

Perspectives of Koori men accessing dialysis treatment

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Declaration

This is to certify that the thesis comprises only my original work towards a Master of Social Health (by research), due acknowledgement has been made in the text to all other material used and the thesis is less than 20,000 words in length, exclusive of pictures, tables and references.

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Date

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List of Abbreviations

ACCHO	Aboriginal Community Controlled Health Organisation
ACCHS	Aboriginal Community Controlled Health Services
CEO	Chief Executive Officer
ESRD	End-Stage Renal Disease
HEAG	Human Ethical Advisory Group
HREC	Human Research Ethics Committee
GP	General Practitioner
VACCHO	Victorian Aboriginal Community Controlled Organisation
VAHS	Victorian Aboriginal Health Service

“As Aborigines began to sicken physically and psychologically, they were hit by the full blight of the alien way of thinking. They were hit by the intolerance and uncomprehending barbarism of a people intent only on progress in material terms, a people who never credited that there could be cathedrals of the spirit as well as of stone...It is my belief that Aboriginal Australia underwent a rape of the soul so profound that the blight continues in the minds of most blacks today” (Kevin Gilbert)

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Perspectives of Koori men accessing dialysis treatment.

Abstract

Background: End-stage renal disease (ESRD) is a major concern for Australian Indigenous peoples. Australian Indigenous people are a minority group most at risk of contracting ESRD or kidney failure for a variety of reasons that are discussed in this thesis. This project examines the perspectives of Koori men accessing dialysis treatment. The areas of discussion include symptoms of renal failure, responses to diagnosis of kidney disease, understandings of kidney disease, responses to dialysis treatment, as well as access to service providers that range from Aboriginal community controlled health sectors to other health services outside of the community controlled sector and finally, family support.

The study aims to document Koori men's perspectives on access to dialysis treatment, to empower Koori men by giving them a channel to voice their views on their access to dialysis treatment, and to provide feedback for the administration of a user-friendly health care system for Koori men, by highlighting the views of Koori men currently being treated for ESRD.

The key questions of this research are;-

- What are the perspectives of Koori Men regarding the access to dialysis treatment?
- What are the Koori perspectives of factors affecting the uptake of health care services by Koori men?

Methods

Four Koori men aged 18 and over were interviewed regarding their perspectives of accessing dialysis treatment. The men were receiving or about to receive dialysis treatment for End-Stage Renal Disease. They were all recruited through the Victorian Aboriginal Health Service with the interviews being semi-structured. Data were collected by recording interviews (with informed consent), recording research memos and maintaining a journal to record theoretical ideas and analytical insights. Interviews were analysed using thematic analysis

Results

The main themes found in this study were, that Koori men's experience of accessing dialysis and impending dialysis was strong with emotional and historical resonances. The study, although relatively small, provided some important insights into the experiences and perspectives of Koori men accessing dialysis treatment. All four men reported powerful emotional responses, including shock, denial, grief, anger and fear. All four men reported fear as a driving emotion to being diagnosed with kidney disease and fear was a predominant response to engaging with dialysis treatment. Fear also stemmed from historical stories shared within the families regarding treatment of Aboriginal members by what is perceived as the 'White' health system. Other themes that emerged from the interviews were the importance of material and social support from the Victorian Aboriginal Health Service, the generally supportive nature of dialysis services at hospitals (particularly from nurses but less so from doctors), and the importance of family support.

Conclusions

Support from staff at VAHS was acknowledged as superior to that of mainstream hospitals and this supports a more user-friendly health service for Koori men, which is in line with cultural protocol.

Dissemination of findings

The study findings will be disseminated in community based organizations Victorian Aboriginal Health Service Co-operative (VAHS) and the Victorian Aboriginal Community Controlled Health Organisation (VACCHO).

Chapter 1. Introduction

1.1 Social determinants of Aboriginal Health

Social and economic factors are known to determine the health status of a population and this is a concept that has been evident since the nineteenth century (Anderson et al, 2007). The social and economic factors that determine health status have been termed 'social determinants.' Moreover, these social determinants describe 'behavioural influences on health' (Anderson et al, 2007) as well as the physical and social environment. In the following sections I will discuss social determinants of Indigenous health. This will be done by giving an overview of circumstances that begin with first contact between Indigenous Australians and Europeans in 1788. I will then discuss dispossession, highlighting the social determinants of Indigenous health throughout this section. The discussion will then move to government policy, where I will explain how assimilation as a racist policy has had a profound affect on Indigenous peoples and their health. The next section will discuss the current social determinants of Indigenous health, such as living, working and lifestyle. I will conclude by arguing that the current situation of Indigenous social derminants is directly related to colonisation, dispossession and government policies of removal, separation and assimilation.

1.2 Dispossession

The fact that there were no treaties made out with the traditional owners by the British upon their arrival in Australia suggests they had little or no regard of Indigenous ownership and rights to land, oceans, rivers and lakes. This lack of recognition of

Indigenous peoples' traditional ties to land by the British invaders amounted to nothing less than spiritual and cultural genocide. Soon after the invasion in 1788, Europeans 'annexed' land for their own use and as Aboriginal people were considered in the eyes of many Europeans to be 'little more than vermin' (Reid, 1991), the process of dispossession took place. Aboriginal people were simply either killed or removed from their land and sent to 'reserves and settlements' (Reid, 1991).

This is not to say that Aboriginal people did not resist Europeans invading their country. Continued attacks were carried out by Aborigines on individuals and small groups of Europeans and whilst these attacks were interpreted by Europeans as acts of criminal tendencies, they were nevertheless still acts of resistance (Reynolds, 1973). The view that Aboriginal people were committing crimes against the Europeans was due to differing world views. From the European perspective Indigenous people did not labor on land and as such they felt that they had no rights to land. Therefore, if Indigenous peoples did not have any right to land the belief was that they (Europeans) were protecting their own property and would call on colonial administrators to punish Indigenous people (Rowley, 1970).

Land theft and genocide would take place periodically across Australia, wherever 'settlement' took place. Initial contact brought with it all of the destructive forces mentioned previously and continued to decimate Indigenous peoples. For example, in Western Australia during the colonial period, Indigenous societies felt the full brunt of invasion, due to the fact that they were not recognised as 'sovereign tribes'. Thus

allowing for the British to declare all the surrounding area Crown land and disregarding the Aborigines' right of possession (Biskup, 1973).

Change in diet brought about by introduced foods such as sugar and flour and a more sedentary lifestyle also contributed to a rapid change of health in Indigenous societies at this time (Reid, 1991). The introduction of alcohol along with other ills radically changed the social determinants of Indigenous health (Reid, 1991). Finally, research suggests introduced diseases such as influenza, small pox, venereal diseases, whooping cough and measles had a profound affect on Indigenous health, causing “depopulation and social disruption throughout Indigenous Australia” (Carson, 2007).

1.3 Government policies

Once colonisation had taken root in what is now known as New South Wales, Indigenous peoples were subjugated by continued racist policies and procedures, first from state and, eventually, federal governments. Over short periods of time the British invaders would spread out over the continent bringing rapid destructive changes to Indigenous societies. In the following paragraphs I will discuss initial removal of Indigenous peoples from land annexed by the British, the state Protectionist Acts, before ending the discussion on a section of the assimilation policy.

Aboriginal Protection Act

The brutality and violence of colonialism had devastated Indigenous populations and as such a new era of 'protecting' Aboriginal people was ushered in. Queensland was the first state to move from the 'killing times' of colonialism to a period of systematic regulation and bureaucratic colonisation in 1897. The new legislation from the Queensland government came under the Aboriginal Protection and the Restriction of Opium Act and was brought about in preparation of Federation (Bavivanua-Mar, 2005). Other states would soon follow suit and legislate their own Aboriginal Protection Acts. South Australia for example, and under the 'universal belief' that Indigenous Australians were a 'dying race', introduced the 1911 Aborigines Act and as such protectionist era was entrenched nationally.

Under the Queensland Aboriginal Protection and the Restriction of Opium Act, Indigenous Australians were to become 'state wards' even though they were not yet recognised as Australian citizens in their own country (Smith, 2008). In Queensland the aim of this act was to prevent the continuation of past errors and preserve the Indigenous race from extinction (Bavivanua-Mar, 2005). However, to achieve this Indigenous peoples would have to come under total control of government regulation. This legislation in effect gave state government's representatives total authority and control over Indigenous people as individuals and allocated them the rights to 'remove and keep' Indigenous peoples in any district and reserves and missions against their will. It also enabled the protectors of Aborigines control of Indigenous people's wages, control over Indigenous marriages and the power to exempt Indigenous people from its provision

(Smith, 2008). Moreover, under the key terms of protection and control, the chief protector was considered the legal guardian of all half-caste Indigenous children irrespective of whether they had living parents or relatives (Foster, 2000).

In Victoria, The governing body over Koories was The Central Board for the Protection of Aborigines. The Board was established to regulate over all facets of Koori life, including forcing Koories from their homelands, attempting to control who they married, what they ate, worked and learnt (Vickery, 2005). After the Kulin nation had been forced off a block of land called Acheron in a somewhat dubious land swap deal negotiated by a failed farmer by the name of Stephen Jones and the Board, they (Koories) successfully negotiated another small piece of land from the Central Board for Protection of Aborigines called Coranderrk reserve. The history of Coranderrk is one of ultimate failure and signals the authority the Central Board for Protection of Aborigines had over Koori lives (Perkins, 2008).

The outcomes of the 'protection era' for Indigenous peoples were varied and damaging on many levels. The first and most significant outcome was that it re-shaped Indigenous identity by way of separating 'kin from country', causing massive disruption to Indigenous law by interrupting promised marriages, which also had the dual effect of destroying culture by severing ties between countrymen (Smith, 2008). Moreover, life at the missions for many Indigenous people had other destructive impacts upon them and their health. Some of the destructive impacts were caused by unhealthy diet, sedentary lifestyle, unhygienic living standards, as well as overcrowding and the admission of lead

based medicine (Carson, 2007). It can be argued that the missionaries did on the one hand attempt to save Indigenous peoples from ongoing colonial violence by keeping them away from the frontier, as well as trying to prevent the poor health of Indigenous peoples by supplying them with food and clothing as well as some medical techniques. However, it could also be argued that the missionaries were ignorant, paternalistic and hostile of traditional culture, as the missionaries viewed Indigenous people as heathens that needed to be saved (Carson, 2007).

Assimilation policy

In 1937 the Federal government made the declaration that Indigenous Australians that were not 'full blood' were to be absorbed into the wider community (Brown, 1999). The Assimilation policy had commenced. The policy was formulated to only include half caste and fair skinned Aboriginal people in an attempt to merge Indigenous Australians within the wider Australian community (Anderson et al, 2007). The theory of those who endorsed assimilation was that Aboriginal people would adopt the ways of the colonisers' life and dislocate from their own culture (Anderson et al, 2007). This policy was performed, in effect, by committing acts of genocide including cultural genocide and is recognised today as being an extremely detrimental policy to Indigenous peoples for reasons that are explained below.

Assimilation as a policy had two distinct forms of intergration, the first being ‘biological absorption.’ This aim of this function was to remove all Aboriginal physical traits. Biological absorption was of course the ‘breeding out’ of Aboriginal people. This form of genocide was keenly supported by authorities such as A.O. Neville in Western Australia, Cecil Cook in the Northern Territory and other more prominent advocates of intergration such as the famous Sydney anthropologist A. P. Elkin (Chesterman, 2004).

The second form of integration, social or cultural integration, would come from half caste Aboriginal people blending into the wider community and no longer practising their culture (Chesterman, 2004). The theory behind this policy was founded on the federal government’s ignorant assumption that by asborbing Aboriginal people into the wider community the Aboriginal ‘problem’ would disappear, because Aboriginal people would eventually lose their cultural links and identity (Brown, 1999).

