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The Experiences of Patients Receiving Haemodialysis Treatment in an Open Setting Environment at an Academic Hospital in Johannesburg

Mayamiko Munthali Khomba

**A Research Report Submitted to the Faculty of Health Sciences,
University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements
for the degree
of**

Master of Science in Nursing

Johannesburg, 2014

DECLARATION

I, Mayamiko Munthali Khomba declare that this research report on: "*The experiences of patients receiving haemodialysis treatment in an open setting environment at an academic hospital in Johannesburg*" is my own original work. It is being submitted for the degree of Master of Science in Nursing at the University of the Witwatersrand, Johannesburg and has not previously been submitted for any degree at this or any other university.

Signature……MKhomba……

Signed in Johannesburg on this ___19th___ day of _____March____ 2014

Ethics clearance number: **M120410**

DEDICATION

I dedicate this research work to my beloved parents, Mr and Mrs Kabuzi Munthali, for the prayers and support they provided me throughout my studies. Your prayers were the source of my strength. This work is also dedicated to my dear husband Misheck for your unconditional love and support. Thank you for dedicating your time and providing excellent care to our small children- Ruth and Praise. My daughter Ruth, I will never forget your telephonic prayers, they gave me hope, encouragement and motivation. To my daughter Praise, I left you whilst you were so young (two years of age) without motherly love and care nevertheless you persevered. I wept when I thought of you but the lord gave me strength and I managed to cope and move on. I finally dedicate this work to my brother Chumba and his wife Bayani Munthali for the support you gave to my children.

This research work is now a success.

ABSTRACT

BACKGROUND: Patients receiving haemodialysis (HD) treatment experience a significant symptom burden and their needs are multifaceted. In HD unit, patients receive treatment in a diverse cultural and open ward setting. However, patients' experiences of receiving HD treatment in an open ward setting are not known.

OBJECTIVES: The central aim of this study was to explore and describe the experiences of patients receiving HD treatment in an open setting environment at an academic hospital in Johannesburg.

DESIGN: A qualitative, exploratory and descriptive study was conducted at a public, tertiary level academic hospital in Johannesburg after obtaining ethical approval from Wits University and relevant authorities.

SETTING: The research setting for this study was an adult Chronic Renal Dialysis Unit.

POPULATION: Sixteen adult (age 18 and above) patients receiving chronic HD treatment were recruited purposively in this study.

INTERVENTIONS: An in-depth semi-structured interview was conducted either before or after receiving HD treatment, which was audio-recorded, transcribed then analysed by using Giorgi Phenomenological method.

FINDINGS: *A mood enhancer* appeared a major theme as participants positively valued the open setting environment for their overall and psychological well-being. Participants expressed by *being with others* and *sharing experiences*, a sense of community likened to a family developed. Common to all participants' language was the use of the "we" in relation to being in the open setting environment. This expression of the "we" by participants was interpreted as a *community concept.* The use of "we" associated with the concept of community described as a space to which every patient receiving HD belonged. They described their experiences in a collective manner. *This was evident in repetitive reference to their common space, being together, sharing experiences, and finding identity from one*

another, being understood and a sense of being protected with personal relations that extend beyond 10 years for some.

This open space contributed to shaping their perception of body image and illness. The nurse's role in timeously providing HD care was appreciated by many.

However, being exposed to multiple situations of chronic illness and treatment a sense of fear developed. Any negative event experienced, watched, observed, or heard in the HD unit triggered fear in the patients. Two *common fears were of HD complications and the constant threat of death*. Complications such as clotting, muscle cramps and collapsing because of hypotension as well as watching somebody dying on the machine were all reported in this study and so psychological counselling was felt to be very important.

CONCLUSION

The recommendations proposed in this study hopefully will assist HD staff to intervene and make adjustments to support patients' holistic needs. Further studies into patients receiving HD in open settings and mixed-gender space are required for diversity of experiences and knowledge from different settings.

Keywords: Haemodialysis, hospital environment, open setting, patient experiences

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LIST OF ABBREVIATIONS

ESRD	End Stage Renal Disease
HD	Haemodialysis
KDOQI	Kidney Dialysis Outcomes Quality Initiative
ANKF	American National Kidney Foundation
NKF-K/DOQI	National Kidney Foundation -Kidney Disease Outcomes Quality Initiative
P	Participant
R	Researcher
NRC-SA	National Renal Care in South Africa
SARS	South African Renal Society
UK	United Kingdom

CHAPTER 1

AN OVERVIEW OF THE RESEARCH STUDY

1.1 INTRODUCTION

This chapter provides description of the background and an overview of the research study, which explores the experiences of patients receiving haemodialysis (HD) treatment in an open setting environment at an academic hospital in Johannesburg, South Africa. This chapter provides a statement to the problem, purpose and objectives of the study, theoretical framework, the researcher's assumptions including the meta-theoretical assumptions, methodological assumptions and relevant definition of terms. An outline to the plan of the research process and methods used to meet the study objectives is included.

1.2 BACKGROUND OF THE STUDY

End Stage Renal Disease (ESRD) is an insidious and progressive disease in which kidneys cease to function (Taskintuna & Ozcurumez, 2011: 252) and reportedly is a major problem worldwide. Despite growing research regarding patient experiences with ESRD, to date no research has investigated these experiences in an open setting environment. In Africa, glomerulonephritis, hypertension and diabetes are reportedly the main causes of ESRD (Kasonde, 2011: 131); in South Africa, hypertensive nephropathy is reported at 45.6% (Naicker, 2010: 649). In 2003, 430 000 South Africans were estimated to be living with ESRD (Fincham, Kagee & Moosa, 2008: 7). Treatment options for this disease include lifelong HD treatment, peritoneal dialysis or kidney transplantation (Small, 2010: 187), which help to achieve the normal functions of kidneys. This study focused on experiences of patients receiving HD, therefore reference only to this will be made.

The prevalence of patients requiring maintenance HD treatment worldwide is increasing at a rate of 7% per annum (Tanyi & Werner, 2007: 141; Fincham, *et al*., 2008: 7). In Africa, dialysis care is influenced by late referral, co-morbidities and lack of resources including lack of dialysis facilities and shortage of staff to provide the services (Naicker, 2010: 649).

HD is the most common treatment modality for ESRD (Taskintuna & Ozcurumez, 2011: 252) and is a viable, safe and efficient life maintaining treatment for patients (Fincham, *et al*., 2008: 7). Although not curative, HD is life sustaining but required indefinitely unless the patient receives a kidney transplant. Patients receive HD three times a week and each treatment can take between four and five hours (Axelsson, Randers, Jacobson & Klang, 2012: 45). Within this time, an hour is usually taken in setting up the machine, connecting and disconnecting the patient. Patients interact repetitively with the healthcare environment, as they are restricted to lifelong regular treatment (Calvey & Mee, 2011: 202; Bennett, 2011: 247; Schick Makaroff, 2012: 26).

In South Africa, the demand for HD remains high because kidney transplants are comparatively low (Naicker, 2010: 649). From the editorial reports by Kasonde (2011: 132), the current estimate for South African dialysis is approximately 70 per million and for transplant, the rate is 9.2 per million. However, the annual demand for kidney transplant exceeds the supply by 75%. Reports show that lack of knowledge about kidney disease, its treatment, religious and traditional beliefs are some of the contributing factors that influence the unwillingness of a person to be a kidney donor. This affects hospitals negatively as they are burdened HD's soaring budgets.

The cost for dialysis, being financially demanding and expensive, consumes an escalating proportion of the health budget (Naicker, 2010: 649), mainly because HD demands high technological equipment including expensive machines, dialysis supplies and medication. In South Africa, 82% of patients on dialysis rely on the State for health funding and 18% on privately funded medical schemes (Moosa & Kidd, 2006: 1110). The goal for HD is to provide the best quality of care for patients with ESRD. These patients attend the same hospitals for years, receiving HD treatment in a diverse cultural and open ward setting. In this study, the *open setting environment* is described as an open ward system where patients sit side-by-side receiving HD treatment in one large open area.

The open setting environment enables nurses to monitor patients' on the machines (Curtis, 2008). This ensures safety since each patient's face, vascular access site and bloodline connections are visual throughout treatment to enable recognition of and response to

emergencies. The open setting environment may be advantageous in lessening the burden of staff shortage, as South African reports indicate shortage in skilled dialysis nurses (Moosa & Kidd, 2006: 1111). Treating patients in a large open area may be cost effective, but their experiences of receiving this long-term treatment in an open ward setting are unknown. During this long-term period, patients receiving HD may face many challenges for example, ESRD and HD can impact on a patient's physical, social, spiritual and psychological well-being (Tanyi & Werner, 2007: 143; Axelsson, *et al*., 2012: 51).

Physically, these patients are dependent on the technology of the HD machine and the healthcare team for survival (Moran & Scott, 2012: 88). ESRD causes accumulation of fluid and waste products in the body and is both life threatening and a chronic illness (Small, 2010: 187). Fluid overload can build-up around the lungs, causing shortness of breath, hypertension and eventually pulmonary oedema, congestive heart failure and shortened patient survival (Fincham, *et al*., 2008: 7) consequently, this makes individuals feel sick and unattractive due to changes in body image (Thomas, 2008: 89). HD treatment provides palliative care and ameliorates these illness symptoms (Tanyi & Werner, 2008: 34); stopping or skipping treatment can affect the patient's overall health and risk death. The physiological effects from HD may produce discomfort such as hypotension, nausea, vomiting, muscle cramps, headaches, loss of muscle tone and change in skin colour (Morton & Fontaine, 2009: 735; Krueger, 2009: 380) and so being treated in an open setting environment and watching others can be challenging.

Socially, patients receiving HD face unemployment and complex lifestyle changes (Small, 2010: 189). Financially many are challenged due to medication costs, HD and transport expenses to the units; for others, frequent hospitalisation and loss of job affects their financial status, which can result in poor compliance to treatment. Patients may experience social dejection and isolation, as they feel shy in seeking support for physiological problems such as sexual dysfunction due to their reduced libido (Kastrouni, *et al*., 2010: 129). These authors describe the loss of libido in these patients as resulting from elevated parathyroid hormones, hypotension and from antihypertensive side effects. Reduced libido can cause disrupted marital relationships (Krueger, 2009: 380) and may result in divorce due to sexual dissatisfaction.

The American National Kidney Foundation (ANKF) reports that emotional issues such as depression or fear of death can also affect sexual function. Therefore, access to social support improves relations and promotes healthy behaviour such as adherence to HD prescriptions, schedules, dietary and fluid restrictions (Fincham, *et al*., 2008: 8; ANKF, 2009: 31). Patients are dependent on family, friends and HD staff for support, which helps to improve their recovery.

Spiritually, patients receiving HD can question the meaning of illness and life as a consequence of living with a long-term illness and associated stress (Tanyi & Werner, 2008: 34). Patients search for spiritual responses as they worry about their life and feel death approaching. However, spirituality is associated with a more positive illness adjustment amid life-threatening illness (Tanyi & Werner, 2007: 142). Consequently, understanding patients' experiences and providing support in the HD unit can enhance guidance, hope and comfort.

Psychologically, patients receiving HD experience a greater sense of anxiety, depression, sadness, anger, disappointment, frustration and uncertainty about their future (Kastrouni, *et al*., 2010: 126; Axelsson, *et al*., 2012; Schick Makaroff, 2012). Suicide rates are reportedly higher in patients receiving HD than the general population (Keskin & Engin, 2011). Unfortunately, the psychological aspect is often neglected and the understanding of the day-to-day psychological experiences of receiving HD in a hospital environment was central in this study. Studies suggest the hospital environment should meet the current evidence to provide for patient's individual needs (James, 2008: 33; Rowlands & Noble, 2008: 768; Rebmann & Barnes, 2011: 72); therefore, the experiences generally felt by these patients will be discussed next.

1.2.1 General Experiences of Patients on HD Treatment

Experiences, according to Draper and Swift (2011: 8), are concerned with individual meanings, the so-called 'life-world' of an individual. Experiences relate to feelings and opinions held about a particular situation as lived by that person. Patients receiving HD treatment experience psychological trauma, restricted freedom, fear, depression and anxiety (Taskintuna & Ozcurumez, 2011: 250; Axelsson, *et al*., 2012: 45; Schick Makaroff, 2012: 27).

Distressing emotional responses, such as uncertainty about their future, hopelessness and depression have also been reported (Moran, Scott & Darbyshire, 2011: 502). HD treatment and the machines are the lifelines that prevent death and whilst important, they place restrictions upon patients' lives (Schick Makaroff, 2012: 25). In Sweden, Herlin and Wann-Hansson (2010) investigated patients' experiences of being dependent on HD treatment at the ages of 30 to 45. For these patients HD treatment meant life was constant and not progressive, in addition, living with fear and being dependent on caregivers was a concern.

Published experiences of patients receiving HD treatment suggest that psychological factors are amongst the highest with anxiety and depression being the most reported (Calvey & Mee, 2011: 204; Taskintuna & Ozcurumez, 2011: 250; Kohli, Batra & Aggarwal, 2011: 177). The psychological problems so far reflected occur because of the complexity of ESRD and HD treatment (Taskintuna & Ozcurumez, 2011; Ramirez, Macedo, Sales, Figueiredo, Daher, Araujo, Pargament, Hyphantis & Carvalho, 2012; Theofilou, Synodinou & Panagiotaki, 2013).

There appears to be a gap in South African literature concerning patients' experiences of an open ward setting for receiving HD treatment, given the current diversity and history of the country. Current knowledge indicates patients' suffering from advanced cancer preferred open wards to allow interaction with each other for mutual support (Rowlands & Noble, 2008: 773). Negative experiences relate to issues on personal privacy, confidentiality, noise and infection risk and challenging person centred care (James, 2008: 34; Morton & Fontaine, 2009; Bennett, 2011: 247; Rebmann & Barnes, 2011: 73). What HD patients' experiences regarding open setting environment mean and entail, not only for their daily life, but also for quality of renal care, is yet to be researched. *The person centred care* refers to the recognition of the patient as a whole-person, which emphasises the integration of the mind-body-spiritual dimension of care (Tjale, 2007: 117) meaning a patient receiving HD treatment is whole with all the attributes of a person.

1.2.2 Patient Receiving HD Treatment as Whole-Person

In response to the physical, social, spiritual and psychological well-factors experienced by patients' receiving HD, abundant nursing literature has brought the concepts of holistic and whole person care into managing these patients. To enhance healing one has to treat the whole-person. According to the National Renal Care in South Africa (NRC- SA), holistic care that embraces whole-person is inclusive of mind, body and spirit (NRC-SA, 2011).

Similarly, Crawford and Thornton (2010: 24) state that holistic care involves caring for patients as a whole. All spheres of life affect the patient receiving HD treatment (Theofilou, *et al*., 2013: 20), and each person manifests unique physical, mental, emotional, spiritual and social attributes (Tjale, 2007: 98).

Living with a chronic illness disrupts the whole concept of one's life (Tanyi & Werner, 2008: 34; Calvey & Mee, 2011: 201; Tropea, 2012: 941). Experiencing physical complications such as hypotension during treatment can disrupt patient's emotions and feelings, which may cause anxiety, loss of personhood, social and psychological instability (Morton & Fontaine, 2009: 735; Calvey & Mee, 2011: 204; Schick Makaroff, 2012: 27; Theofilou, *et al*., 2013: 22). These experiences affect patients as a whole including their psychological well-being. In whole person nursing care, mind, body, social and spiritual dimensions are included.

Reportedly, nurses working in HD units have a biomedical focus. In Norway, Aasen, Kvangarsnes and Heggen (2012: 65) observed that nurses working in HD units and teams exercised power and control over the patients. The health-care team possessed the knowledge and decided what the patients needed to know, to such an extent that patients felt powerless and were afraid of what might happen if they refused to follow instructions. This situation threatened patients' identity, well-being and the quality of their daily lives. Such a fragmented approach to patient care contributes to the much reported stress and anxiety of patients. Understanding the HD patient as merely a physical being defeats the purpose of individualised holistic care proposed in their nursing care (Tanyi & Werner, 2008: 34; Calvey & Mee, 2011: 201; Tropea, 2012: 941).

South Africa is a country rich with diversity of cultures and the representation of patients in hospitals reflects this diversity (Tjale & de Villiers, 2004: 207). Although being in the same space receiving HD treatment, individuals may experience things differently.

Age and gender factors can also influence the psychological symptoms in patients receiving HD treatment (Chan, Brook, Steel, Heung, Erlich, Chow & Suranyi, 2012; Bornivelli, *et al*., 2012: 94). Holistic care acknowledges that no aspect, physical, mental, emotional, or spiritual dimension can be viewed or treated in isolation, as they all make the whole person (Crawford & Thornton, 2010: 24). It is, therefore, important to acknowledge individual differences, feelings and opinions to treat each patient as whole.

This study reflects the holistic approach to patient care. Care refers to those assistive, supportive or facilitative acts toward or for another individual or group with evident or anticipated needs to improve a human condition (Galt, 2000: 224).

Addressing aspects of patients and treating a whole person, can therefore make important contributions to the critical understanding of experiences of patients receiving HD treatment (Tanyi & Werner, 2008: 34; Tower, Rowe & Wallis, 2012). Inclusion of patient opinions into care may improve therapeutic outcomes and reduce stressors. Therefore, patients' feelings and opinions with regard to the HD setting can enhance well-being.

1.2.3 Significance of the Study

In investigating experiences in an open setting environment, the goal is to attempt to understand the psychological experiences including feelings and opinions of the patients receiving HD treatment. Findings from this study will provide baseline data and the knowledge gained will assist HD staff to intervene or make adjustments to meet patients' holistic needs, including their psychological needs, to improve health related outcomes.

1.3 PROBLEM STATEMENT

The presumption in this study is that the psychological well-being of diverse patients receiving HD may be compromised by being treated in an open ward, however this setting may also interfere with cultural and emotional needs of patients. The inclusion of patients with different ages and genders in the same open space may have a psychological effect on some patients, which may compromise patient rights, as care focuses largely on the physical care. Exploring patients psychological experiences in this research setting, valuable knowledge can be gained, which would help renal health practitioners adjust their care to meet the individual's emotional needs, as informed by patient's perspective.

1.4 RESEARCH QUESTION

From the above the following question emerged:

What are the experiences, including the feelings and opinions, of patients receiving HD treatment in an open setting environment in a Chronic Renal Dialysis Unit at an academic hospital in Johannesburg?

1.5 PRPOSE OF THE STUDY

The purpose of this study was to explore and describe the experiences of patients receiving HD treatment in an open setting environment at an academic hospital in Johannesburg.

1.6 RESEARCH OBJECTIVES

The objectives of this study were to:

- Explore and describe the experiences of patients receiving HD treatment in an open setting environment at an academic hospital in Johannesburg;
- Examine and describe patients' feelings and opinions with regard to accessing HD treatment in an open setting environment at an academic hospital in Johannesburg.

1.7 THEORETICAL FRAMEWORK

The theoretical framework for this research study incorporates holistic care embracing the mind-body-spirit dimensions (Tjale & Bruce, 2007: 47). The holistic model advocated by Tjale (2007) is used to underpin this study. According to Tjale and Bruce (2007: 48) a person is whole and manifests unique physical, mental, emotional, spiritual and social attributes; that wholeness embraces the mind, body and spirit. This is consistent with National Renal Care in South Africa (2011), embracing the integration of body, mind and spirit in treating patients suffering with renal diseases.

The NRC-SA (2011) defines the body as the vehicle to move through the life of renal patients that requires maintenance by keeping HD appointments and having peace of mind that comes from knowing what is best. Patients with renal failure are encouraged to stay involved in their environment, socialise and participate in activities to keep their mind active. The spirit dimension emphasises that patients must connect with people who give them positive feedback and support for their feelings. As pointed out by Tjale (2007: 7) all the dimensions, mind, body and spirit are interconnected and nursing care should focus on totality of the whole person.

To meet the holistic needs of a whole person, nurses must engage in bio-psychosocial and spiritual care through a mind-body-spirit approach (Tjale & Bruce, 2007: 50). Crawford and Thornton (2010: 24) define holistic care as the caring for a patient as a whole: physical, mental, emotional and spiritual dimensions; it values caring, therapeutic presence, patient empowerment and healing as foundations when delivering care. Dossey (2010: 15) embraces the practice of healing the whole person through understanding the interrelationship of the bio-psycho-social-spiritual dimensions of an individual as an integrated whole who interacts with and is acted upon by both the internal and external environment. This model is appropriate for this study in treating each unique patient receiving HD holistically.

1.8 RESEARCHER'S ASSUMPTIONS

Assumptions reflect basic principles believed to be true without proof or verification (Polit & Beck, 2012: 12). The following assumptions guided the researcher's actions.

1.8.1 Meta- theoretical Assumptions

These refer to the concepts that identify the phenomena of central interest to the discipline and have philosophical origins that guide and influence decisions (Alligood & Tomey, 2006: 71). They are shared by the scientific community, provide guidelines and criteria for decisions to the study and are accepted as true (Meleis, 2005: 11). The researcher made meta-theoretical assumptions to guide the study.

For the purpose of this study, key concepts in nursing theory guided the research: person, environment, nursing and health. The researcher's assumptions regarding these concepts, in the context of HD care, are defined to serve as a point of departure.

1.8.1.1 Person

Person refers to a human being who is viewed as a holistic being with mind-body and spirit interrelated. A person is expressive of feelings and opinions from which knowledge can be generated and who contributes to his or her own care. There is reciprocal nature of social interaction of a person and environment in which the person lives. The patient receiving HD treatment is central to the context of this study.

1.8.1.2 Environment

The environment is the setting or surrounding where a person exists or interacts. There is a mutual interaction of the physical, psychological, social, spiritual and emotional aspects of a person receiving HD with the environment. The environment influences the interaction of the mind-body and spirit aspects of that person, because the patient receiving HD treatment and the HD care environment are inseparable. However, the HD care environment is dynamic as individuals come from diverse cultures with unique and specific needs therefore, patient's interaction with the environment can broaden his or her life experiences, giving meaning to the situations.

1.8.1.3 Nursing

Nursing refers to the science and practice of nurturing a person in his environment to meet the demands of health. The art of nurturing involves creative work and knowledge exhibited by a nurse based on the science and art of care. The approach to nursing care is whole and the focus is on individual's emotions, psychological, physical, social, spiritual and cultural aspects within or outside the healthcare environment.

1.8.1.4 Health

The World Health Organization's definition of health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (www.who.int/about/definition/en/print.html). In this study, health is further defined as a dynamic state of well-being in which a person experiences a balance between mind, body and spirit, all of which are interrelated and relate to the environment (Tjale, 2007: 17) and is uniquely perceived and embraces one's physical, psychological, emotional, cultural, spiritual and social aspects.

1.8.2 Methodological Assumptions

According to Burns and Grove (2009: 507), the methodological approach to qualitative studies is guided by broad qualitative research assumptions. Mouton and Marais (quoted in Tjale, 2007: 18) define methodological assumptions as those that pertain to the process considered as scientific and to the methods and instrumentation by means of which a given view is scientifically valid. Thus, scientific research is defined as systematic, controlled, empirical and critical investigation guided by theory and assumptions (De Vos, Strydom, Founche & Delport, 2005: 41). Provision of HD care is based on scientific knowledge; hence research requires extension to generate new knowledge. The methodological assumptions in this study focused on how HD patients make sense of their experiences in a Chronic Renal Dialysis Unit to contribute to the scientific knowledge from a patient's perspective.

It was therefore assumed that:

> "*Experiences, including feelings and opinions, of patients receiving HD treatment in an open setting environment in a Chronic Renal Dialysis Unit at an academic hospital in Johannesburg would be derived from subjective experiences and could be taken as a valid source of knowledge."*

1.8.3 Theoretical Definition of Terms

Definitions are provided only as guidelines for the concepts used in the study (Meleis, 2005: 10). The following terms were defined by the researcher as a point of departure to provide clarity for the concepts applicable to the context of this research study.

1.8.3.1 Open setting environment

An open setting environment in this study refers to an open ward system where patients sit side-by-side to receive HD treatment in one large open area.

1.8.3.2 Experience

Experiences are conditions that have happened to a person, which influence the way he or she thinks and behaves (Oxford Advanced Learner's Dictionary, 2010: 514). Experiences, according to Draper and Swift (2011: 8) are concerned with individual meanings, which are the so-called 'life-world' of an individual. In this study, experiences refer to the actual events or situations that patients receiving HD go through in an open setting dialysis environment, including feelings and opinions.

1.8.3.3 Feelings

Feelings in this context are part of experiences, which refer to emotional state of consciousness in response to conditions, situations or events either pleasant or unpleasant, as experienced in an HD unit. As defined in the Oxford Advanced Learner's Dictionary (2010: 544), feelings refer to emotions, attitudes, opinions or something that you feel through the mind or the senses.

1.8.3.4 Opinions

Opinions, according to the Oxford Advanced Learner's Dictionary (2010: 1031), refer to the feelings, thoughts or views of people about something; personal perceptions, views and judgments held about a particular situation. In this context, a patient receiving HD treatment evaluates situations or conditions in the open setting dialysis environment and makes inferences or passes conclusions.

1.9 RESEARCH METHODS AND DESIGN

1.9.1 Methodological Approach

This study adopted a qualitative methodological approach, using exploratory and descriptive research design. Qualitative approach, according to Draper and Swift (2011: 3), is a large, diverse and evolving field offering broader techniques of gathering data and aims at enriching our understanding of human experiences or perceptions (De Vos, *et al*., 2005: 74; Polit & Beck, 2012: 14) especially when little is known about the phenomenon under study (Burns & Grove, 2009: 23; Polit & Beck, 2012:17). The qualitative studies require exploration and understanding of participant experiences (Creswell, 2008: 456), are more in-depth and generate rich data (De Vos, *et al*., 2005: 351; Polit & Beck, 2012: 15). A qualitative approach was therefore appropriate for this study as the researcher aimed at exploring and understanding the meaning of experiences of patients' receiving HD in an open setting environment.

1.9.2 Research Design

Research design refers to the overall plan for obtaining answers to the research question and is the architectural backbone to the study (Polit & Beck, 2012: 58). The research design aims at directing the researcher to the selection of a population, sampling of procedures and plan for data collection and analysis to minimise bias (Burns & Grove, 2009: 41; Polit & Beck, 2012: 58).

This study used an exploratory and descriptive research design, utilising qualitative methods, because in health and social sciences they assist in understanding the meaning people attach to their daily-lived experiences (De Vos, *et al*., 2005: 74; Creswell, 2008: 456; Polit & Beck, 2012). The exploratory study aimed at gaining insight into participant's feelings and opinions about the open dialysis unit, thus, a qualitative exploratory and descriptive design was chosen to achieve experience-based knowledge from patients. Chapter Two discusses the detailed account of the research design.

1.9.3 Research Methods

Research methods relate to the techniques researchers use to structure a study and gather and analyse information relevant to the research question (Polit & Beck, 2012: 12). The research question for this study was, "*What are the experiences including the feelings and opinions of patients receiving HD treatment in an open setting environment in a Chronic Renal Dialysis Unit at an academic hospital in Johannesburg?*" To effectively respond to this research question and justify the research process, the methodology employed in this study was based on the target population, sample, sampling technique, data collection and data analysis. Draper and Swift (2011: 3) caution that choosing data collection and sampling methods for a qualitative research study can be overwhelming as there is no single, universally accepted 'correct' option, therefore selecting appropriate research methods was crucial to ensure high-quality data.

This study utilised a purposive sample of sixteen patients, with ESRD, receiving HD treatment in a Chronic Renal Dialysis Unit, at an academic hospital in Johannesburg. An in-depth semi-structured interview was carried out on patients aged 18 and above, able to speak English and willing to participate in the study to generate data. The interviews were audio-recorded, transcribed word for word and then analysed by Giorgi's phenomenological method. Lincoln and Guba's model of trustworthiness, based on credibility, dependability, confirmability, transferability and authenticity was utilised (Polit & Beck, 2012: 585).

Ethical considerations and detailed research methods are described in Chapter Two. Figure 1.1 summarises the research process and detailed research methods employed in this study.

