Impact of Dialysis on Rurally Based Mäori Clients and Their Whänau

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Abstract

This paper is a report of a study seeking to understand the experience of New Zealand rural dwelling Mäori clients with end-stage renal disease who receive haemodialysis. End stage renal disease (ESRD) is related to lifestyle, genetic factors and environment, and Mäori are at higher risk of renal disease which results of need for renal replacement therapy to sustain their lives. Dialysis clients are a group of 'silent' clients under the care of the dominant health professionals. Adherence with therapeutic regimes has been a main issue for health care professionals and service delivery, as it directly contributes to the efficacy of the treatment and cost effectiveness. Mäori clients' experience of living with haemodialysis has not been explored. Although there are a number of studies describing the experience of patients living on dialysis so far, no studies have yet focused specifically on the experience of Mäori clients towards their renal replacement therapy. The continual demands of dialysis treatment are significant and given the high proportion of Mäori having dialysis. It is timely to explore the experience of Mäori clients and their family/whänau in order to understand the need for quality of care and to promote Mäori health outcomes in chronic kidney disease management.

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Introduction

This research portfolio discusses renal disease, which can lead to end stage renal disease (ESRD) and the need for dialysis. The rapid increase of the dialysis population in New Zealand is both stressful for people experiencing ESRD and their families, and also a significant burden for the health system. This study is going to introduce what dialysis is; the burden of the disease; and how to manage of the disease in Chapter One. Chapter Two explores what causes ESRD, and why the kidneys have become damaged (nephropathy). Then Chapter Three explores the impact of facing regular dialysis for a specific population. Finally, Chapter Four examines (as a results of findings from this research) ways to improve health care to this population and how to reduce the burden for renal diseases.

Chapter One --- Impact on those who have end stage renal disease and receive dialysis

Kidney function involves removing wastes and extra fluid from the blood; balancing acids and bases, chemicals and electrolytes; producing Erythropoietin (EPO); releasing hormones; activating vitamin D (facilitating calcium absorption; keeping bones strong) and producing the enzyme renin helping control blood pressure (Sherwood, 2005). There are dramatically increasing needs for managing the ongoing treatment for people living with end stage renal disease (ESRD). When kidney function declines, fatigue and oedema are obvious signs. Dialysis and transplantation are the only way to continue life (Ellingson, 2007).

What is dialysis?

Dialysis is a procedure that is performed routinely on people who have acute or chronic renal failure. Dialysis is a life sustaining treatment when kidney function declines to the stage that waste products and fluid can no longer be adequately removed from the circulation. Dialysis treatment is a process which involves management of anaemia, blood pressure, dietary and fluid restriction, medication compliance as well as lifestyle changes (National Kidney Foundation, 2007).

There are two types of dialysis: haemodialysis (HD) and peritoneal dialysis (PD). In HD, a special type of access, called an arteriovenous (AV) fistula is placed surgically, usually in the arm. This involves joining an artery and a vein together. HD access fistula generally takes 6-8 weeks to get develop. Blood is passed through a dialyser (a filter-artificial kidney) machine to clean it. The waste products and excess water pass from the blood through the membrane (dialyser) into the dialysis fluid, which is then discarded. The cleaned blood is returned to the bloodstream (Daugirdas, Blake, & Todd, 2006; The Kidney Foundation, 2004). Peritoneal dialysis (PD) requires surgically placing a hollow tube (Tenckhoff catheter) into the lower abdomen. After the tube is placed, a special solution called dialysate is instilled into the peritoneal cavity by diffusion process to remove waste products (National Kidney Foundation, 2007).

Haemodialysis (HD) includes hospital in-centre HD, satellite unit HD and home HD. If a client is capable of managing haemodialysis at home by themselves or with support from their family (caregiver), after training they can have the machine set up in their home which provides a more relaxed and flexible environment to suit their lifestyle. Peritoneal dialysis (PD) includes automated peritoneal dialysis (APD) and continuous ambulatory peritoneal dialysis (CAPD). After training by a renal specialist, people can manage it by themselves at home. APD means that the fluid exchange is done automatically by a machine. CAPD means dialysate solution continuously, inside the adbdomen, moves waste products from the blood and this is performed manually, normally requiring an exchange solution four times a day (Khanna & Nolph, 2000). Rabindranath, Adams, Ali, MacLeod, Vale, Cody, et al. (2007) found no difference between CAPD and APD in terms of clinical outcomes. However, APD may be more suitable for the younger population and those in employment or education due to its ability to be performed during the night when people are asleep, which means less interruption during the day (National Kidney Foundation Singapore, 2007).

Burden of disease

End stage renal disease (ESRD) is resource-intensive, with people requiring dialysis and/or kidney transplantation for survival. Diabetic nephropathy is the major cause of ESRD and premature death in New Zealand. Indeed, diabetic patients are more prone to

kidney disease than non-diabetic people. Diabetes mellitus is the major non-communicable world health problem, with estimates of more than 250 million people affected (Wild, Roglic, Green, Sicree, & King, 2004; Zimmet, 2003).

Nephropathy is considered the most common microvascular complication being present in 30 to 50% of type I and 10% of type II diabetics after 10-20 years of the disease. Chronic kidney disease (CKD) remains the second most likely cause of death and morbidity after cardiovascular disease in diabetics, and CKD is a major independent risk factor for cardiovascular disease (Endre, Beaven, & Buttimore, 2006). The uraemia-related risk factors and hypertension contribute to the high mortality of cardiovascular events in the patient with dialysis (Foley, 2004; Ronco, Brendolan, & Levin, 2005). ANZDATA Registry (2004) suggests 40 percent of deaths of clients on haemodialysis are related to cardiac origin.

The international dialysis population was estimated as over one million dialysis patients in 2001 (Lysaght, 2002) and it was estimated that this number would increase to two million by 2010 (Global Dialysis Care, 2008). The number of New Zealand haemodialysis patients being treated in an outpatient setting increased 11% from 2005 to 2006, and the haemodialysis rate grew 140% from 2003 to 2008 in Northland (ANZDATA Registry, 2008a; Northland District Health Board Renal Unit, 2009).

There were 461 new dialysis patients in New Zealand in 2007 and most of these people had diabetic nephropathy (41%). The majority of these people were 45-74 years old (83%) (ANZDATA Registry, 2008a). Ashton & Marshall (2007) reported dialysis has been growing rapidly amongst the fragile elderly populaton; with people from 64 to 94 years old making up nearly a third of new dialysis patients (31%). The cause of ESRD by hypertension were 49/461 and the old people's group (64-94) made up 41(84%) (ANZDATA Registry, 2008a).

New Zealand is experiencing a disproportionate increase in new clients accepted for renal replacement therapy (RRT) (dialysis and transplant) in the age group above or equal 65 years (Roake, 2004). As life expectancy increases, people's kidney haemodynamic function has declined symmetrically. The reason is kidney function diminishes approximately one percent each year after age 40; if a person lives until age

80 kidney function may decrease by 40% of glomerular filteration rate (GFR). Physiologically, older people's kidney size is smaller, renal clearance of drugs is impaired and the average blood urea nitrogen levels rise by 21% at age 70 (Springhouse, 2008). If there are hypertensive, hyperglycemia and/or hyperlipidemia situations present then the prospect of kidney function would be even poorer.In addition, cardiovascular disease and/or atherosclerosis cause decreased blood flow to the kidneys and further impair function. It is clear that with growing numbers of the older age group, even more dialysis will be required which is predominantly caused by hypertension and its complications (Madhan, 2004; Roake, 2004).

Collins & Metcalf (2003) reported on Mäori patients who have been treated for ESRD and showed 73% had diabetes compared with 21% of European origin. In New Zealand there were 937 dialysis patients (this includes peritoneal and haemodialysis) in 1996; within a decade there has been a growth rate of 110% (4.76 per 10,000) (ANZDATA Registry, 1997, ANZDATA Registry, 2007). Among those receiving dialysis treatments, 34 % were of Mäori descent (ANZDATA Registry, 2007). According to 2006 statistics of NZ census, Northland Mäori population was 43529, and Mäori dialysis clients occupied 17.2 per 10000 compared with non-Mäori 7.1 per 10000 in Northland (Statistics New Zealand, 2006; Northland District Health Board Renal Unit, 2009). There were 150 dialysis clients in the Northland area in 2008 and 50% are Mäori. There is one outpatient satellite dialysis service in the mid north of New Zealand, and this unit currently has 26 clients receiving regular HD. Of these clients, 88.5% are of Mäori descent (Northland District Health Board Renal Unit, 2009).

The leading causes of ESRD are diabetes nephrology 42%, glomerulonephrology 21% and hypertension 12% (ANZDATA Registry, 2007). McDonald & Russ (2003a) report that indigenous people in New Zealand have a higher rate of ESRD compared with non-indigenous peoples. Figures show that between 2002-2004 the incidence of end stage renal disease (aged above 15) caused by diabetes nephropathy were 9.4 times higher in Mäori compared with non-Mäori (Ministry of Health, 2008). The Mäori rate of mortality irrespective of haemodialysis, peritoneal dialysis treatment or transplant was 70% higher than non-indigenous. The Mäori clients median age entry to dialysis was 44 years versus 58 for all clients (McDonald & Russ, 2003b).

The health profile of Mäori people has been poor, with life expectancies considerably less than non-indigenous groups (The Mäori Party, 2008). The higher rates of comorbidities present in Mäori people starting dialysis treatment reflect their poor health management. The rates of coronary artery disease and lung disease are 1.5 to 2 times higher among Mäori ESRD clients. Other issues associated with Mäori is the characteristic of difficulty from the predicament of social, cultural and environmental transition, and include high birth rates, poor nutrition, poor education, high rates of unemployment, tobacco use, alcohol use, poverty, and overall low socioeconomic status (McDonald & Russ, 2003a).

ESRD is a huge cost to the health system. The cost of RRT in New Zealand is conservatively estimated at NZ $90 million annually in 2003. The cost of diabetic nephropathy (microalbuminuria, overt nephropathy and CKD) could amount to as much as $146 million per annum in NZ (Endre, Beaven, & Buttimore, 2006). Estimates are that hospital care HD cost $64,000 per person / per year; satellite unit patient outlay $48,000 per person/per year; home HD patient $34,000 per person/per year and PD about $18,000 per person/per year (ANZDATA Registry, 2005; Ashton & Marshall, 2007; Endre, Beaven, & Buttimore, 2006; Local Diabetes Team Canterbury, 2005). This accounts for direct medical costs and does not include numerous daily medications, hospitalisation and transport costs etc, which the patient and their family/whänau bear.

Clients who live in areas further away have to travel for their HD treatment, thus their cost is considerably higher than that of a home dialysis client. The ratio of PD and HD clients is 741/1323 in NZ in 2007, more than one third of dialysis patients have in PD (ANZDATA Registry, 2008a). The cost-utility ratio is most favorable for PD as the primary method of treatment for clients eligible for both PD and HD (Sennfält, Magnusson, & Carlsson, 2002).

Management of dialysis

Dialysis clients have to face different stages of challenge in their life such as psychologically and physiologically stressors. They have to live with a crisis phase at the beginning of dialysis treatment. Family support, liaison, psychologist and the renal team have an important role to facilitate the client to conquer the very difficult time at

the initial stage. After an initial grieving stage, client will eventually need to accept the truth of needing dialysis and acquire the knowledge and skills to manage their illness. The first stage of dialysis is related to the beginning of crisis, second stage of dialysis sees the development of an accepting and learning self-control of illness; and final stage is the critical terminal phase (UK National Kidney Federation, 2009).

First stage:

The stress of illness in the renal population involves psychological and physiological issues. Psychological stressors include feelings of mortality, feeling disabled, socio-economic stress, and adjusting to a new lifestyle. There is a long journey in ahead of clients. The multiple losses of different roles in the family; and social activities impact dialysis clients tremendously in their everyday lives (Chilcot, Wellsted, Silva-Gane, & Farrington, 2008). They may feel hopeless, anxious, and worry about finances, loss of sexual function, being a family burden, and loss of independence (Baxter, 2002). Physiological stress includes fatigue, headache, dizziness, cramp, dietary & fluid restriction, medication compliance and medical complications such as heart disease and/or neuropathy (Evans & Forsyth, 2004).

The stress commences with the client first receiving news of their end stage renal disease and needing dialysis. Clients have to face a series of emotional stages in their lives such as shock, denial, bargaining, guilt, anger and depression, when facing a life-sentence-like announcement (Kübler-Ross, 1969, as cited in Bruce, 2007). Fear and dread of an uncertain future can sometimes be alleviated by a caring and knowledgeable renal team (Pucheu, 2004). Depression is associated with multiple stressors from chronic illness and numerous losses (Chilcot, Wellsted, Silva-Gane, & Farrington, 2008). Psychological distress and non-adherence are common among ESRD clients, and both have contributed to higher morbidity and mortality in this group of clients (Christensen & Ehlers, 2002).

Depression is a significant problem that occurs in 25% of dialysis client and it is associated with higher comorbidity, poorer nutritional status, anaemia, lower residual renal function, and increased hospitalization rates (Lew & Piraino, 2005). Dialysis clients usually have a sense of hopelessness, such as pessimism, moodiness, frequent

sighing, frowning, eye-closing and negative thinking. Depression affects their physical, mental and spiritual wellbeing; and has a negative clinical impact upon subject with chronic illness. Under-recognition of depression in this population has significantly impacted on comorbidity and quality of life (Chilcot, Wellsted, Silva-Gane, & Farrington, 2008). Finkelstein & Finkelstein (2000); and Kimmel (2000) suggested that psychosocial factors are important predictors of client outcome.

Cukor & Friedman (2005) suggested that cognitive behavioural therapy (CBT) may be effective in relieving depression in the dialysis population. This therapy aims to identify any harmful, unhelpful, and 'false' ideas or thoughts which trigger client health problems, or make it worse. It seeks to modify client's the way of thinking, to help their thought patterns to be more realistic and helpful (Bennett, Flett, & Babbage, 2008). To relieve psychological stress requires the renal team to encourage and support the family (Life Options Rehabilitation Advisory Council, 1999). Consultants may prescribe anti-depression medications to help if CBT, psychologist, liaison or social worker interventions are deficient in improvement (Fazio, 2009).

Non-adherence impacts tremendously on younger dialysis clients and also those with low socio-economic levels which can impact on receving a kidney transplant (Baines & Jindal, 2000). Low treatment adherence was associated with poor adjustment to diagnosis and dialysis; adolescents tended to have poorer adherence than younger children. Psychosocial studies showed low adherence related to anxiety, depression, low family socioeconomic status and family structure. These findings demonstrate the importance of psychological interventions at improving treatment adherence (Brownbridge & Fielding, 1994). Christensen & Ehlers (2002, p.712) pointed out that "Patient non-adherence and psychological distress are highly prevalent among ESRD patients, and both have been found to contribute to a greater morbidity and earlier mortality in this population".

There are multiple factors affecting adherence, such as cultural and personal beliefs, socioeconomic status, self-efficacy and the manner of delivery of care. Leventhal, Weinman, Leventhal, & Phillips (2008) found behaviour of interventions enhanced treatment compliancy by up to 80%. Behaviour changes benefit client's wellbeing holistically and can improve their quality of life. Furthermore it is cost effective and

applicable in any clinical settings. Adherence and adjustment occur when a client accepts the fact of dialysis, as well as the demands of the renal intervention (Christensen & Ehlers, 2002).

The attitude of the family/whänau or caregiver plays a critical role, and without their support clients cannot possibly feel fully well (Faber, 1999). Caregivers of older dialysis patients experience a significant burden and adverse effects on their quality of life. Belasco, Barbosa, Bettencourt, Diccini, & Sesso, (2006) comfirmed that thirty-two percent of caregivers showed signs of depression due to the stress from clients' comorbidities and physical deterioration. Schulz & Beach (1999) reported that older spousal caregivers who experience care giving related stress have a 63% higher mortality rate than non-caregivers of the same age. Additionally, the well-being of the client depends on the well-being of the caregiver (Bennett, 2008). Educational, social, and psychological support interventions should be considered to improve the quality of life of the client and caregiver.

Health professionals can, through listening and understanding, discern the individual's requirements (Ashford, Eccles, Bond, Hall, & Bond, 1999). Later, clients may learn to express their feelings and release stress in order to allow them to adjust their lives and accept how it has with the illnesses. It takes time to learn to face the impact of illness with a positive attitude. The best intervention for depression is to identify the problem earlier to prevent risk of psychological difficulties (Fazio, 2009).

Physical stress initially involves symptoms in HD and PD, the most common being fatigue (respectively 82-87%) and itching (pruritus) (68-73%) (Merkus, Jager, Dekker, de Haan, Boeschoten, & Krediet, 1999). Other symptoms that can impinge their daily life include constipation, anorexia, pain, chest pain, dyspnea, sleep disturbance, anxiety, numbness in the extremities, restless legs and depression (Murtagh, Addington-Hall, & Higginson, 2006).

Fatigue is associated with a declined albumin level (poor appetite or/and proteinuria) and haemoglobin level (Burrows-Hudson, 2006). Anaemia is common in people with kidney disease because kidneys fail to produce the erythropoietin (EPO) stimulating hormone (stimulates bone marrow to produce red blood cells). Anaemia contributes to

heart complications such as myocardial ischemia and angina pectoris (The National Kidney and Urologic Diseases Information Clearinghouse, 2008). Anaemia management includes EPO therapy, iron therapy, folic acid, and vitamin B12 supplements (Busko, 2007, National Kidney Foundation, 2008a; National Kidney Foundation, 2008b).

Itchiness is generally related to having a high level of phosphorus accumulate in the skin (calcium phosphate). A diet restriction for high phosphorus content food is required because dialysis does not effectively remove serum phosphorus. Phosphorus binders (Alutab & Calcitab), generally precribed by a nephrologist prevent phosphorus absorption into the bloodstream (National Kidney Foundation Singapore, 2007). Dry skin can also cause itching which is related to renal failure causing changes in the sweat glands and oil glands. Dry skin can lead to infections and can cause skin wounds to heal slower than they should. Hyperpigmentation (grayish or metallic colour skin) caused by skin discoloration is related to pigments called urochromes being retained in the skin (The National Kidney and Urologic Diseases Information Clearinghouse, 2008).

