Pain management of patients with chronic renal failure: A case study of patients in a private renal facility

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Shamanie Govender

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Supervisor: Professor J. K. Adam

Co-supervisor: Doctor A. A. Khan

AUTHORS DECLARATION

This study represents original work by the author. It has not been submitted in any other form to any other Tertiary Institution. Where use of the work of others was made, it has been duly acknowledged in the text.

The research described in this dissertation was conducted at the Fresenius Durban Kidney and Dialysis Centre, based in Durban. Professor J. K. Adam (IREC: Chairperson): Research and Postgraduate Support, at the Durban University of Technology provided academic supervision and Doctor A. A. Khan, (Specialist Nephrologist) provided professional guidance at the Centre.

SIGNED: …… Date:……

Miss S Govender

I hereby certify that the above statement is correct.

SIGNED:…… Date:……

PROFESSOR J. K. ADAM

(M. Med Sc, HED, D.Tech: Clinical Technology)

SIGNED:…… Date:…….

DOCTOR A. A. Khan

(M.B.Ch.B, M.R.C.P., FRCP)

DEDICATION

I dedicate this work to:

Almighty Lord Ganesha, remover of all obstacles, who has guided and blessed me throughout my life, studies and career.

My father and mother, Nithia and Shanoo, who have showered their children with an abundance of love and support, to succeed in all of our endeavours. My heart is full of gratitude for all your guidance and inspiration. To my sisters, Devashya and Komeshni, who have been my biggest critics and supporters, thank you for your patience and understanding.

ABSTRACT

Introduction

At least 82% of patients with chronic kidney disease (CKD) report pain of moderate to severe intensity (Davison, 2006: 1). Despite this high prevalence, a growing body of literature has shown that pain in the CKD population is under-recognised and ineffectively treated (Weisbord, 2016; Harris et al., 2012; Davison, 2007).

There are multidimensional causes of pain, for example, from the kidney disease itself, the dialysis procedures or diabetic neuropathy (Curtin et al., 2002: 569). Pain has consistently shown to negatively impact health-related quality of life (Koncicki et al., 2015; Barakzoy and Moss, 2006). Pain also causes other symptoms, such as, depression, cramps, aching bones and headaches and pain is associated with sleep disturbances and may adversely affect dialysis treatment such as non-compliant behaviour. (Brkovic et al., 2016; Davison, et al., 2014; Danquah, 2009).

Pain management is highly complex in patients with CKD because there is a very narrow margin between pain relief and toxicity. Opioids can accumulate in the body and cause adverse effects, such as, respiratory distress, sedation and myoclonus (Davison, 2003; Kurella et al., 2003). In the last decade research has demonstrated that the implementation of the World Health Organisation (WHO) three-step analgesic ladder significantly reduces pain in CKD patients (Barakzoy and Moss, 2006; Davison, 2005; Kurella et al., 2003). Non-pharmacological strategies to relieve pain symptoms such as psychological and cognitive behavioural therapy, for example, relaxation techniques, and spiritual counselling should also be recommended and supported by the renal professional team (Santoro et al., 2013; Davison, 2005).

Nephrologists and dialysis nursing staff are often inadequately prepared to recognize and treat pain, primarily due to the fact that pain management is not part of the Kidney Disease Outcomes Quality Initiative (K/DOQI) guidelines (Patel, 2013:270). With the increase in the number of patients with CKD, it is increasingly relevant that measures should be implemented to identify, assess and provide appropriate analgesia and / or non-pharmacological therapies to reduce pain and bring comfort to patients experiencing debilitating types of pain.

Aims and objectives of the study

The overall aims and objectives of this study was to investigate the types, frequency and severity of pain experienced by patients with chronic kidney disease and to suggest strategies that patients and staff could use to manage the patients' pain that was experienced.

Methodology

A total of 60 patients and 22 renal staff participated in the study. Questionnaires were administered to staff and patients at the Durban Kidney and Dialysis Centre. Inclusion and exclusion criteria were applied to the participants. Medical records of the patients were analysed. Minutes of staff meetings and the protocols of the Centre were scrutinised in terms of pain management strategies. The study was conducted between September 2017 and March 2018. Relevant statistical methods were used for analysis.

Results

Patients were on average 57 years of age and all were on haemodialysis. Results for this study show that 98.3% of patients reported pain symptoms during dialysis and for 72.3% of the patients, the pain experienced was moderate to severe indicating that pain is a major symptom burden in this patient population. The most frequently reported symptoms were lower back pain (80%), lower leg pain (51,7%) and upper chest pain (46,7%%). Pain was

frequently experienced by patients following the dialysis session (78,35%). Between 53, 3% and 65% of patients reported that pain affected them mostly, for example, when climbing stairs or walking. Patients in this study had substantial co-morbid diseases with 26,7% reporting hypertension, diabetes and cardiac stent. Thus, the causes of pain are multi-factorial and make management thereof challenging. There was a significant association with pain and older age, long years of being on dialysis and the period at the end of the haemodialysis (HD) treatment session itself ($p< 0.0\ 5$). Patients (72,7%) shortened their time on dialysis because of severe pain experienced. Thus, this study shows that there is significant relation between compliance and pain. In this study, pain was not related to gender or race.

Depression was experienced by a large percentage (85%) of patients in this study. The severity of pain experienced caused 66,6% of the patients to be hospitalised and 86,6% stated that pain affected their ability to have a restful sleep. When this is seen in conjunction with the fact that 78% of patients responded that their pain impacted on their ability to work, one can see the distinct link that pain adversely impacts their functional status.

The pain medication that was primarily used by patients was Panado (53%) and nearly 60% of the patients reported using alternative means of pain relief such as a physiotherapist. Non-steroidal anti-inflammatory drugs (NSAIDs) use appears to be high and there is a low use of opioids. In addition, there was no indication that adjuvants were prescribed or used. Thus, the patterns of pain medication recommended and / or taken by the patients in this study show a simple, generalised pharmacological approach rather than a targeted therapeutic intervention specifically tailored to the type of pain experienced by the patient; an approach which has also been reported by Davison et al., (2014). Several international studies have

shown that analgesic use is not high in CKD patients despite the high prevalence of pain (Murtagh et al., 2007; Dean, 2004; Kurella et al., 2003).

Interesting to note that 90,9% of staff reported that Lyrica was recommended for muscle pain, joint pain and numbness but patients reported high usage of only Panado (53%). This could possibly indicate under-education of patients with regard to analgesics; under-recognition of the type of pain or lack of follow-up by staff. High cost of medication for the patients (68%) and unawareness of pain management strategies (72%) are also barriers to use of analgesics.

It is evident that all patients in this study do not do any form of exercise. It would, therefore, be important for these patients to be referred to a physiotherapist or bio-kinesthesis so that they receive appropriate physical training to help alleviate their pain symptoms.

The renal staff in the Centre are highly qualified to perform their duties. However, they did not offer analgesics for pain relief at the end of the dialysis session when many patients complained of pain and terminated their session early (72,7%). 100% of the staff ensured that patients were comfortable rather than offer analgesics to relieve pain (54,5%) during or after dialysis. However, there were no pain assessment instruments for staff to clinically assess types, frequency and severity of pain that was experienced by the patients. There was a lack of guidelines to assist staff to make decisions about analgesic use.

Conclusion

It is evident from the results of this study that pain management was neither done in a strategic manner nor was it tailored to the patient's specific needs. For staff, there were no formal, clinical pain management assessment instruments or follow-up regarding adherence to the recommendations for pain analgesics. The patients (72%) revealed that they did not

have in-depth knowledge of pain management treatments and associated with the fact that many did not comply with the full duration of the dialysis session, indicating that focused attempts must be made to instil patient education about pain management therapies in this vulnerable group. Both patients and staff would benefit from awareness about different types of pain management therapies, (both pharmacological and non-pharmacological) and the long term impact if pain continues to be under-diagnosed and under-treated.

The development of guidelines by the Centre to assist the staff to make decisions about analgesic use for the patients is essential. The specialist nephrologists should investigate and implement a combination of analgesics tailored to the needs of the patient. Future decisions can be based on the WHO three-step ladder on analgesic use. The patients would benefit from appropriate interventions to manage their pain.

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LIST OF ABBREVIATIONS

ADPKD	Autosomal Dominant Polycystic Kidney Disease
AIDS	Acquired Immune Deficiency Syndrome
AVF	Arterio-venous fistulas
AV	Arterio-venous
BPI	The Brief Pain Inventory
CHEQ	CHOICE Health Experience Questionnaire
CKD	Chronic kidney disease
CNS	central nervous system
CPR	Cardiopulmonary Resuscitation
CTS	Carpal tunnel syndrome
CUA	Calcific uraemic arteriolopathy
DH	Dialysis headache
DRA	Dialysis-related amyloidosis
DSI	Dialysis Symptom Index
e.g.	Example
ESRD	End- stage renal disease
GFR	Glomerular filtration rate
HD	Haemodialysis
HIV	Human Immunodeficiency Virus
HRQoL	Health-related quality of life
HTEMS.	High tone external muscle stimulation
K/DOQI	Kidney Disease Outcomes Quality Initiative
KDQoL-SF	Kidney Dialysis Quality of Life-Short Form
m-ESAS	Modified Edmonton Symptom Assessment System
mg	Milligram
ml/min/1.73 $m^{2.}$	Millilitres per minute per 1.73 meter square
MPQ	McGill Pain Questionnaire
NKF	National Kidney Foundation
NSAIDS	Non-steroidal anti-inflammatory drugs

NSF	Nephrogenic systemic fibrosis
PDN	Painful diabetic neuropathy
PENS	Percutaneous nerve stimulation
pmp	Per million population
PNS	Peripheral nervous system
POS-renal	Palliative Care Outcome Scale-renal
PSDS	Physical Symptom Distress Scale
SARR	South African Renal Registry Report
SCS	Spinal cord stimulation
SD	Standard deviation
SPSS	Statistical Package for the Social Sciences
SSA	Sub-Saharan Africa
RRT	Renal replacement therapy
TENS	Transcutaneous nerve stimulation
TNT	Nitro-glycerine
VAS	A Visual Analogue Scale
Vs	Versus
WHO	World Health Organisation
WBPS	Wong-Baker FACES Pain Rating Scale

CHAPTER ONE

INTRODUCTION

1.1 Brief overview of kidney function

The kidneys play a vital regulatory function in the body. For example, the kidneys filter metabolic waste, toxins and excess ions and fluid from the blood while returning needed substances to the blood; the kidneys maintain the correct balance of water and salts and acids and bases and the kidneys are an endocrine organ that produce the hormone erythropoietin which stimulates red blood cell production in bone marrow (Kumar and Clark, 2012: 562).

1.2 Chronic kidney disease

In susceptible populations, for example, those with diabetes mellitus and hypertension, loss in renal function may occur. Chronic kidney disease (CKD) is a progressive, irreversible decline in glomerular filtration rate (GFR) and eventually leads to end-stage renal disease (Rosenburg et al., 2008; Daugirdas et al., 2006). CKD is defined as “the presence of markers of kidney damage for three months as defined by structural or functional abnormalities of the kidney, with or without decreased GFR, that can lead to decreased GFR, manifest by either pathological abnormalities or other markers of kidney damage, including abnormalities in the composition of blood or urine, or abnormalities in imaging tests” (National Kidney Foundation, 2002: 47). Furthermore, an estimated GFR above 60 mL/min/1.73m^2, for three months, with or without other signs of kidney damage indicates CKD (NKF, 2002: 47).

CKD has emerged has a worldwide public health problem (Stanifer et al., 2014; Levy, Atkins and Coresh, 2007; NKF, 2002). Glassock et al. (2017: 110), comment that the estimated global prevalence of CKD (Stages 1 – 5) is 500 000 000 persons. The estimated prevalence of CKD in Sub-Saharan Africa (SSA) is 13. 9% (Hill et al., 2016: 3). The data provided by

the South African Renal Registry Report reflect only those CKD patients that are on renal replacement therapy. The report indicates that the total number of patients on renal replacement therapy continue to increase and at the end of 2015 was 10 360 reflecting a prevalence of 189 per million population within South Africa (Davids et al., 2017: 206).

Once the person has been diagnosed with renal impairment, it is recommended that treatment regimens be started. Decisions about treatment therapies are complex. However, the patient, the family and the physician will be collectively involved in the final type of treatment chosen. Dialysis is necessary for the removal of waste products from the blood. Peritoneal or haemodialysis are options, with haemodialysis being the most prevalent dialysis therapy used worldwide. It removes waste and excess fluids using an access (catheter, fistula or graft) to allow blood to flow through plastic tubing to an artificial semi-permeable membrane called a dialyzer or artificial kidney (Danquah, 2009: 11).

1.3 Pain in patients with chronic kidney disease

CKD has multitude of physical and psychological symptoms, with pain being one that is most troublesome and distressing and which significantly affects the quality of life of the patient (Danquah, 2009:4). Several international studies have described the impact and severity of pain in these patients (Davison et al., 2014; Williams and Manias, 2008; Davison, 2006; Weisbord et al., 2005). At least 82% of CKD patients report pain of moderate to severe intensity (Davison, 2006: 1). Despite this high prevalence, a growing body of literature has shown that pain in the CKD population is under-recognised and ineffectively treated (Weisbord, 2016; Harris et al., 2012; Davison, 2007). The patient with CKD will suffer various types of pain, for example, chronic or acute pain with the former type having an extended duration and the latter being of a finite period of time, with differing etiology. Patel (2013: 268), highlight that pain can also be classified as “nociceptive” (somatic and

visceral),"neuropathic", and "psychogenic" although there may be an overlap in some particular cases. If pain is not explicitly acknowledged and resolved, pain negatively affects the quality of life of the dialysis patient and may also influence decisions on whether to continue with dialysis treatments.

There are multidimensional causes of pain, for example, from the kidney disease itself, the dialysis treatment itself, chemotherapy or diabetic neuropathy (Curtin et al., 2002: 569). The International Association for the Study of Pain (2013), defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage" (Merskey and Bogduk, 1994: 240).

Pain has consistently shown to negatively impact health-related quality of life (HRQoL) in the CKD patient population (Koncicki et al., 2015; Barakzoy and Moss, 2006). Pain experienced by CKD patients also causes other symptoms, such as, depression, cramps, pruritus, aching bones and headaches and pain is associated with sleep disturbances (Brkovic, Burilovic and Puljak, 2016; Davison et al., 2014; Danquah, 2009). Observational studies by Weisbord (2016), Musci (2008) and Unruh, Weisbord and Kimmel (2005), suggest that under-managed pain has the potential to exacerbate co-morbid conditions in CKD patients which may adversely affect dialysis treatment such as non-compliant behaviour.

1.4 Pain management in patients with CKD

Pain management is highly complex in patients with CKD because there is a very narrow margin between pain relief and toxicity. In addition, the patients' concomitant health problems may influence the type of analgesia given (Williams and Manias, 2007: 820). Opioids can accumulate in the body and cause adverse effects, such as, respiratory distress, sedation and myoclonus (Davison, 2003; Kurella, 2003). Furthermore, pain relief may be ineffective if the analgesia is easily removed with dialysis (Castro et al., 2013: 30). In the last decade,

research has demonstrated that the implementation of the WHO three-step analgesic ladder significantly reduces pain in CKD patients (Barakzoy and Moss, 2006; Davison, 2005; Kurella, et al., 2003). Some analgesics were found to be safe, such as, acetaminophen and fentanyl; others needed dose adjustments, for example, tramadol and methadone. Some analgesics, such as, morphine and codeine should be avoided altogether (Koncicki et al., 2015; Murtagh, et al., 2007; Barakzoy and Moss, 2006; Davison, 2005). Adjuvants such as anticonvulsants and antidepressants may be co-administered at any stage of the WHO ladder for neuropathic pain (Glick and Davison, 2011; Davison, 2006). In general, analgesic should be started at low doses and titrated carefully for CKD patients. Davison et al. (2014: 191), warn that careful attention should be paid to issues of efficacy and safety because there is insufficient evidence to provide definitive guidelines about the use of various opioids for CKD patients.

Patients with CKD have a polypharmacy of medication and with potential adverse effects of many of the drugs, non-pharmacological strategies to relieve pain symptoms should also be recommended and supported by the renal professional team (Santoro et al., 2013: S 8). There is a wide array of non-pharmacological treatments such as psychological and cognitive behavioural therapy, for example, relaxation techniques, hypnosis, breathing exercises, yoga and spiritual counselling (Davison, 2005: 327). Other non-pharmacological approaches, such as, the use of heat, ice and massage should also be considered as part of a multimodal approach to pain management. Santoro et al. (2013: S 8), found that different forms of electro-therapy are effective in pain relief, the most commonly used one, being transcutaneous nerve stimulation (TENS).

The professional renal team play a crucial role in patient care. However, nephrologists and dialysis nursing staff are not adequately prepared to recognize and treat pain, primarily due to the fact that pain management is not part of the K/DOQI guidelines (Patel, 2013: 270). In

most cases the staff are only prepared to assist with pain relief if it pertains to the dialysis treatment itself and not pain that arises from co-morbidities such as cardiovascular pain. Furthermore, Davison et al. (2014: 189), reports that data on the exact causes and diagnosis of pain in CKD patients are lacking, which may hinder the development of targeted therapeutic interventions above general pharmacologic approaches to pain management.

With the increase in the number of patients with CKD, it is increasingly relevant that measures should be implemented to identify, assess and provide appropriate analgesia and / or non-pharmacological therapies to reduce and bring comfort to patients experiencing debilitating types of pain.

Despite this, there has been no reported South African-based research to increase the knowledge of CKD-associated pain management from a patient's perspective. While pain often accompanies CKD, little is known of how decisions are made to manage pain in clinical practice and pain management has not been researched within a South African dialysis unit. Insufficient understanding and underassessment of pain, together with a lack of patient involvement in decision-making may lead to inadequate care provision (Manias and Williams, 2008: 201).

A detailed literature study was conducted and according to my knowledge no study was undertaken to specifically investigate pain management, the prevalence of different types of pain, its severity and impact on CKD patients within the South African context.

The overall purpose of this study was to investigate the types, frequency and severity of pain experienced by patients with CKD. In addition, specific objectives focussed on how the patients managed the distress and discomfort they experienced and how the renal staff responded to the pain experienced by patients in their care. A long term goal of this study is to develop efficient and effective interventions and strategies to manage patient's pain and

thereby provide a level of comfort and improving overall HRQoL for patients with this debilitating disease.

1.5 Conclusion

Chronic pain is a common and incapacitating symptom for a high number of CKD patients. This chapter presented a brief background on chronic kidney disease, types of pain and pain management approaches. Regular pain assessments should be implemented in dialysis facilities to improve patient care. Specific pain management therapies were described and various analgesics were reviewed. The study aimed to assess the types of pain, the severity and impact on the CKD patient. In particular, it sought to determine how the professional renal team approached pain relief and the pharmacological and non-pharmacological approaches that were implemented in the private renal centre.

Chapter Two covers the literature review focussing on a description of chronic kidney disease, types of pain, and approaches to pain management relevant to the CKD patient population. Chapter Three describes the research methodology used for this investigation. Chapter Four briefly comments on the results of the findings obtained from the questionnaires that were administered to the staff and patients who participated in the study. Chapter Five presents the discussion of the findings pertinent to the study. Chapter Six describes the limitations of this study, recommendations for future research areas and the overall concluding remarks to this research study.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

Dialysis is a life-saving therapy for patients with chronic kidney disease (CKD). However, this therapy is ineffective in decreasing many of the physical and psychological symptoms associated with advanced CKD (Davison, Koncicki and Brennan, 2014: 188). This patient population experiences tremendous symptom burden and of all the symptoms; pain is one of the most common and distressing one (Davison et al., 2014; Bourbonnais and Tousignant, 2012; Manias and Williams, 2008). Despite this however, according to Weisbord (2016), Barakzoy and Moss (2006) and Davison (2003), there remains a lack of clinical consensus on approaches to the assessment and overall management of pain in patients with CKD.

To my knowledge there is limited clinical and research focus in the area of pain management within the South African context and specifically for the CKD patient. Thus, there is an urgent need to develop a framework to provide a sound approach to address the spectrum of issues pertaining to the management of pain in this patient population.

2.2 Chronic Kidney Disease

2.2.1 Functions of the kidney

The kidneys are vital in the regulation of the body's fluid environment, keeping it in a constant and homeostatic state. The kidneys filter metabolic waste, toxins and excess ions and fluid from the blood stream while retaining needed substances for the blood. While the kidneys perform these functions they simultaneously regulate the volume and chemical makeup of blood, maintaining the correct balance of water and salts and acids and bases. The kidneys have other regulatory functions. For example, the kidneys help to convert Vitamin D to its active form. The kidneys produce the enzyme renin which helps regulate blood pressure and

kidney function and also produces the hormone erythropoietin which stimulates red blood cell production in bone marrow (Kumar and Clark, 2012: 562).

However, in susceptible populations, renal function loss can occur. CKD is a progressive, irreversible decline in glomerular filtration rate (GFR) and eventually leads to end-stage renal disease (Rosenburg et al., 2008: 279).

2.2.2 Definition of chronic kidney failure

In 2002, the National Kidney Foundation: Kidney Disease Outcomes Quality Initiative (NKF – K/DOQI): Clinical Practice Guidelines for Chronic Kidney Disease, recommended that CKD be defined "as the presence of markers of kidney damage for three months as defined by structural or functional abnormalities of the kidney, with or without decreased GFR, that can lead to decreased GFR, manifest by either pathological abnormalities or other markers of kidney damage, including abnormalities in the composition of blood or urine, or abnormalities in imaging tests" (NKF, 2002: 47). Furthermore, an estimated GFR (eGFR) above 60 mL/min/1.73m², for three months, with or without other signs of kidney damage (as explained previously) indicates CKD (NKF, 2002: 47). The normal kidney function is said to equate to an eGFR of 120-125 ml/min/1.73 $m^{2.}$ (McLaughlin, 2004: 9).

2.2.3 Causes of chronic kidney failure

Many debilitating factors affect the ability of this filtration mechanism to function optimally, causing the kidneys to become diseased. Some of the main causes of kidney failure are as follows (Warnock, 1996: 75):

- Diabetes and diabetic nephropathy which damages the nephrons in the kidneys.
- Hypertension or untreated high blood pressure which damages the nephrons causing nephrosclerosis.

- Inflammation which causes swelling of the nephrons resulting in glomerulonephritis and collagen disease such as lupus (an auto-immune disease).
- Obstructions in the urinary system such as kidney stones or structural birth defects.
- Hereditary conditions such as polycystic disease and glomerulonephritis and a family history of renal failure.
- Chronic infection of the kidney and urinary tract such as cystitis and pyelonephritis.
- Other causes of kidney failure include bacteria, tumours, accidents, allergies and injury caused by medication, drugs, poisons and radiation.

2.2.4 Impact of kidney failure in the body

The kidneys are responsible for a complex series of tasks in the maintenance of homeostasis in the body and therefore kidney failure has a tremendous impact in the overall health of the person. Kidney failure causes a number of physical and psychological symptoms which progresses over a number of years and comes and goes depending on the individual patient and the level of kidney function (McLaughlin, 2004: 7). It is important to remember that a patient can have significant kidney damage (more than 50%) before clinical symptoms develop (Thomas and Mathew, 2000: 26). Table 1 shows common symptoms experienced by the patient with kidney disease and the table also highlights the devastating impact kidney disease has on all major organs in the body (McLaughlin, 2004: 7):

Table 1: Symptoms of kidney disease and manifestations in the body (McLaughlin, 2004: 9).

SYMPTOMS IN THE BODY	MANIFESTATIONS
Fluid and electrolyte imbalance	• Pulmonary oedema, weight gain, hypertension, pleural effusion • Cough dyspnoea, peri-orbital oedema, peripheral oedema, congestive heart failure • High or low levels serum sodium, phosphorus, calcium, potassium, magnesium and associated complications

Uraemia	• Headaches, drowsiness, confusion, memory loss, insomnia, apathy, sleep disturbances • Paraesthesia, muscle twitching, restless leg syndrome, gait abnormalities, hearing loss, decreased cough reflex • Pericarditis, cardiac arrhythmia, cardiac tamponade • Increased susceptibility to infections, • Increased bleeding tendencies, epistaxis, ecchymosis • Pruritus, dry skin, skin colour changes, pallor • Nausea, vomiting, constipation, anorexia, metallic taste in mouth, gingival hyperplasia, gastritis, diarrhoea
Anaemia	• Fatigue, pallor, decreased appetite, cold intolerance, hypotension, reduced exercise tolerance • Shortness of breath, hypoxia • Tachycardia, increased angina, left ventricular hypertrophy, heart failure
Cardiovascular disease	• Hypertension, ischaemic heart disease, congestive heart failure, arteriosclerosis, cardiomyopathy cardiac arrthymias, heart failure, cardiac arrest
Lipid disorders	• Cardiovascular disease, elevated triglyceride levels, elevated cholesterol levels
Acid/base imbalance	• Metabolic acidosis or alkalosis, confusion, nausea, vomiting, hyperkalaemia, hyperventilation, convulsions, cardiac arrest
Calcium and phosphate imbalance and bone disease	• Bone pain, pathological fractures, metabolic calcification • Hyper-phosphatemia • Secondary hyperparathyroidism, renal osteodystrophy
Malnutrition	• Weight loss, anorexia, low serum albumin, muscle wasting, poor healing • Susceptible to infections
Endocrine disorders	• Hyperthyroidism, impotence, dysmenorrhea, amenorrhoea, decreased libido • Glucose intolerance, hyperparathyroidism, hypertension
Psychosocial problems	• Depression, anxiety • Loss of self-esteem • Job loss/reduced employment opportunities. • Loss of income • Change of family dynamics/community standing • Impaired Health Related Quality of Life

2.2.5 Diagnosis and stages of chronic kidney disease

Classification of CKD requires establishing the presence or absence of renal injury, estimate of GFR, and that kidney disease has persisted for three or more months. Evaluation of kidney function is more dependent on an estimated GFR or the presence of other markers of kidney

impairment, rather than a single serum creatinine reading (Tawfic and Bellingham, 2015: 7). Diagnosis is made by doing a urine test for the presence of protein. If protein is found, a blood test is performed to measure the person's GFR which is an accurate method to test overall kidney function (Levy et al., 2003: 137). In the past there was a lack of consensus on how the progression to CKD should be defined and classified. This could have contributed to under-diagnosis and under-treatment of early kidney disease resulting in lost opportunity for slowing or preventing the progression of the disease (Levy et al., 2003, NKF, 2002; Pereira, 2000).

The NFK classification (2002: 57), as shown in the Table 2, defines five stages of CKD by increasing severity of impaired kidney function, diagnosis, treatment and prognosis:

Table 2: Stages of chronic kidney disease (National Kidney Foundation, 2002: 57).

STAGE	DESCRIPTION	GFR (ml/min/1.73 m^2	RELATED TERMS
Stage 1	Early onset with minimum kidney damage, with normal or slightly decreased GFR, usually no clinical symptoms making diagnosis difficult	≥90 ml/min/1.73 m^2	Albuminuria, proteinuria, haematuria
Stage 2	Mild degree of kidney damage, with mildly decreased GFR	60 – 89 ml/min/1.73 m^2	Albuminuria, proteinuria, haematuria
Stage 3	Further decline of kidney function, clinical symptoms appear, moderately decreased GFR	30 – 59 ml/min/1.73 m^2	Chronic renal insufficiency, early renal insufficiency
Stage 4	Severe kidney damage, preparing for renal replacement therapy (RRT), severely decreased GFR	<15 - 29 ml/min/1.73 m^2	Chronic renal insufficiency, late renal insufficiency, early end-stage renal failure
Stage 5	Kidney failure, RRT needed to sustain life	< 15 ml/min/1.73 m^2 and dialysis	Renal failure, uraemia, ESRD, RRT

This classification provides worldwide consensus on detecting kidney disease and provides for effective treatment and research. As kidney damage progresses the remaining nephrons compensate for the reduction in nephron mass by increasing the single nephron filtration rate,

with this hyperfiltration promoting further injury at each stage (Brenner, 2003: 371). Patients with CKD need to be monitored for progression to kidney failure, and patients who advance to CKD stage 3 require increased monitoring and control of hypertension, anaemia, renal bone disease, and nutrition. It is thought that for patients in early stages of CKD, early recognition and administration of appropriate treatment may delay the onset of ESRD. Delayed referral for ESRD treatment has been associated with less than the optimal vascular access placement, failure to manage renal bone disease and nutrition, poor anaemia control, impaired quality of life, and increased risk of severe hypertension, uraemic symptoms, pulmonary oedema, and emergency dialysis (NKF, 2002; Pereira, 2000).

2.2.6 Prevalence of chronic kidney disease

CKD has emerged as a worldwide public health problem, with major economic implications to the patient and society (Levy et al., 2007: 247). Glassock et al. (2017: 110), comment that a comprehensive analysis was undertaken in 2012 which showed that the estimated global prevalence of CKD (Stages 1 – 5) was 500 000 000 persons, ranging from 3 – 18% across 32 countries, with an incidence of 10.4% in men and 11.8% in women. Of this, about 230 000 000 people fall in the CKD 3 – 5 stages as defined by an eGFR < 60 ml/min/1.73 m^2 and 50% of the individuals are > 60 years of age (Glassock et al., 2017: 110).

The estimated prevalence of CKD in Sub-Saharan Africa (SSA) is 13.9%, which is similar to global estimates of 13.4% (Hill et al., 2016: 3). According to Etheridge and Fabian (2017: 1), the incidence of CKD is predicted to rise substantially in SSA because of rapid urbanisation, improved life expectancy and population ageing. Systemic issues such as poor infrastructure, absence of early screening and prevention programmes for kidney disease increase risk for CKD. Thus, in most instances CKD is often diagnosed at an advanced stage when (Renal Replacement Therapy) RRT may be necessary to maintain life.

In South Africa very little is known about the prevalence of CKD and rates of progression to ESRD. The South African Renal Registry Report, compiled by Davids, Marais and Jacobs provides data on RRT for the country. Davids et al. (2017: 206), report that the total number of patients on RRT continue to increase and at the end of 2015 was 10 360 reflecting a prevalence of 189 per million population (pmp). Of these, 13.4% had a functioning renal transplant, 16.1% were on peritoneal dialysis and 83.9% were on haemodialysis.

Data from the South African Renal Registry Report (SARR) shows that the most common cause of ESRD in adults was hypertensive renal disease (33.7%) followed by diabetic nephropathy (14.4 %) and glomerulonephritis (9.5%) (Davids et al., 2017: 208). However, Naicker (2003: S 120), notes that the statistics provided by SARR reflect patients selected for RRT and does not accurately reflect the etiology of chronic renal failure because few patients with diabetic ESRD are offered dialysis or transplantation because of co-morbid conditions. Due to financial costs the South African National Health Department has adopted the policy that state facilities will offer RRT only to patients who are eligible for transplant (Etheridge and Fabian 2017; Naicker, 2003).

The prevalence of CKD has been addressed in several studies (Glassock et al., 2017; Hill et al., 2016; Anand, Bitton and Gaziano, 2013; NKF, 2002) and differs from country to country and among ethnic groups worldwide (Martins, Agodoa and Norris, 2012: 2). Naicker (2003: S 120), indicate that nephrotic syndrome accounted for 0.8 % of hospital admissions in Zimbabwe, 2% in Uganda and 2.4% in Nigeria. CKD affects mainly adults aged 20 – 50 years in SSA and is primarily due to hypertension and glomerular diseases (Fogazzi et al., 2003: S 59), unlike in developed countries where CKD presents in middle-aged and elderly patients (50% are > 60 years) and is predominately due to diabetes mellitus and hypertension (Glassock et al., 2017: 112).

When defined as an eGFR < 60 ml/min/1.73 $m^{2,}$, then the prevalence of CKD is reflected as 16% of the population in Ghana, 6% of the population in Sudan, 24% of population in Zambia and 5% in Nigeria (Stanifer et al, 2014: e 177). CKD prevalence in China is 10. 6% (Glassock et al., 2017: 110), and 14.7% of the population in Australia have CKD (Hill et al., 2016: 8). In the US, 14,44% of the population have CKD stages 3 -5, whilst in Europe it is 11.86% (Hill, et al., 2016: 8).

CKD is usually asymptomatic until later stages and accurate prevalence data is lacking (Hill et al., 2016: 1). Furthermore, estimates of prevalence data varies widely within and between countries (Glassock et al., 2017: 104). The reasons are multifactorial and include, for example, a lack of screening programmes for high risk groups with early symptoms of kidney disease, a lack of national registries for all stages of CKD and an absence of reliable and validated measures of kidney function (Stanifer et al., 2014: e 179).

2.2.7 Approaches to treatment regimens for patients with kidney disease

Once the individual has been diagnosed with renal impairment, it is highly recommended to start treatment regimens immediately. Optimising the health of the individual suffering from CKD during the early stages offers the opportunity of an improved quality of life and fewer complications. In stage one, usually no clinical symptoms are apparent and this makes diagnosis difficult. The damage to the kidney progresses undetected for some time before signs and symptoms are apparent. The patient may feel well and may find it difficult to comprehend the long-term consequences of the disease. However, it is the ideal time to provide treatment for the underlying kidney disease, along with appropriate management of associated conditions such as hypertension and diabetes (McLaughlin, 2004: 10).

At stage two, the patient has a mild degree of kidney damage and aggressive management of the underlying causes of the disease and emerging symptoms, for example, calcium and

phosphate imbalance, hyperglycaemias and anaemia are recommended (St Peter et al., 2003: 906).

At stage three there is further decline in kidney function and clinical symptoms manifest. Even at this stage it is possible that patients may not know that they have kidney disease. On-going specialist treatment and follow-up of these patients are essential to try and maintain kidney function and prevent complications of cardiovascular disease, anaemia, malnutrition and bone disease (McLaughlin, 2004: 10).

Stage four of chronic kidney disease means that end-stage renal failure is imminent and preparation for renal replacement therapy is necessary. The patient has to seriously consider decisions about their future health care management. Stage five is defined as end-stage kidney failure where renal replacement therapy is required to sustain life (McLaughlin, 2004: 10).

Decisions about treatment options are complex. For example, prognosis, anticipated quality of life (with or without dialysis), treatment burden (if dialysis is used), co-morbid conditions, and patient preferences all play a role in the option chosen (Murtagh et al., 2007: 1955). The patient may choose not to have any RRT, in which case conservative treatment is provided. It is important to recognise that conservative management (without dialysis) is not simply defined by the absence of dialysis but it entails active management (for example, active treatment of anaemia) and detailed supportive care, which often becomes increasingly complex towards the end of life (Murtagh et al., 2007: 1956). Some patients (pre-dialysis or on dialysis) are given the option to have a kidney transplant from a live donor or from a cadaver if they are assessed to be medically fit (McLaughlin, 2004: 12). The patient must be made aware from the renal team that there is a possibility that the transplantation may be

rejected by the patient's body and will therefore need dialysis to stay alive (McLaughlin, 2004: 12).

Accepting the opportunity to commence dialysis therapy is the other option available and one that most patients choose. There are two types of dialysis: haemodialysis and peritoneal dialysis. The patient and their families, with advice and support from the nephrology health team make the final decision on the type of dialysis that will be used (McLaughlin, 2004: 12). Peritoneal or haemodialysis are options, with haemodialysis being the most prevalent dialysis therapy used worldwide. It removes waste and excess fluids using an access (catheter, fistula or graft) to allow blood to flow through plastic tubing to an artificial semi-permeable membrane called a dialyzer or artificial kidney (Danquah, 2009: 11).

There are many challenges and treatment decisions that the patient faces as their kidney disease progresses. Unfortunately, chronic kidney disease is a terminal condition and patients will ultimately need palliative care as they reach a stage where no other treatment options will benefit the patient.

2.3 Pain in patients with chronic kidney disease

Besides having to cope with pain caused by the disease itself, patients with CKD, experience debilitating pain arising from other associated conditions such as musculoskeletal pain. However, pain in this patient population is often underdiagnosed and inadequately treated. The seminal research study by Binik et al., in 1982, assessed multiple facets of pain in 53 patients with CKD and 25% reported significant problems with pain. While limited in scope, this early study was among the first to characterize pain in this patient population. Several further international studies have described the impact and severity of pain in these patients (Davison et al., 2014; Williams and Manias, 2008; Davison, 2007; Weisbord et al., 2005). These studies indicate that 37–50% of CKD patients experience chronic pain of which more

than 82% is moderate to severe in intensity (Davison, 2006: 1). However, there is a lack of research in this area within the South African context. Furthermore, there is a paucity of information, nationally, regarding patients experience of pain, effects of pain on their daily lives and optimal pain management within this patient population. Brkovic, Burilovic and Puljak (2016: 1131), emphasise that it is important to diagnose the severity of pain and the optimal treatment of pain in order to improve the quality of care and overall quality of life in patients with CKD.

Merskey and Bogduk (1994: 210), define pain as an “unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage”. In patients with CKD, pain is a common problem and may be due to the condition itself, concurrent comorbidity or disease following renal failure (Gamondi et al., 2013: 1). However, McCaffery and Pasero (1999: 17), define pain as “whatever the experiencing person says it is, existing whenever he says it does”. This highlights that pain is a subjective experience and will need careful assessment and monitoring because some patients may not display behaviours commonly associated with pain, such as crying or limping.

Research by Bourbonnais and Tousignant (2012: 13), show that RRT, including dialysis, has helped patients live longer. However, there has been a concomitant increase in the patients complaining of other symptoms, including chronic and acute pain. It is found that pain levels experienced by CKD patients are similar to those of other patients such as, patients with chronic heart disease, cancer and acquired immunodeficiency syndrome (Davison and Jhangri, 2010; Saini et al., 2006; Solano et al., 2006).

2.3.1 Epidemiology of pain

CKD is a worldwide public health issue affecting 3%-18% of the population worldwide, and is associated with increased morbidity, mortality, poorer health outcomes and more extensive

health care usage than the general population (Glassock et al., 2017; Rivera, 2017; Hill et al., 2016; Levy et al., 2007; Davison, 2007). Improvements in dialysis techniques, pharmacology and broadening of clinical expertise makes it possible to dialyse older and sicker patients which has also contributed to the increased numbers of CKD patients (McLaughlin, 2004: 14).

Despite pain being highly prevalent in CKD patients, for example, with more than 82% experiencing moderate to severe pain intensity (Davison, 2007: 1), a growing body of research show that pain remains poorly managed in dialysis treatment centres (Weisbord, 2016; Harris et al., 2012; Davison, 2007). Bailie et al. (2004: 2419), found that although there is an increase in the prevalence of chronic pain, analgesic use *decreased*, which suggests possible under-prescription. A systematic review conducted by Wyne et al. (2011: 327), reported that up to 84% of CKD patients with significant pain received *no* analgesia. Therefore, it is evident that for effective management, pain needs to be timeously assessed and appropriate analgesia be administered to improve the quality of care of the CKD patient population.

2.3.2 Pathophysiology

Research by Gamondi et al. (2013: 1), indicate that whilst dialysis is lifesaving, the underlying systemic diseases and related painful syndromes such as ischaemic limb, musculoskeletal pain or neuropathic symptoms persist throughout the patients' life. Davison et al. (2014: 189), reports that data on the *exact* causes and diagnosis of pain in CKD patients are lacking. However, in an earlier study Davison highlights that pain experienced by CKD patients is often multifactorial and includes nociceptive, neuropathic and complex regional pain syndromes (Davison, 2003: 1240). The etiology of pain may be secondary to co-morbidities such as diabetes and hypertension. Another cause of severe pain is the primary disease itself such as polycystic kidney disease. The dialysis treatment itself may contribute to pain symptoms such

as recurrent needle insertion of AV (Arterio-venous) fistulas (Davison, 2003: 1241), and patients experience headaches as a result of shifts of large amounts of water and electrolytes (Göksan et al., 2004: 284).

Weisbord et al. (2005: 161), assessed the prevalence of a multitude of symptoms, including pain in a cohort of CKD patients and found that bone / joint pain was experienced by 50% of patients, showing it as a predominant symptom. Further results of this investigation indicate that muscle cramps and muscle soreness, which represents other manifestations of pain, were reported by 43% and 28% of patients, respectively (Weisbord et al., 2005: 161). In addition, sources of pain related to the uraemic environment are renal bone disease such as osteitis fibrosa, osteomalacia and amyloidosis (Santoro et al., 2013: S 3). Neuropathic pain is a common symptom in CKD patients with a high incidence of 70%-100% experiencing this symptom while on dialysis (Krishnan et al., 2009: 267). Neuropathic pain is caused by primary nerve lesion or nervous system dysfunction (Naylor and Raymond, 2011: 34). Distinguishing between the different types of pain, its severity and causes is important in developing appropriate management strategies in this patient population.

2.3.3 Impact of pain on patients health-related quality of life

Pain has consistently shown to negatively impact health-related quality of life (HRQoL) in the CKD patient population (Koncicki et al., 2015; Barakzoy and Moss, 2006). Pagels et al. (2012: 1), explain that HRQoL is a significant factor of how a condition affects the patient's life. The concept of HRQoL is multidimensional and is described as the "subjective assessment of the impact of disease on the patient and its treatment across a range of issues such as the physical, emotional, psychological and social domain of functioning and well-being" (Peterson and Bredow, 2009: 22).

Research by Sanders (1985: 5), support the view that pain impacts multiple aspects of the patients' well-being because it is associated with physical, social and psychological distress, impairment of interpersonal relationships and significant functional limitations in work, family and society. Pagels et al. (2012: 2), observed that although some disturbances do emerge, the patients' health experience at CKD stages 1 – 3 are not usually considered to be severely affected. However, patients on dialysis, with a more severe renal insufficiency and especially those at a higher CKD stage, do have impaired HRQoL.

The demands of chronic and physically demanding, daily or thrice weekly dialysis treatment and the side effects of the medications also contributes to decline in HRQoL. The time-consuming dialysis regimen makes it difficult for patients to maintain work and leisure activities and also implement exercise and self-management activities of dealing with this disease (Griva et al., 2013: 18).

Brkovic et al. (2016: 1132), make clear that pain affects HRQoL and is a major cause of depression, severe irritability, disturbed sleep patterns and impaired dialysis adequacy (if unable to complete full sessions). Depression is common in CKD patients (with a prevalence of up to 50%) and is associated with increased risk of hospitalisation and mortality (Unruh et al., 2005: 86). Chronic persistent painful diabetic neuropathy (PDN) may also be associated with depression (Davison et al., 2014: 196). Depression interferes with the patient's ability to cope with chronic pain (Davison, 2007: 1280). Thus, unresolved pain has a profound effect on the patients' quality of life and even impacts on the decisions on whether or not to decrease the number of days on dialysis or to discontinue dialysis treatment (Koncicki et al., 2015: 385). It is important to note that pain is a subjective feeling and can only be measured by the person who is experiencing it. Furthermore, the frequency and tolerance of pain varies

among individuals and is influenced by for example, the person's background, expectations, and physical and emotional health (Kafkia et al., 2011: 115).

Koncicki et al. (2015: 384), comment that uncontrolled pain leads to increased utilisation of health care because of increased readmission rates and longer hospital stays. Furthermore, research by Gamondi et al. (2013: 1), illustrate that because of the pain experienced, two out of every five dialysis patients experience troubled sleep, and 38% to 45% suffer some degree of anxiety.

Observational studies by Weisbord (2016), Musci (2008) and Unruh et al., (2005), suggest that under-managed pain has the potential to exacerbate co-morbid conditions in CKD patients which may adversely affect dialysis treatment such as non-compliant behaviour.

These findings highlight that the ramifications of under-treated pain are extensive and is reflective of a decrease in the quality of life. Optimising pain management strategies in the CKD population is essential to prevent the progression of psychiatric co-morbidities, optimise the use of health care resources and, ultimately improve the patients' quality of life (Davison, 2005: 326). However, the subjective nature of pain poses a challenge to health care workers because of the differences of perception and interpretation of pain experienced by each individual CKD patient.

2.3.4 Barriers to suitable and sustainable pain management

There are several unique challenges for the management of pain in the CKD patient population. This is largely due to the constraints that very poor renal function places in the use of medication (Murtagh et al., 2007: 6). These authors note that many of the common causes of pain in renal patients are long term and this may influence both patients' attitudes to pain and the professionals approach to identifying and addressing pain symptoms (Murtagh et al.,

2007: 7). A primary challenge is a lack of recognition by the nephrology profession concerning the extent and severity of the problem and hence a lack of clinical and research focus in this area (Davison, 2007: 1280).

Williams and Manias (2009: 200), highlight several barriers to adequately recognising and treating pain in CKD patients. From the perspective of the nursing staff, these include lack of standardisation of pain assessment and management tools, misconceptions that chronic pain is difficult to assess and treat and that pain is an unavoidable outcome of ageing and of dialysis. Furthermore, from the nursing staff perspective, there may be bias and disbelief of patients' reports of pain, a challenge that is further exacerbated because of possible language barriers between the patient and staff (Manias and Williams, 2008: 205). There is a lack of time to conduct effective pain management practices because of the nurses' busyness with other clinical and administrative duties. Many nurses lack knowledge of the effects of analgesics and their excretion for the patients with CKD, and lack time and training to guide pain management. Nurses do not routinely assess pain but administer analgesia according to schedules and not according to the needs of the patient (Williams and Manias, 2007: 821). This may lead to staff under-recognising the severity, frequency and effect of pain in the CKD patient.

A study conducted by Feldman et al. (2013: 1530), indicate that 35% of renal professionals do not assume responsibility to treat symptoms arising from co-existing conditions such as peripheral vascular disease or bone disease, which cause severe pain, and are reluctant to prescribe analgesics for pain arising from co-morbidities. The renal professionals alluded that they would deal with pain arising from dialysis procedures itself but pain from other co-morbidities should be dealt with by other specialists. In any event, CKD patients are

frequently on multiple drugs with consequent increase in risk of adverse drug interactions (Davison and Ferro, 2009: 187).

Koncicki et al. (2015: 385), state that the patients themselves are a major barrier, for example, ethnic or cultural factors regarding use of medicines, fear of opioids, fear of addiction, poor compliance because of unexpected adverse effects and not wanting to increase an already large pill burden. Furthermore, Williams and Manias (2009: 202), found that many patients did not want to increase the dosage because they assumed that it would further damage their already compromised kidneys. Williams and Manias (2007: 821), report that the most common barrier is that most patients are reluctant to report their pain in the first instance.

Research by Manias and Williams (2008: 207), indicate that although patients may be experiencing pain, they prefer not to be involved in decisions to treat their pain and defer to nurses to administer pain medication when available to do so. This study shows an overall lack of patients' involvement in decisions for their pain relief, with 76% of pain activities and decisions between nurses and patients involving a passive decision-making style (Manias and Williams, 2008: 208).

Another major challenge according to Davison (2007: 1280), is the altered pharmacokinetics and pharmacodynamics of most analgesics in CKD patients, which is largely unknown. Furthermore, the adverse effects of analgesics are mimicked by uraemic symptoms and may result in the impropriate withdrawal of analgesics.

The cost of medications is a barrier for many patients. Some patients stop taking opioids because adverse effects such as nausea and vomiting which are mistaken for an allergic reaction (Davison, 2007: 1280). There is also an increased risk of constipation with opioids and as CKD patients are generally on fluid restrictions this also prevents them from taking

pain medication (Kafkia et al., 2011: 119). The study by Griva et al. (2013: 19), also found that patients have difficulty remembering treatment regimens especially when medications are changed and because patients have to deal with their normal routines such as work.

Health care professionals should not only aim to extend patients life span but also improve their quality of life through appropriate and timely pain relief strategies. Patients should be confident to voice their concerns about the pain experienced to their healthcare team. More research within renal units is essential to identify particular challenges that make pain management difficult. To facilitate this, the nephrology community should develop guidelines to assess and manage pain tailored to the needs of the CKD patient and these guidelines should be provided to renal nurses (Bourbonnais et al., 2012: 18). The guidelines should, according to Williams and Manias (2007: 821), for example, provide analgesics and non-pharmacological guidelines to deal with different types of pain experienced by the individual patient. Furthermore, the guidelines should help nurses determine optimal dosage to be administered depending on the level of renal dysfunction and the type and cause of pain experienced.

Communication between the patient and the inter-disciplinary renal team is important to provide quality, individualised care. Education of both patients and renal staff should be undertaken to enhance patient participation in making informed decisions and their overall adherence to treatments.

2.3.5 Types of pain relevant to patients with CKD

Patients with chronic kidney disease experience a wide variety of pain. Distinguishing between the different types of pain and their potential causes is important in determining optimal pain management strategies (Weisbord 2016; Castro et al., 2013; Murtagh et al., 2007; Davison, 2005).

Santoro et al. (2013: S 2), distinguishes between three broad categories of pain:

2.3.5.1 **Nociceptive pain** which is often time limited and generally responds well to opioids. The nerves are not damaged. Pain results from stimulation of peripheral or visceral nociceptors which subsequently send their signals via the spinal cord to the brain. Davison and Ferro (2009: 187), further explains that nociceptive pain results from tissue damage and may be described using terms such as sharp or like a knife (e.g. joint pain in dialysis) or dull, poorly localised pain (e.g. gut ischemia). Somatic pain can be due to, for example, trauma, inflammation and muscle spasms while visceral pain results from serosa irritation, distension or ischemia of tissues as well as inflammation of internal organs.

2.3.5.2 **Neuropathic pain** is described as aching, stabbing, burning, paroxysmal and electric shock-like. Pain is generated from an alteration of the afferent, somato-sensory pathways caused by damage of the peripheral (PNS) or central nervous system (CNS). It is associated with sensitivity such as numbness and allodynia (Santoro et al., 2013: S 2). According to Davison and Ferro (2009: 187), it characteristically occurs in an area of abnormal sensation, and may be felt at a site distant from its cause. The pain of peripheral neuropathy and phantom limb fall in this category. Neuropathic pain may be poorly responsive to opioids or require doses of analgesia that are associated with unacceptable toxicity. The patient may often require adjuvant analgesics such as antidepressants and anticonvulsants. Naylor and Raymond (2011: 34), state that neuropathic pain is a chronic neurological complaint in more than 70% of CKD patients. It manifests as paraesthesia, weakness, muscle wasting or reduced or absent tendon reflexes.

2.3.5.3 **Mixed pain**, such as ischemia and calcific uraemic arteriolopathy (CUA), which comprises both nociceptive and neuropathic pain (Santoro et al., 2013: S 2).

Pain in patients with CKD is described further by Kafkia et al. (2011: 115), as follows:

2.3.5.4 **Acute pain** which is of recent onset and is usually transient in nature, and which lasts from several minutes to several days or weeks. It is caused by tissue damage and is often associated with some degree of inflammation.

2.3.5.5 **Chronic pain** is pain that persists beyond the usual course of an acute illness or injury (usually beyond three months) and is associated with a pattern of recurrence over months or years.

2.3.5.6 **Constant pain** which is continuing and does not cease but continues for long periods of time.

2.3.5.7 **Sharp pain** which is intense and severe in nature.

2.3.5.8 **Intermittent pain** which occurs occasionally or at regular or irregular intervals.

2.3.5.9 **Idiopathic pain** is of spontaneous origin and the causes are unknown.

Koncicki et al. (2015: 385), divides pain in CKD patients into two main categories and gives some examples of common types of pain in each one:

2.3.5.10 **Intradialytic Pain** which is a unique subset of pain syndromes that requires specific attention and includes pain related to arteriovenous (AV) access, dialysis related

headaches and muscle cramps. These particular types of pain are described as follows:

a) Arteriovenous Access Pain

Brkovic et al. (2016: 1146), suggests that this type of pain can be expected in all CKD patients receiving dialysis as vascular access is required to permit this treatment. AV fistulas (AVF) is the most effective and efficient method of achieving vascular access. The etiology of AV access pain includes cannulation discomfort and central vein stenosis. Pain is more common in patients who have had AVF for less than one year. Brachiobasilic AVFs are associated with the highest incidence of severe pain, suggested to be a result of scarring from superficialisation and transposition, as well as deep tissue injury with cannulation. The authors highlight that if dialysis is performed three times per week via AVF, this will repeatedly expose patients to the stress and pain of approximately 320 needle punctures per year.

Furthermore, Brkovic et al. (2016: 1146), observe that it is often necessary to make more than one attempt at cannulation to maintain an adequate blood flow. It is often necessary to use large needles to achieve the required rate of flow for dialysis, which can often lead to bruising and pain, particularly in patients with new fistulas. The pain frequently leads to avoidance or shortening of dialysis sessions and even abandonment of otherwise well-functioning fistulas. This type of pain is common in patients with diabetes, chronic hypertension and coronary heart disease. Severe symptoms include chronic pain, cyanosis, paralysis, ischemic ulcers and gangrene.

b) Headaches

Koncicki et al. (2015: 384), found that an estimated 48% of dialysis patients experience this pain syndrome. Antoniazzi, Bigal, Bordini and Speciali (2003: 147), state that in order to

distinguish dialysis headache (DH) from other types of headache disorders, the International Headache Society defined DH, in 2004, as:

- Patient is on haemodialysis (HD).
- Headaches develop during at least half of HD sessions.
- Headaches resolve within 72 hours of HD session and / or ceases altogether after successful transplantation.
- At least three attacks of acute headaches fulfilling the last two criteria.

Antoniazzi et al. (2003: 147), comment that the etiology of DH is unclear, though likely related to physiological changes that occur during dialysis. Associations with elevated calcium and phosphate and low magnesium may cause cerebral vessel vasoconstriction and an inability of auto-regulation.

c) Muscle cramps

Koncicki et al. (2015: 386), describe muscle cramps in CKD patients as sudden, recurrent, painful involuntary contractions, probably neurological in origin, which usually involves the lower extremities, but may also involve the abdomen, arms and hands. Many factors have been associated with cramps, including volume contraction in the setting of increased ultra-filtration, hypotension and changes in plasma osmolality (Kobrin and Berns, 2007: 398). Cramps affect 33-85% of dialysis patients, a quarter of whom report occurrence at least weekly. In addition, they contribute to 18% of early termination of treatment (Rocco and Burkart, 1993: 1182).

2.3.5.11 Neuropathic pain

Koncicki et al. (2015: 388), comment that there are a wide variety of neuropathic pain in CKD patients.

a) Painful Diabetic peripheral neuropathy (PDN) is a significant cause of pain in CKD patients. A study by Innis (2006: 13), found that 50% of dialysis patients experienced PDN. This painful syndrome is associated with increased risk of lower limb amputation. PDN causes impaired HRQoL, functional incapacity and disrupted sleep. The impact may be exacerbated by other CKD symptoms, for example, of uraemic pruritus and restless leg (Davison et al., 2014: 196).

b) Uraemic neuropathy is a chronic progressive sensory-motor disease particularly of the lower extremities and is related to the severity of renal impairment. Clinical symptoms are paraesthesia, pain, numbness and in later stages muscle atrophy and generally manifests when the eGFR is less than 10%. The pathogenesis of uraemic neuropathy is not fully understood but could be associated with accumulated dialyzable toxins and hyperkalaemia. Beneficial effects are found after kidney transplant, change to high flux dialysis membranes as well as drug therapy with, for example, pyridoxine, gabapentin or thiamine (Santoro et al., 2013: S 4).

2.3.5.12 **Carpal tunnel syndrome**

According to Davison et al. (2014: 197), carpal tunnel syndrome (CTS) has been estimated to affect about 9% to 63% of dialysis patients and is positively correlated with time on dialysis. The main cause of CTS in these patients is depositions of amyloid (beta-2 microglobin) on the surface of the teno-synovium of the flexor tendons. This deposition leads to compression of the median nerve by increased hand volume and venous pressure in the arm and AV may be a contributing factor. Symptoms include pain, numbness or tingling in the elbow, distal arm, medial hand or fifth digit which can lead to functional impairment if untreated.

2.3.5.13 **Arthritis and joint pain**

Dialysis arthropathy is described as a range of symptoms including shoulder pain of no known etiology, restricted range of motion and inflammatory signs including morning stiffness and painful night-time awakenings in patients on dialysis (Davison et al., 2014: 196). Dialysis-related amyloidosis (DRA) involves deposition of amyloid composed of 2-microglobulin in bone, joint and synovium. Major manifestations of DRA include bone cysts, spondylarthopathy, pathologic fractures, CTS, and swollen and painful joints (Davison et al., 2014: 196). Singh (2009: 19), states that rheumatologic conditions are encountered frequently in patients on dialysis and are painful and include various forms of arthropathy. Muscle weakness is an important clinical problem in some patients and spontaneous tendon rapture may also occur (Daugirdas et al., 2006: 127).

Davison (2007: 1278), mentions several other painful syndromes experienced by CKD patients:

2.3.5.14 **Pain which is caused by the primary renal disease itself, for example, Autosomal Dominant Polycystic Kidney Disease (ADPKD).** Research by Davison et al. (2014: 197), indicate that ADPKD affects 4-6 million people worldwide. Causes of acute pain include pyelonephritis, infected cysts, cyst haemorrhage and mass effect on the surrounding renal parenchyma, acute expansion of cysts and distension of the renal capsule, and nephrolithiasis. Chronic pain in ADPKD may be due to increased lumbar lordosis, hypertrophy of the lumbodorsal muscles and degenerative changes in the spine secondary to enlarging cysts. Asymmetric growth of cysts and presence of polycystic liver disease may adversely affect posture and lead to worsening back pain and disc

disease. Chronic, localised pain due to mass effect of the cysts on renal parenchyma and capsule may be uncomfortable, worsened by standing and exertion. Pain also includes headaches (48%), chest pain (30,4%), and leg pain with symptoms of radiculopathy.

2.3.5.15 **Nephrogenic systemic fibrosis (NSF)** is a fibrosing disorder in patients with kidney failure that causes significant pain and disability (Davison, 2007: 1279). The patients are on dialysis and present with acute onset of hardening skin of the extremities and trunk, papules and nodules with hyperpigmentation. It also affects internal viscera. Patients typically have pain, causalgia, and pruritus at the site of this fibrosis. It is diagnosed by a skin biopsy. The pathophysiology remains to be explained and there is no effective treatment for this unremitting disease.

2.3.5.16 **Calciphylaxis or calcific uraemic arteriolopathy (CUA)** is a relatively rare disorder seen almost exclusively in patients with CKD and end-stage renal failure, with an incidence of up to 4% (Wilmer and Magro, 2002: 173). Davison (2007: 1278), state that patients present with painful mottling of the skin that progress to painful, well-demarcated non-ulcerating plaques. If untreated, it will progress to ulcers and becomes superinfected. The pathogenesis remains unclear but appears to result from hyperthyroidism, increased calcium and phosphate products and vitamin D compounds. Being female, having morbid obesity and being of Caucasian ethnicity also seem to be risk factors. Davison (2007: 1278), caution that treatment is difficult and is often unsuccessful.

2.3.5.17 **Renal Osteodystrophy** refers to three different types of bone diseases in CKD patients (osteitis fibrosa, osteomalacia and adynamic bone disease). CKD is known to always accompany changes in mineral metabolism and bone structure (Davison, 2007: 1278):

a) Osteitis fibrosa

According to Davison (2007: 1278), this condition is characterised by accelerated bone resorption and deposition. Resorptive loss of acral bone, for example, terminal phalanges and distal ends of clavicles and skull is experienced. Osteosclerosis in the upper and lower two thirds of the vertebra and Brown's tumours are visible in patients x-rays. Patients with osteitis fibrosa tend to experience pain in joints and bone on exertion. Osteitis fibrosa is often associated with calcium phosphate deposition in arteries, joints, soft tissues and the viscera.

b) Osteomalacia

The CKD patient has a reduction in bone turnover and it is usually caused by aluminium deposition in bone as a result of aluminium contained in dialysis water and aluminium contained in phosphate binders. Vitamin D deficiency is also a known cause of osteomalacia. The patient presents with localised bone pain and even fractures. This condition has decreased, with the avoidance of aluminium in dialysis water (Davison, 2007: 1278).

c) Adynamic bone disease

In this bone disease, there is decreased bone turnover along with a decrease in osteoblastic and osteroclastic cells. It represents a major bone lesion in dialysis patients and affects up to 60% patients. Patients with this bone pain are prone to bone and joint

pain, both at rest and exertion, fractures, skeletal deformities and hypercalcemia (Davison, 2007: 1278).

2.4 Assessment of pain in patients with CKD

The use of regular pain assessment tools will allow for the effective treatment of painful syndromes in the CKD patient population. Evaluation starts with a pain history that includes documentation of sites of pain, severity, possible causes, previous pain relief measures and its effectiveness and toxicity, and the impact of pain on the patient's psychosocial and spirituality. There are eight validated symptom assessment tools for use with CKD patients (Davison et al., 2014: 197):

2.4.1 **Modified Edmonton Symptom Assessment System (m-ESAS):** this is a short, practical and easy to understand tool, rapidly completed by patients and can be easily incorporated into routine clinical care. It is a visual analogue scale with a super-imposed 0-10 scale for pain, depression and other symptoms. The scale range from 0 for no pain to 10 which is severe. The sum of all scores indicates overall symptom distress ranging from 0 -110.

2.4.2 **Palliative Care Outcome Scale-renal (POS-renal):** this assesses 17 symptoms such as pain, restless leg and other bothersome symptoms. The patients rate their pain in terms of impact over the last week from 0 (not at all) to 4 (overwhelming). It is a simple tool and can be easily incorporated into routine clinical care.

2.4.3 **Physical Symptom Distress Scale (PSDS):** assesses 16 symptoms, for example, headaches, muscles cramps and stiffness in joints. Rated by points on a 4 point Likert scale with 0 (not bothered at all) to 4 (extremely bothered). The disadvantage is that

there is some redundancy with regard to items relating to pain. However, it is simple and practical to use.

2.4.4 **Dialysis Symptom Index (DSI):** assesses 30 symptoms such as muscle cramps, bone pain and headaches. Rated on a scale from 1 (not bothered at all) to 5 (very much bothered). Easy to use and can be completed by the patients themselves but the disadvantage is that there is some redundancy with regard to items relating to pain.

2.4.5 **The Brief Pain Inventory (BPI):** the standard 32 questions tool has been condensed into 9 questions short-form. It assesses the location, type (nociceptive or neuropathic), and intensity of pain. it evaluates, for example, impact on patient's general mood, work ability, sleep patterns and ability to walk. This tool has been successfully used in clinics and research settings internationally to assess pain. Seriously ill patients have successfully completed this questionnaire. It is short and simple to use with minimal respondent burden.

2.4.6 **The short form McGill Pain Questionnaire:** describes the quality and intensity of pain on a scale ranging from 0 to 75 with the higher scores indicating increase in severity of pain. It assesses the patients' experience of pain over the last week and consists of 24 questions. This is not a simple tool to use and does not assess other symptoms such as depression, anxiety, inability to sleep and loss of appetite. It is incomplete because it does not assess the impact of pain on functioning and HRQoL of the CKD patient.

2.4.7 **Kidney Dialysis Quality of Life-Short Form (KDQoL-SF):** This is a self-reported HRQoL measure developed for CKD patients as a less burdensome version of the

longer KDQoL questionnaire. It focuses on physical and emotional symptoms, effects on daily life, burden of disease, cognitive functioning, work status, social functioning, sexual functioning and sleep ability. It has three quality of life scales, focussing on social symptoms, staff encouragement and patient satisfaction. There are 37 questions. It provides comprehensive HRQoL information but is more suited for research settings when assistance is provided to administer and score the responses. It is unsuitable for the very ill, frail and elderly patient because it takes a very long time to complete.

2.4.8 **CHOICE Health Experience Questionnaire (CHEQ):** is a self-reported HRQoL tool and incorporates an assessment of symptoms. Elderly and frail patients need assistance to complete it. It provides comprehensive HRQoL information but is more suited for research settings when assistance is provided to administer and score the responses.

Kafkia et al. (2014: 54), provide additional pain assessment tools for measuring pain symptoms in patients with CKD as follows:

2.4.9 **Wong-Baker FACES Pain Rating Scale (WBPS):** this uses a scale consisting of 6 figures ranging from no pain (smiley face) to extreme pain (crying face) and can be used to determine pain symptoms in, for example, children.

2.4.10 **A Visual Analogue Scale (VAS):** which ranges from none to extreme pain and can be used in order to measure the amount of pain felt at the moment of the interview. Operationally a VAS is a horizontal line, 100 mm in length, anchored by a word description at each end (no pain on the left hand side and very severe pain on the right

hand side). Renal patients are asked to mark on the line the point that represents their current perception of pain. The VAS score is determined by measuring in millimetres from the left-hand side of the line to the point that the patient has marked. This is a simple, uni-dimensional pain assessment tool.

Clinic staff and renal nurses play a major role in assessing and managing the patients' pain because of their close contact and level of rapport developed with patients during dialysis sessions. Koncicki et al. (2015: 389), advise that the assessment of specific pain syndromes by renal health care professionals may aid in improving patient compliance and HRQoL. Efforts to increase the identification of the etiology of pain by the renal providers and systematically addressing the reasons for under-treatment are certainly long overdue. Thus, assessment may, according to Weisbord (2016: 163), help to implement strategies to relieve pain and improve HRQoL of this highly co-morbid and chronically ill patient population.

2.5 Principles of pain management in patients with CKD

Renal health care professionals should not only aim to extend the patients' life span but also to improve their quality of life. Studies by Koncicki et al. (2015), Williams and Manias (2008), Davison (2006), Weisbord et al. (2005) and Binik et al. (1982), indicate that CKD patients have a high pain burden which is not effectively identified and inadequately managed. However, Murtagh et al. (2007: 5), note that there is growing awareness of the pain control needs of patients with CKD. The provision of medication to relieve pain in CKD patients is challenging because of the combination of multiple co-morbid painful diseases, the number of medications needed to manage the condition, the dialysis procedures itself and the margin for pain relief and toxicity is very narrow (Koncicki et al., 2015; Kafkia et al., 2011; Barakzoy and Moss, 2006). Bawja et al., (2001: 1631), advise that a systematic approach in determining the

etiology of the pain in CKD patients will assist in determining strategies in the management of the pain.

Bawja et al. (2001: 1636), recommend that the renal health care professionals should not set the expectations of the patient with chronic pain too high. That is, if the patient is led to believe that they will be *completely* cured of chronic pain from the planned intervention, than they will be disappointed and frustrated. This may lead to the disgruntled patient taking a long list of non-pharmacological and narcotic analgesics and even may encourage "doctor-shopping". The staff should repeatedly emphasise that the goal of treatment is to have the patient adapt to their pain, since a complete cure of chronic pain is infrequent (Bawja et al., 2001: 1636).

Pagels et al. (2012: 1), highlight that when evaluating and improving health care in CKD patients with chronic pain; functions in daily life and overall well-being are important patient outcomes. Pagels et al. (2012: 9), advise that it is necessary in renal care, for face-to-face discussions and feedback with patients on their expected HRQoL outcomes. This is especially important in the early stages of CKD which will make the patient more aware of possible growing decreases in functioning and well-being and may help them to find timely and healthy coping strategies. Reduction of interference with a desired lifestyle should be an expressed principle of treatment. This generalised approach aligns with the framework of psycho-behavioural modification and should be an integral part of chronic pain treatment programmes (Bawja et al., 2001: 1636).

Bawja et al. (2001: 1636), state that the most important first step is for the physician to non-judgementally listen to the patient, and validate the significance of their suffering caused by the pain. Since pain is so subjective, an expression of understanding by the physician of their situation is a major part of the patients' therapeutic intervention.

Davison (2007: 1281), observe that a simple pain assessment tool can be used. The physician has to gain insight into the site, character, intensity, extent and aggravating or relieving factors of the pain. Patients may have more than one kind of pain; therefore each pain syndrome must be independently diagnosed and treated to a level that is acceptable to the patient. Education of the patient and caregivers is essential such as the goals and management of the pain therapy, possible complications, including home pain assessment and recording (Davison, 2007: 1281).

It is important clinically, according to Davison (2007: 1281), to differentiate patients with recurrent pain who remain functional from those whose pain produces significant disability and suffering. Many people function quite effectively with a background of mild pain. Severe pain which cannot be ignored may become disruptive to many aspects of the patients life and will therefore need effective management to optimise pain relief in order to make the patient more functional in their daily activities.

2.6 Pharmacologic approach to pain management in patients with CKD

Data of analgesic use in CKD patients' remains limited since many studies in relation to CKD patients are small or single-dose studies. Some studies are conducted over a very short period of time, which makes it difficult to evaluate efficacy and safety. Williams and Manias (2007: 820), stress that pharmacological pain management in kidney disease is complex because of the small margin between pain relief and toxicity, since essentially, all analgesics are potentially nephrotoxic. In addition, the patients' concomitant health problems may influence the type of analgesia given. Therefore, it is difficult to advocate for specific treatments for this patient population.

Koncicki et al. (2015: 384), advise that firstly a thorough pain history should be undertaken in an effort to identify the underlying etiology to assist with therapy. The presence of CKD alters

the pharmacodynamics of many analgesics and most opioids (Davison et al., 2014: 191), resulting in numerous adverse side effects which may even exacerbate the symptoms of CKD. Disturbed pharmacodynamics is caused by the lowered renal excretion of the parent compound and / or their active metabolites in renal failure. The hepatic removal of opioids may be altered in these patients (Santoro et al., 2013: S 7).

Evidence-based guidelines for chronic, non-cancer pain in the general population advocates for the use of the World Health Organisation (WHO) three-step analgesic ladder (Murtagh et al., 2007: 6). This is a tool devised and evaluated to promote effective pain relief in patients with cancer. A study conducted by Barakozy and Moss (2006: 3200), adapted this tool (Figure 1) and found that this approach has validity in CKD patients, with 96% achieving pain control after a four week treatment period.

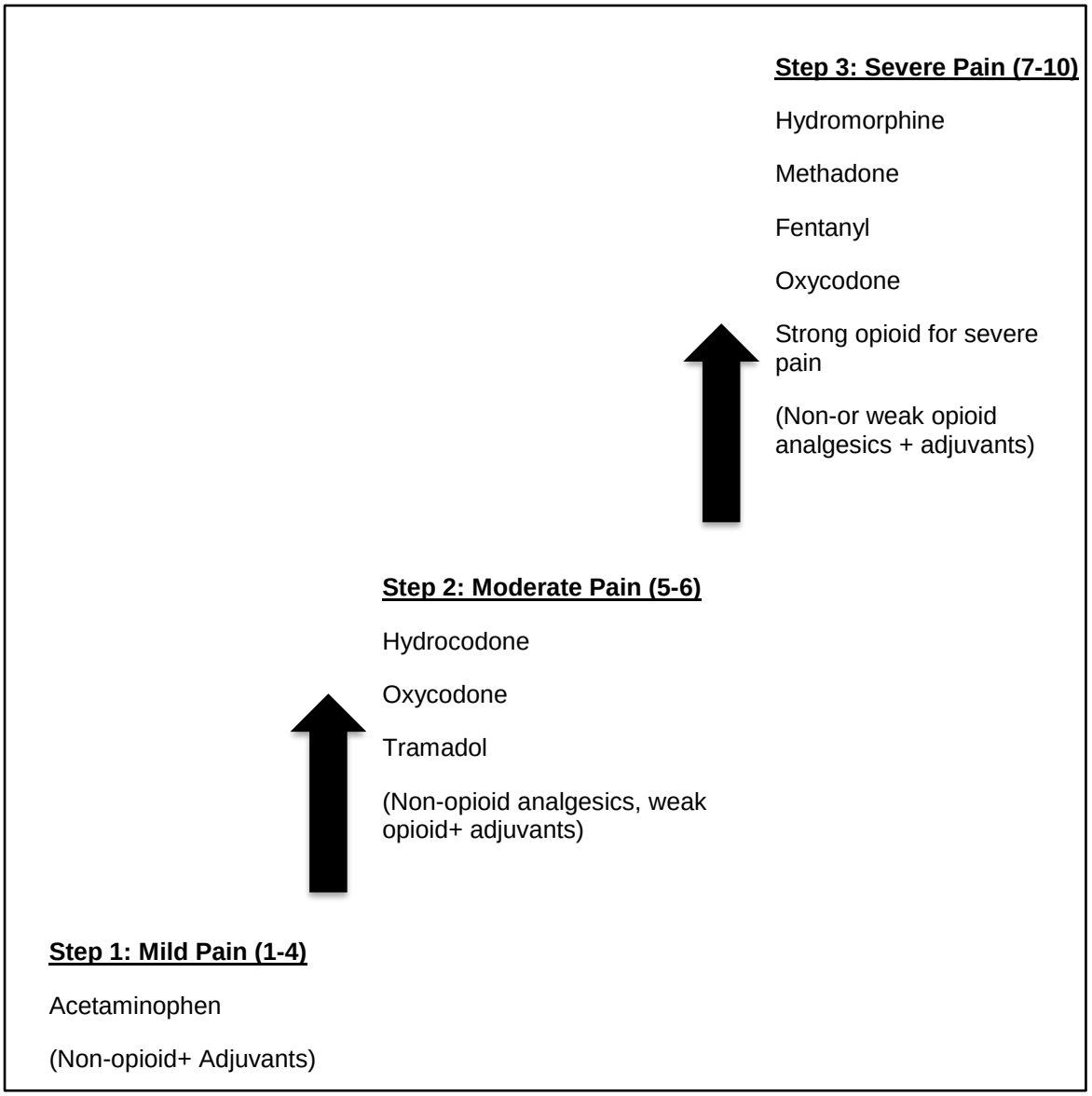


Figure 1: The World Health Organization three-step analgesic ladder modified to exclude drugs contraindicated in renal failure (Barakzoy and Moss, 2006; Davison, 2005)

2.6.1 Description of the World Health Organisation three-step analgesic ladder

Koncicki et al. (2015: 386), provide a description of the WHO step-wise approach of analgesic administration for the CKD patient:

Step 1 of the ladder is for treatment of mild pain, rated 1-4 on a 10 point scale. The recommendation is the use of non-opioid medication or with analgesics, including acetaminophen and non-steroidal anti-inflammatory drugs (NSAIDS). Some nephrologists recommend an increase in the doses interval from every 6 to 8 hours when eGFR<10 ml per minute (Murtagh et al., 2007: 6). However, Davison et al. (2014: 189), observes that the use of acetaminophen, despite its safety in CKD patients remains extremely low. The National Kidney Foundation recommends acetaminophen as the non-narcotic analgesic for mild to moderate pain in CKD patients. NSAIDS are generally not preferred due to concern for worsening hypertension, oedema, hyperkalaemia and reduction in glomerular filtration rate, but can be used cautiously for time limited trials in CKD patients under close supervision of the physician (Koncicki et al., 2015: 386). NSAIDS should be avoided in patients' receiving peritoneal dialysis. This dialysis treatment requires adequate solute clearance and maintenance of volume balance depends on a little renal function, which can be threatened by NSAIDS use (Pastan and Bailey, 1998: 1430).

Step 2 is an escalation of treatment of moderate pain, rated 5-6 and includes mild opioids such as codeine/dihyrocodeine (Koncicki et al., 2015: 386). A study by Davison (2014: 189), found that NSAIDS use appeared to be inappropriately high, and despite severe pain, there appeared to be a low prevalent use of opioids. Most opioids used are weak and those often selected are inappropriate for use in CKD patients.

Step 3 on the WHO three – step analgesic ladder is regarded as severe pain, is rated 7-10 and is treated with strong agents such as morphine and fentanyl (Koncicki et al., 2015: 386). Here substitution and titration of strong opioid analgesics is administered until the patient is free of pain. A fourth step has been recommended for management of pain crises and includes interventional procedures or patient controlled analgesics.

This three step approach to administering the right drug, in the right dose, at the right time is inexpensive and as demonstrated by Barakozy and Moss (2006: 3200), it leads to effective treatment of pain in 96% of CKD patients. In addition, if adverse effects are experienced, medications on the same “step” can be interchanged, as well as incorporating use of adjuvants and non-pharmacologic treatments (Koncicki et al., 2015: 386).

Dean (2004: 501), warn that as renal failure develops, the excretion of metabolites and / or parent drug would decrease and gradual accumulation would occur with associated clinical effects. According to Kafkia et al. (2011: 118), pharmacologic treatments for and against use of different opioid medications, in CKD patients, can be divided into three groups:

2.6.2 The three main groups of opioid medication for use in patients with CKD

2.6.2.1 **Free administration:** Those that can be administered to CKD patients after assessment without changing dosage, for example, paracetamol which has weak anti-inflammatory effects and is used to treat mild to moderate pain. Fentanyl has slower hepatic clearance due to uremia. It has lower incidence of constipation and affords greater cardiovascular stability than morphine (Davison, 2007: 1285). According to Murtagh et al. (2007: 11), this is the preferred opioid for CKD patients because it is rapidly metabolised in the liver to norfentanyl and other metabolites that are all inactive and non-toxic. It is available for chronic pain management in transdermal or injectable forms but not for on-going treatment or for uncontrolled, chronic pain.

2.6.2.2 **Dose adjustment:** administered with either lower doses or greater intervals, with close monitoring due to side effects such as gastrointestinal bleeding, oedema, hyponatraemia, respiratory depression and seizures and therefore used only for

short periods of time. NSAIDS are used for mild to moderate pain, such as, codeine which is used with aspirin or paracetamol. Its elimination half-life is extended in dialysis patients (Kafkia et al., 2011: 118).

Koncicki et al. (2015: 387), have reported that hydromorphone is a preferred short acting opioid in CKD patients and appears well tolerated in dialysis patients. It undergoes hepatic metabolism into by-products including hydromorphone-3-glucoronide which has neuroexcitatory effects but does not provide analgesia. It is not recommended for patients with advanced CKD and who are not on dialysis because of risk of toxicity if not carefully monitored. Side effects include tremors, agitation and cognitive dysfunction.

Tramadol undergoes hepatic metabolism into active metabolites of which about 95% is renally excreted and therefore dose adjustment is mandatory for CKD patients. It is used for moderate pain in CKD patients and is anti-addictive. However, it may reduce the seizure threshold in uraemic patients and is known to cause respiratory depression (Koncicki et al., 2015: 389). Cautious use in dialysis patients include reducing doses and increasing dosing intervals, for example, starting at 50 mg every 12 hours with a maximum daily dose of 200 mg (Koncicki et al., 2015: 387).

Oxycodone is a semi-synthetic opioid used for moderate to severe pain. Due to lack of data on its safety in CKD patients, it should be administered with caution only when alternative opioids are unavailable. If used, dosing intervals should be increased and patients should be monitored closely for opioid toxicity.

Gabapentin and pregabalin have been specially evaluated in CKD patients and are the preferred medications for neuropathic pain (Koncicki et al., 2015: 389). Both agents are successful at improving pain, symptoms of depression and overall HRQoL scores. Gabapentin is excreted unchanged by the kidneys. The recommended dosing of gabapentin for CKD patients on dialysis is 300 mg daily. However, Davison et al. (2014: 192), state that with older patients a more conservative dosing regimen for gabapentin should be adopted. It is important that patients are closely monitored for efficacy or adverse effects and doses titrated appropriately and in a timely manner (Koncicki et al., 2015: 389).

Methadone undergoes hepatic metabolism and is a preferred agent in CKD patients. It has prolonged pharmacological action because of slow release from the reservoirs in tissue of up to 60 hours. It is excreted mainly in the faeces with metabolism into pharmacologically inactive metabolites mainly in the liver (Davison, 2007: 1284). Serum levels of methadone have been noted to be in the normal range in CKD patients. Close monitoring during titration is recommended with starting doses of 50-70% (Koncicki et al., 2015: 387).

2.6.2.3 **Avoid:** these analgesics have severe adverse effects in CKD patients, for example, it may not be removed by RRT or they increase the risk of seizures, toxic agitation and cause severe respiratory depression (Kafkia et al., 2011; Davison, 2007). Murtagh et al. (2007: 10), warn that morphine and diamorphine are not recommended because of significant accumulation of potentially toxic metabolites such as morphine-3-glucuronide and morphine-6-glucuronide. These are known to depress the central nervous system and cause toxic agitation and respiratory depression. These opioids should only be given if no

other alternatives are available, for a very short period of time and in small doses, such as, morphine 5 mg and with careful monitoring by staff.

Desipramine, nortiptyline and amitriptyline are poorly tolerated in CKD patients due to anticholinergic, histaminergic and adrenergic properties resulting in urine retention, dry mouth and orthostatic hypotension. Furthermore, they are not effectively removed by dialysis (Kafkia et al., 2011: 118).

Meperidine is a short-acting opioid which is renally cleared and is linked to increased risk of seizures (Kafkia et al., 2011: 118). Propoxyphene is related to methadone and is renally excreted. It is not removed by dialysis and cardiotoxicity cannot be reversed by naloxone (Kafkia et al., 2011: 118). These analgesics should be avoided in patients with CKD and ESRD. Table 3 below provides a brief overview of analgesics used in patients with CKD and ESRD:

Table 3: Analgesics recommended for patients with CKD and ESRD (Davison, 2006; Dean, 2004).

Class of drug	Renal handling	Comments for use in ESRD
Non-opioid analgesics		
Acetaminophen	Metabolised in liver. 2-5% excreted unchanged in urine	No dose adjustment required. Accumulation of inactive metabolites. Analgesic of choice for mild-moderate pain.
Non-steroidal anti-inflammatory drugs:		Exacerbates sodium and water retention, hypertension, hyperkalaemia and loss of residual renal function. Increased gastrointestinal toxicity. Not recommended for chronic use although effective for acute pain management.
Tramadol	Metabolised by liver. Active metabolites are excreted in urine, 30% excreted unchanged in urine.	Dose adjustment required. Maximum dose 50 mg twice daily. Associated with lower seizure threshold. Use with extreme caution. Consider another opioid.
Weak opioids		
Codeine	Metabolised in liver to form morphine and norcodeine, conjugated to form glucuronides and sulphates. Metabolites are excreted in the urine and accumulate in ESRD.	Several case reports of prolonged narcosis. Profound toxicity can be delayed and has occurred after trivial doses. Although some patients may it tolerate well, use with extreme caution. Consider another opioid.
Dextropropoxyphene	Renally excreted with decreased	Associated with central

	elimination and accumulation of active metabolites in ESRD	nervous system and cardiac toxicity. Not recommended for use.
Strong opioids		
Morphine	5-10% excreted unchanged in urine, metabolised in liver to active metabolites that are excreted in the urine and accumulate in ESRD	Chronic administration and not well tolerated. Not recommended. Use with caution for acute pain management.
Hydromorphone	Metabolised in liver, metabolites excreted in the urine and accumulate in ESRD	Better tolerated than morphine. May be a safer and effective analgesic if carefully monitored.
Methadone	Excreted mainly in the faeces, 20% excreted unchanged in the urine. No evidence that it accumulates in ESRD	Maybe a safe effective analgesic in ESRD if carefully monitored.
Fentanyl	Rapidly metabolised in liver to inactive metabolites, 5-10% excreted unchanged in the urine, accumulation appears minimal.	The transdermal patch may be safe effective analgesic for use in ESRD if carefully monitored.
Oxycodone	Metabolised in liver, 10% excreted unchanged in the urine, accumulation of parent compound and metabolites in ESRD	Reports of central nervous system toxicity and sedation. Use with extreme caution. Consider another opioid.
Pethidine	5% excreted unchanged in urine. Metabolised by liver to active and inactive metabolites that are excreted in the urine and accumulate in ESRD.	Not recommended for use due to accumulation of norpethidine and neuroexcitatory effects. Induces seizures.

According to Koncicki et al. (2015: 386), the International Association for the Study of Pain developed evidence-based guidelines for management of neuropathic pain. Treatment in the CKD population follows these general guidelines as limited studies have specifically included these patients. Recommended first-line treatment includes antidepressants, such as tricyclic antidepressants, serotonin, and norepinephrine reuptake inhibitors, and topical lidocaine. Naylor and Raymond (2011: 35), highlight that because neuropathic pain is a chronic condition and is difficult to treat, it is also important to recognise and treat common comorbidities such as anxiety and depression in this patient population. Davison (2007: 1282), recommend that pregabalin or gabapentin be used as the preferred first-line drugs for the treatment of neuropathic pain for CKD and ESRD patients. In addition, Koncicki et al. (2015: 386), propose the use of adjuvant therapy such as steroids, anxiolytics, anticonvulsants, antidepressants and cannabinoids to control side effects of opioids, uncontrolled pain or as opioid-sparing medications and which are also beneficial in the effective treatment of neuropathic pain. Table 4 provides a brief overview of adjuvant drugs used for patients with CKD and ESRD.

Table 4: Adjuvant drugs for pain management in patients with CKD and ESRD (Davison, 2006: 5).

CLASS OF DRUG	RENAL HANDLING	DOSE SCHEDULE	COMMENTS FOR USE IN CKD/ESRD
Tricydic antidepressants			
Amitriptyline	Metabolised in the liver, <5% excreted unchanged in the urine	10-100 mg once a day (od)	Doses alteration not usually necessary in ESRD although it may be poorly tolerated due to common anticholinergic side effects. Lowers seizure threshold.
Desipramine	Metabolised in the liver as above	10-150 mg once a day	Less sedating and anticholinergic side effects, may be better tolerated than amitriptyline.
Anticonvulsants			
Carbamazepine	Metabolised by the liver and eliminated via the kidneys	200 mg once per day than weekly to effectiveness, maximum dose of 1 600 mg.	No dose adjustment required in ESRD. Effect may occur within 2-3 days. Plasma concentrations reduced by other anticonvulsants.

Gabapentin	Excreted unchanged by the kidney. Accumulates in ESRD	100-300 mg post-dialysis or at bedtime.	Accumulation of gabapentin and cases of neurotoxicity in ESRD have been reported when using >300 mg daily. Used for neuropathic pain.
Benzodiazepines	Avoid long-acting benzodiazepines in ESRD		No dose adjustment required for most benzodiazepines in ESRD. Used for insomnia
Temazepam		7.5-15 mg at bedtime	Used for insomnia
Flurazepam		15-30 mg at bedtime	Used for insomnia, manufacturer does not recommend for ESRD.
Lorazepam		0.5-1.0 mg once daily	Used for insomnia and anxiety
Oxazepam		10-30 mg three times daily or at bedtime	Used for anxiety and restless leg
Clonazepam		0.5-2.0 mg daily	Used for insomnia and anxiety

2.6.3 Guidelines for the use of adjuvants

Davison (2007: 1281), provide guidelines for the use of adjuvants, for example, it may be used judiciously for specific pains that are not responding well to opioids such as for neuropathic pain. It may also be used as an “opioid-sparing” agent to decrease the dose of opioids when the side effects of opioids become troublesome (Davison, 2007: 1281).

Topical analgesics, such as, lidocaine prilocaine cream, may be of benefit for cannulation pain but needs to be given 45-60 minutes before puncture for maximal absorption into cutaneous tissue. Vapocoolant sprays can also be used topically and works through evaporation that decreases skin temperatures and causes desensitisation of receptors that are involved with pain transmission. It can be given just before puncture (Koncicki et al., 2015: 387). Both are well tolerated with mild side effects such as local skin reactions.

2.6.4 Guidelines for analgesic dosing:

Davison and Ferro (2009: 187), have identified several essential guidelines for analgesic dosing of CKD patients to bring relief from their pain symptoms.

1. *"By mouth"* that is whenever possible, and usually orally.
2. *"By clock"* that is dosing is scheduled over 3-4 hours and is on a regular basis and available as needed by the patient.
3. *"By the ladder"* indicating that the medication is given in a step-wise manner according to the WHO analgesic ladder.
4. *"For the individual"* in which case there is no standard dosing of strong opioids but rather the right dose is what relieves the pain without causing unacceptable side effects.
5. *"Attention to detail"* whereby the pain is recognised as changing over time and is assessed on an on-going manner and is treated accordingly.

Davison et al. (2014: 191), warn that careful attention should be paid to issues of efficacy and safety because there is insufficient evidence to provide definitive guidelines about the use of various opioids. In addition, there are insufficient studies on the long-term use of any analgesics in patients with CKD. Pharmacological approaches include conservative dosing of opioids with small increases in doses titrated to analgesia and monitoring adverse effects for patients (Koncicki et al., 2015: 389). It is important to always assess the patient's level of renal function when determining type and dosage of the analgesic.

2.7 Non-pharmacological treatment of pain in patients with CKD

Patients with CKD have a polypharmacy of medication and with potential adverse effects of many of the drugs, non-pharmacological strategies to relieve pain symptoms should also be

recommended and supported by the renal professional team (Santoro et al., 2013: S 8). There is a wide array of non-pharmacological treatments such as psychological and cognitive behavioural therapy, for example, relaxation techniques, hypnosis, breathing exercises, yoga and spiritual counselling (Davison, 2005: 327). Furthermore, distraction techniques such as watching television, reading, listening to music or crossword puzzles can reduce the patient's attention to their pain. Kuphal, Fibuch and Taylor (2007: 990), highly recommend regular physical exercise to relieve pain. Davison et al. (2014: 198), suggest additional conservative measures, for example, heat/ice application, physical therapy and massage, use of supporting garments such as corsets and lifestyle modifications if pain is musculoskeletal.

Santoro et al. (2013: S 8), found that different forms of electro-therapy are effective in pain relief. The most commonly used forms are transcutaneous nerve stimulation (TENS), percutaneous nerve stimulation (PENS), spinal cord stimulation (SCS) and high tone external muscle stimulation (HTEMS). TENS is an application of low frequency electrical currents to the skin above the painful area and is effective in, for example, diabetic neuropathy. PENS combines low frequency TENS and acupuncture like needle probes. For SCS treatment, an electrode is implanted in the appropriate segment of epidural space and is successful in relieving pain due to ischaemic peripheral artery disease and back pain. Santoro et al. (2013: S 9), state that HTEMS uses high frequencies at short intervals and is a useful strategy to relieve symptomatic neuropathic symptoms such as burning, numbness and pain in CKD patients.

Topical thermal therapy may be applied to the affected area in addition with pharmacological therapies. Cryotherapy (ice-packs) has been found to reduce local inflammation and pain and offers better restorative impact compared to topical heat application (Pham et al., 2017: 291). Superficial heat is, however, helpful in decreasing local muscle spasm. Pham et al. *(*2017:

291), also advise that any modifiable social issues, psychological or physical factors that may contribute to pain should be identified and quickly managed.

2.8 Conclusion

From the above information it is clear that CKD patients have a multitude of pain syndromes of differing etiology which needs to be effectively assessed. This will facilitate appropriate pain management strategies to be implemented for each individual patient to bring some relief to them.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Study design

A qualitative research approach was used, because it was deemed appropriate for this study as the primary emphasis is on the subjective meaning of an experience which is communicated by the participants to the researcher. Qualitative research aims at understanding and interpreting the meanings and impact of given phenomena experienced by the sample population (De Vos et al., 2002: 270). In this study, the pain experienced by the patient is subjective and they attach meaning to it, for example, if it is unbearable, they may consider limiting the duration of the dialysis session or withdrawing from the dialysis treatment altogether. The qualitative research paradigm refers to research that elicits accounts of meaning, experience and behaviour (De Vos et al., 2002: 273). The use of qualitative research methodology, thus enables the researcher to obtain a more holistic understanding from the data elicited.

The study was designed to investigate the types, frequency and severity of pain as experienced by patients with CKD. It explored phenomena without any manipulation and control of human behaviour. Therefore, the researcher was able to obtain a greater understanding of the patients' pain experience and its impact on their HRQoL. In addition, specific objectives focussed on how the patients managed the distress and discomfort they experienced and how it reflected on their decision-making regarding the treatment of the pain experienced. The response of the renal staff to the pain experienced by patients in their care was also investigated. There is a paucity of information within South Africa on this topic; thus an exploratory design was used for the purpose of asking questions in a structured manner and seeking new insights to grow the body of knowledge on this under-recognised problem. Babbie and Mouton (2001: 243), state that the less developed an area is, the more likely

exploration should be used to build a foundation of general ideas and to propose theories, for example, in this particular area of pain management of the patient with CKD. Ultimately, strategies would be suggested to both the renal staff and the patient so that the patient would cope with the pain and achieve a bearable level of comfort.

De Vos et al. (2002: 106), state that descriptive research presents a picture of the specific details of a situation whereas exploratory studies seeks to become familiar with the basic facts and create a generalised picture of prevailing conditions. The researcher was able to do both in this study, as there were no previous qualitative studies of the CKD patient pain experience and pain management in South Africa. Thus, this study was both exploratory and descriptive because the patients' account of their pain experience will add new insights and information to the area of renal care and clinical practice.

3.2 Ethics

The study was approved by the Ethics Committee of The Durban University of Technology (Appendix 1). Informed consent was also obtained from the Head of the Clinical Department of the Durban Kidney and Dialysis Centre (Appendix 2). The relevant patients attending this private renal facility were included in the study and they signed consent forms as well.

3.3 Study population and sampling

According to Brink (2006: 124), sampling refers to the researcher's process of selecting the sample from a population that represents the general population of study. In this study, non-probability sampling was used because according to Babbie and Mouton (2001: 276), the researcher is able to handpick the sample, selecting those elements that are information-rich in relation to the nature of the research problem and topic under investigation. This was an exploratory, descriptive study and thus non-probability sampling was used to identify, explore

and understand the pain experiences and barriers to effective pain management faced by the CKD patient population in this private renal facility.

The patients attend a private Kidney and Dialysis Centre in Durban for their dialysis treatment, which they receive thrice a week. The Centre can accommodate 74 patients at any given time with a renal staff complement of 26. The staff that comprised the sample population was 22; the remainder were support and administrative staff who did not directly attend to the patients. There are 3 specialist nephrologists who attend to the patients on a daily basis. However, the sample comprised of sixty patients (as per the exclusion criteria in 3.3.2 below and on recommendation from the statistician). Patients from both genders and all race groups were accepted to participate in this study. A total of 60 patients were interviewed at the bedside at the Centre. Sufficient data was gathered for the analysis. Patients had to meet the selection criteria in order to participate in the study.

3.3.1 Inclusion criteria

All patients had to comply with the following:

- Are on a chronic haemodialysis schedule at the Durban Kidney and Dialysis Centre.
- Had received dialysis for more than six months so that they had adapted to the procedures.
- Are haemodynamically stable and alert during the interview session.
- Are eighteen years and above.
- Are cognitively able to give consent and understand the questions asked.
- Of any gender.
- Of any race.

3.3.2 Exclusion criteria

The following patients were excluded from the study:

- Those not on a chronic haemodialysis schedule.
- Patients under the age of 18 years.
- Those medically unfit to participate (confirmed by the consulting specialist).
- Those unwilling to comply with protocol and unwilling to sign the consent form.

All staff had to be qualified in dialysis patient care and employed at the Durban Kidney and Dialysis Centre. The researcher met with the staff and explained the purpose of the study and the processes that would be followed (Appendix 5). Participation in the study was voluntary and staff and patients had the opportunity to withdraw from the study at any time.

All patients received a copy of the patient information document (Appendix 3) to ensure that they understood the details of the study before signing the consent form (Appendix 3). The patient information and informed consent form, originally in English was translated into isiZulu because this is a first language for most of the patients (Appendix 4) being treated at the Centre.

The researcher is employed at the Durban and Kidney Dialysis Centre and, therefore, had knowledge of the patients and procedures used. The researcher had direct contact with the sample chosen to discuss availability and willingness to participate in the study. The researcher thereafter set up appointment schedules with the patients and staff. Altogether 60 patients and 22 staff were interviewed.

3.4 Data collection

The researcher was fortunate to access the patients' medical records which were a rich source of information, particularly information relevant to pain management. These were analysed and recorded in terms of, for example, their analgesic usage, pain symptoms, and types and frequency of pain, both on and off dialysis. The records were scrutinised for the past three months prior to the study. At all times the researcher respected the ethical procedures of the Centre in terms of usage of the patients' records. The age, gender, cause of CKD/ESRD, co-morbid conditions, occupation, the duration of therapy and marital status was noted. Cardiac conditions, hypertension and diabetes were recorded to evaluate the possible causes of pain experienced.

Staff clinical assessment practices and their response to the pain symptoms of the patient was also scrutinised. Minutes of staff meetings and procedures for recording patients' pain symptoms were analysed. (Appendix 8)

A structured Pain Interview Questionnaire (Appendix 7) based on McGill Pain Questionnaire (MPQ), developed by Melzack and Torgerson in 1975, was administered to the patients during their dialysis treatment. The questions were divided into three classes which corresponded to the sensory, affective and evaluative aspects of pain and several were ranked-ordered according to pain intensity. The questionnaire also included specific questions concerning the nature, duration, intensity, frequency, location, impact of pain and methods of dealing with the pain. The instrument has been validated with numerous studies on types of pain (Binik et al., 1982: 824). The interviews ranged from 25 to 45 minutes. The variation in time also was influenced by the amount of pain and discomfort experienced by patients. Prompts were used by the interviewer as the need arose. This qualitative approach allowed the researcher to capture the complexity of the challenges of the patients and the concerns

they faced pertaining to the pain they experienced. A structured questionnaire was administered to the staff (Appendix 6). The questions were related to their perceptions of and decisions in assessing and managing the pain experienced by the patient. Knowledge of staff regarding pharmacological and non-pharmacological approaches to pain management was also probed. All information was strictly confidential and anonymity was guaranteed.

3.5 Statistical analysis

Statistical analysis was performed using the Statistical Package for the Social Sciences (SPSS) version 24.0. A $p < 0.05$ was considered statistically significant. The results are presented as descriptive statistics in the form of graphs, cross tabulations and other figures for the qualitative data that was collected. Inferential techniques include the use of correlations and chi square test values, which are interpreted using the *p*- values.

Patient characteristics were described as frequencies and percentages or as a mean / standard deviation (SD). Staff information was described as frequencies and percentages

Content analysis of the data collected was undertaken from the interview questionnaire to establish themes that emerged. The themes reflected commonalities in the data obtained from the interviews.

A clear gap is the lack of evidence-based guidelines for pain management that are specific for the CKD patient population, particularly within the South African context. Pain cannot be completely eliminated from this patient population but they can be assisted to relieve the pain symptoms to a bearable level. The proposed study will contribute to the existing literature (currently, mainly international) on pain management of the patients with CKD. Regular assessment of patients' pain symptoms by renal staff and effective communication of the

symptoms to the specialist nephrologists will enable timely strategies and interventions that will lead to improved patient outcomes and HRQoL.

3.6 Conclusion

There is no doubt that pain management for patients with CKD is complex. However, nephrologists and nursing staff in renal units should not only aim to extend the life of the CKD patients but also aim to improve the quality of care and the quality of life. According to Davison et al. (2014: 199), this can be made possible by the development and evaluation of pain management strategies and protocols that evaluates both efficacy and safety in diverse CKD patient populations.

The patient needs to be aware that pain in most instances is chronic but that renal care professionals will aid in reducing pain to a more tolerable level. This may be done by using multiple pharmacological and non-pharmacological combinations before achieving a reduction of pain. For the patient to receive adequate and timely treatment for their pain, it is imperative that renal staff and specialist nephrologists assess the etiology, types, severity and frequency of pain and address all potentially beneficial pharmacologic and non-pharmacological therapeutic options. Appropriate and timely pain management therapies may aid in, not only bringing relief to the painful conditions, but in improving overall patient compliance and HRQoL.

CHAPTER FOUR

RESULTS

4.1 Introduction

This chapter presents the results and briefly comments on the findings obtained from the questionnaires administered to staff and patients who participated in this study. Statistical analysis was performed using the Statistical Package for the Social Sciences (SPSS) version 24.0. A $p < 0.05$ was considered statistically significant. The results are presented as descriptive statistics in the form of graphs, cross tabulations and other figures for the data that was collected. Inferential techniques include the use of correlations and chi square test values, which are interpreted using the *p*- values.

4.2 Introduction to staff results

This section presents the results and discusses the findings obtained from the staff questionnaires in this study. The questionnaire was the primary tool that was used to collect data and was distributed to 22 staff members. The data collected from the responses was analysed using SPSS version 24.0. The results present the descriptive statistics in the form of graphs. The traditional approach to reporting a result requires a statement of statistical significance. A *p*-value is generated from a test statistic**.**

A second Chi square test was performed to determine whether there was a statistically significant relationship between the variables (rows vs columns).

The null hypothesis states that there is no association between the two. The alternate hypothesis indicates that there is an association.

4.2.1 Sample size pertaining to staff

In total, 22 questionnaires were despatched and 22 were returned which gave a 100% response rate.

4.2.2 The research instrument

The research instrument consisted of 14 items, with a level of measurement at a nominal or an ordinal level.

4.2.3 Analysis

The section that follows analyses the scoring patterns of the respondents per variable per section. The results are first presented using summarised percentages for the variables that constitute each section. Results are then further analysed according to the importance of the statements. The table / figures that follow summarise the scoring patterns.

4.2.4 Occupation of staff in the Centre.

Figure 2 represents the occupation of the staff that are employed in the Centre.

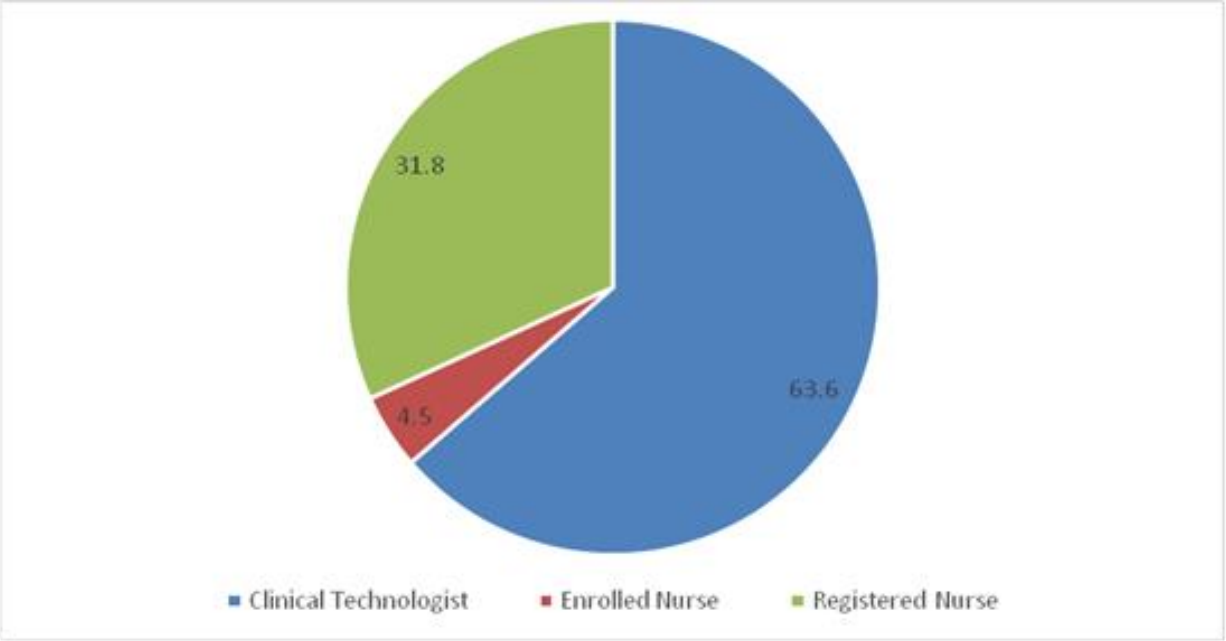


Figure 2: Occupation of staff in the Centre.

Nearly two-thirds of the respondents (63.6%) were Clinical Technologists, with a third being Registered Nurses (31.8%) and the remainder 4.5% being Enrolled Nurses. These results are indicative that the renal staff in the Centre are well qualified in renal care.

4.3 The following section represents the staff responses to the questionnaire:

4.3.1 Phase when patients report the severest pain experienced during dialysis.

Figure 3 represents the stage which patients experienced the most pain during the dialysis session.

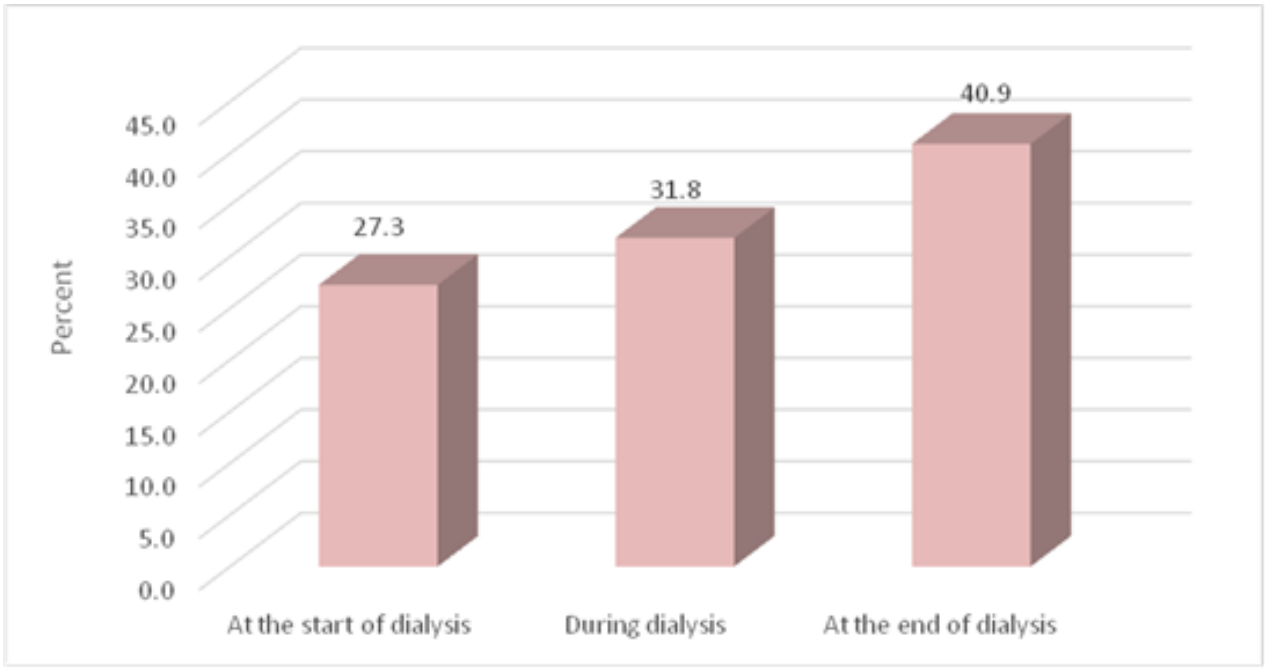


Figure 3: Phase when patients report the severest pain experienced during dialysis.

The following patterns were observed:

- Some statements show significantly high levels of agreement.
- There was no significant difference in the observed patterns (p = 0.727). It was noted however, that the most pain reported by patients was at the end of the dialysis session (40.9%). Some contributing factors for the pain expereinced are mentioned in Section 4.16.14, e.g. long hours of sitting in one position or pain from the fistulas.

- For more than 30% of patients it appears that the dialysis procedure does not bring relief from the pain being experienced.
- With 27,3% of patients complaining about pain at the start of the dialysis session, it foregrounds several questions. For e.g. is there compliance of pain medication as recommended by the doctor, is a different type of pain being experienced and is the severity of pain different to what was previously experienced? These questions could not be validated in a clinical manner as there was no evidence of documented pain assessment protocols in the Centre.

4.3.2 Staff role to assist patients in relieving pain experienced during dialysis.

Figure 4 represents the assistance given by staff to relieve patients pain experienced during the treatment.

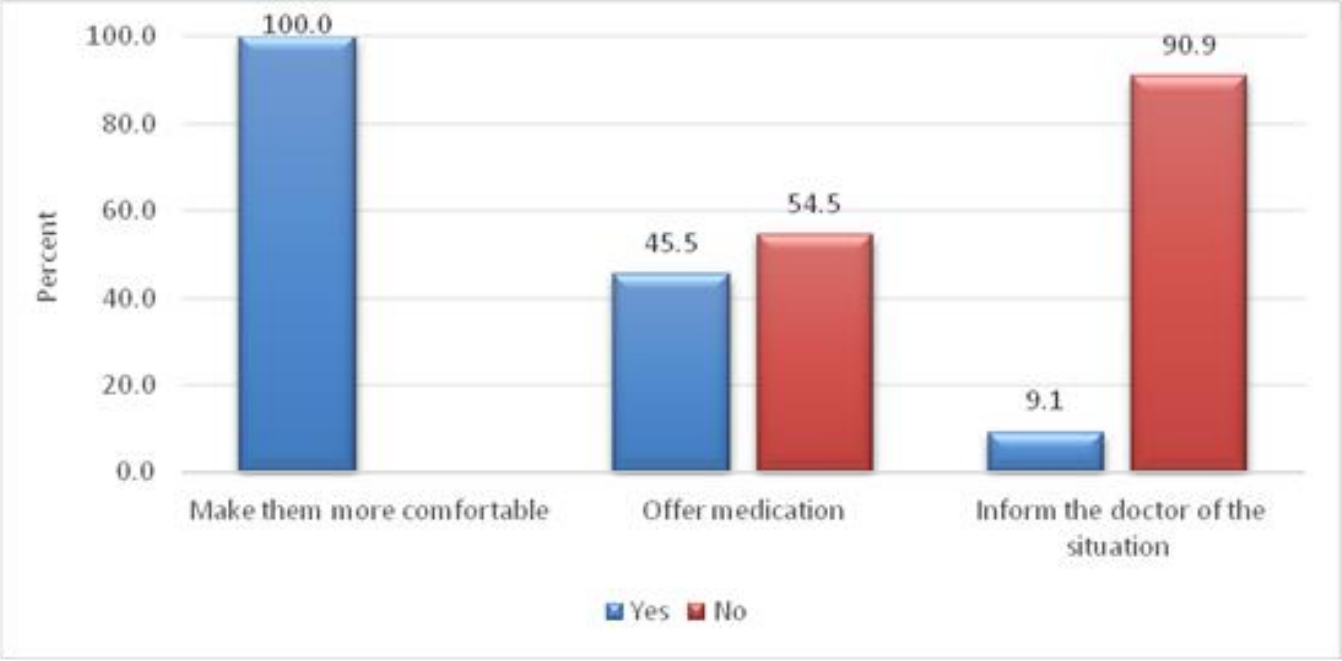


Figure 4: Methods staff use to relieve patients' pain.

To determine whether the scoring patterns per statement were significantly different per option, a chi square test was done. The null hypothesis claims that similar numbers of respondents scored across each option for each statement (one statement at a time). The alternate states that there is a significant difference between the levels of yes and no.

There was no significant difference in the number of respondents that offered medication compared to those that did not (p = 0.670). Significantly fewer respondents informed the doctor (9.1%) (p < 0.001). However, patients' complaints of pain are recorded on their medical records by all staff.

All of the respondents indicated that they did make the patients more comfortable. This only brought marginal pain relief as compared to administering appropriate analgesics. The renal health team could use the WHO three-step analgesic ladder which is an important framework for managing pain in patients with CKD (Samuel et al., 2014; Barakzoy and Moss, 2006). According to Rehm (2003: 340), the renal team can begin with the non-opioid analgesics for mild to moderate pain. The "ladder" approach is to start low and go slow, increasing doses and changing the types of medication used based on the patients response. However, Brown et al. (1996: 1), found that effective pain management in this patient population is hampered because primary care providers and nephrologists receive limited training in the assessment and treatment of chronic pain. This is further exacerbated within the South African context because this study shows that there is a dearth of evidence-based pain management strategies specifically for this patient population.

4.3.3 Staff advice on treatment options for patients to manage their pain.

The researcher asked staff if they provided advice on pain treatment alternatives, for the patients in their care, which is represented in Table 5.

Table 5: Staff advice to patients on options for pain treatment.

	Frequency	Percent
Yes	17	77.3
No	5	22.7
Total	22	100.0

More than three quarter of the respondents (77.3%) advised patients on options for treatment of pain (*p*= 0.011). Staff are highly qualified so this is not unexpected. However, there was very little follow-up from the staff regarding patient compliance and implementation of the recommendations for pain relief.

4.3.4 Staff advice to patients to manage a new pain symptom.

Figure 5 indicates staff recommendations for patients to manage any new pain symptoms that emerge.

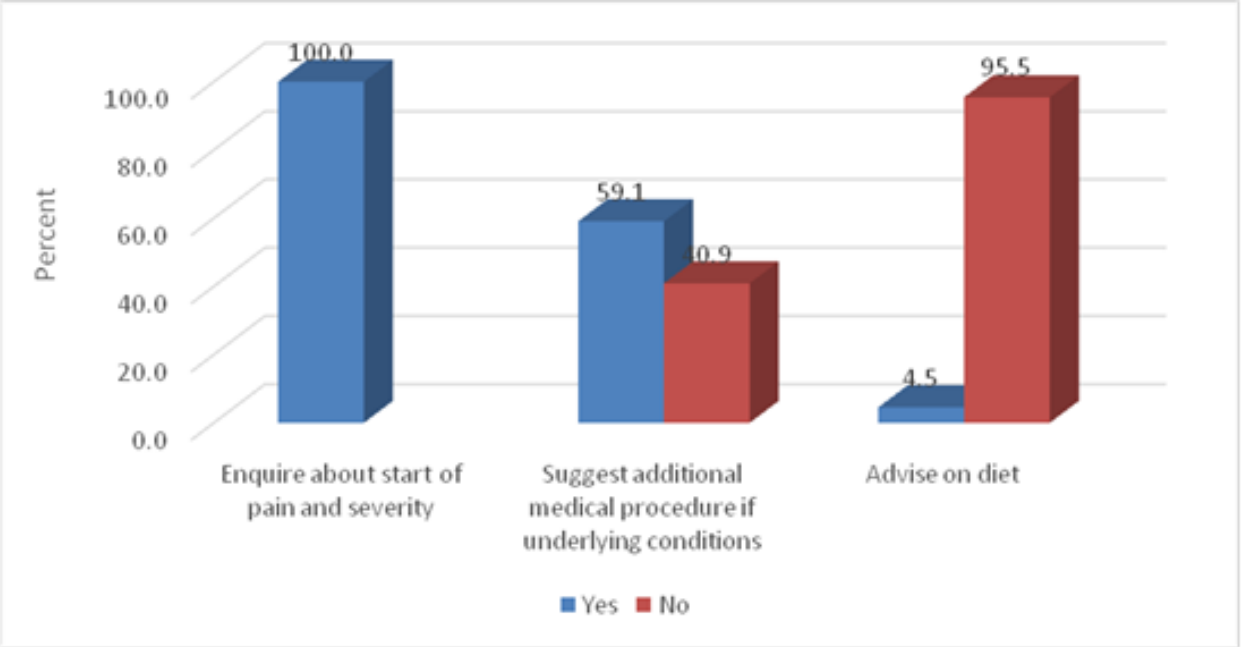


Figure 5: Staff advice on management of new pain symptom.

A high number of respondents suggested additional medical procedures (59.1%), whilst a significant number advised only on diet ($p < 0.001$). For example, if foods that are rich in potassium are consumed in high quantities, this would result in cardiac compilations and associated chest pains (Daugirdas et al., 2006). However, there were no comments about the use of appropriate pharmacological or non-pharmacological therapies.

All of the respondents enquired from the patients about the start of pain and its severity. However, this was informal and routine and there was no evidence of a clinical pain assessment instrument being administered. A study conducted by Feldman et al. (2013: 1530), indicate that 35% of renal professionals do not assume responsibility to treat symptoms arising from co-existing conditions such as bone disease, which cause severe pain, and are reluctant to prescribe analgesics for pain arising from co-morbidities. The renal professionals alluded that they would deal with pain arising from dialysis procedures itself but pain from other co-morbidities should be dealt with by other specialists.

Besides the WHO three-step ladder analgesic approach, staff should advise patients on a wide variety of non-pharmacological approaches to address pain and manage any psychological and emotional components associated with pain. Patients will benefit from cognitive and psychological therapies or relaxation techniques. The Centre could consider the use of a pain management specialist for the patients to assist them cope with their pain.

4.3.5 Number of staff who record and report, to the attending doctor, the pain experienced by patients.

Table 6 shows the percentage of staff who report and record the pain symptoms of the patients.

Table 6: Indication of percentage of staff reporting and recording the pain experienced by patients.

	Frequency	Percentage recorded	Percentage reported
Yes	22	100.0	27.3%

About a quarter of the respondents (27.3%) reported the pain to the attending doctor - (p = 0.033). Staff were of the opinion that the attending doctor will read the patients' medical records and advise the patients accordingly.

All the respondents (100%) recorded the pain experienced in their medical records.

4.3.6 Impact of pain on the patients' dialysis session.

Figure 6 shows the patients response to the pain experienced during dialysis treatment.

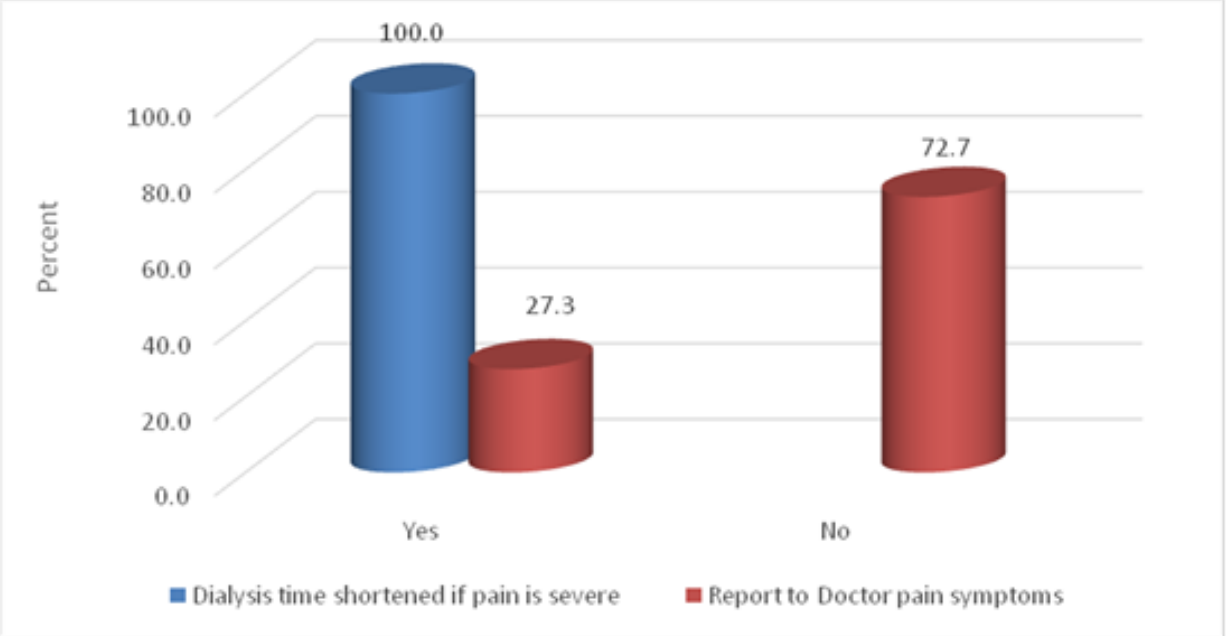


Figure 6: Staff observation of impact of pain on patients' dialysis session.

All of the respondents indicated that the patients shortened the dialysis time with increased levels of pain. This is of concern as decreased time on dialysis will result in fluid retention and fluid overload. In addition, patients will not have adequate clearance which will result in high urea and creatinine levels. If patients continuously decrease their time on dialysis, this will cause further degeneration of the remaining nephrons in the kidney, exacerbating their CKD/ESRD condition. According to Miguel et al. (2009: 119), as renal function declines, patients with Stage 5 CKD develop other co-morbid conditions such as secondary hyperthyroidism, soft tissue calcification, coronary artery calcifications and bone remodelling and turn-over, contributing to increased mortality risk for this patient population.

A high percentage of staff (72,7%) did not report the pain symptoms experienced by the patient. This could indicate that the staff in the Centre feel capable of administering pain relief for *minor* pain symptoms such as headaches and cramps. However, there is an inconsistency because of the lack of reporting *major* pain symptoms such as chest pains.

It is clear that the patients in the Centre must be supported and advised to adhere to current recommended pain relieving medication or those that are appropriate for their condition and in line with the WHO three-step analgesic ladder. Timely and approximate pain management strategies are critical in preventing worsening of their condition because dialysis is an important process to remove waste and excess fluids from the blood.

4.3.7 Types of medication that can be administered (in consultation with the doctor) to patients experiencing the following symptoms.

The common pain medication recommended by staff to patients who experience pain in shown in Table 7.

Table 7: Types of pain medication recommended by staff.

	Athrexin	Calcium	Carloc	Dextrose	Disprin	Lyrica	Nsaids	Panado	Stilpain	TNT*
Back pain								95.5		
Chest pain			13.6		4.5					77.3
Headache								100.0		
Cramping		54.5		40.9						
Numbness						90.9				
Muscle						40.9		13.6	40.9	
Joint	4.5					50.0	4.5	9.1	31.8	

All the staff stated that the patients found Panado to be the most effective for alleviating their headaches and back pain (95,5%). Lyrica was a preferred medication, recommended for 90.9% of the patients for muscle pain, joint pain and numbness that was experienced, with 77.3% patients using *nitro-glycerine (TNT) for chest pain that they experienced.

4.3.8 Staff follow-up of patient compliance to prescribed pain medication.

All the staff (100% of the respondents) stated that they do a follow up with patients to ensure pain medication is adhered to as prescribed by the doctor. However, as this was done verbally, there was no clinical, evidence-base for this claim.

4. 3.9 Staff use of a pain assessment tool to evaluate the pain experienced by patients.

All the staff indicated that they did not use a pain assessment tool to evaluate the pain experienced by patients. A major shortcoming in the Centre is an absence of a pain assessment tool. A major barrier to pain management as reported by Carr (2004: 64), and Manias and Williams (2008: 206), is that renal staff do not routinely assess pain, do not use

pain assessment tools and do not reassess the effects of analgesia. It is acknowledged that the time required to assess pain can be lengthy, thus reinforcing the need for the managers of the Centre, in this study, to develop a tool that is simple and contextualised to meet the needs of the busy clinical setting.

4.3.10 Staff use of guidelines to administer analgesics to relieve pain experienced by individual patients while they are in the Centre.

All the respondents indicated that they were not given guidelines from the managers or doctors in the Centre to administer analgesics to relieve pain experienced by individual patients while they are on dialysis.

4.3.11 Staff training to assess the pain experienced by patients.

All staff indicated that they did not receive training to specifically assess the pain experienced by patients

4.3.12 Staff awareness of pharmacological therapies according to K/DOQI guidelines that are suitable for pain relief for CKD patients.

All staff indicated that, because of their background in renal care, they were aware of pharmacological therapies according to K/DOQI guidelines that were suitable for pain relief for CKD patients.

4.3.13 Staff awareness of non-pharmacological therapies suitable for CKD patients.

All staff indicated that, because of their background in renal care, they were aware of several non-pharmacological therapies that were suitable for pain relief for CKD patients.

4.3.14 Types of support that could be provided by the Durban Kidney and Dialysis Centre to patients to manage their pain.

Figure 7 depicts the types of support that the Centre can provide for pain management of their patients.

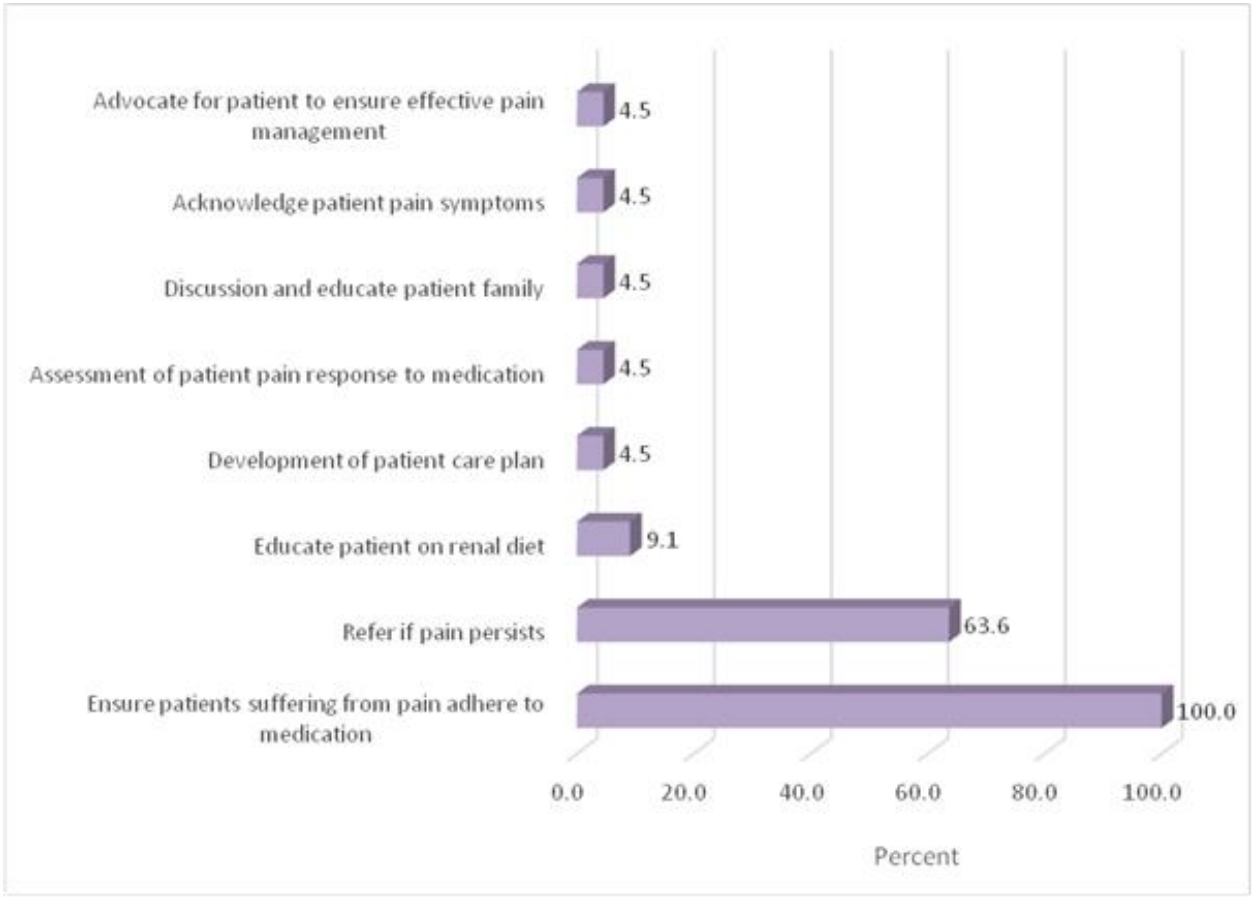


Figure 7: Methods in which the Durban Kidney and Dialysis Centre could support patients in the management of their pain.

The two main suggestions were referrals to other specialist physicians (63.6%) and adherence to medication (100%). Education of the patient renal diet was suggested by 9.1% of staff whilst 4.5% stated that they acknowledged the pain symptoms experienced by the patient.

The results of the section of staff response to pain management issues indicate that whilst all staff are highly qualified in renal care and are aware of pain management strategies and

therapies, there are serious areas of concern relevant to a wide spectrum of issues on the topic under investigation. The fact that that there are no pain assessment tools, training or guidelines for analgesic administration for staff means that most of enquiries are verbal and informal. Furthermore, there are indications that although patients do not complete their full time on dialysis, there are no robust measures to alleviate the severe pain that patients experience towards the end of the dialysis session. This puts them at risk of further escalation of their CKD condition due to non-compliance. The results highlight that there are suboptimal approaches to pain management in the Centre.

4.4 Introduction to patients results

This section presents the results and discusses the findings obtained from the questionnaires administered to patients in this study. The questionnaire was the primary tool that was used to collect data and was distributed to patients experiencing pain. The data collected from the responses was analysed with SPSS version 24.0. The results present the descriptive statistics in the form of graphs, cross tabulations and other figures for the data that was collected. Inferential techniques include the use of correlations and chi square test values; which are interpreted using the *p*-values. The traditional approach to reporting a result requires a statement of statistical significance. A ***p*-value** is generated from a **test statistic.** A significant result is indicated with "$p < 0.05$".

A second **Chi square test** was performed to determine whether there was a statistically significant relationship between the variables (rows vs columns).

The null hypothesis states that there is no association between the two. The alternate hypothesis indicates that there is an association.

4.5 The sample size of patients

In total, 60 questionnaires were administered to the patients and 60 were returned which gave a 100% response rate. This sample size was recommended by the statistician.

4.6 The research instrument

The research instrument consisted of 20 items, with a level of measurement at a nominal or an ordinal level.

4.7 Reliability statistics

The two most important aspects of precision are **reliability** and **validity**. Reliability is computed by taking several measurements on the same subjects. A reliability coefficient of 0.70 or higher is considered as "acceptable" (indicated in the yellow shaded column).

Table 8 shows the impact of pain on patients' daily activities.

Table 8: Rotated Component Matrix indicating impact of pain on daily activities.

Question 8: Impact of pain on daily activities.	Component	
	1	2
Vigorous activities e.g. strenuous sports or lifting heavy objects	0.800	0.208
moderate activities e.g. pushing a vacuum cleaner or playing golf	0.751	0.335
Carrying groceries	0.830	0.252
Climbing a flight of stairs	0.713	0.146
Bending or kneeling	0.800	0.124

Walking a few metres or cooking	0.868	0.142
Walking a kilometre	0.789	0.098
Bathing or dressing yourself	0.446	0.758
Relation to other people	0.085	0.914
Outlook to life in general	0.158	0.945
Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization.		
a. Rotation converged in 3 iterations.		

Factor analysis is a statistical technique, the main goal being data reduction. A typical use of factor analysis is in survey research, where a researcher wishes to represent a number of questions with a small number of hypothetical factors. All of the conditions are satisfied for factor analysis for Question 8. With reference to the table above:

- The principle component analysis was used as the extraction method, and the rotation method was Varimax with Kaiser Normalization. This is an orthogonal rotation method that minimizes the number of variables that have high loadings on each factor. It simplifies the interpretation of the factors.
- Factor analysis/loading show inter-correlations between variables.
- Items of questions that loaded similarly imply measurement along a similar factor. An examination of the content of items loading at or above 0.5 (and using the higher or highest loading in instances where items cross-loaded at greater than this value) effectively measured along the various components.

It is noted that the variables that constituted Question 8 loaded along two components (sub-themes), meaning that respondents identified different trends within the section. Within the section, the splits are colour coded. The yellow component indicates vigorous to medium activity that causes patient to feel pain. The green component indicates very little to no activity but the patient still experiences pain symptoms.

4.13 Biographical data of patients

This section summarises the biographical characteristics of the respondents. Table 9 depicts overall gender distribution according to the age of the sample patient population.

Table 9: The overall gender distribution by age.

			GENDER		**Total**
			Male	**Female**	
Age	20 - 29	Count	0	1	1
		% within Age	0.0%	100.0%	100.0%
		% within Gender	0.0%	4.0%	1.7%
		% of Total	0.0%	1.7%	1.7%
	30 - 39	Count	3	3	6
		% within Age	50.0%	50.0%	100.0%
		% within Gender	8.6%	12.0%	10.0%
		% of Total	5.0%	5.0%	10.0%
	40 - 49	Count	5	5	10
		% within Age	50.0%	50.0%	100.0%

		% within Gender	14.3%	20.0%	16.7%
		% of Total	8.3%	8.3%	16.7%
	50 - 59	Count	12	3	15
		% within Age	80.0%	20.0%	100.0%
		% within Gender	34.3%	12.0%	25.0%
		% of Total	20.0%	5.0%	25.0%
	60 - 69	Count	8	8	16
		% within Age	50.0%	50.0%	100.0%
		% within Gender	22.9%	32.0%	26.7%
		% of Total	13.3%	13.3%	26.7%
	70 - 79	Count	6	3	9
		% within Age	66.7%	33.3%	100.0%
		% within Gender	17.1%	12.0%	15.0%
		% of Total	10.0%	5.0%	15.0%
	80 - 89	Count	1	2	3
		% within Age	33.3%	66.7%	100.0%
		% within Gender	2.9%	8.0%	5.0%
		% of Total	1.7%	3.3%	5.0%
Total		Count	35	25	60
		% within Age	58.3%	41.7%	100.0%
		% within Gender	100.0%	100.0%	100.0%
		% of Total	58.3%	41.7%	100.0%

According to the respondents in this study, the gender representation comprised of 35 males and 25 females patients, with an overall ratio of males to females being approximately 3:2 (58.3% : 41.7%) respectively. There was no significant correlation for gender to any of the main objectives of this study. The incidence of pain was experienced as affecting both genders equally.

Table 10 shows the spectrum of ages of the patients being treated in the Centre. However, it should also be read in conjunction with Tabe 9.

Table 10: The descriptive measures for age of patients.

	N	Minimum	Maximum	Mean	Std. Deviation
Age	60	22	85	57.30	13.900

The youngest patient in this study was 22 years old and the oldest was 85 years old, representing a wide range across the different age groups. Within the age category of 60 to 69 years, 50.0% were male. Within the category of males (only), 22.9% were between the ages of 60 to 69 years. Thus, the category of males between the ages of 60 to 69 years formed 13.3% of the total sample. It was observed that the older patients had a higher incidence of pain experienced than the younger patients.

There was a significant difference in the manner of the age distribution (p = 0.001), whilst gender was not significantly different (p = 0.197).

4.14 The racial composition of patients

The racial distribution of patients in the Centre is depicted in Figure 8.

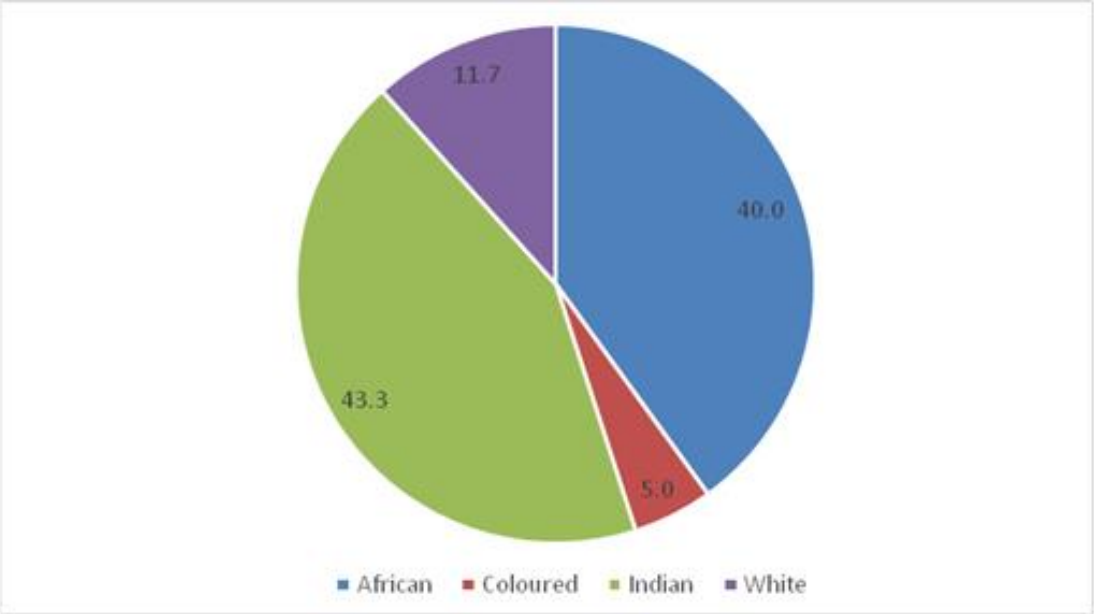


Figure 8: The racial composition of patients

There were similar numbers of African and Indian respondents. These groups were significantly more than the other race groups ($p < 0.001$) that are treated for CKD at the Centre. The racial demographics did not show any significance for any of the main onjectives of this study. However, the patients demographic characteristics of this study are not comparable to the broader South African dialysis population.

Figures from the South African Renal Registry (Davids et al., 2015: 207), show the national figures of RRT patients:

- Indian: 53, 2%
- Black: 12,2%
- White:19,1%
- Coloured: 15,6%

Thus, this study limits gneralisation to the wider CKD patietns.

The marital status of patients in the Centre is shown in Table 11.

Table 11: Descriptive statistics for marital status of patients.

	Frequency	Percent
Yes	50	83.3
No	10	16.7
Total	60	100.0

According to the marital status of the patients, there was also a significant difference ($p < 0.001$) with 83,3% being married. However, this study did not investigate this aspect and its relevance to pain management.

4.15 Section analysis

The section that follows, analyses the scoring patterns of the respondents per variable per section. The results are first presented using summarised percentages for the variables that constitute each section. Results are then further analysed according to the importance of the statements.

Table 12 indicates the descriptive measures for the number of years on dialysis.

Table 12: The descriptive measures for the number of years on dialysis.

N	Minimum	Maximum	Mean	Std. Deviation
60	0.25	23.00	4.6250	3.93956

The mean and standard deviation was 4.63 ± 3.94 years, with a range of 22.75 years. This indicates that dialyis is a life-saving treatment for patients with CKD.

Table 13 indicates the descriptive measures for the number of dialysis sessions per week.

Table 13: The descriptive measures for the number of dialysis sessions per week.

N	Minimum	Maximum	Mean	Std. Deviation
60	2.00	3.00	2.7000	0.46212

4.16 This section represents the data that emerged from the questionnaire.

Patients completed the questionnaires while they were on HD during a midweek treatment. The detailed pain questionnaire was based on the McGill Pain Questionnaire (1975). The questionnaire probed patients explicitly about problems with chronic pain; its severity, frequency, causes, types of medication taken for pain relief and impact of pain on their lives. The researcher was on hand to assist patients to complete the questionnaire when necessary. In this study, chronic pain was defined as pain of greater that three months duration.

4.16.1 Type of pain medication recommended by your doctor

According to the patients the various types of pain medication recommended by the attending doctors are indicated in Table 14.

Table 14: Types of pain medication recommended by doctor.

	Frequency	Percent
Mybulen	1	1.7
Lyrica	7	11.7
Panado	32	53.3
Stilpain	20	33.3
Total	60	100.0

Table 14 shows that Panado (53.3%) is the medication most recommended by the doctor and Stilpain (33.3%) as an alternative recommendation for pain management. This represents a very generalised and conservative analgesic pain management approach that is comparable to that which is recommended for pain in the general population. A study by Davison (2003: 1246), found that there is significant under-treatment of pain in 75% of patients with CKD. Interesting to note is the responses of staff (Table 7) as compared to the responses of patients, as indicated above, regarding pain medication that is recommended. These results indicate the limited knowledge of analgesics that patients have as compared to the staff.

4.16.2 Use of other treatment/s to manage the pain.

Figure 9 shows the alternative treatment/s utilised by patients.

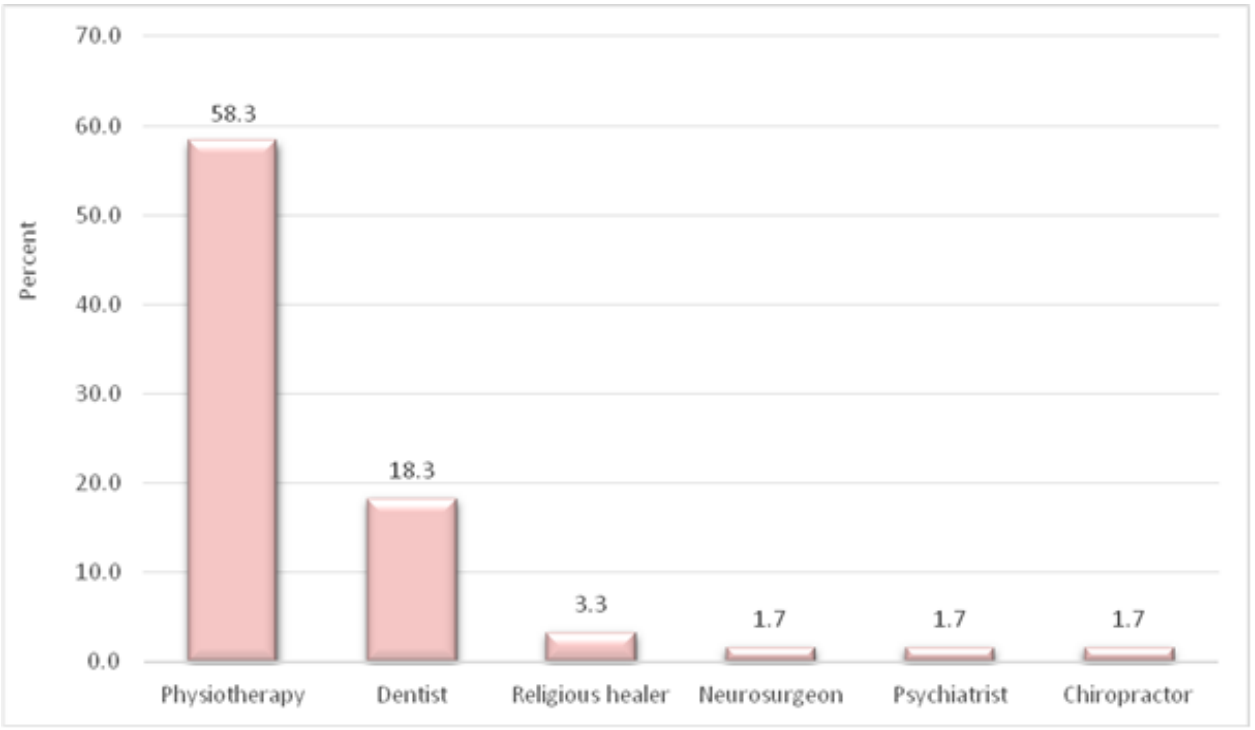


Figure 9: Use of alternative treatment/s besides the medications.

Nearly 60% of the patients used physiotherapy, whilst 18.3% of the patients utilised the dentist as alternative treatment to relieve pain. Minimal patients (1,7%) utilised the services of a neurosurgeon, psychiatrist and chiropractor, whilst 3,3% of patients used the alternative

services of a religious healer to help cope with their pain. It is highly recommended that the Centre regularly provides the services of a pain management specialist to assist patients cope with their pain.

4.16.3 Use of non-pharmacological treatment for pain relief.

Non-pharmacological pain relief treatment/s that patients use is depicted in Figure 10.

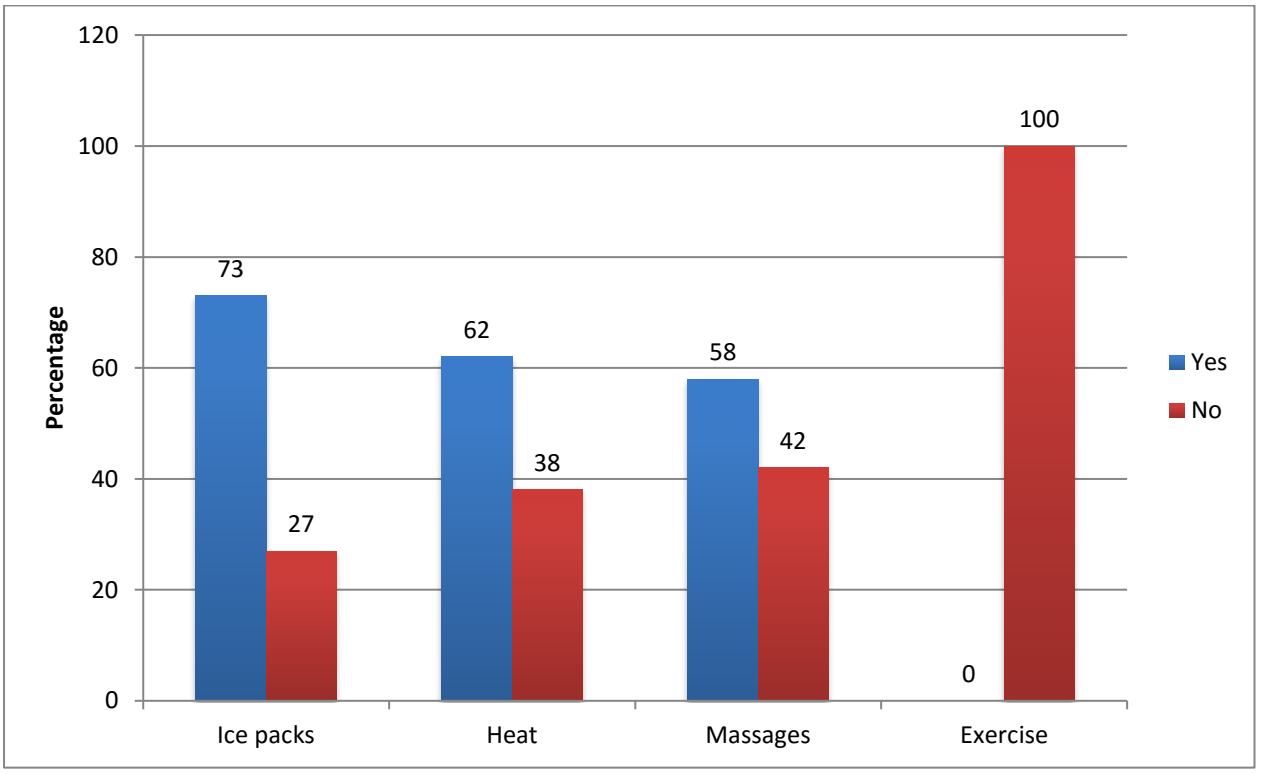


Figure 10: Non-pharmacological treatment for pain relief.

To relieve their pain, 44 (73%) patients said they used ice packs; 37 patients (62%) used heat and 35 (58,3%) had massages. Massage of a painful limb by the patient themselves or a therapist helps to decrease muscle tension and relieve pain (Kafkia et al., 2014: 58). In addition, it brings about mental and physical relaxation. Heat application, such as warm blankets or electric heat pads, causes vasodilatation resulting in increased blood flow and reduces pain levels.

Patients with CKD/ESRD are predisposed to physical limitations. As all patients indicated that they do not do any form of exercise, the staff in the Centre should encourage patients, if possible and in consultation with the consulting physician, to do some form of exercise because studies indicate that exercise does offer pain relief, better sleep and may prove beneficial to all domains of quality of life (Knap et al., 2005; O'Sullivan and McCarthy, 2009; Singh, 2009).

4.16.4 Co-morbid conditions of patients.

Table 15 indicates the various co-morbid conditions of the patients in this study.

Table 15: Indication of co-morbid diseases of the patients.

	Frequency	Percent
Hypertension	16	26.7
Hypertension and Cardiac Stent	1	1.7
Hypertension and Diabetes	27	45.0
Hypertension, Diabetes and Cardiac stent	16	26.7
Total	60	100.0

Hypertension was present in all patients had (100%). However, most patients (44) presented hypertension in combination with other illnesses. The highest grouping was for hypertension and diabetes (45.0%). CKD often presents with substantial co-morbidities and could be contributing factor for the pain experienced.

4.16.5 Patients experiencing pain whilst on dialysis.

The total number of patients who experienced pain during dialysis is shown in Table 16.

Table 16: Number of patients experiencing pain whilst on dialysis.

	Frequency	Percent
Yes	59	98.3
No	1	1.7
Total	60	100.0

All but one of the patients was currently experiencing pain whilst on dialysis ($p < 0.001$). Patel (2013: 269), found that although practitioners are aware of pain during the dialysis procedure (for example, muscle cramping or headaches), persistent painful symptoms before and after a haemodialysis (HD) session are underappreciated.

4.16.6 The frequency and severity of the pain experienced by the patient.

The types, frequency and severity of the pain symptoms experienced by the patients in this study is shown in Table 17.

Table 17: Descriptive measures of the frequency and severity of pain experienced by patients.

		Back pain	Itchiness	Chest pain	Headache	Cramping	Numbness	Muscle	Joint
Chi Square p-value (1)		0.000	0.000	0.000	0.000	0.000	0.071	0.302	0.606
frequent	continuous	8.5	5.9	0.0	4.5	5.5	17.4	3.8	7.1
	regularly	38.3	33.3	56.7	54.5	41.8	39.1	65.4	75.0
	occasionally	29.8	39.2	26.7	22.7	32.7	30.4	23.1	14.3
	seldom	23.4	21.6	13.3	13.6	18.2	8.7	3.8	0.0
	momentary	0.0	0.0	3.3	4.5	1.8	4.3	3.8	3.6

Chi Square p-value (2)		0.0304	0.0042	0.0002	0.0000	0.0000	0.0435	0.0000	0.0000
severe	unbearable	0.0	0.0	0.0	0.0	7.3	4.3	0.0	0.0
	severe	12.8	11.8	6.7	14.0	23.6	4.3	11.5	7.1
	distressing	25.5	21.6	26.7	9.3	12.7	21.7	15.4	10.7
	discomfort	46.8	51.0	53.3	65.1	54.5	56.5	65.4	67.9
	mild	14.9	15.7	13.3	11.6	1.8	13.0	7.7	14.3
Chi Square p-value (3)		0.0034	0.0002	0.0016	0.0000	0.0000	0.0002	0.0000	0.0000

The chi-square (1) *p*-values that are highlighted indicate that there are significantly more patients who suffer with pain symptoms, such as, back pain and chest pain. The remaining chi-square tests, in Table 17 indicate that the frequency and severity for each pain type had significantly different scoring patterns. For example, for back pain frequency, significantly more respondents indicated that they regularly experienced pain (38.3%). For back pain severity, significantly more respondents indicated that the pain levels were distressing and discomforting (72.3%).

Patients' pain varied from mild to unbearable and pain is experienced in their daily routines. Muscle (65.4%) and joint pain (75%) was the most regular pain experienced and was the most severe and caused the most discomfort (65.4%) and (67.9%), respectively.

This study demonstrated that pain can be severe causing distress and discomfort in patients with CKD. Consistent with the results from previous studies (Weisbord et al., 2005; Curtin et al., 2002; Merkus et al., 1999), itching, numbness, cramping were severe and were seen in more than half of the patients.

4.16.7 Location of pain experienced by patients.

Table 18 represents the descriptive measures of the location of patients' pain and should be read in conjunction with Figure 11.

Table 18: Descriptive measures of the location of the patients' pain.

	Yes		No		Chi Square
	Count	Row N %	Count	Row N %	p-value
Neck	18	30.0%	42	70.0%	0.002
Temples	10	16.7%	50	83.3%	0.000
Forehead	20	33.3%	40	66.7%	0.010
Entire Head	9	15.0%	51	85.0%	0.000
Upper Chest	28	46.7%	32	53.3%	0.606
Lower back	48	80.0%	12	20.0%	0.000
Hands	23	38.3%	37	61.7%	0.071
Lower leg	31	51.7%	29	48.3%	0.796
Upper leg	21	35.0%	39	65.0%	0.020
Calf	25	41.7%	35	58.3%	0.197
Entire leg	8	13.3%	52	86.7%	0.000
Abdomen	19	31.7%	41	68.3%	0.005
Shoulders	19	31.7%	41	68.3%	0.005
All over skin	15	25.0%	45	75.0%	0.000

Figure 11 represents the site of the most severe to the lease severe pain experienced by patients.

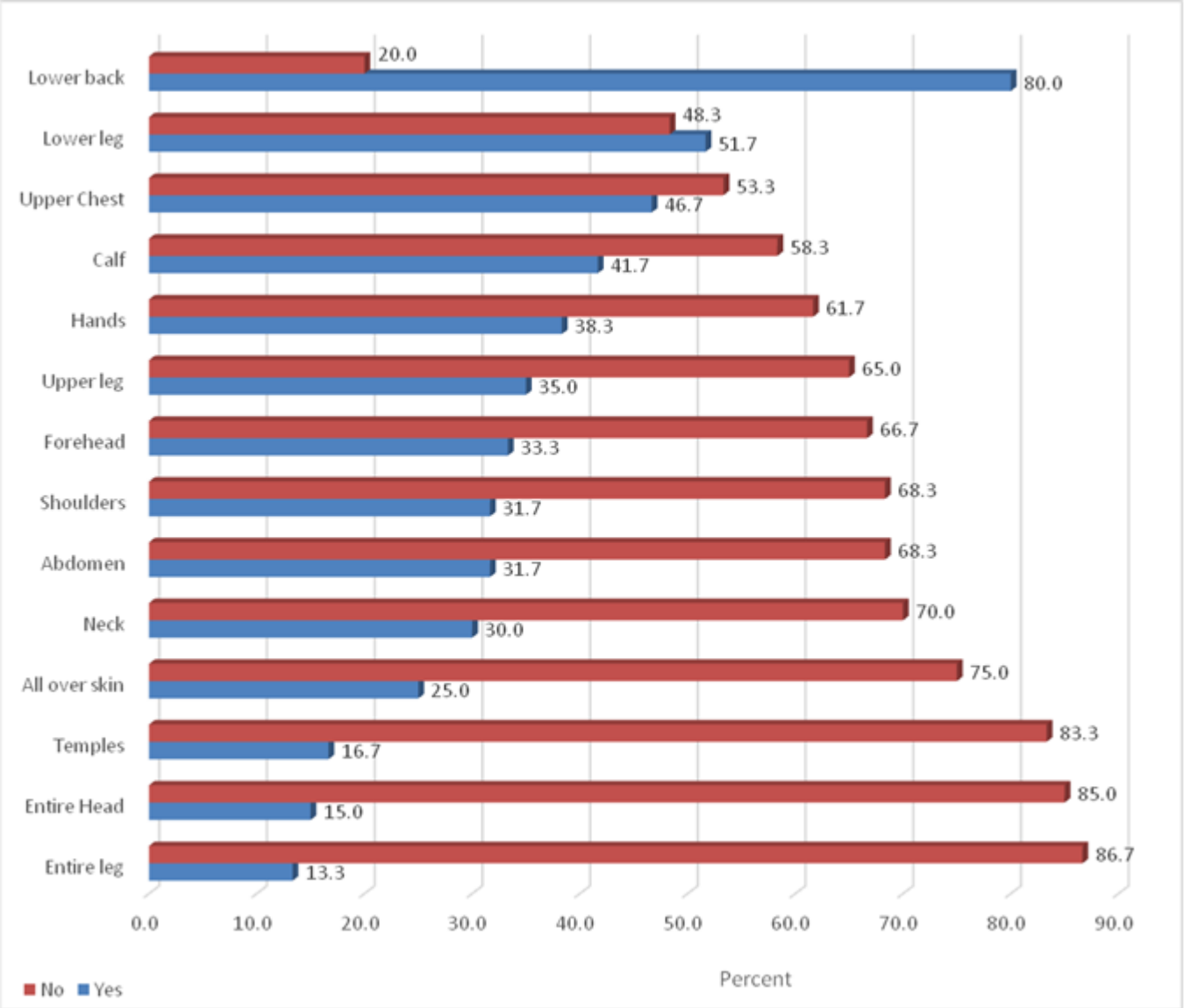


Figure 11: Location of pain experienced by the patients

The highlighted values indicate that significantly more patients experienced pain in some regions more than others. The most common location of pain experienced by patients were the lower back (80%), lower leg (51.7%) and upper chest (46.7%) areas of the body. Thus, in this study pain appears to be mostly musculoskeletal in nature. This is similar to the study by Davison (2003: 1245), where 63% of the patients reported musculoskeletal pain.

4.16.8 The impact of pain on patients' daily activities.

Table 19 portrays the impact of pain on the patients' daily activities.

Table 19: The impact of pain on patients' daily activities.

	yes, limited a lot	yes, limited a little	not limited at all	Chi Square p-value
Vigorous activities e.g. strenuous sports or lifting heavy objects	53.3	43.3	3.3	0.000
Moderate activities e.g. pushing a vacuum cleaner or playing golf	38.3	51.7	10.0	0.000
Carrying groceries	46.7	40.0	13.3	0.004
Climbing a flight of stairs	65.0	28.3	6.7	0.000
Bending or kneeling	63.3	28.3	8.3	0.000
Walking a few metres or cooking	45.0	41.7	13.3	0.004
Walking a kilometre	63.3	28.3	8.3	0.000
Bathing or dressing yourself	10.0	26.7	63.3	0.000
Relation to other people	0.0	8.3	91.7	0.000
Outlook to life in general	0.0	11.7	88.3	0.000

The following patterns were observed:

- Some statements showed (significantly) higher levels of agreement (yes) whilst other levels of agreement (yes) were lower (but still greater than levels of disagreement (no).
- The significance of the differences was tested and shown in Table 19.

To determine whether the scoring patterns per statement were significantly different per option, a chi square test was done. The null hypothesis claims that similar numbers of respondents scored across each option for each statement (one statement at a time). The alternate states that there was a significant difference between the levels of yes and no. The results are shown in Table 19.

The highlighted significant values (*p*-values) are less than 0.05 (the level of significance), it implies that the distributions were not similar, i.e. the differences between the ways respondents scored were significant.

4.16.9 Pain medication taken by patient during the dialysis session.

All of the patients (100%) responded that they did not take any medication during the session.

4.16.10 Pain relief during this dialysis session.

All of the patients (100%) reported that there was relief from pain during the session. However, this contrasts sharply with the high percentage that complained, to staff, of severe pain at the end of the session (78,3%) as indicated in Figure 3.

4.16.11 Phase during which pain symptoms are experienced the most.

Figure 12 illustrates the phase during dialysis where the pain symptoms of the patients' are the most severe.

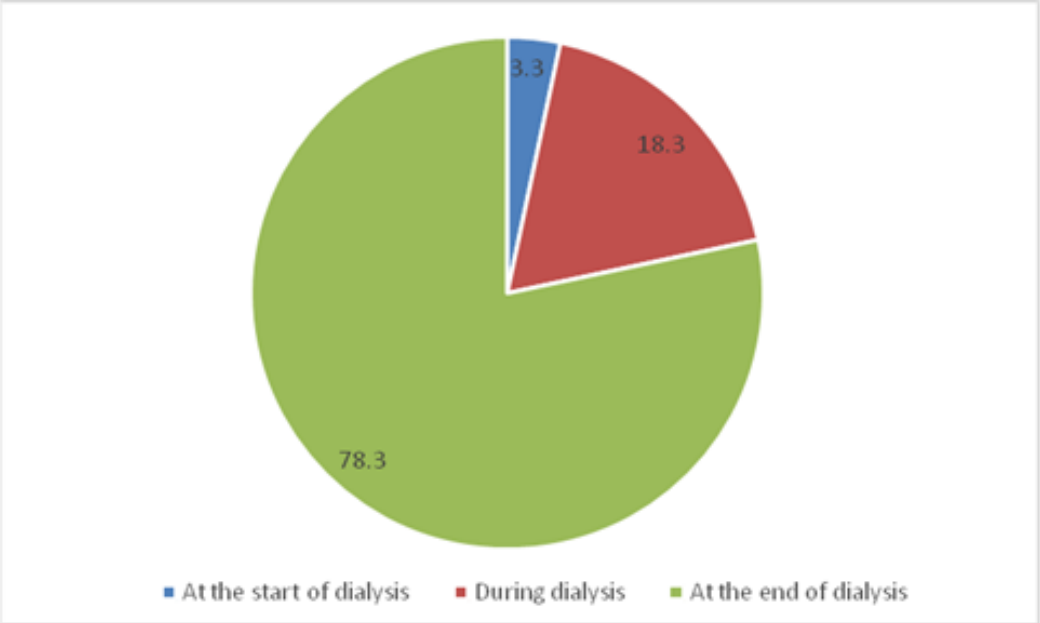


Figure 12: The phase during dialysis that pain symptoms are most severe.

Significantly more respondents (78.3%) indicated that pain occurred most at the end of the dialysis session ($p < 0.001$). However, there was no clinical pain assessment tool administered to patients in the Centre. Patients are asked about their pain in an informal manner. The American Medical Association (1995: 60), found that unless patients were asked explicitly about their pain, they did not report it. The implication of this finding is that for dialysis patients to receive adequate treatment for their pain, an explicit pain assessment must be part of the treatment they receive.

4.16.12 Adherence of the pain medication prescribed by your doctor.

All of the respondents (100%) indicated that they adhered to the medication prescribed by the doctor to manage their pain. However, the researcher has noted anomalies of some of the

types of medication used as indicated by the varying responses of staff (Table 7) and patients (Table 14).

4.16.13 Time that patient communicate pain symptoms to the renal staff.

Figure 13 indicates the time the patients reported their pain symptoms to the staff.

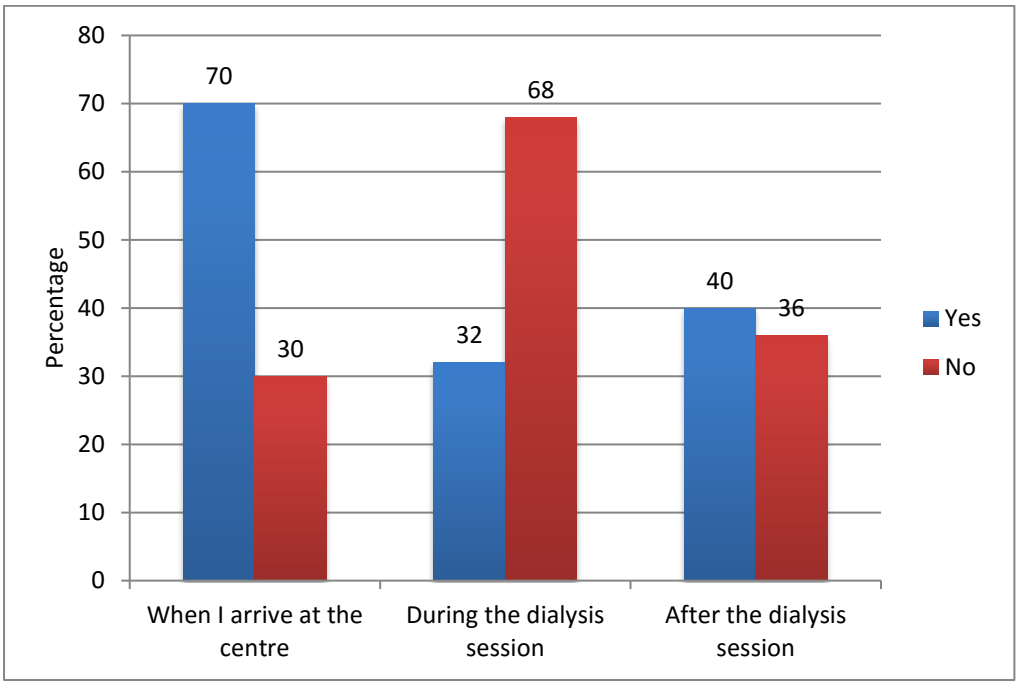


Figure 13: Time that patient communicates pain symptoms to renal staff.

While 100% of the patients did not feel intimidated by the staff and all felt confident to ask for pain medication; 37% felt that they should not bother staff as the dialysis treatment was the most important reason for the attendance. A high percentage of patients (70%) did complain about their pain before the dialysis session (Figure 13). It is of primary importance to note that patients are susceptible to pain at any stage of dialysis session and even before the session starts and yet pain is still under-treated and under-assessed.

What is more important is that both staff and patients indicated that patients did not complete their time on dialysis due to severe pain experienced; these responses shows that patients themselves are unaware of the effects of pain on their treatment outcomes and will warrant

firm recommendations about education and advocacy for pain management for the patients in the Centre.

4.16.14 The patients' perception of the causes of pain

The perception of the causes of patients' pain is illustrated in Figure 14.

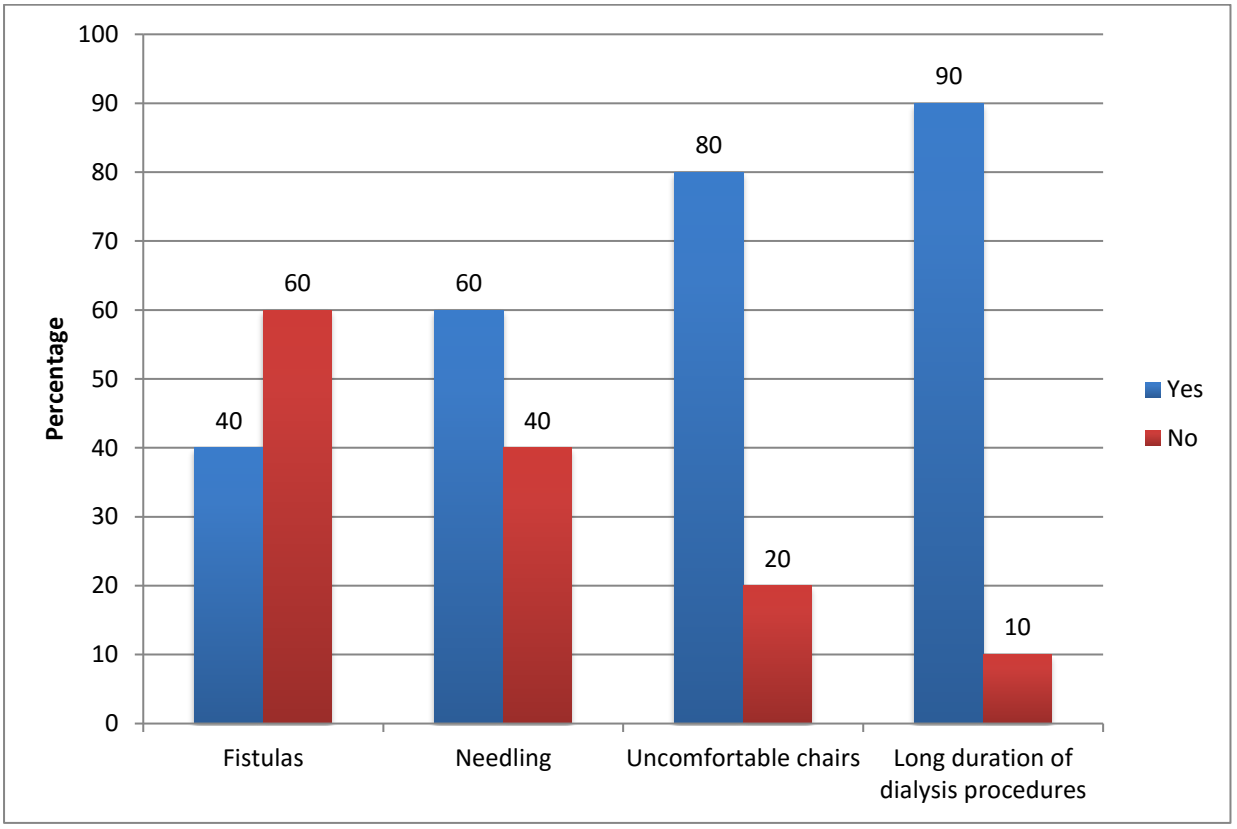


Figure 14: The patients' perception of the causes of pain.

Fifty four (90%) patients complained that the long duration (3 hours) of the dialysis session and sitting in one position for that time caused them severe pain and discomfort. A significant number of patients (48) complained of the chairs being uncomfortable (80%). Patients complained of pain caused by needling (60%) and fistulas (40%). It is clear that the dialysis process itself is not necessarily a painful procedure (Binik et al., 1982: 847), but some requirements associated with dialysis are, for example, sitting for the required time and fistulas. Alternative treatment such as topical analgesics could be used to alleviate pain caused by fistulas and needling.

4.16.15 The barriers for optimum pain relief

The hurdles that patients perceive to prevent optimum pain relief is shown in Figure 15.

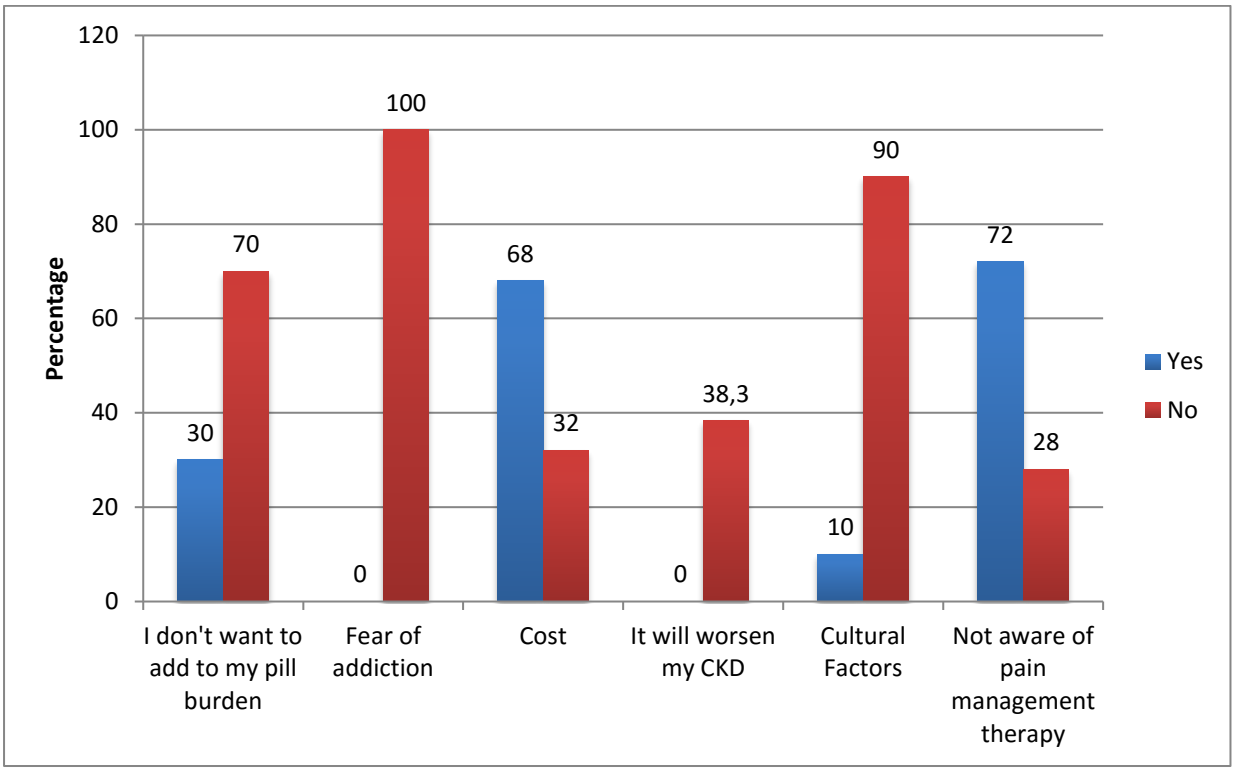


Figure 15: The patients' perception of barriers for optimum pain relief.

While all the patients in this study did not fear addiction of pain medication, a high number, 43 patients (72%), were unaware of different pain management therapies. Patients (62%) were concerned that added pain medication would worsen their condition, thus, there seems to be a need for pain management advocacy and education.

According to Lindburg and Lindburg (2008: 573), patients with CKD use many pharmacological agents to treat, correct or prevent concomitant diseases and the average daily intake is between 10-14 different drugs. This is confirmed by the high percentage of patients in this study (70%) who stated that they did not want to add to their pill burden. Effective pain management is possible (Koncicki et al., 2015; Murtagh et al., 2007; Barakzoy and Moss, 2006). Thus, it is vitally important that staff explicitly state the various

pharmacological and non-pharmacological therapies which are appropriate for patients with CKD and the benefits of these to the patients in the Centre.

A high percentage of patients (68%) complained of the high cost of medication, which together with the dialysis session costs, hospitalisation costs and consultation with different specialists physicians, they stated is prohibitive. In addition, unawareness of pain management therapies could be a contributing factor for non-adherence to time on dialysis and the consistent chronic pain experienced. The patients did not receive comprehensive information brochures or pamphlets about the range of pain management therapies that could be used and the benefits thereof. An understanding of a range of issues pertaining to under-treated and under-diagnosed chronic pain is important since it is associated with many undesirable outcomes such as diminished HRQoL (Kimmel et al., 2003; Curtin et al., 2002).

4.16.16 Effects of chronic pain for the CKD patient.

The impact of pain on patients HRQoL is shown in Figure 16.

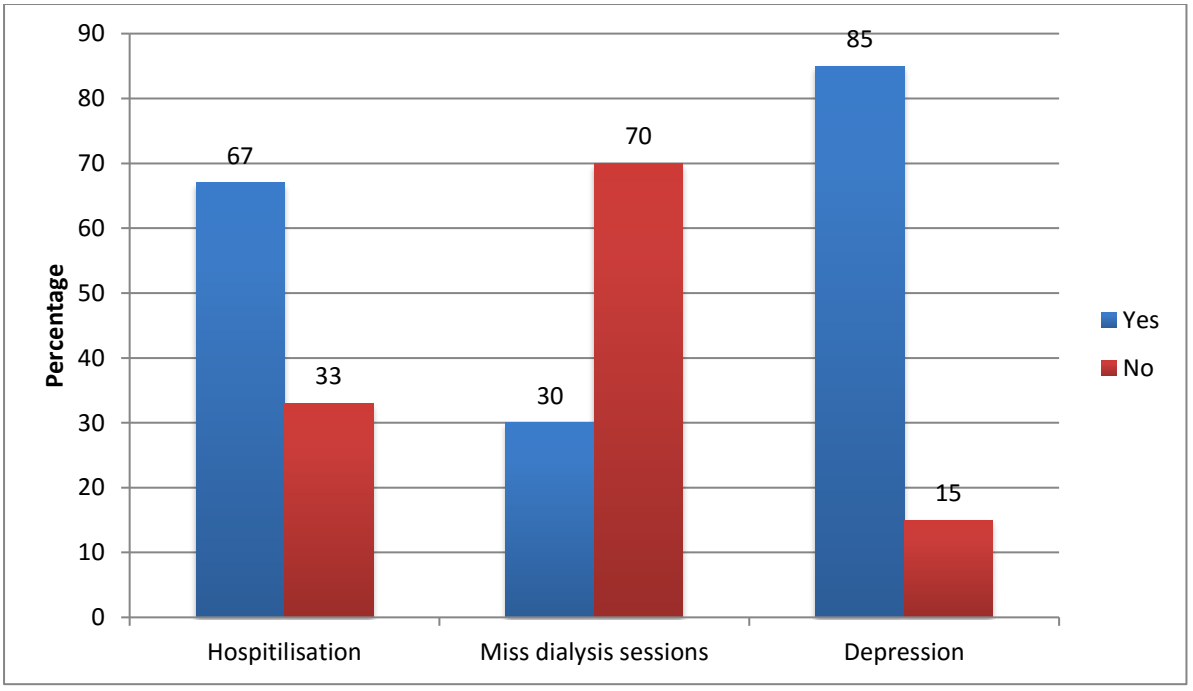


Figure 16: Effects of chronic pain for the CKD patient.

More than two thirds, of the patients (66,6%) stated that the pain they experienced caused them to be hospitalised. The policy in the Centre is that patients are generally admitted to hospital for acute pain which is for a short period of time. Pain such as muscle cramps and other associated symptoms such as dyspnoea frequently occur in the setting of psychosocial morbidity such as anxiety and depression which contributes to the overall perception of pain (Patel, 2013: 269). A significant number (85%) of patients experienced depression. The interplay of pain, depression and decreased HRQoL has been linked to increased morbidity and mortality in patients on dialysis (Brkovic et al., 2016; Weisbord et al., 2005: 2491). The figures in this study are consistent with the international research (Pagels et al., 2012; Unruh et al., 2005; Davison, 2003) on the debilitating impact of pain in CKD patients, particularly pain that is under-diagnosed and under-treated.

4.16.17 Impact of the pain on the lifestyle of the patient.

The impact of pain on patients lifestyle is shown in Figure 17.

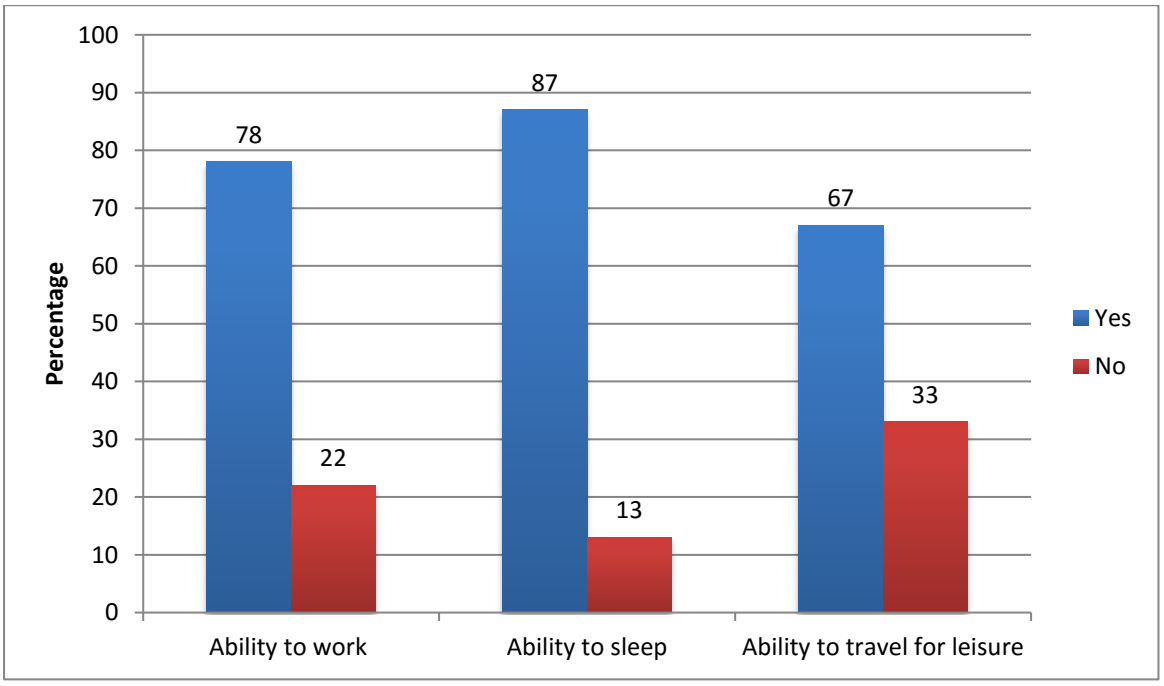


Figure 17: Impact of pain on patients' lifestyle.

A significant number of patients stated that pain adversely affected their lifestyle:

- 52 patients (86%) stated that their sleep was disturbed. This is comparable to the 45%-86% prevalence reported in studies of dialysis patients (Brkovic et al., 2016; Sabbatini et al., 2002).
- 47 patients (78%) stated that pain affected their ability to work.
- 40 patients (67%) stated that pain prevented them from travelling, especially traveling for leisure.

Pain has been associated with decreased HRQoL (Kimmel et al., 2003; Curtin et al., 2002) in this patient population. However, longitudinal studies by Davison et al. (2006: 3193), found that effective pain management may improve HRQoL for these patients.

4.16.18 Suggestions for improvement of pain management from the Durban Kidney and Dialysis Centre.

All of the respondents (100%) were satisfied with their treatment at the Centre. Despite the pain that patients experienced, they did not recommend any improvements in terms of pain management from the staff or management of the Centre.

4.17 Document analysis

4.17.1 Patient records

The records of the patients showed that they are compliant in taking medication for hypertension, diabetes and / or cardiovascular-related conditions. However, there was no consistent recording of compliance with recommended pain medication.

4.17.2 Minutes of staff meetings

A scrutiny of the minutes of staff meetings revealed that no discussions were held on any of the areas within the realm of pain management of the patients being treated for CKD/ESRD in

the Centre. There were no plans for staff development regarding assessment tools or development of guidelines for the administrations of analgesics.

The overall purpose of this study was to investigate the types, frequency and severity of pain experienced by patients with CKD. In addition, specific objectives focussed on how the patients managed the distress and discomfort they experienced and how the renal staff responded to the pain experienced by patients in their care. These objectives were achieved through information elicited from staff and patients, minutes of staff meetings and the patients' medical history records.

4.18 Conclusion

Chapter four provided the results for this study and an analysis of the questions asked of the patient and staff population in the study sample. The results highlighted that pain is a very common complaint of all the patients in the sample population, with 72.3% reporting moderate to severe pain experienced. There are no instruments for the clinical assessment of pain in the Centre and it has emerged that patients are not recommended pain analgesics for specific types of pain besides the generalised pharmacological analgesic, for example, Panado. Most patients shorten their time on dialysis when they experience severe pain. Also worth noting is that the staff are not provided guidelines for analgesic usage for specific types of pain. The results of this study indicate that there is a need for pain assessment tools and analgesic guidelines to assist the staff in pain management of patients in their care. The next chapter provides a discussion of the results.

CHAPTER FIVE

DISCUSSION

This chapter presents the discussion of the findings that have emerged from this single-centre study on the topic of pain management in patients with CKD. The aims and objectives of the study are reviewed and an account of whether the researcher achieved each aim is also provided.

5.1 Prevalence of pain in patients with CKD

The literature review from several international studies have described the impact and severity of pain in patients with CKD (Davison et al., 2014; Williams and Manias 2008; Davison, 2007; Weisbord et al., 2005). These studies reveal that 37 – 50% of CKD patients experience chronic pain. Results for this study show that 98.3% of patients reported pain symptoms during dialysis and for 72.3% of the patients; the pain experienced was moderate to severe indicating that pain is a major symptom burden in this patient population. This result is similar to research by Davison (2006: 1), who found that pain which is moderate to severe in intensity affected 82% of patients.

The sample that responded and the methodology used yielded a result that was very representative of the perceptions of staff and patients at the Centre regarding pain and management thereof. Therefore, the results of this study will provide useful information to add to the understanding of the vital role of effective pain management therapies for these patients. Of all the staff and patients who were approached to participate in the study, 100% completed the questionnaires. Patients were on average 57 years of age and race distribution ranged from 5% Coloured patients to 43,3% comprising Indian patients. The ratio of male to female patients was 58,3% : 41,7%. The study was conducted between September 2017 and March 2018.

5.2 Medical conditions associated with the causes of CKD

It emerged from a scrutiny of the medical history records that the main causes of CKD, for this patient group, is reflected in Table 20.

Table 20: Causes of CKD in the patient study sample population.

NUMBER OF PATIENTS (%)	CAUSE OF RENAL FAILURE
24 (40%)	Diabetes mellitus
18 (30%)	Hypertension
10 (16,6%)	Glomerulonephritis
5 (8,3%)	Polycystic kidney disease
3 (5%)	Other

The mean for number of years on dialysis was 23.00 and haemodialysis was the prevalent dialysis treatment used. Hypertension was the most common medical condition, being present in 100% of all the study patients. This is in line with studies by Longenecker et al. (2002), and Young et al. (2009), who found hypertension present in 99.0% of dialysis patients. Patients in this study had substantial co-morbid diseases with 26,7% reporting hypertension, diabetes and cardiac stent. Thus, the causes of pain are multi-factorial and make management thereof challenging.

5.3 Impact of pain in patients' daily routine and HRQoL

Figure 11 summarises the location of each pain symptom. It is clear from the data gathered in this study that the dialysis procedure itself is not necessarily a painful procedure. Pain was experienced by all patients, with the most frequently reported symptoms being lower back pain (80%), lower leg pain (51,7%) and upper chest pain (46,7%%). Pain was frequently experienced by patients towards the end of the dialysis session (78,35%). Between 53, 3% and 65% of patients reported that pain affected them mostly, for example, when climbing

stairs or walking. There was a significant association with pain and older age, long years of being on dialysis and the period at the end of the HD treatment session itself (p< 0.0 5). In this study, pain was not related to gender or race.

According to Weisbord et al. (2005: 2488), dialysis patients frequently experience multiple complex symptoms (such as cardiovascular disease and bone disease) and together with chronic pain (for example, arising from the disease itself, surgical procedures or co-morbidities), it ultimately impairs their overall HRQoL (Davison and Jhangri, 2010; Murtagh et al., 2007; Kimmel et al., 2003; Curtin et al., 2002), and decisions about the duration and whether to continue with the dialysis treatment. It was noted in this study and is of concern that 100% of staff indicated that 72,7% (Figure 6) patients shortened their time on dialysis because of severe pain experienced. Thus, this study shows that there is a significant relation between compliance and pain. This decision would exacerbate the progress of the CKD condition.

On a positive note, the relationships of the patients in this study appear to be functioning optimally, with 91.7% stating that it did not affect their relationships and 88% responding that it did not affect their outlook on life in general. However, chronic pain has been shown to be associated with diminished HRQoL (Davison and Jhangri, 2010; Murtagh et al., 2007; Kimmel et al., 2003; Curtin et al., 2002). Pain is a multi-dimensional phenomenon affecting the physical, psychological and social aspects of the patient (Davison and Jhangri, 2010: 478). Failure to treat pain timeously and effectively could lead to disruption in many aspects of life such as functional status, mood and sleep.

The chronicity of their illness, thrice weekly dialysis treatments, adjustments to diet and lifestyle functioning and particularly the consistent and chronic pain experienced contributes to the depression experienced by a large percentage (85%) of patients in this study. 51% and

21,6% of the patients responded that itchiness contributed to their pain burden and caused discomfort and distress, respectively. The severity of pain experienced caused 66,6% of the patients to be hospitalised and 86,6% stated that pain affected their sleep. When this is seen in conjunction with the fact that 78% of patients responded that their pain impacted on their ability to work, one can see the distinct link that pain adversely impacts their functional status. Davison and Jhangri (2010: 481), reiterate that pain is a strong predictor of depression and poor sleep quality, factors that in turn are associated with a higher rate of mortality.

5.4 The patients approach to management of their pain

Patients with CKD manage many aspects of their own treatment, such as, managing their fluid intake, maintaining diet restrictions, taking multiple types of medication and scheduling their dialysis treatment. Respondents in this study have lived successfully from 4 years to 23 years while being on dialysis and many have actively managed their own health-care. However, it has been noted from the literature, that many patients will selectively report their symptoms so as not to “bother the providers” (Curtin and Mapes, 2001; Manias and Williams, 2007). In this study, 37% of patients felt that they should not bother staff about their pain symptoms.

The pain medication that was mainly used by patients was Panado (53%) and nearly 60% of the patients reported using alternative means of pain relief such as a physiotherapist. NSAIDS use appears to be high and there is a low use of opioids. In addition, there was little indication that adjuvants were prescribed or used. Thus, the patterns of pain medication recommended and / or taken by the patients in this study show a simple, generalised pharmacological approach rather than a targeted therapeutic intervention specifically tailored to the type of pain experienced by the patient; an approach which has also been reported by Davison et al., (2014). Several international studies have shown that analgesic use is not high in patients with CKD despite the high prevalence of pain (Murtagh et al., 2007; Dean,

2004; Kurella et al., 2003). This trend is also prevalent in this study because 100% of the patients reported that they had not taken any medication prior to their dialysis session and 53% reported use of only Panado.

Interesting to note that 90,9% of staff reported that Lyrica was recommended for muscle pain, joint pain and numbness but patients reported high usage of only Panado (53%). This could possibly indicate under-education of patients with regard to analgesics; under-recognition of the type of pain or lack of follow-up by staff. High cost of medication for the patients (68%) and unawareness of pain management strategies (72%) are also barriers to use of analgesics.

It is evident that all patients in this study do not do any form of exercise. It would, therefore, be important for these patients to be referred to a physiotherapist or bio-kinesthesis so that they receive appropriate physical training to help alleviate their pain symptoms.

5.5 Staff approaches to the management of the pain of the patients in their care.

The renal staff in the Centre are highly qualified to perform their duties. However, they did not offer analgesics for pain relief at the end of the dialysis session when many patients complained of pain and terminated their session early (72,7%). All of the staff ensured that patients were comfortable rather than offer analgesics to relieve pain (54,5%) during or after dialysis. This could indicate, for example, a reluctance of the renal staff to administer analgesics, a lack of communication between staff and patients or a lack of guidelines to assist staff to make decisions about analgesic use. As a start, staff, together with the attending doctors, could consider the use of the following for relief of pain or discomfort in patients on dialysis as suggested by clinical trials (Celik et al., 2011; Young et al., 2009; Che-Yi et al., 2005; Gunal et al., 2004; Ashmore et al., 2000; Alon et al., 1994; Breneman et al., 1992). For example:

- Needle pain: use of topical lidocaine or a vapocoolant
- Pruritus: acupuncture or gabapentin
- Anti-itch: anti-itch cream containing pramoxinet or capsaicin

Appropriate and effective pain management will enhance the level of comfort of the patient by reducing pain to a tolerable level, reducing the incidence of missed treatments or early termination of sessions and hospitalisation.

5.6 Content analysis

There were four key themes that emerged from this study: physical pain, distress and discomfort, managing pain and HRQoL:

5.6.1 Physical pain: some form of pain was experienced by all patients, with the most frequently reported symptoms being lower back pain (80%), lower leg pain (51,7%) and upper chest pain (46,7%%). Thus, the pain experienced in this study was primarily musculoskeletal in nature, with 65,4% patients having muscle pain and 75% patients experiencing joint pain. Pain was frequently experienced by patients following the dialysis session (78,35%). The results highlighted that pain is a very common complaint of all the patients in the sample population, with 72.3% reporting moderate to severe pain experienced. Between 53,3% and 65% of patients reported that pain affected them mostly, for example, when climbing stairs, walking or doing any sport. It is of concern that 72,7% of patients terminated their dialysis sessions early due to the severe pain experienced.

5.6.2 Distress and discomfort: the main causes of distress experienced by more than a quarter of patients in this study, was chest pain (26, 7%) and back pain (25, 5%). The pain that caused the most discomfort experienced by more than half the patients were from headaches (65 %), numbness (56 %), cramping (54 %) and itchiness (51%). More than two

thirds, of the patients (40) stated that the pain they experienced caused them to be hospitalised and a significant number (85%), experienced depression. These figures are consistent with international research (Koncicki et al., 2015; Davison, et al., 2014; Williams and Manias, 2008; Weisbord et al., 2005), on the debilitating impact of pain in CKD patients, particularly pain that is under-diagnosed and under-treated.

5.6.3 Managing pain: It is of concern to note that Panado was the main analgesic used by patients (53 %) to relieve pain. Furthermore, many patients decreased their time on dialysis because of the extreme pain felt towards the end of the session. Nearly 60% of the patients used physiotherapy to assist with their pain relief. To relieve their pain, 73% patients said they used ice packs; 62% patients used heat and 58,3% had massages. As all patients indicated that they do not do any form of exercise, it is incumbent that the staff in the Centre encourage patients, if possible and in consultation with the attending physician, to do some form of exercise because studies do indicate that exercise does offer pain relief and may prove beneficial to all domains of quality of life (Knap et al., 2005; O'Sullivan and McCarthy, 2009; Singh, 2009).

5.6.4 HRQoL: This study shows a strong relationship between pain experienced and its impact on physical and emotional components of HRQoL.

There are a significant number of patients that stated that pain adversely affected their lifestyle:

- 52 patients (86%) stated that their sleep was disturbed.
- 47 patients (78%) stated that pain affected their ability to work.
- 40 patients (67%) stated that pain prevented them from travelling, especially travelling for leisure.

Pain has been associated with decreased HRQoL (Brkovic et al., 2016; Koncicki et al., 2015; Pagels et al., 2012) in this patient population. However, it is interesting to note that 91,7% of the patients stated that pain did not limit their relations with others and 88,3% stated that it did not limit their outlook to life in general. These indicate that patients in this study, in general, had a positive attitude to their CKD condition and the associated pain symptoms and it did not interfere with their everyday life or dealings with others.

5.6.5 An analysis of the main objectives of the study

An analysis of the main aims of the study and how it was addressed during the study:

Objective 1: To identify and describe the perception, frequency and severity of the different types of pain as experienced by patients receiving dialysis treatment:

Pain is a very subjective trait in patients and only the person experiencing it can state with certainty how severe it is. Pain is frequently present in the daily routine of the patients and varied from mild to unbearable. Itching, numbness, cramping were severe and were seen in more than half of the patients. The most common location of pain experienced by patients where the lower back (80%), lower leg (51.7%) and upper chest (46.7%). Thus, in this study pain appeared to be mostly musculoskeletal in nature.

Objective 2: To determine which types of pain cause the most discomfort and examine how the patients manage their pain:

Muscle (65.4%) and joint pain (75%) was the most regular pain experienced and was the most severe and caused the most discomfort (65.4%) and (67.9%), respectively. 90% of patients said that sitting for three hours in one position caused them severe pain and discomfort. Needling pain was experienced by 60% of the patients. 78.3% complained about severe pain at the end of their dialysis session.

Panado was the main analgesic used by patients (53%) to relieve pain. Furthermore, many patients decreased their time on dialysis because of the extreme pain felt towards the end of the session. Nearly 60% of the patients used physiotherapy to assist with their pain relief. To relieve their pain, 73% patients said they used ice packs; 62% patients used heat and 58,3% had massages.

Objective 3: To investigate how the staff assist in the management of patients pain:

All staff assisted the patients to be more comfortable. None offered analgesics for pain relief. Panado was the main analgesic used by patients (53%) to relieve pain. There were no written guidelines for analgesic administration and there were no methods for the clinical assessment of pain. Enquiries about pain experienced by the patient were verbal and informal.

Objective 4: To identify strategies to assist both staff and patients to manage the patients' pain:

The specialist nephrologists and the Health Professional Council of South Africa should put pressure on the NKF to finalise pain management strategies and the use of analgesics for this patient population.

The renal staff have to receive training to assess pain experienced by the patients in their care by the use of appropriate pain assessment instruments that is contextualised for the Centre. A casual or informal query by the staff about the pain experienced by the patient is insufficient. Thus, another critical step for management of the Centre would be to develop a holistic and simple pain assessment tool to be regularly used.

Another critical area that needs addressing is the development of guidelines for the renal staff regarding pain management. Choice of medication and dosage should be assessed taking into consideration the patients' age, co-morbidities and degree of renal failure, whether the

drug is removed from the body by the kidneys, liver or dialysis and the nephrotoxicity of the drug (Murtagh et al., 2006; Bailie et al., 2004). Anticonvulsant and antidepressant therapy for patients with neuropathic pain and non-pharmacological approaches for chronic pain management is also recommended (Glick and Davison, 2011; Rehm, 2003). This will result in appropriate, tailor-made and timely pain management interventions for each patient. Thorough follow-up by staff on recommendations regarding analgesic use is essential. Open and meaningful communication about pain management between patients and staff should be part of the culture of the Centre.

5.7 Conclusion

It is evident from all the data gathering methods used in this cohort study, that pain management is neither done in a strategic manner nor is it tailored to the patient specific needs. There are no formal, clinical pain management assessment instruments or follow-up regarding adherence to the recommendations for pain analgesics. The patients (72%) revealed that they did not have in-depth knowledge of pain management treatments and associated with the fact that many did not comply with the full duration of the dialysis session, means that targeted education on the deleterious impact that these aspects have on their future health must be urgently addressed in the Centre. Patients have shown a desire to know more about pain management relevant for CKD and on-going information sharing sessions must be provided by the Centre. Focussed attempts must be made to instil patient education about pain management therapies in this vulnerable group. This should be also reinforced by pharmaceutical companies, specialist nephrologists and caregivers at home. Both patients and staff would benefit from awareness about different types of pain management therapies, (pharmacological and non-pharmacological) and the long term impact if pain continues to be under-diagnosed and under-treated.

The findings as described in chapter four and five certainly warrant further investigation. The development of guidelines by the Centre to assist the staff to make decisions about analgesic use for the patients is one such consideration. The specialist nephrologists should investigate and implement a variety and combination of analgesics tailored to the needs of the patient. The current selections used are generalised approaches to pain. Future decisions can be based on the WHO three-step ladder on analgesic use. Furthermore, patients should also be encouraged to choose from a variety of safe, non-pharmacological approaches to help ease their pain symptoms, particularly exercises. The patient at all times must be an active participant in their renal care, particularly issues relating to pain management.

CHAPTER SIX

CONCLUSION

This chapter provides the limitations of the study, recommendations for future improvements/research areas and the conclusion.

6.1 Limitations of the study

This study has several limitations such as the use of an explorative-descriptive methodology; the small sample size and this was a single-centre study. In addition, the demographic sample, in terms of race, does not represent the national figures of CKD patients (as explained in Figure 8). Thus, it prevents generalisations to the larger dialysis population.

This was the first time that such a questionnaire on pain was administered to the patients and staff, but the respondents were honest in their responses, alert and stable. Some patients privately expressed their opinion to the researcher that they felt that this study gave them an opportunity to voice their experiences of pain associated with their condition, which was never done previously.

Owing to time and financial constraints, the researcher could not administer analgesics (according to recommendations of the WHO three-step analgesic ladder and in consultation with the specialist doctors) to the patients who had acute and chronic pain. In future studies, this could be analysed to assess if the analgesics contributed to, e.g., more restful sleep, decrease in leg pain and lower back pain. A decrease in pain could make the patients more active and more importantly it would contribute to them tolerating the full three hour dialysis session without the severe pain that they currently experienced.

Although some comments were made to the researcher when the questionnaire was administered, the questionnaire itself did not attempt to examine all determinants of HRQoL,

for example, spiritual beliefs and perception of social support. This is a limitation of the McGill Questionnaire. A few questions on HRQoL such as the last two statements in Table 19 and questions on pain and its association with depression, work, sleep and travel for leisure were included (Figure 17). However, it is noted that 91.7% and 88.3% responded that the pain experienced did not limit their relation to other people or their outlook on life in general. However, 85% admitted that chronic pain caused them to be depressed and more than 86% stated that it affected their sleep. From the literature review it is clear that chronic pain affects HRQoL (Brkovic et al., 2016; Kimmel et al., 2003; Curtin et al., 2002). This aspect of impact of pain on HRQoL would be a worthwhile future research area to pursue to fully understand the impact of chronic pain.

6.2 Recommendations for future improvements/research areas

The results show that pain is a major symptom burden but the use of analgesics is under-prescribed. Pain management, interventions and strategies should be a research priority because pain is a valid and considerable health concern in the increasing CKD patient population. These strategies would need to evaluate various analgesics and adjuvants at all levels of the WHO analgesic ladder (Glick and Davison, 2011; Barakzoy and Moss, 2006; Davison, 2006; Kurella et al., 2003).

Pharmaceutical companies should play a part in future studies as this ambit has an important role to play in CKD patient care and education. Further research, for example, over a larger sample and longitudinal studies could be undertaken. This research could be expanded to include other private and public Dialysis Centres in the province and nationally. Although there was no significant correlation for gender and race in this study, future studies could take these demographic aspects into consideration. In addition, other variables, such as HIV status and chemotherapy and its association with chronic pain in CKD patients could be

investigated. This would comprehensively show the link with chronic pain and the risk for increased morbidity and mortality in this patient population.

Naylor and Raymond (2011: 38), observe that patient education is also very important to the treatment of pain. The patient needs to be aware that pain in most instances is chronic but that renal care professionals will aid in reducing pain to a more tolerable level. This may be done by using multiple medications or different combinations of medications before achieving a reduction of pain. Importantly the patient must be an active participant in his/her treatment pertaining to pain management. Promotion of patient education that focuses on pain hygiene must be stressed at all times. This can be facilitated by the patients accurately describing the type, severity, impact and duration of pain experienced.

Williams and Manias (2008: 822), state that renal nurses need guidelines to assess and manage pain tailored to the context in which they practice. In addition, the barriers to effective pain management should be identified and resolved in a supportive manner. Importantly, there is a need to have open communication between the renal health professional team and the patient regarding optimum pain management practices for that particular patient.

Notwithstanding the busy clinic context, it is imperative that the specialist nephrologists assess the etiology, pathophysiology, types, severity and frequency of pain and address all potentially beneficial pharmacologic and non-pharmacological therapeutic options. Furthermore, the specialist nephrologists and the Health Professional Council of South Africa should put pressure on the NKF to finalise the use of analgesics for this patient population. Appropriate and effective pain management will enhance the level of comfort of the patient by reducing pain to a tolerable level, reducing the incidence of missed treatments or early termination of sessions and hospitalisation.

Undoubtedly the renal staff are critical in the first-line care of the patients with CKD. However, in order to manage and treat pain in the patients with CKD, it will be essential to re-train the renal staff to assess pain experienced by the patients in their care by the use of appropriate pain assessment instruments that is contextualised for the Centre. A casual or informal query by the staff about the pain experienced by the patient is insufficient. On the part of staff, accurate diagnosis through the use of pain assessment instruments is useful. Thus, a first critical step for management of the Centre would be to develop a holistic and simple assessment tool to be regularly used (at least once per month) to determine, for example, the types and severity of pain. This would be a new and challenging area for renal care and not one seen in practice in the region and goes beyond just ensuring that "the patient is made comfortable" when they complain of pain. There are a number of ways to assess or measure pain as discussed in the literature review, for example, there are numeric scales, visual analogue scales and verbal descriptive scales.

Another critical area that needs addressing is the development of guidelines for the renal staff regarding pain management. This should be aligned with the WHO three-step ladder of analgesic usage as advocated by (Barazkoy and Moss, 2006; Kurella et al., 2003; Davison, 2003) as well as NKF K/DOQI guidelines. Choice of medication and dosage should be assessed taking into consideration the patients' age, co-morbidities and degree of renal failure, whether the drug is removed from the body by the kidneys, liver or dialysis and the nephrotoxicity of the drug (Murtagh et al., 2006; Bailie et al., 2004). The patient tolerance and adverse effects will need to be monitored over time. This will result in appropriate, tailor-made and timely pain management interventions for each patient. Anticonvulsant and antidepressant therapy for patients with neuropathic pain and non-pharmacological approaches for chronic pain management is also recommended (Glick and Davison, 2011; Rehm, 2003).

Thus, pain assessment and management should be an integral part of every patient care plan. Results of this study will assist in the development of strategies for renal staff to manage and decrease the frequency and severity of pain experienced by the patient. The researcher is optimistic that this research provides a strong imperative for the dialysis community in the region as well as nationally to establish pain management as a clinical and research priority.

6.3 Conclusion

It is evident that pain affects a substantial number of patients with CKD which has detrimental impact not only on their HRQOL but as shown in this study, decreases time on dialysis treatment, which will lead to further renal impairment. Renal health care professionals should not only aim to extend the patients' lives but also improve their quality of life through appropriate and timely pain relief strategies. According to Davison (2014: 199), this can be made possible by the development of pain management strategies and interventions that evaluates both efficacy and safety in diverse CKD patient populations.

Focused attempts regarding patient and staff education about pain management therapies must be initiated. This must be reinforced not only by the renal staff but also by the pharmaceutical companies, specialist nephrologists, and caregivers at home. Continuous pain management education through for example, patient workshops, staff seminars, educational pamphlets (in all languages) is essential to promote patient awareness and adherence to alleviate pain in this vulnerable group.

There is a clear inter-relational link between pain and functional capacity. From a functional capacity perspective, 78% of patients stated that their ability to work effectively was hampered by the chronic pain they experienced which was exacerbated by lack of sleep as reported by 86% of patients. Appropriate and timely pain management therapies may aid in improving

patient compliance and HRQoL. If their pain is effectively managed, there are enormous potential benefits for patients' especially in terms of improved HRQoL, decreased hospitalisations and decreased desire to shorten dialysis treatment time.

Dialysis patients do face significant financial burden, including cost of medication. Investigation into other barriers to pain management could provide further insights into challenges faced by the dialysis patients in coping with pain. Investigating staff and patients perceptions about pain management gives a deeper insight on a range of pain-related issues so that renal health care professionals can better understand the impact of pain from the patients' perspective. This small study is an attempt to contribute information to the general body of knowledge with regards to pain management in patients with CKD, particularly from a South African perspective.

Notwithstanding the limitations, this study revealed valuable insights that will inform current practice within the Centre. Further research could be carried out with this cohort of CKD patients as to whether there is a correlation with targeted pain management therapies and perceived benefits of such therapies on their overall health and HRQoL, once appropriate interventions are implemented. Furthermore, data should be collected from different centres, nationally and further investigations and research should be conducted for a better understanding and management of pain in this chronically ill patient population. Pain management therapies are essential to bring some level of comfort and relief as mandated by K/DOQI guidelines. It is reasonable to ensure that patients with chronic kidney disease do not suffer unnecessary pain, distress and discomfort. It is paramount that renal health care professionals ensure that the patients in their care are aware of and comply with recommended pain management therapies that will not only enhance patient outcomes but have a positive impact on their comfort, function and satisfaction of care. Pain management of

patients with CKD is challenging but not impossible. By reducing their pain to a tolerable level, through a systematic approach in the selection of analgesics, prompt management of side effects, on-going pain assessment, and the use of non-pharmacological therapies, patients can have a high quality of life.

CHAPTER SEVEN

REFERENCES

Alon, U. S., Allen, S., Rameriz, Z., Warady, B. A., Kaplan, R. A., and Harris, D. J. 1994. Lidocaine of the alleviation of pain associated with subcutaneous erythropoietin injection. *Journal of American Society of Nephrology.* 5(4): 1161-1162.

Anand, S., Bitton, A., and Gaziano, T. 2013. The gap between estimated incidence of end-stage renal disease and use of therapy. *PLoS ONE, e72860.* 8 (8): 1-8.

Antoniazzi, A., Bigal, M., Bordini, C., and Speciali, J. 2003. Headache associated with dialysis: the international headache society criteria revisited. *Cephalagia.* 23: 146-149.

Ashmore, S. D., Jones, C. H., Newstead, C. G., Daly, M. J., and Chrystyn, H. 2000. Ondansetron therapy for uraemic pruritus in hemodialysis patients. *American Journal of Kidney Disease.* 35 (5): 827-831.

Babbie, E., and Mouton, J. 2001. *The practice of social research.* South Africa: Oxford University Press.

Bailie, G. R., Mason, N. A., Bragg-Gresham, J. L., Gillespie, B. W., and Young, E. W. 2004. Analgesic prescription patterns among hemodialysis patients in the DOPPS: potential for under-prescription. *Kidney International.* 65 (6): 2419-2425. PubMed PMID: 15149355. Epub 2004/05/20.

Bajwa, Z. H., Gupta, S., Warfield, C. A., and Steinman, T. I. 2001. Pain management in polycystic kidney disease. *Kidney International.* 60: 1631-1644.

Barakzoy, A., and Moss, A. H. 2006. Efficacy of the World Health Organisation analgesic ladder to treat pain in end-stage renal disease. *Journal American Society Nephrology*. 17: 3198-3203.

Binik, Y. M., Baker, A. G., Kalogeropoulos, D., Devins, G. M., Guttmann, R. D., Hollomby, D. J., Barré, P. E., Hutchison, T., Prud'Homme, M., and McMullen, L. 1982. Pain, control over treatment, and compliance in dialysis and transplant patients. *Kidney International.* 21: 840-848.

Bourbonnais, F. F., and Tousignant, K. F. 2012. The pain experience of patients on maintenance hemodialysis. *Nephrology Nursing Journal.* 39 (1): 13-19.

Breneman, D. L., Cardone, J. S., Blumsack, R. F., Lather, R. M., Searle, E. A., and Pollack, V. E. 1992. Topical capsaicin for treatment of hemodialysis related pruritus. *Journal of America Acad Dermatology.* 26 (1): 91-94.

Brenner, B. M. 2003. Nephrology forum: Retarding the progression of renal disease. *The International Society of Nephrology.* 370-378.

Brink, H. 2006. *Fundamentals of research methodology for health care professionals.* Cape Town: Juta and Company LTD.

Brkovic, T., Burilovic, E., and Puljak, L. 2016 .Prevalence and severity of pain in adult end-stage renal disease patients on chronic intermittent hemodialysis: a systematic review. *Dovepress.* 10: 1131-1150.

Brown, J. A., Torres, V. E., King, B. F., and Segura, J. W. 1996. Laparoscopic marsupialization of symptomatic polycystic kidney disease. *Journal Urology.* 156: 22-27.

Brown, S., Lascarides, P., and Stickervers, S. 2014. Treating pain in patients with chronic kidney disease: a review of the literature. *Practical Pain Management.* 14 (9): 1-17. [online]. [Accessed 12/02/2016].

Carr, S. J. 2004. Assessing clinical competency in medical senior house officers: how and why should we do it? *Postgraduate Medical Journal.* 80 (940): 63-66. [online]. [Accessed 12/02/2016].

Castro, de, C., Murphy, L., and Battistella, M. 2013. Pain assessment and management in hemodialysis patients. *The Canadian Association of Nephrology Nurses and Technologists Journal.* 23 (3): 29-34.

Celik, G., Ozbek, O., Yilmaz, M., Duman, I., Ozbek, S., and Apiliogullari, S. 2011. Vapocoolant spray vs lidocaine / prilocaine cream for reducing the pain of venepuncture in hemodialysis patients: a randomized, placebo-controlled, crossover study. *International Journal of Medical Science*. 8(7): 623-627.

Che-Yi, C., Wen, C. Y., Min-Tsung, K., and Chiu-Chiang, H. 2005. Acupuncture in hemodialysis patients at the Quchi (LI11) acupoint for refractory uraemic pruritus. *Nephrology Dialysis Transplant.* 20 (9): 1912-1915.

Christofolini, T., Draibe,S., and Sesso, R. 2008. Evaluation of factors associated with chronic low back pain in hemodialysis patients. *Nephron Clinical Practice*. 108 (4): 249-255.

Corbin, J., and Strauss, A. 2008. *Basics of qualitative research.* 3rd ed. California: Sage Publications, Inc.

Curtin, R. B., Bultman, D. C., Thomas-Hawkins, C. T., Walters, B. A. J., and Schatell, D. 2002. Hemodialysis patients symptoms experiences: effects on physical and mental functioning. *Nephrology Nursing Journal.* 29 (6): 562-574.

Curtin, R. B., and Mapes, D. L. 2001. Health care management strategies of long- term dialysis survivors. *Nephrology Nursing Journal.* 28 (4): 385-394.

Daines, P. A. 2004. Pain management at the end of life in a patient with renal failure. *CANNT Journal.* 14 (2): 20-23, 26.

Danquah, F. V. N. 2009. Frequency, severity and distress of dialysis-related symptoms reported by patients on hemodialysis. *Ph. D Thesis in Nursing: The University of Texas.*

Daugirdas, J. T., Blake, P. G., and Ing, T. S. 2006. *Handbook of dialysis*. 4th edition. Philadelphia: Lippincott Williams & Wilkins (LWW): 523-527.

Davids, M. R., Marais, N., and Jacobs, J. C. 2017. South African Renal Registry. Annual Report 2015. *African Journal of Nephrology*. 20 (1): 201-213.

Davison, S. N. 2003. Pain in hemodialysis patients: prevalence, cause, severity, and management. *American Journal of Kidney Disease*. 42 (6): 1239-1247.

Davison, S. N. 2005. Chronic pain in end-stage renal disease. *Advances in Chronic Kidney Disease.* 12: 326-334.

Davison, S. N. 2006. The management of chronic pain in end-stage renal disease. *CML Nep & Hyp.* pp 1-9.

Davison, S. N. 2007a. Chronic kidney disease: psychological impact of chronic pain. *Geriatrics*. 62(2): 17-23.

Davison, S. N. 2007b. The prevalence and management of chronic pain in end-stage renal disease. *Journal of Palliative Medicine.* 10 (6): 1277-1287.

Davison, S. N., and Ferro, C. J. 2009. Management of pain in chronic kidney disease. *Progress in Palliative Care.* 17 (4): 186-195.

Davison, S. N., and Jhangri, G. S. 2005. The impact of chronic pain on depression, sleep, and the desire to withdraw from dialysis in hemodialysis patients. *Journal of Pain and Symptom Management.* 39 (5): 465-473.

Davison, S. N., and Jhangri, G. S. 2010. Impact of pain and symptom burden on the health-related quality of life of hemodialysis patients. *Journal of Pain and Symptom Management.* 39 (3): 477-485.

Davison, S. N., Jhangri, G. S., and Johnson, J. A. 2006. Longitudinal validation of a modified Edmonton symptom assessment system (ESAS) in hemodialysis patients. *Nephrology Dialysis Transplant.* 21 (11): 3189-3195.

Davison, S. N., Koncicki, H., and Brennan, F. 2014. Pain in chronic kidney disease: a scooping review. *Seminars in Dialysis.* 27 (2): 188-204.

Dean, M. 2004. Opioids in renal failure and dialysis patients. *Journal of Pain and Symptom Management.* 28 (5): 497-504.

De Vos, A. S., Strydom, H., and Fouché, C. B. 2002. *Research at grass roots for the social sciences and human service professionals.* Delport: Van Schaik Publishers.

Etheridge, H., and Fabian, J. 2017. Challenges in expanding access to dialysis in South Africa – expensive modalities, cost constraints and human rights. *Healthcare*. 5 (38): 2-12.

Feldman, R., Berman, N., Reid, M. C., Roberts, J., Shengelia, R., Christianer, K., Eiss, B., and Adelman, R. D. 2013. Improving symptom management in hemodialysis patients: identifying barriers and future directions. *Journal of Palliative Medicine.* 16 (12): 1528-1533. doi:10.1089/jpm.2013.0176

Fogazzi, G. B., Attolou, V., Kadiri, S., Fenilia, D., and Priuli, F. 2003. A nephrological program in Benin and Togo (West Africa). *Kidney International*. 63: S 56-S 60.

Fox, S. I. 2006. *Human Physiology.* 9th ed. New York: McGraw-Hill.

Gamondi, C., Gali, N., Schönholzer, C., Marone, C., Zwahlen, H., Gabutti, L., Bianchi, G., Ferrier, C., Cereghetti, C., and Giannini, O. 2013. Frequency and severity of pain and

symptom distress among patients with chronic kidney disease receiving dialysis. *Swiss Medical Weekly.* 143: w13750. 1-11.

Glassock, R. J., Warnock, D. G., and Delanaye, P. 2017. The global burden of chronic kidney disease: estimates, variability and pitfalls. *Nature Reviews: Nephrology.* 13: 104 -114.

Glick. N., and Davison, S. N. 2011. Managing chronic pain in advanced chronic kidney disease. *US Nephrology.* 6 (1): 21-28.

Göksan, B., Karaali-Savrun, F., Ertan, S., and Savrun, M. 2004. Hemodialysis-related headache. *Cephalalgia*. 24 (4): 284-287.

Griva, K., Ng, H. J., Loei, J., Mooppil, N., McBain, H., and Newman, S. P. 2013. Managing treatment for end-stage renal disease – a qualitative study exploring cultural perspectives on facilitators and barriers to treatment adherence. *Psychology and Health.* 28 (1): 13-29.

Gunal, A. I., Ozalp, G., Yoldas, T. K., Gunal, S. Y., Kirciman, E., and Celiker, H. 2004. Gabapentin therapy for pruritus in hemodialysis patients: a randomized, placebo-controlled, double-blind trial. *Nephrology Dialysis Transplant.* 19 (12): 3137-3139.

Harris, T. J., Nazir, R., Khetpal, P., Peterson, R. A., Chava, P., Patel, S. S., and Kimmel, P. L. 2012. Pain, sleep disturbance and survival in hemodialysis patients. *Nephrology Dialysis Transplantation.* 27 (2): 758-765.

Hays, R. D., Kallich, J. D., and Mapes, D. L. 1994. Kidney disease quality of life short form (KDQOL-SF), Version 1.3: a manual for use and scoring. *Qual Life Res*. 3: 329-338.

Henning, E. 2009. *Finding your way in qualitative research.* Pretoria: Van Schaik Publishers.

Hill, N. R., Fatoba, S. T., Oke, J. L., Hirst, J. A., O'Callaghan, C. A., Lasserson, D. S., and Hobbs, F. D. R. 2016. Global prevalence of chronic kidney disease – a systematic review and meta-analysis. *PLoS ONE*, *e0158765*. 11 (7): 1-18.

[online]. [Accessed 12/02/2016]. www.mdpi.com/journal/healthcare

Innis, J. 2006. Pain assessment and management for a dialysis patient with diabetic peripheral neuropathy. *CANNT Journal.* 16 (2): 12-28.

International Association for the Study of Pain. 2004. IASP pain terminology.

[online]. [Accessed 12/02/2016]. http://www.iasp-pain.org/terms-p-html

Kafkia, T., Chamney, M., Drinkwater, A., Pegoraro, M., and Sedgewick, J. 2011. Pain in chronic kidney disease: prevalence, cause and management. *Journal of Renal Care.* 37 (2): 114-122.

Kafkia, T., Vehviläinen-Julkunen, K., and Sapountzi-Krepia, D. 2014. Assessment and management of pain in hemodialysis patients: a pilot study. *Prog Health Sci.* 4 (1): 53-59.

Kimmel, P. L., Emont, S. L., Newman., J. M., Danko, H., and Moss, A. H. 2003. ESRD patient quality of life: symptoms, spiritual beliefs, psychosocial factors, and ethnicity. *American Journal of Kidney Disease*. 42 (4): 713-721.

Kimmel, P. L., and Patel, S. S. 2006. Quality of life in patients with chronic kidney disease: focus on end-stage renal disease treated with hemodialysis. *Seminars in Nephrology*. 26 (1): 68 – 79.

Kimmel, P. L., Peterson, R. A., and Weihs, K. L. 1995. Aspects of quality of life in hemodialysis patients. *Journal American Society of Nephrology*. 6: 1418-1426.

Knap, B., Buturovic-Ponikvar, J., Ponikvar, R., and Bren, A. 2005. Regular exercise as a part of treatment for patients with end-stage renal disease. *Therapeutic Apheresis and Dialysis*. 9 (3): 211-213.

Kobrin, S., and Berns, J. 2007. Quinine – a tonic too bitter for hemodialysis associated muscle cramps?. *Seminars in Dialysis.* 20: 396-401.

Koncicki, H. M., Brennan, F., Vinen, K., and Davison, S. N. 2015. An approach to pain management in end stage renal disease: considerations for general management and intradialytic symptoms. *Seminars in Dialysis.* 28 (4): 384-391. doi:10.1111/sdi.12372.

Krishnan, A. V., Pussell, B. A., and Kiernan, M. C. 2009. Neuromuscular disease in the dialysis patient: an update for the nephrologist. *Seminars in Dialysis.* 22 (3): 267-278.

Kumar, P., and Clark, M. (ed). 2012. 8th Edition. *Clinical medicine*. Edinburgh.

Kuphal, K. E., Fibuch, E. E., and Taylor, B. K. 2007. Extended swimming exercise reduces inflammatory and peripheral neuropathic pain in rodents. *Journal of Pain.* 8: 989-997.

Kurella, M., Bennet, W. M., and Chertow, G. M. 2003. Analgesia in patients with ESRD: a review of available evidence. *American Journal of Kidney Disease.* 42 (2): 217-228.

Leedy, P. D., and Ormond, J. E. 2005. *Practical research: planning and design.* 8th ed. New Jersey: Merrill Prentice Hall.

Levy, A. S., Atkins, R., and Coresh, J. 2007. Chronic kidney disease as a global public health problem: approaches and initiatives – a position statement from Kidney Disease Improving Global Outcomes. *Kidney International.* 72: 247-259.

Levy, J. B., Chambers, J., and Brown, E. A. 2004. Supportive care of the renal patient. *Nephrology Dialysis Transplant*. 19: 1357-1360. doi:10.1093/nf/ghf 178.

Levy, A. S., Coresh, J., Balk, E., Kausz, A. T., Levin, A., and Steffes, M. W. 2003. National kidney foundation practice guidelines for chronic kidney disease: evaluation, classification, and stratification. *Annals of Internal Medicine*. 139 (2): 137-149.

Lindburg, M., and Lindburg, P. 2008. *International Journal of Clinical Pharmacy and Pharmaceutical Care.*

Available at http:www.springerlink.com.content/v15n36r8127xt46/fulltext.html.

[online]. [Accessed 10/02/2015].

Longenecker, J. C., Coresh, J., Powe, N. R., Levey, A. S., Fink, N. E., Martin, A., and Klag, M J. 2002. Traditional cardiovascular disease risk factors in dialysis patients compared with the general population: The CHOICE Study. *Journal of America Society of Nephrology.* 13: 1918-1927.

Manias, E., and Williams, A. F. 2008. Managing pain in chronic kidney disease: patient participation in decision-making. *Journal of Advanced Nursing.* 61 (2): 201-210.

Maree, K. (ed). 2007. *First steps in research.* Pretoria: Van Schaik Publishers.

Martins, D., Agodoa, L., and Norris, K. C. 2012. Hypertensive chronic kidney disease in African Americans: strategies for improving care. *Cleve Clin J Med.* 79 (10): 726-734. doi: 10.3949/ccjm. 79 a. 11109.

McCaffery, M., and Pasero, C. 1999. *Pain: clinical manual*. 2nd ed. St. Lois: Mosby.

McClellan, W. M., Anson, C. A., Birkeli, K., and Tuttle, E. 1991. Functional status and quality of life: predictors of early mortality among patients entering treatment for end- stage renal disease. *Journal of Clinical Epidemiology*. 44: 83-89.

McLaughlin, K. 2004. Nephrology nursing: early intervention in chronic kidney disease. Thesis submitted for Masters of Arts (Applied) in Nursing.

[online]. [Accessed 12/02/2016]. https://www.researchgate.net/publication/28800130

Melzack, R. 1975. The McGill pain questionnaire: major properties and scoring methods. *Pain*. 1: 277- 299.

Merkus, P. M., Jager, K. J., Dekker, F. W., Haan, R. J., Boeschoten, E. W., and Krediet, R. T. 1999. Physical symptoms and quality of life in patients on chronic dialysis: results of the Netherlands co-operative study on adequacy of dialysis (NECOSAD). *Nephrology Dialysis Transplantation.* 14: 1163-1170.

Merskey, H., and Bogduk, N. 1994. *Classification of chronic pain*. 2nd ed. Seattle, WA: IASP. Press. 240 p.

Miguel, S. S., Curtale, M., Knage, D., Nhaan, C., and Chow, J. 2009. Improving patient understanding of phosphate binders: A bony challenge. *Renal Society of Australasia Journal.* 5 (3): 119-125.

[online]. [Accessed 28/02/2015].

Morse, J. M., and Field, P. A. 1995. *An overview of qualitative methods*. In Foster, D.S., and Dickens, G. (eds). Qualitative research methods for health professionals. Thousand Oaks, CA: Sage Publications. (pp 21-41).

Murtagh, F. E., Addington-Hall, J. M., Donohoe, P., and Higginson, I. J. 2006. Symptom management in patients with established renal failure managed without dialysis. *EDTNA ERCA Journal*. 32 (2): 93-98.

Murtagh, F. E., Addington-Hall, J. M., and Higginson, I. J. 2007. The prevalence of symptoms in end-stage renal disease: a systematic review. *Advances in Chronic Kidney Disease.* 14: 82-99.

Murtagh, F. E., Chai, M. O., Donohoe, P., Edmonds, P. M., and Higginson, I. J. 2007. The use of opioid analgesia in end –stage renal disease patients managed without dialysis: recommendations for practice. *Journal of Pain and Palliative Care Pharmacotherapy.* 21 (2): 5-16.

Murtagh, F. E., Marsh, J. E., Donohoe, P., Ekbal, N. J., Sheerin, N. S., and Harris, F. E. 2007. Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. *Nephrology Dial Transplant*. 22 (7): 1955-1962.

Musci, I. 2008. Health-related quality of life in chronic kidney disease patients. *Primary Psychiatry.* 15 (1): 46-51.

Naicker, S. 2003. End-stage renal disease in sub-Saharan and South Africa. *Kidney International*. 63, supplement 83: S 119 - S 122.

National Kidney Foundation. K/DOQI. 2002. Clinical practice guidelines for chronic kidney disease: Evaluation, classification, and stratification. *American Journal of Kidney Disease*. 39 (supplement 1): S 1 - S 266.

Naylor, H. K., and Raymond, C. B. 2011. Treatment of neuropathic pain in patients with chronic kidney disease. *The CANNT Journal.* 21 (1): 34-39.

O'Sullivan, D., and McCarthy, G. 2009. Exploring the symptom of fatigue in patients with end stage renal disease. *Nephrology Nursing Journal*. 36 (1): 37-47.

Pagels, A. A., Söderkvist, B. K., Medin, C., Hylander, B., and Heiwe, S. 2012. Health-related quality of life in different stages of chronic kidney disease and at initiation of dialysis treatment. *Biomed Central.* 10: 1-11.

Pastan, S., and Bailey, J. 1998. Dialysis therapy. *New England Journal of Medicine.* 338 (20): 1428-1437.

Patel, S. 2013. Treating pain to improve quality of life in end-stage renal disease. *Seminars in Dialysis.* 26 (3): 268-273.

Pereira, B. 2000. Chronic renal disease. *British Medical Journal*. 325: 85-89.

Peterson, S. J., and Bredlow, T. S. 2009. 2nd edition. *Middle range theories: application to nursing research.* Philadelphia, Pa: Wolters Kluwer Health/Lippincott, Williams & Wilkins.

Pham, P. C., Khaing, K., Sievers, T. M., Pham, P. M., Miller, J. M., Pham, S. V., Pham, P. A., and Pham, P. T. 2017. 2017 update on pain management in patients with chronic kidney disease. *Clinical Kidney Journal.* 10 (5): 688-697. doi: 10.1093/ckj/sfx080

Rehm, M. N. 2003. Pain in end-stage renal disease. *Nephrology Nursing Journal.* 30 (3): 340-342.

Rivera, S. 2017. Identifying and eliminating the barriers to patient education for patients in the early stages of chronic kidney disease. *Nephrology Nursing Journal.* 44 (3): 211-216.

Rocco, M., and Burkart, J. 1993. Prevalence of missed treatments and early sign-offs of hemodialysis patients. *Journal American Society of Nephrology.* 4: 1178-1183.

Rosenburg, M., Klada, R., Kasiulevičius, V., and Lember, M. 2008. Management of chronic kidney disease in primary health care: position paper of the European forum for primary care. *Quality in Primary Care.* 16: 279-294.

Sabbatini, M., Minale, B., and Crispo, A. 2002. Insomnia in maintenance haemodialysis patients. *Nephrology Dialysis Transplant*. 17 (5): 852-856.

Saini, T., Murtagh, F. E., Dupont, P. J., McKinnon, P. M., Hatfield. P., and Saunders, Y. 2006. Comparative pilot study of symptoms and quality of life in cancer patients with end-stage renal disease. *Palliative Med*. 20 (6): 631-636.

Sanders, S. H. 1985. Chronic pain: conceptualisation and epidemiology. *Annals of Behavioural Medicine.* 7: 3-5.

Santoro, D., and Satta, E. 2014. Pain in renal disease. *Journal of Pain and Palliative Care Pharmacotherapy.* pp. 409-411.

Santoro, D., Satta, E., Messina, S., Costantino, G., Savica, V., and Bellinghieri, G. 2013. Pain in end-stage renal disease: a frequent and neglected clinical problem. *Clinical Nephrology.* 79 (supplement 1): S 2-S 11.

Singh, S. 2009. The effect of exercise on solute removal during haemodialysis in end-stage renal disease. M. Tech thesis. Durban University of Technology.

Solano, J. P., Gomes, B., and Higginson, I. J. 2006. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *Journal Pain Symptom Management.* 31: 58-69.

Stanifer, J. W., Jing, B., Tolan, S., Helmke, N., Mukerjee, R., Naicker, S., and Patel, U. 2014. The epidemiology of chronic kidney disease in sub-Saharan Africa: a systematic review and meta-analysis. *Lancet Glob. Health*. 2: e174-181.

St Peter, W. L., Schoolwerth, A. C., McGowan, T., and McClellan, W. M. 2003. Chronic kidney disease: issues and establishing programs and clinics for improved patient outcomes. *American Journal of Kidney Disease*. 41 (5):903-924.

Tawfic, Q. A., and Bellingham, G. 2015. *Journal of Anaesthesiology Clinical Pharmacology*. 31(1): 6-13.

The American Medical Association and the Robert Wood Foundation. 1999. *The EPEC project: education for physicians on end-of-life care.* pp. M4: 1- M4: 33. [online]. [Accessed 28/02/2018].

Thomas, M., and Mathew, T. H. 2000. Slowing the progression of adult renal disease. *New Ethics Journal.* 25: 25-29.

Ulrich, B. (ed). 2012. Let's talk about pain. *Nephrology Nursing Journal.* 39 (1): 9.

Unruh, M. L., Weisbord, S. D., and Kimmel, P. L. 2005. Health-related quality of life in nephrology research and clinical practice. *Seminars in Dialysis.* 18: 82-90.

Warnock, D. G. 1996. *Chronic renal failure*. In: Bennett, C., Cecil, R. L., and Plum, F. *Cecil textbook of medicine.* 20th edition. Philadelphia: W. B. Saunders. 1: 556-663.

Weisbord, S. D. 2016. Patient-centered dialysis care: Depression, pain, and quality of life. *Seminars in Dialysis.* 29(2): 158-164. [online]. [Accessed 12/02/2016].

Weisbord, S. D., Fried, L. F., Arnold, R. M., Fine, M. J., Levenson, D. J., Peterson, R. A., and Switzer, G. E. 2005. Prevalence, severity, and importance of physical and emotional

symptoms in chronic hemodialysis patients. *Journal American Society of Nephrology.* 16: 2487-2494. doi: 10.1681/ASN.2005020157

Welman, J. C., Kruger, F., and Mitchell, B. 2005. *Research Methodology.* 3rd ed. South Africa: Oxford University Press.

Williams, A. F., and Manias, E. 2007. Balancing safety with effective pain control in patients with chronic kidney disease. *Journal of Evaluation in Clinical Practice.* 13: 820-822. *ISSN 1356-1294.*

Williams, A. F., and Manias, E. 2008. A structured literature review of pain assessment and management of patients with chronic kidney disease. *Journal of Clinical Nursing.* 17 (1): 69-81.

Williams, A. F., and Manias, E. 2009. Perceptions of pain control by consumers with chronic kidney disease. *Journal of Nursing and Healthcare of Chronic Illness.* 1: 199-209.

Wilmer, W. A., and Magro, C. M. 2002. Calciphylaxis: emerging concepts in prevention, diagnosis, and treatment. *Seminars in Dialysis.* 15: 172-186.

Wyne, A., Rai, R., Cuerden, M., Clark, W. F., and Suri, R. S. 2011. Opioid and benzodiazepine use in end-stage renal disease: a systematic review. *Clin J Am Soc Nephrol.* 6 (2): 326-333.

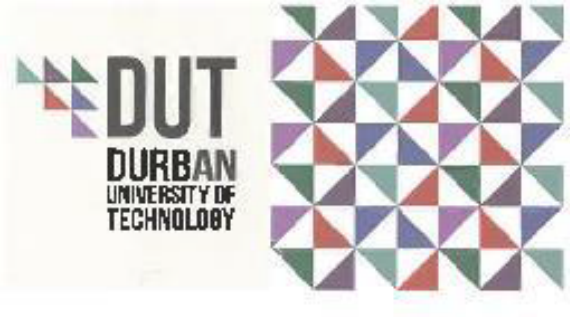
Young, B.A., Hynes, J., McComb, T., and Blagg, C. R. 2004. Associations with home hemodialysis modality failure and mortality. *Hemodialysis International.* 8: 344-348.

Young, T. A., Patel, T. S., Camacho, F., Clark, A., Freedman, B. I., Caur, M., Fountain, J., Williams, L. L., Yosipovitch, G., and Fleischer, A. B. Jr. 2009. A pramoxine-based anti-itch lotion is more effective than a control lotion for the treatment of uraemic pruritus in adult hemodialysis patients. *Journal of Dermatology Treatment.* 20 (2): 76-81.

CHAPTER EIGHT

APPENDICES

Appendix 1



Institutional Research Ethics Committee
Research and Postgraduate Support Directorate
1st Floor, Berwyn Court
Gate 1, Steve Biko Campus
Durban University of Technology

P O Box 1334, Durban, South Africa 4001

Tel: 031 373 2375
Email: irecshad@dut.ac.za
http://www.dut.ac.za/research/institutional_research_ethics

www.dut.ac.za

31 August 2017

IREC Reference Number: **REC 27/17**

Ms S Govender
P O Box 50418
Musgrave Road
Musgrave
4062

Dear Ms Govender

Pain management of patients with chronic renal failure: A case study of patients in a private renal facility

The Institutional Research Ethics Committee acknowledges receipt of your notification regarding the piloting of your data collection tool.

Kindly ensure that participants used for the pilot study are not part of the main study.

Please note that FULL APPROVAL is granted to your research proposal. You may proceed with data collection.

Yours Sincerely,

[redacted]

Professor C E Napier
Chairperson: IREC (Acting)

Appendix 2

FRESENIUS MEDICAL CARE

Fresenius Medical Care South Africa (Pty) Limited

Fresenius Medical Care South Africa (Pty) Ltd

31A Lake Road
Longmeadow Business Estate
Edenvale, 1609

Private Bag X10039
Edenvale, 1610

T +27 (0)11 457 9300
F +27 (0)11 457 9552/3

29 July 2016

Student Name: Shamanie Govender
I.D. Number: 8807200097087
Student No: 20609227 – Durban University of Technology
Degree: M/TECH

Topic : **Pain Management of patients with chronic renal failure: A case study of patients in a private renal facility**

Dear Sir/Madam

This is a letter of confirmation that the above mentioned student will be conducting his/her research in our Durban Kidney & Dialysis Centre.

Fresenius Medical Care South Africa (Pty) Ltd is permitting this student to make use of patient data without disclosing the identification of the patient.

Yours sincerely

[redacted]

DERICK SWANEPOEL
NEPHROCARE OPERATIONS MANAGER

Appendix 3

LETTER OF INFORMATION
PATIENTS

Title of the Research Study: Pain Management of patients with Chronic Renal Failure: A Case Study of patients in a private renal facility.

Principal Investigator/s/researcher: Shamanie Govender (B Tech:Clinical Technology)

Co-Investigator/s/supervisor/s: Prof J K Adam (Doctoral Degree in Clinical Technology)

Dr A.Khan (MBChB, Specialist Nephrologist)

Brief Introduction and Purpose of the Study:

Good Day. My name is Shamanie Govender and I am registering for my Master's degree at the Durban University of Technology. I work in a renal unit and am aware that many patients complain of pain during dialysis. Pain is a distressing symptom in dialysis patients and can affect your quality of life and willingness to continue with treatment. I would greatly appreciate it if you would take part in my research. The study aims to investigate the types of pain experienced and your frequency and severity. More importantly the research is intended to identify strategies and make recommendations to assist the patient and staff to effectively manage pain.

Outline of the procedures:

Sixty eight patients on dialysis and twenty two staff members in the renal unit will be required to participate in the study. Both you and some staff will need to complete the structured questionnaire. This will be completed while you are on dialysis. Your demographic details, blood pressure readings and medication will be recorded from your medical records. The staff clinical assessment record of you will also be considered. All information will be strictly confidential and anonymity will be guaranteed. Participation is voluntary.

Risks or Discomforts to the Participant:

There will be no risks or discomfort to you as there will be no changes to your treatment. Patients who are disorientated will be excluded from the study.

Benefits:

The research is intended to identify strategies and make recommendations to assist the patient and staff to effectively manage pain.

Reason/s why the Participant May Be Withdrawn from the Study:

Your participation in this research is completely voluntary and without prejudice. You may withdraw at any time and this will not affect your treatment. Patients who are disorientated will be excluded from the study.

Remuneration:

You will not be paid. Participation is voluntary.

Costs of the Study:

You will not be asked to cover any cost relating to the study.

Confidentiality:

All the information collected will be kept confidential. You will be allocated a number and all your details will be recorded under that number. This means that anyone who looks at my records will not be able to trace it to you. This is done to protect you privacy. In addition, a statement of confidentiality will be signed by both my supervisors and me.

Research-related Injury: There will be no research –related injury as there will be no alterations made to your dialysis treatment.

Persons to Contact in the Event of Any Problems or Queries:

Please contact the researcher (0312611244),my supervisor (0313733093),or the Institutional Research Ethics Administrator on 031 373 2375. Complaints can be reported to the Director: Research and Postgraduate Support, Prof S Moyo on 031 373 2577 or moyos@dut.ac.za

General:

Potential participants must be assured that participation is voluntary and the approximate number of participants to be included should be disclosed. A copy of the information letter should be issued to participants. The information letter and consent form must be translated and provided in the primary spoken language of the research population e.g. isiZulu.

CONSENT

Statement of Agreement to Participate in the Research Study:

- I hereby confirm that I have been informed by the researcher, _____ (name of researcher), about the nature, conduct, benefits and risks of this study - Research Ethics Clearance Number: _____,
- I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.
- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

_____	_____	_____	_____
Full Name of Participant	**Date**	**Time**	**Signature / Right Thumbprint**

I, _____ (name of researcher) herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

_____	_____	_____
Full Name of Researcher	**Date**	**Signature**
_____	_____	_____
Full Name of Witness (If applicable)	**Date**	**Signature**
_____	_____	_____
Full Name of Legal Guardian (If applicable)	**Date**	**Signature**

Please note the following:

Research details must be provided in a clear, simple and culturally appropriate manner and prospective participants should be helped to arrive at an informed decision by use of appropriate language (grade 10 level
- use Flesch Reading Ease Scores on Microsoft Word), selecting of a non-threatening environment for interaction and the availability of peer counselling (Department of Health, 2004)

If the potential participant is unable to read/illiterate, then a right thumb print is required and an impartial witness, who is literate and knows the participant e.g. parent, sibling, friend, pastor, etc. should verify in writing, duly signed that informed verbal consent was obtained (Department of Health, 2004).

If anyone makes a mistake completing this document e.g. a wrong date or spelling mistake, a new document has to be completed. The incomplete original document has to be kept in the participant's file and not thrown away, and copies thereof must be issued to the participant.

References:

Department of Health: 2004. *Ethics in Health Research: Principles, Structures and Processes*
http://www.doh.gov.za/docs/factsheets/guidelines/ethnics/

Department of Health. 2006. *South African Good Clinical Practice Guidelines*. 2nd Ed. Available at:
http://www.nhrec.org.za/?page_id=14

Appendix 4

Incwadi yencazelo

Isihlo ko so cwaningo: Ukuphathwa kwezinhlungu kuziguli ezinokuhluleka kwezinso kusebenza.

Umcwaningi: Shamanie Govender (oneziqu ku B.Tech;Clinical Technology)

Umphathi Womcningi: Usolwzi J.K Adam (oneziqu zobudokotela ku Clinical Technology).

Umsizi Wompthathi:Udokotela A.Khan (one MBChB ogxile ku Nephrology)

Isingeniso nenhloso yocwaningo kafushane:

Sanibonani.Igama kami ngingu Shamanie Govender.Nkanti futhi ngibhalisele khufunda izifundo zeziqu ku Masters.Esikhungweni semfndo ephkemeyo iDurban University of Technology.Elapha ethekwini maphethelo.Ngisebenza eyunithini yezinso,ngiyauonda ukuthi iziguli eziningi zikhala ngezinhlungu ngesikhathi zidayalaza kanti futhi yenza impilo yazo.Icikizele futhi zingabi nawo umdlandla wokuqhubeka nokulashwa ngingakujabulela kakhulu uma ngase ube yinxewe yalolucwaningo lwami ucwaningo luholuhlose ukuphenya ngezinhlobo zezinhlungu eziziwa yiziguli nangezikhathi ezigxi ngazo okubalulekile ngalocwaningo ukuthi luhlose ukuthola amasu nokuthi lenze izincomo ukusizi izigule nabasebenzi ngokulaphisisa izinhlungu.

Uhlalo lwezinqubo:

Izigule ezingamashumi ayisithupha ezidayalazayo nabasebenzi abayishumi nanhlanu eyunithini yezinso ukubamba iqhaza kululucwaningo.Iziguli nabasabenzi bazodinga ukuthi bagcwalize izimpendulo ngokwemibuzo ehleliwe ngokuka McGill Pain Questionnaire (MPQ).Lokhu kuzophothulwa ngesikhathi iziguli zadayalaza ukuhlukana kwemininingwane yokushaya kwegazi nofundwa kwalo nokulashwa kwezigule kuzoqoshwa kususelwa emimmimgwaneni yazo eqoshiweyo uhlolo olwenziwe abasenzi baluqopha ngokwesiguli luzosetshenziswa loke ulwazi lukuligekiswa ukuba liba yimfihlo nokuthi ngeke ludluliselwe komunye umuntu ukubamba iqhaza kulocwaningo kuzokuya ngokuthanda kumuntu akukho ozophoqwa.

Izingozi noma ukungakhululeki kwabambe iqhaza kulolucwaningo:

Azizikubakhla izingozi noma ukungakhululeki kuwena njengesiguli ngoba akuzobakho ushintsho ngokulashwa kwakho.

Izigule ezigula ngokwengqondo azizobandakanywa kulolucwaningo.

Inzuzo Ngaloucwaningo:

Ucwaningo luhlose kuthola amasa nokwenza izincomo zokusiza izigule nabasebenzi ngokunashwa kwezinhlungu nguempumelolo.

Izizathu Zokuthi kungani ukumba iqhaza kulolu cwaningo kungahoxiswa:

Ukumbamba iqhazo kulolu cwaningo kungkuthanda kwakho futhi kungaphandlekokucwasa ungahoxa noma yini futhi lokho angekekukuthikameze ukulashwa kwakho iziguli ezithikalezekile ngokomqondo angeke zimbandakangwe kulolu cwaningo.

Inkokhelo:

Akuzobakhona ukuhlonula nomainkoma inkokhelo kulabo abazobamba iqhaza khulolucwaningo ukubamba iqhaza kwakho akuphoqiue kungokuthanda kwakho.

Izindleko zocwaningo:

Akukho zindleko ezihokhwa nguwe kulolucwaningo.

Imfihlo:

Imininingwane yakho yonke yalolucwaningo ngeke idalulwe kumuntu izogcinwa iyimfihlo.Kuzoba khona inombolo ozonikwa yona ekuzofakwa kuyo yonke imininingwane yako.Ulwazi lonke kanye nemiphumela etholwe emva kwalolucwaningo ezofakwa kuzincwadi zochwepheshe noma ezincwadini zokuqhakambisa ngeke idalule noma iveze ukuthi isiguli esithize besizimbandakanye nalolucwaningo.

Ukulimala ngesikhathi socwaningo:

Angeke kube khona ukulimala ngesikhathi socwaningo njengoba kungezoshintshwa ukwelashwa kokukhuculula igazi lakho.

Abantu ongaxhumana nabo uma unenkinga noma unemibuzo:

Ungathintana nomcwaningi (0312611244),umcwaningi omkhulu (0313735291),noma umqaphi wocwaningo (0313732900).

Kwemvume

Isitatimende sesivumelwano ngocwaningo:

- Ngiqinisekisa ukuthi ucwaningo olwenziwe u Shamanie Govender ngesimo,ukuziphaha,inzuzo nobungozi balo ucwaningo – Inombolo yokucacisa:_____.

- Ngibuye ngamukela,ngaqonda lolulwazi olungenhla (participant incwadi yokwaziswa) mayelana nocwaningo.

- Ngiyaqondo ngemiphumela yocwaningo,kuhlanganise nemininingwane ngobulili,iminyaka yobudala,usuku lokuzalwa,iziqalo zamagame ami kanye nemiphumela yami ngeke idalulwe makuqhutshwa lolucwaningo.

- Ngenva yezidingo zalolucwaningo,ngiyavuma ukuthi imininingwane ethokale idluliswe ngohlelo lwe khomputha ngumcwaningi.

- Uma kungenzeka,nginoxise ucwaningo kuyobe kungahlangene nokucwasa.

- Ngibe nethuba elenele ukubuzu imibuzo,ngendlela engithanda ngayo.Ngazivumela ukuba ingxenye yalolucwaningo.

- Ngiyaqondo ukuthi kukhona okubalulekile okusha okutholakele khathi kuqhubeka lolucwaningo,ekuhlanganyeleni kwami.

_____ _____ _____ _____

Igama eligcele umhlanganyeli Date Isikhathi Isignesha

I, _____ (igama umcwaningi) lapha ziqinisekisa ukuthi iqhaza ngenhla azisiwe ngokuphelele ngesimo,ukuziphatha kanye nezingozi ze-ncwaningo ngenhla.

_____ _____ _____

Igama eligcwele umcwaningi Date Isignesha

_____ _____ _____

Igama eligcwele lafakazi(Uma Kufanele) Date Isignesha

_____ _____ _____

Igama eligcwele lafakazi(Uma Kufanele) Date Isignesha

Appendix 5

LETTER OF INFORMATION: STAFF

Title of the Research Study: Pain Management of patients with Chronic Renal Failure: A Case Study of patients in a private renal facility.

Principal Investigator/s/researcher: Shamanie Govender (B Tech:Clinical Technology)

Co-Investigator/s/supervisor/s: Prof J K Adam (Doctoral Degree in Clinical Technology)

Dr A.Khan (MBChB, Specialist Nephrologist)

Brief Introduction and Purpose of the Study:

Good Day. My name is Shamanie Govender and I am registering for my Master's degree at the Durban University of Technology. Pain is a distressing symptom in dialysis patients and can affect their quality of life and willingness to continue with treatment. I would greatly appreciate it if you would take part in my research. The study aims to investigate the types of pain experienced and its frequency and severity. More importantly the research is intended to identify strategies and make recommendations to assist the patient and staff to effectively manage pain.

Outline of the procedures:

Sixty eight patients on dialysis and twenty two staff members in the renal unit will be required to participate in the study. Both patients and staff will need to complete the structured questionnaire which is based on the McGill Pain Questionnaire (MPQ).Patients will complete the questionnaire while they are on dialysis. The patient's demographic details, blood pressure readings and medication will be recorded from their medical records. The staff clinical assessment record of the patient will also be considered. All information will be strictly confidential and anonymity will be guaranteed. Participation is voluntary.

Risks or Discomforts to the Participant:

There will be no risks or discomfort to you.

Benefits:

The research is intended to identify strategies and make recommendations to assist the patient and staff to effectively manage pain.

Reason/s why the Participant May Be Withdrawn from the Study:

Your participation in this research is completely voluntary and without prejudice. You may withdraw at any time.

Remuneration:

There will be no form of remuneration. Participation is voluntary.

Costs of the Study:

You will not be asked to cover any cost relating to the study.

Confidentiality:

All the information collected will be kept confidential. You will be allocated a number and all your details will be recorded under that number. This means that anyone who looks at my records will not be able to trace it to you. This is done to protect you privacy. In addition, a statement of confidentiality will be signed by both my supervisors and me.

Research-related Injury: There will be no research –related injury.

Persons to Contact in the Event of Any Problems or Queries:

Please contact the researcher (0312611244),my supervisor (0313733093),or the Institutional Research Ethics Administrator on 031 373 2375. Complaints can be reported to the Director: Research and Postgraduate Support, Prof S Moyo on 031 373 2577 or moyos@dut.ac.za

CONSENT

Statement of Agreement to Participate in the Research Study:

- I hereby confirm that I have been informed by the researcher, ___ (name of researcher), about the nature, conduct, benefits and risks of this study - Research Ethics Clearance Number: _____,
- I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.
- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

_____	_____	_____	_____
Full Name of Participant	**Date**	**Time**	**Signature / Right Thumbprint**

I, _____ (name of researcher) herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

_____	_____	_____
Full Name of Researcher	**Date**	**Signature**
_____	_____	_____
Full Name of Witness (If applicable)	**Date**	**Signature**
_____	_____	_____
Full Name of Legal Guardian (If applicable)	**Date**	**Signature**

Please note the following:

Research details must be provided in a clear, simple and culturally appropriate manner and prospective participants should be helped to arrive at an informed decision by use of appropriate language (grade 10 level
- use Flesch Reading Ease Scores on Microsoft Word), selecting of a non-threatening environment for interaction and the availability of peer counselling (Department of Health, 2004)

If the potential participant is unable to read/illiterate, then a right thumb print is required and an impartial witness, who is literate and knows the participant e.g. parent, sibling, friend, pastor, etc. should verify in writing, duly signed that informed verbal consent was obtained (Department of Health, 2004).

If anyone makes a mistake completing this document e.g. a wrong date or spelling mistake, a new document has to be completed. The incomplete original document has to be kept in the participant's file and not thrown away, and copies thereof must be issued to the participant.

References

Department of Health: 2004. *Ethics in Health Research: Principles, Structures and Processes* http://www.doh.gov.za/docs/factsheets/guidelines/ethnics/

Department of Health. 2006. *South African Good Clinical Practice Guidelines*. 2nd Ed. Available at: http://www.nhrec.org.za/?page_id=14

Appendix 6

Staff Questionnaire **Study Code:**

Surname: _____ First Name: _____

Occupation: _____

1. From your knowledge, do patients report pain experienced the most:

At the start of dialysis ☐

During dialysis ☐

At the end of dialysis ☐

2. Describe your function in assisting patients with their pain experienced during dialysis:

_____
_____

3. Do you advise patients on treatment options available to manage their pain?

Yes ☐ No ☐

4. How do you advise a patient who reports a **New** pain symptom?

_____
_____

5. Do you record and report to the attending doctor the pain experienced by patients during treatment?

Yes ☐ No ☐

6. How does the pain experienced affect the patients dialysis session?

_____
_____

7. State the different medication that can be administered (in consultation with the doctor) to patients experiencing the following symptoms:

Type of pain experienced	**Medication recommended**
Back pain	
Chest pain	
Headache	
Cramping	
Numbness	
Muscle	
Joint	

8. Do you follow up with patients if pain medication prescribed by doctor is adhered to?
   Yes ☐ No ☐

9. I use a pain assessment tool to evaluate the pain experienced by patients

   Y N

10. I have guidelines to administer analgesics to relieve pain experienced by individual patients while they are in the Centre

    Y N

11. I receive training to assess the pain experienced by patients Y N

12. I am aware of pharmacological therapies according to K/DOQI guidelines that are suitable for pain relief for CKD patients Y N

13. I am aware of non-pharmacological therapies suitable for CKD patients

Y N

14. How can the Durban Kidney and Dialysis Centre support patients in their management of pain?

_____
_____

Thank you for your co-operation.

All your responses are confidential and will be used for educational purposes only.

Appendix 7

PATIENT QUESTIONNAIRE **Study Code:**

Biographical information

Surname: _____ First Name: _____

Date of birth:_____

Race: _____ Gender: _____

Occupation: _____

Marital status: _____

Number of years on dialysis: _____

Number of dialysis sessions per week: _____

This questionnaire has been designed to tell us more about your pain.

1. Type of pain medication recommended by your doctor:

_____

2. Besides medication is there other treatment/s being used to treat the pain? You can choose more than one option.

Physiotherapy ☐

Neurosurgeon ☐

Endocrinologist ☐

Orthopaedist ☐

Psychiatrist ☐

Dentist ☐

Chiropractor ☐

Religious healer ☐

Other ☐

3. Do you use any of the following to relieve pain?

Ice packs	Y	N
Heat	Y	N
Massage	Y	N
Exercise	Y	N

Other _____

4. Medical conditions

_____

_____

Please tick the appropriate response:

5. Are you currently experiencing any pain symptoms?

Yes ☐ No ☐ Unsure ☐

6. If yes, tick appropriate response. Thereafter indicate on a scale of 1 – 5 how **frequent** and **severe** that pain symptom is:

Type of pain experienced	How **frequent** is it. If yes, on a scale of 1 – 5: 1 = continuous 2= regularly 3= Occasionally 4= seldom 5= momentary	How **severe** is it? If yes, on a scale of 1 – 5: 1= unbearable 2= severe 3= distressing 4= discomfort 5= mild
Back pain No Yes ⟶		
Itchiness No Yes ⟶		
Chest pain No Yes ⟶		
Headache No Yes ⟶		
Cramping No Yes ⟶		
Numbness No Yes ⟶		
Muscle No Yes ⟶		
Joint No Yes ⟶		
Other No Yes ⟶		

7. If yes, where is the pain located?

LOCATION OF PAIN	YES	NO
Neck		
Temples		
Forehead		
Entire Head		
Upper Chest		
Lower back		
Hands		
Lower leg		
Upper leg		
Calf		
Entire leg		
Abdomen		
Shoulders		
All over skin		
Other		

8. Does your pain impact on your daily activities, if so please tick appropriate response:

Activities	1= yes, limited a lot	2= yes, limited a little	3= not limited at all
Vigorous activities e.g. strenuous sports or lifting heavy objects			
moderate activities e.g. pushing a vacuum cleaner or playing golf			
Carrying groceries			
Climbing a flight of stairs			
Bending or kneeling			
Walking a few metres or cooking			
Walking a kilometre			
Bathing or dressing yourself			
Relation to other people			
Outlook to life in general			
Other			

9. Have you taken any pain medication during this dialysis session?

Yes ☐ No ☐

10. If yes, name the pain medication: _____

11. Has the pain eased during this dialysis session?

Yes ☐ No ☐

12. From your knowledge, is your pain symptoms experienced the most:

At the start of dialysis ☐

During dialysis ☐

At the end of dialysis ☐

13. Do you adhere to the medication prescribed by your doctor to manage your pain?

Yes ☐ No ☐

14. Do you communicate your pain symptoms to the renal staff?

When I arrive at the Centre	Y	N
During the dialysis session	Y	N
After the dialysis session	Y	N

15. I feel that I should not bother them because the dialysis is the most important reason for my attendance Y N

I feel intimidated by the staff Y N

I feel that it would be a weakness to complain: Y N

Other:

Are you confident to ask for pain medication? Y N

16. Do you experience pain caused by
Fistulas Y N

Needling Y N

Other dialysis procedures:

17. What are the **barriers** for your optimum pain relief?
I do not want to add to my pill burden Y N

Fear of addiction Y N

Cost Y N

It will worsen my CKD Y N

Cultural factors Y N

I am unaware of what the pain management therapy is Y N

Other:

18. Chronic pain associated with CKD has caused you to be:
hospitalised Y N

miss dialysis sessions Y N

depressed Y N

19. Does the pain affect your

Ability to work	Y	N
Ability to sleep	Y	N
Ability to travel for Leisure	Y	N
Other effects on my life		

20. Suggest further methods in which the Durban Kidney and Dialysis Centre can assist you to manage your pain.

_____

Thank you for your time and co-operation.

All your responses are *confidential* and will be used for educational purposes only.

Appendix 8

Imibuzo Oyibuza **Inhlobo Yesifundo:**

Imininigwane yesiguli

Isibonga: _____ Igama Lokuqala: _____

Usuku lokuzalwa:_____

Ubuzwe: _____ Ubulili: _____

Umsebenzi owewnzayo: _____

Ushadile: _____

Mingaki iminyaka ukwa dialysis: _____

Udialyser ngangaki ngesonto: _____

Lemibuzo isitshela kabanzi ngezinhlungu onazo.

1. Inhlobo yemithi athi udokotela isebensize ngaaphandle kwemithi oyinikwa udoktela ikhona:

_____

2. Eminye oyisebenzisayo ungakhetha okukodwa kulokhu okulandelayo

Udokotela wokuzivocavoca ☐

Udokotela wenqondo ☐

Udokotela wabaphukile ☐

Udokotela wabaphambene ngenqondo ☐

Udokotela wamazinyo ☐

Dokotela wezenkolo ☐

Okunye ☐

3. Kukhona yini kulokhu okulandelayo okusebenzisayo ukuqeda izimhlungu?

Amaqhwa	Y	N
Ukushisa (Ukuthoba)	Y	N
Ukubobozwa	Y	N
Ukuzivocavoca	Y	N

Okunye okungabhaliwe _____

4. Izimo Sempilo

_____

_____

Cela ubeke uphawa endaweni etanele:

5. Izikhona izinhkingo nezimpawu ozizwayo?

Yebo ☐ Cha ☐ Anginaso isiqiniseke ☐

6. Uma uthi “yebo” dwebela impendulo.Emvakwalabho khombisa kulesikwele ukuthi izinhlungu zenzeka kangaki and zibu hlungu kangakanani kanye nezimpawu zazo:

Inhlobo yezinhlungu ozizwayo	1 = Akupheli 2= Njalo 3= Kunezikha thi 4=Ngalesdsi khathi 5= Kungalindelekile	1= Akubekezeleleki 2= Kakhulu 3= Kuyakhathaza 4= Ukungahlaliseki 5=Kuphakathi nendawo
Izinhlungu zangemava Cha Yebo ⟶		
Ukuluma Cha Yebo ⟶		
Izinhlungu esifubeni Cha Yebo ⟶		

Ubuhklungu bekhanda Cha Yebo ⟶		
Amajaqamba Cha Yebo ⟶		
Indikindiki Cha Yebo ⟶		
Muscle Cha Yebo ⟶		
Ukuhlangana Cha Yebo ⟶		
Okunye Cha Yebo ⟶		

7. Uma Uvuma izinhlungu zikuyiphi indawo?

Izindawo ozwakuzo ubuhlungu	**YEBO**	**CHA**
Intamo		
Isiphongo		
Lonke ikhanda		
Ingenhla lesifuba		
Iqolo		
Izandla		
Isingegansi		
Isingenwa		
Isisu		
Amahlombe		
Isikhumba sonke		
Okunye		

8. Izinhlungu ozizwayo ziyakuphazamisa empilweni uma kunjalo khetha kulokho okulandelayo:

Izinto Ozenzayo	**1= yebo,kakhula**	**2= yebo,kancane**	**3= Akungiphazamisi**
Umsebenzi onzima njengo kuphakamisa izinsimbi			
Umfebenzi ongenzima njengo kushanela			
Ukuphatha ukudla			
Ukunyuka indawo ephakeme			
Ukugabo noma ukuquqa			
Ukuhamba ibanga elijana noma ukupheka			
Ukuhamba ibanga elide			
Ukuzigeza noma ukugqoka			
Bakhona abantu ohlobene wabo			
Bakhona okhumene nabo empiweni ngokwwayelekile			
Okunye			

9. Ikona eminye imithi owake wayithatha ngaphambi kokuthi udialysis?

Yebo ☐ Cha ☐

10. Uma kunguyebo,yisho igama laleyo mithi: _____

11. Izinhlungu ziyehla uma udialyser?

Yebo ☐ Cha ☐

12. Ngokwazikwakho izihlunguwezimpawu zezeka:

Ekuqaleni ☐

Uphakathi ☐

Ekupheleni ☐

13. Emgabe imithi osuke uyinikwe udokotela lyakazi ukungoba izihlungu?

Yebo ☐ Cha ☐

14. Uyabazisa abasebenzi abakuhlengayo ngezinhlumgu ozizwayo?

Uma ufika eDialysis Y N

Uma usuphakathi nokuhlanzwa izinso Y N

Uma usuqedile Y N

Ngibona sengathi ngiyaba phazamisa ngoba ukuzohlanza izinso isona sizathu esibalulekile esenza ngibe khona _____

Abasebenzi bayangithvsa _____

Ngizizwa ngingenawo amandla okusho okungiphatha kabi

15. Unako yini ukuzithemba ekuceleni iziqeda ndlungu? Y N

16. Uyazizwa yini izinhlungu kulezindawo ezilandelayo

KwiFistula Y N

Kwizinaliti Y N

Nezinye izindlela ezingabalwango ezisebenziswayo ekuhlanzweni izinso

_____

17. Iziphi izinkinga obanazo uma udinga ukvqeda izinhlungu.

Angifuni ukongeza amaphilisi kulawa engivele nginawo

Usaba ukujwayela izidakamizwa Y N

Izinga lokubiza Y N

Izokwenza lesifo sami sezinso ezingapheli sibhede kakhulu Y Y

Isimo sama sikho Y Y

Angazi kahle ukuthi kuyini ukulashwa kwezinhlungu Y N

Okunye okungabhaliwe

18. Izinhlungu ezingalapheki/ezingapheli eziphathelene nesifo sezinso ezingalapheki zikubangela ukuthi:

Ulaliswe esibhedlela Y N

Ungayi ukuyohlanza izinso ngosuku lokuya Y N

Ube nomzwangedwa Y N

19. Izihlungu Ziphazamisa

Ekwenzeni Imisebenzi Y N

Ukungakwazi ukulala Y N

Ukungakwazi ukuzi khipa Y N

Nokunye okungi phazamisayo empilweni yami

20. Lisho ezinye izindlela u Durban Kidney and Dialysis angakusiza ngazo ukubhekana nezinhlungu.

_____

Siyabonga ngesikhathi sakho nangosizo lwakho

Zonke izimpendulo osiphe zona ziyimfihlo yethu sizo zisebenzisa ukufundisa abanye