

Coping behaviours of haemodialysed patients' families in a private clinic in Gauteng

**A dissertation in partial fulfilment of the requirements for the degree
Magister Curationis**

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November 2010

DECLARATION

I hereby solemnly declare that this dissertation presents the work carried out by myself and to the best of my knowledge does not contain any materials written by another person except where due reference is made. I declare that all the sources used or quoted in this study are acknowledged in the bibliography.

David Mphuthi

November 2010

ACKNOWLEDGEMENTS

I would like to thank the following people who stood by me during my three year journey. You were truly a source of inspiration:

- The Almighty God Father who gave me the wisdom and power to sail and jump over the storms and the hurdles of life during my studies. Thank you God for providing me with a supervisor and co-supervisor that assisted me all the way.
- Fresenius Medical Care (South Africa) management for allowing me to use their facilities for the study.
- Dr. Ronel Pretorius, my study supervisor for guidance and support during my studies.
- Professor Christa Van Der Walt, my co-supervisor for motherly advice and support.
- Professor J. Bruce, my Head of Department at the University of the Witwatersrand (WITS) for the time needed away from the office and your support.
- My lovely wife, Jeridah Mphuthi who has been my pillar of strength during my studies. Without you, this would have not been easier.
- My mother, Sarah Mphuthi for her continued motherly support.
- Mr MJM Zikalala and family for encouragement and support.
- My two children, Leoka and Mathapelo Mphuthi to whom I would like to dedicate this work.
- Mrs R Magcai for assisting with qualitative data.
- Dr. R. Crouch, for your support to post graduate students at the University of Wits.
- Dr. S. Ellis (NWU), for assistance with the quantitative data analysis.
- Dr. A. Swanson, for the language editing.
- Professor A. Greeff and Dr. D. Ind (Australia), for all the articles supplied.
- Mrs I. Janse Van Noordwyk, for translating my abstract from English to Afrikaans.
- Dr Abel Pienaar for the final Afrikaans abstract editing.

In loving memory of:

Dr John Nojaja (1947-2009).

My sister, Mrs. Rhinah Motaung (1963-2010) and uncle, Mr Liau Mphuthi (1950-2010).

ABSTRACT

[Keywords: Coping behaviour, family, haemodialysis, chronic renal failure]

INTRODUCTION AND AIM: Chronic renal failure patients are confronted with many challenges and often express feelings of being a burden to their families. Since the inception of haemodialysis in 1913, limited research has been conducted to explore the coping behaviours of the families of haemodialysed patients, especially in the South African context. The family's inability to cope with the condition and treatment, may impact on their wellness as well as that of the family member on haemodialysis. In light of the limited research available on the coping behaviours of families of haemodialysed patients, this study set out to describe the coping behaviours using the mixed method.

RESEARCH DESIGN AND METHOD: The study followed an explanatory mixed method approach with sequential design and was divided into two phases. Phase one addressed the first objective in identifying and describing the coping behaviours of the families using the Family Crisis Orientated Personal Scale (F-COPES) developed by McCubbin, Larsen and Olson. During phase two, the researcher conducted interviews to explore the coping behaviour identified in phase one.

RESULTS: The mean scores of the subscales of the F-COPES scale ranged from 3.05 to 4.16 with reliability indices found to be within the normal range. The average mean score for the subscale "seeking spiritual support" measured highest at 4.16, followed by "mobilising the family to acquire and accept help" (M=3.94). "Acquiring social support" measured lowest at 3.05. Four categories emanated from the thematic analysis of the data from the second phase namely, challenges, coordinated care, support structures and beliefs about disease.

CONCLUSION: The subscales "seeking spiritual support, mobilising the family to acquire and accept help, reframing and acquiring social support" showed concordance with the categories derived from the qualitative data analysis. Supporting evidence for "passive appraisal" as a sub-scale from the first phase and "challenges" as a category from the second phase could not be found.

OPSOMMING

[Sleutelwoorde: Hanteringsgedrag, / gesin, hemodialise, chroniese nierversaking]

INLEIDING EN DOEL: Chroniese nierversaking-pasiënte word daaglik met vele uitdagings gekonfronteer en voel dikwels dat hulle 'n las vir hulle gesinne is. Sedert die begin van hemodialise in 1913 was beperkte navorsing gedoen, veral in die Suid Afrikaanse konteks, om die hanteringsgedrag van gesinne van gehemodialiseerde pasiënte te verken. Die gesin se onvermoë om die toestand en behandeling te hanteer mag dalk bots met hul eie welstand sowel as van die pasiënt op hemodialise. Die doel van hierdie studie was om die hanteringsgedrag van gesinne met gehemodialiseerde pasiënte te beskryf deur gebruik te maak van die 'Family Crisis Orientated Personal Scale (F-COPES)' ontwikkel deur McCubbin, Larsen en Olson.

NAVORSINGSONTWERP EN METODEDE: Die studie het 'n verklarende gemengde benadering met chronologies ontwerp gevolg, wat verder in twee fase verdeel was. In die eerste fase is die hanteringsgedrag van die gesinne ge-identifiseer en beskryf deur van die 'F-COPES' vraelys gebruik te maak. Die navorser het gedurende fase twee, onderhoude gevoer om die hanteringsgedrag wat in fase een geïdentifiseer was verder te verken.

RESULTATE: Die gemiddelde telling van die 'F-COPES' sub-skale het tussen 3.05 en 4.16 gewissel. Betroubaarheid is geïllustreer met waardes wat binne normale grense geval het. Die gemiddelde telling vir die sub-skaal "seeking spiritual support" het die hoogste gemeet (4.16) gevolg deur "mobilising the family to acquire and accept help" (M=3.94). "Acquiring social support" het die laagste gemeet (M=3.05). Vier kategorieë het vanuit die tematiese ontleding van die data in die tweede fase gevloei, naamlik: "challenges, coordinated care, support structures and beliefs about disease".

GEVOLGTREKKING: Die sub-skale "seeking spiritual support, mobilising the family to acquire and accept help, reframing and acquiring social support" het ooreenstemming getoon met die kategorieë afkomstig van die kwalitatiewe data-ontleding. Ondersteunende bewyse vir "passive appraisal" as 'n sub-skaal van die eerste fase and "challenges" as 'n kategorie van die tweede fase kon nie gevind word nie.

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ACRONYMS

AIDS	Acquired immuno-deficiency syndrome
ARF	Acute renal failure
CRF	Chronic renal failure
ESRD	End stage renal disease
F-COPES	Family crisis orientated personal scale
FMC	Fresenius Medical Care
GFR	Glomerular filtration rate
HIV	Human immune virus
ICU	Intensive care unit
M	Mean
NWU	North-West University
SADTR	South African Dialysis and Transplantation Registry
SPSS	Statistical package for social science
USA	United States of America
WITS	University of the Witwatersrand

CHAPTER 1

OVERVIEW OF THE STUDY

1.1. INTRODUCTION TO THE STUDY

The focus of this study was to explore and describe the coping behaviours of the families of patients who have been diagnosed with chronic renal failure and are haemodialysed. Heiwe and Dahlgren (2004:147-154) found that patients with chronic renal failure have several physical activity impairments and that patients experienced renal failure as a limiting factor in their daily lives. Some of the contributing factors to the limiting conditions included anaemia, malnutrition, abnormal glucose and muscle metabolism, reduced quality of life and reduced psychosocial functioning. Understanding the coping behaviours of the families will guide the specialist nephrology nurse in supporting the families and improve the quality of family life. In light of the limited research and the culturally unique and context-specific environment of South Africa, this study aimed to describe the coping behaviours of the families of haemodialysed patients using the Family Crisis Orientated Personal Scale (F-Copes) developed by McCubbin, Olson and Larsen (1991), followed by a qualitative exploratory inquiry to fully understand the nature of their coping behaviours.

1.2. BACKGROUND AND RATIONALE

In 1994 the South African Dialysis and Transplant Registry (SADTR) indicated that 3399 patients were on treatment for end-stage renal failure, with 754 having started therapy in 1994 (Naicker, 2003:21-24). To date in South Africa there are no current accurate and comprehensive statistics available, however there is a general impression that renal failure is three to four times more frequent in Africa than in more developed countries (Naicker, 2003:21-24). Renal failure is a complication of diseases such as: diabetes mellitus, hypertension, kidney neoplasm as well as hereditary diseases (Levy, Morgan & Brown, 2003: 6-7).

Chronic renal failure is defined as a condition whereby the kidney loses more than 60% of its function and waste products such as urea and creatinine accumulates in the body

(Daugirdas, Blake and Ing, 2001:3-4). Smeltzer and Bare (2000:40-41) define renal failure as a condition where the kidneys are unable to excrete the body's metabolic waste resulting in a disruption in endocrine and metabolic functions leading to fluid, electrolyte and acid-base imbalances. Renal failure is divided into two phases, namely the acute phase and the chronic phase. The most common treatment for both acute and chronic phases is through a process known as haemodialysis. Haemodialysis is the procedure whereby blood of the patient is purified by means of semi-permeable membrane two or three times a week by means of a dialysis machine (Daugirdas *et al.*, 2001:15 -18).

This study focuses on the experiences of families of the haemodialysed patient, and the researcher argues that supporting families is crucial, not only for their wellness but also for that of the patient. Patients with chronic renal failure who are haemodialysed and their families face a number of problems and challenges for which they are ill prepared. It was observed that chronic renal failure patients are confronted with many challenges that include staying far from the treatment centre resulting in patients not attending their dialysis treatment regularly. In a study by Ashby (2005:389-496) participants expressed feelings of being a burden to their families, and that termination of the therapy might prove a solution for them and their families, although that choice is life threatening. Patients with renal failure often experience problems such as depression, sexual dysfunction and some attempt suicide with which they and their families have to deal with (Daugirdas *et al.*, 2001:413-418). Moreover, about two thirds of the patients do not return to work once they have been diagnosed with renal failure (Daugirdas *et al.*, 2001:416-418).

Patients with renal failure often develop bone diseases that include soft tissue decalcification and osteoporosis which can be very frustrating for the patient and family as patients will complain of pain in their long bones and joints. Moreover, these patients also develop severe electrolyte imbalances leading to acidosis because all the renal mechanisms for excreting acid and the formation of nitrogen hydroxide are impaired (Catto & Power, 1988:184). Catto and Power (1988:188) as well as Daugirdas *et al.* (2001:107-108) have indicated that patients are susceptible to viral attacks as their immune systems are weakened by acidosis and they often feel sick and weak. In addition, they also noted that

four hours after dialysis most of the patients complained of post dialysis tiredness that resulted in family members having to care for their every need.

In a study conducted in the United Kingdom, families of patients with renal failure who participated in the study had to help patients reach their treatment centres two or three times a week, and they commented on the disruptive influence the treatment had on their social life (Auer, 2002:141-144). This practice also seems to occur in South Africa as observed by the researcher. In addition, Qyinan (2005:25) recorded that families also experienced a great deal of stress and were overwhelmed by the suffering of their loved one due to a lack of information or knowledge about the condition. A study conducted by Guillement, Rolland and Roy (1988:3) in a United Kingdom hospital indicated that their departments, either in the hospital or the dialysis centre, knew very little about the coping strategies of the families of the haemodialysed patient, except for what the patients might reveal to them. For this reason little is known about the interaction between the chronic renal unit staff and the families of the haemodialysed patients and the coping strategies used by these families. However, Marriner-Tomey (1994:429) describes care as a phenomena related to assistive, supportive or enabling behaviour towards or for another individual (or group) with evident or anticipated needs in order to improve a human condition or way of life. The above statement confirms the need for support for the individual as well as the group which in this study are family members of the haemodialysed patients.

Most commonly the health care provider sees the family of the patient during an acute phase of the condition when the patient is still in hospital and has been admitted to an intensive care unit (ICU). Once the illness becomes chronic, there is little interaction between the family and the dialysis unit staff. The chronic stage starts when the patient has been diagnosed with the assistance of the biopsy, and in most cases discharged and comes from home to the dialysis centre for treatment as an outpatient. The healthcare personnel concentrate on the patient and his/her problems and the family is often left out of the plan of care as evidenced by a study conducted by Guillement *et al.*, (1988:3), which indicated

that the families of haemodialysed patients had no idea about renal failure and haemodialysis.

The Family Crisis Oriented Personal Scale (F-COPES) instrument developed by McCubbin, Olson and Larsen (1991) was used in this study to explore and describe the coping behaviours of families of haemodialysed patients in order to make recommendations on how best to support these families in coping with the demands that renal failure presents. This scale has been used in South Africa by Greeff and Fillis (2008) in studying resiliency in poor single-parent families, as well as Greeff and Holtzkamp (2007: 189-200) in studying the prevalence of resilience in migrant families. Both studies indicated that the F-COPES accurately measured the stress and coping behaviours in families exposed to stressful situations.

The way patients cope with the constraints of their treatment as well as the condition itself, affects the behaviour of the people around them. These constraints include but are not limited to the following: restrictions on income and possible loss of work, dietary restrictions, and the inability to go on family holidays as there might not be any dialysis facility available in the destination of choice. Furthermore patients have reported lowered libido due to uraemia and anaemia. These restrictions often frustrate family members, sometimes resulting in tacit or open aggression leading to feelings of guilt on the part of the patient (Guillemet *et al.*, 1988:3). According to Ashby *et al.* (2005:389-396) patients felt that they are a burden to their families when it came to nutrition as food had to be prepared differently, regarding what to eat and how food should be prepared.

As mentioned above Daurgirdas *et al.*, (2001:414-415) found that patients with renal failure may experience sexual dysfunction. Duval (1999:1-9) affirmed this saying that the illness became more than her marriage as her husband went to great lengths to make her feel as comfortable as possible, but clearly mourned the woman he had married. Furthermore Danielson, Hame-Bissell and Winstead-Fry (1993:21-60) stated that experience has shown that two families faced with the same illness may react completely different through the adjustment phase into the adaptation phase, where one family may bond in healthy adaptation or bond adaptation while the other may face a crisis in a maladaptation.

In light of the limited findings of studies with a specific focus on the coping behaviours of haemodialysed patient's families in the South African context, the aim of this study was to identify and describe the coping behaviours of these families, from which recommendations will be made on how to support the families caring for the haemodialysed patients.

1.3. PROBLEM STATEMENT

According to Duval (1999:1-9) family members feel concerned because they are seldom included in the comprehensive care of the patients. The family's inability to cope with the condition and treatment, may impact on their wellness as well as that of the family member on haemodialysis. Furthermore, family wellness will be promoted if the renal staff members have an understanding of how they cope with their family member's illness and treatment. The study focussed on the coping behaviours of the haemodialysed patient's family as ineffective coping behaviour may result in family disorganisation. Furthermore the study will benefit both families and patients in understanding the needs of the haemodialysed member.

1.4. RESEARCH QUESTION

From the problem statement the following research question arises:

What are the coping behaviours of haemodialysed patients' families in a private clinic setting in Gauteng?

1.5. CENTRAL THEORETICAL STATEMENT

Care for the haemodialysed patient takes place at home as well as in the centre, and for this reason the family needs support to take care of the haemodialysed member. Holistic nursing care includes the social aspect of care of the family and therefore understanding their coping behaviour will contribute to better quality nursing care, and the prevention of the development of a crisis. In exploring and describing the coping behaviour of the family of a haemodialysed patient, recommendations to support these families might be formulated and contribute to better adaptation for the patient as well as the family.

1.6. RESEARCHER'S ASSUMPTIONS

1.6.1. Meta-theoretical assumptions

I believe that **man** is an individual, unique human being with an integrated physical, psychological, spiritual and cultural nature; forever in contact with their surrounding and people around them. Man is capable of making decisions and is in control of their lives. Culturally I view the **family** as an organisation which comprises of the father as head, the mother as sub-head and the children as the members; in which milieu children may be socialised in a specific cultural belief system. Family also comprises extended members such as grandparents, uncles, aunts as well as cousins who also have an input into this organisation. I view the **environment** as all circumstances, conditions as well as changes that challenge each individual as an adaptive being. The environment can either be internal or external. I believe that **health** is the ability humans' have in adapting to the changes around them without being adversely affected. When affected, illness results, as health and illness are viewed to be on a continuum. All of which is in agreement with the interactions theory. I believe that **nursing** is the care provided to enable people to cope with or recover their health, when their health has been compromised by the disease or illness. It also adds value to the quality of life of an individual until death. In order to do this, nurses need to undergo scientific training in nursing science. I believe **nursing science** incorporates knowledge and the application of this knowledge is concerned with individuals, groups as well as the community, in order to make it easy for people to adapt to a changing environment.

1.6.2 Theoretical assumptions

For the purposes of this study, Roy's adaptation model for nursing, first introduced in 1960 and put to use in 1970 at the University of California, has been adopted. This model is largely based on the systems theory, although account has been taken of some thoughts of the interactionist theory (Pearson, Vaughan & FitzGerald, 2005:125-129). The focus of this model is adaptation and its aim is to identify actual and potential behaviours of the client which are seen to be maladaptive or inappropriate. Roy's model can be used as a guide for assessment, problem identification, setting goals as well as evaluation (Pearson *et al.*, 2005:125-130). The application of the model in this study can contribute to assessing how families of haemodialysed patients cope with and adapt to chronic illness situations.

The following definitions are key concepts applicable to this study:

1.6.2.1 Coping behaviours – defined as an individual's response to a change in the environment; that can be positive or negative (Morton, Fontaine, Hudak and Gallo, 2005:28).

1.6.2.2 Haemodialysis - described by Daugirdas *et al.*, (2001:4-6) as the procedure whereby the blood of a patient in acute or chronic renal failure is purified by means of a dialysis machine two to three times a week. A semi-permeable membrane is required to combine four principles of dialysis namely diffusion, osmosis, absorption and filtration in order to permit the removal of metabolic wastes, excess electrolytes and fluids from patients with renal failure (Stellenberg & Bruce, 2007:337-339).

1.6.2.3 Patient – an individual who requires assistance to achieve health of body and mind and independence or a peaceful death. Furthermore a patient and family are viewed as a unit (Marriner-Tomey, 1994:105). In this study a haemodialysed patient is an individual who is on a chronic haemodialysis and is with the family at home.

1.6.2.4 Family – a group of individuals sharing a specific physical and psychological space. Although they may take different forms, families are all considered to be natural social systems containing personal properties such as specific rules, assigned member roles, organised hierarchical structures, overt and covert communication forms, as well as possessing elaborate ways of negotiating and solving problems (Ross & Deverell, 2009:258). In this study the family is the primary caregiver as identified by the patient, who can be a spouse, live-in partner, officially registered partner, children, parents, siblings as well as officially adopted children.

1.6.3 Methodological assumptions

The methodological assumptions of this study are based on pragmatic views. This methodological view is described by Creswell (2009:10-11) as not committed to any one system of philosophy and reality. The pragmatic view system applies to mixed method research as mixed method elicits the inquiry from both quantitative and qualitative

approaches. This study followed the mixed method approach hence the use of pragmatism. Furthermore this view opens doors to multiple methods, different worldviews, different assumptions as well as different data collection and analysis methods.

1.7. AIM AND OBJECTIVES OF THE STUDY

In light of the problem statement and the research question the overall aim of the study is to explore and describe the coping behaviours of haemodialysed patients' families in order to make recommendations on how families can be supported when caring for their haemodialysed family member.

In order to achieve the main aim of the study the following objectives have been identified:

- To identify and describe the coping behaviours used by families caring for haemodialysed patients using the Family Crisis Oriented Personal Scales (McCubbin *et al.*, 1991) (Phase 1),
- To explore and describe the identified coping behaviours from the first objective using focus group interviews (Phase 2).

1.8. RESEARCH DESIGN AND METHOD

1.8.1. Study Design

The study followed a non-experimental, explorative and descriptive explanatory mixed method approach with a sequential design as described by Creswell (2003:208-216; 2009:211). In this study the sequential strategy is characterised by the collection and analysis of quantitative data followed by the collection and analysis of qualitative data. A comprehensive discussion of the design is presented in chapter three. The research study was divided into two phases, the quantitative phase and the qualitative phase. During phase one, the F-COPE Scale was used to identify coping behaviour, whilst phase two employed focus group interviews to explore the coping behaviours identified in phase one. A discussion of the integration of the findings related to the phases will be presented in chapter five. Table 1.1 provides an overview of the data collection and analysis process. A discussion of each of the phases follows.

1.8.2. PHASE ONE:

Phase one addressed the first objective in identifying and describing the coping behaviours of the families using the F-COPES scale (McCubbin, Larsen & Olson, 1991). The findings of phase one were used as a source of information for the interview schedule of phase two. A discussion of the method and procedure of each phase is provided in the paragraphs that follow.

1.8.2.1. Population and setting

The population in this study were the family members of patients receiving chronic haemodialysis in a private clinic in Gauteng. The unit of analysis was the family member of a haemodialysed patient who takes responsibility for his/her care and could either be a spouse, child or anybody who stayed with the haemodialysed patient. The settings for the study were the haemodialysis units of Fresenius Medical Care (FMC) in Gauteng. Data was collected from a group of private clinics in Gauteng that offer haemodialysis.

Participants' names were not be used in the questionnaires as to ensure anonymity. The units treat on average 20 patients per day excluding Sundays. The units treated 654 patients in 2007 and 786 patients in 2008. These figures were provided by the clinical manager of the private clinics for use in this study. A statistician from the NWU was consulted to assist in determining the sample size of the study and sampling method for phase one.

Table 1.1: Research methods used in each phase

OBJECTIVE	METHOD OF DATA COLLECTION	POPULATION AND SAMPLE	DATA ANALYSIS	CREDIBILITY/VALIDITY
<p><u>Phase One</u> To identify and describe the coping behaviours used by families caring for haemodialysed patients using the Family Crisis Oriented Personal Scale</p>	<p>F-COPE Scale (McCubbin, Larsen & Olson, 1991)</p>	<p>Population: Families of the haemodialysed patient Sample: All inclusive sampling (n=57)</p>	<p>Descriptive statistics.</p>	<p>Validity and reliability (De Vos <i>et al.</i>, 2006)</p>
<p><u>Phase Two</u> To explore the identified coping behaviours from the first objective using focus group interviews</p>	<p>Focus group interviews (Krueger 2002, Kvale & Brinkmann, 2009)</p>	<p>Population: Participants from phase one who volunteered to take part in the focus group interviews. Sample: Purposive sampling (n=9).</p>	<p>Thematic analysis steps was be followed (Creswell, 2009:184) Integration of the findings (Creswell, 2003).</p>	<p>Strategies of trustworthiness (Lincoln & Guba, 1985)</p>

1.8.2.2. Sampling

An all inclusive sample (n=57) of the FMC units treating patients with renal failure in Gauteng was obtained. A sample size of at least 40 participants was recommended by the statistician. The primary caregiver as identified by the patient had to meet the following inclusion criteria:

- 1 Proficiency in English
- 2 Be older than 18 years

1.8.2.3. Data collection

A discussion of the instrument and procedure for data collection for phase one follows is presented in the paragraphs below.

