

# LIVED EXPERIENCES OF HAEMODIALYSIS PATIENTS WITH ERECTILE DYSFUNCTION: A PHENOMENOLOGICAL STUDY

by

# **SOUNDALAY GOVENDER**

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Supervisor: Dr E S Janse van Rensburg Co-supervisor: Dr R G Visagie

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# **DECLARATION**

I, SOUNDALAY GOVENDER, declare that the research study, *Lived experiences of haemodialysis patients with erectile dysfunction: A phenomenological study,* is my own work and has not been submitted for a degree or an examination at any other university. I further declare that all sources used and quoted in this research study have been indicated and reflected by means of a complete reference list.

## **SOUNDALAY GOVENDER**

Signature:	
Date:	

I would like to take this opportunity to acknowledge and give recognition to:

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# **SUMMARY**

"Hearing is one of the body's five senses. But listening is an art." (Tyger, 2005:para.1).

While working in the haemodialysis unit in KwaZulu-Natal, I observed that patients preferred not to disclose their experiences of erectile dysfunction with the professional nurse practitioners but to the health care workers and to other patients in the unit. The non-disclosure served as a barrier to the patients receiving the assistance and support they required to be able to cope with erectile dysfunction.

Added to this, there were no therapy groups or supportive groups available for the patients to allow them the platform to voice their experiences of erectile dysfunction and to provide them with strategies to cope with these experiences. The professional nurse practitioners lacked the knowledge and skills to assist the patients to cope with their experiences of erectile dysfunction. Therefore, there was a shortcoming in the provision of holistic nursing care to these patients, threatening their mental health specifically. The Theory for Health Promotion in Nursing (University of Johannesburg [UJ], 2009:4) states that a person is seen holistically in interaction with the environment in an integrated manner therefore the need for holistic nursing care.

From the problem identified above I envisioned the need to conduct a study on the lived experiences of patients with erectile dysfunction from a holistic perspective that includes a mental health perspective. The overall aim of this study was to generate an in-depth understanding of the lived experiences of patients with erectile dysfunction who were on a haemodialysis programme in three units of a renal disease management organisation in KwaZulu-Natal. The aim was achieved by exploring and describing the patients' lived experiences of erectile dysfunction.

My understanding of the lived experiences of these patients formed the basis for proposing recommendations to facilitate the mental health of patients with erectile dysfunction in the context of this study with reference to nursing practice, education and research. The facilitation of mental health care to the patients in the haemodialysis units would require the provision of holistic nursing care to be implemented by the professional nurse practitioners with the assistance and support of the advanced psychiatric professional nurse practitioner.



A phenomenological research design that was qualitative, explorative and contextual was followed to achieve the aim and objectives of the study. Purposive sampling was used for the sample selection based on the inclusion and exclusion criteria. The number of participants selected for this study was guided by data saturation. The total number of participants selected for this study was nine.

The data collection methods utilised were phenomenological interviews, naïve sketches and field notes. In the phenomenological interview the participant was asked: "How is it for you to live with erectile dysfunction?" Thereafter the participants were requested to "Write a story on living with erectile dysfunction." The field notes included observational, methodological, theoretical and personal notes.

The phenomenological interviews were audiotaped and transcribed. An independent coder and I analysed the transcribed phenomenological interviews, written naïve sketches and field notes. I made use of Creswell's method of data analysis (Creswell, 2007:156) in analysing the data.

The measures taken to ensure trustworthiness in this study included credibility, dependability, confirmability, transferability and authenticity. The three primary ethical principles articulated by the Belmont Report (beneficence, respect for human dignity and justice) and the Declaration of Helsinki guided this study.

There were two major themes with sub-themes that emanated from the collection of multiple data. The first major theme was that the participants' lived experiences of erectile dysfunction reflected psychological, physical and social losses that seemingly negatively influenced their mental health. An alternative story of two of the participants' acceptance of living with erectile dysfunction which positively influenced their mental health emerged as the second major theme. Therefore the essence of most of the participants' experiences of erectile dysfunction was reflected by losses in the psychological, physical and social dimensions that seemingly negatively influenced their mental health. However, two participants had embraced the challenges of erectile dysfunction and managed to deal with the losses in the psychological and social dimensions.

Based on the findings and the literature control recommendations were proposed for nursing practice, education and research. The recommendations were guided by the Theory for Health Promotion in Nursing from the University of Johannesburg (2009:1). These recommendations served as a frame of reference to enable the professional nurse



practitioner to facilitate the mental health of patients who experience erectile dysfunction within the context of rendering holistic nursing care.

The advanced psychiatric nurse practitioner has both developmental and consultative roles to implement in the haemodialysis unit. In implementing these roles, the professional nurse practitioner is assisted by the advanced psychiatric nurse practitioner to mobilise the internal and external resources to meet the patient's needs on a holistic level. A psychiatric nursing qualification for professional nurse practitioners treating patients in the haemodialysis units is recommended to assist and support the patients to cope with their experiences of erectile dysfunction, thus facilitating their mental health.



# **OPSOMMING**

"Gehoor is een van die mens se vyf sintuie; maar om te kan luister, is 'n kuns." (Tyger, 2005:para.1)

Terwyl ek in die bloeddialise eenheid in KwaZulu-Natal gewerk het, het ek waargeneem dat pasiënte verkies het om nie hul ervarings van erektiele disfunksie met die professionele verpleegpraktisyns te deel nie, maar wel aan die gesondheidsorgwerkers en ander pasiënte in die eenheid openbaar te maak. Die nie-openbaarmaking het as struikelblok gedien vir pasiënte met betrekking tot die hulp en ondersteuning wat hulle benodig het ten einde erektiele disfunksie die hoof te bied.

Boonop was daar geen terapie- of ondersteuningsgroepe vir die pasiënte beskikbaar waarbinne hulle hul ervarings van erektiele disfunksie kon verwoord en wat hulle van strategieë kon voorsien ten einde hierdie ervarings die hoof te bied nie. Die professionele verpleegpraktisyns het die kennis en vaardighede geskort om die pasiënte ten opsigte van hul ervarings te ondersteun. Daarom was daar 'n tekort aan die bied van holistiese verpleegsorg aan die pasiënte, wat spesifiek hul geestesgesondheid bedreig het. Die Teorie van Gesondheidsbevordering in Verpleging (Universiteit van Johannesburg [UJ], 2009:4) vermeld dat 'n persoon holisties in interaksie met die omgewing, op 'n geïntegreerde manier, gesien word; daarom die behoefte aan holistiese verpleegsorg.

Na aanleiding van die probleem wat hierbo geïdentifiseer is, het ek die behoefte voor oë gestel om 'n studie te loods oor die beleefde ervarings van pasiënte met erektiele disfunksie uit 'n holistiese perspektief wat 'n geestesgesondheidsperspektief insluit. Die uiteindelike doel van hierdie studie was om 'n in-diepte begrip te bewerkstellig van die beleefde ervarings van pasiënte met erektiele disfunksie wat op 'n haemodialise program in drie bloeddialiseenhede in 'n bestuursorganisasie van renale versteurings in KwaZulu-Natal was. Die doel is bereik deur die pasiënte se beleefde ervarings van erektiele disfunksie te ondersoek en te beskryf.

My begrip van die beleefde ervarings van hierdie pasiënte het as die basis gedien vir die maak van aanbevelings om die geestesgesondheid van pasiënte met erektiele disfunksie, in die konteks van hierdie studie, met verwysing na verpleegpraktyk, -opvoeding en -navorsing, te fasiliteer. Die fasilitering van die geestesgesondheidsorg aan die pasiënte in die bloeddialise-eenhede sou die verskaffing van holistiese verpleegsorg, geïmplementeer deur



die professionele verpleegpraktisyns, met die hulp en ondersteuning van die gevorderde psigiatriese verpleegspraktisyn, vereis.

'n Fenomenologiese navorsingsontwerp wat kwalitatief, ondersoekende en kontekstueel is, is gevolg om die doel van die navorsing te bereik. Doelbewuste steekproefneming, gebaseer op insluitings- en uitsluitingskriteria, is vir steekproefseleksie gebruik. Die aantal deelnemers wat vir die studie gekies is, is deur dataversadiging bepaal. 'n Totaal van nege deelnemers is vir die studie gekies.

Die dataversamelingsmetodes wat gebruik is, is fenomenologiese onderhoude, naïewe sketse en veldnotas. Tydens die fenomenologiese onderhoude is die pasiënte die volgende gevra: "Hoe is dit vir jou om met erektiele disfunksie saam te leef?" Daarna is die deelnemers die volgende gevra: "Skryf 'n storie oor hoe dit is om met erektiele disfunksie saam te leef." Die veldnotas het waarnemings-, metodologiese, teoretiese en persoonlike notas ingesluit.