Intradialysis hypotension occurs frequently during HD treatment due to autonomic neuropathy or cardiac dysfunction (Calvo, Maule, Mecca, Quadri, Martina, & Perin, 2002, Winearls, 2000). Hypotensive symptoms include: abdominal discomfort; yawning; sighing; nausea; vomiting; muscle cramps; restlessness; dizziness or fainting; and anxiety. It can cause ischemic events such as cardiac arrhythmias, vascular access thrombosis; even cerebral infarction (Port, Hulbert-Shearon, Wolfe, Bloembergen, Golper, Agodoa, et al., 1999). Symptom burden is associated with raised morbidity and mortality in dialysis clients, and it may be not easy to treat due to underlining of pathology (Murtagh, Addington-Hall, & Higginson, 2007). The reduction of physical symptoms plays an instrumental role in improving a renal client's quality of life (Mapes, Lopes, Satayathum, McCullough, Goodkin, Locatelli, et al., 2003)

Second stage:

When clients triumph over the first stage of crisis they start to engage with their physical complexity. It means being accepted for what they are and do. Clients begin to recognise the need of dialysis for their rest of life. Renal clients commence to learn

about all the internal chemistry and blood results that correspond to their well-being; they learn to manage their fluid restriction, diet and lifestyle in order to keep up their quality of life. There are two key elements to support adjustment: optimal clinical care to improve how clients feel, and rehabilitation management to improve their ability to function. Clients can live longer, enjoy a higher quality of life, and live independently both physically and mentally (Life Options Rehabilitation Advisory Council, 1999).

Fluid restriction is crucial for maintaining cardiac function. Fluid overload causes swelling, shortness of breath and an increase in blood pressure and the heart has to pump harder. The long term consequences of excess fluid in the body include causing the cardiac muscles to enlarge and weaken as well as an increase in cardiovascular complications. When this happens, the body will have more difficulty maintaining blood pressure and tolerating dialysis (London, 2003). Cramps are a symptom of intradialytic hypovolemia or low sodium concentration which occurs frequently during haemodialysis treatment (Rho, Perazella, Parikh, Peixoto, & Brewster, 2008).

Dietary restriction includes low sodium and potassium intake in order to keep electrolyte levels in the recommended range. Renal clients are unable to get rid of excess electrolytes from the body due to little or no urinary output. Sodium restrictions help achieve optimal blood pressure control and prevent fluid retention. Clients have to limit the amount of high potassium content food they eat; in order to prevent, consequentially, having high level serum potassium induced arrhythmia or death (National Kidney Foundation Singapore, 2007).

Dietary control of low protein (0.6g/Kg/day) intake is crucial for renal clients in order to decrease the nitrogenous waste products from protein which assists in decreasing the occurrence of anorexia and lethargy from uraemia. The nephrologist generally prescribes phosphate binders each day for dialysis patients to take with three meals in order to prevent phosphate absorption into the bloodstream. Phosphate is generally found in dairy products (milk, cheese) as well as: eggs, legumes, shellfish and meat. Over time, phosphorus accumulates in the soft tissues and causes the skin to itch. Having high phosphate levels in the bloodstream for long periods causes the secondary parathyroid hormone level to elevate and results in an imbalance of the calcium and phosphate ratio in the serum, thus causing vascular calciphylaxis and bone disease

which requires parathyroidectomy surgical intervention before complications get worse (National Kidney Foundation Singapore, 2007).

Nearly half of clients reported being bothered with three or more symptoms. Clients' perceptions of symptoms should be routinely assessed to improve self-management strategies (Thong, Dijk, Noordzij, Boeschoten, Krediet, & Dekker, 2009). When health professionals provide education and information to dialysis clients it should be presented according to the clients' level of education, and should take their socio-economic status and cultural beliefs into consideration. Some researchers have found that to minimize non-compliance, nurses needed to understand clients' attitudes and beliefs (Hailey & Moss, 2000; Polaschek, 2006). Appropriate education is essential to enhance adherence; and reduce comorbidities, hospitalization as well as cost effective to the healthcare system (Saran, Bragg-Gresham, Rayner, Goodkin, Keen, & Van Dijik, 2003).

Encouraging self-management is the best way to promote dialysis clients' quality of life. Home haemodialysis (HD) has the best client outcome and is a cost-effective dialysis modality and it is the trend in Australia and New Zealand and some other developed countries (McGregor, Agar, & Blagg, 2006). Home HD, offers clients the return of self-control and self-esteem. It also allows reconnection with family, friends and (re)employment (Agar, 2008). Disappointingly, olderly people living in rural areas may have difficulty managing by themselves or with a caregiver's support, and some other issues such as housing and water supply impede them achieving home HD by themselves.

Promoting employment among ESRD clients has been found to improve their quality of life (Kutner, Bowles, Zhang, Huang, & Pastan, 2008). Employment can increase self-esteem, promote adherence to therapeutic regimes and provide a source of identity and a sense of contributing to society (Life Options Rehabilitation Advisory Council, 1999). Unemployment or loss of valued leisure activities impacts on motivation of self-regulation (Polaschek, 2006).

Final stage:

Dying is an inevitable natural process and is part of life. End-of-life care has become an important medical requisite (Feinberg, 1997). Dialysis cessation is a decision which is becoming increasingly widespread in medicine. Withdrawal from life-support treatment is an option being chosen by clients and their families (Germain, Cohen, & Davison, 2007; Prendergast & Luce 1997). It is estimated that 15-29% clients with ESRD in USA are withdrawn from dialysis prior to their death (U.S. Renal Data System, 2004). In France, the decision to stop dialysis was made most often by a physician (77.5%) and was due to severe medical complications or cachexia (Birmelé, François, Pengloan, Testou, Brillet, Lechapois, et al., 2004). However, withdrawal is related to human rights, ethical and legal issues; for this reason the decision of withdrawal is mainly made by clients and their family in NZ (Roake, 2003). The rates of withdrawal of clients from dialysis have been shown to vary across countries and across dialysis facilities. The variations depend on the attitudes of HD clients across facilities, client comorbidities and the practices of the doctors and nurses who care for dialysis clients (Lambie, Rayner, Bragg-Gresham, Pisoni, Andreucci, Canaud, et al., 2006)

The barriers to terminal care include situations such as having a renal physician who feels uncomfortable discussing end of life issues with patients and family. Poor communication can result in clients not telling their physician and family what their wishes are. Clients and family have fears and misperceptions about end of life care or they may not have a clear understanding of their prognosis. Poor symptom management, particular pain, as well as the patients and family lacking knowledge concerning withholding and withdrawal of dialysis may result (Germain, Cohen, & Davison, 2007). Withdrawal from dialysis is certain death in days or weeks, and pain, dyspnoea and twitching are common terminal symptoms due to accumulation of toxins in the final days of life (Cohen, Germain, & Brennan, 2003).

Palliative care focuses on the whole of the client's being; body, mind and spirit. Palliative care includes relief from pain and other distressing physical symptoms, integrates the psychological and spiritual aspects of client care. It offers a support system to help the family cope during the patient's illness and in their own bereavement. Palliative care should be provided to ESRD patients throughout their

course of care; it improves dying client's quality of death (Cohen, McCue, Germain, & Kjellstrand, 1995).

Health care providers need an understanding of end-of -life issues that may arise in their facility. Sometimes such planning is not done because health providers are reluctant to engage in end of life discussions for fear of destroying clients' hope. Healthcare providers have an obligation to promote, maintain, and instill hope in their clients, empowering clients and enhancing relationships with staff and loved ones (Davison & Simpson, 2006).

Nurses need to provide supportive listening when a client wants to talk about the end of his or her life. Health care providers are required to know about the resources and prepared to respond to their clients and their whänau appropriately, respectfully and be honestly to share decision making about what options are best for them (Germain, Cohen, & Davison, 2007). Psychiatric assessments can offer considerable benefit to clients, families, and staff in clarifying these difficult therapeutic junctions (Cohen, Steinberg, Hails, Dobscha, & Fischel, 2000). Medical teams can advise treatments to help with pain management and improve a client's comfort and emotional, social and spiritual well-being as well as their integrity and dignity (Davison & Simpson, 2006). Furthermore, health care providers have to learn to be aware of their own grief and learn skills for positive self-management of stress and depression **(**Lyons, O'Luanaigh, O' Dowd, & Gallagher, 2009).

Quality of life is to have one's needs satisfied in the context of physical, psychological, social, and environmental conditions. Self-confidence or self-respect is the basic element of a good quality of life; which involves family relationships, friendships, finances, physical and psychological status, adjustment to therapy and feeling of security during the treatment as these are all significant to dialysis clients' well-being in their limited time (Hornquist, 1990). Health care providers, by collaborating effectively with multidisciplinary team members and clients, can ensure the goals and objectives of each individual are respected, protected and supported.

Discussion

Epidemiological studies have shown that the prevalence of CKD is estimated a 5-10% in Western countries, leading to its recognition as a major public health problem (Indridason, Thorsteinsdóttir, & Pálsson, 2007). The prevalence of CKD in the US adult population was 4.5 % (eight million), with persistent albuminuria with a GFR of 15 to 59 mL/min/1.73 m^2 (stage 3 and 4). Aside from hypertension and diabetes, age is a key predictor of CKD, and 11% of individuals older than 65 years without hypertension or diabetes had stage 3 or worse CKD (Coresh, Astor, Greene, Eknoyan, & Levey, 2003).

In Japan, the prevalence of ESRD is increasing and is currently more than 2,000 per million. More than 40% of incident ESRD is due to diabetes mellitus (DM). The prevalence of a low GFR (less than 60 mL/min/1.73 m^2) is estimated to be 20% of the adult population. Studies suggested that Japan has a higher prevalence of CKD than any other country (Iseki, 2008).

New Zealand has soaring numbers of CKD clients. Diabetes is responsible for more than 40% of all clients with ESRD. CKD accounts for about one third of New Zealand's health costs in 2006. To help combat this alarming trend we need to prevent chronic kidney problems from progressing to ESRD and the need for dialysis. (University of Otago Media release, 2007).

CKD and anaemia are risk factors for adverse outcomes in clients with heart failure. Anaemia is associated with a rapid decrease in kidney function in clients with heart failure, particularly in those with underlying CKD (Bansal, Tighiouart, Weiner, Griffith, Vlagopoulos, Salem, et al., 2007). Early detection and treatment of CKD are necessary to decrease the incidence of ESRD and cardiovascular disease (Iseki, 2008).

Current World Health Organization (WHO) (1999) protocols suggest that screening yearly for microalbuminuria, beginning at the time of diagnosis of Type II diabetes and within 5 years of onset of Type I diabetes, or at puberty in juvenile onset diabetes mellitus (DM), plays a crucial role in preventing people from reaching end stage renal disease. There is significant demand for a pre-dialysis interventionist and educator in the community to target people with CKD in the early stage (Yousef, Omar, Morsy,

Abd EI-Wahed, & Ghanayem, 2005). By providing proper resources and information to educate people to recognize early signs of kidney damage, it may be possible to delay or prevent the progression to ESRD.

The advantage of early intervention is to preserve a client's kidney function as well as their quality of life. Early detection provides enomous opportunities for the renal team to act meticulously to manage the client's blood sugar, blood pressure, hyperlipidaemia and provide diet advice. Early detection can diminish the impact on CKD clients and their whänau, reducing financial stress, resulting in lower co-mobidities and complications as well as being cost-effective.

Conclusion

Clients with CKD are best provided for in a clinic setting that integrates nephrologic expertise, client education, and comprehensive supportive services. CKD clinic settings are able to provide effective of anaemia management and show improved GFR and CKD outcomes. Stabilization of GFR is a goal that can be accomplished with comprehensive renal care provided in an organized community setting (Ghossein, Serrano, Rammohan, & Batlle, 2002; Serrano, Huang, Ghossein, Nishi, Gangavathi, Madhan, et al., 2007).

From the literature researched, it is clear that early detection is a key to preventing or stopping people progressing from CKD to ESRD. Health professionals can encourage and empower clients to implement lifestyle changes and endeavour to bridge the gap between lack of understanding and education. Through the education of primary HPs and Mäori health providers, we can move towards developing care plans that best suit clients' needs. It is necessary to provide resources and information to promote a CKD client's health self management skills in order to support their quality of life and well-being as well as effectively slowing down the growing rate of renal replacement therapy.

There is a need to understand the pathology of CKD in order to understand how to prevent the endemic prevalence in a specific population. The next chapter will explore the causes of kidney disease, and describe the prevalence of CKD among New

Zealanders and in particular Mäori clients.

Chapter Two --- Pathology of End–Stage Renal Disease

During the past decade the population with End-Stage Renal Disease (ESRD) has more than doubled. This has a huge impact on worldwide healthservices, especially as there is a rapid increase in the group of people age over 65 (Obrador, Pereira, & Kausz, 2002; Trivedi, Pang, Campbell, & Saab, 2002). This chapter will clarify the physiology of the kidney and explore the pathology of ESRD. The next section will then concentrate on the main cause of diabetic nephropathy and other nephropathies that frequently occur in people with ESRD.

Physiology of Kidney

The two kidneys process about 180 litres of blood a day to sift out about 1.5 litres of waste products and extra water that eventually leave the body as urine (National Kidney Foundation, 2007). Blood enters the kidneys through arteries that branch inside the kidneys into tiny clusters of looping blood vessels (glomerulus). There are approximately one million nephrons in each kidney. Plasma is ultrafiltrated through the nephron to form urine. Each nephron is composed of glomerulis (filtration units) connected to a tubular system that finally drains into a collecting duct (Sherwood, 2005). The filtrated product (primary urine) is normally free of plasma proteins, as plasma proteins are mostly reabsorbed by tubular networks (Patrakka, 2001).

Glomerular blood flow is regulated by the juxtaglomerular apparatus, which consists of juxglomerular cells, the macula densa, and mesangial cells. The role of juxglomerular cells is as sensors of intra-renal pressure and secretion of renin, as these cells are sited in the wall of afferent arterioles of the glomerulus. The macula densa senses fluid flow rates and sodium concentration in the distal tubule. The macula densa acts on the adjacent afferent arterioles to decrease glomerular blood flow, by secreting active vasopressor (Tortora & Derrickson, 2002). Mesangial cells are between the loops which together with the surrounding matrix form the mesangium. The mesangium contains myofilaments which function as a regulator of glomerular filtration through its contractile characteristics, by altering the capillary surface area available for filtration.

Mesangial cells are phagocytic in nature, take up immune complexes, and play a role in the formation and degradation of the extracellular matrix (Smith, 1998).

Pathophysiology of glomerulus

The glomerular filtration barrier is composed of three layers: A fenestrated endothelial layer, a glomerular basement membrane (GBM), and podocyte foot processes connected by a slit diaphragm (such as nephrin). Podocytes are specialized epithelial cells that envelope the portion of the glomerular capillary loop facing the urinary space; and comprise a major permeability barrier between the capillary lumen and the urinary space. Proteinuria indicates the presence of intraglomerular hypertension and abnormal glomerular permeability. Dysfunction of the podocyte is associated with proteinuria and may also contribute to sclerotic damage of the glomeruli in chronic kidney disease (Mundel & Shankland, 2002).

The kidneys normally reabsorb protein in the renal tubules, and failure of the proximal tubule to reabsorb filtered proteins results in proteinuria; which may be related to genetic disposition, systemic disease or drug therapies. Proximal tubules reabsorb albumin via an endocytic pathway, by receptor mediation. Albumin overload may be induced by proinflammatory and profibrotic reactions, which will progressively lead to renal and vascular disease (Pollock & Poronnik, 2007). Glomerulosclerosis only partially explains the development of proteinuria. Chronic proteinuria may lead to increased tubulointerstitial damage in the kidneys, which leads to renal failure (Moriya, Moriya, Yajima, Steffes, & Mauer, 2002).

Extracellular matrix (ECM) is composed of fibrous connective tissue, which is secreted by fibroblasts, and its function is providing support to cells. The subendothelial extracellular matrix contains elastic fiber molecules (fibrillin-1& fibulin-5) which provide stable endothelial cell anchorage through interactions with cell surface receptors; it also inhibits smooth muscle cell migration and proliferation (Williamson, Shuttleworth, Canfield, Black, & Kielty, 2007). These elastic fiber proteins are regulated by growth factors and contribute to the mechanical stability and elastic strength of the glomerular capillary tuft (Sterzel, Hartner, Schlötzer-Schrehardt, Voit, Hausknecht, Doliana, et al., 2000). The role of glomerular's extracellular matrix is to

promote cell proliferation. When cells disrupt the matrix by being over productive, the unregulated deposition causes progressive mesangial and glomerular sclerosis (Schlöndorff, 1996).

Glomeruli act as a very sensitive filter membrane, any changes of filtration pressure (hypertonic or hypertensive), metabolic pathways, or inflammatory status will damage its function. When the glomerulus is disrupted, the tubules reabsorption of electrolytes and albumin is also directly affected.

Renal Failure

There are two types of kidney failure: acute and chronic. Acute renal failure (ARF) is a temporary decline in kidney function that can often be corrected. Chronic renal failure (CRF) is a permanent condition that is characterized by persistent systemic inflammatory response, which may be caused by prolonged medical conditions, such as high blood pressure or diabetes. People with CRF (more than 10-15 years duration) and GFR less than 15 mL/ min/1.73 m^2 are referred to as having ESRD (National Kidney Foundation, 2007).

Acute Renal Failure

Acute renal failure (ARF) is classified as prerenal (renal hypoperfusion), intrinsic renal (involving structural damage to the renal parenchyma or acute tubular necrosis), and postrenal (urinary tract obstruction). Patients with intrinsic ARF have a poor prognosis with a high mortality rate (40 to 80%) (Lameire, Van Biesen, & Vanholder, 2005). There are four major factors of ARF; these include a decrease of glomerular capillary permeability, back-leak of glomerular filtrate, tubular obstruction, and intrarenal vasoconstriction. Intrarenal vasoconstriction is related to the balance between endothelin (vasoconstrictor) and endothelium-derived nitric oxide (vasodilator) (Komers, Allen, & Cooper, 1994). An outer medulla ischemia or the abrupt fall in glomerular filtration rate (GFR) contributes to ARF. In severe and prolonged ischemia, the tubular epithelial cells can undergo either sublethal or lethal cell damage; cell death occurs by necrosis and apoptosis (Lameire, 2005).

