respondents were also asked ‘do you feel your requests are being considered whilst in treatment, if no why?’ One hundred and seventy-one participants (92.4%) answered ‘yes’ and 14 (7.6%) answered ‘no’. Some of the responses were, “not all the time.” “Specialists don't listen.”

Feeling secure

The respondents were asked ‘do you feel secure whilst participating in treatment?’ Most of the respondents answered ‘yes’ (N=186, 96.4%) and seven (3.6%) answered ‘no.’ Four respondents expanded upon their answers, “yes, but it depends on procedures being done (e.g. graft issues).” “Yes, because I have a phone close at hand.” “Yes, providing there are no problems.”

Nurses responses

The respondents were then asked, ‘how important is the nurse’s response to your requests?’ There was a seven-point scale provided for the respondents to choose from (Table 12). The majority selected ‘very important’ (N=78, 40.8%). Two respondents added extra information, “I can't remember the last time I rang the nurse or seen one” and “I would not contact a nurse unless it was an extreme emergency.”

Table 12: *Patient requests*

		How important is the nurse's response to your requests			
		N	Percent	Valid Percent	Cumulative Percent
Valid	Not at all important	4	2.0	2.1	2.1
	Very unimportant	20	10.2	10.5	12.6
	Somewhat unimportant	5	2.5	2.6	15.2
	Neither important nor unimportant	5	2.5	2.6	17.8
	Somewhat important	39	19.8	20.4	38.2
	Very important	78	39.6	40.8	79.1
	Extremely important	40	20.3	20.9	100.0
	Total	191	97.0	100.0	
Missing		6	3.0		

Total	197	100.0		
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Level of care

The respondents were also asked ‘do you feel your care level is adequate, if no why? The majority of the respondents reported that ‘yes’ their care level was adequate (N=184, 96.3%) and seven (3.7%) answered no to this question. Some respondents expanded on this answer, “no, you’re just left there and expected to know how to set up your machine, and not shown how to set up properly.” “No, you feel no one really cares, it’s just a job.” “No, the nurse is very busy with other patients.” “Yes, fantastic support from all concerned.” “Yes, but I have noticed a few document errors along the way.” “Yes, although better on call support at home would be a great improvement.”

Health Rating

The respondents were asked ‘how would you rate your health in general now? In total 192 respondents completed this question. There was a scale of answers provided from ‘much better’ to ‘much worse’ (Table 13). The majority answered ‘better’ (N=42, 21.9%) and ‘somewhat better’ (N=41, 21.4%). Some respondents added, “It will never be like before dialysis but the proof is in the monthly blood test.” “Much better than before dialysis.” “Ten years ago, I was given a 2% chance of reaching fifty now I have one year to sixty.”

Table 13: *Health rating*

How would you rate your health in general now

		N	Percent	Valid Percent	Cumulative Percent
Valid	Much better	34	17.3	17.7	17.7
	Better	42	21.3	21.9	39.6
	Somewhat better	41	20.8	21.4	60.9
	About the same	36	18.3	18.8	79.7
	Somewhat worse	25	12.7	13.0	92.7
	Worse	9	4.6	4.7	97.4
	Much worse	5	2.5	2.6	100.0
	Total	192	97.5	100.0	

Missing	5	2.5		
Total	197	100.0		

Activities

The patients who completed the questionnaire were asked about activities they prefer to do whilst in treatment. The most popular activity for the respondents was to watch TV (N=118, 60.8%).

Table 14: *Treatment activities*

		What activity do you prefer to do whilst in treatment			
		N	Percent	Valid Percent	Cumulative Percent
Valid	Watch TV	118	59.9	60.8	60.8
	Listen to music	17	8.6	8.8	69.6
	Talk to staff	1	.5	.5	70.1
	Read	22	11.2	11.3	81.4
	Use a computer	14	7.1	7.2	88.7
	Phone family / friends	1	.5	.5	89.2
	Other	21	10.7	10.8	100.0
	Total	194	98.5	100.0	
Missing		3	1.5		
Total		197	100.0		

Section Three: Social Provisions Scale-Short Version

In total 188 respondents completed the Social Provision Scale (SPS). The minimum score was 17 and the maximum was 40 (M=31.66, SD=4.39).

Cronbach's alpha was used to measure the internal consistency reliability of the SPS. In psychology, a good measure should have a Cronbach's alpha of at least .60 and preferably closer to .90 (Aron, Aron, & Coups, 2009). Cronbach's alpha of the overall SPS subscale was α .84 indicating good reliability.

A t test was conducted between the total SPS scores and the age of the respondents to determine if age was an indicator for social support. There was a statistically significant difference between the SPS scores and age. SPS scores (N=188, M=31.66, SD=4.40) and age (N=193, M=60.73, SD=12.68), $t(379) = -29.74$, $p < .001$, are predictors of social support. The 95% confidence interval was -30.99 to -27.14, and Cohens $d = 3.0$, a large effect size.

A further t test was conducted between the total SPS scores and the amount of time a patient had been on dialysis. There was a statistically significant difference between the SPS scores and the amount of time a patient had been on dialysis. SPS scores (N=188, M=31.66, SD=4.40) and time on dialysis (N=190, M=56.92, SD=57.14), $t(376) = -6.04$, $p < .001$, are predictors of social support. The 95% confidence interval was -33.45 to -17.03 and Cohens $d = .60$, a medium effect size. Therefore, age and the amount of time a patient has been on dialysis affect the perception of social relationships and social support. An explanation of "cohens effect size conventions for mean differences are: small = 0.20; medium = 0.50; and large = 0.80" (Aron et al., 2009, p. 183).

An analysis of the five SPS subscales and the role family have in their care was completed, this was to determine what subscales were important to the respondents to feel they were being supported (Table 15).

Table 15: *SPS subscales and family care*

Mann-Whitney U Test

	Do your whanau/family/significant other have an active role in your care	N	Mean Rank	Sum of Ranks
Guidance	Yes	132	98.62	13018.00
	No	50	72.70	3635.00
	Total	182		
Reassurance of worth	Yes	132	95.04	12545.00
	No	50	82.16	4108.00
	Total	182		
Social interaction	Yes	132	95.91	12659.50
	No	50	79.87	3993.50
	Total	182		
Attachment	Yes	132	96.32	12714.50
	No	50	78.77	3938.50
	Total	182		
Reliable alliance	Yes	132	94.18	12432.00
	No	50	84.42	4221.00
	Total	182		

Test Statistics^a

	Guidance	Reassurance of worth	Social interaction	Attachment	Reliable alliance
Mann-Whitney U	2360.000	2833.000	2718.500	2663.500	2946.000
Wilcoxon W	3635.000	4108.000	3993.500	3938.500	4221.000
Z	-3.086	-1.576	-1.929	-2.081	-1.171
Asymp. Sig. (2-tailed)	.002	.115	.054	.037	.242

The results of this test indicate that the subscale guidance ($p=.002$), which includes having people who can provide suggestions, solutions and advice, and the subscale attachment ($p=.037$) which is emotional support, were important factors contributing to the respondents feeling that the family have an active role in their care.

An analysis of the five SPS subscales and the respondent's perception of the families understanding of their illness was completed, this was to determine what subscales were important to the respondents to feel understood (Table 16).

Table 16: *SPS subscales and family understanding of ESKD*

Mann Whitney U Test				
	Do your whanau/family/significant other understand the nature of your illness	N	Mean Rank	Sum of Ranks
Guidance	Yes	172	93.53	16088.00
	No	10	56.50	565.00
	Total	182		
Reassurance of worth	Yes	172	91.95	15816.00
	No	10	83.70	837.00
	Total	182		
Social interaction	Yes	172	93.73	16122.00
	No	10	53.10	531.00
	Total	182		
Attachment	Yes	172	94.71	16290.50
	No	10	36.25	362.50
	Total	182		
Reliable alliance	Yes	172	93.30	16047.00
	No	10	60.60	606.00
	Total	182		
Test Statistics^a				
Guidance	Reassurance of worth	Social interaction	Attachment	Reliable alliance

Mann-Whitney U	510.000	782.000	476.000	307.500	551.000
Wilcoxon W	565.000	837.000	531.000	362.500	606.000
Z	-2.250	-.515	-2.491	-3.535	-2.003
Asymp. Sig. (2-tailed)	.024	.607	.013	.000	.045

The results of this test indicate that the subscales, guidance ($p=.024$), social interaction ($p=.013$) which denotes a sense of belonging to a group, attachment ($p<.001$) and reliable alliance ($p=.045$) which is a perceived access to assistance when needed are important factors for the respondents to feel that their family understand the nature of their illness.

Therefore, the SPS subscales guidance, attachment, social interaction and reliable alliance are important factors for a person on dialysis to feel they received social support and were connected to social relationships.

Further tests were completed with the factors gender, ethnicity and treatment options but the analysis did not return any significant results, thus they are not reported in this study.

Section Four: Beck Depression Inventory (BDI) – Second Edition

The BDI is an indicator of the presence and degree of depressive symptoms. One hundred and ninety-seven questionnaire respondents completed the BDI. The overall score results from this research consisted of a minimum score of 1 and a maximum score of 44, ($M=13.97$, $SD = 9.33$). A total of 111 respondents (56.3%) scored between 1-13 indicating minimal symptoms, 38 respondents (19.3%) scored between 14-19 indicating mild symptoms, 28 respondents (14.2%) scored between 20-28 indicating moderate symptoms and 20 respondents (10.2%) scored between 29-63 indicating severe depressive symptoms.

The moderate and severe results combined totalled 24.4% which indicates these participants have levels of depression in line with the 20-30% reported in the literature (Kimmel, 2001). The mean score for the respondents was 13.97 which is lower than the reported mean score for ESKD patients which is >15 for HD or PD patients (Kimmel, 2001).

Cronbach's alpha was used to measure the internal consistency reliability of the 21 BDI test items. The Cronbach's alpha coefficient of the overall test items was $\alpha .87$ indicating good reliability. The BDI tests were also analysed by test items to gauge which items patients were reporting as areas of concern (Table 17). These items were all somatic symptoms, which included items 'changes in sleep patterns' and 'changes in appetite'. Also, the items loss of interest in sex, loss of energy and tiredness or fatigue. All these symptoms are listed in the DSM-V as diagnosis criteria for a major depressive disorder or persistent depressive disorder. This indicates that the respondents are showing a high number of diagnosable depressive symptoms.

Table 17: *BDI test items*

Descriptive Statistics					
	N	Minimum	Maximum	Mean	Std. Deviation
Changes in Sleeping Pattern	197	0	6	2.65	2.054
Changes in Appetite	197	0	6	1.45	1.251
Loss of Interest in Sex	197	0	3	1.32	1.099
Loss of Energy	197	0	3	1.24	.638
Tiredness or Fatigue	197	0	3	1.16	.804
Loss of Pleasure	197	0	3	.82	.829
Concentration Difficulty	197	0	3	.69	.708
Loss of Interest	197	0	3	.61	.905
Self-Criticalness	197	0	3	.58	.953
Self-Dislike	197	0	3	.55	.798
Agitation	197	0	3	.52	.773
Pessimism	197	0	3	.50	.806
Irritability	197	0	3	.49	.682
Indecisiveness	197	0	3	.44	.687
Punishment Feelings	197	0	3	.44	.922
Crying	197	0	3	.44	.834
Guilty Feelings	197	0	3	.39	.601

Past Failure	197	0	3	.39	.724
Worthlessness	197	0	3	.38	.624
Sadness	197	0	3	.28	.515
Suicidal Thoughts or Wishes	197	0	2	.15	.396
Valid N (listwise)	197				

A t test was completed between the BDI scores and the age of respondents. The BDI scores (N=197, M=13.97, SD=9.33) and age of respondents (N=193, M=60.73, SD=12.68), $t(388) = -41.55, p < .001$, is a significant factor for increased risk of depression. The 95% confidence interval was -48.97 – -44.55, with a Cohens $d = 4.0$.

A t test was completed between the BDI scores and the amount of time respondents have been on dialysis. The BDI scores (N=197, M=13.97, SD=9.33) and time on dialysis (N=190, M=56.92, SD=57.14), $t(385) = -10.41, p < .001$, is a significant factor for increased risk of depression. The 95% confidence interval was -51.06 – -34.83, with a Cohens $d = 1.0$. There was a statistically significant difference between the BDI scores and age and the amount of time a patient has been on dialysis, indicating that these are risk factors for depression.

Further tests were analysed with the factors, gender, ethnicity, income, treatment options and type of treatment, the perceptions of how much the respondent's family understand of their illness and how much of an active role they have in their care. These analyses did not return any significant results therefore, they are not reported in this study.

Section Five: Beck Anxiety Inventory (BAI)

The BAI was completed by 197 questionnaire respondents who scored between a minimum of 0 and a maximum score of 49, (M= 12.26, SD = 10.42). A total of 85 respondents (43.1%) scored between 0-7 for minimal anxiety, 54 respondents (27.5%) scored between 8-15 for mild anxiety, 30 respondents (15.2%) scored between 16-25 for moderate anxiety and 28 respondents (14.2%) scored between 26-63 for severe anxiety.

Cronbach's alpha was used to measure the internal consistency reliability of the four subscales which examined neurophysiological, subjective, panic and autonomic symptoms. Cronbach's alpha coefficient of the subscales was $\alpha .84$ indicating good reliability. A t test analysing the four subscales (N=197) was completed. Overall the subscale for 'neurophysiological' symptoms had the more statistically significant results of the four subscales, which indicated that the respondents who completed this test were more concerned with the physical symptoms of anxiety they experienced.

Cronbach's alpha was also used to measure the internal consistency reliability of the 21 items used in the BAI test. The Cronbach's alpha coefficient of the 21 items was $\alpha .92$ indicating good reliability. The test items were analysed to determine which items respondents reported as areas of concern (Table 18). The four most reported areas of concern were all neurophysiological symptoms and included wobbliness in legs, being unsteady, dizzy or lightheaded, experiencing numbness or tingling.

Table 18: *BAI test items*

Descriptive Statistics					
	N	Minimum	Maximum	Mean	Std. Deviation
Wobbliness in legs	197	0	3	1.05	.949
Unsteady	197	0	3	.98	.895
Dizzy or lightheaded	197	0	3	.96	.820
Numbness or tingling	197	0	3	.93	.904
Heart pounding or racing	197	0	3	.72	.880
Unable to relax	197	0	3	.72	.839
indigestion or discomfort in abdomen	197	0	3	.67	.807
Fear of the worst happening	197	0	3	.64	.879
Difficulty breathing	197	0	3	.60	.866
Feeling hot	197	0	3	.60	.800
Shaky	197	0	3	.49	.697

Nervous	197	0	3	.47	.760
Hands trembling	197	0	3	.45	.665
Fear of losing control	197	0	3	.43	.743
Fear of dying	197	0	3	.42	.808
Scared	197	0	3	.41	.800
Faint	197	0	3	.40	.627
Terrified	197	0	3	.35	.758
Sweating (not due to heat)	197	0	3	.35	.617
Feelings of choking	197	0	3	.31	.687
Face flushed	197	0	3	.31	.591
Valid N (listwise)	197				

A t test was completed between the BAI scores and the age of respondents. The BAI scores (N=197, M=12.26, SD=10.42) and age of respondents (N=193, M=60.73, SD=12.68), $t(388) = -41.28, p < .001$, is a significant factor for increased risk of anxiety. The 95% confidence interval was -50.78 – -46.16, with a Cohens $d = 4.0$.