Die fenomenologiese onderhoude is digitaal opgeneem en getranskribeer. 'n Onafhanklike kodeerder en ekself het die getranskribeerde fenomenologiese onderhoude, geskrewe naïewe sketse en veldnotas ontleed. Ek het Creswell se dataontledingsmetode gebruik (Creswell, 2007:156) om die data te ontleed.

Maatreëls wat geneem is om die betroubaarheid van hierdie studie te verseker het geloofwaardigheid, betroubaarheid, bevestigbaarheid, oordraagbaarheid en egtheid ingesluit. Die drie hoof etiese beginsels wat duidelik deur die Belmont verslag uitgespreek word (weldadigheid, respek vir menswaardigheid en regverdigheid), sowel as die Verklaring van Helsinki, het hierdie studie gelei.

Twee hooftemas met sub-temas het uit die versameling van meervoudige data voortgevloei. Die eerste hooftema is die deelnemers se beleefde ervarings van erektiele disfunksie wat psigologiese, fisiese en sosiale verliese weerspieël het en wat hul geestesgesondheid skynbaar negatief beïnvloed het. 'n Alternatiewe storie oor twee deelnemers se aanvaarding van die saamleef met erektiele disfunksie, wat hul geestesgesondheid positief beïnvloed het, het as die tweede hooftema na vore gekom.

Die wesenlike van die meeste van die deelnemers se ervarings van erektiele disfunksie is daarom weerspieël in die verliese in die psigologiese, fisiese en sosiale dimensies wat hul geestesgesondheid skynbaar negatief beïnvloed het. Twee deelnemers het egter die



uitdaging van erektiele disfunksie aangegryp en hulle was by magte om die verliese in die psigologiese en sosiale dimensies die hoof te bied.

Gebaseer op die bevindinge en die literatuurkontrole is aanbevelings vir die verpleegpraktyk, -opvoeding en -navorsing gemaak. Die aanbevelings is gelei deur die Teorie van Gesondheidsbevordering in Verpleging van die Universiteit van Johannesburg (2009:1). Hierdie aanbevelings dien as 'n verwysingsraamwerk ten einde die professionele verpleegpraktisyn in staat te stel om die geestesgesondheid van pasiënte wat erektiele disfunksie beleef, in die konteks van die verskaffing van holistiese verpleegsorg, te fasiliteer.

Die gevorderde psigiatriese verpleegspraktisyn het beide 'n ontwikkelings- en konsulterende rol om in die bloeddialise-eenheid te speel. Die gevorderde psigiatriese verpleegspraktisyn help die professionele verpleegspraktisyn met die implementering van hierdie rolle om die interne en eksterne hulpbronne te mobiliseer ten einde die pasiënte se behoefte op 'n holistiese vlak te bevredig. 'n Psigiatriese verpleegkwalifikasie vir professionele verpleegspraktisyns wat pasiënte in die bloeddialise-eenhede behandel word aanbeveel ten einde die pasiënte te help en te ondersteun om hul ervarings van erektiele disfunksie die hoof te bied, en sodoende hul geestesgesondheid te fasiliteer.



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# **CHAPTER 1**

## **OVERVIEW OF THE STUDY**

"We must now emphatically refuse to deal with single components, but instead to the concept of wholeness. We need to think and act systematically to enable us to effectively handle all parts of a system simultaneously in an interrelated manner, thus avoiding the fragmented and isolated nature of past functioning in nursing."

Betty Neuman (in George, 1990:265)

#### 1.1 INTRODUCTION

Improvements in dialysis therapy for patients in chronic renal failure have extended their life expectancy. However, patients in chronic renal failure have reported changes in their routine, lifestyle and relationships that are not addressed by current interventions for chronic renal failure. It has been reported that the patients and their families are suddenly thrown into a total lifestyle change and given little or no preparation for starting dialysis (Goliath Business knowledge on demand, 2010:1, para. 2). The changes experienced can include decreased energy and stamina as well as changes in sex drive and sexual habits (Centre for Health Information-Renal Dialysis Centre, 2002:1). These changes necessitate an increase of nursing intervention on a holistic level to ensure total patient care, and as such it must include the mental health facilitation of patients. However, the patient either does not receive all the necessary information or the information is too task orientated for the patient to grasp in order to modify his behaviour (Goliath-Business knowledge on demand, 2010:1, para. 2). This study focused on the phenomenon of erectile dysfunction as a potential lifestyle changing experience for male patients in chronic renal failure and on a haemodialysis programme.

The professional nurse practitioner's training is closely related to the medical model which is concerned with diagnosis, treatment and cure of physical ailments (Basaranthappa, 2007:60). It was with holistic nursing care in mind that I undertook this study, envisioning that the male patients on the haemodialysis programme should receive holistic nursing care with reference to their experiences of erectile dysfunction. An overview of the study of the lived experiences of patients with erectile dysfunction who were on a haemodialysis programme in three renal disease management organisation units in KwaZulu-Natal is the focus of attention in Chapter 1.



## 1.2 BACKGROUND AND RATIONALE

Naicker (2009:1) reports that chronic renal failure is at least three to four times more frequent in Africa than in developed countries. In South Africa the current dialysis (haemodialysis and peritoneal dialysis) treatment rate ranges from 70 per million of the population, while the rest of sub- Saharan Africa accounts for fewer than 20 per million of the population. The rate for haemodialysis in South Africa is 45 per million of the population.

In South Africa hypertension is one of the causes of chronic renal failure in 21% of male and female patients on renal replacement therapy (haemodialysis and peritoneal dialysis) while diabetic nephropathy as a cause of chronic renal failure accounts for 14% to 16% of these patients (Naicker, 2009:1). The treatment of haemodialysis is provided by the health system in South Africa which is characterised by the existence of both private and public sectors (Department of Health [DOH], 2009:2). This study was conducted in a renal disease management organisation that forms part of the private sector providing a haemodialysis programme in South Africa. This study was conducted in three of the 12 units of a renal disease management organisation in KwaZulu-Natal.

Haemodialysis increases the incidence of sexual dysfunction in male and female patients with chronic renal failure. In support of this statement, Ayub and Fletcher (2000:1525) maintain that the estimated prevalence of sexual dysfunction in pre-dialysis male and female patients is 9%, but increases by 61% to 70% in dialysis patients. According to these authors, the reported presence of erectile dysfunction among haemodialysis and renal transplant male patients ranges from 21% to 43%.

Sexual dysfunction refers to experiencing difficulties in engaging in sexual intercourse and encompasses a variety of disorders including erectile dysfunction. Levy, Morgan and Brown (2004:100) assert that the most frequently reported symptoms of sexual dysfunction in male patients include decreased libido, erectile dysfunction, and premature or delayed ejaculation. For the purpose of this study, erectile dysfunction experienced by male patients with chronic renal failure who were on a specific haemodialysis programme was the sexual dysfunction investigated. Erectile dysfunction is the inability to achieve and maintain an erection (Merck manual of medical information, 2003:1206).

The causes for erectile dysfunction in male patients with renal failure are reported to be multifactorial. Contributing factors include vasculogenical, neurological, endocrinological,



psychological, biochemical and pharmacological aspects (Wong, <u>et al</u>. 2007:383-387). Psychological (mental health) co-morbidities increase the incidence of erectile dysfunction.

In a study conducted by Cerqueira, Morales and Glina (2002:65) concerning dialysis in male patients who had psychological co-morbidity such as anxiety and depression, it was confirmed that 34.8% of them experienced erectile dysfunction. Co-morbidity refers to having two or more conditions or diseases in the same person at the same time (McGraw-Hill Concise Dictionary of Modern Medicine, 2002). An example of mental health co-morbidity is to have depression as a result of the diagnosis of chronic renal failure coupled with anxiety caused by the inability to achieve and maintain an erection at the same time. According to Levy, Morgan and Brown (2004:100), the common mental health factors impacting a haemodialysis patient are depression, anxiety, fear of failure, marital discord, changes in the body image, and a low self-esteem. These mental health factors can be exacerbated by a sexual dysfunction, such as erectile dysfunction, which can affect the male patient in three dimensions: physically, psychologically and socially.

Basaranthappa (2007:104) refers to the Philosophy and Science of Caring theory by Jean Watson which advocates that sexual dysfunction is categorised as a functional need that must be attended to on a holistic level otherwise stress will result. Tierney (2007:1) defines holistic health as a philosophy concerned with the well-being of the whole person; thus including the body, mind and spirit. Holistic health care therefore looks at the whole person and recognises that health is influenced by many interacting elements including the person's body, mind, spirit, family, emotions, lifestyle and her or his environment. When a functional need (activities of daily living) of a person is not met, then holistic treatment includes an analysis of the person's physical, emotional and spiritual state, support structure, lifestyle and the environment. The goal of holistic practitioners is to focus on the person's health within the context of the aforementioned dimensions (Tierney, 2007:2).

The World Health Organization (WHO) (2003:1) reaffirms the need for holistic nursing care by defining 'health' as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". Mental health is the level of the mental well-being of an individual as affected by physical, social and psychological factors. Holistic nursing care is the provision of nursing care on a biopsychosocial perspective to facilitate the healing process (Dossey & Keegan, 2009:52).