Acute tubular necrosis (ATN) is the most common cause of ARF. ATN is the death of tubular cells, which may cause by prolonged ischemia from hypotension, hypovolemia or nephrotoxins such as drugs or heavy metals. Fortunately, new tubular cells usually replace those that have died. The pathology of ATN shows a striking vascular congestion, endothelial damage, and leukocyte accumulation (Devarajan, 2006). Acute interstitial nephritis is a rapid developing inflammation that occurs within the interstitial related to acute allergic reaction to drugs, infection or autoimmune diseases (Michel & Kelly, 1998). Other causes of glomerular damage are related to glomerulonephritis, vasculitis or haemolytic uraemic syndrome. Vascular damage can be related to renal artery occlusion, renal vein thrombosis, cholesterol emboli, scleroderma renal crisis, and malignant hypertension. Ischemic ARF is often associated with multiple organ failure and sepsis (Bonventre & Weinberg, 2003).

Pathology of Acute Renal Failure (ARF)

Proximal tubular dilation and distal tubular casts indicate that obstruction to tubular fluid flow occurs in ischemic acute kidney injury (AKI). Apoptosis and oxidant injury in the tubule cells are caused by the adenosine triphosphate (ATP) depletion. Endothelial cell swelling, death, and detachment of viable cells are associated with septic shock. The inflammatory response results in the inflammatory cascades (such as C4 complement) that are initiated by endothelial dysfunction; then produce a number of potent mediators. Leukocytes then aggregate in the peritubular capillaries, interstitial space, and even within tubules after ischemic AKI (Devarajan, 2006).

In summary, ARF generally occurs with a sudden onset, and is caused by poor renal perfusion, autoimmune reaction or immune reaction triggering an inflammatory response causing ischemia in the glomerulus and tubular cells. The post-ischemic kidney displays congestion and hypoperfusion of the outer medulla, and cortical blood flow reperfusion will improve the ischemic insult. If the ischemic status can not be corrected immediately, the prognosis of kidney function might be poor, and the damage may be irreversible.

Definition of End Stage Renal Disease (ESRD)

Early stages of nephropathy are asymptomatic. End-stage renal disease is when kidney impairment is irreversible, cannot be controlled by conservative management alone, and requires dialysis or kidney transplantation to maintain life (Kidney Transplant Program, 2008). The failure of the kidneys means that they cannot function to excrete wastes, concentrate urine, or regulate electrolytes. It usually occurs when kidney function is less than 10% of normal or GFR is below 15mL per minute per $1.73m^2$ body surface areas. At this stage, there will be multiple severe complications, and death will occur from accumulation of fluids and waste products in the body (National Kidney Foundation, 2007).

Classification of Chronic Kidney Disease

According to renal pathology, kidney disease is classified as glomerular diseases, tubular and interstitial diseases; diseases involving blood vessels, cystic disease and tumors (Tortora & Derrickson, 2002). These diseases generally include nephrotic and nephritic syndrome.

Nephrotic syndrome is a nonspecific kidney disorder, includes massive proteinuria (>3.5 g protein / 24 hours). Its syndrome involves hypoalbuminemia, oedema, hyperlipidemia, and lipiduria. The possible causes are minimal change disease (MCD), focal segmental glomerulosclerosis (FSGS), membranous nephropathy (MN), diabetic kidney disease, systemic lupus erythematosus (SLE), and amyloidosis. The glomerular capillary wall is responsible for the sieving of plasma components from the circulating blood in the kidney, and failure of this barrier leads to nephrotic syndrome such as epithelial cell injury caused by an immune complex reaction (Mayo Clinic, 2007).

Nephritic syndrome is an inflammation of the kidneys that specifically damages the glomeruli. Nephritic syndrome includes signs of haematuria, proteinuria, azotemia, oliguria, malaise, oedema and hypertension; which is also known as rapidly progressive glomerulonephritis. It is causes by a post infectious, immunoglobulin A (IgA) nephropathy, immunologically mediated, proliferative changes and inflammation (Hewan-Lowe, 2008).

Immunological causes of glomerular disease

Glomerulonephritis (GN) is inflammation of the glomeruli. It may be the result of the immune system going 'haywire', with antibodies starting to attack organs or tissues. Sometimes the kidney is on the receiving end of this. Primary glomerular diseases result from immune complex formation binding antibodies to renal antigens, or deposition of circulating immuno-aggregates within the glomerulus. Immune reactions trigger the complement cascade resulting in degranulation of the granulocytes and platelets, which will release protease and oxygen radical, causing lysis of the cell membrane and matrix component (Glassock & Cohen, 1996). Glomerular diseases are characterized by one or more of tissue reactions that involve cellular proliferation, thickening of the basement membrane, leucocytic exudation and sclerosis (National Kidney and Urologic Diseases Information Clearinghouse, 2008).

Minimal change disease (MCD) can cause nephrotic syndrome (proteinuria), and with this a kidney biopsy reveals little or no change to the structure of glomeruli or surrounding tissues. Tiny drops of a fatty substance may be present (lipiduria), but no scarring may be found within the kidney. MCD patients with steroid resistance may progress to focal segmental glomerulosclerosis (Wernerson, Dunér, Pettersson, Widholm, Berg, Ruotsalainen, et al., 2003). MCD may occur at any age, but it is most common in childhood (National Kidney and Urologic Diseases Information Clearinghouse, 2008). Podocytes and the slit diaphragm (such as nephrin) play a primary role in the development of proteinuria. Proteinuria in congenital nephrotic syndrome of the Finnish type (NPHS1) already begins before birth (Patrakka, 2001). The structure of the nephrin gene (NPHS1) in patients with Minimal Change Nephrotic Syndrome (MCNS) has been shown to be related to different severities. Genetic changes in nephrin may have a pathogenetic role in some patients with MCNS. The amount of nephrin is reduced in foot process and becomes granular in the MCNS (Lahdenkari, Kestila, Holmberg, Koskimies, & Jalanko, 2004).

Focal segmental glomerulosclerosis (FSGS) describes scarring in scattered regions of the kidney, typically limited to one part of the glomerulus and to a minority of glomeruli in the affected region (Ponticelli, Villa, Banfi, Cesana, Pozzi, Pani, et al.,

1999). FSGS may result from a systemic disorder or it may develop as an idiopathic kidney disease, and it is difficult to treat since there are unknown causes. Proteinuria is the most common symptom of FSGS. A leading theory for the pathogenesis is single nephron hypertension, hyperperfusion, and hyperfiltration, which will result in increased glomerular size (glomerular hypertrophy) (Deegens, Steenbergen, Borm, & Wetzels, 2008). Plasma constituents exuded into the glomerular tuft and the walls of arterioles cause hyaline arteriolosclerosis and hypertension (Jennette, 2008).

Membranous nephropathy (MN) is the most common nephrotic syndrome in adults, which can be caused by infections, drugs, systemic lupus erythematosus (SLE), tumours or could be idiopathic. MN involves changes and inflammation of the glomerulus. The inflammation leads to immune complex coarsely granular IgG and C3 deposits along basement membranes causing thickening of the glomerular basement membrane (National Kidney and Urologic Diseases Information Clearinghouse, 2008).

Most children with persistent hematuria of glomerular origin have one of three conditions IgA nephropathy (IgAN), thin basement membrane nephropathy (TBMN), or Alport syndrome. Alport syndrome and TBMN are primary genetic disorders of the glomerular basement membrane (GBM). The earliest sign of a histologic lesion is diffuse thinning of the GBM. Type IV collagen gene is the primary molecular defect in Alport syndrome; it is inherited in both X-linked and autosomal forms, as well as TBMN (Kashtan, 2004). TBMN and IgA N cannot be distinguished on the basis of clinical or pathological variables (Packham, 2007).

IgA nephropathy is a form of glomerular disease that is caused by immunoglobulin A (IgA) forming deposits in the glomeruli of the mesangial, where it creates inflammation. IgA nephropathy is the most common primary glomerulonephritis worldwide, with about 20%–40% of patients going on to develop ESRD. The most common symptom of IgA nephropathy is blood in the urine, but it is often a silent disease that may go undetected for many years (U.S. Renal Data System, 2003).

Post-infectious causes of glomerulonephritis (most common in children between age three to seven, and boys are more susceptible) usually occurs after streptococcus throat infection, which would have inappropriately stimulated the immune system to

overproduce antibodies, circulating immune complexes deposited in the glomeruli which causes damage. Post streptococcus glomerulonephritis (PSGN) describes the inflammation of the glomeruli membrane tissue. PSGN occurs after upper respiratory infection with symptoms of edema, hematuria, and oliguria (nephritic syndrome) (National Institutes of Health, 2008).

Good Pasture's syndrome involves an autoantibody that specifically targets the lungs and the kidney's glomerular basement membrane. Signs of Good Pasture's syndrome include nephritic syndrome, breathing difficulties and hemoptysis. Often the first indication that patients have the autoantibody is when they cough up blood. Lung damage in Good Pasture's syndrome is usually superficial compared with progressive and permanent damage to the kidneys. Good Pasture's syndrome is a rare condition that affects mostly young men. Treatments include immunosuppressive drugs and a blood-cleaning therapy called plasmapheresis (removes the autoantibodies). Permanent damage to the kidney could lead to ESRD (Silberberg, 2007).

Systemic lupus erythematosus (SLE) is an autoimmune disease (antibodies or immunoglobulins that attack the body itself). SLE affects many parts of the body: primarily the skin and joints, but also the kidneys. Lupus nephritis is the autoantibodies (IgG, IgA, IgM C3, C4 and C1q) which deposit in the glomeruli, causing inflammation, which will later create scars that reduces the kidneys' function. The damage includes diffuse and global intracapillary proliferation; some capillary loops are thickened, cellular proliferation, and mesangial matrix expansion (D'Cruz, Khamashta, & Hughes, 2007).

To summarize, autoimmune reactions and immune reactions can cause permanent damage, even dispite prompt anti-inflammatory therapy. Resistance to steroid therapy may lead to chronic renal failure.

Non- immunological origin causes of glomerular disease

Hypertension, hyperglycemia and hyperlipidemia are non-immunological origin causes of glomerular disease. Diabetic nephropathy (DN) is the leading cause of glomerular

disease and of total kidney failure in the United States and New Zealand (National Kidney and Urologic Diseases Information Clearinghouse, 2008, ANZDATA Registry, 2008a). Only 5-10 % of patients with Type II diabetes develop end-stage nephropathy, but they account for nearly two thirds of diabetes related ESRD, due to the 20 fold higher prevalence of Type II diabetes in comparison with Type I diabetes (Yousef, Omar, Morsy, Abd El-Wahed, & Ghanayem, 2005).

Diabetic nephropathy (DN)

Early DN changes involve glomerular hyperfiltration, glomerular hypertrophy, increased albumin excretion rate (AER), increased glomerular basement membrane (GBM) thickness, and mesangial expansion with the accumulation of proteins such as collagen, fibronectin, and laminin (Fogo, 2000). Advanced DN is characterized by proteinuria, a decline in renal function, decreasing creatinine clearance (CrCl), progressive occlusion of glomerulus and glomerular capillaries resulting in glomerulosclerosis, and interstitial fibrosis that eventually leads to chronic renal insufficiency (Winter & Jernigan, 2000).

The renal medulla has a remarkably low oxygen tension (PO2) and a high degree of non-oxygen dependent energy metabolism. Nordquist & Palm (2007) reported that sustained hyperglycemia has been shown to induce a pronounced reduction in preferentially renal medullary PO2. Alterations in either blood perfusion or oxygen delivery to the medullary region will therefore have significant effects on both regional metabolism and total kidney function.

Diabetic nephropathy (DN) can be placed in two categories: systemic diseases and sclerotic diseases. Diabetes itself is a systemic disease (vascular disease) and the specific damage to the kidneys is associated with scarring of the glomeruli or hardening of the tiny blood vessels (glomerulosclerosis). Elevated glucose levels appear to increase the speed of blood flow and this raises blood pressure into the kidney, damaging the filtering system and allowing protein to pass into the urine (proteinuria). If damage to the blood vessels (scarring) continues over time, the entire filtration system is destroyed, resulting in ESRD (American Diabetes Association, 2005).

Hyperglycemia increases intraglomerular pressure and affects different pathogenic mechanisms, and this will alter the endothelial function resulting in DN. Hyperglycemia affects multiple pathways and the hypotheses are (1) increased activity of growth factors; (2) activation of protein kinase C (PKC); (3) activation of cytokines; (4) formation of reactive oxygen species (ROS); (5) increased formation of glycation products; (6) increased activity of the aldose reductase pathway; and (7) decreased glycosaminoglycan content in basement membranes (Caramori & Mauer, 2002; Chiarelli, Santilli, & Mohn, 2000). The following section will describe each of these pathways.

Multiple pathways of diabetic renal pathology

Increased activity of growth factors

Transforming growth factor-β (TGF-β) can induce fibrosis and cause renal insufficiency. Several pathways may be involved in the elevation of TGF-β expression in diabetes. High glucose in vitro increases TGF-β levels in mesangial and tubular cells (Fraser, Wakefield, Phillips, 2002; Weigert, Sauer, Brodbeck, Pfeiffer, Haring, & Schleicher, 2000). High glucose stimulates of TGF-β protein synthesis resulting in hypertrophy in mesangial cells. Reduced latent TGF-β binding proteins may be genetically determined and associated with diabetic nephropathy protection (Huang, Kim, Caramori, Fish, Rich, Miller, et al., 2002). Tubulointerstitial fibrosis is an important component in the development of DN. Hyperglycemia and TGF-β stimulates renal fibroblast production, resulting in excessive fibroblast deposits in the matrix (Lam, van der Geest, Verhagen, van Nieuwenhoven, Blom, Aten, et al., 2003). Lam, et al., (2003) demonstrated that both connective tissue growth factor and insulin-like growth factor expressions were found to be increased in renal fibroblasts under hyperglycemic conditions.

Connective tissue growth factor (CTGF) stimulates extracellular matrix formation, fibrosis, and angiogenesis. CTGF is over expressed in DN, which explains its role in the pathogenesis of DN and possibly in diabetic retinopathy (Kuiper, Witmer, Oliver, Goldschmeding, & Schlingemann, 2004). Renal CTGF expression is mainly localized in podocytes and parietal glomerular epithelial cells. Furthermore, albuminuria is strongly

correlated with urinary CTGF excretion (Roestenberg, Nieuwenhoven, Joles, Trischberger, Martens, Oliver, et al., 2006). In patients with nephropathy, elevated plasma CTGF is an independent predictor of ESRD and mortality in patient with Type I Diabetes (Nguyen, Tarnow, Jorsal, Oliver, Roestenberg, Ito, et al., 2008). Immune reactivity and CTGF levels are increased greater than two-fold in DN patients (Tikellis, Cooper, Twigg, Burns, & Tolcos, 2004).

Activation of protein kinase C (PKC)

PKC is an important intracellular pathway that can be activated by many of the metabolic and hemodynamic factors involved in the pathogenesis of diabetic nephropathy. PKC can be a stimulus for several growth factors and cytokines. In patients with DN, the mesangial PKC expression is related to serum creatinine, interstitial macrophages, and interstitial fibrosis (Ceolotto, Gallo, Miola, Sartori, Trevisan, Del Prato, et al., 1999).

Activation of cytokines

Cytokines are a category of signalling proteins and glycoproteins (such as interlukin and tumour necrosis factor) used extensively in cellular communication. It binds to a specific cell surface receptor the subsequent cascades of intracellular signalling alter cell functions. Cytokines are critical to the development and functioning of both the innate and adaptive immune response. They are often secreted by immune cells that have encountered a pathogen, thereby activating and recruiting further immune cells to increase the system's response to the pathogen as pro-inflammatory reaction (Phagoo, Poole, & Leeb-Lundberg, 1999).

Formation of reactive oxygen species (ROS)

ROS are an unavoidable by-product of cellular respiration. Oxidative stress is one of the main causative factors inducing endothelial dysfunction and changes in plasma protein or platelet function. Hyperglycaemia, dyslipidaemia, obesity and other factors may accelerate the process of glycoxidation and lipid oxidation, causing injury of the vessel wall (microangiopathy or/and macroangiopathy). This induces hypercoagulability

characterised by impaired fibrinolysis and hyperaggregability eventually developed to atherosclerosis (Skrha, 2003). ROS can damage other molecules and cell structures; these are the actions of free radicals on the fatty acid side chains of lipids in the various membranes of the cell, especially mitochondrial membranes (which are directly exposed to the superoxide anions produced during cellular respiration). Houstis, Rosen, & Lander, (2006) suggested that increased ROS levels are an important trigger for insulin resistance.

Metabolic factors: advanced glycation end-products (AGEs)

Glucose and other carbonyl compounds react non-enzymatically with proteins, lipids, or nucleic acids, and rearrangement and modification leads to the generation of diverse advanced glycation end products (AGEs). AGEs alter the structure and function of intra and extracellular molecules, increase oxidative stress, and modulate cell activation, signal transduction, and the expression of cytokines and growth factors through receptor-dependent and receptor-independent pathways (Qin, Goldfine, Krumrei, Grubissich, Acosta, Chorev, et al., 2004). AGEs serum concentrations were associated with the development of diabetic microangiopathy in patients with Type II Diabetes (Aso, Inukai, Tayama, & Takemura, 2000).

Increased activity of the aldose reductase pathway

Hyperglycemia causes glucose flux through polyol pathways (the way to get rid of excess glucose in non-insulin-dependent tissues, such as the brain), formation of advanced glycation end-products (AGEs), and activation of PKC and nicotinamide adenine dinucleotide phosphate oxidase (NADPH) (Ishii, Tada, & Isogai, 1998, Kapor-Drezgic, Zhou, Babazono, Dlugosz, Hohman, & Whiteside, 1999; Nordquist & Palm, 2007). Polyol pathways play a substantial role in the non-enzymatic glycation of proteins. Aldose reductase is localized to podocytes and distal convoluted tubules; sorbitol is one of the reaction products. Sorbitol is an osmoregulator in the kidney, and accumulation of sorbitol is believed to play a role in diabetic retinopathy, nephropathy, neuropathy, and microangiopathy (Rubin & Farber, 1995).