A t test was completed between the BAI scores and the amount of time respondents had been on dialysis. The BAI scores (N=197, M=12.26, SD=10.42) and time on dialysis (N=190, M=56.92, SD=57.14), $t(385) = -10.78, p < .001$, was a significant factor for increased risk of anxiety. The 95% confidence interval was -52.80 – -36.51, with a Cohens $d = 1.0$. There was a statistically significant difference between the BAI scores and age and the amount of time a patient had been on dialysis, indicating that these are risk factors for anxiety.

A Kruskal-Wallis Test was conducted between the BAI scores and household income over twelve months (Table 19). There was a statistically significant difference between the BAI scores and income. Respondents with low income of up to \$30,000 were at higher risk for anxiety.

Table 19: *BAI and income test*

Kruskal Wallis Test

	Household Income over 12 months	N	Mean Rank
Beck Anxiety Inventory	20,000 or less	71	105.72
	20,001 - 30,000	45	103.32
	30,001 - 50,000	28	77.86
	50,001 - 70,000	19	76.13
	70,001 - 100,000	12	63.50
	100,001 or more	9	52.89
	Total	184	

Test Statistics^{a,b}

Beck Anxiety Inventory	
Chi-Square	18.721
df	5
Asymp. Sig.	.002

A Kruskal-Wallis Test was conducted between the BAI scores and the dialysis treatment options currently used by the respondents (Table 20). There was a statistically significant difference between the BAI scores and treatment options in-care haemodialysis and continuous ambulatory peritoneal dialysis patients were at higher risk of anxiety.

Table 20: *BAI and dialysis treatment option*

Kruskal Wallis Test

	Treatment option	N	Mean Rank
Beck Anxiety Inventory	In care Haemodialysis	82	106.32
	Home Haemodialysis	31	70.50
	Continuous Ambulatory Peritoneal Dialysis	25	100.20
	Automated Peritoneal Dialysis	45	76.17
	Total	183	

Test Statistics^{a,b}

Beck Anxiety Inventory	
Chi-Square	15.752
df	3
Asymp. Sig.	.001

The completed analysis of the BAI would suggest that age, the amount of time on dialysis, low income and the treatment options in-care haemodialysis and continuous ambulatory peritoneal dialysis are significant factors for anxiety.

Further tests were analysed with the factors gender, ethnicity, type of treatment, the perceptions of how much the respondents' family understand their illness and how much of an active role they have in their care. These analyses did not return any significant results thus they are not reported in this study.

Summary

The majority of the questionnaire respondents were using in-care HD, the next highest number were using APD, followed by home HD users and the least amount who were using CAPD. This is consistent with Wilkie (2011) who found that in-care HD is continuing its dominance over home based treatments. The amount of time the respondents have been dialyzing ranged from one month to 30 years, with most respondents being in the up to five years range. Only a few of the respondents reported that they were on the transplant list. These participants

will on average have to wait two to three years for a cadaveric kidney in NZ (New Zealand Kidney Foundation, 2007). The coping mechanisms respondents described using whilst in treatment included watching TV, listening to music and reading, however a surprisingly large number of respondents indicated that they had no coping mechanisms.

There was a mainly positive response from the respondents about the level of care they received. They reported that whilst in treatment they felt their requests were being acknowledged, whether they were using in-care dialysis or home dialysis. Furthermore, they reported feeling secure during treatment providing no problems arose. It was very important to the respondents that the nurses responded when needed, however some pointed out that they very rarely request to see a nurse. Some respondents noted that the health professionals were always very busy, however they reported that overall the level of care they received was satisfactory.

The results of the SPS indicated that relationships and social support were very important to the respondents. Significant factors for determining this support were age and the amount of time a patient had been on dialysis. Out of the five subscales, guidance and attachment were considered statistically significant as to whether they felt their families were having an active role in their care. The subscales guidance, social interaction, attachment and reliable alliance were important with regard to the families understanding of the nature of the illness. Kimmel (2005) found that social support can be a source of strength and consolation promoting well-being. The support of friends and family is especially important for ESKD patients because of the huge adjustments they must make in their lives.

The BDI tests indicated a range of depressive symptoms with most of the respondents in the mild range, however there were respondents who reported severe depressive symptoms. The highest-ranking symptoms reported from the respondents all correlated with a clinical diagnosis for depression. The significant factors affecting the risk of depression included age and the amount of time on dialysis. Depression is common in ESKD patients and this was confirmed in this study (Keskin & Engin, 2011; Kimmel, 2001).

The results of the BAI indicated that the anxiety symptom rates in respondents were higher than the depressive symptoms. It was found that severe anxiety was being experienced by some of the respondents, and the neurophysiological symptoms were the most reported area of distress. The significant factors found to impact on levels of anxiety included, age, the amount of time on dialysis, low income and treatment option, with those using in-care haemodialysis experiencing the highest levels of anxiety. These findings are consistent with the literature reporting that ESKD patients have high levels of anxiety which is often under diagnosed because of confusion with the physical symptoms displayed by the patient due to the illness (Alavi et al., 2009).

In the next chapter I analyse the completed interviews, and discuss these findings and the implications of these for patients and the health professionals working with them.

Chapter Four: Qualitative Findings

In this chapter, I present the results of my analysis of the qualitative data. Three broad interconnected themes emerged from my analysis of interview data with patients (N=11) and health professionals (N=14) and I have woven their voices together in the presentation of their information. Unless otherwise stated, the quotes presented are from patients. For each of the three major themes, a number of sub-themes were identified. The main themes identified are as follows and form the structure for this chapter:

Impacts affecting renal patients' psychological well-being

Need for psychological support for renal patients

Need for enhanced communication and education

Section one: Impacts on psychological well-being

This section details a range of factors that impact on the psychological well-being of the participants. The data analysis revealed five aspects pertinent to this which were experienced by the participants, and consistent with the literature on ESKD for renal patients in general. These aspects are explored below as sub-themes and include; screening for renal disease, pre-dialysis care, reactions to diagnosis and treatment, depression, anxiety and compliance.

Screening for renal disease

A study by Nikolajenko (2013) analysed five years of results for abnormal GFR in 8798 participants, looking at levels of CKD. Although they all had results consistent with different stages of CKD and eight with stage 5 ESKD, the vast majority of participants were not aware that they had CKD. Unsurprisingly, Nikolajenko (2013) recommended screening for early detection and the establishment of a register to more robustly monitor the stages of CKD in patients with decreased GFR. Early detection of renal failure is important because pre-dialysis education and care can then be implemented. Pre-dialysis education helps patients accept their diagnosis and treatment and can decrease the need for commencing urgent dialysis (Walker et al., 2010). In my interview with *Amy*, she told me that if she had had better pre-dialysis care she could have delayed starting

dialysis. The implementation of pre-dialysis has been shown to facilitate better overall clinical outcomes for renal patients (Walker et al., 2010).

Reactions to diagnosis and treatment

Being given the diagnosis of CKD, particularly if dialysis is required, is an overwhelming experience. It is compounded by the subsequent necessity for patients to learn an extreme amount of new information regarding their disease, which is often difficult for them to comprehend. Shock and fear dominated participants narratives when they described being diagnosed with renal failure. *Bob* told me he cried, and that he was very scared and found the dialysis procedure “disturbing.” *Ned* reported being “in shock.” He said that “they made it sound like it was a holiday park to go to; they weren’t really upfront about what you have to go through before you go on dialysis.” *Eva* described her experience as “inconvenient.” *Rob* commented that he “had never heard of kidney failure, but to actually go through it and do it is quite a challenge.” *Joy* a health professional told me how “a new dialysis patient is usually stunned and numb when they come in for treatment. In the first week, we simply dialyse them because they can’t absorb information.”

The information about kidney disease that dialysis patients must acquire is complex and vast. They must learn to balance their nutrition regarding their levels of sodium, potassium and phosphate and strictly regulate their fluid intake. Fluid is derived from any foods containing liquid content such as soups, yoghurt and gravy not just from drinks such as milk, tea, coffee, water and juice (New Zealand Kidney Foundation, 2007). Different treatments also influence fluid retention with PD patients having fewer problems than HD patients (Fouque et al., 2011). *Bob* suggested that “a support group would be beneficial to help the new ones learn how to cut down on fluids.” The monitoring of food intake and limiting of fluid intake is challenging. As *Meg*, one of the health professionals told me,

new patients struggle with the acceptance of all the limitations and constrictions we give them once they are on dialysis. One day they are eating normally, drinking normally, the next day they come in to dialysis

and we tell them you're not allowed to drink this much, you're not allowed to eat this, you're not allowed to do this.

A question pertaining to changes in appetite was included in the questionnaire. The participants who reported their appetite was 'less than normal' was 39.1%, and 'much less than before' was 22.3%. This would seem to indicate that appetite changes are common for these patients, which is consistent with the literature. Learning about medications is also important for a renal patient. They must be aware that a large proportion of all medications are metabolized or filtered by the kidneys, and due to reduced GFR medications, must be strictly monitored (Weir & Fink, 2014). *Joy*, a health professional, said that "not only are they starting dialysis, but they have changes in medications which can change how they physically feel." *Val*, who is on twenty-five tablets a day told me that they make her feel "sick and bloated."

Amy discussed how she felt that there was

discrimination regarding treatment options. I'm not sure if it is discrimination or a lack of allowing things like holistic treatment to be considered. It's just a Western approach and not enough consideration or information is available for staff regarding traditional knowledge. I have had traditional treatment and access to traditional medications and a holistic way of care and treatment.

Patel (1987) recommends that holistic medicine for renal patients be complementary to standard treatment options and could include treatments such as acupuncture, ayurvedic medicine, massage or homeopathy. In the questionnaire for this study three examples of alternative techniques were suggested for participants. They were asked if they would be interested in learning about meditation and 50.8% answered 'no'. When asked if they would like access to massage 50.3% answered 'yes'. The question regarding whether learning about visualization techniques would be of interest was asked and 51.9% answered 'no.' This indicates that massage was the form of relaxation more favoured by the participants. However, according to Stanley, Leither, and Sindelir (2011) the benefits of using holistic breathing techniques whilst on HD have reportedly shown reductions in anxiety, fatigue, insomnia and pain.

Depression

Depression is common in renal patients and it is reported that 20-30% of patients with renal failure experience depression (Keskin & Engin, 2011). I asked patients about depression in their interviews. Two participants stated that they had never suffered from depression or anxiety, three hoped the staff would pick it up if they showed any signs of depression or anxiety, and six participants said that no help was offered when they were suffering with depression and or anxiety. *Zoe* said that staff “are more interested in the numbers and figures and getting the dialysis right, so no, I don’t think depression is taken into consideration.” *Ned* shared,

you do get stressed, it wasn’t easy leaving work. I went through a stage of depression, I won’t lie. Leaving work and being home not having the strength to be able to mow the lawns, let alone walk is hard. I’m not a depressive person so experiencing it was a bit of a shock.

Meg a health professional told me “we don’t know what’s running through their minds but I think, most commonly, they do get depression.”

ESKD patients are confronted with so many major changes to their lives. They must deal with ongoing lifestyle adjustments to accommodate invasive treatments and cope with the physical and emotional stress of their illness and all the while facing the fear of the unknown (Shih & Honey, 2011). In the questionnaire 79.2% of the participants answered that they had not been offered psychological services, and 19.2% had themselves sought psychological services. Psychological services were never offered to *Ned*, who witnessed another patient on dialysis who he says, “gave up hope and nearly died.” *Rob* recalled that when he went on dialysis he was “very depressed, not to the point of suicide, but thinking, what the hell, some help would be appreciated.” *Amy* stated that “no psychological services have been offered and there have been times when I’m very low and have had ideations about suicide, with all the poking, prodding and cutting of my body.” According to Keskin and Engin (2011), suicidal ideation increases as the severity of depression increases in patients with CKD. Patients with renal failure are 100-400 times more inclined to suicide compared with the general population. Fortunately, most of the questionnaire participants (86.8%) answered that they did not have any thoughts of killing themselves, however 13.2% said that they have

these thoughts or would like to die. As reported by De Sousa (2008) ESKD patients have higher suicide rates than the normal population and can cause their own death by withdrawing from treatment and monitoring. Zalai et al. (2012) proposes that “suicide and withdrawal from dialysis are complex, socially and legally separate, multicausal phenomena, but both are expressions of the desire for hastened death” (p. 433).

Anxiety

Anxiety in patients with ESKD has not received as much attention as depression even though there are many studies that support a correlation between depression and anxiety in such patients (Alavi et al., 2009; Hmwe et al., 2015; House, 1987; Kohli et al., 2011; Öyekçin et al., 2012; Rajan & Subramanian, 2016). These studies all rate anxiety levels as being lower than depression. As part of the questionnaire, participants completed the BAI, the mean score was 12.26, which indicated a level of mild anxiety, however severe anxiety results were also reported.

The four subscales in the anxiety screen administered to the questionnaire participants are; neurophysiological, subjective, panic and autonomic symptoms. According to the results of the BAI completed by the renal patients the top four symptoms they experienced were neurophysiological symptoms. This included wobbliness in the legs, feeling unsteady, dizzy or light-headedness and numbness or tingling. This indicates that these patients are more troubled by the physical symptoms that they are experiencing. These symptoms do not match well with the DSM-5 diagnosis of Generalized Anxiety Disorder (GAD), which refers to more psychological symptoms, suggesting that the anxiety the participants are experiencing could be related to the physical effects of ESKD not GAD. Physical symptoms were experienced by *Bob* a renal patient who talked about how he used to get anxiety, “especially if I was overloaded with fluid.” Many participants mentioned needles. An example was *Amy* who spoke of experiencing high anxiety “before needling which I hate, and it has taken a long time to get through to the nurses and doctors that anxiety and stress affects blood pressure and dialysis session outcomes.”

Compliance

Renal patients are expected to ‘comply’ or be ‘compliant’ with all the aspects of the management of their disease. “Compliance is a behaviour resulting from a specific set of cues and consequences. It is self-care behaviour which entails obedience to a directive” (Bakshi Anjani, 2014, p. 997). The term compliance which was talked about in the interviews was not embraced by many of the participants or health professionals. This term was used because it is the medical term to describe renal patients’ participation in treatment. *Pam*, a health professional, pointed out that “the million things the hospital sees as non-compliant, we see as part of a daily struggle and they are doing their best.”