Assimilation was also utilised as a policy to exclude and disperse Aboriginal people - removing Indigenous peoples onto reserves and missions was an extremely successful way of excluding and marginalising them (Anderson et al, 2007). The removal of Indigenous peoples from country would be replicated over time within Australia.

Removal of half caste children would climax to a period in what is now termed ‘the stolen generations’ (Reid, 1991). Such policies and procedures gave government the power to systematically outcast, forcefully remove, and entrench Indigenous people

within the welfare system and have successfully entwined Indigenous peoples as a socio-economically disadvantaged, marginalised group (Reid, 1991). The introduction of the Assimilation policy brought with it a great deal of pain and disempowerment to Indigenous peoples and allowed for the government of the day to continue to wreak havoc on Indigenous peoples through the systematic break down of culture and tradition, which in turn brought with it identity issues such as denying Aboriginality and restricting movement, which were strategies that flowed on from the protectionist era. The disparities of colonisation along with past policies such as the Aboriginal Protection Act and the Assimilation Policy have inflicted Indigenous peoples in such a dramatic way that has transended through time and has and continues to have devastating impacts on the health and wellbeing of Indigenous people today (Clarke, 1999).

1.4 Current social determinants

Today we continue to see the remarkably poor health statistics of Indigenous Australians that can be directly attributed to dispossession, marginalisation, and dependancy on government and welfare services (Reid, 1991). The social determinants of poor health that Indigenous peoples face in Australia today are not much different to past generations of Indigenous Australians. We still see today the more frequently measured combination of poor employment, income and educational levels that have received most coverage in regards to social determinants. However, other social factors that influence health range from housing, food and social support as well as transport (SCRGSP, 2005). In addition, determinants of health specific to Indigenous populations have been identified, including for Victorian Aboriginal populations. A study in the Goulburn-Murray region highlights

five major themes that arose from questions in relation to social determinants of health and what it means to Koori people. The themes that were prevalent related to history, relationships with mainstream, threats to wellbeing, connectedness and sense of control (Reilly, 2008).

1.5 Introduction to Koori History and Health

Koori is the word to describe the Indigenous peoples from the south east of Australia. Prior to invasion, there were around 38 Koori language groups having up to 150 dialects within the Victorian region. It was not uncommon for Koori people to speak a variety of languages as they traversed the countryside. The social structure of societies was based upon small clan groups that,

“may have consisted of related families; or the family of a particular man, his wife (or wives) and children. The clan was never particularly large-perhaps about a hundred individuals” (Anderson, p. 1998, p, 2).

Smaller clans would merge into bigger groups called ‘tribes’. Each of the smaller clans ‘belonged to a particular area of land’ (Anderson, 1998) and would utilise resources from that particular area. Semi-nomadic practice was the norm at the time due to specific ecological and seasonal sustainability of food supplies in the area. Koori peoples lived a fairly sustainable life with a healthy diet and plenty of exercise, enriched with a holistic spiritual life. It is evident in documents written at the time of early contact by non-Indigenous historians that Koori people were reported to be in good health, slim and

athletic. Although there is no real way of understanding the types of health problems Koori peoples faced prior to pre-contact, infectious diseases such as influenza, measles, small pox and many others were unknown at the time and killed large numbers of Aboriginal people in the early periods of colonization (Anderson, 1998).

1.6 Health Statistics and the Emerging Epidemic of Renal Disease amongst Indigenous men

Current literature suggests that Indigenous men's health is of grave concern to the nation, and whilst Australia has one of the best health care systems in the world, Indigenous life expectancy is still at substandard levels. "At the national level for 200-2007, life expectancy at birth of Indigenous males is estimated to be 67.2 years, 11.5 years less than life expectancy for non-indigenous males (78.7 years)" (ABS, 2008).

Indigenous Australians are facing an epidemic of chronic disease particularly in remote areas, and renal failure or otherwise known as End Stage-Renal Disease (ESRD) is an important component' (Hoy et al, 2005). Although the incidence of ESRD among Indigenous men in Victoria is lower than in other States of Australia, the highest admissions into hospital amongst Koori men aged between fifteen to forty four years includes mental disorders, renal dialysis, and admissions for drug and alcohol incidences and injuries. Older Koori adults, both men and women, aged between forty five to sixty four years are most often being admitted for renal dialysis, circulatory and respiratory diseases as well as diabetes (Koori Human Services Unit, 2008).

The figure below shows age-specific prevalence of renal disease cases and the incidence of hospitalisation for renal disease among Koori men in Victoria, compared to other Victorian males. There are higher incidences of hospital admissions by Koori men as opposed to non-indigenous males in Victoria, and a higher prevalence of renal disease cases, in all age brackets from adolescents to older mature age men up to 64 years of age. Whilst Koori males aged 65 and over are not being admitted to hospital for dialysis treatment alone they are still being “admitted for renal conditions other than dialysis” (Koori Human Services Unit, 2008, p. 81).

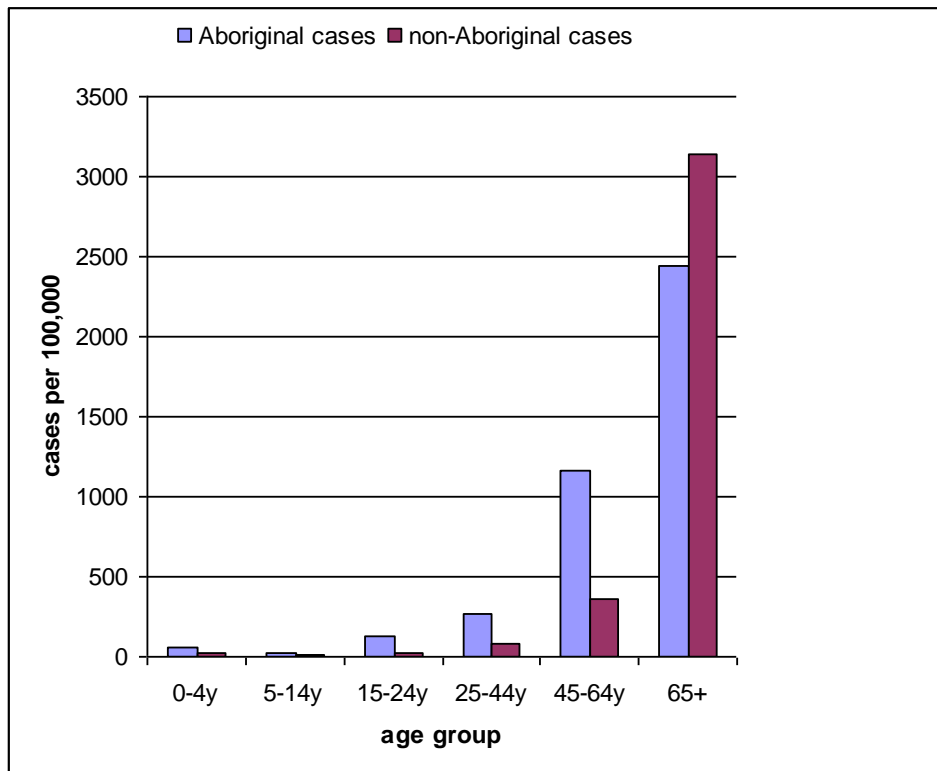


Figure 1. Age specific prevalence of renal disease of Victorian males. Data from (Koori Human Services Unit, 2008, p. 81).

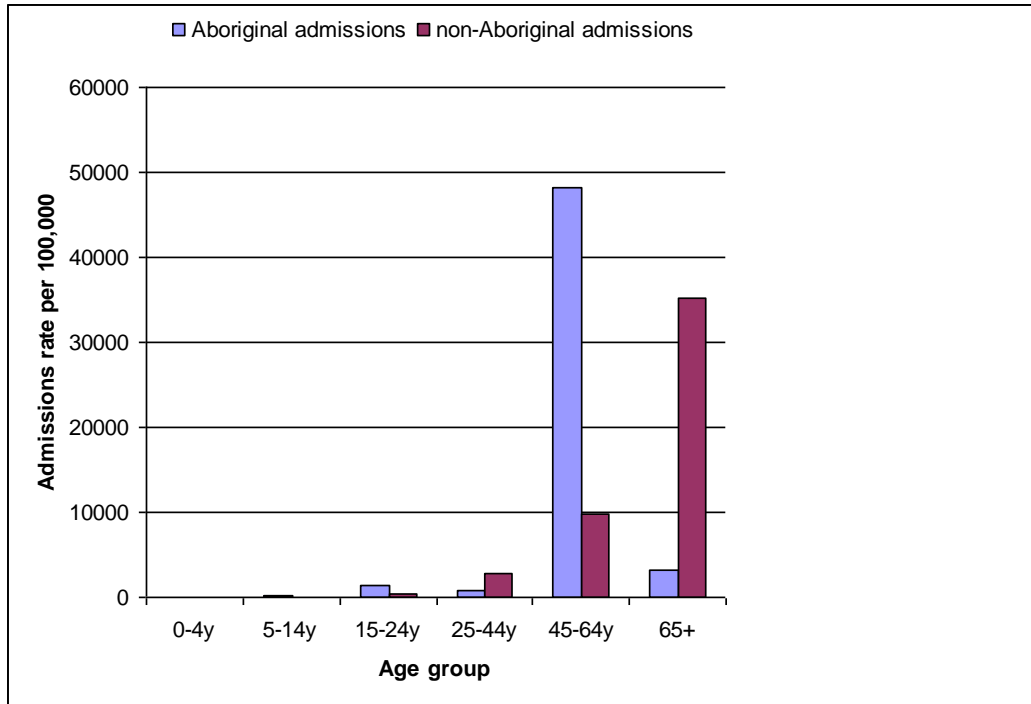


Figure 2. Age-specific incidence of hospital admission for renal disease for Victorian males. Data from (Koori Human Services Unit, 2008).

It is important to acknowledge that Indigenous women are also at a health disadvantage, both in terms of risk of ESRD but also for many other reasons. However, I am focussing on men as I felt there was a strong need to acknowledge appropriate respect for gender roles regarding who can speak on particular themes regarding their health concerns and feel that this approach is imperative to this study project.

1.7 Contributors to Risk of Renal Disease

There are a number factors that place people at risk of progressing to chronic kidney disease and these have been called risk factors. These risk factors have been broken down into three groups: Fixed, Behavioural and Biomedical (Table 2, reproduced from

Kidney Health Australia, 2008). Many, but not all of these risk factors occur at high prevalence in Aboriginal populations, particularly the biomedical factors, smoking and poor nutrition. End Stage Renal Disease (ESRD), is a condition in which the kidneys fail to function effectively and which requires dialysis treatment or kidney transplant.

Table 2: Risk factors for chronic kidney disease

Fixed	Behavioural	Biomedical
Family history and genetics	Tobacco smoking	Diabetes
Increasing age	Physical inactivity	High blood pressure
Previous kidney disease or injury	Poor nutrition	Cardiovascular disease
Low birth weight		Overweight and obesity
Male sex		Systemic kidney inflammation

Risk factors

There are two sets of risks for people that may contract chronic kidney disease, these are modifiable risk factors and non-modifiable risk factors. The modifiable risk factors include smoking, high blood pressure, obesity and diabetes. The non-modifiable risk factors are being aged over fifty years of age, having a family history of kidney disease and being an Aboriginal or Torres Strait Islander person (Kidney Health Australia, 2008).