Decreased glycosaminoglycan content in basement membranes

Glycosaminoglycan, a layer of proteoglycans covering the endothelium, has the ability to protect the vessel wall. Heparan sulfate (one of the glycosaminoglycan) has been implicated as a major component of the glomerular anionic filtration barrier, and its decreased content in diabetic basement membranes may contribute to proteinuria (Jaackle-Meyer, Szukics, Neubauer, Metze, Petzoldt, & Stolte, 1995). A decrease in the concentration of heparan sulphate proteoglycan in the glomerular basement membrane (GBM) is thought to cause the increased GBM permeability in congenital nephrotic syndrome (Vogel, 1994; Iozzo, 1998). Hyperglycemia is associated with increased susceptibility to glycosaminoglycans (Nieuwdorp, van Haeften, Gouverneur, Mooij, van Lieshout, Levi, et al., 2006).

Hemodynamic factors: the renin-angiotensin system, the endothelin system, and the nitric oxide system.

Kidneys appear to have an independently regulated local renin-angiotensin system (RAS). Renin produced in the juxtaglomerular cells of the kidney convert angiotensinogen, derived primarily from hepatocytes, to inactive Angiotension I, which is then converted to biologically active Angiotension II by Angiotension Converting Enzyme (ACE). The angiotensin-converting-enzyme gene insertion/deletion polymorphism has been associated with hypertension and diabetic nephropathy in Japanese, but not in Caucasian Type II diabetic patients (Miller & Scholey, 2004; Tarnow, Gluud, & Parving, 1998).

Endothelin system (ETs) includes two receptors, and two activating peptidases (the most potent vasoconstrictor), these act as paracrine and autocrine factors. The role of ETs is to regulate renal hemodynamics, water and sodium homeostasis, cell proliferation, and matrix formation in the kidney. Plasma endothelin concentrations have been found to correlate with the severity of diabetic nephropathy (Iwase, Doi, Goto, Ichikawa, Iino, & Yoshinari, et al, 2000).

In the kidney, Nitric Oxide (NO) is involved in the regulation of renal plasma flow, GFR, sodium excretion, extracellular fluid volume, and the maintenance of renal

structural integrity (Kone & Baylis, 1997). The renal medulla is the main site for NO synthesis in the kidney (Kone, 1999). The majority of studies found glomerular hyperfiltration in the presence of increased urinary NO involving people with TypeI diabetes excretion, which suggested that increased NO synthesis contributes to diabetic hyperfiltration (Shin, Lai, Wen, Hsiao, Hsieh, & Tzeng, et al, 2000). People with Type II diabetes plasma levels of nitrite were found to be higher than in nondiabetic people, this increased with the progression of diabetic nephropathy, and was positively correlated with AGEs (Maejima, Nakano, Himeno, Tsuda, Makiishi, Ito, et al., 2001).

In summary, diabetes alters systemic metabolism status, and it especially has an impact on both the macro and microvasculature, as well as neuropathy complications. Intensive control of blood glucose levels can postpone risk such as coronary complications, retinopathy and nephropathy. A well controlled blood pressure and lipidaemia will also facilitate reduction in diabetic complications.

Diabetic Pathogenesis

Satko, Langefeld, Daeihagh, Bowden, Howard, Campbell, et al., (2002) confirmed genetic predisposition is the most important determinant of diabetic nephropathy risk in both Type I diabetes (T1D) and TypeII diabetes (T2D). A familial risk of nephropathy is associated with diabetes through relative hypoinsulinaemia and long standing hyperglycaemia. The more prolonged and severe the hyperglycaemia, the greater the risk of DN. Diabetic siblings of parents with Type I Diabetes and DN had a high prevalence of DN (70% versus 25%) (Fagerudd, 2000). Chowdhury, Dronsfield, Kumar, Gough, Gibson, Khatoon, et al., (1996) stated that parental history of hypertension, diabetes or cardiovascular disease appears to predispose to DN in diabetic patients. The Pittsburgh Epidemiology of Diabetes Complication Study found the estimated glucose disposal rate can predict diabetic nephropathy in T1D patients (Orchard, Chang, Ferrell, Petro, & Ellis, 2002).

Genetics plays an important role; T1D patients who have one or two deletions of the angiotensin-converting enzyme (ACE) gene, a defect in the sodium proton pump or a family history of hypertension are at increased risk for progression to DN (Tesař & Zima, 2008). Studies in normal individuals and in those with diabetes mellitus have

shown that sodium status and glycemia can alter the impact of genotype (Osawa, Koya, Araki, Uzu, Tsunoda, Kashiwagi, et al., 2007). Genetic linkage shows that certain ethnic groups are at higher risk of developing DN (Maltais, Bachvarova, Maheux, Perron, Marceau, & Bachvarov, 2002). On the other hand, proper diet and exercise to avert obesity can lower the risk of developing diabetes and further complications.

Hypertensive nephropathy

Hypertension represents a common and powerful predisposing factor for cardiovascular disease and renal failure. Approximately 90% of patients with ESRD have a history of hypertension (Scaglione, Argano, Parrinello, Colomba, Di Chiara, Ferrante, et al., 2002). Hypertensive renal disease includes benign nephrosclerosis (granular kidney and arteriolar hyalinization) and malignant nephrosclerosis. Benign nephrosclerosis is hyaline thickening of the walls of small arteries and arterioles causing luminal narrowing of these vessels cwhich lead to chronic glomerular ischemia, global sclerosis of glomeruli, and atrophy of nephrons with interstitial fibrosis. Malignant nephrosclerosis is described as 'flea bitten' kidneys; and is caused by vascular damage to the kidney also increased permeability of the small vessels and endothelial cell injury, which causes plasma, fibrinogen and other plasma proteins deposition (Ono & Ono, 1997). Intimal smooth muscle hyperplasia and fibrinoid necrosis of arterioles with intravascular thrombosis causes ischemic kidneys. Glomerular filtration pressure is decreased, resulting in increased renin-angiotensin secretion by the juxtaglomerular apparatus and leading to hypertension via aldosterone secretion and sodium retention (American Heart Association, 2005). High blood pressure may initiate renal damage and also increase the rate of progression to renal insufficiency. Persistent high blood pressure represents the early trigger mechanism for renal disease (Scaglione, et al., 2002).

Atherosclerosis is a generalized and inflammatory vascular disease frequently associated with renal disease (O'Hare, Glidden, Fox, & Hsu, 2004). Renal vascular diseases including atherosclerotic renal vascular disease account for more than one third of all cases of ESRD (U.S. Renal Data System, 2003). Diabetes, hypertension, and dyslipidemia are associated with acceleration and exacerbation of atherosclerosis that elevate the risk of CKD especially in older adults (Shlipak, Fried, Crump, Bleyer,

Manolio, & Tracy, et al. 2002). Systemic blood pressure elevates which is caused by increased vascular tone resulted from decreased production of vasodilators (endothelium derived nitric oxide) or/ and increased production of vasoconstrictors (Russo, Leopold, & Loscalzo, 2002).

The mechanisms of atherosclerosis primarily involve the formation of atheroma. Atheroma occurs when endothelial cell injury induces monocytes and lymphocytes to adhere to the injury lesion. Then smooth muscle cells migrate into the vessel wall and cause the proliferation and release of cytokines (Rainger & Nash, 2001). Oxidized low density lipoproteins (LDL) produced free radicals from injured epithelial cells and macrophage cells become foam cells and fatty streaks that enlarge and disrupt the endothelial surface. Platelets adhere to the damaged endothelium and release platelets derived growth factors (PDGF); the smooth muscle cells synthesize collagen, elastin, and protoglycans; which result fibrous plaques formation (called atheroma) (Ross, 1999).

Hyaline arteriolosclerosis is a common vascular lesion caused by aging, hypertension, diabetes mellitus, and focal segmental glomerulosclerosis (FSGS) (Olson, 2003). The mechanisms of arteriolosclerosis include hyalinized narrowing of the lumen (Ono & Ono, 1997). Hypertension increases the frequency of hyaline arteriolosclerosis more in the kidney than in other organs (Olson, 2003). Palmer (2002) suggests that when long-standing hypertension is accompanied by hyaline arteriolosclerosis, the autoregulation of blood pressure is impaired as well as glomerulus function.

When lifestyle changes, a low fat diet and exercise cannot reduce the triglyceride and LDL levels, medical intervention is crucial. Maintaining lipids and blood pressure in a reasonable range can diminish the incidence of nephropathy as well as other vascular complications.

Drugs induced nephropathy

Chronic tubulointerstitial nephritis and nephritis of unknown origin account for 15 to 30 percent of the cases of ESRD in the United States and Europe (Ronco & Flahault, 1994). An example of a group of drugs linked to nephropathy is analgesics (Burry, 1978;

Trinkhaus, Nathan, Beane, & Meltzer, 1997). Combination analgesics, especially those coformulated with caffeine, have been implicated as giving a greater risk of nephropathy than single or co-formulated analgesics without caffeine (Bach, Berndt, Delzell, Dubach, Finn, Fox, et al., 1998).

Drugs exert their toxic effects by one or more common pathogenic mechanisms. The nephropathy of non-steroidal anti-inflammatory drugs (NSAIDs) can cause acute renal failure by patchy necrosis of the loop of Henle and medullary interstitium, tubular atrophy and interstitial fibrosis (Choudhury & Ahmed, 1997; Rossi, 2006). Chronically, NSAIDs can cause elevated blood pressure and renal impairment by decrease glomerular perfusion and GFR (Rose, 2008).

Other nephrotoxin drugs may induce swelling and blunting of foot processes with narrowing of filtration slits (Cheville, 1994). Drug-induced nephrotoxicity tends to be more common among older people (age over 60) and is association with co-morbidities (underlying renal insufficiency, volume depletion, diabetes, heart failure, and sepsis) (Naughton, 2008).

Health care providers must be aware of the potential dangers of analgesic and non-steroidal anti-inflammatory drug (NSAID) misuse as well as drugs that may disrupt renal function. Three monthly checks are important for those patients who require long term use or who are older.

Inherited renal disease

Cystic diseases can be classified as adult polycystic kidney disease, childhood polycystic disease and medullar cystic disease. These are caused by the mutations in an autosomal dominant gene. Adult polycystic kidney disease is a type of autosomal dominant where the person develops enlarged kidneys full of cysts, though usually no symptom until there are in their 30s (Smith, 1998). Childhood polycystic kidney disease is an autosomal recessive type and where numerous small cortical cysts are found and often associated with liver cysts. These children often die in infancy. Medullar cystic disease is a kind of chronic renal failure in children, which is a complex inherited condition, where the person has many cysts in the kidneys. The cysts grow out of

nephrons but there cysts eventually separate from the nephrons and continue to enlarge and this condition progresses to ESRD (Grantham, Nair, & Winklhoffer, 2000).

Tumours of the kidney

There are two types of tumours which cause kidney disease: renal cell carcinoma and bladder carcinoma. Renal cell carcinoma is derived from tubular epithelium, and may be caused by smoking, hypertension, and cadmium exposure. The clinical symptoms include haematuria, abdominal mass and flank pain. Bladder carcinoma is derived from transitional epithelium and people present with painless haematuria. Normally, bladder carcinoma has good prognosis after surgical removal or other medical treatments if it is detected early. Secondary spread from adrenal or other retroperitoneal sites or eventually metastases to bone often a poor prognosis (Godley & Ataga, 2000). Unless both kidneys require nephrectomy or if they suffer from complications, the progress to ESRD is rare.

Conclusion

This chapter has described the many different factors or diseases that may lead to ESRD. The most common cause is inadequate blood flow or blockage outflow in the kidney, which leads to reduced GFR or damage to the glomerulus. Renal failure is often characterized by systemic inflammatory responses through immunological or non-immunological origin causes. DN is a very common cause of ESRD; and there is evidence that genetic predisposition and different ethnicities are more vulnerable to DN. However, aggressive control of blood pressure, blood sugar and LDL levels can delay the progression of ESRD. Overall, the most important issue is early intervention and lifestyle changes.

Chapter Three----- Research: Impact of dialysis on rurally based Mäori clients and their whänau

Abstract

Aim: To understand the experience of New Zealand rural dwelling Mäori clients with end-stage renal disease who receive haemodialysis.

Background: End stage renal disease (ESRD) is related to lifestyle, genetic factors and environment, and Mäori are at higher risk of renal disease and end up requiring renal replacement therapy to sustain their lives. Renal replacement therapy (RRT) includes home-delivered and institutional haemodialysis, peritoneal dialysis, and renal transplantation. As mentioned already dialysis clients are a group of 'silent' clients under the care of the dominant health professionals (Polaschek, 2003a). Adherence with therapeutic regimes has been a main issue for health care professionals and service delivery, as it directly contributes to the efficacy of the treatment and cost effectiveness. Mäori clients' experience of living with haemodialysis has not been explored. Although there are a number of studies describing the experience of patients living on dialysis (Polaschek, 2003a; Polaschek, 2003c; Polaschek, 2006), so far, no studies have yet focused specifically on the experience of Mäori clients towards their RRT.

Method: This interpretive study explores the experiences of Mäori clients having haemodialysis (HD) as outpatients while living in a rural area of Northland. A purposive sample of seven Mäori clients and their whänau were interviewed in 2008. The interview was taped and transcribed, then analysed to formulate a number of themes that summarize the client's perspective.

Findings: Understanding Mäori clients' experience of having HD provides an insight regarding those clients' requirements. Despite their differing journeys to requiring HD, four basic themes are revealed: 1.facing fear; 2.stress from HD; 3. learning, adjusting and changing attitude; and 4. individual needs.

Introduction

This qualitative study explores the experience of being an outpatient on haemodialysis while living in a rural area of Northland. This project has a unique focus because it addresses chronic illness requiring dialysis in a New Zealand population which has not previously been studied, thus adding to the growing body of knowledge concerning renal clients and this can improve their psychological and physical care in New Zealand. There is only one outpatient dialysis service in the mid Northland region of New Zealand. Of the clients using this service 88.5% are of Mäori descent. The continual demands of dialysis treatment are significant and given the high proportion of Mäori having dialysis, it is timely to explore the experience of Mäori clients and their family/whänau.

Literature Review

Mäori people are, arguably, disadvantaged with regard to the optimal management of their chronic diseases. Socioeconomic, educational, cultural and historical factors may impede access to services which also impacts on health outcomes (Baxter, 2002). Mäori people tend to experience ESRD more than the general population (Ministry of Health, 2008); again the above factors are indicated. Understanding Mäori clients' experience of ESRD would allow health professionals including nurses, to identify the key elements involved in the healthcare of haemodialysis clients from the dialysis client's perspective, and therefore improve the quality of care to renal clients and provide patient-centred health care that supports their lifestyle.

One of the main reasons for needing dialysis is ESRD. The leading causes of ESRD are diabetes nephrology 42%, glomerulonephrology 21% and hypertension 12% (ANZDATA Registry, 2007). McDonald & Russ (2003a) reported that indigenous peoples in Australia and New Zealand have a higher rate of ESRD compared with non-indigenous peoples. Figures show that from 2002 to 2004 the incidence of ESRD, in people over 15 years of age, caused by diabetes nephropathy were 9.4 times higher in Mäori compared with non-Mäori (Ministry of Health, 2008). While some of this difference can be attributed to the higher prevalence of diabetes among Mäori, the

disproportionately higher rate would suggest that Mäori with diabetes are more likely to have renal failure than non-Mäori (Baxter, 2002; Simmons, Shaw, Scott, Kenealy, & Scragg, 1994). Furthermore, survival rates of indigenous ESRD people in Australia and NZ were lower than non-indigenous people irrespective of treatment with haemodialysis, peritoneal dialysis or transplant (ANZDATA Registry, 2007).

The Ministry of Health (2004a) estimated that between 2002 and 2051 the proportion of people aged 65 and over in the population will increase from 11.9 percent to 25.3 percent; thus the number of people with chronic diseases will also increase. There are dramatically escalating requirements for managing the ongoing treatment of people living with multiple chronic illnesses, including ESRD, cardiac complications, diabetes, and chronic obstructive pulmonary disease (Ellingson, 2007). Dialysis treatment needs healthcare providers to recognize patients' perspectives such as their health beliefs and health behaviours in order to provide efficient service and improve the quality of care (Dines, 1994). Many studies focus on renal clients' adherence problems (Brady, Tucker, Alfino, Tarrant, & Finlayson, 1997; Friend, Hatchett, Schneider, & Wadhwa, 1997; Lev & Owen, 1998; Takaki, Nishi, Shimoyama, Inada, Matsuyama, Sasaki, et al., 2003). A number of researchers have concentrated on quantitative studies to assess renal clients' health outcomes without necessarily addressing the reason why clients do not follow instructions from health professionals (Bosch-Capblanch, Abba, Prictor, & Garner, 2007; Weich & Thomas-Hawkins, 2004). This does not address the experience and reality of living on dialysis. There are some international studies exploring people's experience of living on dialysis (Hagren, Pettersen, Severinsson, Lutzen, & Clyne, 2001; Kaba, Bellou, Iordanou, Andrea, Kyritsi, Gerogianni et al., 2007; Polaschek, 2003b; Rittman, Northsea, Hausauer, Green, & Swanson, 1993) and two studies (Polaschek, 2003c; Polaschek, 2006) were in New Zealand. However, no studies have provided insight about the experience of Mäori dialysis clients.

Method

The aim of this study was to describe the experience of a group of Mäori clients living in the rural areas of Northland, receiving haemodialysis. An interpretivist methodology was used; through interview to reveal their experiences about what it is like requiring living with haemodialysis three times per week. The interview contents then are

transcribed to written documents. Participants were identified by purposive sampling of clients receiving haemodialysis from a rural renal satellite unit. The data was collected in 2008.