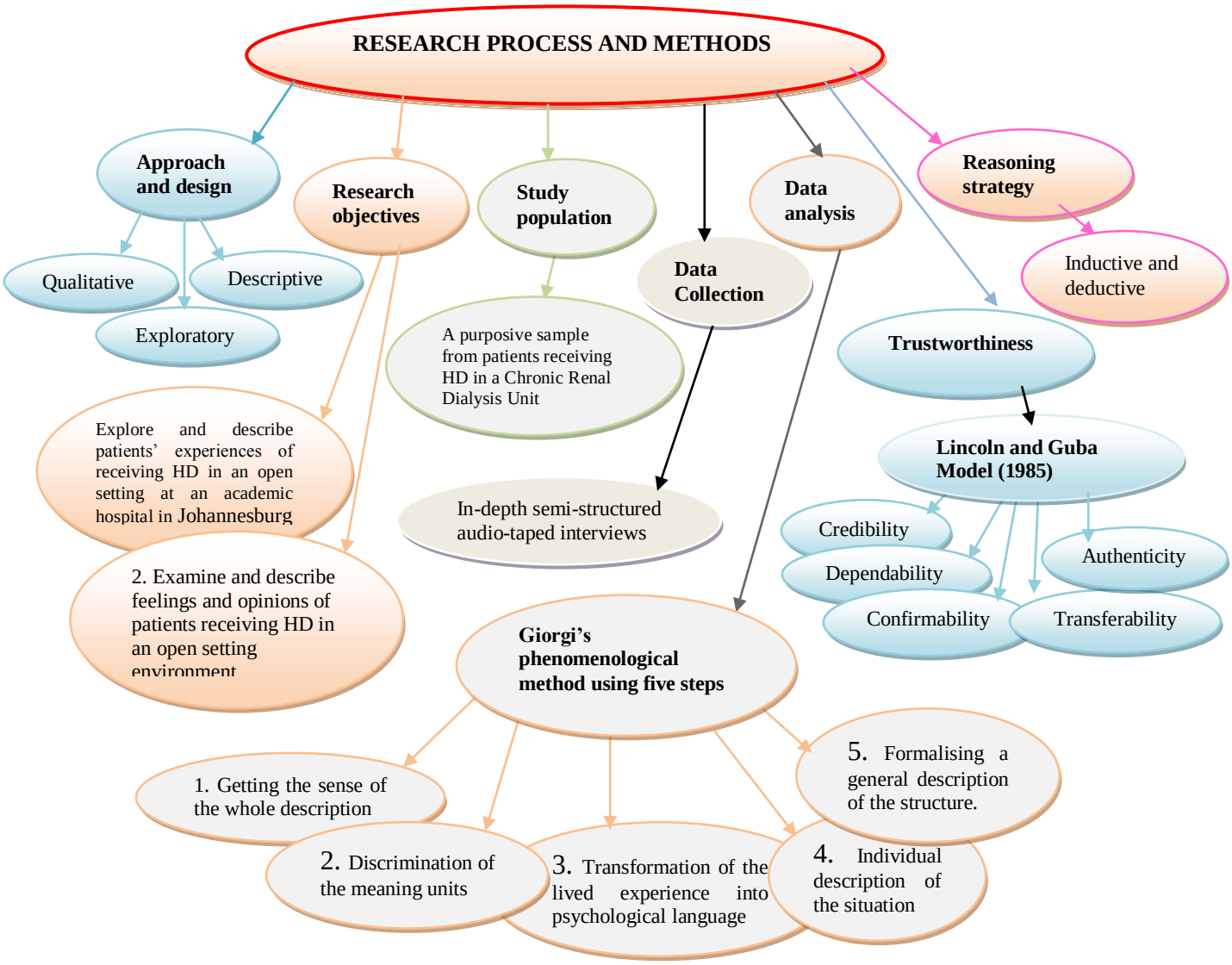

Figure 1.1 Summary of an overview of the research process and methods

OUTLINE OF THE RESEARCH REPORT

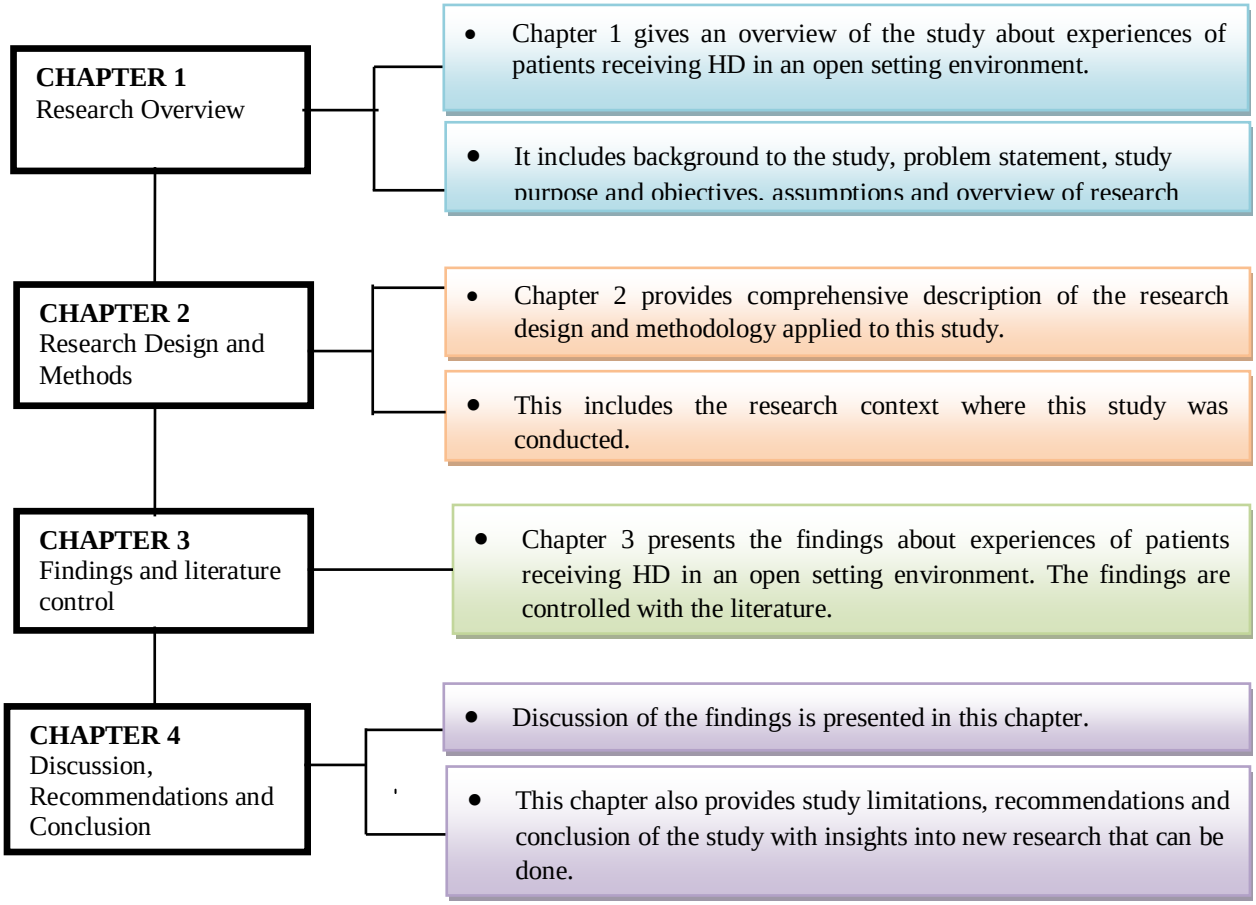

FIGURE 1.2: Research chapters and outline of the research report

1.10 CONCLUSION OF THE OVERVIEW OF THE STUDY

This chapter has provided an overview to this research study. This included the background, objectives and significance of the study and described the problem statement, the research methods and the design applied. Findings will help to support provision of holistic care as reported from patients' perspective. Chapter Two discusses detailed research methods used in the study.

CHAPTER 2

RESEARCH DESIGN AND METHODS

2.1 INTRODUCTION

Chapter One provided an overview of the study, this chapter discusses the research methods and design utilised. Research methods are the research actions and techniques for collecting and analysing data (Draper & Swift, 2011: 9). This chapter will focus on and present, in a systematic way, how the study was structured and the techniques used to gather and analyse data. It includes the methodological approach, design, population, sample and sampling techniques, data collection and analysis procedures, including the reasoning strategy, culminating in its measures of trustworthiness and ethical considerations.

As described in Chapter One, the purpose of this study was to explore and describe the experiences of patients receiving HD in an open setting environment at an academic hospital in Johannesburg.

The research questions that directed the investigation and established the research method was, "*What are the experiences, including the feelings and opinions, of patients receiving HD treatment in an open setting environment in a Chronic Renal Dialysis Unit at an academic hospital in Johannesburg*?" Burns and Grove (2009: 167) define a research question as "a concise, interrogative statement worded in the present tense and including one or more concepts." This shapes the researcher's decisions on how to gather data. Consequently, the research methods will help to respond correctly to the research question (Polit & Beck, 2012: 741).

The research objectives of the study were:

- To explore and describe the experiences of patients receiving HD in an open setting environment at an academic hospital in Johannesburg;

- To examine and describe patients' feelings and opinions with regard to accessing HD in an open setting environment at an academic hospital in Johannesburg.

2.2 METHODOLOGICAL APPROACH: QUALITATIVE

To meet the research purpose and objectives of this study, a qualitative approach using an exploratory and descriptive design was utilised. Burns and Grove (2009: 51) define qualitative research as a systematic and subjective approach to describe and give meaning to life experiences. Weiner, Amick, Lund, Lee and Hoff (2011: 6) describe qualitative research as a process of understanding, based on distinct methodological traditions of inquiry that explore a social or human problem. Thus, qualitative studies are interested in understanding people's experiences.

The researcher adopted qualitative approach for this study to gain an understanding of patients' experiences in an open setting dialysis environment. The qualitative approach does not aim at quantifying but at enriching our understanding of human experiences (Tower, *et al.*, 2012; Polit & Beck, 2012: 515). Qualitative research reveals concepts to understand better the subjective meaning of the phenomenon under study and not to generalise relationships, or to a population as in quantitative research (Creswell, 2008: 213, Toloie-Eshlaghy, Chitsaz, Karimian & Charkhchi, 2011: 106; Tower, *et al*., 2012: 40). A phenomenon is a term used to describe an idea about an event, a situation, a process, a group of events, or a group of situations (Meleis, 2005: 11).

Creswell (quoted in Weiner, *et al*., 2011: 6) described qualitative studies, conducted in a natural setting, as where the researcher explores in-depth and builds a holistic picture about the phenomena to generate new knowledge. It involves analysing words and reporting detailed views of participants. A qualitative approach breaks the traditional research methodology of

focusing on the objective data and is concerned rather with discovering meaning of experiences where little is known about an area of interest (Toloie-Eshlaghy, *et al*., 2011: 107; Polit & Beck, 2012: 515). Where quantitative studies are primarily concerned with techniques and instruments of obtaining data in hypothesis testing, qualitative studies are concerned with meaning of experiences (Burns & Grove, 2009: 51). These experiences become more meaningful when values, beliefs and feelings are explored within a framework of participant culture and generate new insights for nursing practice (Tower, *et al*., 2012: 40).

Scammell (2010: 1150) and Toloie-Eshlaghy *et al*. (2011: 107), highlight that qualitative studies enhance understanding of people's opinions, beliefs and motives about an experience, which cannot be understood quantitatively. The qualitative research is not concerned with numerical but meaning and shape opinions of decision makers whose action affects people's health and well-being (Polit & Beck, 2012: 525). Likewise, Tower *et al*. (2012: 40) emphasise that qualitative studies are important for nurses who seek to understand or describe patients' experiences of health, illness and care rather than predict outcomes.

The qualitative approach was therefore relevant to this study to capture the patients' experiences and meaning in receiving HD in an open dialysis unit. Patient's feelings and opinions were vital to understand fully their experiences, as psychological experiences cannot exist separately but require exploration from human beings (De Castro, 2003: 46). Knowledge yielded from such exploration contributes to human science which aims at enriching other researchers with shared understanding (Applebaum, 2012: 46) and so the knowledge of patients receiving HD can be useful for practical guides and patient support, helping identify effective implementation strategies for care in the practice setting (Leeman & Sandelowski, 2012: 174).

2.3 RESEARCH DESIGN

Research design, according to Burns and Grove (2009: 218), is the blueprint for conducting a study. It aims at guiding the researcher in planning and implementing the study in a way that is most likely to achieve the intended goal, thus enhancing trustworthiness of the findings. This study used an exploratory and descriptive design, which is discussed below.

2.3.1 Exploratory Research Design

An exploratory research design was used to understand the open setting dialysis environment as experienced by patients. An exploratory design is conducted when more insight is required about a given situation to examine the phenomenon carefully (De Vos, *et al*., 2005: 106). It helps to take preliminary investigation into new areas of interest, look for insight and generate rich data (De Vos, *et al*., 2005: 373; Polit & Beck, 2012: 60). To allow for a full investigation and elucidate experiences of patients on open setting, an exploratory design was chosen as it allowed the researcher to explore real-life experiences of people with first-hand knowledge of the phenomenon (Polit & Beck, 2012: 18). Mouton (quoted in De Vos, *et al*., 2005: 106) clearly points out that answers to a "what" question, constitute an exploratory study. Consistent with the present study, participants were responding to "*what are the experiences of patients receiving HD treatment in an open setting environment?"* This allowed approaching an individual in a holistic manner to obtain self-reported experiences and help understand whole-needs. Qualitative research seeks and provides information regarding a variety of experiences and by exploring and describing how experiences are lived helps produce knowledge for practice (Tower, *et al*., 2012: 39).

2.3.2 Descriptive Research Design

A descriptive research design was utilised to precisely express participants' lived experiences of the open setting environment. Descriptive studies present a picture of the specific details of a situation (De Vos, *et al*., 2005: 106) and are used in studies where more accurate information is required (Burns & Grove, 2009: 237). This type of study helps to intensively examine and experience the world as it occurs naturally (Leeman & Sandelowski, 2012: 172) in order to describe the dimensions, meanings, and importance of the phenomenon (Polit & Beck, 2012: 18) and so the description of people's experiences is provided from a participant's viewpoint. This yields detailed descriptions about a complex phenomenon and was applicable to this study. A descriptive research design was appropriate to illustrate patients' experiences of receiving HD in an open setting. The description has included expression in the participants own words to convey greater meaning of their lived experiences, enabling the reader to gain deeper insight into patients' daily life situations in an open setting dialysis unit.

2.4 REASONING STRATEGY: INDUCTIVE AND DEDUCTIVE REASONING

Inductive reasoning, according to Burns and Grove (2009: 6), moves from the specific to the general, whereby particular instances are observed and then combined into a larger whole or general statement whilst deductive is usually described as moving from the general to the specific. In this study, the researcher used inductive reasoning as a thinking strategy in approaching the data. For example, during data analysis, the researcher categorised the individual participant's transcribed data into general themes and sub-themes that represented all those receiving life-maintaining HD. Deductive reasoning was used to draw up conclusions for the study findings such as extracting meaning units from each transcript.

This was in line with qualitative data, as arguments based on human experiences are best approached by means of understanding the particulars in terms of the whole (Meleis, 2005: 94; Burns & Grove, 2009: 610). For example, arguments based on experience or observation are best expressed inductively and those arguments based on laws, rules, or other widely accepted principles are best expressed deductively (De Vos *et al*., 2005: 47; Meleis, 2005: 94).

2.5 STUDY POPULATION

Population refers to all individuals with common and defining characteristics or elements who are the focus of research (Burns & Grove, 2009: 343; Polit & Beck, 2012: 59). De Vos *et al*. (2005: 193) define population as the total set from which the individuals of the study are chosen. For the purpose of this study, the population of interest comprised adult patients with ESRD currently receiving HD treatment in a chronic renal dialysis unit at a public sector and tertiary level academic hospital in Johannesburg. A total population of 64 patients receive HD treatment in adult Chronic Renal Dialysis Unit. Each patient receives treatment three times every week and each session lasts four hours. On average, 2300 patients are seen every three months.

2.6 RESEARCH SETTING

The research setting is defined as a site for conducting research (Burns & Grove, 2009: 362). The setting for this study was an adult Chronic Renal Dialysis Unit at a public sector, tertiary level and academic hospital in Johannesburg, Gauteng Province.

Provision of HD treatment to patients with renal failure at this hospital varied:

- children's Renal Dialysis Unit,
- adult Acute Renal Dialysis Unit,
- adult Isolation Renal Dialysis Unit,
- adult Chronic Renal Dialysis Unit
- patients in High Care and Transplant Units.

For the purpose of this study, the setting was only in an adult Chronic Renal Dialysis Unit, which operates from Monday to Saturday with two HD treatment shifts daily - morning and afternoon shift. The morning shift begins at 5:30am, the afternoon at around 11:30am and finishes approximately at 7pm. At the time of this study, this unit was caring for approximately sixty-five patients receiving life maintaining HD treatment three times a week, for an average of four hours per session. A maximum of sixteen patients receive HD during each shift and thirty-two patients receive HD each day in this unit, with approximately 760 sessions performed every month. However, the total number of patients receiving HD at this hospital is not reported in this study.

This study setting is one large open area demarcated by a glass partition, making two big rooms where patients receive HD. One side accommodates twelve patients at a time and the other side accommodates four patients. HD chairs are separated by curtains where usually two patients are treated within a single curtained area, particularly at commencement and termination of treatment thereafter, both rooms are left open for visibility and monitoring during the four-hour period of treatment. All patients once connected to the HD machine are in full view of other patients and staff making this setting appropriate for this study's aim of exploring patient experiences of receiving lifelong HD treatment in an open setting environment.

2.7 SAMPLE AND SAMPLING METHOD

Sampling is described as a technique used to find a sample that is representative and specifies how the sample is selected and recruited in the study (Polit & Beck, 2012: 59). A sample is a "subset of individuals selected from the population chosen for the study" (Burns & Grove, 2009: 42). A sample is composed of elements that contain the most characteristic, have typical attributes or are representative of the population. In this study, a purposive sampling technique was used in choosing the participants from a population of patients with ESRD receiving HD treatment. The aim of purposive sampling is to select participants with an explicit purpose in mind and choose individuals who could give a rich source of data to address the research purpose (Creswell, 2008: 214; Draper & Swift, 2011: 5; Erlingsson & Brysiewicz, 2013: 94), entirely based on the judgment of the researcher (Burns & Grove, 2009: 355). In a purposive method, a sample is selected on grounds of the existing knowledge of the population to provide special information for deep analysis (Tower, *et al*., 2012: 43), hence the selection of patients receiving HD in an open setting for this study.

2. 7.1 Inclusion Criteria

Inclusion criteria are "characteristics that must be present for the element or subject to be included in the sample" (Burns & Grove, 2009: 345). The inclusion criteria for this study were:

(a) male and female patients who were receiving life maintaining HD in a Chronic Renal Dialysis Unit at an academic hospital in Johannesburg;

(b) patients 18 years and older who could give consent for participation in the study;

(c) patients who were able to understand and speak English as the researcher could not speak other indigenous languages;

(d) patients who were willing to participate in the study and showed ability in understanding the research purpose.

This also reflects the aim of purposive sampling which selects subjects upon the researcher's judgment and knowledge of the participants to provide rich experiences (Burns & Grove, 2009: 355; Draper & Swift, 2011: 9).

2.7.2 Exclusion criteria

Exclusion criteria are characteristics or elements not suitable for inclusion in the study (Burns & Grove, 2009: 345). The following were the exclusion criteria:

(a) patients who were receiving acute HD treatment temporarily in a Chronic Renal Dialysis Unit;

(b) patients who were not willing to participate in the study;

(c) patients who could not articulate their experiences in English.

2.7.3 Sample Size

Sample size refers to the number of people who participate in the study (Polit & Beck, 2012: 742). Nineteen patients receiving HD treatment were invited to participate in a face-to-face in-depth interview and of this number, only sixteen took part in the study. Three patients were willing to participate in this study but wanted to be interviewed while on the machine therefore were excluded. The researcher recruited a sample size of sixteen (n=16) as data became saturated, which included seven male and nine female patients. Qualitative research samples are determined adequate by saturation of data when no new information emerges and data becomes redundant during collection (Polit & Beck, 2012: 521). Qualitative studies' focus is therefore on quality and richness of the information and not sample size (Draper & Swift, 2011: 5).

2.7.4 Saturation of Data

Saturation is a point in a study's exploration when data becomes repetitive and redundant to such an extent that no new information appears from further interviews (Polit & Beck, 2012: 62). A point where the researcher intuitively says: "I have thoroughly explored the data and have acquired a satisfactory sense of what is going on" (Blanche, Durrheim & Painter, 2006: 372). The biggest challenge in qualitative research is to determine sample size.

Erlingsson and Brysiewicz (2013: 94) describe qualitative research as typically requiring a small sample; Draper and Swift (2011: 6) point out that an adequate qualitative sample size is one sufficiently large enough to answer the research question. What is preferred is a small sample and in-depth work (Maggs-Rapport, 2001: 380).

Sample size in qualitative studies can be limited but provide rich information, which is facilitated by prolonged engagement between the researcher and the participants (Creswell, 2008: 585; Polit & Beck, 2012: 515). This is in line with quality standards for qualitative data collection (De Vos, *et al*., 2005: 294). The researcher explores and learns the experiences until enough data is obtained to write a full descriptive, logical and rich study (Toloie-Eshlaghy, *et al*., 2011: 112; Bourbonnais & Tousignant, 2012: 14). Conversely, findings from a small sample can limit results for generalisation.

2.7.5 Gaining entry

Gaining entry to the research site was an important step in this study, so to begin the researcher sent the research proposal, including the details and purpose of the study, to the Chief Executive Officer and the Head of Department of Nephrology of an academic hospital. Clearance letters from the Postgraduate Committee of the Faculty of Health Sciences (*Appendix G*) and the Human Research Ethics Committee of the University of the Witwatersrand (*Appendix H*) and approval from the Department of Health, Gauteng Province (Appendix I) were also provided. This was in line with qualitative studies where the researcher often seeks and obtains permission at many levels from individuals and sites (Creswell, 2008: 219). Finally, the unit manager for the Chronic Renal Dialysis Unit was approached and provided entrance to the Unit, assisted in identifying patients and locating the place for conducting the interviews.

2.8 DATA COLLECTION PROCESS

Data collection as defined by Burns and Grove (2009: 43) "is the precise, systematic gathering of information relevant to the research purpose or the specific objectives, questions, or hypotheses of a study." The aim is to gather quality data for the topic under study (De Vos, *et al*., 2005: 419). Qualitative data collection commenced upon receipt of permission from all relevant research committees and management (*Appendices G, H, I, J and K*).

2.8.1 Instrument for data collection

An in-depth semi-structured interview was an appropriate method of data collection for this study to explore patients' experiences of receiving HD in an open setting. Semi-structured interviews are organised around areas of particular interest, whilst allowing considerable flexibility in scope and depth (De Vos, *et al*., 2005: 292, 296). De Vos and colleagues recommend the researcher have a set of predetermined questions on an interview schedule to guide the interviews. The researcher formulated an interview guide (*Appendix A*), which was reviewed by the researcher's supervisor to prevent loss of meaning. Semi-structured interviews capture the participants' own stories and experiences of the phenomenon under investigation (Draper & Swift, 2011: 8), offering an opportunity to express their life experiences, feelings and opinions and allowing the researcher to elicit a wealth of information (Polit & Beck, 2012: 62, 543).

The researcher generates data by asking open-ended questions (Kvale, 1996; De Vos, *et al*., 2005: 296) and participants have freedom to express opinions without being restricted. It has to be noted that qualitative researchers embrace various methods of collecting data such as interviews, observations, fieldwork, focus groups and archival materials (Weiner, *et al*., 2011: 6). Interviews attempt to understand participants' viewpoint, to unfold the meaning of people's experiences and uncover their lived world prior to scientific explanations (Kvale in De Vos, *et al*., 2005: 287) therefore, semi-structured interviews, conducted by the researcher, were ideal for this study to allow participants to share their experiences of receiving HD in an open setting environment. The qualitative researcher becomes the primary data collection instrument (Schammell, 2010: 1146; Polit & Beck, 2012: 15).

2.8.2 Pilot Study

A pilot study is a small version of the proposed study used to refine the methodology and test the research questions (Burns & Grove, 2009: 44). The qualitative researcher begins by talking to a few people with first-hand experience about the study (Mitchell, Farrand, James, Luke, Purtell & Wyatt, 2009: 101; Polit & Beck, 2012: 62).

A pilot study, undertaken according to the designed research methods, was conducted by interviewing two patients who met the inclusion criteria; this was to enhance credibility of the study and to test some practical aspects of the interviews. For example, suitability of the interview venue was assessed with regard to maintaining privacy and the audio-recorder was tested for picking up voices and functioning well.

Besides this, the researcher became alert to one's own level of interviewing skills (De Vos, *et al*., 2005: 294) and approximate length of the interview, relevance and clarity of questions was determined. The venue was appropriate and the researcher was able to facilitate the interview discussion contentedly. Some guiding questions were attuned to ensure participants understood the area under discussion. This is consistent with Whiting and Sines (2012) state that data collection tools can be refined to seek a full understanding of the participants.

Qualitative pilot studies are therefore particularly relevant for the novice researcher not already immersed in the field (Gibbs, *et al*., 2007 as cited in Draper & Swift, 2011: 8).

2.8.3 Participant Selection

To gain rich and in-depth information, the researcher had a meeting with the Nursing Unit Manager of the chosen study setting prior to conducting the study. The rationale was to discuss the details and purpose of the study, criteria for participant selection and identification of the interview venue. Participants who met the inclusion criteria were selected from the Monday to Saturday patients, from both the morning and afternoon shifts. Participants were approached in person and given an information letter inviting them to participate in the study (*Appendix C*).

The purpose of the study was explained verbally in a quiet and private place, with sufficient time allowed for reading the information letter and asking of questions. Participants were selected in advance of the interview dates and a mutually convenient time was agreed with each participant for the interviews. The interviews were conducted either before or after receiving HD with participants who had been on HD for one year to more than 20 years in this unit and were considered experienced about the study topic. For the interview setting refer to Chapter Three on page 47.

2.8.4 Interviewing Phase

The researcher collected data between October 2012 and March 2013. Erlingsson and Brysiewicz (2013: 96) clearly point out that time can be underestimated by the researchers but the process of qualitative studies is often time consuming. Interviews were conducted in a private room to allow participants to express their experiences without being influenced by others. This enabled gathering of high quality qualitative data, which requires deep concentration and energy (Polit & Beck, 2012: 534) and guaranteed confidentiality. Prior to each interview, the researcher made sure the purpose of the study was explained, the audio-recorder was in working order and that extra batteries were available. The researcher thanked the participant for agreeing to participate in the study. Permission to audio-record the interview was obtained and a consent form signed by the participant and then researcher.

Data collection was limited to one interview per day, allowing time for the researcher to transcribe the data. The researcher conducted all the interviews, which lasted between 42 to 65 minutes, with one participant at a time to ensure consistency. Polit and Beck (2012: 542) supported this decision, acknowledging that qualitative interviews are typically long to enable participants to re-construct their experiences. De Vos *et al*. (2005: 297) also highlight that semi-structured interviews require considerable amount of time to allow the researcher to seek and capture the complexity of the participant's experiences and illuminate their opinions.

Qualitative interviews were guided by the research objectives and covered description of participants' experiences including their feelings and opinions about the open setting. The interviews were audio-taped and field notes (Refer page 31) were made (Polit & Beck, 2012: 557), as accuracy can be improved by using such aids (De Vos, *et al*., 2005: 250; Creswell, 2008: 225). Audio-taping gave an accurate record of the conversation and a detailed account of the participant's responses. All interviews were transcribed word for word into typescripts in preparation for critical data analysis (*Appendix M*).

Accurate transcriptions reflect authentic experiences of participants (Polit & Beck, 2012: 557). All interviews, transcriptions and write-ups were conducted in English, optimising accuracy as the researcher made sense of the data (De Vos, *et al*., 2005: 336; Schamell, 2010: 1146; Erlingsson & Brysiewicz, 2013: 94), allowing them to be immersed in the data and generate emergent insights.

2.8.4.1 The interview guide

To guide and ensure consistency of all the interviews, the researcher formulated a set of predetermined questions (*Appendix A*) to ask participants, based on the research objectives (De Vos, *et al*., 2005: 296), which facilitated conversation during each interview. The central question posed was, *"What are your experiences with regard to receiving HD treatment in an open setting environment in a chronic renal dialysis unit?"* Qualitative interviews are generally designed to ask open ended questions to allow participants' to express themselves freely (De Vos, *et al*., 2005: 297), enabling the researcher to hear and derive meaning from the responses (Schammell, 2010: 1146). Such questions also seek an unprompted description of the experiences through the participant's own voice (Creswell, 2008: 225). Therefore, open-ended question create options for responding to the subject matter.

Probing questions were also posed to help clarify points and expand ideas (Kvale, 1996; Creswell, 2008:229). Probes, allowed the participant to express clearly and elaborate on ideas, thus enriching the data gathered as more information was elicited. Probes also helped to keep the conversation on track and ensured accurate interpretation of the intended meaning (Theofilou, *et al*., 2013: 20). The use of interviews enabled the researcher to gain rich

information about the study topic and collect demographic details such as gender, age, race and period on HD treatment.

2.8.4.2 The Skill of Interviewing

The interviewing skills were in line with standards of the research interviews (Kvale, 1996; De Vos, *et al*., 2005: 288-290; Creswell, 2008; Polit & Beck, 2012).

1. Questioning:

The open-ended questions stimulated participant's self disclosure about their feelings and opinions of the open setting dialysis environment. Words like 'what' and 'how' were helpful to allow participants to think first and then proceed with the relating of the experiences without interruption (Kvale, 1996). The goal of asking participants' own experience, comprehends human experience as it is actually lived daily (De Castro, 2003: 47). The ability to question skilfully, paraphrase and reflect on the description formed part of analysis. Examples of the interview questions are presented in Table 2.1

Table 2.1 Examples of the Interview Questions:

Opening question:

How are you feeling today?

Main research question:

- *What are your experiences with regard to receiving HD treatment in an open setting dialysis environment?*

Probing questions:

- *Could you please tell me more about your positive experiences of the open setting?*
- *Tell me more about the stories that you share?*
- *What does receiving lifelong HD treatment with all people around you mean to you?*
- *How easy do you find that?*
- *In your experience, what are the problems of receiving HD together in an open area?*
- *How did you react to that?*
- *.....could you please elaborate on that?*
- *You talked about feeling scared....., what can the nurses do to lessen these fears?*
- *Can you give more examples about that?*
- *What in your opinion, would you recommend for improvement?*
- *Is there anything else?*

2. Listening:

The researcher listened attentively to participant's responses. The ability of the interviewer to listen, remain engaged and show interest assists in collecting in-depth information without the participants feeling they are being interrogated (Draper & Swift, 2011: 7). The period of silences was noted including short and long pauses. Silences or pauses allowed participants ample time to reflect on the experience (Kvale, 1996). Qualitative data collectors must create an atmosphere that allows participants to share their experiences and feelings (Polit & Beck, 2012: 535).

3. Body language and phatic cues:

In responding to what was just said, body language such as nodding or phatic cues such as '… mmh' or 'sure,' were used to encourage talking (De Vos, *et al.*, 2005: 289; Draper & Swift, 2011: 7). The researcher reflected and paraphrased participant's words to verify meaning of the experience as described. Qualitative data requires ongoing feedback and continuous efforts to verify accuracy (Polit & Beck, 2012: 557) as it seeks to understand the subject being investigated and prove the explanations of the individual experiences (Whiting & Sines, 2012: 22). This establishes confidence in the descriptions of the participants. Eye contact also encouraged participants to tell more about their experiences. This open and relaxed atmosphere promoted the interview process.

2.8.4.3 Field Notes

Field notes were also taken during data collection to deepen the audio-recorded information obtained during the interviews. This is in line with qualitative inquiry as a complex and evolving field which embraces a wide range of approaches, methods, and techniques (Applebaum, 2012). Therefore, field notes contained participant code, date and time of interviews, what the researcher saw and heard throughout the discussion and the researcher's feelings about the discussion (*Appendix N*). Field notes ensure highest possible reliability of data and prevent loss of information (De Vos, *et al.*, 2005: 281; Polit & Beck, 2012: 543). The researcher made observations about the conversation and general behaviour of the participants during the interviews.

Notes were made during the course of interviewing or immediately afterwards. The researcher also noted the participant's condition and/or any distracting activity such as a participant's phone ringing, which was useful at the time of analysing the data.

2.8.4.4 Bracketing

Bracketing "is suspending or laying aside what is known about the experience being studied" (Burns & Grove, 2009:545). It allows the researcher to identify, define and analyse the structures of the problem area (Denzin in Tower, *et al*., 2012: 43). In this study, the researcher bracketed personal experiences throughout data collection and analysis. The researcher's feelings, ideas, thoughts, misconceptions and opinions about the open setting dialysis environment remained neutral. Participants' experiences were precisely as described in their own words; their voice embraced throughout the study.

The researcher remained open to participants' descriptions in order to grasp the full meaning of their experiences. As cautioned by Giorgi (2012: 4), when using descriptive phenomenology, concentrate on the given experience and resist from conjecturing on an existing point or state of affair about the phenomenon. De Castro (2003: 50) stresses the use of bracketing in qualitative studies to enhance trustworthiness of data as this helps to minimise bias towards the research data since the aim is to openly inquire and attend to the data as given by participants (Applebaum, 2012: 48). Finding meanings and relationships that stand out provides revelations of an individual's personal reality and viewpoint.

Hale, Treharne and Kitas (2007) however criticised bracketing, stating it suggests an emotional detachment from the research process since personal beliefs and values are not used in data analysis. As highlighted, bracketing ensures and observes the experience under study free from personal bias and so the critiques of Hale *et al*. (2007: 143) imply that complete objectivity is unachievable in any research project because researchers make value judgments throughout the design, execution and dissemination process. Nevertheless, bracketing was an important concept in this study to understand fully the participants' viewpoint.

2.9 DATA ANALYSIS

Data analysis followed the five steps of Giorgi's (1985) phenomenological method (cited in De Castro, 2003: 50-55; Makoe, 2007: Burns & Grove, 2009: 531; Giorgi, 2012: 5-6). Data analysis is the categorising, ordering, manipulating and summarising of data to obtain answers to the research questions (De Vos, *et al*., 2005: 218). The main purpose of phenomenological analysis is to illuminate the essence or general structure of the phenomenon (Giorgi, 2012: 5). It reduces data to an intelligible and descriptive form so that the relations of research problems can be studied, tested and conclusions drawn (Applebaum, 2012: 49-50). Data analysis began as soon as initial data were collected, as supported by qualitative studies. This allows the building of a coherent interpretation of the data (De Vos, *et al*., 2005: 335; Polit & Beck, 2012: 62, 556), whilst the initial concepts deepen understanding for the researcher with further data collection and analysis. The transcribing of the data, the use of intuition by the researcher and Giorgi's phenomenological method, including the five steps of data analysis, will be discussed next.