In their study with the Tiwi population, Hoy et al (1998) highlight several major known risk factors for ESRD, these being hypertension, diabetes, streptococcal infection, and low birth weight resulting in reduced nephron numbers. It is evident that low birth weight of Indigenous children is prevalent (Hoy et al, 1998). Other research also indicates that

Indigenous adults in Australia have an extremely high prevalence of risk factors for chronic vascular disease such as diabetes, hypertension and proteinuria (Cass, 2004)

Hypertension, or high blood pressure, is associated with several circulatory risk factors that affect health including stroke, heart attack and angina. Furthermore, hypertension restricts the blood flow to many organs which can lead to deteriorating vision as well as kidney disease. Research highlights it is more prevalent for Aboriginal and Torres Strait Islander peoples to have high blood pressure than other Australians (Council, 2006).

Diabetes is a chronic disease caused by either the pancreas not being able to produce insulin (Type 1), or by the body not being able to use the insulin produced by the pancreas (Type 2). Insulin is a hormone that is important in that it helps to turn the food we eat into energy by promoting the uptake of glucose from blood into muscle and other tissues. Diabetes is associated with an increase in risk of chronic kidney disease and ESRD. The risk factors causing the onset of diabetes could possibly be increased by stresses that occur across the lifespan such as young children being undernourished, then reversing this in adulthood due to over-nutrition and a lack of physical exercise. In populations that are in transition such as Aboriginal people, Type 2 diabetes is more prevalent and affects people at an earlier age (Koori Human Service Unit, 2008).

Proteinuria is increased protein in the urine and is a key marker for kidney damage and can lead to the progression of renal disease (Kidney Health Australia, 2008).

Renal failure develops ‘out of the background of overt albuminuria’, as indicated by the albumin/creatinine ratio (ACR) detected in urine. A study by Hoy et al (1998) on Bathurst Island found that in the Tiwi population ACR was linked “with the presence of scabies at screening, with a history of poststreptococcal glomerulonephritis” (Hoy et al, 1998, p. 1296). Screening Indigenous children who have been affected by scabies or poststreptococcal glomerulonephritis found significant albuminuria (Hoy et al, 1998). Other studies have shown that albuminuria is associated with hypertension, diabetes and obesity in Aboriginal and Torres Strait Islander adult populations (Rowley et al, 2000).

The term for the co-occurrence of hypertension, diabetes, obesity and dyslipidaemia (all clinical determinants of kidney disease) has been called ‘metabolic syndrome’, also known as the ‘insulin resistance syndrome’ (Schutte, 2005). Metabolic syndrome has been used to group the “elevation of risk factors for and mortality from cardiovascular diseases (CVD)” (Rowley et al, 2003, p. 80.). The formation of the metabolic syndrome grouping originally included hypertension, glucose intolerance, hyperinsulinemia and dyslipidemia. More recently metabolic syndrome has been expanded to include “abdominal obesity and abnormalities of hemostasis, and elevated circulating concentrations of fatty acids and urate” (Rowley et al, 2003, p. 80). These factors (excess body fat deposited in the abdominal region, a propensity to blood clotting, and high levels of lipids in blood) are common in Aboriginal populations and have a direct influence on

kidney disease which eventually leads to dialysis treatment. Moreover, within Aboriginal Australia, research indicates that there are direct links between metabolic syndrome and kidney disease that is ‘considered to be part of the deteriorating metabolic and haemodynamic profile...and is associated with poverty, marginalisation and community and cultural breakdown’ (Fried, 2003).

A study of the main diseases causing renal failure in Aboriginal people by Renal Physician Kirubakaran, “identified Type II diabetes in 17% of patients with renal failure, obstructive uropathy in 5%, proteinuria in 5%, renal calculi in 4.5% and other unidentified causes 14%” (Carney, 2000, p. 9). Kirubakaran also found “primary glomerular disease as the cause of renal failure in a further 28% of patients”. The glomerulus is primarily a small cluster of capillaries within the nephron, the structure which acts as the filtering mechanism of the kidney. Dr Kirubakaran then divided glomerular disease into two categories, “glomerulomegaly in approximately half and immune mediated glomerulonephritis in the other” (Carney, 2000, p. 9). A report by Wendy Hoy (in Carney 2000, p. 9) “proposes that glomerulomegaly marks a predisposition to renal disease, that it may have a genetic basis or reflect other factors.” Glomerulonephritis on the other hand is considered to be “a variety of nephritis characterized by inflammation of the capillary loops in the glomeruli of the kidney” (Dorland, 1985, p. 557). Inflammation of the kidney occurs in “acute, subacute, and chronic forms and may be secondary to haemolytic streptococcal infection” (Dorland, 1985, p. 557). Kidney disease among Indigenous Australians has become an epidemic in recent times with devastating affects on the Indigenous population.

Poverty

ESRD has been labelled a 'lifestyle' disease, caused by poor habits such as lack of physical activities, inappropriate diet, smoking, excessive alcohol intake and other ills. However (Eades, 2000) argues that it has been through neglect and exclusion that the origins of this disease were manufactured within the Aboriginal population.

Indigenous Australians have high prevalences of the standard risk factors mentioned previously. However, they also have a unique set of circumstances that further exacerbates the effects of the above mentioned risk factors that initiate chronic kidney disease that add to higher incidences and hospital admission for dialysis treatment. Whilst research highlights that Indigenous peoples have a high prevalence of smoking, lack of exercise, obesity, poor nutrition, and hazardous alcohol intake (Cass et al, 2004). Other research suggests poorer socioeconomic factors as well as geography also contribute to risk factors for poor health (McDonald and Russ, 2003). Socioeconomic factors that have influenced poor health amongst Aboriginal people are interrelated and encompass factors such as family employment and income levels, educational participation and achievement, along with appropriate accommodation, transport and safety and crime measures (Council, 2006). In Australia, the incidence of ESRD is directly correlated with SES indicators (Cass et al 2001). For reasons that are unclear, incidence of ESRD among Indigenous peoples in Australia is also strongly associated with geography, with much higher incidences in the northern parts of the country (Cass et al 2001).

1.8 Treatment of Renal Disease

Blood Pressure Control - High blood pressure can be controlled by taking medication and offers significant protection against developing serious circulatory complications such as heart attack, stroke, angina as well as kidney disease. However, it is understood that prevention of high blood pressure is a better alternative and this can be achieved by eating a healthy diet as well as leading an active and healthy lifestyle, by getting plenty of exercise and avoiding obesity and diabetes (AHMAC, 2006).

Glycaemic Control-or the management of high blood sugar, can be achieved by eating a well balanced diet, regular exercise, maintaining a healthy weight and taking steps to help you relax as well as avoiding exacerbating stress levels. Glucose lowering medication is an important part of blood glucose control for many diabetic persons (Kidney Health Australia, 2008).

Dialysis is used when the kidneys stop working or are functioning at less than ten percent of their capacity. Dialysis removes waste products and extra water from the blood through a special membrane to remove waste products. There are two types of dialysis, haemodialysis and peritoneal dialysis. To receive dialysis the patient must attend a dialysis unit three times per week and attach themselves to a dialysis machine where blood is cleaned using the dialysis machine or artificial kidney, this procedure can take between four to five hours and blood is cleaned about six times. Dialysis must be received for the rest of the patient's life or until they can receive a kidney transplant.

Peritoneal dialysis is performed at home by yourself and replaces some of the lost kidney function. There are three steps to this procedure: fill, dwell and drain. Some training is required to perform peritoneal dialysis as it requires for the participant to insert a tube (catheter) with fluid into the peritoneal cavity. The catheter is inserted into the abdomen during surgery and remains there for the duration of dialysis. The peritoneal cavity is the space between the fine layers of tissue that covers the abdominal wall and that covering the stomach, spleen, liver and intestines. Step one (Fill) involves the cavity being filled with the fluid. The fluid is called dialysate and it remains there for a period of time (dwell). During the dwell period, waste and other fluid are drawn from the blood vessels and through the membrane into the dialysate. The final step (drain) is when the dialysate is drained and replaced with fresh fluid and the process is repeated. The choice of dialysis depends on health, age, lifestyle and other factors (Kidney Health Australia, 2008).

Kidney transplantation - Kidney transplants are available for people suffering from kidney disease, however, it is not a cure. It does offer a better quality of life free from dialysis and dietary restrictions, but a lifetime of care is required for the new kidney. Kidney transplants come from living or deceased donors and can be received by family, partners and friends. To receive a transplant one must be medically suitable and stable on dialysis. The operation can be done prior to dialysis if the transplant is from a living donor. Unfortunately, not everyone can receive a transplant due to other medical problems and dialysis may be the better option (Kidney Health Australia, 2008).

1.9 Access to Dialysis for Indigenous people

Access to health care providers for Indigenous people has been a contentious issue for some time and research suggests there are substantial barriers to access that afflict the Indigenous population in the process of accessing health care. In the following sections I will discuss access to dialysis and highlight relocation from a remote setting, accommodation, family and cultural factors, poverty and two way lack of understanding as barriers to access for Indigenous dialysis patients. I will then discuss Indigenous community Health Services perspectives on access to services and what they perceive to be barriers for chronically ill patients.

Relocation- Research has found that the highest incidence of ESRD among Australian Indigenous peoples is in remote areas, where it is up to thirty times the national incidence for all Australians. Although the numbers are much lower in the urban setting the standardised incidence is still significantly higher than the national incidence (Cass et al, 2001).

In the remote setting, Indigenous people face a barrage of barriers to accessing dialysis treatment. First, relocating into towns to receive dialysis treatment has the initial burden of leaving family. The reason being, Indigenous dialysis patients living in remote areas feel most of their care should come from within their own household with family members providing the support and care (Willis, 1995). Moreover, financial costs needed to travel often long distances for dialysis patients going into hospitals can be a barrier to access (Gruen, 2002). Cultural beliefs may assist with non-compliance due to sorcery being linked to the cause of illness, as well as a lack of understanding of kidney

disease and treatment that can also influence dialysis patients' access to treatment (Kellie & Hardie, 1995). There is the added communication barriers between the dialysis patient and staff due to language differences, described as being a 'deep cultural interface' as well as a lack of understanding from patients and their families regarding dialysis (Devitt, 1996). Finally, the added burden that further assists as a barrier to accessing dialysis treatment is the costs of suitable accommodation and budgeting for food and extra costs that comes with relocating into major towns to receive treatment (Willis, 1995).

Community Health Service - Indigenous Community Health Services, whilst playing a vital role for dialysis patients in assisting with attendance to dialysis treatment, often face unique circumstances that they state hinders their approach to care. The reason given for this is that staff are overwhelmed by providing 'sickness care' to Indigenous patients who are acutely unwell due to the high rates of illness in Indigenous communities. There are high staff turnovers and whilst acute care is ongoing they also need to focus on chronically ill patients (Damin, 2008). Community Health Services do well in managing chronic diseases, however they claim that they find 'prevention and early detection' difficult because of the demands 'of acute care over chronic care' (O'dea, 2006). Finally, there is also to add to the frustration of the previously mentioned barriers, the fact that the Community Health Services generally have a shortage of funding to purchase equipment such as vehicles, support activities related to chronic care and train staff. My search of the literature found no publications on access to dialysis treatment by koori men.

1.10 Aim

The aims of the research project are:

- (1) To document Koori men's perspectives on access to dialysis treatment;
- (2) To empower Koori men by giving them a channel to voice their views on their access to dialysis treatment;
- (3) To provide feedback for the administration of a user-friendly health care system for Koori men, by highlighting the views of Koori men currently being treated for ESRD.

1.11 Significance

There are a number of reasons why this study is significant. First, it adds to the limited knowledge regarding Koori men's views on ESRD, as well as their understanding of kidney disease and access to dialysis treatment. By incorporating Koori men's perspective into literature we can provide invaluable insights into how best to provide a better treatment regime for Koori men accessing dialysis treatment. Moreover, this project aims to empower Indigenous men by giving them a voice in health care research literature. Research supports the argument that culturally appropriate approaches to the health care of Indigenous patients who suffer from chronic diseases are deemed to be more successful (Shephard, 2000). Hence, the importance of receiving Koori men's perspectives on accessing dialysis treatment.

