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ATTITUDES AND BELIEFS OF PATIENTS WITH CHRONIC KIDNEY DISEASE IN THE RUSTENBURG AREA, NORTH WEST REGARDING KIDNEY DYSFUNCTION

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Research Report submitted to the
Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfillment of the requirements for the degree
Of

Master of Science in Nursing

Johannesburg, 2015

DECLARATION

I, Magdeline Njoro, hereby declare that this research report is my own work. It is being submitted for the degree of Master of Science in Nursing at the University of the Witwatersrand in Johannesburg. It has not been submitted before for any degree at this or any other University.

Signature _____

Date _____

Protocol number: M130734

DEDICATION

I dedicate this study to my late mother, my grandmother who was my pillar of strength and all the patients diagnosed with chronic kidney disease at dialysis unit where the study took place. A special thank you to all my participants, thank you very much sharing your experiences with kidney disease me, I am really grateful for your contribution in making this study possible.

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I am thankful to Almighty God for giving me the opportunity, the strength and wisdom to complete this study.

A special thank you to my husband who stood by me through out and never stopped believing in me. Your support, patience and words of encouragements enabled me to complete this study.

To my two daughters, Lesego and Palesa, thank you guys for your support, patience and understanding for neglecting you all the years during my study.
To my two sisters and brother, thank you for understanding when I could not join you for family gathering while I was working on this project. I am grateful to each and every one of you.

My sincere gratitude and special thanks also goes to the following:

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- My friends and colleagues in the renal unit, guys your support and words of encouragement kept me going, thank you very much.

ABSTRACT

Aim: The aim of this study was to investigate the attitudes and beliefs of patients with chronic kidney disease regarding kidney dysfunction in the Rustenburg area.

Background: Kidney disease is still regarded as a low risk disease in Rustenburg, particularly among the rural community with low literacy level. Some of the people believe that chronic kidney is caused by driving heavy duty vehicles and hard labour whilst some associate the symptoms of chronic kidney disease with cultural disease resulting from failure to undergo cultural practices after the death of spouse or life partner. Low awareness of kidney disease results in patients seeking traditional cure that may cause further deterioration of their kidney dysfunction and progress to end stage renal disease, and therefore need lifelong dialysis or kidney transplantation.

Research Methods: An explorative, descriptive qualitative research method was chosen for this study. Participants were patients with chronic kidney disease attending haemodialysis treatment at a dialysis unit of a level II public sector hospital. This dialysis unit provides both acute and chronic haemodialysis treatment and peritoneal dialysis training, and has eight chronic and two acute haemodialysis machines. Individual, face-to-face, semi-structured interviews were conducted using an interview guide (Appendix A). Participants were conveniently sampled until point of saturation was reached, and nine participants constituted the sample. Inclusion criteria were 18 years old and above, men and women, on haemodialysis for more than six months and willing to be interviewed. Patients who did not attend haemodialysis on the day of the interviews were excluded from the study. The interviews were audio-taped, transcribed verbatim and analysed according to Tesch's method of qualitative data analysis.

Significance of the study: This study uncovered the attitudes and beliefs of patients with chronic kidney disease regarding kidney dysfunction. Uncovering their attitudes and beliefs has enlightened nephrology nurses on future renal care initiatives that may improve both patients and the community's attitudes and beliefs regarding kidney disease.

Findings: The study has shown that chronic kidney disease has a profound and devastating impact on the patient, his family and significant others. The study further revealed that traditional healing and cultural health is still widely practiced by most of the patients with chronic kidney disease particularly in the rural areas. There is poor

awareness of kidney disease as well as risk factors associated with kidney disease among this community.

Conclusion: This rural population was not knowledgeable about kidney disease nor the risk factors associated with this condition. Nephrology nurses should conduct kidney awareness campaigns in order to educate the patients and public about kidney disease order to correct their attitudes and beliefs towards chronic kidney disease.

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CHAPTER ONE

OVERVIEW OF THE STUDY

1.0 INTRODUCTION

Chapter one is the overview of the research study. The reader is introduced to the background of the study, the problem statement, the aim and objectives of the study, the significance of the study and the researcher's assumptions are included. Measures to ensure trustworthiness of the study, ethical considerations, research methodology that was adopted and lastly is the study outline are included in this chapter.

1.1 Background of the study

Chronic kidney disease is a worldwide public health problem that affects mainly young adults who are still in their productive years in Sub-Saharan Africa (Sumaili, Cohen, Zinga et al. 2009). Marais and Jacobs (2014) reported in the South African Dialysis and Transplant Registry that 32.5% of kidney disease in South Africa was due to hypertension. Non-compliance with prescribed treatment results in grave complications such as chronic kidney disease.

Chronic kidney disease cannot be cured but can be managed and its progression may be slowed with angiotensin calcium exchange inhibitors or angiotensin receptor blockers and lifestyle adjustments. However, the diagnosis may be unacceptable and difficult to understand for many patients and their families, based on their attitudes and beliefs for instance, "there is no such thing as incurable disease" (Tan, Hoffman and Rosas 2010:106).In a study on perception of hypertension Anthony, Valinsky, Inbar et al. (2012) showed that 66% of the patients who had difficulty accepting the diagnosis of hypertension were influenced by their knowledge and beliefs about hypertension.

According to Ibrahim, Desa, Chiew-Tong (2011) the chronicity of kidney disease affects how the patients see themselves or relate to others and this may add to their stressful situation and therefore a desperate need to find a cure. At this stage the type of treatment that the patients or their families sought will depend on what they believe have caused the illness, which may be culturally influenced (Atobrah 2012).

According to van der Hoeven, Kruger and Greeff (2012) different cultures may differ in their understanding of chronic disease and its treatment. If cultural causes of the disease

such as witchcraft or ancestral problems are suspected, traditional healing methods are often sought (Mphuthi, 2010). In modern society cultural perceptions of illness may be considered as old fashioned (Lakika, 2011). However, anecdotal evidence shows that in South Africa most of the patients particularly in the rural communities, often seek traditional help for their chronic kidney dysfunction. These patients often when they present themselves at the health care facilities for medical help, their kidneys dysfunction may have progressed to end stage needing dialysis treatment.

In South Africa traditional herbal medicine is widely used for primary health care (van der Hoeven, et al. 2012).The World Health Organization (2000) define traditional medicine as the sum of knowledge, skills and practices based on the theories, beliefs and experiences of different cultures that are used to maintain health, to prevent, diagnose, improve or treat physical and mental illnesses. Most of the people who use traditional medicines consider them natural and safe (Torri 2013). However, according to Kara (2009) herbal products may be dangerous in patients with failing renal function. In addition to that, in a nephrology seminar report on natural medicine Vivekanand and Manish (2008), pointed out the renal toxicity and other adverse effects of traditional herbal remedies. On the other hand, seeking traditional help first often delays early diagnosis and initiation of proper medical intervention.

The kidneys are the main organ for excretion of most of the substances in the body, including herbal substances (Vivekanand 2010). When the kidneys are damaged, they are unable to eliminate normal waste products including these herbal substances as well as maintaining fluids and electrolytes balance (Morton and Fontaine 2009).
“If diagnosed early, patients with chronic kidney disease can be successfully managed with renal protective medication” McManus (2011). Unfortunately, the early stages of chronic kidney disease have no recognisable warning signs (Thomas-Hawkins and Zazworsky 2005). To add to that, Kara (2009) pointed out that some of the patients who used traditional medicine before seeking medical treatment do not often admit to having used herbal medication.

When the kidneys have lost renal function, renal replacement therapy is often initiated. Renal replacement may be in the form of dialysis (haemodialysis or peritoneal dialysis) or kidney transplantation (Mucsi 2008). Although renal replacement therapy may improve the patients’ quality of life, the three renal replacement therapies are not without challenges particularly for the patients and their families. The patient who is receiving

dialysis therapy may feel overwhelmed by treatment demands and lifestyle changes that come with chronic kidney disease.

Additional factors are the minimum dialysis resources particularly haemodialysis slots, lack of kidney donors resulting in limited transplantation (Naicker 2003) and transplant rejection. In addition, “rationing of services” limits the accessibility of renal replacement therapy for patients with chronic kidney disease in the public sector in South Africa (Naicker 2010). Nevertheless, unless patients with chronic kidney disease receive kidney transplantation they will need to continue with lifelong dialysis, diet and lifestyle adjustments (Ibrahim, Desa and Chiew-Tong 2012).

The number of patients with end stage kidney failure receiving dialysis treatment in South Africa is increasing rapidly. The “latest reliable report of the South African Dialysis and Transplant Registry in 2012 showed that 8559 patients (52.3 per million populations) were on treatment for end-stage renal failure” (Marais and Jacobs 2014:12). This indicates the need for more educational interventions to prevent or slow the progression and the prevalence of chronic kidney disease.

On the other hand, activities like world transplant games, education programs such as the annual International World Kidney Day and Kidney Awareness Week are intended to provide kidney awareness worldwide. However, ignorance on the part of the community, and or inability to access the media for this awareness campaigns information and inability of health care practitioners to reach all target groups including the people in the rural communities may render these activities ineffective.

Despite the availability of dialysis therapy to sustain the lives of patients with chronic kidney disease some of the patients seem to favour traditional healers (Lotika, Mabuza and Okonta, 2013). This strong belief in traditional healers and traditional healing methods could stem from the knowledge about traditional medicinal plants acquired from their elders. Furthermore, traditional healing practice is considered African, and could be the way of people identifying themselves with their cultural background. Some of the people, particularly in the rural community, may not be familiar with chronic kidney disease (Sengwana and Puoane 2004), adding to their frustration about the diagnosis. In addition, the patient or family may not believe the medical diagnosis and may want to seek confirmation or cure from the traditional healers. However, whatever the reasons the patient has, Saleem, Hassali, Shafie, et al. (2011) state that patients suffering from

chronic conditions tend to employ self-management strategies that often result in worsening of symptoms.

The communities of Rustenburg are mostly the Tswanas, and have their own cultural beliefs about health, illness and healing methods. Anecdotal evidence shows that majority of patients with chronic kidney disease in Rustenburg consult traditional healers for a cure after being diagnosed with chronic kidney disease. This results in patients not accepting their diagnosis and delaying seeking proper medical help (Mesfin, Newell, Walley, et al. 2009). They only seek hospital help when their condition has already progressed to chronic kidney disease.

Sulimaili et al (2009) state that early warning signs of chronic kidney disease can be detected during routine renal screening. Unfortunately, Osamor (2011) found that most of the villagers prefer to consult traditional healers when they are sick before seeking professional care. Faith in traditional healers interferes with early diagnosis and effective management of chronic kidney disease (Goldstone, Mokone, Mongangane, 1978). The negative attitudes towards the diagnosis and non-adherence to recommended treatment lead to unfavourable clinical outcomes in patients on maintenance haemodialysis (Kim and Evangelista 2010).

In her encounter with patients in the renal unit, the researcher confirmed acknowledgment by most of the patients of having consulted traditional healers and used traditional remedies after being diagnosed with chronic renal disease. This prompted the researcher to investigate the attitudes and beliefs of patients with chronic kidney disease regarding kidney dysfunction and its treatment. Positive attitudes towards chronic kidney disease and its treatment may facilitate the patients' adjustment to the disease, and in turn improve their quality of life.

1.2 PROBLEM STATEMENT

Every culture has its own beliefs about health, illness, illness causality and treatment, or healing methods. Despite the availability of modern medical technologies proven to improve the quality of life in the management of chronic kidney disease (Kara 2009), poor awareness of chronic kidney disease influenced by cultural beliefs about causes and treatment of kidney dysfunction poses a major challenge for the renal team in the Rustenburg area.

The community of patients at the public hospital in Rustenburg, in the North West Province is largely rural and traditional community mainly from the Tswana cultural group, many of whom first seek assistance from traditional healers for their chronic health problems, based on their cultural beliefs about illness and illness causality. Anecdotal evidence shows that majority of patients with kidney dysfunction consult traditional healers for cure before or after being diagnosed with chronic kidney disease. This result in patients presenting late at health care facilities when their kidney dysfunction has already progressed to chronic kidney disease requiring renal replacement therapy.

It is therefore important that nephrology nurses acquire an understanding their patient's attitudes, cultural beliefs and practices about health and their healing methods. The information gained from the participants of this study may provide nephrology nurses with valuable information for informing on kidney awareness. According to Chang and Kelly (2007) an understanding of cultural influences on health care practices will enable the nephrology nurse to effectively individualize renal teaching plan. Educating the patients and the community of Rustenburg about kidney dysfunction will improve their attitudes and beliefs towards chronic kidney disease. This will ensure that patients pay attention to their kidney problems and seek professional help earlier. Community awareness of kidney disease is important in order to slow the progression of kidney dysfunction and better management of kidney dysfunction in future.

1.3 AIM OF THE STUDY

The aim of the study was to investigate the attitudes and beliefs of patients with chronic kidney disease regarding kidney dysfunction in the Rustenburg area.

1.4 RESEARCH QUESTION

What are the attitudes and beliefs of patients with chronic kidney disease at a level II public hospital regarding kidney dysfunction and its treatment?

1.5 OBJECTIVE OF THE STUDY

- The objective of the study was to explore and describe the beliefs of patients with chronic kidney disease regarding kidney dysfunction.

- To explore and describe the attitudes of patients with chronic kidney disease regarding the management of kidney dysfunction.

1.6 SIGNIFICANCE OF THE STUDY

This study will uncover the attitudes and beliefs of patients with chronic kidney disease regarding kidney dysfunction and its management. Uncovering the patients attitudes and beliefs towards the management of kidney dysfunction may provide nephrology nurses with valuable information that will together with the patients' inputs help to develop appropriate and effective health education strategies to improve community awareness of kidney disease in order to prevent or slow the progression and better manage kidney dysfunction in future.

1.7 OPERATIONAL DEFINITIONS

According to Burns and Grove (2007) operational definitions derive from set of procedures or progressive acts that a researcher performs to receive sensory impressions that indicate the degree of existence of a variable. Operational definitions that are consistently used in this study are as follows:

Patient: a patient is a physical, social and psychological human being who is having health problems or health needs that are not met. For the purpose of this study, patient means a person diagnosed with irreversible chronic kidney disease.

Chronic kidney disease: Is a well-known concept used in nephrology which refers to damage to the kidney. Morton and Fortaine (2009) define chronic renal failure as irreversible damage to the kidney tissue resulting in the kidneys inability to maintain fluid and electrolyte balance and excrete waste products

End stage renal failure: According to Kidney Disease Outcomes Quality Initiative (2002) end stage renal failure refers to patients whose renal function has irreversibly deteriorated to a point that they are eligible for, or are receiving renal replacement therapy

Attitudes: A manner of thinking, feeling or behaving that reflects a state of mind or disposition. (American Heritage Dictionary of English Language, 2011). For the purpose of this study, attitudes refers to the way patients with chronic kidney disease and think about kidney dysfunction and their behaviour towards healing or treatment methods, which can be either positive or negative.

Beliefs: Are a collection of thoughts, ideas and concepts moulded by education, culture, religion and parental and family influence which play a major role in opinion and

behaviour (Random House Kernerman Webster College Dictionary, 2010). For the purpose of this study, beliefs refer to(cultural, western or religious) practices that influence patients with chronic kidney disease regarding kidney dysfunction, causes and treatment.

Traditional healer: According to Krige (2014) is someone who is recognised by the community in which he lives as competent to provide health care by using vegetable, animal and mineral substances and certain other methods based on the social, cultural and religious background as well as the prevailing knowledge, attitudes and beliefs regarding physical, mental and social well-being and the causation of disease and disability in the community.

Traditional leader: is a respected member of the community, may be elected or born and is recognised by the community as their leader.