This study focused on the lived experiences of male participants with erectile dysfunction from a holistic perspective. The Theory for Health Promotion in Nursing of the University of



Johannesburg (UJ) (2009:1) states a person is seen holistically in interaction with the environment (internal and external) in an integrated manner. The internal environment consists of three dimensions: the body, mind and spirit. The external environment consists of the physical, social and spiritual dimensions. The Theory for Health Promotion in Nursing is described in detail in this chapter, section 1.6.1.

A person's interaction with the internal and external environments can result in physical and psychosocial stressors. These stressors pose a threat to human health because they are challenges that can alter the workings of the human body (Lovallo, 2005:24).

According to Sorensen (2003:1), how people think about themselves or the world around them seems to have a major impact on their level of vulnerability to stress. In other words, when the experiences of sexual dysfunction negatively affect how a male thinks about or views himself, it is quite possible that he can become anxious and stressed. Tomlinson and Wright (2004:328) concedes by explaining that the loss of sexual functioning poses a threat to a male person's masculine identity and how he views himself; the loss of the masculine identity can make him very vulnerable to stress. The mental and emotional effects of stress may evoke feelings of being inadequate, anxious and angry while ruminating upon the reasons causing the stress (Scott, 2009:1).

In a study to investigate the extent of life impairment as reported by female and male patients receiving haemodialysis, sexuality was reported as the fifth most important life stressor which resulted in changed lifestyle functioning (Messina, et al. 2007:673-678). These authors published the following findings: 65% of the patients reported they were dissatisfied with sex since they had started dialysis, 40% had stopped having sex and 27% reported they had no desire for sex. Neto et al. (2002:19-26) similarly report that one of the problems experienced by both female and male patients with chronic renal failure, was sexual dysfunction.

In this study I departed from the position that the participants, who were all male, might have endured a lifestyle change because of their experiences of erectile dysfunction while on the haemodialysis programme. Samarrai (2004:1-3) confirms that the persistent inability to achieve an erection to allow satisfactory sexual activity is viewed as a distressing abnormality of male sexual functioning. Erectile dysfunction affects all areas of human functioning, thus also the physical, psychological and social dimensions. If erectile dysfunction is not addressed it can have a significantly negative impact on not only the quality of a male individual's life, but on his mental health as well (Neto, et al. 2002:19-26).



Intili and Nier (1998:185-187) validated the link between depression, self-esteem and erectile dysfunction in a study using a depression scale and a self-esteem scale on male participants who experienced erectile dysfunction. In a study conducted by Seidman <u>et al.</u> (2001:1623) with 152 males with erectile dysfunction, the authors also confirmed that a change in erectile functioning was highly correlated with depressive symptoms.

In order to decrease stress and thereby maintain mental health, male patients who are experiencing erectile dysfunction need to adjust and adapt to the changes in their lifestyle functioning associated with the decrease in their sexual functioning. Therefore, by learning to accept their situation and by being taught how to implement alternative coping methods to deal with the experience, the mental health of male patients who experience erectile dysfunction can be improved and retained. Kreigh and Perko (1983:31) assert that successful adaptation in daily living requires individuals to balance wants, needs, abilities, values and feelings within their societal and environmental context to maintain their physical and mental health.

Adaptation to lifestyle functioning is closely linked to a professional and personal support system that would address all patients' needs not only on a physical level, but also on a psychological and social level by utilising holistic patient care. Such a support system includes support from the patients' partners and health professionals. The latter includes professional nurse practitioners, advanced psychiatric nurse practitioners, doctors, psychologists, psychiatrists and sexologists. Van Reenen, de Villiers and Uys (2010:246-266) view group therapy and counselling as therapeutic interventions to assist individuals (patients and their partners) in situations where they are unable to cope, thus improving their mental health. The implementation of group therapy, support sessions, psycho-educational therapy, and programmes to enhance the participants' insight and coping skills connected with their changed sexual functioning (in this context with erectile dysfunction), could facilitate the participants' mental health, thereby promoting their health on a holistic level.

Professional nurse practitioners who work in haemodialysis units play a key role in facilitating the mental health of all patients as an integral part of holistic nursing care. A 'professional nurse practitioner' refers to a nursing practitioner who is registered with the South African Nursing Council ([SANC], 1984:2). Since 1985 professional nurse practitioners in South Africa have had to undergo a four year comprehensive training course – which includes general, psychiatric, community and midwifery training – in order to render comprehensive nursing care (Subedar, 2005:98). Comprehensive training pertains to the ability of the nursing practitioner to integrate knowledge and skills for the provision of



comprehensive nursing care. The professional nurse practitioner is educated and competent to provide comprehensive nursing treatment and care to persons in all health care settings (Subedar, 2005:98). In this study comprehensive nursing care was connected to holistic nursing care.

I have worked in the haemodialysis units of three renal disease management organisations in KwaZulu-Natal for the past 10 years. During this time, I observed that most of the haemodialysis units were staffed with professional nurse practitioners, enrolled nurses, enrolled nursing auxiliaries and clinical technologists - personnel who were trained at a University of Technology to perform certain procedures, including haemodialysis, on patients. Many of the professional nurse practitioners working in the haemodialysis units did not have a psychiatric qualification; in other words, considering that mental health is regarded as an integral part of holistic nursing care, they did not have the necessary training and skills to facilitate the mental health of the male patients who experienced erectile dysfunction. At the time the study was conducted, there were 25 professional nurse practitioners working in the twelve haemodialysis units in the renal disease management organisation in KwaZulu-Natal and 70% of them did not have a psychiatric qualification (the renal disease management organisation where the study was conducted). One reason for the high percentage of them not having this qualification was that some had qualified before the four year comprehensive training course for professional nurse practitioners was implemented in 1985. A second reason was that some had bridged from enrolled nurses to professional nurse practitioners and consequently did not have a psychiatric qualification. The outcome of the training was that the professional nurse practitioners' nursing care was based on the medical model of diagnosis, treatment and a cure of physical ailments. It was therefore evident to me that there was a need for the professional nurse practitioners to receive support and assistance to render holistic nursing care to male patients experiencing erectile dysfunction and who were on a haemodialysis programme of a renal disease management organisation in KwaZulu-Natal.

There is a lack of resources in the haemodialysis context with regards to the training and development of the professional nurse practitioners to provide holistic nursing care to the patients who experience erectile dysfunction. In line with this it has been noted that the advanced psychiatric nurse practitioner can be a key role player in assisting the management of haemodialysis programmes to meet the developmental needs of professional nurse practitioners who lack the comprehensive training. Since the advanced psychiatric nurse practitioner has a clinical master's degree in psychiatric nursing science with comprehensive knowledge and skills in psychiatric nursing science (Greef &



Poggenpoel, 1991:32), she or he can plan and conduct training and developmental workshops for the professional nurse practitioners to enhance their knowledge and understanding in order for them to assist and support male patients experiencing erectile dysfunction in a holistic manner. The supports systems for the patients and the training workshops for the professional nurse practitioners are critical resources that can be mobilised to facilitate the patients' mental health from a holistic perspective. The mobilisation of resources is a mutual, purposeful activity between the nurse and the patient where opportunities for the promotion of health are utilised (UJ, 2009:1).

Besides the perceived inability of the professional nurse practitioners in the specific haemodialysis units in KwaZulu-Natal to provide holistic nursing care, another problematic reality which emerged was the non-disclosure of experiencing erectile dysfunction by the patients to the professional nurse practitioners. Ayub and Fletcher (2000:1525) confirm that not only is erectile dysfunction a common problem for male patients receiving haemodialysis, but it is a problem that remains difficult to diagnose and treat because the patients feel too embarrassed to disclose it. Therefore, the professional nurse practitioners are often unaware that the male patient is experiencing erectile dysfunction. The non-disclosure of erectile dysfunction in the professional nurse practitioner-patient relationship may further compromise the male patients' mental health. This is confirmed by Intili and Nier (1998:185) who state that not disclosing his erectile dysfunction can be harmful to a male's mental health. Since his self-esteem and self-image is already negatively influenced by experiencing such a sensitive problem, not sharing it with professionals who can assist him to come to terms with it and cope with it can lead to a downward spiral in his mental health.

The above research and literature suggests that erectile dysfunction is closely related to the mental health of the male patient receiving haemodialysis. It is further clear that male patients challenged by erectile dysfunction face enormous difficulties in adapting to a changed environment. It confirms the need to conduct research to gain an in-depth understanding of these patients' experiences of living with erectile dysfunction. Added to this, the fact that not all the professional nurse practitioners working in the haemodialysis programme of a renal disease management organisation in KwaZulu-Natal had psychiatric qualifications possibly compromised the mental health care of these particular patients as an integral part of holistic nursing care.

Considering the above background, it was my belief that a need existed to explore the phenomenon and to make recommendations for nursing practice, education and research focusing on the facilitation of the mental health of male patients with erectile dysfunction.