It was proposed that all clients attending the satellite renal unit in mid Northland, who met the study inclusion criteria, would be invited to participate in the study. Inclusion criteria was as follows: All patients at an outpatient renal unit, over 20 years of age, and been having dialysis treatment for at least three months. The participants, after giving informed consent, were invited to participate in a semi-structured interview at a location to suit them, such as their home. Eighteen participant information sheets were distributed, twelve were returned with a signed consent form, giving a response rate of 66.7%. Seven clients (three male and four female) and their whänau were randomly selected. The participants' age range was from 46 to 77 years (average 57) and these participants had been having haemodialysis for between four and ten years. Mäori translations were provided for each question, although interviews were conducted in English.

Each interview lasted approximately an hour and took place with clients and their whänau at their own homes, or at the renal unit, as the clients chose. They were encouraged to talk openly on a range of topics related to their treatment. Three research questions guided the interview: 1.What is it like to have renal failure? 2. What things stand out for you as you have lived with renal failure and dialysis treatments? 3. How did you feel when you found out that you were in kidney failure and you needed dialysis treatment on a regular basis to keep well? The taped interviews were transcribed for review and analysis. Ethical approval was obtained for this study from the Northern Regional Ethics Committee and Northland District Health Board Mäori Ethics Committee.

Data Analysis

Data analysis was styled on Diekelmann, Allen and Tanner (1989) seven stages of Heideggerian hermeneutical analysis in order to produce trustworthy conclusions. The seven stages are:

1. Reading the interviews as a whole, to get an overall understanding of the texts.
2. Identify the meanings evoked by the interviews and identified possible themes in the data.
3. Independent analysis of each document by the principal investigator. An in-depth interpretation of each text was written and given to participants in the study.
4. Determine the credibility of the finding by returning to participants for their evaluation of how well it represents their experiences
5. Analysis of interpretations continued as new data were introduced from further discussions with participants.
6. Identify the themes as the researcher reviewed and re-examined the data, the interpretations, and the discussions with participants.
7. Preparation of the final report using sufficient excerpts from the interviews to allow for the reader to participate in validation of the finding (Polit & Beck, 2006, pp.411-412).

From the interviews some themes were identified and these themes were refined by all the participants' statements within their original context in the interviews.

Findings

From the participants' perspective four themes were revealed: 1.facing fear, 2.stress from HD, 3. learning, adjusting and changing attitude, and 4. individual needs. These themes are drawn from the interviews. Each theme is now discussed more fully with quotes from participants. To maintain anonymity, participants are referred to as client A, B, or C etc.

Facing Fear

This theme is described by the participants to convey their overall experience when facing the fear of a life-threatening condition. The rationale underneath the fear is related to lack of information and late referral.

When participants first received the diagnosis of renal failure, most participants felt overwhelmed by the changes to their way of life and many of them believe that these changes would be extremely difficult to deal with. The fear of their dependency and negative thoughts on their long-term survival become a major factor in their emotional state. These direct quotes illustrate the above:

Client A-"When I first got the letter telling me I needed dialysis. I tried to hide it. I felt like I was half a person, I was disabled. I wanted to just give up. I didn't want to depend on a machine. I didn't know what to do."

Client C-"When I found out I had a kidney problem and required dialysis; I was more shattered than anything else. I was frightened. I ran away for as long as I could."

Client E-"It was a shock finding out I had kidney failure. I was too sick at that point to try to run away from it. I didn't want to go on dialysis. It's terrible to have renal failure."

Client F-"Having diabetes from a young age angered me more; I'd always fought it with frustration and not really accepted it. I was in denial about it but my body made it obvious I couldn't deny it for much longer. I first thought continuous ambulatory peritoneal dialysis (CAPD) would fix me up, my expectations were way off. I came to hate being on CAPD. I suffer from depression and if I don't see that things are coming right, it brings me down."

It is widely accepted that seven distinct stages in the grieving process (shock, denial, bargaining, guilt, anger, depression, acceptance and hope), requires time, compassion, support and awareness to overcome (Kübler-Ross, 1969). Shock is seen in the first breaking of the news of their kidney failure and some found the anxiety of the situation

difficult to bear. Denial might last for quite some time for many. Anger then marks the beginning of their acceptance (Register, 1987). Many participants felt depressed when starting dialysis, or even after several years of treatment. All of the stages have very inward responses except for anger. Finally acceptance and hope will return. Nevertheless, accepting life with kidney failure is not easy. Renal clients need to have a positive attitude, good medical care, and a lot of family and community support (Auckland District Kidney Society, 2009).

Lack of information, lack of education, and/or poor understanding

Shock and denial may be involved and influence the prospect of learning about renal failure. However, lack of information, lack of education, and poor understanding of health management were significant issues revealed by participants. Most participants did not truly comprehend what the causes of their end stage renal disease (ESRD) were, and how to deal with their illness in order to improve their prognosis.

Client D-"No-one told me what the consequences were with diabetes. They didn't explain anything to me. I didn't know anything about diabetes. There was a lack of education so I didn't really know what was going wrong with my body."

Client G-"I didn't understand what was going on with my body, why I ended up like that. It was a hard time. My kidney blood flow was getting worse and worse. I think my high blood pressure was why a lot of the problems started." This quote indicates, even now a tentative understanding of the cause of ESRD and the learning between blood pressure and renal damage.

Client B- "I lost 17kgs of fluid in my first 3 days of haemodialysis (HD). I felt much better. I had thought that 3 days dialysis treatment was all I needed." This participant did not understand the permanent nature of ESRD and the need for ongoing renal replacement therapy.

Lubkin & Larsen believed that: "Lack of resource often contributes to feelings of powerlessness which may limit an individual ability to seeking access needed services and treat physical health problems"(2006, p.310). Powerlessness was shown by

participants alongside fear related to lack of resources and knowledge, as well as deficiencies in direct educational approaches to help them.

Late referral

Data from the Australia and New Zealand Transplant Registry showed that 26% of dialysis patients were referred less than 3 months prior to commencing dialysis in 2002 (ANZDATA Registry, 2003). "Late referral is associated with greater initial morbidity, including increased severity of uraemia, a greater need for emergency haemodialysis, and longer and more costly initial hospitalization" (Jungers, Zingraff, Albouze, Chauveau, Page, Hannedouche, et al., 1993, as cited in Cass, Cunningham, Arnold, Snelling, Wang, & Hoy, 2002, p.135). Late referral diminishes the renal client's opportunities to preserve kidney function and prevent chronic kidney disease progression to ESRD, as well as maintain their quality of life (McLaughlin, 2004).

Examples for participants of this study include:
Client B—"When the doctor first told me I had renal failure, I didn't know what it meant. I didn't want to go to the hospital. But he told me if I didn't I'd have less than a month to live. That's what frightened me to go."

Client D—"I remember the day I first found out I had renal failure; I had been weak and tired. I went to Hospital I didn't know there were such things as dialysis until I found out I myself had renal failure. The doctor said you'll have to go on dialysis."

Client F—"I first became aware of how puffy I was. I was just getting tired a lot, low concentration, I am a diabetic. I went in to get some blood tests and my GP contacted me to tell me my results weren't very good. I was very scared because I didn't understand what was wrong and I thought I was really in trouble. I thought I was going to die." This quote points out lack of understand the consequence of poor blood sugar management; how this affect his/her kidneys function, how to delay to reach End-Stage Renal Disease.

Worldwide 25% to 50% of clients who have ESRD and commence renal replacement therapy (RRT) are referred late to a nephrologist. In European up to 25% to 30%

patients with type 2 diabetes mellitus are referred to a nephrologist less than 1 month before initiation of dialysis (Wavamunno & Harris, 2005). Prognosis and outcomes in patients with CKD have been related to the quality of predialysis care and the timing of referral. Late referral is related to poor outcome, higher risk of death and especially higher mortality in the elderly (Huisman, 2004; Jungers, Massy, Nguyen-Khoa, Choukroun, Robino, & Fakhouri, 2001; Kazmi, Obrador, Khan, Pereira, & Kausz, 2004; Kessler, Frimat, Panescu, & Briancon, 2003; Roderick, Jones, Drey, Blakeley, Webster, Goddard, et al., 2002; Schwenger, Morath, Hofmann, Hoffmann, Zeier, & Ritz, 2006; Sesso & Belasco, 1996).

Stress from Haemodialysis (HD)

Living with HD is a stressful, lifestyle changing event. Participants expressed issues surrounding their quality of life with regards to barriers to health management, as HD being time consuming HD and having long distances to travel to the satellite unit. Social isolation is considered to impact on participant's social life especially for the elderly. Adherence to therapeutic regimes is a big challenge for participants especially making changes to their fluid and dietary intake habits. To be on a transplant waiting list is a hope for most participants but the consequence of long waiting and not having much opportunity to have a kidney transplant can be very frustrating.

Barriers to health management

Two significant barriers to health management are involved. These are financial and cultural issues, and these impacts on the participant's self-care regulation and health promotion.

Financial barriers

Socio-economic status is associated with poor health outcomes (Sporle, Pearce, & Davis, 2002). An example of this is described below:

Client F—"On dialysis days I got into a habit of only really eating two meals a day which I knew wasn't good but it was about socioeconomics and our financial situation too. It would make me angry when the health professional told me to eat healthier and

that what I was eating was bad. It's not that I wanted to eat sausages or other fatty foods; it was just what we could afford. I didn't tell the doctor, when he brought it up that I wasn't eating well, I would just say the quickest thing and tell him I wasn't hungry."

Few participants have admitted to reduce adherence to advised therapeutic regimes as a result of the costs of care, such as not enough in the budget to get healthy food or for transport to go for clinic appointments, yet these have contributed to poor health outcomes. Most of participants could not hold their jobs. Two participants returned to part time work later on. Most of participants stopped being the breadwinner and felt the loss of independence, as well as control of their lives. The cost of attending numerous specialist's appointments, prescriptions, and maintaining a healthy renal diet all have a detrimental impact on daily expenditure.

Culture issues

One cultural barrier is a lack of confidence to negotiate for aspects of health care needed. Generally, people of Mäori descent are accustomed to being passive recipients of health care or previous experiences of inadequate health care services cause emotional disempowerment (Durie, 1999; Penney, McCreanor, & Barnes, 2006). Some might act this way from lack of knowledge worry about resources, or feel fear, shame, or anxiety towards health management (Crengle, 2000). Some believe that the cause or cure should be sought spiritually or from within (Simmons, Swan, Lillis, & Harr, 2007). These factors are illustrated in the examples given below.

Client A—"A doctor had warned me earlier on, he said my kidneys were only functioning 70%. I couldn't understand what the doctor meant by 70%. I wasn't sure if my kidneys were failing or what. I didn't have much of an understanding for it at the time. I never questioned him."

Client E—"The main thing for me was my faith in the Lord. I felt that my faith was so strong that I would survive."

Client D--"If I had been educated properly from an early stage about how to look after myself. I don't think I would be on dialysis right now."

These quotes demonstrate participants did not ask for clarification about their illness from health professionals, nor did they not understand the ramifications, and how best to management their condition.

Seeking professional help may be necessary and should not be perceived as a sign of weakness. Yet why are most of the participants in this study not questioning health professionals? Health professionals need to recognise cultural influence on client's perception and encourage feedback to ascertain how much has been retained. Lee, Sullivan, & Lansbury (2006) suggest that health professionals be aware that cultural identity of clients should be considered but never presumed.

Durie (1985, p.483) pointed out that "Mäori cultural view of well-being is achieved with a balance of soul, body, mind and whänau (family) as shown in the Te whare tapa whä model. This model represents a dimension of Mäori health: taha wairua (spiritual), taha tinana (physical), taha hinengaro (mental, intellect), and taha whänau (extended family)." It symbolises four walls of a house, where any aspect weakened will impact on the entire constitution. Thus a culturally appropriate approach to client's lifestyle is essential. Health professionals should avoid prescribing overly radical lifestyle changes; focusing on adaptation rather than reinvention as this is much more culturally sensitive (Baxter, 2002).

Use of Time

Dialysis therapeutic regimes and travelling takes up much time in the lives of participants and sometimes that of their significant others.

Therapeutic regimes

Haemodialysis treatment is a lifelong process. Generally, each renal replacement treatment (haemodialysis) requires four to six hours of dialysis (depending on a client's body size and blood results), three times a week. Additional to this is the time required

to attend appointments such as renal clinic, eye clinic, podiatry clinic, appointments surrounding fistula creation, fistula assessment, cardiac function investigation and General Practitioner (GP) visits, and admission to hospital if there are any complications.

Client A—"It's stressful. I'd think, oh damn it's my dialysis day again. Have to wake up early, travel in. But getting up early is hard."

Travelling

The growing demand for haemodialysis services has extended to nine satellite units in New Zealand (New Zealand Kidney Foundation, 2009). The number of people needing dialysis treatment was doubling every five or six years (Bennett, McNeill, & Polaschek, 2009). Northland's annual growth rate in kidney disease was 13 per cent, ahead of the New Zealand average of nine per cent (Laird, 2008). There are 13 haemodialysis clients living in the Far North, seven of them aged above 70. The number of elderly requiring HD has been increasing dramatically. Participants described that they generally wake up at approximately four am, get eady, and then wait for the shuttle to bring them to dialysis. Once there they spend four to six hours seated in a lazy boy chair. Once treatment is completed, they wait for members of their shuttle group to complete their HD before returning home. If there are no complications they eventually arrive home approximately three pm. The afternoon clients have a later start and get home around nine pm. If any one has any crisis during or post-haemodialysis, the members of the shuttle group will need to wait and will be delayed getting home.

Client E—"A big issue for me is the travelling since we live so far away. It's the worst thing and does get stressful. We're sitting for all that time. It takes a lot out of us elderly; two hours on the travel, more than four hours on the machine and two hours back. Most of us are over 60, it's a long day. I think it's a big part of what makes people sick of being on dialysis. "

Social isolation

Treatment three times a week and the many appointments with specialists occupies a lot of time which makes it difficult for participants to take part in other activities which can lead to social isolation for a number of reasons.

Client B—"You miss out on a lot of things you used to do in the past. You lose your social life; you can't go visiting or go away. You lose your quality of life, but when you think about it, without it, you lose your life."

Fluid and diet restrictions make them unable to unreservedly eat and drink like other people either in the Marae setting or at other special occasions. This may stop them attending community activities. The reason is they want to be seen as a "normal" person, but because of the restrictions having renal disease imposes upon them and being Mäori they feel that it is culturally impolite not to accept the hospitality offered (Nursing Council of New Zealand, 2005). As with many cultures the sharing of food is a deeply embedded more.

Therapeutic regimes adherence

For the participants in this research fluid and dietary restrictions, attending HD and medication adherence required lots of commitment in order to reach their preferred state of well-being. Most dialysis clients can not get rid of excess fluid (little or no urinary output), or electrolytes and waste products from the body; they have to limit fluid intake below one litre per day (including fruits, jelly and soup; and avoid all foods high in water content). A diet low in sodium is required to prevent thirst or a rise in blood pressure. A low potassium diet is essential in reducing the risk of cardiac arrhythmia and death caused by hyperkalemia (Putcha & Allon, 2007). Effective control of serum phosphate is crucial in preventing calcium phosphate deposits in the soft tissues such as arteries, veins and organs (calciphylaxis). Taking phosphate binders (Alutab & Calcitab) with meals is a fundamental requirement. The recommended intake of protein (dairy products, legumes and meat) is 0.6 g/kg/day which means an 80 kg person's suggested intake of protein is 48 g/day due to the phosphate contained in protein (Davison & Cameron, 2005; National Kidney Foundation, 2002a).

Client F—"I got into a bad habit about taking my pills; I often didn't take it with food. I guess I knew the reasons why I need to take it with food but it just didn't cross my mind at the time. It was frustrating having to take so many different types of pills each day. I had had enough."

Client G—"I really struggled with all the potassium and phosphate at the beginning of dialysis."

Client D—"That's the hardest part, trying to get my body back to the way it was after dialysis. I try not to change my lifestyle because of dialysis. I try to motivate myself but it's hard."

If there is an inadequate intake of high dietary phosphate or the person did not take phosphate binders as per the nephrologist's prescription, then serum levels of phosphorus, calcium and parathyroid hormone (PTH) will become elevated. A long term effect is bone disease and calcification complications such as the tunica media of blood vessels losing their elasticity (Mazzaferro, Pasquali, Farcomeni, Vestri, Filippini, Romani, et al., 2008; National Kidney Foundation, 2008c). Additionally oxidative stress and hyperphosphataemia influence vascular calcification (Hirasaka, Liang, & Mune, 2004). It is important that clients do not shorten or miss dialysis sessions and their phosphate binders.

Intradialytic hypotension (IDH) that can occur during HD, may be caused by autonomic neuropathy, decreased cardiovascular reflexes or by fluid removal rate being faster than the refilling from interstitial areas into the bloodstream resulting in a decrease in systolic blood pressure by greater than or equal to twenty mmHg (Winearls, 2000; National Kidney Foundation, 2008d). Hypotension during HD is a main concern for health providers and is a very unpleasant experience for clients. When fluid intake and weight gain interdialysis is too high then haemostasis will require a removal fluid rate more than the body can tolerate which causes hypotension (National Kidney Foundation, 2007).

Client D: "I still have a problem with my fluids restrictions. I get exhausted as I get cramps".

Client E: “I hate the experience of going hypotensive during haemodialysis, I became flat like a pancake and afterward I feel worn out for a long period of time”.

Hypotension impairs the patient’s well-being, and can induce cardiac arrhythmias, potentially leading to coronary and/or cerebral ischemic events. Intradialytic hypotension is associated with morbidity and mortality (National Kidney Foundation, 2005). Cramp is a symptom of intradialytic hypovolemia or low sodium concentration which occurs frequently during haemodialysis treatment (Rho, Perazella, Parikh, Peixoto, & Brewster, 2008).

Being on a waiting list for transplant

Kidney transplant prevalence is relatively low in New Zealand due to the low donor rate ten per million (Organ Donation New Zealand, 2006). The donor statistics showed only 3.5% from Mäori and also a low rate is noted for living donors related to the influence of cultural beliefs (Ashton & Marshall, 2007).

Client D- “My concept is God gives us what we have and we go out when we leave this world; we still have what we have at the first. I tried hard to keep up on the waiting list for many years; I feel aggravated sometimes. I have been on the transplant list for many years and nothing happened. I hope that the next one may be me, but I am always disheartened.”