According to Seiketso (2005) boswagadi (widowhood) refers to a cultural disease that is sexually transmitted if the remaining partner did not comply with mourning and ritual requirements. According to Tswana culture when a person's spouse dies, the remaining partner must abstain from intercourse for a certain period, and be cleansed so he or she does not make any new partner ill.

Sejeso: According to Golooba-Mtutebi and Tollman (2007) sejeso is something once ingested turns into live organism that move about and eats the victim from inside the body.

Muthi: Refers to traditional medicines made primarily from plants or animals dispensed by herbalist or traditional healers.

1.8 OVERVIEW OF RESEARCH METHODOLOGY

A qualitative, exploratory, descriptive and contextual design was chosen as the most appropriate research approach to gain the information required in this study. Exploratory-descriptive qualitative research is conducted with the purpose of exploring and describing a topic of interest. According to de Vos, Strydom, Fouche and Delport (2011:46) "qualitative approach is used to answer questions about the complex nature of phenomena, with the purpose of describing and understanding the phenomena from the participant's point of view".

Data obtained from qualitative research is subjective and incorporates the beliefs of the participant and the researcher alike (Burns and Grove 2007). For the purpose of this study, the subjective beliefs of patients with chronic kidney disease are regarded as a valid source of information because they are experiencing the illness. In this study it is

assumed that attitudes and beliefs regarding kidney illness would best be described by patients with chronic renal illness themselves.

1.8.1 Research Design

Polit and Beck (2012: 22) define research design is "an overall plan for obtaining answers to the questions being studied, indicate where the study took place, how data were collected and how data were analysed. A qualitative research design was chosen for this study. According to Burns and Grove (2007:24) qualitative design is a systematic, subjective approach, used to describe people's life experiences and give them meaning. The main focus of qualitative research is to gain insight into the people's attitudes, behaviour, value system, concerns, motivations, aspirations, cultures and lifestyle (Jooste 2010). In this study, the attitudes and beliefs of patients with chronic kidney disease regarding kidney dysfunction will be explored and described using an exploratory descriptive and contextual design.

Explorative research design

According to Jooste (2010) exploratory research is conducted in order to provide a better understanding of a situation. Polit et al (2012:24) further state that "exploratory qualitative research is designed to shed light on the various ways in which a phenomenon is manifested". According to de Vos et al (2011) exploratory research can provide very rich, meaningful information or definitive explanations for particular individuals. Exploratory research is conducted when the researcher encounters issues that are already known but wants to know why things are the way they are". In this study the researcher intends to explore the attitudes of patients with chronic renal disease living in the Rustenburg area, in order to gain insight into their attitudes and beliefs towards kidney dysfunction and its treatment.

Descriptive research design

Burns and Grove (2007), state that descriptive research is designed to gain more information about characteristics within a particular field of study. In qualitative descriptive design, the researcher "identifies a specific lack of knowledge that can be addressed only through seeking the viewpoints of the people most affected" (Grove, Burns and Gray 2013:66).

Furthermore, descriptive qualitative studies "present the comprehensive summaries of a phenomenon or of events" (Polit and Beck 2012:26). In this study the attitudes and beliefs

of patients with chronic renal disease living in the Rustenburg area, were best described by the patients experiencing the disease.

Contextual

This study is of contextual design. According to Botma et al (2010), in a contextual study data are only valid in a specific context and findings are not necessarily generalized. The researcher focuses on specific phenomena because of their intrinsic and immediate contextual significance. This study was conducted in the dialysis unit of a level II public hospital in Bojanala district in the North West province. The unit was officially opened in 2012 and patient using the service of this dialysis unit are mainly Tswana people in and around Rustenburg. Many patients receiving dialysis at this unit are unemployed and are using public transport to and from their dialysis sessions.

1.9 OUTLINE OF THE STUDY

The remainder of this research study is as follows:

Chapter Two: Literature review

Chapter Three: Research design and research method

Chapter Four: Results and findings and

Chapter Five: Discussion, limitations and recommendations

1.10 SUMMARY

Chapter one is the overview of the research study and it presented the outline of the study, the problem statement, purpose, research questions and objectives and significance of the study of has been described. The assumptions of the researcher have been discussed and the operational terms defined.

The following chapters will include a review of the literature, the methodologies, data analysis, the description and interpretation of research findings. The final chapter presents the discussion of the study findings, limitation of the study as well, and recommendations for future research and conclusions.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter introduces the literature reviewed for the purpose of this study. According to De Vos, et al (2011), literature review is aimed at contributing to a clearer understanding of the nature and meaning of the problem that has been identified. Since the focus of this study is on the attitudes and beliefs of patients with chronic renal disease regarding kidney dysfunction and its treatment, literature pertaining to attitudes, knowledge practice and beliefs towards chronic disease, culture and chronic diseases, help seeking behaviour and behaviour change have been reviewed.

2.2 SEARCH METHODS

In order to review literature on attitudes and beliefs of patients with chronic kidney disease an online search for published and unpublished articles were retrieved through the following data bases were; Google scholar, Pubmed, BiomedScienceDirect, African Journals Online, Medscape and SAGE. Although the initial search was for articles that are five year old or less some of the outdated article were included because they were relevant to the current study. Only English articles were reviewed. Excluded were articles on transplantation since this is a topic on its own.

The Harvard referencing style was followed. Since many of the citations contain multiple authors, I have selected to insert the first three authors for the first citation and thereafter only the primary author, in the document. In the reference list all authors are cited.

2.3 CHRONIC KIDNEY DISEASE AS A CHRONIC DISEASE

World Health Organization (2008) defines chronic diseases as a disease of a long duration and generally slow progression. Most of the chronic diseases cannot be cured but can be controlled and managed with treatment. Puoane, Tsolekile, Sanders, et al. (2008) state that chronic non-communicable diseases are largely due to preventable and modifiable risks factors such as high blood pressure whilst diet and lifestyle modification may reduce the risk factors. On the other hand, Thomas (2008) defines chronic kidney disease as irreversible damage to the kidneys characterized by inability of the kidneys to maintain fluid and electrolyte balance and excrete waste products from the body.

Chronic kidney disease is a worldwide public health problem, both in developed and developing countries affecting mainly young adults in Sub-Saharan Africa (Sumaili et al. 2009). In a recent review article on complications of chronic diabetic mellitus in Africa Tesfaye and Gill (2011:45) reported that “diabetic nephropathy was the major cause of end stage renal disease in Sub-Saharan Africa”. Adding to available data on chronic kidney disease Naicker (2010), estimated that 45-52% of patients on renal replacement therapy in South Africa were as a result of hypertension and glomerulonephritis. In 2012 the South African Dialysis and Transplant Registry, reported that 8559 patients (52.3 per million populations) were alive and on renal replacement therapy for end-stage renal failure (Marais et al. 2014).

Chronic kidney disease is associated with an increased risk of cardiovascular disease and death (Tan et al. 2010). Theofilou (2011) assessed the health beliefs and quality of life in end stage renal disease and found that the high burden of cardiovascular comorbidities affect the quality of life of the patients and dramatically shorten their life expectancy.

An increase in the number of patients needing dialysis will have an impact on the already over stretched dialysis resources in South Africa. Since “1994, the population of South Africa has increased from 40.4 to 52.3 million people and (83.4%) of the population rely on the public health sector for services, with only a small proportion, about (16.6%) covered by medical insurance and being serviced by the private sectors” (Marais et al 2014:10). Furthermore, Theofilou, (2011) stated that as the cost of death and disability due to chronic kidney disease rise, productivity particularly in the developing countries will significantly reduce economic growth

Unless kidney donors are available for transplantation, patients with end stage renal disease undergo lifelong dialysis therapy. Unfortunately, rationing of renal services in South Africa limits the accessibility of renal replacement therapy in the public sector (Naicker 2010).

The incidence of end stage kidney disease requiring dialysis continues to increase at an alarming rate despite the available treatments to slow the progression of kidney disease (South African Dialysis and Transplant Registry 2012). As stated earlier, the progression of kidney disease can be slowed, therefore the challenge lies upon nephrology nurses to develop and implement effective health education programs to improve awareness of chronic kidney disease in their communities. According to Plantinga, Boulware, Coresh

(2008) better management of patients with chronic kidney disease can slow the progression of the disease which depends largely on early recognition of the disease. However, medication adherence is affected by patients' beliefs about their illness and treatments (McManus 2011). Patients with positive attitudes towards chronic kidney disease and belief in the manageability of the condition will facilitate effective management of their condition.

Nephrology nurses should be aware of their patients' attitudes and beliefs towards kidney dysfunction and its treatment in order to better manage patients with kidney dysfunction in future. This study sought to explore the attitudes and beliefs of Tswana patients with chronic kidney disease regarding kidney dysfunction and its treatment.

2.3 ATTITUDES, KNOWLEDGE AND BELIEFS ABOUT CHRONIC KIDNEY DISEASE

According to Timmers, Thong, Dekker, et al. (2008) once a diagnosis of chronic kidney disease has been made, the patients will create their own models and representation of the illness in order to make sense of, and respond to the illness they are faced with. Atobra (2012) states that culture greatly influences how the patient will respond to the disease and their choice of treatment they will make. If the patients believe that the cause of their illness is supernatural or witchcraft they are more likely to seek traditional or spiritual healing (Atobrah, 2012).

An article on anthropological issues in renal care Crowley-Matoka (2013) examined the beliefs and practice that people in some of the European countries have regarding their kidneys. In this study Matoka found that in the United States kidneys are culturally less important, whilst in China the kidneys are of vital importance. Based on how they perceive their kidneys, Chinese are more likely to take care of their kidneys than in the United States.

The absence of the signs and symptoms of the disease on the other hand, may lead to patients not accepting their condition and become non-compliant. A study on perception of hypertension Anthony et al. (2012) showed that 66% who had difficulty accepting diagnosis of hypertension were influenced by their knowledge and beliefs about hypertension.

In another study Costantini, Beanlands, McCay et al. (2008) explored the self-management experience of people of people with mild to moderate chronic kidney disease. The study found out that the absence of signs and symptoms of an illness is a barrier to self-care since the patients cannot make the link between the need for medications and feeling well. This may result in the patients underestimating the seriousness of their condition (Thomas-Hawskins and Zazworsky 2005).

Most of the patients including those who are at risk of developing chronic kidney disease lack knowledge about chronic kidney disease. Regrettably, even some of the patients who have been diagnosed with chronic disease do not understand the disease. Wilkinson, Randhawa, Farrington (2011) assessed awareness of renal complications in diabetes mellitus and they found that familiarity with diabetes did not lead to awareness and understanding of diabetes renal complications. Similarly, a cross-sectional survey aimed at assessing the patients' awareness of chronic kidney disease Plantinga et al. (2008) found poor awareness of chronic kidney disease in patients with stages 1- 4 chronic kidney disease.

Poor awareness of chronic kidney disease might be due to various reasons. It could be lack of effective health education strategies to address the patients' level of understanding or inadequate knowledge on the part of healthcare professional. The other reason may be a lack of knowledge about the seriousness of the condition or ignorance on the part of the patient or due to the absence of the symptoms of the disease as stated by Costantini et al. On that note, Boulware, Carson, Troll (2009:1127) concluded that "low perceived risk and concern regarding chronic kidney disease development or progression among hypertensive and diabetes may reflect lack of knowledge of chronic kidney disease".

Several studies have documented factors that may influence the patients' attitudes toward chronic kidney disease. Age of the patient at the time of a diagnosis with a chronic disease plays an important role in the attitudes and beliefs of the patients toward the disease. Kara (2009) investigated the attitudes of patients with chronic kidney disease undergoing dialysis in Turkey, and found that elderly patients had accepted their condition as terminal and opted for palliative care. However Thomas (2008), found that the diagnosis of chronic kidney disease was more devastating for young patients. In contrast, in her study Atobrah (2012:50) stated that "narratives by young people specified that they readily accepted chronic disease diagnosis without showing any feelings of denial".

The acceptance on the part of the elderly could be due to the fact that elderly patients might feel that they have lived long enough, that they are ready to die. Patients who show positive attitudes towards chronic kidney disease are able to adapt easily and are able to positively live with the condition.

Furthermore, due to the nature of the disease and its demands on lifestyle, psychosocial problems are also common in patients with chronic kidney disease and may put a lot strain on them. Morton, Tong, Howard et al. (2010) studied the views of patients and carers in treatment decision making for chronic kidney disease and found that “most of the patients and their families perceived chronic kidney disease as a life threatening disease that caused a lot of uncertainty about their future”.

According to Partridge and Robertson (2010) the prevalence of anxiety and depression in adult dialysis patients ranged between 24.7% and 18.6%, with high levels of body image disturbance in for both male and female respondents respectively study on illness perception and depression in patients with end stage kidney disease, Ibrahim, et al. (2011:221) found that depression was a common psychological problem among Malaysian patients with end stage renal disease.

Negative attitudes towards chronic disease as manifested by emotional response might stem from difficulty accepting the diagnosis and treatment to lack of proper counselling after being diagnosed and lack of support structures. However, a study aimed to evaluate end of life-care preference and needs of patients with chronic kidney disease in Canada, Davison (2010) found most of the study participants have accepted chronic kidney disease as a terminal disease and were willing to discuss end of life issues with family and nephrology staff. Negative attitudes towards chronic kidney disease delay adjustment to the disease whilst positive attitudes help the patients make meaningful decisions about their lives. Kim and Evangelista (2010:271) “state that negative perception of disease may lead to unfavourable clinical outcomes in patients on maintenance haemodialysis”.

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2.4 CULTURAL PRACTICE AND CHRONIC KIDNEY DISEASE

Cultural beliefs play an important role in determining the people’s attitudes and beliefs towards chronic disease. According to Leininger (1985) culture is learned, shared, and transmitted values, beliefs, norms, and life ways of a specific individual or group that guide their thinking, decisions, actions, and patterned ways of living.

Cocks and Moller (2002) found that using medicines to cleanse the body through purging is common a practice, and is believed to be a “cure all” among Africans. In their study

Cocks et al. (2002) also examined the use of traditional medicines for customary purposes. One example is that of curing boswagadi [widowhood] (Seiketso 2005). On the other hand, Shaw, Huebner, Armin, et al. (2008) state that in some cultures patients with diabetes may be reluctant to modify their eating habits when they feel that the recommended changes require them to give up culturally meaningful habits and practices for example, fasting as related with Muslim religion.

The treatment method that is decided on may be based on advice from a family member, friends or peers based on their attitudes and cultural beliefs. However, the type of treatment that the patient will follow will impact on the disease outcome, either positively or negatively.

2.4.1. Impact of culture on chronic kidney disease

Although chronic kidney disease cannot be cured, the progression of chronic kidney disease can be slowed with renal protective medication" McManus (2011). When end stage kidney renal failure is diagnosed dialysis therapy can be initiated in order to sustain the life of the patients. However, cultural practices may impact on the management of chronic kidney disease. If patients or the family members strongly believe that there is a cure for the disease, it may be difficult to convince them otherwise. The patient or family members may refuse hospital treatment and leave and leave the hospital to seek different healing methods. As indicated by Osamor (2011) some of the patients or family members may continue to consult different healers even if there is no improvement with traditional healing methods.

In "South African black culture everything happens for a reason" (Mphuthi 2010). Chronic disease may be attributed to the ancestral anger or witchcraft, and help or treatment will be sought from a traditional healer who will advise on an appropriate solution, for example a cleansing ceremony to ask for forgiveness from the ancestors or to cast out the evil spells.

According to Fyhrquist (2007) medicine is widely used by many South African people for their primary health care. However nephrotoxic potential of herbal remedies is being increasingly recognised (Vivekanand 2010:11) according to Naicker (2010) the intrinsic functions of the kidney expose them to high concentration of toxic substances.

Vivekanand and Manish (2008) found that most of the patients admitted to South African hospitals with acute renal failure followed the use of traditional remedies. In addition, about 60% of the cases that were hospitalised were severe and required dialysis (Vivekanand et al. 2008). A study in Bangladesh by Hossan, Hanif Agarwala et al. (2010)

found that traditional plants are used treat some ailments such as sexually transmitted diseases and urinary problems. In another study in Turkey, Kara (2008) found that some herbal products are used to prevent kidney failure. However, Vivekanand (2010) maintains that patients with pre-existing chronic kidney disease can develop complications due to herbal medicine.

Furthermore, some of the patients may receive lay advice from friends or family elders and self-medicate with medicines bought over the counter or use home remedies. In a study on use of complementary and alternative medicines in Australia, Armstrong, Thiébaut, Brown, et al. (2011) found that most of the chronically ill population use complementary or alternative medicine to treat their chronic condition". According to Armstrong et al. (2011), alternative or complimentary medicines are vitamin/ mineral supplements or natural/herbal treatments, whether they are prescribed or bought over the counter.

According to Cocks and Moller (2002) self-medication using traditional Xhosa remedies bought at *amayeza* stores (chemist) is the first choice when illness is diagnosed and it is common practice among most African population. However, the safety of all these medicines that are not prescribed remains a concern, particularly in patients with impaired kidney function. Torri (2013:27) argues that firstly, these "herbs sold as food supplements or as over-the-counter items are unlicensed, secondly, are not regulated by the Federal Drug Administration with the same scrutiny as conventional drugs, and thirdly, there may be risks of contamination or adulteration with poisonous metals, and non- declared herbs or conventional medicines".

On the other hand, some of the lay community may associate chronic kidney disease with unsafe living conditions. The perception that the patients have about the causes of their chronic kidney disease may result in them not seeking help for kidney problems.

2.4.2 Spirituality and chronic disease

According to Finkelstein, et al (2007), spirituality refers to an attempt to understand the meaning and purpose of life and in patients with chronic kidney disease spirituality reflects a broader interest in quality of life issues.

It is common for some of the patients, particularly those who are diagnosed with chronic disease to seek spiritual help for healing or to cope with the disease. As evidenced by recent mass media regarding the different denominations, spiritual healing also plays an important role in the lives of patients with chronic illness. However, the concept of spirituality may be understood differently by individuals or societies based on their cultures and beliefs. Regrettably, according to Finkelstein, West, Gobin et al. (2007)

some of the patients may misunderstand spiritual cure and abandon hospital care or prescribed treatment in favour of spiritual healing.

Religion is a powerful source of hope, meaning in life and peace of mind in patients with end stage renal disease Ibrahim, et al. (2012).

In another study on the treatment of epilepsy in the rural community of Northern Tanzania, Winkler, Mayer, et al. (2010:162) found that "34.1% of the participants believed that Christian prayers can cure the cause or treat the symptoms of epilepsy".

In a study on knowledge of hypertension among traditional healers, Meli, Nken-Chunag, Doutsop (2009) found that some of the traditional healers who believed that hypertension results from non-respect of traditional rites, suggested spiritual healing methods for their patients. Furthermore, Finkelstein et al. (2007) found that there was longer survival for those patients who were more religious.

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2.4.3. Impact of culture on compliance

Non-compliance to prescribed treatment is still a major problem especially among patients with chronic diseases. Compliance to medication can slow the progress of the course of the disease, reduce development of complications and prevent morbidity and mortality" (Ibrahim, Jirjees and Mahdi 2011). Cultural beliefs about chronic diseases interfere with the effective management of chronic diseases, for example a patient with chronic kidney disease upon becoming a widow/widower, depending on their cultural beliefs may be required to undergo cleansing ritual by drinking traditionally brewed medicine for a certain period to cure boswagadi (widowhood).

Cocks and Moller (2002) did a case study on the use of indigenous and indigenised medicines to enhance personal well-being in South Africa. In this case study they found that applying medicines to purge or clean the body internally taken as an emetic or enema to prevent or to cure an illness is a common health practice among Africans.

A study carried out in Gauteng province in South Africa, found that "hypertensive patients with poor blood pressure control were also taking traditional medicine concurrently with western medicine" (Lotika et al. 2013:2). Furthermore, a study on perceptions and experiences of a patient on anti-retroviral therapy in Gauteng by Mongwenyana (2012:35) revealed that "patients stopped taking their anti-retroviral medication on the advice of traditional healers with the belief that the patient has been bewitched". On the other hand, in a study that explored patients', traditional healers' and psychological counsellors' perception of illness, Zondo (2008) found that traditional healers valued the importance of western medicine and has been referring their patients for the treatment of chronic diseases like human immune virus, diabetes and imikhuhlane (common colds) However, McManus (2011:3) maintains that the "patients' beliefs about their illness and treatment

affect adherence." A patient with chronic kidney disease with swollen legs who believes that he has been bewitched because he walked over muthi may not accept the diagnosis thus not comply with prescribed treatment.

2.4.4. Cultural lifestyle and chronic kidney disease

Culture, as previously defined by Leininger (1985) guides the thinking, decision and action of an individual or a group. Obesity due to rapid urbanization and change in lifestyle predisposes people to hypertension and type II diabetes (Puoane, et al. 2008). Hypertension and diabetes affect all age groups, men and women, irrespective of one's socioeconomic standing. However, there are still widespread misperceptions about hypertension and diabetes mellitus.

In their study on the difference in help seeking behaviour in South Africa, van der Hoeven et al. (2012) pointed out that chronic diseases are associated with persons of high socio-economic status whilst infectious diseases are only prevalent among persons of low socioeconomic status. A person from a poor background may deny or ignore a diagnosis of hypertension or diabetes which could lead to serious complications including renal complications.

Puoane et al. (2008:79) examined measures for the prevention of non-communicable disease in South Africa and stated that "beliefs and attitudes about body image such as "thinness" are associated with personal problems or Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome is a barrier to maintaining a healthy body weight". However, maintenance of a healthy weight through diet and physical activity reduce the risks of developing hypertension Puoane et al. (2008). These beliefs about disease could be a potential key barrier to healthcare seeking and adoption of preventative measures (Gulshan et al. 2011).

The association of chronic diseases with a person's social standing can also have a negative impact on the medical management of chronic disease. Puoane et al.(2008) further indicated that some of the people may ignore complying with healthy eating habits and maintenance of a healthy body weight in order to avoid being stigmatized, and may in turn develop hypertension or diabetes that may result in renal complications.

2.5 HEALTH EDUCATION AIMED AT BEHAVIOUR CHANGE

According to the World Health Organization 2002, health education refers to any combination of learning experiences designed to help individuals and communities to improve their health by increasing their knowledge or influencing their attitudes (www.who.int/topics/health.educ).

Mshuhqane, Stewart, and Rothberg (2012) state that health behaviour are actions of individuals, groups, and organisations that develop into consequences that include social change, policy development and implementation. In order to develop an effective health education plan for patients with chronic kidney disease, nephology nurses should first assess the patients' level of understanding, of the disease including their cultural beliefs about chronic kidney disease.

According to Thomas-Hawskins and Zazworsky (2005) assessing the patient's perceptions is important because firstly beliefs strongly influence self-management and supportive approaches should be tailored accordingly. On that note, Nkosi (2012:92) also concluded that "understanding all the causes of illness whether from ethno medicine point of view or from a bio-cultural perspective is important and must guide the approach to prevention and treatment strategies".

Secondly, nephrology nurses should consider the psychological readiness of their patients and their family members. Psychological preparedness will improve and enhance patient's understanding of the information being given and will cooperate during health education. If the patient or family members are struggling to accept the condition they should first receive social and psychological counselling before being given health education. According to Verschuren, Enzlin, Dijkstra et al. (2010) acceptance plays an important role in the psychological functioning of patients with chronic diseases.

Thirdly an appropriate teaching model for the patients should be developed. Lastly plan and agree with the patients on both dialysis slots, health education dates and times that suite them all in order to ensure full participation. Bodenheimer, Loring, Holman et al. (2002) highlighted two elements of the chronic care model. The first element of the model embraces collaborative care in which the renal team as an expert in chronic kidney disease and the patient as an expert in their care both share the responsibility and form partnership in the management of the disease.

As the main role player in this partnership the patient's health education needs should therefore be assessed by both the patient and the nurses who are planning the program. Addressing and treating the patient as clients rather than as a patients may boost their self-esteem and feel that their opinion are valued not as a patient but someone who can make a positive change in their lives. Health education programs that include easy to understand information on chronic kidney disease, the causes, including risk factors and management of the condition and importance of adhering to prescribed treatment will yield positive results. According to Vermeire, Hearnshaw, Van Rooyen et al. (2001) presenting health education in a clear and simple manner may correct the patients' perception and aid recall of information given.

Health education should focus on removing the possible barriers to seeking medical help for chronic kidney disease. All the patient's concerns and health problems should be taken seriously. The possibility of these liquid mixtures of worsening the condition of the patients with chronic kidney disease should be thoroughly explained to the patients and the family members. Educating and advising patients against the use of these medicines should be non-judgemental but rather be informative. Vermeire, Hearnshaw, Van Rooyen et al. (2001) suggest a coaching and non-judgemental approach and examination of what can achieved by the patient. A discussion time may be arranged as a one on one session depending on the patients' preference to provide an opportunity for personal questions and answer time.

The second element that Bodenheimer et al. (2002) highlighted is self-management education whereby the patients are taught techniques on how to manage their chronic kidney disease. Patients' health education program must be tailor-made to empower patient with basic knowledge and skills on how to cope with chronic kidney disease for instance, fluid management. According to Nunes, Wallston, Eden et al. (2011) more knowledge of disease increases patients' participation and self-management behaviours in patients with end stage renal disease. Furthermore, health education talks should emphasize that chronic kidney disease is not curable but manageable and the dangers of using of non- prescribed medicines should be stressed. Follow-up sessions on health talks given or one on one sessions should be done to evaluate the patient's understanding and behaviour and progress. Vermeire et al. (2001) state that in order to aid recall information given to the patient must be repeated, stressing critical points and the patients' understanding must also be checked through feedback.

In order to maximize health promotion intervention Vaughn, Jacquesz and Backers (2009) suggested the use of lay health workers for promotion of health education. Lay health workers can either be home based care assistants or community leaders who will be used as gatekeepers. Vaughn et al (2009) believe that lay workers are effective because being from the same community they are able to use their cultural knowledge when providing service to their community.

As described by Mphuthi (2010) social support is very important in the management of chronic kidney disease therefore, family members should be involved in every aspect of the patient's care. Health education aimed at behaviour change should focus on the patient's family. The family members should also be included in the health education planning and implementation. Mshunqane et al. (2012) suggested that health talks should not be given to the patient in isolation but should include the patient's family members.

Peer education may be a valuable patient education tool to facilitate effective learning. Patients can be encouraged to talk to each other and share information on how to cope with their disease on living with the disease. Funnel (2009) suggests that peers with the same problem for example strong cultural beliefs on traditional imbiza (traditional brewed mixture) can either be paired together or the one who has had a successful behaviour change coaching others.

Lastly, the importance of follow up and the reasons for honouring appointments should be explained and discussed with the patient during all health education sessions. According to Vermeire et al. (2001) non-compliance with scheduled appointment may create problems for health care delivery and also have important effects on health outcomes. Primary health care professionals working in the community close by and are often the first ones to see the patient before the hospital professionals, and they are therefore an important source of information at primary level. Thomas (2004) suggests that nephrology nurses should work with primary health care professionals and develop a patient-centred health education programme to empower patients to effectively manage their hypertension and diabetes mellitus focusing on renal care awareness. As indicated earlier, early diagnosis and treatment is important, therefore this partnership will also ensure early referral to the renal doctor/nephrologist.

Educational interventions aimed at empowering patients are successful in chronic kidney disease management (Erick 2012) Community awareness campaigns using radio and television talk shows and in local newspaper can be used to educate the public about kidney disease. Vapputuris, Hogan, and Shoham (2010) assessed community

perspectives on kidney disease and health promotion in North Carolina and participants suggested canvassing, mail, newspaper advertisements, and television spots to provide community with information on kidney disease. According to Pouane et al. (2008) a television educational program like Soul City was effective in educating the public and led to positive behaviour change towards diseases like hypertension. This program resulted in increased knowledge and awareness of high blood pressure, including adoption of lifestyle to prevent and treat hypertension (Puoane et al. 2008). The programme was also presented on radio in order to reach those who do not have television sets.

To add to that, Wakefield, Loken and Hornik (2010) pointed out direct and indirect methods to affect behaviour change using mass media campaigns.

- Directly:

Mass media can directly and indirectly reach and change behaviour of the whole population.

Mass media is aimed at evoking emotional response of the audience.

Mass media intend to affect individual decision making.

Remove or reduce the obstacle to change, help people adopt healthy or recognise unhealthy behaviours.

- Indirectly:

Mass media can set and increase agenda for discussion about a particular health issue.

Since media can reach a large audience, behaviour change can be influenced without the person being directly involved with the campaign.

Prompt public discussion on health issues that can influence behaviour change.

2.6 SUMMARY

This chapter has provided a review of the literature regarding chronic kidney disease as a chronic disease, attitudes and beliefs towards chronic kidney disease, impact of culture on chronic kidney disease and on compliance. Lastly health education for behaviour change. The next chapter the research methodology will be discussed.

CHAPTER THREE
RESEARCH METHODS

3.1 INTRODUCTION

This chapter presents the research methodology adopted for this study and includes the study design, the study setting, population, sample and sampling methods, the inclusion criteria, data collection methods as well as data collection procedure. Measures to ensure trustworthiness of the study and ethical procedures followed are also discussed in this chapter.

3. 2 AIM OF THE STUDY

The aim of the study was to investigate the attitudes and beliefs of patients with chronic kidney disease regarding kidney dysfunction in the Rustenburg area

3.3 OBJECTIVES OF THE STUDY

- The objectives of the study were to explore and describe the beliefs of patients with chronic kidney disease regarding kidney dysfunction.
- To explore and describe their attitudes and beliefs towards the management of kidney dysfunction.

3.4 RESEARCH DESIGN

An overview of the research design and methods used in the study will be discussed. The research design is the overall plan for obtaining answers to the question. According to Polit and Beck (2012), research design indicates the type of study, where the study will take place, how data were collected and how data were analysed. A qualitative approach was chosen for this study. According to Polit and Beck (2012), qualitative methods are useful for exploring the full nature of a little-understood phenomenon. In this study a qualitative exploratory descriptive approach was employed with the purpose of exploring and describing the attitudes and beliefs of patients with chronic kidney disease regarding kidney dysfunction

Qualitative Research

Qualitative research is a systematic enquiry. It tries to find meaning in something and usually addresses areas of human behaviour and existence. Qualitative research methods entail an in-depth exploration and description of a phenomenon (Botma, et al. 2010). Qualitative studies employ interviewing techniques in order to understand respondents' feelings, meanings, and behaviours. According to Jooste (2010) the focus of qualitative research is to gain insight into people's attitudes, behaviour, value system, concerns, motivations, aspirations, cultures and lifestyle In this study, the researcher sought to explore and gain insight into the attitudes and beliefs of patients with chronic kidney disease towards kidney dysfunction and its management.

Exploratory study

According to Jooste (2010) exploratory research is conducted in order to provide a better understanding of phenomena. Exploratory study is conducted when the researcher encounters issues that are already known but wants to know why things are the way they are (de Vos et al 2011). Exploratory qualitative research is designed to shed light on the various ways in which a phenomenon is manifested (Polit and Beck 2012).

Objective of exploratory research is to discover ideas and insights. Exploratory research can provide very rich, meaningful information or even definitive explanations for particular individuals. In this study the researcher gained insight into the attitudes and beliefs of patients with chronic kidney disease towards kidney dysfunction.

Descriptive study

Descriptive study is designed to gain more information about characteristics within a particular field of study (Burns and Grove 2007).

The researcher identifies a specific lack of knowledge that can be addressed only through seeking the viewpoints of the people most affected (Grove, Burns and Gray 2012).

In descriptive research, the researcher intends to describe a population with respect to important variables. In this study the researcher intends to describe beliefs of patients with chronic renal disease living in the Rustenburg area, regarding treatment of chronic kidney disease.

Context of the Study

According to Jooste (2010), context is the setting of the study and refers to the environment, the geographical location where the study will take place and where the researcher can guarantee the results obtained.This study is of contextual design, focusing on patients with chronic kidney disease receiving dialysis treatment at a level II

provincial hospital in the Rustenburg area. In contextual studies, data are only valid in a specific context and findings are not necessarily generalized (Botma et al 2010).

Research setting

The current study was conducted in the dialysis unit of a level II public hospital in the Bojanala district, in the North West province. Bojanala Health District is situated in the eastern part of the North-West Province, at the border of Gauteng in the South, Mpumalanga in the East and Limpopo in the North. Bojanala is one of the four districts in the North-West Province and it is made up of 5 Sub-Districts namely, Kgetleng, Madibeng, Moretele, Moses Kotane and Rustenburg. This District has 1 provincial hospital, 4 district hospitals, and 13 community health centres, 16 clinics operating on a 24 hour basis, 88 clinics, 646 mobile points and 15 health points.

Within Bojanala district, the City of Rustenburg represents the major industrial and mining infrastructures as well as tourism facilities. Bojanala Health District serves a total population of more than about 1.3 million which forms more than a third of the whole population in the province, with only one state owned dialysis unit at the level II provincial hospital in Rustenburg. This state of the art dialysis unit was officially opened in February 2012 by the North West Member of Executive Committee of Health.

The unit has nine nephrology trained nurses, three professional nurses, one 2nd year Bachelor of Technology clinical technologist and two general professional nurses. Since the unit was opened, it was under the supervision of a physician, who was also the head of department of internal medicine at the institution. After the physician resigned in April 2014, a nephrologist from the Gauteng province offered his voluntary service and has been visiting the unit once a month since then, to assist the medical officer who has been assigned to take over the care of patients.

The unit has eight haemodialysis machines for chronic haemodialysis patients. The unit also offers acute haemodialysis and peritoneal dialysis training for patients who opted for home dialysis, and runs a monthly conservative clinic as well. The unit receives patients referred with kidney disease from all the Bojanala health care facilities mentioned above. Many patients using the service of this dialysis unit are from a Setswana cultural background from the rural communities around Rustenburg. Most of these patients are unemployed and use public transport to access the dialysis unit.

3.5 RESEARCH METHODS

3.5.1. Study Population and Sample

Research population is the entire group of persons or objects that is of interest to the researcher or meet the criteria that the researcher is interested in studying (Brink, et al 2012). Patients on haemodialysis come to the dialysis unit on alternate days for their dialysis treatment. The population in this study included all patients with chronic kidney disease receiving haemodialysis treatment for longer than six months at a level II public sector hospital.

The researcher personally approached the participants and invited them to participate. Information rich participants, with background knowledge of chronic kidney disease were deliberately selected based on the inclusion criteria. These patients were selected, as they are on haemodialysis, which indicates that they have progressed to end stage kidney disease and should have gained experience and understanding of their kidney disease and its management. It was therefore, assumed that they can best inform the researcher about the topic under study.

Participants were recruited using convenience sampling method. Convenience sampling entails using the most conveniently available people as study participants (Botma et al. 2010). Participants were selected until the point of saturation was reached and nine participants constituted the sample. According to Polit and Beck (2012), data saturation, is sampling to the point at which no new information is obtained and redundancy is achieved. In this study saturation was reached with nine interviews. All participants were given information letters (Appendix B) and the contents were explained in Setswana to ensure that they understood.

Inclusion criteria

All men and women between the ages of 25 and 52 were included in the study. Participants were receiving haemodialysis treatment for more than six months and were able to communicate well. Participants who willingly agreed to be interviewed and have signed consent (Appendix C) and also agreed to have the interview recorded evidenced by signed consent form (Appendix D) were included.

Exclusion criteria

The study excluded all patients who were hospitalized or did not report for haemodialysis on the days of the interviews. Pregnant patients were also excluded from the study.

3.5.2. Data collection

Data collection took place while the participants were connected to their dialysis machines as agreed with participants so as not to take additional time. The researcher gave information letters to each participant and explained the contents of the information letter before commencing with the interview. The researcher was responsible for collection of data. The participants were informed about the use of an audio-tape during the interviews and written consent forms (Appendix D) were obtained from each participant. Each participant was reminded against the use of identifiable names during the recordings and confidentiality was assured. A tape recorder was used to record the interviews. The researcher collected data through an individual face-to-face semi-structured interviews guided by self-developed interview guide, (Appendix A.) consisting of five open-ended questions.

According to de Vos, et al. (2011) semi-structured interviews are used in order to gain a detailed picture of a participant's beliefs about or perceptions or accounts of, a particular topic. The interview schedule was used to keep the participants focused on the research topic. Face-to-face interviews helped the researcher to gain cooperation from the participants. The researcher was able to observe non-verbal gestures, clarify ambiguous answers by seeking follow up answers. After each interview the recorded data was copied and electronically kept on the computer for later coding. An access code only known by the researcher and her supervisor was used to access the recorded data. Data was collected over a period of two weeks however data analysis was challenging and time consuming therefore it took two months to complete.

3.5.3. Data collection procedure

Once all patients were connected to their machines, and all patients served and finished their breakfast, and everyone had settled down the researcher commenced with data collection. The researcher then made all staff members aware of the interview in progress and requested not to be disturbed. The curtains were closed for each participant before commencing with the interview in order to ensure privacy and to minimize distraction. The researcher introduced herself to the first participants. The researcher then asked if the participant was ready for the interview and whether we could start. Demographic data including age, sex, marital status, living arrangements were noted (Appendix E) for each participant prior to the interview.

Guided by the interview guide (Appendix A), the researcher posed a series of questions as per interview schedule. Central questions that each participant was asked are as follows:

" How did you feel after you were told that you have kidney failure"?

"What is your opinion or experience regarding the use of traditional medicine/healers to treat kidney disease"?

"Some people believe that kidney problems are due to failure to undergo cultural practice after the death of spouse/life partner. What is your comment on that"?

Clarification and reasons were sought through probing but the participants were allowed the freedom to answer in their own words. Field notes were taken during the interviews on non-verbal communication as well as participant behaviour during the interviews. One participant per day was interviewed and each interview lasted between 20-30 minutes although more time was initially allocated.

Language used
Participants in this study were Setswana speaking and mostly had secondary education. Participants requested to be interviewed in their home language and the request was granted. This removed language barriers and allowed the participants to approach the topic with clear understanding and confidence.

3.5.4 Data analysis

The purpose of data analysis is to organize, provide structure to and elicit meaning from data and it occurs concurrently with data collection (Polit and Beck 2012). The assistant utilized as a translator transcribed data verbatim in Setswana from the audiotapes, and thereafter translated the transcribed data from Setswana to English. The translator is a qualified professional nurse with a Master's Degree in nursing administration and public service administration and is employed as a nursing service manager at the local district hospital. She is Tswana speaking and she can speak, write and understand both Setswana and English well. Data analysis occurred concurrently with data collection. Two co-coders, one a nephrology nurse specialist and lecturer and a nurse educator with a PhD assisted the researcher with data analysis guided by Tesch's (1990) eight steps of qualitative data analysis.

The results of the study were obtained and an explanation of each step is presented below:

1. Get a sense of the whole. Read all the transcriptions carefully. Jot down some ideas [in the one margin] that came to mind.

2. Pick one document (i.e. transcript of an interview) most interesting one, shortest one, the one on the top of the pile. Read through it, asking yourself 'What is this about?' Do not think about the substance but look for the underlying meaning. Jot thoughts down in the [same] margin.

3. Read through several participants' data and do the same as in step 2. Now make a list of all the topics which comes to mind. Form these topics into columns (maybe major topics, unique topics, and leftovers).

4. Now take this list of topics and go back to the data. Abbreviate the topics as codes and write codes next to the appropriate segments of the text. See if new categories and codes emerge.

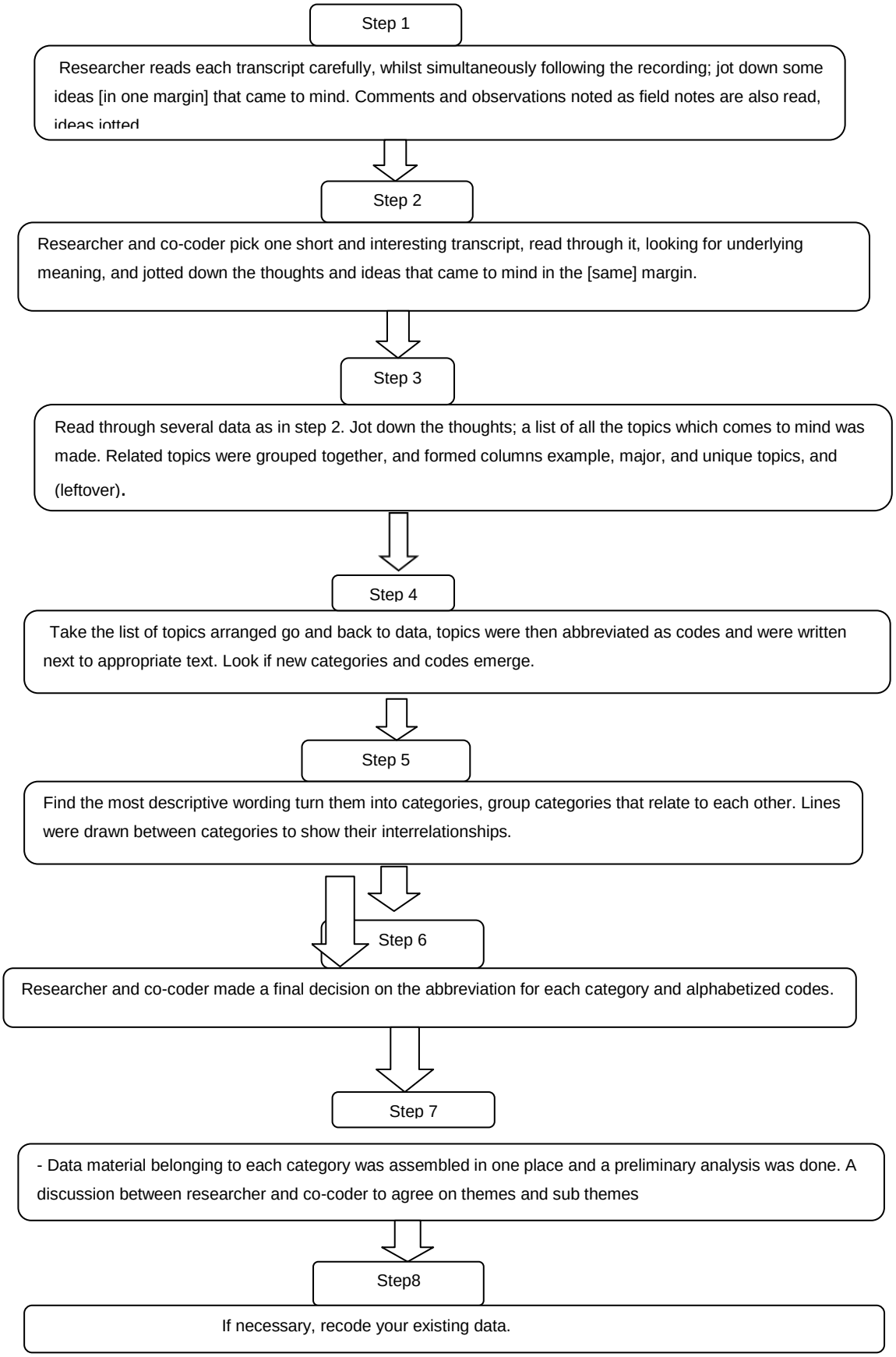
5. Find the most descriptive wording for your topics and turn them into categories. Look for ways of reducing your list of categories by grouping categories that relate to each other. Perhaps draw lines between categories to show interrelationships.

6. Make a final decision on the abbreviation for each category and alphabetize these codes.

7. Assemble the data material belonging to each category in one place and perform a preliminary analysis.

8. If necessary, recode existing data.

Figure 3.1 Practical approach employed for data analysis using Tesch's methods for qualitative data analysis.



3.6 MEASURES TO ENSURE TRUSTWORTHINESS

According to Polit, and Beck, (2012), trustworthiness refers to the degree of confidence qualitative researchers have in their data. To ensure trustworthiness in this qualitative research report, the model of Lincoln, and Guba (1985) was used. The model focuses on the following four constructs:

Credibility

Credibility relates to truth-value in which the goal will be to demonstrate that inquiry will be conducted in such a manner as to ensure that participants are accurately identified and described (de Vos et al. 2011). To ensure trustworthiness in this study:

The research design and research methodology relevant to the purpose of the study were identified and described.

Member checking through probing and follow up answers were done in order to clarify and verify whether the participant was correctly understood.

Meeting was held with research supervisor and co-supervisor and findings of study were consolidated with those of the co-coder in order to ensure truth in research findings and consensus was reached.

Dependability

Dependability of qualitative data refers to the stability of data over time (Jooste 2010). Using an audit trail, decisions made within the research process to produce findings will be traceable to ensure dependability (consistency) of data. Lincoln and Guba (1985) argue that in practice, demonstration of credibility ensures dependability; it is therefore assumed that dependability in this study was also ensured by demonstrations of credibility above.

Confirmability

According to Brink (2009) confirmability guarantees that the findings, conclusions and recommendations are supported by data and that there is internal agreement between the investigator's interpretation and the actual evidence.

To ensure this construct, the researcher provided an audit trail, by keeping track of all references used. All electronically stored data and hard copies including consent forms signed by the participants and the tape recorder will be kept safely in a manner that ensures confidentiality.

Transferability

Transferability refers to the extent to which the findings of the research can be transferred from a specific situation to another or generalized to other settings, contexts, or

populations (de Vos et al 2011). Although the researcher did not intend to generalize the findings of this study, a thick description of the research context and research methodology was provided, in order to provide other researchers with sufficient information to assess applicability of the study in their own setting. Despite the smaller sample size, saturation of data was achieved indicating that the sample was adequate.

3.7 ETHICAL CONSIDERATIONS

Permission to conduct the study was also obtained from the following authoritiesPost-Graduation Committee of the Faculty of Health Sciences of the University of Witwatersrand.

Ethical clearance certificate M130734, was obtained from the university of Witwatersrand Medical Human Research Science Ethics committee. (Appendix F).

The researcher wrote a letter to the Chief Executive Officer of the hospital where the study was conducted requesting permission to conduct the study (Appendix G).

Permission to conduct the study was obtained from the North West health department and the Chief Executive Officer of the hospital where the study will be conducted. (Appendix H).

Each participant was given an information letter detailing (Appendix B)

Each participant signed a consent form agreeing to be interviewed participation for the study (Appendix C)

Each participant signed a consent form agreeing to be recorded during the interview (Appendix D)

The researcher upheld the principles of fundamental human rights throughout this research study as required by the Human Science Research Council (Brink, 2009).

Informed consent

According Polit and Beck (2012) informed consent means that the study participants have adequate information about the research, has comprehend that information and have the ability to consent or decline participation voluntarily. Before the interview, all participants received information letters (Appendix B) detailing the overall goals and plan of the study. Participants were informed that their participation in the study is voluntary. Participants

were also informed about their rights to withdraw from the study at any time, or refuse to answer any questions should they so desire without victimization. Written consent forms for voluntary participation (Appendix C) and agreeing for the use of tape recorder during the interview (Appendix D) were signed prior to data collection. Verbal consent was obtained to refer the patient for professional counselling by the hospital psychologist or social worker in case it was necessary.

Anonymity

Participants were reminded to guard against using any names during the recording of the interview that could be linked to any participant. Participants were referred to as participant number (N1, N2) and so on, when reporting the finding of the research study. Participants were also assured that should the results of the study be published it will be published anonymously, that readers will not be able to link study results to anyone who participated in the study.

Protection from discomfort and harm

Research participants have the right to be protected from discomfort and harm. In research according to Burns and Grove (2007), discomfort and harm can be physical, emotional, social, or economic or any combination of these four. In this study the participants were required to describe their feelings after finding out about their chronic renal disease, which could result in the resurfacing of the emotions experienced at the time.

To ensure participant's psychological wellbeing the hospital psychologist and social worker were informed about the research and the interview program and were requested to be on standby in case the researcher needed to refer participants.
During each interview the researcher made sure that the participant was comfortable by asking if the participant was all right and whether the interview should continue or stop especially after the participant gave an emotional response. Again after each interview, participants were asked how they felt in order to assess if they needed to be referred for professional counselling.

Confidentiality

Confidentiality can be viewed as a continuation of privacy, which refers to the agreements between persons (in this case the researcher and participant) that limit others' access to private information (de Vos et al. 2011). Participants were guaranteed confidentiality with regard to the information they disclosed to researcher. Information obtained during the

interview was not shared with anyone except the translator, the co-coder and research supervisors. The research supervisors are qualified professional nurses, nurse administrator and nurse educator registered with the South African Nursing Council and have pledged to confidentiality as per Nurse's pledge of service. As experts in research the supervisors are conversant with ethical issues in research. Participants were also informed about the need for translation of tape recordings into English by someone not directly involved with this research. In order to ensure confidentiality, person who was utilized as the translator is a professional nurse who is familiar with ethics in research and is also committed to professional secrecy. Participants were also reassured that all electronically stored data and hard copies including consent forms signed by the participants and the tape recorder will be kept safely in the manner that ensures confidentiality and will be destroyed after five years following completion of the research report.

3.7.1. Gaining permission to conduct research

The researcher complied with the research requirements of the University of Witwatersrand.

The researcher presented a copy of the research proposal to the department of nursing committee for peer review.

A copy of a research proposal was submitted and presented to the Post-Graduation Committee of the Faculty of Health Sciences of the University of Witwatersrand for approval.

After approval was granted a copy of the proposal was submitted to the Medical Human Research Ethics Committee of the University of Witwatersrand, the study was approved and ethical clearance certificate was issued (Appendix F).

A letter requesting permission to conduct the study was written to the North West Department of Health and the Chief Executive Officer of the institution where the study was conducted (Appendix G). A copy of the research proposal was also submitted to the Chief Executive Officer and to the North West Department of Health.

Permission to conduct the study was received from the chief executive officer of the hospital (Appendix H)

3.8 SUMMARY

This chapter presents the detailed description of the methodology of the study. The design, population and sample were outlined. Data collection and analysis have also been discussed, measures to ensure trustworthiness were described and ethical considerations explained. In the next chapter, chapter four, the findings and discussion of the study are presented.

CHAPTER FOUR

FINDINGS AND DISCUSSION

4.1 INTRODUCTION

This chapter presents the findings of the study. Themes and sub-themes that emerged during data analysis are presented and discussed. Discussion included in this chapter is supported with literature in order to make the findings more meaningful.

The objectives the study were

- To explore and describe the beliefs of patients with chronic kidney disease regarding kidney dysfunction.
- To explore and describe their attitudes and beliefs towards the management of kidney dysfunction.

4.2 SOCIO-DEMOGRAPHIC DATA OF PARTICIPANTS

To add richness to the context of this study it was important to provide the demographic profile of the sample summarized in Table 4.1 below. A total of nine participants, five males and four females were interviewed. The sample comprised of young adults mostly from the rural villages around Rustenburg. Of the nine participants four are unemployed, two have been granted social pension and three are still employed. All participants have been on dialysis treatment for more than six months.

Table 4.1 Summary of the demographic data

1	Age in years	Range between 26 - 50	Total = 9
2	Gender	Males Females	5 4
3	Marital status	Married Single	5 4

4	Religion	Christians Other	9 0
5	Residence	Village Township	8 1
6	Living arrangement	Alone Spouse only Spouse and children Parents and siblings	0 0 5 4

Following a discussion between the researcher and the co-coders, an agreement was reached on the themes and sub-themes identified. Table 4.2 presents both the themes and sub-themes generated from data.

Table 4.2 Themes and sub-themes

Theme	Sub-theme
4.2.1 Emotional response	Shock and disbelief Disempowerment Change in employment Change in lifestyle Knowledge adequacy Relationships Partner

	Family Renal team
4.2.2 Attitudes and Beliefs	Cultural influence arising from: Peer and friends Family members Culture on compliance

4.3. THEMES

Following coding of direct quotes from the participants themes and sub-themes were identified. Two major themes that were generated are: emotional response and attitudes and beliefs.

4.3.1 Theme 1: Emotional responses

An emotion is an affective state of consciousness in which joy, sorrow, fear, hate or like is experienced as distinguished from cognitive state of consciousness (Dictionary.com 2015). Chronic kidney disease affects all aspects of the patients' life, the physical, mental, social and financial status and can be very traumatic to the patients. According to Thomas (2008) patients with chronic kidney disease needing dialysis therapy may express series of mixed emotions ranging from denial, anger, sadness and depression.

Sub-themes

4.3.1.1Shock and disbelief

Loss of kidney function and dialysis therapy could be a frightening. Upon being told about their chronic kidney disease many participants expressed a series of mixed emotions as expressed by participants (N2, N6 and N7) below;

"*I was very hurt, because I knew that kidney illness was affecting elders, so that hurt me the most, asking myself where did I get it, because I didn't even know about it,*

doctor told me "you have kidney failure", I did not understand what the doctor meant by that, yes [paused]*"(N2)*

"I cried a lot [paused]*…my heart was very sore because my age [paused]I was very young, I was thought that it is an age illness, like may be if you are, starting from fifty something years or like, [paused] I did not expect that at that age I could suffer from kidney disease.(N6)*

"My head went crazy, I told myself that it was only a two days or a week thing, [short while] *having things* [temporary dialysis catheter] *put on my neck, you know* [paused] *it gives stress (N7)"*

Based on the direct quotes of participants, it is clear that reacted with mixed emotions to the diagnosis of chronic kidney disease. A study by Finnegan-John and Thomas (2013) assessed psychosocial experience of patients with end stage renal disease. The study revealed negative feelings such as anxiety, depression and suicidal ideation as a result of end stage renal disease. Another study that assessed awareness of kidney complications among diabetic patients Wilkinson et al. (2011) state that patients were frightened upon realizing that their kidneys were failing. The fact that the illness is chronic that the patients has to commit to three times a week four hours haemodialysis treatment may add to the stress experienced by the participants. It is therefore that patients are properly counseled as soon as the diagnosis is made.

4.3.1.2 Disempowerment

Disempowerment is defined as reducing or controlling someone's freedom to do what they want or someone's ability to be effective (Free Thesaurus). Patients diagnosed with chronic kidney disease may see the disease and dialysis sessions as an obstacle to engaging in activities that were previously possible prior to the disease. Disempowerment is classified and discussed under the three aspects below.

Change in employment

Patients with chronic kidney disease are encouraged to continue working in order to earn a salary unless advised otherwise by the medical practitioner. However, during the acute stage of chronic kidney disease, participants who were employed felt that their jobs were too strenuous and they decide to leave their jobs. Some of the participants felt dialysis sessions (three times week) rendered them unemployable. On the other hand there is the

unsympathetic employer who may refuse the employee time off for dialysis, thus making it difficult for the patients to continue working. The participants explained how their jobs were affected by chronic kidney disease and haemodialysis treatment sessions.

> "*The only thing that changed is work. When I started to be sick, I was working I left the job because I could feel that I wasn't coping with work, because I was working with takeaways. I was standing the whole day, walking and busy, so it is only work, so like right now who will hire you to work three days in a week? Unless if you were working at the time and never stopped working, that might be better" (N3)*

> "*I believe that the conditions under which I was working wouldn't allow me* (to work) *because of my kidney failure. The type of work I was doing, I was travelling, I also believed that the working conditions wouldn't allow me, yes.(*wouldn't allow me to work). *(N9)*
>
> "*Hey! [Paused], at work it was not possible to continue (working) as I had to dialyse three times a week and employers do not allow that, so they gave me disability and had to stop working"(N5).*

Not every dialysis patient has to stop working especially when the patient is stable and his/her quality of life has improved. Depending on the employer, some of the participants in this study had a choice of either to be given an alternative job or be placed on temporary incapacity, whilst others had to re-negotiate their working days and hours. Although the employer appeared to be helpful, there was evidence of employment problems:

> "*They said they will find me work and move me to surface so that I will be able to work."(N6)*

However, at the time of data collection, this participant was still waiting for the employer to find him an alternative job on the surface and this will also affect his salary since he was working underground at the mine before his chronic kidney disease.

As sincere as it may sound, one participant (N4) mine worker at the time, felt that the alternative job that was offered by the employer meant the loss of his initial career and a cut in salary. This participant declined employers' offer and stopped working. Describing the impact of chronic kidney disease on his career and salary, this is what the participant had to say;

> *"They told me that with high creatinine and urea I can't work underground they will find me work on surface, only to find that when I arrive at surface they give me work*

that, like I will earn 70% less of what I was earning, so I felt I will rather go and stay at home, they were giving me less, like right now they have given me medical incapacity and I am getting 75% of what I was earning, so it is better than what they previously offered"(N4)

Some of the participants in different employment sectors faced a different situation with their employers. These participants stated that they had to negotiate with their employers and come up with a solution to keep their jobs, and accommodate haemodialysis time, However, It was not without some challenges as expressed by the participants below;

*"That is where I had problems,[*paused] *I had to work night shift only in order to be able to come for dialysis in the morning and also reduce my working hours, I could not do some tasks that are heavy at work, there were days, dialysis days that I could not work" (N8).*

"I cannot get a full salary because you are working Monday, Tuesday not working Wednesday I am working, Thursday I am not working and Friday I am working." (N7).

The above quotes shows that patients with chronic kidney disease needing dialysis experience employment problems that result in some of them losing an income. Employment challenges experienced by patients with chronic kidney disease on haemodialysis treatment are consistent with other studies. Jansen (2012) found that 53% of patients on dialysis treatment experienced limited work capacities, 61% reported inability to work, and 52% experienced limitations with respect to vacation activities. Similar findings were reported in Ghana by Ansong and Donkor (2012) who found out that haemodialysed patients experience challenges, such as loss of income, lowered productivity, dependence on other people and difficulties to pay for the dialysis treatment and for expensive medications. It is important that patients with chronic kidney disease and their employers should work together towards a solution to keep the patient employed. This also emphasise the need for kidney awareness campaigns at all employment sectors in order to educate employers and to encourage them to keep these patients employed as much possible so that they do not lose their self-worth.

- Changes in lifestyle

Many of the participants in the current study were young adults with mean age ranging between 26-50 years, who at the time of their diagnosis with chronic kidney disease, were still looking forward to living their lives. Lifestyle changes were too overwhelming for the participants in this study. Lack of energy and feeling tired were the common reason given

by participants as the cause of their lack of interest in activities that they used to like. Some of the participants stated that the illness affected their home life whilst others mentioned that it affected their outside life as well as body image as evidenced by the quotes below;

> *"Yes it has really changed me a lot* [paused] *I used to make myself look beautiful but now all these things make me tired, yes."* (N2).

> *"yes it is true my life is affected a lot by kidney disease, uhm…, before I got kidney disease I was an active person, I was living my youth life, going up and down without any problems I was a hard worker at that time but now most of the time I can't do anything because it depends how you feel that day when you wake up."(N9)*

The impact of life style changes was summed up by one participant who mentioned that he was a soccer player before being ill, and spoke passionately about his love of soccer. On the day of the interview this participant was wearing his favourite soccer team's colour T-shirt, and he highlighted;

> *"I was a soccer player straight, every time I was at the practice ground, even when this illness starts I was still going for practice but when I am practicing I will feel tired, I was not able to finish the session* [paused].*I cannot play ball like, because of fistula, falling (afraid of falling) (N6)*

Patients' direct quotes show that chronic kidney disease has a major impact on their lifestyle. Finnegan-John and Thomas (2013) studied psychosocial experience of patients living with end stage renal disease. In this study patients mentioned that time consuming nature of haemodialysis reduce their time for leisure and social activities. According to Bapat & Kedlya (2012) chronic disabling conditions interfere with the daily life activities of both the patients and their families thus compromising their quality of life. Patients with chronic kidney disease should be encouraged to continue with their normal active lives when their condition is stable. It is therefore important that the multidisciplinary renal team work together in order to successfully rehabilitate patients with chronic kidney disease.

- Knowledge adequacy

Patients diagnosed with hypertension are managed as outpatients. These patients acquire the knowledge about hypertension and how to take care of themselves through health educations given by the nurses while they are still admitted or during follow up visits at their clinics. Participants in this study felt that they were not given enough

information on hypertension. Many participants stated that if they had known that high blood pressure could cause kidney failure things could have been different. It is understandable that patients feel angry and disempowered if they are not given adequate information about high blood pressure and some blamed the care givers that nobody told then about renal complications as highlighted by quotes below;

> *I never knew anything about kidney failure before* [paused] *doctors only spoke about stroke and heart attack" "I never knew." "I didn't know what is kidney disease, it was the first time I heard about kidney failure (N3*).

> "*The doctor explained to me that I have kidney disease because I had uncontrolled high blood pressure, and because I didn't go for check-up, I didn't know whether I had high blood or not, and that high blood pressure damaged some of my kidney veins."(N8)*

However for some of the patients there was an element of ignorance because despite being diagnosed with uncontrolled high blood pressure and put on treatment, they were non- compliant. Participants below mentioned that they developed chronic kidney disease because they had inadequate information about hypertension, hence they defaulted their treatment;

> *"I was defaulting most of the time, like when I was feeling better I stopped taking them, when I go back and they found it was high, I start drinking them again but along the way I stop again*. *I started going from one clinic to the other (changing clinics) you see, and always when I get to the clinic I was told I have high blood pressure but did not want to belief, told myself high blood pressure is condition that affect older people, all told me one thing, that I have high blood pressure. Even the doctor, when I was not feeling well and I decided to see the doctor, he told me that "you ignore these pills; you don't want to take the blood pressure pills." "Always when I went to the clinic, I was told that I have high blood pressure but I didn't want to believe, I never thought I would have kidney disease*, *I told myself that high blood pressure is a condition that affects older people,."(N2)*

> *"they told me that it is long standing high blood pressure, like… that, obviously I didn't take care of it, I had a problem that I had to drink pills for the rest of my life, I was defaulting most of the time, like when I was feeling better I stop taking them, when I go back and they found it was high, I start drinking them again but along the way I stop again, something like that (4)*

On the other hand, some of the participants despite having had family members who had high blood pressure, they lacked the knowledge of risk factors associated with high blood pressure and they were not aware that they were at risk of developing chronic kidney disease;

> *"When I grew up my grandmother had high blood pressure. When you grow up they (*the elders) *say the child takes from the father's side, yes, so because my aunts and grannies from my father's side, they are old and don't have high blood pressure."(N7)*

> *"My mother is the one who is having high blood pressure, sugar and cholesterol, so this is within the family, we didn't know, all we know was that our mother had it and that it cannot be passed on to us, we didn't have that knowledge."(N9)*

It is clear from the interview that participants in this study had inadequate knowledge to manage their hypertension and thus prevent its complications. Khalil and Abdairahim (2014) evaluated knowledge and attitudes towards chronic kidney disease prevention. Participants in that study lacked knowledge of risk factors, signs and symptoms and the importance of early prevention of complications. According to Chow, Joshi, Tin et al (2012) education to improve knowledge plays an important role in the prevention of chronic kidney disease regardless of whether it is primary, secondary or tertiary prevention. Therefore, patients on chronic medication and their families should continuously be educated about their illness in order to adequately equip them with knowledge on how to effectively manage their condition and prevent renal complications.

- Relationships

Chronic kidney disease does not only affect an individual who has been diagnosed with the disease, it affects the whole family. According to Morton & Fortaine (2009), patients with chronic renal failure and their families may have difficulty coping due to stress or ineffective coping mechanisms. The following three aspects with regard to relationship were identified as playing an important role in patients with chronic renal failure.

Relationship with the partner

Chronic kidney disease has a psychosocial and physical impact on relationships (Finnegan-John et al. 2013). Both the patients and their partners may face challenges related to role change, sexuality and financial problems (Thomas 2008). A partner is either a spouse who is legally married to the patient or a companion with whom the patient stays and shares an intimate relationship with. Some of the participants

experienced negative feelings from their partners when they found out about their condition as evidenced by the quotes below;

> *"Yes I did tell her, but we quarrelled [*paused*] even now as we speak, she has left me because of this illness. She could not accept, she didn't see that I will get well, the way I was so sick, right now I am single, I don't have partner. (N6)*

> *"He wasn't coming home, not buying food on the other hand I was working* [paused] *I was supposed to* [paused*]* [take care of the family on my own] *it was difficult."* (N7)

> *It affected her a lot, she didn't express her feelings, but she was very worried, you could see with her reactions on a daily basis, we ended taking her to psychologists, yes, at this time we are no longer together, yes (N9)*

Some of the participants experienced positive feelings from their partners when they told them about their condition and this is what they had to say;

> *"She was supportive and by my side all the way even now I am still with her, she hasn't left or anything even the time we had spent together there have never been any problems, (N4)*
>
> *"Especially at home, I got a lot of support from my wife, it did not affect me, and nothing changed* (N8).

On the other hand, disagreements with regards to where and how to treat kidney disease and lack of understanding of chronic kidney disease affect the relationship between the patients, their partners and family members, furthermore, the patient who is advised otherwise by the health care professional expressed their frustrations below;

> "*we fought a lot, my husband and his family, actually they believe too much in traditional healers, neh, they told me that if I go back to the hospital I must know that that I won't come back, you will be admitted, they will do this and that on you and you must know you will not come back, you will be quiet (dead) when we fetch you, yes…" (N1)*

> *"But now when I am at home with my husband, he will continuously tell you to drink water, if you refuse it's like you don't want to get better so that he can nurse you and do everything for you." (N7)*

Sexual relationship was also a concern raised by some of the participants. The thought of not being able to perform sexually especially in sexually active patients affected their self-esteem and result in some patients being reluctant to engage in sexual relationships as experienced by the participant below;

*"Yes, personal stuff like, at that age you are in love, those things, you become scared thinking maybe you will not be able to perform sexually and now you start to be scared of girls, like maybe I am no longer as good like before"(N6)*Out of the five male participants who initially stated that they experienced sexual problems at the onset of their illness, only one participant stated that he had a permanent change regarding his sexual performance. Most of participants especially males, besides experiencing dialysis related fatigue, acknowledged that their sexual problem was short-lived;

Yes the only thing is when you are from the machine you don't desire anything except that you want to rest. I am fine; it is just that you cannot be like before, when you were a normal (healthy) person (N4)

I do meet with the mother of my child, we end up having err…., you know people, she was also frightened and surprised that, err, she said "I thought they say, you won't be able to perform" performance is there, it's good you ejaculate, do everything like a normal person(N6).

"No at first when I started while I was still on peritoneal dialysis I didn't have sexual desire, but as time went by I started to have the desire, it came back, yes like before" (N9)

On the other hand, married female participants mentioned the negative impact of chronic kidney disease on their sexual relationships. Participants described how they were unable to meet their partner's sexual needs due to lack of energy and sexual desire;

"Hey!, it did affect our sexual relationship a lot because most of the time I am tired you find that I am very tired, I could see that he wants us to play as man and wife but I would be tired, I was complaining all the time Heeehee [*laughs*] *at times it becomes a fight, strike, hey, hey, hey there will be a lot of complaints" (N2)*

"The marriage was about to fall apart because sometimes when he wants I us to play like husband and wife should, you find that I am not in the mood for that, you are tired, even at times sexual desire is not there, at times when he wants to play you are not well, tired or have headache, so he become impatient." (N7)

Although from the interview male participants stated that their sexual problem improved with time, it is clear that both male and female patients with chronic kidney disease had an impact on their sexual lives. Daugirdas, Blake, Ing, (2007) indicated that patients with

end stage renal disease experience decreased libido, erectile dysfunction, menstrual discomfort and infertility. According to Bellinghieri, et al (2008) anaemia, which is a common complication of chronic kidney disease, has been linked with a reduction of libido and erectile dysfunction. However, "efficient dialysis and treatment of anaemia with erythropoietin may be enough to restore sexual function" Thomas (2008:87). It is therefore important that patients comply with their haemodialysis sessions as required, comply with the diet as advised by the dietician, and take their erythropoietin as prescribed. This must be communicated to the patient in the form of continuous health education.

Relationship with the family

A supportive family will stand by the patient and together with the patient find ways to cope with the challenges that they may face as a result of the condition. On the other hand, misconceptions about chronic kidney disease based on cultural beliefs impacted negatively on some patient-family relationships. For the participants below negative experience with kidney disease had serious implications, this is what they have to say;

> *"My in-laws, they came to me and asked to accompany me to the clinic to do some blood test, I told them it means that you are not accepting my illness, "they said may be you have been cheating aside, we are fighting for our child whom you have been sleeping with, now you see you have given her the disease (N1).*

When the participant was asked about her biological family, she responded;

> *My family [*paused], *eish they believed me but eish you could see that they did not know how to deal with it, but they were very suspicious* "*I even thought of, like taking tablets and drink them so that it is over with me." (N1)*

> *"They* [siblings, friends and relatives] *did not support me, they were reluctant, like, when you are with them you can see that they ignore you, you will be feeling lonely where you are. I am talking about friends and relatives, and my siblings they were also like that, not that very supportive" "They were surprised why amongst the whole family I have kidney disease, when they have never heard about anyone suffering from kidney disease, it was for whites, not blacks" (N5)*

Fortunately not all the participants shared the same negative experience about family relationships. Although participants in this study did not state how family support helped

them cope with their illness, most of the participants mentioned that their family were supportive and some offered to donate a kidney for transplant.

> "*My mother, once I told her, she and my sister were intending to give me a kidney but here at the hospital they said they don't want a person who has high blood pressure. (N2)*
> *"my brothers and sisters are staying far from us so during the first months they used to come and check on us to hear what was going on, then they all promised that when that time come I should tell them so that they can test and see if they can help* [donating a kidney]*(8)*

> *"with that point that I must attend dialysis they became worried, they were worried about dialysis asking themselves what kind of treatment it was whether this illness is not curable, cause isn't that the elders when they hear about chronic diseases they don't know, yes, but at this pointing time they are just ok they don't have any problems is just that I have a brother who from the onset has been supportive to me" (N9)*

Based on the interview, it is clear those patients with chronic kidney disease experience positive or negative family relationship that impact on their coping ability. According to Daugirdas et al. (2007), patients with chronic kidney disease experience strain on interpersonal relationships with their families. On the other hand, the type of treatment preferred by the patient particularly the wife might be overruled by the husband as the decision maker in some cultures as indicated by Thomas (2008). However, in the case of adolescent patients Atobrah (2012) states that when family members consult a healer, a priest or prophet often without the patients knowledge is their way of showing care. It is therefore important that family members are also educated about chronic kidney disease in order to change their attitudes towards the patients with chronic kidney disease and provide the necessary support for these patients. Furthermore, referral to the multidisciplinary renal team for counselling as soon as the diagnosis is made is very important in order to help the patient and family to understand chronic kidney disease.

Relationship with renal team

Patients with chronic kidney disease receiving haemodialysis treatment are managed as out-patients. These patients rely on the renal team for information regarding their health and treatment progress. It is therefore important that they supported through guidance and motivation by their renal team. Although some of the participants had some element

of resentment towards the health professional, participants mentioned that the information given to them by the renal team helped them to understand their condition.

> *"They are supportive and they motivate us. Like, it is not the end of the world, you can still live with this illness. Like the time when we went to the workshop in Gauteng, I was able to hear that a person can live 20years with kidney disease, when we thought that if you suffer from kidney disease, you will die next week. (N5)*

> *"To tell the truth at first I did not want to come to commercial (provincial) hospital because of the treatments you will be hearing, but since I came here, I was even surprised, communication is good everything is good, they are smiley, that is why I recovered so fast because they made me feel at home, when I had a problem they attack (solve) it fast. Communication and treatment to tell the truth is good. I feel happy, like I don't see the difference between this renal unit and (private) or elsewhere and this one is even better (N6)*

> *"But doctors at government hospitals, they don't have time and take efforts for u like at private you see, when you go to private doctor he tells you everything he find, but these ones from government, hey, doctor can just change your treatment without telling you what those pills are for. He will just give you. (N5)*

> *"I was pregnant with twins in 2007, they were giving me high blood pressure medication when I was pregnant, so it happened that after I deliver, it was during the time when nurses were on strike, it happened that I delivered normally and went home. The clinics were closed; I stayed without medication only to find out that high blood pressure was busy damaging my kidneys."* (N7)

According to Finnegan-John et al. (2013), support within the renal setting may improve the patients' coping mechanism and enhance their quality of life. A study that assessed the persons' experience on haemodialysis therapy in the UK, Moran (2008) stated that it is important that the nurses spend time with the participants and address their questions and concerns to enhance the patients' adjustment to dialysis therapy.

Summary of theme 1

Chronic kidney disease cannot be cured and require the patient to take lifelong medication, commit to dialysis treatment change lifestyle. Chronic kidney disease affect all aspects of the patient's life for instance, many patients feel they cannot continue with

their social lives. Inadequate knowledge about management of chronic disease results in patients developing complications.

4.3.3 Theme 2: Attitudes and beliefs

In chapter one, attitudes were defined as personal evaluations of and reaction to people, situations and objects and may be positive or negative. On the hand beliefs were defined as collection of thoughts, ideas and concepts moulded by education, culture, religion and parental and family influence which play a major role in opinion and behaviour.

Cultural beliefs influence the patient's attitudes towards chronic illness. According to Shaw et al. (2008) cultural beliefs around health and illness contribute to an individual's ability to understand and act on a health care provider's instructions. If an illness is believed to be due to witchcraft, the patient will seek help from the traditional healers (Atobrah 2012).

Sub- themes

Attitudes and beliefs towards chronic kidney disease may stem from various sources based on cultural, religious or western beliefs and the perception of the illness. Three sub-themes were identified under the main theme and are discussed as sources that influence attitudes towards chronic kidney disease and healing methods and these are attitudes and beliefs arise from:

Peer and friends

Family members

Cultural influences

4.3.2.1 Influences from Peer and Friends

It is common that when diagnosed with an incurable chronic disease, patients will discuss their illness with their friends or colleagues with the hope of finding a cure. Some of the patient will receive advice from peers or friends on healing method that the patient should adopt. Although some of the advice may be negative, the quotes highlighted below are the positive advice received by some of the participants;

> *"My niece told me to stop drinking it, [traditional medicine] then they said, thank you, we didn't know what your nephew's problem [illness] was but `now that you have told us, thank you it means she will enlighten us."(N1)*

"it once happened here in the renal unit, one lady I was dialysing with was having a bottle of traditional medicine and she said look they say it helps with kidney disease, because I did not believe in it and didn't even like them, I just took it, looked at it and said sharp, she said drink, I said no, I don't want to, and as we speak she passed and she was very stronger than me."(N2)

"When I went to collect the medicine/muthi bottles from the healer, we once found his nephew who works in the mine, he asked me what was wrong with me, I told him I have kidney disease and he took those muthi bottles and pour them out and said if you suffer from kidney disease you should not touch this, he said at the mine they are being taught what you should and should not do if you suffer from kidney disease and it is true all those who continued using them have passed, they experienced serious problems. He even told his uncle to stop, that he should stop to help me. (N8)

*A colleague at work who is a Zionist prophet told me that he prophesized that I was given sejeso [*something once ingested turns into live organism that move about and eats the victim from inside the body] *at work that is why my kidneys are not working, and for me to get well I should do this and that," "The Zion Christian Church healers told me that they will heal me, I was drinking their tea and coffee, but it kept on getting worse, like creatinine and urea wasn't coming down, And they will give you things, [traditional medicine] saying they are cleansing you, only to find that, isn't that if you are suffering from kidney illness you are not supposed to drink a lot of water and now you will be drinking, making matters worse"(N4*).

"*I was told by people I lived with, I knew nothing about these herbs, and it was recommended by friends."(N9)*

All the participants who consulted the traditional healer acknowledge that they had a negative experience with traditional healing methods for chronic kidney disease, however it was a lesson learnt for some of the participants as they shared their experience with traditional healers. Participants also spoke about their knowledge about kidney disease and their experience with western medication and gave peer advice;

"*Traditional healers cannot treat kidney disease, traditional healers and kidney disease does not meet, traditional medicine is not tested, does not have limits and measurements, use a lot of water"*

"they are not to be used for any other illness, let me say all diseases because even a person with HIV is advised to drink medication on time, to eat well, stop and

forget traditional medicines, its true traditional medicines does not help at all not even for the kidneys" (N2)

"I don't believe that traditional doctors can cure kidney disease according to my experience, when a person has kidney failure, just go to the hospital and dialyse" (N3)

"Right now I am dialysing, I can see I am getting better, my energy is back, there is progress, it is just if I can be fortunate and get a donor then I will be thankful"(N4)

"Haai, for me, it did not work, though they will tell you that we helped/cured so and so for me they did not work for me, so I would not advice somebody to go there, will advise that go straight to the doctor, clinic or hospital you will get help there"(N 4)

"if you drink medication from the doctor there is a big difference because the doctor prescribe how much you should drink because he know the effect of the medication he has given you, also if you take more than the prescribed dose what it will do to your body (side effect), but these herbs we just drink without knowing the side effects/complications, yes. I am coping very well on dialysis, I believe it has help me a lot because I was very sick but now the condition I am in right now is very stable so I don't have a problem with it([dialysis]) (N8)

"No, unless a prophet, a person can go for a prophet because traditional doctors like money, even if he is aware that this is not witchcraft he will say it is witchcraft, you end up having lost money, but the prophet yes I can belief in them".(N7)

"Traditional muti is prepared with water uses a lot of water to prepare two litres and if you take those 2litres having kidney disease and drink them and the water cannot come out because your kidneys are not working, there is overload of fluid." (N8)

From the quotes above it is clear that participants are happy and have confidence in western treatment for chronic kidney disease and do not trust traditional healers to treat chronic kidney disease. According to Funnell (2009) peers can positively influence the patient and help them to make positive lifestyle changes.

4.3.2.2 Influences from family members

In African traditional families, it is common that the senior member of the family make decisions on important family matters including where to seek help for a family member who is sick. However, in some instances the type of cure decided on by the family may be against the patient's will as experienced by participants below;

"they took me to the traditional healer, *I just went because he said we should go, you see, there was no way I could refuse because I needed help, but eish, I just wanted to satisfy them, not because, I saw that at the hospital it was better than traditional doctors. Then I thought, maybe that is why the mutis did not work with me, it is because I did not have faith in them and I forced myself to go there"(N1)*

"My husband, and the whole family will tell you to drink water or sometimes they come with the medicine and they will say, there are this medicine at the chemist written something about kidneys clean bladder, yes, they would come with them but after I have drank them I don't become well, you vomit you know, even the water you feel like drinking, but, and then my husband will buy water, he believes that I shouldn't drink tap water, he will buy water from Shoprite and say I should drink it and clean my bladder" (N7)

Based on the above quotes it is clear that most of the patients, particularly those with chronic diseases, often experience pressure from the family about how to manage or where to seek help for their illness. In his study Kara (2009) found that 84.4% patients who reported using herbs identified relatives and friends as the most important sources of information about herbal products.

According to Zondo (2008) in African culture, the family is the one that decides on the type of help that would be appropriate for the patient's symptoms.

Chronic kidney disease and haemodialysis treatment demand may be overwhelming for the patients. It is therefore important that the family members offer the patient all the necessary support.

4.3.2.3 Influences from cultural beliefs

As defined by Leininger (2001) culture refers to learned, shared, and transmitted values, beliefs, norms, and life ways of a specific individual or group that guide their thinking, decisions, actions, and patterned ways of living. As stated earlier, cultural beliefs influence people's attitudes and beliefs towards chronic disease thus play a major role in patient compliance. Aspects arising from cultural influence were identified as follows;

Delayed consultation

Non-acceptance of the diagnosis

Cultural influence on compliance

The knowledge and skill about the use of traditional medicinal plant were learnt from the older generation as acknowledged by participants below;

"*I thought about it because I grew up drinking traditional medicine because my father was a traditional healer and believes in traditional medicine…"As I was growing up they used to say if you have stomach ache you should go to the field and feed on the leaves of a particular tree like a goat, these leaves are bitter but used to help. (N5)*

"Traditional medicine, when we grew up, we blacks we grew up with it. Traditional medicine has been used, I did drink it, I grew up like any other African person, I only stopped taking them when I started to suffer from kidney illness".(N6)

"According to the belief at home, while I was growing up traditional muti were used a lot…. When you had headache or what…. U will go to the traditional doctors and not western doctors and you will get help, which is why when I heard that I have kidney disease I thought of them first…my wife agreed with me… I do trust that they (wife and family) also grew up like that, with our traditional medicines, yes and she agreed and said let's try it and see how it goes."(N8)

I thought I was cleaning my system because there were medicines/muti that I used, thinking I was cleaning myself but were not working, but these herbs were working for me"(N9).

my grandfather is a person that believes in traditional things to tell the truth he will shout at you, if you are sick, "you don't check yourself that is why you get sick ya… uhm… they took me to people/traditional doctors and they will say it is man- made/ witchcraft, it is just that as I grew up I did not belief in traditional practices.

According to van der Hoeven et al (2012) 80% of the black population in South Africa use traditional herbal medicine for their primary health. Several studies have reported on the use of traditional medicines for health problems. A study on herbal product use by haemodialysed patients in Turkey, Kara (2009) indicated that 87.6% of the participants reported that they used herbs to treat their health problems and 37.5% reported beneficial effects on their health.

However, trust and belief in traditional healers tend to be so strong that even when there were no improvement in their condition after the first consultation at the traditional healer some of the participants, continued to consult more traditional healers, thus delaying consultation at the health care centres;

"Yes we consulted three. They gave me muthi, but the doctor (traditional), the third one the third one said I walked over the bones of the snake at the gate, isn't he saw the legs were swollen, he gave us muthi (N1)

"I ended [up] *going to the ZCC (Zionist healers) and they told me that they will heal me, drinking tea and coffee, but it kept on getting worse, like… creatinine and urea wasn't coming down"(N4)*

"The doctor told me I have kidney disease. The first thing I did, I went to the traditional healers [to see] *if they could try and help me in what way" (N8).*

Majority of the eight of the nine participants consulted the traditional or spiritual healers after being diagnosed with chronic kidney disease. The diagnoses made by traditional healers were based on supernatural causes Meli, et al. (2009) whereby traditional cure or solution will be advised as an option and this result in patients not accepting their condition. The quotes below illustrate the diagnosis given to some of the participants;

"I went to the traditional because I actually wanted to hear whether what I was told by the medical doctors is what they will tell me and again I hoped that I will be healed at the traditional, yes." He (traditional healer) *said I am having boswagadi, I have been bewitched, it is (sejeso), the third one said I walked over the bones of the snake at the gate, isn't that he saw my legs were swollen" (N1)*

"We went to the traditional healer, who they said I have spiritual calling, to become a prophet, he told us that what he saw is spiritual power and not high blood…, the nose bleeding was a sign of spirituality, and that I should become a sangoma. My mother explained to him that I was operated, and have a pipe (dialysis catheter) on my chest, she said it was punishment from the ancestors that I should be a spiritual healer" (N3)

"Yes honestly they did promise to heal me, they said if they can give me this and that they can unblock the veins and blood can flow the way it should" (N8).

"I was told there is something buried in front of gate that I walked over and that thing got to me through my feet, and when it got to my kidneys it killed them." (N5)

Cultural influence may be so strong that some of the participants when their condition does not improve with prescribed medical treatment they either stopped taking their antihypertensive medication or used both the traditional healer and health care facility, affecting their compliance. Participants below mentioned that they used both traditional and prescribed medical treatment;

"I was having nosebleed and would go to the clinic, they will plug my nostril, I drank the treatment but was not getting better, and then we went to the traditional doctor. I couldn't understand what the problem was because I was dialysing and I was well. I

was sick but was on treatment and attending dialysis well, why am I not getting better like at the beginning when I started" "I consulted for about two weeks, but I was still coming for dialysis, for two weeks I was coming to dialyse and consulting the healer, using his muthi, (N3)

"*I was taking blood pressure medication, collecting it every month from the doctor but was also taking traditional herbs). (N9)*

Thomas-Hawkins et, al. (2005) state that living with chronic kidney disease often involves managing other chronic conditions such as hypertension. However, due to cultural influence Osamor (2012) patients often find it difficult to follow treatment and lifestyle advice given by healthcare professionals (Tan et al. 2010). On the other hand, the preferable choice for traditional medicine as pointed out by Saleem et al. (2011) could be due to the fact that patients place more value on self-management than orthodox treatment.

This emphasizes the importance of patients taking responsibility by being compliant with prescribed treatment. According to Beya (2010) compliance is regarded as a specific problem focused on coping strategies; patients weigh up whether the proposed treatment is in line with what they believe about their illness in order to decide whether or not to comply with it. Renal team need to educate the community and traditional leaders and healers through kidney awareness campaigns in order to promote renal health education. Nephrology nurses also need give health education to all patients who are at risk of chronic kidney disease in order to correct misconception about hypertension and its treatment in order to prevent renal complications.

The question aimed at exploring participants' beliefs regarding Boswagadi of the nine participants interviewed only one participant associated kidney dysfunction with boswagadi. However, anecdotal evidence shows that, some of the people, based on their cultural beliefs, the symptoms that the patients with chronic kidney disease present with for example, abdominal distension, swollen leg, and inability to pass urine changes in skin colour (dark colour) are associated with boswagadi. Although many participants did not associate kidney disease with boswagadi, they shared what they know or heard regarding boswagadi;

"Let me say what I know, boswagadi what I heard they say it is dirty blood, you see, so they believe that your blood has mixed and you can make the other person sick should you sleep with that person" (N1)

"For me, to tell the truth, eh boswagadi is when your body swells and skin becomes dark, but I don't know if there is any relationship or not" (N3)

"Honestly, it is very true, if you are black and you start to have swelling and they know you have lost a spouse or a child, they will tell you have sefifi (dark cloud hanging over you) or you have dirty blood of the person who passed and they must prepare traditional muti for you to drink to be cleansed so that the blood of the deceased can be removed from you" (N8)

In a study on traditional thoughts and politics of witchcraft in Botswana Seiketso (2005), found that boswagadi (widowhood) was believed to be linked with human immune virus and acquired immune deficiency syndrome infection.

According to Seiketso Boswagadi is a major Setswana taboo which means that when a person's spouse dies, the remaining partner must abstain from intercourse for a certain period, and be cleansed so he or she does not make any new partner ill.

Summary of theme 2

Theme 2 discussed cultural influence towards treatment of chronic kidney disease arising from peer and friends and family pressure. Peers and friends can have both a positive and negative influence on the patient regarding treatment for their kidney disease. On the other hand family members may also pressurise the patient, based on their cultural beliefs and perception about the disease advice the patient to seek alternative treatment for their chronic kidney disease. Cultural beliefs about health and illness particularly chronic diseases result in delayed consultation and non-acceptance. On the other hand, delayed consultation and non-acceptance of diagnosis as a result of cultural influence lead to poor compliance.

4.4 SUMMARY

At the beginning of this chapter the aim of the study and a brief outline of demographic data of participants was presented, thereafter an in-depth discussion of the findings of this study presented. The next chapter will discuss the limitation of this study and recommendations for future for studies.

CHAPTER FIVE

DISCUSSION, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION

5.1 INTRODUCTION

This chapter presents the main findings of the study followed by limitations of this study and the recommendations based on the findings of this study. Lastly the recommendations for future research were highlighted.

5.2 SUMMARY OF THE STUDY

Chronic kidney disease is on the increase in South Africa (Marais and Jacobs 2014). Hypertension and Diabetes are the most common causes of chronic kidney disease. Chronic kidney disease is incurable however some of the patients still consulted different healers with a hope of finding a cure.

The aim of the study was to investigate the attitudes and beliefs of patients with chronic kidney disease regarding kidney dysfunction in Rustenburg area. Understanding the patients' attitudes and beliefs towards kidney dysfunction provides health care practitioners with valuable information. This should be used together with patient's inputs to develop appropriate strategies to improve patients and community awareness of kidney disease. This would prevent or slow the progression of kidney dysfunction among the rural communities.

Research Question

The research question for this study was: what are the attitudes and beliefs of patients with chronic kidney disease regarding kidney dysfunction and its treatment?

5.3 DISCUSSION OF THE FINDINGS

This study explored the attitudes and beliefs of patients with chronic kidney disease towards kidney disease and its treatment. During data analysis two major themes were identified:

- Emotional response and
- Attitudes and beliefs towards kidney disease

The findings of this study indicate that chronic kidney disease has a negative impact on the lives of the patients receiving dialysis treatments in this study. Participants revealed emotional responses ranging from fear, sadness, shock and disbelief and hopelessness upon finding out about their diagnosis. Furthermore, the majority of participants in the current study were young, and were looking forward to living their lives. Evidenced by direct quotes from the participants, they were not expecting to be diagnosed with a chronic kidney disease that early in their life. The findings of the first theme gave insight into the emotional, social and financial problems experienced by individuals at this public dialysis unit as a result of chronic kidney disease. The findings of the current study are consistent with the findings of other studies. Finnegan-John and Thomas, (2013) assessed the psychosocial experiences of patients diagnosed with end stage renal disease. This study reported emotional responses such as fear, sadness, anger and even suicidal thoughts towards a diagnosis of chronic disease.

The negative emotions expressed by participants in the current study could be due to poor awareness of kidney disease and lack of knowledge about the manageability of the disease that caused a lot of uncertainties about the future. Although participants in this study had positive attitudes towards the medical management of chronic kidney disease, participants reported the negative aspects that the disease has on their daily lives. . Furthermore, participants felt that their illness also prevented them from engaging in activities that they were used to. Constant fatigue, ill health and dialysis treatment demands were the reasons given by participants for discontinuing work and lifestyle changes. Jansen et al. (2012) asserts that chronic kidney disease interferes with regular paid employment, participating in sporting and other social activities. Supporting the findings on social life disruptions as a result of chronic disease, Bapat and Kedlya, (2012) indicated that the style of living for both the patient and their families becomes disrupted upon a diagnosis of a chronic condition. This goes on to compromise their quality of life by interfering with activities and leisure time. It is therefore important that nephrology nurses provide continuous supportive care to the patients and their families from as soon as the diagnosis is made, through counselling and ultimately referral to the greater renal team. Additionally, nephrology nurses should engage with the employers if necessary to educate them about renal disease and the importance of patient compliance with treatment. Building a good relationship with employers may assist the patient with chronic kidney disease to remain employed as long as possible.

Despite the availability of advanced medical technology to diagnose and manage various illnesses, traditional medicine is still practiced. Based on the findings of this study it is evident that some of the participants used traditional healing methods to manage and treat their health problems. The findings of this study show that in some instances traditional medicine was initially considered more trustworthy than western medicine. These findings are consistent with Saleem et al. (2011) who concluded that participants placed more value on self-management than orthodox medicine. The majority, of the participants, seven out of the nine that were interviewed consulted traditional healers after being diagnosed with chronic kidney disease.

Other studies have reported the preference of traditional medicine over western medicine. In a study on herbal product use in Turkey Kara (2009) reported that nearly 30% of the participants in that study used herbal substances after the diagnosis of renal disease. A strong cultural belief that all diseases can be cured may encourage this trust in traditional healing. It may have been a desire to confirm the medical diagnosis. Alternatively it could be their way of conforming to their African traditional values since traditional healing methods are considered.

The findings of this study further revealed the role that is played by family members. The majority of participants were accompanied by their families to seek traditional help for their chronic kidney disease. According to Kara (2009) family and friends are the source of information on where to seek help for a person who is sick.

Although participants in this study initially considered seeking help from traditional healers for their chronic kidney disease, the findings of the study clearly indicate that there is a lot of resentment and mistrust towards traditional healers particularly in treating kidney dysfunction. In contrast Kara (2009) found that traditional herbal products were used during the pre-dialysis period with the belief that it would slow the progression of kidney failure.

Participants openly discussed their disappointing encounter with traditional healing methods. Endorsing these findings is Shilubane et al. (2007) who indicated that the family members in their study did not believe that traditional healers could not cure diabetes. However, some of the participants acknowledged the efficacy of traditional healing methods for certain cultural health problems for instance, boswagadi (term for a sexually transmitted cultural disease resulting from widowhood).

Endorsing the finding on the efficacy of traditional medicine is the study on the role of traditional medicine in Ghana (Gyasi, Mensah, Adjei, et al. 2011). In this study, participants claimed that traditional medicine was more effective in treating medical conditions than orthodox medicine. When asked their opinion regarding the relationship between kidney dysfunction and boswagadi, most of the participants could not connect the two however, some of the participants admitted to knowing boswagadi. Participants highlighted what they know about this experience. In this study, only one patient associated kidney dysfunction with the occurrence of boswagadi.

5.4 RECOMMENDATIONS

5.4.1 Educational aspects

Education of health care professionals

At post-graduation level

Cultural competency should be incorporated into nephrology nursing tutorial lectures.
This will ensure that nephrology nurses acquire knowledge and understanding on cultural issues that impact on renal care.

Institutional level

The nephrology nurses could give monthly in-service education programs for all other nursing categories, health care workers including allied health workers professional on chronic kidney disease, risk factors associated with development of chronic kidney and prevention of renal complications.

Motivations should be made for more nephrology posts and to send more professional nurses for nephrology training. This may ensure more culturally competent nephrology nurses who will provide culturally sensitive renal care to the patients with chronic kidney disease.

A partnership with community health managers should be established which may enable nephrology nurses to provide renal care in-service training for community health care nurses.

Education of the patients

Nephrology nurses should provide culturally sensitive health education to address the misconceptions about chronic kidney disease and its treatment.

Patient and their families should be given continuous health education and counselling during each visit to the health care facility.
Health care professionals should provide public awareness and health education to the patients about kidney disease, causes, risk factors and prevention of renal complications. Prevention of chronic diseases of lifestyle such as hypertension and diabetes type II and the importance of treatment adherence should be stressed as priority in all patients' health education programs. Support groups should be established for patients on haemodialysis, in the dialysis unit, to share information that will facilitate peer learning. This would empower those involved in the support group to share concerns and coping strategies.

5.4.2 Recommendations to other stakeholders

Renal nurses should work towards a partnership that will encourage an active working relationship between the hospital, traditional and spiritual healers and traditional leaders (community headmen) to ensure easy access to community members for health education and awareness campaigns.

A dialogue to share information on chronic kidney disease and its treatment should be implemented to be held with health care professional, traditional healers including spiritual healers, and traditional leaders, through workshops and lekgotla (Setswana term for traditional meeting).

Expose traditional health care givers to modern hospital practice through information sharing on knowledge about the management of chronic kidney disease. These platforms should be organised frequently in order to keep both parties updated and to sustain their working relationship. Kidney awareness campaigns, particularly during the calendar days specifically marked for kidney awareness campaigns, should be taken to the work place. Health care professionals/nephrology nurses to be allowed to visit employment sectors to educate company managers about kidney disease and its treatment. Employers must be encouraged to support and keep their employees with chronic kidney disease on the job as much as possible

5.4.3 Recommendations for Nursing Research

Future Nursing Research

This was a small study using participants from a single ethnic group. It may be useful to replicate as a large multicultural study. Further research should be done to assess the knowledge of kidney disease among traditional healers. Forums could be held at which all stakeholders including traditional healers could discuss the approach to kidney disease before support therapy is needed.

5.5 LIMITATIONS

The study has the following limitations:

The sample for the study comprised of nine participants and due to the small sample size, the result of this study cannot be generalized beyond the context of this study.

Only participants from Tswana cultural background participated in the study thus creating bias of the results towards Tswana cultural practices. Participants from a different cultural background could have yielded different results.

In addition to that, interviews were conducted in Setswana and translated into English and misinterpretation during translation may have occurred although every effort was made to eliminate this possibility.

The sample comprised of patients on haemodialysis, a sample comprising of patients on other renal replacement modalities might have yielded different results.

Strength of this study

The study uncovered the attitudes and beliefs of patients with chronic kidney disease in the Rustenburg area. The findings of the study reflected on the challenges that these patients experienced in living with chronic kidney disease.

Summary

In this chapter a summary of the study was outlined. Thereafter, a brief description of the research methodology was given. Main findings were then discussed. The limitations of the study namely, small sample size and sample demographics have been outlined. Thereafter, suggestions for education of patients and health professional, nursing management and future research have been outlined.

5.6 CONCLUSION

In conclusion, this small study has shown that chronic kidney disease has a profound and devastating impact on the patient, their families and significant others. The devastating implications of kidney disease include personal, economic, social and cultural factors. The fact that chronic kidney disease is largely preventable means that health professionals and community leaders have to take accountability for providing members of the community with the knowledge and motivation for preventing kidney disease. It is clear from the findings of this study that there is poor awareness of kidney disease coupled by lack of knowledge influenced by negative attitudes and cultural beliefs regarding chronic kidney disease compromise the management of kidney dysfunction. It is imperative that we address these issues urgently before another generation of people suffer. In order to fulfil the requirements of the study two objectives were set. They have been achieved.

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APPENDIX A

Interview schedule on patient's perceptions regarding kidney disease.

Questions were developed in English and translated into setswana

1. After being diagnosed with kidney disease how did you feel?

Morago ga go bolelelwa ke ngaka /mooki gore o nale bolwetse ba diphilo o ne wa ikutlwa jang?

Have you ever thought of seeking traditional help after being diagnosed with kidney dysfunction?

2 .A o kile wa akanya go batla thuso ya setso morago ga go itsesiwe ka bolwetse bag ago ba diphilo?

3. What is your perception regarding the use of traditional medicine in treating kidney disease?

Maitemogelo a gago ke eng mabapi le tiriso ya melemo ya setso/ ditswa mmung go alafa bolwetse ba diphilo?

4. Now that you are receiving medical treatment for your kidney illness, do you think you still need to consult a traditional healer?

Jaanong ka o dirisa kalafi ya sekgoa go alafa bolwetse bag ago ba diphilo, a o santse o akanya gore go tlhokega gore o bone ngaka ya setso?

5. Some people believe that there is a relationship between cultural practice and kidney disease, what is your opinion in this regard?

Batho ba bangwe ba dumela gore go kgolagano magareng ga bolwetse ba diphilo le meetlo ya setso, tshwaelo ya gago ke eng mabaapi le se?

Thank you for your time.

Ke lebogela nako ya gago

APPENDIX B

PATIENT INFORMATION LETTER

Hello, my name is Magdeline Njoro, I am a masters' student in nephrology from the department of nursing at University of Witwatersrand. I am conducting a research study in the dialysis unit at this hospital and would like to request your participation

What is the study about?

The aim of the study is to investigate the attitudes and beliefs of patients with chronic renal illness regarding kidney dysfunction in Rustenburg.

How will the study find out?

A semi structured interview will be arranged to get your input on your attitudes and beliefs regarding kidney dysfunction. All patients with chronic renal illness who agree to participate in the study will be interviewed to share their attitudes and beliefs regarding kidney dysfunction. No staff member in the unit has been involved in selecting you as a possible participant. It will take between 45 minutes- 1hr to answer the questions. The interview will be recorded and I will also be taking some notes during the interview so that I can refer when analysing the information

Will it affect my visit to the dialysis unit?

There is no right or wrong answer to the questions, my role is to listen and not to pass judgement and the way you answer the questions will not discriminate you in the unit positively or negatively. I will not discuss your answer with the nursing staff or other patients. All answers will be incorporated anonymously into an overall assessment of how perceptions regarding kidney disease and its treatment can be improved.

How will I know the information I give will be kept confidential?

The information gained from you will be kept confidential. The consent form that you sign will be kept separately from the answer that you give. During the interview your name will not be recorded and all interviews will be assigned codes and these will be known to me and my supervisors. No names will be revealed in any written report resulting from the

study. The answers given by all participants will be analysed to look for common views. The information will be written up in the form of a research report. If I use any direct quotes from your interview it will be done anonymously.

Did you get permission to carry out the study?

Permission to carry out the study was obtained from the university of Witwatersrand ethics committee. If you have any questions about your rights as a study participant or concerns about any aspect of the study you may contact the University of the Witwatersrand Ethics Office at (011) 717 1234). They have given us rules that we have to comply with, and this includes getting you to sign a consent form to say you have read this information and that you freely consent to participation in the study. For this study in order to ensure confidentiality, and that there is no way your answers can ever be traced back to you, quotes will be used and no names will be used.

Will there be any benefits or harm from participating?

There will be no direct benefits to anyone who participate in the study and there will be no negative consequences if you refuse to be interviewed. You have the right not to answer questions that you feel you are not comfortable with.

Who do I contact if I want to ask more questions?

This study is being controlled by department of Nursing at the University of Witwatersrand. If you have questions about the research that I cannot answer or you have concern about how the research has been conducted you can contact my supervisors at the university, their contact details are stated below.

Dr Sue Armstrong (senior lecturer) at Department of Nursing

Office Tel: 0114883094 email: sue.armstrong@wits.ac.za

Mrs Andy Hayward (Nephrology lecturer) at Department of Nursing

Office Tel: 0114884271 email: andrea.hayward2@wits,ac,za

APPENDIX C

CONSENT FORM FOR SEMI STRUCTURED INTERVIEW WITH PATIENTS

I, the undersigned agree that I have been given the information about the research study. I have read and understood the contents of the information letter and all my questions have been answered satisfactorily.

I understand that it is up to me whether or not I would like to participate in the semi structured interview and that there will be no negative consequences if I decide not to participate. I also understand that I do not have to answer any questions that I am uncomfortable with and that I can stop the interview at any time.

I understand that the researcher involved in this study will make every effort to ensure confidentiality and that my name will not be used in the study reports; and that comments that I make will not be reported to anybody else.

I understand that if the researcher uses any direct quotes from my interview, it will be done anonymously and agree to this.

I consent voluntarily to participate in the interview for this study. I have been given telephone numbers that I may call if I have any questions or concerns about the research study.

Participant's signature: _____ Date: _____

Interviewer's signature: _____ Date: _____

APPENDIX D

CONSENT FORM FOR RECORDING SEMI-STRUCTURED INTERVIEW WITH PATIENTS.

I the undersigned understand that I can decide whether or not the interview should be recorded, and that there will be no consequences for me if I do not want the interview to be recorded.

I understand that the information from the recording will be transcribed and transcripts will be given codes and my name will not be mentioned. I was also informed that should the result of the study be published, the recording device will be locked in safe which has an electronic password and will be destroyed after two years following publication. I also understand that I can ask the person interviewing me to stop recording the interview altogether at any time.

I therefore consent to the recording of semi-structured interview.

Participant's signature: _____ Date: _____

Interviewer's signature: _____ Date: _____

APPENDIX E

Socio–demographic data: Please tick the correct box or answer the question

1.	Age (in years)	
2.	Gender	Female ☐ Male ☐
3.	Marital status	Married ☐ Single ☐ Divorced ☐ Widow ☐ Widower ☐
4.	Religion	Christianity ☐ Traditional religion ☐ Others ☐
5.	Employment	
6.	Place of residence	Urban ☐ Township ☐ Village ☐
7.	Living arrangement	Alone ☐ Spouse only ☐ Spouse and Children ☐ Extended family ☐

APPENDIX F

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M130734

NAME: (Principal Investigator) Ms Mmampu Magdeline Njoro

DEPARTMENT: Nursing Education
University of Witwatersrand

PROJECT TITLE: Attitudes and Beliefs of Patients with Chronic Renal Illness Attending Dialysis Treatment at a Public Sector Hospital in Rustenburg, the North West regarding Kidney Dysfunction (revised title)

DATE CONSIDERED: 26/07/2013

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR: Dr Sue Armstrong

APPROVED BY:
Professor PE Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 22/11/2013

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.
I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature M130734Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX G

PERMISSION LETTER TO CONDUCT THE STUDY

The Director

North West Department of Health

Mafikeng

The Chief Executive Officer

Job Shimankana Tabane Hospital

Private Bag X1078

Rustenburg

0300

Re-permission to conduct a research study at Job Shimankana Tabane Hospital.

Sir/Madam

My name is Magdeline Njoro, I am a master student, studying Nephrology Nursing Science at University of Witwatersrand. As part of the requirement to fulfil the course; I have to conduct a research study.

The study is about the perceptions of chronic renal failure patients regarding kidney disease, and will be conducted at the renal unit at Job Shimankana Tabane Hospital. The study consists of semi-structured interviews, which will be recorded. Participation will be voluntary and a written informed consent will be obtained from participants. Confidentiality will be maintained at all times and anonymity will be assured during reporting and publication of research results.

I therefore request permission to conduct the study at the above named institution.

The result of the study will be made available to you upon request.

Regards

M.M Njoro cell no: 0834727950 e-mail: njoro63@gmail.com

APPENDIX H

health
Department of
Health
North West Province
REPUBLIC OF SOUTH AFRICA

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Job Shimankana Tabane
Hospital

JOB S.TABANE HOSPITAL: CLINICAL MANAGER'S OFFICE

To : **Ms Andrea Hayward**
Postgraduate Coordinator
Nursing Education University of the Witwatersrand

From : **Dr Bogosi Moagi**
Senior Clinical Manager

Date : **27 November 2013**

SUBJECT: APPLICATION TO PERFORM RESEARCH- M M NJORO

This communique serves to confirm receipt of Ms M M Njoro's application to perform research at JST Hospital.

The hospital shall permit Ms Njoro to peform research, however we wish to have the following in order to regularise this application:

i. All correspondence from Ms Njoro and the University to have signatures of the authors.
ii. The research proposal
iii. Formal communique of the approval by the ethics committee
iv. The consent form that is to be used
v. The questionaire that is to be used

These the hospital need to also mke a submission to the NWP Dept of Health Research Unit.

Dr Bogosi Moagi

APPENDIX I

EXAMPLE OF HOW DATA WAS ANALYSED USING TESCH'S METHODS.

The first question that was asked: How did you feel when you were told that you have chronic kidney disease?

After reading each transcript, the researcher grouped categories that relate to each other to generate themes and sub-themes

Participant	Participants' response	Sub-theme	Theme
(N2)	*I was very hurt, I knew that kidney disease was affecting older peoples so that hurt me the most, asking myself where did I get it, because I didn't even know about it, doctor told me "you have kidney failure, I did not understand what the doctor meant*	Shock and disbelief	Emotional response
(N6)	*I cried a lot, my heart was very sore because my age [*paused*] I was very young. I thought it was an age illness, like may be if you are fifty something or like..[paused] I did not expect that at this age I could suffer from kidney disease*		
(N7)	*My head went crazy, I told myself it was only for two days or a week thing, having things put on neck you know [*paused*] it gives stress*		

A follow up question on the first question: How has the disease affected your life?

participant	Participants' responses	Sub-theme	theme
(N3)	*When I started to be sick I was working, I left the job because I felt I was not coping, I was I was delivering takeaways, walking standing and busy the whole day. So like right now who will hire you to work three days a week?*	Employment changes	Disempowerment
	They told me that with high urea and creatinine I cannot work underground, they will find me work on surface, only to find that when I arrived at surface they offer work, like I would earn 70% less of what I was earning, I felt that will rather go and stay at home, they have given me medical disability.		
(N4)	*That is where I had a problem, [paused], I had to work night shift only in order to be able to come for dialysis in the morning and reduce my working hours, I could not do some of the task that are heavy at work and there were days that I could not work*		

The second question asked was: After being diagnosed with chronic kidney disease, did you think of consulting traditional healers, and why?

participant	Participants' responses	Sub-theme	Theme
(N5)	*I thought about it because I grew up drinking traditional medicine because my father was a traditional healer and believed in traditional medicine. As I was growing up they used to say " if you have stomach ache you should go to the field and feed on the leaves on a particular tree like a goat, these leaves are bitter but used to help*	Cultural influence	Attitudes and beliefs

(N6)	*Traditional medicine, when we grew up, we blacks we grew up with it. Traditional medicine has been used, I did drink it, I grew up like any other African person, I only stopped taking them when I started to suffer from kidney dysfunction*		
(N8)	*According to our belief at home, while I was growing up traditional medicine was used a lot. When you had headache or what, you will go to the traditional healers and not western doctors and you will get help, that is why when I heard that I have kidney disease I thought of them first*		

What was your experience with traditional healing methods and kidney disease?

participants	Participants' responses	Sub-theme	Theme
(N3)	*Traditional healers cannot treat kidney disease, traditional healers and kidney disease does not meet, traditional medicine is not tested, does not have limits and measurements, use a lot of water*	Influence of culture on compliance	Attitudes and beliefs
(N4)	*I ended up going to a Zion Christian church healers, they told me that they will heal me, drinking their tea and coffee but it kept getting worse*		

participant	Participants' response	Sub-theme	Theme
(N1)	*They took me to the traditional healer, I just went because he said we should go,* *you see, there was no way I can refuse because I needed help, but, eish, I just*	Influence from members	Attitudes and beliefs

	wanted to satisfy them not because the traditional healer was better than at the hospital		