#### 1.3 PROBLEM STATEMENT

The Centre for Health Information - Renal Dialysis Centre (2002:1) confirms the adverse mental health influence caused by erectile dysfunction can reflect in an array of emotional and behavioural responses. These include anxiety, embarrassment and frustration with repeated erectile dysfunction, anger resulting in discord and lashing out at a partner, guilt that the partner has been let down, depression, and a loss of interest in sex.

The negative influence that erectile dysfunction can have on a male patient's mental health was confirmed in a study conducted by Pontin (2002:264) which focused on the experiences of males living with erectile dysfunction. He identified "loss" and "being alone with it [experiences of erectile dysfunction]" as central themes related to how males construe and interpret this phenomenon. The theme of "loss" was related to a perceived sense of the loss manhood, self-esteem and self-confidence due to the inability of satisfying sexual needs. "Being alone with it" was concerned with not disclosing experiencing erectile dysfunction to anyone, including a partner or medical personnel. This inability evoked intense feelings of humiliation and a fear of being stigmatised, resulting in non-disclosure. Not sharing these feelings increased stress in these patients to the extent of threatening their mental health.

Intili and Nier (1998:185) confirm that male persons rarely discuss their sexual difficulties with friends, acquaintances or their physicians because the emotional discomfort of their loss of manhood is too great for them to face. The authors further suggest that male patients may not disclose experiencing erectile dysfunction to female professional nurse practitioners because they may be embarrassed and uncomfortable to discuss this phenomenon with a female. They add that a male patient's view may be clouded by depression and low self-esteem which accompanies his feeling that he has "lost his manhood".

As a psychiatric nurse and nephrology nurse working in a haemodialysis unit in KwaZulu-Natal, I observed a similar pattern of non-disclosure by male patients who experienced erectile dysfunction. It seemed as if these patients disclosed their experiences to the care workers – staff members who were employed to clean the machines and prepare the environment for the next session of haemodialysis – rather than to professional nurse practitioners. According to an account from a male patient, most patients who do disclose experiencing erectile dysfunction do so with other patients.

This pattern of reluctance to disclose erectile dysfunction is potentially problematic in the context of the haemodialysis programmes. Male patients may not receive the mental health



support, knowledge, and assistance from the professional nurse practitioners that they (the patients) need to deal with their problem; this can potentially have an adverse influence on holistic nursing care. Reluctance to disclose erectile dysfunction also has the potential to contribute to a lowered self-esteem, cause more anxiety, and lead to the loss of the male patients' self-image as well as the loss of their identities as husbands (partners) and masculine males (Intili & Nier, 1998:186).

I observed that there did not seem to be psycho-educational, therapy and support groups available for these patients which could have afforded them the opportunity to voice their concerns. All the professional nurse practitioners in the haemodialysis units of a renal disease management organisation in KwaZulu-Natal were female. As mentioned before, the stance of Intili and Nier (1998:185) is that the embarrassment of experiencing erectile dysfunction silences male patients from disclosing their experiences to professional nurse practitioners. However, I believe that patients on haemodialysis should be treated holistically and the focal point should be on the physical, psychological and social dimensions. In a context where there is limited support from professional nurse practitioners for male patients experiencing erectile dysfunction and a high incidence of mental health challenges, reluctance or even the inability on the part of the patient to disclose their problem further diminishes these patients' opportunities for mental health support and assistance rendered by female professional nurses working in renal care settings.

Professional nurse practitioners who are able to discuss the male patient's experiences of erectile dysfunction afford their patients the possibility of effective and enduring treatment success and the restoration of a satisfying relationship with their partners (Dunn, 2004:6). Professional nurse practitioners therefore need to develop an understanding that even though the physiological issue may not be solved, psychological support can facilitate the mental health of their male patients and thus improve the quality of life experienced by them.

#### 1.4 RESEARCH QUESTIONS

In view of the problem statement the following research questions were asked:

 What are the lived experiences of male patients with erectile dysfunction who are on a haemodialysis programme in three units of a renal disease management organisation in KwaZulu-Natal?



 What can be done by the professional nurse practitioners to facilitate the mental health of male patients who are on a haemodialysis programme in three units of a renal disease management organisation in KwaZulu-Natal?

#### 1.5 AIM AND OBJECTIVES OF THE STUDY

The aim and the objectives of the study are discussed next.

#### 1.5.1 Aim of the study

The overall aim of this study was to generate an in-depth understanding of the lived experiences of patients with erectile dysfunction who were on a haemodialysis programme in three units of a renal disease management organisation in KwaZulu-Natal. This understanding formed the basis for proposing recommendations to facilitate the mental health of these patients in the context of this study. The recommendations focused on nursing practice, education and research.

"Nursing practice" refers to the actual provision of holistic nursing care by nurses based on the assessment of the patient's health needs. (This is discussed in Chapter 4, section 4.4.1).

"Nursing education" refers to the theoretical and practical training provided to nurses with the purpose of preparing them for their duties as nursing care professionals. (This is discussed in Chapter 4, section 4.4.2).

"Nursing research" is a detailed systematic study of a problem in the field of nursing. (This is discussed in Chapter 4, section 4.4.3).

# 1.5.2 Objectives of the study

The objectives of this study were:

Explore and describe the lived experiences of patients with erectile dysfunction who are
on a haemodialysis programme in three renal disease management organisation
haemodialysis units in KwaZulu-Natal.

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 Propose recommendations for professional nurse practitioners to facilitate the mental health of patients with erectile dysfunction on a haemodialysis programme in three renal disease management organisation haemodialysis units, with reference to nursing practice, education and research.

#### 1.6 PARADIGMATIC PERSPECTIVE

A paradigm may be viewed as a set of beliefs that deals with principles. It represents a world view that defines the nature of the world including an individual's place in the world and the individual's range of possible relationships to the world (Denzin & Lincoln, 2005:191). The paradigmatic perspective of this study included the Theory for Health Promotion in Nursing (UJ, 2009) on a meta-theoretical and theoretical level. Phenomenology represents the methodological perspective and will be described in more detail in Chapter 2, section 2.3.1.1.

# 1.6.1 Meta-theoretical perspective

The meta-theoretical perspective refers to the nature and structure of scientific theories, the nature of scientific growth and progress, and the meaning of truth, explanation and objectivity (Henning, 2005:14). In this study I applied the Theory for Health Promotion in Nursing from the University of Johannesburg (2009) as the meta-theoretical perspective. This theory aims to promote the health of the individual, family, group and community. I chose this theory as a guiding meta-theoretical framework because of the holistic nature thereof.

The Theory for Health Promotion in Nursing (UJ, 2009:4) defines a person as a whole person who embodies dimensions of body, mind and spirit. The person functions in an integrated, interactive manner with the environment. The environment includes an internal and external environment. The internal environment consists of the body, mind and spirit; the external environment embodies the physical, social and spiritual dimensions (UJ, 2009:4). The dynamic interaction between the internal and external environments of the participants pertaining to this study is discussed below. In the context of this study the "person" was a male patient who experienced erectile dysfunction, was in chronic renal failure and on a haemodialysis programme. In the next section, the concept "participant" will be used to refer to the male patient.



The participant is in interaction with the internal (body, mind and spirit) and external (physical, social and spiritual) environment. According to the Theory for Health Promotion in Nursing (UJ, 2006:6), the *body* refers to the anatomical structures and physiological (biological) processes pertaining to the individual, family, group and community. The participants' bodily functions were altered in the context of this study because they had been diagnosed with chronic renal failure. Hypertension and diabetes were the most common causes for chronic renal failure in them. Due to their chronic renal failure they were on the haemodialysis programme. Ayub and Fletcher (2000:1525) report that erectile dysfunction in male patients with chronic renal failure results from endocrine disorders, namely, diabetes (diabetic neuropathy and arteriosclerosis) and an imbalance in the hypothalamic and pituitary glands (lowered testosterone levels). Other causes for erectile dysfunction are uraemia, hyperprolactinaemia and a decreased vascular supply to the male genital organ.

The *mind* refers to the psyche which includes all the intellectual, emotional and volitional processes of the individual, family, group or community (UJ, 2009:6). The intellect refers to the capacity and quality of the psychological processes of thinking, association, analysis, judgement and understanding of which the individual, family, group, and community are capable. The emotional process is divided into affection, desire and feelings of the individual, family, group, and community. The volitional is the process of decision making in the executing of a choice by the individual, family, group, or community.

Ayub and Fletcher (2000:1525) report that the psychological factors that can result in erectile dysfunction are chronic fatigue, anxiety, stress, a low self-esteem, and depression arising from experiencing a chronic illness. In this study, the participants' emotional processes of living with erectile dysfunction affected their feelings about themselves, their partners and sexual intercourse. Their intellectual processes had an impact on the coping methods that they implemented to deal with their experiences of erectile dysfunction. This included their insight into their experiences of erectile dysfunction and the judgements and decisions that they made in order to manage their problem. The mind (psyche) affects the participants on both the psychological and the social dimensions (UJ, 2009:6).

Spirit refers to that part of the individual, family, group, or community reflecting his or her relationship with God. The spirit consists of two interrelated components which have an integrated function, namely, the conscience and relationships (UJ, 2009:6).

With reference to the external environment, erectile dysfunction had an effect on the social dimension with regard to the relationship between the participants and their partners. The



social dimension refers to the human resources in the external environment of the individual, family, group, and community (UJ, 2009:6). In this study the human resources included the participant's partner, the professional nurse practitioner, the advanced psychiatric nurse practitioner, doctors, psychologists, psychiatrists and sexologists. The inability of the participants to engage in sexual intercourse with their partners and their apparent non-disclosure of their experiences of erectile dysfunction to their partners can result in a loss where the social dimension is concerned. The loss of communication connected to experiences of erectile dysfunction may result in diminished emotional affinity in the relationship between the participant and his partner; in effect thus it means loss in the social dimension.

## 1.6.2 Theoretical perspective

The theoretical perspective for this study reflected the four central components of the Theory for Health Promotion in Nursing (UJ, 2009:4-5), namely, person, environment, nursing and health (mental health).

As discussed in the meta-theoretical perspective (section 1.6.1) the person (the male patient in the context of this study and referred to here as the "participant") is seen as holistic and functions in an integrated, interactive manner with his internal and external environment. The participant's internal environment consists of body (anatomical and biological structures), mind (intellectual, emotional and volitional processes), and the spirit (conscience and relationships). The external environment consists of physical (physical structures), social (human resources) and spiritual (values and religious) dimensions. (Refer to the discussion of the participants' internal and external environments in section 1.6.1).

Nursing is an interactive process where the professional nurse practitioner, as a sensitive therapeutic professional, facilitates the promotion of health through the mobilisation of resources (UJ, 2009:4). The professional nurse practitioner in this study rendered nursing care to the participants while the latter were on the haemodialysis programme. Nursing interactions is a mutual involvement between the professional nurse practitioner and the participants.

Health is a dynamic interactive process in the patient's environment which reflects the relative health status of the patient and either contributes or interferes with the promotion of health (UJ, 2009:5). In this study the focus was on the mental health of the participants who were on a haemodialysis programme and experienced erectile dysfunction. The promotion of



health refers to the mobilisation of resources to assist the participants. The mobilisation of resources refers to the mutual, purposeful activity between the nurse and the patient where the opportunities for the promotion of health are utilised (UJ, 2009:7). Resources in the patient's environment (internal and external resources) include any assets or means of facilitation in the promotion of health (UJ, 2009:7). In this study the resources that can be mobilised to facilitate the mental health of the participants include internal resources (insight and coping skills through education on erectile dysfunction, psycho-education, therapeutic groups and supportive sessions), and external resources (partners, professional nurse practitioners, advanced psychiatric nurse practitioners, doctor and referrals to professionals such as psychologists, psychiatrists and sexologists).

# 1.6.3 Methodological perspective

Stewart and Mickunas (1990:5) describe the four philosophical perspectives in phenomenology which were addressed in this study. The first philosophical perspective is the return to the traditional task of philosophy, namely, a search for wisdom. Secondly, phenomenology is a philosophy without presuppositions where the approach is to suspend all judgements about what is real until they are founded on a concrete basis. Suspending judgement is referred to as the "epoch". The intentionality of consciousness is the third philosophical perspective where consciousness is always directed towards an object. The reality of the object is related to one's consciousness of it. Lastly is the refusal of the subject-object dichotomy which flows from the intentionality of consciousness. The reality of an object is perceived only within the meaning of the experience of an individual.

According to Creswell (2007:17), the philosophical assumptions in phenomenology include the epistemological, ontological, rhetorical and methodological assumptions. The epistemological assumption relates to the relationship between the researcher and that which is being researched (Creswell, 2007:17).

In my relationship with the participants I maintained a rapport with them even before the study commenced. I prolonged the time spent with the participants during the phenomenological interview to make them feel comfortable when describing to me their experiences with erectile dysfunction. I attempted to maintain an honest and open relationship with the participants in this study and informed them of the processes throughout the study. During the unstructured and open-ended phenomenological interviews I applied the appropriate interviewing skills to elicit in-depth information from the participants regarding their experiences of erectile dysfunction.



The ontological assumption relates to the nature of reality and its characteristics (Creswell, 2007:17). When researchers conduct qualitative research they embrace the idea of multiple realities. Qualitative researchers conduct a study with the intention of reporting these multiple realities. In this study I reported on the multiple realities which were in the form of multiple quotes or statements and different perspectives from the participants on their lived experiences of erectile dysfunction.

The axiological assumption refers to the fact that the study is value laden and that biases are present (Creswell, 2007:17). I applied the axiological assumption by recognising the value-laden nature of the study and by attempting to minimise biases in the study as evidenced by the measures that I took to ensure the credibility of the study as discussed in detail in Chapter 2, section 2.4.1.

The rhetorical assumption determines the language of the study (Creswell, 2007:17). With reference to the rhetorical assumption I made use of qualitative terms and language and engaged in a personal and narrative style.

The methodological assumption determines the research process (Creswell, 2007:17). I made use of inductive logic, studied the topic within its context and made use of a phenomenological research design. I applied inductive logic, whereby logic is from specific observations to more general rules. In my search for knowledge, it was my aim in this study to generate an in-depth understanding of the lived experiences of male patients with erectile dysfunction who were on a specific haemodialysis programme. I made use of "reduction" when entering the world of the participants to discover the core of the phenomenon, namely erectile dysfunction. Reduction is attaching meaning to elements in the data and then classifying the data into categories (Burns & Grove, 2005:548).

I was aware that the reality of any perceived experience always relates to one's consciousness of the experience. In the intentionality of consciousness I was open to the participants and their lived experiences of erectile dysfunction and to my own perceptions of the phenomenon. I applied bracketing to close off my preconceived ideas on erectile dysfunction. (This is described in Chapter 2, section 2.3.3).

Bracketing is where the researcher sets aside all preconceived experiences to best understand the experiences of the participants in the study (Creswell, 2007:234). Therefore, I attempted to suspend and bracket all my preconceived ideas on erectile dysfunction through the use of my reflexive notes and by having a bracketing interview with my two



supervisors; in this way I could set aside my thoughts and feelings about the phenomenon. Rolls and Relf (2006:286; 291; 302) state bracketing interviews provide an important research focused relationship that adapts the skill of clinical supervision in the context of research. The presence of a skilled "bracketer" contributes to the production of knowledge by increasing objectivity and amplifying the researcher's own reflexive capacity. Bracketing interviews enable the researcher to investigate the participants' experiences and at the same time hold in abeyance her own experience and suppositions. In this study, my preconceived thoughts and feelings on erectile dysfunction changed as described in Chapter 2, section 2.3.3.

The common experiences of the participants with regard to erectile dysfunction may have presented diverse meanings to them. Therefore, phenomenology provided a deep understanding of the phenomenon of erectile dysfunction as experienced by the participants in this study.

#### 1.7 CLARIFICATION OF CONCEPTS

The key concepts used in this study are described below.

#### 1.7.1 Patient

Reber, Reber and Allen (2001:515) define a patient as "someone who is receiving treatment for a diagnosed illness or injury from a doctor or in a hospital". Thus "patient" refers to "an individual who is dependent on another for services provided". The patients in this study were male persons who were between 34 and 70 years old. They had been diagnosed with renal failure and experienced erectile dysfunction after the commencement of haemodialysis. The patients made use of the services rendered by health care professionals implementing a haemodialysis programme in KwaZulu-Natal.

In this study the term "patient" instead of "mental health care user" will be used. According to the Mental Health Care Act (2002), a mental health care user is an individual who receives care, treatment and rehabilitation services, or makes use of a health service at a health establishment aimed at enhancing the health status of the user. The similarities in meaning between the terms "mental health care user" and "patient" in this context was perceived to be obvious since both focus on the dependency of an individual on another individual or health care service for the enhancement of the specific individual's health status. The decision to use the term "patient" was also influenced by the fact that all documents such as



the patient information leaflet (see Annexure D); the written handouts to the male patients (the one before the research was begun [see Annexure G]) and the one to set an appointment for the phenomenological interview (see Annexure H) used this term. In addition, I wanted to ensure semantic consistency of the terminology throughout the study.

# 1.7.2 Erectile dysfunction

For the purpose of this study the term "erectile dysfunction" will refer to "the inability of the male to attain and maintain a sufficiently rigid erection of the penis to allow for penetration and ejaculation or successful intercourse" (Unger, 2004:28).

## 1.7.3 Haemodialysis programme

Stam (2010:22) defines haemodialysis as "a medical treatment in which dialysis is used to remove poisons and toxins from a patient's blood. The poisons and toxins cross the dialysis membrane of an artificial kidney through a haemodialysis machine and is discarded. After the blood is filtered it is returned back to the patient from the haemodialysis lines through the patient's access, namely the catheter or fistula".