Finally, this research project is significant for reasons that encompass facets of Human

Rights such as loss of Indigenous self-determination, and recognition of culture through political and historical landscapes that have entwined Indigenous peoples and is a direct result from the disparities of colonialism. From an anthropological perspective this research offers a continued recognition and acceptance of Indigenous rights as well as adding to the dearth of knowledge collected in the area of this topic (Kelly, 2007). This research project seeks to not only explain some of the Koori perspectives whilst accessing dialysis treatment, but also to give insights into and promote culturally appropriate programs and initiatives that could be successful. Therefore, the priority of this study is to examine and discuss at length perspectives of Koori men suffering end-stage renal disease, regarding their access to dialysis treatment in the hope of promoting holistic programs when dealing with Indigenous peoples and health care.

Chapter 2. Research Design/Methods

2.1 Researcher Standpoint

I am *Nhunda Yamatji* (Aboriginal man), my people come from the mid-west of Western Australia and I am focussing on Aboriginal men and their access to dialysis treatment as a research topic for a number of reasons. First, it became apparent to me whilst in the honours program at Charles Darwin University that a substantial amount of the material I was reading on Indigenous men admitted to renal dialysis treatment referred to Aboriginal men in the second person. First person accounts of Indigenous men in this area have been lacking, with Jeannie Devitt's collaborative research being the exception. Leading researchers suggest, "Exploring accounts of patients' 'lived experience' of chronic disease can provide insights into their engagement with treatment" (Anderson et al, 2008, p. 499).

Second, as an Aboriginal man, I feel it is important that another Aboriginal man ask Aboriginal men about their views on issues regarding their own health and report both these perspectives and the methodological challenges involved in undertaking ethical and appropriate investigations from an Indigenous standpoint. For example, the methods of this study acknowledge gender in Indigenous culture and its importance in studies with Aboriginal people. As an Aboriginal male I felt there was a strong need to acknowledge appropriate respect for gender roles regarding who can speak on particular themes regarding their health concerns and so I interviewed men only in order to reveal their

particular perspectives.

I believe that as a direct result of colonialism, Indigenous men have been marginalised from many public forums on issues that are related to them and as a by-product we feel less confident speaking up. In many instances we have let Aboriginal women do our talking for us. That is not to take anything away from our Indigenous women who are and continue to be the backbone of Indigenous societies globally. Indigenous peoples have been subjected to detrimental intergenerational treatment through government policies that continue today. Finally, I would like to point out that regrettably this treatment of Indigenous men reverbrates through many western institutions including through the western biomedical model. Understanding the responses of Koori men in terms of their illness can make a small contribution toward a more user-friendly health care system for Aboriginal men.

2.2 Respect for Koori protocols

From the beginning of this research project I have endeavoured to follow every aspect of Koori cultural protocol. From the outset, I engaged in discussions with key Koori people and Koori Health organisations with the view of having them guide me in this project regarding what is and isn't an acceptable approach to research in this particular sphere. I worked closely with Indigenous staff members at Onemda VicHealth Koori Health Unit and The Victorian Aboriginal Health Service to build a rapport with them throughout the period of my project. I highlight this process in order to give a robust understanding of the significance of Indigenous cultural protocols whilst doing research in this area. I

understand that collaborations between university researchers and Indigenous peoples must be built upon respect, reciprocity, collaboration and trust and as such I have endeavoured to honor both throughout this project.

Coming to Melbourne from the Northern Territory has had its fair share of difficulty for me, adjusting to Melbourne city life and Melbourne weather being two major challenges that come to mind. Being of Aboriginal descent but not being a Koori has also been significant in this project, the standout challenge being not having any obvious kinship connections within the local Koori community. Having to establish connections within an unknown community can be a daunting prospect for anyone. My first point of call was to introduce myself and be introduced to staff members at Onemda VicHealth Koori Health Unit, who over time became my guides and mentors. All the staff within Onemda were approachable and they are well known concerning research within the Koori community.

2.3 Entering the research site

This project originally focussed on two sites of field work: St Vincent's Hospital and the Victorian Aboriginal Health Service (VAHS). I was first introduced by my supervisor to the Koori Liason Officer at St Vincent's Hospital. Eventually, I was also to meet the Chief Executive Officer (CEO) at VAHS both of whom I have continued to collaborate with throughout this project. I cannot stress the importance of keeping in contact with these people as well as Onemda staff. This regular contact was helpful in a variety of ways. First, one should understand that the practice of Indigenous research particularly

within the last half century has been bound by a history of colonisation, with Indigenous peoples having been subjected to relentless and invasive studies by non-indigenous fields of science including western biomedicine, history, anthropology, and sociology. The constant barrage of scientific study has led to a process of theft of Indigenous knowledge and has done little in the way of promoting positive outcomes for Indigenous peoples. (Humphrey, 2000).

As an Indigenous person involved in research I must ensure that I proceed with respect and transparency at all times. I feel it is paramount to have an open dialogue and be transparent with Koori people if you are involved in research that involves them. It is important to always ask what Koori people think of what you are doing, or about to do in research. This ensures that there is no harm, miscommunication or disrespect to the Koori people, who are either directly or indirectly involved in the project. Finally, it is extremely important for me as a Yamatji man to seek advice wherever and whenever I can, as I am acutely aware that I am a guest in Koori country and Koories are putting their trust in me by allowing me to work with them. I also acknowledge and respect the fact that these people are extremely busy and my project may not be of importance to them. I have continued to keep an open dialogue and have not assumed that my project is the most important issue of the day.

I along with my supervisor arranged for a meeting with the CEO and other staff of VAHS and met them at VAHS on a time that suited them. I explained what my project was about and asked if I could get a letter of support from the CEO as I needed support in

writing from an Aboriginal organisation to support my ethics application. I also approached the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) and requested a letter of support. I was asked to send a proposal of my project and did this by email on numerous occasions.

I understood that this would be a lengthy process, as I did not have the contacts within the Koori community and was prepared to wait for them to decide whether this project was acceptable to them. The process of ethics is also a lengthy one and there was in this case a lot of reapplying and rewriting my ethics application. I was even asked to have the letter of support written by the CEO of VAHS changed as the wording did not sit well with members within Human Ethical Advisory Group (HEAG). In the meantime I began working on a part-time basis with a community based project and was fortunate enough to be introduced to other Koori community members in and around Melbourne.

Once I received notification that my ethics application had been given approval I set about re-introducing myself and my project to the CEO of VAHS and St Vincent's Hospital. From St Vincent Hospital's perspective, I was asked to forward on more than one occasion my proposal and ethics approval letter to the head of research. When I did so, I was then informed that I would have to seek further ethics approval from their Ethics Committee. Around this time I also organised another meeting with the CEO of VAHS and informed him that my ethics application had been given approval by The University of Melbourne ethics committee. During this meeting I offered to do some volunteer work with the organisation. I also asked if it would be alright to discuss my

project with other staff within VAHS to which he gave his approval.

The next stage of this project was to organise to meet with the medical staff at VAHS to present my project and request assistance from them in attracting potential participants to this study. I called the CEO of VAHS to inform him of my meeting with the staff. However, he was on annual leave at the time. I again called the CEO after he came back from annual leave and informed him of my movements within his organisation. I also asked for permission if it would be acceptable for me to buddy up with one or two of the Aboriginal Health Workers based at VAHS.

I became actively involved with another Koori community based organisation of where I undertook some volunteer work. I also participated in some of their community based projects. These engagements further strengthened my informal connections with the Koori community and helped develop their trust in me.

2.4 The participants and Engaging the participants

The participants were Indigenous men who are currently or about to access dialysis treatment. They were asked to provide first hand accounts of their experience regarding issues they have faced or face as Indigenous men coming into the health care system with kidney disease.

In order to access the participants, I introduced myself to Koori health clinic staff at VAHS to discuss my research topic and build a rapport with them. Through these relationships I met Koori men who were in the process of dialysis treatment or had

recently been diagnosed with kidney disease (and as yet are not receiving treatment).

As this research entailed dealing with chronically ill people, the scheduling of interviews was very flexible. The timing of interviews varied on a day-to-day basis depending on the patients' wellbeing at any given time. I would spend a substantial amount of time liaising with potential participants and their families to gauge their everyday sense of wellbeing and activities, and would alter interview times, and pitch questions appropriately in terms of the participant's health, their daily schedules of dialysis treatment and other priorities related to their responses to kidney disease.

A fifty dollar gift voucher was offered to the participants after the interview and without their prior knowledge.

2.5 Data collection

Data were collected by recording interviews (with informed consent), recording research memos and maintaining a journal to record theoretical ideas and analytical insights. The research memos and journal were kept to record my approach to data collection as the primary research instrument. Together, these data inform both the standpoint of the researcher and key emergent considerations in undertaking ethical and appropriate research within Indigenous contexts from the standpoint of an Indigenous man. The interview schedule, plain language statement and informed consent form are shown in Appendix I.

Data collection methods within this study supported the co-operation and engagement of

Indigenous men. I utilised semi-structured interviews in the study. I chose this method due to the fact that the research project focused on Indigenous men, their health and their access to dialysis treatment. The semi structured interview method utilised within this study is interactive and enables a conversation between researcher and respondent. The interviews in affect were based on ‘yarning’, the oral tradition which is more in line with Indigenous culture. In this way, I hoped to gain a better understanding of the participants views and illustrate their experiences.

Recorded interviews were transcribed by myself and sent to each participant for them to read. I then followed up with telephone calls to ensure the participants had received it and gave verbal approval of the material I had recorded to use in writing this thesis.

2.6 Data analysis

Interviews were analysed using thematic analysis. This requires careful identification of themes by reading and rereading of the data collated from interviews. The methodology is inductive, building up concepts and theories from the data, compared with the deductive methodology of content analysis (Rice & Ezzy, 1999).

2.7 Challenges of the Research

As expected there were many challenges in undertaking this particular research project. I have previously pointed out the initial challenges of moving interstate and adapting to Melbourne lifestyle, as well as having to build a rapport with key Koori staff members within Onemda VicHealth Koori Health Unit. However, further collaboration and

networking was essential in the initial stages, and throughout this study period. Prior to lodging an ethical application with the University of Melbourne, I met and discussed my project with the Chief Executive Officers (CEOs) of the Victorian Aboriginal Health Service (VAHS) and the Victorian Aboriginal Community Controlled Health Organisation (VACCHO). I continued to keep an open dialogue with them and their respective organisations over a period of time. This was achieved mainly through correspondence via email and telephone. I also attended cultural functions over the period of this project and had the opportunity to meet with, in particular the VAHS CEO in an informal manner. As such, I feel as though I gained their trust, support and approval to continue with this project.

I requested support letters from both CEOs and followed the appropriate procedures that were required by these organisations to receive these letters of support. Both organisations requested a proposal of my project and interview questions. I further sent information introducing myself along with my resume. I continually followed up on meetings and kept both these organisations aware of where I was at with my study.

Simultaneously, I focussed on writing and lodging an ethical application to be presented to the University of Melbourne School of Population Health Human Ethical Advisory Group (HEAG). The process for this was lengthy as they have a turn around period of about six weeks. Lodging an ethical application from within the University of Melbourne's School of Population Health required that I would need to send my application to HEAG and meet their requirements prior to lodging an ethical application

with the University of Melbourne's Human Research Ethics Committee (HREC). The time taken for this process was around eight months and there was a substantial amount of writing and re-writing of the ethical application as well as re-writing the support letter that the CEO of VAHS had so kindly forwarded to me. After receiving ethical approval I again proceeded to meet with the CEO at VAHS and discuss my project with him. At this meeting I requested permission to meet with the Health workers to introduce myself and to inform them of the study. A meeting was arranged at VAHS two weeks later, where I had the opportunity to discuss my project with the head doctor, nurses, health workers and other staff members within VAHS. I continued to keep an open dialogue with the staff members and requested for them to either call or email me with potential participants that would be interested in being interviewed. Over the next two months I attended as many field trips as possible with VAHS staff, and other community based organisations.

