

EXPERIENCES OF PATIENTS WITH CHRONIC RENAL FAILURE  
REGARDING HEMODIALYSIS IN OSHANA REGION,  
NAMIBIA

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## **DEDICATION**

I dedicate this study to his excellence Founding Father Dr Sam Shafiishuna Nuuyoma, for his distinguished support and care through Sam Nuuyoma Scholarship Foundation and my daughters Rosa Shange-Elao Angula and Felisa Mercy Haufiku. This is for you!

## **DECLARATION**

I, Auguste N. Petrus, hereby declare that this study is my own work and is a true reflection of my research, and that this work, or any part thereof has not been submitted for a degree at any other institution.

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## **ABSTRACT**

**Motivation:** Hemodialysis is a life-sustaining procedure for the treatment of patients with chronic renal failure. Long-term hemodialysis therapy is very costly, time-extensive and requires adherences to treatment regimens, fluids and dietary restrictions. This usually results in many limitations such as freedom, social life, physical activities and loss of financial income. These changes affect the whole person and may also affect how the patients on hemodialysis experienced it. All health care workers need to understand the experiences of patients on hemodialysis in order to give proper evidence-based quality care. It is against this background that a descriptive study on the patient's experiences with chronic renal failure on hemodialysis was undertaken.

**Aim:** The overall aim of this study was to explore and describe the lived experiences of patients diagnosed with chronic renal failure on hemodialysis in the Oshana Region of Namibia with the intention of making recommendations on how to address future improper administration of hemodialysis procedures.

**Methods:** The research design was qualitative, explorative, and descriptive in nature. The population consisted of participants who were diagnosed with chronic renal failure on hemodialysis, and purposive sampling was utilized. The data was collected through in-depth interviews conducted at an intermediate hospital in Oshakati. A total of twelve (12) participants were interviewed, and the data collection ended as saturation was reached. The sample size was determined by saturation of data as reflected in repeated themes. Data on participant's experiences with chronic renal failure on hemodialysis was obtained through individual interviews. During these interviews, participants were asked one (1) central question: "What are your experiences as a patient with chronic renal failure on hemodialysis?" followed by probing questions to encourage the participants to expand on the given responses. Interviews were tape recorded and field notes were taken during the interview to ensure that all experiences of the participants were captured. Interview data was transcribed verbatim. The data was analyzed according to Tesch's eight (8) steps of coding.

**Findings:** The study findings were presented in six (6) main themes namely; diverse emotions and misconceptions regarding chronic renal failure and hemodialysis as

experienced by the participants, the effects of hemodialysis, challenges encountered by participants during hemodialysis treatment, experiences regarding lifestyle modification, experiences with regard to coping with the condition and strategies for improving the care of chronic renal failure patients on hemodialysis.

Findings revealed that hemodialysis patients have different experiences: experiences of lifestyle modification, experiences of physical discomfort and physiological body changes, problems and challenges such as financial burden.

**Recommendations:** It was recommended that supportive care toward patients with chronic renal failure on hemodialysis should be emphasized to reduce the burden from various experiences. Community mobilization and health education programs as well as support groups to create awareness should be established to improve the quality of life, improve their knowledge to foster life style changes. Furthermore, there is a need for extensive and intensive research in this area.

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## **LIST OF ABBREVIATIONS**

<b>CRF</b>	Chronic renal failure
<b>HD</b>	Hemodialysis
<b>HIS</b>	Health Information System
<b>IHO</b>	Intermediate Hospital Oshakati
<b>MOHSS</b>	Ministry of Health and Social Services
<b>PS</b>	Permanent Secretary
<b>UNAM</b>	University of Namibia

# CHAPTER ONE

## INTRODUCTION AND BACKGROUND

### 1.1 INTRODUCTION

Hemodialysis is a procedure where a dialysis machine and a special filter called artificial kidney or dialyzer are used to clean the blood of a person with chronic renal failure. Thus, it is a life-sustaining procedure for the treatment of individuals with chronic renal failure. Chronic renal failure refers to a condition involving a decrease in the kidneys' ability to filter waste and fluid from the blood resulting in uremic encephalopathy, metabolic acidosis, and endocrine disorders (National Kidney Foundation, 2018).

However, this condition requires artificial means of excretion for survival. Saroj and Chithra (2017) stated that hemodialysis is the most common protective treatment process in which toxic nitrogenous substances, water, and electrolytes are refined by a hemodialysis machine three times a week for six hours at the hemodialysis unit. Consequently, patients with chronic renal failure on hemodialysis do not get cured and depend on hemodialysis for their whole life, experiencing serious physiological, psychological, and socio- economic implications (Rojas, 2017).

Nevertheless, hemodialysis is one such form of therapy that enables patients to live longer and healthier lives. Yet, the outcomes of treatment are not certain, and the experience of living between the promise of treatment, prolonged life, or cure and the threat of disease progression is not well understood (Mulongeni, 2016). The required time commitment for this life-sustaining therapy must be integrated into the daily routines of individuals. Additionally, long-term hemodialysis therapy is time-consuming, expensive and requires adherence to medication regimens and several restrictions, including sexual, marital, work and financial, fluid and dietary restrictions, in order to accommodate the patient's illness (Shash & Chithra, 2017). However, it has been argued that a number of restrictions and modifications accompanying this treatment have a detrimental impact on the quality of life and affect an individual's physical and psychological wellbeing.

Hence, the patient's ability to adapt is influenced by many factors such as: the quality of family relationships, life development stage, personal beliefs about health and cultural values, communication, technological developments, family structure, race, age, low facilities, inadequacy of counseling for facilitating adaptability, and lack of mechanisms for changing jobs and employment (Jha, 2019). In addition, the adaptation process promotes survival, growth, reproduction, mastery, and transformations of people and the environment. Jenaabadi and Mir (2019) stated that the most frequently used adaptation method was to put trust in God. On the other hand, Shash and Chithra (2017) found that the most common coping strategies used by patients and their families are, when they are being socially supported by them in order to maintain a sense of normalcy. In addition, the families also described the importance of communication to all family members to decrease stress and help them in the adaptation process.

In spite of all these changes in patients' lives, which have a negative effect on patients, their family and their community, most studies have placed attention on the medical and clinical dimensions of chronic renal failure. Few studies around the world have given attention to the experiences of those patients. Therefore, nurses and health professionals need to understand the experiences of patients with chronic renal failure regarding hemodialysis in order to respond appropriately to these physical, psychological, emotional, and spiritual changes. Thus, the purpose of this study is to explore and describe the experiences of patients on routine hemodialysis treatments from their own perspectives.

## **1.2 BACKGROUND TO THE STUDY**

Chronic renal failure is a worldwide public health problem in terms of incidence and prevalence. According to Cockwell and Fisher (2020) diseases of the kidney and urinary tract infections contribute to the global burden with approximately a million deaths every year. Hemodialysis continues to be the most common mode of therapy worldwide, evidenced by data showing that, in over 79.6 percent of reporting countries, at least 80 percent of patients are on this mode of therapy (Van, Duangpaeng, Deenan & Bonner, 2019). Himmelfarb, Vanholder, Mehrotra and Tonelli (2020) indicated that chronic renal

failure significantly impacts the activities of daily living as it affects physiological and psychological functions. The rate of people needing hemodialysis has increased more than 40% since 1990; consequently access to this life-saving treatment is still markedly inequitable. From the current global perspective: current costs are not sustainable, even for high income countries and globally most people who develop chronic renal failure forego treatment, resulting in millions of death every year. It is further stated that despite a rapid expansion in the provision of hemodialysis and most notably in high income countries (HIC), the rate of true patient-centered innovation has slowed down. To improve bodily functions and prolong life, patients require renal replacement therapy in the form of hemodialysis. According to a study conducted in South Africa by Ward (2018) 95 percent of patient experiences many difficulties in socioeconomic limitations and 15 percent rely on state funding or aid hence they tend to undergo significant financial expenditures related to the burdens outside psychological needs.

In sub-Saharan Africa, chronic renal failure affects young adults aged 20–50 years and is primarily due to hypertension and glomerular disease. There is a challenge of a large number of patients with chronic renal failure and inadequate hemodialysis facilities, lack of funding, and an unavailability of support systems. According to a qualitative study conducted by Al Arabi (2020), it was revealed that the current dialysis treatment ranges from 100 million dollars per person in South Africa and less than 20 per million dollars per population in most of sub-Saharan Africa. The five-year survival rate of this population is 50%, and the 10-year survival rate is 30%. In this population, 71.4% have either diabetes or cardiovascular disease, which significantly increases mortality risk (National Kidney Foundation, 2018).

Namibia is one of the African countries that have been affected by the challenges of non-communicable diseases such as chronic renal failure, as reported by Katjitae that the prevalence of chronic renal disease is increasing and more than 300 Namibians are on hemodialysis treatment for renal failure (Mulongeni, 2016). Hence, renal failure is ranked as the fourth of the top five causes of death for all ages in Oshana. In the same vein, 98 people died of renal failure in the year 2016 (Ministry of Health and Social

Services: Oshana regional directorate, March, 2017). The number of patients on hemodialysis in Oshana region was 72.

### **1.3 PROBLEM STATEMENT**

Hemodialysis is a lifelong treatment that is time-consuming, expensive, and requires adherence to medication regimens. Patients on hemodialysis are adapting poorly to hemodialysis and find it difficult to cope with everyday challenges. The researcher has observed that patients with chronic renal failure have different experiences and express different emotions regarding hemodialysis. Some patients even demanded and requested the dialysis catheter to be removed in order for them to discontinue with hemodialysis. However, patients with chronic renal failure on hemodialysis need to be equipped with the necessary knowledge to facilitate compliance and slow down the cumulative effects on other organs. Consequently, as cited by Saroj and Chithra (2017) on lived experiences of patient undergoing hemodialysis, patients on hemodialysis face many challenges due to their illness and hemodialysis therapy.

In Thailand, a study conducted by Dejvorakul, Kumar, Srirojanakul, Panupichit and Somrongthong (2019) about the factors predicted with quality of life among hemodialysis patients, revealed that patients on hemodialysis do not only experience treatment-related stressors but also deal with changes in self-concept, self-confidence, family role reversal, and loss of dignity. Similarly, Rohini and Punitha (2016) stated that patients on hemodialysis experience many lifestyle restrictions that significantly influence their social functioning, illness, beliefs, and sense of personal control, leading to anxiety and depression and inhibiting coping and adjustment. Hence, findings from studying experiences of chronic renal failure patients on hemodialysis will help to improve health care services by proposing collaborations between health professionals, researchers and policy makers to design solutions for the encountered problems.

However, to date, no in-depth study has been undertaken locally regarding the experience of patients who have been diagnosed with chronic renal failure and are receiving hemodialysis. It is also not known as to how patients are effectively prepared for hemodialysis and educated on the lifestyle changes associated with chronic renal failure. This study findings will fill the gaps by exploring the real experiences of chronic

renal patient on hemodialysis. It is for this reason that the guiding research question was: What are your experiences as a patient with chronic renal failure on hemodialysis?

#### **1.4 SIGNIFICANCE OF THE STUDY**

The study findings will help health care providers to identify changes in practice that will be necessary to integrate best holistic practices into standardized care for this population. It will also contribute to the body of nursing knowledge by helping nephrology nurses to realize the needs of patients on hemodialysis and to give supportive care so that these patients can continue to be active, non-dependent, and contributing members of society. Study findings on the experience of patients with chronic renal failure regarding hemodialysis may be introduced in the nursing curriculum to serve as a guiding tool for academic learning so that student nurses will be fully equipped with valuable insight regarding patients' experiences to enable them to advocate for patients.

#### **1.5 PURPOSE OF THE STUDY**

The purpose of this study was to explore and describe the experiences of patients with chronic renal failure regarding hemodialysis in Oshana region, Namibia.

#### **1.6 OBJECTIVES**

The objectives of the study were to:

- Explore the experiences of patients with chronic renal failure regarding hemodialysis in Oshana, Namibia.
- Describe the experiences of patients with chronic renal failure regarding hemodialysis in Oshana, Namibia.

## **1.7 PERSPECTIVES ON PARADIGMS**

Research paradigms, as defined by Shajahan (2019), are long-established practices within the academic community for conducting generally accepted types of study. A paradigm is a pattern that is used to illustrate theoretical points and provides a tool to identify one's own worldview (Thomas & Dave, 2017). Creswell (2018) chimed in to say that both positivism and interpretivism stand out as viable theoretical frameworks from which new research paradigms can develop. This study employs an interpretivism paradigm because of this reason. In nursing, interpretivism paradigms is viewed as a set of assumptions, a framework, or a worldview that is based on people's philosophy about the social world, the nature of knowledge, and how the researcher understands and interprets the material about reality (Kumar, 2018). Therefore, a paradigm acts as a perspective that provides a rationale and commits the researcher to a particular method of data collection, observation, and interpretation.

A paradigmatic perspective implies a collection of meta-theoretical and theoretical assumptions that guide the research process (Gournelos, Hammonds & Wilson, 2019). Paradigm played a very important role in this study by influencing the research problem, identification of research methods and the relevant data collection techniques, analysis and interpretation of the research findings. Hence, interpretivism paradigms assisted in structuring the research question of this study. Since this study interpreted the study's components and since interpretivism research provides several perspectives to the researcher, it fits under the interpretivism paradigm (Baker, 2018). The researcher had selected the following assumptions from the paradigmatic perspective based on the research domain.

### **1.7.1 Meta-theoretical assumptions**

According to Polit and Beck (2021), meta-theoretical assumptions are more or less conscious or unconscious assumptions behind theoretical, empirical and practical work. They serve as a framework within the researcher's view of human beings and society. Assumptions are accepted for the purpose of the investigation at hand, and they function

as foundational beliefs or statements that support whatever decisions the researcher makes throughout the research process. Meta-theoretical assumptions with regard to person, health, environment, and nursing were considered.

#### **1.7.1.1 Person**

A person represents an individual, a family member, a community or even the whole human race. In this study, a person represents the patients diagnosed with chronic renal failure who is receiving hemodialysis for this chronic condition, a family member of the patient, the nurse, and the researcher. According to Alligood (2018), in the nursing meta-paradigm, a person promotes the practice of satisfying human needs through human care. It is believed that every individual patient has their own unique and an unpredictable set of needs, and it is imperative to accept and honor a person's needs regardless of their race, customs, and beliefs.

However, for each person to be fully healed, a holistic approach which focuses on the mind, body, and soul is imperative. Each individual patient needs to be valued and understood with the nurse always being authentically present and each patient deserves the right to have their dignity maintained at all times. Moreover, the person constantly interacts with the internal and external environment in a biophysio-psychosocial manner to achieve his wholeness. This may encompass things such as a person's spirituality, culture, family and friends or even their socioeconomic status (Nikfarid, Hekmat, Vedad & Raab, 2018). For example, a patient who has suffered a chronic renal failure may feel powerless and vulnerable. It is of utmost important for the nurse to understand his experiences and spend quality time with the patient in order to prevent these types of feelings from occurring.

#### **1.7.1.2 Health**

According to Sian (2017), health is defined as unity and harmony within the mind, body, and soul of an individual. It is also a state of wellbeing. It represents a total absence of physical disease and other health-threatening social problems. Although curing is important, it is much more than a physiological response, and for health to be achieved,

a holistic approach with a patient needs to be taken. Moreover, for healing to be effective, it is essential for all the components to be unified and functioning at their highest capacities for an individual to achieve health (Alligood, 2018).

In this study, the health of a patient suffering from chronic renal failure is very important because it enables them to reflect on themselves, to symbolize their experience, and communicate with others. Another crucial aspect of health involves nursing assessment. To maintain optimal health, it is important to assess patients based on their individual health needs and experiences with chronic renal failure. Patients with chronic renal failure require multiple assessments daily depending on their conditions. This can be accomplished through implementation of nursing care plans that are structured not only to treat current illness but also to assess and prevent potential illness as well.

### **1.7.1.3 Environment**

Nikfarid, Hekmat, Vedad and Raab, (2018) stated that environment is a context, background, physical surrounding or place inhabited by a person or where a patient lives or finds him or herself. Patients find themselves at different places or environment such as at the villages, towns and health facilities. Therefore, the concept of environment is crucial due to the fact that it directly impacts the patients. A therapeutic environment that embodies the ideas of safety, support and health will improve patient's outcome. This is because therapeutic environment facilitates patients' health and improve their health care experiences.

In this study, the environment refers to both internal and external physical surroundings in which patients find themselves which influence their health. The variables of the internal environment include the body, mind, and spirit. Interaction in the environment is necessary as it influences various health threats, such as chronic renal failure, and helps these individuals utilize resources to promote their health (Yoo, Lim & Shim, (2020). The environment of a patient on hemodialysis includes both internal and external factors, where the internal environment includes the total well-being of the patient such as their state of mind, emotional stability, and physical wellbeing. This ultimately

determines how these patients thrive towards restoration of their health. In terms of the external environment, their diet plays a crucial role, as does the ventilation, physical fitness, and the availability of proper resting facilities.

#### **1.7.1.4 Nursing**

Nursing is a learned, practical, humanistic profession that contains a body of knowledge that is practiced as part of the profession for the purpose of assisting human beings to maintain maximum health and wellbeing (Mosby, 2021). It is the paradigm of compassion, the reason nurses become nurses: to help and ease suffering. The meta-theoretical assumption with regards to nursing is that a nurse is someone who should not only understand the science of physiology behind an illness when treating patients but should also genuinely care for the well-being of others. Nurses should possess compassion and empathy and be able to set aside any personal biases regardless of things such as religion, race, and socioeconomic status (Leone, 2021).

Patients with chronic renal failure receive nursing care at two levels depending on the severity of their condition: at an out-patient level and at an in-patient level when they are admitted. In this study, the nurse and the patient interact mainly at both inpatient and outpatient level.

#### **1.7.2 Ontological assumptions**

Ontology is a philosophical belief system about the nature of the social reality that can be known and how it can be known. Ontology is defined by Moon and Blackman (2018) as “the study of being”. It is concerned with what actually exists in the world about which humans can acquire knowledge. Ontology helps the researcher to recognize how certain one can be about the nature and existence of objects they are researching. Killam (2020) stated that ontological assumptions relates to the existence of one single reality which can be studied, understood and experienced as a truth according to how individuals experiences it at any given time and place. A researcher’s ontological

assumptions impact the topic selection, the formulation of research questions, and strategies for conducting the research.

The ontological assumption in research entails an indication of the researcher's preference by specifying what are considered truths about knowledge, information, and the world (Hashil, 2021). The conscious and unconscious questions, assumptions and beliefs that the researcher brings to the research project serve as the initial basis for an ontological position. Moon and Blackman (2018) further stated that qualitative researchers believe that people construct their own reality through their lived experiences (ontological perspective) and support the theory that knowledge is developed by interacting with people, and that we construct our own interpretation and meaning of the experience (epistemology) within a phenomenological methodology. This is done by using methods such as interviewing and observation. In this view, the research question is not about the reality of the world, but about people's interpretation of that reality.

In this study, reality is contained in various experiences of the participants. It is assumed that every patient with chronic renal failure on hemodialysis in Oshana region had different experiences. The central question to be answered by the participants was, "What are your experiences as a patient with chronic renal failure on hemodialysis?" The leading assumption was patients on hemodialysis in Oshana region had different experiences after being diagnosed with chronic renal failure. The question attempted to explore how the phenomenon is subjectively explained or viewed by the participants as well as to determine the extent of the truth about the particular phenomenon (Hashil, 2021). The researcher used direct quotations from the in-depth interviews to validate the data and they are included in chapter 3. On the other hand, themes and sub-themes were developed that gave clear meanings to the experiences and the reality of hemodialysis patients with chronic renal failure (Gray & Groove, 2020).

### **1.7.3 Epistemological assumptions**

This refers to the assumptions we make about the kind or the nature of knowledge, or how it is possible to find out about the world. Killam (2020) stated that epistemology is about the assumptions which one makes about “the very bases of knowledge, its nature and form, how it can be acquired and how it can be communicated to other human beings”. The epistemology is about the information that counts as acceptable knowledge and how it should be acquired and interpreted. On the other hand, epistemology addresses the origins, nature, methods, and limits of human knowledge while focusing on questions relating to the nature of knowledge. The researcher’s epistemological and ontological positions form the philosophical basis of a research project.

The researcher interacted with the participants and obtained the findings through in-depth interviews. The researcher attempted to address the question by collaborating and investing time in data collection activities that facilitated an in-depth understanding of the experiences of patients with chronic renal failure on hemodialysis (Creswell, 2018). Simultaneously, the researcher also gained an in-depth understanding of the phenomenon as well as specific views, perceptions, cultural background and experiences from the participants. Therefore, epistemology is concerned with all the aspects of validity, scope and methods of acquiring knowledge, how knowledge can be acquired and how the extent of its transferability can be assessed.

In this study, it is assumed that data collected through semi-structured in-depth interviews with patients with chronic renal failure on hemodialysis in Oshana region Namibia enabled the researcher to gain knowledge regarding the experience of patients with chronic renal failure.

### **1.7.4 Axiological assumptions**

Axiology refers to the role of values and addresses the nature of ethical behavior (Babbie & Mouton, 2019). In research studies, axiology is concerned with the nature and meaning of values and judgement in the research process and how it had been applied to uphold ethics. Basic beliefs about what is ethical are embedded in research paradigm

and guide the research decision making. According to Dean (2018) axiological assumptions try to address what is considered ethical and moral behavior by the researcher, and how one's values influence the research question and design. Axiology also includes how people view themselves in relationship to others with more emphasis on the role of values and ethics in research. Moreover, phenomenological researcher attempt to bracket out prejudice and discern the essence of the phenomenon through being unbiased regarding the significance ascribed to it by those who experienced it (Aledo-Tur & Dominguez-Gomez, 2017). Values shape the interpretations made by the researcher as well as those of the participants. The purpose of the study needs to be balanced with what the researcher values as well as other ethical consideration in the conduct of the research. In this study it can be assumed that participants with chronic renal failure on hemodialysis brought their own values and were truthful and honest when expressing their experiences during the individual interviews. The researcher continuously identified and examined her own beliefs and opinion regarding the phenomenon under study and strived to remain objective regarding the experiences of patients with chronic renal failure regarding hemodialysis.

#### **1.7.5 Rhetorical assumptions**

The rhetoric of research is the art of speaking or writing effectively. It refers generally to how language is employed and includes the art of persuasion or elaboration in literature (San Diego State University, 2021). The rhetorical structure of research paper pertains to how the researcher goes about persuading the reader of the paper's worth. The overall rhetorical assumption in qualitative research is not truth seeking as such, but instead reporting on reality through the eyes of the research participants. This applied to all studies, as it reports on what was seen and heard in the most objective possible way. There are certain formatting expectations for all scientific rhetorical reports such as APA style and more specific expectations for different types of research. The research paper's rhetorical style is therefore referred to as a humanistic interpretation and a description of the research results (Creswell, 2018).

Qualitative methods express the assumptions of a positivistic paradigm, which holds that behaviour can be explained through objective facts. Design and instrumentation indicates how bias and errors are eliminated. Rich descriptions show that the researcher

was immersed in the setting, whereby the reader is given enough detail to make sense of the situation (Denscombe, 2019). In this study, the researcher reported on what she saw through her observations and heard during the interviews, enabling the researcher to engage in a discussion with participants about their experience with chronic renal failure regarding hemodialysis. Purposive sampling was employed to enable the researcher to identify the participants with experiences regarding hemodialysis. Detailed descriptions were obtained from the participants during the individual interviews.

### **1.7.6 Methodological assumptions**

Methodological assumptions are philosophical assumptions that guide the research process (Thomas & Dave, 2017). In this context, it is concerned with the process and procedures of scientific research and involved the controlled and approved methods according to which the researcher will conduct the research study to generate knowledge. A qualitative approach has been used for this study because it is more convenient to explore and describe the experiences of the participants in their natural setting.

Qualitative research is concerned with the in-depth description of people or events as the researcher attempts to obtain rich, real, and deep validity data. It focuses on gaining insight and understanding about an individual's perception of events (Nieswiadomy, 2018). The researcher believes that the participants will relate their own experiences through qualitative design by means of an explorative method. This approach involves collection of real life stories expressed by participants themselves. It required the researcher to become intensively involved in the participants' real world. This interaction between the participants and the researcher leads to understanding of the patients experiences, thus the quality of the research study and trustworthiness of the study findings is enhanced (Creswell, 2018).

Methodological assumptions deal with the question on how the researcher attains knowledge of the participants regarding the research phenomenon. In this study the researcher explored the experiences of patients with chronic renal failure on hemodialysis in Oshana Namibia and the researcher served as a research instrument by

utilizing in-depth interviews as the primary method of collecting data and the data were analyzed qualitatively. The study's conclusions revealed the need to support patients with chronic renal failure on hemodialysis to help them cope with the challenges emanating from hemodialysis procedure.

### **1.7.7 Theoretical assumptions**

Theoretical assumptions are measurable and testable statements derived from theories and models. These assumptions are useful in directing research decisions and often pronounced in the research field which forms part of the existing and accepted theory of a discipline (Jelen-Sanchez, 2017). Moreover, assumptions give shape to central theoretical statements and conceptual framework of the study. In this study, the theory of nursing systems: a partly compensatory and supportive- educative nursing system of Orem's theory of 2001 was used by the researcher to guide the research process. Orem's perspective in nursing is based on the idea of self-care as a strategy for coping with life events and tensions (LoBiondo-wood, 2021). However, it should be noted that study results were reflected within these theories after data was collected and data analysis was finalized. The researcher collected the data without pre-conceived ideas or opinion-refrained from being influenced by pre-existing knowledge.

## **1.8 OPERATIONAL DEFINITIONS**

For the purpose of this study, the following concepts or terms have been defined operatively as follows:

### **Experience**

This entails the first-hand subjective perception of one's experience of health or illness (World Health Organization, 2019). In this study, lived experience refers to how patients go through their life experiences with regard to social life, working life, family life

including their sexual lives after being diagnosed with renal failure and put on hemodialysis.

### **Patient**

A patient refers to a person receiving medical treatment (Dawn & Sian, 2017). In this study, "patient" refers to a person with chronic renal failure who has been put on hemodialysis.

### **Chronic renal failure**

A condition characterized by a gradual loss of kidney function over time (Chiaranai, 2016).

### **Hemodialysis**

A medical procedure to remove fluid and waste products from the blood and to correct the electrolyte imbalance of a person whose kidneys are not functioning normally (Laffin, Liakiopoulus, Saadi, Tantisattamo, Ulasi & Lui, 2022).

## **1.9 CHAPTER ORGANIZATION**

This chapter comprises of four chapters which are presented in line with the guideline of postgraduate writing of University of Namibia.

### **Chapter 1: Introduction and historical context**

This chapter covers the introduction and background of the study and thereby sets the scene for the research. The problem statement, significance of the study, purpose for the researcher to conduct the study, the study's objectives as well as the perspectives on paradigms and operational definitions are included in this chapter.

### **Chapter 2: Research methodology**

The methodology that the researcher adhered to during the study is described as well as ethical considerations, data collection methods and the processes followed. It also contains the measures employed to ensure trustworthiness during the study.

### Chapter 3: **Discussion of the findings**

In this chapter, analysis of the data, discussion and the literature control are described. Themes and sub-themes that emerged are also outlined in this chapter, as well as the literature that supports the study's findings. Direct and verbatim quotes from interviews and field notes are incorporated and aligned with the discussions. Various similar findings obtained by other researchers are reflected on in this chapter, and the literature is integrated into the discussions to serve as additional evidence of the study's findings.

### Chapter 4: **Conclusions and recommendations**

As the study's last chapter, this chapter outlines the conclusion and the summary of the findings in context. In addition, it includes information on limitations and recommendations with regard to the experiences of patients with chronic renal failure regarding hemodialysis in Oshana region. The conclusions were used to determine whether the study's objectives were achieved. Therefore, the conclusion was based on the study's findings, which addressed the research question.

## **1.10 SUMMARY OF CHAPTER ONE**

The purpose of the study was to explore and describe the experiences of patients with chronic renal failure on hemodialysis in Oshana region, Namibia. In this chapter the background to the problem, the problem statement and the significance, purpose and objectives of the study were discussed. The paradigmatic perspectives: meta-theoretical assumptions, ontological assumptions, axiological assumptions, rhetorical assumptions, methodological assumptions as well as theoretical assumptions on which the study is based were thus outlined. Chapter two (2) consists of a comprehensive discussion of the research designs and methods.

## **CHAPTER TWO**

### **RESEARCH METHODOLOGY**

#### **2.1 INTRODUCTION**

In the previous chapter, the researcher described the introduction and historical context of the study, problem statement, purpose of the study as well as the objectives of the study. Moreover, the previous chapter explained the study significance, paradigmatic perspective, meta-theoretical assumptions, definition of concepts and the summary of chapter one.

In this chapter, the researcher explains the study design and methods used to conduct this research study. It includes study population, sampling, research instrumentation, and data collection procedures. A research design is the overall plan for gathering data in a research study (Patton, 2018). It also refers to a set of logical arrangements from which a prospective researcher can select one that is suitable for their specific research goals.

Research methodologies are the principles and ideas on which researchers base their procedures and strategies. The researcher briefly describes the methodology adopted and the reasons and justification for it (Creswell, 2018). In this chapter the focus will be on the methodology used under the following headings; research design, population, sample and sampling, data collection, pilot study, data analysis, ethical consideration as well as measures to ensure trustworthiness.

#### **2.2 RESEARCH DESIGN**

A qualitative, exploratory, contextual, and descriptive approach was used to conduct the study to elicit the first-hand experiences of patients with chronic renal failure regarding hemodialysis. Qualitative study focuses on describing individual experiences and is particularly useful for understanding people's beliefs and perceptions, which aims to

describe the phenomena under study in real-life situations (Holloway & Galvin, 2016). In this study, a qualitative design utilized in-depth individual semi-structured interview as a tool to capture the true meaning that underpins the reality of living with chronic renal failure on hemodialysis.

The researcher adopted the descriptive method to obtain rich detailed, descriptive insight into a phenomenon, of which is, patients' experiences regarding hemodialysis, typically through examining the meaning and interpretation of data derived from using semi-structured individual interviews and direct observation with relevant population to provide information related to the study (Denscombe, 2019). Thus it enabled people outside the phenomenon to understand the reality of those inside the phenomenon, namely, patients' experiences regarding hemodialysis.

### **2.2.1 Qualitative design**

Qualitative research explores attitudes, behaviors, and experiences and attempts to obtain an in- depth view from the participants (Timpany, 2020). This refers to a broad range of research designs and methods used to study phenomena of social action about which we do not have an understanding. Qualitative research usually commences with a conscious effort where the researcher tries to avoid preconceived ideas regarding the phenomena under study (bracketing).

It focuses on the qualitative aspect of meaning, experience, and understanding, and these methods are used to study human experiences from the point of view of the research participants in the context in which the action takes place (Brink, 2018). A qualitative design was used because it is regarded as a systematic approach that would allow the researcher to explore the experience of patients and their problems in totality. A qualitative design was selected for this study for the following reasons: it examines human experiences through the rich and thick data that was obtained from the participants concerning their life experiences. In this study, the focus was on the experiences of patients who are living with chronic renal failure and on hemodialysis. According to Kumar, (2018), qualitative research studies involves the collection of verbal data from a small number of participants, organizing the data into themes and also

uses verbal descriptions to explain the phenomenon under study. Hence, in this study verbal data about the experiences of chronic renal failure patients regarding hemodialysis were collected through in-depth semi-structured individual interviews, then organized into themes and sub-themes and thoroughly described using quotes from the verbal descriptions of the participants.

The data was collected in a natural setting at Intermediate Hospital Oshakati in the Oshana health region. To ensure that the researcher has selected the right participants with relevant experiences of the subject under study, purposive sampling was used. According to Creswell (2018), purposive sampling considers only participants with specialty knowledge and experience on the topic under study. This eliminates the chances of dealing with participants with irrelevant data about the study. The researcher was interested in the meanings implied in the ways in which the participants made sense of their lived experiences as well as the structures they encountered in their world (Creswell, 2018).

### **2.2.2. Explorative design**

An exploratory research design is conducted for a problem that has not been studied more clearly (David, 2017), and it aims at establishing the facts in order to obtain and gather new data to gain insight into a phenomenon. Exploratory research in this case was conducted to gain insight in respect of the experiences of patients with chronic renal failure regarding hemodialysis in the Oshana region.

The purpose of this study aimed at examining the participants' experiences by way of conducting an in-depth study in which a certain individual or group experienced the phenomenon of which a researcher had little knowledge about (Babbie & Mouton, 2019). Thus, the study facilitated the gathering of new ideas that helped the researcher to obtain a broad view of what is actually happening in the life of patients with chronic renal failure on hemodialysis. In addition, the researcher explored the experiences of patients with chronic renal failure on hemodialysis in the Oshana region through semi-structured individual interviews and got a deeper understanding of the participants' life stories. An extensive literature review related to the phenomenon under study was

undertaken. Subsequently, literature control, identification of the concepts, themes, and subthemes were described in chapter three of this study.

### **2.2.3 Descriptive design**

Patton (2019) defines descriptive research as "a study with the main objective of describing an accurate portrayal of the characteristics of persons or situations." Descriptive research design gives a picture of a specific situation and it focuses on finding the answers to the how and why questions.

Holloway and Galvin (2016) further explain that the purpose of a descriptive design is to observe, describe, and document aspects of a situation as it naturally occurs, with the purpose of serving as a starting point for theory generation. A qualitative descriptive design was used to gain accurate data and comprehensive understanding by giving the participants time to describe their experiences with regard to hemodialysis. The participants provided information about the phenomenon under study through semi-structured individual interviews that were conducted at Intermediate hospital Oshakati.

### **2.2.4 Contextual design**

The study's context refers to the environment and the conditions in which the study took place, as well as the participants' culture and location (Nieswiadomy, 2018). It is important to understand the context in which the research study was conducted. Therefore, the context is the situation in which a research project takes place and comprises of human, environmental, professional, and organizational qualities (Babbie & Mouton, 2019). According to Mays (2020) contextual study is any study wherein the phenomenon of interest is studied in terms of its immediate context. Context refers to a particular setting in which a study is taking place, which can include the environment, people, and so forth. If the researcher understands the context, she can locate the experiences of participants and grasp the meanings that they communicate, because in qualitative research the events and actions are studied as they occur in an everyday, real life setting.

The purpose of using a contextual design in this study was to study the experiences of the patients with chronic renal failure on hemodialysis, and the study was conducted in an urban area at their own health facility, namely Intermediate Hospital Oshakati in the Oshana region, Namibia. Qualitative researchers focus on describing and understanding events in their natural context and claiming that these events are understood (Nettina, 2018). It is therefore important for the researcher to be sensitive to the context of the research and immerse herself in the setting and situation because both personal and social context are important. Thus, a contextual design provides an understanding of the circumstances that shape human meanings.

### **2.3 RESEARCH SETTING**

The study setting is the physical location of the research, for instance a ward in a hospital, a clinic or the community (Holloway & Galvin 2010). This study was conducted at Intermediate Hospital Oshakati, a public hospital in the Oshana region. It served as a referral hospital catering to the four northern regions of Namibia: Oshana, Oshikoto, Omusati and Ohangwena. The hospital consists of various departments including the outpatient department (OPD), the casualty department, the laboratory services department, the operating theatre, the central sterilization supply department (CSSD), the intensive care unit (ICU), the dental clinic, the physiotherapy department, the communicable diseases clinic (CDC), the eye clinic, the nuclear medicine department, the plastic surgery department, the x-ray department and the male circumcision department. This study was conducted through in-depth semi-structured individual interviews with chronic renal failure patients on hemodialysis in the following departments/wards: dialysis unit (private ward 1), male internal medicine department (ward 7) and female internal medicine department ward (ward 8).

### **2.4 POPULATION**

Jooste (2018) confirms that a population is the whole group of people or an object that is of interest to the researcher and shares the same characteristics. The population for this

study was all patients with chronic renal failure on hemodialysis at the Intermediate Hospital Oshakati units. The estimated total population of patients with chronic renal failure on hemodialysis in Oshana is seventy two (72) (Ministry of Health and Social Services: Oshana regional directorate, March, 2017) of which a sample size of 12 participants who met the inclusion criteria were interviewed.

**Inclusion criteria were:**

- All the patients with chronic renal disease as a medical diagnosis, on hemodialysis, who are over the age of 18 years and who were treated at the Intermediate Hospital Oshakati dialysis unit were included in this study.
- Patients who have been on hemodialysis for five (5) months or more.

**Exclusion criteria were:**

- All the critically ill patients with chronic renal failure as a medical diagnosis and who are on hemodialysis.
- All patients with chronic renal failure as a medical diagnosis, on hemodialysis but less than 18 years of age.
- Patients who have only been on hemodialysis for less than five (5) months

## **2.5 SAMPLE AND SAMPLING**

According to Moser and Korstjens (2017), qualitative study uses criterion sampling in which participants meet predefined criteria. The most prominent criterion is the participant's experiences with the phenomenon under study. The researcher looks for participants who have shared an experience but vary in characteristics and in their individual experiences. Sampling is a process whereby the subjects or participants are selected from the target population to ensure that the selected subjects or participants are representative of the total (Jooste, 2018). A sample is a portion of the target population that contains characteristics of the population of interest and represents it (Gray &

Groove, 2020). The researcher applied a non-probability sampling technique utilizing purposive sampling to select the participants.

Purposive sampling enables the researcher to search for a particular participant who can illuminate the phenomenon under study, therefore allowing the researcher to include those who are especially knowledgeable regarding the question at hand which is chronic renal patient on hemodialysis. Nettina (2018) stated that purposive sampling maximizes the range of specific information obtained from a particular context and enable the researcher to purposively choose elements that one wants to include in the sample and exclude those that do not meet the selection criteria as mentioned above.

Purposive sampling was used because it is considered the most appropriate method to address the purposes and is useful for exploratory study (Giorgi, 2019). Hence it was used to explore and describe the experiences of patients with chronic renal failure regarding hemodialysis in Oshana region. Semi-structured Individual interviews were conducted, and the sample size of twelve (12) participants was determined by the saturation of data. According to Mertens (2016), saturation, therefore, refers to the moment when the subjects' descriptions become repetitive, with no new or different ideas emerging during the data collection process. The researcher purposefully select and handpicked participants who were more knowledgeable about the phenomenon under study, that is, renal failure patients on hemodialysis to get in-depth information about their experiences. The sample size was initially comprised of twenty (20) participants who met the inclusion criteria. During the actual data collection process only twelve (12) participants were interviewed due to the fact that data saturation was reached at participant number nine (9) and no new information was being obtained. Copland, (2016) recommended that qualitative sample sizes be large enough to allow the unfolding of a new and richly textured understanding of the phenomenon understudy but small enough to allow for deep, case-oriented analysis.

## **2.6 COLLECTION OF DATA**

Data collection is the systematic approach of gathering information from a variety of sources to get a complete and accurate picture of an area of interest (Jooste, 2018). The

actual steps of data collection are specific to each study and data collection entailed the collection, analysis and interpretation of the results regarding the experiences of chronic renal patient on hemodialysis in Oshana region. In this study, it was necessary to ensure cooperation between the participants and the researcher during the process of actual data collection. This was accomplished by thoroughly explaining the reasons for conducting this study to the participants and allowing them to participate voluntarily. In this study, the tape recorder and field notes were used during the interview to ensure that all the participant's expression were captured. Stahl (2020) cautioned about researchers without high quality data collection techniques, that the accuracy of the research results will be challenged. It is essential that the researcher is familiar with the various data collection techniques to enable him or her to choose the most suitable techniques for the study purpose, population and settings. Therefore, the best way to record the exact words during the interview is through tape recording (Aledo-Tur & Dominguez-Gomez, 2017).

### **2.6.1 Research instrument**

In qualitative study, the research instrument selected should be credible. Creswell (2018) stated that a credible or valid research instrument is the one that captures all the objectives of the study and will produce credible study results. An instrument that is not congruent to the objectives of the study is invalid or not credible. The semi-structured individual interview was used to gather the data because it is particularly an appropriate instrument for exploratory or qualitative research studies as it is more free-flowing in its structure and is limited only by the focus of the research (Gray & Groove, 2020). In this study, an interview guide was used as well as field notes as tools for data collection

#### **2.6.1.1 Semi-structured individual interview**

An individual interview is a method of data collection in which the researcher obtains responses from the participants during a face-to-face encounter. Conducting interviews

is one of the most common qualitative research methods. An interview procedure often involves a need for the researcher to establish rapport with and gain cooperation of the participants by making them feel comfortable and competent enough during the interview (Gray & Grove, 2020). This semi-structured individual interview was carried with one participant at a time and invites opportunities to get details in depth from the participants. The purpose was to ensure sufficient flexibility for the researcher to follow up on interesting ideas. Holloway and Galvin (2017) stated that one of the advantages of this method is that it provides a great opportunity to gather precise data about what people believes in and the motivation in such beliefs.

In addition, it also gives the researcher an opportunity to read the body language of the participants and match with their responses. It was conducted with participants who were regarded as key informant during a face-to-face encounter. Before the interview, the researcher invited and welcomed the participant in the interview room, and reassures the participant regarding confidentiality of the information shared. The researcher also requested consent from the participants after explaining the study objectives and requested for consent of the audio tape recorder. All the participants were informed about their right to seek for clarification if a question was not understood and their right to opt out of the study if they wished not to proceed anymore.

These interviews were held in a private room in which there was no possibility of intrusive noise. In this study, all participants were asked one question. The researcher started with a broad opening question: "Tell me about your experience as a patient with chronic renal failure on hemodialysis." The researcher used probing questions to encourage the participants to give more information or to elaborate more on the given answers. An interview guide was used to enable the researcher to maintain the consistency of the questions during the interviews and not to miss out on any question that could assist in the gathering of rich data. According to Creswell (2018), the purpose of the interview guide is to help the researcher to remember the points to cover especially with probing questions.

Mertens (2018) describe probing as eliciting more useful information. However, the participants' responses would determine whether a probing question should be asked for

more clarification of their experiences or not. This is a way of encouraging participants to talk more freely and explain themselves more clearly while providing detailed information. A total of twelve (12) participants were interviewed and soon after each interview was over, the researcher and the participant listened to the audio tape recorder to check for audibility and completeness of the recorded data. Verbatim transcription of each interview was commenced immediately to maintain rich description and to promote credibility of the study results.

#### **2.6.1.2 Field Notes**

Field notes were taken during each interview session and used after the interviews during data analysis. The researcher did this by writing verbatim notes (the exact words of the participants). The objective of this process is to remember what happened during the interviews and to incorporate and correlate this information with the tape-recorded data in order to meet the requirement of trustworthiness (Gil, 2016). Field notes are helpful in maintaining comments, environment contexts and nonverbal cues (Creswell, 2018).

Field notes also serve to supplement the data that cannot be portrayed by audio taped interviews; for example, nonverbal communications such as gestures, lack of interest, enthusiasm, and uncertainty, as well as a description of the layout of the health facilities. The researcher utilized these notes to interpret and infer where possible when certain narratives needed additional member checking.

#### **2.6.2 Data Collection Procedure**

Qualitative data collection allows collecting data that is non-numeric and help to explore how decision are made and provide detailed insight (Mays & Pope, 2020). In this study, the researcher conducted semi-structured individual face-to-face interviews with the participants at IHO using an interview guide and recorded field notes. The data collected was about the experiences of patients with chronic renal failure on hemodialysis. The researcher introduced herself to the participants and explained the purpose of the research to them.

The semi-structured individual interviews enabled the researcher to delve deeper into the information provided by the participants and obtain more comprehensive quality data (Sian, 2017). The interviews were audio recorded with the permission of the participants, and that ensured precise transcripts. Informed consent obtained included the purpose and objectives of the research study, methods and duration of the semi-structured individual interview.

### **2.6.3 Assurances of trustworthiness**

Trustworthiness is a term used in the evaluation of qualitative data by using specific criteria to establish the trustworthiness of the data. In addition, trustworthiness refers to the degree of confidence that the qualitative researcher has in their data by using the criteria of credibility, transferability, dependability and conformability (Stahl, 2020). The researcher applied these criteria to enhance the trustworthiness of this study.

#### **2.6.3.1 Credibility**

Credibility refers to the confidence in the accuracy of the data and the relevant interpretations (Thomas & Dave, 2017). Timpany (2020) pointed out validation strategies that are frequently used by qualitative researchers: prolonged engagement and persistent observation, peer review or debriefing, member checking, and external audits. Creswell (2018) added that some other techniques for enhancing credibility in qualitative research are saturation, member checks; audit trails, and peer debriefing. Prolonged engagement and persistent observations in the field include building trust with participants, learning the culture, and checking for misinformation that stems from distortions introduced by the researcher or informants (Creswell, 2018). Credibility is enhanced when the researcher spends long periods of time with the participants in order to understand them better and gain insight into their lives (Kumar, 2018).

Patton (2019) further stated that the common benefit from preliminary qualitative work is the researcher's ability to build relationships with people who will respond to his or her research questions. This not only allows the researcher to learn more about the people, but it also allows the researcher to get to know the research participants.

Peer review or debriefing provides an external check of the research process. Member check involves asking participants in the study to check whether they agree with the researcher’s interpretations of the findings (Denscombe, 2019). External audits allow an external consultant or auditor to examine both the process and the product of the account by assessing its accuracy. The table below shows how credibility has been applied in this study.

Table 2.1: Criteria and application of credibility

<b>CRITERIA</b>	<b>STRATEGY</b>	<b>APPLICATION</b>
<b>Credibility</b>  <b>(Truth Value)</b>	Prolonged engagement and field observation	<ul style="list-style-type: none"> <li>• The researcher is a registered nurse and has worked at male &amp; female medical ward.</li> <li>• This enabled the researcher to gain trust from the participants by establishing rapport with them.</li> <li>• Good rapport with participants helps to access to richer information.</li> <li>• Staying in the field until data saturation was reached.</li> </ul> <p>The researcher participated fully in the research study and was not just an observer.</p> <ul style="list-style-type: none"> <li>• Individual interviews were used in data collection.</li> <li>• Field notes were also taken during data collection process.</li> </ul>
	Persistent observation	
	Triangulation	
	Member checking	
	Peer examination	<ul style="list-style-type: none"> <li>• Research proposal was analysed by the members of research committee of the University of Namibia and Ministry of Health and Social Services</li> <li>• Seven (7) seminars were conducted with research experts in the nursing field.</li> </ul>
	Referential adequacy	The researcher made sure that all materials needed to document findings were available.

### 2.6.3.2 Transferability

Transferability refers to the extent to which qualitative findings can be transferred to other settings as an aspect of a study's trustworthiness (Stahl, 2020). As a result, through dense description and purposeful sampling, the researcher ensured transferability. The amount of information qualitative researchers provide about the study context allows the readers to evaluate the data's relevance and importance, thus making decisions regarding transferability because the reader is able to describe the participants of the study in details.

With such detailed description, the researcher enables readers to transfer information to other settings and determine whether the findings can be transferred because of the shared characteristics (Holloway & Galvin, 2016). It is important for the researcher to ensure transferability by providing thick descriptive data in the research report for readers to evaluate the applicability of the data to other contexts.

Table 2.2: Criteria and the application of transferability.

<b>CRITERIA</b>	<b>STRATEGY</b>	<b>APPLICATION</b>
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data collection as well as the results of the research study (Creswell, 2018). The researcher sent the field notes taken during interviews, interpretations, and audio recorders that were recorded during the interviews to supervisors to check whether the researcher had adhered to acceptable standards in the research process.

According to Noble (2019), triangulation means using more than one method to collect data on the same topic. Triangulation can validate a researcher’s findings and ensure accuracy. The following table 2.3 shows the application of dependability

Table 2.3: Criteria and application of dependability

CRITERIA	STRATEGIES	APPLICATION
<b>Dependability</b>	Dependability audit	<ul style="list-style-type: none"> <li>• Dense description of the methodology.</li> <li>• Intense guidance from the study supervisors to ensure compliance with the institution’s protocols.</li> <li>• Experts in the research field were conducted.</li> <li>• Literature controls were also carried out.</li> </ul>
	Dense description	<ul style="list-style-type: none"> <li>• Research methods such as sample and, data collection and analysis were clearly described in the study.</li> <li>• Complete comprehensive transcriptions of the interviews were created.</li> </ul>
	Peer debriefing	Research experts were involved to give opinions on the study in Unam seminars.

	Triangulation	<ul style="list-style-type: none"> <li>• Individual interviews, field notes, were used as methods of data collections.</li> <li>• The researcher was able to verify the sources of data so as to increase chance of controlling the researcher findings.</li> </ul>
	Coding procedure	<ul style="list-style-type: none"> <li>• The researcher analysed the data after which themes and sub- themes for the study were identified.</li> <li>• An external auditor was employed by the researcher to determine whether procedures are acceptable.</li> </ul>

#### 2.6.3.4 Conformability

Conformability describes objectivity; that is, the potential for congruence between two or more independent people about the data’s accuracy, relevance, or meaning (Tenny, Brannan, Brannan & Sharts-Hopko, 2019). It guarantees that the findings, conclusions, and recommendations are supported by the data and that there is internal agreement between the investigator’s interpretation and the actual evidence (Denscombe, 2019). For conformability to be achieved, findings must be transcribed verbatim without the researcher’s biases, motivations, or perspectives (Mertens, 2018). The application of conformability is shown in table 2.4 below:

Table 2.4: Criteria and application of conformability

CRITERIA	STRATEGIES	APPLICATION
Conformability	Conformability audit	The researcher attended research seminars at the University of Namibia which equipped the researcher with the necessary knowledge to pursue the study.

		The researcher conducted a literature control during the study to find out what other researchers found out and hence establish any relevant research gaps that may need further exploration.

#### **2.6.4 Pilot study**

A pilot study is a small-scale preliminary study conducted in order to evaluate feasibility, time, cost, adverse events, and effect size. This process is carried out to test the prospective research design. Pre-interviews with selected participants can assist the researcher to focus on particular areas that may have been overlooked before the commencement of the main study. The pilot study was conducted at Oshikuku Catholic Hospital among patients with chronic renal failure on hemodialysis. Five (5) participants were sampled and participated in the pilot study interviews. The following problems were identified: there was a need for simplifying and translating some of the interview questions from English to Oshiwambo and the translation was done.

### **2.7 DATA ANALYSIS**

Killam, (2020) described data analysis as the process of reducing, bringing order, structure and meaning to the mass of collected data and can be done qualitatively, quantitatively or combination of both. Data analysis is determined by the purpose of the research, and in qualitative research it is done simultaneously with data collection. Leaving the information to pile up may make data analysis difficult and frustrating. Qualitative data analysis is a process of reducing, organizing, and giving meaning to the collected data. Many qualitative researchers use a series of various steps for analyzing their data, which begins at the start of the data collection phase (Gil, 2016). Qualitative data analysis requires insight, creativity, initiative, and conceptuality, as well as

sensitivity, and is more complex than the statistical analysis of quantitative data (Gournelos, Josua, Hammonds & Wilson, 2019).

In this study, the data about the experiences of patients with chronic renal failure on hemodialysis were recorded with an audio recorder as outlined in the data collection procedure. These data were translated, transcribed, and coded before being used to generate themes and sub-themes. The data analysis was done in line with Tesch’s eight (8) steps in the coding process (Creswell, 2018). These eight (8) steps entail a process of breaking down, examining, comparing, and categorizing the raw data.

The following steps of Tesch’s approach to data analysis were applied in this study:

Table 2.5: Tesch’s steps for data analysis

<b>Tesch’s steps of data analysis</b>	<b>Application to the study</b>
<p>1. Make sense of the whole. Read through transcripts carefully and make notes as they come to mind. This step necessitates careful and repeated reading of the transcripts obtained to identify significant words or phrases.</p>	<p>The researcher read through all the verbatim transcripts and made notes when ideas came to mind. That was done in order to extract the meaning from the interview transcripts.</p>
<p>2. Pick the shortest and most interesting interviews, go through it and find the underlying meaning.</p>	<p>After reading the responses during the interviews repeatedly, the researcher wrote the notes in the margin and identified main topics that emanated from the interviews.</p> <p>The researcher makes a list of all the topics and cluster similar topics together. The data from the individual interviews and field</p>

	notes where then triangulated.
3. Arrange those topics into columns of major topics, unique topics and leftovers.	Descriptive wording was used to label the main and subtopics with the aim of identifying and noting those topics in the transcripts. Similar topics were grouped together and labeled under major topics, unique topics, and additional topics.
4. Assign each topic codes and write the codes next to the appropriate segment of the text to see whether new categories and codes emerge.	Codes were allocated to the topics, simply by abbreviating them and the researcher was also mindful of new major categories that could emerge. The researcher highlighted the topics by using different color highlighters for each category.
5. Find the most descriptive wording for your topics and turn them into categories, try to reduce the total list of categories by grouping topics that relate to each other.	Related topics were grouped together. Data was reduced and organized into meaningful categories by means of a coding system, and interpreted in reference to relationships that emerged from data reduction. That was done by creating major themes and subthemes with the purpose of grouping similar topics

	according to a particular theme.
6. Make a final decision on the abbreviation of each category and alphabetize these codes. To arrive at the final set of categories and codes, the researcher must go through the materials many times.	At that stage, the researcher identified names for the categories or themes with the aim of organizing the coded data into meaningful phenomena.
7. Bring the data material belonging to each category in one place and perform a preliminary analysis. Data reduction is a form of analysis that sharpens sorts, focuses, discards and organise data in such a way that final conclusions can be drawn and verified.	The researcher listed the data that belonged to the same category to prepare the data for analysis.
8. Recode your data, if necessary.	The data was analyzed according to the identified themes and subthemes. Recoding of data was done in order to formulate meaningful concepts within the framework and objectives of this study. A literature control was then carried out to determine how it relates to other studies and the relevance for the research field.

## **2.8. ETHICAL CONSIDERATION**

The ethical aspects involved in this study included permission to conduct the study; informed consent; confidentiality; anonymity; and privacy.

### **2.8.1 Permission to conduct the research**

The research proposal for this study was approved by the Ministry of Health and Social Services and the University of Namibia. Permission to use the health facilities was obtained from the hospital superintendents.

### **2.8.2 Informed consent.**

Written consent was obtained from the participants. The purpose, objectives, method, and duration of the study, as well as the researcher's identity and qualification, were explained to the participants. Participants were made aware of their right to withdraw at any time they wanted to do so. Permission to capture data using an audio recorder was also requested and they were assured that the recorder would be kept under lock and key for a period of five (5) years after the completion of the study.

### **2.8.3 Anonymity and confidentiality**

At all times during the study, the participants' worth and dignity were protected at all times. The instrument and methods used were made known to the participants. Participants were asked not to reveal their names; they were allocated numbers in order to identify them. The master list with the participants' names and code numbers will be kept separate from the data collected in order to protect the participants' anonymity. For the health institution in the study setting, the researcher used real names and only excludes participants' names to protect them. During data collection, the researcher did not gather information illegally without the knowledge of the participants, such as using hidden cameras or microphones. With regard to audio recording, participants were all made aware that the audio recordings would only be made available to the researcher

and the study supervisors, meaning no one would have access to the audio recorder throughout the study except the researcher and the study supervisors.

#### **2.8.4 Rights to Privacy**

An invasion of an individual's privacy might cause loss of dignity, or result in feelings of guilt, anxiety, or embarrassment. Therefore, consent was obtained from the participants and interviews were conducted in a private room where the right to privacy was ensured. To maintain participants' worth and dignity, information was guarded by ensuring that no information would be shared without the knowledge of the participants or against their will.

#### **2.8.5 The principle of respect**

People should be treated as autonomous agents with the right to self-determination and the freedom to participate or not participate in research, according to the principle of respect for persons (Gray & Grove, 2020). On the other hand, the right to self-determination is based on the ethical principle of respect for people and indicates that humans are capable of controlling their own destiny. To ensure respect, the participants were allowed to voluntarily participate in the research study without any risk of penalty or prejudicial treatment. Moreover, participants had the right to withdraw from the study at any time. They were further requested to give information or ask questions for clarity about the purpose of the study and any potential dangers the study may have on their personal wellbeing.

#### **2.8.6 Principle of Beneficence**

With regard to the principle of beneficence, people must take an active role in promoting good and preventing harm in the world around them as well as in research studies (Thomas & Dave, 2017).

To ensure the principle of beneficence, participants have the right to protection and no harm at all. In this study, the researcher protected the participants from discomfort and harm at all times by ensuring that the benefits of the study outweighed the risks

(Timpany, 2020). Therefore, in this study, the researcher did not conduct any medical or other physical experiments on participants.

### **2.8.7 Principle of Justice**

Thomas and Dave (2017) defined the principle of justice as the participant's right to fair selection and treatment in the research study. The fundamental ethical principle of fair treatment is based on the ethical principle of justice, which implies being fair and impartial (Burns & Grove, 2017). This principle was ensured in the study because the study subjects were all selected for reasons directly related to the research and not because they were readily available or could be easily manipulated (Brink, 2018).

All subjects who met the eligibility criteria were interviewed, and all research subjects were asked similar questions in order to ensure the principle of justice. Other important principles that the researcher used throughout the study included honesty and integrity in conducting the research, sharing and utilizing data responsibly, truthful reporting of results, and assigning authorship in scientific publications describing the research (LoBiondo-Wood, 2021).

## **2.9 SUMMARY OF CHAPTER TWO**

This chapter focused on the methodology under the following headings: research design, population, sample and sampling, data collection, pilot study, measures to ensure trustworthiness, and ethical consideration were clearly explained. The ethical principles were maintained, that is, the principles of respect, autonomy, beneficence, confidentiality, and justice.