In this study the term "haemodialysis programme" will relate to a specific dialysis programme that is managed by a renal disease management organisation in South Africa.

# 1.7.4 Lived experiences

"Lived experiences produce insight into the world of the patients and allows for the collection of data that is rich through the use of narrative" (Henning, 2005:9). Lived experiences refer to the patients' description of their perceptions, thoughts and experiences as they relate to the phenomenon being investigated. In this study the phenomenon was erectile dysfunction. Henning adds "the environment is dynamic and patients render individual interpretations to every experience. Every individual experience must be seen as embedded in and bearing the imprint of a conceptual world that is continually changing" (Henning, 2005:9).

In this study the term "lived experiences" will refer to the patients' experiences (thoughts and feelings) relating to erectile dysfunction and the effects thereof on their mental health.

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# 1.7.5 Professional nurse practitioner

The term "professional nurse practitioner" applies to a nursing practitioner who is registered with the SANC as a registered nurse (SANC, 1984:2).

In this study, the term "professional nurse practitioner" will refer to the professional nurse practitioners implementing the haemodialysis programme for patients in specific renal units of a renal disease management organisation in KwaZulu-Natal. As mentioned previously, the majority of the professional nurse practitioners did not have a psychiatric qualification due to the fact that they had either qualified prior to the commencement of the comprehensive training for professional nurse practitioners in 1984, or had bridged from being enrolled nurses to professional nurse practitioners. This could therefore indicate that they lacked the necessary knowledge and skills to facilitate the mental health of patients who were on the haemodialysis programme.

# 1.7.6 Advanced psychiatric nurse practitioner

An advanced psychiatric nursing practitioner is a professional nurse practitioner who has obtained a clinical master's degree or an advanced diploma in psychiatric nursing science, with additional clinical experience under the supervision of an advanced psychiatric nurse specialist and/or specialists in related disciplines. The advanced psychiatric nursing practitioner has comprehensive knowledge and skills in the practice of psychiatric nursing science (Greeff & Poggenpoel, 1991:32).

#### 1.7.7 Mental health status

The Mental Health Care Act (2002) defines mental health status as "the level of mental well-being of an individual as affected by physical, social and psychological factors and which may result in a psychiatric diagnosis".

According to the World Health Organization (2008:1), mental health is "a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community". Mental health is therefore an evolving process reflecting an individual's adaptation to internal and external environmental demands (Kreigh & Perko, 1983:32; UJ, 2009:4). For successful adaptation to the internal and external environments, the individual may require the interaction of the professional nurse practitioner to facilitate the promotion of



his or her health. The promotion of health by the professional nurse practitioner requires the mobilisation of resources according to the patient's needs (UJ, 2009:7). Therefore, the lack and non-utilisation of these resources may impair the patient's health and lead to mental health impairment. In this study, the focus was on the lived experiences of patients with erectile dysfunction within a framework of holistic mental health care (UJ, 2009:1).

# 1.7.8 Holistic nursing care

The Theory for Health Promotion in Nursing (UJ, 2009:4) states that a person is seen holistically in interaction with the environment in an integrated manner. Dossey and Keegan (2009:52) define holistic nursing as "all nursing practice that has healing the whole person as it's goal by protecting, promoting and optimizing health and wellness". "Holistic nursing is a body of knowledge and an advanced set of nursing skills applied to practice that recognize the totality of the human being and the interconnectedness of body, mind, emotion, spirit, energy, society, culture, relationships, context and environment. Holistic nursing care is centered on the relationship with the person (patient) and is healing orientated. The nurse is the facilitator of the healing" (Dossey & Keegan, 2009:52).

In this study holistic nursing care will refer to the total nursing care to be provided by the professional nurse practitioner with the aim of promoting the health of the participants in this study and the patients who experience erectile dysfunction. The nursing care is reflected on the psychological, physical and social dimensions.

#### 1.8 RESEARCH DESIGN AND METHODS

Following is a description of the research design and methods.

# 1.8.1 Research design

A phenomenological research design was utilised to achieve the objectives of the research, situated within a qualitative, descriptive exploratory and contextual design. This research design is described in detail in Chapter 2, section 2.3.1.

#### 1.8.2 Research methods

Polit and Beck (2006:509) define research methods as "the techniques used to structure a study and to gather and analyse information on a relevant research question in a systematic



way." The research setting, selection of participants, sampling criteria, the researcher as instrument, data collection and data analysis is described in detail in Chapter 2, section 2.3.2.

#### 1.8.2.1 Research setting

The study was conducted in three haemodialysis units of a renal disease management organisation in KwaZulu-Natal. The participants were on the haemodialysis programme in these units. A detailed description of the research setting is provided in Chapter 2, section 2.3.2.1.

## 1.8.2.2 Selection of participants

The participants were selected from a specific population. Polit and Beck (2006:506) describe the population as "an entire set of individuals having some common characteristics". The accessible population in this study were male patients between 34 and 70 years old who were on the haemodialysis programme in the aforementioned haemodialysis units in KwaZulu-Natal and who were experiencing erectile dysfunction. Purposive sampling was utilised during the selection process. Polit and Beck (2006:271) explain purposive sampling is when the researcher handpicks the cases or type of cases that will best contribute to the information needs of the study. The selection of participants is described in detail in Chapter 2, section 2.3.2.2.

# 1.8.2.3 Sampling criteria

The inclusion and exclusion criteria which applied to this study are described in detail in Chapter 2, section 2.3.2.3.

#### 1.8.3 The researcher as instrument

According to Onwuegbuzie, Leech and Collins (2008:2), "the researcher is considered as the main instrument for data collection, data analysis and data interpretation". The researcher as instrument is described in Chapter 2, section 2.3.3.



#### 1.8.4 Data collection

The data collection methods that were utilised included phenomenological interviews, naive sketches and field notes. The data collection methods are described in detail in Chapter 2, section 2.3.4.

# 1.8.5 Data analysis

Data analysis was conducted using the steps of phenomenological data analysis according to Creswell (2007:156). The analysis of the data is described in Chapter 2, section 2.3.5. A description of the findings of the study is presented in Chapter 3, section 3.3.

#### 1.8.6 Literature control

In qualitative research the literature review provides the rationale for the problem and positions the current study within the ongoing literature about the topic. A phenomenological study addresses the need to know more about a particular phenomenon and describes the common experiences of individuals experiencing the phenomenon (Creswell, 2007:103). Therefore, the findings of this study were verified through a literature control to compare the similarities and differences of this study with other research studies concerned with the participants' experiences of the phenomenon. The literature control is presented in Chapter 3.

#### 1.9 MEASURES TO ENSURE TRUSTWORTHINESS

Measures that were implemented in this study to ensure trustworthiness included credibility, dependability, confirmability, and transferability (Polit & Beck, 2006:332). Authenticity is another measure that was implemented to ensure the trustworthiness of this study. According to Bryman (2004:276), authenticity raises issues concerning the wider political impact of research.

The measures undertaken in this study to ensure trustworthiness and authenticity are described in detail in Chapter 2, section 2.4.

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#### 1.10 ETHICAL CONSIDERATIONS

Several ethical issues were considered in conducting this study. The ethical issues pertained to those articulated by the Declaration of Helsinki and the Belmont Report. The World Medical Association (2010:1) developed the Declaration of Helsinki as a statement of ethical principles for medical research involving human subjects, including research on identifiable human material and data. According to Polit and Beck (2006:87), the Belmont Report articulates three primary ethical principles that should be taken into account, namely beneficence, respect for human dignity, and justice. These ethical principles are described in detail in Chapter 2, section 2.5.

#### 1.11 SIGNIFICANCE OF THE STUDY

The significance of this study is linked to the intent that future improvements in haemodialysis programmes should incorporate the mental health facilitation of male patients experiencing erectile dysfunction from a holistic perspective. This study aimed to add to the knowledge field of professional nursing practice as well as to improve the practice area of professional nurse practitioners working with male patients experiencing erectile dysfunction through the proposal of recommendations to enhance nursing practice, education and research.

#### 1.12 LAYOUT OF THE STUDY

- Chapter 1: Overview of the study
- Chapter 2: Research design and methods
- Chapter 3: Descriptions of the findings and literature control
- Chapter 4: Discussion of conclusions, limitations and recommendations

#### 1.13 SUMMARY

This chapter gave an introduction to the phenomenon investigated, namely the lived experiences of haemodialysis male patients with erectile dysfunction. The background, rationale and problem statements identified the presence of erectile dysfunction experienced by these patients with chronic renal failure who were on a haemodialysis programme. The aim of this study was to generate an in-depth understanding of the lived experiences of male patients with erectile dysfunction who were on a haemodialysis programme. The aim was



achieved through exploring and describing the these patients' lived experiences of erectile dysfunction as a basis to propose recommendations for nursing practice, education and research in order to facilitate the mental health of male patients who are on a haemodialysis programme. The paradigmatic perspective was described in this chapter. The research design and methods will be described in Chapter 2.



# **CHAPTER 2**

## RESEARCH DESIGN AND METHODS

"The important thing in science is not so much to obtain facts as to discover new ways of thinking about them." (Bragg, 2010:para.1)

#### 2.1 INTRODUCTION

After identifying the need to conduct research on the lived experiences of patients with erectile dysfunction who were on a haemodialysis programme, I reflected on conducting a study that would reveal answers concomitant to understanding the problems experienced by these patients in order to propose recommendations to facilitate their mental health. My aim was to generate an in-depth understanding of the lived experiences of patients with erectile dysfunction in a specific setting. I therefore departed from a qualitative research paradigm, employing a phenomenological design. The focus of this chapter is to present a dense description of the chosen design and research methods that were utilised in this study.

## 2.2 AIM AND OBJECTIVES OF THE STUDY

The aim and objectives of this study are presented next.

## 2.2.1 Aim of the study

The overall aim of this study was to generate an in-depth understanding of the lived experiences of patients with erectile dysfunction who were on a haemodialysis programme in three units of a renal disease management organisation in KwaZulu-Natal. This understanding formed the basis for proposing recommendations for professional nurse practitioners to facilitate the mental health of these patients with erectile dysfunction in the context of this study. The recommendations focused on nursing practice, education and research.

## 2.2.2 Objectives of the study

The objectives of this study were:



- to explore and describe the lived experiences of patients with erectile dysfunction who were on a haemodialysis programme in three units of a renal disease management organisation in KwaZulu- Natal, and
- to propose recommendations for professional nurse practitioners to facilitate the mental health of patients with erectile dysfunction who were on a haemodialysis programme with reference to nursing practice, education and research.

### 2.3 RESEARCH DESIGN AND METHODS

The researcher makes decisions about the methods that will be utilised to address the research question and the plan for the collection of data (Polit & Beck, 2006:55). Following, the research design, research methods, research setting, the selection of participants, sampling criteria, the researcher as an instrument, data collection, data analysis, measures to ensure trustworthiness and ethical considerations are described in detail.

## 2.3.1 Research design

The research design is the "blueprint" of how the researcher intends conducting the research (Mouton, 2001:4). The research design refers to the entire process of research from conceptualising a problem to writing the research questions, the data collection, analysis, interpretation and report writing (Creswell, 2007:5). In the design the researcher needs to justify why certain methods were utilised and also why the sampling of participants and the research proceedings – events and actions – were undertaken in a specific way (Henning, 2005:144). Hence the design is the logical sequence that connects the empirical data from the initial research questions to the conclusions (Creswell, 2007:5). In this study a phenomenological research design that was qualitative, explorative and contextual in nature was utilised to achieve the aim and objectives of the study.

## 2.3.1.1 Phenomenological research design

Holloway (2005:104) describes phenomenology as having a strong philosophical and epistemological heritage and being an important source of reference for the development of qualitative research in general. This is because it provides a philosophical rationale for approaching the intelligibility of human experience on its own terms as a source of study.



Edmund Husserl (1859-1938) is considered as the father of the phenomenological movement (Watson, et al. 2008:233). According to Groenewald (2004:4), Husserl was a student of Franz Brentano (1838-1917) who provided the basis for phenomenology. It was Brentano who first stressed "intentional nature of consciousness" or the "internal experience of being conscious of something" which would receive a central place in Husserl's own phenomenology.

Giorgi (2008:2) observes that Husserl was dissatisfied with the progress of philosophy spanning centuries and he wanted philosophy to be as rigorous and dynamic as the sciences. He proposed a method for analysing conscious phenomena. According to Giorgi, Husserl believed that if there was going to be progress in philosophical knowledge, methodological procedures would have to be followed. Husserl's philosophical method was based on adopting the phenomenological attitude; encounter an instance of the phenomenon that one is interested in studying in order to determine the essence of the phenomenon, and describing the essence that was discovered. Groenewald (2004:4) reports that Husserl named his philosophical method "phenomenology"; the science of pure "phenomena."

In Giorgi's (2008:2) opinion, to use a phenomenological method that is based on the thought of Husserl, phenomenological reduction must be implemented. He perceives this to mean that, in the first place, the researcher has to bracket personal past knowledge and all theoretical knowledge not based on direct intuition regardless of its source so that full attention can be given to the phenomenon that is in the researcher's consciousness. Secondly, the researcher must withhold the positing of the existence or reality of the object. The researcher takes the object or event to be something that is appearing or presenting itself to the researcher but does not make the claim that the object or event really exists in the way that it appear. It is therefore seen to be a phenomenon. It is commonplace to refer to Husserlian phenomenology as a descriptive discipline and to treat phenomenologists' findings as descriptive in nature (Giorgi, 2008:2).

For Giorgi (<u>in</u> Groenwald, 2004:5) the operative word in phenomenology is "describe". Groenewald (2004:5) cites Giorgi when explaining that the aim of the researcher is to describe as accurately as possible the phenomenon, refraining from any pre-given framework, but remaining true to the facts. Finlay (2009:6) agrees that phenomenological researchers aim for fresh, rich descriptions of a phenomenon as it is concretely lived; thus the "life-world" or "lived experience".



Holloway (2005:104) describes the two concepts that are important when considering the practice of descriptive phenomenology as "life-world" and "essences". According to Holloway (2005:104), "life-world" indicates the flow of experiential happenings which provide the "thereness" of what appears prior to categorising it into "packages", and "essences" refer to "the most essential meaning for a particular context". It is the essence that forms the consciousness and perception of the world.

Husserlian descriptive phenomenology is based on the intuition that when one is open to phenomena as relationships, there is an intrinsic intelligibility to what appears; this intelligibility can "come to language" and be described in productive ways. Experience is restored as a valid focus for inquiry on its own terms without reducing it to biology, behaviour or sociology. According to Watson <u>et al</u>. (2008:233), descriptive or Husserlian phenomenology is aimed at "uncovering and describing the essence of the phenomena of interest".

A phenomenological descriptive design was therefore an appropriate choice to actualise the aim and objectives of this study based on the exploratory and descriptive intent. Creswell (2007:57) explains that a phenomenological study describes the meaning that their lived experiences of a phenomenon have for several individuals. Phenomenologists focus on describing what all participants have in common as they experience the phenomenon.

Creswell (2007:58) proposes the procedural steps to be followed when conducting a phenomenological study. The researcher must firstly identify the phenomenon of interest to be studied, and then collect data from the participants who have experienced the phenomenon. Next, the researcher writes a composite description of the essence of the experience for the participants in the study. This composite description consists of "what" the participants experienced (textural) and "how" they experienced it (structural). Creswell's procedural steps for conducting phenomenological research (Creswell, 2007:58) were followed in this study. The concept "participants" was used and referred to the patients who were experiencing erectile dysfunction while on a haemodialysis programme in a renal disease management organization unit.

The study required in-depth and detailed descriptions of the participants' lived experiences of the phenomenon of erectile dysfunction. The aim here was to generate an in-depth understanding of the lived experiences of participants with erectile dysfunction who were on a haemodialysis programme in three units of a renal disease management organisation in KwaZulu-Natal. The use of the data collection and data analysis methods in the



phenomenological descriptive design enabled me to explore and describe the participants' lived experiences of erectile dysfunction in this context. The essence of the participants' lived experiences of the phenomenon was presented after the data analysis had been completed, and recommendations were proposed to facilitate their mental health with reference to nursing practice, education and research.

## a) Qualitative design

Qualitative research is an "inquiry process of understanding based on a distinct methodological tradition of inquiry that explores a social or human problem" (Creswell, 2007:240). Qualitative research involves an "interpretive, naturalistic approach to the world. It focuses on phenomena that occur in natural settings that are in the 'real world'. It also involves studying these phenomena in their complexity to make sense of and to interpret the phenomena in terms of the meanings people bring to them" (Leedy & Ormrod, 2005:133).

By using a qualitative design the researcher is able to "investigate the phenomenon of interest in an in-depth fashion through the collection of rich narrative materials using a flexible research design in order to understand and explain the participants' experiences of the phenomenon" (Polit & Beck, 2006:508). Qualitative research allows the researcher to empower individuals to share their stories through voicing their experiences of the phenomenon (Creswell, 2007:40). The experiences of the participants in this study were communicated through phenomenological interviews, naïve sketches and field notes. Qualitative data are rich narrative descriptions classified in themes and processes to understand the participants' experiences of the phenomenon (Polit & Beck, 2006:370). According to Creswell (2007:39), qualitative researchers give a holistic account of the issue being studied by reporting on multiple perspectives and identifying the many factors involved in a situation thereby sketching the larger picture that emerges. The reporting of the phenomenon of interest is done by applying inductive reasoning. Inductive reasoning is the process of reasoning from specific observations to more general rules (Polit & Beck, 2006:501). Inductive reasoning is discussed under reasoning strategies, section 2.3.3 in this chapter.