Although the staff at VAHS were in the main extremely helpful I was mindful of their high workloads and tried not to infringe on them with my project. This caused some delays in the process as staff were often too busy to either get back in touch with me or had other more pertinent issues to attend to at the time. There was a substantial amount of follow-up work I was doing during this period. I had received verbal confirmation from a doctor at VAHS a month earlier that there were three potential participants that showed some interest in being interviewed. This was very rewarding to hear as I had received information from other community members around the same time that some of these same men had shown an interest and wanted to meet me. The result of these actions

confirmed to me that I had been on the right track by applying the methods I had over the period of this project. Once I had received contact from the first potential participant I focussed on scheduling a time to do an interview with him. This was a slow process and in the meantime I continued to follow-up on other potential participants deliberately. I did not infringe or harrass the potential participants and instead gave them my contact details as well as information of the project after receiving verbal consent from them that they were willing to participate in the study. I also let them decide on a time and place for the interview. My rationale for this procedure was that they were as much a part of this process and trust would be gained from them due to them having control and ownership of the study.

2.8.Limitations of the research

The obvious limitations of this research project were the small number of participants involved in the study. I had very little indication that I would receive any participants throughout the ethical application period due to the fact I was not allowed to contact potential participants. This caused a fair amount of anxiety due to the nature and time frame set out by the University HREC. Once contact was made with the potential participants I had to rely on the fact that I was an Aboriginal researcher and that they would entrust me with their responses. I sought a wide range of diverse views from the Koori men in this project and this was exceedingly difficult due to not having kin connections within the Koori community. I was also relying on an untried method of obtaining Koori assistance for this project which to many was of very little significance. Moreover, I completely understood the fact that historically research has had very

unfavourable outcomes for Indigenous peoples and that this project may not be seen to be of importance to them.

The information received from the interviews is important on a number of fronts. First, this study gave Koori men a channel to voice their views on kidney disease and their access to dialysis treatment. Second, I feel that the way in which I have been able to utilise the resources offered to me compared to other larger projects of Koori people has allowed for a more personal and informal study, that is more in line with Koori Culture. The interaction and responses the men gave in the lead up, during and after the interview stages signals that research can be proactive, engaging, empowering and ethical at the same time.

2.9 Qualitative study from an Indigenous Researcher's Perspective

From my standpoint as a relatively new Indigenous researcher I understand that this project was an extremely time consuming and difficult process. I also understand that other researchers might glean very different information from such a study, however, my interpretation is valid in itself. It is refreshing as an Indigenous researcher new in the field to engage with other Koories in what has largely been off limits to us and to also be free to assist in removing any negative experiences inflicted by research that Koori people have had to endure in the past. I feel that the insights these men have given are significant in that their responses in the interviews regarding kidney disease were a poignant reminder that Koori men are diverse and assumptions should not be made regarding Indigenous peoples from the wider community.

Chapter 3. Results of the interviews

The four Koori men who participated in this study were all at different stages of entering into dialysis treatment for kidney disease. One was yet to receive dialysis treatment and was dealing with ongoing visits to specialists, one had accessed dialysis treatment for the first time as recently as three weeks prior to being interviewed, whilst the two other respondents had been on dialysis treatment for a period of six and eighteen months respectively.

In the following sections, I discuss the variety of responses the men gave in interviews regarding kidney disease and access to service providers. I begin by explaining the symptoms of renal failure they experienced, before discussing the range of emotional responses the men had in learning they had kidney disease. The following sections move from examining the men's understandings of kidney disease onto responses from the men regarding their access to treatment, access to service, including both services from those service providers outside the Aboriginal community controlled sector, and services from within the Aboriginal community controlled sector. Finally, I discuss the importance of family support.

3.1 Symptoms of renal failure experienced by Koori men

Effectively, kidney disease occurs when damaged kidneys are not able to remove excess fluid and waste products from the blood and convert them to urine for excretion. When

kidney function is impaired, waste products accumulate in the blood stream in poisonous concentrations. If not treated, this leads to kidney failure and death. Kidney disease sufferers often report symptoms such as tiredness, headaches, dizziness, and nausea.

Reflecting the above description of the documented effects of kidney disease, prior to being diagnosed with kidney disease, participants in this study reported feeling sick, feeling weak, having trouble walking and difficulty breathing. All of the men described feeling “*sick*” prior to their diagnosis, indicating that they had little or no energy and felt weak.

P1: *“I just felt sick, just had no energy to do anything...”*

P2: *“Um, feeling sort of you know, ah...Heavy walking, um breathing a little but and...Like getting this, like I don’t know how you put it but like ah, sickness like you know...”*

P3: *“constantly feeling sick or constantly feeling off...”*

P4: *“just felt weak, couldn’t walk...”*

After investigating this question and hearing the men’s responses to other questions throughout the interview I at first remember feeling privileged to receive their rare insights into a very personal and confronting situation. I felt honoured that they had entrusted me by opening up and discussing their diagnosis and relieved at the same time due to the fact that all the time and effort I had put into this study was finally coming to fruition.

I understood that we shared historical and cultural commonalities as contemporary Aboriginal men. I was younger than all of the men interviewed, and I perceived the relationship to be that of an uncle-nephew relationship which I felt enriched the overall experience. This approach to the men made me feel very at ease with each and every one of them throughout the interview process. I sensed this kinship relationship was reciprocated from the men I interviewed, and as such I was completely assured of the integrity of their answers and responses given throughout the interviews. What astounded me throughout the interview process was just how well the men looked. For example, I remember leaving a dialysis unit with one of the men and having lunch with him prior to doing an interview. It was a very relaxed atmosphere with plenty of laughter. He seemed like any other man; not one who was dependent on a dialysis machine to keep him alive.

3.2 Responses of Koori men to Diagnoses

Kidney disease is well known to the Koori community and affects a large number of Aboriginal Australians. Two of the participants in this study knew of other people with kidney disease. Nevertheless, when confronted with the diagnosis themselves they exhibited powerful emotional responses. These included shock, denial, grief, anger and fear. Expressions of shock and denial included disbelieving it could ever happen to them:

P4: *“thought I would never ever have it. I thought me old ticker would have went first...”*

P2: *“Didn’t sort of want to know...Didn’t believe that...That. I were trying to put it*

away... I thought how could this happen to me? Why me?"

Fear was the one emotion that all of the men reported experiencing. Participant One reported feeling scared due to his lack of understanding of the diagnosis:

P1: *"I was scared and didn't know what was going on..."*

Participant Two's fear led him to deny the severity of his illness, fighting it until his kidneys nearly failed:

P2: *"I had trouble because I was trying to fight..fight it by myself..."*

This respondent went on to add that he feared dying and not seeing his grandchild grow up if he didn't receive dialysis treatment,

[The doctor asked,] "How many kids do you have?" I said, 'Three.' He said, 'Any grown up kids...grand kids' I said, 'Yeah one.' He said, 'do you want to see your little grand daughter grow up?' And I said... 'She only two, my grand daughter.' I said, 'I do.' 'Well', he said, 'if you don't get treatment,' he said, 'you won't last long.'"

Participant Three, who was yet to receive dialysis treatment, was at first fearful and then angry when asked about how he felt about being diagnosed with renal failure:

P3: *"...There's not enough words to describe how angry, annoyed, miffed, pissed off, I don't know, all these words they all fit."*

My sense was this man was struggling to come to terms with the fact that he been diagnosed with kidney disease after having to deal with Type 2 Diabetes over a period of some thirty years. I also sensed that he was almost lost for words as to how best describe his feelings and grasped at various words to describe his response. Beyond emotional responses, Participant Three described his struggle with self control regarding dietary restrictions and the requirements of treatment.

P3: “ I had elements of being sick...And then I...Okay lets control this, lets control, the blood pressure, lets control the cholestrol, control the eating habits. Ticking them off feeling pretty good about it and then we get to kidney and it wasn't ticking off..Um, yeah so you feel...You start searching for answers. Okay, why won't this...Why can't we get control of this one? Well, now I'm about to find out. I'm going to a specialist and having seen me once and not seen any tests results and he's already talking dialysis.”

Participant Three had not accepted his prognosis and was still coming to terms with juggling diabetes control as well as dealing with the everyday regime of specialist appointments for kidney failure. I recall trying to digest this man's response to this question and felt his anger and confusion about the struggle to regain control over his life. The sheer frustration of not being able to have control or be in control of yourself would be excruciatingly difficult to deal with in any regard. I witnessed first hand a determined, intelligent, independent Koori man trying desperately to come to terms with the enormity of his current situation.

As an Aboriginal man I understand that most, not all, Aboriginal people given the right situation through following cultural protocol and respect will open up and give insights into their emotions and understandings under the right circumstances. I particularly felt

this to be the case whilst interviewing these men. I also struggled in trying to control my own emotions whilst in the interview process. In particular whilst interviewing Participant Two, I understood the defiance in his response to trying to ‘fight it’ by himself. I understand that Aboriginal men are particularly defiant about most personal matters and will try to deal with things on their own, not unlike many other men.

Although I do feel reluctant to speak on behalf of Koori men, I don’t think it to be true that Koori men are more emotional than other men. In fact, I feel it could be the opposite at first glance. In my view, as an Aboriginal man, I am of the understanding that Aboriginal people can be very perceptive and will not respond to being questioned if they believe they are being patronised, or feel intimidated or uncomfortable. This could be due to historical implications linked to colonialism or it could be a cultural factor such as shame. However, I am more familiar with Aboriginal men withdrawing from displaying any emotional response until they have an element of trust and feel secure within themselves and the people around them. I felt comfortable with the four men I interviewed and understood the feeling to be mutual and reciprocal throughout the interview process.

3.3 Understandings of Koori men regarding kidney disease

When asked about their understandings of kidney disease, three of the men in this study indicated that they had little or no understanding of their illness and gave various reasons for their lack of understanding. Participant Four at first claimed that the information given to him from his doctor was good. However, when prompted further, he observed

“... *They tell me nothing.*” Participant Two suggested that he had contracted kidney disease through the tablets he was taking for diabetes. He reported this from his first visit to a kidney specialist who asked about his tablets:

P2: “*When I said, ‘Dinafor’, he said, first words he said, ‘That’s it, don’t take them’... ‘He said’ ‘That’s what’s damaging your kidney!’*”

When asked what he knew about kidney disease, Participant Three replied, “*almost nil.*” However, in comparison to the two other participants mentioned above, he gave a detailed account of kidney disease and mentioned a previous discussion he had with his specialist. This man was is in the early stages of diagnosis and was still being tested. He was confident of knowing what was going on but also fearful of knowing:

P3: “*I’m assuming he’s going to explain those results to me and what that means to me. And, like the doctors at the health service, tell me what symptoms I can expect...I know I’m not asking all the questions. Partly because I’m not ready to hear the answer.*”

Participant Three had some knowledge of kidney disease through family members, as did

Participant Two:

P3: “*A couple of members, just relatives in the family have had to go through dialysis it’s not totally unknown to me...*”

P2: “*Me cousin he was the same age as me today, and he was ah, same treatment as what I’m going through today.*”

Participant Three had a general understanding of kidney disease, however he did not understand the specifics of kidney disease:

P3: “*I feel as though I’ve only just found out that I have serious kidney problems ah, and I have no idea what sort of kidney disease I have.*”

Participant Four reported that he didn't know much about his illness because the doctors seemed reluctant to inform him fully:

P4: [the doctors] “ *Just say, ‘Oh, come back in another two weeks.’*”

While the above two men felt that they new little about kidney disease, Participant One, previously a nurse, was very capable regarding researching his own illness,

P1: “*They gave me a lot of things to read about kidney disease, but also when I got back to work, I got on the internet.*”

The responses from the men regarding their understanding of kidney disease varied and at times seemed to be contradictory. On one hand, three of the men stated that they had very little understanding of kidney disease. However, when prompted there was sufficient evidence to suggest that at least two of the men interviewed had some knowledge about their condition. Two of the participants cited receiving information about kidney disease through family members and one a nurse, stated that he had received good information from renal staff and went on further to do his own research on the matter over the internet. It seems apparent that educational level and access to the right tools was pertinent in this man's case.