“Non-compliance is a self-care deficit which calls for rejection of particular behaviour which may result in dissonance and may lead to the development of metabolic abnormalities in renal patients” (Bakshi Anjani, 2014, p. 997). Non-compliance is correlated with higher morbidity and mortality rates. Godbold (2013) and Christensen and Ehlers (2002) report that the non-compliance rate among renal dialysis patients is between 30% and 60%. Calia et al. (2015) report that the inability to recognise and express emotions, as well as the inability to manage negative emotions may influence compliance. *Amy*, an in-care HD patient pointed out that “treatment is frustrating, constantly being tied to treatment can bring you down.” *Val* a PD patient who uses CAPD thinks that dialysis is a “real hassle because I can’t go out for long. Everything has been put on hold, because I want to get better not worse.” *Bob*, who is on home HD stated that he has more control because he “decides when to go on and for how long.” *Amy* thought that “more flexibility around treatment times would improve compliance.” *Eva* talked about dialysis being a “jolly nuisance, but you can’t let it ruin your life.”

The perceptions of the health professionals regarding compliance issues were varied. *Rae* discussed the differences in patient groups,

we’ve got young people, males, they cope differently than females, sometimes males struggle quite a bit with coping. Older people are a little more resourceful sometimes. Often the young ones I guess are the people not turning up to clinics, people not coming to dialysis. Getting into their

headspace about why they drink too much fluid, why they don't follow the diet and why they don't turn up for dialysis is important. I just try to understand that they must have low mood often, it must be like being in a black hole.

Jan suggested that "sometimes non-compliance can come down to finances, you know, lack of support in their wider community and their families." *Eve* revealed that "there is not a lot of give and take. More flexibility is needed to make it (dialysis) accessible to patients' lifestyles." *Mia* also stated, "I think something that would help is more flexibility when they can dialyse and more psychological support, someone to talk to." *Eve* reported that,

a lot of patients would prefer their clinic to be when they are on dialysis, the doctor could come and see them then. They can't understand why we keep it separate, they think it's enough that they are already coming in here three times a week.

Mia said "I think dealing with it is huge and some people just don't deal with it very well. People who have come to the acceptance that this is it maybe comply a little bit better." An example of this was the patient *Jim* who stated that "I guess I accepted it pretty well, because there are no options. If you want to live you have to do it." *Mia* reported that "the ones who are compliant and do everything they're supposed to do definitely enjoy better health."

Leo also said that patients need "choice if we can give it but we cannot always."

Kim indicated that what patients need is

education, because people need to understand why they are being asked to do something. It is also important to have consistency in training. I think we do really badly with compliance. It's a huge impact on their lives and I don't think we can minimise this. I get frustrated sometimes with our consultants when they talk to patients about doing another hour of dialysis. Asking them to do one more thing can break them.

Pat expressed her way of helping patients "from my experience, I've been here a few years now with my patients and I'm always reassuring them." *Leo* concurred "listening to them, so that we know what they like, don't like, want and don't

want. Compassion I think would help with compliance, empathy, warmth and genuineness.” And *Joy* also endorsed this, “it’s about looking at people as individuals and what’s going on for them, and if there is something you can help them with.” Other health professionals adopted a different viewpoint. *Deb* pointed out that patients need to “get through the denial, because those that aren’t able to get through don’t grow and flourish.” *Meg* also spoke of the need for “an acceptance on the part of the patient that they need help, acceptance of all the limitations and all the restrictions we give them once they are on dialysis.” *Fay* admitted that “I don’t know, sometimes you just cannot understand why the compliance isn’t there or why they go off the rails, that would be a fantastic thing to know. Their lifestyle changes every step along the way, and they just have to learn to cope.”

According to Chan, Zalilah, and Hii (2012) non-compliance is linked to a lack of adequate knowledge, inadequate self-efficacy skills, forgetfulness and financial constraints. Whereas Kimmel (2001) reports that “patients increased satisfaction with physicians, but not nursing or technical personnel, correlated with improved attendance and greater total time compliance with the dialysis prescription” (p. 1608). *Emma* summed up the situation by saying,

we need to address the reasons they’re not compliant. I think that compliance is not because people are simply choosing not to do it; I think non-compliance is a symptom of something else going wrong and I think if they had someone to talk to they would do a lot better. I think it’s about looking after people holistically, your physical health and your mental health are just as important.

Implications

In the section above, I presented the voices of the interview participants, that is, those who were renal patients and health professionals, and discussed their comments in relation to the literature and psychological well-being. In their narratives, I identified five significant themes: screening for renal disease; pre-dialysis care; reactions to diagnosis and treatment; depression and anxiety; and compliance. In this section below, I consider the implications of these findings

before moving on to present those findings related to the need for psychological support for renal patients.

In New Zealand, screening for kidney disease only occurs among diabetes patients but previous research on screening found that other medically unwell cohorts would benefit from screening to secure early diagnosis (Nikolajenko, 2013). Molitoris (2013) suggests screening will help with the early detection and early intervention of kidney disease and reduce the likelihood of kidney failure. Kirby (2010) states that screening will help the people with CKD who present with ESKD and their only option is RRT. If pre-dialysis care and education is put into place immediately on diagnosis, renal patients will better manage their disease and possibly delay the need to begin dialysis (New Zealand Kidney Foundation, 2007; Walker et al., 2010). The findings are clear on the need for effective early education for renal patients on how to manage their diet and fluid restrictions, medications and lifestyle changes. These findings also underline the advantage of psychological support at the pre-dialysis phase to give patients the resources to begin to accept their diagnosis and adjust to the very difficult changes they must make to cope with their illness. The fact that pre-dialysis care also facilitates better overall patient and clinical outcomes suggests that pre-dialysis care and education should be a priority for individuals in the early stages of CKD (Walker et al., 2010).

Many participants spoke of experiencing high anxiety regarding the needling required for HD treatment, and their rates of anxiety in general were much higher than in other studies. In view of the fact that the BAI revealed that 30 participants had moderate anxiety and 28 participants were suffering from severe anxiety, this strongly suggests the need for intervention. Approximately half the patients, when asked about three alternative relaxation techniques, said they would be interested in learning about either meditation or visualization and just over half would like access to massage. This indicates a willingness by a sufficient number of patients to justify pursuing ways to make relaxation options available at the renal unit. Holistic breathing techniques have been shown to reduce anxiety, fatigue, insomnia and pain in patients on HD, and it would seem apparent that implementing these would benefit those patients that want to use them (Stanley et al., 2011).

The BDI completed by the participants indicated that almost one quarter (24.4%), of this group of participants have moderate to severe levels of depression potentially contributing to non-compliance. Many participants in this research agreed that incidences of non-compliance impacted negatively on their health with greatly increased hospitalisation rates. Lack of autonomy is a feature of non-compliance for renal patients and the participants made some suggestions which could help. Participants said compliance would be easier if they had the ability to have more choice and flexibility regarding dialysis times and lengths. Another proposal was for clinic appointments to be scheduled on the same day that in-care patients have their dialysis, to avoid an additional trip to the hospital to see the doctor.

The impacts pertaining to the psychological well-being of the participants have been discussed and areas of concern raised for consideration. ESKD patients are high risk for depression, anxiety and non-compliance all of which require continued support.

Section two: Need for psychological support for patients

This section explores why psychological support is particularly important for renal patients. The data analysis revealed five different aspects pertinent to this, which is consistent with the literature on ESKD for improving outcomes for renal patients. These aspects are explored below as sub-themes and include; health professional training, psychological screening, family support, psychological support and spiritual support.

Psychological training

Acknowledging the widely reported view in the literature that depression and suicide are prevalent in renal patients, the health professionals interviewed were asked what training they had in mental health. According to the health professionals their training in mental health was minimal. Eleven said they had no training apart from a small component in their nursing degrees. The two social workers said that they had mental health training. *Pam* is a registered psychopaedic nurse and *Leo* is trained as a health social worker.

The health professionals' interest in training in relaxation techniques was gauged. Two were disinterested, their reason being that they work alongside a wellness person who specialises in relaxation for renal patients. Seven of the participants answered in short form ranging from 'probably not at this point' to 'most definitely'. The remaining health professionals gave more descriptive answers which were positive towards learning about relaxation techniques. *Mia* stated that "it would be really useful for us with people who are really needle phobic. Breathing techniques, visualisation... I don't know, just something because we get a lot of people where that's the biggest barrier is the needling." *Eve* conveyed that relaxation techniques "would be good, but I just know I wouldn't have the time in this job to fulfil anything that I had learnt." *Joy* a home HD nurse stated that "it would be quite good; I think it would be very beneficial for some people particularly in our area where we're training people." *Leo* a social worker thought that it is a "very good idea. I have downloaded a few resources myself, abdominal breathing, building resilience." *Kim* has done "a biofeedback course that can help with needling, so they can cope better." *Emma* thought "staff might get some benefit as well."

When queried on how they assess their patients' mental health status most of the health professionals remarked that this was gauged in the course of the relationship formed working with the patients. *Joy* said that she measures their well-being through developing "a therapeutic relationship...We get to know our patients very well, it's an ongoing relationship." If they witnessed a change of behaviour they would then ask how the patient was feeling and take steps to help this person. *Joy* said, "we would use our powers of observation and if they need assistance we will contact a doctor or social worker for help." However, *Mia* recollected one young man who refused any help and she expressed that "it can be very tricky." *Kim* stated that "I've referred people to mental health services for a consult liaison sometimes successfully, sometimes unsuccessfully. I've also sought for assistance in the community and find a huge lacking in this area." The health professionals who I interviewed, confirmed that there is overwhelming support for the implementation of psychological support for renal patients, and the acknowledgement that it had been lacking for a long time. As identified by *Mia* "depression is a huge issue here and psychological services would benefit the patients." It was stated the services that are available are very hard to access. *Deb* shared that

we don't have much in the way of psychological support, we can access psychological help but it's always in the extreme. What we neglect is all the other levels of psychological need, especially with those young people. Our rates of survival are not good with our young people.

Kim told me that getting psychological assessments for patients in smaller towns is "near on impossible." *Rae* discussed how she doesn't like the label of psychologist and counsellor. "Oncology, hospice and palliative care have people that really understand illness, and they engage at a human level which I think would be great if we had the right person for this illness." *Pam* felt that "every renal unit should have access to a health psychologist." The consensus was that improved access to psychological services would be hugely beneficial and should be made available to the patients.

Psychological Screening

When the health professionals were asked if they measure or test patients for depression or anxiety, only one health professional was found to use a variety of screening tests. *Leo* a social worker said that he uses “standardised screening such as the Hospital Anxiety and Depression Scale.” Eight health professionals thought that screening would be a good idea, and six remarked that they did not think it would be a good idea. *Emma* answered that screening should take place “because they have problems with compliance, not turning up to clinics, not taking their medications and I’m sure a lot of that is involved in their mental health.” *Mia*’s response was “absolutely, especially men of a certain age just seem to really struggle.” Whereas, *Joe* did not think screening was necessary “because they’ve got a long term medical condition they’re going to have some form of reactive depression so why check for it.” *Leo* agrees saying “the benefits wouldn’t outweigh the risks” as screening may overly focus patients on the subject of depression therefore causing it to manifest. *Zalai et al. (2012)* recommend that psychological screening should be routine in renal care. *White and McDonnell (2014)* suggest the BDI as a screening tool because patients can complete it in less than five minutes. However, *Hedayati et al. (2008)* point out that a distinction must be made between depressive affect as assessed by self-report questionnaires and a diagnosis based on the DSM-5.

Family support

Family members need to understand the effects of ESKD to remain supportive and active in the health-care equation along with health professionals and family members who are patients. When asked if their family members understood the nature of their illness the questionnaire participants’ results were positively skewed with 94.1% (N=177) indicating ‘yes’, and 5.9% (N=11) stating ‘no’. This indicated that they felt their families did have sufficient understanding about ESKD. Of those who wrote comments, one participant *Ned* indicated that his family had “no clue.” He stated that his family did not understand “no they think I’m sick and dying.” Ten of the patients who were interviewed felt there was a good understanding of the illness by their family members. *Bob* stated that “they all know I must charge my battery up every second day.” While from the participants perspective there seems to be a high level of understanding by their

family members about ESKD, some of the health professionals doubted the degree of families' understanding. *Eve* expressed that "I don't think they do understand, I can tell that from the phone calls that I get from the family members and the questions we get asked." *Meg* discussed how "some are really scared to be too involved with what is going on with their family member, and they shut off once the situation gets out of hand." Massey et al. (2011) support home based education programmes that involve family and friends, however, they stress that the patient needs to be the priority. Shih and Honey (2011) also posit that ongoing education for the family is a necessity so they are aware of the many ways they can assist an individual on dialysis.

In their interviews, many of the health professionals concurred. *Joy* commented "educating support people and family is huge. They need to learn about fluid and diet restrictions." Another health professional *Pam* said that "the cook of the house should be at the dietitian's meetings. It's pointless if the person going to see the dietitian has never cooked a meal in their life." *Emma* believes that "bringing whanau or friends to education sessions and to clinics is beneficial, so people can start to grasp what's happening." Some patients noted the need for family to learn "more about understanding symptoms, to be more understanding when I am emotionally worn out or tired." *Zoe* conveyed that she would like her partner to see a psychologist, so that he has a better understanding of what's going on or how he can help. "Often that's a hard one for him because he doesn't quite know what to do." Statements from the health professionals reiterated that it takes time for families to understand such a complex illness. They acknowledged the many changes that the patient and family must make. These findings suggest that as a significant amount of information is required to really understand the complexities of ESKD, being open to learning seems to be a first prerequisite for family members. Knowledge about ESKD would seem to be an advantage for both the patient and family members, to enable the right kind of support for the patient.

The questionnaire participants were asked about the level of support offered by their family members. Detailed responses were offered by 144 participants. Their answers ranged from 'nothing' to 'full care.' Some examples of the wide range of

support requirements also mentioned in these entries by respondents to the questionnaire included “supportive financially, emotionally and spiritually. They keep me happy by visiting and allowing me to see my mokopuna. They support the decisions I make concerning my treatment or my life.” Some were more specific; “provides transport, is my support person when dealing with health professionals.” “Massage, miri miri.” “Watches my medication, weight, liaises with the nurse, checks blood results and now puts me on dialysis using a permacath.” Many of the entries were centred around practical help in the home setting which illustrates the extra day to day responsibilities placed on the family; “cleaning and cooking,” “helps carry heavy boxes,” and “helps to set up and sort out any problems.”

In the patient interview, participants were also asked about their perceptions on levels of family support. The majority discussed how both practical and emotional help is required from their family. *Kay*’s comment demonstrates this, “they help by supporting me and encouraging me to keep up my treatments, and take my medication and check that I’m alright.” *Zoe* described how her partner

does so much extra around the house, that I sometimes don’t have the energy to do. Even now my energy goes in ups and downs, I can be really motivated one day and the next day blah. So, he’s brilliant with doing the actual practical stuff. Mum is there for the psychological stuff.

Amy states that “they take care of more of my holistic health and well-being which is not done here in clinic or renal treatment. It’s very much westernised, it’s more the medical model whereas my family come from traditional healers.” *Ian* stated that he has a “very supportive wife and she always comes in with me every clinic, which I think is important.” However, some participants stated that no help was required. *Ned* pronounced that he needs “nothing, apart from my partner.”

The overall impression from the health professionals’ answers about families was the recognition of the burden the extra responsibilities placed on them and that what families do is often undervalued. *Leo* acknowledged that “sometimes we only focus on the patient, yet we should also focus on their family.” *Jan* advised that a “greater number of support networks are better otherwise the carer burns

out, and you do see that.” Pomaki, DeLongis, Anagnostopoulou, and Heining (2011) discussed the problems families and patients can have in the home environment. Despite the best intentions family members can behave in an overprotective manner, which can unnecessarily limit activities for the patient. *Fay* a health professional confirmed this “if their supportive role is a little bit over the top and they’re answering for them, telling us everything, it’s difficult.” Sometimes feelings of tension, frustration and anger resulting from the experience of living with a family member with ESKD can affect the carer and patient. Health professional *Joe* talked about how he tries “to put their tension levels down low, make the person on dialysis realise family members are actually living and doing this as well.” However, *Jan* expressed concern for carers “it’s such a burden isn’t it to suddenly find that you’re it, you’re going to have to look after him as well.” Emma described how

sometimes I look at those wives and husbands and think you’re amazing. They travel and they come in and out of hospital and their whole lives are turned upside down for a long time. Some of them have to watch their partners fade away and it must be really hard. Being away from the home with frequent or prolonged hospitalisations can also impose stress on families.

Coping with renal failure is difficult and demanding but there are tasks that family members can do to support the patient. In the questionnaire participants were asked what tasks or activities their family members could be involved in to make coping with renal failure easier for them. The majority (N=139, 70.6%) answered that no extra tasks were required to be done. Most of the participants expressed that help with practical jobs was what helped them to cope, and that emotional support was also important to them, “yes there is a lot of minor things I can’t do on my own,” “they keep me sane,” “everything they do for me is awesome.” In general, the interview participants responded that their families were already doing enough to help them.

Another perspective was sought from the health professionals regarding tasks family can undertake. They told me that the most important aspect was to keep the family engaged so they continue to provide their loved one with practical help

and support. *Leo* was positive saying “there is always a possibility at the in-centre for whanau input.” *Jan* pointed out that “a lot of it is transport and some of them sit through the whole dialysis. They are probably the exception rather than the rule.” *Pat* suggested that “there are lots that the family can do to come and help them. Like the family members they will come there and they will set up the chair and bring the blanket, bring water, get everything set up.” However, *Eve* considered that “there probably isn’t a huge amount of tasks as we wouldn’t want them to touch any dressings or anything on their bodies. It’s probably just perhaps having more skills to understand what it is like to live with a person that has a chronic illness.”

Deb, a PD nurse, discussed how she does not recommend carers help with medical tasks

because we don’t know if we can rely on them and we can’t give them a task, it might be to the detriment of the patient. Although sometimes like for instance if you’re training somebody onto a ‘cyclor’ and they are in a wheelchair, you have to ask the partner to bring the bags in. They are six litre bags, they are quite hard to lift from a wheelchair. Sometimes the tube that comes out of the tummy, if they’ve got a big tummy and the position of the catheter is out of sight, we ask and rely and encourage the wife to do the dressing. But some will say I’m not doing anything, but that’s part of their grief.

Meg conveyed that

on the self-care side, we do encourage a support person to be there with the patient. Here in PD we just try to get a family member to be with them during the training because of the information overload we are giving them during their training week. Somebody who can help them understand so they can focus on training and how to do their dialysis alone.

Patients who use home dialysis, either HD and PD or self-care HD can require more active assistance from family. In NZ 23% of renal patients use self-care HD

and 27% use home HD (Sinclair, 2009). PD is the most common form of home dialysis, and overall in NZ PD usage is 35%, home HD 18%, and in-care hospital dialysis 47% (Walker & Marshall, 2014). Walker, Blagg, and Mendelsohn (2015) list a key attribute for the home HD patient is family or caregiver support. de Maar, de Groot, Luik, Mui, and Hagen (2016) also recommend that optimal home HD training will involve a family member who is willing or able to support the patient. Joy who works in the HD home training unit points out that

it is not a requirement for people to have a support person or family member, but we do suggest that it's more helpful to have somebody there. Even for those coming from outside Hamilton we provide accommodation for two people when they are training, so a support person is included. I would say 60-70% would have a support person.

The positive factors when using home either HD or PD, include a higher quality of life and longer survival rates (Kutner et al., 2005). However, Wilkie (2011) points out that the international trend for home dialysis continues to decline, with full in-care HD continuing its dominance. Holman (2011) states that home dialysis carers provide unpaid care to ill, frail or disabled friends or family members. It is important for health professionals to give carers of home dialysis patients time, space and permission to talk about how caring impacts on their lives.

Psychological support

Different forms of psychological therapy were included in the questionnaire to measure the interest of the participants. When they were asked if they would be interested in group therapy, 13.8% (N= 26) answered 'yes', 31.7% (N=60) answered 'maybe' and 54.5% (N=103) answered 'no.' Two participants expanded their responses, "more for support for my dialysis friends" and "all depends where it is and cost." The participants were also asked if they would be interested in individual therapy, 20.3% (N=38) answered 'yes', 30.5% (N=57) answered 'maybe' and 46.7% (N= 92) answered 'no'. Three expanded on their answers, "but it is the cost," "always hard to get extra time off work," and "if they are on dialysis so they know what we are talking about, not reading out of a book." Duarte, Miyazaki, Blay, and Sesso (2009) conclude from their research

that cognitive behavioural group therapy is an effective treatment for major depression in HD patients. Improvements were reported in the areas of sleep, quality of social interactions, overall health and the burden of renal disease. Kimmel (2005) states that social support can be a source of strength and consolation promoting well-being. *Bob* states that “I would do group so I could share my feelings and experiences.” *Dan* expressed an interest in therapy with this proviso “later, not right now, closer to my death.” *Ned* thought that “any session would be great, in a group you could share information with each other.” *Kay* would prefer individual therapy, “I’m more of a one on one person.”

Eva conveyed that she “tried to organise a morning tea for people on dialysis or coming up to go on dialysis. No one came, no one seemed to be very interested.” *Bob* also “tried to start up a support group for new dialysis patients, to give them practical advice about the machine and what to expect.” *Zoe* has already done individual therapy and told me that it was “very good, the group one sounded really cool because often it’s good to know that somebody else is feeling like you do, just being around other people so you don’t feel so isolated.” Williams, Manias, Liew, Gock, and Gorelik (2012) found that culturally and linguistically diverse people with kidney disease can feel isolated and are often excluded from intervention studies. Their participants were appreciative of the one-on-one home visits and were open to learning and taking advice. Chiou and Chung (2012) proposed that multimedia interactive DVDs might be used to educate ESKD patients. In their research, the participants who only had written information were more unsure about treatment options and information pertaining to ESKD. *Ned* agreed that “a DVD to learn from would be simpler and easier, the book was confusing with too many pages.”

Most of the health professionals thought that either individual and / or group therapy could assist the renal patients. *Meg*’s opinion was that the patients would prefer group therapy, “some of them really enjoy spending time with other patients, being able to relate to someone. Some patients tend to push everyone out of their life but if they spend time with another patient it makes it more normal.” *Eve* mentioned “they are trying to get a support group for the young people, so that could be good for them.” *Joy* also thought that “individual and group would be really beneficial for some people.” *Fay* discussed transplant patients “we can

see that when they come to transplant clinics they see patients who are in the same boat. I would imagine group therapy would be fabulous.” But *Rae* raised the concern that some patients may not participate, “if they were a bit depressed or whatever they are less likely to want to do therapy, so in actual fact the people who need it most, probably aren’t going to get the benefit of a group. Getting someone to engage with help initially is actually quite difficult.” *Leo* a social worker suggests that “individual sessions ‘yes’, group therapy sessions ‘no’, that’s from my personal experience. We’ve tried different ones and not had great uptake”. *Emma* a renal transplant nurse discussed her patients,

would probably like more individual therapy, once they’re transplanted it’s about other stuff. They have like a survivor guilt. Their mate is still in in-centre and they’ve got the transplant. For young people that are struggling with fluid balance might prefer a group where you can have a chat about what’s a barrier to them and how that works and strategies they have developed that might help other people. So, I suppose it just depends on what population.

However, *Joe* had a different perspective to the other health professionals. He was adamant that therapy sessions were not a good idea, telling me that “they want to be getting on with life, they want normality.”

Spiritual support

Spiritual support was inquired about in the questionnaire and whether this form of support was important to the participants, and 52.8% (N=102) answered ‘yes’, 5.7% (N=11) answered ‘maybe’ and 41.5% (N=80) answered ‘no’. Some expanded on their answers, “that’s why I go to mirimiri,” “I am a Jehovah’s Witness,” and “committed Christian.” *Leo* a social worker remarked that

I believe that more emphasis on psychological services in renal would give better credence to Dr Mason Durie, Te Whare Tapa Wha, it’s not just about physical it’s about the mind as well, the spiritual side, people don’t often talk about that, but the ones who do, my God it’s important to them. The interesting things I’ve seen, the variances of some Pacifika people believing in God’s intervention, that’s the faith part, the wairua.

Shih and Honey (2011) reported that Te Whare Tapa Whā, would be appropriate for ESKD patients. Egan et al. (2014) indicate that people with ESKD have a shortened life expectancy and carry a high symptom burden, and that attending to the renal patients' spiritual needs may contribute to an improvement in their quality of life. Spiritual support was important for over half of the participants, however according to Egan et al. (2014) renal specialists may lack an awareness of patients' spiritual and palliative care needs. Palliative care is offered to renal patients whose condition is deteriorating when they are in stage four or five. They will present with at least two of the following indicators:

Patient for whom the surprise question is applicable, which means for patients with advanced disease or progressive life limiting conditions, would you be surprised if the patient were to die in the next few months, weeks, days.

Patients choosing the no dialysis option, discounting dialysis or not opting for dialysis if their transplant has failed.

Patients with difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy.

Symptomatic Renal Failure, nausea and vomiting, anorexia, pruritus (itchy skin), reduced functional status, intractable fluid overload (Palliative Care Council of New Zealand, 2014, p. 4).

Palliative care is available wherever the patient is, be that home, hospital, residential care or hospice (Ministry of Health, 2007). The health professionals in this study deal with death on a regular basis. *Emma* states that “we feel really sad when people we have had a long relationship with die.” *Deb* conveyed that she would like to “try to teach them about the grieving process, but time is of the essence around here and there’s no time for it.” *Leo* pointed out that “Te Puni Oranga, the Māori unit here at Waikato is really great. They come in, do a karakia after a death and engage whanau support.”

Implications from this research

At the renal unit, apart from the social workers, I was unable to identify (via my interviews) any health professionals who had training in mental health. It was not

a pre-requisite to working in this unit and there was no training provided at the unit to develop this component of health care. It is puzzling that this important area of training and care is overlooked for the health professionals working with this vulnerable population. In view of the increased risk of undiagnosed depression and suicidal ideation in renal patients, it would appear that more mental health training is required for the staff that work with them. In the words of one health professional “we don’t know what’s running through their minds but I think most commonly they do get depression.”

This study revealed that there are patients at the clinic experiencing depression, some severe and others less so. No help was offered to six of the interview participants when they were suffering with depression and or anxiety, while other patients in this study said that they hoped the staff would pick it up if they showed any signs of depression or anxiety. So, the expectation of help is there but the delivery of this type of help is not possible at present at the unit. Considering that patients with renal failure are more inclined to suicide than the general population, it is surprising the lack of psychological support available at the unit for these patients. As reported 13.2% of patients in this study admitted having suicidal thoughts.

In the questionnaire 156 participants reported that they had not been offered psychological services. As part of the BDI results participants also reported that they were sleeping less, eating less, less interested in sex, they had less energy, were more fatigued and do not enjoy things as much as they used to. The necessity of access to appropriate strategies to increase psychological well-being is very apparent for renal patients at the Waikato Renal Centre that I engaged with. Both health professionals and patient participants clearly identified the need for increased psychological services with varying recommendations for the form this could take. The majority proposed that a psychologist would be a valuable addition to the treatment team for dialysis patients.

The findings showed areas where this would be advantageous. A health psychologist working with renal patients could implement routine screening for depression and it is suggested the BDI be implemented as a screening tool because it can be completed by patients in less than five minutes (White & McDonnell, 2014). Once a diagnosis of the level of a patient’s depression has

been made a psychologist could then facilitate CBT or other appropriate treatments. There are many patients who are needle phobic or have fearful reactions to needling that are a barrier to their treatment. A specialist in mental health would be useful to give patients strategies to deal with the anxiety that they feel. They could instigate the use of relaxation techniques when patients become overwhelmed with the many different procedures they must undergo or are just not coping with the burden of their disease.

Pre-dialysis care is important because it has been shown that it can slow down the rate of progression on to dialysis. A person experienced in mental health could instigate an effective pre-dialysis programme. This would be beneficial for patients regarding acceptance of their diagnosis and treatment and provide for better management earlier in the disease process. Non-compliance is clearly linked to poor outcomes, and as psychological support to promote self-efficacy has been shown to facilitate increasing compliance, the implication is that for renal patients access to a mental health professional would be highly beneficial if not essential (Wu et al., 2016). Moreover, as this study found outside psychological services were very hard to access for patients when needed, a psychologist on staff at the renal unit would negate the need to rely on this less immediate and inconsistent option.

Psychological support at the unit could facilitate communication with patients' families. This study seems to reinforce the literature emphasising how important social support is for the psychological well-being of renal patients. Ongoing education for the families who provide this support was suggested by both health professionals and patients, including psychological support (Massey et al., 2011; Shih & Honey, 2011). The findings also appear to support the idea that shared decision-making helps patients with their treatment choices, and also encourages family involvement (Jayanti et al., 2015; Walker, Marshall, & Polaschek, 2013). This model could be introduced to promote the increased family engagement proposed in the study if there was a psychologist at the unit. Te Whare Tapa Whā, would be an excellent overarching framework to facilitate the instigation of any changes or additional services.

The next section examines the challenges renal patients and health professionals experience, and the impact of challenges on outcomes. The need for improved communication between patients, health professionals and family is raised for discussion as well as what actions can be implemented for change.

Section Three: Need for improved communication

Lack of effective communication is a strong recurring theme in the findings of this study. In this section, the patients identify areas with a need for improved communication. The participants discuss frustrations they have had with the healthcare system and services provided. Resources that could conceivably improve the services provided by health professionals are mooted. Also, the health professionals discuss the difficulties they encounter working with renal patients. There are five sub-themes in this section which are; negative experiences with the healthcare system, resources, pain, challenges for health professionals and the coping mechanisms they utilise.

Negative experiences with the healthcare system

In the patient interviews, they were asked whether they had any concerns and if they felt they were being listened to by the health professionals. *Amy* described how she has been “very frustrated for the last four years because no one has really listened, I felt very bullied like many other patients who have voiced concerns.” *Rob* pronounced that the renal department of course have got to say, “if anything goes wrong ring us, but that’s a load of bull-shit too.” *Zoe* discussed that “we had to be really proactive about wanting to go onto dialysis, it’s so important to have a support person. I had to push the whole way and that’s even to get on the transplant list.” *Rob* concurred,

they let me go too long without dialysis. My kidneys were working at 40% when they first picked it up but by the time they decided to do anything about it my kidneys were working at 4%. I didn’t know what to expect. There was not a great deal of information about how it all works. They first said that I would be up and running within six weeks. It’s now two and a half years later. For the past 8-9 months, I’ve had no help from the renal department; I think I told you I had a go at them. The only ones that have contacted me is the Kidney Society.

Zalai et al. (2012) purport that negative experiences with the health care system can trigger depression in CKD patients. *Eva* talked about having a doctor who

at a clinic appointment informed me that I was taken off the transplant list. The doctor said we have been talking about you and we have decided to

take you off the transplant list. That's how I found out and then she threw me a box of tissues. It had something to do with the mortality calculator. To be told like that was really horrible.

Rob was also concerned about his chances of a transplant dwindling,

I was on the transplant list and I got a letter from them at Waikato to say that within three months we will be looking at you, it's now coming nine months, no phone call, no letter, no nothing. I keep telling renal can you check it up for me please, to get me back on to this bloody list, heard nothing not a thing.

The interpersonal relationship between patients and healthcare professionals was found to be the cause behind the majority of patient complaints in a study by Schaad et al. (2015) which analysed the reasons behind hospital patients' grievances. Several of the participants in my study reported making formal complaints to the DHB. *Jim* stated that he

complained about one of the doctors. The first question he asked me was how long have you been on dialysis? which said to me you haven't even opened my bloody folder mate. And he went on with several other things that annoyed me as well, so I came home and wrote a letter of complaint. Another doctor was talking about statistics and all the rest of it and he said to me, you only have five years to live. I don't think that was the right thing to be telling me.

Val explains that she wrote to the DHB about her renal doctor. The DHB came back and said "no he didn't say that about the transplant. I know he told me from day one that I would get a transplant and he now says no." *Ian* described being prepared for PD surgery,

the clinic has a system where they mark above the belt line where the tube should go. Unfortunately, the surgeon took the belt line as the mark, so I can't wear a belt any more, I have to wear braces. I can't wear anything tight around my waist. We wrote a letter to the hospital board about that, that there seemed to be something wrong with their systems. They said they would do something about it, but I don't think they have because

nurses have told me that they are still doing this. So, I have a problem with that aspect of it.

Ned expressed anger about going to see “a renal doctor about something and he referred it back to my GP, he could have just signed it off. They are too busy, I get given the run-around.” *Ned* told of his experience with training. “Self-care dialysis was frustrating, you are expected to set up the machine, and the nurses were not showing me anything.” However, he also stated that “I’m gaining a bit of control with knowledge and how to set up everything, I’m feeling a little bit better.” *Kay* had a positive response to and conveyed that she has “had good support from the nurses and doctors.”

Some of the health professionals also had concerns regarding hospital processes. *Eve* pointed out that “I guess a lot of them might be frustrated with the hospital system. They have to wait forever for any kind of procedure, their life is based around a machine.” *Jan* worried about a “lack of discretion sometimes among staff, a lack of respect and sensitivity to the patients who are listening in.

Generalisations are going on and I think the staff can get a bit cynical, not overall but there is an element there being judgemental.” White and McDonnell (2014) stated that the role of the nephrology nurse and other health professionals working with ESKD patients is to help them cope and adjust to the significant psychosocial challenges they are confronted with every day. For quite a few of the participants in this study this has not always been their experience which can be detrimental to their potential for well-being. Kimmel (2001) gave an example of physical changes that occur in patients when they found that “patients increased satisfaction with staff and their perception that staff cared about them correlated with higher serum albumin levels” (p. 1608). Serum albumin is the most abundant protein in human blood plasma. Zalai et al. (2012) suggest that CKD healthcare teams can learn from treatment models already implemented in other medically ill populations, such as those with cancer.

Resources

During their interviews, the patient participants were asked if there were any additional resources that they felt would, if provided, improve their outcomes. *Amy* discussed this,

I think there needs to be more education for medical staff regarding holistic care and individualised treatment planning, more preventative care in the early stages of renal failure, and better education around diet and nutrition. I think they leave it until you are acutely unwell before you can access all these things.

Stanley et al. (2011) presented a similar view inferring that using holistic physiological techniques such as controlled breathing, may offer a unique and alternative tool for nurses to help increase health related quality of life in patients on HD. In this respect, Singhania and Mandalika (2012) have developed the Holistic Health Assessment Tool for use with people with kidney dysfunction. *Eva* raised the point that “I think one of the problems is that basically when you go to the hospital you see a different doctor, you hardly ever see the same one two times running.” *Jim* compared this situation with his experience at another hospital. “In Whangarei where I started dialysis you have a primary nurse and primary doctor, so you are seeing the same doctor all the time,” which he felt was a much better system. *Jim* also pointed out that

less waiting at the hospital would be helpful. The problem in my belief is they have all sorts of sundry people bringing people in for dialysis. In Whangarei, they had one contractor who used to bring everyone in for dialysis, so in other words the unit knew exactly when they were getting their patients.

Ned also identified the need for “better access to travel when you live out of town, and financial help.” *Rob* stated that the “smaller towns need two or three haemodialysis machines, because travelling to Hamilton three times a week is too gruelling.” *Ned* indicated the need for more “support with Work and Income, I would love to go to work but I can’t. They keep sticking me on benefits I shouldn’t be on.” *Rob* said,

I reckon more communication, even to this day I would have preferred to talk to somebody who has been through it, who is doing it, who has lived it. So, I could get their point of view on what to expect, how it all works, one on one.

Kimmel (2001) report that how staff interact with patients is important for mediating improved outcomes for renal patients. *Val* talked about this, “I would like to know more from the hospital. Why can’t my nurse ring me and say everything’s good or my blood pressure is too high, or I have to drop some of my foods to bring something down low?” *Zoe* proposed access throughout treatment “to a psychologist that you could ring, and maybe a little bit more regular contact from the PD nurse. Because I find with me not being bedridden or really sick they forget that I need help.” White and McDonnell (2014) state that psychological stressors were more troublesome than physiological ones, thus easy access to a psychologist or other mental health providers would be beneficial.

Nearly all the health professionals in this study felt that the key additional resource required for patients, was psychological services. However, they added the proviso that any such service must recognise the specific needs of renal patients and that any psychological resource must not be a standalone specialty area. *Kim* said, “It should be seen as an integral part of the service because I think there is still a stigma attached to mental health support.” *Rae* stated that

I think that would be helpful. I use our social worker as much as possible because that’s all we have really. It would be great to have somebody who could be regular and they could develop the relationships, because I do feel that’s key. Someone who actually understood everything there is to know about what they have to go through and what’s coming.

Emma expressed that “having a psychologist that we can refer to would be fabulous, someone who has an interest in renal and understands the journey that people go through.” *Eve* talked about having

a psychiatrist of some description. In the old days, we used to have more access to psyc liaison and they would come and see the marginal patients that we felt were struggling. Perhaps we need someone who’s a little bit more qualified that can pick up on things, rather than just the lay chaplains.

Deb shared that she has been

working in renal for 30 years and way back over 20 years ago we had a psychologist as part of our renal team, which was fantastic. Wouldn't it be just wonderful if we had a psychologist and we could walk into his or her office, it would be a natural thing to include a psychologist.

Meg stated that

sometimes they feel like everyone is against them, like the nurses, doctors, dietitians we are ganging up on them if they're not doing the right thing. They cannot speak freely to a nurse or doctor so a different person who they feel is there for them would actually be helpful.

Joy believes that "having some psychology input would be a big benefit, particularly when people are not turning up for dialysis and become more unwell and turn up acutely to ED." *Leo* agrees that having a psychologist attached to the staff would be beneficial.

I would have made referrals. In the past, we've made referrals to consult psych liaison that have had some input but not always when we want it and for the length we wanted. I don't think mental health is strongly resourced here at Waikato, so it would be great to have more resources here.

Emma discussed transplant patients, "all the recipients and donors have to see a psychological person and they have to see the people separately and together and we have never been able to provide that service here. People have always had to go to Auckland to get that done." *Pat* suggested "more input from our social workers, and more input from our kaitiaki. We used to but I haven't seen them here for a long while." *Joe* proposes that "a lot of people don't even know they have a social worker, what they actually need is a list of who's in the team, what their role is and a contact number." *Jan* agreed with renal patient *Jim* that "the waiting time for patients before treatment and the shuttle service need to be improved."

Pain

Pain is acknowledged as the most common yet unrecognised symptom experienced by patients with ESKD. In their study, White and McDonnell (2014) report that 50% of patients with ESKD experience pain. In my study, inadequate opportunities to discuss pain and the reluctance to prescribe adequate pain relief were considered a problem. Pain resulting from dialysis procedures can be due to the cannulation or needling of the fistulae for HD patients, while PD patients can suffer from abdominal cramps, distension and back pain (White & McDonnell, 2014). *Kay* described the pain she experienced when she started PD “how awful it was getting all of that fluid pushed into you. I thought I was going to explode, it was very painful.” *Ian* said that when he started PD “they had to peel me off the roof; it was just so damned painful. I was allergic to the dialysate.” The undertreatment of pain has a significant impact on the physical and mental well-being of renal patients with poor pain management being linked to depression and anxiety (Salisbury et al., 2009). Barakzoy and Moss (2006) state that pain symptoms for renal patients should be more constantly monitored. Although some medications need to be avoided. The World Health Organisation (WHO) scale of analgesic medications adjusted for renal patients allows for the use of more medications to adequately manage pain relief (Brown, 2015).

Challenges to renal health professionals

Working in renal care requires not only medical training and in most cases direct contact with the families of the patient. The health professionals discussed how they felt about family interactions. *Leo* “although it can be a two-edged sword regarding family. I have had to politely say to one patient with school age children not to bring them into treatment.” *Pat* also pointed this out, “sometimes it can be hard when whanau bring their little ones. It’s hard for them to understand when we tell them you need to limit the numbers, especially with kids because some kids go and touch everything and you don’t want that.” Families can impact on the patient's’ treatment and can make the health professionals’ job more difficult. *Leo* mentioned an example of this, “when transport is something the family have said they will do but they aren’t able to follow through with it, the person either misses their dialysis or is late and that can be quite disruptive for other patients and staff.” *Rae* spoke of this also,

I can never understand if they have family, why aren't they bringing them in if patients aren't turning up to in-centre. Then obviously if we get families that are coming in and they're being difficult, disruptive, abusive that can be difficult as well.

Kim points out "it's when they don't understand and they whisk the patient off, miss appointments that sort of thing." *Pam* suggested that "it's always the loudest voice rules the house and the loudest voice is quite often the least informed, and that there are a lot of choices made by misinformed or well-meaning but very bossy or bullying family members." *Joe* referred to a problem when family "make the patient dependent on them, not allowing the person to keep their independence." The main point raised by these health professionals was that communication with the family was very important and working out how to bridge the gap so that everyone is well informed is the desired goal. *Leo* stated that "communication will help because if family perpetuate a lack of knowledge or a fear of something that doesn't help the patient." These different perspectives demonstrate some of the difficulties with families that health professionals encounter in their work environment.

Coping mechanisms

Working in a stressful environment requires coping mechanisms to be applied by the health professionals. When asked about the ways they cope with stress they mainly agreed that the best strategy was communication with other colleagues who understood the challenges of the job. Some preferred formal meetings with colleagues while others preferred a more casual debrief over coffee. Stanley, Worrall-Carter, Rahman, McEvedy, and Langham (2015) call attention to the value of mentorship and collaboration in their model of care for dialysis nurse practitioners to help them manage work stress. However, the two overarching strategies used by the health professionals to alleviate pressure were to share with colleagues and to not take work home. *Meg* discussed this,

I try as much as I can to leave work at work, but sometimes you can't help it. You get too attached to your patient because you get to see them almost every day of your life, and then suddenly you see them get sick and you lose them. I think PD is even harder because we go into their home. You

enter their safe zone, and then just one day you'll find out they had a heart attack and the patient has died. Us nurses would usually, if we lose a patient, we would gather around and spend some time talking about that patient. Sometimes we would have a minister come in and if a patient sits on one particular chair the minister would bless the chair and say a prayer.

Emma talked about what she finds hard. "When a patient dies, I always, a week or so later, ring the spouse. Those phone calls are really hard, I try not to take it home but it is quite consuming." Josland, Brennan, Anastasiou, and Brown (2012) recommend that being well informed and well versed in renal knowledge assists the renal carers as well as the ESKD patients. Knowing the details about what to expect from the time of diagnosis through to death and about bereavement enables renal health professionals to better manage the stress involved in their job.

Implications for improved communication from this research

The health care equation for renal patients relies significantly on communication that is clearly understood and therapeutic. There is a significant amount of information that is communicated. Sometimes this is done effectively, but often, especially in the context of un-wellness, complexity and stress, communication is sometimes compromised, misunderstood, or simply not received. Communication impacts all aspects of renal care and negative healthcare experiences cannot be underestimated, particularly for renal patients (Christensen & Ehlers, 2002). In my study, a large number of the participants have had negative experiences which demonstrates the need for communication to be addressed. Some of the situations described by the renal patients make it easy to understand how these could trigger depression and or anxiety which in turn negatively affects health and well-being. Interpersonal interactions between patients and providers are the leading cause of hospital complaints (Schaad et al., 2015). As the examples given in this study in the main referred to poor communication between patients and health professionals, this reflects the need for re-evaluating best practice for communicating with patients. Health professionals need to be able to deliver the practical medical advice and information to patients with sensitivity and empathy. They need to be mindful of the precarious psychological and physical situation of their patients as they negotiate the complexity that is kidney disease. As much as

possible, health professionals need to make every effort to assist and facilitate an easy passage for these patients.

Other changes that may well improve the services provided by the renal unit were proposed by participants. They indicated a lack of continuity with the doctors they saw. The implication of that being that there was no ongoing communication with a specifically assigned physician. Many studies deem the therapeutic relationship to be vital for patient well-being and positive outcomes and this is not possible with ever changing doctors. A solution was proposed that each patient be assigned one primary doctor that they could have continuity with and build a stable therapeutic relationship. A further suggestion was that a contact list where patients could easily access information and support at any time be made available to them. Several participants raised the need for better access of travel to and from the unit, and the long waiting times for patients before treatment at the unit.

White and McDonnell (2014) found that pain is the most common symptom experienced by renal patients, which was confirmed in this research by the participants. Inadequate opportunities to discuss pain and the reluctance to prescribe adequate pain relief were considered a problem. The under-treatment of pain has a significant impact on the physical and mental well-being of renal patients and may induce many arguably avoidable negative ramifications. As poor management of pain is linked to depression and anxiety it is essential that health professionals facilitate the improved communication necessary with renal patients to better ascertain their levels of pain (Barakzoy & Moss, 2006).

Communication between fellow health professionals was found to be the main way to cope with stress. They found the best strategy for stress relief was talking to other colleagues who understood the challenges of the job. Because of the nature of renal disease, the key stressor the health professionals must deal with is losing a patient which occurs frequently at the unit. Many said what helps the most is to gather together and spend some time talking about that patient with fellow colleagues.

Continuing communication with the family to keep everyone well informed regarding the patient's requirements is vital to bridge the gap between the hospital and the home. Misinformed family members though well-meaning may

unwittingly cause problems to arise for renal patients through a lack of knowledge. The challenges identified for the health professionals in the study could also perhaps be resolved with enhanced communication channels and ongoing education for families. If the patient and family members have clear explanations of what is expected of them, some of the problems would be reduced.

Non-compliance is also linked to a lack of adequate knowledge and as it has been found that patients' increased satisfaction with their physicians correlated with improved attendance and greater total compliance (Kimmel, 2001). The inference is that quality communication between patients and their doctor giving comprehensive explanations on all aspects of their treatment programme would go a long way to facilitating increased compliance. This improved communication was suggested by nurses in the study when they talked about the need to find out the reasons why patients are not compliant and that non-compliance is a symptom of something going wrong. Communicating with patients about any concerns that they may have and giving them the reasons why they are being asked to do something would make it easier for them to comply.

Although from the patient's perspective the level of understanding about ESKD amongst their family members was high, the health professionals gave reasons to doubt the degree of families understanding. Greater communication between the hospital and the families and ongoing education will assist their level of understanding and show them the many ways they can support their family member. If family members are kept well informed the implementation of the shared decision-making model found to be effective for renal patients by Jayanti et al. (2015) would be conceivable at the unit.

In view of the fact that the positive outcomes for patients on home dialysis outweigh in-care dialysis and as reported by Wilkie (2011) that the international trend for home dialysis is continuing to decline, another benefit of effective communication with family may be the potential for increased numbers of patients being able to undergo home dialysis. If health professionals were to give carers of home dialysis patients the recommended time, space and permission to talk about how caring impacts on their lives more may be able to support their

family member to dialyse at home. This would have a positive effect on patients' psychological well-being due to the increased control, freedom and autonomy that comes with home dialysis.

The impacts of poor communication between patients, health professional and families have been discussed and areas of concern raised for consideration. The support required for ESKD patients is complex, thus more transparent communication is imperative to obtain positive outcomes for the participants in this study.

Chapter Five: Discussion and Conclusion

The primary aim of this research was to examine the psychological well-being of renal patients who are using dialysis under the care of the Waikato Regional Renal Centre. This involved interviews with dialysis patients and renal health professionals and a more widely distributed questionnaire survey of patients.

In this chapter, the findings that affect dialysis patients' psychological well-being will be identified and discussed. Of particular note are two recurring themes pertaining to both patients and health professionals: the need for ongoing education; and the need for effective communication. The discussion begins with the reactions of patients when given their diagnosis and treatment options. This is followed by examining the issue of pre-dialysis. The implications of diet, fluid restriction, medication, depression, anxiety and pain for renal patients are discussed. The health professionals' training in mental health and their methods of assessment of patients' psychological well-being are reflected upon. I then consider the participants' perspectives on changes and resources that could improve issues of compliance and outcomes. The importance of support networks for patients which include family, psychological and spiritual support will be explored. And finally, challenges for renal health professionals and patient experiences with the healthcare system will also be discussed. I conclude this chapter by considering areas for future research.

Impacts on psychological well-being

Factors affecting psychological well-being in renal patients begin immediately upon diagnosis. When diagnosed with renal failure most of the patients who were interviewed expressed that their initial reaction was that of shock and fear. This was confirmed by the health professionals who see newly diagnosed patients presenting as stunned and apprehensive. These reactions arise for a variety of reasons explained in the literature. Firstly, renal patients' very reality is altered as their identity immediately changes from being 'healthy' to 'sick'. Secondly many of the lifestyle changes attendant with renal disease are very difficult to manage for new patients. They must follow strict dietary and fluid constraints and experience disruptions to their freedom. The removal of choice from renal patients' lives eliminates their ability to exercise free-will which depletes their

sense of autonomy. Additionally, they must cope with the effect of chronic kidney disease on their financial and social circumstances (Zalai et al., 2012).

A diagnosis of renal failure with the need for dialysis is usually unexpected, which may be in part due to an absence of early screening. An interesting finding in this research is the lack of screening for renal disease in NZ. Pre-dialysis education is reported by Walker et al. (2010) to be necessary so that patients have time to accept their diagnosis and understand treatment options. According to New Zealand Kidney Foundation (2007) the need for dialysis can be delayed by careful monitoring of diet and fluid intake in pre-dialysis care. However, the patients in this study reported a lack of early access to this type of information or assistance. Many participants described a loss of appetite and the difficulties associated with having to be selective about various foods. Steiber (2014) reported that renal patients under the care of a dietician have lower mortality rates.

The notion of compliance is raised frequently in the findings. Compliance regarding fluid and diet restrictions, the taking of medication, accepting treatment and attending clinic appointments were significant issues discussed by the participants. It was suggested that more flexibility and choice regarding dialysis treatment times for patients might improve compliance. One suggestion raised was to have the option of clinic appointments on the day of dialysis for the in-care participants. This was proposed to avoid the need for an additional trip to the hospital for these already stretched patients. The results from both patients and health professionals found that education is considered to be important for patients in order for them to understand why they need to comply. This was consistent with other research which found that non-compliance is linked to a lack of adequate knowledge (Chan et al., 2012). Christensen and Ehlers (2002) established that the issue of non-compliance is due to the various psychological aspects and lack of autonomy that challenge renal patients. Similarly, Calia et al. (2015) found that when renal patients are provided with specific psychological support their compliance increases. This suggests that psychological assistance with the complex problems that renal patients experience could decrease rates of non-compliance. The findings in this research were consistent with those of Calia et al. (2015) and the widely held view of the participants emphasised that

psychological support should be an integral part of treatment for patients with renal disease.

Participants in this study highlighted a lack of access to the pre-dialysis care needed to educate patients and their families on aspects of the disease, including how to prepare meals suitable for a renal patient. The difficulty of having to stringently control fluid intake was raised throughout the findings by a vast majority of the participants. The overarching theme conveyed by the renal patients was the constant worry of becoming 'overloaded' with fluid in-between dialysis treatments. The negative effect of fluid overload is widely researched as it contributes to shortened patient survival (Christensen & Ehlers, 2002; White & McDonnell, 2014). The patients reiterated that the management of this aspect of the disease was very challenging for them.

Because ESKD patients are reported to experience high rates of depression associated with adverse dialysis outcomes, mental health screening in this population would be advantageous (Zalai et al., 2012). This would identify depression earlier and enable the necessary psychological support to be put in place. The argument that diagnosis for depression in ESKD patients is problematic should not negate the provision of support. Even though there are similarities between the somatic symptoms of depression and the physical symptoms associated with the side effects of ESKD these still need to be addressed. A key finding of this research was the lack of psychological services provided at the Waikato Regional Renal Centre. A majority of participants stated that they had never been offered any psychological support. It appeared that while most of the participants were coping quite well with depression, there were at risk participants who indicated they were suffering with severe depression. Furthermore, a small proportion of the participants expressed that they would like to die, and have experienced suicidal ideation at varying times since being diagnosed with ESKD. This is confirmed elsewhere as De Sousa (2008) found that ESKD patients have higher suicide rates than the normal population. These findings are not surprising and indicate that the patients in this study need to have access to considerably more psychological services than are available at present.

This research also found that age of the patient and the amount of time a patient had been on dialysis were significant factors affecting the BDI results. The results of the BAI performed by the questionnaire participants suggest a proportion of the participants were suffering from severe anxiety. These results are not surprising given that depression and anxiety are highly correlated (Alavi et al., 2009). Causes of anxiety for dialysis patients include the dialysis treatment routine, and the alarm sounding on the dialysis machines. For HD patients having their fistula cannulated by new dialysis staff caused anxiety (Hmwe et al., 2015). It was found that the neurophysiological aspects, such as wobbliness in legs and feeling unsteady were the most problematic for the participants to tolerate. The BAI results found that the age of the participant, their income and treatment option were all significant factors affecting anxiety. These findings could assist health professionals working with renal patients to recognise those at risk of depressive and or anxiety symptoms. In this research screening for depression was raised as a possible solution for monitoring the mental health of the patients. It is widely recommended in the literature that all ESKD patients should be carefully screened for depression (Cukor, Rosenthal, Jindal, Brown, & Kimmel, 2009). Wuerth, Finkelstein, and Finkelstein (2005) suggest that regular screening using the BDI gives the patient an opportunity to talk to a mental health professional, which may relieve situational stress. Although research has clearly identified that screening could benefit renal patients, the surprising view of social workers interviewed for this research was that it was not necessary.

Need for psychological support for patients

This research sought to determine what training renal health professionals had in the area of mental health and well-being. It was found that apart from the social workers other health professionals had minimal or no training in mental health and none was undertaken in the unit. Fairly rudimentary observational methods to probe a patient about depression and or anxiety were put into effect by the health professionals to assess the mental health status of a patient. This was often only when the patient already had obvious indications that they were struggling. The staff were not able to provide a diagnosis or treatment for what was wrong. This would appear to indicate that the mental health symptoms in these renal patients are in danger of being underdiagnosed. Furthermore, the hospital and community

health professionals expressed that even when requested psychological services were inconsistent and very hard to access. They articulated the desire for convenient and regular access to psychological services as part of the treatment team. Several conveyed that this had been sadly lacking for a long time. As *Deb* stated, “I’ve been here 30 years and way back over 20 years ago we had a psychologist as part of our renal team, which was fantastic.” As would be expected the overwhelming sentiment of the renal patient participants was that psychological support was for them an urgent priority. These findings demonstrate the need for either additional training in mental health for the health professionals, and or better access to permanent psychological services at the renal unit. Furthermore, the social workers believed that individual therapy would be more beneficial than group therapy. An interesting finding in this research was that most of the renal patients were either ambivalent or not interested in either form of therapy when asked about it in the questionnaire which probably suggests a lack of knowledge.

Egan et al. (2014) found that attending to the renal patients’ spiritual needs contributes to their improved psychological well-being which leads to a better quality of life. The results in this study indicated that approximately half of the participants considered spiritual support to be important. However, the health professionals stated that although they might want to discuss topics like the grieving process and spiritual support, they do not have the time to do so. Furthermore, it was proposed by one health professional that better availability of psychological support for renal patients would give credence to the Te Whare Tapa Wha health model. In view of the research findings that renal specialists may lack an awareness of patient’s spiritual needs and also palliative care needs, using this model as a framework could address this (Egan et al., 2014). The findings repeatedly stressed the need for improved psychological services and this was expressed by both patients and health professionals. As depression is a prevalent under- treated comorbidity in patients with ESKD and is associated with increased mortality the need for psychological services is very apparent for these patients (Hedayati, Yalamanchili, & Finkelstein, 2012). Time and time again it was suggested in this study that access to psychological services would greatly complement the treatment delivered to ESKD patients.

The results of this research were consistent with others regarding social support in that it was found that a key component for psychological well-being for renal patients was that their requirements for help and support be met. Schick Makaroff (2012) found that social support can be received from family, friends and medical personnel. The participants discussed how important family support was and the findings confirm that most families had a representative who accompanied the renal patient to the education sessions for dialysis. Being open to learning is a prerequisite for family members of renal patients. The health professionals agreed that educating family is huge, and encouraged bringing a support person to education sessions and to clinics as they felt this was beneficial. This fits with the literature which postulates that ongoing education for the family is a necessity so that they are aware of the many ways to assist an individual on dialysis, and support home based education programmes that involve the family (Massey et al., 2011; Shih & Honey, 2011).

Pomaki et al. (2011) suggest that some family members are overprotective and unnecessarily limit the patient's activities. The health professionals confirmed this, citing the example of family members speaking for the patient. An interesting finding in this research was that according to most of the renal patients they felt that their family members had a good understanding of renal disease. They reported that their families understood the implications of dialysis and why they required extra help with practical tasks. However, the perception of some of the health professionals was contradictory as they expressed doubt at the degree of many families understanding about the renal patients' illness. They concluded this because of their observations and personal exchanges with family members. They also communicated that there were a lot of things a family could learn to do to help their member with renal disease. Conversely, the patient participants conveyed that their family were already doing enough to help them. Overall, the patients stated that they were satisfied with the levels of support they were receiving from family. This may be explained by previous findings across the literature that indicate that renal patients often feel as though they are a burden on their family members (Karamanidou, Weinman, & Horne, 2014; Schick Makaroff, 2012). Many of the patients themselves talked about feeling this way in this study. This may be why they overestimate their family's understanding of

their disease and do not expect them to give any more support than at present. They are reluctant to make any more demands on their family members for fear of adding to the 'burden' on the household of their disease. As stated by McQuoid, Jowsey, and Talaulikar (2017) ESKD is a complex juggling act between illness management and other everyday activities. It was found in this study that the level of practical support offered by the family members was considered helpful to the renal patients.

Other support received from family discussed by the participants included financial, emotional and spiritual support. Walker et al. (2013) point out that renal patients have many ongoing decisions to make and that a shared decision-making model helped make this easier for them, whereby the treatment options were discussed with the patient and family and decisions were made according to what would be most appropriate within that particular family. Likewise, Jayanti et al. (2015) suggest that end stage renal patients are faced with incrementally complex decision making throughout their treatment journey and to be supported in this process is key. Crail et al. (2013) recommend that all decisions regarding end of life care need to involve the patient and family as a decision in palliative care to decline treatment will lead to death within a short period of time (New Zealand Kidney Foundation, 2007).

Patients who use home dialysis can require more active assistance from the family. Walker et al. (2015) suggest a key attribute for home dialysis patients is family or caregiver support. de Maar et al. (2016) indicated that optimal home dialysis training involves a family member. In this research, the literature suggests that the positive outcomes for home dialysis such as quality of life and longer survival rates outweigh the in-care dialysis outcomes (Kutner et al., 2005). Despite this Wilkie (2011) states the international trend for home dialysis continues to decline perhaps due to a lack of suitable support. Holman (2011) points out that health professionals need to give carers of home dialysis patients time, space and permission to talk about how caring impacts on their lives. It was established in this research that it was important to keep the family engaged so they can continue to provide practical help and support. The health professionals acknowledged that it takes time for families to understand such a complex illness. In this study, some health professionals also acknowledged that families are often

undervalued. In this study family support was found to be very important to the renal patients. They appreciated the practical help within the home as well as emotional support from family. This research highlighted how renal disease affects the whole family not just the patient, and how complex these relationships can become when a person has a chronic illness.

Patients need for improved communication

When asked whether their concerns about treatment were listened to and acted upon, a surprising nine out of eleven patients interviewed had one or more negative experiences with health professionals that they wished to recount. While it was reported by some that they have experienced continued provision of good care from doctors and nurses, most participants expressed frustration with staff over problems they felt were preventable. Many complained about being unable to comprehend poor explanations causing an information overload. Others felt that though they had an understanding of their medical requirements they had to bring constant pressure to bear to obtain services. Whilst patients said they were dissatisfied with aspects of the hospital system, more significantly many patients criticised the interpersonal communications between health professionals and themselves. This was not just about the information they were being told, but also the way in which it was delivered. It has been found that how staff interact with patients is important for mediating improved outcomes for renal patients (Kimmel, 2001).