2.9.1 Transcription of data

Transcription of data is a critical step in preparing for data analysis to ensure accurate and valid reflection of the interview experience (Polit & Beck, 2012: 557). Generally, research interviews are audio-recorded then transcribed to produce transcripts for rich analysis (Draper & Swift, 2011: 4). Immediately after the interview, the researcher listened to and checked for auditability, which entails examination of the data and decisions involved to ensure rigour during analysis (Burns & Grove, 2009: 546, 612) and completeness of data. The transcription of the audiotapes was word for word and empty spaces filled. Symbols such as 'P' indicated participant and 'R' researcher. Numbering against the P symbol such as P10, P5 indicated the participant code number, however, this numbering did not follow the order of interviewing. Expressions such as laughing or periods of silence were written and closed in parentheses i.e. (laughing). Audio-recordings, transcripts and field notes received the same code for easy identification. Transcription accuracy was checked by listening simultaneously to the audiotapes and reading of transcripts. Van Manen (2006: 715) supported this by stating that for qualitative research data to emerge and insights obtained, the process of intense reading and writing has to be undertaken.

2.9.2 Giorgi's Phenomenological Method

The basic idea of Giorgi's phenomenological method is to capture and describe data according to lived experiences (De Castro, 2003: 49; Giorgi, 2012: 5). The description is based upon what is given and articulated by the person living the experience and presented exactly as experienced in order to catch the whole meaning of the expression as lived (De Castro, 2003: 47). The idea is to grasp the whole meaning of the experience, as the approach is holistic, searching for rich meaning of the experience (Makoe, 2007, Applebaum, 2012). This is consistent with qualitative analysis, which makes sense of data while ensuring the participant's voice is heard (Schammell, 2010: 1146). The researcher takes an attitude and practices a certain attentive awareness to the lived experiences rather than conceptualising or theorising them (van Manen, 2006: 720). Therefore, description forms part of constructing meaningful experiences. In describing, the act of reflection detects the meaning given by the participant, precisely as it appears and lived (Giorgi, 2012: 6-7).

According to Giorgi (2012:8), phenomenology seeks to establish scientific criteria by understanding the life-world events as confronted by human subjectivity. This enhances qualitative rigour (Applebaum, 2011: 519-521), as it grasps the whole experience. Maggs-Rapport (2001) advises researchers using descriptive phenomenology, that the meaning of data should be described in its ambiguous, complex and multiple forms, for the focus is to grasp the whole meaning of the experience (Giorgi, 2012: 5). Thus, bracketing was vital to approach experiences from participant's perspective.

2.9.3 Intuition

Burns and Grove (2009: 5) refer to intuition as "an insight or understanding of a situation or event as a whole that usually cannot be logically explained." In descriptive phenomenological, intuition, which was applied in this study, is vital as it help researchers respond to the study phenomena in the way they are experienced (Maggs-Rapport, 2001: 376; Burns & Grove, 2009: 529), enhancing validity. The researcher, in this study, attained clear and evident participants' experiences by being open to the description and all meaning attributed to the given experience of the open setting dialysis environment. Adequate time was taken to concentrate on the data, with the researcher staying in a quiet environment to read, listen and

reflect until finally immersed in the data. This increased insight of the participants' experiences. In this manner, true judgments of the open setting context were produced (De Vos, *et al*., 2005: 92).

2.9.4 Giorgi's five steps to data analysis

2.9.4.1 First - **"*getting the sense of the whole description*".** In this step, the researcher generated rich aspects of patients' experiences of receiving HD in an open setting environment as a whole. Transcribing the data into typescripts occurred immediately after each interview. Primarily, the researcher listened repeatedly to the audiotapes of each interview and re-read transcripts and field notes several times, to obtain a general feeling of participants' experiences (De Castro, 2003: 50), which meant being open to the text to get the sense of the whole description (Makoe, 2007; Burns & Grove, 2009: 532). For van Manen (2006: 715), texts evoke people's understanding about the life-world and produce research knowledge. According to Giorgi, if the given experience is divided into parts before understanding how the person who lives that experience articulates it, the researcher creates abstract concepts that do not have any sense for that person (De Castro, 2003: 47). In other words, the researcher does not grasp the sense of the whole experience.

2.9.4.2 Second - **"*discrimination of the meaning units*".** The researcher re-read the data to identify phrases that stood out (De Castro, 2003: 51). At this stage, the whole description was broken into several parts to determine participant's own meaning of the experience relevant to the study (Herlin & Wann-Hansson, 2010: 695). The researcher divided the text into parts, which expressed meaning about the open setting. Words, phrases and sentences expressing the description were highlighted and essential text was extracted. The researcher understood whole meaning of each expression. Qualitatively, words are analysed to understand meaning (Weiner, *et al*., 2011). The researcher's supervisor reviewed each step of analysis to ensure meaning that had not been expressed was not imposed, as stressed by De Castro.

2.9.4.3 Third - **"*transformation of the lived experiences into psychological language*".** According to Giorgi, the researcher re-describes the meaning of participants' experiences from a naive language into one more psychological to produce more concrete expressions (De Castro, 2003: 52; Giorgi, 2012: 5).

The aim is to transform the data into expressions that are more revealing of what the participant said about the study phenomenon (Giorgi, 2012: 5). This involves organising and translating the raw data into a disciplinary language (Herlin & Wann- Hansson, 2010: 695) to be understood in the healthcare field that was as simple as possible while retaining meaning of what the participant had said. A further detailed re-reading and questioning of the selected text was done. Polit and Beck (2012: 557) advise qualitative researchers to scrutinise and interrogate their raw data carefully by reading over and over. To ensure accuracy the researcher's supervisor verified all the transcribed data. Participants' own expressions about the open setting were revealed and remained consistent with their experiences without the meaning changing.

2.9.4.4 Fourth - **"*the individual description of the situation*".** A descriptive statement was made of each participant's specific characteristics about the open setting environment. The researcher analysed and synthesised the data gathered to come up with findings (Makoe, 2007; Burns & Grove, 2009:531). This was carried out after synthesising the meaning units of each description to ensure essential network among the parts. A given experience was not separated from the concrete meaning structure of the participants, to avoid losing the meaning the participants were trying to affirm in their daily life in the HD unit. Themes from individual participants were identified. Good qualitative studies are descriptively sound and explicit to generate rich and insightful work (Polit & Beck, 2012: 584).

2.9.4.5 Fifth - **"*formalising a general description of the structure*".** The idea is to bring an essential understanding of aspects of the general situation of the raw data into research findings (De Castro, 2003: 55; Giorgi, 2012: 6). Themes and sub-themes extracted from individual participants were compared to generate findings. Common experiences and contradictions were established. Themes that appeared common to all study participants were identified. The similarities and differences were identified, which enhanced credibility and authenticity (Polit & Beck, 2012: 585). Qualitative analysis involves describing information and clustering together the related information into coherent schemes and developing themes (Creswell, 2008: 458; Burns & Grove, 2009: 532; Polit & Beck, 2012: 62, 556). Thus, data becomes richer than the perspective brought to it that makes the analysis feasible (Applebaum, 2012: 47).

In the latter, as data were comprehensively analysed, verbal responses contained more information than appeared initially during data collection. As the researcher and the researcher's supervisor made a general analysis of what participants had in common to generate findings, the meaning of the data emerged and was made explicit. This is in support of qualitative studies, which embrace multiple truths because each person has an understanding of the reality from an individual perspective (Erlingsson & Brysiewicz, 2013: 94). Direct quotations from participants' responses, written in italics to distinguish the text, are used under each theme and sub-theme to indicate how conclusions were drawn.

2.10 MEASURES OF TRUSTWORTHINESS

Trustworthiness refers to the strategies that diminish threats to research integrity and enhance rigour or truth-value in qualitative studies (Polit & Beck, 2012: 584). The concept of trustworthiness is equivalent to validity and reliability in quantitative studies (De Vos, *et al*., 2005: 346), however they are not addressed in the same manner as in quantitative studies. Trustworthiness provides confidence in the accuracy and insightful representation of the report given (De Vos, *et al*., 2005: 346). Lincoln and Guba's (1985) five criteria for ensuring trustworthiness, including credibility, dependability, confirmability, transferability and authenticity (Polit & Beck, 2012: 584-585) were applied in this study. The Lincoln and Guba (1985) model is well developed conceptually and has been expansively used by qualitative researchers (Small, 2010: 189). Each criterion will be discussed in relation to this study and summarised in Table 2.2.

2.10.1 Credibility (Truth-value)

Credibility is related to confidence in the truth-value of the data (Polit & Beck, 2012: 585). Credibility in qualitative research is the concept equivalent to internal validity in quantitative research (Lincoln & Guba, 1985: 290). It refers to the degree to which findings and the methods used to generate the findings can be trusted (De Vos, *et al*., 2005: 353).

Therefore, how credibility was enhanced throughout the research process to the presentation of the findings will be discussed. To establish credibility, the researcher carried out the following strategies:

- *Prolonged engagement* was ensured, as data was collected between October 2012 and March 2013. Sufficient time was given to each participant prior and during interviews to build trust and collect rich data. Interviews took between 42 and 65 minutes. Sufficient time was also taken afterwards for further data analysis.

- The study took place in a *natural setting* within the dialysis unit and interviews were held in a meeting room, which was generally quiet, private and familiar to the participants.

- *Triangulation* was ensured, for example: - the researcher collected data at different times of the day i.e. before or after receiving HD treatment. Interviews were conducted in different months and year (October 2012 to March 2013). Field notes, audiotapes and transcripts also triangulated the data. The sample included different races (Whites, Blacks and Indians), age groups, gender and period on HD varied. During the interviews, the researcher observed participant's words, tone of voice and periods of silence and probed more to gather rich data. Interviews were transcribed word for word whilst listening to the audiotapes concurrently (Weiner, *et al*., 2011). Qualitative, exploratory and descriptive research methods were employed. This enhanced credibility as methods were triangulated.

  All aspects of the research process were verified by the researcher's supervisor, including the research problem, study setting, research methods and design, population and sampling technique, data collection, analysis and presentation of the findings. The researcher's supervisor followed up each step of the research process and provided intensive guidance and feedback throughout the study. The purpose of triangulation was to validate the conclusions drawn in the study through multiple perspectives (Burns & Grove, 2009: 392).
- *Bracketing* was maintained throughout the study allowing the researcher to remain truthful to patients' descriptions.

- A *search for confirming and disconfirming evidence* from the literature was carried out. Literature was reviewed extensively from different domains in nursing and other social studies to control the findings.

- *Researcher's credibility* was vital to establish confidence in the collection of data and was based on the researcher's qualifications and experience in interview techniques during data collection (Creswell, 2008; Polit & Beck, 2012). In this study, the researcher is a trained nephrology nurse with previous clinical experience obtained at this hospital. Therefore, interaction with the study participants was not new because the researcher had attained prior experience working with these study participants. Part of the researcher's clinical experience involved talking to and counselling patients with regard to their physical, psychological, social and spiritual aspects, which is similar to interacting with participants during research interviews. Collins (cited in De Vos *et al*., 2005: 293) advises that interviews are social interactions in which meaning is negotiated between persons.

2.10.2 Dependability (Consistency)

Dependability refers to the consistency and reliability of data to remain stable over time and conditions (Polit & Beck, 2012: 585). To ensure consistency, the researcher used the same interview guide and procedures to conduct all interviews. An inquiry audit was undertaken to make decisions, which involved keeping track and comparing all data recordings including audiotapes, transcripts and field notes to achieve decisions. Accuracy of audio-recordings, transcribing of data word for word, listening and reading repeatedly to all recordings, provided in-depth reliable qualitative data.

To ensure consistency, a compact description of the study is given in this report. The basis of merit of qualitative studies is on reporting detailed data (Creswell, 2008; Weiner, *et al*., 2011). The extensive follow up of the study by the researcher's supervisor enhanced dependability, which in turn improved achievement of credibility (Polit & Beck, 2012: 585).

2.10.3 Confirmability (Neutrality)

Confirmability refers to the neutrality or objectivity of the research to show congruence about accuracy, relevance, or meaning of the data (Polit & Beck, 2012: 585). To meet the criterion of confirmability in this study, the researcher ensured clarification, during the interviews, of certain areas that needed verification from the participants to understand the given experience. The researcher also provided an audit trail, by keeping track of all references used, audio-tapes, field notes and transcripts for auditability.

According to Burns and Grove (2009: 612), auditability refers to the rigorous development of a decision trail, where the researcher reports all decisions involved in the transformation of data to the theoretical representation. The researcher, to validate how the results were obtained, kept all narratives along with all references and rough copies of coded data for analysis. The researcher's supervisor verified all recorded research data including the findings. Bracketing was ensured throughout the study and findings emerged from the participants own view (Polit & Beck, 2012: 585). Direct verbatim quotes from participants, filled with rich information, were supplied in this report to support the findings and reduce bias. The search for confirming evidence to the research findings enhanced neutrality. Copies of the interview transcripts are included for auditing (*Appendix M*). Conversely, quantitative studies never contain raw data (Polit & Beck, 2012: 63).

2.10.4 Transferability (Applicability)

Transferability is the applicability of the findings where judgments made from the study can be useful in similar settings or groups (De Vos, *et al.*, 2005: 346; Polit & Beck, 2012). Lincoln and Guba (1985: 290) refer to transferability as an alternative to external validity or generalisability in quantitative studies. Generalisability of qualitative findings becomes problematic as it involves studying a small number of individuals. However, Applebaum (2012: 48) shed light on generalisability of qualitative findings, which are not argued by means of statistics but in terms of meanings. Qualitative findings cannot be generalised in a statistical context, however, the qualitative findings are in a sense transferable to similar samples in a similar context.

To meet the criterion of transferability, the researcher ensured the holistic framework, mind, body and spirit dimensions, utilised in this study were distinctively and unambiguously articulated to make certain future researchers understood and employed the framework in alignment with this study. An accurate and thick description of the research process, methods, and findings has been provided (Blanche, *et al*., 2006: 381). Detailed findings were properly documented to allow other researchers to make comparisons with their own work in other contexts (Weiner, *et al*., 2011). Finally, the researcher has clearly described the limitations of this study, enhancing transferability.

2.10.4 Authenticity

Authenticity is another criterion to measure trustworthiness (Polit & Beck, 2012: 585). The term authenticity elicits a sense of genuineness; the true-self or the inner truthfulness (Nosek, 2012: 829-830). According to the Oxford Advanced Learner's Dictionary (2010: 83), authenticity refers to the state or quality of being genuine, real or true and made exactly the same as the original. Polit and Beck (2012: 585) define authenticity as the extent to which researchers fairly and faithfully show a range of realities conveying the voice of the participants' lived experiences. However, the use of authenticity in qualitative studies is relatively new and its application becomes a challenge (Wilson & Clissett, 2011: 685).

To establish authenticity, this report carries verbatim quotations of participant's feelings and opinions about the open setting environment. Polit and Beck (2012: 585) stress that direct quotes with relevant descriptions of an experience allow the reader to feel the voice and tone of the participants, to carry the authenticity of their lived experience. Some embedded quotations were also briefly used within the text to illustrate a point in support of a theme or sub-themes (De Vos, *et al*., 2005: 352). The interview quotation commonly gives an impression of the interaction that took place (Kvale, 1996). Thus, qualitative results are reported in a rich literary style based on the transcribed narratives from individual interviews to strengthen trustworthiness (Erlingsson & Brysiewicz, 2013: 94). Consequently, quotes also demonstrate the 'truth' value of the study. Table 2.2 summarises measures of trustworthiness applied in this study.

Table 2.2: Strategies used to establish trustworthiness in the study

Criteria	Strategy	Implementation
Credibility (Truth-value)	-Natural setting	• Interviews were conducted within the HD unit
	-Prolonged engagement	• Participant and researcher had enough time to discuss the experiences. Interviews lasted 42 to 65 minutes.
	-Triangulation	• Used audio-recording, field notes and transcripts. • Employed qualitative, explorative and descriptive methodology using in-depth semi-structured interviews on a purposive sample.
	-Saturation	• Adequacy of sample size was determined with data saturation.
	-Bracketing	• Researcher reflected on participants' experiences.
	-Confirming and disconfirming evidence	• Scholarly literature was searched to control the findings.
	-Researcher's credibility	• Researchers background- renal nurse
Dependability (Consistency)	-Dense description	• Comprehensive and clear description of research methods was provided to allow researchers to trace methods used.
	-Same interview guide	• Same interview guide was used on all study participants
	-Inquiry audit	• Inquiry audit: tracked the audio-tapes, field notes and transcripts to compare all data recordings to achieve decisions.
	-Data triangulation	• Data triangulation as highlighted in credibility
Confirmability (Neutrality)	-Audit trail	• All narratives, references and rough copies used to analyse data including audio-recordings, field notes and transcripts were kept securely to validate findings, and until publication.
	-Decision trail	• All decisions involved to reach findings were carefully reported and documented. • The researcher's supervisor verified all the research data including decisions made
	-Verbatim quotes	• Searched for confirming evidence • Direct quotes from participants were provided
Transferability (Applicability)	-Thick description of the research process and findings	• Thick and vivid description of data was provided in the research report including the process, methods and findings. • Provided demographic data for participants • Study limitations were provided.
	-Searched for confirming evidence	• As highlighted in credibility
	-Data saturation	
Authenticity	-Prolonged engagement	• Interviews lasted between 42 and 65 minutes • Sufficient time was taken to collect data- October 2012 to March 2013, and sufficient time was taken to analyze data
	-Evocative writing of patients' expressions.	• Direct quotations from participants were provided
	-Thick description	• Audio-recorded interviews were transcribed word for word.

2.11 ETHICAL CONSIDERATIONS

Ethics in research involves the application of various ethical codes and regulations that govern the scientific research (Burns & Grove, 2009: 184). The participants for this study involved patients receiving HD treatment therefore, to protect their rights and ensure ethical human research conduct, the researcher adhered to the ethical considerations in accordance with the University of the Witwatersrand's Code of Ethics for research on human participants and the guidelines for nursing research (Polit & Beck, 2012: 150). Ethical issues applied in this study are discussed.

2.11.1 Authorisation to Conduct Research

The researcher submitted a research proposal and sought formal permission from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand to conduct this study. Upon receipt of the ethics approval, reference number M120410 (*Appendix H)*, approval was obtained from the South African Department of Health, Gauteng Province (*Appendix I*). Thereafter, individual letters requesting permission and entry were sent to the Chief Executive Officer, the Nursing Service Manager and the Head of Nephrology Department of the participating hospital. Their approval was communicated in writing (*Appendix J and K*) whilst the nursing and unit manager of the Chronic Renal Dialysis Unit communicated verbally.

2.11.2 Informed Consent and Voluntary Participation

The participant's right to informed consent and voluntary participation was assured. According to Burns and Grove (2009: 186), "the voluntary consent of the human subject is absolutely essential." The participants received an information letter written in simple English (*Appendix C)* explaining the purpose and objectives of the study and giving them the option to voluntarily participate or not (Burns & Grove, 2009: 201). Questions were addressed before consenting to the study. Participants signed two written consent forms, for participating in the study and use of a tape recorder (*Appendix D*); obtaining informed consent is vital part of the recruiting process to offer participants the opportunity to express their experiences with the

researcher (Draper & Swift, 2011: 6). The researcher as an instrument also signed below the participant signature showing commitment and adherence to the ethical procedures outlined.

2.11.3 Anonymity, privacy and confidentiality

Participant's rights to anonymity, privacy and confidentiality were emphasised (Burns & Grove, 2009: 196-197). All participants were receiving HD treatment at this hospital and to ensure their rights, the researcher used the following strategies:

- all information obtained from each participant remained confidential;
- each participant's data was coded with a number to protect identification and enhance trust. Participants' names were not used (Kvale, 1996).
- interviews took place in a private room (De, Vos, *et al*., 2005: 294).
- audio-recorder, field notes, transcripts and demographic data were managed and kept in secure place under lock and key and used only for the intended purpose (Polit & Beck, 2012).
- all data stored on the laptop and USB were locked with a password. Only the researcher's supervisor had access to the audio-tapes, transcribed data and field notes.

The raw data will be kept in secure place by the researcher for a minimum of six years unless publication of the study ensues in which case data will be retained for two years once the information is published. Publication is important to communicate and impart knowledge to others and enhance accumulation to the body of knowledge (Applebaum, 2012: 46).

2.11.4 Protection from discomfort and harm

Burns and Grove (2009: 198) emphasise that the researcher must ensure participant's rights to protection from discomfort and harm based on the ethical principle of beneficence, which requires the researcher to do good and above all do no harm. To enhance this principle, the interview venue was quiet, private and easily accessible to the participants. Comfortable chairs were provided, food was available to promote well-being and conversation and the interviews were completed punctually, within approximately one hour.

Throughout the interview period, safety of the participant was paramount (Draper & Swift, 2011: 4). The researcher observed the participant's condition, bearing in mind they had just completed or were about to receive HD treatment. Thorough information was given beforehand about the study purpose. Participant's rights to voluntarily participate or to withdraw from the study were emphasised, but no one withdrew. Money for bus fare was provided to those who requested. At the end of each interview, the researcher ensured that the participant was safe, and where necessary information about counselling was offered.

2.11.5 Accessibility to reported Research Findings

These research findings will be distributed to the authorities at the Department of Health, Gauteng Province and to the Nursing Services Managers and HD staff working in the Chronic Renal Dialysis Unit at the specified hospital in Johannesburg, as well as presented to the Department of Nursing Education at the University of the Witwatersrand's research day. Finally, an article encompassing the study will be published in an accredited Nursing Journal. As pointed out by Applebaum (2012: 46), scientific knowledge is never a private achievement, but completely a communal one and requires circulation.

2.12 CONCLUSION OF THE RESEARCH METHODS AND DESIGN

This chapter provided a detailed description of the research methodology used in this study. An explorative and descriptive design, using a qualitative methodological approach, was used to elicit the experiences of patients receiving HD treatment, in an open setting environment, in a Chronic Renal Dialysis Unit at a Johannesburg academic hospital. This included discussions on the population and sampling method, sample size, methods of data collection and analysis, ethical considerations and measures used to establish trustworthiness. A purposive sampling technique was utilised to select sixteen patients who were the research sample. Semi-structured interviews were conducted to generate research data from the participants. Ethical principles that govern the human research conduct were ensured throughout the study including obtaining an informed consent from all the participants. The researcher's supervisor verified each step of the research process including how data was analysed. The next chapter (Chapter Three) will discuss the in-depth description of the data analysis and presentation of the findings, which are controlled by literature.

CHAPTER 3

PRESENTATION OF FINDINGS AND LITERATURE CONTROL

3.1 INTRODUCTION

This chapter presents the analysis and findings of the sixteen interviews conducted purposely with patients receiving HD treatment in an open setting environment in a Chronic Renal Dialysis Unit at an academic hospital in Johannesburg, including the application of Giorgi's (1985) phenomenological method of data analysis, participants' profile and interview setting. From the analysis, the emerging themes and sub-themes derived are described and situated within the body of literature on patients' feelings and opinions about the open setting.

> *Qualitative research requires being attentive to other voices, to subtle significations in the way that things and others speak to us. In part, this is achieved through contact with the words of others.*
>
> van Manen (2006: 713)

To have a deeper understanding of patients' experiences, direct quotations are provided in the findings. This supports the quality of the qualitative findings, which should generally provide textual accounts of the diversity of individual's lived experiences (Erlingsson & Brysiewicz, 2013: 94). This helps researchers deepen their understanding of what it means to be human and living with experiences.

To guide the study the research objectives were:

(1) to explore and describe the experiences of patients receiving HD in an open setting at an academic hospital in Johannesburg;

(2) to examine and describe patients' feelings and opinions with regard to accessing HD in an open setting environment at an academic hospital in Johannesburg.

3.2 INTERVIEW SETTING

The interviews took place in privacy in a separate room at the dialysis unit to ensure the rights of the participants were guaranteed (Draper & Swift, 2011: 4). The Unit manager identified the room, which was arranged in a manner that created a relaxed atmosphere with no interruptions (De Vos, *et al*., 2005: 294). Two comfortable chairs were provided and arranged to allow the researcher and participant to sit squarely for easy communication and observation. Snacks and light refreshments, according to renal diet, were provided to create a relaxed atmosphere. After obtaining informed consent from the participant, a tape-recorder was turned on. The room was quiet and doors were kept closed throughout the interview period, which allowed for good conversation without noise or disruption (Kvale, 1996), thus enabling the researcher obtain rich data. This method was maintained for all the sixteen interviews. A comfortable and non-threatening environment that meets the needs of the researcher and the participant is recommended when conducting interviews (Burns & Grove, 2009: 510, 511).

3.3 LITERATURE CONTROL: THE HOLISTIC NURSING CARE FRAMEWORK

Tjale's holistic care, mind-body-spirit dimensions, is a holistic nursing care model, with the purpose of developing a framework for holistic nursing care that can be utilised in diverse education and clinical nursing practice settings. Tjale introduces the goal of holistic nursing care as whole care designed to meet the needs of the whole person with mind-body and spirit (Tjale, 2007: 204). Whole care has five dimensions: physical, emotional and psychological, spiritual, social and cultural dimensions.

Physical dimension involves the care that is designed to meet the diseased part of body of a whole person. It meets the physical needs of a person with respect to the presenting health problem and prevention of potential complications (Tjale, 2007: 211).

The ***emotional and psychological dimension*** refers to the care that focuses on the mind or emotions of a person, address fears and anxieties resulting from stresses in a hospital environment (Tjale, 2007: 214).

The ***spiritual dimension*** was conceptualised by Tjale as a quest for a divine connection with God, a life force or a Supreme Being. It has vertical and horizontal levels. The vertical level translates a desire to acknowledge the individual as a spiritual being and accept the diversity of beliefs to help find meaning in the higher power or God. This level gives an awareness of deep connection to God or life force. The nurse may facilitate with prayers, meditations, pastoral care, counselling, being there and caring. In applying horizontal level, the nurse has the desire to care for other human beings with, compassion and respect for their values and beliefs. The horizontal level translates to social issues, i.e. showing empathy, and concern for others, which brings hope, a sense of comfort, wholeness and peace amidst life threatening situations and illness (Tjale, 2007: 117).

Social dimension refers to social commitments to share one's individual humanity with others. It engages in wholesome relationships that increase human value, trust and dignity. Tjale recognises that to be human is to affirm one's humanity by recognising that of others.

Cultural dimension, involves recognition of a person and family's beliefs and values. The care in this dimension has to be culturally sensitive and so Tjale advises healthcare workers that conflicts may be experienced in practice between biomedicine and cultural values of a patient. Therefore, a nurse has to recognise the good and bad practices, for example, cultural rituals practiced in certain families, and find better ways to incorporate one's beliefs and values.

The five dimensions are integrated and relate harmoniously (Tjale, 2007: 204). From her research, Tjale conceptualised the nurse's uniqueness as whole-person, an agent in providing whole-person care and advises nurses to be more humane, respectful, empathetic, and sensitive to the patient and family (Tjale, 2007: 194).

The integration of Tjale's model in daily patient care can help to eliminate barriers to the healing process and facilitate well-being. Providing whole care will support individuals to find meaning in their experiences and become connected or whole to themselves, other people or higher powers and ultimately improve their overall health including psychological well-being (Tjale & Bruce, 2007; Dossey, 2010; NRC-SA, 2011). The aim of applying this model in this study was to understand the patient's holistic experiences of receiving HD treatment in an

open setting environment with the goal of supporting their holistic needs. The model was appropriate as it embraces the concept of treating the whole person. The research data that informed the model was collected in the same hospital and most participants shared common values and beliefs.

The mind-body-spirit model has been critiqued by Nathenson (2012: 114) as lacking in the social aspect. Tjale's model incorporates the social dimension in aspects of whole person care, which is used extensively in palliative care (Tanyi & Werner, 2008; Kolewaski, Paterson, Yeates & King-Van Vlack, 2010; Clarkson & Robinson, 2010; Joseph, Laughon & Bogue, 2011; NRC-SA, 2011; Nathenson, 2012; Puchalski, 2012; www.jblearning.com). Holistic care is advocated in the provision of renal care in the South African context (NRC-SA, 2011). Joseph et al. (2011) also encourage viewing patients as a whole and to render care holistically, mind-body-spirit, especially during assessments and interventions. Application of the whole person care will be discussed in Chapter Four.

3.4 APPLICATION OF GIORGI'S PHENOMENOLOGICAL METHOD

The analysis was carried out phenomenologically, by means of Giorgi's (1985) five steps. The interviews were audio-taped, transcribed and analysed manually. Upon completion of the transcriptions, data were approached inductively (refer page 22) for detailed and systematic analysis (Tjale, 2007: 59; Burns & Grove, 2009: 532, 610). Conclusions were drawn from each transcript to come up with findings by deductive reasoning. To facilitate the process, the researcher and the researcher's supervisor immersed themselves in the data and discussed the interpretation of the text on a regular basis to enhance rigour. This involved reading the transcripts, writing the themes and sub-themes on a wallboard and refining them intermittently. Table 3.1 discusses how each step was applied in this study. (For the detailed description of the Giorgi's steps refer to Chapter 2, section 2.9.4 on pages 36-38).

Table 3.1: Application of the five steps of Giorgi phenomenological method

Step 1: Getting the sense of the whole description
It was at this point the audiotaped sessions and entire transcripts were reviewed numerous times to get an overall sense of the entire description about the open setting dialysis environment. The researcher listened repeatedly to each audiotape paying attention to the tone of voice and the pauses to extract meaning. This was a hands-on analysis that involved the reading and re-reading of a single transcript as a whole and immersing oneself in the text to understand how the experience was articulated by the participant (De Castro, 2003: 50; Erlingsson & Brysiewicz, 2013; 96). The whole feeling with the raw data was grasped in such a way that recurrent key issues and meaningful parts of the text were highlighted. The interesting concepts and phrases were noted. This step was overwhelming because of the amount of work to comprehend the whole meaning as intended by the participants.
Step 2: Discrimination of the meaning units
The researcher, at this stage, looked and examined the data to identify particular meaning units. Listening to each single audiotape and re-reading the transcripts was a continuous task. The text containing relevant experiences about the open setting environment were isolated and broken into several parts to determine their meaning. Meaning units contained a word or sentence and others, several sentences. Erlingsson and Brysiewicz (2013: 96) state meaning units can contain few words or several sentences or paragraphs, provided they convey one central meaning.
Step 3: Transformation of the lived experience into psychological language
At this point of data analysis, meaning units were transformed into a psychological perspective (De Castro, 2003: 52; Giorgi, 2012: 5) to reveal patients' experiences in the open setting. This involved interrogating the meaning units and transforming the experience into a more understandable language whilst retaining meaning as described by the participants. This was with respect to and revelation of the open dialysis setting. The researcher's supervisor cross examined the description to arrive at the meaning in a psychological language, particularly a language that could be understood in the healthcare field (Makoe, 2007; Burns & Grove, 2009: 531-532).
Step 4: Individual description of the situation
A descriptive statement of the specific characteristics of each participant was made. This step involved examining, understanding and organising the descriptions coherently (De Castro, 2003: 54). It involved searching for connections of individual experiences, as at times participants were repetitive, rambled or jumped around before describing their lived experience in the open setting environment. Significant statements were reduced and organised into individual themes and sub-themes to ensure an essential network of the relationship of parts and meaning of the whole experience stood out.

Step 5: The general description of the situated structure

At this point of data analysis, each individual structure was compared to others. The aim was to search for patterns to establish similarities and differences that connected different elements from individual participants (De Castro, 2003: 55; Makoe, 2007). It involved searching for relationships between themes to look for possible explanations. Individual audiotapes, transcripts and field notes were analysed. Quotes from participants were compared and a general structure from all the interviews was made explicit. Themes and sub-themes that appeared to be common to all the participants were identified and will be discussed (Figure 3.1).

3.5 DATA PRESENTATION

Presentation of the data will be in two sections. The first part presents the demographic information of the participants elicited at the onset of each interview session. The second part presents the themes and sub-themes that emerged from the data through systematic analysis using Giorgi's phenomenological method. Literature controlled the findings to confirm and disconfirm the evidence.

3.5.1 SECTION A: DEMOGRAPHIC INFORMATION

This section focuses on the demographic characteristics of the participants: gender, age, race and period on HD treatment. The majority of the participants were between the ages of 26 to 40 and 56 to 70 years. Table 3.2 provides the demographic data of the participants. (For individual participants demographic data, *Appendix K*).

Table 3.2 Demographic variables for the sample of patients (n=16).

Variable	Frequency
Gender	
Female	9
Male	7
Age	
18-25 years	2
26-40 years	5
41-55 years	4
56-70 years	5
Race	
Whites	3
Blacks	12
Indians	1
Period on HD treatment	
1-2 years	2
Above 2 years	14

3.5.2 SECTION B: THEMES AND SUB-THEMES

This section presents the themes and sub-themes related to receiving HD in an open setting environment. According to Giorgi's phenomenological method, the data in the first place present the sense of the whole description. In this study, receiving HD treatment in an open setting environment was largely viewed positively as participants said it enhanced patients overall health and psychological well-being because of the interactions and support from "others". Three themes emerged from the interviews: *a mood enhancer*, *experiences of nursing care* and *a sense of fear*. The subthemes in this report are noted throughout the text in italics. Figure 3.1 presents the themes and sub-themes;

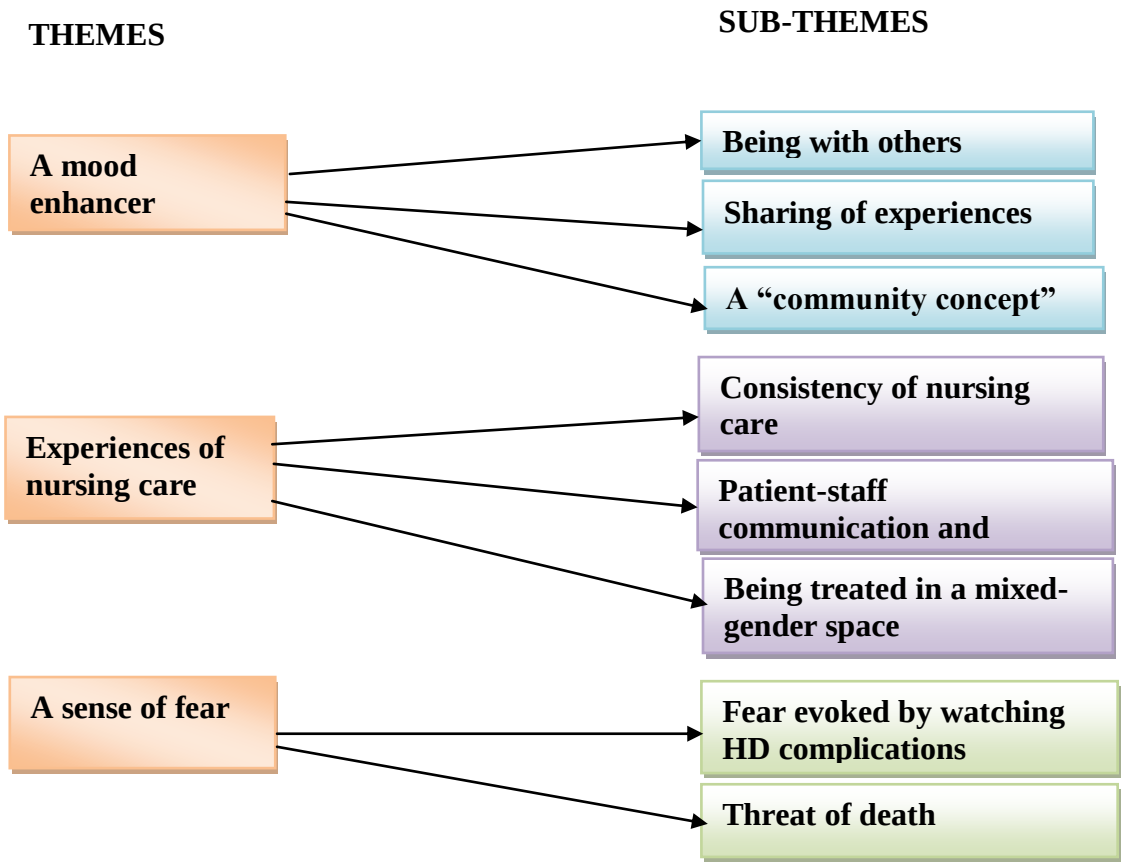

FIGURE 3.1: Themes and sub-themes that emerged from experiences of patients receiving HD treatment in an open setting environment at an academic hospital in Johannesburg.

3.5.2.1 THEME ONE: *A MOOD ENHANCER*

A mood enhancer appeared as a major theme from all the participants (n=16). A mood enhancer, as described by the participants, relates to the HD care environment which provides professional support, increases patients' feelings of happiness and promotes positive thoughts about the treatment. It appeared to relate to a healing environment, as participants described '*being with others'* in the unit increased patient interaction, motivation, understanding, and support for one another and *sharing of experiences*. The description of sharing experiences was the sharing of information, acting together preparing the HD machines, assisting others in need, discussing and comparing life experiences and also how they felt about the relations with each other. Participants describing their experiences consistently used 'we' in describing their experiences.

This '*community concept'* sustained their togetherness and brought joy to the patients, which reduced the distressing moods from what was experienced individually and collectively.

In literature, the concept *mood* is related to a psychological state of feeling (Esposito, 2005: 2), the state of mind or experiences of the affective and emotional states. Affect refers to the emotional states of an individual such as depression or anxiety (Chan, *et al*., 2012: 566). The Oxford Advanced Learner's Dictionary (2010: 486) defines an enhancer as a substance or device designed to improve the good quality, value or status of something and in literature they are generally associated with drugs designed to improve the psychological functions of individuals (Esposito, 2005: 2). Drugs such as selective serotonin reuptake inhibitors, for example fluoxetine (Prozac), are given to improve the state and quality of mind as they reduce negative moods and increase affiliation behaviours (Esposito, 2005: 2). In other words, the open setting improves association and relationships, ultimately enhancing the psychological aspect of being.

Moran and Scott (2012: 91) reported that patients receiving HD were living a disrupted life, which meant living with anxiety and distressing moods such as sadness, depression and despair. Mood swings such as depression, stress, anxiety, fear, worthlessness and hopelessness are very common in patients receiving HD, as their dependence on a machine to stay alive can result in a grief reaction (ANKF, 2009: 41-43; Bornivelli, *et al*., 2012: 94-96; Bayhakki & Hatthakit, 2012: 301). Experiencing a change in body image such as change in their skin, living with a catheter in their neck or chest and bumps in fistula sites is an overwhelming experience (Kazemi, Nasrabadi, Hasanpour, Hassankhani & Mills, 2011: 91).

Calvey and Mee (2011: 202) highlight that body, mind and spirit challenges are common in patients receiving HD, therefore being with others and having empathetic friends during treatment for Axelsson *et al*. (2012: 48) is medicine. The three sub-themes, described below, emerging from a mood enhancer were *being with others, sharing of experiences* and *a "community concept."*

3.5.2.1.1 SUB-THEME: *BEING WITH OTHERS*

The first sub-theme of a mood enhancer is *"being with others" (n=16).* According to participants, *being with others* in an open setting had advantages as participants enjoyed having conversations with others, reaching out to others, giving advice to one another, telling stories, laughing together and experiencing feelings of happiness. The stories brought smiles, joy and encouragement and were motivational, which could only be good for every patient. Participants expressed:

> *"You know three times a week; it's the same thing over and over. In an open environment you can have a conversation with someone. Coming to dialysis it's a situation that is long-term so keeping by yourself in a closed environment it is not going to do you better. In an open setting we reach out people and you know more people. If sometimes you are in a bad mood and you need help or people give you advice..... It really make you laugh, feel happy, make you smile, and it's really good for yourself"* **(P9).**

> *"...I get to know new people; get to socialize a lot with everyone. This helps us to gain a lot of knowledge about our situation; it's more like an eye opener to really think that renal failure is maintainable. You find patients that have been here more than 20years, so it actually helps and gives encouragement. Being with people, make friends ..... is good"* **(P16).**

In literature, *being with others* acknowledges human beings with common experiences (Nosek, 2012: 830). Tjale (2007: 25) confirms that being with others is about caring for others and being actively involved in the life world experiences of other patients. *Talking to friends* helps to resolve depressed feelings (Clarkson & Robinson, 2010: 32).

Participants expressed that by being in association with others, positive feelings were shared. By watching others going through the same suffering and some overcoming serious illnesses, a sense of hope is renewed and feelings of loss of body image diminished as they experienced similar problems, whether physical or psychological, as P13 described:

> *"Being in an open ward I find it really helpful. Most of us have problems with our bones, problems with legs and physically we look dark in complexion. Some people outside make fun of us. This happened even last week, another guy started making fun of my legs actually walking the way I walk in front of me, you can imagine, making his*

friends laugh at me. But because I have learnt how to deal with it, I didn't cry, it's part of life. We are unusual to some people thus why they make fun of us....

... I have seen in our unit an old lady walks exactly like me. I'm thinking I'm not the only one. You see other patients in the ward like that. When I look in the mirror in the morning I think I am too dark, but when I get to the dialysis unit I found that all of us are dark, bone problems or legs problems whatever, you are not alone, well! Actually being with others makes you feel better when you see other people with similar stories" **(P13).**

The body image in patients receiving HD treatment can also be lost due to oedema and the presence of vascular access cannulae site, for example, arteriovenous fistula or a central venous catheter (Theofilou, *et al*., 2013: 19). In order to maintain their body image, patients avoid wearing short-sleeved clothes and cover their vascular access sites especially when their skin has darkened because of the ESRD (Yodchai, Dunning, Hutchinson, Oumtanee & Savage, 2011: 220). This can have an impact on patients' physical and psychological health, social functioning and general well-being. Acceptance of bodily changes helps self-management (Mitchell, *et al*., 2009: 103; Kastrouni, Sarantopoulou, Aperis & Alivanis, 2010: 130).

Self-management is the positive effort one makes to manage and participate in one's own care to optimise health, prevent complications, control symptoms and position lifestyle in a better perspective (Bayoumi, 2012: 44). These patients experience conflict between life and death, fear and anxiety of HD and complications. In dealing with issues of life and death, patients receiving HD search for comfort and security from others and connection to a higher power (Ramirez, *et al*., 2012: 129).

In agreement with others, participants described the presence of nurses as beneficial in recognising and managing patients, which is reflected by the following statement:

"It's even better in this environment because nurses are always available and being with nurses when there is a problem with machine they easily recognise and assist you, that's the most important thing for our own good, so we feel much better" **(P10).**

Reference to "other" in literature includes other patients, family, friends, staff and higher forces or God. In the HD unit, the *other* provides motivation and expresses acceptance and aversion to isolation (Tanyi & Werner, 2008: 40; Clarkson & Robinson, 2010: 30; Chan, *et al*.,

2012), which protects patients from maladjustment. Tanyi and Weiner (2008) found that *being with others* is also a source of spiritual growth and connection to friends, loved ones and staff. Tjale (2007: 240) describes this connection as a horizontal relationship that fosters hope when sharing illness and suffering. This connectedness can lead to understanding and add some meaning and *a sense of belonging* (Small, 2010: 192; Calvey & Mee, 2011: 204; Axelsson, *et al*., 2012: 47; Theofilou, *et al*., 2013: 19).

For Schick Makaroff (2012: 26) this relationship is termed a *'distance connection'* referring to the coexistence of isolation and closeness within relationships in the dialysis units. Relationship, as defined by Tjale (2007: 164), is a means of expression for exchange of information and concomitant transfer of power from nurse to patient and vice versa. Whilst there is such a relationship in the HD unit to maintain connection with others, a sense of independence exists, which is vital for freedom and to influence decision making.

3.5.2.1.2 SUB-THEME: *SHARING OF EXPERIENCES*

All sixteen (n=16) participants spoke of the need to share their experiences, which accordingly refers to mutual understanding, compassion and sense of duty towards each other. It relates to providing and listening to information about what the patient is going through, enabling others to see and hear from those who have lived the experience. They believed adapting to HD was not easy and sharing experiences was a reassurance to others (n=10). These experiences are diverse, ranging from talking to new patients in the unit about ESRD and HD, medication and changes in lifestyle, to how they handled different situations (n=8). They expressed the importance of sharing personal experiences of hopelessness and inspiring others to relate to their present situation of despair and giving them hope. One participant precisely expressed his experiences as follows:

> *"They keep you going, to move away your mind of what you are thinking.....as we share and give each other positive thoughts, we motivate each other. Because when it comes to dialysis and you think that I am in dialysis three times a week, you say I've got nothing with my life. Sometimes you come to the idea that should I commit suicide? I have nothing left; I don't know what to do! But now when you share experiences you don't have those negative thoughts"* **(P7).**

Another participant remarked:

> *"There are things I didn't know about dialysis but I got information from other patients in the unit. Thus why I say it is an advantage for me to be in an open ward …uuh…... mmh… in order to discuss with other patients because some patients are 10 years, 20 years on dialysis ....so they have got more experience and they can tell you more information"* **(P14).**

Sharing information can extend beyond disease related problems

Sharing information was believed to be important as it diverted their minds from the negative impact of ESRD. Many participants shared family matters with others in the ward, others spoke of sharing bible messages, whilst some spoke of the dangers of taking herbs or muti (traditional medicines) and felt that making the decision to adhere to renal advice was facilitated by sharing information with others. Some discussed transport problems, whilst others shared news from what they read in newspapers or watched on TV. Some chatted about *football* or about *outings* where they could go and relax, others shared feelings and how to manage their stress. Three participants stated:

> "*….if I have a problem at home when I come to the dialysis unit I feel much better because I talk about it ... because other patients or nurses give me advice rather than to be alone in the room"* **(P6).**

> *"In an open setting we chat, there is a TV, we share ideas, we laugh you know being there with everybody is (being) normal"* **(P13).**

> "*Someone will tell you that if your family is treating you like this, do like this; because as a man...when you become ill, you are no longer working, everybody no longer likes you, they say he is sitting at home, he doesn't do anything, sometimes you can get a divorce. But now when we sit here on the machine, sometimes we talk about the family, we start giving ideas and advice then you find things change even if they cannot change as such but they become better"* **(P1).**

Sharing of stories and experience

In this study, sharing of stories and experiences of what participants were going through was believed to be very important to facilitate adjustment. Some spoke of what they felt after receiving HD treatment:

> "*You come off the dialysis machine, and become weak, tired, somebody cannot understand but (HD) patients understand, and at home they think I don't want to cook"* **(P14).**

Another said:

> "*You see people going through problems, getting sick and later becoming better' 'going through major operations and ..... still surviving"* **(P11).**

Others spoke of fistulas that never worked whilst others shared the experience of having a fistula that was working well but later stopped functioning. Their stories were different and such sharing of real stories enabled them to understand whatever situation they were going through.

For example, two other participants stated:

> *"When someone is talking about a story, you know what story is talking about, you see and feel how that person feels also and inside it makes you feel important also"* **(P9).**

> *"Open setting its fine ..mmmhmmh..! You become more experienced of HD because you share knowledge. You learn to do your machine fast, you know the machine, you know what to do, you don't struggle with the machine, you line your machine, and you become experienced"* **(P1).**

Sharing experiences included life-threatening problems. In this journey, good and bad experiences are shared promoting support for adjustment, coping and hope. This was evident in the following statement:

> *"When we sit in here (HD unit) or in the waiting room and start talking, I tell them about my experiences what I have gone through where God has carried me through. It wasn't easy; I had a very hard life. I suffered a lot of stress...I went twice into depression when my youngest son gave me a kidney; everything was perfect about 17-18 years ago….*
>
> *This operation (Kidney transplant) had to go through and everybody thought everything had to work and I'm telling you I had the operation and it (**graft or new kidney**) lasted only 2 days and my body rejected. I didn't want to take this kidney from my son but you know (- short silence)... you get very selfish because you yearn for a better life.....so it's important to be in an open ward, really, because we can talk about*

> *the same thing, if you don't feel well, we talk to each other and it's so nice to have somebody who knows exactly what you are going through"* **(P2).**

From the above quotation, the inference is that P2 was filled with grief and her spirit broken and how she coped with the overwhelming disappointment helped others to adjust and accept their experiences.

Although patients played an important role and had the capabilities of supporting each other, they also realised their limitations and the need for professional support. They acknowledged extending sharing experiences to the nurses. One participant stated:

> "*Some patients are new here like one patient clots most of the times when she is on the machine. I would ask her what are you using she will say Fragmin, how much? 5000, but why are you clotting because this thing is too much, speak to the sisters, the sisters will know what to do"* **(P5).**

Sharing of experiences is a common theme in nursing literature on patients in HD units (Clarkson & Robinson, 2010: 33; Axelsson, *et al*., 2012: 48; Aasen, *et al*., 2012: 67). The sharing of previous experiences brings meaning and understanding to the present experience. It helps to stabilise patients' emotionally and their state of being, as it brings joy, peace and contentedness (Burns & Smyth, 2011; Nosek, 2012: 833).

The culture of sharing experiences is critical, as ESRD is a debilitating and complex illness requiring continuous support (Tanyi & Werner, 2008: 33; NRC-SA, 2011). Patients on HD are faced with lifestyle and lifelong behavioural changes, therefore social and psychological interventions are vital in the HD units (Bayoumi, 2012: 48). Sharing experiences may have a positive impact on the mood as patients need adjustment in cognitive, emotional and behavioural terms (Bornivelli, *et al*., 2012: 96). A study by Calvey and Mee (2011: 206) found that listening to patients' experiences is vital since those on HD feel good having friends who can listen to their needs. This improves their mood, level of happiness, quality of life and satisfaction. Eilers (2013) encourages HD staff to have a give and take attitude, to trust and share experiences, what she terms "care partner" which implies valuing patients' feelings and opinions.

In a study by Kazemi *et al*. (2011) researching experiences of Iranian patients receiving HD treatment, it was found that mental aspects of fatigue in patients on long-term HD created despair and social isolation. These patients commonly experienced fatigue after dialysis and often, not being in the mood to do anything which resulted in the inability of patients to interact and communicate with others creating a social isolation.

3.5.2.1.3 SUB-THEME: "A COMMUNITY CONCEPT"

Of the particular interest is the collegiality and support offered by experienced members of the group of patients evidenced by their empathy and care for one another. The use of pleural in reference to the group appeared to exhibit many of the best attributes of well developed therapeutic support groups is important. This was interpreted as referring to a collective "we". This expression of the "we" by participants was interpreted as a *community concept*. The "community concept" was first introduced by Ruel Khoza in 1993 (Tjale & de Villiers, 2004: 209). Community is often defined as a place or setting, or a suburb or city where people by some common elements live (Delaune & Ladner, 2006: 313). Communities are the very essence of how people live and socialize with others.

In this study, the expression of "*we*" during the interviews formed a sense of oneness. The use of "we" associated with the concept of community described as a space to which every patient receiving HD belonged. They described their experiences in a collective manner. This was evident in repetitive reference to their common space, being together, sharing experiences, and finding identity from one another, being understood and a sense of being protected with personal relations that extend beyond 10 years for some.

This "we" has its links to the Ubuntu principles (Metz & Gaie, 2010: 274). Ubuntu has the central premise of connection where different beings are united as beings. It is the link binding individuals and groups together; not only of the unity in multiplicity, but of the concentric and harmonic unity of the visible and invisible worlds (Tjale, 2007).

Ubuntu flows within people's existence, an epistemology in which Ubuntu aspect constitute a wholeness and oneness.

According to Metz and Gaie (2010: 274-285) Ubuntu means living harmoniously with others or honouring communal relationships. These authors describe 'a person is a person through other persons' or 'I am because we are'. This indicates the dependence of the participants relating to others in a positive way. Every member is expected to be an integral part of the whole and to play an appropriate role towards achieving the good of all'. It includes emotional and practical concern for others' well-being. 'Thus the fundamental meaning of community is the sharing of an overall way of life, inspired by the notion of the common good'. Ubuntu therefore expresses first the oneness of being human and the wholeness because Ubuntu cannot be fragmented, it is continuous and always in motion (Teffo, 1996; Blankenberg, 1999; Venter, 2004; Tjale, 2007: 24, Metz & Gaie, 2010: 274).

One participant described this as follows:

> *"We help each other....., on how to line the machines.... we teach each other, observe…,"* **(P1).**

P1's statement is consistent with that of Tjale and de Villiers (2004: 209) who state that the community concept is built on close interpersonal relationships and group interactions. This brings security and harmony. These authors highlight that members submit their hopes, plans and themselves to their community.

Participants expressed that being treated together facilitated adjustment and achieving HD treatment objectives. Each member's role in observing and reporting any change in others' condition to the nurses was valued. This was described as beneficial to minimise negative effects of dialysis.

> *"What I experience being in an open environment, we check on others, because we learn more from seeing others. Sometimes we even tell the sisters that patient so and so is not fine, can you please check on her. It's even much better in that ward because we have people who are experienced..."* **(P3).**

How this community was built is similar to that of general socio-behavioural knowledge (Bayoumi, 2012: 48). The author confirms the need for love and belonging in dialysis patients

which is demonstrated by the nature of family relations. Reference to being a family is beautifully illustrated below:

> *"...when we are here **we are like a family**, we spent most of our time here in hospital; it is like our home ..... **a second family**"* **(P5).**

> *"I have been on dialysis for 23 years. It is like a family,... we do the same thing....we all come together,... we all live together....It's like we are in a boat,... same boat, and if you want to survive we have to paddle together and carry on and be part of each other. And for nurses we are paddling together"* **(P11).**

These findings are consistent to the findings of De Sousa (2008) where a common sense of belonging to one family among HD patients was found to enhance their mood. Aesen *et al*. (2012: 65) reported similar findings.

The shift from "I" to a "we" is also associated with the African ethic of Ubuntu (Metz & Gaie, 2010). In Ubuntu, an individual person is an integral part of society and individuals can therefore exist corporately.

Participants waited for each other to finish treatment and some booked the same means of transport to take them to different homes. Those who experienced difficulties and needed assistance were helped. This kind of support is reflected in the following statements:

> *"Once we are done, we eat together, get on the taxi together ..... it helps,.... because there is this bond,"* **(P5).**

> *"...being together and have a prayer for each other is good.....I remember one time a patient was taken to the ward and we prayed for that patient and he recovered and is still dialysing up to now, the power of prayer,...if you call upon the lord, you know, you are talking to the father who instantly answers you"* **(P3).**

In literature, social support and visual contact in shared rooms has been found to be a way of reducing anxiety, stress and improving recovery (Rowlands & Noble, 2008: 771; Mitchell, *et al*., 2009: 103).

Clarkson and Robinson (2010: 30) refer to social support as social networks or relationships provided by others which conveys a sense of tender affection and encouragement. Social support and unity in patients receiving HD enhances a sense of belonging, and thus counteracts negative effects on mood (Kastrouni, *et al*., 2010: 131; Keskin & Engin, 2011; Bayoumi, 2012).

Expressions of religious beliefs and practices were commonly shared and new patients were introduced to these practices to enhance patients' psychological well-being and hope (Tanyi & Werner, 2008; Clarkson & Robinson, 2010; Kohli, *et al*., 2011; Yodchai, *et al*., 2011); improving their ability to adjust and adapt better. There is a co-existence and tolerance to one another that extends beyond their individuality.

CONCLUSION OF A MOOD ENHANCER

In this study, a mood enhancer was revealed as the major theme as participants positively valued the open setting environment for their psychological well-being. Participants described that by *being with others* and *sharing experiences*, a sense of community likened to a family developed. This reciprocal nature of social interaction in the HD unit contributed to shaping their perception of body image and illness. Watching others and offering support and knowledge helped to improve their state of mind, happiness and ultimately contributed to their psychological well-being. The collegiality and support offered experienced by members of the group of patients and their empathy and care for one another was an exciting finding in this study. Common to all participants' language was use of "we". This finding and how some of the participants develop the therapeutic roles and others as group facilitators require further exploration.

3.5.2.2 THEME TWO: *EXPERIENCES OF NURSING CARE*

'Experiences of nursing care,' according to participants, is the care that relates to the complexity of the provision of HD treatment by nurses in an open setting environment. Receiving treatment in such an environment, patients observed and listened to what nurses

were talking about or were doing to others. Having nurses within the therapeutic care space, monitoring and caring for both the patient and the HD machine was key to the trust relationship. Responding timeously to the patients' requests, observing and informing patients of what was happening were deemed important. For example, responding timeously to HD alarms and complications played positive roles in creating a favourable HD care setting. Providing consistent nursing care to all patients and understanding patients' feelings, with proper communication and interaction was felt vital. Knowing individual patients and focusing on all aspects of their needs during HD treatment contributed to their well-being. Three sub-themes emerged from the data analysis: '*Consistency of nursing care',* '*patient-staff communication and interaction*' and '*being treated in a mixed gender space*'.

The description of experiences of nursing care, which nurses should focus on all the needs of a HD patient, is consistent with the findings in nephrology literature (Herlin &Wann-Hansson, 2010; Heiwe & Tollin, 2012; Aesen, *et al*., 2012; Schick Makaroff, 2012). It is the desire of a patient on to be treated as a real person and not just someone with ESRD (Aesen, *et al*., 2012: 65) and being cared for with holistic management (De Sousa; 2008: 47).

Care is a basic element of a person (Muller, 2009: 20) and care and caring are ultimately the acts or behaviours specifically intended to improve, heal or maintain a person's health (Galt, 2000: 224). Caring involves knowing the patient in order to make proper decisions and plan for nursing care, for example, a plan to educate patient about their HD treatment. The nurse working in the dialysis unit incorporates holistic care concepts into his/her professional conduct and provides care in a respectful and therapeutic manner. The nurses ability to listen, appreciate, understand and share experiences with the patient is vital for both patient and nurse outcomes. The nurse takes into consideration each patient's unique situation and intervenes aptly. Consequently, patient feels being cared for and expresses satisfaction with the care provided. Thus in healing, one is made healthy, whole, or sound of body, mind and spirit.

Holistic nursing care restores wholeness and caters for the physical, spiritual, emotional and psychological, social and cultural aspects (Tjale, 2007: 39) and nurses are in the best position to provide the whole care needed by patients. The emergent sub-themes of 'consistency of nursing care', 'being treated in a mixed gender space' and 'patient-staff communication and interaction' are discussed below.

3.5.2.2.1 SUB-THEME: *CONSISTENCY OF NURSING CARE*

Consistency of nursing care emerged as a sub-theme in the study. Both positive and negative statements were made with regard to 'consistency of nursing care' received in the HD unit. Positive expression about consistency of nursing care was generally noted. Nurses' availability during treatment was valued for patient safety and monitoring, as to have staff listen, properly assess and monitor patients during treatment. The continuous support and encouragement from nurses was motivational. The open dialysis unit allowed participants to understand the care elements from observing the nurses. Consistency of nursing care was necessary and embraced as a norm from observation and experiences in the unit.

Two participants stated:

> *"In an open setting environment if you have problems with the machine, sisters quickly look into the machine, they act fast, and if you are sleeping and something goes wrong, they are able to see what's happening. But in a closed environment if something happens to you it might be difficult for sisters to help you in time but with this environment any sister who is around comes to help you; the impact is she acts faster, so it helps"* **(P8).**

> *"Someone a little bit worse like myself last week on Tuesday I came in on a wheel chair, I was feeling sick, I'm telling you it was wonderful to be in this setting, even the youngsters (young nurses), even the patients, they all came to me, everybody wanted to know what was going on with me.... we get encouragement ya! That is very important to have encouragement from everybody because when you are sick, I tell you, you feel like dying, and patients know this ... As I said you watch more like blood pressure drops because we all had it and the sisters are wonderful because they all come and they know exactly what to do..."* **(P2).**

The present findings are consistent with Taskintuma and Ozcurumez (2011: 253) findings that ESRD as a life threatening experience, requires not only focus on HD as a treatment but also support for the patient's emotions to promote patient's survival and psychological well-being. This is evident also in the findings of Axelsson *et al*. (2012: 48) who remarked that the presence of nurses and their cheering words made patients laugh and feel being cared for. Other nursing literature reveals that care offered by nurses and being there for patients during treatment enhances healing (Nathenson, 2012: 115). This emphasis on nursing care complies

with the principles of nursing professionalism, which states caring that involves feeling for and being there for the patient (Muller, 2009: 20) is healing.

Thus caring, stemming from strong opinion about feeling for someone, contributes to the good, worth, dignity and comfort of a person.

Any deviation from what was felt to be a norm was interpreted as lack of nursing care. In some instances, participants noted a lack of care with hand washing and assessment of patients prior to treatment or observed a lack of intra-dialysis monitoring; and in some instances, they felt disrespected. Despite these encounters, participants valued their staff and the care they received.

The following statements confirm this:

> *"We see others ... ask you how do you feel, do you still pass urine, while others will not ask you anything. Like myself, I still pass urine but they don't ask me about this. Thus why it surprises me to hear others being asked such questions, so I tend to ask myself why?"* **(P15).**

> *"I have been 22 years here receiving HD treatment and for that experience I have been seeing a lot of things. I see some nurses are just coming in and they don't know much... They come in do it quickly, put us on the machine which I don't like because the sisters are supposed to scan (assess) us when they connect us on the machine"* **(P12).**

> *"All nurses must provide the same level of care towards all the patients. Because what we observe... some sisters have got their favourites, when you are not their favourite, you will call them they will never come; they will ignore you even if the machine is alarming (long silence). Yes yes! You feel very bad in the eyes of other patients....You will shout for petrol (dialysate solution) they will not come in time. Like on Wednesday when they were taking me off the machine I did clot a lot they had to throw my blood away, which was really not good"* **(P1).**

James (2008: 35) found that when an alarm sounds on an HD machine, it disturbs patients trying to rest, some become annoyed and others become anxious, especially new patients causing a more stressful situation. Literature research on health and the human spirit noted that the mind, body and spirit are more often treated as separate entities by health providers (www.jblearning.com), which creates gaps in the care and healing of the whole person.

Although HD nurses can be burdened with a variety of sources that affect their performance in the unit (Wilson, Harwood, Oudshoorn & Thompson, 2010: 39), patients need to be treated holistically. Patient assessment may include physical, psychological, socio-cultural, environmental, lifestyle and spiritual, as well as cognitive and functional abilities (Tjale, 2007; Tanyi & Werner, 2008; ANKF, 2009; Morton & Fontaine, 2009). Sometimes nurses override patients' wishes, as they want to dictate a patient's treatment (Aesen, *et al*., 2012). Holistic assessment of patients during HD will allow patients to feel equally treated, especially in an open ward, which in turn will enhance understanding of their treatment.

Comfort during dialysis

There were many similarities in the participants' experiences about the boredom and time-consuming aspects of HD care in a hospital setting. They felt intra-dialysis activities, such as *listening to health messages*, *poems* or *interesting speeches*, *intra-dialysis games* such as *cycling*, were vital to cheer and carry them through the day. Access to the unit *television* in an open ward was appreciated by many. One participant stated bedside TVs would provide more comfort and the ability to select programme of choice. This helped people to interact and pass time.

Others felt HD recliner chairs should be fixed to provide for more comfort during their four hours of treatment, as some stated sitting for so long caused discomfort. However, cleanliness of the unit was commended. Participants expressed as follows:

> *"…we are a family, they should make the ward happier, not just sit on the machine, they should introduce some kind of games, they can organize speeches from patients or staff because we just sit on the machine; why not makes it look happier? Life is not easy all the time...*
>
> *Let the patients bring suggestions how to create a happier HD environment. They can start exercises, like intra-dialysis cycling...Other patients sleep while on the machine, they feel tired, they have been in the taxi, so I can't love music but TV is ok...."* **(P11).**
>
> *"…we need comfortable beds because those beds are very painful, we are not comfortable during dialysis...and each bed if we can have our TV, something to make patients happy during dialysis"* **(P10).**

These comments are similar to the Canadian study by Bourbonnais and Tousignant (2012), where patients experienced discomfort such as back pains, shoulder pains and whole body pain due to being immobilised in a dialysis chair and being unable to reposition adequately or get up to walk around during treatment.

Heiwe and Tollin (2012: 72) studied the implementation of intra-dialysis cycling and found that patients described time on dialysis as boring and monotonous. They also found that routine intra-dialysis activities not only improved the physical fitness but also HD efficiency, reduced fatigue and improved psychological well-being. Intra-dialysis activities also improved quality of life and decreased self-reported depression (Ouzouni, Kouidi, Sioulis, Grekas & Deligianniset, 2009). Such activities could be a way of promoting their sense of being.

3.5.2.2.2 SUB-THEME: *PATIENT-STAFF COMMUNICATION AND INTERACTION*

The strongest sub-theme to emerge was the importance of patient-staff communication and interaction. Participants commented on different aspects in which staff communicated and interacted with patients in the unit. Good communication and interaction was characterised by *being friendly*, *responsive* and *paying attention* to their feelings.

It also relates to approaching a patient warmly and keeping patients informed and embraces regular counselling, emotional support and discussing solutions to their problems. Participants revealed talking to patients with respect in calm and humble manner was vital and impacted positively on their psychological well-being.

This was felt to strengthen patient-staff relationships and distracted from their suffering. Shouting or discussing private issues with patients in public or in the presence of other patients was defined as poor communication and interaction.

One participant said:

> *"...sisters are really friendly, considering my situation because I was diagnosed with renal failure at the age of six. So most of my life I've been at this hospital…being in an open ward it's something that is normal because it's like I've been born with most of the sisters and some patients when I see them I take them as a family, we treat each*

other very well…they give you support, they tell you if you have problems talk to us,…they will always help you….I find speaking to sisters better than my family…" **(P16).**

Another participant stated:

"*There was this sister (mentions the name) she was very good once she connects you on the machine she tells you observe yourself, she will tell you when I put you on the machine make sure I must close this (line for normal saline), I must put you on this fragmin (anticoagulant) because sometimes we (nurses) forget, so each time I am dialyzing I observe that because she taught me... So this is good because you also teach others"* **(P5).**

Keskin and Engin (2011) and Bayhakki and Hatthakit (2012) found that good communication and interaction enriches the lives of patients receiving dialysis. Communication is the interactive behaviour between people and involves the transmission of a message from one or more persons to others (Muller, 2009: 202). It involves open discussion, negotiation, communicating in an honest and direct manner, being listened to and valued and being informative (Tjale, 2007: 164; Moran & Scott, 2012: 98). In the HD unit, a close prolonged interaction between patients, nurses, and physicians and other health care workers exists and evidence has shown that good communication can lead to compliance and shared understanding (Nosek, 2012; Kastrouni, *et al*., 2010: 131).

However, research into psychology and health undertaken by Griva, Ng, Loei, Mooppil, McBain and Newmanet (2013), described how the dialysis environment creates more opportunities for regular patient interaction yet meaningful health-related communications and exchange of information may be limited.

Correspondingly, in this study, not all experiences were positive. Participants described shouting at patients overtly was regarded as poor communicative behaviour. This was felt to be stressful as participants felt reserved to approach staff, in particular nurses, because of poor communicative behaviour. They stated that some HD staff regarded them as troublesome or '*they know all things'*.

Participants expressed the following:

> *"Like eeh when you make a mistake they don't come to me and talk about and solve the problem, they just shout, so everyone watches you, I feel bad that why didn't they come to me and talk to me nicely so that day I don't dialyze nicely, I feel bad! I just keep quiet"* **(P6).**
>
> *"When you come to dialysis you think sister so and so...you feel like not coming....Sometimes patients are afraid as I explained earlier on that eeh,* ***they will say I think you know all****, so sometimes patients don't speak about their problems..."* **(P5).**

Axelsson *et al*. (2012) found that patients in HD units are depersonalised and strive to be liked. This resulted in withholding concerns, as they did not want to trouble healthcare providers for fear of being regarded as complainers. Likewise, Bornivelli *et al*. (2012) found that patients on HD felt reserved in openly seeking information for fear of being regarded as a nuisance.

Such punitive responses can potentially damage patient-staff relationships (Prescott, 2006; Kolewaski, *et al*., 2010) and such shallow patient-staff relationships can lead to unmet expectations, disappointment, anger, frustration and lack of satisfaction (Schick Makaroff, 2012).

Based on the findings of this study, participants were of the opinion that HD staff should engage in good communicative and interactive discussions with their patients. Speaking to patients in a calm manner and not shouting was felt important. Such an approach was felt vital in addressing patients' concerns and enhancing adherence to treatment.

One participant stated:

> *"...I think if they could be talking to that patient separately it would help more instead of letting the whole ward know what that person has done because once a sister start shouting then everyone watches you and that watching is not nice…you find patients don't talk about their issues, they end overloading or condition getting bad... because of the approach whilst if they can sit down with the patient and talk about the issue in a calm and humble manner so you find people skipping dialysis sessions..."* **(P16).**

Gap in providing explicit information

Participants reported that often the lack of information about ESRD, HD and its related complications resulted in negative emotional experiences especially when seeing others complicating. Getting clear messages from HD professionals such as renal nurses, doctors, psychologists and social workers was felt to be very important in this study. They expressed that getting sufficient information about their treatment was vital as knowing this could minimise and prevent stressful situations.

This was motivated by statements such as:

> *"'...because when one complicates on the machine I just thought may be its time (time to die), I felt that way....I just pray oh lord give me power.....The medications they give us they don't tell, they don't explain to you that this is for what...."* **(P6).**

> *"....in my case when a doctor speak to another patient, I listen because I want get proper information because sometimes you don't know how to approach the situation so.... it gives you a chance to listen what must he correct... so you learn....."* **(P8).**

Nephrology nursing literature confirms that lack of information adds to loss of control and feelings of being an object by the patient, because they cannot influence their treatment (Axelsson, *et al*., 2012: 49). Dialysis as a procedure, in the absence of proper education, becomes stressful (De Sousa, 2008: 47), as some medications may cause psychological symptoms. Educating patients, increases their knowledge about the disease, treatment and management, thus they develop better coping strategies and manage their lives. Moran and Scott (2012: 98) highlight the need for collaboration of physicians, physiotherapists, psychologists and social workers to manage effectively the concerns of patients receiving HD. However, patient education should be simple and concise to avoid overload and confusion (Clarkson & Robinson, 2010: 31) and so nurses' ability to provide clear and adequate information would enhance patient's well-being.

Seeking information from experienced patients

In this study, participants expressed seeking information from experienced patients in the unit. Those who were knowledgeable and experienced enough to help others were often patients who had been receiving HD for a long time, for example those who had been on dialysis for more than 20 years.

Two participants commented:

> *"Because there was nobody to give me enough information even the doctors they don't give you more information you know! So I got the information from other patients"* **(P14).**

> *"I am well experienced and I can speak to other patients...if there is a problem on the machine and there are no nurses we can help each other"* **(P11).**

Griva *et al*. (2013: 19) reported that patients receiving HD sought information about the disease and its treatment from other patients, as they saw them as having intimate knowledge of the difficulties and being able to share life experiences. Learning from others can act as a source of inspiration (Mitchell, *et al*., 2009: 105). In addition, understanding the treatment regime makes patients feel safer and more secure (Herlin & Wann-Hansson, 2010). What one does not know often elicits feelings of fear, helpless, inadequacy and becomes a barrier to the healing process. Lack of education may increase stress and failure to adjust (Dermody & Bennett, 2008: 31; Kolewaski, *et al*., 2010), whereas clear messages facilitate acceptance and adjustment to situations.

Engaging families in HD care

Although patient care is regarded as important, most of this study's participants felt provision of information should take into account and engage their families as they felt they lacked knowledge about ESRD and its treatment. Some said being in HD care environment was stressful and they hoped for a transplant, therefore families had to be kept informed.

One mentioned that '*donating an organ in her culture was regarded as witchcraft'* and said family members were fearful of donating an organ such as kidney. They voiced such statements because they longed for a kidney transplant and ultimately leaving the HD care environment.

Most participants described the control of visitors to the unit was done with good intentions to benefit patients, as they felt respected and protected from infections during treatment. Herlin and Wann-Hansson (2010) noted that patients receiving HD reported fears of contracting diseases in the ward.

Participants spoke accordingly:

> *"...there are possibilities of getting a germ ...and sisters won't allow a lot of people in the ward. But if somebody gets ill, they allow parents to sit for a while and then go"* **(P2).**

> *"...our families are not aware, they don't know what will happen if they donate their kidney. They don't know whether a person can live with one kidney...*
>
> *... I've got that belief that one day I will be out of the machine, uh! I will (laughing). That's something keeps me going. I believe I will be healed and I believe that when I get transplant it will be God that has supplied it to me so it won't reject, it will just go well, because it will be coming from God..."* **(P14).**

3.5.2.2.3 SUB-THEME: *BEING TREATED IN A MIXED-GENDER SPACE*

From the findings of this study, both male and female participants expressed positive feelings and happiness about receiving HD treatment in the open setting environment. They spoke about sharing experiences in the open setting and the ability of nurses to act fast which was felt helpful.

However, based on participants' responses, there were widely divergent feelings about receiving treatment in a mixed-gender HD environment. Being treated together (male and female patients) was controversial. The majority of females (n=6) valued the HD Unit being open single-gender space only, whilst male participants felt being treated in a mixed-gender space was good. Most female participants raised concerns about privacy if male patients were around. This was particularly with regard to exposing their femoral or central venous catheter (vascular access) in the thigh or breast respectively. They felt embarrassed and expressed the need to ensure respect, dignity and comfort to share personal experiences with other women during treatment. As much as participants had contrasting views with regard to the mixed-gendered space, most participants (both male and female) were in support of the open setting environment. They praised about different aspects in the open setting environment how nurses and patients interacted, providing each other with company which even distracted patients from their fears.

They expressed their thoughts as follows:

> *"Sometimes I get embarrassed, you see men and women closed together in curtains….and there is a man near me but I have to open my chest because I don't have a fistula, I have a perm catheter but now I think these men gonna see my breasts, so it's not nice"* **(P15).**

> *"It is not nice especially for a woman to pull the skirts thus why we try to put on trousers because we are afraid of male patients to see us. Sometimes you see a man just pulling his trouser and yet there is a woman there but he is just doing it, even if you look aside, you see there is another man still doing the same things. I think we need to respect each other"* **(P14).**

> *"Sometimes there are things that women want to do during dialysis but they don't feel comfortable. Like there are women who still pass urine so they may want to urinate but to go out of the machine and visit the toilet it's time consuming, thus why we want a private place where there are women and men separated, so that we can be free"* **(P10).**

Participants expressed exposing breasts or thighs in the presence of men as lack of respect and gender-insensitive. One participant stated:

> *"Sometimes they don't close the curtains ya, and our breasts become exposed, so by exposing our breasts they are degrading us.....*
>
> *I don't think its fine for me to see male patients sleeping in front of me and their access lines are on the thigh….in my culture the only person who is allowed to see you naked is your wife. So, I am not a wife to my neighbour in the ward, so thus how it contradicts my culture"* **(P4).**

Sitting on a bedpan in front of others was equally disrespectful in spite of using curtains but for the sake of treatment, participants had no choice but to be adaptive. P15 stated:

> *"You see some are vomiting and you can't say no! Some want to pass urine and nurses are bringing chambers, you see! So it's not comfortable at all. Sometimes we just finish eating then you see somebody asking for a bed pan, or vomiting then you too you also feel like mmuh, vomiting. But there is nothing you can do, you must accept because it's an open ward, you can't run away, you are on the machine, you must just accept it, there is nothing you can do"* **(P15).**

This was in contrast with male participants (n=7) who expressed support for a mixed-gender treatment space and had no problems receiving HD with female patients or being treated in a

male area only. Of the nine female participants, only three (n=3) were positive about the mixed-gender space.

A male participant stated:

> *"...the thing is I am here to get dialysis so are the females in the unit, I don't mind"* **(P9).**

The findings that patients should be accommodated in single-gender space concurs with Andreucci, Kerr and Kopple (2004) who emphasise that where facilities exist, dialysis patients should be accommodated in single-sex renal wards managed by nephrology staff. In a recent English study, Peate (2012) noted that mixed-gender accommodation had to be changed as it caused distress, except where it was in the best interest of the patient. Gerry (2011) reported that patient's choice is important in view of ward setting. However, Tanyi and Werner (2008: 33) indicated that women respond to stressful circumstances differently and their adjustment may be different to that of male patients. Thus, HD nurses need to be more psychologically aware of individual patients' needs in the HD unit.

Therefore these findings should, however, be viewed cautiously, as most male participants viewed the mixed-gender space positively whilst most females demonstrated the need for a single-gendered space and therefore cannot be generalised to HD units in other hospitals and requires further exploration.

Each HD chair to be screened with its own curtains

Participants felt each patient should be separated by curtains when on treatment (n=7), especially at commencement and termination, as it was important for privacy and respect. Privacy, according to participants, relates to protection from exposure of breasts and thighs because of vascular access sites. Creating a private space for critically ill patients was also important. It was felt private personal conversations should be discussed in separate areas before or after HD. Shouting at patients in the presence of others was disrespectful and for the sake of dignity they expressed the need to be treated as adults.

This was evident in the following statements:

> *"...each bed should have its curtains and not one curtain for two patients so that during examination we should not see each other. Because when doctors examine us, like on Wednesday I had this infection and everybody wanted to hear what I was explaining to the doctor, I had to draw attention of everyone"* **(P15).**

> *"It doesn't sound fine sharing curtains, because it's a female and I am male in the same curtains and the two are combined, I feel a person taking care of you should make sure that no one invade someone's privacy"* **(P8).**

Gerry (2011) advises providers that attitudes and behaviours should aim at promoting respect by ensuring availability of space for personal identity and confidentiality, which promotes privacy and dignity. The UK Department of Health defined privacy as 'freedom from intrusion' and dignity as 'being worthy of respect' (Gerry, 2011) and intrinsically refers to the individual's physical, mental, emotional and spiritual well-being. However, Gerry found that maintaining privacy in shared rooms is difficult because other patients and visitors overhear the conversations.

Open wards lead patients to withhold important information however, Magill-Cuerden (2006) argues, in the maternity care context, that healthcare providers cannot offer advice and observe patients spontaneously when curtains are used around each bed. Nevertheless, respect for patient's needs, privacy and decisions enhance one's emotional support (Curtis, 2008; Peate, 2012). Nosek (2012) emphasises that everyone has a right to their own values, based on what is determined as meaningful and important to them.

CONCLUSION OF THE THEME 'EXPERIENCES OF NURSING CARE'

This theme strongly reveals that nurses and other HD staff should approach dialysis care holistically and maintain consistency of nursing care towards all patients. Patients see nurses caring for other patients and feel they should receive the same care. The nursing care should focus on both the patient and the HD machine. The findings put emphasis on the need for nurses to listen and timely respond to patients' requests. Patients feel valueless in the presence of other patients when they shout for help and nurses take a long time to respond.

Responding timeously in an open environment was interpreted as means to prevent HD complications and the nurses actions encouraged other patients watching. This includes proper assessments, timely responding to HD alarms, keeping patients informed and the ability to act fast in case of a complication. The findings emphasise that patients should be adequately informed about HD to facilitate adjustment and that patients want respect and privacy to be ensured during treatment.

3.5.2.3 THEME: A SENSE OF FEAR

A sense of fear appeared as a consistent theme in this study. Participants described being treated in an open setting environment and being exposed to multiple situations in the HD unit which evoked fears. A sense of fear also resulted from the consequences of the chronic illness. Participants' stated that any negative event experienced, watched, observed, or heard in the HD unit triggered fear in the patients; a common fear was evoked by observing HD complications. Events such as *seeing friends dying*, *watching patients collapsing* or *clotting* on the machine, *bleeding from fistula sites, experiencing low or high blood pressure* and *being exposed to very sick patients* triggered fear. These circumstances resulted in *feeling sad*, being *scared* and *frightened*, experiencing *anxiety* and *stress*. Participants expressed that a nurse caring for patients' emotions was paramount; talking to social workers and psychologists was very important for emotional comfort. Two sub-themes emerged;

(1) *Fear evoked by watching HD complications*

(2) *Threat of death*.

This is corresponding with Herlin and Wann-Hansson's (2010: 695) findings. These authors found that patients' receiving HD had a sense of fear due to seeing very sick patients. Similarly, Yodchai *et al*. (2011: 220) confirm that patients receiving HD experience psychological reactions such as fear of dying, worry, anger and uncertainty of their health.

De Sousa (2008: 48) verifies that fears are common amongst patients receiving HD because of the treatment process and its related complications. Mistrust and fear of malpractice by health professionals, sadness, embarrassment and disappointments were also reported in Greek patients (Kastrouni, *et al*., 2010: 130). Patients observe almost everything happening in the

Unit, thus Tjale (2007: 39) points out that illness experiences can be shaped by what patients perceive through daily observations as they seek holistic health.

3.5.2.3.1 SUB-THEME: *FEAR EVOKED BY WATCHING HD COMPLICATIONS*

Participants expressed these fears were evoked from what they heard, observed and were exposed to during treatment. They all stated watching friends complicating, i.e. collapsing, clotting, cramping and vomiting whilst connected to the HD machine evoked many fears, leaving them scared, anxious, worried and uncertain. Just hearing that someone's blood pressure had dropped, or observing other patients struggling to breathe because of fluid overload or bleeding from fistula sites evoked fears in both the affected and the observers. One male participant expressed the following:

> *"I saw somebody collapsing on the machine….emotionally I was affected…I had never seen it before and I thought what if it happens to me, what if I? (Silence) because if you collapse on the machine, you just stop breathing, ya! ...the sisters were just up and down to help the person"* **(P7).**

Another participant expressed:

> *"One thing I must admit is that when something happens to a patient on the machine you sit and you watch and you hear all the things going on and it's a very sad feeling when you know the patient who passes away. And they have to wait for the family and the body is still here and we have to carry on dialyzing ....I feel uneasy, I feel very ..very.. sad"* **(P2).**

Complications encountered whilst receiving HD were said to affect patients' emotions. Patients expressed feeling sad, scared and frightened when they saw what was happening.

Participants expressed as follows:

> *"What I saw this other day was not pleasant, there was a patient who did not dialyze for seven days so he came in and they put him on the first machine so the sisters*

wanted to put on the curtains so that we couldn't see. But this doctor…he said no no no! open, open so that these guys could see when you don't do what you are supposed to do, this is what happens. I'm telling...you could see him dialyzing but now he was breathing heavily and at the same time there were foams coming from his mouth and that never set well with me because I was so scared" **(P5).**

".....it's very very sad, it's sad, losing someone you know is not nice. I think of another guy you know he was just ok and one day he just came sick...you know we get used to have someone to talk too, long time you make jokes, you get used to that person, for years you have been together on the machine, you know so it disturbs you so much" **(P9).**

"...you know you become scared, the best thing is that every shift there must be a doctor around us...they must be like the way nurses sit here, they must have their office here so that when one complicates they must assist immediately because.....a patient may die you know, and for others watching you become anxious **(P1).**

However, another participant stated:

"Sometimes when you see one overload, you also try and control yourself. You reduce your fluids, because you have seen somebody complicating or may be dying and doctors have been running around and you became scared. So it makes you strong again because you know what to do and what not to do" **(P14).**

As reported by Wilson, *et al*. (2010) HD patients observe and hear the experiences of others and it scares them. HD Patients live with feelings of sorrow, as they live with the threat of complications (Axelsson, *et al*., 2012; Mahrova & Svagrova, 2013:768). Fear is an emotion experienced in direct response to a threat, i.e. when one is in danger or a particular thing frightens you (Oxford Advanced Learner's Dictionary, 2010: 541) and this can lead to anxiety. Numerous studies reveal that patients on HD may experience the physiological effects of treatment such as hypotension, nausea, vomiting, muscle cramps, headaches and clotting problems, all of which can evoke fear (Phipps & Turkinton, 2001; Krueger, 2009; Bourbonnais & Tousignant, 2012).

However, some participants in this study expressed that, as time passed, the feelings of being scared or sad lessened because they became used to watching such things - a finding also reported by Bayhakki & Hatthakit (2012: 302).

Another fear of HD complications was that of watching fistula/graft miscannulation. This refers to the unsuccessful needling of the arteriovenous fistula or graft. Participants said observing or hearing of unsuccessful cannulation or dialysis needling evoked stress in the patients watching as they could feel the pain from the fistula needles. Participants stated they watch and talk to each other about the experience.

One participant expressed:

> *"Needling wrongly, you all feel anxious....Sisters can't see that because are on the other side but we patients see things on the other side. So it is quite frightening for other patients to see somebody needles and something goes wrong... Because I see if nurses are needling in a wrong way, honestly it is stressful"* **(P11).**

Participants remarked they were sceptical about being treated by inexperienced nurses and some waited for more experienced nurses to commence the treatment, even though it consumed their time.

One participant stated:

> *"when a sister is new and wants to needle the fistula we are sceptical because this is our life so if they prick me and this thing is dead I am the one who is going to suffer…so I observed they would talk to each other that I don't want to be put by other sisters, so they would avoid me to put me on the machine"* **(P5).**

Some participants were of the opinion that skilled nurses should cannulate the fistula and that nurses from other wards should be oriented and familiar with fistula needling. As one stated:

> *"Even if they are in other wards like acute ward they should have a day to just come to the chronic unit and learn about fistulas"* **(P8).**

Similar to the Swedish research, Herlin & Wann-Hansson (2010: 695) found that patients receiving HD revealed fears related to fistula needling. According to National Kidney Foundation-Kidney Dialysis Outcome Quality Initiative (NKF-K/DOQI) (2006), an arteriovenous fistula is a "lifeline" vascular access for individuals receiving HD and the access of choice because of its longevity and lower complication rates. Wilson, Harwood and

Oudshoorn (2013) in a Canadian study found that nurses described patients on HD wanted things done in certain ways, dictated which nurses to needle their fistula, which sites were to be cannulated and how HD sessions were initiated. This had the potential to create tensions. Unsuccessful dialysis cannulation may cause damage to the fistula resulting in pain and sometimes bleeding during insertion or after removal of needles (Wilson, *et al*., 2010; Bourbonnais & Tousgnant, 2012: 15; Wilson, *et al*., 2013: 16).

It is evident in the findings of Wilson *et al*. (2013) that avoidance of fistula cannulation does occur because some nurses feel nervous with it. To gain confidence support from the nurses who have the skill and experience is important. Lack of proper assessment has been shown to result in miscannulation (Wilson, *et al*., 2010: 39). Herlin and Wann-Hansson (2010) found that HD patients generally, were sceptical and felt insecure about being handled by new nurses, which resulted in mistrust. Patients' expectations are to have a successful fistula needling to maintain its functionality, therefore it is advisable that new nurses achieve the core competences relating to cannulation and HD care to support patient needs (Wilson, *et al*., 2013).

3.5.2.3.2 SUB-THEME: *THREAT OF DEATH*

Threat of death was revealed by many participants. Threat of death was accentuated when patients experienced their friends complicating or dying on the HD machine or when they saw others reporting to the unit very sick, for example, a patient being fluid overloaded and unable to breathe. Ultimately, threat of death had a space in their experiences. This was evident in the following statement as one participant spoke of her emotions:

> *"My experiences with dialysis, anything can happen while receiving the treatment....our friend came to dialysis she was fine, she came in lined up the machine, they connected her, some five minutes after connection she said I'm feeling cold, they bring blankets, she then started screaming and jumping to the bed, they ask her what's wrong, they try to help and check her BP…but she never responded, she died on the HD machine in front of my eyes... I was very depressed…I couldn't look on the bed she died on. I was so sad..."* **(P15).**

Another said:

"The other thing is when you see the other patient is very ill, what happens, how you feel,...like the one who died on the machine, you can't hold it, I feel sorry when I go home I speak to my children about it.....

I am telling you when somebody dies or gets very ill and when you open your eyes and see it haunts you all the time….it affects not only me, but most of us are affected. But we are for years in an open setting environment. No-one has asked these questions, you are the first person to ask these things…." **P12.**

These findings are consistent with Mahrova and Svagrova (2013: 768) who reported that the constant threat of death is brought by loss of friends, treatment and fear of connection to a HD machine, fear from watching other patients during complicated cases. These experiences take their toll and patients realise that HD cannot make them completely well. HD schedules also facilitate feelings of approaching death as weeks pass rapidly (Axelsson, *et al*., 2012: 48). Likewise, patients' experiences of waiting for a transplant also bring fear as they become uncertain as to whether they will get a kidney and they also fear for their future (Herlin & Wann-Hansson, 2010: 696; Ramirez, *et al*., 2012; Schick Makaroff, 2012; Moran & Scott, 2012: 90-92).

The experience of losing friends, or someone you know, can engender great distress and even cause suicidal ideations. Ramirez *et al*. (2012) and Keskin and Engin (2012: 2722) found that losing hope of recovery and rejection of treatment can trigger suicidal ideations which are the most feared complications of depression. Consistent with this, Yodchai *et al*. (2011: 222) found that Thai patients receiving HD experienced feelings of depression and suicidal thoughts. Some participants confirmed that as time passed these fears diminished with recurring reassured from other patients. Bayhakki and Hatthakit (2012: 302) reported similar findings.

Accepting situations

Accepting dialysis situations was felt important to counteract fears. At the same time being exposed to negative events during treatment with time becomes normal, analogous to war where soldiers have to fight and survive. From being exposed to such situations, lessons on how to live better were learnt and patients felt encouraged.

> *"If something happens on the machine, everybody sees it, this causes everyone to be stressed, if someone is sick everybody is stressed. But there is nothing much you can do about it. So that is part of culture of dialysis, it's not on play ground. Dialysis is not a children's game, it's tough. People don't really know, but we have to survive. When we are in the situation, we have to take the situation, we have to make the best of it, and otherwise you will not survive"* **(P11).**

Another articulated:

> *"Where I am in the situation I try to get used to it. You know there is a lot we are going through each treatment but I try to get and make the best of it"* **(P9).**

Consistent with a Canadian study conducted by Kolewaski *et al*. (2010: 115) found that patients receiving HD treatment expressed the importance of accepting their condition. Acceptance facilitated healing balancing the mind, spirit and body. Axelsson *et al*. (2012: 48) describes the expression of "there *is nothing to do/ you have to accept the situation*" means acceptance of the present situation. Acceptance of chronic illness has been equated to acceptance of loss. Acceptance influences health-promoting behaviour, self-management and improves quality of life (Weinert, 2008: 368).

Previous findings show that positive and negative experiences are accepted as normal in patients receiving HD and are integrated into a meaningful personal life story (Schick Makaroff, 2012: 27). Such adaptive behaviours may improve the general well-being, gratitude and quality of life in dialysis patients. Through adjusting, one solves the problem, improves the mind and the psychological aspect of being (Bayhakki & Hatthakit, 2012: 302). The fears may be buffered by enhancing social support, treatment adherence and psychological adaptation (Weinert, 2008: 367). The degree of adaptation achieved by each patient depends on patient-staff quality of relationship, cultural values, beliefs, communication, technological devices and the ability to accept the inevitable situations (Mahrova & Svagrova, 2013).

Table 3.3 Illustrates overwhelming situations experienced in an open setting environment evoking fears (data analysed from participants' transcripts).

Participants' experiences	Participants stating the responses															
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
When it comes to dialysis you end up losing hope				x			x						x	x		
You see people, friends dying	x	x			x	x			x	x	x	x	x	x	x	
Patients live in a very stressful situation	x			x		x					x			x	x	
People go through a hard time						x			x		x		x			
To be on the machine for four hours - it's not easy					x			x		x		x				x
Cramps or clotting on the machine...I feel sad, scared	x	x			x	x			x			x	x		x	
It's quite frightening...needles and something goes wrong	x		x	x	x			x			x					
Needling wrongly you become anxious...stressful	x			x							x					
Being needled for the first time by new nurses...	x			x	x			x			x				x	
Sisters can't see that...patients see things on the other side				x		x					x	x				
I saw somebody collapsing on the machine...What if I?	x	x		x		x	x						x	x	x	
Emotionally I was affected because it was my first time				x			x								x	
Sisters were up and down to help the person			x				x							x	x	
I too think I'm gonna die soon....				x		x							x			
Most...go for transplant...come back (for HD)... and they die												x	x		x	
You see fistulas that fail, perm catheters not working											x				x	
The environment so depressing			x											x		
They've to bring the bedpan to patient, my God!!!...feel the smell										x			x		x	
When you sit on the machine you...see other patient's condition											x	x			x	
If someone is too sick everyone is stressed...		x				x					x	x	x	x	x	

CONCLUSION OF THE THEME: A SENSE OF FEAR

In conclusion, this study shows fear appeared to be mostly related to being exposed to stressful events. By being with others during dialysis needling and resolving troubleshooting of HD machines can reduce fears and enhance emotional support. It is clear that emotional and psychological support is vital for successful adjustment therefore, by enhancing the open setting can result in positive feelings about HD. The ability to assess these fears could contribute towards patient's psychological well-being. The empirical evidence in support of the holistic care shows that healing of the whole-person includes recovery from negative emotions and daily mood distresses (Tjale, 2007: 160; Nathenson, 2012: 116; Moran & Scott, 2012: 98) and facilitates adaptation.

3.5.3 CONCLUSION OF FINDINGS AND LITERATURE CONTROL

In summary, the data collected from this study was analysed and the findings presented in this chapter and controlled with confirming and disconfirming evidence from other studies. Data were analysed manually and followed Giorgi's phenomenological method, which yielded three themes and eight sub-themes.

Theme One: A mood enhancer was identified as the major theme in this study. From the participants' point of view, being with others, sharing of experiences and a community concept expressed as "we" resulted in positive experiences of the open setting environment. This reduced the distress and the anxiety experienced resulting from negative situations experienced from the general illness and situations they experienced in the Unit.

Theme Two: Experiences of nursing care regarded as consistent and timely caring communication and interaction were appreciated by all participants. Timely response to HD alarms and complications played positive roles in creating a favourable HD care environment. Talking to patients in a calm and humble manner positively influenced those receiving HD in the open setting environment. Contradicting views with regard to a mixed-gender space were also reported in this theme, male participants had no problems being treated in such a space, whilst most females were against it, preferring a single-gender space.

Theme Three: A sense of fear was the last theme identified in this study. Sense of fear resulted from multiple situations experienced within the ward and from the illness as whole. The findings indicate that what patients observed and heard in the HD care environment relating to negative events, triggered fears. Two common fears were of HD complications and the constant threat of death. Though complications during HD treatment were reported as uncommon, participants experienced fear from seeing others who had such a situation. Complications such as clotting, muscle cramps and collapsing because of low blood pressure, as well as watching somebody dying on the machine were all reported in this study and so psychological counselling was felt very important.

Chapter Four, will present a summary of the findings based on the research objectives, the study limitations, recommendations, implications to nursing practice, nursing education and research and the conclusion of the study.

CHAPTER 4

DISCUSSION, RECOMMENDATIONS AND CONCLUSION

4.1 INTRODUCTION

In this chapter, the study's findings, limitations, recommendations and conclusion are discussed, including the summary of the research methods and application of the holistic framework to the findings. The researcher will highlight what is already known about this topic and what this research adds to the body of knowledge. To guide the study, all participants responded to the main research question: *"What are the experiences of patients, including feelings and opinions, with regard to receiving HD treatment in an open setting environment?"* This study aimed at exploring and describing the experiences of patients receiving HD in an open setting environment at an academic hospital in Johannesburg.

The specific research objectives were:

- To explore and describe the experiences of patients receiving HD in an open setting environment at an academic hospital in Johannesburg.

- To examine and describe patients' feelings and opinions with regard to accessing HD in an open setting environment at an academic hospital in Johannesburg.

The open setting environment in this study was described as a one large open area, where patients with ESRD sit side by side receiving HD treatment.

4.2 METHODOLOGICAL CONSIDERATIONS

A qualitative, exploratory and descriptive design was used to get an overview of patients' experiences regarding receiving HD in an open setting environment in a Chronic Renal Dialysis Unit. A purposive sampling method was used to select participants who met the inclusion criteria and the sample size was determined by saturation of data. The data were collected using in-depth semi-structured interviews to obtain rich and detailed data. Participants were free to reject the use of an audiotape if they so wished, however everyone consented.

Participation in the study was voluntary and any refusal did not negatively affect the patients. Field notes were made and an audiotape recorder captured the data. The researcher collected, entered, coded and analysed all the data, which minimised inter-observer bias. The qualitative data were analysed by employing Giorgi's phenomenological method.

The use of a qualitative approach helped identify and capture the essence of the phenomenon under investigation (Schamell, 2010: 1146). This approach was significant in yielding an in-depth understanding of patients' experiences (Toloie-Eshlaghy, *et al*., 2011: 106). As pointed out in the background of the study, there is no known research into the experiences of patients receiving HD treatment in an open setting environment. Previous studies have looked into the experiences of patients receiving HD in general terms, therefore researching this area was in line with qualitative studies that aim at and are well suited to addressing knowledge gaps (Weiner, *et al*., 2011: 6). The exploratory and descriptive study design has uncovered the experiences of patients receiving HD treatment in a tertiary level academic hospital in the Johannesburg region in South Africa and provides an insight into these patients' lived experiences.

The description of participants' experiences was based on the natural understanding of their experiences as guided by the five steps of Giorgi's phenomenological method of data analysis (Giorgi, 2012: 5-6). The researcher regarded each participant as an experiential expert on open setting environment. This trust enabled participants to give details of their experiences openly and honestly, improving the quality of the empirical data and allowed the researcher to gain a holistic understanding of the participants' subjective experiential meanings as a whole.

Consequently, common themes and sub-themes were gathered which were controlled by literature.

Trustworthiness was ensured and the criteria of credibility, dependability, confirmability, transferability and authenticity were applied (Polit & Beck, 2012: 585). To increase credibility, sufficient time was taken to delve into their experiences and so each interview lasted approximately one hour. Participants included both male and female patients with different age groups and race. Bracketing was ensured to minimise the threats to credibility. This reduced the unsuitable influence of the researcher's feelings and opinions towards the study and allowed better reflection on participants' experiences (Schamell, 2010: 1146).

The researcher's supervisor reviewed each stage of the research, which strengthened dependability. Direct quotations confirmed and authenticated the findings. These findings cannot be generalised to other hospitals however, other settings with similar situations can replicate the study and compare their findings. Qualitative research makes no claim to generalise its findings on basis of statistics, trustworthiness is argued in terms of meaning (Applebaum, 2012: 48).

4.3 DISCUSSION OF THE DEMOGRAPHIC CHARACTERISTICS:

Sixteen patients representing a reasonable diversity in age, gender and race distribution participated in this study. The ages varied from 18 years (18-25, 26-40, 41-55, and 55-70); gender included both male and female patients, however, the number of females was slightly higher than male participants (56% versus 44%); race also varied as White, Black and Indian patients participated. The period on dialysis also varied as some had been receiving HD for only two years, whilst others for more than twenty years, allowing for a diversity of perspectives. The greater the period on HD confirms how vitally important the treatment is in sustaining life (Yodchai, *et al*., 2011: 217). It can also be argued that that the longer the stay on HD facilitates their adaptation and acceptance to pervade certain situations. However, the qualitative data available for this study is not sufficient to support such a conclusion. Generally, the diversity in the demographic data helped to yield and attain the uniqueness of the lived experiences about the open setting environment.

Observations most female participants age 26-40 year expressed concerns with regard to receiving HD in a mixed-gender space. These participants felt mixed-gender space compromised their privacy, respect and dignity.

It can be concluded that all participants expressed similar responses regarding receiving HD in an open environment.

4.4 DISCUSSION OF THE FINDINGS

In summary, the data collected from this study were analysed manually following Giorgi's phenomenological method. The findings were presented in Chapter Three and controlled with confirming and disconfirming evidence from other study findings. Data yielded three themes and eight sub-themes. Despite some negative emotional experiences, which participants expressed about receiving HD in an open setting, a number of positive experiences emerged.

4.4.1 Theme 1: A mood enhancer

A mood enhancer emerged as a major theme, generated from three inter-related sub-themes (i) "being with others", (ii) "sharing of experiences" and (iii) a "community concept". These sub-themes were not entirely discrete and some of their descriptions overlapped. The study revealed that the open setting provided a sense of hope and happiness and allowed patients to share experiences and discuss ways of managing their illness. They shared information and compared life experiences, acted together as one family and got support from "others". The "others," including nurses, patients and friends, were the agent's enhancing such a state of feeling as they got involved in caring for each other in the unit. This contributed to positive feelings and adaptation to their general ill health. They felt reassured amid chronic illness and HD treatment.

The findings reveal that "being with others" in the unit influenced patients' ability to learn and disregard things as they imitated *others*. Those with limited experience about HD had the ability to ask others and felt secure in the presence of staff and other patients during treatment.

Thus the description of the open setting, in a more understandable language, was as *a mood enhancer*. The open setting brought reassurance, happiness and safety for patients, reducing the distressing moods and negative emotional responses from what was experienced individually and collectively. Additionally, "sharing of experiences" had a positive influence on patients' understanding and coping mechanisms of their illness. This can be interpreted as the development of a support group. Yalom and Leszcz (2005: 272) describe that in group therapy individuals are treated together as a group in such that a member is inspired and encouraged by another member who has overcome the problems with which they are still struggling. The members achieve a great level of awareness through the process of interacting with others. Members felt a sense of belonging when hearing other patients telling their story.

From real stories and experiences, the shared words of encouragement in the HD unit played a positive impact on their mood. They shared information and learnt from each other about HD, including how to line the HD machine and set the treatment parameters on the machine. Where possible, patients on life maintaining HD are taught to be independent for easy adaption to treatment (ANKF, 2009, NRC-SA, 2011). Thus, educating and sharing useful information helps to render appropriate support. What they saw and heard from nurses and other patients in the HD unit helped them accept their current situation that happiness and a sense of hope became real. Reich and Michaels (2011: 21) researched the role of storytelling for healing and stated that when people begin to reflect on their own stories they already possess the skills to listen and be present with another human, to create ease and to heal others. This occurs because individuals listen holistically to other human beings without judgment or sympathy, but with empathy. It is in this empathetic presence that healing is possible for both the storyteller and the listener.

Although HD treatment affects body image, making patients feel different, unattractive and ill at ease within their own bodies (Thomas, 2008: 89), this study reveals that the open setting environment enables the changes to be easily accepted and viewed positively. Kolewaski (2010: 129) found that receiving HD with others and coping with similar challenges promoted bonding amongst patients.

Consistently, participants in this study revealed their sense of belonging, viewing their relationship in the HD unit as a family. In a family, roles and behaviours are learned and transmitted within the family unit and community to help the members fulfil their functions (Delaune & Ladner, 2006: 308). As a family, HD patients motivated each other and strongly felt motivation kept them going. Being together in an open setting was analogous to a working environment where different people meet with one common goal. This community of oneness enhanced their adjustment and improved their psychological health and overall well-being.

It can therefore, be noted that the reciprocal nature of interactions in an HD unit is vitally important to help patients find meaning in their experiences and address psychological needs. Weinert (2008: 367) confirms that social support buffers the negative impact of life events on health, which positively influences adjustment and better management of the chronic illness. Consistent with the findings of Rowlands and Noble (2008: 768), patients in multi-bedded rooms were happy to interact and discuss issues which affect their daily way of living.

4.4.2 Theme 2: Experiences of nursing care

The experiences of nursing care were described with reference to consistency, communication and interaction in an open setting and being treated in a mixed-gender space. The findings strongly support provision of consistent and timely nursing care with focus on both the patient and the HD machine. Timely care means *acting fast*, ability to *timeously recognise* and *respond to HD complications* and *being in a state to help* when the need arises, *listening* to patient's requests and o*bserving* and *informing* patients of the care rendered. Timeously responding to HD alarms and complications, played a positive role in creating a favourable HD care setting, which was vitally important in preventing complications.

In this study, participants watched and scrutinised the nursing care, observing the nurses conduct, their actions, general behaviour and how they talked to other patients in the unit. The nurses were judged on their knowledge, skills and attitudes, hence whatever was not consistent was judged as lack of care.

This study reveals that talking to patients with respect and in a calm and humble manner was vital and impacted positively on patients' psychological well-being, strengthening their relationship and facilitating communication. Shouting or discussing private issues with patients in the presence of other patients was defined poor communication and interaction. Griva *et al*. (2013: 22) agree and are of the opinion that good relationships facilitate greater communication and collaboration in an HD unit, ultimately improving knowledge and skills.

The findings of this research highlighted favouritism amongst some nurses, for example participants observed that nurses would choose whom to connect on the machine. Some participants stated they were not free to express their concerns for fear of being told '*they know it all'*. Communicating and providing patients with adequate information on how care is rendered in the HD unit could counteract these misunderstandings.

Dermody and Bennett (2008: 31) report that positive aspects of HD nurses, such as making contacts with patients and teamwork, can make the HD environment less stressful. Axelsson *et al*. (2012: 50) describe focusing just on the medical specialty can increase feelings of insecurity, which was noted when patients receiving HD treatment strove to be liked and felt reluctant to express worries due to fear of the staff.

This study also reveals that participants wanted to know more of their practical situations in the HD unit. They needed to understand what they saw and heard, but the HD staff were not proactive in providing adequate information, which is why excellent quality information and nursing care is required. Having explicit information gives the opportunity to learn how to deal with certain issues and enhance adaptation. Burns and Smyth (2011: 82) support the view that better communication provides patients with more information about the unit and their treatment, which can help reduce incidents of aggression. Lack of knowledge can cause suffering in patients instead of healing (Axelsson, *et al*., 2012: 50).

Contrasting views, with regard to receiving HD in a mixed-gender space, were reported in this theme. Male participants felt positive about being treated in a mixed-gender space whilst most female participants were against it, they preferred a single-gender space.

Most female participants' felt mixed-gender space compromised their privacy, respect and dignity and became a challenge, especially as breasts or thighs were exposed when revealing an access site. Some revealed feeling uncomfortable asking for a bedpan in the presence of male patients, but visiting the toilets was time consuming. As recommended by the South African Renal Society (SARS), respect and privacy should be promoted in chronic dialysis units to maintain the dignity of patients (Moosa, Naicker, Naiker, Pascoe, & Van Rensburg, 2010: 27). The need to maintain privacy was demonstrated by all participants with most suggesting each HD chair should be screened with its own curtains especially at commencement and termination of treatment, thereafter the unit could be left open. More studies are required to investigate this aspect.

4.4.3 Theme 3: A sense of fear

A sense of fear appeared as a consistent theme in the study participants. Sense of fear resulted from multiple situations experienced within the HD unit and from the consequences of the chronic illness as whole. The findings revealed that any negative event that patients experienced, observed or heard in the HD unit evoked fears. One common fear was accentuated by watching HD complications and another was the constant threat of death. In this study, complications during HD were reported as uncommon in individual patients, however being treated in an open setting the patients were exposed to such events which evoked fear. Watching situations such as clotting of HD lines, muscle cramps, hypotension or any sudden change in patient condition, as well as dying on the machine triggered the fears. Observing miscannulation not only brought fear but also mistrust of the providers because patients could see, hear and judge how the nurse performed the task. Knowing the standards of nursing care, in the event of emergencies such as clotting of bloodlines and dialyser, hypotension or bleeding from fistula sites, are fundamental to HD care (Thomas, 2008: 211-217).

The findings also emphasised the importance of accepting and adapting to experiences patients go through. For example, participants revealed adapting to seeing friends collapsing, clotting or dying on the machine. Others spoke of adapting to needling and long-term suffering. Axelsson *et al*. (2012: 50) describes suffering as an experience of threat to some crucial aspect

of one's self, being, or existence. Weinert (2008: 368) defines acceptance as an integration of the disease into one's overall lifestyle in order to get on with living. Although the open setting brought a sense of fear, participants felt adaptive. Others revealed that exposure to stressful events reminded them of the dos and don'ts of HD treatment, such as control of fluid intake and dangers of skipping treatment.

Griva *et al*. (2013: 19) state being aware of the negative consequences of non-adherence to treatment reminded and motivated patients to align their behaviour with the treatment recommendations. Similarly, Calvey and Mee (2011: 205) found that emotions might be shocking and daunting at first but become a way of accepting and adapting to the lifestyle changes when patients acquire knowledge and experience about their condition. HD staff may decrease patients' sense of fear through listening to their experiences, because not attending to distressing experiences can result in low quality of life (Theofilou, *et al*., 2013: 25). These may result from lack of information and lack of patient's participation in their own care (Axelsson, *et al*., 2012: 49).

The findings revealed the value of enabling social workers and psychologists to be involved in routine visits to the HD unit for psychological assessment and counselling. Prescott (2006: 34) emphasised the need for social workers in the HD unit to help patients with psychological problems that acted as barriers to psychosocial functioning and appropriate behaviour. Likewise, Small's (2010: 192) findings demonstrated the need for social workers and psychologists in an HD unit.

The SARS guidelines state that nurses, social workers should provide ongoing support and education to patients on dialysis to enhance holistic care (Moosa, *et al*., 2010: 19), however nurses, being closest to the patients, can assist in identifying problems and initiate the psychological counselling. Thus, a supportive teaching and effective counselling programme for patients receiving HD can be essential (Calvey & Mee, 2011: 206). Such supportive care can facilitate acceptance of life events.

Care is fundamental to nursing (Muller, 2009: 20). It is an ethical obligation for nurses to promote the good of and being concerned about the patient and care should meet the patients' needs. From the findings, it is clear that nurses working in an HD unit need broader caring

skills to treat patients holistically. Patients receiving HD are exposed to different situations in a hospital setting and require much more support, therefore nurses' working in this setting require knowledge and skill to provide care according to the standards of nursing.

According to Tjale (2007: 150) nurses are viewed as whole-person and nurses view patients as whole-person with mind, body and spirit. The nursing assessments and interventions focus on whole care and are sensitive to both family and patient's needs. Generally, knowing the needs of others, especially within their environment is vital. Joseph *et al*. (2011) confirm that nurse as a primary coordinator for whole-person care delivery should be engaged in listening, support, laughter and prayers. This is part of therapeutic use of self as a professional nurse.

Therapeutic communication includes listening, touch, collaboration and observation of patients' body language and response, empathy and compassion (Delaune & Ladner, 2006: 276-279; Tjale, 2007: 153; Joseph, *et al*., 2011: 993). This demonstrates an emotional connection between patients and their staff, and embracing the professional standards.

Standards are the written description or statements of the expected level of work performance (Muller, 2009: 258). The research by Wilson *et al*. (2013: 11-18) on nurses from one HD in-centre in Canada, indicated that nurses working in HD units require specialised skills and move between perpetual novice to expert nurse, based on Benner's theory of skill acquisition in nursing. Many procedures such as commencing HD, cannulation, troubleshooting of the HD machine, as well as passing information to the patient require specialised knowledge.

Lack of specialised skills in HD nurses can result in serious complications for patients and compromise the quality of renal care. The ability of nurses to listen and render competent patient care will minimise HD complications and the sense of fear will eventually diminish, thus enhancing patient-staff relationships. Patients' expect any nurse available in the HD unit to be of help in providing appropriate and timely care. All aspects of care must reflect holistic care as stipulated in Tjale's (2007: 132) five dimensions of whole care, which is inclusive of physical, emotional and psychological, spiritual, social and cultural dimensions. Holistic nurses listen to others to create a collaborative healing environment (Reich & Michaels, 2011: 21).

4.4.4 Conclusion of the discussion

In conclusion, HD is a life-saving and maintenance treatment for ESRD. The patient usually has to accept a changed lifestyle in order to remain healthy. By being with others in an open setting, an understanding of each other's life experiences with ESRD and HD is developed, which means acceptance of their new life situation and adaptation are enhanced. The interactions with other patients and staff increases happiness. These overall findings support the methodological assumption that the experiences, including feelings and opinions, of patients receiving HD treatment in an open setting environment of a Chronic Renal Dialysis Unit at an academic hospital in Johannesburg would be derived from their subjective experiences and could be taken as valid sources of knowledge.

4.5 DISCUSSION OF FINDINGS THROUGH FRAMEWORK APPLICATION

This is a further discussion of the holistic care model applied in this study. Tjale's holistic care model is based on the rationale that a person is whole with mind, body and spirit interconnected. The model was adapted for this study in patients receiving HD treatment because of its holistic approach to care. The model's foundation is that a person is whole and in order to meet the mind-body-spirit needs of a whole person, approach to patient care should be whole. Whole care, according to Tjale (2007: 132) is inclusive of five dimensions: physical, emotional and psychological, spiritual, cultural and social dimensions and will be discussed according to the study findings.

4.5.1 Physical dimension

Physical dimension of care refers to the care designed to meet the diseased part of the body of a whole-person (Tjale, 2007: 133). The body is the biological aspect of physical care (Nathenson, 2012). Findings of this study show that watching others complicating during HD treatment had a negative impact on patients' overall well-being. Participants felt nurses should recognise and respond to all HD machine alarms in a timely manner to prevent complications and ultimately lessen fears. Care should be given by any nurse in the unit to promote patient safety. In addition to promoting physical comfort, participants suggested all patients should be offered comfortable HD chairs during treatment to minimise discomfort.

They also expressed the need for intra-dialysis activities to reduce boredom. Maintaining a clean environment and hand hygiene was expressed for their safety. Thus, physical needs of patients receiving HD need to be assessed holistically.

Numerous studies report that ESRD, chronic HD and medical technology has associated physical and psychological stressors, therefore care should focus on whole-person (Thomas, 2008; NRC-SA, 2011, Bennett, 2011; Bayoumi, 2012; Chan, *et al*., 2012, Theofilou, *et al*., 2013). Intra-dialysis activities within patient abilities not only improve the physical fitness but also HD efficiency, reduces fatigue and improves psychological well-being and quality of life (ANKF, 2009; Ouzouni *et al*., 2009; Heiwe & Tollin; 2012). Patients also feel time in the HD unit is meaningful when they get involved and this too enhances achievement of holistic care. The ability of staff to adhere to hygiene helps prevent cross contamination and infections.

4.5.2 Emotional and psychological dimension

The psychological dimension was the core to this study. Emotional and psychological dimension refers to the care that focuses on the mind of a person, planned to address fears and anxieties resulting from stresses in a hospital environment (Tjale, 2007: 134). This dimension of care helps to lower fears and enhances comfort, love, encouragement and overall psychological health. The psychological aspect is inclusive of the emotional, cognitive, intellectual and creative components of self (Nathenson, 2012: 114). Therefore, these terms are used interchangeably (Tjale, 2007: 134).

It was evident from this study that receiving HD in an open setting evoked different types of emotional and psychological responses including fear, stress, anxiety, sadness and depressed feelings. Participants experienced a sense of fear evoked by watching HD complications and miscannulation by inexperienced staff. The findings reveal another fear, "threat of death". Participants described seeing and hearing about negative events in the unit became a threat to their life. They clearly pointed out that these fears resulted from the complexity of ESRD as a whole. However, this study provides a unique perspective that regardless of the several emotional responses, patients had the ability to accept and adjust positively. Thus, nurses need to recognise and respond holistically to patients' experiences, which are negative

consequences of ESRD and HD. Participants felt provision of clear information and being with patients and staff during treatment was vital to minimise such negative emotions. In addition, routine ward rounds by a psychologist and social worker was vital.

Literature demonstrates that many emotional responses to HD can be expected due to loss of job, loss of future aspiration, depression, family breakdown, financial constraints and transport problems to get to the dialysis unit (Bennett, 2011; Axelsson, *et al*., 2012; Schick Makaroff, 2012, Aesen, *et al*., 2012). Psychological counselling in HD patients helps control their negative emotions (Keskin & Engin, 2011). Similarly, the routine involvement of the psychologist and social worker in the HD unit is equally important for patient's emotional and psychological well-being, as concurred in other studies (De Sousa, 2008; ANKF, 2009; Bayhakki & Hatthakit, 2012).

4.5.3 Spiritual dimension

According to Puchalski (2012), spiritual care refers to whole health care amidst serious disease and dying where people find recognition of healing as a way to cope with suffering. From the findings, spiritual activities such as listening and reading spiritual messages and prayers offered in the unit were important. This allowed patients to connect with other patients, staff, higher powers or God to find comfort source healing. Spirituality has been used by patients receiving HD as the basic and most important aspect in life (Tanyi & Werner, 2007; Tanyi & Werner, 2008; Bayoumi, 2012).

4.5.4 Cultural dimension

The cultural dimension of care, according to Tjale (2007), is initiated with recognition of patients as individuals with beliefs and values. In line with holistic nursing care, it is culturally sensitive to person's beliefs, ideas, norms and values (Dossey, 2010; Nathenson, 2012; www.jblearning.com). Participants described culture in relation to their personal values, in an open setting environment. For example, most female participants felt breast exposure in the presence of male patients was culturally unacceptable and disrespectful. The findings also revealed participants holding some misconceptions about ESRD and HD treatment.

However, from the sharing of experiences and information in the unit they realised what was right and wrong for them in order to sustain their life, therefore culturally sensitive care must understand and appreciate the patient traditions, beliefs and values facilitated by good verbal and non verbal communication, skills, warmth, respect, openness and a non-judgmental attitude (Tjale, 2007: 117). A cultural adjustment is necessary for individuals receiving HD in order to adapt to the treatment (Kolewaski, *et al*., 2010).

4.5.5 Social dimension

The social aspect emphasises the connectedness of all people and the importance of relationships for self-esteem and identity (Nathenson, 2012). Involvement of social workers, other patients, nurses and HD staff, family members, visitors and friends was vital.

This study highlighted the importance of patient relationships and being harmonious with the staff. This was motivational in helping them through the day and minimised that feeling of being alone with the disease. Their bodies made more sense when with "others" and they described interactions with other patients, making jokes, laughing, chatting, providing motivational talks and sharing experiences as being vital. Participants also felt support for their social needs, such as transport to take them to the dialysis unit, was an important issue however, this cannot be discussed further as it was beyond this study.

Tjale (2007) refers to social care as being congruent with Ubuntu way of communal living, which considers involvement of significant others in the care. Ubuntu is concerned with the other person, connecting and uniting with other people. Socially, patients receiving HD experience role and life-style adjustment, time spent and lost in HD unit, changes in their relationship with partners and being dependent on others (Schipper & Abma, 2010, Axelsson, *et al*., 2012). Hence, to ensure whole care, HD nurses must consider social relevance in HD care.

In conclusion, HD care is deeply rooted in high technological interventions that encourage and motivate patients receiving the treatment in a hospital setting to sustain life and a journey of overall well-being. To enhance psychological well-being of a patient receiving HD, the

approach to care should be holistic; mind-body-spirit dimensions should be integrated. This will enable treating a whole person and by employing whole care, physical, emotional and psychological, spiritual, social and cultural attributes of care may facilitate overall well-being of a patient receiving HD. Holistic care has been a perfect framework for this study because of its interconnectedness with all the aspects of a person.

4.6 SUMMARY OF THE STUDY FINDINGS

This study aimed at investigating the experiences of patients receiving HD treatment in an open setting environment. The findings revealed this environment to be a mood enhancer, allowing patients to share life stories and experiences, but that it could also be fear provoking. Thus, nurses' ability to recognise and provide timely care to all patients was vital in preventing HD complications that generally triggered these fears.

This study however, shows that patients were adaptive to new situations. Good support from nurses was key to facilitating adjustment; the ability to listen and respond to patient's experiences including psychological counselling was described as essential. The findings suggest that each HD chair should be screened with its own curtains to promote respect and privacy however, contrasting views emerged with regard to mixed-gender space. Most female participants viewed mixed-gender space negatively, whilst male participants felt positive about it. More studies are needed to investigate this area.

4.6.1 What is known about this topic?

- The experiences of patients receiving HD are complex and affect whole being. Patients experience distressing moods such as anxiety, sadness and depressed feelings, stress and uncertainties about their life.
- Every HD complication and all negative events in the HD care environment evoke fears.
- Generally, the HD care environment can be stressful.

4.6.2 What this paper adds

- An open setting environment is a mood enhancer. It improves the quality of happiness amongst patients receiving life maintaining HD treatment.
- Timely care in recognising and responding to HD complications in an open setting can minimise the negative emotional experiences including fears.
- Patients receiving HD are whole and require assessments and care that is holistic - mind, body and spirit aspects. This is achievable by embracing the five dimensions of whole care, physical, emotional and psychological, spiritual, social and cultural dimensions, to treat a person as whole.
- The community concept and inclusion of Ubuntu principles from what was expressed as "we" - in HD care setting can facilitate patient adjustment. This includes introducing a *concept of family and community* within the HD care space.
- Most female participants preferred receiving HD treatment in single-gender space rather than a mixed-gender space. This was in contrast with male participants who viewed the mixed-gender treatment space positively.

4.7 LIMITATIONS OF THE STUDY

The present study had the following limitations:

Firstly, this study was conducted at only one academic hospital in Johannesburg and the setting of the study was an Adult Chronic Renal Dialysis Unit. Therefore, the findings may not be representative of all patients receiving HD. The inclusion of patients from Acute and Children's Unit may have provided a clearer picture of the open setting.

Secondly, the study setting was a public sector, tertiary and academic hospital and there may be differences between public and private HD Units.

Thirdly, the small sample limited the study and so it was difficult to establish whether their feelings and opinions were representative of all patients on HD.

Furthermore, the study was conducted in English, which may have limited other patients from fully articulating their experiences. It was also possible that the presence of a tape recorder had an inhibitory effect on the full expression of the experience. However, there are no known studies investigating this topic, therefore, these results provide baseline data to replicate a similar study in another context with a comparable setting.

4.8 RECOMMENDATIONS

This study's findings provided a valuable description of patient experiences including feelings and opinions of receiving HD in an open setting dialysis unit. Ways of improving the quality of HD care have been suggested and recommendations for this study, which were developed in line with participants' feelings and opinions as regard receiving HD treatment in an open setting environment, are highlighted in Table 4.1.

TABLE 4.1: RECOMMENDATIONS OF THE STUDY

PARTICIPANTS' FEELINGS	PARTICIPANTS' OPINIONS	RECOMMENDATIONS
A mood enhancer: **Participants felt the open setting acts as a mood enhancer. It improves happiness and contributes positively to their psychological well-being. The distressing moods such as stress, anxiety, sad and depressed feelings reduced in this setting, hence being with others was vital for mutual support.**	**Sharing of positive feelings** The participants were of the opinion that the reciprocal nature of interaction existing amongst the patients and staff in the unit should be encouraged to promote adherence and happiness. Sharing of stories and experiences was valued. The availability of others, patients and staff, was expressed crucial also for their safety	Positive experiences can enhance adjustment, therefore, HD staff to incorporate patients' feelings and opinions into their care. Ask patients things that can improve therapeutic interactions in the HD unit. Develop an attitude of listening to patients experiences and understanding their feelings and opinions. This will support the goals of holistic care that incorporate patients' ideas into their care. The Unit Manager to facilitate meetings with patients to share stories and experiences, which are informative, foster hope and offer encouragement. Discuss programmes that can enhance positive conversations and reach out to others to cheer and motivate patients. Encourage health messages including real life stories from HD patients, staff and families that will enhance happiness in the HD care environment. The physical presence of HD staff throughout treatment to be encouraged as it is more meaningful for safety and psychological aspect of a patient.

	Motivation was felt to be vital to keep them going	The unit manager and all nurses working in the HD unit to be creative and promote an environment that can be motivational. Help patients believe in their own abilities and bring forth suggestions that will enhance their psychological well-being.
Experiences of nursing care **Both positive and negative experiences as regard consistency of nursing care, communication and interaction in an open setting environment were expressed.** **With reference to being treated in an mixed-gender space participants had mixed feelings**	**Good communication:** Good communication was expressed as critical in creating a better HD environment. Participants suggested that patients should be approached in a calm and friendly manner, since a threatening approach led to the decision of skipping HD treatment.	HD staff including nurses, doctors and other staff to maintain a friendly and build an attitude of approaching the patient holistically in order to understand their needs. Patient receiving HD is whole with mind, body and spirit. Aloofness and insensitivity to patients needs would produce lower rates of compliance. Thus, staff working in HD unit who treats patients holistically, including psychological aspect may yield higher rates of compliance. HD staff when speaking to patients should be open and pay attention to patients' feelings. Identify a separate room for individual counselling. Maintain professional standards to all patients receiving HD to provide consistent care that would serve and meet patients' expectations and improve quality of HD care. The unit manager should be aware of the performance of its members in the unit and where appropriate take action to discipline the members. Proper assessments through history taking and physical examination should be ensured. The dimensions of whole care can be utilised when assessing the patient receiving HD. These include the physical aspect, emotional and psychological, spiritual, social and cultural aspects. Training, debriefing and orienting new nurses in the HD unit should be an ongoing process for them to develop professional care attributes, *competences, compassion, conscience, confidence, commitment as well as communication.*

	Maintaining respect Participants suggested that HD staff should maintain respect that patients deserve. They were of the opinion that they should be treated as adults. Participants expressed the need for HD staff to have skills on how to handle and manage patients receiving HD. For instance, skills to listen, talk, attend and understand patient's feelings.	Nurses to organise dialysis ward meetings to discuss skills that can maintain respect for patients and demonstrate effective communication and find ways of improving such skills. The HD staff should be kind, gentle and empathetic so that patients could build confidence in staff. This will also promote human relations in the unit and ultimately reflect the holistic caring attitude. Nurses must be sensitive to individual differences of patient's emotional needs in the HD unit. A positive HD care environment is created and promoted when staff works with individual patients to find solutions to their particular problems. HD staff, particularly nurses, must not only emphasise the physical and technological aspects of HD care, but also the psychological, spiritual, cultural and social aspects of patient care. This will result in more effective and satisfying nursing care. Let nurses embrace in their actions the pledge of service that says 'I will maintain by all means in my power the honour and the noble traditions of my profession' or 'the total health of my patients will be my first consideration.' In the above quotation, the nurse's pledge reflects the holistic approach to patient care. Enhance practical competences of staff working in HD unit through on-the-spot education with trained HD practitioners. Knowledge and skills achieved in this manner would increase patient satisfaction and compliance. Consequently, complications during HD treatment will be reduced. Reinforce reading and adherence to the HD unit policies and regulations. Nurses should be trained on holistic care, mind, body and spirit aspects of being, to equip them with skills of treating the patient as a whole being. This embraces the five dimensions of whole care, which are physical, emotional and psychological, spiritual, social and cultural dimensions.
	Giving explicit information: Participants were of the opinion that patients should be adequately informed about their condition and HD. They also suggested that families should be	Nurses should keep patients informed about the physiological changes of ESRD. Provide clear information about HD and medication. This knowledge will enable patients to understand their bodies and help to prevent and detect complications promptly. Teaching approaches should still be planned for individual patients even though they are in an open setting. Make new patients and families aware of the context and environment in which they find themselves. This will help them feel more supported and cared for.

engaged in their care and be given adequate information, in particular, kidney transplant.	Staff working in the dialysis unit should listen to patients, share information about their condition and its treatment. This could facilitate patient independence as they get involved into their care.
Maintaining privacy Participants also expressed the need for each dialysis chair to be shrouded with its own curtains and not two or more patients closed together in same curtains. Participants expressed the need for privacy, in particular when commencing and terminating treatment thereafter keep the HD unit open for social interaction.	Nurses must ensure privacy by asking patients privacy needs. For example, privacy can be arranged by screening patient's HD chair at commencement and termination of HD treatment. Ensuring privacy will enhance comfort. Enhance privacy by providing screens when body exposure is expected. Privacy and confidentiality: it is important to remind staff that individual patient problems may not be discussed with other patients, as they may feel devalued. The control of social contacts when appropriate should be encouraged as it does not only control infections but also promotes privacy. Therefore limiting visitors into the HD unit, allows respect for patients which further may satisfy patient's need for privacy. Recognise patient's preferences, values and beliefs to support the individuals needs in an open setting environment. Critically ill patients can be cared for in their own curtained area to lessen negative emotional responses and promote the privacy and dignity of that individual patient.
Being treated in a mixed-gender space raised mixed feelings and opinions Most female participants were of the opinion that male and female patients should be treated in separate areas. However male participants felt the decision to have mixed-gender space was appropriate.	Policy about mixed-gender space, if available, may be given to the patients to promote comfort. Separate female and male HD units may be advocated as viewed by most female participants to enhance comfort, respect and dignity. A further investigation into this area is required. A culturally sensitive HD care environment should be promoted. Learn from patients what is culturally acceptable and unacceptable and integrate them in their routine HD care. Counsel patients appropriately when need arises. More studies including quantitative studies will be required as a compliment to this and further qualitative studies.

Fear in HD care environment **Being exposed to a stressful environment resulted in different sorts of fears: fear of HD complications, unsuccessful dialysis needling and fear of death.**	**Responding timeously to any complication** Most participants expressed the need for HD staff to a*ct fast, timely recognise* and *respond to HD complications.* Staff working in HD unit to be *in a state to help* when need arises without favouritism. Able to timeously resolve troubleshooting of the HD machine.	The researcher recommends whole person care in managing HD patients. Nurses to be helpful and responsive to HD complications. This knowledge can be acquired through in-service education and training, encourage nurses to attend seminars and conferences. Engage patients in active participation of their care and provide training about HD treatment. Include its complications to promote self-care management. Inform patients how to prevent, recognise and manage complications. Nurses must understand emotional reactions of individuals in the unit and respond professionally to their particular needs.
	Teamwork and social support Participants suggested that nurses must work as a team especially during dialysis needling. They suggested that a senior nurse should be present, in particular, when inexperienced nurses are carrying out such procedures to prevent traumatising the patient which results in stressing all patients. Teamwork & collaboration was emphasised to achieve emotional support	Nurses' willingness to collaborate when patients are receiving HD should be promoted. This may have positive influence on the patient's health emotionally and support for adherence. Nurses to facilitate informed patient consent for care i.e. obtain permission before needling the fistula to provide ethical and legal care. Inexperienced staff should work under supervision of trained professional and senior HD nurses for best practices and safety of patients. Seeking advice on 'practical know-how' enables professional growth and gaining competences. Continuous information about HD care should be provided to enhance patients' psychological well-being. This can involve group counselling and in some other situations individual counselling might be very important. Update knowledge and skills of HD staff through in-service training. Knowledge of fistula, dialysis needling and timely care to be emphasised. The staff working in HD unit should discuss ways to improve teamwork and collaboration. Nurses to be working hand in hand with other staff in the Unit such as technicians while maintaining professional boundaries. This would allow quick management to a patient and increase knowledge.

Emotional and Psychological support: Regular routine visits by the psychologist and social worker in the HD unit was emphasised. This was required for psychosocial support and counselling.	Psychological support; whenever possible a routine psychologist dialysis unit round may be carried out which will give a step forward in promoting holistic care. Provide positive reinforcement to patients receiving HD for they are vulnerable to psychological stresses. Nurses may specify a day, fortnight or month to counsel patients and refer where appropriate. This would help early identification of patient's psychological and social needs in the dialysis unit. Encourage HD staff to ask, look and feel for patient's psychological problems and record the psychological status regularly in patient's file. Explore social needs of individual patients and support should be provided where available and referred to a social worker for routine assessment and regular counselling. It is vital for nurses to spend time with patients, especially when new to the chronic renal dialysis unit. Explain to them the nature of ESRD, HD as a treatment, HD care and environment including policy and their expectations. It is also important to assess patient concerns critically. This should be done in a private area to allow open conversation to facilitate talking and expressing feelings and offer good support in terms of counselling. Promote coordinated care through a multidisciplinary approach. Patient's emotions should be understood and nursed holistically without prejudices. Thus, assessing and listening to patient carefully is important. In situations where complications or death occurs in the Unit, debriefing to patients after death can be important for emotional and psychological support
Spiritual care including ward prayers. Participants recommended HD unit prayers to be organised for both morning and afternoon shifts. Spiritual messages to take into account and respect individual beliefs.	Nurses should elicit and assess the level of spiritual expectations from each patient receiving HD. Ethical respectful care should be taken to consider those patients who may not be in agreement with the general view about prayers. In creating an accepted routine of prayers, cautions and careful analysis should be done in order to respect individual views. While families who pray together stay together application of this general statement needs wisdom in multi-faith environments. The nurse's physical presence in the ward reflects caring. This therapeutic presence in these patients is recommended.

Intra-dialysis comfort: The participants suggest that HD staff should incorporate some activities such as educative poems to minimise the boredom. They also suggested that HD chairs should be fixed to increase comfort	Simple games or activities can be initiated according to patient capabilities. Ask patients to bring ideas about these simple games that can enhance a happier HD care environment. Find out from patients what television programmes which patients may wish to watch. Encourage the HD staff to ask patients things that can increase their comfort to achieve the best outcomes of their treatment.

4.9 IMPLICATIONS OF THE STUDY

4.9.1 Implications for Nursing Research

- It is worth noting that this study was conducted in an Adult Chronic Renal Dialysis Unit and public hospital. Therefore, there is need to conduct more research to explore the experiences of patients receiving HD treatment in an open setting environment in other settings, including private hospitals. Similar studies can also be explored amongst patients receiving HD treatment in Acute and Chronic Paediatric HD Units. The findings from such studies could be beneficial as they can be examined and compared to this study.

- The long existing patient opinion gap in HD care should be acknowledged. Suggestions for further research include exploring opinions of patients about receiving HD treatment in a mixed-gender treatment space, since in this study participants had contrasting feelings and opinions.

- Further research with regard patients' opinions in creating a therapeutic HD care environment may be crucial. This will facilitate diversity of patients' experiences and knowledge from different settings, which can be incorporated into their care.

4.9.2 Implications for Nursing Practice

- Findings revealed that patients receiving HD want to be treated as a person, with focus on total needs (patient as well as the HD machine). Therefore, provision of HD care has to be holistic, ***mind, body*** and ***spirit.*** This can be achieved by implying whole care, physical, emotional and psychological, spiritual, social and cultural aspects to be integrated in the care of a patient receiving HD. This will help identify patient's needs and offer holistic care.

- Holistic care not only focuses on HD technology, but on the patient as whole, therefore, family concerns, social, cultural, spiritual and psychological needs of a patient should be taken into consideration. This will allow treating the patient as a holistic being.

- Timely care is paramount in patients receiving HD treatment. Timeously recognising and responding to HD alarms can help prevent HD complications, which evoke fears. This will improve patients' emotional and psychological well-being during HD treatment.

- Routine psychological and social services in patients receiving HD were felt important. Routine psychological assessment and counselling can improve positive emotions of patients in the HD care environment. Thus, a psychologist and social worker should be appointed to review patients routinely in a Chronic Renal Dialysis Unit.

- Engaging patients to share their ideas, feelings and opinions on how to support their well-being would improve quality of renal care and bring positive emotions. Some fun activities suggested by patients during HD treatment can cheer patients, therefore, it is important to discuss with patients what realistic activities could be regularly scheduled into the unit. This would help patients to be creative and show off their talents.

- Keeping patients busy with intra-dialysis activities according to patient capabilities can minimise the boredom, lessen negative emotional and psychological responses including fears and promote adherence to treatment.

- Shrouding each dialysis chair with its own curtains will allow and improve privacy during HD, as suggested by participants, mainly at commencement and termination of treatment.

This will enable culturally and ethically sensitive care. In a diverse society, patients' feelings are to be considered.

- Patients should be counselled in advance about troubleshooting the HD machine. This is indicated by HD machine alarms to alert both the patient and staff of situations such as clotting of blood access lines, air leakage and empty dialysis solutions, which can occur with HD treatment. Debriefing will help alleviate the fears.

- Update all patients with clear and adequate information with regard to ESRD and HD treatment in a hospital setting. This will allow patients to understand their situation and share updated information with other patients in the unit.

- The need for spiritual care was expressed. For example, prayers organised by nurses were appreciated by many participants. Allowing a diversity of patient views with regard to HD Unit prayers would help them to form warm and friendly relationships. Again, preserve self-identity and promote happiness.

4.9.3 Implications for Nursing Education

- The findings reveal patients receiving HD need more practical information about different situations encountered. This brings attention to nursing institutions to promote awareness amongst renal nurses to fully understand ESRD, its implications and management.

- The researcher believes that the concept of ***mind, body*** *and* ***spirit*** dimension should be promoted in nursing education institutions and in hospitals during refresher courses. This would allow effective application of the concept in the clinical setting to better support patient holistic needs.

- Aspects of whole care, inclusive of physical, emotional and psychological, spiritual, social and cultural dimensions, should be emphasised. This would enable comprehensive identification of patient's needs and provide holistic care.

- The community concept suggested from this study has to be taught in the general training of nurses so that by the time some of the graduates specialises in renal health have the foundational theory and language accepted contextually especially where nurses spent long hours with patients as in the HD open setting.

4.10 FINAL CONCLUSION OF THE STUDY

This study has successfully explored the experiences of patients receiving HD in an open setting environment, which from the participants' perspective there was a mixture of feelings. The findings revealed that an open setting environment was preferred by both male and female. For example, being with staff, friends and other patients is a mood enhancer. Patients share smiles, jokes and laugh together. From the stories and experiences they share, there is mutual understanding from a perspective of a disease to a person as a whole. Another factor is the uniqueness of their relationship, being there with everybody was described as a family and the uniqueness of developed community. This increased interaction and support and was motivational in bringing happiness and facilitated adjustment and adherence to treatment.

However, the majority of female participants expressed the need for sensitivity to privacy in an open space. This study has also revealed a sense of fear that often exists in an open setting environment. A sense of fear often resulted from watching HD complications and consequences of ESRD which posed threat to their lives, affecting patient's psychological well-being. Therefore good staff support and listening to patients was felt critical to patient well-being. Again, effective support for patients receiving HD is multidimensional; hence a routine ward round by a psychologist and social worker might be an important step to enhance optimal care. Nevertheless, the bottom-line is a holistic approach by nurses to HD care. This should consider the five dimensions of whole care, physical, emotional and psychological, spiritual, social and cultural dimensions.

Further research is required to explore patients' feelings and opinions about the mixed-gender treatment space in a Chronic Renal Dialysis Unit. This study revealed most female participants viewed the space negatively and demonstrated the need for a single-gender space. This was in contrast with male participants who viewed mixed-gender space positively. Again, further

qualitative studies on experiences of patients receiving HD in an open setting environment could help extend this knowledge.

In this study nurses are recognised as the carriers of knowledge and skill in HD care. While the participants' express the role of the nurse within the "*community concept* and within the HD *"family"* derived from being in the same open space; nurses appears to carry a responsible role based on the health related *knowledge* (cognitive, skill and attitudes) and *knowing* of the patient as a person transcends the professional boundaries. Knowing the patients as person is consistent with Ubuntu principles. And it is at this level of knowing the power-base are levelled revealing common humanity based on long-term relationships with some of these patients.

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APPENDIX A

SEMI-STRUCTURED INTERVIEW GUIDE

Thank you for your willingness to participate in this research study. The topic for this study is "*the experiences of patients receiving haemodialysis treatment in an open setting environment at an academic hospital in Johannesburg"*. There is little known about this topic under study. It is my request that you participate actively, feel free and be honest as much as possible as we will be discussing these experiences.

Research Questions

- What are your experiences with regard to receiving haemodialysis treatment in an open setting environment in a Chronic Renal Dialysis Unit?

- What are your feelings and opinions with regard to receiving haemodialysis treatment in an open setting environment in a Chronic Renal Dialysis Unit?

Probes

- Please can you tell me more about your psychological experiences when receiving HD treatment in an open setting environment?

- The current practice is that male and female patients receive HD treatment together in the same room, what are your feelings and opinions about this?

- HD is a life maintaining treatment, how does it make you feel emotionally, culturally, spiritually, psychosocially and physically when you receive treatment in this open setting dialysis environment?

- In your own opinion, what would you recommend for improvement?

- Is there anything else you would like to tell us?

APPENDIX B

PARTICIPANT CODE:

DEMOGRAPHIC DATA FOR PARTICIPANTS

(What is appropriate to participant will be ticked)

Gender

Male		Female	

Age in years

18-25		26-40		41-55		56-70		71+	

Race

Black		Indian		Coloured		White		Other	

Period on haemodialysis

< 1 year		1-2 years		Above 2 years		

APPENDIX C

PATIENT INFORMATION SHEET

Dear _____ (name of patient)

My name is Mayamiko Khomba and currently I am registered as a student at the University of the Witwatersrand in Johannesburg, in the Department of Nursing Education. I am pursuing a Master of Science in Nursing (Nephrology). I hope to conduct a research study on "*the experiences of patients receiving haemodialysis treatment in an open setting environment at an academic hospital in Johannesburg"* and I would like to invite you to participate.

The purpose of this study is to explore critically your experiences including the feelings and opinions with regard to receiving haemodialysis treatment in an open setting environment. The study will enable renal practitioners to identify needs of individual patient's whilst on haemodialysis. This will also contribute to the provision of holistic care that meets individual needs as you receive haemodialysis thereby improving the quality of renal care.

Participation in this research study is completely voluntary and refusal will not negatively affect the care you receive as a patient in this hospital. Anonymity and confidentiality will be maintained throughout the study by coding data. Code numbers will be used instead of your names. The interviews are to be conducted in a quiet and private area and will take approximately one hour. You are free to withdraw from the study at any time you wish. The information from the study will be used for the intended purpose only.

Should you agree to participate, I will ask you to sign consent that will indicate your acceptance to participate in the study. I will request your permission to use an audiotape recorder during the interview and you are free to reject this if you so wish. During the process of data collection and analysis, access to this information will be made available to the researcher supervisor only. I will obtain information on your experiences, which will include your feelings and opinions with regard to receiving HD in an open setting environment.

Confidentiality of the taped recordings and transcribed data will be ensured. The tapes, transcripts, field notes and demographic data will be kept in a secure area under lock and key.

All the audiotapes and recordings will be destroyed within five years after research publication.

There are no direct benefits from participating in the study. The findings from this study are expected to benefit participants, as baseline data of patients on hospital based treatment will be provided and this knowledge will assist renal practitioners to intervene and make adjustment to meet the holistic needs of patient's treatment environment. Refreshments will be provided and money for taxi or bus fare will be given to patients requiring it.

The following appropriate people have approved the study: - The Human Research Ethics Committee of the University of the Witwatersrand, the Gauteng Department of Health and Johannesburg Academic Hospital. Should you require any further information regarding the aspects of this research study, you are free to contact me on this cell number: 079 76 138 84. Thank you for reading and responding to my invitation. Your participation in this research is valuable and appreciated.

Yours Faithfully,

Mayamiko Khomba (MSc Nursing Student)
Date_____

APPENDIX D

PATIENT CONSENT FORM FOR THE STUDY

I…… (Name of participant), hereby give my consent willingly to this study.

My acceptance to participate is voluntary and no coercion has been made. I have been given adequate information on the purpose of the study. The researcher has assured me that the ethical issues of confidentiality and anonymity will be maintained and that codes will be used instead of my name. I have been informed that I can withdraw from this study anytime I may wish to.

Participant signature……..

Witness…….

Date _____

PATIENT CONSENT FOR THE TAPE- RECORDER

I…… (Name of participant), hereby give consent willingly to the audiotape recording of the interview.

I have understood the content given in the information letter. The researcher clarified verbally the purpose of audiotaping the interview and the freedom to reject the audiotape.

Participant signature…….....

Witness……..…

Date_____

APPENDIX E

University of the Witwatersrand
Faculty of Health Sciences, Department of Nursing Education
7 York Road, Parktown 2193
Email: khombamayamiko@yahoo.com

The Chief Executive Officer, the Nursing Manager and the Unit Manager
Academic Hospital,
Parktown, 2193,
Johannesburg.

Dear Sir/Madam,

RE: PERMISSION TO CONDUCT RESEARCH AT THE HEMODIALYSIS UNIT

I am Mayamiko Khomba, a student at the University of the Witwatersrand, Johannesburg. I am currently registered for Master of Science in Nursing (Nephrology) in the Department of Nursing Education. I hereby ask permission to undertake a research study at Johannesburg Academic Hospital. I am investigating "*The experiences of patients receiving HD treatment in an open setting environment at an academic hospital in Johannesburg".*

A healthy and safe environment is paramount to the quality of HD care. An environment that is healing, safe and supportive of the whole patient for better patient outcomes. Environment plays a central role to meet the holistic needs of individual patients. However, little is known about the experiences of patients receiving HD treatment in an open setting environment. The purpose of this study is to critically explore the experiences including the feelings and opinions of renal failure patients receiving HD treatment in an open setting environment in a Chronic Renal Dialysis Unit. The study will contribute to the provision of holistic care that meets individual HD patient needs, thereby improving the quality of renal care.

Participation in this research study is completely voluntary and confidential. The participant's name will not appear anywhere and only code numbers will be used. The interviews will be conducted in a quiet and private area and will take approximately one hour. The information will be used for the intended purpose only. The participants are free to withdraw from the study at any time they wish. An informed written consent will be obtained from all patients to be recruited in the study, which will indicate acceptance to participate. A tape recorder will be used during data collection and permission will be sought. Participants will be free to reject the audiotape if they so wish. I hope to conduct this study in an Adult Chronic Renal Dialysis Unit where participants receive chronic HD treatment.

The name of the participating Hospital and patients involved will not be divulged in the research report. Ethical clearance has been sought from the Human Research Ethics Committee of the University of the Witwatersrand. Please see the attached copy of my research proposal. Thanking you in advance for allowing me to conduct this study. Your permission is valuable and highly appreciated. For more information please contact me on 079 76 138 84.

Yours Faithfully,

Mayamiko Khomba (MSc Nursing Student)

Date_____

APPENDIX F

University of the Witwatersrand
Faculty of Health Sciences, Department of Nursing Education
7 York Road, Park town 2193
Email: khombamayamiko@yahoo.com

The Director of Health Services,
Gauteng Department of Health,
Johannesburg.

Dear Sir/Madam,

RE: PERMISSION TO CONDUCT RESEARCH AT THE HEMODIALYSIS UNIT

I am Mayamiko Khomba, a student at the University of the Witwatersrand, Johannesburg. I am currently registered for Master of Science in Nursing (Nephrology) in the Department of Nursing Education. I am hereby asking for permission to undertake a research study at Johannesburg Academic Hospital. I am investigating "*The experiences of patients receiving HD treatment in an open setting environment at an academic hospital in Johannesburg".*

A healthy and safe environment is paramount to the quality of HD care. An environment that is healing, safe and supportive of the whole patient for better patient outcomes. Environment plays a central role to meet the holistic needs of individual patients. However, little is known about the experiences of patients receiving HD treatment in an open setting environment. The purpose of this study is to explore the experiences, including the feelings and opinions of renal failure patients receiving HD treatment in an open setting environment in a Chronic Renal Dialysis Unit. The study will contribute to the provision of holistic care that meets individual HD patient needs thereby improving the quality of renal care.

Participation to this research study is completely voluntary and confidential. The participant's name will not appear anywhere and only code numbers will be used. The interviews will be conducted in a quiet and private area and will take approximately one hour. The information will be used for the intended purpose only. The participants are free to withdraw from the study at any time they wish. An informed written consent will be obtained from all patients to be recruited in the study, which will indicate acceptance to participate. A tape recorder will be used during data collection and permission will be sought. Participants will be free to reject the audiotape if they so wish. I hope to conduct this study in a Chronic Renal Dialysis Unit where participants receive chronic HD treatment.

The name of the participating Hospital and patients involved will not be divulged in the research report. Ethical clearance has been sought from the Human Research Ethics Committee of the University of the Witwatersrand. Please see the attached copy of my research proposal. Thanking you in advance for allowing me to conduct this study. Your permission is valuable and highly appreciated. For more information please contact me on 079 76 138 84.

Yours Faithfully,

Mayamiko Khomba (MSc Nursing Student)

Date_____

APPENDIX G

Faculty of Health Sciences
Medical School, 7 York Road, Parktown, 2193
Fax: (011) 717-2119
Tel: (011) 717-2076

Reference: Ms Salamina Segole
E-mail: salamina.segole@wits.ac.za
04 September 2012
Person No: 563960
PAG

Mrs MM Khomba
University of the Witwatersrand
Faculty of Health Sciences
No 7 York Road
Parktown
2193
South Africa

Dear Mrs Khomba

Master of Science in Nursing: Approval of Title

We have pleasure in advising that your proposal entitled "*The experience of patients receiving haemodialysis treatment in an open setting environment at academic hospital in Johannesburg*" has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX H

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Ms Mayamiko M Khomba

CLEARANCE CERTIFICATE	**M120410**
PROJECT	The Experiences of Patients Receiving Haemodialysis Treatment in an Open Setting Environment at an Academic Hospital in Johannesburg
INVESTIGATORS	Ms Mayamiko M Khomba.
DEPARTMENT	Department of Nursing Education
DATE CONSIDERED	04/05/2012
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 04/05/2012 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Dr Adele Tjale

DECLARATION OF INVESTIGATOR(S)
To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

APPENDIX I

CONDITIONS OF APPROVAL OF A RESEARCH STUDY PROPOSAL

GAUTENG PROVINCE
REPUBLIC OF SOUTH AFRICA

POLICY, PLANNING AND RESEARCH (PPR)
Enquiries: Dr B Ikalafeng
Tel: +2711 355 3500
Fax: +2711 355 3675 Email:bridget.ikalafeng@gauteng.gov.za

CONTACT DETAILS OF THE RESEARCHER	
Date	01 August 2012
Contact number	N/A
Email	N/A
Researcher /Principal investigator (PI)	Ms Mayamiko Khomba
Supervisor	Dr Adele Tjale
Institution	Department of Nursing Education
Research title	The experiences of patients receiving haemodialysis treatment in an open setting environment at an academic hospital in Johannesburg

This approval is granted only for a research proposal submitted to GDH by Ms Mayamiko Khomba entitled "The experiences of patients receiving haemodialysis treatment in an open setting environment at an academic hospital in Johannesburg."

Approval is hereby granted by the Gauteng Department of Health for the above mentioned research study proposal for a study to be conducted within GDH domain. Approval is limited to compliance with the following terms and conditions:

1. All principles and South African regulations pertaining to ethics of research are observed and adhered to by all involved in the research project. Ethics approval is only acceptable if it has been provided by a South African research ethics committee which is accredited by the National Health Research Ethics Council (NHREC) of South Africa; this is regardless of whether ethics approval has been granted elsewhere.

   Of key importance for all researchers is that they abide by of all research ethics principles and practice relating to human subjects as contained in the Declaration of Helsinki (1964, amended in 1983) and the constitution of the Republic of South Africa in its entirety. Declaration of Helsinki upholds the following principles when conducting research, respect for:
   - Human dignity;
   - Autonomy;
   - Informed consent;
   - Vulnerable persons;
   - Confidentiality;
   - Lack of harm;
   - Maximum benefit;
   - and justice

2. The GDH is indemnified from any form of liability arising from or as a consequence of the process or outcomes of any research approved by HOD and conducted within the GDH domain;
3. Researchers commit to providing the GDH with periodic progress and a final report; short term projects are expected to submit progress reports on a more frequent basis and all reports must be submitted to the Director: Policy, Planning and Research of the GDH;
4. The Principal Investigator shall promptly inform the above mentioned office of changes of contact details or physical address of the researching individual, organisation or team;
5. The Principal Investigator shall inform the above office and make arrangements to discuss their findings with GDH prior to dissemination;
6. The Principal Investigator shall promptly inform the above mentioned office of any adverse situation which may be a health hazard to any of the participants;
7. The Principal Investigator shall request in writing authorization by the HOD via PPR for any intended changes of any form to the original and approved research proposal;
8. If for any reason the research is discontinued, the Principal Investigator must inform the above mentioned office of the reasons for such discontinuation;
9. A formal research report upon completion should be submitted to the Director: Policy, Planning and Research of the GDH with recommendations and implications for GDH, the Directorate will make this report available for the HOD.

This approval is granted only for a research proposal submitted to GDH by Ms Mayamiko Khomba entitled "The experiences of patients receiving haemodialysis treatment in an open setting environment at an academic hospital in Johannesburg."

AGREEMENT BETWEEN THE GAUTENG DEPARTMENT OF HEALTH (GDH) AND THE RESEARCHER

Sue le Roux
Director: Policy Planning & Research

Date: 2/08/2012

Signature:

Name and surname of Principal Researcher

Research/Academic Institution

Date: 25.09.2012

Signature:

3

This approval is granted only for a research proposal submitted to GDH by Ms Mayamiko Khomba entitled "The experiences of patients receiving haemodialysis treatment in an open setting environment at an academic hospital in Johannesburg."

APPENDIX J

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Office of the CEO
Enquiries:
Ms. L. Mngomezulu
(011): 488-3793
(011) 488-3753
27th September 2012

Ms. Mayamiko Khomba
Department of Nursing Education
University of Witwatersrand

Dear Ms. Khomba

RE: "The experience of patients receiving Haemodialysis treatment in an open setting environment at an Academic Hospital in Johannesburg"

Permission is granted for you to conduct the above research as described in your request provided:

1. Charlotte Maxeke Johannesburg Academic hospital will not in anyway incur or inherit costs as a result of the said study.
2. Your study shall not disrupt services at the study sites.
3. Strict confidentiality shall be observed at all times.
4. Informed consent shall be solicited from patients participating in your study.

Please liaise with the Head of Department and Unit Manager or Sister in Charge to agree on the dates and time that would suit all parties.
Kindly forward this office with the results of your study on completion of the research.
Yours sincerely

Dr. T.E. Selebano
Chief Executive Officer

APPENDIX K



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL (CMJAH)

Division of Nephrology

8 October 2012
Ms Mayamiko Khomba
Dept of Nursing Education
University of the Witwatersrand

Dear Ms Khomba
Re: MSc research project "The experience of patients receiving haemodialysis in an open setting environment at an academic hospital in Johannesburg"
Approval is granted for you to conduct the study at the chronic haemodialysis unit at Charlotte Maxeke Johannesburg Academic Hospital, provided:

1. Informed consent is obtained from the participants
2. Strict confidentiality is observed
3. Your study shall not disrupt clinical services in any way

Please liase with the Unit Manager and Sister in Charge to arrange suitable times for your study.
Kindly forward us with the results of your study on completion.
Wishing you every success with your project

Yours sincerely

Professor S Naicker
Head, Division of Nephrology

APPENDIX L

TABLE 3.1 Participants characteristics

Participant Code	Race	Gender	Age Range	Period on HD (in Years)
11	WHITE	MALE	41-55	Above 2 years
12	INDIAN	FEMALE	56-70	Above 2 years
13	BLACK	FEMALE	18-25	Above 2 years
14	BLACK	FEMALE	41-55	Above 2 years
15	BLACK	FEMALE	26-40	1-2years
16	BLACK	MALE	18-25	Above 2 years
1	BLACK	MALE	56-70	Above 2 years
2	WHITE	FEMALE	56-70	Above 2 years
3	BLACK	FEMALE	56-70	Above 2 years
4	BLACK	FEMALE	26-40	1-2years
5	BLACK	MALE	56-70	Above 2 years
6	BLACK	FEMALE	41-55	Above 2 years
7	BLACK	MALE	26-40	Above 2 years
8	BLACK	MALE	41-55	Above 2 years
9	WHITE	MALE	26-40	Above 2 years

APPENDIX M

Transcript for P11

R: *Good morning, how are you feeling today?*

P: I am alright (mentions the researcher's name) and how are you..... I hope we will keep time because I'm getting on the machine at 11am.

R: (*Explains about the study, issues of confidentiality, ethical issues as stipulated in the proposal, duration of the interview-approximately one hour*)

R: ..... *What are your experiences with regard to receiving HD treatment in an open setting dialysis environment?*

P: Ah, aah I have been on HD for a long time and I am happy with it. I don't see any problem with the open setting environment. It doesn't matter to be in an open setting environment. Every day is different, we sit in different chairs every day, every session is different, and we see different people. It doesn't make any difference to me. I have been on dialysis for 23 years. It is like a family, we have to do it three times a week, we do the same thing, and I don't have to be in a separate thing (place).

R: *Could you please elaborate on that?*

P: Sitting in an open ward setting it's like working with people. I have to adapt to it. I don't find it difficult; I find it very easy to do it in an open setting environment. It is a normal thing to me. May be some patients find it difficult, I don't know? It does not affect me in a negative way. It helps me in a positive way if I am in an open setting environment. I am well experienced and I can speak to other patients. I am probably the most experienced patient in this ward; I can speak to other patients.

R: *Could you please tell me more about your positive experiences of the open setting?*

Positive way means I can help other patients in that setting. I can see the nurses, sisters and if there is a problem on the machine and there are no nurses we can help each other. Thus why I think in an open setting environment it's a very good thing, mmmh. Had it been it was in a closed environment, you wouldn't be observed, you can't be seen. I see it as a positive. We don't have problems with it, if there are problems we sort them out. They are no secrets in this open environment. So it is positive, it's a good thing. Aah ah I don't know. May be other patients may feel in a different way.

R: *The current practice is that male and female patients receive HD treatment together, how do you feel about that?*

P: Look uuh! For a male patient it's a bit easier. I don't have problems with it but for the female patients. If it is the perm catheters we have dividers (curtains), portable dividers (screen) that close the area. So I think you have to ask more to female. A male don't have problems. Male patients have no problems with combination of male and female. For female patients they need to look for more privacy for certain procedures but I have nothing against it. Being exposed with perm catheter, I don't have problems with that.

R: *Emotionally, how do you feel being together in an open setting environment?*

P: I am fine, like I said to you before, you see everything, I am very acceptable, it is easier, and its good and emotionally it is a positive thing. Emotionally, I can speak to other people; interact very well with other people. I find it important for me to be in an open setting environment.

R: *What about spiritually?*

P: I am not in the religious setting but I am positive about that, you know some people are very religious but I have no problems if they sing, pray, praise in the morning, to me it doesn't mean anything but I have no problems with that. I am not part of the religious beliefs but I accept everybody religion and if they pray, they do other things, I don't have problems. If you agree you agree and if you disagree you disagree. I have my own beliefs.

It is a good thing for those patients; it helps them, because it's good to discuss things with dialysis, that's my opinion.

R: *What about socially?*

P: Visitors are not allowed, so this is ok. We get very well to each other in the ward and I have good rapport with people coming in the ward. As for me, I have never had a fight with anyone in the ward, no arguments. Sometimes if disagreements with sisters on a certain treatment, it's normal it happens but with patients I have never had those social experiences (silencing). Socially it is just ok, we chat, talk to each other so it is really a positive experience.

R: *Physically, how does that affect you in an open setting environment?*

P: What happens with dialysis you have to understand first, like for me I have been through many operations, procedures and what other people are experiencing for the first time, I have been through, and I understand. First time it's a problem to experience that. So I take time to speak to them, explain to them. To be on the machine for 4 hours it's not easy, we have a lot of problems, you experience a lot, you see people dying, you see your friends dying, it's (HD) a very different procedure ah! Ah... It's a long term thing every three times a week we see each other, everybody does so uuh! It becomes part of your family.

R: *How do you react to that?*

P: I am fine, I am used to it, seeing, observing complications. So you know I adapt to every new situation. I am fine with it, because I adapt to it. Not many people in the world have been on the HD machine for 23 years, thus why I have been on the machine for 23 years. So in certain things I am unique. There are a few of us, to be on the machine for long time for 23 years, you need to be positive on the machine and sometimes I am a good example for other patients, which also is a good thing.

They see me I have been through a lot of things and I come out (successfully go through) because I am positive so it's also a good thing for other patients when they see me. So it really helps them not to see dialysis as a negative thing. So that's why I say in an open setting environment its a good thing because

you also see other patients again as an example the way they see me. We all learn from each other's problems.

Mmmh, when you see people going through a lot of things, going through problems, getting sick and later becoming better, therefore, it helps you, ya. People go through major operations and ..... still surviving. When they stop getting better, shame.

R: *Could you please give more examples about that?*

P: Ya! I have been through every problem that you can get through dialysis, I have been through. I have been major surgeries, 2 transplants, 2 hip replacements, fistulas, these other things I have been through a lot of things. Not many people go through what has been to me. So I am unique. And a lot of things have been done on me to help others in the future; my body is used to dialysis. New doctors and surgeons have done new procedures on me so I believe my body has been put here (Academic hospital environment) for that purpose. May be its God who has done this to be like this, so that's why I think I am unique.

I survive because I see the open setting environment. Again this is a teaching hospital and our treatment is good, we also put this in the hands of the sisters. Being in an academic hospital, we have been through many experiences, people they needle us for the first time and people don't see that, ah, but us (patients) we do. Sisters can't see that because you are on the other side and we (patients) see things on the other side. So it is quite frightening for other patients to see somebody needles and something goes wrong because I see. If nurses are needling in a wrong way, honestly it is stressful.

If some patients are sitting on the other side and you are there, and sisters needles wrongly and something goes wrong, you see it, so all patients live in a very stressful situation. You know you have a lot of stress you learn from other patients; you learn to overcome the stresses. It may hurt you. In an open ward setting people are always there to help, thus why in an open setting environment its better.

R: *So how do you feel in those situations, being in open environment?*

P: Needling wrongly, you all feel anxious. Because sometimes you have new sisters and staff who are inexperienced, sometimes they don't understand and sometimes they don't listen to the patient. When patients see technically that staff has a procedure done in a wrong way like needling, it stresses all the patients, it stresses everyone; we all live together.

But! On the other hand, it depends on your attitude, like my attitude, I am willing to help, I don't mind if somebody comes to needle me for the first time, as long as a senior person is there, there is no problem, I accept that. Patients understand that these are new staff and somebody has to start something. We are in an academic hospital; it is ok provided there is a senior person. So we accept it, I do, I accept and understand why am at this hospital. I have only been in academic hospital. I am glad about that.

R: *You talked about feeling stressed....., what can the nurses do to improve the situation?*

P: Relating to stress in a dialysis environment, ah, ah ... I think dialysis as a treatment, unless you have your own like home dialysis, it's a bit different, obviously you gonna be stressed. If something happens on the machine, everybody sees it, this cause everyone to be stressed, if someone is sick everybody is stressed. But there is nothing much you can do about it. So that is part of culture of dialysis, it's not on play ground. Dialysis is not a children's game, it's tough. People don't really know, but we have to survive. It's like we go to war, we want to survive, it's not fun, and we don't love coming here. When we are in the situation, we have to take the situation, we have to make the best of it, and otherwise you will not survive.

I have seen people dying because they can't adapt to the situation, the stress, they can't accept it. If you accept it then you gonna make the best you can. Make the environment the easiest and the best you can, build good attitude. In other words you have to have a good attitude. Look, sometimes I also get upset, sometimes am in bad mood, something has gone wrong, may be traffic problems, so I come in the ward, it's not always easy for me, I have to try and make myself ok.

But if you project a negative attitude then you project a negative thing to watch and negative things happen. It's to do with attitude. Like for our patients they are one to two patients that have got attitudes but overall everybody does the best they can.

It doesn't matter which culture you come from, dialysis is dialysis, perm catheter is perm catheter, fistula is fistula, khosa, Indian, zulu, white, coloured, it doesn't matter, treatment is the same.

There is no discrimination and really this should not be practiced, we don't expect. No favouritism, we all know, we don't expect because we are from different cultures. That's it. It is quite unique in an open setting environment regardless of different backgrounds, different values, gender, whatever, religious, we all come together, people come and meet together three times a week and we all live together. It is quite unique. People quite often don't come together like we do and meet.

R: *In your opinion, what would you recommend for improvement?*

P: You see, mmmuh! ... I don't know it's really difficult. You wonder what really can.....but we are just used as it is. Aaa mmmh, it's hard to say what you can improve. You know.....dialysis; it's quite a difficult thing. Eeh eeh uh (long silence) you know, they could be more interaction in certain things, may be if we introduce the kind of things into dialysis. More interactive is needed and educating more. I think they should be more of a social worker environment, more social worker interactive.

I don't think we are given enough chance to express ourselves more about our social problems because no social workers are available in the dialysis unit. Dialysis brings a lot of problems; it affects our dignity and how to handle social problems. I think they should be social interaction; someone who is professional and psychologically help patients more. That's what I believe, should be done more. More psychological support is required through interactions. And also from a medical side uh! Communication between medical side and patient side there is a little bit of a gap in terms of your possibilities e.g. getting transplant, how to improve your dialysis.

There is a communication gap between medical side and patients. Being an academic environment, we expect to be more of academia. There should be more involvement of a social worker, doctors, and

psychologists to be more involved with the patients. You understand what I mean? There is a gap in this area and it should be used more academically for patients. I have been here 23 years getting treatment and doctors used to interact with patients on dialysis and see the patients more previously every dialysis session and see the patients but now we see doctors may be after 2 months. When we see them, if we got real the big problem; I don't think this is right. If that problem could have been sorted out before, it requires doctors to see us more often.

So in an open setting environment doctors come around to see the patients and so many different patients have different problems, not all patients are the same, thus why social workers should come in to assist.

I have been here for many years and ever since I have not seen any social worker coming in to assist, talk to the patients. I think they should come in at least once a month to assist patients asking how they are doing.

Patients are willing to talk to them but can't see them. It's like your study is good for patients too. So I think there is a gap. There is a gap in educating the patients so that patients can also cope with the dialysis setting..... This is an academic hospital, so it is important for patients to be seen. Each patient is different and their opinions are different. Myself I am happy with the open setting, but it might be different with the other patients.

R: *Is there anything else to say, add?*

P: My opinion regarding open setting might be different from others. Myself I have had 2 transplants, 23 years on dialysis and my opinions might be different from the time, I started dialysis so this can happen to other patients, and they might say their opinions.

R: *Can we say the experience of the open setting environment differs because of the period on HD?*

P: To me it has been always the same, no difference in experiencing the open setting with reference to period on dialysis because I am a very communicative person, I try to make it easy, some (patients) are so quiet, but myself its part of my adapting, my coping, I feel so. I am so open, so to me it's the same, its normal.

R: *Can I just reflect on what we have discussed may be you have comments*

R: We have discussed that you feel happy about the open setting, despite stressful situations, you take it in a positive way, (P: uuh) *as patients you interact together* (P: mmh muh) *and that contributes to your well-being....*

P: Ya! Sure, also it does, it's like we are in a boat, we are in the same boat, and if you want to survive you have to carry on and be part of the each other. And for nurses we are paddling together. If you take

it in a negative way, you can't survive. You can't be just negative because if you become negative, you don't survive here and it's not easy sometimes it's very difficult.

Like we say in an open setting environment you see other patients really very sick, you see a lot and you don't feel you are a lot in yourself, you experience a lot by seeing others. People go through a hard time. If it was like you just come on the machine and go home uh,... Eeh shih! But it's not like that. You go through a lot you can even call them side effects.

Dialysis brings side effects, it's not doubt, there is no doubt, you see fistulas that fails, perm catheters not working, there are so many things that we see.

It's quite stressful and frustrating especially to new patients because in open ward environment you see everything. Like myself, I can tell when people are in trouble, I can tell that this patient will complicate and this patient will die, that this patient is passing away.

R: *How can you tell that?*

P: Because I can see how they look. Because when you sit on the machine you observe and see other patient's condition, I can tell somebody is in trouble. Being here for a quite long time, I can tell that something is not right because I have been on dialysis for a long time. I can tell, I can tell (silencing) and that's quite scaring because I don't love that. However, there is nothing that you can really do about it, you know... (- *silence*).

R: *What can nurses do about that?*

P: That's why I say to you, the social worker, should come in, psychologist to help. It requires a professional to do it. From my experience this being an academic hospital professional should help more, speak to patients, just to help, sometimes patients feel reserved, they don't want to express themselves. So they keep in too much, but that is not good for your healthy, and for your own dignity. I express myself while others can't.

Myself I have gone to the psychologist alone while others can't do that. They (psychologist) help a lot. But it's not the same if psychologists can be coming to the ward themselves and talk to patients. The sisters may be available but may not have that kind of expertise so we can't expect them to do it. So they should be professional health workers to advise because sisters here they don't have that kind of time and may be they don't study this so we can't expect them to do this.

R: *How can we improve this?*

P: The in-charge of the ward should speak to the social workers, psychologists about this need and say to them. *Psychologists can come in and will look at a different angle*. They should make it more of a happy environment; uplift the patients a little bit more. *We are a family*, they should make the ward happier. Not just sit on the machine, they should introduce some kind of games, you know we spent so much time together. They can organize speeches from patients or staff because we just sit on the machine; to make it more happy. Why not make it look more happy? *Life is not easy all the time*. Let

the patients bring suggestions how to create a happier dialysis environment. *Nurses should talk to the patients how to make the ward more happy*, what they want.

Can start exercises, previous we used to do it 15 years ago. They were brought by physiotherapists and we could do two to three minutes while on the machine and we could feel better, something like cycling, put on legs. But it did not last long. The physiotherapist lost interest. To help the open setting environment, people can think about that. *Interaction between patients helps a lot*. We have a lot of time. Other patients sleep while on the machine, they feel tired, they have been in the taxi, so I can't love music. But television is ok though myself I am not interested in it, I don't watch here, I watch at home, but doesn't worry me. Loud music is disturbing because we have different preferences so music might not be a good idea because other patients like to sleep while on the machine.

But doesn't worry me I'm used to it, you adapt. What worries me is if they put on music. TV is ok. But if you want your own music put on head phones because one time we had problems with that (music). That's that.

R: *Thank you very much, I really appreciate*

P: It's a pleasure

R: *Reflective summary of the interview*

Positive experiences: happy with open setting environment, it's like a family, take it in a positive way, help them to cope, nurses are available, able to observe each other, patients able to help each other, living by examples, it's like working in an office, togetherness, learning from other patient experiences, sees everyone, no secrets, people interact, patient willing to help, you learn to overcome stresses, find it easy, its good, fine, it's quite unique, experiences a lot in seeing others, patients paddles together with nurses, building a positive attitude towards open setting, it's like going to war- they have to survive, it's like in a boat- they have to survive hence the need for togetherness, open setting is normal.

Negative experiences: scaring, seeing friends dying, stressful, frustrating, tough, sees wrong techniques of needling, seeing complications, it's not fun, other patients die because can't adapt to stressful situations, it's not a play ground, it's not children's game, sickness is part of dialysis environment, don't love experiencing one in trouble; no-one really can do, observes fistulas and perm catheters not working, hard time, sees very sick patients, communication gaps, inadequate time for patients to express themselves, can't see doctors, social workers, become anxious, other patients feel reserved, can't speak, patients look on things at a different angle while nurses sees on the other angle.

Opinions: the need for a social worker, psychologists, education to patients, creating happier environment through introduction of games, health promoting messages inform of speech, exercises, patients to give suggestions, more interaction needed, more senior person to be present when needling by inexperienced staff, good rapport, patients to clearly understand about HD, the need for discussion about dialysis with other patients, accept each other.

Transcript for P14

R: *Welcome and good morning. How are you feeling today?*

P: I am fine and you. How are your studies? .....

R: ....*What are your experiences with regard to receiving HD treatment in an open setting dialysis environment?*

P: Mmmh, from my experience, the open setting generally is fine. Of course there are part of good and bad of it. It is good when we are together mmh. You know, when somebody is not feeling ok, you can call the sisters. When you see somebody dialyzing especially for the first time or you are a new patient in that ward (Chronic Renal Dialysis Unit) it is good because you don't feel that I am alone. So you actually see that they are many people with this renal disease, that's the good part of it.

However, myself I feel we should at least have male and female wards separately because if we are together, male and female patients together, it is not nice especially for a woman to pull the skirts thus why we try to put on trousers because we are afraid of male patients to see us. Sometimes you see a man just pulling his trouser and yet there is a woman there but he is just doing it, even if you look aside, you see there is another man still doing the same things. I think we need to respect each other. Sometimes you feel faint or you can't control yourself, so it could be good if the authorities can give us separate wards for male and female patients.

But the open setting ward is good because you don't feel to be alone. Sometimes the sisters move just a little bit and in those few minutes, you can be attacked (have a complication) and if others are near can assist you. So it is good to be in an open environment. Since every minute something can happen.

R: *When you say you can't control yourself… could you please elaborate on that?*

P: I mean clothes! Sometimes clothes can be pulled off and become naked and you can be seen by males, so it's embarrassing. But if you are all females there is no problem, you can't even feel ashamed.

Even if you use curtains but if the next patient to you is a man you still feel ashamed because the male patient will still see you because two patients use one curtain. So it doesn't make sense to use the curtains. Sometimes it's a male and a female put together (closed together in curtains), I feel they should be female and male wards separately.

R: *You talked about you don't feel to be alone; could you please elaborate on that?*

P: You see when somebody crashes on the machine and you have never experienced this, and now you see somebody crashing in the ward, you know these things happen. You understand much better about dialysis but if you are alone and you will not know and you can't know what to do. In the open setting you call the sisters, we do shout for help to get their attention.

R: Y*ou mean your feelings and opinions with regard to open setting environment….*

P: I mean the open setting environment its fine; it is fine with me, fine. But only for the things I have elaborated that there should be female and male wards. Otherwise the open set up is ok.

R: *Could you please talk more about your psychological experiences in an open setting environment?*

P: Psychologically it's good to be in an open ward, we discuss, we have some conversations among patients, you know. Some of the topics that we discuss help us that you don't have stress because you communicate with others, whatever you feel. Other patients will tell you about their experiences and you tell also about your experiences, you know! So it helps.

You don't stress, I feel you don't stress when you are in an open setting environment unlike when you are alone. When you don't have somebody to talk too, somebody to discuss things with or ask another patient because sometimes you feel like asking another patient about what you feel, and how they feel, their experiences because we are not with the sisters all the time.

R: *Anything else?*

P: Uh! I feel that uh….. that summarizes it.

R: *HD as a life maintaining treatment, how does it make you feel emotionally with all people around you?*

P: Emotionally I feel ok because I have realized that I am not the only one. Anybody can have this disease and you are hoping for a transplant. I can discuss some of the things with my fellow patients' things that sometimes I can't discuss with my family. The family do not understand but my friends here in Chronic Renal Unit understands even if I (- *short silence*) …you know they are days when you are up and down and when you are down they understand you but the family don't understand you.

May be you come off the dialysis machine and you are weak, tired, somebody cannot understand, and at home may think you are lazy, you don't want to do things, may be you don't want to cook but when you tell other patients (HD patients) they do understand because they feel it, you know! So I think its fine when you are together because at the beginning when you start dialysis, like myself I didn't know that I will stay such a long time. I thought maybe I will dialyze may be for two or three weeks then I will be fine, and I will go home. So all these things, I got the information from other patients that you know you will be here until you get a kidney transplant. I didn't know about that, I thought it is just a treatment that I'm going through at that particular time and I will be back home so yoo! Its like that.

R: *How does that affect you?*

P: Family doesn't know, especially this kidney disease. The awareness part of it, people are not aware about this disease. It's unlike other diseases like cancer and AIDS. Like AIDS even a small child knows about it because it's on the TV, on the news but this kidney disease awareness is not enough. Even when it comes to kidney donation, people including our families are not aware because they don't know what will happen if they donate their kidney. They don't know whether a person can live

with one kidney so thus why I say the awareness part of it, if we can educate people out there especially our families they are not educated. If there can be a day to bring our families and educate them. We hadn't had that chance to come together with our families and discuss about our condition.

R: *What about culturally, how easy do you find that in an open setting environment?*

P: I can say I'm better now because I am a Christian now, because with African cultures there are a lot of things, they will tell you don't involve yourself with other patients they will give you the disease, illness, you know the African culture! But I am a Christian and my family is a Christian, so I am not bothered about the open setting environment. I think its fine; I think it's on the advantage again.

R: *What do you mean by that?*

P: I have obtained so much information from other patients. They are things I didn't know about dialysis but I got information from other patients so thus why I say it was an advantage for me to be in an open ward uuh! Mmh…in order to discuss with other patients Because there was nobody to give me enough information even the doctors they don't give you more information you know! So when you discuss with other patients, some are 10 years, 20 years on dialysis…. so they have got more experience so they will tell you this and that. You know! So you get more information … (pause).

Sometimes we discuss those things we believe in such as traditional medicine that they can heal you but as a renal patient, I know that I must not take those herbs. And to make that decision is through other patients when you get that information. There are some cultures they will tell you that if you want to be ok you can take this 'muti', but if you discuss with patients here who have been more than 10 years on dialysis they will tell you their experiences that "I have done that and the results were like this". So as a new patient you take that information and use what you feel is good for you. But anyway I am a Christian, I don't believe in cultures (laughing).

As patients we discuss that you are not supposed to do this, not to take muti and others, we discuss this sometimes while we are on the machine, receiving treatment. And other patients they come to realize this is wrong and this right. They realize that they are doing wrong things, so it's good to discuss uuh! During those 4 hours we discuss so many things mmh.

R: *What about spiritually?*

P: Spiritually, ya, I know one day I will be healed (laughing) they are miracles you know (laughing) I'm going to be healed, I will be healed. Because when Jesus was here he healed so many illnesses so why not now uuu! mmmh because he has done it already, he can do it again. I've got that belief that one day I will be out of the machine, uh! I will (laughing). That's something keeps me going that ah! I believe I will be healed and I believe that when I get transplant it will be God that has supplied it to me so it won't reject, it will just go well, because it will be coming from God whether it is a transplant or miracle happening in my body ya! I will be fine. So one day I will not be on the machine. I know one day he (God) will do it.

R: *How do you feel spiritually in an open setting environment?*

It's good because they are some people who don't believe in God, but sometimes we discuss the importance of believing in God. They are some people who are strongly rooted in their culture and they don't know about God or Jesus, so when we discuss there we try and encourage each other and pray and believe ummmhu! So I think it's good because the word of God is going mmh. We share the word of God. Unlike when you are alone, you can read the bible, but you cannot share it with somebody eeh (laughing).

Sometimes it's difficult because when we start discussing about our beliefs and religion you know! We tend to debate, and I don't like debate, when it comes to debate, we try and change subject matter because you cannot debate on those things because each and everyone has got his or her own beliefs, we've got to respect that. We come to an understanding that we can only discuss about the bible, what this verse says and try not to discuss about religion itself. Because if we discuss about religion it won't be alright because we are of different religions but the common denominator is that we all believe in God and Jesus eeh, you see! Those are sensitive discussions we try and avoid, depending with the situation.

R: *In your experience, what can nurses do to improve this?*

Yes! There are things, because some people are new patients and they say I must not stay on the machine my religion does not allow to dialyze I would rather die home but at least with chronic patients they know. They are some religions like that, so when you find a patient like that you try and discuss at length that God has provided this machine for us to live, God has provided the sisters, nurses, doctors to help us, he has given the knowledge to scientists who they came up with this machine through God, so you can't say no, I will not dialyze because it's not my culture. Some people are changed that way so they discover the importance of dialysis if we are together. So if we discuss a lot, some patients are changed because some patients they don't know. Not that we know everything but through discussion we get to know and understand. Ok, ok!

R: *What about socially?*

P: We try and socialize (laughing) we really and try to socialize. We discuss things with our shift. We try and put some money so that we can have some Christmas parties. We discuss things with our shift about these parties and contributions. Since I have been here these past four years we have been doing this. May be we contribute R10 a month and if we see we have much money to buy things then we do it. And if one of our members passes away, it's very sad you know! We also contribute something, and we support each other when somebody is sick, encourage each other, visit each other if is admitted.

R: *What about family involvement in a dialysis unit?*

P: About our families visiting, they don't usually visit but sometimes, you know. But it differs like husband and wife because some say I will bring my wife everyday to the hospital and take her home, so that time is always there for families to go in and out. For me I think that's nice because you don't get stressed because you know there is somebody who is supporting you ya! Then …….. for some you don't have anybody who can visit you, you don't have even a child or not even a relative, not even one

to visit you. You are always alone so I feel you know! Sometimes it's not fair as you see others get visitors all the time and you start thinking my relatives they don't like me because I am sick, you see this one is always having visitors, they are always bringing something to eat, you know, it's like that.

R: *How does that affect you?*

P: Because if you take it (silence) eeh, like I have said that you feel your family doesn't love you more because you see somebody relatives coming in, they check on you, that are you alright, bring you food but for you, you don't have somebody so it stresses you now. So sometimes we discuss that even if you are just alone don't say you are alone because sometimes our families, they really don't have the time, may be they don't have transport, may be they are at work and when they at work, they are doing thing to try and support you. Don't take it in a negative way.

Sometimes you feel that need to have someone to assist you to go in the bus, especially if you are not feeling alright. But as patients we encourage each other, we assist and help each other if we see there is nobody who is coming we help each other. Of course, sometimes you feel it's too much; they are people who do it extra eeh! What can I say, you visit today, tomorrow, and everyday you are always visiting. The one visiting should limit the number of visits because patients are not the same, we are from different backgrounds. You should think about other patients, how they feel. Because they don't have somebody who can visit them, somebody who can care for them, you know! You have to control yourself.

R: *What about physical experiences in an open setting environment?*

P: Yes! Sometimes you become scared, uh! You become scared that one day it will be me who will become like that because anything can happen with HD. You see a patient going in the machine is fine, is ok and all over a sudden the patient start crying that my chest is so painful and its critical, you know! So you become scared yoo! … So you feel one day I will feel like that. So sometimes (laughing) you see you become scared. Sometimes somebody comes overloaded, can't breathe, such situations make you become scared because you know we are in the same train, that one day I will be like that. But sometimes when you see one overload, you also try and control yourself. You reduce your fluids, because you have seen somebody complicating or may be dying and doctors have been running around and you became scared. So it makes you strong again because you know what to do and what not to do. Ya! .... Because of seeing that patient, yes! I think so!

R: *Can you give more examples about that?*

P: Like I have said incase of overloading you know I don't breathe and I can even die, so you try and control yourself that I must not drink too much. And when you see somebody drinking a full bottle like that you tell him don't finish that bottle, you remind each other the limits how much to take in a day.

So like this patient came in overloaded, he couldn't breathe, and unfortunately when he came all the machines were occupied and he couldn't get the machine and at that moment when he needed the machine, he couldn't breathe, and he couldn't get the machine, so you can imagine how it was. Even if they (nurses) try to put oxygen on you it doesn't help because you need to remove that fluid and it's only the machine that can remove that fluid and it's only the machine that can remove that, you see!

So that taught me a lot that though I am going on the HD machine but I should not drink too much. Because when you reach hospital and there is somebody already on the machine who is also critical and you don't have the machine that particular day and you have told yourself I am going on the machine let me drink, what will happen if you don't dialyze that time? So every day you must look after yourself because I have seen somebody. I have seen people dying with that so yo!

That's why I say in an open setting environment is better because you learn a lot. Uh uh!

R: *What in your opinion, would you recommend for improvement?*

P: Ya! I think in situations like I was telling about critical situation, doctors and others must try to remove that patient from others because we don't have the strong hearts, we are not the same, some come when you are already panicking, they (staff) don't understand what I'm going through with that illness so they should remove that patient as quickly as possible from others and isolate. But because there are no isolation rooms what they do is just to assist that patient while everybody is watching, whether that patient will make it or not. We see every stage so sometimes when you go home you feel you are not alright you feel that yoo, there are things that happen like that (silence) so you become scared.

But I think the hospital can have one isolation ward within the chronic ward just for such situations eeh. Just another room for these patients so that when a patient is critical can just go into that room to dialyze separately. Because as it is now there is nothing, patients just dialyze while in that situation.

So sometimes it becomes too much for us patients seeing all those situations. Like somebody is overloaded like I have said, is not breathing, and may be passes away so I feel may be they should do something about that. Because even if they close the curtains but there is another patient near who sees so it's still the same. There is really nothing they could do unless if we could get a small ward, I think so.

R: *Is there anything else?*

P: You know like I have said, you have to pull out your skirt to be dialyzed and next to you is a male, you know you don't really feel free. You know you really feel if sisters can connect me quickly if it is on the breast you remove your top and your breasts are out and it's just open and there is a man here and there is a man there, you know, you can't control the situation. Thus why I say I feel there should be a female and a male ward separately. Because now you see a man just pulling his trouser and yet there is a woman there but he is just doing it, even if you (turning aside) look aside, you see there is another man there. They still do the same things so I feel that's not nice, I think we need to respect each other because in this mixed environment you can't, there is no respect. So I would recommend separate wards a male ward and a female ward.

R: *Let's reflect on what we have discussed?*

R: We have discussed that the open setting environment is fine with you. Your positive experiences of the open setting environment are:- patients are able to discuss with staff and other patients. You talk, share experiences, discuss things, teach and learn from each other.

New patients learn from experienced patients. You make jokes, laugh and you chat. You advise each other on what is best for a renal patient. However, you would have loved to be dialyzing in separate HD units- male and female patients to be dialyzing in separate wards (P: Yes, mmh …. mmh). Your experiences of being treated together in the same curtains you feel brings discomfort especially when you want to expose access sites. Again, you have this sense when you watch dialysis complications or a patient is critically ill. We have discussed that this brings sad and you just feel like its you and just felt like someone is dying. Hence your suggestions to improve the dialysis environment, you have said each patient should be treated in your own curtains, need more education about dialysis and other treatment options. We have talked about family members to be given adequate information about ESRD including treatment options such as transplant. Acceptance of the situations is also very important.

Is that a true reflection of your experiences?

P14: YES, YES! That's the true reflections of my opinions.

R: Thank you very much for taking your time participating in this study. I want to assure you that confidentiality will be maintained and your name will not appear anywhere else.

Thank you.

APPENDIX N

Researcher's Observational, Theoretical, Methodological and Personal notes

Observational notes are the observer's in-depth descriptions about events and conversations experienced in naturalistic settings (Polit & Beck, 2012:548). The researcher reports the events that were experienced through watching and listening in the process of data collection. **Theoretical notes** are the researcher's purposeful attempts at deriving sense of what is going on (De vos, *et al*., 2005). The researcher thoughtfully describes and infers the observational notes to ultimately build a starting point for subsequent analysis. Likewise, **methodological notes** are reflections about observational strategies (Polit & Beck, 2012). The critique of one's tactics reminds about methodological approaches that might be beneficial. Finally, **personal notes** are comments about the researchers own emotions, feelings in the field.

Observational notes

All prospective participants signed the consent for audio taping. The appointments were set for either before or after dialysis for both the morning and the afternoon shift. However, the researcher observed that some willing potential participants were not recruited because they strictly wanted to be interviewed whilst connected to the HD machine (intra-dialysis) where they could be seen and heard by other patients, which in this study was not ethically acceptable for the purpose of maintaining privacy, confidentiality and anonymity. During the interviews, participants reflected also on other needs like transport problems, which they felt were crucial to be addressed. Some mentioned the dialysis lines were not user friendly and caused frequent alarming of the HD machines.

Theoretical notes

Feeling light tiredness was verbalised in some participants who were interviewed after receiving the treatment. Tiredness, across many studies, is reported common amongst patients receiving HD treatment (Axelsson, *et al*., 2012; Heiwe & Tollin, 2012; Bayhakki & Hatthakit, 2012). For patients who wanted to be interviewed whilst on treatment, it is postulated that they were rushing for work. Studies reveal that HD patients have limited time, as most of their time is spent receiving treatment. Some felt needs expressed during the interviews, such as

transport problems, were genuine but could not be further explored in this study because the focus was on the open setting environment. Therefore, feedback was given to the unit manager in general terms on those areas whilst maintaining confidentiality.

Methodological notes

A small protocol was drawn on each page where field notes of each participant were written to remind of important areas contained in the interview such as, participant code, opening statement made by each participant, probes and reflective summary. Methodologically, it was proposed that the interviews be conducted after the patient had received treatment however, appointments were dependent upon mutual agreement with the participant and so were conducted either before or after HD.

Personal notes

The interviews were quite interesting and sometimes challenging, for instance, transport problems and the use of the non-user friendly HD lines at the time of the study causing clotting and air leakages leading to frequent alarming of the HD machines. From the expressions of some participants, I could empathise with them, provide psychological support and refer them for further counselling. This was challenging because I was in the field as a researcher, as opposed to my role as a nephrology nurse. It was difficult to continue probing certain issues that were irrelevant to this study. I also felt accountable and guilty for the missed opportunities that renal nurses could take to counsel and support these patients. From the experiences in this study, I wondered why can't we, as nurses, have our own nursing counselling day for these patients?