1.8.2.3.1. Instrument (F-COPE Scale)

Data was collected by means of the F-COPES (McCubbin *et al.*, 1991). The F-COPES (included as Appendix 2) is a self-administered survey consisting of 30 items that describe a variety of coping behaviours that family members may use in times of stress or crisis. The F-COPES was drawn from a sociological research tradition based on family stress literature (McCubbin *et al.*, 1991). The participants were asked to rate the items on the F-COPES using a five point Likert scale with 1, “strongly disagree”, and 5, “strongly agree”, as responses to a statement. The 5 factors included in the scale were:

1. Acquiring social support
2. Reframing
3. Seeking spiritual support
4. Mobilizing family to acquire and accept help
5. Passive appraisal.

A discussion of these factors and their related items will follow in chapter three. The psychometric characteristics of the instrument were found to have a satisfactory internal consistency and good structural validity and reliability. The Cronbach’s alpha coefficients were described as acceptable as the values ranged between .77 and .86 in two studies conducted by Greeff and Fillis (2008) and by Greeff and Holtzkamp (2007) in South Africa.

The F-COPES scale is straightforward and easy to administer, take and score. A manual and norms are available and copyright to use the scale was granted . The average time to complete the questionnaire was estimated to be between 5-15 minutes. A separate sheet on the demographic data (refer to Appendix 1) was used to describe the population profile and characteristics of the family member completing the F-COPES scale. Demographic data collected included the following variables: role and relationship to patient, age, race, and gender as well as employment status and will be presented in chapter four.

1.8.2.3.2. Procedure for data collection

The unit managers of FMC in Gauteng were trained to assist as field workers to distribute and to collect the F-COPES questionnaires from participants. Questionnaires were completed by the family member who met the inclusion criteria and included a guide for the participants on how to fill in their responses. An envelope was provided for the participants and the sealed responses were hand delivered to the unit manager. Participants were provided with contact details of the researcher should they need any clarification. The questionnaires were collected by the researcher from the unit managers. Data collection occurred over a period of two months.

1.8.2.3.3. Data analysis

Assistance was provided by a statistician of NWU in the analysis of the quantitative data and the interpretation of the descriptive statistics derived from the collected data. The findings will be presented in chapter four of this study.

1.8.2.3.4. Rigour

The instrument was tested for validity and reliability in the previous studies by Greeff and Fillis (2008), and Greeff and Holtzkamp (2007). The results for both studies were acceptable with Cronbach's alpha of .77 and .86. Internationally the instrument was used in the United States of America by Tway, Connolly and Novak (2006) and the Cronbach's alpha was .86 with a retest of .81. This testing made sure that the instrument measured what intended to measure. A discussion of the validity and reliability related to the F-COPES in this study will be presented in chapter four.

1.8.3. PHASE TWO

Phase two addressed the second objective of the study and included the use of focus group interviews to further explore the findings from the first phase of the study. A comprehensive discussion on these findings is presented in chapter five.

1.8.3.1. Population and setting

The population in this phase were the participants from phase one that indicated an interest to participate in follow up focus group interviews. A separate invitation to participate in the second phase was provided to those participants who completed the questionnaires. Their positive responses were inserted in a separate envelope so that no one could be linked to the questionnaire they had completed. All those that showed interest were included in the second phase. The setting where the interviews were conducted was the area agreed to by both researcher and participants. The focus group interviews took place in the offices of the Fresenius Medical Care as these locations were familiar to and within reach of the participants. More information about the focus group setting is discussed in chapter three.

1.8.3.2. Sampling

The sampling in this second phase was purposive. This is a non-probability sampling method in which a researcher selects participants based on personal judgement about which ones will be most informative, it can also be called judgemental sampling (Polit & Beck,2008: 763). The participants indicated their willingness to be interviewed by making a tick in the box provided and giving their contact details. The date, time and place for the focus group were communicated to the participants well on time. Detailed data was collected and an open-ended question method was used during the interview. The interview guide was developed after the data from phase one had been analysed as it gave an indication as to which part needed to be explored more extensively.

1.8.3.3. Data collection

The interviews were arranged so as to explore the coping behaviours of the families of the haemodialysed patient. The participants were informed about the use of an audio-tape

during the interviews and their consent was asked and obtained. Henning (2007:74-77) advises that the scene for the interview has to be such that the participants do not feel threatened and furthermore, during the recording an eye has to be kept on the machine as they are prone to technical as well mechanical problems. The focus group in this study comprised 3-4 individuals at a time for proper control of the discussion and allowed participation by all participants. A total of 9 (n=9) participants were interviewed. De Vos *et al.*, (2000:314) describe a focus group interview as a number of individuals between whom a distinguishable pattern of interaction exists. The focus group interview as described by Krueger (2002) was followed, during which a professional colleague assisted with data collection by managing the audio-tape and acting as moderator. The interview was tape recorded and a notepad was used for field notes.

1.8.3.4. Data analysis

The data was analysed following the steps of qualitative data analysis as Creswell (2009:184):

- Organising and preparation of data. The interviews were transcribed and field notes typed and the interviews were arranged according to sources and types.
- The interviews were read through so as to obtain a general impression and meaning of what the participants had said during the interview.
- Once the general feelings of the participants had been identified, the information was organised into smaller components, categorised and labelled.
- Thereafter information was coded, themes identified and described.
- Some form of meaning was attached to the themes and words most often used by the participants were listed and the chronology of events as described by the participants was checked.
- Finally clearer meanings were given to the themes and data was interpreted.

Following the analysis of the qualitative data from phase two the findings of both phases were integrated (Creswell, 2009:208) in order to provide an overview of the coping

behaviours described by the participants in this study. The integrated findings are presented in chapter five.

1.8.3.5. Trustworthiness

To ensure trustworthiness the model of Lincoln and Guba (1995) was used. The model focuses on four items: credibility, transferability, dependability and confirmability. A discussion on each of these strategies is presented in chapter five. In ensuring that the above criterion be met, an attempt was made to answer the following questions:

- Is the research well defined to ensure theoretical validity?
- Can the research findings be trusted? Will credibility be assured when the population has been chosen, data collected and analyzed? What is the authority of the researcher?
- Can the research findings be applied elsewhere?
- How consistent are the research findings?
- Are the research findings neutral? Was the research done without prejudices and can it therefore be said to have operational validity?

1.9 ETHICAL CONSIDERATIONS

This study complied with the ethical requirements of nursing research and that of NWU (refer to Appendix 8) (Brink, 2008:30-43; Bak, 2005:28). The study proposal was submitted to the Ethics Committee of the North-West University (Potchefstroom Campus), Fresenius Medical Care (Pty) management and was approved. Informed consent was obtained from all participants for both phases of the study (refer to Appendixes 3 and 4). In both cases the raw data did not include any information by which any of the participants could be identified. The inquiry was guided by the following principles:

- **Respect**

Participants were informed about their right to withdraw from the study at any point without any fear for their family members being prejudiced, that they participate voluntarily, and what was expected of them. The participants were also given covering letter informing them about the study and that all information would be treated confidentially.

They were also informed that no names were to be written on the questionnaires except in the case where they were volunteering for the focus group interviews. There were no risks anticipated in the study. The participants' autonomy was respected and no participants were coerced into the study, or coerced into answering all questions. An audio tape was used with the consent of participants during the focus group interviews, so as to make sure that the interview was recorded in its entirety. The tape was placed in an area where it did not disturb the participants.

- **Beneficence**

The participants were protected from any form of discomfort by providing counselling when needed. The service of a psychologist was made available for the participants especially the focus group interviews. Information obtained from the participants would benefit them by understanding what coping mechanisms they were using when caring for the haemodialysed patient at home.

- **Justice**

Participants were selected because they were directly involved in caring for the haemodialysed patients at home. Data was processed anonymously as the information was returned to unit managers in sealed envelopes and placed in the box provided. This was done so as to make sure that no one involved would know who returned the questionnaire and who did not. Completed questionnaires were collected on a two weekly basis no forms could not be found in the boxes after two weeks. Data was recorded and stored safely.

- **Informed Consent**

Informed consent was obtained from each participant. The informed consent documents were sent out as a comprehensive document containing: information letter, informed consent and questionnaire for each participant. Unit managers were trained as field workers to distribute and collect the questionnaires from the participants. The researcher's contact details were provided on the information letter should any of the participants or unit managers need assistance. The researcher and participants signed the consent form as an agreement between the two parties (Creswell, 2003:65). During the second phase the

participants were informed that their real names were not to be used during the interview and the coding system was used to ensure confidentiality. The participants were also informed regarding the purpose of the recorded information. In the second phase of the study use was made of process consent (Polit, Beck & Hungler, 2001) because during the focus group interview, participants had to be part of decision making and therefore their collaborative role and ongoing participation needed to be gained.

1.10 CHAPTER OUTLINE

Chapter one:	Study overview
Chapter two:	Review of the literature
Chapter three:	Research methodology
Chapter four:	Phase one: Quantitative data analysis: F-COPE Scale
Chapter five:	Phase two: Qualitative data analysis and integration of the findings
Chapter six:	Limitations and recommendations

1.11 CONCLUSION

This chapter gave an overview of the study, its significance and assumptions made. The following chapter will focus on a review of the literature pertaining to study.

CHAPTER 2

REVIEW OF THE LITERATURE

2.1 INTRODUCTION

In chapter one an overview of background and rationale of the study was presented. In light of the limited research related to the coping behaviour of the family of the haemodialysed patient, the aim of the study was to explore and describe the coping behaviours used by families caring for the haemodialysed patients. Taking into account the limited research in the area of focus, as comprehensive an overview as possible of the literature related to the phenomenon under investigation will be provided in this chapter. In examining the literature on the coping behaviours of the family confronted with a chronic illness such as renal failure, the following databases were consulted: Science Direct, Scopus, and Medline, EbscoHost as well as ANNA and books using the following keywords:

- Haemodialysis, coping behaviour, family, end stage renal failure.

The search revealed 967 292 publications inclusive of articles, references and citations. Most of the articles had information on children that have renal failure and the impact thereof on their siblings and parents. A total of 243 articles considered relevant were included in the review. Although this seems like a great deal of information, many of the articles included in the study may be partly outdated, and were included only because there were no recent articles with information relevant to the study. Most literature seemed to focus on the impact of haemodialysis on a patient. Less was said about the impact on the family and how these families cope.

In an attempt to familiarise the reader with the severity of a chronic illness such as renal failure and to illustrate the possible influence thereof on the patient and family, a thorough review of the literature on renal failure is presented in the paragraphs that follow. To that end literature pertaining to the anatomy and physiology of the renal system, the pathophysiology with a specific focus on chronic renal failure and end-stage renal disease, renal dialysis, and the impact of the condition on the patient and the family will be discussed.

2.2 OVERVIEW OF THE ANATOMY AND PHYSIOLOGY OF THE RENAL SYSTEM

2.2.1 Anatomy of the kidney, ureters and urinary bladder

Kidneys are bean-shaped and lie retro-peritoneal in the lumbar region and extend approximately from T₁₂ to L₃. Extending from each kidney medially are the ureters which end in the urinary bladder which acts as a reservoir for urine (Marieb & Hoehn, 2007:997). One kidney has approximately 10 000 tiny structures called nephrons which form the functional unit of the kidney (Thomas, 2008:28-30). Each nephron is made up of several distinct structures: the glomerulus which is the high-pressure capillary bed that serves as the filtering point for the blood, the Bowman's capsule which is a tough membranous layer of epithelial cells that completely surrounds the glomerular capillary bed. Furthermore, the nephron is also made up of the proximal convoluted tubule, loop of Henle, distal convoluted tubule and the collecting duct (Urden, Stacey & Lough, 2006:787-790). A visual presentation of the anatomic structures of the kidney is provided in figure 2.1.

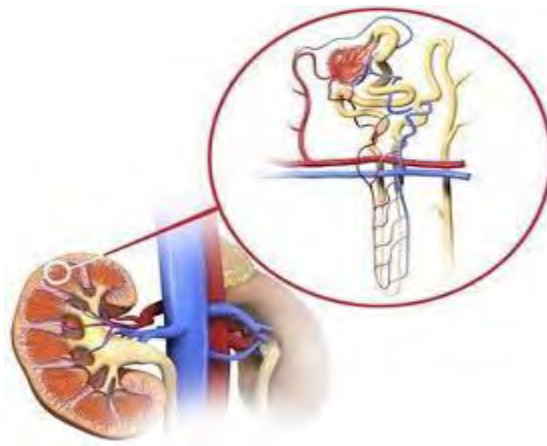


Figure 2.1: A structure of the kidney and nephron (Nucleus Medical Art, 2008)

2.2.2 Blood supply to the kidneys

The blood supply to the kidneys is delivered by the renal arteries and drained by the renal veins. The incoming artery going into each kidney divides into four or five branches, and then forms arterioles. At the level of the capillaries, the renal venules combine to form the renal vein (Marieb & Hoehn, 2007:1000).

2.2.3 Urine production and filtration

According to Marieb and Hoehn (2007:1006-1014), urine formation consists of three processes namely:

1. Glomerular Filtration

This is the passive, non-selective process in which hydrostatic pressure forces fluids and solutes through a membrane. About 1200 ml of blood passes through the glomeruli per minute for filtration.

2. Tubular Reabsorption

This process begins immediately when the filtrate enters the proximal tubule. At this level water and ions as well as the nutrients are taken back from the filtrate into the blood stream.

3. Tubular Secretion

This is the final step in the formation of urine as all the unwanted products are being excreted in the form of urine. The kidney at this stage will eliminate all the unwanted substances and regulate the pH of the blood. The excess water will then be drained into the renal pelvis, through the ureters to the bladder and be urinated through the urethra.

2.3 PATHOPHYSIOLOGY OF THE RENAL SYSTEM

Following the overview of the anatomy and physiology of the normal renal system the following paragraphs will focus on the pathophysiology of chronic renal failure (CRF) and end stage renal disease (ESRD) and the treatment thereof.

2.3.1 Chronic renal failure

CRF is the condition whereby the kidney loses more than 60% of its function and waste products accumulate in the body (Daugirdas *et al.*, 2001:3) resulting in a disruption in endocrine and metabolic functions leading to fluid, electrolyte and acid-base imbalances (Smeltzer & Bare, 2000: 1146-1151). Thomas (2008:55) defines CRF as kidney damage or a glomerular filtration rate of less than 60 mL/min/1.73m² for three months or more irrespective of cause.

CRF usually occurs as a result of:

- The progression of a primary disease like diabetes mellitus or hypertension due to vascular changes leading to decreased blood flow to the kidney.
- Direct trauma to the kidneys.
- Nephro-toxic drugs that can cause permanent kidney failure, for example vancomycin.
- Hereditary conditions whereby the disease is passed through the genes from generation to generation such as polycystic kidney disease.
- Repeated damage infections of the kidneys like glomerular-nephritis.
- Prolonged pressure on skeletal muscles (myoglobin release).

2.3.2 End stage renal disease

CRF will progress to end stage renal disease (ESRD), a condition where renal failure cannot be controlled by conservative management and day-to-day dialysis or a transplant is required to maintain life (The Renal Association, 2002: 156). The progression of CRF to ESRD requiring dialysis, takes place in five stages, as described by the National Kidney Foundation (Stellenberg & Bruce, 2007: 335). The stages are based on calculating the glomerular filtration rate (GFR) which is indicative of the rate of waste accumulation in the body (refer to table 2.1). In this study both CRF and ESRD patients' families will be included as the patient will be on haemodialysis when in either stage.

Renal failure can also be divided into an acute and chronic phase. Acute renal failure (ARF) is described as an abrupt decline in kidney function as defined by increases in blood urea nitrogen (BUN) and plasma creatinine levels. The urine output is usually less than 40ml/hr or may be normal or increased (Monahan, Sands, Neighbors, Marek & Green, 2007:1251). During this phase the patient is admitted to the hospital and cared for in the Intensive Care Unit (ICU) because the patient can be acutely ill from pulmonary oedema, uraemia and metabolic acidosis. The patient will be treated conservatively, and if the disease still progresses the patient will be dialysed while the kidneys recover for a period of three months. Diagnosing chronic renal failure requires a description of ill health (sickness) of the kidneys through elicitation of symptoms, observation of abnormal physical signs and

investigation (Glassock & Winearls, 2010:123). Furthermore, they concluded that less doubt exists regarding the validity of a diagnosis of chronic renal failure when one finds (and confirms over a 3-month period of observation) an abnormality in a urinalysis (e.g. tubular proteinuria, glomerular haematuria and other elements indicative of parenchymal renal disease) or in biopsy. Glassock and Winearls (2010:125) are of the opinion that the rate of change in the glomerular filtration rate (GFR) with aging is about 8-10ml/min per 1.73m² per decade. This study then showed that the higher population was the age group of 41-50 years. This then brings the conclusion that renal failure affects middle aged people more than the younger people.

Table 2.1: Stages of kidney failure (Kidney Diseases Outcome Quality Initiative, 2002)

STAGES	GFR	DESCRIPTION	TREATMENT
1	>90mL/min/1.73m ²	Normal kidney function but urine or other abnormalities point to kidney disease	Observation, control of blood pressure
2	60-89mL/min/1.73m ²	Mildly reduced kidney function, urine or other abnormalities point to kidney disease	Blood pressure control, monitoring, investigations.
3	30-59mL/min/1.73m ²	Moderately reduced kidney function	As above, and probably diagnosis, if not already made.
4	15-29mL/min/1.73m ²	Severely reduced kidney function	Planning for ESRD
5	<15mL/min/1.73m ²	Very severe, or end stage kidney failure (sometimes call established renal failure)	Here patient needs dialysis or transplantation.

Chronic renal failure (CRF) is a slow, progressive, irreversible deterioration in renal function that results in the kidney's inability to eliminate waste products and maintain fluid and electrolyte balance and ultimately, it leads to end stage renal disease and the need for renal replacement therapy (dialysis) or renal transplantation (Morton & Fontaine, 2009:767-768). CRF can only be prevented if the predisposing factors to acute renal failure can be managed. CRF becomes a family affair because the patient needs to go to the hospital for the dialysis treatment weekly.

2.3.3 Treatment of chronic renal failure/end stage renal disease

Treatment for CRF/ESRD comprises diet and fluids management, dialysis and as the last resort renal transplantation depending on the availability of the kidney. The diet of the patient with renal failure has to be protein based, and salt and potassium restricted. The fluid intake will be according to the amount of urine output, and in the case where the patient is completely anuric (no urine output); they are allowed to have only 500 – 800ml of fluids in 24 hours (Morton & Fontaine, 2009:727-740). The treatment of choice for CRF/ESRD is haemodialysis that will be discussed in section to follow.

2.4 HAEMODIALYSIS

Haemodialysis is described by Daugirdas *et al.*, (2001:4-6) as the procedure where the blood of the patient is purified by means of a dialysis machine two to three times a week. Furthermore it requires a semi-permeable membrane to combine the principles of diffusion, osmosis, absorption and filtration in order to permit the removal of metabolic wastes, excess electrolytes and fluids from patients (Stellenberg & Bruce, 2007:337-339). Haemodialysis is given to the patient in both acute and chronic phases of renal failure. When renal failure becomes chronic, a permanent central venous catheter is inserted or an arterio-venous fistula is constructed as an access port for the dialysis treatment. The latter procedure predisposes the patient to the risk of bleeding should an accident occur to the operated arm; furthermore infection and bleeding may result from puncturing the fistula during dialysis. Figure 2.2 provides a visual illustration of a fistula used as point of access for dialysis treatment, whilst figure 2.3 illustrates a typical dialysis machine.

Chronic haemodialysis is the treatment of choice when both kidneys of the patient have reached ESRD and the glomerular filtration rate is less than $15\text{mL}/\text{min}/1.73\text{m}^2$. Krespi, Bone, Ahmad, Worthington and Salmon (2004:189-196) add that the treatment of ESRD involves dialysis, fluid and diet restriction, medication and in some patients kidney transplant. Chronic haemodialysis is carried out as an outpatient treatment, as the patient will have to come to the centre two or three time a week without fail because of its life sustaining nature.

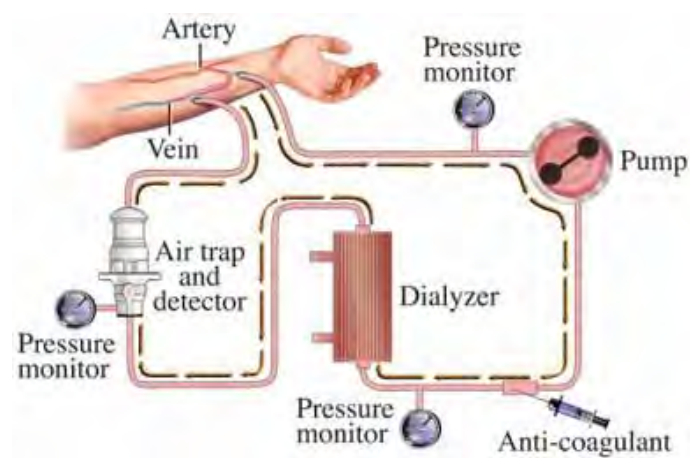


Figure 2.2: Diagrammatic presentation of the patient on haemodialysis (Nucleus Medical Art, 2008)



Figure 2.3: An example of a dialysis machine (Nucleus Medical Art, 2008)

In 1994 in South Africa 3399 (99 per million of the population) people were on treatment for ESRD with 754 new patients for the year 1994 (Naicker, 2003:119-122). An overview of the patient per million populations on dialysis in selected developing countries is provided in Table 2.2 (Moosa, Naicker, Hahn, Assounga Pascoe, Van Rensburg, Moshesh & Potgieter, 2001).

Over a ten-year period, where 368 patients with CRF were studied in Nigeria (Naicker, 2003:119-122) the aetiology of renal failure was undetermined in 62% of the participants, and in the remaining patients whose aetiology was ascertained, hypertension accounted for 61%, diabetes mellitus 11% and glomerulo-nephritis 5.9%. Patients with renal failure constituted 10% of all medical admissions in the centre where the study was done (Naicker, 2003: 119-122). In addition, Grassman, Gioberge, Moeller and Brown (2005: 2587-2593) found in a study conducted in the United Kingdom that the number of patients treated for terminal renal failure had grown at a rate that is in excess of the growth rate of the general population.

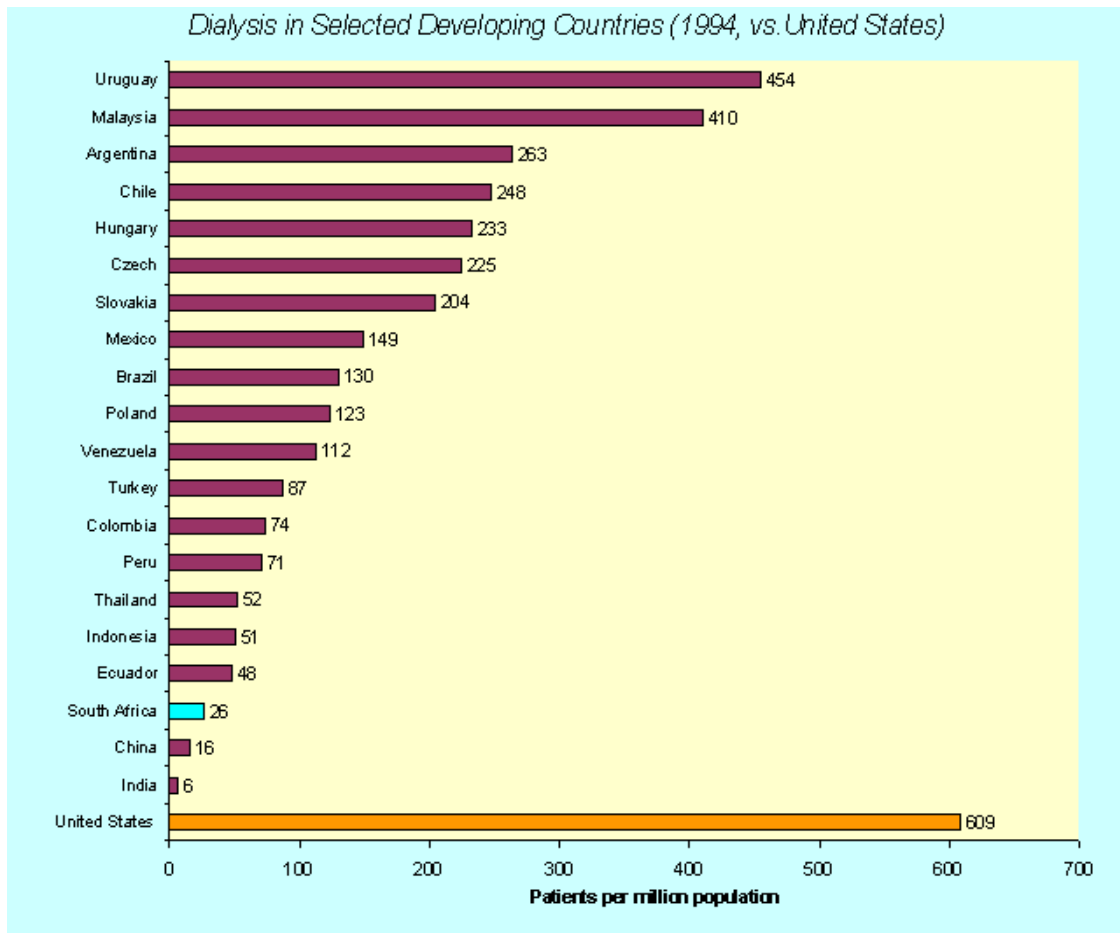


Figure 2.2: Dialysis in selected developing countries (Moosa *et al.*, 2001:659-692)

Nobel, Kelly Rawlings-Anderson and Meyer (2007) concluded that there were approximately 1.5 million patients around the world receiving dialysis treatment. Furthermore the same study indicated that the number was growing at an annual average of 7% in those privileged populations that have access to such treatment. Wicks, Bolden, Mynatt, Rice and Acchiardo (2007:623-626) also reported that America had 341 000 patients on haemodialysis in 2005 with the population of 297 million, while in Europe with an estimated population of 376 million the incidence was 120 per million (Wicks *et al.*, 2007: 632-629).

Because current resources cannot cope with the demands of the fast growing numbers of patients with renal failure, the South African Department of Health (Dirk & Levin, 2006:982-984) had to come up with certain selection criteria for patients to be admitted into the dialysis programme. The implementation of these criteria meant that some of the patients

would not be given the chance of being on the dialysis programme. The exclusion criteria were based on some of the following reasons (Dirks & Levin, 2006:119-122):

- lack of financial and human resources,
- late diagnosis of CRF,
- other priorities like HIV/AIDS,
- lack of basic amenities,
- the inaccessibility of rural populations, and
- lack of government resources to provide dialysis facilities.

These criteria were put in place with the aim of encouraging those on the programme to attend their treatment sessions, and to relieve the load of public sectors providing these services. On the other hand it also placed an immense amount of pressure on the nephrologist having to decide which patients to admit to the programme.

Globally and nationally the prevalence of renal failure continues to rise. In a combined study between South Africa and Australia in 2006, the Dumisani Mzamane African Institute of Kidney Disease and Centre for Chronic Disease (Katz *et al.*, 2006:115-122), showed evidence that there is a sharp increase in chronic diseases such as diabetes mellitus and hypertension which are the leading cause of renal failure. Furthermore, the study indicated that by 2020 the burden of diabetes and cardiovascular disease will have increased by 130% in Africa alone, with concomitant increases in prevalence of CRF. The Australian Health and Welfare Statistics (2005) reported a similar situation amongst the Australian Aboriginal community with an epidemic of renal and related chronic conditions appearing in remote Australian Aboriginal communities since the 1980's.

A combined report conducted on Maintenance Dialysis and Transplant in South Africa revealed that glomerulo-nephritis was the leading cause of renal failure in 1771 (52%) patients compared to hypertension as a cause in 1549 patients (45,6%) (Du Toit, Pascoe, MacGregor & Thomson, 1994). In addition, hypertension was reported as the leading cause of renal failure in 394 patients in Kwazulu-Natal. The results further indicated that 32% of these patients were black, 24% Indians and 29% of mixed race. In other words these results

showed that for most blacks, hypertension was the leading cause of renal failure in the South African context when compared with Indians and mixed race population.

A study conducted in the United States of America (USA) where gender and race were also taken into account, showed that 341 000 African Americans required dialysis during 2000-2005 (Wicks *et al.*, 2007:623-629). The incidence rate for this group was almost four times higher than that of the white population (Wicks *et al.*, 2007:628). Lampey-Davis (2002:46-49) also found that most of the people caring for persons with CRF/ESRD were often black women. On the whole the above statistics indicate that both internationally and locally blacks and females seem to be the most affected group when referring to CRF. In light of the severity of CRF and the subsequent treatment thereof with haemodialysis, the following paragraphs will focus on the impact of haemodialysis on the patient and the family.

2.5 IMPACT OF CHRONIC RENAL FAILURE AND HAEMODIALYSIS ON THE PATIENT

Although the focus of this study is on the family of the patient, the state of health and the state of mind of the patient is considered important due to the impact thereof on the family. It was therefore considered relevant for discussion in order to gain a better understanding of the reaction of family members when these symptoms occur. CRF as well as dialysis becomes part of the patient's life once diagnosed and confirmed. The patient has to adapt to the changes that both CRF and haemodialysis bring and, at the same time, will have to deal with both psychological as well as physical changes occurring due to renal failure and dialysis. Some of the possible changes that a newly diagnosed patient on haemodialysis has to cope with will be discussed in the paragraphs to follow (Thomas, 2008:289; Daugirdas *et al.*, 2001:413-418).

2.5.1 Exhaustion

Most patients on chronic haemodialysis have to give up work on the days when they attend dialysis due to low and short concentration levels and complaints of exhaustion. This can be attributed to low haemoglobin levels that leads to low oxygen carrying capacity and tissue hypoxia.

2.5.2 Change in body image

Dialysis treatment affects body image to the extent that patients often feel different and unattractive. Patients with fistulae constructed on their arms have reported that they are viewed as drug addicts by the public, owing to the multiple puncture marks on the arm. Some patients often feel embarrassed appearing naked before their partners due to skin colour changes associated with renal failure.

2.5.3 Sexual dysfunction and low fertility

Patients on haemodialysis frequently report sexual dysfunction that can be attributed to uraemia, some chronic medication as well as low haemoglobin. This happens in approximately 70% of men on dialysis, while women report diminution in the frequency of orgasm and pain on penetration during intercourse (Daugirdas *et al.*, 2001:413).

2.5.4 Change in diet and eating habits

The diet of a renal failure patient plays an important role in the management of the patient's condition and can be a source of problems for the patient if not well controlled. Very often cultural and religious eating habits need to be adapted leading to frustration in the patient because of the severe restrictions on dietary intake and fluids.

2.5.5 Anxiety in anticipation of an early death

Those who have a life-threatening illness such as renal failure live on 'the edge', maintained on a life-support system. They are always waiting for the worst to happen to them and this state causes anxiety. The other cause of anxiety could be fear related to needling as well as the needling technique of the personnel. Pain is also cited as a cause of anxiety, especially in the early phase of the chronic stage where the patient is using a fistula or graft as access port for treatment. Lysaght and Mason (2000:253-256) view haemodialysis as a lifelong procedure associated with a significant reduction in quality of life. Depression is often a common problem for those patients faced with it.

2.6 IMPACT OF CHRONIC RENAL FAILURE AND HAEMODIALYSIS ON FAMILY

Considering the evidence presented in the paragraphs above it is evident that a patient with CRF faces a number of challenges and that these challenges also affect family. As stated in chapter one, the immediate family members can include: the spouse, live-in partner, officially registered partner, children, parents, siblings or officially adopted children living in the same house as the patient. Wright and Leahey (1994) defines the family in a clinical setting as “who they say they are”. The family are not only the providers but also the recipients of care and are close to the patient in the course of his/her everyday life (Zieger, 2005:353-361). When a family member has to be taken care of, this predisposes the family to some stress caused by the impact of the condition. Ross and Deverell (2009: 128-129) confirm this statement by saying that the sudden and dramatic physical, social and occupational changes associated with the chronic renal condition can result in a series of identity crises and psychological stress for both the patient and family. Family takes on the responsibility of caring for the sick member a task of which the true extent is seldom realised or acknowledged by the patient (Ross and Deverell, 2009:128-129).

Family becomes an important resource when the patient has to deal with the demands of CRF and haemodialysis. The impact of CRF and its treatment on everyday life, quality of life and the health of the family have been poorly researched, resulting in the family being left out of continued patient care. Mant, Carter, Derick and Winner (2000:808-813) and Berg (2004) report that there are few studies that have investigated the family’s self-perceived everyday health and life. Studies available have concentrated on groups of family members of other conditions than those of haemodialysis patients. In addition Mant *et al.*, (2000:808-810) also feel that the family members of the haemodialysis patient lack knowledge about the patient’s condition and the influence of the disease on their everyday life together. Healthcare professionals on the other hand possess technical and medical knowledge about the specific diagnosis and treatment. It is therefore important to communicate professional knowledge with the family so that they know what to expect when the patient is at home. Furthermore a coordinated approach to the condition will reduce stress related problems in both family and patient, as both parties will share the same understanding of the condition.

Following a review of the literature it was evident that few studies have been conducted in South Africa focusing on the family members' coping behaviour when faced with CRF. Aneshensel, Pearlin, Mullan, Zarit and Whitlatch (1995) reported that the everyday life situation and health of family members have received little national or international attention. They further regard the family member as a resource when dealing with the demands and strains that arise in connection with serious chronic diseases. In Sweden the Swedish National Board of Health and Welfare (2005) reported that family members have assumed increasing responsibility for their chronically ill family members, which is particularly true of the family member of patients who require haemodialysis (National Board of Health and Welfare, 2005). To date the focus has primarily been on the coping mechanism of the patients, as the recipients of the haemodialysis treatment. Nordenmark (2004:115-126) states that many family members voluntarily assume responsibility for the care of a sick family member, and this role is welcomed but not supported by society. This often lead to strain in a person's life, due to the need to combine the role of breadwinner with the responsibility of running the household and caring for a sick family member.

CRF implies a life-long process of change for the patient and his/her family (George & Nelson, 2000:160-169). Hagren, Pettersen, Severinsson, Lützén and Clyne (2001:196-202) confirmed this in saying that patients on haemodialysis spend most of their time at home, which means that their next of kin must be available on a 24-hour basis. Ross and Deverell (2009:265-266) are of the opinion that as the family endeavours to support the patient in dealing with CRF, they may cross the line from support to over protection, not wanting to leave the patient alone and watching his/her every move. Wicks *et al.*, (2007:623) noted that women, in general, report twice the prevalence of serious depression and dysthymia or sub-clinical depression when compared to men caring for a family member with a chronic condition. In most cases men are the bread winners, and when they are sick, the wife has to take over their role. According to Harris (2003), black female caregivers were found to be most affected when caring for a family member with chronic kidney failure as suppose to their white female counterparts. This was also confirmed by this study (Fig. 4.3) were most of the participants were found to be females with approximately 57.8%. Harris (2003) attributed these findings to low levels of education and unemployment among black females. Wicks *et al.*, (2007:623-625) further reported that income is inversely correlated

with both major depression and depressive symptoms. Additionally, most of the caregivers reported on lost time from work, the inability to seek career advancement and salary decreases as a direct result of their caregiver role. The cost of chronic treatment like dialysis as well as the cost of travelling to the centre also places great stress on the family, especially in developing countries where most people still live in poverty (Ross & Deverell, 2009:128-129). Moosa and Kidd (2006) reported that in developed countries dialysis costs between 30 000 to 60 000 US dollars per year, and 6000 to 40 000 US dollars in developing countries. Furthermore in Ghana one session costs 100 US dollars which is way out of reach for most of the people in that country. These costs and the inability to afford dialysis treatment often lead to families having to face their loved one dying of renal failure.

Tossani, Cassano and Maurizio (2005:78-82) classified CRF as a terminal disease that gives rise to a crisis, instability in everyday life and a sense of loss among the family members of the patient. Similarly, Janes (1990:26-28) affirms the statement saying ESRD/CRF implies a life-long process of change for these patients as well as their families, because renal failure, once it is chronic, cannot be cured but can only be controlled. As the survival of the patient depends on haemodialysis, this means that he/she will always have to be taken to a centre for haemodialysis at least three times a week. The impact of the disease on the family will vary according to the family's way of living, the size of the family as well as the number and ages of the children in the family (Wicks *et al.*, 2007:632). It is therefore important for renal nurses to know the family they are dealing with as these families are going to react differently and the support system needed has to be individualised. The younger family with young children will think of how their children are going to be raised. The unmarried, either females or males, would think of who would marry them with that condition and how they will live with the condition. The older generations will think of the grandchildren and how they are going to grow up without them. When a chronic condition strikes a family; it will affect the way that family will think about the disease and this will be manifested in how the family adapts to the situation (Wicks *et al.*, 2007:632).

In most cases if the head of the family is the one who is sick, the partner fears taking over this role, while the children may think of leaving school due to a lack of financial support often leading to the development of crisis in the family (Danielson, Hamel-Bissell &

Winstead-Fry, 1993:217-219). Crisis in the family may develop according to the way in which the family views the situation that they are faced with. Successful adaptation to a situation implies that a family understand the condition the patient is suffering from and what haemodialysis entails as treatment. The process of adaptation differs from family to family, and according to Danielson, Hamel-Bissel and Winstead-Fry (1993:218) can be classified as either maladaptation or bond adaptation. It must however be noted that when the family is faced with a crisis of one member being sick, everybody in the family will react differently from one other. Danielson *et al.*, (1993:217) stated that the family system and its functioning involve a very complex process of interacting individuals, personalities, and family unit characteristics, all of which influence each other to shape the family's course of action. Furthermore these changes may lead to successful adaptation, or bond adaptation, meaning that the family is able to stabilise with instituted patterns in place, promote the individual development of its members, and achieve a sense of coherence and congruency even when faced with major changes in the pattern of family functioning (Danielson *et al.*, 1993:219). However, the changes could also result in unsuccessful adaptation, or maladaptation, where the family members sacrifice personal development and growth, the family unit functions in a more chaotic state, and the family's overall sense of well-being, trust, and coherence become very low.

Messer and Meldrum (1995:69-71) mentioned that nurses treating adults with a chronic illness need to take the following factors into account: that the distress felt by the patient's partner about the patient's condition may be as great as the distress of the patient; that the partner may need emotional support to cope with the illness and concrete support to cope with day-to-day tasks; the partner, rather than the patient, may be instrumental in implementing lifestyle changes recommended by the nurse and/or may be as involved in the treatment regime as the patient. When the information is only given to the patient much can be lost if the family or spouse is not involved in the management of the condition.

The way the family reacts to a situation such as illness, will be influenced by the belief system of the particular individual family. Carter and McGoldrick (1989) classify the anxieties experienced by a family into two types, namely vertical and horizontal stressors. The vertical stressors are those that are passed down through generations such as family

belief systems, taboos as well as hereditary conditions, whilst the horizontal stressors refer to those that the family meets over time in the form of external and internal stressors.

Messer and Meldrum (1995:73-74) believe that events occurring at unexpected times in the lifecycle of a family are more likely to be traumatic, as the family is primed to expect certain changes such as the death of a member. Reis and Heppner (1993:100-108) believe that it is not only the onset of illness that can bring problems or stress to a family but, as an illness runs its course, it will present the family with qualitatively different challenges and tasks.

It is clear from the above statement that the family will not only have stress when informed about the illness of the family member, but will carry that stress and face the challenges for as long as the patient is alive and on treatment. Nordefeldt (2001) and Schneider (2004) both agree that when one member of the family is diagnosed with a chronic condition, the family members protect the sick family member at the expense of their own health. The burden and lack of freedom in the family member's everyday lives diminish their chances of realising their own important goals, which can lead to emotional strain and has the potential to make them ill. A study conducted by Schneider (2004:219-225) confirmed that family members of patients on haemodialysis can suffer from fatigue and depression as well as feelings of guilt and hopelessness.

Cohen, Moss, Weisbord and Germain (2006:977-992) concluded that it is accepted that patients with renal failure are at a higher risk of dying than the general population. Therefore family members of these patients often live with fear of their loved one dying resulting in the level of the spouse's distress being the same as that of the patient. In light of the mortality risk associated with CRF, Seymour, Clark and Phillip (2001:269-270) believe that the term end-of-life care is a broad term that seems to identify more than the phase immediately before death. It has been referred to as the last year of life, although this can only be determined retrospectively. During this phase the family might not know where to go and what to do and it is very important for the healthcare team to understand how these families cope with the challenges from pre-diagnosis to treatment to the end of life phase.

To that end the National Council for Palliative and Specialist Palliative Care Services (2002:3) in the UK described supportive care as care that: helps the patients and family to cope with the illness and its treatment, from pre-diagnosis, through the process of diagnosis and treatment to cure, continuing illness or death and into bereavement. Supportive care helps the patient to maximise the benefits of treatment and to live optimally despite the effects of the disease. It is given equal priority alongside diagnosis and treatment with the key elements of supportive care derived from evidence on research about cancer patients (Seymour, Witherspoon, Gott, Ross & Payne, 2005:269-270). The same attention however has not been applied in the renal arena and little is known about the end-of-life requirements of patients with renal failure. In chapter one it was mentioned that some of the patients see themselves as a burden to their family members and wanted to terminate the dialysis. It is still unclear how the family should be supported when faced with a member who has a chronic renal condition and a possible end of life reality. In a study done in the United Kingdom by Levy, Chambers and Brown (2004:1357-1360) the authors concluded that support for the family is essential in renal supportive care situation. This was also confirmed by Reiter and Chambers (2004:15-24) saying that the family caring for patients with chronic, terminal illnesses face a number of problems, such as fear of the unknown, and losing a loved one. There is also the understanding that without haemodialysis treatment the patient with renal failure will almost certainly die in days of being off dialysis due to increased urea, creatinine and potassium (Saini, Murtagh, Du Pont, McKinnon, Hatfield & Saunders, 2006:631-636). Saini *et al.*, (2006:634-636) concluded that families live through this trauma with their loved ones and require psychological and spiritual support. However, due to financial pressures, in many institutions supportive care may often be lacking, as there is a tendency to focus on the patient and not their families.

2.7 THE RENAL NURSE AND FAMILY

As mentioned in earlier paragraphs, it is important for the renal nurse to know the type of family as well as the cultural background of the family. Tjale and De Villiers (2004:13) are of the opinion that people's culture and underlying belief system influence how they perceive health, illness and care, and what their expectations are with regard to how and by whom health problems should be prevented, diagnosed and treated. According to the black South African culture, things often happen due to a specific reason: families may attribute a

chronic condition to anger from the ancestors and this can cause both the patient and family not to agree with or adjust to what is being said by the healthcare professional. Tjale and De Villiers (2004:13) concluded that there are two ways of curing the disease namely, lay care and professional treatment. Lay care refers to assistance that is based on the same cultural experiences or belief systems. This type of care is very common and is divided into four categories: Family care, care provided by the patient's social network, care from self-help groups and self-treatment or self-medication (Tjale & de Villiers, 2004:12-13). The other category, professional treatment involves the traditional healer as well as the medical doctor or even the spiritual healer that can include the church pastor.

Nolan, Grant and Keady (1996) believe that when a patient commences haemodialysis treatment, questions and hopes are raised in family members. Furthermore family members subsequently become involved in the patient's disease and care process, and often depend on the renal nurse for information. Ziegert, Fridlund and Lidell (2005:353-361) claim that by listening to the family member's experiences of caring for the patient at home, nursing staff can acquire knowledge about their everyday life situation, thereby making it possible to improve co-ordinated care planning. Charmaz (1997) states that in most cases renal disease and its treatment have assumed a central role in the life of patients and their families, as symptoms create uncertainty in their everyday lives. This statement is also confirmed by Dingwall (2003) who says families of patients on chronic haemodialysis treatment exist in a state of uncertainty and have to reconcile themselves to a series of losses as the patient becomes weaker both physically and mentally. Furthermore Rolland (1999) feels that the role of the family changes when the family becomes involved in the care which, can lead to a change of lifestyle and restrictions in daily life as patients receiving chronic haemodialysis treatment spend most of their time at home after and between the dialysis sessions.

McGee and Bradley (1994) stated that haemodialysis is a highly technological and expensive form of treatment that places great demands on the family, and that it is essential for them to understand the complexity of the patient's everyday life and how it is affected by the treatment. Calvin (2004:558-567) said that haemodialysis patients and their family members accept the changes in their everyday life, because treatment makes it possible for

the patient to survive, but they need high level of professional support. Roepke (2001:403-422) stated that haemodialysis is a highly technological treatment and can therefore be difficult to understand for the family member who live in close proximity to the patient.

Christensen, Wiebe and Wray (1994:521-525) have found that the mortality rate in haemodialysis patients with poor support from next of kin is approximately three times higher than the estimated mortality of high support patients. Häggström (2004) feels that even though the mortality rate is so high amongst renal failure patients; there are those next of kin who derive great satisfaction from caring for someone close to them. The healthcare professional must take this into account in order to provide support and minimise the negative aspects and stressors inherent in care (Häggström, 2004). Auer (2002:141-144) feels that the professional support provided to the family of patients receiving haemodialysis treatment is inadequate considering the fact that they are the main providers of care for the older sick and disabled people. This is also confirmed by Theobald (1997:595-601) who says this problem may be due to a lack of knowledge about how to deal and communicate with this group. Ziegert *et al.*, (2005:353-360) feel that support from the family together with knowledge on the part of the professional staff can help reduce the sick person's need for care as well as provide several additional health benefits for the patient.

Ziegert *et al.*, (2005:353-360) recommended that studies focusing on family members' coping behaviours may provide important information that can be used to improve the planning of treatment and support interventions aimed at reducing the strain in the everyday life of family member, thus arresting the development of stress and related conditions and protecting their own health.

2.8 CONCLUSION

In this chapter the reader was provided with an overview of the anatomy and pathophysiology related to renal failure. Evidence of the impact of renal failure on the patient, their families and the relationship of the renal nurses to the families was also discussed. It is evident that renal failure affects most people around the world. The family is also seen as the main focal point when dealing with all the problems that the patient will

be undergoing during his/her life on haemodialysis having to adjust and adapt to the new lifestyle. As stated in earlier paragraphs, patients with CRF or ESRD have higher mortality rates than those who are not having this condition, which causes family to live in anticipation of death at anytime. Facing death makes some patients feel that they are a burden to their families and some may even ask to terminate the treatment. Termination of treatment may have some mental effects on the family as they may be required to give consent to the termination of treatment.

It is also evident that the healthcare professional's advice and teaching will help the patient understand the situation they are faced with. When the family is faced with a chronic illness, they have to adjust by adapting to the situation, and adaptation can either be bond or mal-adaptation. The culture and belief system of the patient play an important role in the way they view and understand illness and death. This then tells us that different cultural groups will have different view of the same situation. It is therefore important to differentiate between the cultures and the way they experience the same situation. Culture will also affect the health seeking behaviour of the person who is ill. Ziegert *et al.*, (2005:353-360) recommended that studies focusing on family members' coping behaviours may provide important information that can be used to improve the planning of treatment and support interventions aimed at reducing the strain in the everyday life of family member, thus arresting the development of stress and related conditions and protecting their own health. A discussion on the research methodology and how it applies to the study will be presented in the chapter that follows.

CHAPTER 3

RESEARCH METHODOLOGY

3.1. INTRODUCTION

In chapter two a comprehensive overview of the relevant literature was presented. The review illuminated gaps in current literature on the coping behaviours of haemodialysed patients' families which justified the importance of undertaking this research. As stated in chapter one, the main aim of this study was to explore and describe the coping behaviours of the haemodialysed patients' families. In order to address the main aim of the study, a questionnaire examining coping behaviours was distributed to family members of haemodialysed patients during the first phase of the study. In the second phase focus group interviews with the families who indicated their willingness to participate were conducted to further explore the coping behaviours identified during phase one of the study.

In this chapter the reader is presented with an overview of the research methodology utilized in the study. A discussion on the collection of the data, the target population, sampling, and analysis for both phases as they occurred in the study is also presented.

3.2 RESEARCH DESIGN

According to Burns and Grove (2005:50) a research design is a plan outlining how information is to be gathered for an assessment or evaluation that includes: data identification, gathering methods, instrument to be used, how to administer the instrument, and how information is organised and analysed. It is a plan for collecting and utilising data so that the desired information can be obtained with sufficient precision or a hypothesis can be tested properly.

The study followed a descriptive and explanatory mixed method approach with a sequential design as described by Creswell (2003:208-216; 2009:211). Creswell (2009:203-211) distinguishes between three types of sequential strategies in mixed methods, namely sequential explanatory, sequential exploratory and sequential transformative. A sequential

explanatory strategy was chosen for this study in which quantitative data was collected and analysed in the first phase followed by the collection and analysis of qualitative data in the second phase. Weight is typically given to the quantitative data and the results of the second phase of the study builds on the results from the first phase (Creswell, 2009:211). The sequential explanatory design was chosen to explain and interpret the quantitative results by collecting and analysing follow-up qualitative data. This is in line with the pragmatic methodological view that the researcher ascribes to, in that the strengths and weaknesses of both methods are considered in addressing the research question posed by the study.

3.3 RESEARCH METHODS

According to Creswell (2009:15-16) research methods represents the third major element that involves data collection, analysis and interpretation. Furthermore it can be divided into quantitative, qualitative and/or mixed methods. The qualitative and quantitative research methods can be used separately or in combination. This study followed a sequential explanatory approach which combined both quantitative and qualitative methods for collecting data in the same study. A major weakness of this approach involves the length of time involved in data collection (Creswell, 2009:211) - a fact that the researcher can attest to. An overview of these methods and how they were applied in the study follows.

3.3.1 Phase One : Quantitative inquiry

Burns and Grove (2005) describe quantitative research as a formal, objective, systematic process to describe and test relationships and to examine cause-and-effect interactions among variables. The quantitative phase is a major focus in this study, and involves the generation of numerical data to address the first objective of the study. A quantitative survey was used during this phase and will be discussed in section 3.5.1.1 of this chapter. A total of fifty seven questionnaires (n=57) were analysed for this segment of the study and will be discussed in section 4.3 of chapter 4. According to Matveev (2002:59-67) a quantitative survey has both advantages and disadvantages.

3.3.1.1 Advantages of a quantitative survey:

- Provides a basis of comparing one result with another. Within the context of the study the results of the fifty seven (n=57) surveys could be compared with one other.
- Numbers can be subjected to mathematical procedures and worked with on a computer, so quantitative methods provide ways to deal with large bodies of data. The data collected from all fifty seven questionnaires was subjected to analysis using SPSS 16.0 (SPSS, 2007).
- Statistical techniques permit hypotheses to be rigorously tested. The testing of hypotheses did not apply to this study.

3.3.1.2 Disadvantages of a quantitative survey:

- Failure to provide the researcher with information in the context of the situation where the studied phenomenon occurs.
- Inability to control the environment where the respondents provide the answers to the questions in the survey.
- Limited outcomes to those only outlined in the original research proposal due to closed type questions and the structured format.
- Not encouraging the evolving and continuous investigation of a research phenomenon.

In an attempt to address the disadvantages of the quantitative survey, focus group interviews were employed to ensure that the data converted to numbers was not removed from the actual behaviour and experiences of the participants. The interviews contributed to reflecting the true nature of the responses. Furthermore a checklist (Appendix 1) collecting data on the demographic profile of the participants provided the researcher with information related to the context of the study.

3.3.2 Phase two: Qualitative inquiry

De Vos, Strydom, Fouché, Poggenpoel and Schurink (2000:241) define a qualitative inquiry as the exploring and describing the lived experiences of the participants. This could entail one common aspect, namely the interpretation or construction of the lived experiences of

the participants. When the group has the same experiences, it will help to keep the discussion focused for the duration of the interview. During phase two of the study, the researcher planned to conduct focus group interviews to further explore the identified coping behaviour of the families caring for a haemodialysed patient. A total of two focus group interviews with 3-4 participants in each (n=2) were conducted. A follow-up focus group interview could not be organised as participants were unable to agree and meet on a date that suited each person's diary. Individual interviews (n=2) were then arranged with the remaining participants until data saturation occurred, resulting in a total of nine participants being interviewed for this segment of the study (n=9).

3.4 STUDY POPULATION AND SETTING

A population is defined as all the elements (individuals, objects, events or substances) that meet the sample criteria for inclusion in a study; it can also be referred to as the target population (Burns and Grove, 2005:746). The setting for this study was based on the criteria as described by Burns and Grove (2007:326) and Polit and Hungler (2007:468). As such the setting was accessible to the participants and conveniently situated. The room where the interviews took place had adequate lighting, low noise levels, privacy with no telephone and comfortable chairs. In order to describe the context and population profile of the family members completing the F-COPES questionnaire a demographic sheet (Appendix 1) was included in the F-COPES questionnaire. The sheet collected data on the following variables: relationship to patient, age, race, and gender. The study population as it related to the individual phases are discussed in the paragraphs that follow.

3.4.1 Phase one

The study population for phase one included the family members as identified by the patient receiving chronic haemodialysis treatment. It was assumed by researcher that the family members of the patients in private clinics were literate and had a basic understanding of English thus enabling them to complete the questionnaire on their own. The study was conducted in the haemodialysis units of Fresenius Medical Care (FMC) South Africa, which offers haemodialysis to private patients in Gauteng. FMC has approximately 10 clinics (N=10) situated in and around Johannesburg, Vereeniging and Carletonville. The units treat on average 20 patients per day, excluding Sundays. According to the clinical manager of

these private clinics, the units collectively treated 654 patients in 2007 and 786 patients in 2008.

3.4.2 Phase two

The study population for phase two included the participants that indicated their willingness to participate in the focus group interviews. Participants were recruited by means of a separate letter attached to the questionnaire. Anonymity and confidentiality was maintained in that the completed invitation was collected separately from the completed questionnaires.

3.5 SAMPLING

Sampling as it occurred in the different phases is presented in the paragraphs that follow.

3.5.1 Phase one

In the sampling for phase one the researcher made use of an all inclusive sample of the FMC units (N=10) treating patients with renal failure in Gauteng. A total of six units (n=6) agreed to participate in the study. According to Burns and Grove (2005:343) inclusion criteria refer to the characteristics that a participant must possess to be included in the sample. Hence the inclusion criteria in this study were:

- Both men and women were included in the study, and in the event where the spouse of the patient was not available, then the primary person that took care of the patient and stayed in the same house was included.
- The participant had to have a basic understanding of English.
- The participants had to be over the age of 18 years.

The consulted statistician at NWU indicated that a sample size of above 40 participants was needed for this phase of the study. The total number of completed questionnaires returned amounted to 57 (n=57).

3.5.2 Phase two

The sampling for phase two of the study was purposive. Purposive sampling is described as a method entirely based on the judgement of the researcher, in that a sample is composed of elements which contain the most characteristics, or attributes representative of the

population (De Vos *et al.*, 2000:198-199; Burns & Grove, 2005:747). In this study only family members of the patients on haemodialysis were invited to participate in the focus group interviews. The place, date and time where the focus group interview took place were communicated to the participants two weeks in advance. As stated in section 3.3.2 an additional two individual interviews from the same sample was also included in the data analysis.

3.6 DATA COLLECTION

Data collection is defined as the precise and systematic gathering of the information needed to address a research problem. As such the method must be relevant to the research purpose or specific objectives, and questions (Burns & Grove, 2005:733; Polit, Beck & Hungler, 2001:460). An overview of data collection as it occurred in the two phases follows.

3.6.1 Phase one: Quantitative phase

Data was collected by means of a self-administered questionnaire (refer to Appendixes 1 & 2) for this phase of the study. Babbie (1999:39) defines a questionnaire as a set of questions on a form, which is completed by a participant in respect of a research project. In this study, the F-COPES questionnaires was hand delivered to the unit manager of the FMC units (n=6) that participated in the study. The unit managers were trained to obtain informed consent, explain the research process, distribute and collect the completed questionnaires. The questionnaire had closed-ended questions, with short simple sentences. When using questionnaire as a data collection method, it is important to make an appointment for collecting the questionnaires within 48 hours after delivery (Struwig & Stead, 2001:88). This ensures that fewer questionnaires will be lost if they are collected within a short space of time.

3.6.1.1 Instrument

Data was collected by means of the F-COPES questionnaire (McCubbin *et al.*, 1991). The F-COPES questionnaire is a self-administered survey consisting of 30 items that describe a variety of coping behaviours that family members may use in times of stress or crisis (refer to Appendix 2). The F-COPES questionnaire was drawn from a sociological research tradition based on the family stress literature (McCubbin *et al.*, 1991). It was decided to make use of

this questionnaire because it showed high clinical utility and reliability as described by McCubbin, Olson and Larsen (1982:363-366). The F-COPES recognises that family management of stress requires the integration of intra-familial resources with community resources. From a clinical perspective, using this questionnaire to assess the family's means of coping with stress, the clinician may become aware of the strategies that are involved in the family coping process. Diagnostically, the clinician can then suggest changes if needed, in the family's coping mechanism.

On completion of the F-COPES questionnaire the participants were asked to rate the items using a five point Likert scale with 1, "strongly disagree", and 5, "strongly agree". The 5 factors included in the instrument as sub-scales included: acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, and passive appraisal. Tway, Connolly and Novak (2007:251-259) defined the subscales as follow:

1. **Acquiring social support:** This subscale included nine items and measured the participant's ability to actively acquire support from relatives, friends, neighbours and extended family.
2. **Reframing:** This subscale encompassed eight items that focussed on the participant's ability to redefine stressful events in order to make them more manageable.
3. **Seeking spiritual support:** This subscale looked at the participants' ability to acquire spiritual support and included four items in the survey.
4. **Mobilizing family to acquire and accept help:** This subscale measured four items and evaluated the participants' ability to seek out community resources and accept help from others.
5. **Passive appraisal:** Passive appraisal included four items and focused on appraising problems by way of passive or inactive behaviour such as avoidance.

3.6.1.2 Reliability and validity of the instrument

The psychometric characteristics of the instrument were found to have a satisfactory internal consistency and good structural validity and reliability. The Cronbach's alpha coefficients were described as acceptable as the values ranged between .77 and .86 in two

studies done by Greeff and Holtzkamp (2007), again by Greeff and Fillis (2008) when they studied the resiliency in families. The overall alpha for the questionnaire from two samples was 0.86 and 0.87. The alpha reliability of the five individual subscales ranged from 0.62 to 0.84. Test-retest reliability for the five factors ranged from 0.61 to 0.95. Both studies were conducted in a South African context.

The F-COPES questionnaire is straightforward and easy to administer and score. A manual and norms are available and the copyright to use the scale was granted by the University of Wisconsin (Appendix 9). The average time to complete the questionnaire was estimated to be between 5-15 minutes. As stated in section 3.4 a demographic sheet (Appendix 1) collecting data on the context and population profile was also attached to the F-COPES questionnaire. Instructions on how to complete the questionnaires were also provided to the participants on the information sheet (Appendix 3) that was attached. The procedure for the collection of data in phase one of the study as well as the implementation thereof will be discussed in of chapter four.

3.6.2 Phase two: Qualitative phase

Data was collected by means of focus group interviews from all the participants that volunteered to be interviewed (n=7). Focus groups are group interviews, whereby the researcher guides the interview while a small group discusses the topic that the interviewer has raised (Morgan, 1998:1). Furthermore De Vos *et al.*, (2000:314) explain the focus group interview as a number of individuals among whom a distinguishable pattern of interaction exists. The assumption underlying the use of focus groups is that group dynamics can assist people to express and clarify their views in ways that are less likely to occur in a one-to-one interview. The participants were informed about the use of audio-tape during the interviews and consent was obtained to use a tape recorder to tape the interviews. Henning (2007:74-77) advises that the scene for the interview has to be set as free as possible so that the participants does not feel threatened and this was done. Proceedings for the interview were explained to the participants. Henning (2007:76) further advises that during the recording an eye has to be kept on the audio recording as these instruments are prone to technical as well mechanical problems.

The focus groups in this study comprised 3-4 individuals allowing for proper control of the discussion and equal opportunity to participate. A total of 7 participants were interviewed (n=7). An interview schedule with a set of initial open-ended questions that was derived in part from the literature and the research question was used to guide the exploration (Appendix 6). The questions included in the interview schedule were intentionally open-ended to elicit thick and rich descriptions from the participants. The researcher further adhered to the principles described by Krueger (2002) in conducting the interviews:

1. Participants were carefully recruited, with 3-4 in a group per session. The participants' relationship to the patient was varied ensuring a certain degree of homogeneity among the group.
2. The environment was comfortable with participants seated at a round table. The interview was audio-taped with the consent and knowledge of the participants.
3. The researcher was skilled in group discussions and established a permissive environment.
4. The interviews were systematically analysed, verified and appropriately reported. A comprehensive report will be provided in chapter 5 of this study.

As stated earlier the researcher also had to conduct two individual interviews in light of the fact that a suitable date and time for a final focus group interview could not be arranged. An alternative approach was considered and participants were invited to an individual interview. Saturation of the data occurred after two interviews resulting in a total of nine participants (n=9) for this phase of the study. Although focus group interviews and individual interviews are independent data collection methods; their combination can be advantageous to researchers as complementary views of the phenomenon may be generated (Lambert & Loiselle, 2007:236). The researcher had to combine the two methods of data collection because of striving towards data completeness as described by Adami (2005:19-29). Taking into consideration the fact that focus group interviews often allow for more dynamic discussion among participants, the individual interviews also proved to collect data that was rich and full of detail.

A notepad was used to document any field notes during the interviews and included non-verbal communication as well as participant behaviour during the interviews.

3.7 DATA ANALYSIS

Data analysis is defined as the systematic organisation and synthesis of research data (Polit, Beck & Hungler, 2001:460). The analysis of the data as it occurred in the study is provided in the paragraphs that follow.

3.7.1 Phase one

The consulted statistician of the NWU assisted with the analysis of the quantitative data and the interpretation of the descriptive statistics derived from the data. The data was captured using the EpiData 3.1 (Lauritsen, 2008) and was analysed using SPSS 16.0 (SPSS, 2007). A discussion on rigour as it applies to this phase of the study is presented chapter four.

3.7.2 Phase two

The data for both the focus group interviews and individual interviews was analysed following the steps of qualitative data analysis as described by Creswell (2009:184):

- Organising and preparation of data. The interviews were transcribed and field notes information was arranged according to sources and types.
- The information was read through so as to obtain a general impression and meaning about what the participants had said.
- When the general feelings of the participants had been identified, the information was organised into smaller sections, categorised and labelled.
- The information was then coded and themes were identified and described.
- Some form of meaning given how often specific words were used by the participants was checked as well as the chronology of the events as they were described by the participants.

A comprehensive discussion of the results of phase two of the research study and the trustworthiness of the data will be presented in chapter 5.

3.7.3 Integration of the data

Creswell (2003:212; 2009:208) states that the integration of the two methods can happen at any stage of the study. In this study the integration of the methods followed a sequential explanatory design meaning that the integration of the data occurred once data collection

and analysis in both phases had been completed. According to Creswell (2009:208) the collection of data in one form (quantitative) and have the other form (qualitative) provide supportive information can be viewed as embedding a secondary form of data in the primary form of data. The following diagram provides a visual illustration of the integration of the methods as they occurred in the study. A discussion of the integration of the findings is presented in chapter 5.

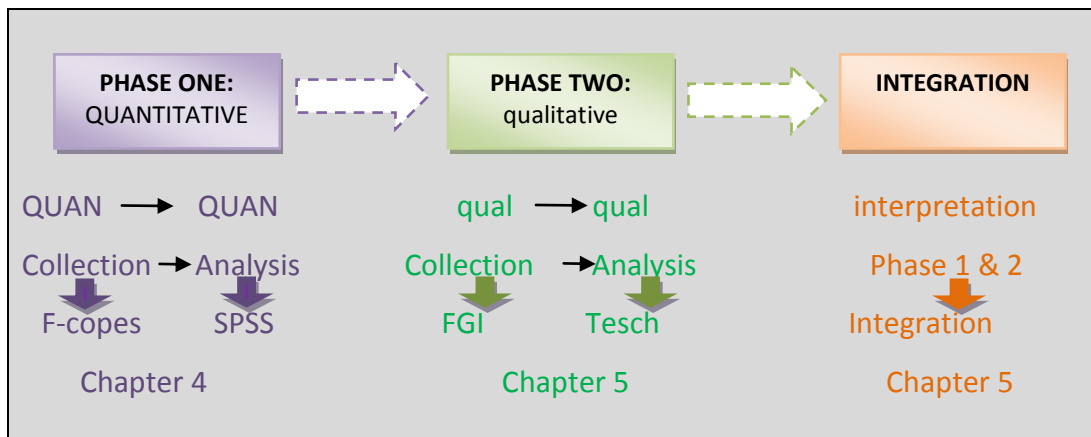


Figure 3.1: Integration of methods following a sequential design (adapted from Creswell, 2009:209)

3.8 ETHICAL CONSIDERATIONS

This study complied with the ethical requirements of nursing research and those of the NWU (Brink, 2008:30-43; Bak, 2005:28). The study proposal was submitted to the Ethics Committee of the North-West University (Potchefstroom Campus ref. number NWU- 00023-09-A1), Fresenius Medical Care management, and informed consent was obtained from all participants for both phases of the study (Appendixes 3 and 4). Informed consent was negotiated for the completion of the questionnaires; focus group interviews as well as the individual interviews conducted. The raw data collected did not include any information by which any of the participants could be identified. The inquiry was further guided by the following principles:

3.8.1 Respect

The researcher gave all the relevant information to the participants and informed them that participation in the study was voluntary, and that they could withdraw at anytime without

any fear of prejudice to their family members on haemodialysis. There were no risks anticipated in the study and the participants felt free to participate. The participants' autonomy was respected in that no coercion was used to obtain participation and information. An audio tape was used with agreement from participants during the focus group interview. The names of the participants were protected by using codes.

3.8.2 Beneficence

The participants were protected from any form of discomfort by providing counselling when needed. The service of a psychologist was available for the participants especially during the focus group interviews since some of the information required the services of a psychologist because of their sensitivity. Brink (2006:33) states that researchers should bear in mind that they are guests in the private spaces of the world of the participants and that our manners should be good and their code of ethics strict.

3.8.3 Justice

Participants were selected because they were directly related to the research study. Privacy was maintained by not discussing any information with anybody except for research purposes. All the participants were made aware of the audio-tape in use during the interviews. Data was processed anonymously as the information was returned to unit managers in sealed envelopes. Data was recorded and kept safe by the researcher. All the participants were treated the same and no one was given any advantage over the others.

3.8.4 Informed Consent

Informed consent was obtained from each participant in both phases. The informed consent documents were sent out as a comprehensive document containing: information letter, informed consent and questionnaire for the participants for phase one. Phase two consent was obtained from the participants before the interview. The unit managers were trained as field workers who distributed and collected the questionnaire responses from the participants for phase one. The researcher's contact details were provided on the information letter in case the participants wanted some clarification before agreeing to participate in the study. The researcher and participants had to sign the consent form as an agreement between the two parties (Creswell, 2003:65). During the second phase the

participants were informed that their real names were not to be used during the discussion so as to maintain confidentiality of the information. The participants were informed as to what would happen to the recorded information during the interview, which would be kept safe at the North-west University and only the researcher and the supervisors would have access.

3.9 CONCLUSION

In this chapter the research methodology of the study has been described as it unfolded in each of the phases. The applicable ethical considerations have also been discussed. The following chapter will present a discussion of the data analysis of phase one of the study.

CHAPTER 4

PHASE ONE: QUANTITATIVE DATA ANALYSIS: F-COPES QUESTIONNAIRE

4.1. INTRODUCTION

The previous chapter provided the reader with an overview of the research methods used in this study. In this chapter a description of the data collection and analysis of phase one is provided. Data was collected by means of the Family Crisis Oriented Personal Scale (F-COPES) questionnaire (McCubbin *et al.*, 1991). A total of 57 participants (n=57) completed and returned the questionnaire. Descriptive statistics was used to report the results and to address the first objective of the study namely, to identify and describe the coping behaviours used by families caring for haemodialysed patients.

4.2. CONTEXT AND PARTICIPANT CHARACTERISTICS

In order to describe the characteristics of the context and participants of the study, a demographic sheet was developed (Appendix 1) that addressed the following variables: the size of the family, relationship to the patient, gender, age and race of the participant. A discussion of these variables is presented in the paragraphs that follow.

4.2.1. Renal dialysis unit demographics

As stated in chapter 3, renal dialysis units of Fresenius Medical Care were selected as the research setting for the study. A total of six units (n=6) located in Gauteng were included in this segment of the study. Two of the units are based in Johannesburg, one in Soweto, two in Vereeniging and one in Carletonville. A visual presentation of the number of responses of the participants per unit is provided in Figure 4.1.

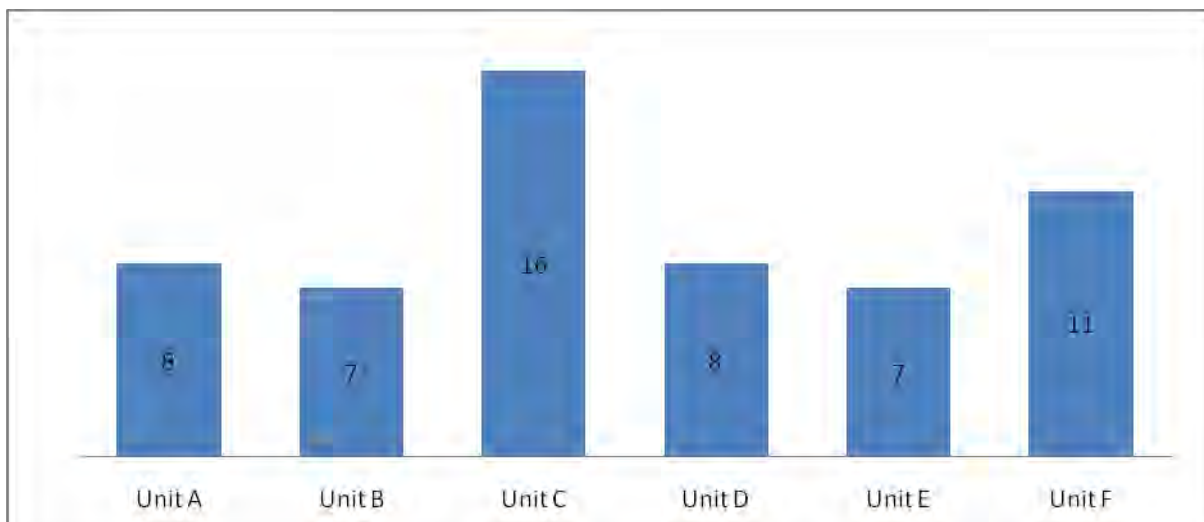


Figure 4.1: Participant responses per unit (n=57)

4.2.2. Participant demographics

A total of 57 completed questionnaires (n=57) was included in the analysis for this segment of the study. Family sizes ranged between 2-5 members per family with 28% (16/57) of the participants indicating a family size of four members. A total of 42.1% (24/57) of the participants reported to be wives of the patients, whilst 31.5% (18/57) reported to be husbands. Approximately 18% (10/57) of the participants were children and 8.7% (5/57) indicated other relationships that included nieces and nephews. The relationship of the participants to the patients is visually presented in Figure 4.2.

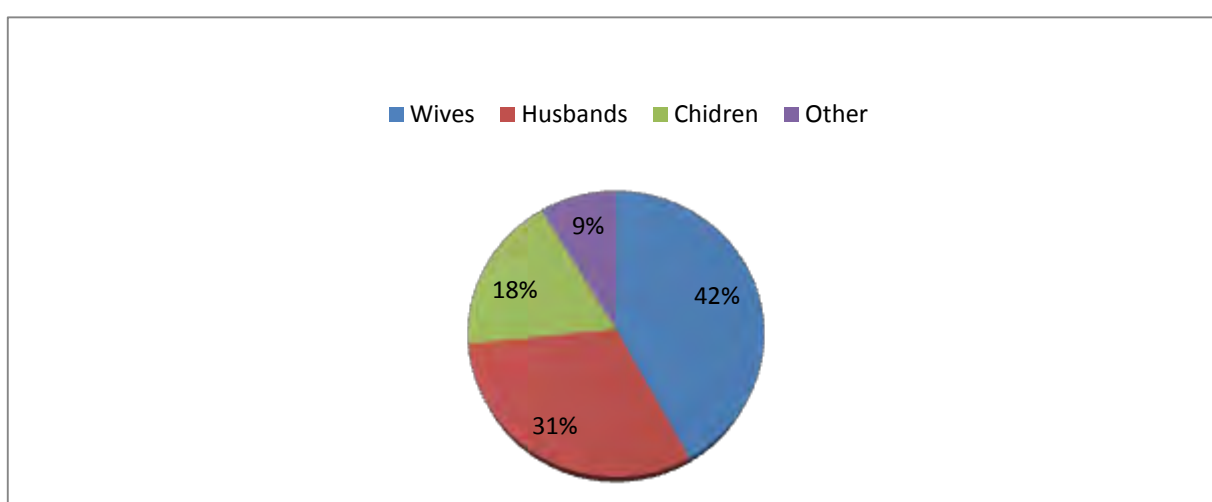


Figure 4.2: Relationship to the patient (n=57).

Approximately 57.8% (33/57) of the participants were female and 42.1% (24/57) male, as illustrated in figure 4.3.

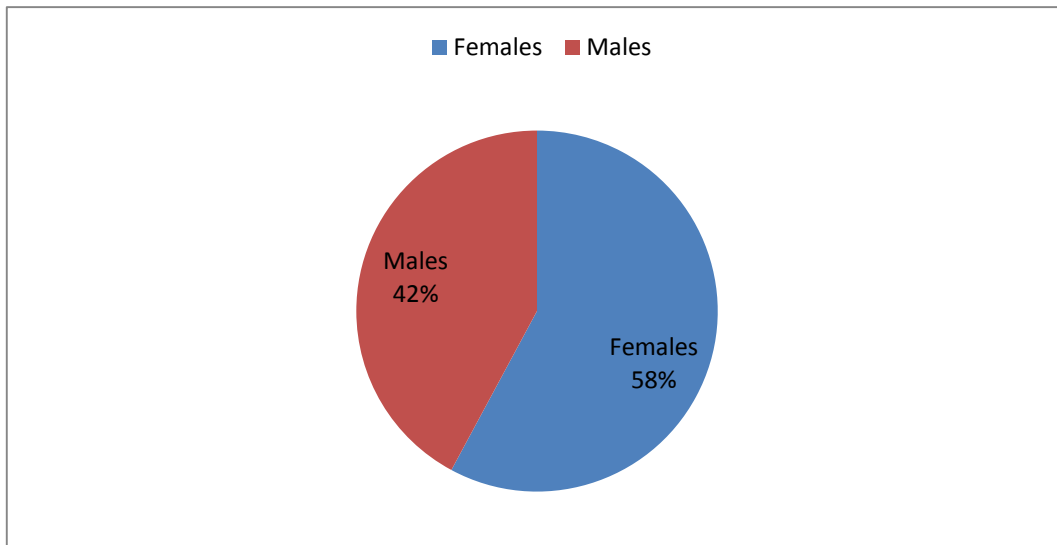


Figure 4.3: Gender of participants (n=57).

Approximately 43.8% (25/57) of the participants were in the age group 41-50 years whilst 10.5% (6/57) were aged between 31-40 years. An overview of the ages of the participants is provided in Figure 4.2.

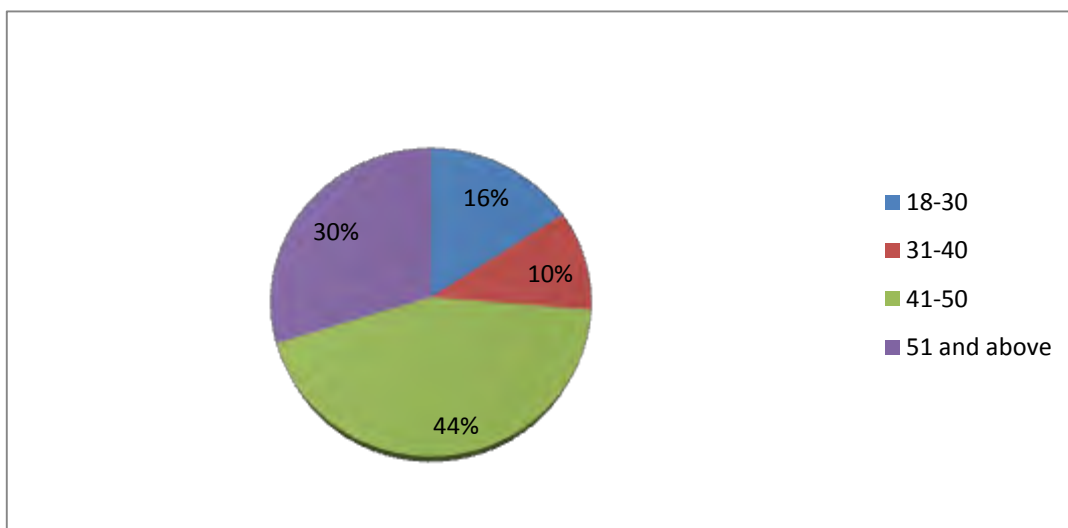


Figure 4.4: Ages of participants (n=57).

Of the 57 participants approximately 71.9% (41/57) were African, 15.7% (9/57) were Caucasian, 8.7% (5/57) were Indian and 3.5% (2/57) were Asian. The large population of black females caring for haemodialysed family members are not exclusive to the South African context. In a study reporting on haemodialysis in the USA, Harris (2003) found that black female caregivers was most affected when caring for a family member with chronic kidney failure. A separate sheet inviting participants to join in a follow-up focus group interview was sent with the survey in a separate envelope to participants. Of the 57 participants a total of 13 (1/57) indicated their willingness to participate in a follow-up focus group interview. The interview schedule was derived from the analysis of the quantitative data and the findings will be discussed in chapter five of the study.

4.3. DATA COLLECTION

As outlined in chapter 3, the Family Crisis Oriented Personal Evaluation Scale (F-COPES) questionnaire (McCubbin *et al.*, 1991) was used to collect data in order to address the first objective of the study which was to explore and describe the coping behaviours of family members of a haemodialysed patient (refer to Appendix 2). A brief overview of the instrument and the collection of the data for phase one of the study, is provided in the paragraphs that follow.

4.3.1. Instrument

The F-COPES questionnaire is a self-administered survey consisting of 30 items that describe a variety of coping behaviours that family members may use in times of stress or crisis. As stated in chapter 3, the questionnaire comprises five subscales, namely: acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, and passive appraisal. According to Hashemi, Razavil & Shahriari (2007:124-128) the subscales of the instrument can further be divided into two dimensions, namely internal family coping strategies and external family coping strategies:

4.3.1.1. Internal family coping strategies

Internal family coping strategies refer to the confidence of the family in active problem solving methods as well as more passive methods which include the following subscales (Hashemi, Razavil & Shahriari, 2007:124-128).

- Reframing

When the family redefines the problem in terms of the meaning it has for them, which can either be positive, negative or neutral.

- Passive Appraisal

When the family tends to do nothing during the crisis situations but hopes that the situation will fade away.

4.3.1.2. External family coping strategies

According to Hashemi *et al.*, (2007:124-128) external family coping strategies refers to the use of resources such as the church, support of the external family, friends and neighbours as well as available community resources. This coping behaviour includes the following subscales:

- Acquiring social support

This happens when the family obtains support outside the family, for example from friends and or neighbours.

- Seeking spiritual support

When faced with the crisis, family seeks religious support from church and members.

- Mobilising family to acquire and accept help

When the family is mobilised to obtain and accept help which can be professional or community based.

4.3.2. Procedure for data collection

The unit managers of FMC in Gauteng were provided with guidance in distributing questionnaires, assisting the participants with the completion thereof and their collection. The questionnaires contained guidelines for the participants on how they should respond to the questions, and questionnaires were filled in by the primary caregiver as identified by the patient. An envelope was also provided to the participants to return their sealed responses to the unit managers. The contact details of the researcher were also included. Data collection occurred over a period of two months and the questionnaires were collected from the unit managers within 48 hours after distribution.

A pilot study was not conducted as the instrument had undergone rigorous testing and retesting that showed it to be valid and reliable. Separate studies conducted in the United States of America (Troy *et al.*, 2007:259) as well as in South Africa (Greeff & Holtzkamp, 2007; Greeff & Fillis, 2008) had used the instrument and confirmed that the F-COPES questionnaire is a reliable and valid tool to study resilience in families coping with chronic illnesses. On completion of the F-COPES questionnaire the participants were asked to rate the items using a five point Likert scale with 1, “strongly disagree”, and 5, “strongly agree”, as they agreed or disagreed with a statement. The scale consisted of the 5 subscales as mentioned in section 4.3.1 and chapter 3. Each of the subscales contained several items that related to the conceptual meaning of the subscale. The mean values of the items as they relate to the subscales are discussed in section 4.5 of this chapter.

4.4. DATA ANALYSIS

A comprehensive discussion of the study population and sampling for phase one was presented in chapter 3. It was assumed that family members of the patients in private clinics were literate and had a basic understanding of English thus enabling them to complete the questionnaire on their own. As stated earlier a total of 57 questionnaires were received for analysis resulting in a 47.5% response rate. Table 4.1 provides a visual overview of the response rate for the study.

Table 4.1: Response rate of the participants for phase one

PARTICIPANTS	NUMBER (%)
Questionnaires administered	120
Returned questionnaires	57
TOTAL	57
RESPONSE RATE	47,5%

4.4.1. Data cleaning and capturing

The raw data was entered into Epidata 3.1 (Lauritsen, 2008) on two individual sheets and correlated for error eradication. The data was then imported into a software statistical program known as SPSS 16.0 (SPSS, 2007) for statistical analysis. None of the questionnaires were excluded from the analysis process.

4.4.2. Statistical analysis

In the process of data analysis, the frequency, mean scores of the subscales and standard deviation were determined. The mean was used to measure the central tendency of data distribution. The mean scores of the subscales ranged from 3.05 to 4.16 (table 4.7). Standard deviation was used to indicate how the values varied around the mean and also to determine how far out of mean the scores were. The individual subscale's means and standard deviations are presented in tables 4.2 to 4.6¹, whilst a discussion of the reliability indices is presented in section 4.5.1 and table 4.7.

4.5. FINDINGS

As stated in section 4.3, the F-COPES questionnaire encompassed five subscales that consisted of 30 items. Overviews of the sub-scales, the related items, the mean subscores as well as the standard deviations and a discussion of the results are presented in the paragraphs that follow.

4.5.1. Subscale 1: Acquiring social support

Acquiring social support referred to the participant's ability to actively acquire support from relatives, friends, neighbours and extended family. As indicated by the individual scores related to the items most of the participants preferred to share their problems with their close relatives rather than with extended families and neighbours. The average mean score for this subscale measured the lowest at 3.05 (table 4.7) and indicated that the participants did not look at social support as the most important aspect in their coping strategy.

¹ In this study, all figures with decimals were rounded off to two decimal places for ease of presentation.

Table 4.2: Acquiring social support: Related item means and standard deviations

Subscale 1: Acquiring social support		
ITEM	MEAN(M)	Standard deviation (SD)
1. Sharing our difficulties with relatives	3.80	1.07
2 Seeking encouragement and support from friends.	3.47	1.25
5. Seeking advice from relatives (grandparents)	3.68	1.41
8. Receiving gifts and favours from neighbours e.g. food, taking in mail	2.00	1.22
10. Asking neighbours for favours and assistance	2.14	1.39
16. Sharing concerns with close friends	3.47	1.31
20. Doing things with relatives (get-together, dinners)	3.71	1.38
25. Asking relatives how they feel about problems we face	3.01	1.56
29. Sharing problems with neighbours	2.21	1.34

4.5.2 Subscale 2: Reframing

This subscale focused on the participant's ability to redefine stressful events in order to make them more manageable. The average mean score for this subscale measured third highest at 3.89 (table 4.7), indicating that the participants believed that if they redefined their problems, they would be able to cope better with them. This subscale measured more toward the positive way of looking at how families coped when faced with a problem. The highest mean score in this subscale was found in item 24 that related to defining a family problem in a more positive way in order to prevent discouragement. All the mean scores in this subscale's items were above 3 indicating that all the items in this scale were viewed by the participants as strategies of coping when faced with a problem.

Table 4.3: Reframing: Related item means and standard deviations

Subscale 2: Reframing

ITEMS	MEAN(M)	Standard deviation(SD)
3. Knowing we have the power to solve problems	3.91	1.25
7. Knowing that we have the strength within our own family to solve our own problems	3.87	1.16
11. Facing the problems “head-on” and trying to get a solution right away	4.05	1.23
13. Showing that we are strong	3.84	1.19
15. Accepting stressful events as a fact of life	3.82	1.33
19. Accepting that difficulties occur unexpectedly	4.01	1.10
22. Believing we can handle our own problems	3.43	1.40
24. Defining the family problem in a more positive way so that we do not become too discouraged	4.15	1.13

4.5.3 Subscale: Seeking spiritual support

This subscale focused on the ability of the participants to seek spiritual support when facing a stressful situation. The average mean score for this subscale measured 4.16 (table 4.7) and was the highest mean score of all the subscales, indicating that “seek spiritual support” was the preferred method of coping behaviour for most participants in this study. Although many participants showed to they had faith in God (M=4.75), they did not seek advice from the minister (M=3.56). Some of the participants indicated that they would attend church services (M=4.22) even though they did not show any trust in the minister.

Table 4.4: Seeking spiritual support: Related means and standard deviations

Subscale 3: Seeking spiritual support		
ITEM	MEAN(M)	Standard deviation(SD)
14. Attending church services	4.22	1.11
23. Participating in church activities	4.00	1.13
27. Seeking advice from minister	3.56	1.50
30. Having faith in God	4.75	0.57

4.5.4 Subscale 4: Mobilising family to acquire and accept help

This subscale evaluated the ability of the participants to seek out community resources and accept help from others. The average mean score for this subscale measured 3.94 (refer to table 4.7) and indicated that most of the participants believed that family support would make them cope better with the problems they are facing. In this subscale the family doctor played an important role, as most of the participants exhibited trust in seeking advice from the family doctor when facing a problem. Though some participants felt they would seek professional counselling, almost the same number indicated they would make use of community programmes designed to help families in their situation.

Table 4.5: Mobilising family to acquire and accept help: Related means and standard deviations

4.5.2 Subscale 4: Mobilising family to acquire and accept help		
ITEMS	MEAN(M)	Standard deviation(SD)
4. Seeking information and advice from persons in other families who have faced the same or similar problems	4.19	1.12
6. Seeking assistance from community agencies and programmes designed to help families in our situation	3.52	1.55
9. Seeking information and advice from the family doctor	4.29	1.19
21. Seeking professional counselling and help for family difficulties	3.75	1.39

4.5.3 Subscale 5: Passive appraisal

This subscale focused on appraising problems by being inactive or doing nothing about the problem and hoping that the problem would fade away. Most of the participants answered that if they waited long enough, the problem would go away (M=3.98). There seemed to be no significant difference between item 17, “Knowing luck plays a big part in how well we are able to solve family problems” (M=3.59) and item 26, “Feeling that no matter what we do to prepare, we will have difficulty handling problems” (M=3.57). All the items in this subscale scored well above the average except for watching television (M=2.92).

Table 4.6: Passive appraisal: Related means and standard deviations

Subscale 5: Passive appraisal			
ITEMS	MEAN(M)	Standard deviation(SD)	
12. Watching television	2.92	1.57	
17. Knowing luck plays a big part in how well we are able to solve family problems	3.59	1.39	
26. Feeling that no matter what we do to prepare, we will have difficulty handling problems	3.57	1.41	
28. Believing if we wait long enough, the problem will go away	3.98	1.27	

In order to identify and describe the coping behaviours of families caring for haemodialysed patients by means of the F-COPES questionnaire, the reliability indices and mean scores of the subscales are presented in table 4.7.

Table 4.7: Reliability indices and mean score for the F COPES scale

SUBSCALE	Number of items	Cronbach's Alpha (n=57)	M (SD)
Acquiring social support	9	0.84	3.05 (0.89)
Reframing	8	0.74	3.89 (0.73)
Seeking spiritual support	4	0.64	4.16 (0.79)
Mobilising family to acquire and accept help	4	0.66	3.94 (0.94)
Passive appraisal	4	0.56	3.52 (0.93)

The above table reflects 29 items. Item number 18 is not taken into account, neither in the subscales nor the total scores, as per instructions on the scoring manual for the F-COPES questionnaire. The table indicates that most of the participants seem to rely on spiritual support when faced with a crisis as evidenced by the mean of 4.16. Participants also seemed to rely on the mobilisation of the family to acquire and accept help (M=3.94). "Acquiring social support" showed the highest reliability with a Cronbach's alpha of 0.84 though it measured the lowest in terms of mean scores (M=3.52).

4.5.1. Validity and reliability

De Vos, Stydom Fouché and Delport (2005:160) define validity as the extent to which an instrument accurately reflects the concepts it is to measure. In other words, validity in this study implied that the instrument measured the coping behaviours of the haemodialysed patient's family. In ensuring face validity, the instrument was reviewed by two experts in the field of nephrology nursing and was found to include variables considered relevant to the phenomenon under investigation in this study. In terms of content validity three separate studies (Tway *et al.*, in 2007; Greeff & Holtzkamp, 2007; Greeff & Fillis, 2008) concluded that content validity was established on the basis of judgement, that is, the researchers or experts was of opinion that the questionnaire covered the full range of meanings of the variable being measured.

Reliability is primarily concerned with how well an instrument measures what it is supposed to measure. Reliability therefore refers to the consistency of measurement, meaning that if the same variable is measured under the same conditions, the instrument will produce identical findings (De Vos *et al.*, 2005:163). Burns and Grove (2007:365) stated that reliability exists in degrees and is therefore indicated as a correlation coefficient. As such a correlation coefficient of 1.00 is indicative of perfect reliability whilst a coefficient of 0.00 indicates no reliability. The Cronbach's alpha coefficient is the most commonly used measure of reliability (Pretorius, 2010:103). The Cronbach's alphas for the subscales of the F-COPES ranged between 0.56 to 0.84 and were considered satisfactory. The subscales "Passive appraisal" and "Seeking spiritual support" had modest reliabilities with alpha values of 0.56 and 0.64 respectively (Nunnally & Bernstein, 1994; Field, 2005).

4.6. SUMMARY

In this chapter the researcher presented the results of the first phase of the study. The findings for each of the subscales have been presented as well as their reliability indices. From the findings it was evident that most of the participants seemed to rely on spiritual support and mobilisation of the family to acquire and accept help as the coping behaviours of choice when faced with a chronic illness. A description of the context as it related to the information obtained from the demographic sheet was also presented. The following chapter will focus on qualitative data collection and analysis and how it related to the second objective of the study.

Chapter 5

PHASE TWO: QUALITATIVE DATA ANALYSIS AND INTEGRATION OF THE FINDINGS

5.1. INTRODUCTION

In the previous chapter the researcher presented the quantitative data analysis of the first phase of the study. The data from this phase was used to inform the interview schedule (refer to Appendix 6) for the second phase of the study. The overall intent of the study was to describe and explore the coping behaviors of the families of a haemodialysed patient in a private clinic setting. In this chapter the researcher will present the strategies used to collect and analyse the data for the second phase of the study. Finally the results of the second phase will be integrated in an attempt to provide supportive evidence for the results from the first phase (Creswell, 2008:208).

5.2. CONTEXT AND PARTICIPANT CHARACTERISTICS

The context for this phase of the study was similar to that of the first phase. Private rooms at the included FMC dialysis units (n=6) were used for the focus group interviews, whilst the individual interviews were conducted at the participants' homes. The rooms at FMC units formed part of the main building but were a distance from the operational site. In terms of the relationship to the patients, all of the participants indicated to be wives and their ages ranged from 45 to 62 years. All the participants interviewed were of the black African descent and their family sizes ranged from 4-6 members.

5.3. DATA COLLECTION

Data was collected by means of focus group- and individual interviews. As stated in chapter three, the researcher had to provide for an alternative strategy in terms of data collection because a third focus group interview could not be arranged. A total of two focus group interviews with 3-4 participants in each (n=7) were conducted followed by two individual interviews (n=2) bringing the total number of participants to nine (n=9). As stated in chapter three the researcher adhered to the principles described by Krueger (2002) when

conducting interviews. Participants were recruited for the focus group interviews; with 3-4 in a group per time to allow for adequate discussion time and that each participant was allowed the opportunity to voice an opinion. The participants' relationship to the patient was that of wife ensuring a certain degree of homogeneity among the group. The environment in case of the focus group interviews was comfortable with a round table sitting style. A quiet room with comfortable chairs at the participants' homes were used for the individual interviews. The interviews were audio-taped with the consent and knowledge of the participants. The researcher also documented any non-verbal communication as well as participant behaviour by means of field notes. Data was collected until no new information emerged from the participants, denoting data saturation. The interviews and field notes was systematically analysed and verified by a co-coder.

5.3.1. Recruitment of participants

As stated in chapter 3, participants for the second phase of the study were recruited by means of a separate invitation that was attached to the F-COPES questionnaire (refer to Appendix 5). A total of nine (n=9) participants completed and returned the invitation. The researcher telephonically contacted all the participants to arrange for a suitable date and time for the interview. Some of the participants however indicated that they were no longer interested in participating in the interview, whilst the phone numbers of others seemed to be inaccurate. In light of this the researcher decided to approach additional family members present on the days that patient's received their haemodialysis treatment. The researcher subsequently informed these family members of the aim and objectives of the study, invited them to participate, and obtained informed consent from the willing family members. A focus group interview was scheduled for Johannesburg and Carletonville. The two individual interviews were conducted at the participants' homes as per their request. The collection of data across the units in Gauteng allowed for variation in the perspectives of the participants regarding coping behaviours. Nine participants (n=9) were purposively selected to participate in the interviews.

5.3.2. Execution

The researcher conducted both the focus group and individual interviews and made use of an interview schedule (refer to Appendix 6) with a set of open-ended questions to guide the

exploration. The questions were derived in part from the findings of phase one of the study and the literature reviewed related to the research question. The interview guide ensured that the researcher asked participants the same questions in virtually the same manner. Participants were informed that the interviews would be audiotaped and informed consent was obtained prior to conducting the interviews. The use of an audiotape allowed the researcher to fully engage with the participants during the interview and provided detailed data after the interviews. In this study, a tape recorder was used for the interviews and in transcribing the interviews. The verbatim transcriptions ensured an accurate account of the data was captured. The audio recordings during the interviews did not seem to bother or influence the responses of any of the participants. The non-verbal communication, posture and speech tone of each of the participants indicated a high degree of comfort in discussing the phenomenon under investigation.

A space for the participant code and the date of the interview was indicated on each of the verbatim transcriptions (refer to Appendix 7). Each transcript was typed one and a half spaced with double spacing between the speakers. A margin of 10 centimetres was set on the right-hand side of the page for coding purposes and each line was numbered for easy reference. Field notes for each of the interviews were compiled immediately after the interview noting the participants' non-verbal communication, posture, speech tone and any other noteworthy changes or episodes.

5.4. DATA ANALYSIS

The data was analysed following the steps of qualitative data analysis as described by Creswell (2009:185-187). According to Creswell (2009:184) qualitative data analysis is an ongoing process that involves continuous reflection and asking analytical questions about the data. Although the steps for the analysis of the data are presented in a hierarchical fashion it was by no means a linear process as some of the steps was interactive and interrelated (Creswell, 2009:185). The steps are presented below:

- Organising and preparation of the data for analysis: The researcher transcribed the interviews and typed field notes and arranged the information according to the sources. As stated earlier the transcriptions were assigned a participant code to assist in the organisation of the data.

- Read through the data: The information was read through so as to obtain a general understanding of what the participants said. At this stage the researcher added notes in the margin provided on general thoughts about the data.
- Detailed analysis and coding of the data: Once the researcher had a general feeling of what the participants said the information was organised into smaller chunks (so called sub categories). This process is known as coding the data and also included organising the chunks of data into categories. The categories were then labelled with a term representative of the conceptual meaning of the category (Creswell, 2009:186). The researcher also consulted Tesch's guidelines for the analysis of qualitative data (Tesch, 1990:142-145) at this stage. To that end the shortest interview was read first and notes added in the margin. The researcher repeated this process with the remainder of the interviews and the notes were then clustered together as major topics. These topics (representative of the categories) were then labelled with a descriptive term.

In exploring the coping behaviors of the families of haemodialysed patients in private clinics the following categories emerged from the data: challenges, support structures, coordinated care, and beliefs about diseases. A discussion of the categories as well as a visual illustration (refer to table 5.1) thereof are presented below.

Table 5.1: Categories and subcategories related to the coping behaviour of families of the haemodialysed patient.

CATEGORY 1: CHALLENGES	CATEGORY 2: SUPPORT STRUCTURES	CATEGORY 3: COORDINATED CARE	CATEGORY 4: BELIEFS ABOUT DISEASE
<p>Psychological challenges:</p> <ol style="list-style-type: none"> 1. Not getting a donor 2. Diet changes 3. Being on the waiting list for a long time 4. Patient's health not being well/ not progressing 5. Patient ageing 6. Patient going to die 7. Partners/husbands giving up on life e.g. preferring to die 8. Forgetfulness 9. Not being able to go for holidays i.e. restricted social life or entertainment. 	<ol style="list-style-type: none"> 1. Telling themselves they are not the only ones. 2. Talking to other people i.e. socializing/ extended family, friends at church. 3. Counselling others from work. 4. Support groups/ Social clubs. 5. Praying /direct contact with God. 6. Support groups helps but temporarily. 	<ol style="list-style-type: none"> 1. Nurses have knowledge that can encourage coping. 2. Dialyzing as a control measure for a long time. 3. Have contact with the unit/nurses all the time. 4. Establish support groups which will information on diet, life adjustments/ life style modifications to be done. 5. Support groups should be with their husbands- to create space for opening up. 6. Group counselling so as to 	<ol style="list-style-type: none"> 3. Disease can be natural and supernatural. 4. Believes that God can heal both.

<p>Challenges related to partners behaviour:</p> <ol style="list-style-type: none"> 1. Anger (having to submit to their anger, ignore) <p>Women submit and men ignore the behaviour</p> <ol style="list-style-type: none"> 1. Stress and frustration 2. Bottling up the real feeling to avoid trouble <p>Exclusion by patients:</p> <ol style="list-style-type: none"> 1. Being regarded as an extended family by husbands. 2. Discussing other things with their families i.e. sisters, brothers. 3. Partners trusting their families more. 4. Emotional abuse. 5. Hurt due to exclusion e.g. asking daughter to for something than partner. 6. Rejection. 	<ol style="list-style-type: none"> 8. Men accept help from families easily. 9. Women find it hard to get assistance from the families. 	<p>assist each other.</p>	
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5.4.1. Category 1: Challenges

According to the Collins Concise Dictionary (2001:247) a challenge is defined as a demand on something or somebody. From the interviews it was evident that the challenges confronting the family of a haemodialysed patient seem to be more psycho-social in nature. The patient however experience both physical and psychological effects on them and these often lead to stress in the family. According to Thomas (2008:289) both the patient and the family face many potential changes and these can be related to: role change, change in appearance, sexuality, and financial challenges. From the data the following subcategories emerged related to the challenges faced by the families in this study.

5.4.1.1. Psychological challenges.

- Age

Some of the participants were concerned about the age of the patients as some of the patients' ages were over 50 years. The family often did not know what to expect from dialysis in older people. Some of the participants reported that patients give up on life and some preferred to die. This is confirmed by Daurgirdas *et al.*, (2001:413-418) reporting on the high rates of suicide among renal failure patients. According to Thomas (2008:84) the attitude of many elderly patients is that they have already 'had a good life 'and have reached an age when death would not be unlikely in any case. Furthermore they also feel that they have not been cheated of a normal lifespan by their illness. As some of the participants stated:

"...Yeah....okay...with me I think the main challenge eeeehhh it's his age...and the other thing is ntate (sotho word meaning father but used here as a sign of respect to the husband) is diabetic and we are happy when he comes back from dialysis but with complaints of cramps and will be miserable the whole day"

"...eeehhh... my husband will most of the time say "if it is the will of God, I will die and I think it will be better for the family.....???"

- Dialysis as a temporary measure

Most of the participants viewed dialysis as a temporary measure that exposed their husbands to more physical problems like fatigue, cramps and weight loss. The participants seemed knowledgeable about permanent interventions such as kidney transplants:

“...for now it is working, but the solution is to get a donor...”

“It will be six years now, the challenge is that you can see that he is not progressing well, this is just a control measure but not a solution to the problem...and you know....”.

Participants seemed unsure of the dialysis process and were also concerned about the diet of a chronic renal failure patient. Participants often have to rely on information from the patient as contact with the renal nurse is limited. Information mostly goes to the partners via the patient and not the renal nurses. This gap in communication between the healthcare team and the family was also described by Auer (2002:141-144) who feels that the professional support provided to the family of patients receiving haemodialysis treatment by the health care team is inadequate considering the fact that they are the main providers of care for the older sick and disabled people. This was also confirmed by Theobald (1997:595-601) who said this problem may be due to a lack of knowledge about how to deal and communicate with the family members of patients. As one of the participants stated:

“Hmmm....we need more information on this....as nate will come home and say my food has to be soaked and we all eat what he says...sometimes he does not want salt and same applies to all the in the family as a way of showing support to him but....know...he does not appreciate....”.

Irrespective of whether a therapeutic diet is recommended to treat any of the other conditions the patient may have, all patients with chronic renal failure should receive a dietary assessment and be screened for malnutrition (Thomas 2008:319; Daugirdas *et al*, 2001:420).

- Frustrations

Most of the participants reported on feelings of frustration related to the forgetfulness and behaviour of patients at home. Some of the participants were of opinion that their partners engaged in this behaviour to deliberately frustrate them (participants). Daugirdas *et al.*, (2001:3) reported on patients' altered mental status that is often related to uraemia. Subtle changes in personality were also reported in chronic renal failure patients. According to Thomas (2008:83) patients often present with irritability, quick to take offence and unwillingness to follow medical advice. Furthermore the spouse and family may take the brunt of the negative feelings and often lament that on hospital visits, the patient claims all is well and yet complains of numerous physical problems at home (Thomas, 2008:83). The above is confirmed by the following statements:

"...sometimes you don't know what to say to them which can make them feel better..."

"...Hmmm... my wife is lazy to think...she is stubborn... she is selfish..."

"Yeah.... I sometimes feel that I am not in the picture of his life... and ..."

"Okay...I thought I was the only one who was faced with this forgetfulness"

Chronic renal failure affects one family and this condition can have an impact on the individual and this impact affects everybody around the patient. Ross and Deverell (2009:303) are of the opinion that the family is a complex social system; stress in one of the family member is likely to impact on every other family member and affect the functioning of the family as a unit.

5.4.1.2. Challenges related to partner's behaviours

Most of the participants in this study fulfilled the role of wife in caring for their partner and reported on the submissive role they had to take in reaction to their partners' behaviour:

"...ntate...you know what...? I will ignore him for few seconds and go back again to the same abusive words.....hey...I really don't know..."

"...for me ignoring him does not work as he will also sit there and read the news paper until he falls asleep on the couch...so...as a wife I will go back and ask...are you ok..?"(Laughter)

According to Wright and Leahey (1994:24) this type of behaviour can be described as complementary relationships. Complementary relationships usually consist of one individual giving and the other receiving. This patriarchal structure leads to unwillingness of a female member to determine her own preference or accept responsibility without consultation with a senior male member of the family (Thomas 2009:85). According Strozier (2002:46) patriarchy is defined as an androcentric social system in which the role of the father is central to social organisation, and where fathers hold authority over women, children and property. In a study conducted by Therborn (2004:17-44) about African families in a global context, it was concluded that the traditional African family, in all its main variants was strongly patriarchal. In addition, the backbone of African patriarchy was the power of the elders in societies where age, as the basis of authority and solidarity, was more important. Furthermore the study also showed that classical patriarchal family had decisive power clearly vested in the husband and/or his father to whom the wife owed submission and obedience, and wives are considered investments for husbands (Therborn, 2004:33). It is from this concept that most of the participants were submitting to their husbands as most of all of the participants are of black African descent where this hierarchy of male dominance is practised. A study conducted in Europe by Robila (2004:1370-1373) showed that the views of the woman on patriarchy were still maintained as their primary responsibilities were childcare and household. In addition the study also revealed that while both spouses were expected to work, the woman was also expected to assume housework and childrearing responsibilities. This native hierarchical structure though not so strong in this new era, is still being practised by most of the families especially in South African context.

5.4.1.3. Exclusion by partners/patients

The final challenge related to the exclusion of the participant by the patient. Participants expressed feelings of hurt as the patients excluded them in their daily living problems. Some of the participants felt rejected by their partners when the patients trusted their extended family (such as brothers and sisters) more than the spouse. This is confirmed by Thomas (2008:95) when saying family structures and hierarchy should also be taken into account, since some cultures regard any major decision as traditionally the preserve of the senior male member of the family. As some of the participants stated:

"I am not related to you by blood... we are just related by marriage..."

"...hmm... (silence) you know even if I am the wife, my husband will always consult with his siblings, because he feels they are his blood and he trust them more than this person (pointing at herself) who is an outsider"

"...eee... sometimes I feel disregarded and not being taken seriously by my husband..."

"...my wife does as I say in my house (laughter)ntate...I am the man of the house..."

5.4.2. Category 2: Support structures

In terms of support structures the participants seemed to rely on experiences of others in coping with their partner's illness. Participants had the following words to say about coping:

"...Okay... I see now that I am not the only one with all these problems I have at home...forgetfulness, irritability and complain..."

"hmm... I did consult one Psychologist because I wouldn't say anything to my husband soooo...I was looking for professional help...you know...eee...I would think maybe I am overreacting this man is still behaving normally..."Silence"...I also attended EAP (Employee Assistance Program at work because I needed counselling..."

"...When you organise support groups... please let the patients be there as well..."

"....so! we are very grateful to have been invited to come here today and share all this...it's really a healing process...I have learnt so much from bomama (mothers) and we have to ask God to give us power (looking sad)...as I think he is on our side and I always gather my strength from these verses: Matthew 11:28 and Psalm 103".

"Yeah...(Sigh) all I can say is that God can never give you a burden bigger than your strength...thank you 'ngwanaka'(my child) for this meeting as we've opened up and this is a healing on us...we must go back and start afresh...." (Exchanging telephone numbers)

In this section it was also evident that most of the participants seemed to agree that their only hope was God and Him performing a miracle so as to get them out of these challenges.

None of the participant confirmed seeking advice from the priest, thus supporting the findings from phase one. All of the participants regarded the priest as an outsider and stated that they would rather pray to God by themselves. Davies and Byock (2004:15-26) feels that spiritual and mind care has to be integrated in both patient and family care. However they also feel that this is the part that is left until the last moment when family is faced with end-of life care. On the other hand, a family's support for its members can act as a social buffer against the stresses and strains of daily life and can have a positive effect on coping (Ross & Deverell, 2009:303). Men appear to accept help from the family easy while women seem to experience problem.

5.4.3. Category 3: Coordinated care

Ziegert, Fridlund and Lidell (2005:353-361) claim that by listening to the family member's experiences of caring for the patient at home, nursing staff can acquire knowledge about their everyday life situation, thereby making it possible to improve co-ordinated care planning. The following statements from the participants are provided in support of the above literature:

"...nurses have knowledge that they must give to us as the spouse as well as the patients themselves as there are so many things going on with this disease, things like diet..."

"...I think the support groups for everybody will help us understand the situation of our spouses and what they are going through...."

Thomas (2008:79) feels that the philosophy behind information groups is, therefore, to present a realistic but not over detailed picture, which sets the scene for a cooperative and interactive relationship with the team. Furthermore it is very important to discuss the possible dialysis options at some length with the individual patient and family, preferably in the home surroundings but, if this is not possible it can be done in the hospital. In addition, spouses need to know that they can contact the unit with their concerns, without being labelled as tiresome (Thomas, 2008:80-81). Tjale and De Villiers (2004:13) are of the opinion that people's culture and underlying belief system influence how they perceive health, illness and care, and what their expectations are with regard to how and by whom health problems should be prevented, diagnosed and treated.

5.4.4. Category 4: Beliefs about disease (Reframing)

In this category, participants stated their beliefs about how people get diseases or sickness. This can be attributed to reframing (from the findings of the first phase of the study) as the participants are trying to view the condition from another perspective. They would like to redefine the problem as to how it came about and how they can solve it. Furthermore Tjale and De Villiers (2004:13) concluded that there are two ways of curing the disease namely, lay care and professional treatment. Lay care refers to assistance that is based on the same cultural experiences or belief systems. This type of care is very common and is divided into four categories: Family care, care provided by the patient's social network, care from self-help groups and self-treatment or self-medication (Tjale & de Villiers, 2004:12-13). The following excerpts are provided:

"...I think the this disease came to us because God will not give you the burden that is too heavy for you to carry....God is the only one who can give and take..."

"...When my wife is at home, she is sicker than when she is with my sister-in-law and her husband...I think my neighbours are bewitching her..."

Ross and Deverell (2009:204-205) believes that socio-cultural beliefs are likely to influence people's perceptions regarding how one contracts the disease and how it can be treated. In a study done on 23 black South African women by Riffe and Fouché (2001:1-19) revealed that they believed that HIV is caused by violating *magome*. *Magome* is described as the period of mourning that a spouse must observe after the death of his or her partner. This phenomenon needs to be investigated more.

5.5. RIGOUR

Rigour is the umbrella term used to describe the strategies employed by researchers in ensuring the validity of their findings (Klopper & Knobloch, 2009:3; Pretorius, 2010:143). Over the last few decades, scholars have increasingly been debating the numerous standards of rigour in qualitative research (Chiovitti & Piran, 2003:428). Traditionally, rigour in qualitative research is encompassed by a concept known as trustworthiness. Trustworthiness includes strategies of credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985:290; Klopper & Knobloch, 2009:3; Pretorius, 2010:143).

An overview of the strategies applied in the research study to ensure the trustworthiness of the findings is provided in table 5.2.

Table 5.2: Strategies to ensure trustworthiness

STRATEGY	APPLICATION	SOURCES
CREDIBILITY	<p>To conduct the investigation in such a manner that will increase the believability of the findings.</p> <ul style="list-style-type: none"> -Prolonged engagement with the participants to build trust and rapport -Remained in the field until data saturation was achieved. -Spent sufficient time in the field to gain understanding of the context. -Triangulation: multiple methods to collect data, multiple perspectives in interpreting the data, the use of co-coder to analyse the data. -Member checking: participants confirmed the interpretation of the data. 	<p>Lincoln and Guba (1985:294) Polit, Beck & Hungler (2001: 313) Polit, Beck & Hungler (2001: 313)</p>
TRANSFERABILITY	<p>The degree to which the research may be applied to another context and yield similar results.</p> <ul style="list-style-type: none"> -Saturation was achieved, indicating an adequate sample. -Provided a detailed description of the realisation of the data. -Thick description: rich thorough description of research setting. 	<p>Lincoln and Guba (1985:297). Burns and Grove (2005:358) Polit, Beck & Hungler (2001: 316)</p>
DEPENDABILITY	<p>The stability of the data over time and conditions</p> <ul style="list-style-type: none"> -Data has to be stable over time and under any conditions. Data has to be undergo audit inquiry as it is supposed to have supporting documents 	<p>Polit, Beck & Hungler (2001: 315)</p>

CONFIRMABILITY

The degree to which the results are confirmed by the data and not the subjectivity of the researcher.

- Use of the co-coder.
- Eliminating researcher bias as for as possible.
- Confirming the findings with participants.

Lincoln and Guba (1985:298).

Polit, Beck & Hungler (2001: 315-316)

Polit, Beck & Hungler (2001: 315-316)

5.6. INTEGRATION OF DATA

As stated in chapter three, the study followed a sequential explanatory design whereby quantitative data was collected and analysed followed by the collection and analysis of qualitative data (Creswell, 2009:211). The findings of the first phase were used to inform the data collection for the second phase. In this study the quantitative data was given more weight than the qualitative, thus embedding the qualitative data in the quantitative data (Creswell, 2009:208). During the integration of the findings the categories derived from the qualitative phase (phase two) of the study was compared to the results of the quantitative phase (phase one). This was done to assess concordance (Riegel, Dickson, Kuhn, Page & Worrall-Carter, 2010:891) by comparing the narrative account of the participants with the quantitative results obtained from the F-COPES questionnaire. An overview of the results and how the findings were integrated is presented in table 5.3.

From the findings of the first phase of this research study it was evident that most of the participants would utilise spiritual support (*seeking spiritual support*) when faced with a crisis. These findings were supported by the evidence that emanated from the analysis of the data in the second phase of the study (**support structures**). Most of the participants relied on their faith and God's supernatural ability to heal their family member. It was also confirmed that although family members placed a high value on spiritual support it did not necessarily implied support from the priest or minister. *Mobilising the family to acquire and accept help* measured second highest on the F-COPES questionnaire in phase one. Findings from the second phase also seemed to report on participants' relying on **support structures** provided by the family as a coping behaviour. Interesting to note was that in phase two, participants placed a high value on support from others who are facing similar challenges or have faced similar challenges. In phase one however, this item did not measure highest as participants seemed to place a higher value on information and advice received from the family doctor.

In terms of *reframing*, which measured third highest on the F-COPES questionnaire, the category related to **beliefs about diseases** provided support for this subscale. In the context of this study participants redefined the problem in terms of cultural beliefs related to diseases. Though most of the participants believed that disease can come as a natural way

of living, some believed that diseases can have a supernatural meaning. This was explained in terms of so-called bewitchment and western medicine is not typically used in curing supernatural occurrences. In terms of *acquiring social support*, both **coordinated care** and **support structures** seemed to concur with the findings of this sub-scale. Participants cited the lack of knowledge about renal failure and how this contributed to them not knowing what to do when faced with a crisis. Support groups were advocated for by most but professional counselling was not utilised by the participants. This can probably be attributed to the fact that husbands (often the patients) did not approve of their wives discussing the details of their disease with a so-called outsider. The participants seemed to agree with sharing their problems with relatives but did not seem to ask for advice thus supporting the findings from phase one of the study.

When reviewing table 3.5 it was evident that *passive appraisal* as a sub-scale from phase one, (implying being inactive or doing nothing about the problem and hoping that the problem would fade away) was not supported by any of the evidence from phase two. Similarly **challenges** as a category for phase two did not relate to any of findings from the subscales presented under the F-COPES questionnaire. This can probably be attributed to a number of reasons that was beyond the scope of this study.

5.7. SUMMARY

This chapter provided the reader with an overview of the second phase of the research study. The chapter concluded with a discussion of the trustworthiness of the findings as well as the integration of the results. In the next chapter the researcher will conclude with an overview of the limitations and recommendations applicable to the study.

Table 5.3 Integration of the results

RESULTS FROM PHASE ONE RANKED ACCORDING TO MEAN VALUES	CATEGORIES FROM PHASE TWO
1 Seeking spiritual support (M=4.16)	1 Beliefs about diseases
2 Mobilising family (M=3.94)	2 Support structures
3 Reframing (M=3.89)	3 Coordinated care
4 Passive appraisal(M=3.52)	4 Challenges
5 Acquiring social support (M=3.05)	

Chapter 6

LIMITATIONS AND RECOMMENDATIONS

6.1. INTRODUCTION

In this chapter the researcher present the limitations encountered during the study, recommendations for nursing science, nursing practice and nursing research.

6.2. LIMITATIONS OF THE STUDY

- The study was conducted in the dialysis units of one private company in Gauteng province therefore limiting the findings to that context.
- Only six of the ten units invited participated in the study thus making it hard to generalise the findings.
- The study sample proved insufficient (n=57) for generalisation of the results.
- In the second phase some of the participants did not have an interest in participating in the interviews anymore.
- Some of the participants could not be reached by the researcher. The researcher had to change the method of data collection to include individual interviews.

6.3 RECOMMENDATIONS

The following recommendations originated from the research study and will be discussed as they relate to nursing science, nursing practice and research in research in nursing:

6.3.1 Recommendations for nursing science

- Introduce nephrology nurses to holistic care of the clients with chronic renal failure including the family.
- Focusing nephrology nurses' attention on the impact of chronic renal failure and haemodialysis on the family.

6.3.2 Recommendations for nursing practice

- Nurses in dialysis units need to start and strengthen the already existing support groups as most of the participants cited lack of knowledge about the condition.
- Establish networks between different dialysis units so as to try to have a uniform approach to the treatment of renal failure.
- Present the findings of the study to the management of FMC units in order to facilitate holistic nursing care.

6.3.3 Recommendations for research in nursing

- Further studies on a larger scale involving both provincial and private hospitals related to dialysis treatment.
- Further exploration of participants' view of the subscale "passive appraisal" and the category "challenges".
- Validation and extension of the F-COPES questionnaire in an African context.
- Intervention studies to determine the impact of the implementation of support structures in haemodialysis units.

6.4 SUMMARY

In this chapter the researcher presented an overview of the limitations of the study as well as recommendations for nursing science, nursing practice and nursing research. In drawing this study to a close, it was evident that spiritual support and support from family was considered the most important coping behaviours of the families of patients on haemodialysis treatment.

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APPENDIX 1: DEMOGRAPHIC SHEET

Participant code: _____ centre code _____ (official use only).

Dear Participant,

In order to describe the context of this research study, the following information must be obtained. Please do not write your name on any of the pages included in this package.

Please mark the applicable option.

BIOGRAPHIC DATA

1. What year did your family member start with haemodialysis? _____
2. Size of the family (People living in house hold with the patient _____)

	Husband		1
	Wife		2
	Child		3
	Other (Specify)		4
	Male		1
	Female		2
	18-30		1
	31-40		2
	41-50		3
	51 and above		4
	African		1
	Asian		2
	Caucasian		3
	Indian		4

APPENDIX 2: FAMILY ORIENTED PERSONAL SCALES: F-COPE SCALE

Dear Participant,

Please read the following information before completing the scale.

- First, read the list of “Response Choices” one at a time.
- Secondly, decide how each statement will best describe your attitudes and behaviour in response to problems or difficulties.
- If the statement describes your response very well, then select the number 5 indicating that you STRONGLY AGREE; if the statement does not describe your response at all, then select the number 1 indicating that you STRONGLY DISAGREE; if the describes your response to some degree, then select a number 2, 3 or 4 to indicate how much you agree or disagree with the statement about your response.

Example

1	2	3	4	5√
---	---	---	---	----

When we have a problem in the family we call the neighbours.

- Do not write your name on the questionnaire
- Use a black pen please
- In case of any uncertainties, please contact the researcher:
David Mphuthi: 083 732 0065 (Mobile)

Thank you for taking time to complete the scale.

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:

Statements	Strongly Disagree 1	Moderately Disagree 2	Neither Agree nor Disagree 3	Moderately Agree 4	Strongly Agree 5
1. Sharing our difficulties with relatives					
2. Seeking encouragement and support from friends					
3. Knowing we have the power to solve major problems					
4. Seeking information and advice from persons in other families who have faced the same or similar problems					
5. Seeking advice from relatives (Grandparents, etc)					
6. Seeking assistance from community agencies and programs designed to help families in our situation					
7. Knowing that we have the strength within our own family to solve our problems					
8. Receiving gifts and favours from neighbours(e.g. food, taking in mail, etc)					
9. Seeking information and advice from the family doctor					
10. Asking neighbours for favours and assistance					
11. Facing the problems "head-on"					

and trying to get a solution right away					
12. Watching television					
13. Showing that we are strong					
14. Attending church service					
15. Accepting stressful events as a fact of life					
16. Sharing concerns with close friends					
17. Knowing luck plays a big part in how well we are to solve family problems					
18. Exercising with friends to stay fit and reduce tension					
19. Accepting that difficulties occurs unexpectedly					
20. Doing things with relatives (get-together, dinners etc)					
21. Seeking professional counselling and help for the family difficulties					
22. Believing we can handle our own problems					
23. Participating in church activities					
24. Defining the family problem in a more positive way so that we do not become too discouraged					
25. Asking relatives how they feel about problems we face					
26. Feeling that no matter what we do to prepare, we will have difficulty handling problems					
27. Seeking advice from a minister					
28. Believing if we wait long enough,					

the problems will go away					
29. Sharing problems with neighbours					
30. Having faith in God					

Scoring of questionnaire

F-COPES

Responses are weighted as indicated on the questionnaire. Take note that **item 18** is taken into account in neither the subscales nor the total score. Summarise scores subscales and total.

Acquiring social support:	1, 2, 5, 8, 10, 16, 20, 25, 29
Reframing:	3, 7, 11, 13, 15, 19, 22, 24
Seeking spiritual support:	14, 23, 27, 30
Mobilising family to acquire and accept help:	4, 6, 9, 21
Passive appraisal:	12*, 17*, 26*, 28*
[The scores of the last subscale must be reversed:	1=5, 2=4, 3=3, 4=2, 5=1]

APPENDIX 3: PARTICIPANT INFORMATION LEAFLET & INFORMED CONSENT FOR QUESTIONNAIRE¹

Researcher's name: David Mphuthi

School of Nursing Science

North-West University, Potchefstroom Campus

Dear Participant,

I am a Masters student in the School of Nursing Science of the North-West University, Potchefstroom Campus. You are invited to volunteer to participate in my research project on the coping behaviours of family members of haemodialysed patients. This letter gives information to help you to decide if you want to take part in this study. Before you agree you should fully understand what is involved. If you do not understand the information or have any other questions, do not hesitate to ask me. You should not agree to take part unless you are completely happy about what I expect of you.

I would like you to complete a questionnaire. This may take about 5-15 minutes. The unit manager will give you the questionnaire with an envelope. The envelope is for you to put in the completed questionnaires for confidentiality. It will be kept in a safe place to ensure confidentiality. Please do not write your name on the questionnaire. The Research Ethics Committee of the North-West University, Faculty of Health Sciences, granted permission for this study. Your participation in this study is voluntary. You can refuse to participate or stop at any time without giving any reason. As you do not write your name on the questionnaire, you give us the information anonymously. Once you have given the questionnaire back to me, you cannot recall your consent. I will not be able to trace your information. Therefore, you will also not be identified as a participant in any publication that comes from this study.

I sincerely appreciate your help.

Yours truly,

David Mphuthi

¹ Adapted from University of Pretoria's Research and Ethics Committee (2007)

APPENDIX 4: INFORMATION LEAFLET AND INFORMED CONSENT FOR FOCUS GROUP INTERVIEW & INDIVIDUAL INTERVIEWS¹

Dear Participant,

1) INTRODUCTION

I invite you to participate in a research study. This information leaflet will help you to decide if you want to participate. Before you agree to take part you should fully understand what is involved. If you have any questions that this leaflet does not fully explain, please do not hesitate to ask me.

2) THE NATURE AND PURPOSE OF THIS STUDY

The aim of this study is to describe the coping behaviours of family members of haemodialysed patients. You as a participant are a very important source of information for this study.

3) EXPLANATION OF PROCEDURES TO BE FOLLOWED

You are invited to participate in a focus group interview together with 6-7 people who are also family members of haemodialysed patients. We will discuss with you the findings of the questionnaire (the part of the study in which you already participated) in order to obtain more information.

4) RISK AND DISCOMFORT INVOLVED

There are no risks in participating in the focus group interview. If any of the questions makes you feel uncomfortable, you need not answer them if you don't want to. The interview will take about 1 hour of your time.

5) WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

Your participation in this study is entirely voluntary. You can refuse to participate or stop at any time during the interview without giving any reason. Your withdrawal will not affect your family member's treatment in any way.

¹ Adapted from University of Pretoria's Non Clinical Research Website (2007).

6) HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This study has received written approval from the Research Ethics Committee of the Faculty of Health Sciences at the North-West University and the Fresenius Medical Care. Copies of the approval letter are available if you wish to have one.

7) COMPENSATION

As a token of appreciation for your participation in the study, the researcher will provide each participant with R20-00 (Twenty Rands only) towards travel expenses.

8) CONFIDENTIALITY

All information that you give will be kept strictly confidential. Once we have analyzed the data from the interview no one will be able to identify you. Research reports and articles in scientific journals will not include any information that may identify you or your family member.

CONSENT TO PARTICIPATE IN THIS STUDY

I confirm that the person asking my consent to take part in this study has told me about nature, process, risks and possible discomforts of the study. I have also received, read and understood the above written information (Information Leaflet and Informed Consent) regarding the study. I am aware that the results of the study, including personal details will be anonymously processed into research reports. I am participating willingly. I have had time to ask questions and have no objection to participate in the study. I understand that there is no penalty should I wish to discontinue with the study and my withdrawal will not affect any treatment / access to the centre in any way. I have received a signed copy of this informed consent agreement.

Participant's name

Participant's signature: Date.....

Investigator's name:

Investigator's signature: Date.....

APPENDIX 5: INVITATION TO PARTICIPATE IN AN INTERVIEW

Would you be interested in a follow- up interview with the researcher?

PLEASE CIRCLE YOUR CHOICE: YES NO

Please give a telephone number or cell phone number where I can contact you to make an appointment for the interview.

Name: _____ Tel/Cell: _____

You are welcome to contact the researcher at anytime for any further information.

David Mphuthi (Researcher)

083 732 0065 (Mobile)

011 488 3305 (Office Hours)

018 786 3307 (Home)

dmphuthi@ananzi.co.za (email)

Ditaba.Mphuthi@wits.ac.za (email)

APPENDIX 6: INTERVIEW SCHEDULE

Introduction:

- Introduction and welcome.
- Informs the participants about the use of the audio-tape during the discussion.
- Participants are informed about the confidentiality as well as the no name use during the interview and their names will not be reflected in the transcribed text.
- Consent forms discussed and signed by participants.

Session starts:

Good day and welcome to this session. Thank you for taking time to come and join us to talk about the challenges you are facing in caring for your haemodialysed family member and how you cope with the situation. The information will be used for research purposes only.

You are invited because you have shown interest in the focus group interview following the questionnaire you completed some time ago.

There are no wrong answers to the questions except different points of view. Feel free to share with us your experiences and how you are dealing with them. We will use the names you have provided us for the interview purposes only. **No names** will be written in the research report. You are assured of complete **confidentiality**.

RESEARCH QUESTION:

What are the coping behaviours of haemodialysed patients' families in a private clinic setting in Gauteng?

MAIN QUESTIONS:

1. From your demographic information we concluded that most families consisted of four members, that it is mostly wives caring for their husbands and that the participants caring for the haemodialysed patients are aged between 41-50 years. Would you agree with this?
 - 1.1. Probing questions:
 - 1.1.1 **Is there anything that you think might be important for me to know regarding your demographics in order to understand your coping behavior better?**

2. When we measured social support in the questionnaires that you completed we looked at how you acquire support from relatives. Most of the participants suggested that you prefer to share your problems with your relatives and not your extended family or neighbors. Tell me more about this...
 - 2.1. Probing questions:
 - 1.1.1 **Why would you rather seek support from your relatives than extended family?**
 - 1.1.2 **How does support from relatives help you to cope? / Could you discuss the role family support plays in your particular difficulties?**
 - 1.1.3 **“Having social support” measured the lowest on your score indicating that you did not consider it as important as “seeking spiritual support”. Can you tell me more about this?**

3. When we looked at how you “redefine” stressful events, in other words, how you make coping with your family members’ haemodialysis more manageable, most participants seem to redefine their problems by facing them head-on and looking at it in a more positive way so that you do not become too discouraged. Tell me more about this...

4. Tell me more about the spiritual support that you need in caring for your family member.
 - 4.1 Probing questions:
 - 4.1.1 **Do you often seek advice from the minister? If not who else will you seek for spiritual support?**
 - 4.1.2 **How does spirituality help you to cope?**

4.1.3 Why do you think that seeking spiritual support plays such an important role in coping with your family members' haemodialysis as suppose to using family support?

5. Most participants indicated that they relied on the family doctor for advice and will also seek advice from families facing similar problems. Tell me more about how you use family support to cope?

5.1 Probing questions:

5.1.1 Is there a difference between professional counseling and community programmes?

6. Do you sometimes think that if you ignore your family members' haemodialysis it will go away?

6.1 Probing questions:

6.1.1 What helps you to escape from the problem?

7. Lastly I want to ask you – how can the nurses working in the haemodialysis units' assist you in coping with your haemodialysed family member's illness?

Closing the interview:

1. Is there anything else that you would like to add that you think may help me to understand your coping behaviour better?
2. All participants are thanked once more and the session closes.

27 Participant 1: For now it is, it's working but the solution is to
28 get a donor.
29
30 Researcher: A donor? Okay.....can you tell me more.....?
31
32 Participant 2: Nna Ntate, you know what, he last got a donor
33 neh.
34
35 Researcher: Mmmmmm...when was this?
36
37 Participant 2: From 2002 he is not alright I think he will get better by getting a
38 donor, it will help him to cope but now he is in a process of getting a
39 donor, all the...to get a donor but now he is not alright sometimes he
40 is not coping, he is not coping and that thing makes me to have stress.
41
42 Researcher: mmmm... stress?
43
44 Participant 2: Yea, because sometimes he does not sleep he wakes me up, I'm also
45 taking medication and I forget...you will find that in the morning he
46 will say 'you know I have been watching TV in the dinning room, I'm
47 asleep I do not know what has been happening.
48
49 Researcher: Mmmmm, sooo...much as the previous speaker has said you are also a
50 bit worried about him.
51
52 Participant 1: Yes.
53
54 Researcher: That is the main challenge?
55
56 Participant 3: Yea.... Okay, with me I think the main challenge eeh it's his age.
57
58 Researcher: Age?

59 Participant 3: Then the other thing Ntate is diabetic hai! For us in the house you find
60 that you are happy when he comes from dialysis but sometimes when
61 he comes from dialysis he will complain of cramps and he is irritable
62 the whole day, so irritability affect everyone in the house, so one of
63 them the daughter we got two children in the house, a boy and a girl
64 so the boy wanted to donate a kidney he is 13 years old Ntate felt that
65 it would be unfair because he has lived his life, he is 65 yrs he felt that
66 he would be unfair he must leave the child, so he refused that the
67 tests for donor be done, he feels that he is comfortable and then it
68 worries you that Ntate is going to die because he is old.
69 Most of the time you find yourself having stress and worry but
70 somewhere on the way you feel that he is not the only one you forget
71 and life goes on.
72

73 Teacher: Mmmmm...

74 Now that most of you live with this worry, then one thing seems to be
75 the major factor in all of you ...so then how do you cope with this
76 worry? What do you do in order to cope with this?

77 Participant 2: It's very difficult to cope but sometimes you let it go and then when
78 you go to other people talking to others and socialising you seem to
79 forget but then when you come back you find how we live.
80

81 Researcher: Talking about socialisation, whom do you
82 socialise with?
83 Who do you talk with about the problems that you are having in the
84 house?
85

86 Participant 3: You have extended family sometimes the friends at church or
87 sometimes you have got the societies or talking to people at work.
88 Sometimes when you see other people, I'm working at the clinic you
89 start consoling yourself saying that if you are not the only one; maybe
90 its God's will that's how... you take it as it is.

91 **Researcher:** Ooooh...!

92

93 **Participant 2:** We try to support by all means but he is an elder in church so most of

94 his time he spends in church. During the day he tries to keep him busy

95 in church, he is

96 Busy with the conformant classes and the youth group in church, we

97 keep you know, our table of prayer with family and we have got the

98 social club but the family club, we talk about the issues but let me tell

99 you, Ntate does not appreciate that especially when we talk about his

100 condition.

101 At some stage I think I remember we had family gathering at our

102 place and we somehow touched only to say, Ntate is not well,

103 complaining of you know, having pains, fatigue.

104 Ntate does not appreciate he always say well, well if it's the will of

105 God they will die, I will die and I'm saying to him all people who

106 passed on it does not really matter if you are diabetic, HIV infected or

107 cancer if its time its your time, and HIV patient will merely die through

108 accident you know, they will never write on the death certificate

109 cause of death is HIV, they will always say something else I'm not sure

110 why but they will always say cause of death its T.B or something else

111 but Ntate does not appreciate taking about his condition.

112

113 Addition to that, I once asked him a question about his siblings

114 because my blood group is 'o' and I consulted a doctor before to ask if

115 it's possible for me to donate for someone.

116 Ntate at some stage said u can donate because 'O' cater for

117 everybody, and I said maybe if its for our own blood, I'm not born in

118 your family remember I'm not your blood related.

119

120 **Researcher:** Mm...mm...

121

122 Participant 2: I'm someone else related to you through marriage you know, I'm not
123 related to you by blood, so he said, NO! People told me that 'o' cater
124 for everybody, but I said I don't think so because I consulted a doctor
125 behind your back you know, why do not you say your siblings,
126 because Lerato the 16 years old your worried that he can not and of
127 cause he is a baby.
128

129 Researcher: Mm...mm...

130 Participant 1: But isn't your family more appropriate for this?
131

132 Participant 2: He said no, I cannot decline them of their lives but they are grownups
133 eeeeeee...let them life their lives.
134

135 Researcher: Mm... mm...and then?
136

137 Participant2: The only person that can donate the kidney for me is you, because
138 you are 'o'.
139 *Laughter.*

140 Researcher: Is it common to all the families?
141

142 All participants: Yes.
143

144 Researcher: Is it?
145

146 Researcher: Okay, so on top of all this issues that you have actually said, you
147 mentioned that you are basically praying and you mentioned they are
148 also basically praying, so what do you think you also...go on?
149

150 All participants: Yes.
151

152 Participant3: If we have the prayer meeting we do pray for
153 everybody.

154 Researcher: Okay.....you mentioned that.... sorry can I ask
155 you a question.

156 Participant 3: Yes.

157

158 Researcher: For the fact that other people have got the support group, do dialysis
159 people have support group?

160 Participant1: Yes, they do, they do.

161

162 Researcher: Okay.

163

164 Participant2: They do have a support group but the thing is eish...I wanted to study
165 but its fell on its faith because of the poor attendance, they need to
166 be motivated to attend.

167

168 Participant3: Okay, so you are mentioning, eeh... opening it
169 up.

170

171 Researcher: Mm... it means like you said he does not want you to talk about his
172 condition and all of you agree on this point that they do not want you
173 guys to talk about their condition.

174

175 Participant1: Yeah...

176

177 Researcher: Okay.....

178

179 Participant2: But he is okay by opening up, because my family know that he is
180 dialysing.

181

182 Participant1: Mm...you are lucky...

183

184 Participant2: Yeah...he does not have a problem with that.....

185

186 Participant3: Okay.....
187
188 Participant2: I have got two boys, the other one is okay he understand but the
189 other one does not understand everything that is going on.
190 Researcher: How do you cope with them when they are in their lowest?
191 "*Silence..*", what do you do?
192
193 Participant1: It's difficult, you know, it's difficult that we get challenge, because you
194 sort of wake up and look at him and wanted to say, how you are
195 feeling, you know, but sometimes you cannot refill.
196
197 Researcher: Mm...and then....?
198
199 Participant1: Because I am sick how will you help me, even if I can tell you how I
200 feel how will you help me, but I think Ntate's biggest challenge is the
201 myth behind the dialysis.
202
203 Researcher: Mm...
204
205 Participant2: When I talked about it at work in 2004 to say my husband has been
206 hospitalised, and they found that he had renal failure.....?
207
208 Researcher: Mm...and then what happened.....?
209
210 Participant2: One of lady actually appears with very sensitive question to say, now
211 how are you going to go through now that you know, the.....condition
212 of your husband
213
214 Researcher: Mm...what was your response to that...?
215
216 Participant2: I said God will see to it, I think one other thing one other thing that
217 our father are afraid of is what people think about their situation.

218 Researcher: What do you mean...?
219

220 Participant2: That maybe he is less than a man.
221

222 Researcher: Ok.....Why do you think like that....?
223

224 Participant1: He is less than a father at home, he cannot provide. If things do not go
225 well in my house then my wife can actually go out and can think
226 maybe she is the role player in the house, the head of the family. It
227 means I'm invidious to my wife and is taking care, is not what the
228 Bible say Jesus is the head of the church and the husband the head of
229 the family.
230

231 Researcher: Yeah...and then...?
232

233 Participant3: But the husbands are the head of their families. So this condition that
234 he is always tired, always sleeping like now he will be sleeping, he will
235 try to look at the TV, but most of the time he is sleeping. Ntate always
236 being the provider even though things are tough, they will keep on
237 saying its better if I die most of the time.
238

239 Researcher: How do you feel when they fell...? You fell like maybe they do not like
240 you anymore. How does that make you feel? How do you cope? Do
241 you sit down and discuss?
242

243 Participant1: Sometimes you don't get time to discuss because he doesn't want to
244 hear anything, like now he is staying with his brother if I don't come
245 during the weekend he will start complaining saying 'motho wa hao'.I
246 said you have to get used to our brother's condition.
247

248 Participant3: They are always full of anger.....
249

250 Participants1&2: Yesssssssssss.....
251 .
252 Researcher: So now you always have to submit to their anger?
253
254 All participants: Yesssss.....and this is frustrating (participant 3) we don't know what
255 to do anymore.....
256
257 Researcher: Most of the responses from the papers that I got where I asked about
258 the relative and extended family, most of the people said they would
259 rather seek support from relatives rather than extended family. So,
260 can you tell me how do you view a relative and how do you view an
261 extended family.
262
263 Participant2: Eeh...extended family meaning yourthe relative would mean
264 your own brothers and sisters. I think the whole thing has to do with
265 trust..
266
267 Participant1: Whom do they trust? You know even if I am a wife I think my husband
268 will always consult with his sister, because he feel she is his blood, he
269 feels he can trust her more than this person and in this case this
270 person is the sell out.
271
272 Participant3: "She always tells people about my condition". This is what my
273 husband will always say...and.....this is when I realised that he does
274 not trust me as his wife.
275
276 Participant1: Yeah.....eeeehhhh I also feel that I am not in the picture of his
277 life...and.....
278
279 Participant3: Maybe these relatives of his can actually comfort him the way he
280 wants.
281

282 Participant2: Eeh...I sometimes feel disregarded and not being taken seriously by
283 my husband...
284

285 Participant2: I think our husband's extended families do not regard us as the family.
286

287 Researcher: Okay.....how do you see yourself as relatives.....?
288

289 Participant3: We are not in the category of relatives. Most of the things are
290 discussed mostly with the siblings like the brothers and sisters, the
291 parents more than with us...
292

293 Participant1: And this makes you feel excluded in their program.
294

295 Researcher: Mm.....ok.....How do you cope with being excluded? Do you just sit
296 there and say let it be or do you try to pull yourself in?
297

298 Participant2: Do you watch generations (soapy)?
299

300 Researcher: I do.
301

302 Participant2: Do you see the relationship of Khethiwe and Dumisani?
303

304 Researcher: Yes...and then.....?
305

306 Participant2: Do you see how Dumisani treats Khethiwe?
307

308 Researcher: Yeah...
309

310 Participant2: Khethiwe to most of us we live just like her, and it's normally how we
311 spent our lives.... when we watch we always say why is he back, why
312 is she back? Can't Khethiwe see that Dumisani does not love her? We
313 blame Khethiwe, we are always there even though they show us that

314 you are not wanted here, keep away, you know, we always come back
315 and say, Ntate how do you feel today? Are you going somewhere can I
316 help you? He will say no, I can do it myself; can I dish up some
317 porridge? No, I can do it myself. "*Laughter*" ...you know, sometimes
318 you dish up neh, he will just say no, I don't want food.

319 Participant3: Then he will also say just go, I'll do it eish..... and myself it's so getting
320 to me.

321

322 Researcher: So the other thing is that....can you say more.....?

323

324 Participant3: They are getting comfort out of the house.... Every time you are
325 hurting, you some of that, get a little of it and then eeeeeh they go to
326 their families they are diabetic in their family, so he more very
327 comfortable with them, by the time they exclude me and by that time
328 he will be laughing, happy and saying I was with my sister.

329

330 Participant1: this makes us very angry (thumping the table)

331

332 Participants2&3: Yesssss ntate. We are very angry (participant3)

333

334 Researcher: Oh-okay....now, in that case, lets look at it from this point, you guys
335 that now you feel, eeh...angry, neglected, you are stressed; frustrated
336 you have been excluded.

337

338 Participant1: We feel frustrated by this situation...participant3 of course we are....

339

340 Researcher: You feel rejected eeh who do you go to for all this, like you mentioned
341 the social groups that you guys have, do those social groups help?

342

343 Participant1: They help because you tend to forget for a time being....

344

345 Participant3: Then you are back to the same situation again...

346
347 Participant1: But when you come back it starts again.
348
349 Researcher: Has any one of you thought about professional counselling? Maybe go
350 professional counselling.
351
352 Participant2: I did...
353
354 Researcher: Then what happened...?
355
356 Participant2: That time I was consulting for the blood group, for the donor
357
358 Researcher: What was the outcome...?
359
360 Participant2: I was consulting with eeh one psychologist for myself because I
361 wouldn't say anything to my husband so I was seeking help you know,
362 say am I over reacting eeh this man behave normal, instead of being
363 frustrated because my children are also frustrated to be looking at
364 their father not communicating with me, maybe common with the
365 daughter most of the time, because maybe he feels I'm some one else
366 from far the people, so the daughter will be the only one who he'll
367 always say "baby can you do this for Papa". *Do you understand that?*
368
369 Researcher: Mm...
370
371 Participant2: But I went through counselling eeh where the department I'm
372 working with has got this EAP, internally where they can offer
373 assistance, so I did go for counselling.
374
375 Researcher: Did it help you?
376

377 Participant2: It did 'cause I then, I can now handle eeh the frustration, the anger,
378 the manner in which he is behaving.
379

380 Researcher: Okay.....then..?
381 Participant2: ...but one thing that still get to me he forget about things, they
382 forget...
383

384 Participant3: Okay.....I thought I was the only one who was faced with this
385 forgetfulness....
386

387 Participant3: Time and again he'll say something and then today I'll remind him and
388 then he will say another thing and so....
389

390 Participant1: Now you are in a situation whereby somebody says something or do
391 something and when you try to sort it out, they've completely
392 forgotten about it.
393

394 Participant2: Mmmm...exactly...
395

396 Researcher: Okay, now that you are in this situation, eeeh sometimes do you think
397 of ignoring them?
398

399 Participants: ...(they are quiet)
400

401 Participant 1: Not really...
402

403 Participant 2: Not really...
404

405 Participant3: Not sure what to do at that moment.....
406

407 Participant 1: Not really because you can tell yourself that, I'm going to ignore him
408 for a minute he won't feel it he won't even realise it.

409 Others: Yea...hmmm...
410
411 Participant2: Mm... he'll keep on with his programme he'll read the newspaper, and
412 watch the TV, not leaving the remote for the whole day, he won't
413 even realise...
414 Others: Laughter....
415
416 Participant2: And go to browse to all channels and ignore you instead
417
418 Others: Mm....
419
420 Researcher: Okay, so the ignore part doesn't work...?
421
422 Participants: Yes, Mm....
423
424 Participants: No, it doesn't work.
425
426 Researcher: Do you think maybe if you can leave them to do their own thing,
427 like you said this is a life time for them and then there is no cure
428 except getting a donor...things can change...?
429
430 Participants: Not really....Mm...*participant3*..even if I think of that...i have stayed
431 with him for most of my life....
432
433 Researcher: Okay, then lastly I would like to ask you how the nurses working in the
434 haemodialysis unit could assist you in coping with your
435 haemodialysed member. Like the staff here, how do you think what
436 they can do in order to make you cope better with a family member?
437
438 Participant3: I think Ntate you talked about support groups...
439

440 Participant1: Yes, support groups I remember there was one here which I attended
441 but I came late 'cause I attended something else....
442

443 Participant2: I think if support groups could be organised especially the spouse we
444 the spouse, so that we are on the same path with our husbands, and
445 the nurses so that we can understand what they go through.

446 Researcher: Mm...
447

448 Participant2: And if they can tell us what is going on, I've gone through that with
449 Ntate, the time he was dialysed in Park Town.
450

451 Researcher: In Park Town....?
452

453 Participant2: I used to go there every time, eeh he was doing it on Tuesdays,
454 Thursdays and Saturday every Saturday I was there.
455 *Silence.....*
456

457 Participant2: I would read my own paper and wait for those hours and we would
458 come back, so if support groups can be, you know....., organised once
459 more....
460

461 Participant1: You know, we would be very happy.
462

463 Participant3: But you know we need more information on this, we need to be
464 informed on what is happening because there's also the diet...
465

466 Researcher: Mm...can anyone tell us more about the diet?
467

468 Participant3: In the diet part, Ntate would be saying, my food should be soaked; my
469 vegetables should be soaked for hours before they could be cooked
470 and we adapted to the meal that he is eating.
471

472 Participant2: We also eat the soaked potatoes, so we soak and eat together, if he
473 does not want salt in his food, we also eat food without salt.
474

475 Participant1: Yeah.....
476

477 Participant1: I think with the support groups, they must sit there with us.....
478

479 Others: Yes, mm... yes.

480 Researcher: The feeling I'm getting here is that there is this closure, that you guys
481 cannot open at home and you think some form of actually breaking
482 this wall would be through a support group, with the information.
483

484 Participant3: Mm... from there.
485

486 Researcher: Then, must they (patients) be included in the support group?
487

488 Participants all: Mm...yessss they must be there as well....
489

490 Participant2: Yes.
491

492 Participant3: And then eeh 'David' when it comes to eeh I've done HIV counselling
493 for about ten years, then they do call us counsellors, so you do find
494 that spouses are not coping because of this secrecy of not sharing the
495 same information.
496

497 Participant3: The other thing, which I think, do frustrate us, I think if you want to
498 maybe go for a weekend maybe four days or fifteen days you cannot.
499

500 Participant3: Because this is now, I'm planning to go for a holiday for about five
501 days, how there is this dialysis on this side so we shouldn't.
502

503 Participant2: If they said okay they're this injection or pill, which can maybe give for
504 those days, and then you can go...
505

506 Participant1: so we are aware that they also try to neglect us, and our part of
507 therapy going out with this person to see the type of therapy, but you
508 cannot at least say, I want to go to Durban for five days, I cannot
509 unless they organised at least there.
510

511 Participant2: Maybe if they can introduce something okay, if you don't come for
512 following days you can have this. I went for counselling in 2007, he I
513 was diagnosed with cancer, they just combined everything and when I
514 told daddy that I've got a problem too. He did not take it
515 seriously...and then...
516

517 Participant2: Yeah, and I need your help too, but since then I don't cope with the
518 help of my...husband...
519

520 Researcher: Yeah.
521

522 Participant1: Sometimes it become so badly and every time. I tell him Daddy you
523 know what on that tile there's every thing and I got scored he says
524 you know Ntate has passed on we are also going. Isn't it I'm saying no
525 man Ntate ...was our senior at school, please pray and he would say
526 Yes I do pray and I say I put all things in the hands of God.
527

528 Researcher: Okay, the feeling that I get here is that on top of the other eeh,
529 problems that you have actually talked about there is this restricting
530 movement....
531

532 Participant3: He doesn't want to hear anything about them; he is no even
533 supported to use them. I said no, I'm not getting there for anything
534 else except for support. I have to understand so that you also

535 understand but what I can just say is that I'm very grateful, I'm sure
536 bo Mom will share the same sentiment that we are grateful to have
537 been invited by this unit, to come and share not only our frustration
538 but also the support that we are giving to our spouses and family
539 supporting us.
540
541 Researcher: Mm...
542
543 Participant1: You know its not only that when they are sick we are the only people
544 offering support, they are also supporting us because I remember I
545 stayed something like 3 months without a car and on Tuesday and
546 Thursday he would wake up and take me to work and I would say no,
547 you can't do that I'm going to use taxis, "I'm working in Soweto and
548 I'm going to reach my place of work at 07:00, you don't do that but if
549 he can wake up he'll definitely take me back to work but most of the
550 time I would wake up and close the door softly take out my clothes,
551 do everything, softly lock the door and to the gate, lock it so that he
552 doesn't take me to work. I didn't want him to wake up on Tuesdays
553 and Thursdays, because I know he's got to rest'
554
555 Researcher: The other thing that you are brining up here is that you are also
556 playing the protective role again.....
557
558 Participants: Mmm.....Yes..... (*silence...*)
559
560 Researcher: ...so you are also like guarding their lives..
561
562 Participants3: Mmm.....(David) you know as mothers to our children, we also play
563 the same role here.....(*laughter*)....
564
565 Researcher: okay, alright
566

567 Participant2:so we are very grateful to have been invited here to come and
568 share all this, I've learnt so much from bo-mama, I've learnt so much
569 from them and we have to ask God...to give us power. I strongly think
570 God is on our side and I always read the following verses: *Matthew*
571 *11:28 and Psalm 103.*
572

573 Participants: Yees.....
574

575 Participant1: To give us strength to go though and may bring a miracle
576 Participant2- You know I'm a movie lover I also watched this movie by Denzel
577 Washington, whereby, John Q, his son needed a donor for the heart,
578 one lady was involved in an accident and you know Denzel held the
579 hospital hostage.....(*laughter*)
580

581 Researcher: mmmm.....then?
582

583 Participant2:because being his son and they told him about the waiting list and
584 he didn't take it because she was a white lady in hospital, 'because
585 I'm black, my son couldn't get a donor' so he held the hospital
586 hostage' and you know by luck one lady was involved in an accident
587 and then they actually got the heart.....(*silence*)
588

589 Participant2: so God can also provide a miracle, something can happen better
590 methods can be sought because I've listened to mama's social life that
591 does not exist anymore, nna, ntate use to go to cape town, we used
592 to say, 'ntate go to CT, for church reasons, on holiday but then there
593 was a unit that side that helped dialyze him, you see, so he used to go
594 there but he needs a friend somehow to cope
595

596 Researcher ... thank you, Mama
597

598 Participant3: David I think I'll repeat what has been said.....

599 Researcher: So you are sharing the same sentiments...
600
601 Participant3but all I can say is that God can never give you a burden bigger
602 than you, so I'm grateful and thankful for our support group and you
603 calling us, I know we've opened up and then it's a healing on us when
604 we go back we'll start afresh
605
606 Participants: Mmm....you are right mama....
607 Researcher: Is the anything that you may wish to say that you think may enhance
608 the information you have just shared with me now?
609
610 Participant2: I think all has been said and I don't want to repeat the same
611 words.....thank you for your time....
612
613 Participant3: I really feel better after this session after realising that I am not the
614 only one with the issues I had with ntate at home...thanks..
615
616 Participant1: god will provide a miracle one day and we will be out of this....let's
617 keeping our faith..... thank you for the invitation....
618
619 Researcher: ..and so ladies thank you for your time and for agreeing to come here
620 today. I really appreciate your input in the whole issue.

APPENDIX 8: NORTH-WEST UNIVERSITY ETHICS APPROVAL



NORTH-WEST UNIVERSITY
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Email Ethics@nwu.ac.za

2009-06-26

ETHICS APPROVAL OF PROJECT

The North-West University Ethics Committee (NWU-EC) hereby approves your project as indicated below. This implies that the NWU-EC grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the project may be initiated, using the ethics number below.

Project title Coping behaviours of the haemodialised patients' family in a private clinic in Gauteng																
Ethics number:		N	W	U	-	0	0	0	2	3	-	0	9	-	A	1
		<small>Institution:</small>			<small>Project Number</small>					<small>Year</small>		<small>Status</small>				
<small>Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation</small>																
Approval date: 26 June 2009								Expiry date: 25 June 2014								

Special conditions of the approval (if any): None

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:

- The project leader (principle investigator) must report in the prescribed format to the NWU-EC:
 - annually (or as otherwise requested) on the progress of the project,
 - without any delay in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.
- The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the NWU-EC. Would there be deviation from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.
- The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date, a new application must be made to the NWU-EC and new approval received before or on the expiry date.
- In the interest of ethical responsibility the NWU-EC retains the right to:
 - request access to any information or data at any time during the course or after completion of the project;
 - withdraw or postpone approval if:
 - any unethical principles or practices of the project are revealed or suspected,
 - it becomes apparent that any relevant information was withheld from the NWU-EC or that information has been false or misrepresented,
 - the required annual report and reporting of adverse events was not done timely and accurately,
 - new institutional rules, national legislation or international conventions deem it necessary.

The Ethics Committee would like to remain at your service as scientist and researcher, and wishes you well with your project. Please do not hesitate to contact the Ethics Committee for any further enquiries or requests for assistance.

Yours sincerely

Prof MMJ Lowes
(chair NWU Ethics Committee)

Prof HH Vorster
(Chairman: NWU Ethics Committee: Author)

APPENDIX 9: AGREEMENT TO USE THE FCOPES SCALE

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From: "Ronel Pretorius" <Ronel.Pretorius@nwu.ac.za>
Subject: Fwd: Re: F COPES Scale
Date: Fri, 06 Feb 2009 09:01:47 +0200
To: <dmphuthi@ananzi.co.za>, <VanDerWalt.Christa@nwu.ac.za>

Hi David,

The attached e-mail refer. You have permission to use the scale.

Regards,

Ronel Pretorius PhD(c); RN
Senior Lecturer: Research
School of Nursing Science
North-West University (Potchefstroom Campus)
South Africa
Office number +27 18 299 1830
Mobile +27 82 823 5596

From: STEPHEN A SMALL <sasmall@wisc.edu>
Subject: Re: F COPES Scale
Date: Thu, 05 Feb 2009 09:09:24 -0600
To: Ronel Pretorius <Ronel.Pretorius@nwu.ac.za>

Dr.Pretorius:

I am the current director of the Center. You have my permission to use the F COPES Scale by McCubbin.

Best,

Stephen Small


----- Original Message -----

From: Ronel Pretorius <Ronel.Pretorius@nwu.ac.za>

APPENDIX 9: AGREEMENT TO USE THE FCOPES SCALE

Date: Thursday, February 5, 2009 5:22 am
Subject: F COPES Scale
To: sasmail@wisc.edu
Cc: dmphuthi@ananzi.co.za, VanDerWalt.Christa@nwu.ac.za

> Dear professor Small,
>
> My name is Ronel Pretorius and I am the supervisor of
> David Mphuthi -
> a Masters degree student at the North-West University
> in South Africa.
> David's research is looking at describing the coping
> behavior of the
> families of patients with chronic renal failure in
> South Africa. Mr.
> Mphuthi want to use the F-COPES scale developed by
> McCubbin HI; Olson
> DH; Larsen AS from the Family Stress Coping and Health
> Project,
> University of Wisconsin-Madison in order to describe
> these behaviors.
>
>
> I have searched the website of the Center for
> Excellence in Family
> Studies at your university but cannot seem to find a
> contact person to
> obtain permission to use the instrument. Can you
> please direct us to
> someone that we can contact in order to get more
> information on the instrument.
>
> I appreciate your assistance in this matter.
>
> Kind Regards,
>
>
>
>
>
> Ronel Pretorius PhD(c); RN
> Senior Lecturer: Research
> School of Nursing Science
> North-West University (Potchefstroom Campus)
> South Africa
> Office number +27 18 299 1830
> Mobile +27 82 823 5596
>
>

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