White and McDonnell (2014) also state that health professionals working with renal patients should help them with the significant psychological challenges they are confronted with every day. Schick Makaroff (2012) note that patients want closer connections with the health professionals who provide their care, therefore a more collaborative relationship with patients would contribute to patients' emotional well-being. Contrary to this, these patients said they were not listened to and sometimes even felt bullied. Several participants reported that when their concerns were serious they followed up by writing official letters of complaint to the DHB. These formal complaints were mainly with regard to communication problems and sometimes also medical issues. Schaad et al. (2015) stated that most complaints in hospitals are due to unhappiness with interpersonal interactions between patients and their providers.

This research explored what other resources the participants thought might improve the outcomes for renal patients. The findings reflect that they have frustrations regarding some hospital protocols. The lack of continuity regarding doctors seen at hospital appointments was raised as an issue. The renal patients desired a more personal doctor and patient relationship with a primary doctor they can rely on. Also discussed was improving communication with health professionals so that the patient felt more informed and secure. More open communication was made with the suggestion that patients have a list of contact numbers for their health team. A reengagement with kaitiaki services who offer cultural support for Māori and their whanau in hospital was also recommended as an extra resource for the patients. The in-care patients proposed that there be less waiting time before starting dialysis by having a more effective shuttle system. Some patients preferring to travel less requested that HD machines be available in smaller communities.

In their interviews, some of the health professionals also voiced concerns about other staff members, stating examples of lack of discretion, respect and sensitivity towards patients on the part of some health professionals. They acknowledged also the long waiting lists and delays for necessary procedures and how unsatisfactory this situation was for the patients. Research has clearly identified that patients suffer from higher anxiety the longer the waiting time is for surgery, and this correlates with decreased health for the patient and the risk of complications during the wait (Oudhoff, Timmermans, Knol, Bijnen, & van der Wal, 2007). Zalai et al. (2012) recommended that renal healthcare teams learn from treatment models already implemented to promote psychological wellbeing in other medically ill populations and that these can be used to support renal patients. The psychological impacts on patients who encounter negative healthcare experiences cannot be underestimated. Renal patients are at higher risk for emotional distress leading to depression, which can culminate in earlier mortality (Christensen & Ehlers, 2002). This is preventable with better communication and training about standards of care that are conducive to patients' psychological well-being.

The finding that pain was an ongoing problem experienced by the participants was also indicated in the literature which concludes that pain is the most common

symptom experienced by ESKD patients (White & McDonnell, 2014). Both HD and PD patients described experiencing pain. The HD patients complained about the pain when their fistula were needled for access, and PD patients about the painful abdominal distension they experience. Furthermore, the participants discussed regular cramping, nausea, skin dryness and the excessive time HD patients must sit for treatment and how hard this is on their body. The patients expressed that there was a lack of communication with the health professionals regarding any pain and also a reluctance to prescribe them with analgesic medication. As Barakzoy and Moss (2006) found the undertreatment of pain has negative effects on both the physical and mental well-being of renal patients, it is recommended that they be closely monitored for pain and that pain relief should be prescribed to adequately manage pain. The implementation of this should perhaps be considered for the participants in this study. There are eight commonly prescribed medications for renal patients and these have been found to cause depression or have side effects that mimic its symptomatology (Kimmel, 2002). The perception of being over medicated was also raised by patient participants as impacting on their psychological wellness. Many felt concerned about the side effects from the drugs. It is therefore likely that this is a valid concern for these participants which needs further investigation.

The health professionals interviewed for this study reported that they have also at times experienced difficulties in their interactions with patients and family members. They suggested that this could occur due to misconceptions in families who lack the appropriate knowledge or have a fear of something because they do not understand it. The health professionals stressed that keeping a family cognisant of their member's situation through regular communication was essential, because misinformed families can make their job more difficult, but also because these misunderstandings do not help the patient. The health professionals discussed how some families wittingly and unwittingly can limit the patient's independence. Sometimes this is done from ignorance but other times family members can be domineering and might even bully the patient. They themselves had also encountered family members who have been disruptive and abusive. The health professionals also spoke of occasions where families were unable to follow through with arrangements they have made and the difficulties that this can cause

for other patients and staff. These challenges described by the health professionals would further suggest the necessity of more effective communication channels and education, so expectations of what is appropriate for the patient and family to follow are made clear.

Another challenge talked about by the health professionals was the stress incumbent with their jobs. This arises as a consequence of their everyday dealings with the grim nature and progression of renal disease in their patients. The coping mechanisms they used to alleviate the pressures of their work were discussed in this study. The most common strategy the health professionals reported was the sharing of thoughts and feelings by talking with another colleague. This is in line with literature which states that mentorship and collaboration between colleagues helps them to manage stress (Stanley et al., 2015). Josland et al. (2012) point out that if health professionals have comprehensive knowledge about what to expect through all the stages of renal disease from pre-dialysis to death, they may be able to partially pre-empt their emotional reactions. The health professionals spoke of the emotional toll of losing a patient. They said they cope by talking about the patient with other colleagues at work and emphasised that it was imperative to not take work pressures home.

This research sought to explore the psychological wellness of renal patients using dialysis who were under the care of the Waikato Regional Renal Unit. The renal patients were asked to share, via face to face interviews and responding to a questionnaire, their experiences about living with dialysis, and the health professionals, again via face to face interviews, about working with patients who have renal failure. This investigation into the lived realities of the participants provided insight into the needs of renal patients, their families and health professionals and generated ideas about how renal services could be more responsive to people with renal failure.

Future research

The results of this study present a solid foundation for understanding the nature of psychological wellness of renal patients on dialysis under the care of the Waikato Regional Renal Centre. Broad in their scope, the findings suggest that there are a

number of areas for improvement to the service that is offered. To strengthen the service and our understanding of dialysis patients, further research information is required of specific groups. Priority needs to be given to a study of young adults who are on dialysis. According to the health professionals in my research “our rates of survival are not good with our young people.” The influence of culture and ethnicity is another under researched area and requires attention especially given the high number of Māori and Pacific peoples with renal disease. There is also a group of patients likely to have not participated in this study because they were too mentally or physically unwell to do so. While deteriorating health might be an expected part of renal disease, it remains incumbent upon us to understand the fullness of the disease journey so as to offer timely and appropriate services and support. Because in the main the interviewed participants were coping relatively well with treatment this was not a true representation of renal patients with end stage kidney disease.

This research has highlighted a need for more inquiry into pain management and the use of appropriate analgesic medication for renal patients. While this area of inquiry is outside the scope of this study and the researchers expertise it is important that the issue is raised for further investigation.

While there is ongoing work in the area of palliative and end of life care it would be useful to more specifically understand the caregiver burden of supporting a dialysis patient. While I surveyed with participants the nature of support they received from family, friends and other support people, their voices remain absent from the conversation.

Possible research for the Waikato Renal Centre would be to conduct cost benefit evaluations on each of the issues raised in this study. This study clearly found that there were areas for improvement that the centre should attend to and consider implementing. It would seem that not only will these implementations benefit patient outcomes but they will likely make financial sense also.

Why this research?

Over the four years I have been visiting the renal unit as a support person to my friend as she undergoes dialysis. It has been my privilege to observe the strength and courage and the acceptance with which the patients cope with their highly

debilitating disease and intrusive treatments. I have witnessed the distress and pain and trauma that are a part of the relentless struggle that is end stage kidney disease. It is for these people that I undertook this research in an effort to determine the psychological toll this disease has on them and the ways this may be remediated for them. I also came to realise, as had been my own case, that very little is known about ESKD and the renal replacement treatments needed to survive. It my hope to raise this awareness and perhaps contribute towards positive change in the difficult lives that renal patients are required to endure. Through the process of this research I have come to truly value my health and autonomy and wish to continue to use these to give support to those who have lost theirs.

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Appendices

Appendix A: Questionnaire confirmation sheet

Thank you

for addressing and posting the questionnaires

Please confirm for statistical purposes the number of envelopes you posted on my behalf:

Satellite dialysis patients

This box contains 50 envelopes

If total amount was handed out posted, please tick here

Or amount handed out _____

Please hand this form to Helen upon collection and I will collect from her, this is so I can accurately analyse the data.

Enjoy the chocolate ☺

Kind regards

Cherie Pepperell

Appendix B: Dialysis patient questionnaire

Kia ora / Greetings

Exploring the psychological wellbeing of renal patients in New Zealand

My name is Cherie Pepperell and I am a Masters psychology student at the University of Waikato. I am conducting research into the psychological health of dialysis patients. I became interested in this topic because my best friend is living with renal failure. I have witnessed and continue to support her through her journey of dialysis and the vast array of emotional difficulties along the way. My goal is to provide more research involving New Zealand dialysis patients because there is limited research available.

You are invited to complete this questionnaire, which takes about fifteen minutes, if you are currently using peritoneal dialysis or haemodialysis. The questionnaire consists of questions about your health and mental wellbeing. The information collected will be used in a data analysis and will be reported in a thesis. This research is supervised by Professor Linda Nikora and Dr Carrie Barber.

A medical issue such as renal failure can be stressful. You are not obliged to complete the questionnaire and can choose to opt out at any time. You have the right not to answer particular questions. This research has been reviewed and approved by the University of Waikato School of Psychology Ethics Committee, and the Waikato District Health Board (DHB). Furthermore, a consultation with Te Puna Oranga Maori Consultation Research Committee, Waikato DHB for cultural and community approval was completed. If you have any questions or concerns about your rights as a participant in this research, you can contact the conveyer of the Psychology Research and Ethics Committee (Dr Rebecca Sargisson, phone 07 5578673, email: rebeccas@waikato.ac.nz)

Your details will be kept anonymous and confidential. You will not be able to be identified in the data as the completed questionnaire will not be linked to any

identifying details. The completed questionnaire will only be seen by me and my supervisor and will remain confidential.

By completing this questionnaire, you are consenting to the data being used in the study. If you would like a brief summary report of the findings, please email me and I will send you a summary after the study is finished.

Contact Details

Cherie Pepperell. Email: csk5@students.waikato.ac.nz or phone: 021 082 17722
Professor Linda Nikora (supervisor). Email: psyc2046@waikato.ac.nz

Background Questions

What is your gender?

- Male
- Female

What is your age?

- please insert _____

What is your marital status?

- Never married
- Married or de facto
- Widowed
- Separated / Divorced

What is your ethnicity?

- NZ Maori
- NZ European
- Other European
- Pacific Islander
- Other _____

Approximate total household income over the last 12 months:

- 20,000 or less
- 20,001 - 30,000
- 30,001 - 50,000
- 50,001 - 70,000
- 70,001 - 100,000
- 100,001 or more

What dialysis treatment are you currently using?

- Peritoneal Dialysis
- Haemodialysis

Which treatment option are you currently using?

- In care Haemodialysis
- Home Haemodialysis
- Continuous Ambulatory Peritoneal Dialysis
- Automated Peritoneal Dialysis

Have you used both treatment options?

- Yes
- No

How long have you been receiving dialysis treatments?

- Please advise _____

Are you on the kidney transplant waiting list?

- Yes
 No

The following question are about social support using the Social Provisions Scale-Short Version.

There are people I can depend on to help me if I really need it.

- Strongly disagree
 Disagree
 Agree
 Strongly Agree

I feel that I do not have close personal relationships with other people

- Strongly Disagree
 Disagree
 Agree
 Strongly Agree

There is no one I can turn to for guidance in times of stress.

- Strongly Disagree
 Disagree
 Agree
 Strongly Agree

There are people who enjoy the same social activities that I do.

- Strongly Disagree
 Disagree
 Agree
 Strongly Agree

I do not think other people respect my skills and abilities.

- Strongly Disagree
 Disagree
 Agree
 Strongly Agree

If something went wrong, no one would come to my assistance.

- Strongly Disagree
- Disagree
- Agree
- Strongly Agree

I have close relationships that provide me with a sense of emotional security and wellbeing.

- Strongly Disagree
- Disagree
- Agree
- Strongly Agree

I have relationships where my competence and skills are recognized.

- Strongly Disagree
- Disagree
- Agree
- Strongly Agree

There is no one who shares my interests and concerns.

- Strongly Disagree
- Disagree
- Agree
- Strongly Agree

There is a trustworthy person I could turn to for advice if I were having problems.

- Strongly Disagree
- Disagree
- Agree
- Strongly Agree

This section is to ascertain levels of depression using the Beck Depression Inventory-Second Edition.

Instructions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the **one statement** in each group that best describes the way you have been feeling during the **past two weeks, including today**. Circle or if completing online choose the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

1. Sadness

- 0. I do not feel sad.
- 1. I feel sad much of the time.
- 2. I am sad all the time.
- 3. I am so sad or unhappy that I can't stand it.

2. Pessimism

- 0. I am not discouraged about my future.
- 1. I feel more discouraged about my future than I used to be.
- 2. I do not expect things to work out for me.
- 3. I feel my future is hopeless and will only get worse.

3. Past Failure

- 0. I do not feel like a failure.
- 1. I have failed more than I should have.
- 2. As I look back, I see a lot of failures.
- 3. I feel I am a total failure as a person.

4. Loss of Pleasure

- 0. I get as much pleasure as I ever did from the things I enjoy.
- 1. I don't enjoy things as much as I used to.
- 2. I get very little pleasure from the things I used to enjoy.
- 3. I can't get any pleasure from the things I used to enjoy.

5. Guilty Feelings

- 0. I don't feel particularly guilty.
- 1. I feel guilty over many things I have done or should have done.
- 2. I feel guilty most of the time.
- 3. I feel guilty all of the time.

6. Punishment Feelings

- 0. I don't feel I am being punished.
- 1. I feel I may be punished.
- 2. I expect to be punished.
- 3. I feel I am being punished.

7. Self-Dislike

- 0. I feel the same about myself as ever.
- 1. I have lost confidence in myself.
- 2. I am disappointed in myself.
- 3. I dislike myself.

8. Self-Criticalness

- 0. I don't criticize or blame myself more than usual.
- 1. I am more critical of myself than I used to be.
- 2. I criticize myself for all of my faults.
- 3. I blame myself for everything bad that happens.

9. Suicidal Thoughts or Wishes

- 0. I don't have any thoughts of killing myself.
- 1. I have thoughts of killing myself, but I would not carry them out.
- 2. I would like to kill myself.
- 3. I would kill myself if I had the chance.

10. Crying

- 0. I don't cry any more than I used to.
- 1. I cry more than I used to.
- 2. I cry over every little thing.
- 3. I feel like crying, but I can't.

11. Agitation

- 0. I am no more restless or wound up than usual.
- 1. I feel more restless or wound up than usual.
- 2. I am so restless or agitated that it's hard to stay still.
- 3. I am so restless or agitated that I have to keep moving or doing something.

12. Loss of Interest

- 0. I have not lost interest in other people or activities.
- 1. I am less interested in other people or things than before.
- 2. I have lost most of my interest in other people or things.
- 3. It's hard to get interested in anything.

13. Indecisiveness

- 0. I make decisions about as well as ever.
- 1. I find it more difficult to make decisions than usual.
- 2. I have much greater difficulty in making decisions than I used to.
- 3. I have trouble making any decisions.

14. Worthlessness

- 0. I do not feel I am worthless.
- 1. I don't consider myself as worthwhile and useful as I used to.
- 2. I feel more worthless as compared to other people.
- 3. I feel utterly worthless.

15. Loss of Energy

- 0. I have as much energy as ever.
- 1. I have less energy than I used to have.
- 2. I don't have enough energy to do very much.
- 3. I don't have enough energy to do anything.

16. Changes in Sleeping Pattern

- 0. I have not experienced any change in my sleeping pattern.
- 1a. I sleep somewhat more than usual.
- 1b. I sleep somewhat less than usual.
- 2a. I sleep a lot more than usual.
- 2b. I sleep a lot less than usual.
- 3a. I sleep most of the day.
- 3b. I wake up 1-2 hours early and can't get back to sleep.

17. Irritability

- 0. I am no more irritable than usual.
- 1. I am more irritable than usual.
- 2. I am much more irritable than usual.
- 3. I am irritable all the time.

18. Changes in Appetite

- 0. I have not experienced any change in my appetite.
- 1a. My appetite is somewhat less than usual.
- 1b. My appetite is somewhat greater than usual.
- 2a. My appetite is much less than before.
- 2b. My appetite is much greater than usual.
- 3a. I have no appetite at all.
- 3b. I crave food all the time.

19. Concentration Difficulty

- 0. I can concentrate as well as ever.
- 1. I can't concentrate as well as usual.
- 2. It's hard to keep my mind on anything for very long.
- 3. I find I can't concentrate on anything.

20. Tiredness or Fatigue

- 0. I am no more tired or fatigued than usual.
- 1. I get more tired or fatigued more easily than usual.
- 2. I am too tired or fatigued to do a lot of the things I used to do.
- 3. I am too tired or fatigued to do most of the things I used to do.

21. Loss of Interest in Sex

- 0. I have not noticed any recent change in my interest in sex.
- 1. I am less interested in sex than I used to be.
- 2. I am much less interested in sex now.
- 3. I have lost interest in sex completely

This section is to ascertain levels of anxiety using the Beck Anxiety Inventory.

Instructions: Below is a list of common symptoms of anxiety. Please carefully read each item in the list. Indicate how much you have been bothered by each symptom during the PAST WEEK, INCLUDING TODAY, by placing an X in the corresponding space in the column next to each symptom.

	NOT AT ALL	MILDLY (It did not bother me much)	MODERATELY (It was very unpleasant, but I could stand it).	SEVERELY (I could barely stand it).
1. Numbness or tingling.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Feeling hot.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Wobbliness in legs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Unable to relax.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Fear of the worst happening.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Dizzy or lightheaded.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Heart pounding or racing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Unsteady.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Terrified.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Nervous.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Feelings of choking.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Hands Trembling.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Shaky.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Fear of losing control.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Difficulty breathing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Fear of dying.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Scared.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Indigestion or discomfort in abdomen.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Faint.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Face flushed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Sweating (not due to heat)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following questions are about psychological wellbeing

Have you ever been offered any psychological services whilst receiving renal treatments?

- Yes
- please describe: _____
- No

What activity do you prefer to do whilst in treatment?

- watch TV
- listen to music
- talk to staff
- read a book
- use your computer
- phone friends / family
- other _____

Do you have any coping mechanisms you use whilst in treatment?

- Yes _____
- No

Do you feel your requests are being considered whilst in treatment, if no why?

- Yes
- No _____

Do you feel secure whilst participating in treatment?

- Yes
- No

How important is the nurse's response your requests?

- Not at all Important
- Very Unimportant
- Somewhat Unimportant
- Neither Important nor Unimportant
- Somewhat Important
- Very Important
- Extremely Important

Do you feel your care level is adequate, if no why?

- Yes
- No _____

Do your whanau/family/significant other have an active role in your care?

- Yes
- No

Do your whanau/family/significant other understand the nature of your illness?

- Yes
- No

What does your whanau/family/significant other do to help support you in your care?

- Please list _____

Are their tasks/activities you would like your whanau/family/significant other to be involved in that would make coping easier for you?

- Please list _____

Would you be interested in attending group therapy sessions?

- Yes
- Maybe
- No

Would you be interested in attending individual therapy?

- yes
- Maybe
- No

Would you like access to massage therapy?

- Yes
- Maybe
- No

Would you be interested in learning about meditation techniques?

- Yes
- Maybe
- No

Would you be interested in learning visualization techniques?

- Yes
- Maybe
- No

Is spiritual support important to you?

- Yes
- Maybe
- No

How would you rate your health in general now?

- Much better
- Better
- Somewhat Better
- About the Same
- Somewhat Worse
- Worse
- Much Worse

Thank you for completing this questionnaire.

Please post the completed questionnaire directly to me in the pre-paid envelope, or you can take it to the renal unit at the Waikato Hospital in Hamilton and place in collection box.

If you have any questions do not hesitate to contact me,
Cherie Pepperell: email: csk5@students.waikato.ac.nz or phone: 021 082 17722

If you feel completing this questionnaire has been emotionally difficult for you and you would like to talk to someone about your feelings and experiences please contact your health professional, or there is a free, confidential counseling service called Lifeline and you can contact them by calling 0800 543 354.

Appendix C: Flyer - Patient

Exploring the level of psychological wellness of renal patients using dialysis in
Waikato, NZ

My name is Cherie Pepperell and I am looking for people to interview who are using dialysis. I am researching the level of psychological wellness for peritoneal and haemodialysis patients for my master's thesis.

I would really appreciate it if you could complete the enclosed questionnaire as well as contact me so that I can interview you about your dialysis journey.

If you would like to talk to me please *text, email or phone using the numbers below:*

Email: csk5@students.waikato.ac.nz

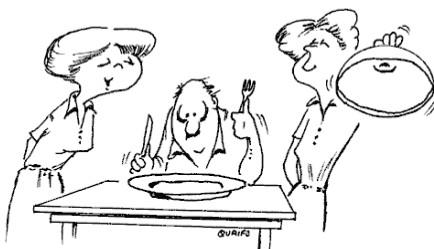
Phone / Text: 021 082 17722



Your information is confidential at all times.

This research has been approved by the Waikato University Ethics Committee, Waikato District Health Board and Te Puna Oranga Māori Consultation Research Review Committee.

www.fightersideofdialysis.com



...and this dish is totally potassium-free!



I do sympathize with you, sir, but I'm afraid it cannot be viewed as 'carry on' luggage.

Appendix D: Flyer – Health Professional

Exploring the level of psychological wellness of renal patients using dialysis in
Waikato, NZ

My name is Cherie Pepperell and I am looking for people to interview who are
working with patients who are using dialysis. I am researching the level of
psychological wellness of dialysis patients for my master's thesis.

I would really appreciate it if you would contact me so that I can interview you
about your experiences.

If you would like to talk to me please *text, email or phone using the numbers
below:*

Email: csk5@students.waikato.ac.nz

Phone / Text: 021 082 17722



Your information is confidential at all times.

This research has been approved by the Waikato University Ethics Committee,
Waikato District Health Board and Te Puna Oranga Māori Consultation Research
Review Committee.



Appendix E: Information sheet - Patients

Information sheet for patients using dialysis

Exploring the psychological wellbeing of renal patients in NZ

What is the project about?

This research project seeks to explore what the level of psychological wellness is for renal patients in the Waikato region. At present there is little information pertaining to the levels of social support, depression, anxiety and psychological wellness for renal patients on dialysis.

Who are the researchers?

I am a Masters student for the School of Psychology at Waikato University. I am working under the supervision of Professor Linda Nikora and Dr Carrie Barber. This research project has been given ethical approval by the University of Waikato, Waikato District Health Board and Te Puna Oranga Māori Consultation Research Review Committee. If you have any concerns, you can contact my supervisor or the Chair of the Ethics Committee (contact detail below).

Why are you being asked to participate?

Your lived experiences of renal failure will provide valuable information.

What will happen to my information?

All information gathered will be held at the University of Waikato and it will only be available to me or my supervisor. If you would like a summary of the final results I can send you a copy.

Will other people know who I am or what I say?

No a pseudonym will be used to protect your privacy. I will be the only person who knows where the information has come from.

What if I agree to participate and then change my mind?

If you change your mind and wish to withdraw your interview data, you have up to two weeks after the interview to inform me and I will remove this data.

Researcher contacts:

Cherie Pepperell (Masters Student), Phone: 021 082 17722

email: csk5@students.waikato.ac.nz

Professor Linda Nikora (Supervisor) email: psyc2046@waikato.ac.nz

If you have any questions or concerns about your rights as a participant in this research, you can contact the conveyor of the Psychology Research and Ethics Committee (Dr Rebecca Sargisson, phone 07 5578673, email: rebeccas@waikato.ac.nz).

Address: School of Psychology
 University of Waikato
 Private Bag 3105
 Hamilton 3240

Appendix F: Information sheet – Health professional

Information sheet for health professionals

Exploring the psychological wellbeing of renal patients in NZ

What is the project about?

This research project seeks to explore what the level of psychological wellness is for renal patients in the Waikato region. At present there is little information pertaining to the levels of social support, depression, anxiety and psychological wellness for renal patients on dialysis.

Who are the researchers?

I am a Masters student for the School of Psychology at Waikato University. I am working under the supervision of Professor Linda Nikora and Dr Carrie Barber. This research project has been given ethical approval by the University of Waikato, Waikato District Health Board and Te Puna Oranga Māori Consultation Research Review Committee. If you have any concerns, you can contact my supervisor or the Chair of the Ethics Committee (contact detail below).

Why are you being asked to participate?

Your experiences working with renal patients will provide valuable information.

What will happen to my information?

All information gathered will be held at the University of Waikato and it will only be available to me or my supervisor. If you would like a summary of the final results I can send you a copy.

Will other people know who I am or what I say?

No a pseudonym will be used to protect your privacy. I will be the only person who knows where the information has come from.

What if I agree to participate and then change my mind?

If you change your mind and wish to withdraw your interview data, you have up to two weeks after the interview to inform me and I will remove this data.

Researcher contacts:

Cherie Pepperell (Masters Student). Phone: 021 082 17722

email: csk5@students.waikato.ac.nz

Professor Linda Nikora (Supervisor) email: psyc2046@waikato.ac.nz

Conveyor of the Psychology Research and Ethics Committee: Dr Rebecca Sargisson, phone 07 5578673, email: rebeccas@waikato.ac.nz

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Appendix G: Consent form - Patients

CONSENT FORM FOR DIALYSIS PATIENTS

A completed copy of this form should be retained by both the researcher and the participant.

Research Project: Exploring the level of psychological wellness of renal patients on dialysis in the Waikato, NZ.

Please complete the following checklist. Tick (✓) the appropriate box for each point.	YES	NO
1. I have read the Participant Information Sheet (or it has been read to me) and I understand it.		
2. I have been given sufficient time to consider whether or not to participate in this study.		
3. I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.		
4. I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study up to two weeks after the interview.		
5. I have the right to decline to participate in any part of the research activity.		
6. I know who to contact if I have any questions about the study in general.		
7. I understand that my interview is being recorded.		
8. I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.		
9. I wish to receive a copy of the findings.		
10. I wish to view the summary report of my interview.		

Declaration by participant:

I agree to participate in this

I agree to participate in this research project. If I have any concerns about this project, I may contact the convenor of the Psychology Research and Ethics Committee (Dr Rebecca Sargisson, phone 07 557 8673, email: rebeccas@waikato.ac.nz)

Participant's name (Please print):

Signature:

Date:

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it. I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: Cherie Pepperell

Signature:

Date:

Appendix H: Consent form – Health professional

CONSENT FORM FOR RENAL HEALTH PROFESSIONALS

A completed copy of this form should be retained by both the researcher and the participant.

Research Project: Exploring the level of psychological wellness of renal patients on dialysis in the Waikato, NZ.

Please complete the following checklist. Tick (✓) the appropriate box for each point.	YES	NO
11. I have read the Participant Information Sheet (or it has been read to me) and I understand it.		
12. I have been given sufficient time to consider whether or not to participate in this study.		
13. I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.		
14. I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study up to two weeks after the interview.		
15. I have the right to decline to participate in any part of the research activity.		
16. I know who to contact if I have any questions about the study in general.		
17. I understand that my interview is being recorded.		
18. I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.		
19. I wish to receive a copy of the findings.		
20. I wish to view the summary report of my interview.		

Declaration by participant:

I agree to participate in this research project. If I have any concerns about this project, I may contact the convenor of the Psychology Research and Ethics Committee (Dr Rebecca Sargisson, phone 07 557 8673, email: rebeccas@waikato.ac.nz)

Participant's name (Please print):

Signature: _____ Date: _____

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it. I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: Cherie Pepperell

Signature: _____ Date: _____

Appendix I: Interview questions - Patients

Questions for renal patients

General Questions

How long have you had renal failure?

When did you start dialysis? What was that like for you?

Do you use haemodialysis or peritoneal dialysis as a treatment option? Have you used both?

How would you describe your experience of kidney failure?

In your opinion what resources do you think would improve your overall wellbeing?

Have you been offered any psychological help since diagnosed with renal failure? Can you tell me about this?

Do you feel factors such as depression, anxiety, stress, family, financial issues are taken into consideration within your treatment programme? Which ones have you been effected by?

Do you work? Have you encountered discrimination regarding your treatment routine?

Do you feel when you have a concern that you are listened to by your health professionals and action is taken?

Do you feel you have any control over your treatment? Can you tell me more about that?

Are you currently on the transplant list? Is this an option you would consider?

How would you rate your health in general now?

What do you do to relax?

Would you be interested in individual or group therapy sessions? Why?

What role does your whanau/family/significant other play in your care?

Does your whanau/family/significant other understand the nature of your illness?

What does your whanau/family/significant other do to help support you in your care?

Are their tasks/activities you would like your whanau/family/significant other to be involved in that would make coping with renal failure easier for you?

Any further comments?

Appendix J: Interview question – Health professional

Questions for health professionals

General Questions

What is your role?

How long have you been working / or worked in renal services?

Do you have any training in mental health? If so what?

Do you measure / test patients for depression / anxiety? If so how?

Do you think that routine screening for depression is a good idea? If so, why?

What do you think would increase compliance for patients?

What impact do you think psychological services has/would have for patients?

How do you gauge the psychological wellness of a patient? What do you do if you feel they are in need of assistance?

What resources do you think would improve the overall wellness of renal patients?

Do you think the patients would be interested in individual or group therapy sessions?

In your opinion what do you think the patients struggle with the most?

Would you be interested in learning about relaxation techniques that may benefit patients?

What techniques do you use to cope with work stress?

What role do you think whanau/family/significant others typically play in the care of patients?

Do whanau/family/significant others typically understand the nature of the illness?

Are their tasks/activities/knowledge that whanau/family/significant others might be more involved with to support the care of patients?

Are their things that whanau/family/significant others do that make your job more difficult?

Any further comments?