## **CHAPTER THREE**

### **DATA ANALYSIS, DISCUSSION, AND LITERATURE CONTROL**

#### **3.1 INTRODUCTION**

The previous chapter focused on methodology under the following headings: research methodology, population, sample and sampling, data collection, pilot study, data analysis, measures to ensure trustworthiness, and ethical considerations. In this chapter, an overview of data analysis, discussion of themes and sub-themes, and literature control using narrative writing style was done.

#### **3.2 AN OVERVIEW OF DATA COLLECTION AND ANALYSIS**

The results to be presented in this study were obtained through semi-structured individual interviews that were audio recorded and from field notes that were taken. An individual interview was conducted with all twelve (12) participants by the researcher. Purposive sampling was used to select the sample that was used to obtain the data regarding the experiences of patients with chronic renal failure on hemodialysis in the Oshana region at Intermediate Hospital Oshakati. The researcher introduced herself prior to the interviews and explained the purpose of the research study to the participants. Consent obtained included the purpose and objectives of the research study and methods.

The interviews were audio recorded with the permission of the participants and the participants described their experiences regarding hemodialysis from their own perspectives. Tesch's descriptive method of open coding was used to analyze the narrative data and field notes according to the research which sought to explore and describe the experience of chronic renal patient regarding hemodialysis. The verbatim transcripts and field notes were read carefully and repeatedly to get a sense of the whole

and reflect on the meaning. Prior to data analysis, audio recorder was replayed to the participants for accuracy and reliability immediately after each interview. Creswell (2018) describes this process as member checking and it involves taking specific description to the participants and determines whether such participants feel they were accurate. Patterns and similarities in the words and phrase used by participants in the individual interview were identified and significant statements were extracted, coded and organized into clusters. The data from the individual interview and field notes were triangulated to validate data and themes and sub-themes were then identified. According to Giorgi (2019) data triangulation involves the use of multiple data sources to validate conclusions. The researcher employed an external auditor to determine whether the coding and all the procedure were acceptable. Literature control was then carried out to determine how it relates to other studies and the relevance for the research study. The study findings will be presented together with the integration of the literature control.

The researcher summarizes the study findings in the research report in this section. In a qualitative study, the researcher attempts to approach knowledge development with the expectation of increasing an understanding of the phenomenon. Therefore, the purpose of qualitative data analysis is to explore and describe the findings of the study.

### **3.3 DISCUSSIONS OF THEMES AND SUB-THEMES**

In qualitative research, themes are the dominant features or characteristics of a phenomenon under study (Gray & Groove, 2020). A theme can be defined as a set of ideals that permeate written work to prove a point or highlight a common matter (David, 2017). Themes allowed the researcher to present large quantity of data in a condensed format. A sub-theme exists underneath the umbrella of a theme. It shares the same organizing concepts as the theme, but focuses on one notable specific element (Gournelos, Josua, Hammonds & Wilson 2019). Identifying themes and sub-themes for this study was one of the fundamental tasks of the researcher after data analysis. Sub-themes are descriptive in nature and include the description of the participants' beliefs and experiences (Mertens, 2016). The themes and sub-themes are therefore substantive

due to the fact that they were taken from the participants' own experiences. Each sub-theme was discussed and supported with direct quotations from the interviews held with the participants. Relevant literature control was cited to support the study findings. In this study, six (6) themes and sixteen (16) sub-themes were identified, and they are described in Table 3.1.

Table 3.1: Themes and sub-themes from participants' experience

Themes	Sub-themes
<p>3.3.1 <b>Theme 1:</b> Diverse emotions and misconceptions regarding chronic renal failure and hemodialysis [as experienced by participants].</p>	<p>3.3.1.1 Sub-theme: Misconceptions about chronic renal failure and hemodialysis.</p> <p>3.3.1.2 Sub-theme: Experience of emotional shock and anger.</p> <p>3.3.1.3 Sub-theme: Experiences of optimism regarding hemodialysis.</p>
<p>3.3.2 <b>Theme 2:</b> The effects of hemodialysis.</p>	<p>3.3.2.1 Sub-theme: Experiences of severe pain and discomfort.</p> <p>3.3.2.2 Sub-theme: Concerns about changes of body image.</p>
<p>3.3.3 <b>Theme 3:</b> Challenges encountered by participants during hemodialysis treatment program</p>	<p>3.3.3.1 Sub-theme: Health care workers' bad attitude toward hemodialysis patients.</p> <p>3.3.3.2 Sub-theme: Participants experienced the side effects of medication and hemodialysis treatment.</p> <p>3.3.3.3 Sub-theme: Experiences of financial burden.</p> <p>3.3.3.4 Sub-theme: Changes in love life and sexual dysfunctions.</p>

<p>3.3.4 <b>Theme 4:</b> Experiences regarding life style modifications</p>	<p>3.3.4.1 Sub-theme: Experiences of limited physical mobility</p> <p>3.3.4.2 Sub-theme: Experiences of restricted nutrition and altered fluid intake pattern</p>
<p>3.3.5 <b>Theme 5:</b> Experiences regarding coping with the condition.</p>	<p>3.3.5.1 Sub-theme: Acceptance of the condition.</p> <p>3.3.5.2 Sub-theme: Support from health care professionals.</p>
<p>3.3.6. <b>Theme 6:</b> Strategies for improving the care of patients on hemodialysis</p>	<p>3.3.6.1 Sub-theme: Hemodialysis patients to be treated with compassion and kindness by health care workers.</p> <p>3.3.6.2 Sub-theme: Establishing support groups for patients on hemodialysis.</p> <p>3.3.6.3 Sub-theme: Accommodation for hemodialysis patients and accessible dialysis centres throughout the country.</p>

**3.3.1 Theme 1: Diverse emotions and misconceptions regarding chronic renal failure and hemodialysis [as experienced by the participants]**

Emotion is defined as a complex state of feelings and an affective aspect of consciousness whereby a conscious mental reaction such as anger or fear is subjectively experienced as a strong feeling usually directed toward a specific object and typically accompanied by physiological and behavioral changes in the body (Mullins, 2018). Emotionality can be positive or negative, which is associated with a range of psychological phenomena, including temperament, personality, mood, and motivation. Human emotion involves physiological arousal, expressive behaviors, and conscious experience. Feelings such as happiness, love, fear, shock, or hatred can be caused by the situations that people find themselves in. In this study, participants experienced

misconceptions about chronic renal failure, emotional shock, anger and optimism regarding hemodialysis.

### **3.3.1.1 Sub-theme: Misconceptions about chronic renal failure and hemodialysis.**

A false or mistaken view or opinion is defined as misconception. Mosby (2021) defines misconception as a wrong belief or opinion as a result of not understanding something. The findings of this study revealed misconceptions about chronic renal failure and hemodialysis. It is important for patients to have adequate and correct information about their conditions and misconceptions can be a barrier to manage chronic renal failure (National kidney foundation, 2022). When participants in this study were asked to narrate their experiences when they were informed about their diagnosis of chronic renal failure and that they would be starting hemodialysis treatment, they described renal failure as a bad disease that only results in death should an individual is diagnosed with it. Their responses indicated misconception of information about chronic renal failure. The following quotation supports this sub-theme.

*"I was feeling bad and still feeling bad because I was thinking that my life had come to an end because there was no cure for chronic renal failure." (P#3)*

Another participant narrated a similar experience:

*At first, when they informed me that I have chronic renal failure, it felt heavy to me because I used to hear that if a person is diagnosed with chronic renal failure, it means it's the end of life and the person will die. ["Petameko okwali shadjuupalelange shaashi onda kala handi udu no kutya oudu woiti yana fiyo opuwo onghalamwenyo yaye opoyaxuulila opo."(P#7)*

*"Hemodialysis will not help you, even if you start the therapy you still have to die, sometimes it will make your sickness worse than before". (P#1)*

In support of the participants' statements, Chia-chia, Chien and Yu (2020) on the misconceptions and determinants of diabetes knowledge in patients with diabetes in Taiwan, their study findings revealed that many patients struggle with their own concerns and may delay treatment therapy at which time it is already sometimes too late,

and if untreated or late commencement of the treatment may lead to serious complications. This means that misconception is not only found in hemodialysis patients but it can also be found among patients with other chronic condition such as diabetes mellitus. Similar findings were reported from study conducted in Greece by Roumeliotis, Roumelioutis, Vaios, Leivaditis, Lialopoulov (2020), on historical misconception in dialysis which revealed that the less educated or elderly patient may had lower knowledge regarding chronic renal failure hemodialysis due to deep-rooted misconception ingrained years ago or perhaps because of difficulty understanding health education materials or newer information. The most common misconception found in this study was patients believed that being diagnosed with chronic renal failure means they will die any time soon especially the newly referred patients and that there is no cure for chronic renal failure. Despite the great progress of medicine in many areas, there is currently no method to completely treat chronic kidney failure (Texas kidney institute, 2019). However, if unfortunately there is chronic renal failure, especially when the disease is detected at an early stage, with rigorous monitoring, management, appropriate activities, the progress of chronic kidney failure may be delayed again and can prevent adverse complications on the organs and on the long-term prognosis of patients (Arnav, Michael, Mathew, Gabriel & Christopher, 2021).

Another misconception found in this study is that hemodialysis therapy is not effective and cannot make them feel better. Contrary to the latter statement, the National kidney foundation (2022) stated that hemodialysis is a treatment that helps clean the blood of fluids and toxins when the kidneys are no longer able to carry out their function well. Needing to start hemodialysis can feel overwhelming and scary but dialysis treatment allows one to live and help you to have a better quality of life. Hence, it is important for healthcare professionals to correct this misconception and emphasize on the management of chronic renal failure during patient encounters.

Similarly, Green, Mor, and Shield (2017) stated that patients receiving maintenance hemodialysis who have false opinion are more likely to miss dialysis, use emergency room care, and get hospitalized due to their kidney disease. Most people suffer from certain health conditions such as kidney disease simply because of misconception about

their own health. The same goes with hemodialysis; very few patients discern its value towards coping and prolonging life. Moreover, the findings of this study identify the knowledge gap related to misconceptions of patients with chronic renal failure on hemodialysis. Chronic renal failure is often surrounded by an aura of myth, and much of what we think we know about it can be based on hearsay. However, one important way of coping with it is to be well informed (National Kidney Foundation, 2018). As such it can be noted that correct information is crucial for patient education and counseling more especially for newly referred patients.

### **3.3.1.2 Sub-theme: Experiences of emotional shock and anger.**

According to Avdal, Ayvaz, Uran, Solufu and Pamuku (2020), psychological shock is when you experience a surge of strong emotions and a corresponding physical reaction in response to a typically unexpected stressful event. Usually, the degree of reaction depends on the situation or event. Participants expressed surprise at learning that they have chronic renal failure and will begin hemodialysis treatment. The following statement was narrated by one of the participants during the interview:

*“At first, it came as a shock to me. I didn’t know what it was and found it hard to understand because to me it was like my kidneys were dead and it meant I was also going to die eventually.”* (P#4).

Another participant said that:

*"I was shocked at the beginning, and I was feeling like I was no longer going to stay alive; I couldn't do heavy work, and I couldn't help myself."* (P#3).

The above sentiments were supported by Al Arabi (2020) who stated that most participants in a study about their experiences with chronic renal disease indicated that they had so much shock owing to the myths surrounding the disease and as such they stated that they got devastated when they were first diagnosed. Similar finding was obtained in the study conducted in UK by Sein, Damery, Baharan, Nicholas and Combes (2020) on emotional distress and adjustment in patients with end-stage kidney disease that the participants experienced emotional burden from their illness as well as feelings of helplessness, loss of control and anger mixed with frustration and distress. In another

study in Ghana, Addae (2018) stated that even family members of the patients would cry bitterly after diagnosis of their relative hence triggering emotions of sadness and anxiety to the victims were noted.

Getting diagnosed with chronic renal failure may come as a shock to anyone, even if they have known about the kidney disease for a while, and it may be difficult to manage the treatment schedule of hemodialysis. Gregory, Way, Hutchinson, and Patrick (2017) on patient perception of their experiences with end-stage renal disease and hemodialysis treatment, point to anger as one of the human emotions characterized by antagonism toward someone or something you feel has deliberately done you wrong. Referring to maintenance of quality of life, a study by Ganu, Boima, Adjei, Yendork, Dey and Yorke (2018) on depression and quality of life on long term hemodialysis affirmed these findings stating that anger is a normal and healthy emotion that everyone feels from time to time. Their study proved that patients in Ghana displayed enormous tantrums during their diagnosis of renal failure. Anger can be a good thing in such a way that it can motivate someone to find a solution to problems, although excessive anger can cause problems. Physical changes associated with anger can make it difficult to think properly and may harm your physical or mental health. In this study, participants pointed it out as follows:

*“This condition is very hard. Every time I wake up, my heart feels heavy and filled with anger. When it is time to go for dialysis, I have to force myself. Of course I have to go to the session, but it is very hard for me. I’m just trying to take it easy. I’m not used to this life of being [“omuntu wa ndokatora”] ‘doctor’s person’ and I find it difficult to come to terms with this condition. Being a chronic renal failure patient who goes to dialysis more often and takes medication everyday plus being unable to perform what I am supposed to do make me feel bad.”(P#6)*

*Sometimes I feel angry because going for dialysis 3 days a week kills my time and is very tiring. My friends and family are not allowed in the dialysis room to keep me company. This dialysis thing is a lifetime commitment and I have no other option.”(P#1)*

*I feel bad and angry. My whole life is affected, be it school work or social life. I am a student, but my education is affected because sometimes I miss lessons to go for my*

*follow-ups 3 times per week. My academic performance is poor compared to before I started dialysis. Every day, this thing of taking medication on a daily basis (ooog) exhausts me, and I miss them. I need someone to remind me to take my medication.”(P#3)*

Another participant stated that:

*“It makes me angry because it is time-consuming since I have to go 3 times a week and spend hours connected to the machine. I don’t have enough time to do my work and sometimes I want to go on holiday somewhere, but I can’t because I have to be at one place where I have access to the center.”(P#2)*

The above sentiments are supported by Carmen, Stefan, Gustavo, and Reyes (2016) on health-related quality of life in chronic kidney disease who pointed out that dealing with an illness like chronic renal failure, can bring up many emotions, anger being one of them. Many people feel it is unfair that they become ill and are angry about it. Mollaoglu and Deveci (2016) in their study on the factors affecting quality of life for renal failure patients indicated in support of these findings that people may also feel angry about the loss of control over their lives because of the changes renal disease and treatments have brought into their lives.

Aiofe, (2021) in the study about the expense of grief in patients with end-stage kidney disease further pointed out that the acts of receiving dialysis and routine medicine taking remind people of their renal disease and loss of personal control. Performing these acts can trigger anger and resentment. This anger may be directed inward, leading to feelings of depression and low self-esteem, or it can be directed towards many sources, including dialysis caregivers, family and friends. In a study by Montilla, Duschek and Paso (2016) regarding health-related quality of life in chronic kidney disease, it was reported that many times, renal patients make dangerous decisions such as not taking their medicines or skipping dialysis treatments in order to create a sense of control. These attitudes might make patients with kidney disease feel powerful, but this behavior will ultimately backfire by making them sicker.

Conversely, a study by Avdal, Ayvaz, Solufu and Pamuku (2020) on opinion of hemodialysis patients regarding depression and psychological problems which they experience revealed that patients experience anxiety and despair during the initial stage of hemodialysis treatment however, their anxiety level decreased gradually and they were able to rebuild their lives and overcome situations by altering their perspective about the disease and the treatment. This study finding reaffirms the notion that patient react differently upon receiving their diagnosis such as chronic renal failure as it is stated in the literature. The psychosocial impact of a chronic disease such as the end-stage of renal failure is intense and deserves attention. In this sense, health care workers should offer supportive care to encourage adherence, positive feelings and help patient achieve emotional equilibrium.

### **3.3.1.3 Sub-theme: Experiences of optimism regarding hemodialysis**

Chronic kidney disease and the method of treatment play an important part in shaping the lives of patients receiving dialysis. In this study, hemodialysis was a procedure that can help patients with end-stage renal disease increase their quantity and quality of life. This sub-theme emerged from the definition of the patient's hemodialysis process that removes toxins from the blood. In this study, participants narrated that:

*“(With a huge smile) I always feel happy and lucky to get a chance to start the dialysis treatment because not everybody that has renal failure has survived this far during the process. I’m counting my blessings everyday as I have the opportunity to be dialyzed and continue living a normal life.”(P#4)*

*“It's not an easy thing due to the fact that sickness is just sickness, but my hope is on the dialysis machine, and I have accepted that I’m a chronic renal patient and I have to go to the dialysis as well as take medication as prescribed.”(P#7)*

Another participant echoed similar sentiments:

*"I feel happy when I’m going for dialysis because I know that it is for my own good and it helps me to feel better and stay alive." (P#8)*

According to the participants, hemodialysis helps them to keep going and improve the quality of their lives. They expressed that before hemodialysis treatment was initiated, life was different and they were sicker compared to the latter. These participants accepted hemodialysis treatment and made it part of their lives, which enabled them to carry out their body functions.

The same response was given by another participant who said that;

*“My life has changed now for the better than at the beginning since I started dialysis treatment. Even though it's not an easy thing, I'm happy about it and if I miss a day without going for the dialysis, I feel like I'm missing something as part of my treatment.”*  
(P #12)

Participant number 12 further expressed that:

*This condition is completely a life changer and one has to accept it, although it depends on the mental and psychological wellbeing of the person affected. One has to remember that dialysis is important and if you miss the session, you will die. I started to appreciate my body and my organs more and thank God that he gave me these organs that I needed to look after and then adjust my life around them.”*(P#12)

These findings correspond with those from a study conducted by Suhair and Khaled (2016), which revealed that participants described the hemodialysis machine as being equal to life; this description is congruent with the findings from a survey during a renal health week in Australia (Chiaranai, 2019). Similarly, from a study by Ibrahim, Desa, Chiew-Tong, Ismail and Zainah, (2018), the participants described the hemodialysis machine as their life. They stated that the hemodialysis machine equals life, and it is everything to them and it becomes a friend because after the session, the general condition of the patients improved.

Another study conducted by Hagren (2015) on coping strategies and quality of life among patients on hemodialysis and continuous ambulatory peritoneal dialysis shows the positive reactions expressed by the patients when the hemodialysis machine helps them to survive and they have no way out. Some patients described the dialysis machine as being their kidney.

Hemodialysis removes metabolic waste from a patient's body. Depending on the patients' view, hemodialysis can have positive effects such as decreasing metabolic waste and fluid excess in the patient's body and making the patient feel fresher. Basically, the hemodialysis machine was introduced to improve the health of the patient and give advantage to patients on hemodialysis. However, the patient's point of view and their level of knowledge about the machine influence how they view, perceive, and respond to their need for the machine (Bayhakki & Urai, 2016). In support of this view Montilla, Duscheks, Paso (2016) in their study regarding health-related quality of life in chronic kidney disease reiterated that patient's positive view of the dialysis machine, may have an impact on the patient's physical or mental state as it will boost the participant's wellbeing and motivate their treatment adherence to hemodialysis. Precisely, a person's optimism is very imperative in boosting quick recovery from any sickness, including a hemodialysis bound person. Seminars of nephrology studies (Jha, 2019) revealed the correlation between positive mind and health recovery; patients on hemodialysis are exposed to positive talk, thoughts, experiences, and literature, which will always boost their medical response. Without belief and faith in the value of hemodialysis, it may lose its value and yield insignificant results in health care facilities. As cited by the literature this study concluded that despite all the limitations imposed by the disease, these patients still manage to maintain a good level of optimism supported by hope, faith, religion and good support network.

### **3.3.2 Theme 2: The effects of hemodialysis**

To be diagnosed with chronic renal failure it may lead to continuous adverse psychological reaction to patients and their families hence they face the predicament of accepting their new image and to adjust to the new condition being on hemodialysis. The quality of life of patients requiring hemodialysis is affected significantly because it is associated with changes in their daily habits and in their lifestyle for both themselves and their families. At the same time, their physical health, their functional status, their personal relationships, and their social and economic status are greatly affected (Franzao, 2016). In this study, participants expressed physical discomfort and psychological changes after being diagnosed with chronic renal failure and were put on

hemodialysis. The following sub-themes emanated from the experiences of physical discomfort and psychological changes in the body.

### **3.3.2.1 Sub-theme: Experience of severe pain and discomfort.**

In this study, pain refers to a strongly unpleasant bodily sensation caused by illness or injury, whereas discomfort refers to a feeling of mental uneasiness or a feeling of slight pain, slight anxiety, or embarrassment. It is well-known that chronic pain is commonly experienced by patients with end-stage renal disease who receive dialysis. There are likely many factors that contribute to pain in this patient population, including the high prevalence of comorbid conditions such as diabetes and its complications, such as polyneuropathy. Dialysis itself is a potential source of recurring painful events such as muscle cramps, abdominal distension, and needle pricks. Overall, physical pain is thought to be the primary factor contributing to the reduction in quality of life for people with chronic renal failure on hemodialysis (Tucson, 2018). In this study, similar experiences were expressed by various participants as follows:

*"The insertion site of the catheter is very painful and makes me scared to come to the dialysis for my sessions, especially when it gets blocked and stops working. They have to try and flush it out or if it's not working at all, they replace it with a new one."(P#5)*

*"Catheter insertion is very painful and blood withdrawal is painful. Sometimes I also have general body pain, I'm not getting used to it."(P#9)*

*"The problem is the pain when they are putting in a new catheter is unbearable. One just has to hang in there and be strong because that is the only way dialysis will be done." (P#10)*

*"Since I started hemodialysis, I always have muscle cramps and headache more especially after the session". (P#1)*

The above findings correspond with those from a study conducted by Dabrowska, Kowska, Zuk, Milewska and Stanszewska (2019) regarding the impact on quality of life of dialysis patients with renal insufficiency which revealed that the appearance of chronic pain in dialysis patients is usually at a rate of 37% to 50%, while 82% of them

show moderate to severe intensity pain. The etiology of pain is multifactorial and may be either due to the process of dialysis (puncture, muscle cramps, headaches) or due to the existence of accompanying systemic diseases and painful syndromes. Pain is the most common symptom and discomfort of patients, which caused a significantly impaired quality of life.

Another study conducted by Suhair and Khaled (2016) regarding management of pain and quality of life in patients with chronic kidney disease undergoing hemodialysis revealed that hemodialysis patients suffered from a range of symptoms, both caused by the effects of end-stage renal failure and the dialysis treatment itself. General fatigue, joint pain, chest pain, drowsiness, hypotension, dyspnea, and tiredness were the most significant symptoms associated with chronic renal failure. They commonly referred to other specific symptoms, particularly pain in all parts of the body, specifically their joints, cramps, and drowsiness following dialysis treatment. All of the participants mentioned that they slept several hours after the dialysis sessions, despite attentive adherence to their therapeutic prescription. A study on the adherence of the renal failure patients by Diaz-Soto, Presiga-Ríos and Zapata-Rueda (2017) also revealed that due to the long seasons of drowsiness and oversleeping, patients are susceptible to failing to adhere to the prescriptions of the dialysis aftermath. With the findings from this study, it was noted that dialysis treatment is not without side effects.

### **3.3.2.2 Sub-theme: Concerns about body image changes**

Mosby (2021) stated that body image is one of the significant components of the individual's self-concept that provides the opportunity to achieve a healthier physical and mental state. In this way, our perception of our body and those feelings that are associated with this image greatly influence not only our self-concept but our self-esteem too. Ward (2018) on their study of depression and quality of life long among hemodialysis patients stated that poor body image comes from negative thoughts and feelings about your appearance, and a healthy body image is made up of thoughts and feelings that are positive. Body image is a major factor in self-esteem, which is the way you think and feel about yourself as a person. In this study, participants experienced negative changes in their body image as supported by the following quotes:

*“(Touching his face), I have a swollen face, bloated abdomen and feet. Sometimes my body feels tired after the dialysis.” (P#3)*

*“My body has changed (with tears in her eyes), my skin is rough and has turned very dark, my beauty has faded away, and I can’t even look at myself in the mirror.” (P#9)*

One participant stated that:

*“I feel uncomfortable undressing in front of my partner because of the catheter that I have. My body image is ruined.”(P#1)*

Another participant said that:

*“My body has changed a lot. I have lost about 30 kg and look ugly and thinner. When I’m on dialysis, I eat to try to regain the kilos I have lost.”(P#11)*

These findings are consistent with another findings from a study conducted by Frazao, Tinoco, Fernandez, Macedo, Freire, and Lira (2016) on body changes experienced by patients with chronic kidney disease undergoing hemodialysis, which revealed that chronic renal disease causes changes in this population's body, increasing the risk of developing low self-esteem. The arteriovenous fistula is one of the changes that cause a visible deformation in a region of the patient's body among the changes imposed by the disease and the treatment. The patient says that this change in the body awakens people's curiosity, and for this reason, they prefer to hide it by wearing long-sleeved clothes to cover the fistula.

Similarly, Addae, (2018) pointed out that impaired self and body image are common psychological consequences of living with chronic renal failure. Mollaoglu and Deveci (2016) concluded similar sentiments in their study that self-image and self-esteem have a bearing on aspects of quality of life, which encompass the physical, social, and emotional elements of wellbeing. Patients may have to adjust to their changing appearance by altering the way they dress and how they relate to others.



Figure 3.1: Patient on hemodialysis machine adopted from [www.google.com](http://www.google.com)

Figure 3.1 illustrates a patient with chronic renal failure on a hemodialysis machine and is presented to justify some of the contributing factors to the alteration of the patient's body image. As it is seen in the picture above, the invasive procedures to create a point of access for dialysis via a fistula, neck line, or catheter, for example, will alter the appearance of the body. In actual fact, all the points to which the machine is connected tend to have negative side effects as far as the body appearance of the patient is concerned (Christensen & Ehlers, 2018). Immunosuppressive medications taken to prevent organ rejection also contribute to obvious bodily changes, impairing self-acceptance. Faced with reality and reflecting upon renal nursing practice, it is clear that the body images of these patients are impaired by the presence of the fistula and catheters. Therefore, there is a need for holistic psychological consideration of body image since they need special attention from the professionals involved in the care (Frazao et al, 2016). In this study patients who reported about body image changes, articulated that they were no longer confident in themselves and felt like everyone know about their condition. The study findings therefore revealed that patients faced

hemodialysis with a bit of worry in fear of their body images although they know that it is a helpful procedure. Therefore, the patients were, in other words, pointing to the need for extensive counseling and psychosocial support during and after being bound to hemodialysis.

### **3.3.3 Theme 3: Challenges encountered by participants during hemodialysis treatment program.**

Hemodialysis is the most common form of renal replacement therapy. Unfortunately, it is considered to be bothersome by many patients because in its course, there occur numerous challenges which deteriorate a patient's quality of life (Hrenczuk, Koziel & Malkowski, 2019). This treatment is also associated with side effects which force the necessity to reduce professional activity among patients on hemodialysis as well as the need to report to hemodialysis treatment three (3) times a week which disturbs the functioning of these patients in all spheres of life. In this study, the following challenges and problems were experienced by the participants:

#### **3.3.3.1 Sub-theme: Healthcare workers' bad attitude toward hemodialysis patients.**

In this study, a negative attitude is a disposition, feeling, or manner that is not constructive, cooperative, or optimistic. These are practices of healthcare workers in the health facility which were found to be contrary to the ideals of the health care profession. Mullins (2018) in the study regarding organizational behavior and management stated that healthcare workers in hemodialysis units, as in many other health fields are faced with ever-increasing administrative and patient time constraint. Consequently, this lends to increase of health care worker demand compounded with diminished resources and individual patient time. The higher prevalence of health care worker burnout may result in negative effects on patient care such as bad attitudes (Kumar, 2016). In this study, some participants revealed having experienced inconsistent physical and psychological care from nurses after the initiation of the dialysis.

One participant said:

*"Staff rotation at the dialysis must be stopped so we have fixed nurses at the dialysis because some nurses are not good; they have bad attitudes and treat us as nobody."(P#9)*

Another participant also said

*"I have been served by some nurses which when they enter the dialysis unit I feel like my sickness increases because they are less of the called nurses who are to bring hope to people rather they do not show any sign that they feel for us." (P #6)*

In support of the above participant's expression, Jonathan (2016) in a study regarding attitudes and behaviours of health care workers and the use of hemodialysis health care services, pointed out that some health workers in the health facility lacked the skills to communicate well with patients. They sometimes talked harshly to patients at the least provocation and easily became angry with patients they considered to be troublesome or irritating. Jonathan (2016) further stated that by their monopoly of medical knowledge, health care workers have competence while patients by definition are incompetent because they need intervention of professional health care workers to cure their ailments. Consequently, health care workers have control over decision and actions of client in respect of their care and treatment.

Similarly, Kumar (2016) in the study regarding burnout and doctors explained that patients who defaulted treatment or considered irresponsible with regard to their treatment were often verbally abused or condemned by some care providers. However, health workers do not take delight in abusing patients but they often get frustrated with patients who do not adhere to treatment after all the efforts put into adherence counseling sessions. Conversely, a study by Joako (2017) revealed that most health workers reach professional ideals in their interactions with patients during care provision. It indicated that some nurses treat clients with attentive kindness and respect and they felt satisfied with service delivered whenever a health worker show courtesy toward them by talking to them politely during consultations.

A strong doctor-nurse and doctor-patient relationship is required to reduce stress in their lives and accurately treat and support them throughout this difficult process. Many patients feel that nurses need to be more like friends and treat them as humans, not as robots with their daily routines. It is supported by the following quotation:

*“Health care workers should be more sympathetic to a person with chronic renal failure in the hospital because it is not by choice that they got the disease; he only finds himself in that condition by accident. Sometimes the patients have psychological issues and need nurses to help them.”(P#11)*

Nelson-Brantly (2018) on leading change in critical access hospital stated that nurses are bound like other professionals to a shared set of behaviors, values, and attitudes that are conducive to a professional environment. The set of professional behaviors nurses possess includes: caring, compassion, effective communication, responsibility, and accountability, a sense of duty or obligation, and collaboration of patients, families, and other members of the healthcare team. The core values that all nurses share include human dignity, integrity, autonomy, altruism, and social justice. Each value is essential to our profession of nursing. From a study which centered on the prevalence of depression, anxiety and other factors in chronic kidney disease patients on hemodialysis Aggarwal, Jain, Dabas, & Yadav (2017), revealed that the values are necessary for nurses to integrate caring behaviors towards their patients and with all members of the health care team. Comparing the literature to this study finding brings out certain parallels.

Generally, nurses should provide supportive care to patients with chronic renal failure and help them meet the physical, psychological, emotional, and spiritual challenges of hemodialysis. The care that nurses should render to these patients includes supporting the patients to gain some feeling of control over the disease and decisions, conveying a sense of caring during physical care, comforting the patient when in pain, and helping the patient and family to set achievable goals (Nettina, 2018). In this study it was unfortunate that some participants experienced bad attitudes from nurses and even with a shared set of values and behaviors, we cannot underestimate the nurse’s attitude

towards others, their patients, their co-workers, and the organization they work for, and towards the profession of nursing.

### **3.3.3.2 Sub-theme: Participants experienced the side effects of medication and hemodialysis treatment.**

In this study, "side effects" refer to undesirable symptoms that occur when treatment goes beyond the desired effects or problems that occur in addition to the desired therapeutic effect (William, 2018). Long-term hemodialysis for the therapy of end-stage kidney disease has dramatically altered the otherwise fatal outcome of progressive renal disease. However, some patients on hemodialysis experience physiological stressors that include fatigue, reduced mobility, hypo-tension, muscle cramps, nausea, and vomiting, imposed limitations and disrupting daily life (Kumar, Mahato, Apidechkul, Sriwongpan, Hada, Sharma, Nayak & Mahato, 2020). In addition, patients often experience many unique daily stressors, such as fluid and food intake restrictions, limitations on physical activities, functional impairment, scheduling problems secondary to dialysis sessions, and unemployment.

The theme was supported by the following quotations:

*"It wasn't easy for me due to the side effects. You know, if I take medication on an empty stomach, I feel nauseous and the bad feelings I get after they disconnect me from the hemodialysis machine. I feel dizzy at the moment. I'm really trying hard to cope."(P#1)*

*"My body feels tired after the dialysis and my feet and face swell up. I go for dialysis without coughing and come back coughing. I also come back with a terrible headache."(P#3)*

Another participant said that:

*"There are some days that I go for the dialysis treatment and nothing happens, but some days I feel a headache, muscle cramps, elevated blood pressure, as well as vomiting, but it depends on the day." (P#8)*

The above findings correspond with the findings from the study conducted by Suhair and Khaled (2016) regarding the lived experience of end-stage renal disease patients,

which revealed that the participants also had a negative attitude towards hemodialysis because the machine may have some adverse complications like cramps, hypotension, tiredness, and others. In the study by Aggarwal, Jain, Dabas, and Yadav (2017) studying the relationship between anxiety and depression versus hemodialysis life, the participants acknowledged that symptoms of insomnia, hypotension, stress, tiredness, and malaise following treatments were considered significant issues in their lives.

Furthermore, Tucson (2018) stated that while other participants in other studies viewed a hemodialysis machine as an essential part of life, reliance on the machine as a symbol of lifetime, some participants suffered the side effects of hemodialysis and identified that all hemodialysis patients had to face increased limitations to their functional independence, especially on the day of dialysis, and this restricted their social participation in family gatherings, work set-up, and social institutions. In the same vein, Smith (2018) revealed that a syndrome of headache, chills, sweating, nausea, and exhaustion during and after hemodialysis is described and likened to metal fume fever. Results were also consistent with Mauro, Molinuevo, Tobalina, Gonzelez and Sanchez (2017) study that illustrated the physical effects on the body which usually started after dialysis and continued the next day, resulting in the inability of the participants to complete daily activities or maintain employment and eventually leading to depression.

The study findings and literature shows that the lives of patients receiving hemodialysis treatments are hugely altered. They encounter physiological stressors and disruptions to their daily lives that include fatigue, reduced mobility, hypotension, muscle cramps, nausea and vomiting, fluid and food restrictions. Prior to this study, the impact of hemodialysis on patients with chronic renal failure in Oshana region had not been documented in the literature.

### **3.3.3.3 Sub-theme: Experiences of financial burden**

In this study, the term "financial burden" was used to describe problems a patient has related to the cost of medical care. This means that not having health insurance or having a lot of costs can cause financial problems and may lead to debt or bankruptcy. A patient's financial burden can affect a patient's quality of life and access to medical care,

especially in hemodialysis patients who have regular hospital follow-ups every week. With regard to financial burden, this is what the participants had to say:

*“Living with chronic renal failure on hemodialysis is not an easy thing. It is like a death sentence. My dreams are shattered as well as my career, because my life now depends on that machine. I was the only bread winner at my house and supported my family, but now my kids' future is affected. My employer did not understand my condition, and now I have lost my job. I struggle to get money to go to the hospital.”*(P#9)

*“I was the bread winner in my family, but since I started getting sick and going to dialysis, I am unable to support my family financially.”* (P#7)

Another participant revealed that:

*“It is a big challenge because this is a new life I have found myself in and everything is very challenging, especially the money for me to come to the hospital. When I’m in bed connected to the machine, thoughts of mixed feelings just come one by one.”* (P#11)

One participant also mentioned that:

*“I can see that the dialysis is helping me, but I travel a long distance to come to the dialysis centre for dialysis. I do not have enough transport money. I am only registered now for the government social grant, but the money is not enough compared to the transport money I spend and other needs, including water and electricity bills in a month. I was a contract builder, but now I’m unable to work such a heavy job due to my condition. That’s why I’m really struggling to put bread on the table for my family.”*(P#6)

The previous quotations are supported in a study conducted in Taiwan regarding the lived experiences of patients on hemodialysis where Bayhakki and Urai (2016) identified that most hemodialysis patients were not employed because of their disease and this affected them financially and psychologically. The transportation from and to hospitals every other day is also very expensive. They did not have enough money to survive. As a result, some of the participants described this disease as the disease of poverty.

Additionally, participants in a study by Tadesse, Gutema, Wasihun , Dagne , Menber, Petrucka, and Fentahun (2021) on lived experiences of patients with chronic kidney disease expressed that financial constraints are challenging issue that prevents participants from accessing hemodialysis service. Almost all participants believed that the service they obtain from the dialysis center was uncertain due to financial constraints. Most participants decreased the frequency of hemodialysis service that they got within a week and also they usually ignore additional ordered supportive medications due to financial constraints.

From another study conducted by Kirkeskov, Carlsen, Lund, and Buus (2021) regarding employment among patients with chronic kidney disease related to renal replacement therapy, it was revealed that patients on hemodialysis are less employable, as a result of the consumed time on hemodialysis and traveling between home and dialysis facility as well as the post-dialysis downtime. The findings in this study revealed that the main reasons for quitting jobs were also due to physical dysfunction due to dialysis time

Literature presented by Coitinho, Benetti, Ubessi, Barbosa, Kirchner and Guido (2017) about challenges of chronic renal failure patients, pointed out that many patients find it hard to maintain a job while following a dialysis center's schedule and the treatment itself can hinder a patient's ability to work. Many dialysis patients do not achieve a state of health that can be considered normal for them to perform ordinary work. They operate with a more limited supply of energy and stamina, and many chronic renal patients have additional health issues (diabetes, heart disease) that impede their ability to meet all of life's challenges. They lose a lot of strength, vitality, and energy, as well as their 'place' in family and community, jobs, careers, hobbies, and recreational activities. Additionally, they lose control of their time, future, and bodily functions (Carey & Forfang, 2016).

Conversely, loss of employment is not an inevitable consequence of end-stage renal disease for working-age individuals. Yet, it is unclear why some maintain employment while their kidneys fail, whereas others do not. One potential factor affecting employment is comorbid conditions such as anemia. American Journal of Kidney Disease (2018) mentioned that the predominant symptom of untreated anemia is fatigue,

which can negatively affect a person's ability to work. A second potential factor is the dialysis modality. In-center hemodialysis usually requires three sessions per week, typically during the work day, with each session lasting 3 to 4 hours. According to the study by Copper (2017) on the lived experiences of in-center hemodialysis patients receiving treatment in Dekalb Georgia, revealed that another factor that may influence employment is the type of health insurance that the chronic renal failure patient has. Patients with employer's group health plans may have more comprehensive coverage and lower out-of-pocket costs, which could motivate them to keep their jobs and their health plans. In this study, participants emphasized that they have challenges of financial burden secondary to loss of employment and chronic renal failure. Although plans are in place to get financial support as social grant from the government they feel that it is not enough to cater for their needs as well as that of their families. In this regards the researcher is contend that the impacts of job loss on hemodialysis patients as well as the readily available government social grant for medical care needs further consideration.

#### **3.3.3.4 Sub-theme: Changes in love life and sexual dysfunction**

Change means an act or the process through which something becomes different (Cambridge Dictionary, 2015). Participants in this study expressed aspects related to their sexuality in the context of sexual function following the diagnosis of chronic renal failure and commencement of hemodialysis. According to Cooper (2017), sexual dysfunction is a psychological disorder involving persistent difficulties in sexual interest, arousal, or response. In this study, erectile dysfunction was quite significant among male participants, while female participants had decreased libido. According to Mosby (2021), erectile dysfunction refers to the inability to achieve or maintain an erection that allows satisfactory sexual performance, while low libido refers to a reduction in sex drive. With regard to change in love life and sexual symptoms of dysfunction, the following quote represents the participant's responses:

*“My love life has changed, from feeling uncomfortable when undressing in front of my partner to having a poor sex drive. (P#1)*

*“I was in a relationship with my boyfriend and now we broke up because there were no more connections after I started going for dialysis. My libido decreased and I lost interest in sex.”(P#4)*

Another participant said:

*"Ever since I started being sick and going for dialysis, I don't get an erection as I used to and cannot satisfy my partner. Our relationship is affected and I can't help. It pains me to be this way.”(P#6)*

As cited in a study conducted in India by Alvarez-Villarreal, Velarde-Garcia, Chocarro Gonzalez, Perez-Corrales, Gueita-Rodriguez, and Palacios-Cena (2019) regarding body changes and decreased sexual drive after dialysis, sexual dysfunction is quite common in patients with chronic kidney disease. Orgasm is not experienced by 40% of male dialysis patients and 5% of female dialysis patients. As cited by Um-e- Kalsoom, Khan, Ahmad, (2020), the contributing factors are multifactorial and usually include a combination of psychological, physiological, and other comorbid factors. Erectile dysfunction in males is mainly due to arterial factors, venous leakage, psychological factors, neurogenic factors, endocrine factors, and medications.

Female sexual dysfunction is thus primarily caused by hormonal factors and manifests as menstrual irregularities, amenorrhea, lack of vaginal lubrication, pain during intercourse and infertility, while male sexual dysfunction in chronic renal failure includes decreased libido, erectile dysfunction, premature or delayed ejaculation, and difficulty in achieving orgasm. Similar results were obtained in a study by Tsujikawa, Yamanda, Hiyamata, Tuniguchi, Tsuruya and Kitazone (2022) on sex differences in the 10-year survival of patients undergoing maintenance hemodialysis that sexual dysfunction is common in all phases of hemodialysis. Similarly, Davita Kidney Care (2022) on male sexuality and chronic kidney disease stated that sexuality is all about feeling attractive and it becomes more difficult when the body undergoes unexpected changes. This affects how people interact with others and their ability to develop intimate relationships. Accordingly, the prevalence of erectile dysfunction in men receiving hemodialysis is markedly higher than that of general population and sexual

activities plus intimacy are significantly compromised (European Renal Association, 2022).

Moreover, Alvarez-Villarreal, Velarde-Garcia, Chocarro-Gonzalez, Perez- Corrales, Gueita-Rodriguez and Palacios-Cena (2019) in their study regarding body changes and decreased sexual drive after dialysis revealed that chronic renal failure has considerable effects on the quality of life of patients, impairing everyday activities and leading to lifestyle changes and intimate relationships. In this study the main cause of decreased sexual activities is disturbed physical appearance, difficulties maintaining sexual relationships and erectile dysfunction in men. The physical appearance of chronic renal failure patients on hemodialysis changes throughout the illness especially after receiving minor surgery procedures to create vascular r access. As a result they must live with catheters, fistulas and associated scars which have a strong influence on the perception of their body image. In physical intimacy, the body is usually exposed, making the physical changes and the presence of devices visible, which make the patients refrain from sexual relations. The results of this study are in line with other studies referred to before which concluded that chronic renal failure and its treatment such as hemodialysis is associated with physical demands that affect the sexuality and quality of life of intimate relations. In this study the above challenges were experienced by the participants, ranging from the financial burden, side effects, and deteriorated sexual life in the long run.

#### **3.3.4 Theme 4: Experiences regarding lifestyle modification.**

Lifestyle modification involves altering long-term habits and maintaining the new behavior for months or years, which is typical in terms of eating or physical activities. Lifestyle modification can be used to treat a range of diseases, including renal diseases. There is increasing evidence that lifestyle factors impact on the risk of developing chronic kidney disease, chronic renal failure, and the risk of progression of chronic renal failure. Equally important is the consideration that patients with chronic renal failure are more likely to die from other diseases, such as cardiovascular disease, than to reach the

stage of end stage renal failure. Lifestyle factors that aggravate progression include, among others, smoking, obesity, dietary salt intake, and alcohol consumption (American Journal of Kidney Diseases, 2018). In this study, the participants experienced limited physical mobility, restricted nutrition and altered fluid intake pattern.

#### **3.3.4.1 Sub-theme: Experiences of limited physical mobility**

Physical limitation refers to having difficulty while performing any physical activity. A person's ability to live independently and overall quality of life are both impacted by physical limitations. Physical well-being is a fundamental component of health and contributes to quality of life, underpinning the ability to engage in daily-living activities and participate in social, recreational, and vocational roles (Yolanda, 2018).

It has long been recognized that physical function is compromised in patients with chronic renal failure on hemodialysis. This can be attributed primarily to the effects of uremic syndrome and the comorbidity associated with chronic renal failure, but inactivity also contributes to physical deconditioning and debilitation. The effects of chronic renal failure on the cardiovascular system, most prominently uremic cardiomyopathy and vasculopathy, are the main causes of high morbidity and mortality in dialysis patients. These patients' social lives are often severely restricted. For many, normal participation at work or in school is all but impossible (Thumfart, Pommer, Querfeld & Muller, 2017).

In this study, the participant felt physically limited in such a way that their life is shackled. The following are the quotes from the participants to validate the sub-theme:

*“My social life is affected by this routine hemodialysis since I cannot travel freely as I used to be. I cannot go on vacation anywhere I want because the dialysis is being done here. I have to stay near the dialysis center, if I go I will not make it”(P#1).*

One participant stated that:

*“Sometimes it is very hard because hemodialysis limits most of my things, such as my work. Now I can only do simple work. I’m a student at a vocational center. I was studying a diesel mechanics course, but now I changed it to information and technology*

*technician because I cannot lift heavy metals. Now I attend classes during the day and go for dialysis at night.”(P#5)*

Another participant expressed that:

*“It is not always good as I have to leave important things at home, such as home chores and studying, when it is time to go for a dialysis session. Sometimes I miss classes and do strenuous exercises as part of my physical education module. Let me say that lots of important things in my life are limited.” (P#8)*

The findings by Eman, Ahmad, and Nabolsi (2017) on prevalence and risk factors for chronic kidney disease in a rural region of Haiti, support this study findings because it revealed that hemodialysis made it hard for the participants to travel even short distances unless they arranged to have dialysis in the place they visited. The younger and working participants were more affected by the restraints of movement while on hemodialysis. In addition, it was revealed in another study by Coitinho, Benetti, Ubessi, Barbosa, Kirchner, and Guido (2017) on complications in hemodialysis and health assessment of chronic renal failure patients that physiological limitations felt by the patients on hemodialysis were obstacles to participate in social activities that they enjoyed. These obstacles include pain from needle sticks, feeling fatigued and dizziness after hemodialysis sessions.

Similarly, according to another study conducted in South Africa by Tannor and Archer (2017) regarding the quality of life for patients on hemodialysis, is consistent with the study findings that patients could not travel away from their dialysis centers to visit family, attend key events such as funerals, weddings, or go on vacations to places where there are no hemodialysis facilities. Young patients found it difficult to start and maintain relationships due to their kidney disease and had difficulty explaining themselves to their prospective partners. In this study, participants described feeling that they were living double lives and not really having the opportunity to live a single life to its fullest. The participants characterized living with hemodialysis as a restricted lifestyle, but they understood the need for hemodialysis treatments, even if hemodialysis did not allow them to live well. The dialysis process itself is very long and boring for the patients, and restricts their activities, such as work, visiting others, doing sports, and

other activities of daily living. To the participants, their freedom had been lost, and they were being forced to live with the disease and the treatment process.

#### **3.3.4.2 Sub-theme: Experiences of restricted nutrition and altered fluid intake pattern**

The body requires different nutrients for its normal functions, survival, growth, development, and activity. The nutrients are required in specific amounts and proportions. Hamlin and Brown (2018) in their study about effectiveness of physical activity on depression, anxiety, stress and hemodialysis mentioned that the body's nutrient requirements are expressed on a daily basis and adequate nutrition is achieved when there is a balance between the amount of nutrients taken by the body and the body's requirements or expenditure. Some participants reported that being a chronic renal patient on hemodialysis has changed their eating pattern, as they have been told to eat a low-fat diet and less salt diet. Not all of them found it easy to follow the instructions, as some have expressed themselves as follows:

*“I was told to eat low salt and no red meat. It is not easy to adjust to the lifestyle that I have been living. It is just a matter of trying your level best and not everyone can do it.”*  
(P#7)

One participant stated that:

*"Coping with changes was difficult for me because I was used to living a normal life. My doctor referred me to a social worker and I was told to eat a low-salt and spice-free diet, no alcohol at all, and limit the amount of water intake." (P#8)*

Another participant said that:

*“I was told about the diet regarding low-salt food, no red meat, and fluid restriction. My doctor said I must stop drinking and limit the amount of fluid because my kidneys are unable to take them out. It was not easy for me to adjust from a normal diet to a low-sodium diet. I'm not able to enjoy a glass of wine.”(P#1)*

Other participants also verbalized that:

*“Certain foods such as bananas and red meat are not allowed; only white meat and minimal water intake because if too much fluid is consumed, the kidney will not be able to take it out. It was difficult at the beginning, but now I’m coping.”(P#10)*

*“I was advised not to eat a high-protein diet and to drink at least 500ml of water per day. I like drinking water, especially now that it's summer time. I sweat a lot and get thirsty easily, but I cannot drink more water. Tasteless food is repulsive to me.”(P#3)*

Participant #5 is of the opinion that:

*"My fellow patients that did not follow the instructions are already despised. You know as a human being, sometimes you find yourself hungry and the restricted food is all you can find. You just have to eat a small amount." (P#5)*

Mcmahon, Campbell, Buer, and Mudge (2015) on altered dietary salt intake for people with chronic kidney disease stated that high salt intake is linked to risk factors for both heart disease and worsening kidney function, including high blood pressure, excess protein in the urine (proteinuria), and fluid overload. It is thought to be particularly important for people with renal failure to have a low salt intake due to their kidneys' role in salt balance. Healthy kidneys control how much sodium is in our bodies. If the kidneys do not work well, too much sodium can cause fluid buildup, swelling, higher blood pressure, and strain on the heart.

In this study, it is evident that participants were aware of the food and amount of water that patients with chronic renal failure on hemodialysis should eat, although they found it very challenging to adjust and adhere to the dietary prescription. They stated that the perceived health benefits for their health and kidneys motivated them to follow the recommended diet. Similar results were revealed in study by Hagren, Pettersen, Severinsson, Lützén and Clyne (2018) about challenges of patient with renal failure in Malaysia that hemodialysis patients are subject to dietary and fluid restrictions. Chronic renal patients on hemodialysis found that adhering to dietary regimens is challenging due to the burden of constant choices about food and drinks, the adaptation to complex eating patterns, and the competing demands of this chronic disease and related illnesses (Nerbass, Correa, Santos, Kruger & Morais, 2017).

The National Kidney Foundation (2018) pointed out that when a patient is on dialysis, the kidneys are no longer able to keep the right balance of body fluids and this will lead to fluid overload. That is why it is very important to limit the amount of salt and fluid you have between dialysis treatments. This helps the body maintain the right amount of fluid, and it makes it easier for dialysis treatment to remove extra water. Kidneys filter harmful substances from the blood, including alcohol. In a study on complications in hemodialysis and health assessment of chronic renal patients, Coitinho, Benetti, Ubessi, Barbosa, Kirchner, Guido (2017) revealed that alcohol is one of the fluids that needs to be controlled by those with chronic renal failure, because it can cause changes in the function of the kidneys and make them less able to filter blood.

In addition to filtering blood, the kidneys have many other important jobs. One of these jobs is keeping the right amount of water in the body. Alcohol affects the ability of the kidneys to dehydrate the body. The drying effect can affect the normal function of cells and organs, including the kidneys (Langham, Katantar-Zadeh, Bonner, Balducci, Hsiao, Kamaraswami, Laffin, Liakopoulos, Saadi, Tantisattamo, Ulasi and Lui (2022). Chronic drinking of alcohol can also cause liver disease, and this adds to the kidney's work. The rate of blood flow to the kidneys is usually kept at a certain level so that the kidneys can filter blood well. Liver disease impairs this important balancing act. In fact, most patients in the United States who have both liver disease and associated kidney dysfunction are alcohol-dependent (Jha, 2019).

The study by Ritz and Schwenger (2015) on depression and quality of life among hemodialysis patients revealed that chronic renal failure patients who do not smoke and consume alcohol, physically active, eat a healthy diet (comprised of more fruits, vegetables, and whole grains and less red meat and sugar) and have a body mass index of between 20 and 25 kg/m<sup>2</sup>, reduced their risk of death by 68% compared to those who did not have these lifestyle qualities. Hence, renal patients on hemodialysis are urged to stick to a low salt diet, drink limited fluid, and avoid alcohol. Having found the above lifestyle findings from various literatures, Jemberie (2016) and this study indicated that there was a difference between patient that adhere to diet restriction and those who do not observe dietary recommendations in term of better health. The participants in this

study revealed a correlation between health lifestyle and the prolonged lives of patients with chronic renal failure. Patients who follow dietary recommendation are at less risk of getting sick and develop renal complications. Jha (2019) cited that Asian countries and Muslim religions have recorded less use of alcohol and drugs, with a high shift of diet to vegetarian meals as well as body control tendencies thus there is decrease number of chronic renal failure complications. Supporting dietary reforms, Ikela (2018) stated that, from the Namibian context, chronic renal disease might get worse because healthy lifestyle still leaves a lot to be desired and with Namibians alcohol consumption topping the African chart, chronic renal disease patients may experience continued hardships due to their reluctance to endorse healthy living.

### **3.3.5 Theme 5: Experience with regard to coping with the condition**

With this theme participant raised their concern about the problems that affect them as they struggle to cope with renal failure. The following subthemes emanated from the main theme:

#### **3.3.5.1 Sub-theme: Acceptance of the condition**

Coping is concerned with facing and dealing with responsibilities, problems, or difficulties, especially in a successful, calm, or adequate manner (Tucson, 2018). Living with kidney disease can be difficult, both physically and emotionally. Balancing illness with other problems such as tight finances, changing family dynamics, or housing issues is not an easy thing, including adjusting to spending 12 hours a week in the hospital on dialysis. All this can feel overwhelming. Many people find it difficult to cope with the changes that go along with having kidney failure. This can lead to emotional stress, and everyone has a specific way of coping. In this study, the life sustaining aspect of hemodialysis was evident to the participants despite the difficulty, frustration, pain, and stress they were enduring.

This is what one participant alluded to:

*“There was a lot of evil things going on in my mind at the beginning, but now I realized that I should just make peace with my condition, be serious with my hemodialysis treatment and I put my hope in God as he helped me to be better now”.*(P# 11)

Another participant also verbalized that:

*“Accepting this condition depends on the mental and psychological status of the individual this is a completely life-changing situation. One has to remember that hemodialysis is very important and I have to manage my time. If I miss my sessions, I will die. I start appreciating my body and my organs and give more thanks to God for giving me these kidneys. I need to look after them and adjust my life around them. If I realize I have a bit of life left and that life is completely dependent on how I manage the disease, then it will become easy for me to make positive changes for a better quality of life”. (P #12)*

Another participant also said that:

*“Yes I accepted and I’m coping although is not easy, but it is the only way that will make me feel better and survive”. (P #4)*

One participant also expressed that:

*“When I’m going for my dialysis session I go with my phone or laptop to watch movies and kill boredom or I just sleep. Sometimes I used to ask myself why God give me this condition, but since I’m still alive, walking on my own, eating and bathing myself I thank God”.(P# 6)*

Participants in this study were exposed to various stressful factors and were required to use coping strategies as supportive processes. These adaptive coping strategies help hemodialysis patients cope with existing concerns in order to reach an acceptable level of health and physical, mental, and social function. Some participants highlighted the resilience that some renal patients have. Being resilient is being able to adapt or modify their reality unpredictably and act appropriately. Resilience is seen as an explanation for why individuals, even in adverse situations, manage to survive and achieve well-being in their lives, while others in the same situations are unable to do so. Coitinho, Benetti, Ubessi, Barbosa, Kirchner, and Guido (2017) in their study on quality of life of chronic renal failure patients pointed that the resilient individual demonstrates an optimistic attitude towards life, maintaining a dynamic balance during and after the conflicts of the treatment against the disease, allowing themselves to overcome the pressures of their

world, developing self-confidence and a sense of self-protection that do not ignore the openness to new events, to changes, and to the underlying reality.

In addition, it was noted that a change in lifestyle and adherence to the treatment, through accepting their new chronic health condition, was motivated by positive thoughts. This also contributed to the improvement of their quality of life and interpersonal relationships.

During the interviews, it was found that the participants kept their beliefs in God as a way to find relief. Regardless of the religion they practice, it is their faith in a higher being that makes them able to handle the treatment and all the burdens caused by the disease.

Participants described receiving a sense of comfort from their spiritual beliefs since it provided a feeling of peace and that brought comfort in their most fearful moments during their hemodialysis journey. Similar findings from a study by Dehkordi and Shahgholian (2017) regarding an investigation of the coping styles of hemodialysis patients in Iran revealed that patients with chronic renal failure on hemodialysis affirmed that spirituality was extremely important in living with illness and necessary treatment regimen.

In support of the study findings, Yaya, Hermann, Moustapha, Ibrahim, Tall, Mohamed and Abdou (2019) on quality of life in chronic hemodialysis patients, also revealed that patients on hemodialysis attempt to deal with their own problems in various ways by applying many individualized coping strategies to cope with the problems that emerge as a result of their illness and the hemodialysis therapy. Based on the findings, two types of coping strategies were identified: internal-approach and external-approach coping. Internal-approach coping is related to the psychological efforts of an individual to cope with problems, accept their condition as part of life, and gain a sense of existential optimism and personal autonomy. These reflect the psychological efforts of internal aspects of patients on hemodialysis in dealing with their problems. Patients do not focus on physical efforts to solve their problems; they rather try to improve their condition through adjusting their mindset and the psychological aspect of themselves.

Conversely, external-approach coping is related to the physical efforts or physical gain of patients on hemodialysis. It was identified by several researchers and included gaining love from others, such as support from family, friends, and a support group (Jha, 2019). Other ways are attempting to manage restricted life and coping with fatigue. In this type of coping, patients on hemodialysis develop physical strategies to cope with their problems or to gain something physically and externally, such as support from other people, and use it to cope with their problems. However, patients on hemodialysis should apply both internal-and external- approach coping because they have to maintain or improve not only their personal, psychological life, but also their social interactional life to achieve optimum life satisfaction (Furman, Joseph & Perrin, 2018).

Therefore, to this point, it is imperative to note that patients on hemodialysis depend on their internal and external coping strategies. However, with less literacy and experience of renal failure, it may be difficult for individual patients to maintain both internal and external coping measures. The researcher noted that some patients may have access to external coping as family and friends are always there for them, but internally, these patients may psychologically torture themselves. They may feel left out, segregated and isolated, or sometimes feel like their life is hanging in the balance. Linking literature and these findings draws a line which confirms that the contexts of patients differ from country to country. Hence, for this study, it showed an abundance of external coping but less of internal coping for hemodialysis patients.

#### **3.3.5.2 Sub-theme: Support from healthcare professionals.**

The public health professionals are pivotal to the administration of the health and the support that the patients with chronic renal diseases are in need of. According to Kaba, Bellou, Iordanou, Andrea, Kyritsi, Gerogianni and Swigart (2017) on their study regarding anxiety and depression in patients with end-stage renal disease in Greece, the patients on hemodialysis were showing less signs of distress and were coping with the treatment very effectively. It was all attributed to the fact that the health care professionals were always on their toes to monitor and support them at every time of need. In this study hemodialysis patient expressed that they received physical and

psychological support from nurses by helping them to manage ailments as well as understand and accept their condition.

One participant stated that:

*“All what the nurses and doctors have done and still doing for us is enough because they are already trying their best even though medical equipment are not enough in our hospital”. (P #11)*

Another participant also said that:

*“Nurses give me counseling and bed rest for body weakness and call doctor to check on me. Nurses and doctors are doing their level best and if a patient is paying attention he/she will appreciate everything” (P #9).*

Another two participants also expressed that:

*“When I have difficulty in breathing, nurses give me oxygen, if I have headache they give me painkillers then I get better but if I’m not getting better they disconnect me from the machine for a while”. (P#7)*

*“When I’m at the center and experienced problems, I immediately report them to my nurses and for instance I have headache they give me paracetamol or feeling dizzy they offer me bed rest and I will feel much better”.(P#4)*

The above statements are supported with the following findings by Shahgholian and Yousefi (2018) in their study regarding supporting hemodialysis patients, which revealed that chronic renal disease and hemodialysis causes numerous physical, psychological and social challenges for patients. Overcoming these challenges is possible only through providing holistic support for the patient by health care workers. Furthermore, Shahgholian and Yousefi (2018) further stated that because of numerous dialysis sessions, participants spent a lot of time with health care workers including nurses as such they expected them to support them psychologically and emphasized their empathy.

In this study, the participant’s statements implied that empathy from the health care workers especially nurses and psychological support made the patient feel safe and less

worried, hence they valued their efforts. The researcher has observed that participants appreciated the support provided to them by healthcare workers at different level. Linking the literature with this study findings, there are limited recent studies regarding support from health care professionals. Hence, it can be concluded that this support concept should be considered in health care planning in order to improve the health and quality of life of these patients and their adaptation to the disease and its treatment process.

### **3.3.6 Theme 6: Strategies for improving the care of patients on hemodialysis**

A recommendation in a research paper can be defined as a critical suggestion regarding the best course of action in a certain situation. The main purpose of a recommendation is to provide a beneficial guide that will not only resolve certain issues but also result in a beneficial outcome (Copland, 2016). Based on their own experiences, some participants in this study have proposed some recommendations regarding the care of patients with chronic renal failure on hemodialysis.

#### **3.3.6.1 Sub-theme: Hemodialysis patients to be treated with compassion and kindness by health care workers.**

Compassion and kindness is about paying attention to another person and acknowledging their situation and point of view. It conveys openness and generosity without judgment and respects the dignity of the other person. It requires us to be other-centered instead of focusing on our own needs (Contributor, 2017). As a nurse, being kind go hand in hand with compassion and requires us to be vulnerable to ourselves while acknowledging distress and vulnerability in others. At times when we cannot offer any solution to another person's problems, kindness lets them just be as they are, offering companionship and acceptance of their feelings. Although kindness and compassion have long been considered synonymous with nursing, with the emergence of chronic renal failure, participants re-emphasized the need to be treated with compassion, dignity, and kindness.

One participant suggested that:

*"Nurses and social workers must not lose hope or give upon us. They must treat us fairly and with kindness just like they treat other patients so that our blood pressure will not rise because we are already in a stressful condition and we need to be supported with kindness."*(P#7)

Another participant further stated that:

*"Healthcare workers should be more sympathetic with people with chronic renal failure in the hospital because it is not by choice that the person gets the disease only to find himself in that condition. Patients with renal failure on hemodialysis have psychological issues and have mental blocks, and they rely on healthcare workers because they know better, they need to be there, explain and show necessary empathy."* (P#12)

One participant expressed that:

*"Nurses need to read more about hemodialysis and increase their knowledge so that they will be able to put themselves in our shoes and understand the needs of people with renal failure on hemodialysis and be able to improve their attitudes toward us and show love to us who have renal failure."* (P#1)

Another participant mentioned that:

*"For me I don't think there is anything that needs to be added, because you are already doing your best to help us".* (P#5)

Pehlivan and Gunner (2020) on compassionate nurse stated that compassion in nursing takes a nurse from competent care that includes the required skills and knowledge to treat their patients to outwardly caring through actions and deeds that involve the emotional aspect of the relationship. A nurse's compassionate care can affect a patient's adherence and outcome. In support of the participant's suggestions, Asghar, Aliakba, Kian, Abbase and Mahdi (2017), on the importance and extend of compassionate nursing from the viewpoint of patients hospitalized in educational hospital reinforced that being a compassionate nurse is vital because it helps ease your patient's pain and suffering while providing the emotional support they need. Another study conducted by Papadopoulos, Sheas, Taylor, Pezzella, and Foley (2019) regarding developing tools to

promote culturally competent compassion also revealed that in the world of nursing, compassionate care is not simply about relieving suffering but it is more on entering into patient's experience and enabling them to retain their independence and dignity. Papadopoulos et al (2019) further stated that knowledge and skills were of the highest importance, mostly important caring behavior and positive attitudes toward patients.

Similarly, Giovannoni (2017) on compassion for others begins with loving-kindness toward self, support the above sentiments that compassionate and respectful care by healthcare workers demonstrates humanity and kindness which lead to patient satisfaction and further improve patient's quality of life and mitigates patient's complaints. On the contrary, Sinclair, Russell, Hack, Kondesewski and Swatzky (2017) in their study about measuring compassion in the healthcare urged that providing emotional support to your patients can also offer tremendous self-gratification, hence health care workers needs to take care not to fall victims of compassion fatigue. This means that when caring for the patient with too much of emotional drain, one could experience a mix of emotional, physical and behavioral symptoms; mental and physical exhaustion plus emotional withdrawal.

Being kind is not only good for the receiving patient; it is good for health care workers too. Being kind and open to possibilities can help reduce anxiety and depression in both the giver and the receiver as it focuses outwards and alters the over-personalized bias of these conditions. Patients remember kind acts and may tell you about a small gesture or conversation years later that had a significant effect on their mood or their health.

Therefore, healthcare workers, including nurses, need to acknowledge patients' thoughts, feelings, and what matters to them. From a position of rapport and empathy, they should extend kindness by instilling hope and noticing or taking account of the patient's fears and vulnerabilities. Hence, their physical and psychological well-being needs to be regularly assessed and addressed. Although no recent literature found regarding compassion and kindness of chronic renal failure patients, literature has shown that patients who receive compassionate, patient –centered care are more satisfied and willing to comply with their medical treatment, which leads to better outcome. In light of these literature and participant's opinions, nurses need to understand patient's

experiences from their point of view to plan a nursing care program based on care priorities identified by patients.

### **3.3.6.2 Sub-theme: Establishing support groups for patients on hemodialysis**

A support group is a group of people with common experiences or concerns who provide each other with encouragement, comfort, and advice. Being diagnosed with chronic kidney disease can be distressing, and many newly diagnosed patients feel uncertain about how the disease is likely to impact their lives and how they can best manage this medical condition, which, apart from regular, on-going dialysis, requires careful management and certain lifestyle changes (Shao, 2020).



Figure 3.2: Chronic renal failure support group Source:  
<http://www.google.com.na/images>

Figure 3.2 illustrates an example of a support group providing guidance, assistance, and support to hemodialysis patients. Support groups bring together people who are going through or have gone through similar experiences. Kidney patients and caregivers' support groups are a growing need in many communities. The exchange of information and important patient-to-patient collaboration that occurs within a support group is one of the most valuable elements of patient participation. Furthermore, talking to others who are also going through the same condition can be a much-needed opportunity to vent, share information, get advice, and receive and provide support. In this study, participants expressed the need for the establishment of a support group for patients

living with chronic kidney failure. Within the support group deliberations, participants share common concerns, exchange views on how to cope with the condition as well as with hemodialysis. The following quotation supported this subtheme:

*“Nurses must refer supportive care groups to help people with renal failure on hemodialysis that patients living with chronic renal failure on hemodialysis can come together and share their ideas.” (P#7)*

In the same vein, another participant stated that:

*“Support group will help us to discuss our health problems, share our worries and support each other”. (P#4)*

Another participant stated that:

*“Nurses need to come up with supportive care group to help us patients with kidney disease” (P#2)*

In support of the above quotations National kidney foundation (2020) revealed that support group offers support for people affected by kidney disease or transplantation. They connect patients who want support with someone who has been there or a trained mentor to share their experiences about dialysis or transplant. Mansouri, Jalali, Rahmati, and Salari (2020) on education and support group therapy and quality of life of hemodialysis patients also support this study findings that psychotherapy and non-pharmaceutical interventions are effective measures to add meaning to life, create goals and motivation in life as well as improving the quality of life of chronic renal patients on hemodialysis. Mansouri et al (2020) further narrated that the group therapy intervention with an educational and supportive approach had a significant effect on special and general health aspect and quality of life of hemodialysis patients.

Similarly, another study conducted by Muhammad, Allan, Ali, Bonacina, Adams (2018) on the renal patient support group supporting people with chronic kidney disease through social media revealed that this online peer support group help raise awareness of chronic renal failure for young people and parents/guardians internationally. Langham, Katantar-Zadeh, Bonner, Balducci, Hsiao, Kamaraswami, Laffin, Liakopoulos, Saadi,

Tantisattamo, Ulasi and Lui (2022) on kidney health for all emphasized that one way to thrive on hemodialysis is by reaching out to people who can encourage you and getting support is essential for crafting a balance, fulfilling life on hemodialysis.

It appears to the participants that support group will play a very important role for patients on hemodialysis as cited by the literatures. Hence, study finding shows that support group will work in the advantage of patients to help them cope with hemodialysis.

### **3.3.6.3 Sub-theme: Accommodation for hemodialysis patients and accessible dialysis centres throughout the country.**

Housing accommodation means a building or portion of a building, whether constructed or to be constructed, that is or will be used as the sleeping quarters of its occupants for boarding and lodging travelers. In this study, participants are of the opinion that they need free accommodation for the night whenever their sessions end very late at night. Below are the comments from the participants:

*"The government must provide free accommodation so that when the person finishes the session very late, at least he has a place to sleep over the night and is able to go home in the morning."* (P#2)

Another participant stated that:

*"All my fellow patients who are under 18 years must be given accommodation and be admitted to schools that are close to the hospital where they go for their dialysis sessions."* (P#8)

Another one also reiterated that:

*"We want dialysis machines to be available at Outapi hospital because the distance we travel from Outapi to IHO three times a week is very long, requiring more money for transport, so that the money I use for transport can be used for my other needs."*(P#6)

Pointing to similar sentiments, another participant said that:

*"The renal failure patients on hemodialysis needs dialysis centres to be in every big hospital or in each town so that patients don't need to travel long distances since transport money is a problem." (P#3)*

Hemodialysis takes 4-6 hours per session per day, and this is time-consuming for patients. This is especially true in areas where there are a lot of patients who will find themselves going for dialysis at night. For those living outside of Oshakati and Ongwediva, it becomes difficult for them to return to their respective houses.

The above statements correspond with the findings of the Kidney Foundation of Canada (2018) that patients with kidney failure and their families face significant out-of-pocket costs. This burden is further compounded by the loss of income that is often associated with starting dialysis. It is important to note that poverty is a determinant of health. It also corresponds with the findings by Hagren, Petterse, Severinsson, Lützén and Clyne (2018) whose study focused on challenges of patients in renal failure in Malaysia; which revealed that patients and their families that live in poverty may not be able to achieve optimal management of their medical issues.

Another study conducted by Tedesse, Gutema, Wasihum, Dagne, Member, Patricka and Fentaunn (2021) regarding lived experiences of patients with chronic kidney disease receiving hemodialysis in Felege Hiwot hospital in Ethiopia also revealed that inaccessibility of hemodialysis was the main issue and most participants travel long distances to access hemodialysis services. Due to travel costs of the treatment for hemodialysis and other supportive care most participants decrease the frequency of hemodialysis services that they got within a week and they usually ignore additional ordered supportive medications. Although there are limited literatures regarding free accommodation for hemodialysis patients, this study showed that inaccessibility to hemodialysis is a barrier to participants making it difficult to reach the dialysis center on time.

Canada Kidney Foundation (2018) revealed some gaps and inconsistencies in support for people on dialysis such as poor social and financial support as well as inequitable hemodialysis services across the country. For these reasons, the Canada Kidney Foundation is calling on governments to act on the above recommendations to address

the financial burden experienced by chronic renal failure patients and their families. In light of this Canadian recommendation, this could be a commendable strategy that the Namibian government can adopt to restore equity in health delivery and optimal management of kidney failure.

### **3.4 SUMMARY OF CHAPTER THREE**

The themes that emerged from the study findings have shown the true reflection of the meaning and experiences of renal failure patients on hemodialysis. The data was obtained from the twelve (12) participants. In this chapter, detailed findings and discussions of the themes and sub-themes were provided. It was evident from participants' verbatim quotes that being a dialysis patient is not a comfortable experience as it affects the quality of life of the patient and his family. Relevant literature, as a control for the research findings, was incorporated into the discussion of the research findings. Chapter four (4) will deal with the conclusions, limitations, and recommendations.

## CHAPTER FOUR

### CONCLUSIONS, LIMITATIONS, AND RECOMMENDATIONS

#### 4.1 INTRODUCTION

The previous chapter focused on data analysis, discussion of the findings, and literature control, where findings were analyzed and presented based on the themes and subthemes derived from collected data. This chapter will focus on conclusions, limitations, and recommendations based on the study objectives.

#### 4.2 OVERVIEW

In this chapter the discussions was done in line with the purpose and the objectives are described as follows:

The purpose of this study was to explore and describe the experiences of patients with chronic renal failure regarding hemodialysis in Oshana region, Namibia.

##### **4.2.1 Objective 1: Explore the experiences of patient with chronic renal failure regarding hemodialysis in Oshana, Namibia.**

Participants were asked to share their experiences with regard to chronic renal failure and hemodialysis treatment. In this study all participants were asked same question, the researcher started with a broad opening question “tell me about your experience as a patient with chronic renal failure on hemodialysis?” The researcher invited the participant to give more information or explain further by probing with follow up questions. The data were collected through face to face semi-structured individual interview and field notes were also taken. The interviews were recorded and transcribed verbatim (Creswell, 2018). Before data saturation was reached, a total of 12 interviews were conducted. Detailed data was obtained and described under objective 2. The data was categorized into six (6) themes and sixteen (16) subthemes. A content analysis was used whereby the data analysis was done using Tesch’s method. Both participants’

positive and negative lived experiences were discussed and it was evident from participants' verbatim quote that living with chronic renal failure on hemodialysis is not easy as it affects not only the patient but also his family.

#### **4.2.2 Objective 2: Describe the experiences of patients with chronic renal failure regarding hemodialysis in Oshana, Namibia.**

A description of experiences was done by analyzing data according to Tesch's eight steps of data analysis. The data was categorized into six (6) themes and sixteen (16) sub themes.

The findings from the participants revealed that chronic renal patients on hemodialysis have misconception regarding hemodialysis and they also expressed different emotions regarding haemodialysis. Experience of anger among participants was mentioned as well as shock causing fear and worrying. These study findings are in line with findings from a study conducted by Avdal, Ayvaz, Uran, Solufu and Pumuku (2020) regarding opinions on hemodialysis and peritoneal dialysis patients regarding depression and psychological problems, which revealed that patients with progressive chronic renal failure endure intense fear and anxiety that may have been brought up by any disability or death and are concerned about professional and social decline. According to Aiofe, (2020) chronic renal failure is associated with long-term psychological effects on patients undergoing hemodialysis.

A chronic illness, such as kidney failure, is a continuous process since these patients try to accept their new image. Study findings regarding fluid adherence reflect the struggles many patients face to adhere to dietary recommendation in order to adapt their lifestyle to dialysis treatment. Participants highlighted negative and positive experiences regarding hemodialysis. The most negative experiences mentioned were physical discomfort and psychological changes among participants causing distress, pain and discomfort as well as changed love life and sexual dysfunction after they started with hemodialysis.

Another significant challenge is financial burden. Financial burden can affect a patient's quality of life and access to medical care especially in hemodialysis patients who have

regular hospital follow ups every week. The study findings are in line with the findings from the study conducted by Carla (2018) regarding lived experiences of hemodialysis and adherence which revealed that patients with kidney disease undergoing regular dialysis face difficulties in maintaining their employment, financial flexibility, social life and their limitation of liquids and foods.

This means that the quality of life of patients requiring dialysis is affected significantly, since it is associated with changes in their daily habits and in their lifestyle for both themselves and their families. At the same time, their physical health, functional status, personal relationships and their social and economic status are greatly affected. Conversely, some patient expressed positive experiences regarding hemodialysis therefore; life-sustaining aspect of hemodialysis was evident to patients, despite the difficulties that they may come across such as frustration, pain, and stress they endure for a long time.

#### **4.3 CONCLUSION**

This study explored and described the experiences of patients living with chronic renal failure on haemodialysis in the Intermediate Hospital Oshakati dialysis unit in order to gain an understanding of their experiences. The study findings showed that participants experienced great challenges during their journey on haemodialysis. Participants also revealed that they experienced different emotions regarding hemodialysis. The complexity and chronic nature of the disease affect the quality of life of patients with chronic renal failure and their health and reduce their life expectancy.

Additionally, participants revealed that through changes in lifestyle and care rendered by the health personnel, they have learned how to cope and adapt to their condition. They have made some recommendations with regards to improvement in the quality of life and care rendered to them. Hence, the role of health care workers and the entire multidisciplinary team should be active in implementing effective interventions and psychological support during their treatment sessions. At the same time, it is of high importance to provide social and psychological support to patients undergoing

hemodialysis. This will be possible through individualized and continuous assessment and evaluation of each patient's needs, that is, those with renal failure.

#### **4.4 LIMITATIONS**

The study was conducted among chronic renal failure patients who undergo hemodialysis in the Oshana region, where the population and sample of the participants for the study were selected. The study's findings will therefore not be generalized to the broader population because of the participants' geographical and cultural orientation, which may not be the same as that of hemodialysis in other regions. However, the study results will be useful for references and future research.

#### **4.5 RECOMMENDATIONS**

Participants suggested some strategies to improve care of patients with chronic renal failure on hemodialysis. Participants proposed the following strategies: healthcare workers should treat them with compassion and kindness; there is a need to establish a support group for patients on hemodialysis to enable them to share their worries and encourage each other; and provision of affordable accommodation near the hospital for overnight when they go for hemodialysis.

The following recommendations are based on the conclusions drawn from objectives 1 and 2. Recommendations were made based on nursing practice, management and prospective research studies.

##### **4.5.1 Nursing practice**

Formal educational programs that provide in-service education and training for health care workers will be an effective care/management and support for patients on hemodialysis, as well as Continuous Professional Development programs to enhance skills for nurses dealing with these patients. Moreover, such in-service trainings should be aimed at equipping health care workers with necessary skills to treat patients with more love and kindness.

#### **4.5.2 Institutions management**

Policy makers with specific references to the leaders from the ministry of health and social services should introduce and implement education and awareness programs regarding renal failure for the communities countrywide. Also the existing support system in terms of sufficient social grants and food parcels for those who are no longer employed due to the illness/ or the effects of the treatment and they are booked for dialysis should be strengthened.

Hospital Management in collaboration with hemodialysis unit should facilitate the establishment of support groups/ accommodation arrangement if possible, for patients on hemodialysis, strengthen the referral policy to other multi-disciplinary team such as psychologists, social workers & dietitians to assist the patients through the treatment regimen. There is a need to establish a support group for patients on hemodialysis to enable them to share their worries and encourage each other regarding their experiences on hemodialysis and provision of affordable accommodation near the hospital to overnight when they go for hemodialysis.

#### **4.5.3 Prospective research**

In order to take proper care of chronic renal patients on hemodialysis and for evidenced-based nursing care to take place, future research needs to be conducted in Namibia on regular basis. The following are some recommendations for further research:

To explore the experiences of registered nurses regarding the care of chronic renal failure patients on hemodialysis.

To assess the knowledge, attitude, and practices of registered nurses regarding chronic renal failure on hemodialysis.

Future studies should apply a quantitative research approach to make effective comparisons of qualitative and quantitative research findings.

#### **4.6 CONTRIBUTION TO KNOWLEDGE**

This study adds to the body of knowledge regarding experiences of patients with chronic renal failure on hemodialysis, as it will increase healthcare workers' understanding regarding different experiences of patients. Furthermore, it may guide physicians and nurses to a better understanding of patients' needs regarding hemodialysis treatment. Seeing that there are no specific policy and guidelines to direct nurses on how to care for patients with chronic renal failure on hemodialysis, the study findings will therefore fill in knowledge gaps such as misconceptions of patients with chronic renal failure on hemodialysis.

This information will enhance evidence-based and quality care rendered to patients regarding the management and care of hemodialysis patients. It also contributes to knowledge concerning the supportive roles that nurse educators play in the training and education of nurses. The level of knowledge regarding chronic renal failure patients on hemodialysis will influence the nursing care rendered to these patients. Accordingly, the outcome of this study will result in better care and an improved quality of life for both patients and their significant others by using this study finding as a reference.

#### **4.7 SUMMARY OF CHAPTER FOUR**

This chapter contained the conclusion, limitations, and recommendations made for this study, in which the experiences of chronic renal failure patients on haemodialysis were discussed. In summary, the recommendations are aimed at enabling improved quality in individualized patient care through an understanding of their experiences.

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**ANNEXURE A: PERMISSION LETTER FROM THE MINISTRY OF HEALTH AND SOCIAL SERVICES**



**REPUBLIC OF NAMIBIA**

*Ministry of Health and Social Services*

Private Bag 13198  
Windhoek  
Namibia

Ministerial Building  
Harvey Street  
Windhoek

Tel: 061 – 203 2562  
Fax: 061 – 222558  
E-mail: [nnamgombc@gmail.com](mailto:nnamgombc@gmail.com)

**OFFICE OF THE EXECUTIVE DIRECTOR**

Ref: 17/3/3 ANP  
Enquiries: Dr. F. Nangombe

Date: 26 March 2019

Ms. Auguste N. Petrus  
PO Box 15443  
Oshakati

Dear Ms. Petrus

*Re: Experience on patients with chronic Renal Failure regarding Hemodialysis in Oshana region, Namibia.*

1. Reference is made to your application to conduct the above-mentioned study.
2. The proposal has been evaluated and found to have merit.
3. **Kindly be informed that permission to conduct the study has been granted under the following conditions:**
  - 3.1 The data to be collected must only be used for academic purpose;
  - 3.2 No other data should be collected other than the data stated in the proposal;
  - 3.3 Stipulated ethical considerations in the protocol related to the protection of Human Subjects should be observed and adhered to, any violation thereof will lead to termination of the study at any stage;

AL

- 3.4 A quarterly report to be submitted to the Ministry's Research Unit;
  - 3.5 Preliminary findings to be submitted upon completion of the study;
  - 3.6 Final report to be submitted upon completion of the study;
  - 3.7 Separate permission should be sought from the Ministry for the publication or the findings.
4. All the cost implications that will result from this study will be the responsibility of the applicant and not of the MoHSS.

Sincerely,  
  
**MR. BEN NANGO**  
EXECUTIVE DIRECTOR



*"Health for All"*

## ANNEXURE B: PERMISSION LETTER FROM UNAM

### CENTRE FOR POSTGRADUATE STUDIES

University of Namibia, Private Bag 1330, Windhoek, Namibia  
340 Mandume Ndemufuro Avenue, Pioniers Park  
☎ +264 61 206 3275/4652; Fax: +264 61 206 3293; URL: <http://www.unam.edu.na>



### RESEARCH PERMISSION LETTER

**Student Name:** Auguste Petrus

**Student number:** 200417428

**Programme:** Master in Nursing Science

**Approved research title:** Experiences of patients with chronic renal failure on hemodialysis in Oshana region, Namibia.

#### TO WHOM IT MAY CONCERN

I hereby confirm that the above-mentioned student is registered at the University of Namibia for the programme indicated. The proposed study met all the requirements as stipulated in the University guidelines and has been approved by the relevant committees.

The proposal adheres to ethical principles as per attached Ethical Clearance Certificate. Permission is hereby granted to carry out the research as described in the approved proposal.

Best Regards

A handwritten signature in black ink, appearing to read "Marius Hedinbi", is written over a horizontal dashed line.

**Prof Marius Hedinbi**  
**Director: Centre for Postgraduate Studies**  
**Tel:** +264 61 2063275  
**E-mail:** [directorpgs@unam.na](mailto:directorpgs@unam.na)

*14 Nov 2018*  
-----  
**Date**

## ANNEXURE C: ETHICAL CLEARANCE CERTIFICATE OF EXEMPTION



### CENTRE FOR RESEARCH AND PUBLICATIONS

Office of the Pro-Vice Chancellor: Research Innovation and Development  
UNIVERSITY OF NAMIBIA, Private Bag, 13301 Windhoek, Namibia

540 Mainline Ndumufyo Avenue, Pioneers Park, Office 0090 ☎ +264-61-2054624 [research@unam.na](mailto:research@unam.na) Fax +264-61-2064624

21 May 2021

Dear Ms Auguste N. Petrus,

### CERTIFICATE OF EXEMPTION FROM ETHICAL CLEARANCE AT THE UNIVERSITY OF NAMIBIA (UNAM)

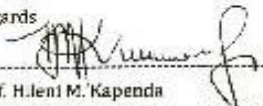
Reference Number: UNAM-21/05/2021

Your application of exemption from ethical clearance at UNAM for the study entitled: **"EXPERIENCES OF PATIENTS WITH CHRONIC RENAL FAILURE REGARDING HEMODIALYSIS IN OSHANA REGION, NAMIBIA"** was considered and granted. The decision was based on the fact that your proposal was submitted and served as agenda item on the Research Ethics Committee and subsequently a research permission letter was issued on 14 November 2018 stating that the research adheres to ethical principles. Hence exemption is hereby granted under the following conditions:

1. During the course of your research activities at UNAM, you are required to observe the required procedures, norms and intellectual property rights in accordance with the UNAM Research Policies and Guidelines. Any deviations and amendments to the original documents submitted (i.e. research proposal) must be submitted again for approval, before the research activities may commence. If unsure, please consult the Centre for Research and Publications at UNAM for guidance.
2. Any significant changes in the conditions or undertakings outlined in the approved proposal must be communicated to the Director Research Services. An application to make amendments may be necessary.
3. Any breaches of ethical undertakings or practices that have an impact on ethical conduct of the research must be reported to the Director Research Services.
4. **The results of the findings must be shared with the PVC: Research, Innovation and Development, and the Centre for Research and Publications, before they are disseminated or published in the public domain.**
5. Upon completion, a copy of the Research Report must be lodged with the UNAM Library for record keeping.
6. Proper, full acknowledgements of the sources consulted must be done in the Research Report and any subsequent publications arising from this research.

If you are in agreement with the above conditions, the document must be completed, signed and returned to the Centre for Research and Publications (Email: [research@unam.na](mailto:research@unam.na)). If you do have any queries, it should be clarified with the Centre for Research and Publications.

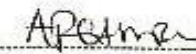
Regards

  
Prof. Helen M. Kapenda  
Director: Centre for Research and Publications

I accept and agree to all the conditions

AUGUSTE N. PETRUS

Full Name and Surname

  
\_\_\_\_\_

Signature

01.06.2021

Date

## ANNEXURE D: HOSPITAL PERMISSION LETTER



9 - 0/0001

**REPUBLIC OF NAMIBIA**

*Ministry of Health and Social Services*

Private Bag 5501

Tel: + 264 65 2233000

OSHAKATI

INTERMEDIATE HOSPITAL OSHAKATI

Fax: + 264 65 224564

Enq: Ms. N. Kadila / Ms. S. Mwandangi

29 April 2019

TO: Ms. A. N. Petrus  
P. O. Box 15443  
Oshakati  
Cell: +264 -812140418

Dear Ms. Petrus


**RE: AUTHORIZATION TO CONDUCT A RESEARCH STUDY**

This is to inform you that your request to conduct a research study in Oshakati Intermediate Hospital has been approved.

Kindly be informed that confidentiality of the patient information seen during your research must be observed. In case of breach of confidentiality, you will be charged by the Nursing Council of Namibia Regulation Act.

We wish you all the best during your research.

Yours sincerely,

  
**DR. A. KIBANDWA**  
ACTING CHIEF MEDICAL OFFICER  
INTERMEDIATE HOSPITAL OSHAKATI



*"Your Health is our concern"*

## ANNEXURE E: PATIENT CONSENT

Dear participant

|

RE: INFORMED CONSENT TO PARTICIPATE IN A RESEARCH PROJECT.

My name is Auguste N. Petrus, a Master of Nursing student at the University of Namibia, Oshakati campus. I'm expected to conduct a research project as part of the requirement.

My study title is **Experiences of Patient with chronic renal failure regarding hemodialysis in Oshana region, Namibia**. Kindly grant me few minutes of your time to participate in this interview. Please take note that information will be kept strictly confidential and will be used for the purpose of the study only. There are no foreseeable risks associated and your participation in this study is voluntarily. If you want to withdraw at any stage you can do so without a feeling of any negative consequences.

Kindly sign below as an indication that you are willing to take part and will in no way coerced to participate. Please assist in submitting a truthful reflection of your thoughts, experiences and feelings.

Signature of participant

.....

Date

## ANNEXURE F: INTERVIEW GUIDE

### Interview Guide

Possible follow up questions.

1. Tell me about your experience as a patient with chronic renal failure on hemodialysis, from the day you were told that you have renal failure and you will start hemodialysis
2. How does it feel to live with chronic renal failure on hemodialysis and at the same time taking medication?
3. Were you fully prepared psychologically/well explained before dialysis initiation?
4. Since you are one of the patients with chronic renal failure, how does it feel to come to Hemodialysis treatment 3 days a week?
5. When you are coming from your house to go for your dialysis session, how do you feel? Do you feel happy, sad or angry?
6. When you are on a bed connected to Hemodialysis machine what comes in your mind?
7. What kind of problems do you encounter when you are going for your dialysis routine?
8. What do you do to address those problems? / How do you overcome them?
9. Where you ever informed about chronic renal failure? If yes: share with me the content of the information that you received regarding life style modification and adherence?
10. Do you find it easy to follow instructions?
11. In your own opinion what do you think can be done to improve the care rendered to patient with chronic renal failure on hemodialysis at the hospital?

**ANNEXURE G: TRANSCRIPT OF AN INTERVIEW ON THE EXPERIENCE OF PATIENTS WITH CHRONIC RENAL FAILURE REGARDING HEMODIALYSIS IN OSHANA REGION, NAMIBIA.**

Participant No: 12

Date: 26.07.2019

Time: 10.00 - 10:24:07

Language of interview: English

Place: Intermediate Hospital Oshakati (Dialysis Unit) Region of the Participant: Ohangwena

Age: 52

Researcher: Good afternoon sir. My name is Auguste Petrus, a student at the University of Namibia studying toward Masters of Nursing science and I'm here to conduct a research on the experience of patients with chronic renal failure regarding hemodialysis in Oshana region. The purpose of the study is to explore and know more about the experience of patients with chronic renal failure on hemodialysis. Your participation in this study is voluntarily and you have a choice to withdraw any time even in the middle of the interview, just feel free and relax.

I have a consent form for you to sign as permission granted that you have given me consent to participate. I also have an audio recorder to record our conversation and the information will be kept confidential. The information will only be shared with my research supervisor for the purpose of the study to help your fellow patients with chronic renal failure on hemodialysis.

Participant: Ok we may proceed.

Researcher: What are your experiences as a patient with chronic renal failure on hemodialysis?

Participant: Well, renal failure is something that you are not fore-warned, it just happened and you just go into renal failure. Sometimes it can be acute or permanent. In

my case it is permanent which means that my kidneys are functioning less than ten (10) percent (10%). The first experience is you became sick, toxins are building up in your body and that makes you quite sick because kidneys are not functioning well. On that basis the doctor will do any analysis and make a conclusion to put you on hemodialysis to help the kidneys remove toxins from the body.

My body became exhausted and sick because the kidneys control many function of the body. Doctor put a temporary catheter on my leg under local anesthesia, hemodialysis was performed, after the dialysis session my energy comes back but there was certain delay. There are many things happening when you are on hemodialysis such as blood pressure dropping, you become very dizzy, (something that's very normal in hemodialysis), you have some sensation in your body, the skin becomes dry and numb.

After four (4) hours of being on hemodialysis, body feels tired, you feel nauseous, painful muscle cramps of the feet, hands and calf muscle. This will take almost an hour or two hours to settle in your hemodialysis and becomes normal again. When you are on hemodialysis you lose appetite, and experience extremely weight loss. (Taking a deep breath).... I have lost over 30kg due to renal failure and hemodialysis. There is also itching of the skin and one has to watch the diet. What you eat is very important in managing renal failure. Water and salt intake should be minimized because if you did not excrete it toxins will build up in your body and get sick.

Researcher: You mentioned that you lose appetite, is there something that takes it away or it just happened?

Participant: Before you start dialysis session appetite goes away because you have imbalance in your body everything taste like little coin in the mouth but after you have hemodialysis session, appetite comes back slowly by slowly.

Researcher: How does it feel to live with chronic renal failure on hemodialysis and at the same taking medication?

Participants: (leaning comfortably on the waiting bed) it depends how mentally and psychologically how you handle this renal failure and hemodialysis. I'm 52 years old now and I believe I have really lived a good life and thank God our creator that given us

time to be here and given us the best possible things we can do. You have to start appreciating your body and organs more including the kidneys. Chronic renal failure is a complete life-changing situation since you have to know how to manage your time due to the fact that if you did not go to the dialysis you will die. You need 3 days in a week to go for hemodialysis and that dialysis is very important because you have to start appreciating your body, your organs more knowing God has given you organs that you need to look after them, because only when they failed you feel their importance. This means going to hemodialysis needs mental acceptance. I have to accept the dialysis, take medication and adjust my life around it.

Researcher: Where you fully prepared psychologically before hemodialysis was initiated?

Participant: (scratching his head) I wasn't prepared for it and it wasn't explained quite well, because I was very sick, there was no time for explanation or taking me through the process of dialysis. It was a matter of emergency and doctor came to me once and had to do emergency

dialysis to save my life. After my body start to function the doctor then explained quite well what hemodialysis is, how it happens and they inserted a permanent catheter.

Research: You stated that it was explained to you quite well, can you share the content of the information including lifestyle modification and adherence?

Participant: Well, your life style obviously needs to be changed. You have to manage your time, the hospital where you attend your dialysis session gives you specific time table when to come to for dialysis and you needs to be on time. That's where you have to psychologically set yourself up that you have your days to go for dialysis and it's very important to adhere to until such a time you will get kidney transplant. You need to know that your life has changed and you can do what you want but you have to put your disease into consideration.

Researcher: What types of lifestyle you need to change?

Participant: diet, unnecessary travelling, looking after your body, taking enough supplements, taking some exercises to help your body regain energy and help your muscle.

Researcher: Did you find it easy to follow instruction?

Participant: Yes... (Nodding his head) once you realize that you have a bit of life left and that life is completely depends on how you manage your disease. Based on that, it becomes very easy to make those changes. It is important to have that bit of life left and make a better quality life even on the next person on hemodialysis.

Researcher: Since you are one of the patients on hemodialysis, when you are coming from your house, how do you feel?

Participant: (Aaagh ) It's a mental thing that you have to decide whether its beneficial to you to go there because it becomes part of your life. You are not happy neither sad but it makes you realize that you need to look after your health.

Researcher: When you are on the dialysis bed connected to the machine what comes into your mind?

Participant: (Stretching his body) Look....there are a lot of things that comes in your mind and basically for myself is how the body function, how I have to be on that hemodialysis machine to survive. If you know how the body functions you will start to look after your organs better. Sometimes you read a newspaper or go into your phone and check on You Tube and educate yourself better. You are just trying to spend some quality time while on hemodialysis machine.

Researcher: There are a lot of things going through your mind example?

Participant: (with a sad face) mmmh.....there are lot of questions you have to ask yourself such as how did I get sick? How did I end up being here? How did I not take care of my kidneys? How possible that this happened? Then you have to realize that it happened and you have to accept.

Researcher: You stated that you asked yourself why you did not take care of your kidneys, did you feel guilty somehow regarding your past lifestyle or something?

Participant: I didn't mean I felt guilty but what I'm saying is that if I knew what I know today and the value of my kidneys, I would have made life changes way back then but because you are not educated. Health workers are at the hospital and got knowledge but people are not regularly educated about their body parts and how to look after them. Doctors only tell you when there is a problem, they never tell you before how to look after yourself. Sometimes we only see doctors when we are sick .I feels that in my situation there should be some programs educating people how to look after their body and lifestyle changes because people don't realize until they have renal failure.

Researcher: You mentioned earlier about nausea, tiredness and blood pressure dropping, how did you overcome them?

Participant: (smiling) those are problems that you have to live with them for the rest of your life. You have to accept them, if you feel tired or nauseous just understand that it is part of the dialysis and part of your problems.

Researcher: In your opinion what do you think can be done to improve the care being given to patient with chronic renal failure on hemodialysis by health care workers at the hospital?

Participants: Chronic renal failure is a disease that is very tough on the person mentally and psychologically. Sometimes a chronic renal failure patient is weak and cannot go to the toilet as quickly as possible and there are many factors happening to the patient, so health care workers need to be more sympathetic with the patient. That patient never asked to get renal failure and his entire body, how it functions starts changing. Sometimes there are mental issues that are happening and the patient is in denial to accept, those are the things health care workers need to assist and care about the patient to make it easier for the patient.

Researcher: Do you mean us health care workers need to go extra mile to be there for the patient?

Participant: Yes the patient is already in a situation and knows that some of his body parts are not function and in many cases people die. That is a mental block that the person has no idea how this work and relies on health care workers for him to

understand because they know better and should not be too harsh but more empathetic and sympathetic.

Researcher: Thank you so much, we have come to the end of our interview.

Participant: Thank you.