Client F: “Regardless of whether I get a transplant or not, I have to live my life as a destiny. I know I have to keep in good health to stay on the transplant list. I don’t want to get too disappointed if I don’t end up getting one.”

Being on the kidney transplant list is a big hope for these Mäori participants. However, the long wait for kidney transplant is heartbreaking for them. There were 46 (19%) Mäori clients aged less than 65 on the kidney transplant waiting list in 2007 (ANZDATA Registry, 2008b). The low donor rates (living and deceased) among Mäori is contributing to the low transplant rate for dialysis clients.

Learning, adjusting and changing attitude: A lesson is repeated until learnt.

Participants have to understand their medical condition through different phases of learning; including overcoming their psychological grief and facing physiological disequilibrium. Participants live according to the institutional routine of the dialysis unit. There are many adjustments to be made, including the symptoms and the events surrounding ESRD (Loewenstein & Haisley, 2007). A basic requirement for life is the removal of waste and extra fluid from the body. Diet and drinking habits are significantly changed. They must learn to live with a fistula (vascular for HD access) and tolerate multiple needle punctures. They are bombarded with information about blood pressure, fluid overload, calcium, phosphate, potassium, medications, diet, and transplant. There is an endless stream of information presented to people with ESRD (Brady, 2008).

Client A- "If I have to wake up earlier for dialysis then I'll go. It's for my own good. There's no other way to win. I feel much more positive now than I did in the beginning. I had to change my whole way of thinking and learn the things that will be better for me. I used to wonder if it was all worth it. But now I know it is."

Client B—"At the beginning I thought, this can't be happening to me. But now it's just something that happened. I actually feel like I've gained rather than lost something with dialysis. As I lost my kidneys, I found my family and the things I'd forgotten to cherish in life. This change in attitude is like seeing every cloud has a silver lining".

Client F: "For my own health and wellbeing I have to look after myself. It's a big change. In the past I just ate whatever; looking back now I see what it's done to me. I know I need to keep positive. Life has its highs and lows but I know I need to just take everyday as it comes. At the end of the day, I know I'm the one I have to rely on. It took me a long time to realize my attitude about my body had to change and the denial had to stop, I had to gradually accept things if I wanted to get better. I had to learn to be more laid back and not let stress get to me. You learn to live with your illnesses and I think in some ways, this is the healthiest I've ever been, not just physically but emotionally and

spiritually. There is no alternative and so I changed my attitude and that's made a big difference."

Client C—"It took me a while to actually accept it and go with the flow. It was easier to do that than to fight against it. After I got on dialysis, things started getting better and better".

Client E—"If dialysis was what was going to bring me back to life again, I would do it. The main thing for me was my faith in the Lord."

If a person can understand the treatment and apply this knowledge on a daily basis, then that person will be in charge of own well-being and have the ability to move toward a better health outcome thus positively benefit on their self-confidence (Prochaska, Norcross, & DiClemente, 1995). Although a positive attitude is the key to successful living with dialysis but client needs to learn to accept ESRD one step at a time. They do have bad days sometimes; to understand and accept that feelings of denial, anger and fear are normal and it is the healthiest way to a positive outcome. Bates (2004) emphasized that, "You are the one in charge of your attitude and future, you make your own happiness."

The more participants learn, the more they understand and the greater the benefit from the knowledge they possess. For ESRD clients, renal replacement therapy can last a lifetime unless a kidney transplant takes place. At this point clients understand that life will never be the same with renal failure but they see hope and meaning in the future as well.

Individual needs

Every person is unique; they come from different genetic pools, different families and backgrounds. Each participant has their priorities and requirements. Participants felt that family/whänau's support is most important to their lives. From the participant's perspective health professional's support and respect is an added personal requirement which contributes in brightening their daily lives.

Family/whänau Influence

Faber (2000) describes that when you love someone who is ill, you are suffering too, and that is the nature of human attachment. Most participants disclosed that their whänau do not want to leave them alone to go on holiday. Their family would worry about them if any problems or complications happened, and they would not forgive themselves if anything happened in their absence. On the other hand, involvement of family members in self management assists in participants' health knowledge (Barr, 1996).

Client B—"I want to see my grandchildren grow up as much as I can. I think dialysis actually brought my family closer together. My lifestyle is better now, I see my kids and I spend more time with my family. They are my happiness. As my eyesight deteriorated, my hearing got better. But it was inconvenient. Now I have my eyesight back, I cherish it. I'm grateful for the opportunity to carry on. As one door closed, another opened. Not just with my eyes but with dialysis."

Client F--The family conference was an eye-opener for me and I learnt that kidney failure is not the end of the world and I'm still here today and I can still do things. The family conference was really good, I found that I could still be put on the transplant waiting list for a kidney and also a pancreas (due to my diabetes) and this added some hope for me. It wasn't so daunting anymore. I realized I had to be in a better frame of mind"

Client E—"Without my family, I wouldn't have the will to keep going. I can't live without them. My Whänau knows my needs. I take my medication, I eat well, and my family makes sure I do."

Client D—"my family is very supportive, caring and understanding of what I am going through. I wouldn't have made it without them; their love means a lot to me. They keep me going and push me and support me."

One client descrided the impact of family/whänau saying: "It is love keeping me alive not the dialysis machine, without their love I would not keep coming back for dialysis".

Family's love and support is the main hope for the participants of this study and their whänau make their lives meaningful. This links to the four dimensions of a Mäori concept of health (soul, mind, body and whänau) (Edward, McCreanor, & Moewaka-Barnes, 2007).

Client's perspectives

The renal nurse is a mediator between the physician and clients, and the nurse's role is to implement the therapeutic regime according to the physician's orders. All health professional includes renal nurses can extend their clinical activities to include supporting client's lifestyle changes to achieve their therapeutic regime by negotiation with clients.

Client A—"My old dietitian used to just tell me all this business about 'other people'. I told her, I'm not other people, I'm me. But the one I have now, she's good. She's made me up a whole menu just for me. She took into account the things I like to eat and I can still eat them, just in smaller quantities."

Client F-"I don't want to go on haemodialysis at home; the health professional pressured me towards it because I was still young and capable of it but I didn't want to. I was quite angry about the way the staff pressured me. I know my own feelings and they didn't take them into consideration. I was at a real low point at that time which I believe has affected my personal life."

Client E.—"I think it's very good to have a good partnership between nurse and patient. Trust between the nurse and patient is very important. The patients should be their number one priority. Efficiency from the nurses makes our day a whole lot easier."

Health professionals, including nurses, have to recognize a client's social context and life experience through a partnership so they can discuss with clients their ongoing care for short term and long term management (Polaschek, 2003a). Without understanding a client's socio-economic circumstances and background, priorities and concerns in context, then progress towards positive health outcomes is unlikely. All health

professionals should support clients in maintaining their autonomy and promote their ability for self-management (Polaschek, 2003a).

Discussion

Reflecting on Mäori renal clients' discourses, haemodialysis treatment has a huge impact on Mäori clients' cultural values, beliefs and lifestyles. From the beginning when the news is first broken to them, they have to learn to face the kidney failure within their body. These findings, indicate that Mäori clients' experience of ESRD is related to education factors, socio-economic status, beliefs and cultural influence.

In Europe and USA, about one third of patients are referred less than four months before the start of dialysis, causing a three-fold increase in the risk of death during the first months of dialysis (Stack, 2003). Early referral, one year before the start of dialysis to a nephrologist improves patients survival rate, and early intervention can slow the progression of chronic kidney disease (Bergrem, 2002; Woredekal, 2008; McLaughlin, 2004; National Kidney Foundation, 2002b; Wavamunno & Harris, 2005). ANZDATA registry showed that late referral of patients, who started dialysis between 1995 and 1998, meant they were less likely to be put on the waiting list for a renal transplant (Cass, Cunningham, Snelling, & Ayanian, 2003).

Early referral of a person presenting with CKD gives enormous opportunities for the renal team to provide health education for self-management (low protein, low sodium and low fat diet). Furthermore, in order to delay the progression of end stage renal disease (ESRD) medical interventions such as blood sugar control, blood pressure control and lipolipid serum levels control must be observed. Cardiovascular disease accounts for more than 50% of ESRD deaths (Collins, 2003). As early intervention has a positive effect on client outcome and reduces the opportunity for risk factors to develop, this approach may also be appropriate for clients who are not yet receiving RRT. Early referral reduces client psychological distress, buying time for improvement to their quality of life, reducing complications with huge cost saving to the health system (McLaughlin, 2004).

From the findings of this study, Mäori clients on dialysis cannot adhere to nephrologists' directives only, although initial complacency is more cost effective for health services. People who do not listen to the renal team's advice should not be tagged with the dishonourable term of "non-compliant". As Dines emphasized "health care providers should avoid the assumption that health is the only goal in life which ought to be pursued" (1994, p.337). For many clients their top priority are families first, therefore their parental and familial roles take precedence over their role as a patient.

Travel and haemodialysis treatment engages approximately 33 hours of a participants' time each week, within that time they travel more than 720 km. On a personal level the combination of travel and dialysis treatment makes many participants feel exhausted and weak. A feeling that is more pronounced for the elderly. On the financial side transporting dialysis clients is a huge expenditure for the health organization, which for Northland is around $500,000 per year. Ideally to benefit both clients and the District Health Board the haemodialysis service should be situated as close to the participant's home as possible. This would save participants travelling, improve their quality of life and be more cost effective in terms of transport requirements.

Kidney transplant is more cost effective than dialysis and can improve clients' quality of life (Howard, Salkeld, White, McDonald, Chadban, Craig, et al., 2009; Niakas & Kontodimopoulos, 2008; Nolan, 2005). Both Mäori donor and receiving of organs rates are much lower than those for non-Mäori, with only 2.9% of Mäori patients receiving a kidney transplant due to low compatibility rates among those of Mäori ethnicity. The reason is related to their traditional customary rules that arise from beliefs about the movement between the realms of the living and the dead, which raises concerns for donors, recipients, and their respective whänau (Lewis & Pickering, 2003). Waiting for kidney transplant is associated with deteriorating health and consumes large amounts of health resources. Transplantation improves quality of life, life expectancy, and is cost efficient (Ashton & Marshall, 2007). Many clients on the kidney transplant lists are waiting quite a few years and transplant may never happen for them.

Education enables clients to achieve an understanding of their illness and treatment. It provides the support for special needs of clients and is tailored to their requirements by health professionals (Klang, Björvell, & Clyne, 2001). Education is crucial, to help the

next generation to change attitudes towards illness management and help influence the older generation to adapt. The terminology used is not understood by many Mäori and this therefore needs to be simplified, explained and discussed (Baxter, 2002; Jones, 2000; Simmons, Upjohn, & Gamble, 2000).

Education, social support, and family support have been shown to foster coping skills among people on dialysis. As they learn more about therapeutic management, medications and diet they gain and maintain a sense of control, a factor linked to improved compliance and life satisfaction (Goldberg, Geltman, Hagberg, Gavin, Delmez, Carney, et al., 1983). Education was shown to be a positive predictor of physical and psychological well-being for people on HD as well as improving their self-confidence in managing their illness (Painter, Nelson-Worel, Hill, Thornbery, Shelp, Harrington, et al., 1986; Renal Rehabilitation Report, 1999).

A number of studies show that clients who are encouraged to learn about their treatment have better outcomes and improved quality of life (Meers, Singer, Toffelmire, Hopman, McMurray, & Morton, 1996; Morris & Jones, 1991). Encouragement and support have been shown to have a positive effect in helping people adjust to renal disease; support from families and dialysis staff has been particularly beneficial; increasing clients' autonomy, control, and participation in treatment (Whittaker, 1984). The role of the healthcare professional is to empower and encourage clients to accept responsibility for their well-being and to fulfil their obligations within the family and society (Keogh & Feehally, 1999).

Nurses' positive attitudes can convey a belief in their clients' potential to live long and well on dialysis. Nurses' encouragement toward patients' treatment goals helps patients form positive attitudes that will allow them to participate actively in life (Renal Rehabilitation Report, 1999). Furthermore, nurses can provide information on the things that the individual is concerned about which helps to assist with self-management, adherence, and self-care (Keogh & Feehally, 1999).

Chambers & Narayanasamy (2008) recommend health promotion should be central to nursing practice; there has been a growing acknowledgement of the importance of the nurses' role in promoting lifestyle choices and self care. "It is not the job of nurses to

tell people what to do. Our job is to let them know what the consequences are if they do or don't do things. Then they have the choice to do something about it or not. Our job is to give them the alternatives" (2008, p.158). Health education and healthy lifestyle choices are unlikely to fit each individual's perception about keeping healthy. If healthy choices are relevant to the person's lifestyle or desire then that would improve their well-being.

There is a need for nurses to be the primary instigators of client health promotion through partnership in negotiating client's health care and by respecting their needs and concerns. Horl (2002) suggested that an individualized and flexible approach may be beneficial to ESRD clients. Nurses can, through listening and understanding a client's background and perception, gain an insight into what their client requires. Then nurses can through partnership develop a care plan according to individual needs. Through this approach nurses will be able to support clients to promote self-management more effectively.

This research has resulted in different findings to a previous study from Polaschek (2003b) who reviewed eight qualitative studies about the experience of living on dialysis including renal replacement therapy. His findings recognise that HD experience creates a distinctive social context which helps maintain clients' hopes from the initial crisis phase, to outcome uncertainty, management of dialysis, through to even more burdens arising from complications in the terminal stage. Similarity with Polaschek (2003b) study reveal family support is essential; as is taking control of life with dialysis. Mäori people have their own characteristic background, cultural beliefs, geographic and social complexities which all may contribute to the diversity of these findings.

Limitations

The sample of Mäori haemodialysis (HD) clients is taken from a small satellite unit situated in rural Northland. Their experience may be quite different from other geographic areas of Mäori HD clients. Mäori clients situated in the in-centre unit may have different experiences from those in the satellite unit. A potential limitation is that the findings have been influenced by the culture of the setting where the study was conducted.

This research did not separate different age or gender groups to obtain data. For clients aged above 65, their perception may vary compared with that of a younger age group. The period of time people have spent on HD may have influenced results. Male HD clients may have dissimilar experiences compared with female clients. A male researcher may be able to get more in-depth information in the context of male clients' life experiences. The different culture and background of the researcher and participants may have resulted in some gaps, or less complete data being collected. Further studies in Mäori for different age and gender groups and regions are needed in order to provide a wider range of knowledge related to Mäori dialysis clients on which to base nursing care.

Conclusion

Through this study a few themes were revealed from Mäori participants in their journey of dialysis. They have to face fear, deal with stress from HD, new learning, adjusting and changing their attitudes toward their new lifestyle, and find their own way to get in control of management ESRD. In understanding Mäori clients' experience of living with dialysis from their perspectives health care providers have a better understanding of the factors that impede client's management of their daily life. Improving Mäori health should concentrate on effective education in order to promote health management and quality of life. Early referral is shown to promote clients with chronic renal disease quality of life and able be cost effective. Advocacy for organ donorship (living and deceased) is crucial to Mäori clients on the kidney transplant waiting list. Advocacy for Mäori donors requires rethinking and must arise from their inherent culture and social surroundings to be effective.

Health care providers have to recognize and respect their clients' cultural dynamics and the individual's autonomy and to creat the best possible health care environment for clients with chronic conditions who are undergoing long term treatment. It is also important that health professionals accept that the client is an unique individual who is able to support lifestyle changes. It is anticipated that the findings from this project can be used by all health care professionals, and consumers of renal services in New Zealand to create a greater understanding of the psychological impact dialysis has on

Mäori clients' quality of life. Using this understanding as a cornerstone nurses can initiate, in partnership with Mäori clients, a care plan that is supportive and proactive in advancing health outcomes.

Chapter Four: Recommendations for practice in chronic kidney disease management

Introduction

Chronic kidney disease (CKD) is recognized as a global public health problem (Levey, Atkins, Coresh, Cohen, Collins, Eckardt, et al., 2007). CKD has a high prevalence and its associated problems all cause mortality, especially in people of low socioeconomic status (Wen, Cheng, Tsai, Chang, Chan, Tsai, et al., 2008). Much evidence indicates that the adverse outcomes of CKD, such as kidney failure and cardiovascular disease causes premature death (Collins, Li, Gilbertson, Liu, Chen, & Herzog, 2003; Eknoyan, Lameire, Barsoum, Eckardt, Levin, Levin, et al., 2004; Levin, Djurdev, Barrett, Burgess, Carlisle, & Ethier, 2001). CKD raises the incidence of end-stage renal disease (ESRD) with poor outcomes and high cost. Unfortunately, CKD is "under- diagnosed" and "under-treated" in New Zealand especially in rural New Zealand, resulting in lost opportunities for prevention (ANZDATA Registry 2004; Excell, Marshall, & McDonald, 2005; National Kidney Foundation, 2000). So far, national monitoring systems have not developed a framework for CKD.

Nevertheless, CKD can be prevented or delayed, if early detection and early intervention strategies are put forward appropriately (Locatelli, Vecchio, & Pozzoni, 2002). For that reason, health providers should make the reduction of CKD a public health priority. Promotion of CKD recognition is the groundwork for diminishing dialysis requirements (Jacobs, 2006). To reduce the incidence and impact of ESRD there is an urgent need to give information of how to best manage CKD, and to minimize inequality in health outcomes for those of Mäori descent.

Geographical inequalities, in limiting access to treatment centres has resulted in an increase in mortality from 15% in 1980 to 25% in 2001 in New Zealand, despite the reduction of inequality being at the top of the government's health agenda (Pearce, Dorling, Wheeler, Barnett, & Rigby, 2006). The status of Mäori health is impacted by socioeconomic factors such as education, employment, income levels, home ownership, household crowding and living in a household without access to telephone and/or a car (Mäori Health, 2009). The major sources of Mäori death are all chronic diseases

(Minstry of Health, 2004). McDonald & Russ (2003a) reported that indigenous people in New Zealand have a higher rate of ESRD compared with non-indigenous people. The Ministry of Health and District Health Boards need to support Mäori health providers and primary health care in education about CKD prevention. CKD prevention requires commitment of health providers' to support changes in lifestyle especially among the rural Mäori population.

This chapter will discuss research findings (Chapter Three) and consider the practice implications for management of CKD in rural Northland. These include recommendations for appropriate education and nursing interventions for Mäori health promotion which can assist to develop effective health services for holistic care to Mäori communities.

Background

Mäori have a high incidence of ESRD. Amongst dialysis clients, 73% of Mäori origin had diabetes compared with 21% of those of European origin (Collins & Metcalf, 2003). Alongside with the current dialysis clients nationwide, 34% are of Mäori descent, and in Northland Mäori clients make up 50% (Northland District Health Board Renal Unit, 2009; ANZDATA Registry, 2007).

The main factors contributing to the continuing growth in the number of CKD cases are the universal ageing of populations, multiple co-morbidities, and the higher life-expectancy of treated ESRD clients (Coresh, Astor, Greene, Eknoyan, & Levey, 2003; Grassmann, Gioberge, Moeller, & Brown, 2005). CKD is a permanent condition that is characterised by a persistent systemic inflammatory response, which may be caused by prolonged medical conditions, such as high blood pressure or uncontrolled diabetes (National Kidney Foundation, 2007). CKD is a silent condition in the early stages without obvious symptoms. Common symptoms of CKD are listed in Appendix Four (McLaughlin, 2004, p.8).

The increased rate of ESRD in Northland will lead to increased requirement for dialysis. Additionally the need for dialysis will cause serious stress for the people with ESRD and their families, as well as being a huge burden for the public health system

(Northland District Health Board Renal Unit, 2009). People with CKD have a long and demanding journey in front of them. Right from the early stage of kidney disease they experience declining energy levels, which continues on to late stage kidney failure with oedema, nausea and/or the feeling of shortness of breath. Preventing ESRD and such symptoms can lead to improved health for individuals which will impact on families, communities and reduce the burden on the health care system.

Process

The results of the research findings (Chapter Three) were presented to colleagues at a Northland based renal unit and they contributed their experience and opinions to a discussion which assisted in the development of recommendations presented here. Staff at the renal unit participate in a weekly in-service meeting held in the unit meeting room, to share research findings and for presentations on key topics by guests. One of these meetings was used as an opportunity to share the findings from this study on the experience of being on dialysis for Mäori clients and their. The presentation took place in two stages. The first consisted of a PowerPoint slide show (Appendix Five) which included an outline of the study and explanation of the four themes from the findings. The second stage was a discussion which followed from this and from which the following recommendations were developed. Eight to ten staff participated in the presentation, and the variation in numbers occurred because of clinical commitments, so at times staff left or joined the discussion.

Furthermore, the research findings were presented to members of the Northland Mäori Health Service Directorate. The findings from Chapter Three were sent two weeks before a face to face meeting was held between the author and the Chairperson and a senior member of Te Poutokomanawa-The Mäori Health Service Directorate. The discussion from this meeting informs all recommendations, but is most strongly presented in Recommendation 5.

Recommendations

A total of five recommendations were developed, though these are very broad and could be divided into smaller steps.

Recommendation 1: LIFESTYLE EDUCATION

To improve health status and prevent the long term complications and effects of CKD a key focus must be on lifestyle education.

Discussion

The literature upholds the importance of lifestyle education and Jacobs (2006, p.2050) suggests that the successful management of CKD must include the following:

- •Lifestyle modifications (control of body weight, exercise, ban on smoking)
- •Blood pressure control
- •Reduction of proteinuria
- •Tight glycaemic control in diabetics
- •Dietary protein reduction
- •Lipid control (low saturated fat diet and/or lipid lowering agents)
- •Avoidance of nephrotoxic agents (NSAIDs)
- •Early referral to nephrologists

A lifestyle approach involves changing eating habits, stopping smoking and drinking and being more active rather than sedentary. The Ministry of Health (2004b) and the He Korowai Oranga Mäori Health Strategy (2001) noted that key factors required for improving Mäori health include: A good plan, leadership and commitment, workforce capacity, and funding and resources.

What changes are needed in order to promote health and self management for Mäori people along their CKD journey? The strength of Mäori communities is built on the well being of each family. To promote and produce better health outcomes for Mäori in relation to the prevention of renal disease, these have to start with the whänau's health education regarding their eating habits. Dietary health risks are associated with high intakes of protein, fats and salt alongside poorly controlled diabetes. Obesity is related to bad eating and lack of exercise (Scholp, 2000).

This first recommendation is based on findings from the present study indicate that to modify any lifestyle one must start with the family for Mäori. Health providers should

take action to improve ongoing education according to the community's needs regarding wellness and disease prevention. These needs could be assessed using family input to identify what they see as their priorities. Each nuclear family acts as a small unit, and extended family members could unite with them to form discussion groups. A family spokesperson could communicate their perceived needs with a health provider regarding what resources they needed for the education of their whänau e.g. how to prepare a healthy meal for their whänau by modifying the dietary resources and cooking methods that they traditionally use, but working within their socio-economic means. With a dietitian for consultation they could develop their own ideas and health practices, maybe at the local Marae. Another idea might be that once a month they share a healthy meal in the Marae and also invite a health educator to address their priorities and check blood pressures, and urine for sugar and protein. Such a gathering is likely to catch those who 'fall through the net' because they rarely make GP visits.

Whänau groups based around their Marae may provide more supportive lifestyle patterns, such as participation in Mäori culture groups and competitions, communal collecting food from the sea or bush, and sporting activities. Rural schools could be encouraged to form 'Gardening groups' where children can learn basic lifestyle skills e.g. collection of organic residue to recycle and build worm farms, which can enrich compost and create a resource for growing vegetables. Home grown vegetables can save daily spending and also be shared with their whänau or used for Marae occasions. Working bees can help their elderly with cleaning, gardening or even painting their homes and so forth to improve physical fitness whilst doing so. Such support of each other has far reaching benefits for health - mental, physical and emotional. Health providers, through contact with family/whänau groups, can cooperate and facilitate the setting of short and long term goals giving people the feeling and knowledge that they have done something important to help themselves and their whänau. Having a healthy family then produces a strong community. Health providers must be committed and enthusiastic in supporting their clients in the quest to reach full potential. Each small step contributes to success for whänau and the community.

Through education and training of professionals such as diabetic nurses, dietitians, GPs, practice nurses, those can provide resources of education to schools, different social groups, as well as Marae and Mäori communities. Improvement in the method of

delivering information or education for high risk clients needs to focus on early detection and early intervention. Renal services need to explore all possible avenues to increase medical, nursing, and the allied health workforce, support for remote area staff, increasing recruitment and developing the roles of Mäori staff.

Recommendation 2: INCREASE EARLY DETECTION AND INTERVENTION

The requirement for dialysis can be prevented by the early detection of kidney disease and interventions that reduce kidney damage, therefore decreasing the incidence of ESRD.

Discussion

Early detection of CKD is considered to be an effective approach to prevent or halt the acquisition of ESRD. Appropriate timing for referral to nephrologists in the pre-dialysis stage would help CKD clients' smooth transition into renal replacement therapy (RRT), as would the provision of psychological support from social workers. Early referral of CKD gives enormous opportunities for the renal team to provide appropriate intervention and education for self-management in order to prolong the progression of CKD and postpone ESRD (McLaughlin, 2004). Early intervention highlights a diminished impact on psychological anguish and decreased physiological complications as well as being a major cost saving (ANZDATA Registry, 2007). People with CKD are many times more likely to die of cardiovascular disease than the general population (Hostetter, 2004; Kundhal & Lok, 2005). Initiation of treatment for cardiovascular risk factors at earlier stages of CKD should be effective in reducing cardiovascular disease events (Johnston, Dargie, & Jardine, 2008).

Educational input is associated with increased client autonomy, improving their quality of life, and increased compliance with therapy leading to a delay in the initiation of dialysis. Education content needs to be simplified and key points put as clear as possible. Inviting Mäori dialysis clients to address their experience in the Marae situation is a good option to deliver clear information without cultural barriers. Two ways of discussions about a renal client's journey makes people aware that is also related to their own quality of life. As people discuss more about CKD, they understand

more deeply about how to look after themselves and their whänau. Clients should be encouraged to seek advice and verify information about their actual medical condition in order to understand how best to utilise prevention techniques or treatment (Holmes, Perron, & Savoie, 2006).

The target population includes those who have or are at increased risk of developing CKD and their families. This population group may manifest relevant pathological abnormalities or have a GFR less than 60 mL/min/1.73m^2 for more than three months, with or without kidney damage. Interested parties in the detection and monitoring of kidney disease should include all health professionals caring for the target population; providing or paying for the health care needs of the task (National Kidney Foundation, 2002c). An action plan for CKD is presented in Appendix Six.

Early stages of kidney disease can be detected through testing the urine for protein. Proteinuria is currently the single best predictor of kidney disease such as in diabetes, glomerular disease, and hypertension (National Kidney Foundation, 2002c). People with bladder outflow obstruction, recurrent urinary tract infections, metabolic disorders causing recurrent kidney stones, long-term (more than 12 months) use of non-steroidal anti-inflammatory drugs (NSAIDs), neurogenic bladder (impaired bladder function) or with surgical urinary diversion should have their kidney function checked routinely also (National Kidney Foundation, 2002c). Identifying high risk populations should include those of Mäori or Pacific Island descent, diabetics, people over 40 years old, hypertensive, or who have a family history of kidney disease, is a smoker or suffers from alcoholism. However, all individuals should be assessed as part of any routine health evaluation within Northland.

Northland District Health Board (NDHB) nephrologists have developed guidelines for managing CKD. The guidelines include education, support and advice to health care providers and educators. Community nurses should lead initiatives such as a liaison nurse working closely with the Tangata Whenua (local indigenous people). Mäori health care providers, primary health organizations, public health nurses, practice nurses, diabetic nurses, dieticians and pharmacists should be involved in the care of people with CKD in order to provide ongoing education for lifestyle modification, health management plan and regular assessments. Best practice in management

strategies include regular assessment of blood pressure, blood sugar, nutrition, cardiovascular disease, anaemia, lipid levels, bone disease and advise clients about smoking cessation, limit alcohol consumption and provision of educational support (National Kidney Foundation, 2002c).

Recommendation 3: INCREASE REMOTE DIALYSIS SERVICES

More locally provided dialysis services will reduce the impact of having regular, ongoing dialysis treatment on people with ESRD and their families/whänau.

Discussion

Satisfaction with the service is likely to improve, and the physical impact from travelling long distances will reduce if local dialysis service can be provided. The effects of isolation are more pronounced for those living a distance from required health services. The advantages of having a local or satellite dialysis unit include the client having less distance to travel for dialysis treatment and thus cost saving for transport, and less waiting time for a vacant machine and therefore a more stable client. For nursing staff there are more opportunities for autonomous nursing practice as satellite units consist of mainly renal nurses on site. Satellite units facilitate partnership between nurses and clients and their whänau, and also promote the self management and regulation of clients (Levy, Morgan, & Brown, 2004). However, staff in a satellite unit can sometimes feel isolated from the main renal unit due to less support such as lack of nephrologists, vascular specialists, dieticians or educators on site. Satellite renal staff are required to be highly skilled in assessment, communication and decision-making.

Satellite units should be accessible to every resident in the country. However, the geographic location within Northland can lead to some differences in the health of local populations and delivery of health care services. Budget constraint is the main resource problem for health departments. The Ministry of Health would need to make satellite units a priority consideration in order to meet the rapidly increasing needs of dialysis populations (Laird, 2008). Mäori have indicated they would like to see Marae based stations for dialysis. However, many issues around this exist especially in regards to ongoing funding. Additional concerns include client safety, monitoring, cultural sensitivity and equipment issues.

Recommendation 4: INCREASE MAORI KIDNEY DONOR RATES

There is a need to encourage Mäori to consider organ donation. Education and discussion amongst family/whänau and within Mäori communities around deceased or living kidney donation is needed to increase the availability of kidneys for transplantation.

Discussion

Kidney transplant offers the best quality of life for ESRD clients and is a cost-effective treatment. Transplant recipients have better health, higher levels of well being and are more likely to return to work (Thomas, Smith, & Jeffrey, 2002). Mäori accounted for 34% of the total number of dialysis clients in New Zealand, but Mäori donorship only engaged 3.5% of donors (ANZDATA Registry, 2008b). The opportunity for a Mäori client to have matched tissue and get kidney transplants is relatively low. The reason for low Mäori organ donorship is related to the influence of cultural beliefs and traditional attitudes (Ashton & Marshall, 2007). Mäori peoples' reluctance to openly discuss the sensitive issue about organ donation may relate to a lack of knowledge and maybe fear (Paterson, 2006).

The increasing waiting times for deceased-donor kidneys have altered people's focus to living kidney donors. Kidneys retrieved from a living donor have a better long-term survival than kidneys from a deceased donor (Nanovic & Kaplan, 2009). A national approach to transplantation for Mäori people should include facilitating discussions around kidney donation in the local community. Donor advocacy for kidney transplants may offer an opportunity for people with ESRD to have a new life. Advantages of living kidney donation include reduced waiting time, prompt organ function, excellent allograft quality, and less kidney injury from cold storage. One considerable disadvantage for a donor is to accept the risks of major surgical intervention for no health gain (Thomas, Smith, & Jeffrey, 2002; Morrissey & Monaco, 2006).

Maintenance of the health and safety of the donor should be the transplant team's foremost concern. The risks of complications to the live kidney donor should be minimized (Morrissey & Monaco, 2006). However, the ethical issues around the

donorship should be considered, for example future risk of CKD and other complications such as hypertension, obesity or the development of nephrolithiasis. A donor advocate should have a sophisticated medical understanding about the risks involved in kidney donation. There is no clear model for such a donor advocacy program currently available (Reese, Caplan, Kesselheim, & Bloom, 2006).

Recommendation 5: CKD MANAGEMENT FOR MÄORI SHOULD CONSIDER INDIVIDUALS, FAMILIES AND COMMUNITIES HOLISTICALLY

The findings from this study support the notion that the best nursing practice for Mäori is to consider individuals, families, and communities holistically. Kaupapa Mäori (Mäori practices, strategies) provides Mäori with culturally appropriate and acceptable health services that take account of their spiritual and cooperative direction (Panelli & Tipa, 2007).

Discussion

Kaupapa Mäori offers a respectful, and in a collaborative manner facilitates nurses and other health professionals to positively improve the health of Mäori (Barton & Wilson, 2008). Mäori health is grounded in Mäori ways of knowing and seeing the world, it emphasises the value of traditional belief systems. Durie presented the Te Whare Tapa Wha model of the four walls of a whare (house), where each wall represents a dimension of Mäori health: taha wairua (spiritual), taha tinana (physical), taha whänau (extended family), and taha hinengaro (mental, intellect) (1985, p.483) (See Appendix Seven He Korowai Oranga Mäori Health Strategy). The strength and health of each family (whänau) is the fundamental building blocks for a strong community. The attributes of Te Whare Tapa Wha model affirm a positive Mäori identity in a context where the Mäori values, beliefs and practices are respected. It provides a holistic view congruent with nursing values and actions in all areas of health (spiritual, physical, and mental and whänau) (Rochford, 2004). This model removes the barriers from services and forwards the delivery of health information to foster Mäori perspectives of health to Mäori communities such as schools, Marae, and whänau (Barton & Wilson, 2008).

Mäori models of intervention assist practitioners to negotiate the tensions which are inherent between these approaches to deliver more effective services. Mäori health care providers should cooperate with Primary Health Organizations (PHOs) to ensure the undertaking of population health initiatives together with client-centred primary care. Thus thereby broaden range of providers and skills used in integrated primary care delivery, improving access to services for disadvantaged populations, and ensuring community participation in health care service.

Health providers need to identify service capacity such as workforce supply, and service gaps according to local health requirements (Barton & Wilson, 2008; He Korowai Oranga, 2001). Health providers' attitudes and behaviours play a significant role in improving Mäori clients' use of healthcare services (Jansen, Bacal, & Crengle, 2009). The Treaty of Waitangi principles (partnership, participation and protection) are central to improving Mäori health in order to minimize disparities in health status between Mäori and non-Mäori (Ministry of Health, 2004b). The Ministry of Health and NDHB play an important role in evaluating the performance of Mäori health promotion. NDHB should provide reliability guidelines and standards in mainstream services to ensure that appropriate services are distributed efficiently (He Korowai Oranga, 2001).

Outcomes

After the research findings were presented to the members of the Mäori Health Service Directorate in March 2009, an internal meeting to discuss the urgent need for education in Mäori communities took place. As of April 2009 there are now two new positions on offer within the Mäori health services as Clinical Specialist and Education Co-ordinator as a result of this research.

Conclusion

This study has focused exclusively on the experience of ESRD for Mäori clients in one specific satellite renal unit in Northland. Although this study has already had an impact on the provision of health care in Northland with the creation of new positions being developed there are still concerns to be addressed leaving major room for improvement and possible future research opportunities. Renal disease is an increasing problem with

the New Zealand population ageing and the impact of poor lifestyle choices. The best hope for reducing the impact of ESRD lies in prevention by targeting high risk populations through education. Early detection and intervention of CKD should be a priority in primary health care, especially in Mäori communities in order to slow CKD progression and avoid associated complications. Appropriate management of earlier stages of CKD is the best the way to reduce the prevalence and incidence of ESRD, and to reduce this endemic disease in New Zealand. A health care provider should approach people appropriately, in a culturally sensitive manner to develop shared sets of beliefs, values, and attitudes to support the prevention of CKD. Health promotion is the process of supporting people to take responsibility and increase control over the factors that influence their well-being and quality of life.

More research to evaluate interventions that contribute to the improvement of Mäori health outcomes is required. Future research opportunities could include the effects of education and preventive measures on the development of CKD in Mäori communities; finding out what are the best cost-effective measures for nephroprotection; and what is 'best practice' in the promotion of Mäori quality of life.

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Appendix One--- Ethics Committee Approval

Health and Disability Ethics Committees
email: cheh_chua@moh.govt.nz

Northern X Regional Ethics Committee
Ministry of Health
3rd Floor, Unisys Building
650 Great South Road, Penrose
Private Bag 92 522
Wellesley Street, Auckland
Phone (09) 580 9105
Fax (09) 580 9001

7 October 2008

Ms Li-Chin Shih
1333 Hukerenui Road
RD2 Hikurangi
Whangarei

Dear Li-Chin

NTX/08/98/EXP	**Impact on Maori clients and their family/whanau who have end stage renal fallure and receive haemodialysis, and who live in rural areas of Northland: PIS/Cons V#2, 7/10/08**
Principal Investigator:	Ms Li-Chin Shih. Northland DHB
Supervisor:	Dr Michelle Honey, University of Auckland

Thank you for your application received 26 September 2008. The above study has been given ethical approval by the Deputy Chairperson of the **Northern X Regional** Ethics Committee under delegated authority.

Approved Documents
The following documents are received and reviewed:

- Participant Information Sheet/Consent Form

They are approved, **subject to the recommended changes below**:

- Please insert the statement "This study has received ethical approval from the Northern X Regional Ethics Committee" as a last paragraph on the Information Sheet
- Insert as a footer the version number and date, ie. **version 2, 7/10/2008** on the Information Sheet and Consent Form.
- The Consent Form needs to include in the first paragraph of "I have read the Participant Information Sheet" the date, ie 7/10/2008.

Please see the highlighted changes in the copies attached.

Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Progress Reports
The study is approved until 31 October 2009. However, the Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project on **7 October 2009**. The report form is available on *http://www.ethicscommittees.health.govt.nz* (progress reports). Please note that failure to provide a progress report may result in the withdrawal of ethical approval.

A final report is also required at the conclusion of the study.

Amendments
It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

Cheh Chua (Ms)
Assistant Administrator
Northern X Regional Ethics Committee

cc: Northland DHB (GM, J E Holden)

Appendix Two--- Consent Form

THE UNIVERSITY OF AUCKLAND
NEW ZEALAND

FACULTY OF MEDICAL AND HEALTH SCIENCES School of Nursing

Consent Form

Research Title: Exploring what is it like having dialysis
Researcher: Li-Chin Shih

I have read the "Participant Information Sheet (07/10/2008) and agree to participate in this study. I have had opportunity to ask questions about the study and I am satisfied with the answers that have been given.
I understood that participation in the research study is voluntary. I understand I am free to withdraw from the research study at any time. I understand that refusal or withdrawal from the study will involve no penalty.
I understand that information gathered during participation in the research will be treated confidentially.
I understand that my interview will be recorded and later transcribed for reading and analysis.
I understanding that all information gathered in the course of the study will be stored securely and destroyed six years after completion of the research study.
I understand that I will not be identified in the research report, though brief exacts of words may be used to illustrate research findings.

I agree to take part in this research.
Signed……

Name …….

Date……..
This study has received ethical approval from the Northern Regional Ethics Committee and Northland District health Board Mäori Ethics Committee
Consent Form Vision 2 , 07/10/2008.

Appendix Three --- Locality Organisation Approval

LOCALITY ASSESSMENT – by Locality Organisation

Refer to pp10 -12 of the Guidelines for Completion of the National Application Form for ethical approval of a research project

Ref No. 2008-11

Full Project Title :	Impact on Maori clients and their family/whanau who have end stage renal failure and receive haemodialysis, and who live in rural areas of Northland
Short Project Title :	Impact on Maori clients and their family/whanau who have end stage renal failure and receive haemodialysis, and who live in rural areas of Northland
Brief outline of study :	This qualitative study, with a small purposive sample of 5-8 Maori clients and their family/whanau, is designed to explore their experiences of having haemodialysis as an outpatient while living in a rural area of Northland. By understanding their experiences it may be possible to identify the key elements involved in the provision of better healthcare for haemodialysis clients and therefore improve the quality of care to renal clients. It is proposed that all clients attending the satellite Renal Unit at Bay of Islands Hospital, who meet the study inclusion criteria, will be invited to participate in the study. The participants, after giving informed consent, will participate in a semi-structured interview at a location to suit them, such as their home. The interview will be taped and transcribed, and analysed.
Principal Investigator :	Li-Chin Shih
Contact details :	1333 Hukerenui Road, RD2, Hikurangi, Northland Tel : Bay of Islands Hospital – extn 5895 Tel : Home 094339983 Email : leejack@slingshot.co.nz
Local Investigators :	Li-Chin Shih
Contact details :	1333 Hukerenui Road, RD2, Hikurangi, Northland Tel : Bay of Islands Hospital – extn 5895 Tel : Home 094339983 Email : leejack@slingshot.co.nz

Locality Organisation Signoff

1. **Suitability of local researcher :**

   Suitable but requires support from a Takawaenga or Kaumatua on home visits.

2. **Suitability of the local research environment :**

   DHB cultural support services can support.

3. **What are the specific issues relating to the local community?**

   This addresses a major issue for Northland Maori for whom it should be helpful.

4. **Information Sheet / Consent Form contact details :**

   Mary-Claire Taffs
   Health and Disability Advocacy Service
   PO Box 1607
   Whangarei

I understand that I may withdraw locality approval if any significant local concerns arise.
I agree to advise the principal investigator and then the relevant ethics committees should this occur.

Signature :  **Date :** 14.11.08

Name : Dr Gloria Johnson **Position** : Chief Medical Advisor

Contact details : Northland DHB
PO Box 742
Whangarei
Tel 09 4304101, extn 8802
Email gloria.johnson@northlanddhb.org.nz

Appendix Four --- Problem & Symptoms of CKD

Problem	Manifestations
Fluid & Electrolyte Imbalance	• Pulmonary oedema, weight gain, hypertension, pleural effusion. • Cough, dyspnoea, periorbital oedema, peripheral oedema, congestive heart failure. • High or low levels of serum sodium, potassium, calcium, phosphate, magnesium and associated complications.
Uraemia	• Headache, drowsiness, confusion, memory loss, insomnia, apathy, sleep disturbances. • Paresthesias, muscle twitching, restless leg syndrome, gait abnormalities, hearing loss, decreased cough reflex. • Pericarditis, cardiac arrhythmia, cardiac tamponade. • Increased susceptibility to infection. • Increased bleeding tendency, epistaxis, ecchymosis. • Pruritus, dry skin, skin colour changes, pallor. • Nausea, vomiting, constipation, anorexia, metallic taste in mouth, gingival hyperplasia, gastritis, diarrhoea.
Anaemia	• Fatigue, pallor, decreased appetite, cold intolerance, hypotension, reduced exercise tolerance. • Shortness of breath, hypoxia. • Tachycardia, increased angina, left ventricular hypertrophy, heart failure.
Cardiovascular Disease	• Hypertension, ischaemic heart disease, congestive heart failure, atherosclerosis, cardiac arrthymias, cardiomyopathy, heart failure, cardiac arrest.
Lipid Disorders	• Cardiovascular disease, elevated triglyceride levels, elevated cholesterol levels.
Acid Base Imbalance	• Metabolic acidosis or alkalosis, confusion, nausea, vomiting, hyperkalaemia, hyperventilation, convulsion, cardiac arrest.
Calcium & Phosphate Imbalance & Bone Disease	• Bone pain, pathological fractures, metastatic calcification. • Hyperphosphatemia, secondary hyperparathyroidism, renal osteodystrophy.
Malnutrition	• Weight loss, anorexia, low serum albumin, muscle wasting, poor healing, susceptible to infections.
Endocrine Disorders	• Hypothyroidism, impotence, dysmenorrhoea, amenorrhoea, decreased libido. • Glucose intolerance, hypertension, hyperparathyroidism.
Psychosocial problems	• Depression. • Loss of self esteem. • Job loss / reduced employment opportunities. • Loss of income. • Change in family dynamics / community standing.

McLaughlin, K. (2004, p.8). Retrieved from researcharchive.vuw.ac.nz/bitstream/handle/10063/51/thesis.pdf;jsessionid

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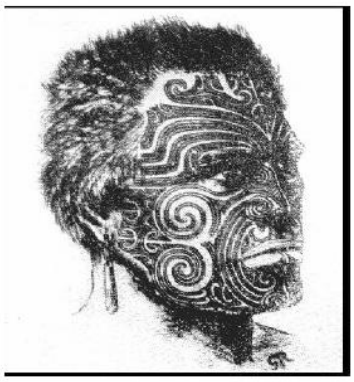
Appendix Five--- Impact on Mäori presentation

Impact on Maori clients & whanau having dialysis

Rural areas of Northland



15 April 2009

Qualitative study

- Consented by Northland Regional Ethics Committee & NDHB Maori Health Directorate Ethics Committee
- Purposive sample from satellite unit
- Participants 7 (12/18 consented)
- Age 46-77
- Interview at client's home

Semi-structured interview

- Heideggerian hermeneutical analysis
- Data analysis was styled on Diekelmann, Allen &Tanner (1989) seven stages
- Identify the themes
- reviewed and re-examined the data, the interpretations
- discussions with participants
- validation of the finding

Findings

- Four themes were revealed:
- 1. Facing fear
- 2. Stress from HD
- 3. Learning, adjusting and changing attitude
- 4. Individual needs.

Facing Fear

- **A. Lack of information: lack of education and/or poor understanding**
- **B. Late referral:** 26% of dialysis clients had less than 3 months referred time prior to commencing dialysis (ANZDATA Registry, 2003).
- Worldwide 25% to 50% of clients on renal replacement therapy (RRT) are referred late (4-6 month) to a nephrologist (Wavamunno & Harris, 2005) .
- **Late referral** related to poor outcome, higher risk of death and especially higher mortality in elderly

Stress from HD

- **A. Barriers to health management**
  (Financial barriers and cultural barriers)
- **B. Time consuming (travelling):**
  (therapeutic regimes and travelling)
- **C. Social isolation**
- **D. Therapeutic regimes adherence,**
- **E. Being on a waiting list for transplant.**

Learning, adjusting and changing attitude

- **A lesson is repeated until learnt.**

- **Individual needs:**
- **A. Family/ whanau influence**
- **B. Clients' perspectives**

Discussion

- Education
- Early detection and early intervention
- Satellite unit requirement
- Advocate for deceased and living kidney donor.

Appendix Six--- Action Plan of CKD

Stage	Description	GFR (mL/min/1.73m2)	Action
	At increased risk	≥90 (with CKD risk factors)	Screening CKD risk reduction
1.	Kidney damage with normal or ↑ GFR	≥90	Diagnosis and treatment Treatment of comorbid conditions, slowing progression, CVD risk reduction
2.	Kidney damage with mild ↓ GFR	60-89	Estimating progression
3.	Moderate ↓ GFR	30-59	Evaluating and treating complications
4.	Severe ↓ GFR	15-29	Preparation for renal replacement therapy
5.	Kidney Failure	<15 (or dialysis)	Renal replacement therapy (if uremia present)

retrieved from (National Kidney Foundation, 2002c)
*www.**kidney**.org/Professionals/**KDOQI**/guidelines_ckd/p1_exec.htm*.

Appendix Seven--- He Korowai Oranga Mäori Health Strategy (Te Whare Tapa Wha Model)

Objective: To foster whänau development and health		
Tapa Wha Dimensions	Pre-requisites or desired conditions	Strategies
Whänau (family)	Participation in society Relationship development Leadership development	Mäori representation and participation in decision-making Capacity building plans Health Care Provider development strategies Education programmes for health providers, school, Marae and whänau
Tinana (physical)	Services organised to meet the needs of Whänau Removing barriers to services	Inclusion of whänau needs in NDHB health needs assessment methodologies. Co-ordination and integration of health services Quality service framework Marae-based services
Wairua (spiritual)	Access to Te Ao Mäori Understanding of Mäori needs, values and beliefs Tikanga & Te Reo Mäori	Mäori models of care Kaupapa Mäori Health promotion programmes
Hinengaro (mental, intellect)	Developing an inclusive society Valuing diversity Strengths-based approach	CKD programmes & services Social and health policy Intersectorial initiatives

Retrieved from *www.nurse.org.nz/submissions/subm_he_korowai.htm*

Glossary

Adenosine triphosphate (**ATP**): ATP is a multifunctional nucleotide, and plays as a coenzyme for the intracellular energy transfer (Campbell, Williamson, & Heyden, 2006).

Anaemia: Reduction below normal of the number of erythrocytes, quantity of hemoglobin, or the volume of packed red cells in the blood. The oxygen-carrying capacity of the blood is decreased (Anderson, 1998).

Automated peritoneal dialysis (APD): A machine called a cycler change the dialysate solution during the night. Clients have to be attached to the machine for 8-10 hours, usually while clients are asleep (National Kidney Foundation Singapore, 2007).

Chronic kidney disease (CKD): It is a progressive loss of kidney function over a period time (more than three months or years), also called chronic renal disease (CRD) (Kennedy & Rosa, 2009).

Diabetic Nephropathy (DN): It is a progressive kidney disease caused by angiopathy of capillaries in the kidney glomeruli. It is characterized by nephrotic syndrome and diffuse glomerulosclerosis. It is due to longstanding diabetes mellitus, and is a prime cause for dialysis in New Zealand (Hauck, 2007).

Dialyser: An apparatus of kidney machine that acts like a filter to remove waste products and excess water from the blood (The Kidney Foundation of Canada, 2008).

End stage renal disease (ESRD): End-stage renal disease is the complete failure of the kidneys function. The kidneys can no longer remove metabolic wastes, urine, and regulate electrolytes. Also called end stage renal failure (ESRF) (Tolkoff-Rubin, 2007).

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Erythropoietin (EPO): A hormone produced by the kidney that promotes the formation of red blood cells in the bone marrow when the oxygen level is low in the kidney (Elliott, 2008).

Glomerular filtration rate (GFR): Describes the flow rate of filtered fluid through the kidney. It is the best test to measure the level of kidney function and determine a stage of kidney disease. Cockcroft-Gault formula GFR = (140-age) x (Wt in kg) x (0.85 if female) / (72 x Cr) (ANZDATA Registry, 2003).

Haemodialysis (HD): Haemodialysis is a treatment of 'cleaning the blood'. Blood is circulated through a machine passes of the membrane (dialyser) to remove waste products and excess fluid from body (The Kidney Foundation of Canada, 2008).

Insulin: It is a hormone that is needed to convert sugar (glucose), starches and other food into energy needed for daily life (American Diabetes Association, 2009).

Iwi: Tribe or nation state **(**New Plymouth District Council, n.d.).

Kaupapa Mäori: The principle of Kaupapa Mäori acknowledges teaching and learning practices that are inherent and unique to Māori, allowing Māori to control their own culture, aspirations and destiny (Rangahau, n.d.).

Mäori: It is the indigenous people of Aotearoa New Zealand **(**New Plymouth District Council, n.d.).

Marae: The meeting place for the Mäori community. The Marae is the focal point for community sentiment (New Plymouth District Council, n.d.).

Nephritic syndrome: The main symptoms are proteinuria and haematuria (blood in the urine). It is an acute inflammation of the glomeruli, leading to salt and water retention (causing hypertension) and a reduction in the kidney function. Other symptoms include hypertension, uraemia, azotemia and low urine output (oliguria). Two classic diagnoses are post-streptococcal glomerulonephritis and crescentic progressive glomerulonephritis (rapidly progressive glomerulonephritis) (Merck Maunal Online Medical Library, n.d.).

Nephrotic syndrome: It is a nonspecific disorder in which the kidneys are damaged, causing them to leak large amounts of protein into the urine, but no hematuria. Primary causes of nephrotic syndrome include: diabetes, minimal change disease (MCD), focal segmental glomerulosclerosis (FSGS) and membranous nephropathy (MN) (Mayo Clinic, 2007).

Non-steroidal anti-inflammatory drugs (NSAIDs): Drugs with analgesic, antipyretic and anti-inflammatory effects (reducing inflammation). The term 'non-steroidal' is used to distinguish these drugs from steroids, which have a similar eicosanoid-depressing, anti-inflammatory action. This group of drugs are aspirin, ibuprofen, voltaren (diclofenac) and naproxen (Anderson, 1998).

Peritoneal Dialysis (PD): A dialysis fluid is entered into the patient's abdominal cavity, which is covered by a thin membrane (peritoneum); containing many small blood vessels. The peritoneum works as a dialysis filter. The waste products move from the blood into the dialysis fluid (The Kidney Foundation of Canada, 2008).

Renal replacement therapy (RRT): RRT is a term used to encompass life-supporting treatments for renal failure. It includes**:** hemodialysis, peritoneal dialysis, hemofiltration and renal transplantation (Merck Maunal OnlineMedical Library, n.d.).

Stage 3 CKD: Moderate reduction in GFR (30-59 mL/min/1.73 m^2) (National Kidney Foundation, 2003).

Stage 4 CKD: Severe reduction in GFR (15-29 mL/min/1.73 m^2). Preparation for renal replacement therapy (National Kidney Foundation, 2003).

Stage 5 CKD: Established kidney failure (GFR <15 mL/min/1.73 m2) or permanent renal replacement therapy (RRT). It is also called end stage renal disease (ESRD) or end stage renal failure (ESRF) (National Kidney Foundation, 2003)

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Tangata whenua: 'People of the land' and is the common reference to the indigenous people of an area **(**New Plymouth District Council, n.d.).

Treaty of Waitangi: The treaty was a document signed between the British Crown and Mäori. The treaty laid the foundation for the rights and obligations of both groups to live together in New Zealand (Nursing Council of New Zealand, 2005).

Type I diabetes (T1D): It is a form of diabetes mellitus. Type 1 diabetes is an autoimmune disease that results in destruction of insulin-producing beta cells of the pancreas. In type 1 diabetes the body does not produce insulin. It is usually diagnosed in children and young adults, and was previously known as juvenile diabetes. It is called insulin-dependent diabetes mellitus (IDDM) (American Diabetes Association, 2009).

Type II diabetes (T2D): It is called non-insulin-dependent diabetes mellitus (NIDDM) or adult-onset diabetes. That is a disorder characterized by high blood glucose in the context of insulin resistance and relative insulin deficiency. Traditionally considered a disease of adults, type II diabetes is increasingly diagnosed in children in parallel to rising obesity rates (American Diabetes Association, 2009).

Whänau: Family groups of Mäori society, includes grandparents and great grandparents and extended family through marriage **(**New Plymouth District Council, n.d.).