In the case of Participants Two and Four, I sensed they may have been too shame

(Shame, being too embarrassed) to ask questions about their illness, hence not asking questions of their doctor about follow up or indeed requesting to know more about procedures of their current status. From my own perspective as an Aboriginal man, I am aware that some Aboriginal people will shy away from any discussion that they feel they do not understand or when they are intimidated by jargon being used around them by other people. It is important to highlight shame as a social and cultural factor here that is prevalent in Aboriginal societies and needs to be understood when dealing with Aboriginal people. However, I must point out that generalised assumptions should not be made about Aboriginal people, as we are an extremely diverse peoples coming from a range of sectors in life that all influence discourse and social interaction in different ways. These influences reflect educational levels, employment, geography, historical influences as well as unique, local, social and cultural influences .

3.4 Response of Koori men to dialysis treatment

As indicated earlier, all the men experienced fear upon being diagnosed with kidney disease. This was a response to what was for them, an unknown disease. Nevertheless, the treatment category “dialysis” also prompted emotional response that linked into the intergenerational stories within Aboriginal families regarding treatment by what is perceived as the “White” health system. When asked about their initial response to dialysis treatment, the men again revealed a range of emotional responses including scepticism, mistrust and grief. Again, fear was a prominent response:

P1: “It was hard I guess coming, coming into dialysis you know. When I first... I knew I had to come on hemo, but...I guess it was some, it was...again, scared.”

Participant Three reported an aversion to learning about dialysis treatment and of worrying about treatment due to fear of the unknown. He reports on his first initial conversation with the doctor:

P3: "He's already talking dialysis, which is a word I don't like the sound of...and realise that I don't know enough about, so...I guess I'm still dealing with the new fear aspect of it."

I sensed this man was scared of both hospitals and of entrusting his life to professionals with whom he had significant mistrust due to past experiences of family members receiving dialysis treatment,

P3: "[My memories are of] older members [of the family] and the processess. I remember... Seems like they're out of the dark ages. You know, you mention...you mention dialysis, and you take three steps back in history."

Participant One reported that the initial fear he felt prior to accessing dialysis treatment dissolved with time as he became familiar with the process of dialysis treatment. Initially he was sceptical of the procedure:

P1: "I was sort of a bit sceptical about this and I didn't know what the procedure was...so it was a bit daunting at the start, but after a while I sort of accepted it"

He was looking for support of familiar others:

P1: *“There was no one there to explain it to me bar the doctors and no other...Koori faces around to come and see what was happening with me...”*

Participant Two revealed that he kept putting the treatment off and was ignoring and resisting the process of treatment:

P2: *“When I had to get treatment... I kept still putting it back.”*

Participant Two experienced grief. I sensed he felt a strong urge not to tell his wife and other loved ones about his illness due to this grieving process,

P2: *“Well, when I found out that, I had that, I did break down...And sorta cried and that...to my family.”*

He did not initially tell his wife about his prognosis,

P2: *“When I did...I did end up telling her the truth and, she end up coming in with me.”*

Grief was not only experienced by the men themselves but also from members of their families. Participant two's wife pleaded with him to go to treatment after he had informed her of his diagnosis. After telling his wife and hearing her cry:

P2: [She was saying,] *“You know, [I] don't want to lose ya'... that's what woke me up.”*

Witnessing her grief made him finally accept he needed dialysis treatment and so he went ahead with the support of his wife and family.

The responses I received from the men regarding both dialysis and impending dialysis was strong with emotional and historical resonances. The men also showed in their responses that family members were also concerned through historical memories of serious illness and engagement with health professionals. The grief expressed from respondents and family members signifies to me the constant loss of family members that seem to be a large part of Indigenous existence. Fear of losing loved ones and dealing with the loss of loved ones has been a constant in my own experience and I feel that this is a commonality that all Indigenous peoples share due to the historical landscape in which we find ourselves immersed.

3.5 Access to services

The Koori men in the study were also asked about access of transport to and from service providers. Three of the men in the study believed that they have been well supported regarding access to services by the Victorian Aboriginal Health Service (VAHS). Two of the men were picked up and taken to dialysis treatment by the community bus belonging to VAHS and later returned home. These men felt that this service was imperative for them being able to attend dialysis treatment on time. They felt comforted by the availability of the service from VAHS and described it as very good. One respondent received taxi vouchers from VAHS to attend treatment. This was due to an amputation of his right foot:

P1: "I couldn't handle myself on public transport...you a little unsteady on your feet so I couldn't handle me-self on trams and trains and getting home and having to get home from the tram stop to my place you know, which is about probably twenty minutes walk."

However, one of the men reported that he drove to VAHS from a regional town. He was resigned to the fact that he would have to continue to do so as he would be on dialysis three times a week. He drove himself despite the fact that his eyesight was failing him due to diabetic retinopathy. He knew he shouldn't be driving:

P3: *"My eyes haven't fully recovered, I know if I were to sit an eye test for a license I would fail unfortunatley."*

He was concerned that in time he would not be able to drive at all and as such would have to rely on public transport to come into Melbourne,

P3: *"There are not too many options, there is a country rail service...I think [home town] is only zone two, so I could buy... a ticket there, come into Melbourne get on a tram and travel to the end of the line."*

He added, *"he was not looking forward"* to coming into Melbourne by public transport when he began dialysis treatment. He said that the time he would have to travel including walking the *"twenty minute walk from my place to the station and that's if I hurry"* and getting back home in the afternoon would be inconvenient. This respondent had not begun dialysis treatment at the time of the interview but will begin treatment before the end of the year. Coming into the city via public transport three times a week for dialysis, he believed would be an extremely difficult burden and he was still trying to work out how this could be achieved on the public transport system.

My observation was that accessible transport provided by the Victorian Aboriginal Health Service (VAHS) was a crucial necessity for the men receiving dialysis treatment. Equally important was transport to assist the participants in attending doctor and specialist appointments. The participants all had additional travel burdens to deal with ranging from physical disabilities to travelling long distances. Participant Three realised that his sight was failing him and that continuing to drive into the city was not an ongoing option for him. Participant One had an amputated right foot and the nearest tram stop from his house was a twenty minute walk. Thus, assisted travel to and from appointments is an extremely important service that is critical to enabling access to specialist health services required by Koori men with kidney disease.

3.6 Services from service providers outside a community controlled sector

There are a variety of health services that can be accessed by Koori people such as General Practitioners (GP) clinics, Government community health services, and non-government Aboriginal Community Controlled Health Services (ACCHS). The General Practitioners' clinics are common in the city and suburbs and can be accessed by all patients including Koori men through appointment and by presenting a medicare card. Government community health services offer GPs and allied health services under one roof and sometimes employ Aboriginal Health Workers to assist Koori clients. Hospitals also offer outpatient services but are generally accessed in cases of emergency. Aboriginal Community Controlled Organisations (ACCHO's) are specialist health

services for Aboriginal clients and offer a range of health and well-being programs, as well as the standard general practitioner services.

In the case of the men interviewed it is evident that they accessed all of the services described above and responded to each of these services in their own individual ways. In the following sections, the participants provide feedback and comments regarding services at clinics outside the community controlled sector. Initially, I discuss participant responses to service provision by nurses, followed by doctors and then participant observations about mainstream hospitals in general.

Three of the four participants described nurses in hospitals and dialysis units with terms such as *“supportive, trustworthy, open, honest, caring and helpful.”* Participant One said that although he was scared going into the dialysis unit for the first time, the nurse had made him feel comfortable and reassured him:

P1: *“There was one nurse who I really got attached to...I wasn't sure [what was going to happen] and they gave me um, a little injection...She said 'look I promise you...you won't feel a thing.'”*

Participant Two reported that the nurses he had come into contact with at both the hospital and within the dialysis unit *“All there were great.”* All the respondents who had been to hospital indicated that most renal dialysis nurses were very helpful.

When asked about the doctors at the hospitals, participants provide a mixed response. Some felt that the doctors were *“pushy”, “assertive”, “rushed”* and *“formal”* in comparison to the relaxed atmosphere they reported at the Victorian Aboriginal Health

Service. Participant One felt there were both good and bad doctors. He felt that one argument he had with a doctor was due to an error on the doctors' part:

P1: "You have your good and your bad...I've had a few run ins with some doctors...This doctor came in and he said to me, You've gotta have an angiogram today...your not allowed to eat...I said, I'm not having an angiogram...Two hours later he come back and apologised to me. He said, There was a patient with the same name. So that's just an example of how some doctors' treat ya."

Although the men felt that doctors could be pushy and assertive, they also felt that they meant well, with Participant Two stating that although a doctor was pushy he had been really good about it:

P2: "Well, [the] doctor...[has] been pretty good to me...and he's been really um...pushy about it."

Finally, when reporting his experiences at a general hospital, Participant Three mentioned that he felt the service from mainstream was a bit rushed:

P3: "You go in, you have a quick consultation, you don't cough more than twice... the things over and you haven't finished talking to a doctor...the people are friendly but, I always feel as though I'm just a number."

In contrast, Participant Three suggested that this was not the case at VAHS and that's why he preferred to attend there rather than a mainstream hospital. He revealed that he mistrusted mainstream hospitals due to the bad history experienced by him and his relatives whilst being patients,

P3: “ *The bottom line is my father died in Saint V’s and we were treated like wall paper...In there, that process went on, so they haven’t got off to a good start.*”

The general consensus amongst the men regarding nurses in hospitals and dialysis units was that they were supportive and helpful. When discussing doctors there was a mixed response from the men. The responses ranged from doctors being pushy, assertive, rushed and formal to an appreciation of their skills and commitment. There was an element of mistrust regarding hospitals amongst the participants due to the history experienced by them and their relatives. In my own experience of engagement with mainstream health services I have had a family member withdraw from dialysis treatment and not comply with the ongoing treatment. I did not at the time delve into the reasons why they were non-compliant and unfortunately they have since passed on. I am however, aware of the bad history experienced by Indigenous people and mainstream health services and as such have an element of empathy to the Koori men’s responses to this question.

3.7 Services from the Aboriginal Community Controlled Sector

I also discussed access to non-government services through the Aboriginal Community Controlled Sector with the Koori men in the study. Responses regarding the Victorian Aboriginal Service (VAHS) were positive with all four respondents reporting a healthy relationship with staff. Comments regarding staff at VAHS included their being “*supportive*”, “*caring*”, “*relaxed*”, “*flexible*” and “*welcoming.*”

All the men reported that the support they received at VAHS came from all staff at VAHS including the doctors. Participant One felt that the support he received from the doctors at VAHS had a lot to do with the fact that they knew him very well:

P1: *“Doctors’ there are very supportive, they know my history as well...”*

Participant Three felt that the informal approach from staff members at VAHS led to extra care being taken by the doctors on the days when he had appointments:

P3: *“All the doctors, they don’t pressure you, they don’t rush you um, if like today, I had to get extra things done to what the appointment was all about, there’s no fuss, you walk in, the doctor talks to a couple of medical staff so they come out and do their little thing...there’s no fuss.”*

Participant Two expressed surprise that the doctor had such a caring and personal attitude toward him in regards to his illness:

P2: *“The day that I went in to get...tested and all that...I went in on Sunday...To my surprise, he came in on Sunday you know, and I thought, ‘That’s unusual for a doctor.’”*

The support of VAHS was summed up by Participant Three, who stated that there was a very different clinic attitude within VAHS to that of mainstream clinics and hospitals that he had experienced and this made for a better relationship between staff and patient:

P3: *“It’s a very different clinic attitude... at VAHS...You just walk in the place and even though you, when you first walk in you don’t really know where to go, the people help you. I s’pose the staff in all clinics are helpful but...there’s just a different feel. You know when you walk into a medical clinic a non-Aboriginal clinic...you know, your just a number.”*

Participant One felt that the staff at VAHS went to enormous lengths to assist him declaring:

P1: *“Anything I need they get for me, they get in...”*

Participant Two reported that the staff at VAHS followed him up and made sure he kept appointments regarding dialysis treatment:

P2: *“They were really sorta worried and you know, and they kept on saying to me about the dialysis and that too...”*

There are obvious differences between the Aboriginal Community Controlled Health Services and other health services. The participants themselves describe a number of differences that range from feeling that you are not number when visiting an ACCHO, a feeling of kinship within the place and a sense that the health professionals employed have a deep commitment to Koori people and their health..

Drawing upon my own experiences as an Aboriginal client of Aboriginal health services, I concur with the Aboriginal men in the study. I am always made to feel welcome when attending ACCHOs, and am confident in being able to approach staff and doctors regarding my own health issues. I experienced the same support for this project. However, I felt I was being tied up with bureaucracy by the hospital that I had tried to access as a site for this study. I felt this procedure to be very formal and stringent and as

such largely felt unsupported and left without following through with their request to lodge an additional ethics application. I felt that the bureaucratic process of the large hospital was highly impersonal with little sense of personal care. My response was not to engage. Other Aboriginal men I have known and observed seem to share a similar response at being subject to an engagement with a large impersonal system. For this and other reasons, I understand why Aboriginal people may avoid other mainstream health services and opt to go to an Aboriginal Community Controlled Health Service if given the choice.

3.8 Family Support

Support from family was paramount to all four participants from the beginning of diagnosis and throughout their treatment. All four men had family support and either lived with family or relied on members of their family to assist them in a variety of ways. One of the men, who lived alone, explained that because he did not have immediate on-site support from family members, although he had been offered home dialysis, he declined the offer because he couldn't imagine administering the treatment himself:

P1: "The only thing I couldn't do is I couldn't do me self...my sister comes down and stays, but, no, if there's anything wrong, what could I do?"

This participant had three sisters living in Melbourne who kept in contact with him regularly by telephone. He also added that his older sister visited him regularly from the country:

P1: “[She would] *stay for sometimes two or three weeks...and she comes in and she does a lot of the work around the place, things I can’t do around the unit.*”

He was adamant,

P1: “[Support from family] *is important, friends as well...*”

He also reported that he had a lot of contact from his cousins:

P1: “*Different one’s ring every week...*”

However, when asked how they responded to him when they found out about his diagnosis, he stated he encountered some ostracism from friends:

P1: “*Well,...when they found out that I was at, the dialysis they all dropped me like hot cakes a lot of them...A lot of em, yeah, specially a lot of friends*”

Being abandoned by kin and friends upset him and he blamed this response from his friends on him having “*stopped smoking and drinking.*” He said that although he was close to his immediate family, when he got sick and gave up alcohol, smoking and going out, some people lost interest in him:

P1: “*They don’t even call, they don’t ring up or nothing and it annoys me’ cos I know what it is, because I don’t drink and smoke and they do, they do all that and go out and stuff and I can’t do that no more.*”

In my own experience I have at times been in the situation where peer group pressure in

relation to drinking alcohol and smoking were considered the norm. These situations have been uncomfortable and have arisen in sporting clubs amongst teammates, as well as from family, friends and other groups of people. I understand that family and friends can put an enormous amount of pressure on an Indigenous person, particularly when it comes to reciprocity within the family kin structure. However, I have been fortunate enough to have other strong family members around me in the way of sisters, brothers, cousin brothers/sisters, aunties/mothers, uncles/fathers as well as a number of grandparents that have guided me through these situations, whenever and wherever they have arisen. I understand that this support by family members is not the case with all Indigenous people. However, I also understand the significance of kin relationships and their importance in guiding young Indigenous people through the drinking and smoking culture, that presents itself by peer group pressure and is considered by some to be the norm.

As indicated earlier, family support was also important to Participant Two. He revealed that it was his wife who pushed him to go to dialysis treatment:

P2: *“And she still...Pushed me. She arg, [argued] you know...Said nah, nah, nah you go!”*

This man said earlier that his family and seeing his grand daughter grow up was instrumental in him adhering to dialysis treatment.

Participant Three observed that dialysis treatment “*upsets the whole family...*”. He narrated a previous experience with a family member needing dialysis treatment. He revealed how ‘*disgusted*’ he had felt at the treatment of him and his uncle and how dissatisfied and angry his family felt with both his and his uncle’s treatment at the hospital.

As indicated above family and family support is imperative to Koori people. Whilst undergoing the interview process, I spent periods of time making follow-up calls and writing emails to the participants and members of their family. I met face-to-face with family of three of the men and with the other I had lengthy telephone calls with his wife prior to meeting and interviewing him. Family is integral to Aboriginal people and I am fortunate to have an intricate understanding of family and its significance from this perspective. I observed that all four of the participants in this study had extremely strong support from family members. I also observed that some of these men may not be with us today had they not had this level of support from family members.

3.9 Summary

In summary, the study, although relatively small, provided some important insights into the experiences and perspectives of Koori men accessing dialysis treatment. All four men diagnosed with kidney disease had powerful emotional responses, including shock, denial, grief, anger and fear. All four of the men reported fear as a driving emotion to being diagnosed with kidney disease.

Fear was also a predominant response to engaging dialysis treatment. While fears of their own mortality were central. Fear also stemmed from historical horror stories shared within the families regarding treatment of Aboriginal members by what is perceived as the 'White' health system.

Such stories are also common from within my own family as an Aboriginal researcher undertaking this study. The responses from the men regarding access to services was positive overall, due considerably to the availability and commitment of service providers at VAHS regarding transport or to their financial support through provision of taxi vouchers. The fact that one of the respondents drove about fifty kilometres while his eyesight was failing him highlights the value Aboriginal people place on Aboriginal health service provision and the need to provide broader support for access. The danger of this man driving with impaired vision also signals the need for regionalisation of services provided by Aboriginal health professionals and organisations such as VAHS. Finally, family support is an integral part of Aboriginal societies and was discussed by all of the men.

All four of the men reported to having family support and either lived with family members or relied on members of their family to assist them in responding in a positive way to diagnosis and treatment for kidney disease. From my perspective, family is significant and family support is paramount when dealing with particular issues that often are outside of our own control. Indigenous peoples and family connections have been

utilised in so many ways to assist in the make-up of who we are as individuals and where we come from. I myself have an extremely large extended family and have developed ongoing robust relationships with family members that continue today.

Chapter 4. Discussion

The relatively small number of participants in this study necessitate that the findings be treated cautiously. First and foremost, this study does not make claims regarding all Koori men and does not suggest that all Koori men will have similar experiences when accessing dialysis treatment. The limitations of the findings emerge in the discussions within this chapter. Nevertheless, considering there has been little previous research on the experiences of Koori men with End-Stage Renal disease, the findings will be useful to health professionals providing services to this client group. In this chapter, I focus on the diversity of Koori men with renal disease, how the responses of the men parallel mainstream understandings of the grief process, the importance of the transmission of health information through family, both the importance of family support and its limitations, particularly in relation to smoking and drinking patterns of Koori men, mistrust of both hospitals and health professionals, and the struggle with fear.

4.1 Ability of Koori men to articulate regarding symptoms

There were a range of powerful emotional responses by the men in this study in relation to how they felt about being diagnosed with kidney disease and about how they felt about the required dialysis treatment. These emotional responses reveal some useful insights regarding this client group. First, the responses show that Koori men are not afraid to express themselves when asked personal questions in relation to their illness. It was encouraging to witness the responses of the Koori men interviewed and their ability to articulate themselves in a way that is often not thought possible by the majority of non-indigenous researchers. I feel the reason for the men's openness was because they felt

comfortable with the interview process, and at ease in talking to another Indigenous male. I believe that they felt in control of the situation, and didn't feel as though they were being forced into talking to me. (McCoy, 2008) highlights gender as a barrier for Indigenous men accessing health services. He observes that communication is attenuated between the nurse (female) and patient (initiated male), and reveals how Indigenous men didn't access the health service in his study due to it largely being the 'female domain'. He argues, as a consequence of the female domain within the health service, men's access to health services has been compromised. He explains, the gender roles and relationships of Indigenous men and women in an Indigenous community setting and how men and women relationships can extend from genial familiarity to strict respect (avoidance)... [and that] men and women can equally experience discomfort and shame in these confined physical spaces of the health service (McCoy, 2008, p. 86). These insights highlight the significance of traditional law and culture and how gender plays such an integral role within Indigenous society, particularly in regard to male-female relationships.

Koori's themselves have long been advocates of change in the way in which research and research projects should be undertaken. They cite numerous barriers to community controlled research and highlight a range of considerations regarding culturally appropriate ways in which the role of Indigenous research should be undertaken (Unit, 2000). The fact that these men gave such emotive responses in these interviews may be a wake up call for many non-indigenous people who, with an interest in research with Indigenous peoples, through no fault of their own, are burdened with the ethnocentric

perspectives and lack of understanding of cultural protocol.

Adherence to cultural protocol and respect is what has been lacking from the majority of research with Indigenous peoples. More needs to be done in this area by creating an awareness of cultural protocol and the historical baggage of inappropriate research practices within this context that have plagued Aboriginal and Torres Strait Islander administration (Unit, 2001). Greater awareness by researchers will assist in enhancing the development of appropriate services for Indigenous people by building better relationships that are inclusive of local Indigenous people and the key concepts and meanings they bring to their understanding of health. Inclusion of these research methods will then ensure positive changes to health care provision for Koori people. Whilst it is generally accepted that Aboriginal people have lower educational levels, what is evident in this study is that given an approach that adheres to proper cultural protocol to inquiry, Indigenous peoples articulate and express personal experiences and their emotional flavours in a unique manner like any other respondent interviewed for research purposes.

4.2 Diversity of Koori men with renal disease.

The Indigenous men interviewed came from diverse backgrounds with equally diverse educational levels. Whilst the manner of which the interviews took place was semi-formal, the men with their diverse story-telling styles, all shaped the structure of the interviews and provided quite diverse responses. Participant One came from a nursing background and as such was well aware of the issues regarding chronic disease and, in particular, kidney disease. He understood the technical side of dialysis and was vocal on

certain issues with doctors regarding his treatment. He utilised the internet and did his own research on kidney disease when diagnosed and kept educating himself whilst undergoing dialysis treatment. This suggests that a solid educational background results in an empowered Koori man, confident in his own ability, with no difficulty responding to hospital staff including doctors' approaches to care. Other participants that did not have the same educational background were not as confident and did not seem confident enough to ask questions about their illness of doctors. Participant's Two and Four seemed reluctant to ask questions and this may have been due them lacking in the confidence to articulate themselves in front of doctors and other hospital staff. This could also have been influenced by cultural factors, in that they may have been 'too shame' to ask any pertinent questions regarding their illness to doctors. Participant Three came from a background with a basic level of education as well as spending many years in the state public service. He was able to articulate himself rather well at the interview and expressed emotive responses to the questions asked. At the time of the interview he had not yet accessed dialysis but was seeing a number of specialists regarding his illness. He insisted that he was not asking all of the right questions regarding kidney disease of his specialist, but pointed out that this was due to him not wanting to know all the answers as yet.

Health professionals need to be extremely careful about making assumptions regarding Koori men's understandings of disease and illness, their interest in their own illness and their commitment to self-care. They need also to be aware of current familial circumstances that will impact on their Koori patients and their interactions with health

professionals. For example, a Koori man may not form a relationship and may seem distant and uninterested in discussing their health with a health professional at first glance. Being prepared to slowly build a rapport and allowing for time ensures that the Koori patient has a certain amount of control in the relationship. Moreover, other outside factors may come into play such as, the daily pressures that bear down upon Koori people such as family disruptions, pressure associated with poverty, and other personal and social influences that may shape the clients' responsiveness and ability to form open relationships with a health professional.

4.3 Parallels with mainstream understanding of grief process

The men interviewed displayed parallels with western understandings of the grief process in response to questions asked to them. Grief came through as a major theme in this study and highlighted the capacity of these men to express their grief when provided with a culturally safe space. (Kubler-Ross, 1969) outlines five key stages of grieving and with respect to death and dying, and outlines each of these stages in detail. The five stages are: denial and isolation, anger, bargaining, depression and finally acceptance. The men in the study highlighted most of these responses in line with the different stages of where they were at with their dialysis treatment. In response to them first being diagnosed the men expressed their emotions as shock, denial grief and anger. These responses correlate with Kubler-Ross' explanations of the first stage being denial and the "No. it cannot be me" attitude. As we moved throughout the interview fear, anger and acceptance came through as themes in the men's responses. Research indicates that there is a substantial burden of unresolved grief in the Indigenous community. Grief and trauma is a constant

within Indigenous societies according to Gregory Phillips, and includes three types (Phillips, 2003). These types are: situational trauma, for example, the death of a close relative that may cause extreme grief; cumulative trauma results from a build up of events over time, and can ‘manifest as repressed rage’, often expressed in response to racism and sexism; intergenerational trauma, which has been linked to holocaust survivors and those forced into removal or separation from traditional societies or family units and can be linked to colonisation. The stresses of colonisation include family oral history of massacres and the removal children (HREOC, 1997).

Indigenous individuals or their family members caught in the grieving process, as previously stated, is a constant within Indigenous societies. Acknowledgement that Indigenous clients are vulnerable to be caught up in the process and an understanding of this process could be helpful for Health professionals in their relationships with Indigenous men in similar situations to the participants in this study.

4.4 Health information through family

All the men indicated in their responses that they received information about kidney disease through family members. This is significant in that it indicates that they often ‘yarn’ together with other family members about issues of the day including health and in this case kidney disease and dialysis treatment. This suggests the need for further investigation regarding the effectiveness of health education being directed at the family collectively. Koori people already have their own discourse going on about critical health issues and much information (and disinformation) is often coming and going and

through family networks. Therefore, the existing information channels that are active within the Koori community may be a vehicle to promote healthy practices and highlight health-based community programs from non-Indigenous health organisations and, as such, assist in educating the Koori community. This approach has been undertaken for a substantial period by Indigenous health organisations.

Not only does specific health information, often contextualised in stories, flow through these networks but also Koori community assessment of health professionals (and researchers) and their practice styles. For these reasons, from my personal perspective, research in this sphere can and should take considerable time with a significant amount devoted to communicating and getting to know family members, as I did within this study. This enables trust and friendships to be built that can only assist in a robust and culturally responsive study. I spent a substantial amount of time interacting with family and community to establish a respectful relationship with the Koori community. This was achieved by continued follow-up of telephone calls, email and presenting myself at community events. Such an approach ensures transparency and that one's own identity becomes known across these family networks. I don't think it is pertinent whether you are a Koori or a non-Koori. Whoever is undertaking research that seeks to understand the meanings and responses of Koori people to the health issues that impact on themselves and their families, I feel requires immersion in community networks - becoming known and showing respect for cultural protocol can only further meaningful research.

4.5 Family support- it's importance & limitations

Family is integral to Indigenous peoples identities. Family connections bind an Indigenous person to their country and create a sense of belonging. Family offer support with everyday issues and are often there to offer advice and help when needed. Family support for Indigenous people runs deeper than the immediate nuclear family unit common in broader Australian society. It incorporates extended family and as such includes links that are supportive in a variety of other ways. For example, family support can be through child rearing. This often means that family members other than the biological parents such as aunties and uncles and in particular grandparents raise young Indigenous children for extended periods. These relationships are recipricol and often become important when the carers become aged or disabled (Genat, 2006). All four participants in this study had strong family support. In particular for ESRD patients, family can assist in a variety of ways that range from emotional support to physical support. Participant One for example, noted that his sister came to stay with him and helped out around the house with cleaning and other duties he could not complete himself.

On the other hand, relationships within the extended family can also cause a large amount of disruption to the household, particularly if drinking and smoking are considered the norm, as was the case for participant One. The constant disruption of extended family members coming and going from a dwelling can make it extremely difficult for core family members to focus on every day living, such as personal health care routines. The extended family can place immediate pressure on the core family, simply because lengthy

stays tend to stretch already limited resources including the supply of food, clothing, power and water. Children may not be attending school, parents may not be going to work or be able to maintain everyday routines necessary for reliable employment. Dysfunction within the family structure due to excessive drinking and all that it brings with it, can destroy the already struggling family unit. Participant One stated that he feels much better now that he has given up drinking and smoking and does not have the constant disruption of certain members of family visiting him whilst he is ill. He also added that his close kin are very much a part of his life and assist and support him which promotes his well-being. Family disruption can have a domino affect that, if left unchecked can inevitably bring about evictions, which in turn inflame the cycle of poverty and ill health that is already entrenched within Indigenous societies.

4.6 Mistrust of health services and health professionals

Historically, Indigenous peoples were subject to indifference or worse within the mainstream hospital system and from health professionals such as doctors. There has been widespread neglect, racism, exclusion and horror stories that are still current throughout the Koori 'grapevine' (the inter-family communication network). These horror stories assist in compounding and maintaining mistrust of hospitals and health professionals by Koori people. The men interviewed indicated that whilst they did stike up relatively good relationships with the nurses within the hospitals and in particular the dialysis units, they sometimes found it difficult to communicate with the doctors. They also suggested that historically their families have been treated poorly from the hospital system. Stories of the past bad experiences have created the mistrust they feel today.

What was evident in this study were the positive views of the men in relation to services from the Aboriginal community controlled sector. All four men gave evidence of a healthy relationship with VAHS and the staff. One of the men highlighted his willingness to attend appointments due to the support and lack of pressure placed on upon him. Another respondent appreciated how well the doctors in VAHS knew him and his history and as such felt completely confident in attending appointments.

The positive responses from the men in regard to VAHS staff as well as the dialysis unit nurses indicate that a positive relationship between mainstream hospital staff and Koori patients is achievable. It is important that mainstream hospitals continue to examine and improve their policies on Koori relationships and access.

Over the past three decades Koories have made significant contributions to strengthening Koori access to hospitals. A recent report, 'The Improving Care for Aboriginal and Torres Strait Islander Patients (ICAP) Program' (Posenelli, 2009) outlines these contributions and achievements. (ICAP) was introduced in 2004 and is an extension and enhancement of the Aboriginal Hospital Liaison Officer (AHLO) Program established by the Victorian Department of Health in 1982. The key aims of (ICAP) are to improve the accessibility, appropriateness and effectiveness of government health services, in particular hospitals. The program aims to go beyond just strengthening the practice on non-Aboriginal health service providers to achieving whole-of-organisation change in order to build the institutional capacity to respond to Indigenous clients and the complex health problems they face. This study demonstrates some success in achieving this for

Koori men with ESRD but also highlights the need for such programs to be ongoing to overcome massive institutional barriers embedded historically.

4.7 Working skillfully with the fear of Koori men

There were several significant moments throughout this study when the men highlighted fear as an emotional response to their experiences regarding dialysis treatment. First, the men highlighted ‘fear’ when asked to reveal their initial response to being diagnosed with having kidney disease. The men were scared due to a lack of understanding of the diagnosis, denied the severity of the illness and fear of death.

The response to dialysis treatment also featured strong fear. The reasons for fear given by the men ranged from fear of the unknown, as well as fear due to historical factors that included bad treatment of themselves and family members within the hospital setting. Fear was also a central response of family members who were also concerned with historical memories of serious illness and engagement with health professionals (Kebler-Ross, 1969).

Chapter 5. Conclusion

This thesis examined the perspectives of Koori men accessing dialysis treatment. The main finding, although numbers were small, was that access to dialysis treatment is acceptable for the Koori men who participated in the study and utilised the Victorian Aboriginal Health Service (VAHS). Access and support given to the participants by VAHS included transport in the form of taxi vouchers and bus pick-ups and drop-offs. Support from staff at VAHS was acknowledged as superior to that of mainstream hospitals. The findings on Koori men's access to dialysis services hospitals were generally positive, however there were some issues from the men regarding the attitudes of some of the doctors at hospitals. Hence the data support development of a more user-friendly mainstream health service for Koori men, which is in line with cultural protocol. Other themes which were identified in analysis of interview transcripts included the importance of social support from family, a lack of knowledge about medical aspects of renal disease, fear of dying, fear of the unknown and historical responses that may inhibit access. The results in this study have important implications for service provision for Koori men with ESRD (the limitations of the study notwithstanding). The study highlights that positive relationships can be established between mainstream hospital staff and Koori patients. However, it is important that mainstream hospitals continue to examine and improve their policies on Koori relationships and access by supporting ICAP and other Koori initiatives that allow a more equitable and user-friendly service for all Koori people, including better communication with patients and their families, and consideration of the strong emotional responses of Koori men to diagnosis and treatment of ESRD and the historical resonances associated with mainstream health care providers.

My aims in this research were to document perspectives of Koori men accessing dialysis treatment, to empower Koori men by giving them a channel to voice their views on their access to dialysis treatment, and to provide feedback for the administration of a user-friendly health care system for Koori men, by highlighting the views of Koori men currently being treated for ESRD. With this I noted emergent themes from the data that indicated Koori men accessing dialysis and impending dialysis was strong with emotional and historical resonances. The study, although relatively small, provided some important insights into the experiences and perspectives of Koori men accessing dialysis treatment. All four of the men reported powerful emotional responses, including shock, denial, grief, anger and fear. All four men reported fear as a driving emotion to being diagnosed with kidney disease and fear was also a predominant response to engaging with dialysis treatment. Fear also stemmed from historical stories shared within the families regarding treatment of Aboriginal members by what is perceived as the 'White' health system.

Limitations

I do not claim that the sample of Koori men in the current study represent the views of all Koori men accessing dialysis treatment. The sample size is appropriate as a pilot study, with the findings available to guide further research and enquiry. The barriers to gaining interviews with Koori men accessing dialysis treatment presented many problems which limited further exploration of the identified themes within the time available. Moreover, the limitation of this study was that all of the men interviewed accessed the Victorian

Aboriginal Health Service which does not represent all Koori men accessing dialysis treatment.

Next steps

Research

As recruitment for this study was from only one metropolitan site and the numbers were small, the findings can be used to guide further research and enquiry. The scope could have widened to include more sites around Melbourne to see if there is a consistency with the themes which emerged in this study. It would also be useful to establish a comparative study asking the same questions of Koori men from country and rural Victoria, to elicit whether the themes of importance to them are the same.

The voices of Koori men accessing dialysis treatment are vastly under-represented in the political, social and medical research literature, particularly when it comes to providing feedback for the administration of a user-friendly health care system. However, when they do speak, they are powerful voices. Koori men are in the best position to be able to determine the way access is provided to them and impact changes to the system. However, stigma through historical landscapes is never far away and impacts on the potential opportunities for these voices to be heard.

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