My reason in choosing to implement the qualitative method in this study was because I believed it would allow me to obtain a detailed understanding of the phenomenon. Talking directly with the participants (phenomenological interviews) and requesting them to write naïve sketches afforded them the opportunity to tell their individual stories. The phenomenological interviews, naïve sketches and my field notes allowed me to expound



their experiences of erectile dysfunction. I was able to inductively present a holistic account on the essence of the participants' experiences of erectile dysfunction through the reporting of these multiple perspectives in the form of themes and sub-themes. This is described in detail in section 2.3.5.

### b) Explorative design

According to Polit and Beck (2006:500), an exploratory research study begins with "some phenomenon of interest and has the aim of exploring the dimensions of the phenomenon. This includes the manner in which the phenomenon is manifested and the other factors to which this phenomenon is related through the collection of data from the participants".

Creswell (2007:40) is of the opinion that an exploration of the phenomenon of interest is essential to hearing silenced voices. The exploration of the phenomenon of interest gave me a detailed understanding of the phenomenon. Therefore, the objective of this study was to explore and describe the lived experiences of patients with erectile dysfunction who were on a haemodialysis programme in a specific context and to facilitate the mental health of these patients.

During the performance of my duties in the haemodialysis units I noticed that the patients had a tendency to informally disclose their experiences of living with erectile dysfunction with the care workers and other patients instead of with the professional nurse practitioners. This stimulated my interest in the reasons for them not voicing their problems to those who professional nurse practitioners who had their interests at heart; wondering what silenced their voices in this context.

### c) Contextual design

It is Creswell's (2007:40) opinion that qualitative research is conducted because the researcher wants to understand the contexts or settings in which participants in a study address a problem or issue. The researcher cannot separate what people say from the context in which they say it, whether this context is their home, family or work (Creswell, 2007:40). According to de Castro (2003:47), the researcher cannot grasp a sense of the whole of a given experience by separating the parts from the general context in which every part is based. If the researcher divides a given experience into parts before having understood how the person who lives that experience articulates it, then he or she will talk about abstract concepts that do not have any sense for that participant. Therefore, the



researcher's explanations of the participant's experiences concerning the phenomenon of interest in the study would be from her or his own perspective and not from that of the participant who experiences the phenomenon under study (de Castro, 2003:48).

This study was contextual in nature and focused on the lived experience of participants (patients) with erectile dysfunction who were on a haemodialysis programme in three units of a renal disease management organisation in KwaZulu-Natal. It was my aim to understand the data obtained from these participants on a holistic level.

#### 2.3.2 Research methods

The research methods refer to the ways in which the data are obtained, organised and analysed (Polit & Beck, 2006:504). It includes the steps, procedures or strategies for gathering and analysing the data. The research setting, selection of participants, sampling criteria, the researcher as an instrument, and the data collection and data analysis are described below.

## 2.3.2.1 Research setting

I conducted the study in three haemodialysis units in KwaZulu-Natal. The participants (who were previously referred to as patients) were on the haemodialysis programme in these units. I selected the three haemodialysis units for the following reasons:

- All three units were managed by a renal disease management organisation in KwaZulu-Natal. In line with the contextual nature of the study, I decided to utilise only one renal disease management organisation for this study to rule out possible negative issues concerned with the competitiveness existing between renal disease management organisations. Renal disease management organisations restrict access to the patients in their haemodialysis units from personnel working in other renal organisations to obviate losing patients to competitors and affecting their profitability. At present I am (and was during the period of the study) employed by a renal disease management organisation and have had sustained access to the 12 haemodialysis units in KwaZulu-Natal.
- While working in these units, I became aware of the negative effects erectile dysfunction
  had on the lives of patients experiencing it. I further observed that patients disclosed their
  experiences with erectile dysfunction to the care workers and, in turn, the care workers
  disclosed it to me.



- One of the units selected for the study was the largest renal unit in KwaZulu-Natal. The
  unit had approximately 120 patients per month on the haemodialysis programme. This
  unit allowed me access to a sufficient number of patients for participant selection.
- The other two haemodialysis units were in the same area, thus eliminating problems with travelling to the units. These two haemodialysis units were smaller with 80 and 30 patients respectively on the unit haemodialysis programmes.

# 2.3.2.2 Selection of participants

The participants were selected from a specific population. Polit and Beck (2006:506) describe the population "as an entire set of individuals having some common characteristics".

The accessible population in this study were male patients between 34 and 70 years old who were on the haemodialysis programme in the aforementioned haemodialysis units in KwaZulu-Natal and were experiencing erectile dysfunction. The majority of these patients were within this age group. They were dialysed three times a week, four hours per session on an outpatient basis.

I made use of purposive sampling during the selection process to select participants based on the inclusion criteria that is described in section 2.3.2.3. Polit and Beck (2006:271) describe purposive sampling as the researcher handpicking the cases or type of cases that will best contribute to the informational needs of the study. In line with Creswell (2007:125), I used purposive sampling and ensured that rich data was gathered from the participants on their lived experiences of erectile dysfunction to enhance my understanding of this phenomenon.

According to Burns and Grove (2005:358), the number of participants in a qualitative study is adequate when saturation of data is achieved in the study area. Data saturation occurs when additional sampling provides no new information but only redundancy of previously collected data.

The total number of participants selected for this study was nine. The nine participants were recruited using written handouts that were distributed in the three haemodialysis units to all male patients (see Annexure G). Data saturation was achieved by the seventh phenomenological interview, but I continued with two more interviews in order to conclude



that data had been saturated as evidenced by recurring themes. The independent coder reported that data saturation was attained in her written report on the analysis of the transcribed data (see Annexure F).

In the handout it was explained it was my intention to conduct a study to identify the effects of erectile dysfunction on the participants. The question, "How is it for you to live with erectile dysfunction?" was not stated in the hand-out because I was not sure at the time whether the participants would interpret it correctly. I therefore rephrased it to read: "...to identify the effects of erectile dysfunction on the participants". However, during the phenomenological interviews it was clear that the participants understood the question and they provided indepth data. In the handout the individuals were asked to contact me if they experienced erectile dysfunction and I included my contact number (see Annexure G).

I was apprehensive as to whether any patients would come forward to participate in the study because I assumed they would find it a sensitive matter to disclose their lived experiences with erectile dysfunction. This assumption was based on my personal observations in the haemodialysis unit, (As described under the sub-heading Problem statement in Chapter 1, section 1.3.). I was surprised when I received calls from some patients who wanted to participate in the study and who were prepared to meet me at their homes, on weekends or on the days of their haemodialysis session. I confirmed with each of these participants the set appointment date, time and venue where his interview would be conducted. Each participant was given a hand-out to inform him of the date; time and venue of the interview (see Annexure H).

### 2.3.2.3 Sampling criteria

According to Polit and Beck (2006:259), researchers specify the characteristics that delimit the study population through implementing the inclusion and exclusion criteria when selecting participants.

#### Inclusion criteria

Inclusion criteria is the criteria used by the researcher to designate the specific attributes of the target population, and by which participants are selected for participation in the study (Polit & Beck, 2006:259).



The inclusion criteria for this study were:

- Male patients who had been diagnosed with chronic renal failure, who were on a haemodialysis programme in one of the identified three units in KwaZulu-Natal.
- They had to be willing to give informed consent and to disclose information regarding their experiences with erectile dysfunction.
- Participants who, at the date of commencement of this study, had been experiencing erectile dysfunction for 8 months or longer while on the haemodialysis programme. It would ensure that patients provided information on their experiences with erectile dysfunction within a specific time frame and context. The time frame was stipulated in order to eliminate any other causes of erectile dysfunction, such as a low level of haemoglobin. The time period was set in such a way that the participants would have adjusted to the treatment and their physical condition would have been stabilised.
- They had to be conversant in English. Since I am English speaking, it was my intention to generate an in-depth understanding of the data and I it was my belief that oral communication in English between me and the participant would allow for this.

#### Exclusion criterion

Polit and Beck (2007:499) describe the exclusion criteria as characteristics not desirable in, or applicable to, the population. The need for exclusion criteria is to prevent distortion of the study which could nullify credibility.

The exclusion criterion for this study was comprised of:

Patients who had participated in research studies concerned with medicines for their problem or for enhancing sexual performance or erections by taking medicine prior to the time the current study was conducted. In such cases, medication could be considered as the cause of erectile dysfunction, while stoppage of the medication also alleviates experiencing erectile dysfunction. In this study the cause of erectile dysfunction had to be due to haemodialysis and chronic renal failure. Patients who were on medication to enhance their erections would not provide credible data on their experiences of erectile dysfunction because they would be able to attain and maintain erections for sexual



intercourse. In such a case, the exclusion criterion would distort the findings of the study thus rendering it not trustworthy.

#### 2.3.2.4 The researcher as instrument

According to Onwuegbuzie, