Factors influencing fluid restriction non-compliance amongst patients undergoing chronic haemodialysis and peritoneal dialysis at Steve Biko Academic Hospital.

FACTORS INFLUENCING FLUID RESTRICTION NON-COMPLIANCE AMONGST PATIENTS UNDERGOING CHRONIC HAEMODIALYSIS AND PERITONEAL DIALYSIS AT STEVE BIKO ACADEMIC HOSPITAL

by

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Submitted in partial fulfilment of the requirements for the degree

MAGISTER TECHNOLOGIAE: CLINICAL TECHNOLOGY

Department of Biomedical Sciences

FACULTY OF SCIENCE

TSHWANE UNIVERSITY OF TECHNOLOGY

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January 2021

DECLARATION BY CANDIDATE

“I hereby declare that the dissertation submitted for the degree M Tech: Clinical Technology at Tshwane University of Technology is my own original work and has not previously been submitted to any higher education, I further declare that all sources cited or quoted are indicated and acknowledged by means of a comprehensive list of references”.

T NDHLOVU

DEDICATION

This study is dedicated to my parents. For their endless love, support and encouragement.

For my late father, in memoriam.

He held no dream worth waking; so he said,

He who stands now on death's triumphal steep,

Awakened out of life wherein we sleep

And dream of what he knows and sees, being dead.

But never death for him was dark or dread;

"Look forth," he bade the soul, and fear not. Weep,

All ye that trust not in his truth, and keep

Vain memory's vision of a vanished head

As all that lives of all that once was he

Save that which lightens from his word; but we?

Who, seeing the sunset-colored waters roll

Yet know the sun subdued not of the sea,

Nor weep nor doubt that still the spirit is whole,

And life and death but shadows of the soul.

– ALGERNON CHARLES SWINBURNE

ACKNOWLEDGEMENT

First and foremost, I have to thank my parents for their love and support throughout my life. Thank you for giving me the strength to reach for the stars and chase my dreams. My little brother deserves my wholehearted thanks as well.

I would like to express my sincerest gratitude and appreciation to my supervisor, Ms. Repsold & Dr. Muranda for their guidance and support throughout this study, and especially for their confidence in me. I was grateful for the discussion and interpretation of some of the results presented in this thesis. I believe I have learned from the best.

I would also like to thank Ms. Magoshi & Mr. Hazelhurst for their comments and questions, which were very beneficial. I have learned a lot from their insight. Both of you are simply the best.

Many thanks to the staff and patients at the Renal Unit at Steve Biko Academic Hospital for being a part of this study.

To all my friends, thank you for your understanding and encouragement in many, many moments of crisis. Your friendship makes my life a wonderful experience.

Thank you, Lord for always being there for me.

ABSTRACT

OBJECTIVE(S): The aim of the study was to investigate factors that influenced fluid restriction non-compliance amongst patients undergoing chronic haemodialysis and peritoneal dialysis, and to ascertain the detrimental effects of fluid restriction non-adherence within the dialysis patients population and how serious these impact on the quality of life of the patients by comparing the results between the two dialysis groups of patients in the two different types of dialysis modalities.

DESIGN: A descriptive, mixed methods (quantitative and qualitative) research design, utilising purposive sampling was used to compare factors that influenced fluid non-compliance between a group of haemodialysis and peritoneal dialysis patients. Data collection was conducted through a questionnaire which comprised of a combination of two internationally published and widely used questionnaires, the SF 36 - Quality of Life Tool and End Stage Renal Disease Adherence Questionnaire.

SETTING: Dialysis unit at Steve Biko Academic Hospital in Pretoria, Gauteng Province, South Africa.

PARTICIPANTS: 90 participants: 45 haemodialysis & 45 peritoneal dialysis patients (60% males, 40% females) aged 18-60 years receiving maintenance haemodialysis and peritoneal dialysis with end stage renal disease.

MAIN OUTCOME MEASURE: Self-efficacy for restricting fluids as per prescribed treatment recommendations. The participants were recruited on the basis of willingness to participate in the study, having been on dialysis for at least three months, receiving haemodialysis three times a week and those on peritoneal dialysis were performing regular exchanges as per recommendations. Non-compliance was defined and associated with a track record of intra-dialytic weight gain in the past three months consecutively with more than 5.8% of the dry weight or intra-dialytic weight gain of more than 2.5 kg in between the haemodialysis sessions and those on peritoneal dialysis with persistent signs of pulmonary oedema and pedal and facial oedema.

RESULTS: Difficulty in managing their fluid allotments were reported by 60% of male participants, with low self-efficacy for restricting fluid intake when compared to the female counterparts. Irrespective of the demographic characteristics, social status, psychological status of all the participants, fluid restrictions as per prescribed recommendations remained a challenge as the general population reported 67% non-compliance.

CONCLUSION: The study findings suggested that the majority of patients encountered difficulty adhering to the dialysis regimen, irrespective of the dialysis modality. There may be a need to reinforce educational interventions, offering intense counseling for each individual. Further investigations are needed to understand the independent psychological effects on adherence to prescribed dialysis fluid restriction recommendations and perceived self-motivation.

KEYWORDS: Adherence, compliance, self-efficacy, haemodialysis, peritoneal dialysis.

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LIST OF ABBREVIATIONS

BHLS	Brief Health Literacy Screen
CKD	Chronic Kidney Disease
CVI	Content Validity Index
ESKD	End Stage Kidney Disease
ESRD-AQ	End Stage Renal Disease Adherence Questionnaire
GDP	Gross Domestic Product
GFR	Glomerular Filtration Rate
GNI	Gross National Income
HD	Haemodialysis
HIV	Human Immunodeficiency Virus
HQL	Health-Related Quality of Life
I-CVI	Item-level content validity index
IDWG	Intra-Dialytic Weight Gain
K/DOQI	Kidney Disease Outcomes Quality Initiative
MHD	Maintenance Haemodialysis
MHQL	Mental Health-Related Quality of Life
NCD	Non-Communicable Diseases
NVS	Newest Vital Sign
PD	Peritoneal Dialysis
PDE5I	Phosphodiesterase-5-Inhibitors
PMP	Per Million Population
PPP	Purchasing Power Parity

REALM	Rapid Estimate of Adults in Medicine
RRT	Renal Replacement Therapy
SA	South Africa
SF-36	Medical Outcomes Study Questionnaire Short Form 36 Health Survey
STATS SA	Statistics South Africa
S-TOFLHA	Shorter Form Questionnaire: Test Of Functional Literacy in Adults
TOFLHA	Test Of Functional Literacy in Adults
US	United States
US$	United States Dollar
WHA	World Health Assembly
WHO	World Health Organisation
WHO HL	World Health Organisation Health Literacy
ZAR	South African Rand

CHAPTER 1

1 OVERVIEW

1.1 Background and Outline of the study

Non-adherence is a recognized problem in the dialysis population for both haemodialysis (HD) and peritoneal dialysis (PD) patients.[1] Most research in the literature focuses on non-adherence amongst HD patients,[2-6] due to a more restrictive treatment regimen and a greater number of objective measurements available,[7] such as intra dialytic weight gain (IDWG). However, PD also requires a strict regime of dialysis exchanges and patients must take an active role in their adherence to fluid restrictions, dietary advice and medication regimes.[8]

PD is a self-managed treatment taking place at home; studies have been conducted to investigate adherence with PD exchanges. Non-adherence to exchanges administered has been demonstrated in around one third of PD patients in objectively measured studies, [9-11] and in self-reported exchanges missed. [12]

Recognizing a dearth of research related to fluid and dietary adherence, a recent study investigating self-reported adherence to the PD regimen found that 36% of patients did not adhere to their fluid restrictions.[13] The authors identified that patients who were younger, male, or who had been receiving PD for longer demonstrated more non-adherent behaviour. Furthermore, documented clinical observations continue to reveal poor fluid self-management among PD patients, [14, 15] and this is a recognized phenomenon amongst the PD care team.[16]

1.2 Significance of the study

Research has demonstrated the importance of fluid adherence in terms of fluid retention (or ‘fluid overload’) and its impact on morbidity and mortality of PD patients. [17, 18] The consequences of fluid overload include shortness of breath, muscle cramping, dizziness, as well as hypertension, oedema (i.e. of the ankle, leg, face), pulmonary oedema, cardiomyopathy and mortality.[18] Achieving fluid balance is crucial in PD and interventions to reduce excess fluid consumption would therefore be beneficial to both patient health outcomes and the larger health economy.

Interventions specifically addressing fluid adherence have been conducted with the HD population with varying success;[19-23] utilizing several approaches including educational, psychological or a combination of both. Lack of specific interventions in PD may be partly explained by the challenge in objectively measuring fluid intake as easily as in HD, utilizing IDWG as indicator. Nonetheless, interventions need to be explored and developed amongst PD patients, given the severe consequences associated with fluid overload.[9]

Areas in need of continued study include psychosocial determinants of compliance in PD as well as HD patients, compliance behaviour patterns over time, and the parameters within which dialysis compliance can vary and still achieve specified treatment goals.

1.3 Assumptions

The general impression is that Chronic Kidney Disease (CKD) is 3-4 times more common in Africa as compared to developed countries; however, there is a lack of registries and databases to confirm this.[24] In sub Saharan Africa CKD affects mainly young adults aged between 20 - 50 years and in the majority of cases is attributed to hypertension and glomerular diseases.[25] According to the South African Dialysis and Transplantation Registry, hypertension was listed as the most common cause of CKD in black South Africans, causing close to 35% of CKD in this population during a six years span.[26]

Therefore, with the above-mentioned gaps in literature pertaining to a South African context, further investigations are warranted and have motivated the researcher to embark on the research project to develop more successful interventions to improve therapeutic compliance within this population.

1.4 Aim of the study

The aim of the study was to investigate factors that influence fluid restriction non-compliance amongst patients undergoing chronic HD and PD and comparing the possible outcome variations between the two therapy modalities.

1.5 Research objectives

OBJECTIVE I

To determine the factors contributing to fluid restriction non-adherence in CKD patients undergoing haemodialysis and peritoneal dialysis.

OBJECTIVE II

To ascertain the detrimental effects of fluid restriction non-adherence within the dialysis patients population and how serious these impact on the quality of life of CKD patients.

OBJECTIVE III

To formulate effective strategies that can assist in combating fluid restriction non-adherence in CKD patients as understanding of these contributing factors will inform the overall planning of CKD management and can also assist in improving the quality of life amongst the dialysis population.

OBJECTIVE IV

To compare the results between HD and PD patients.

CHAPTER 2

2 FRAMEWORKS

2.1 Theoretical Frameworks

In order to understand psychological influences on how people stay healthy, why they become ill, and how they respond when they do become ill, it is of fundamental importance to define health and etiology. There is a biomedical component in health, but it exists in a setting that includes biological, personal, relational, social and political factors.[27] With such a perspective, the definition of health according to World Health Organization (WHO) “is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” is rather outdated.[28] Davies proposes that “health is best seen as an ongoing outcome from the continuing process of living life well”.[27] Living life well would be defined in terms of wealth, relationships, coherence, fitness and adaptability, with disease avoidance playing only a minor part.

2.2 Biopsychosocial model

The biopsychosocial dimension of illness was introduced by Engel in the late 1970’s and its core value is in guiding parsimonious application of medical knowledge to the needs of each patient.[29] The philosophy of this model gives understanding of how suffering, disease and illness are affected by biological, psychological and social factors. Such influence dictates the patient to be an active mediator of change i.e. the behavioural dimension of illness. [29]

The model also gives a practical understanding of the patient’s subjective experience of illness and the management of chronic medical problems. [30] Hence, the biopsychosocial model considers psychological factors not only as possible consequences of illness, but also as contributing factors to its cause and maintenance. The biopsychosocial framework is included in several social-cognitive models of health behaviour e.g. the self-efficacy theory and the social learning theory and its predictive value on patients’ adherence to health-promoting or treatment behaviours have been supported by a large body of empirical findings summarized in reviews by Di Matteo *et al.,* and AbuSabha & Achterberg. [31-32]

2.3 Self-efficacy theory

The conceptual system forming Bandura's (1977, 1982, 1991, 1997, and 2004) self-efficacy theory includes the characteristics of a person, the behaviour of the person and the outcomes of the behaviour (Figure 2.1). It also includes the person's efficacy expectations and outcome expectations.[33] An outcome expectation is the person's estimate that a given behaviour will lead to a specific outcome and can take the form of physical, social or self-evaluative effects. An efficacy expectation concerns the confidence in one's capability to accomplish a specific behaviour and its magnitude and strength of this aspect will determine how much effort people will mobilize and their level of persistence.[33] In other words, the essence in the self-efficacy theory is that the expectations of personal mastery and success determine whether an individual will engage in a particular behaviour. This means that self-efficacy is a temporary characteristic, capable of being influenced and related to situations and tasks. Moreover, the self-efficacy theory helps to explain the discrepancy between an individual's knowledge and behaviour, even though the person is fully aware of what should be done.[34]

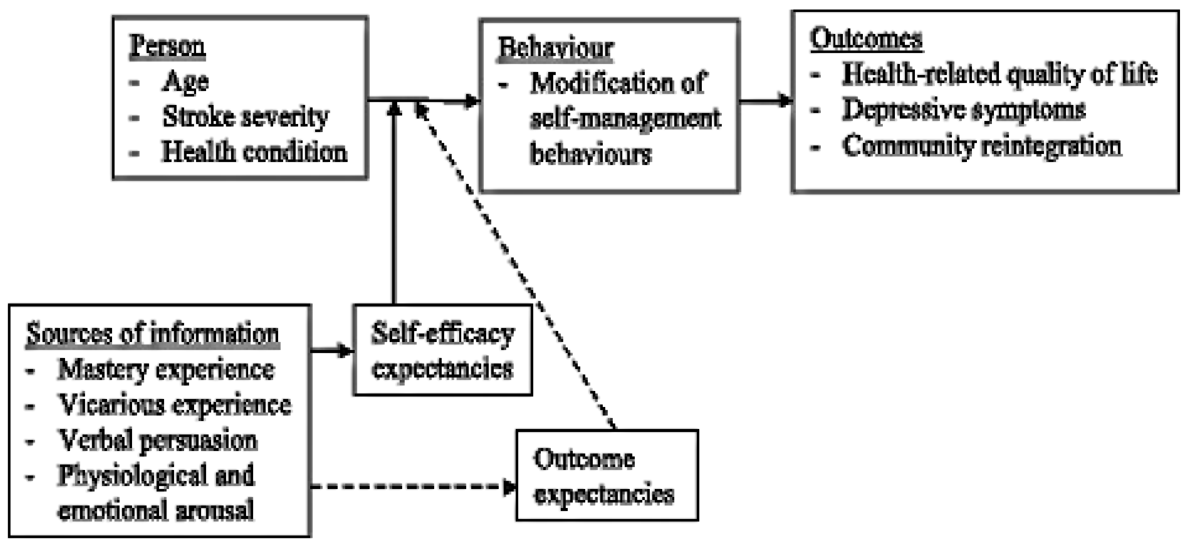

Figure 2.1. Adapted model from Bandura of the proposed causal relationship between self-efficacy and outcome.[33]

2.4. Measurement of self-efficacy

The underlying variables that constitute the concept of self-efficacy appear to predict change and maintenance of health-promoting behaviours.[35]

Self-efficacy is an important but task specific determinant of health behaviour because the posited socio cognitive causal model described by Bandura in 2004 includes paths wherein self-efficacy affects health behaviour both directly and through its impact on other determinants.[36] Self-efficacy is, however, often confused with closely related constructs that often describe more generalized personality traits such as self-esteem and self-confidence. AbuSabha & Achterberg emphasize that it is the specificity attribute of self-efficacy that distinguishes it from most other constructs. [37] Thus, self-efficacy aids in the adoption and maintenance of health promoting behaviours as well as in the control of risky health habits. Individuals with high self-efficacy overcome obstacles by improvement of self-management skills and stay the course in the face of difficulties. Whereas those with a low sense of efficacy do not try to adopt healthy practices and if they do try, they quickly abandon their efforts if success is not immediately achieved.[36]

2.5 A behavioural medicine approach

Self-efficacy is estimated by obtaining ratings of its three dimensions, namely magnitude, strength and generality. [38] The magnitude dimension refers to the judgment a person has on performing a specific behaviour and tasks are ordered according to their level of difficulty; strength refers to the confidence level a person has in performing the specific behaviour; and generality refers to the degree self-efficacy varies across type of activity and domains of functioning in which people judge themselves as efficacious.

To measure these dimensions, individuals are presented with a list of specific behaviours or tasks reflecting various levels of difficulty and are asked to rate the strength of their belief in their ability to accomplish each task. Bandura states that scales measuring self-efficacy must be tailored to the particular object of interest because the concept is not a global trait.[39] People differ in how they think, feel, motivate themselves and how they act in various activities.

Therefore, a measurement of perceived self-efficacy in an all-purposive global scale usually has limited explanatory and predictive value. Although a general focus on mastery is applied in some studies focusing on adherence to CKD treatment.[40] Other studies have adapted a more or less domain specific measure. [40]

The questionnaire used by Brady *et al.,* is described as a proper and theoretically consistent fluid adherence self-efficacy measure.[41] The original was, however, unpublished. Consequently, a scale to measure situation specific self-efficacy for constructive fluid intake behaviour in HD settings was lacking. [42]

2.6 The relevance of the chosen theoretical frameworks to the current research study:

In order to delay CKD progression and achieve a balanced life, patients must learn to incorporate treatment recommendations with their everyday circumstances.[43] Activities of self-management varies from the preventative activities to the day-to-day tasks, such as adhering to recommended daily fluid allowance, taking multiple medications, renegotiating and restructuring their days around treatment appointments and struggling with the prescribed regime and restrictions. These self-management tasks illustrate that patients need to address the behavioural and psychological complexities inherent in their chronic conditions, which also reflect the attributes of self-management of CKD (i.e. self-integration, problem solving, seeking social support and adherence to recommended regimen).[43]

Thus, CKD patients have to adapt to difficult long-term self-management behaviours as it is the responsibility of the patient, not the health care providers, to manage their chronic condition. Greater self-efficacy may improve outcomes through the application of specific self-management behaviours designed to prevent the worsening of chronic illnesses.[44]

On the contrary, failure to have faith in one's ability to carry out recommended self-management behaviours is likely to cause patients to forgo these behaviours and thus lose control both of their disease and of a positive sense of psychological well-being.[45]

Patients with higher self-efficacy have better self-management, such as adherence to therapeutic or medication regimens, performance of recommended self-care activities, problem solving, open communication and patient-medical team partnership.[46] Health care providers should teach the skills related to self-management of chronic diseases accordingly, in a way that helps patients become confident that they can perform these skills on their own as well as solve problems and overcome barriers that may hinder successful chronic disease self-management.[47]

The acceptance of having a chronic illness enables patients to identify their desires or preferences as well as having free will to manage the disease and recommended and prescribed treatment regimens.[48] To achieve a desired life, patients should feel confident in managing treatment plans, discussing illness and treatment plans with health care professionals as well as sharing illness experiences with other patients comfortably.[49]

To live a balanced life, patients with CKD should have the ability to integrate their illness and their self-care activities into a variety of situations (e.g. social activities) within their daily life.[50] Patients with chronic illness often encounter a variety of problems relating to their disease, its treatment and their personal life. If patients want to manage CKD effectively, they must actively gain disease-specific knowledge and skills to solve the problems related to the disease.[51]

CHAPTER 3

3 LITERATURE REVIEW

3.1 CHRONIC KIDNEY DISEASE

3.1.1 Introduction

CKD is an increasingly important cause of morbidity and mortality worldwide. Considering worldwide figures, CKD as a cause of mortality has almost doubled in the twenty years spanning 1990 to 2010.[52] In reality, it is the developing countries, such as South Africa, that are bearing the greatest portion of the burden of CKD.[52]

This is because the prevalence of both communicable diseases (e.g. human immunodeficiency virus (HIV)) and non-communicable diseases (e.g. hypertension and diabetes mellitus) responsible for causing CKD, are increasing.[53] Proof of the escalating burden of these conditions is demonstrated by the fact that of the total of 572 673 deaths registered at the South African Department of Home Affairs in 2009, 20 523 were attributed to diabetes mellitus, 15 386 were attributed to hypertension and 17 570 to HIV disease.

The term CKD is an all-encompassing term. It refers to a heterogeneous group of conditions affecting both the structure and function of the kidney. The definition refers to either, the presence of structural damage to the kidney or a glomerular filtration rate (GFR) of less than 60 mL/min/1.73 m^2, which is indicative of decreased renal functions, for a period of three months or more.[54] The rationale for selecting these cut-off values is that reduction in kidney function to a level of 60 mL/min/1.73 m^2 or lower represents loss of half or more of the adult level of normal kidney function.[55]

3.1.2 Types of dialysis

Dialysis is instituted with the aim of mimicking the excretory function of the kidneys. There are two forms of dialysis available, haemodialysis and peritoneal dialysis. Decisions to institute haemodialysis instead of peritoneal dialysis, and vice versa, are based on a myriad of factors such as patient preference, physician bias, co-morbidities, occupation, time constraints, living circumstances, costs and availability of the equipment and staff necessary for each of these modalities.[56] Both methods of dialysis have advantages and disadvantages associated with them.[57]

Haemodialysis is the most common modality of renal replacement therapy (RRT) used in patients with CKD. It is usually required at least three times per week, with each session lasting approximately 4 hours. Access to the patient's blood is obtained via an arterio-venous fistula or graft, or via a temporary or permanent central venous catheter.

The principal benefit of this form of dialysis is the capacity to rapidly eliminate substances and excess fluid volume. Disadvantages include more severe Anaemia due to blood loss from clotting of blood lines and dialyzers or excess bleeding (from burst dialyzers, over-heparinazation), haemolysis associated with contamination of dialysate water or membrane incompatibility as well as loss of water-soluble vitamins such as folate and vitamin B12 through haemodialysis membranes. The life span of red cells is shortened by approximately 30% in those receiving haemodialysis.[58] Infection is an important cause of mortality and morbidity among these patients, especially in the case of those using a central venous catheter for HD access.[59]

In peritoneal dialysis, the peritoneal membrane acts as the endogenous semi-permeable membrane across which dialysis occurs. Since the early 1980s, PD has been increasingly utilized as a dialysis option worldwide.[60] Peritoneal dialysis patients appear to be more satisfied with their therapy than those on HD.[58,61] Peritoneal dialysis is associated with lower rates and lesser degrees of Anaemia compared to haemodialysis.

The reasons for the lower rates of Anaemia include the better conservation of the remaining renal function in patients on peritoneal dialysis and being exempt from the above described reasons for blood loss and reduced red cell survival that patients on HD are subject to.[60, 62]

3.1.3 Chronic Kidney Disease in South Africa

Africa is the second largest continent in the world, with a population of over 1 billion; 961.5 million people live in sub-Saharan Africa and 195 million in Northern Africa. Africa now faces the dual challenge of infectious illnesses and chronic diseases. Africa's chronic disease burden is secondary to various factors, including increased life expectancy, changing lifestyle practices, poverty, urbanization and globalisation.[63]

The World Health Assembly (WHA) advocated the Global Action Plan for the Prevention and Control of Non-Communicable Diseases (NCD) 2013–2020. One of its targets is to reduce premature mortality from chronic diseases by 25% in 2025. These actions have the potential to make a significant impact on the burden of CKD.[64]

Unfortunately, CKD problem remains underestimated on the entire continent due to lack of epidemiological information from different African countries. There exists only a single systematic review conducted in sub-Saharan Africa, which concluded that CKD is a prevalent and potentially escalating disease across sub-Saharan Africa, with both communicable and non-communicable risk factors.[65] Strategies aimed at managing CKD epidemics in Africa critically depend on a reliable assessment of the burden of the problem and the establishment of affordable early detection programs.

Previous studies reported the prevalence of CKD among the general population or the specific prevalence of this condition in diseases that are recognized as drivers of renal damage (e.g. diabetes mellitus). These estimates have varied across studies due to differences in the methods of glomerular filtration rate measurement, background risk (general population vs. high-risk groups) or demographic characteristics (e.g. age, gender).[66]

According to the Statistics South Africa (Stats SA) mid-year estimates for 2015, the population of South Africa (SA) increased by nearly one million from the previous year to 54.96 million people. There was a slight female predominance (51.1%).[67] Black/ African citizens constituted 80.5% of the population, with people of mixed ethnicity (Colored) making up 8.8%, Whites 8.3% and Indians/Asians 2.5%. The province of Gauteng had the largest population, followed by KwaZulu-Natal.

South Africa is classified as an upper-middle income country by the World Bank, with a Gross National Income (GNI) per capita by the Atlas method (current United States Dollars (US$)) of $6 090 (equivalent to South African Rands (ZAR) 110 818) and by the purchasing power parity (PPP) method (current international US$) of $12 900 (equivalent to ZAR 234 715). Most of the population (84%) relies on the public health sector for services, with only a small proportion (16%) having medical insurance and accessing private sector healthcare.[68]

Life expectancy at birth for 2015 was estimated at 60.6 years for males and 64.3 years for females. The infant mortality rate for 2015 was estimated at 34.4 per 1 000 live births. The estimated overall HIV prevalence rate was approximately 11.2% and 16.6% for adults aged 15–49.[67]

3.1.4 Treatment centres for dialysis and kidney transplantation

An additional 33 treatment centres, 32 of these in the private sector, contributed data for this 2015 report. The total number of centres in 2015 was 258; 228 (88.4%) of these were privately owned. One privately owned unit in Limpopo was established as a public–private partnership on the premises of a government hospital to serve public sector patients. [64]

3.1.5 Mechanism of Rationing Access to Healthcare

Across the world, the provision of health care is expensive, and countries face challenges on how to most efficiently deliver a package of health services. Whether an upper-income country or a low-income country, governments are obliged to consider both the health needs of their populations, and the fundamental premises of their national health policies, and provide health services and interventions on this basis.

This requires rationing, which necessitates the prioritization of certain conditions over others, and perhaps the prioritization of preventative over curative care. In relation to CKD, for example, the per capita gross domestic product (GDP) in the United States (US) is three times greater than that of SA, yet both countries will still need to ration health care. As the United States is the only country in the world where dialysis is a constitutional right, the package of health care available to Americans may be dialysis-intensive compared to the healthcare package in SA. Rationing healthcare services is inevitable, but the manner in which this rationing takes place, e.g., the factors that are taken into account and the transparency of rationing policies, is the core issue. These factors can render rationing decisions ethical or otherwise.[64]

3.1.6 Rationing Access to Dialysis in the South African Health System

The SA health system is distinctly two-tiered, with the private sector serving a smaller percentage (28–38%) of the population than the state sector (62–72%). Annual expenditure across sectors is almost equal, with ZAR 120.8 billion in the private sector, as compared to ZAR 122 billion in the state sector.[69-70] However, because of the higher patient burden, the state sector is considered under-resourced in all areas, including the provision of drugs, the availability of facilities, human resources, and equipment shortages.[71]

Furthermore, the state health sector is considered poorly managed and compromised by wasteful expenditure and corruption.[72] Those who access 'fee-for-service' health care in the private sector in SA enjoy an exponentially larger proportion of options than those accessing government-funded care in the state sector.[73]

Because private medicine is only available to those who are able to pay for it, wealthier, employed people are advantaged over the poorest and most vulnerable in society. This manifestation of advantage can be clearly seen in the mechanisms that dictates the dialysis package available to state patients as compared to that available to private patients.

In fact, the dialysis package of care provided to state patients is so substantively different from that provided to private patients, it is almost antithetical. In the state sector, national guidelines published in 2009 mandate that only individuals who are eligible to receive a kidney transplant are accepted onto dialysis programs, and that this is the primary mechanism for rationing.[74-77]

The government's justification for this policy is that there are limited national resources to fund dialysis in the state sector.

3.1.7 Prevalence of renal replacement therapy

The total number of patients on RRT on 31 December 2015 was 10 360. With a population of 54.96 million, this is a prevalence of 189 per million populations (pmp). The prevalence for 2014 was 178 pmp. In 2015, the province with the highest patient numbers was Gauteng, followed by KwaZulu-Natal and the Western Cape, while the province with the highest prevalence was the Western Cape, followed by Gauteng and KwaZulu-Natal.

The number of patients treated in the public sector in 2015 remained low, with a prevalence of 71.9 pmp. This is lower than the rate of 72.6 pmp reported for 2014. In the private sector, the rate increased from 716.3 pmp in 2014 to 799.3 pmp in 2015. Denominators for prevalence calculations are based on the Stats SA mid-term estimates and the Council for Medical Schemes Annual Report.[68,78] Medical aid beneficiaries who are unclassified with respect to provinces were allocated to provinces in proportion to the numbers of beneficiaries in each province.

3.1.8 Fluid intake behaviour

The intake of fluids may be related to physical needs, habits, customs, social rituals, or disease. People drink to alleviate mouth dryness; to match the ingestion of food; or to enjoy the taste or experience the psychotropic effect of the liquid.[79-80] Fluid intake may also occur as a way to take prescribed medication and it could be a strategy to handle medication-related problems.[81] Some reports indicate that the season of the year may affect fluid consumption, with higher intake in the winter season than in summer.[82]

The reason for this variation is, however, not apparent.[82] Moreover, fluid intake is foremost a regulatory reaction to thirst, which is a physiological response to physical deficit of fluid, or to systematic hypertonicity.[83-84]

The sensation of thirst often results in behavioural activities such as drinking whereas the onset of drinking results from various motivational and cognitive processes that elicit the behaviour.[85-86] Because sodium intake constitutes the main cause of osmometric thirst sensation in HD patients, an anuric patient will consume one liter of water for every 8 g of salt consumed to regain homeostasis.[87]

Research findings indicate that a majority of HD patients drink in response to osmometric thirst.[88] Consequently, sodium intake is an important part of an HD patient's fluid intake behaviour.[89] Drinking considerably more fluid than recommended is, however, a familiar experience for many dialysis patients.[90] Although patients are aware of the need to be adherent to fluid allotment despite the desire to drink normally, to not be allowed creates an uncomfortable state of ambivalence regarding drinking.[91]

In addition, a prescription that restricts fluid intake often generates a treatment-related stressor and non-adherence to permissible fluid volume is used as a strategy to reduce such stress experiences in an attempt to gain some control.[92-93]

The evolving tension between treatment-related constraints and the individual's effort to maintain a sense of autonomy has been described as a 'compliance independence tight rope'.[94] This tension has also been associated with loss of social interaction and HD patients describe fluid management as a constant struggle, regardless if the outcome is successful or not.[95]

Fisher, has conceptualized this struggle in order to describe the psychological processes contributing to excessive fluid intake in dialysis patients.[96] Fisher's model assumes that there is a tension between the need to restrict fluid intake and the desire to drink.[96] Focusing on the notion of thirst will lead to an increased sense of being thirsty. Furthermore, encountering triggers e.g. to see others drink, will start processes of monitoring the degree of thirst or other somatic sensations, which could result in feelings of powerlessness to resist the urge to drink i.e. poor self-efficacy to fluid restriction. [97]

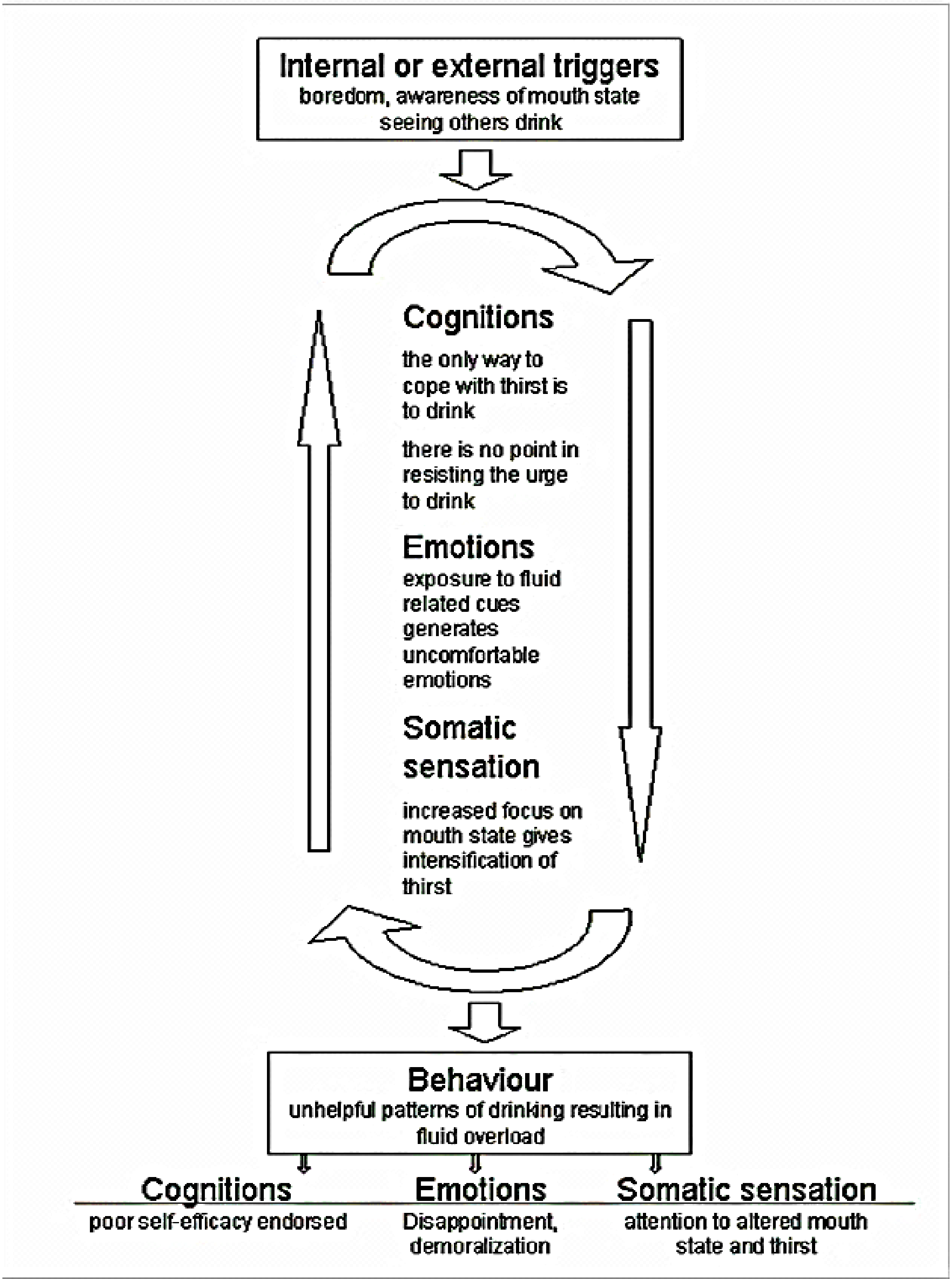

Figure 3.1. Adapted model of suggested psychological processes involved in an increased perception of thirst and unhelpful drinking patterns in HD patients on a fluid restriction.[96]

3.1.9 Adherence to treatment

Two terms are commonly used to describe patients' engagement in their self-management of chronic disease and accompanying treatment. Compliance is the first and most common term for describing the phenomenon of how patients follow their treatment regimen as prescribed.[97] This term is, however, associated with a traditional paternalistic and unequal relationship between the patient and the health care professional and depicts the patient as a passive responder who should obey the authorial advice. [98-101]

According to this designation, non-compliance may be interpreted as refusing orders or showing deviant behaviour.[98] The alternative and less censorious term is adherence, which according to the WHO is defined as "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle change, corresponds with agreed recommendations from a health care provider." [102]

Both compliance and adherence therefore refer to the patient's behaviour in relation to treatment requirements, although the interpretation of adherence indicates that the patient is free to decide whether to adhere to the treatment regimen or not. The failure to adhere should not solely be blamed on the patient because adherence is the product of the patient's behaviour in relation to the treatment; the health care provider's behaviour in relation to the treatment; as well as the environmental conditions under which the patient and provider operate individually and together.[103]

Adherence should be seen as the end product of a relationship that is built on respect, active participation and partnership between the patient and the health care professional, which does not involve coercion or manipulation from either party.[103-105] Nevertheless, in a comprehensive concept analysis of adherence by Bisonnette, no distinct differentiation between the concepts of adherence and compliance could be revealed in the nursing, medicine, psychology or pharmacy literature.[88] This finding implies that researchers need to more carefully define what they mean when using these concepts.

The terms compliance and adherence are, however, used interchangeably within research covering the treatment of CKD although they have a different content.[106] In this thesis, the terms adherence and non-adherence will be used to describe patients' behaviour in relation to approved treatment as they relate to patient choice.

The focus will be within the dietary domain concentrating on adherence to fluid allowance.

3.1.10 Adherence to fluid allowance

The computation of IDWG is claimed as a valid and objective measure of fluid restriction adherence in CKD patients with reduced urinary output and therefore, is widely used as an outcome measure.[107-108]

There are two principal methods for assessing IDWG.[109] The first method is mean IDWG expressed in kilograms.[110] The advantages of this computation are that it is simple to perform; the number of days between treatments is accounted for; and it allows for normal fluctuation in fluid intake during the intra dialytic period.

The primary disadvantage of this method is that dry weight is not considered in the calculation. The alternative method is mean IDWG expressed as percent above dry weight.[111] Some consider this a poor measure because dry weight can only be estimated, while others consider it a better alternative to measure fluid adherence because individuals with a large body mass can tolerate larger fluid weight gains than persons with a smaller body mass.

There seems to be an increasing consensus that IDWG should be defined as a percentage of dry weight.[112] The cut-off defining fluid adherence varies throughout the literature.[113] In order to lower the risk of volume overload between thrice-weekly dialysis sessions, IDWG should be less than 2.5 kg or 3.5% of dry body weight.[114]

3.2 QUALITY OF LIFE

3.2.1 Introduction

Chronic Kidney Disease is a major health problem worldwide, with a prevalence that increases with age and with a significant negative effect on the health-related quality of life (HQL) of patients.[115] HQL is associated with risk of evolution to end-stage kidney disease and increased mortality in those end-stage patients.[116-117] Because of its high impact, research on HQL in CKD has increased over the years. Reported satisfaction of haemodialysis patients with their personal health is positively correlated with HQL.[115]

Negative mental health, e.g. depression, high psychological distress and psychiatric disorders, all of which are prevalent amongst CKD patients, is a negative predictor of HQL in CKD.[118-119] Folkman and Greer suggested that in addition to a symptom-orientated approach to general chronic illness, there should be more focus on achieving psychological wellbeing.[120] Accommodative coping has been described as appropriate for a good psychological adjustment to unchangeable events and is commonly defined as 'adjusting preferences and goals in line with experienced constraints and limitations', e.g. because of chronic disease.[121-122] Within this coping strategy, acceptance is considered a key variable. When patients accept the disease, it is assumed that they will adjust their life goals towards more achievable goals by integrating this difficult life event.[121-123]

Chronic diseases are seen as life events, which upset a person's emotional balance, and acceptance is crucial in establishing a new balance. When patients with chronic pain and chronic fatigue refuse to accept their medical situation and use an assimilative coping strategy, which is characterized by persisting in attempts to seek a cure for the medical problem, at the cost of other valued life goals, they report more catastrophizing and a lower mental HQL (MHQL).[124-126]

Also, in cardiac patients, acceptances positively predict physical functioning and mental well-being, whereas helplessness has a negative influence.[127] For CKD, the type of coping strategy is associated with compliance, and in patients with end-stage renal disease, there is evidence that avoidant coping is related to mortality.[128-129] The five-factor model of personality has been frequently used in research exploring the relationship between personalities and coping.[130-139]

The personality characteristics of the Big Five Personality model are: neuroticism, extraversion, openness, agreeableness and conscientiousness. For CKD, it has been found that conscientiousness is associated with better compliance with prescribed medication and neuroticism is related to outcome measures such as perceived mental health, psychosocial adjustment and coping.[140-143] Neuroticism also appears to be associated with a wide range of disorders of physical health, including kidney disease.[144] However, little is known about the role that personality characteristics have on acceptance.[144]

The association between neuroticism and coping is thought to be reciprocal, with an independent influence both on physical and mental health quality of life.[145-147] As the higher levels of neuroticism are associated with inflexibility, withdrawal, passivity, wishful thinking, negative emotion focus, mental disorders and less adaptive coping, it is not unexpected that a higher degree of neuroticism is negatively associated with acceptance.[148-149] Acceptance is described as 'a central concept in an accommodative coping strategy' and is indispensable in adjusting life goals as a response to an unchangeable event.[150]

CKD is a complex progressive disease. A patient with CKD is faced with constant adjustments to changes in medication, treatment strategies and role patterns with increasing dependence on medical equipment and on his/her environment. Such a patient, therefore, needs an individualized prescription of treatment by a specialist. This prescription is often different to prescriptions for other patients, who have, according to the view of the patient, a similar disease.

Furthermore, treatment can change substantially from one extreme to another during the course of their disease, either because the disease progresses or because of other factors. Adjusting well to these changing treatment protocols assumes acceptance of the disease and flexibility in reorganizing their lives.

3.2.2 Demographic Factors

Patient-related factors appear to affect adherence of CKD patients. Age has been found to be a determinant in adherence issues. Younger patients and those diagnosed as having chronic illnesses are less adherent. Higher adherence behaviour is found in older patients.[151-154] Kutner *et al*., reported similarly that young age is associated with non-adherence in the CKD population.[155] In addition, being male is consistently associated with non-adherence.[156,157] Level of education has also been cited as a determinant in adherence behaviour in chronic illnesses such as CKD. Low education has been found to cause decreased adherence due to poor correlation with knowledge of disease and treatment.[158]

Knowledge appeared to be the chief facilitator of positive adherence to fluid restriction, with accurate self-assessment, positive psychological factors and supportive social contacts also playing a role.[159] Low health literacy has been reported in dialysis patients and this factor, combined with regimen complexity, may contribute to non-adherence.[160-161]

Those with low levels of health literacy find it difficult to follow instructions on how to care for themselves or to adhere to treatment regimens such as taking their medicines.[162] In addition, low health literacy is associated with more hospitalizations, greater use of emergency care, less adherence to treatment recommendations, worse health status, and higher mortality rates.[163] People with good basic literacy and numeracy skills, on the other hand, may struggle to understand and interpret health information in a way that prompts them to act appropriately to protect or enhance their health.[164]

Health beliefs and culture influence how a patient adapts to treatment requirements and have been found to influence phosphate binder adherence in six of nine studies that evaluated health beliefs.[165] In a Chinese population, perceived barriers showed associations with compliance measures, implying that patients who perceived fewer barriers in following the dietary restrictions showed better compliance. Studies have repeatedly shown that forgetting to take medications is a major contributor to non-adherence.[166-167]

The interpersonal dynamics of health care and the patient play an important role in determining a variety of patient outcomes including patient adherence to their treatment recommendations. Patients who feel that their physicians communicate well and actively encourage them to be involved in their own care tend to be more motivated to adhere.[168-169] Empathetic communication, involving a thorough understanding of patient's perspective, improves adherence. Patients who are informed and effectively motivated are also more likely to adhere to their treatment recommendations.[170]

3.2.3 Physical Factors and Barriers

Daily physical activity is reportedly decreased in maintenance haemodialysis (MHD) patients.[171-173] Most of these investigations employed self-reported questionnaires, although some studies used activity-measuring instruments that directly measure daily physical activity.[174-181]

These studies were usually conducted in small groups or for less than 7 days.[170-174] Cardiopulmonary exercise capacity, muscle strength, and physical performance are commonly impaired in MHD patients, but relationships of daily physical activity to physical performance are not well-defined.[185-186]

Reduced daily physical activity and physical performance are also clinically relevant because they are associated with increased hospitalization rates, cardiovascular mortality, and all-cause mortality in different patient groups.[187-190]

The relationship of kidney failure to daily physical activity and physical performance is complicated because MHD patients may be physically disabled due to strokes, limb amputations, or other comorbidities.

Several studies examined daily physical activity or physical performance in MHD patients who used walking assistive devices (e.g., canes or walkers).[187,191] Thus, it is difficult to ascertain the contribution of comorbidities rather than kidney failure and its treatment *per se* to MHD patients' daily physical activity and physical performance.

A study conducted by Kim *et al.,* to examine daily physical activity and physical performance in a comparatively large number of relatively healthy MHD patients who had low degrees of comorbidities. The authors assessed whether relationships existed between patients' daily physical activity and physical performance. Daily physical activity was assessed by an accelerometer. Healthy adults of similar age and gender distribution served as controls.[187] In Summary, the study findings indicated that daily physical activity of MHD patients, measured by the activity monitor and physical performance were substantially reduced compared with normal adults. Also the accelerometer that was used to measure daily physical activity and the three physical performance tests appeared to be reliable and reproducible. [192-193]

Patients with CKD have reduced levels of physical functioning, which, along with low physical activity, predict poor outcomes in patients treated with dialysis.[194-198] The hallmark of clinical care in geriatric practice and geriatric research is the orientation to and assessment of physical function and functional limitations in order to better assess well-being and quality of life and to plan for care needs, including individually appropriate interventions to prevent deterioration in functioning.[199]

Historically, nephrology practices have not included formal assessment or tracking of physical function, nor is there a routine effort to provide interventions for preventing physical function deterioration. The 2005 publication "K/DOQI Clinical Practice Guidelines: Cardiovascular Disease in Dialysis Patients" includes a recommendation for physical activity.[190] Despite this, nephrology practices related to physical activity have not changed as reported in a 2001 survey that only 28.5% of nephrologists routinely prescribe exercise for their patients and only 4.3% of nephrologists provide patients with written material about exercise.[201-202]

3.2.4 Psychological Factors

The rate of psychiatric disorders in a population of CKD patients is considerably higher than in any other population with other chronic illnesses.[203] Depression is the most common psychological problem in CKD patients and is associated with both mortality and morbidity.[204] Biochemical imbalances, physiological changes, neurological disturbances, and cognitive impairment are additional stressors which contribute to depression in CKD patients.[205]

According to Leung, diagnosis of CKD creates a turmoil that reaches into all aspects of the patient's life and precipitates emotions, fear, anger and despair.[205] Consequently, life with CKD becomes challenging, forcing the patient to confront it in a very personal way. Numerous psychosocial stressors affect CKD patients and their families, and their response to such stressors impact negatively on adjustment and response to treatment regimen.

Smith *et al*., cite psychological factors as the most common barriers to fluid restriction predominantly involving lack of motivation.[206] Chilcot *et al*., reported that 20–30% of CKD patients have significant depressive symptoms compared to lifetime prevalence of depression of approximately 16% in the general population.[207]

Depressed patients are found to be three times more likely to be non-adherent with treatment recommendations than non-depressed patients.[208]

Kimmel *et al*., investigated the impact of psychosocial factors on behavioural compliance and survival in urban haemodialysis patients and depression was related to decreased adherence to treatment regimen.[202] In a study which employed a descriptive cross-sectional design to examine the relationship between depressive symptoms and adherence to fluid and dietary restrictions in patients with CKD, common depressive symptoms were identified that were contributing to non-adherence to fluid and dietary intake in the study population.[209]

Irrational thoughts such as mental shortcuts (ignoring some medical conditions), altered risk perception of behaviours, cognitive trickery (distorted views about controlling conditions) and using denial as form of coping have also been reported to contribute to non-adherence.[210-213]

The challenges associated with living with CKD are significant and may contribute to patients feeling that they have lost control of their lives.[212] Disturbance in self-concept may lead to depression, with associated suicidal thoughts and poor self-esteem manifested by poor self-hygiene, excessive dependency and lack of adherence to treatment requirements.[204]

Perceived physical health has also been reported to cause reduced adherence to treatment regimen among CKD patients.[205] Elsevier states that patient's beliefs about their physical health are important because they influence adherence and adjustment to dialysis.[213]

Physical discomfort due to the illness as well as treatment modalities such as oral medications, haemodialysis, renal transplantation, dietary, and fluid restrictions hamper the psychological wellbeing of CKD patients. High prevalence of psychological issues associated with CKD led to the introduction of Psychonephrology.[214-215]

Researchers have identified female gender, living alone, loss of employment, high out-of-pocket expenditure and reduced economic productivity, multi-morbidity, increasing severity of illness, and stages four and five of the disease as factors significantly associated with psychological distress among CKD patients, while social support and coping strategies are known to reduce the distress.[216-219] Improper adherence to medical advice leads to increased morbidity and mortality in CKD.[220-211]

Furthermore, patients with end stage renal failure, a deadly incurable illness, need to undergo dialysis or a renal transplant for survival. This will further aggravate the psychological distress.[222-223] Therefore, periodical assessment of psychological status of CKD patients is needed.[215]

3.2.5 Social Factors

Social support of friends, family and renal health professionals as well as family dynamics have been found to influence medication adherence among kidney failure patients.[223-224] Emotionally or genetically related family members of patients can have significant influence on the patient's engagement in their own care.[225]

Excellence in care requires more than just the best care in diagnosis and treatment; it also requires care that addresses every aspect of a patient's experience. CKD and its treatments can restrict daily activities, employment, family life, and social relationships. This can lead to feelings of isolation. Feeling socially isolated can be stressful and anxiety provoking. Social support has been shown to improve survival and quality of life in dialysis patients.[226]

Living with a chronic illness requires emotional support to help make the changes needed to cope and adapt. Peer support is reported to be beneficial to patients with kidney disease and in long-term dialysis therapy.[227-228] Research shows that people often cope better when they interact with peers with whom they identify and share common experiences.[229]

In this way, feelings are validated, social isolation and stigma are reduced, hope for the future and optimism grows, and experiences are normalized. Peer mentoring has been shown to be highly effective in helping CKD patients adjust to dialysis and approach end-of-life planning. [227-228] It also improves depression, social isolation, self-esteem, and self- management and consequently better adherence, health and survival.

3.2.6 Employment Status

Employment status and income have been investigated in relation to socio-economic status among the CKD population. Low socio-economic status has been reported among CKD patients by Magacho *et al.,* Chironda *et al*., and Assounga *et al.,* where the majority of the reported CKD patients were unemployed.[229-231] Poverty increases the risk of disorders that predispose CKD to progress and worsens outcomes in those who already have CKD. Prosperity increases access to renal replacement therapy. People in the lowest socio-economic quartile are at a 60% greater risk of CKD than those who are in the highest quartile.[232]

The ability of CKD patients to work and lead a productive life is hampered by CKD as they no longer work and are unable to provide for their families.[233- 234] Kaitelidou *et al.,* have reported similar findings and highlight unemployment due to CKD as a significant stressor for CKD patients.[234]

In a study conducted by Kustimah, more than half of patients receiving dialysis were not able to maintain their profession and some had to retire after commencing dialysis. Furthermore, consistent associations with non-adherence were identified for being unemployed.[235-237]

According to World Kidney Day, the majority of patients commencing dialysis in low income countries die or stop treatment within three months of initiating dialysis due to cost constraints.[238] Limited economic resources of patients in developing countries results in reduced frequency of dialysis and eventually discontinuation of therapy.[239]

3.2.7 Family and adaptation

CKD is a very stressful condition, which is capable of producing a wide variety of complications. Chronic illness in a family member invariably affects all the members within the family. Families report that the physical changes in the patients' financial strain of sustaining treatment and the fear of the future of the patient and the disruption of the family structure are the major causes of psychological stress.[240]

Continuous advances in the knowledge of renal physiology as well as in the treatment of various kidney diseases have made it possible to prolong the life and the quality of survival in patients with chronic renal failure.[241]

The availability of dialysis and transplantation has allowed the survival of patients with CKD.[242-243] The options of dialysis and transplantation are complimentary and not competitive. An integrated approach allows the tailoring of the program to fit the medical and social needs of an individual patient in an optimal manner.[244] Patients on dialysis have to follow strict dietary restrictions; social and recreational activities are frequently reduced.

Medical complications, economic pressure, marital discord, sexual dysfunction, emotional stress and anxiety about loss or death are common regardless of the modality and hence, transplantation continues to be the choice of treatment as it offers the greatest potential for the return of healthy life.[242] The successful outcome of renal transplantation depends on the identification and preparation of suitable live donors.[244]

There is evidence to suggest that the patients who have received transplant enjoy a survival advantage over patients who continue to undergo dialysis.[245] In addition, the financial cost of maintaining a transplant recipient is substantially less than the alternative forms of renal replacement therapy.[246] Hence, it is well established that renal transplantation is the choice of treatment over haemodialysis for patients with CKD.[247]

3.2.8 Sexual Issues

Sexual dysfunction is a set of disorders characterized by physical and psychological changes that result in the inability to perform satisfactory sexual activities. The condition has been found to be significantly more common in men and women with CKD than in the general population.[248]

Men with CKD frequently suffer from reduced libido, erectile dysfunction, and difficulty reaching orgasm. [249] Approximately 50% of male pre-dialysis CKD patients and 80% of male dialysis patients have erectile dysfunction.[250-253]

Moreover, the prevalence of erectile dysfunction in male dialysis patients has been found to increase with age (63% versus 40 years 90% versus 50 years). [240] Similar results have been reported in women with CKD, with 55% of female dialysis patients reporting difficulty with sexual arousal.[249] Dysmenorrhea, delayed sexual development, impaired vaginal lubrication, dyspareunia, and difficulties in reaching orgasm are also frequently observed.[254-255]

Multiple factors contribute to the frequent occurrence of sexual dysfunction in CKD patients, including hormonal disturbances (such as hyperprolactinemia, hypogonadism in males, and changes in hypothalamic-pituitary function in women), Anaemia, CKD mineral and bone disorder, psychosocial factors (such as depression, anxiety, poor self-esteem, social withdrawal, marital discord, body image issues, fear of disability and death, loss of employment, and financial difficulties), autonomic neuropathy, medications (including antihypertensive, antidepressant, and histamine receptor blockers), and comorbid illness (such as diabetes mellitus, cardiovascular disease, and malnutrition).[249,251,256-261]

Sexual dysfunction is inversely associated with GFR and is improved after renal transplantation, suggesting that CKD *per se* may contribute to sexual dysfunction in these patients.[254, 262-263] Studies have also identified significant associations between sexual dysfunction in CKD patients and depression, impaired quality of life, and adverse cardiovascular outcomes.[255, 264-266]

Effective treatment of sexual dysfunction in CKD patients may therefore potentially lead to improvement in these patient-level outcomes, although a causal link has not been definitively established.[266] Therapies that have been used to treat sexual dysfunction include phosphodiesterase-5 inhibitors (PDE5i), intra-cavernosal injections, intra-urethral suppositories, hormonal therapy, mechanical devices and psychotherapy. Although many clinical trials and reviews have explored the role of these interventions for sexual dysfunction in non-uremic patients, the effectiveness and safety of these interventions in patients with CKD have not yet been studied thoroughly.[267-271]

Sexual dysfunction nonetheless is common in patients with CKD, 75% of men on dialysis therapy have erectile dysfunction and 30%-80% of women with CKD admit to symptoms attributable to sexual dysfunction.[272] The variability observed in the existing studies is caused in part by case-mix issues, lack of validated assessment tools for sexual function in the CKD population and the presence of confounding variables, such as comorbid conditions.

In addition, the observational data analyzed in this report did not compare the prevalence of response versus non-response. Thus, respondent bias may affect the results of such studies, particularly because socioeconomic factors may drive the relative value of any given patient's symptoms (e.g., financial hardship and the lack of means to purchase food and medications may preempt the recognition and importance of sexual dysfunction in some patients).[272]

According to Tourangeau *et al.,* sensitive questions address highly personal and sometimes even distressing topics which are often in conflict with social norms and frequently result in socially desirable answers or even non-response. Three aspects can make a question sensitive: Firstly, a question can be seen as intrusive when it addresses a taboo topic, independent of what the respondent's answers might actually be. Secondly, fears that answers to a question might be disclosed to a third party can make it sensitive, particularly if there are concerns about potentially negative consequences associated with a response. Thirdly, questions evoking answers that are in conflict with the prevalent social norm can be perceived as sensitive.

However, frequently people are reluctant to answer questions they consider sensitive. Even if they relinquish information the validity of their responses is sometimes in question. Data quality does not only depend on the accurate recall of facts but also depends on the degree of peoples' self-disclosure, that is, the amount of personal information an individual is willing to provide to others.[273]

Sexual dysfunction is associated with anxiety, loss of self-confidence and self-esteem, marital discord, and depression, all of which contribute to impaired quality of life, an area worthy of focused investigation.[274] Unfortunately, several well-meaning investigators pursuing the study of sexual dysfunction in patients with CKD have relied on non-validated instruments to document sexual dysfunction (17 of 50 studies identified by Navaneethan *et al.,* used invalidated instruments).[275]

Moreover, the definition of sexual dysfunction is broad and somewhat variable; perhaps because it is easier to define, erectile dysfunction (made famous and acceptable for public conversation by a US senator and other well-known celebrities) is the most common aspect of sexual dysfunction studied.

Sexual function in men and women is dependent on the coordination of multiple systems, including vascular, neurologic, psychological and hormonal actions. In addition, medications may alter or inhibit some of these systems and lead to alterations in sexual function. In men, normal sexual function depends on sexual interest or libido, erection (achieving and maintaining), and ejaculation. Some would add fertility as a component of normal sexual function.

Men with CKD may have hormonal alterations affecting libido (two-thirds of men on dialysis therapy have low serum testosterone levels), spermatogenesis and sperm motility.[266] Many hormonal changes in men with CKD intensify with worsening kidney function and reverse with successful transplants.[276]

In women with CKD, hormonal changes have been studied primarily in relation to infertility because the observed lack of pulsatile luteinizing hormone release in women with CKD leads to anovulation.[277] As in women without CKD, age-related oestrogen deficiency contributes to the failure of vaginal lubrication, and age-related loss of testosterone likely contributes to loss of libido.[278] Assessing sexual function in women perhaps is more difficult than in men, which may be one explanation for the lack of studies of sexual dysfunction in women with CKD.

3.2.9 Social Isolation

Social support is an understudied, yet important, modifiable risk factor in a number of chronic illnesses, including CKD. Increased social support has the potential to positively affect outcomes through a number of mechanisms, including decreased levels of depressive affect, increased patient perception of quality of life, increased access to health care, increased patient compliance with prescribed therapies and direct physiologic effects on the immune system.[279]

Social support affects health through behavioural, physiological and psychological mechanisms.[279] Provision of social support can be through emotional means, tangible efforts, information sharing or advice giving. The disease characteristics of

CKD and its treatments are functionally debilitating, affecting social relationships and activities of daily living.[280]

Discrepancy in social support expectations between patients and their family and friends results if patients hope to minimize lifestyle changes within the restrictions of dialysis whilst their support network might be unaware or unsure of how to cope with the patients' treatment and dietary needs.[281]

3.2.10 Knowledge Barriers

Many patients with CKD have insufficient knowledge about CKD, which is associated with poorer health outcomes. Effective patient–provider communication can improve CKD patients' knowledge, thereby augmenting their participation in self-care practices. However, barriers to addressing CKD patients' information needs have not been previously characterized.

Effective patient–provider communication is of particular importance for CKD patients, as they require a wealth of knowledge to manage their comorbid health conditions, follow complicated medication regimens and participate in essential self-care practices (i.e. home blood pressure monitoring, weight loss and dietary changes).[282-283] Poor communications can result in inadequate CKD knowledge, insufficient preparation for dialysis and kidney transplantation, poorer self-care adherence and worse health outcomes.[282, 284-289]

CKD patients' desire more information about the disease process, self-care techniques, treatment options and psychosocial implications of ESKD, suggesting the need for improved patient–provider communication.[272,290] Interventions designed to help healthcare providers to better educate patients about their CKD have been shown to increase patients' knowledge and stimulate discussion with physicians. [291-295]

However, educational interventions that focus solely on provider-driven communication position patients to passively receive education. Such an approach is limited because effective communication is preferably bidirectional. Active patient communication behaviour (e.g. asking questions) is important because it can influence physicians to provide information (e.g. give explanations).[296-299]

Interventions that promote patients' question-asking have shown promise for improving health communication outcomes.[300-301] Asking questions is an important component of patient activation, which entails developing the knowledge, skills and confidence to engage in self-care management.[302]

Studies in other chronically ill populations show that patients who actively seek health information and participate in disease management have better treatment adherence, greater satisfaction with care and improved health outcomes than their less active counterparts [302-306] Barriers to patient activation include specific socio-demographic and clinical characteristics (e.g. male gender, inadequate knowledge, low health literacy and depression).[307-308]

Identifying and developing interventions to overcome these barriers may be particularly effective in the CKD population because asking questions that address specific information needs could foster patient engagement in self-care practices and facilitate discussions regarding early planning for dialysis and kidney transplantation.[307]

3.3 HEALTH LITERACY

The level of health literacy is one of the public health concerns and has been estimated to be between 7% and 47% in developed countries. This figure is much lower in developing countries and illiteracy is much higher. However, the level of health literacy is also one of the factors affecting the outcomes and progression of diseases.[309,310]

The low health literacy level is associated with a low level of awareness and poor understanding for treatment regimen, interpretation of health messages, increased hospital admissions, mortality rate and healthcare costs in such a way that the annual costs imposed by low illiteracy levels in the United States is estimated to be between 106 and 238 billion dollars.[309,311]

The concept of health literacy level was first introduced in 1970.[312] Some of the factors that led the researchers to pay more attention to the health literacy over the past years include the inability of the public health system to promote health policies and maintain public health alone, taking into account high costs and limited outcomes in lifestyle changes.

Health promotion is considered as a fundamental right for every human being as well as a determinant of quality of life, including physical and emotional wellbeing in the face of communicable or non-communicable diseases, or any other health threat.[313]

Health literacy is a term used for one's skills to perform effective healthcare activities and appropriately use medical information.[314] Conceptual health literacy is related to capacities affecting the acquisition of knowledge, skills and abilities obtained from health education to provide care for ourselves and others.

Therefore, health literacy is a new concept that refers to the teaching of healthy behaviours and a step forward in empowering patients to make decisions about health management and disease. Important aspects of health literacy include the ability to understand the health information, participate in the healthcare process, and remove barriers from the health system that prevent patients from understanding the health promotion.[314]

Health literacy has been considered as a factor affecting patient information programs, care programs, social networks and health systems over the past two decades.[315,316] According to the WHO Commission's conclusion, eliminating the barriers to accessing primary education is not only an important part of development activity, but also brings benefits to the public health. In fact, health literacy means the ability to access, perform, understand and decide on the use of health information.[305]

High level of health literacy leads to an increase in the level of awareness and understanding reduced health care costs, reduced admission frequency, increased acceptance of treatment, active decision-making on the health field. However, lower levels of health literacy leads to impaired health status, increased health care costs, increased admission frequencies and decreased adherence to treatment in people.[317]

Accordingly, health literacy can be a risk factor, or it can be an asset. A risk factor in the sense that low level of health literacy can threaten the health status of the individual and an asset in the sense that the level of health literacy can be created in people through education in patients, which in turn promotes their health status.[318]

3.3.1 Levels of health literacy

The Nutbeam divides health literacy into three levels: functional, interactive and critical. [319] The level of functional health literacy refers to the basic skills used to obtain health information, such as the use of health systems and health risks.[310] Interactive health literacy describes advanced literacy skills that enable individuals to extract the meaning of health information and provide new information on changing circumstances and interaction with others in order to expand existing information and make decisions. [320]

Critical health literacy describes advanced literacy skills that enable critical analysis of information obtained from a wide range of sources and information about the broader range of determinants of health, as well as the use of this information to better control life events and the conditions affecting their health status.[320] Media literacy has been introduced as the fourth level of health literacy in adolescents.

This level of literacy has been derived from the combination of three types of health literacy as defined by Nutbeam. Specifically, media health literacy includes the identification of health-related media, the recognition of their effects on health behaviours, critical analysis of content and the action or intention to apply a media message at the individual or societal levels.[321]

3.3.2 Health literacy dimensions

The level of health literacy consists of four dimensions (i.e., access to health information, understanding health information, processing and evaluating health information and using health information) and three levels (i.e., health care, disease prevention and health promotion).[320]

The four dimensions of health literacy in the healthcare domain include the ability to access information on medical or clinical issues, the understanding of medical information, interpretation and evaluation of medical information, and informed decision making on medical issues in accordance with medical advices.[320]

The four dimensions of health literacy in the field of disease prevention include the ability to access information about health-related risk factors, understanding of information about risk factors, interpretation and evaluation of information about risk factors and informed decision-making about the health risk factors.[319]

The four dimensions in the field of health promotion include particularly, the ability of patients' to interpret and evaluate information on health determinants in the social and physical environment, and to make informed decisions.[312]

3.3.3 Health literacy measurements

To measure health literacy, there are a variety of tools, one of the most commonly used of which is rapid estimate of adult literacy in medicine (REALM), as noted by researchers. This tool is a 66-word diagnostic test that divides the scores based on the number of words accurately pronounced by the patient and its scores range from 0 to 66.[322]

Test of functional health literacy in adults (TOFLHA) is a questionnaire consisting of two parts. The first part relates to the medical information or the structure of a scenario, such as the guidelines for a diagnostic test. The second part will provide a medical text to the individuals who will fill in the blank spaces using the appropriate words and scores ranging from 0 to 100, with the higher scores representing a better level of literacy.[321]

The shorter form of this questionnaire (S-TOFHLA) consists of 36 questions, which should be answered within 7 minutes and the scores of the questionnaire are divided into three levels: weak, moderate and good. Brief health literacy screen (BHLS) consists of three questions and five options. The scores of this questionnaire range from 3 to 15 with the higher score indicating higher levels of health literacy.[323]

Newest vital sign (NVS) is another instrument for assessing the level of individuals' literacy. This questionnaire provides the subjects with health information, and they are asked to respond to the questions using the information given. Their score is later extracted and classified using the answer key.[324]

Providing four correct answers indicates good health literacy one, two to three correct answers indicating moderate health literacy and one or no correct answer would indicate low level of health literacy.[325]

In this study the researcher did not employ the S-TOFHLA questionnaire as a measuring instrument because it is subject to the next proposed study.

3.3.4 Health literacy in patients with chronic kidney disease

Despite the increasing awareness of the importance of health literacy in patients with CKD, they have a low level of health literacy, according to reports, with 23% of them lacking health literacy, which can cause serious problems, such as the progression of cardiovascular diseases, diabetes, lack of referral for dialysis, and increased admission frequency, a decrease in the number of peritoneal dialysis that leads to an increase in infection rate and an increase in mortality rate.[326]

It also reduces adherence to treatment regime in these patients and increases the use of medical equipment and services, such as increasing the number of admissions and increasing referral to emergency departments.[326]

Considering that managing CKD requires changing one’s lifestyles, including the use of complex diets and therapies, for those with limited health literacy this is challenging and having health literacy increases adherence to treatment through increasing information about the disease.[311] That is, more knowledge about CKD leads to an increase in the acceptance of treatment, and the highest health literacy score in patients with CKD relates to adherence to measures that reduce the treatment costs in these patients.[313] Various factors play a role in the low level of health literacy in these patients.

The results of a review study showed that factors such as social and economic factors can play a role in the health literacy of these patients. Other studies also reported that factors such as low education level, low income, male gender and race reduce the level of health literacy.[314] Promoting the level of health literacy require an educational process, which is considered as the most important tool for increasing the level of health literacy. [314,317]

Educational or therapeutic interventions used to promote the level of health literacy are not only intended to reduce complications, but also to improve the health self-management of each individual. The most important measure is to encourage patients to participate in educational plans on the disease management.

Managing patients with chronic renal disease is a complex process and requires a broad understanding of some of these conditions, such as blood pressure control, weight, consumption of fluids, diet, exercise, medications, as well as moving towards the health system and establishment of communication with many health care providers.

The aim of these measures is to increase the level of health literacy and promotion of self-management behaviours in order to reduce complications in these patients.[318]

3.3.5 Health literacy status in patients with chronic kidney disease

Although various studies have referred to the role of low level of literacy in diabetes, hypertension, acquired immune disease, and other chronic diseases, there is still little information about the role of literacy and CKD.[319] The results of a study conducted on 72 people showed that 21% of patients were illiterate and inefficient in controlling their blood pressure, which can be a long-term risk factor for cardiovascular disease in these patients.[320]

The results of another study conducted on 480 patients showed that 32% of these patients also had a lower level of health literacy, with factors such as gender and low education affecting this result. Also, lower level of health literacy in these patients was associated with an increase in admission frequency and an increase in the treatment cost and CKD progression.[316] The results of a study on 36 kidney transplant recipients, showed a decrease in the level of health literacy by 72%.

Lower health literacy is an obstacle to accessing, understanding, and using health information in patients, which increases the risk of transplant rejection and decreases the adherence to the treatment regimen.[316,321] In various studies, the illiteracy rate is estimated to be between 16% and 32.7%, which has a negative effect on the treatment process and glomerular filtration and increases the risk of cardiovascular diseases.[147, 318]

Considering the importance of the health literacy in these patients, its improvement is also considered as one of the research priorities. It is necessary to pay more attention to the issue of health literacy in these patients in order to reduce complications and improve their quality of life.[312]

3.3.6 Health literacy limitations in patients with chronic kidney disease

Many factors in patients with chronic kidney disease play a role in reducing the level of health literacy and the most important limitations that have reduced the level of health literacy in these patients include age over 65, being a minority group, lack of higher education, immigration, and being a refugee.[319]

Also, the World Health Organization Health Literacy (WHO HL) reports has identified the lack of access to schools for education as the most important cause for low level of health literacy, and considers removal of barriers to education as the most important factor that promotes the level of health literacy in society.[320]

3.4 Self-assessment Barriers Factors

Self-management encompasses adherence and advocates individuals being partners in their treatment, having the knowledge and skills to care for themselves, making decisions about their own care, identifying problems, setting goals, and monitoring and managing symptoms.[320-321]

Self-management includes skills such as problem solving, decision making in response to fluctuating signs and symptoms, and taking action, e.g. learning how to change behaviour. The ability to use skills and knowledge, and to apply these to oneself when appropriate, is vital for efficient self-management.[322]

Welch *et al.,* describes self-management for patients on haemodialysis treatment as a "process of adaptation of particularly relevant behaviours, with the underlying premise being that behaviour change does not usually occur all at once." [323] Non-adherence can be seen as a form of self-management deficit and therefore fostering sustainable strategies for self-management is an important aim for the renal care team. [323-328]

CHAPTER 4

4 MATERIALS AND METHODS

4.1 Introduction

This study was carried out to evaluate and investigate factors that influenced fluid restriction non-compliance amongst patients undergoing chronic HD and PD and comparing the results of the two groups of patients in the two dialysis modalities.

With fluid restriction non-compliant situation and statuses of these patients, effective strategies coupled with understanding will and can assist in combating the detrimental effects of fluid restriction non-compliance and ultimately improve the quality of life within this population.

4.2 Research Design

A descriptive, mixed methods (quantitative and qualitative) research design was used to compare factors that influenced fluid non-compliance between the two groups, i.e., HD and PD population since both modalities of dialysis differ. Haemodialysis patients visit the dialysis clinic in order to receive their treatment as assisted by the medical team within the clinic, whereas with peritoneal dialysis the patient has to perform their own dialysis at home. A purposive sampling method of subjects was employed and participants were provided with a questionnaire during their dialysis sessions to determine the factors that influenced fluid restriction non-compliance.

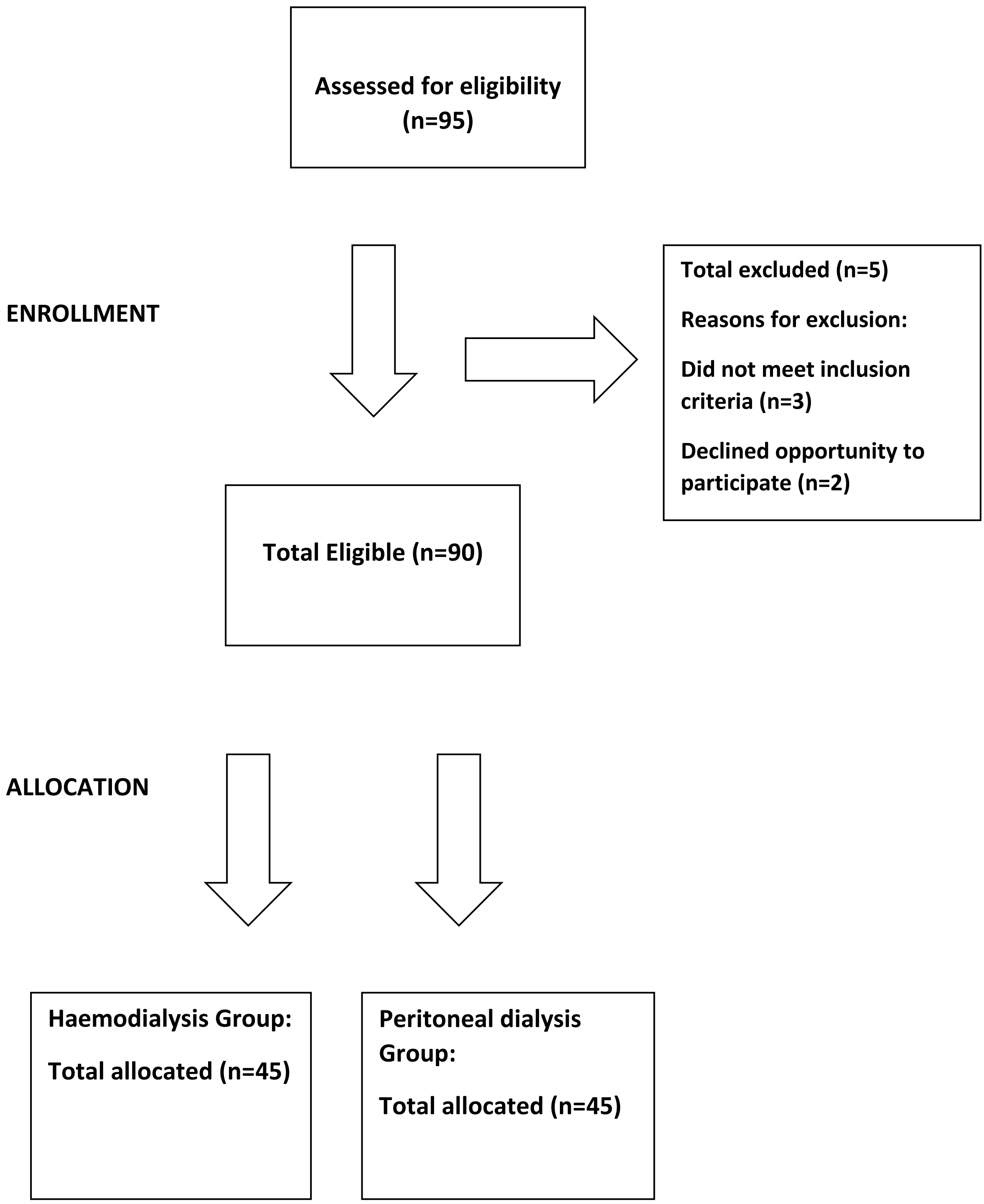

Figure 4.1: Methodology flow diagram.

4.3 Sampling

The study took place at the Dialysis Unit at Steve Biko Academic Hospital, Pretoria, Gauteng, South Africa. The researcher recruited ninety (n=90) (Figure 4.1) haemodialysis and peritoneal dialysis patients (males and females of the ages of 18 and above) and were purposively sampled from this study area. The participants were recruited on the basis of willingness to participate in the study, having been on dialysis for at least three months, receiving haemodialysis three times a week and those on peritoneal dialysis doing regular exchanges as per recommendations. Non-compliance was defined and associated with a track record of IDWG in the past three months consecutively with more than 5.8% of the dry weight or IDWG of more than 2.5 kg inbetween the haemodialysis sessions and those on PD with persistent signs of pulmonary oedema and pedal and facial oedema.

The sampling size was due to the availability of the subjects which was underpowered for the case of comparing expected non-adherence prevalence of 80% in the HD group versus 70% in the PD group. However, continuous theme scores were used for comparisons, which might have reduced the sample size from hundred participants to ninety.

4.4 Data Collection

Data collection was conducted through a questionnaire (Annexure C) which comprised of a combination of two internationally published and widely used questionnaires i.e. SF 36 - Quality of Life Tool (this survey asked for the subjects' views about their health -this information was used to help keep track of how they felt and how well they were able to do their usual activities) and the End-Stage Renal Disease Adherence Questionnaire (ESRD-AQ) tool (this survey asked for the opinion of the subjects about how well they followed their dialysis treatment schedule and about medical recommendations related to fluid intake). [329-332]

Participants (from the HD and PD population) were given the same questionnaires to answer which included questions relating to demographics, psychological-, social-, environmental- and physical-knowledge self-assessment data. This data collection was a once-off process and took place in the dialysis unit at Steve Biko Academic

Hospital in May 2019. The completion of the questionnaire by participants took approximately 30 minutes and some individuals required more time due to English language illiteracy and the researcher assisted those who experienced difficulty in completing the questionnaire. However, about 95% of the participants completed the survey in 15-20 minutes.

Furthermore, the participants were asked a series of closed-ended questions following the administration of questionnaires which encouraged discussion about fluid restriction management (this was a confidential session following the session in which the questionnaire was administered where key points were identified).

Three questions envisaged were asked as part of the follow-up confidential discussion session:

1. Are you aware of the fluid allotment prescribed for you as a dialysis patient? (Yes or No)

2. When do you feel the need to consume or drink more fluids than prescribed? (Summer or winter)

3. Reason for being non-compliant with daily fluid allotment? (Dehydration/thirst or are you under the impression that there are no complications if you consume/drink fluids like someone without end stage renal disease?)

4.5 Data Analysis

A statistician, Mr. Charl Janse Van Rensburg from the Medical Research Council of South Africa assisted with the analysis of the study data. All analysis was done using STATA 14. The descriptive statistics mean, median, standard deviation and inter-quartile range was used to describe the theme scores and other continuous variables. Frequencies and proportions were used to describe the categorical variables. The Fischer’s exact test was also used to determine if there were any significant associations between categorical variables. Theme scores were calculated using sum/mean of relevant questionnaire items.

Spearman’s rank correlation was used to calculate the monotonic relationship between dimensions of quality of life scores. The two-sample Wilcoxon rank-sum

(Mann-Whitney) was used to compare different quality of life scores and the degree of fluid restriction compliance. Logistic regression was used to determine the relationship between demographic, psychological, and other factors and non-compliance. Adjusted odd ratios were accordingly reported. Tests were evaluated at 5% level of significance.

4.6 Trustworthiness

Five specialists in the Nephrology field (two nephrology nurses, Head of the Department - Consultant Nephrologist, 1 Nephrology Fellow and Control Nephrology Technologist) were invited to assess the content validity of the questionnaire [56-59] to ensure that the instrument had an appropriate sample of items to represent the construct of interest.

These specialists in the field of interest were asked to review the content relevance of questions, appropriate use of language, domain coverage of adherence and the scoring system.[327] Ultimately they were asked to rate each item using 4-point scale:

1= Not relevant, 2= somewhat relevant, 3= Quite relevant, 4= Highly relevant

Subsequently, five patients from both the targeted population (PD and HD) were randomly asked to complete the questionnaire and provide feedback on whether each item was relevant and appropriately written. These patients were asked to evaluate each item on whether potential participants would be able to respond to questions about their adherence behaviours (face validity).

The five patients' responses were that the questionnaire was acceptable and content was relevant. These patients' responses were included in the overall (final) data analysis of a total number of 90 study participants.

Evaluating a scale's content is a critical early step in enhancing the construct validity of an instrument, and so content validation is important in order to achieve high-quality measurements.[328] Content validity concerns the degree to which a scale has an appropriate sample of items to represent the construct of interest, that is, whether the domain of the content on it are valid. Among researchers, the most widely used method of quantifying content validity for a multi-item scales is the content validity index (CVI) based on expert ratings of relevance. As a result, the researcher recommended the CVI as an appropriate indicator, based on a comparative evaluation of the CVI and alternative indexes. The final CVI reading for this study was 0.80 (Table 4.1).

Table 4.1: Content Validities of ESRD-AQ (Expert n=5).

ESRD-AQ Area (Item Number)	**Expert 1 to 4**	**Expert 5**	**Experts in Agreement**	**I-CVI**
Fluid (1 to 8)	✓	Rating of 4 for items 7 and 8:	Items 1 to 6=5 Items 7 and 8= 4	0.80
Average I-CVI				0.80

✓ = Rated 3 (quite relevant) or 4 (highly relevant)

\#   = Rated 1 (not relevant) or 2 (somewhat relevant)

I- CVI = Item-level content validity index

Medical Outcomes Study Questionnaire Short Form 36 Health Survey (SF-36): The SF-36 is an indicator of overall health status with 10 items. Most of the studies that examined the reliability of the SF-36 have exceeded 0.80. [329-332] Estimates of reliability in the physical and mental sections are typically above 0.90. The SF-36 is also well validated. The SF-36 has eight scaled scores; the scores are weighted sums of the questions in each section. Scores range from 0 - 100 (lower scores = more disability, higher scores = less disability). It covers sections relating to vitality, physical functioning, bodily pain, general health perceptions, physical role functioning, emotional role functioning, social role functioning, and mental health.

4.7 Ethical Considerations

The study commenced after obtaining the consent of the Tshwane University of Technology Faculty Committee for Research Ethics (Ref: FCRE 2018/06/04 (SCI)) (Annexure A) and the written permission (Annexure B) of University of Pretoria and Steve Biko Academic Hospital where the study was conducted. Informed consent (Annexure D) of the HD and PD treated participants making up the study group was obtained after the aim of the study and the fact that participation was voluntary was explained. The study posed no harm to the participants' health. The study had a basic language of understanding. No financial, rewards, incentives or compensation were offered. The study posed no discrimination pertaining to level of education, gender, race, etc.

All or most patients were English literate and the researcher assisted those participants who required assistance to complete the questionnaire. Feedback on the outcome of the study was reported to both the participants and the Department of Nephrology, Steve Biko Academic Hospital after completion of the study. Participants had the right not to participate in the study. Participants had the right to withdraw from the study at any stage without it affecting their continued care with the medical team. The study exercised confidentiality and anonymity throughout.

CHAPTER 5

5 RESULTS AND DISCUSSION

The study findings are presented in this chapter. Figure 5.1 - 5.5 depict demographic characteristics of HD and PD participants. Ninety participants (both females and males) were selected and enrolled in the study. There was an equal distribution between HD and PD patients recruited, with 45 patients in each group. In both the HD and PD groups, participants were aged between 18 and 60 years with a total mean age of 36.16 (±10.66) (Figure 5.1).

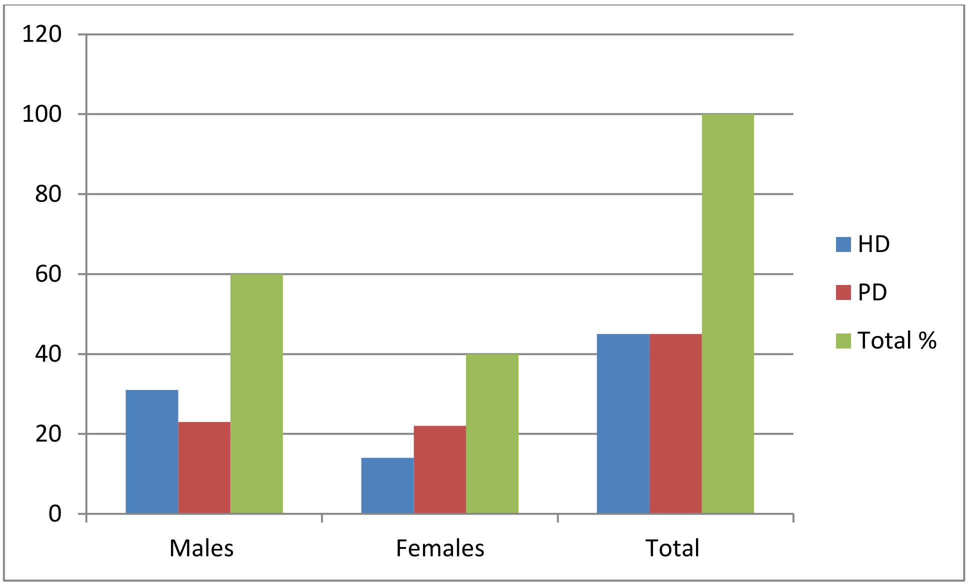

Figure 5.1. Demographic data – gender (HD - Haemodialysis group; PD - Peritoneal dialysis group; % - Percentage).

Considering the SF-36 participants' questionnaire overall rate responses (100%), mostly related to the demographic variables, the majority of the participants /subjects were 53 males (60%) and 36 were females (40%)(figure 5.1). Also, there was significant difference between both groups with regards to sex. Sex may influence the progression of CKD, although the available literature is sometimes conflicting, several studies on the literature within the field of interest have shown that CKD progresses more slowly in women than in men, a finding that may be attributed, at least in part, to the effect of oestrogen. [333]

Our study findings were in agreement with 2003 study done by Saran *et al.,* who found that males were more fluid non-complaint than females. [334]

Hypothalamic, rather than ovarian dysfunction may be the cause of the abnormal reproductive milieu, which can be at least partially reversed by kidney transplantation and increased intensity of haemodialysis. Endogenous sex hormones, and specifically estradiol, appear to be renoprotective in women compared to men, although the effects of exogenous estradiol (as an oral contraceptive and postmenopausal hormone therapy) on kidney function are more controversial.[335-338]

Kugler *et al.,* in 2005 attributed higher compliance among women to their higher self-awareness with respect to their health status. [339] Other studies disputed the argument that women are more compliant. Based on Mollaoğlu and Kayataş' recent 2015 study in Turkey, [340] the research results showed the non-compliance rate was higher among female patients.[341]

Silbiger and Neugarten in 2008 found that men progress to end-stage renal failure more rapidly than women when the underlying etiology is polycystic kidney disease, membranous nephropathy, IgA nephropathy, and chronic renal disease of unknown etiology. In type 1 diabetes mellitus, men may be more likely to exhibit signs of CKD, such as proteinuria. [342]

The majority of participants, 52 (59.77%) were single (figure 5.2). Marital status is an important social factor that is associated with mortality. Unmarried status has been reported to be associated with an increased frequency of unhealthy lifestyle behaviours, depression, low socioeconomic status and non-adherence to medical treatment. [343-346]

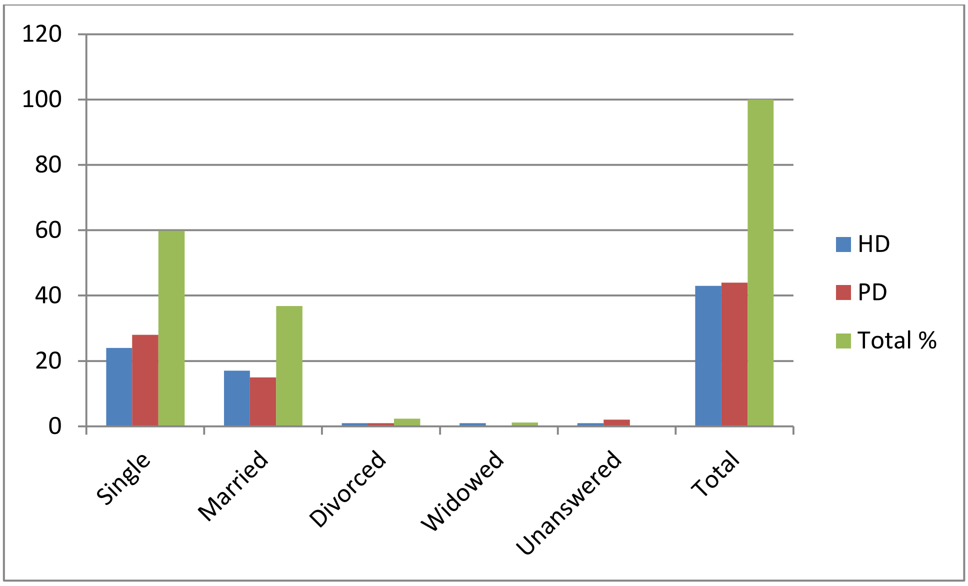

Figure 5.2. Demographic data - Marital status (HD - Haemodialysis group; PD - Peritoneal dialysis group; % - Percentage).

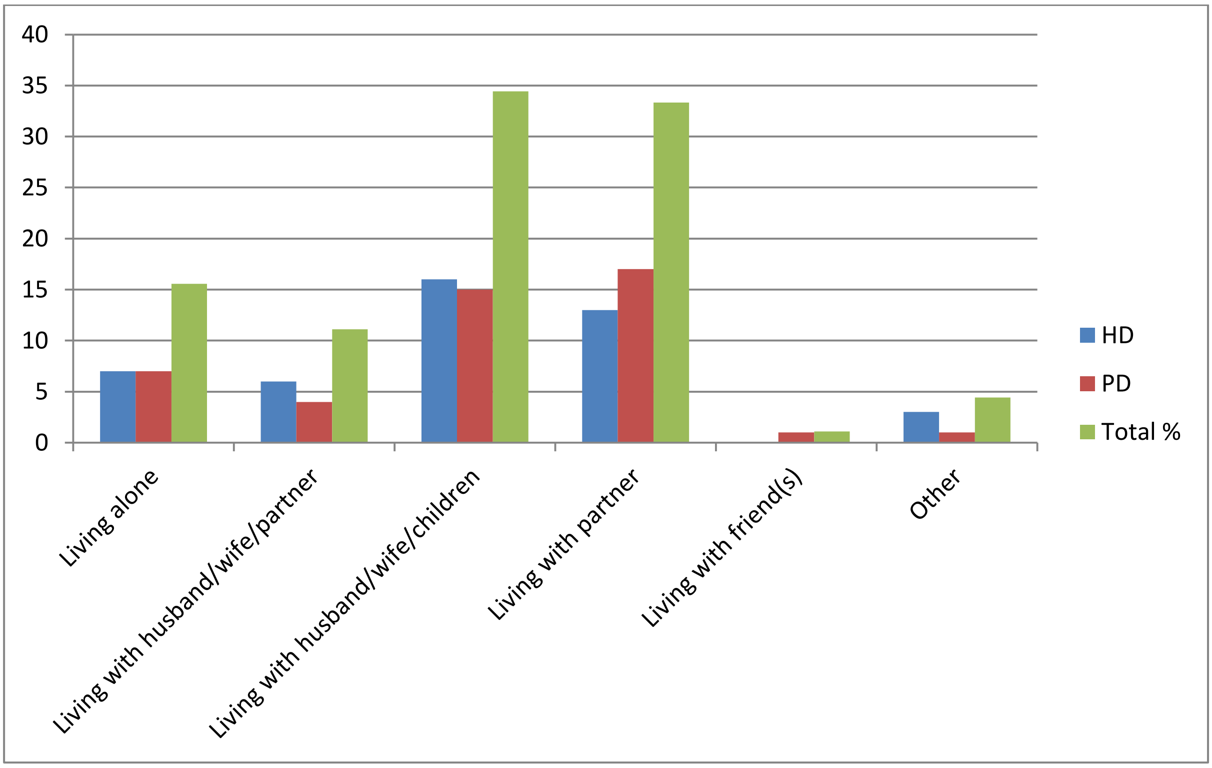

Figure 5.3. Demographic data - Living arrangements (HD - Haemodialysis group; PD - Peritoneal dialysis group; % - Percentage).

Sixteen of the compliant patients (31%) were single compared with twenty of the non-compliant who were married (67%)(figure 5.2).

Five (5.68%) patients attended primary school as the highest level of education, 51 (57.95%) high school education, and 32 (36.36%) frequented colleges or universities (figure 5.4). This result was in agreement with a 2010 study done by Bland *et al.,* who reported that educational level had no significant impact on the compliance of dialysis patients.[347] Patients with a higher level of academic education are mostly employed and have good jobs, good health and lead a comfortable lifestyle giving them wellness and satisfaction, therefore, their quality of life is higher.

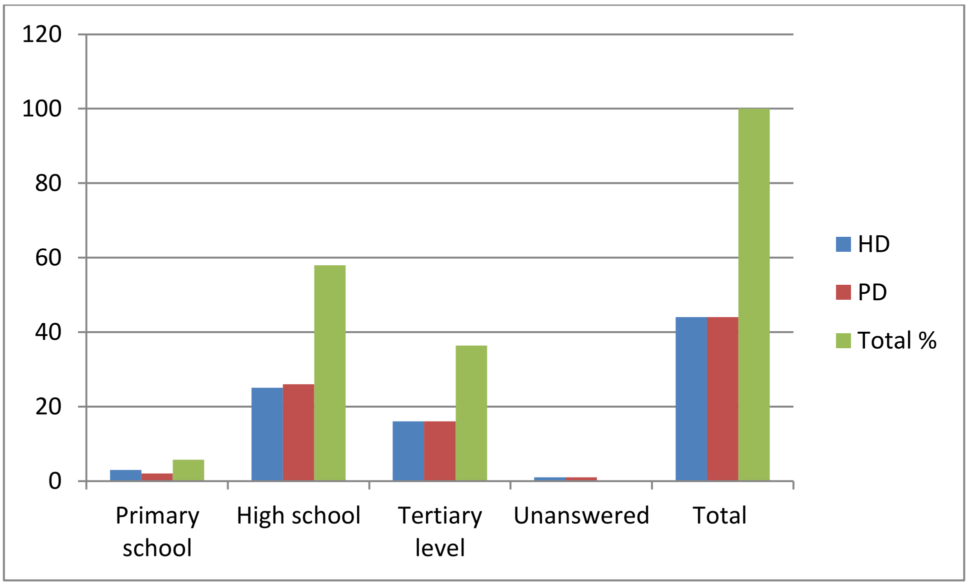

Figure 5.4. Demographic data - Level of education (HD - Haemodialysis group; PD - Peritoneal dialysis group; % - Percentage).

In terms of employment statuses, most of the population 42 (46.67%) were unemployed, approximately 27 (30%) were employed, 11 (12.22%) were disabled, and 4 (4.44%) had retired (figure 5.5).

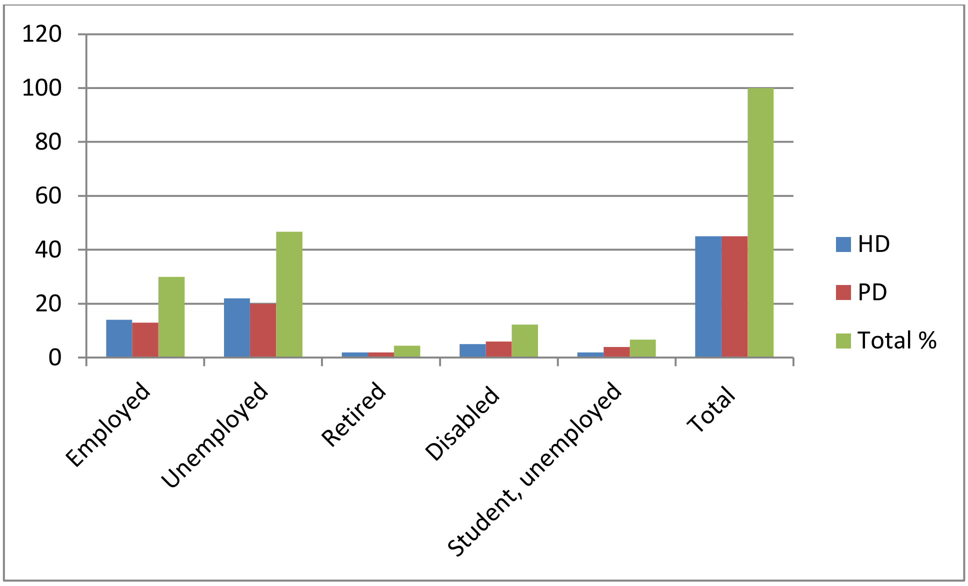

Figure 5.5. Demographic data - Employment status (HD - Haemodialysis group; PD - Peritoneal dialysis group; % - Percentage).

Level of education has also been cited as a determinant in adherence behaviour in chronic illnesses such as CKD. Low education levels have been found to cause decreased adherence due to poor understanding and education with knowledge of disease and treatment. [379]

Half the individuals diagnosed with CKD are of working age and many are at risk for job loss. Large numbers of patients give up jobs or reduce work hours before or after initiating dialysis. [348] This is due to the fact that patients have to attend dialysis program or treatment three times a week for a four hour session. Unemployment of working-age individuals is associated with greater physical and psychological problems such as anxiety, depression, [349] and loss of self-esteem. [350] Unemployment is also financially burdensome.

Loss of employment is an inevitable consequence of CKD for working-age individuals, as those on HD are required to be in hospital on dialysis three times a week, for four hours per dialysis session. However, PD differs from HD in that patients perform dialysis on their own without having to visit the centres for treatment. This type of dialysis modality could be beneficial to those who are working as dialysis can be done anywhere.

Both groups of patients occasionally experience consequences of post-dialysis complications such as tiredness, which might hinder the patients to be able to perform work related tasks. Most of the patients might also require frequent hospitalization from time to time in the first year from initiation of dialysis. Individuals new to dialysis represent the most vulnerable group of CKD patients with increased healthcare utilization.[341-347]

Among these patients, the first 3-month period after dialysis initiation brings substantial life changes especially when hospitalizations are common and mortality risk is the highest.[351, 358-362] With approximately 110,000 patients initiating chronic dialysis yearly, the revolving door of admission and discharge followed by readmission becomes a significant challenge for optimizing quality of life after CKD onset.

Early readmissions are matters of concern in that they may represent premature discharge, suboptimal care during the hospitalization or following discharge during a period of patient vulnerability, and diminished capacity for executing self-care .[363-365]

One key contributor to poor outcomes during the transition to CKD is inadequate medical and psychosocial preparation for dialysis.[366-371] An important underlying cause of such inadequate preparation is limited understanding on the part of the nephrology community regarding the optimal timing of initiation of maintenance dialysis.

Additional factors associated with higher risk of 1-year mortality included presence of specific comorbidities like congestive heart failure and peripheral vascular disease, absence of pre-dialysis nephrology care, presence of nursing home history, male gender, white race, low albumin, and lack of access to transplant information.

Typically, prevalent CKD patients experience an average of two hospital stays per year. The top two causes of hospitalization include cardiovascular events or infection related illnesses.[372-374] There are relatively fewer studies examining hospitalizations in patients with advanced CKD, prior to initiating dialysis.[375] However, despite the frequent need for hospitalizations across the continuum of CKD progression, there are no studies that have examined the impact of pre-dialysis hospitalization on outcomes after initiation of dialysis.[376]

It is unclear why some maintain employment as their kidneys fail, whereas others do not. Some patients have reported that their employers were unable to keep them as employees since they were not productive as per job requirements, thus resulting in job losses as a consequence of CKD.

Statistically, no significant differences ($p \geq 0.05$) were detected between compliant and non-compliant patients with regards to gender, education level and marital status when compared to fluid restriction compliance (figure 5.6- 5.8). Quality of life scores according to gender was $p=0.639$, level of education with $p=0.152$, and marital status $p=0.152$.

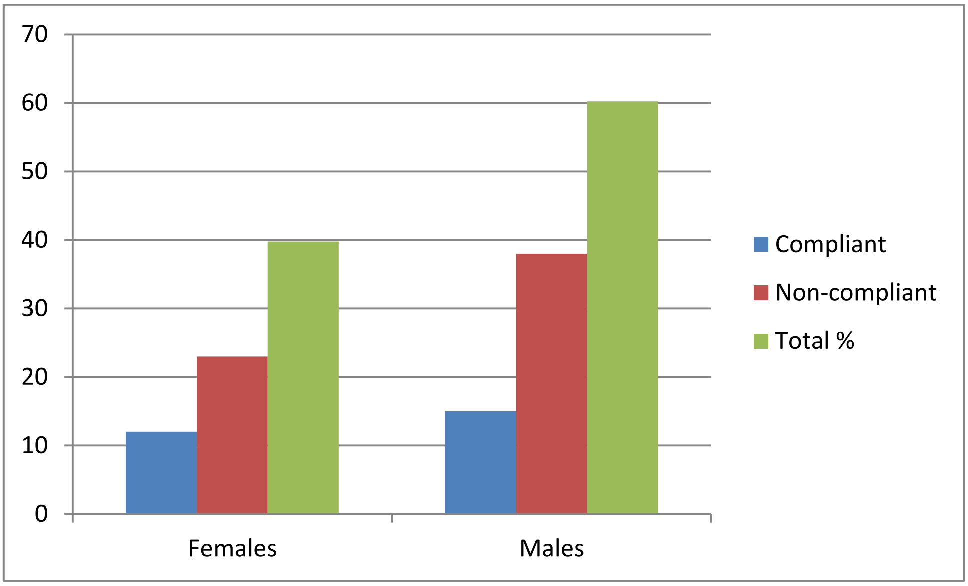

Figure 5.6. Fischer's exact test results, determining non-random association between demographic characteristics (i.e. gender) and degree of fluid restriction compliance (whether all the time – compliant, or not – non-compliant) (% - Percentage).

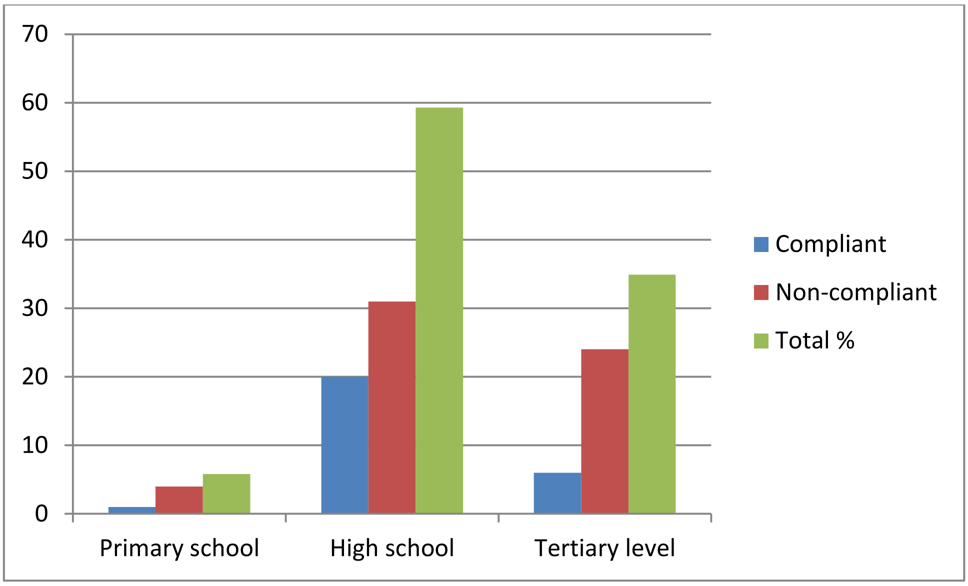

Figure 5.7. Fischer's exact test results, determining non-random association between demographic characteristics (i.e. level of education) and degree of fluid restriction compliance (whether all the time - compliant, or not – non-compliant) (% - Percentage).

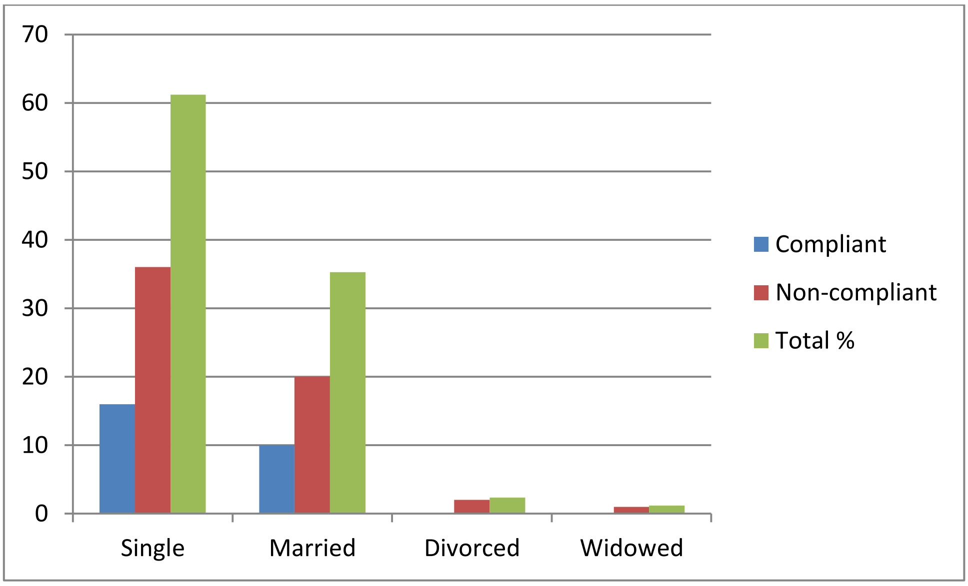

Figure 5.8. Fischer's exact test results, determining non-random association between demographic characteristics (i.e. marital status) and degree of fluid restriction compliance (whether all the time, or not) (% - Percentage).

Leggat *et al.,* in 2005 found HD-treated individuals in the 20–39-year age group to experience more non-adherences to treatment than the 40–59-year age group. [377] According to Kara *et al.,* and Kutner in 2007, young people reported to experience intense feelings of being independent and therefore not wanting to accept being dependent on dialysis and fluid restrictions. [378-379] Though our study findings went into disagreement with the above research findings by Leggat *et al*., in 2005 and Kutner and Kara *et al.,* in 2007 that age in this regard was not a contributing factor to compliance or non-compliance to fluid restrictions recommendations.

Kara and Kugler *et al.,* in 2009 found that non-adherence to dialysis treatment is therefore, more common in younger patients.[378-379] Our study findings related very well with Larsen *et al.,* in 2009 who showed that compliance increased with age and that wide variation existed between countries. [380]

Figure 5.9 - 5.11 identified differences in quality of life score dimensions, highlighting the results of mean values in the health limitation dimension in both HD [42(±39.8)] and PD [35(±41.8)] groups respectively. The mean value difference was noted in the emotional limitation dimension of both the HD [52(±44.5) and PD [44(±45.4)] groups, respectively. These findings suggested that the participants in the HD group's quality of life were negatively affected as compared to the latter. Though both groups of participants were experiencing depression and exhibiting emotions such as frustration, unhappiness and irritability in almost equal levels.

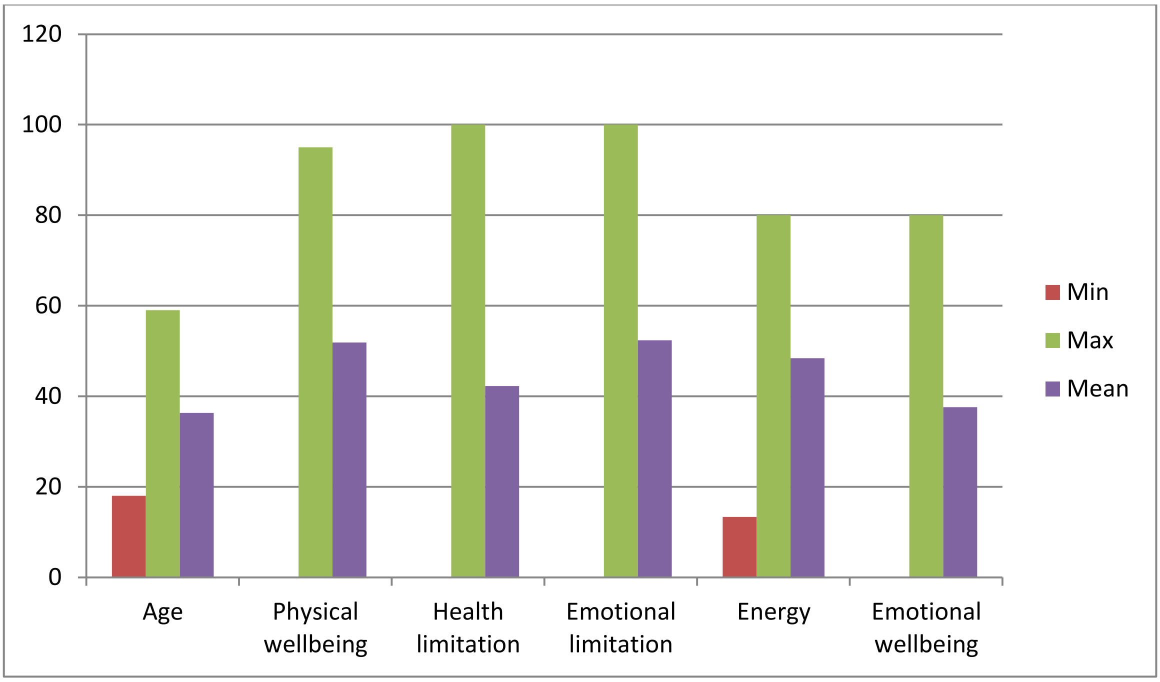

Figure 5.9. Summary statistics of age, summary scores for HD group (Min - Minimum; Max - Maximum).

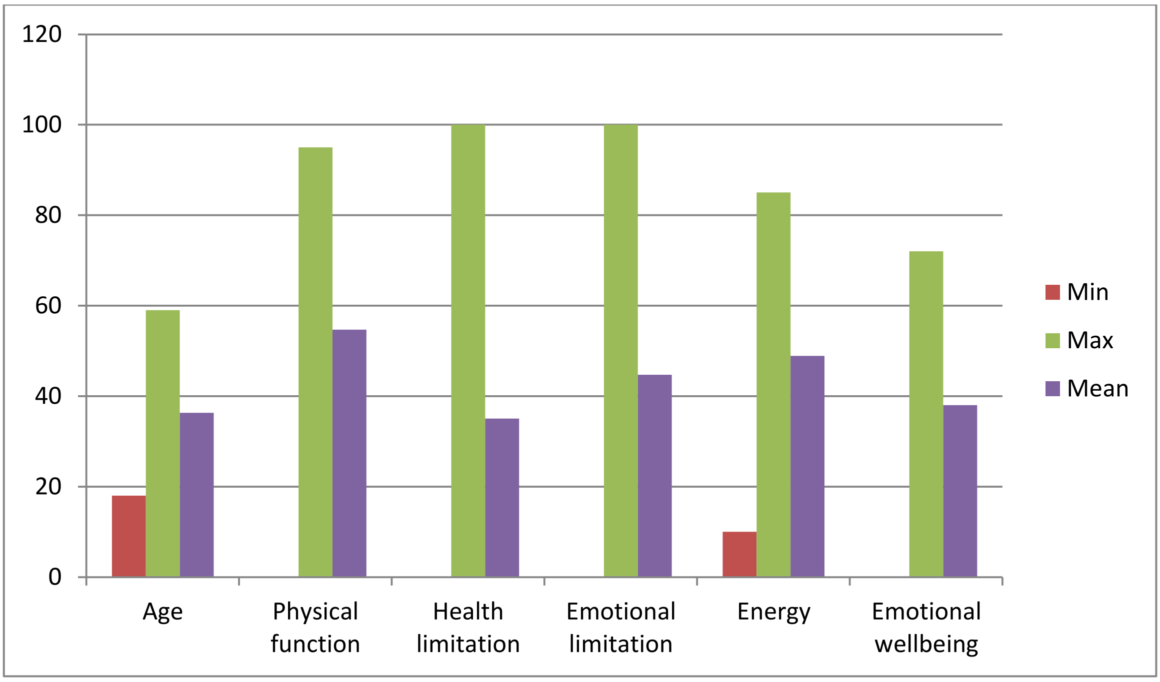

Figure 5.10. Summary statistics of age, summary scores for PD group (Min - Minimum; Max - Maximum).

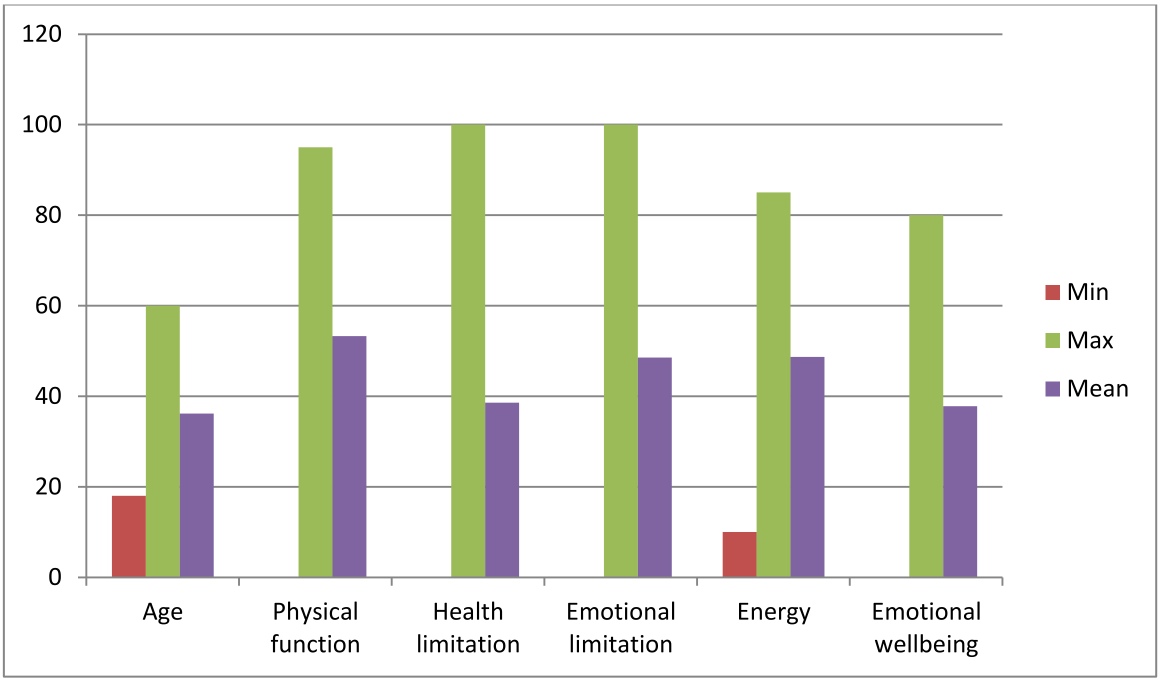

Figure 5.11. Summary statistics of age, summary scores for PD and HD groups (Min - Minimum; Max - Maximum).

Ages of all the participants correlated to fluid restriction compliance (all the time) and non-compliance (responses - Most of the time, half of the time and seldom) respectively (figure 5.12 – 5.14). There was a variation in the outcomes with mean values of compliance and non-compliance in the following quality of life dimensions i.e., health limitation [46(±42.6)], [36(±39.9)], energy [41(±17.5), 51(±17.4)] and social function [60(±29.8), 50(±29.1)].

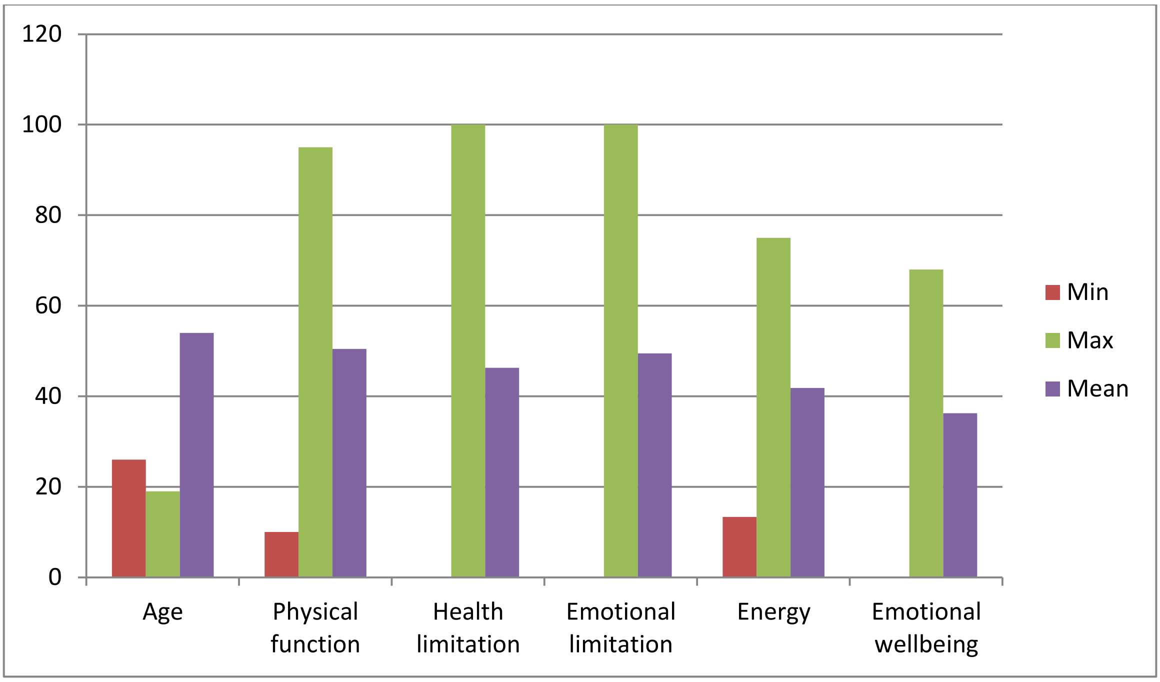

Figure 5.12. Summary statistics for age, summary scores indicated by compliance (based on Question 3 - During the past week, how often have you followed the fluid restriction recommendation?) - All the time (compliant to prescribed fluid restriction) (Min - Minimum; Max - Maximum).

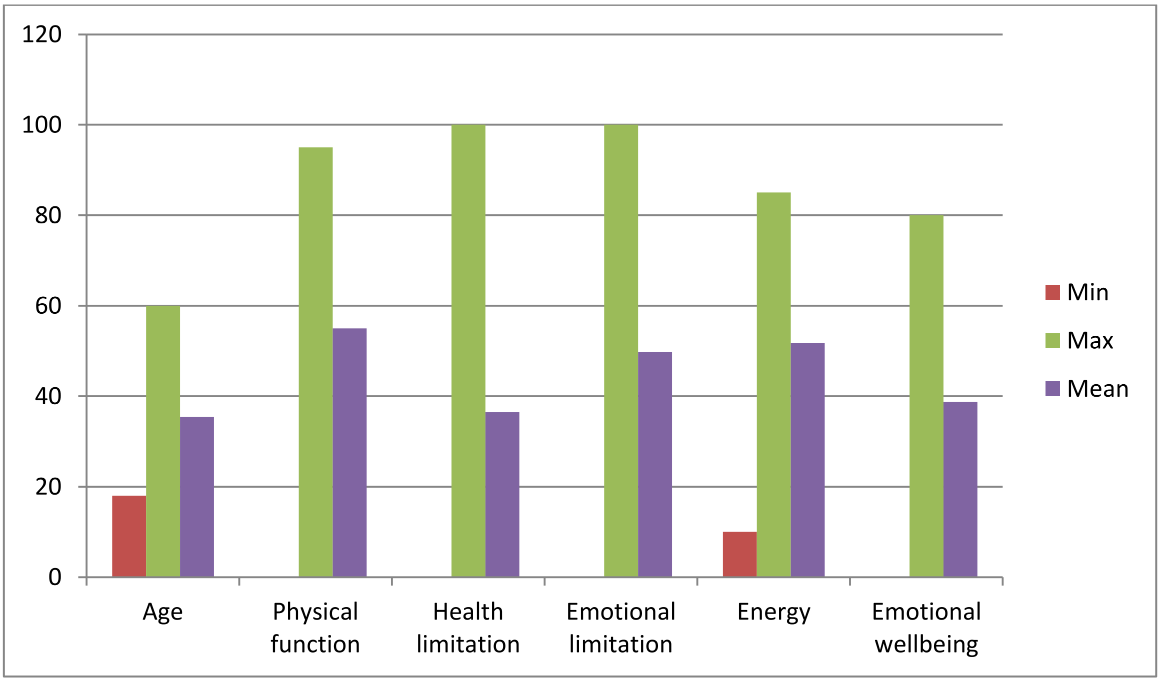

Figure 5.13. Summary statistics for age, summary scores indicated by compliance (based on Question 3 - During the past week, how often have you followed the fluid

restriction recommendation?) - Not all the time (non-compliant to prescribed fluid restriction) (Min - Minimum; Max - Maximum).

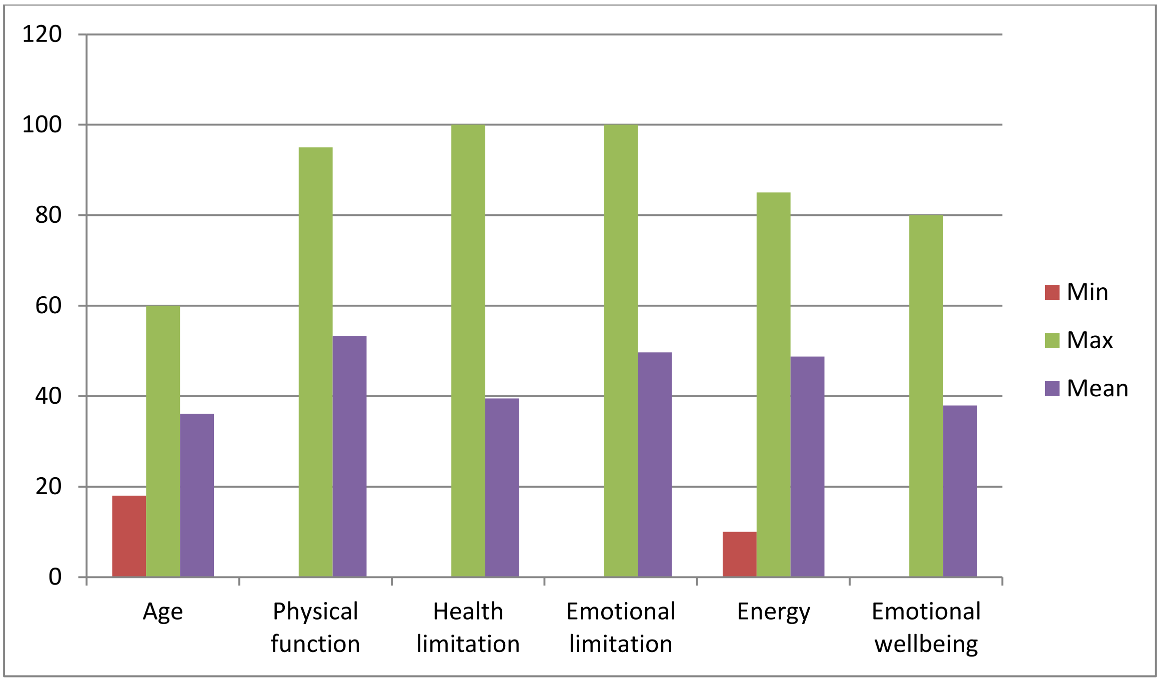

Figure 5.14. Summary statistics for age, summary scores indicated by compliance (based on Question 3 - During the past week, how often have you followed the fluid restriction recommendation?) - Total (Compliance + non-compliance to prescribed fluid restriction) (Min - Minimum; Max - Maximum).

This revelation indicated that participants who were compliant, experienced better quality of life than those who were non-compliant and that lesser energy levels was experienced by those who were regarded as non-compliant. Both groups of participants were also unable to sufficiently engage socially with the family, friends and colleagues due to the fact they felt sick half of the time, thus the impact was significantly negative.

The findings revealed that all participants experienced bodily pains regardless of the type of dialysis modality and the degree of fluid restriction recommendations. Those who reported compliant had a mean value of 52.6(±14.2) and non-compliant 53.7(±9.7).

Adherence scores among participants (figure 5.15) highlighted the total adherence to haemodialysis and peritoneal dialysis scores. The total adherence score was 11 and the minimum expected adherence was 5 among PD participants. The maximum adherence to haemodialysis score obtained in the study sample was 6 out of a total of 11. The researcher adapted an adherence scale to measure the level of adherence across all participants. The scale used was adapted from Kim *et al*., 2010 [381] where zero was identified as absolute adherence, then 50, 100, 150 and 200 were identified as absolute non-adherence to prescribed fluid restriction recommendations.

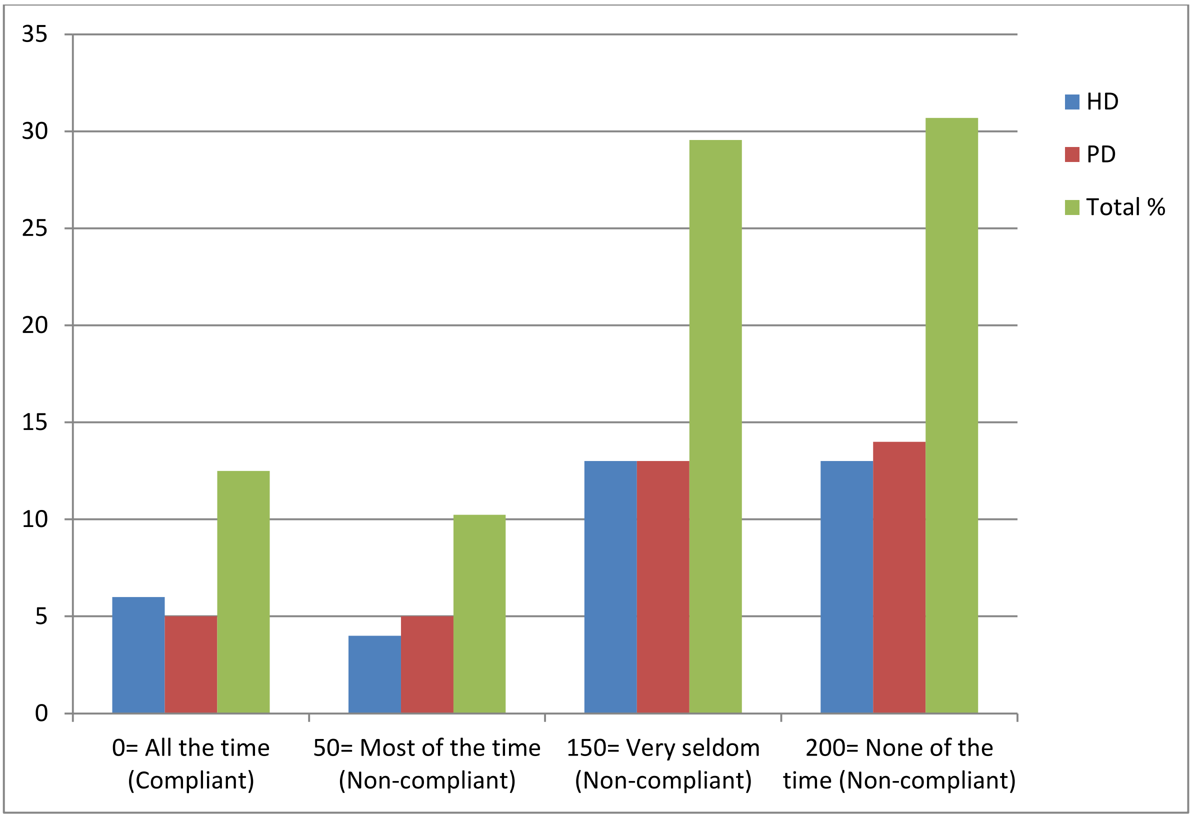

Figure 5.15. Fischer's exact test was used to summarize the participants' responses to the question qc_3 (During the past week, how often have you followed the fluid restriction recommendation?) according to the ESRD-AQ questionnaire scoring methods (% - Percentage).

The results indicated that 12.5% of participants were compliant followed by a reported non-compliance of 87.5% to the fluid restriction recommendations. This gave a high consistency in non-compliance rates between self-reported data and most of the findings within the literature.[382] No statistical significance was found with regards to the questionnaire responses (p=1.000).

Furthermore, Fischer's exact test was used to determine non-random association between question 6 in the questionnaire (which asked the participants if they had any difficulty limiting the prescribed or recommended fluid intake?) and degree of fluid restriction compliance (figure 5.16).

It was found that of the ninety participants, twenty seven participants (30%) responded with 1-No (all the time) (compliant) to question 6, fifty nine (66%) responded with 2-Yes (Most of the time, half of the time, seldom) (non-compliant) and four (4%) did not complete the question.

From these results it is evident that the majority of patients (52%) had difficulty in limiting the prescribed or recommended fluid intake and were therefore non-compliant as a result. These findings are consistent with the literature revelations that the degree of fluid non-compliance varied significantly from 20% to 79% in studies done across the world by Ibrahim *et al*., in 2011, Kugler *et al*., Mollaoğlu & Kayataş in 2015, Pang *et al*., and Rambod *et al*., in 2013.[383-388]

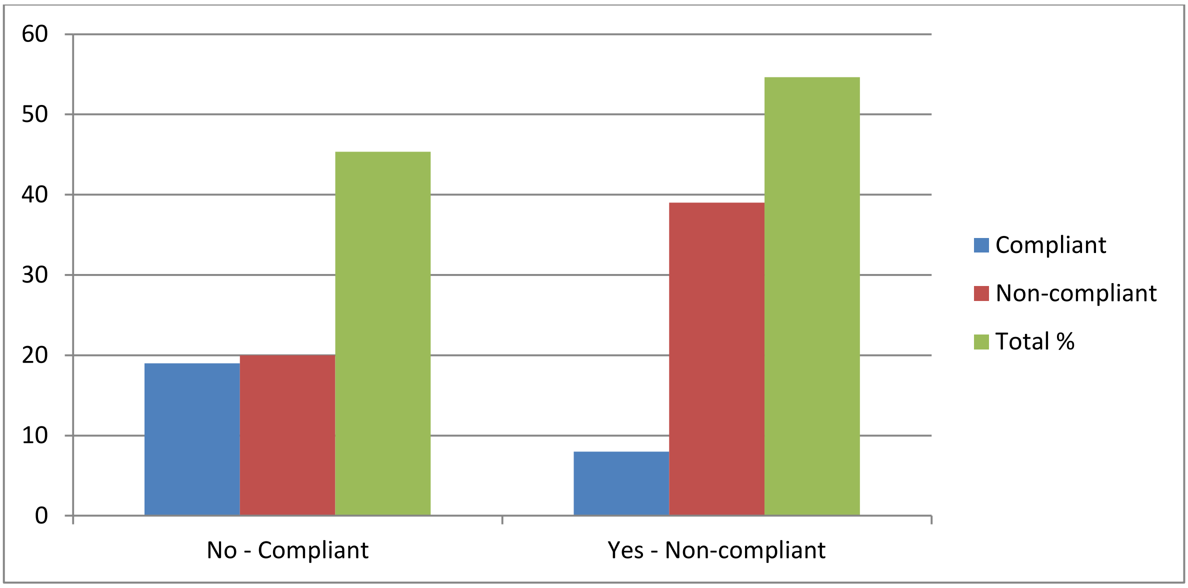

Figure 5.16. Fischer's exact test used to determine non-random association between question Q6 (Have you had any difficulty with limiting your fluid intake?) and degree of fluid restriction compliance (% - Percentage).

On the other hand, there was a statistically significant correlation (figure 5.16) between the participants' ability to limit the recommended fluid intake and fluid restriction compliance (p=0.002), (tested on a 5% statistical level). This indicated evidence against the null hypothesis.

The Spearman's rank correlation (Table 5.1) was used in order to evaluate the monotonic relationship between SF-36 variables, i.e., physical functioning, role limitations attributable to physical problems, bodily pain, and perception of general health, energy, social functioning, role limitations attributable to emotional problems, and mental health.

The World Health Organization in 2013 has estimated that 2.2–3.8% of people worldwide, aged 15 years and older, have significant difficulties in performing daily activities due to loss of physical function. [389]

Studies performed in 2010 by Alschuler, Theisen-Goodvich, Haig & Geisser and Ramage-Morin & Gilmour, have reported associations between physical functional limitations and pain on the one hand and between pain and psychological distress on the other. [390-391] However, to date, only a few researchers, i.e., Jensen, Moore, Bockow, Ehde & Engel have studied the relationship between pain, daily functioning and mental health thoroughly.[392]

The researcher's study analysis showed that there was a meaningful correlation between physical function, limitations attributable to health, limitations attributable to emotional problems and all other aspects of other variables with the exception of energy levels (p=0.0002). The correlation coefficient was negative, which means that physical functioning; limitations attributable to health and limitations attributable to emotional problems had a negative effect on the energy levels of the subjects' quality of life.

According to 2007 studies done by Parmelee, Harralson, Smith & Schumacher, functional limitations are commonly defined as restricted ability to perform necessary daily tasks like carrying and walking, which require functional mobility and strength. There is an important distinction between basic functional limitations and reduced discretionary leisure activities. [393]

In 2009 Christensen, Doblhammer, Rau & Vaupel found that the ability to function physically on a daily basis and in a satisfactory way, is important to mental health. [394] Revelations by Chen *et al.,* in 2012 were that functional limitations might lead to mental health problems, [395] and studies done by Raphael, Schmolke & Wooding and Kojima revealed that mental health problems may increase the complexity, challenges, and difficulties for individuals with functional limitations. [396-397]

Social support, through its ability to increase proactive coping, has been shown to significantly moderate psychological distress through a weakening of the association between physical impairment and depression in the elderly.[398]

Social functioning had a negative correlation with all aspects of quality of life (social functioning, bodily pain and general health) with the exception of energy (p=0.0000). Bodily pain correlates with general health and has an adverse effect on social functioning (p=0.0189). According to Scott *et al.,* the associations between comorbid anxiety and depressive problems and functional limitations were not only consistently significant, but also greater than those with anxiety or depression separately. [399]

Additionally, Jensen *et al*., in 2011 highlighted that high levels of social support are associated with less pain and better physical functioning. [392] Studies done in 2000 by Gazmararian, Baker, Parker & Blazer revealed that high social support can be beneficial for health-related outcomes, low social support is associated with increased risk for compromised health and physical functioning.[400]

The evaluation of a possible correlation of general health showed that there was a significant effect in the population (p=0.0001). These findings suggest that participants' general health suffered as a result of non-compliant behavioural patterns. Functional limitations have previously in 2006 been shown by Yang to be independently associated with sense of mastery. [401]

As described for pain in 2013 by Ross and Mirowsky, a sense of mastery is also known to be independently associated with mental health. [402] Lavikainen, Fryers & Lehtinen and Taylor and Stanton reported that high sense of mastery is commonly associated with both better mental and physical health, as well as improved overall functioning in life, [403-404] and Ross and Mirowsky ascertained a significant negative association has been reported for sense of mastery and episodes of major depression. [402]

In 2002 Jang, Haley, Small, and Mortimer have previously reported that a sense of mastery has the ability to moderate the relationship between functional disability and depression.[405]

Table 5.1. Spearman's rank correlations of quality of life scores.

	Physical function	Health limitation	Emotional limitation	Energy	Social function	Pain	General health
Physical function	1.0000						
Health limitation	0.2393	1.0000					
	0.0283*						
Emotional limitation	0.2691	0.5754	1.0000				
	0.0133*	0.0000*					
Energy	-0.3814	-0.3491	-0.0439	1.0000			
	0.0003*	0.0011*	0.6917				
Social function	0.0518	0.4427	0.2958	-0.2292	1.0000		
	0.6399	0.0000*	0.0063*	0.0360*			
Pain	0.1672	0.2375	0.1727	-0.2501	0.1281	1.0000	
	0.1284	0.0296*	0.1162	0.0218*	0.2455		
General health	0.3995	0.4023	0.3561	-0.4472	0.2557	0.2185	1.0000
***p*-value**	0.0002*	0.0001*	0.0009*	0.0000*	0.0189*	0.0458*	

Table 5.2 shows the results of the two-sample Wilcoxon rank-sum (Mann-Whitney) tested on a 5% level of significance that was used to compare energy levels of participants and question 3 (Which asked the participants how often they followed the fluid restriction recommendations in the past week). Statistically it was found that energy and compliance were significantly different (p=0.0051) and was indicated with 30% of the observed population reporting as compliant, 66.7% reported as non-compliant and 3.3% didn't answer the question. These findings suggested that those

who reported compliant were more likely to be energetic, more so than the non-compliant counterparts.

Table 5.2. The two-sample Wilcoxon rank-sum (Mann-Whitney) test was used to compare energy levels of participants and question 3 (which asked the participants how often they followed the fluid restriction recommendation in the past week?).

Compliance	***Observed***	***Rank sum***	***Expected***	***p-value***
All of the time (Compliant)	27	893.5	1201.5	
Most/Half/Seldom of the time (Non-compliant)	61	3022.5	2714.5	**0.0051**
Combined	88	3916	3916	

Furthermore, in Table 5.3, Wilcoxon rank-sum test was used to compare the following: (1) energy levels of participants, (2) social function, (3) general health, and question 6 (which asked the participants if they had any difficulty with limiting the recommended fluid intake?) using response options: No-(1) or Yes-(2) (Table 5.3). The results revealed statistically significant differences between energy levels (p=0.0094), social function (p=0.0119), general health (p=0.0005) and fluid restriction compliance. Forty-nine non-compliant participants (55.7%) whom reported fluid restriction non-compliance suffered the consequences of such behavioural patterns, which impacted on their general quality of life, social functioning and energy levels negatively.

Table 5.3. The two-sample Wilcoxon rank-sum (Mann-Whitney) test was used to compare (I) energy levels of participants, (II) general health, (III) social function dimensions, and question 6 (which asked the participants if they had any difficulty with limiting the prescribed fluid intake? * 1 - No = compliant *, 2 - Yes = non-compliant).

Question Qc_6	***Observed***	***Rank sum***	***Expected***	***p-value***
1 (No)	*39*	*1428*	*1735.5*	
2 (Yes)	*49*	*2488*	*2714.5*	**0.0094**
Combined	*88*	*3916*	*3916*	

Question Qc_6	***Observed***	***Rank sum***	***Expected***	***p-value***
1 (No)	39	2032.5	1735.5	
2 (Yes)	49	1883.5	2180.5	**0.0119**
Combined	88	3916	3916	

Question Qc_6	**Observed**	**Rank sum**	**Expected**	***p-*value**
1 (No)	39	2146	1735.5	**0.0005**
2 (Yes)	49	1170	2180	
Combined	88	3916	3916	

CHAPTER 6

6 CONCLUSION AND RECOMMENDATIONS

6.1 Introduction

The four objectives of this study were fulfilled and the researcher found that adherence of HD and PD-treated individuals to fluid restriction was affected by many factors such as sex, age, health status, knowledge of existing chronic disease, and familial conditions. The study revealed the detrimental effects of fluid restriction non-compliance among the dialysis-treated participants which have shown to have affected the general health of the population negatively, thus yielding a poor quality of life.

With the current findings, the nephrology team may navigate forward as to how to combat the non-compliance behaviour and to flatten the curve in order to improve the general health of the patients. Adherence and compliance can metamorphosize over time and it is, therefore, imperative to collect data related to the adherence of patients on HD and PD to fluid restrictions at regular intervals of time, and all health interventions related to the variety of factors that influence adherence should be planned and utilized accordingly.

The End-Stage Renal Disease Adherence Questionnaire (ESRD-AQ) tool asked for the opinion of the participants about how well they followed their dialysis treatment schedule and about medical recommendations related to fluid intake. The general instrument consists of 46 questions divided into five sections - general information, haemodialysis, medication, fluid restriction and diet but, for the purpose of this study the researcher focused only on the fluid restriction dimension.

HD patients may feel the negative effects of fluid imbalance more than PD patients or those on short daily HD. Although this doesn't mean PD and HD patients can drink unlimited amounts, their fluid allowance is usually more generous. It's recommended that dialysis patients consume less than a litre of fluid each day.

The answers contained in the instrument use a combination of the Likert scale, multiple-choice, and yes/no responses. Adherence itself is evaluated in six questions, in which the patients receive a score according to their answers: the greater the adherence, the more points and *vice versa*. Another eight questions cover their perception and knowledge of the treatment.[406]

Using this type of tool facilitates the management of nursing care and contributes to the strengthening of the professional-patient relationship, which is considered a variable that can influence negatively or positively the individual's adherence practices. Strengthened relationships allow therapeutic alternatives to be explored and negotiated with the ultimate goal of promoting adherence, which should be discussed frequently.[406]

6.2 Conclusion

The study findings suggested that the greater the ability of patients to limit the fluid intake as per recommendations, the greater and higher the compliance rates. The major perceived barriers and challenges towards better fluid compliance may have been attributed to amongst other factors, lack of adequate knowledge, inadequate self-efficacy skills, forgetfulness and financial constraints.

The above mentioned reasons went in agreement with the null hypothesis of the study, which stated that various factors, such as demographic characteristics, psychological aspects, and social characteristics, knowledge and self-assessment barriers, environmental and physical barriers do not influence fluid restriction adherence behaviour amongst dialysis patients.

Overall, this study revealed a low quality of life in haemodialysis and peritoneal dialysis patients, with regards to the inability to follow the prescribed fluid restriction recommendations, resulting in the majority of the population being classified as non-compliant to their dialysis regime. Non adherence fluid restriction is highly prevalent among CKD patients on various modalities of dialysis therapy. It has been exhibited in this study that general health of participants has been negatively affected by this non-compliant behaviour of dialysis patients. This is an important study in young patients, the mean age was 36 years for participants included in the study, addressing issues relevant to patient outcomes.

To summarize, both SF-36 and ESRD-AQ are effective instruments with psychometric properties designed to assist the dialysis medical team to help patients to achieve optimal heath and understand all the aspects of their care which includes information on the disease, dialysis, education, dietary and fluid restriction behaviours and methods of coping with a chronic disease.

6.3 Recommendations

According to the outcomes of this study, psychotherapeutic interventions should be intensively employed and planned for, so it can cater for each individual's psychological needs thus aiming to improve the overall general health of patients.

Suggestively, the study findings also warrant further implementation and evaluation of educational interventions. However, the literature has revealed that nevertheless, knowledge is a prerequisite for adherence in behaviour and that patient education plays an important role in patients compliance as an increased rate of compliance is directly linked to an effective patient education.

6.4 Study limitations

Most participants who took part in the study needed assistance with completing the questionnaires. This was provided by the researcher through interviews with these patients. Therefore, questionnaires were completed while they were under dialysis and or attending the monthly check up sessions at the PD clinic as a measure of saving time.

CHAPTER 7

7 REFERENCES

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ANNEXURE A: ETHICAL CLEARANCE LETTER

Tshwane University of Technology

Faculty Committee for Research Ethics [FCRE-SCI]

The TUT Research Ethics Committee is a registered Institutional Review Board (IRB 00005968) with the US Office for Human Research Protections (IORG# 0004997) (Expires 30 Jan 2020). Also, it has Federal Wide Assurance for the Protection of Human Subjects for International Institutions (FWA 00011501) (Expires 22 Jan 2019). In South Africa it is registered with the National Health Research Ethics Council (REC-160509-21).The FCRE-SCI is a subcommittee of the TUT Senate Committee for Research Ethics

20 August 2018

Ref #: FCRE 2018/06/04 (SCI)(1)
Name: Mr Ndhlovu, T
Student #: 200900260

Mr Ndhlovu, T (200900260)

Biomedical Science

Faculty of Science

Dear Mr Ndhlovu, T

Decision: Final Approval

Name: Mr Ndhlovu, T
Project title: Factors influencing fluid restriction non-compliance amongst patients undergoing chronic haemodialysis and peritoneal dialysis at Steve Biko Academic Hospital.
Qualification: M Tech: Clinical Technology.
Supervisor: Dr A. Muranda
Co Supervisor: Ms L. Repsold

Thank you for submitting the B Tech proposal for ethics clearance by the Faculty of Science Committee for Research Ethics Committee, Tshwane University of Technology (TUT). In reviewing the proposal, the comments and notes below are tabled for your consideration, attention and/or notification:

Comments

- The comments have been addressed.

The project is approved. The supervisor needs to inform the FCRE when the project is completed..

Kind regards,

Chairperson: Prof EI Olivier

Faculty Committee for Research Ethics

Ref: FCRE 2018/06/04 (SCI)(1)

Cc: Ms L. Repsold

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ANNEXURE B: PERMISSION TO ACCESS PATIENT RECORDS

Permission to do Research and access Records / Files / Data base at the ______SBAH__________Hospital

To: Chief Executive Officer/Information Officer
_______________Hospital
_____________ Hospital

From: The Investigator

Mr T. Ndhlovu

Re: **Permission to do the following research at** Steve Biko Aca **Hospital**

Drs A. Z. Muranda ____________ and I are researchers working at the ___ Renal ______ Unit, Department of Int Med at SBA Hospital. I am requesting permission on behalf of all of us to conduct a study on the SBA ______ Hospital grounds that involves access to patient records.

The title of the study is: Factors influencing fluid restriction non-compliance amongst patients undergoing HD & PD at Steve Biko Academic Hospital

We intend to publish the findings of the study in a professional journal and/ or at professional meeting like symposia, congresses, or other meetings of such a nature.

We furthermore request in terms of the requirements of the Promotion of Access to Information Act. No. 2 of 2000 that we be granted access to clinical records, files and databases.

We undertake not to proceed with the study until we have received approval from the Faculty of Health Sciences Research Ethics Committee, University of Pretoria.

Yours sincerely

Signature of the Principle Investigator

Permission to do the research study at this hospital and to access the information as requested, is hereby approved.

Chief Executive Officer
Steve Biko Academic Hospital
Dr ... Manguqeene

Signature of the CEO

GAUTENG PROVINSIALE REGERING
DEPT VAN GESONDHEID
STEVE BIKO AKADEMIESE HOSPITAAL
STEVE BIKO ACADEMIC HOSPITAL
2018 -02- 27
PRIVAATSAK/PRIVATE BAG X169
PRETORIA 0001
GAUTENG PROVINCIAL GOVERNMENT
DEPT OF HEALTH

Hospital Official Stamp

Tshwane University of Technology

Permission to access Patient Records / Files / Database at the

Steve Biko Academic Hospital / Clinic

To: Chief Executive Officer/Information Officer
Steve Biko Academic Hospital

From: The Investigator
Steve Biko Academic Hospital
Mr T. Ndhlovu
Date: 26 February 2018

Permission to access Patient Records / Files / Database

Research Team
Principal Investigator (Student): Mr T. Ndhlovu (SBAH, TUT)
Supervisor: Miss L. Repsold(TUT, UP)
Co-Supervisor: Dr A.Z. Muranda(SBAH, UP)

The above research team is proposing to conduct a research project at the Renal Unit, Department of Internal Medicine/ Nephrology at Steve Biko Academic Hospital. We are requesting permission to access patient records / files / data base in terms of the requirements of the Promotion of Access to Information Act. No. 2 of 2000.

The title of the proposed study:
FACTORS INFLUENCING FLUID RESTRICTION NON-COMPLIANCE AMONGST PATIENTS UNDERGOING CHRONIC HAEMODIALYSIS AND PERITONEAL DIALYSIS AT STEVE BIKO ACADEMIC HOSPITAL

Find attached a copy of the research proposal for your reference.

No accessing of medical records and files will be required for this particular research study. We hereby request formal permission.

We intend to publish the findings of the study in a research report (e.g. project report, dissertation, and thesis), accredited academic journal/s and/ or professional/academic meeting/s (e.g. symposia, congresses, or other meetings of such a nature).

We will protect the personal identity of the patients by assigning each patient a code number and by deleting/masking all patient names on the relevant documents. In addition, the confidentiality of the patient records/documents will duly protected by storing it in a restricted-access format to which only the research team has access.

Lastly, we will not proceed with the study until we have received the required ethics/proposal approvals from all the relevant institutions, i.e. the Tshwane University of Technology (TUT) and the Steve Biko Academic Hospital.

Yours sincerely

____

Signature of the Principle Investigator

The application for permission to access Patient Records / Files / Database as requested is hereby approved.

Chief Executive Officer

Steve Biko Academic Hospital

Dr ST Mangwane

Signature

GAUTENG PROVINSIALE REGERING
DEPT VAN GESONDHEID
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STEVE BIKO ACADEMIC HOSPITAL
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ANNEXURE C: QUESTIONNAIRE

RESEARCH QUESTIONNAIRE

Fluid Restriction Non-Compliance Amongst Patients Undergoing Chronic Haemodialysis And Peritoneal Dialysis at Steve Biko Academic Hospital.

The survey is organized into 3 parts. It takes approximately15-30 minutes to complete.

- Part A concerns **Demographic** and background information.
- Part B is the **SF 36** quality of life tool.
- Part C is the **End-Stage Renal Disease Adherence Questionnaire (ESRD-AQ)** tool.

The survey consists of closed and open questions. If more space is required to answer any particular question please use the page at the back. All responses to the survey are numbers and an appropriate answer should be circled. The reporting of survey findings will be presented in a non-identifiable way. Please do not sign the survey or identify yourself by name in the survey. The answers provided in this questionnaire will remain confidential. No identifiable information about you will be revealed in written or verbal reports. If there are any questions that are not applicable to you please write not-applicable. If there are any questions that you do not wish to answer, please leave blank.

PART A: DEMOGRAPHICS

Please answer every question by making a circle on the appropriate number in the box.

1. What is your age?

2. What is your sex?

(Circle one)

Male	Female

3. What is the highest level of education?

(Circle one)

Did not attend school	Primary School	High School	Tertiary
1	2	3	4

4. What is your marital status?

(Circle one)

Single	Married	Divorced	Widowed
1	2	3	4

5. What are your current living arrangements?

(Circle one)

Live alone	Live with husband/wife/partner	Live with husband/wife and children	Live with parents	Live with friends	Other, please describe
1	2	3	4	5	6

6. Describe your employment status

(Circle one)

Employed	Unemployed	Retired	Disabled	Student, unemployed and not working
1	2	3	4	5

PART B: SF 36 QUALITY OF LIFE TOOL

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is?

(Circle one)

excellent	**Very good**	**good**	**fair**	**poor**
1	2	3	4	5

2. Compared to one year ago, how would you rate your health in general now?

(Circle one)

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
1	2	3	4	5

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(Circle one number on each line)

ACTIVITIES	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
a. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing **several** flights of stairs	1	2	3
e. Climbing **one** flight of stairs	1	2	3
f. Bending, kneeling, or stooping	1	2	3
g. Walking **more than a mile** h. Walking **half a mile**	1	2	3
i. Walking **one hundred yards**	1	2	3
j. Bathing or dressing yourself	1	2	3

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities <u>as a result of your physical health?</u>

(Circle one number on each line)

	YES	NO
a. Cut down on the **amount of time** you spent on work or other activities	1	2
b. **Accomplished less** than you would like	1	2

c. Were limited in the **kind** of work or other activities	1	2
d. Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(Circle one number on each line)

	YES	**NO**
a. Cut down on the **amount of time** you spent on work or other activities	1	2
b. **Accomplished less** than you would like	1	2
c. Were limited in the **kind** of work or other activities	1	2

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

(Circle one)

Not all	**Slightly**	**Moderate**	**Quite a bit**	**Extremely**
1	2	3	4	5

7. How much bodily pain have you had during the past 4 weeks?

(Circle one)

None	**Very mild**	**Mid**	**Moderately**	**severe**	**Very severe**
1	2	3	4	5	6

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

(Circle one)

Not at all	**A little bit**	**Moderately**	**Quite a bit**	**Extremely**
1	2	3	4	5

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks?

(Circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did you feel full of life?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and low?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

(Circle one)

All of the time	Most of the time	Some of the time	A little of the time	None of the time
1	2	3	4	5

11. How TRUE or FALSE is each of the following statements for you?

(Circle one number on each line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get ill more easily than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5

d. My health is excellent	1	2	3	4	5

PART C: END STAGE RENAL DISEASE ADHERENCE QUESTIONNAIRE (ESRQ-AQ) (Kim *et al*., 2010)

This survey asks for your opinion about how well you follow your dialysis treatment schedule and about medical recommendations related to fluid intake. This information will help us to understand if you have difficulty following your dialysis treatment, fluid restriction. Please circle the numbers to best answer questions in the survey. If you are unsure about how to answer, please choose one best answer that applies to you.

1. When was the last time a medical professional (your doctor, nurse or dietician or other medical staff) spoke to you about your fluid restrictions?

(Circle one)

This week	**Last week**	**A month ago**	**More than a month ago**	**When I began dialysis treatment**	**Never**	**Other (Specify)**
1	2	3	4	5	6	7

2. How often does a medical professional (your doctor, nurse, dietician or other medical staff) talk to you about the importance of fluid restriction?

(Circle one)

Every dialysis treatment	**Every week**	**Every month**	**Every 2 to 3 months**	**Every 4 to 6 months**	**Rarely**	**Irregularly**	**Never**	**Other (Specify)**
1	2	3	4	5	6	7	8	9

3. During the past week, how often have you followed the fluid restriction recommendations?

(Circle one)

All of the time	**Most of the time**	**About half of the time**	**Very seldom**	**None of the time**

4. How important do you think it is to limit your fluid intake?

(Circle one)

Highly important	Very important	Moderately important	A little important	Not important
1	2	3	4	5

5. Why do you think it is important for you to limit your fluid intake (Please choose one best answer that applies to you?

(Circle one)

Because I fully understand my kidney condition requires limiting fluid intake	Because limiting fluid intake is important to keep my body healthy	Because I got sick after I drank lots of fluid	Because I was hospitalized after I drank lots of fluids	I don't think limiting fluid is important to me	Other (Specify)
1	2	3	4	5	6

6. Have you had any difficulty with limiting your fluid intake?

(Circle one)

No	Yes
1	2

7. How much difficulty have you had following your fluid restriction recommendations?

(Circle one)

No difficulty	A little difficulty	Moderate difficulty	A lot of difficulty	I was unable to follow any recommendations at all
1	2	3	4	5

8. If you had difficulty following your fluid restriction recommendations, what types of difficulty have you had?

(Circle one)

No difficulty	Not interested	I was unable to control fluid intake	I don’t understand how to follow the fluid restriction	Other
1	2	3	4	5

ANNEXURE D: INFORMED CONSENT

Tshwane University of Technology

FACULTY OF SCIENCE

DEPARTMENT OF BIOMEDICAL SCIENCES

INFORMATION LEAFLET AND INFORMED CONSENT

PROJECT TITLE: FACTORS INFLUENCING FLUID RESTRICTION NON-COMPLIANCE AMONGST PATIENTS UNDERGOING CHRONIC HAEMODIALYSIS AND PERITONEAL DIALYSIS AT STEVE BIKO ACADEMIC HOSPITAL.

Primary investigator: Mr T. Ndhlovu, B Tech (Clinical Technology)

Internal Supervisor: Ms L Repsold, MSc (Human Physiology)

External Supervisor: Dr AZ Muranda (MBChB) (MMED), Steve Biko Academic Hospital, Pretoria

Dear Research participant,

You are invited to participate in a research study that forms part of my formal M Tech-studies. This information leaflet will help you to decide if you would like to participate. Before you agree to take part, you should fully understand what is involved. You should not agree to take part unless you are completely satisfied with all aspects of the study.

WHAT IS THE STUDY ALL ABOUT?

The purpose of the study will be to investigate factors that influence fluid restriction non-compliance amongst patients undergoing chronic Haemodialysis (HD) and Peritoneal dialysis (PD) and compare the possible outcome variations between the two populations.

Therefore, this study will yield an indicative guide to the staff of the Nephrology Department and other medical teams (dieticians, psychologists, etc) as to how to assist the participants who encounters difficulties in adhering to their daily fluid restrictions to cope better and comply with their treatment requirements as far as fluid restriction is concerned. Further hoping to improve and enhance their quality of life also broadens their scope of knowledge as far as their treatment is concerned with regards to daily fluid restrictions.

WHAT WILL YOU BE REQUIRED TO DO IN THE STUDY?

This study will require you to complete a questionnaire that comprises of questions that covers the factors that influence fluid restriction no-adherence as far as your dialysis treatment is concerned. This may take about fifteen to twenty minutes to complete and it is a once-off assessment. The assessment will take place in the dialysis unit during your dialysis session and no extra time will be required out of you. You will not be billed or charged for participating in this study.

If you decide to take part in the study, you will be required to do the following:

- To sign this informed consent form.
- To complete a questionnaire. You will be asked to respond to questions regarding your compliance to fluid restriction adherence. You will complete the questionnaire in the dialysis unit during your dialysis session. It should not take more than 30 minutes to complete.
- To converse with the researcher through a series of open-ended questions following the administration of the questionnaire to encourage discussion about fluid restriction management (this will be a confidential session where key points identified during analysis of the questionnaires will be further discussed)

ARE THERE ANY CONDITIONS THAT MAY EXCLUDE YOU FROM THE STUDY?

You will not be eligible to participate in this study if you decide to not take part in the study.

CAN ANY OF THE STUDY PROCEDURES RESULT IN PERSONAL RISK, DISCOMFORT OR INCONVENIENCE?

Questionnaire: The study and procedures involve no foreseeable physical discomfort or inconvenience to you or your family. Due to the personal nature of the questions, you may experience some discomfort.

WHAT ARE THE POTENTIAL BENEFITS THAT MAY COME FROM THE STUDY?

The benefits of participating in this study are:

- You will make a contribution towards establishing measures as to how the dialysis team and other medical team can assist you in achieving and optimizing the actual purpose of your treatment and enabling you to adopt a healthy lifestyle
- You will receive a leaflet that consists of information that may assist you in times of difficulties to adhere to the fluid restrictions as per your dialysis treatment requirements and help you understand the chronic disease you are living with better.

WILL YOU RECEIVE ANY FINANCIAL COMPENSATION OR INCENTIVE FOR PARTICIPATING IN THE STUDY?

Please note that you **will not** be paid or rewarded to participate in the study.

WHAT ARE YOUR RIGHTS AS A PARTICIPANT IN THIS STUDY?

Your participation in this study is entirely voluntary. You have the right to withdraw at any stage without any penalty or future disadvantage whatsoever. You don’t even have to provide the reason/s for your decision. Your withdrawal will in no way influence your continued care and relationship with the health care team.

HOW WILL CONFIDENTIALITY AND ANONYMITY BE ENSURED IN THE STUDY?

All information obtained during the course of this study is strictly confidential. The study data will be coded so that it will not be linked to your name. Your identity will not be revealed while the study is being conducted or when the study is reported in scientific journals. All the data sheets that have been collected will be stored in a secure place and not shared with any other person without your permission.

All the data that you provide during the study will be handled confidentially. This means that access to your data will be strictly limited to the researcher, the supervisors of the study and the designated examiners (appointed by Tshwane University of Technology). Also, your data and personal information will be kept and stored in a confidential format which will only be accessible to the researcher.

Confidentiality of data will be maintained - in other words your identity will only be known to the researcher. I will remove/mask all identifying data on transcriptions and final report documents (e.g. thesis and journal articles). Thus, your identity will not be revealed during or after the study, even when the study is published or used in any format.

Only the researcher and the supervisors will have access to the filled-out questionnaires. Your answers will be totally anonymous and your identity will not be revealed under any circumstance. Also, nobody outside the study panel will be able to connect any answer to you in any recognisable way. The results of this study might be published in a scientific journal and/or presented at scientific meetings, but again without revealing the identity of any research participant. The original questionnaires will be stored in a safe place for three years, after which they will be destroyed.

IS THE RESEARCHER QUALIFIED TO CARRY OUT THE STUDY?

The researcher is a qualified clinical technologist in the field of Nephrology who currently works in the dialysis unit at Steve Biko Academic Hospital and has previously completed other research in Nephrology (Dialysis) studies at University of Cape Town and Groote Schuur Hospital. The researcher is a qualified professional in the field of study.

HAS THE STUDY RECEIVED ETHICAL APPROVAL?

Yes, the Faculty of Science Research Ethics Committee of the Tshwane University of Technology has approved the formal study proposal. Also, the executive management of the Steve Biko Academic Hospital have granted written approval for the study. All parts of the study will be conducted according to internationally accepted ethical principles.

WHO CAN YOU CONTACT FOR ADDITIONAL INFORMATION REGARDING THE STUDY?

The primary investigator, Mr T Ndhlovu, can be contacted during office hours at Tel (012) 354-1688.The study leader, Dr AZ Muranda, can be contacted during office hours at Tel (012) 354-2210. Should you have any questions regarding the ethical aspects of the study, you can contact the chairperson of the Faculty of Science Research Ethics Committee, Prof EI Olivier, during office hours at Tel (012) 382-6393 or email at OlivierEI@tut.ac.za.

DECLARATION: CONFLICT OF INTEREST

A researcher and supervisors (both external and internal) will not benefit financially from conducting this study. This study is strictly for academic purposes.

A FINAL WORD

Your co-operation and participation in the study will be greatly appreciated. Please sign the underneath informed consent if you agree to participate in the study. In such a case, you will receive a copy of the signed informed consent from the researcher.

Thank you.

Yours truly,
Mr Tebogo Ndhlovu

INFORMED CONSENT

I hereby confirm that I have been adequately informed by the researcher about the nature, conduct, benefits and risks of the study. I have also received, read and understood the above written information. I am aware that the results of the study will be anonymously processed into a research report. I understand that my participation is voluntary and that I may, at any stage, without prejudice, withdraw my consent and participation in the study. I had sufficient opportunity to ask questions and of my own free will declare myself prepared to participate in the study.

Research participant's name: ________________________ (Please print)

Research participant's signature: ___________________________

Date: ___________

Researcher's name: TEBOGO NDHLOVU

Researcher's signature: T NDHLOVU

Date: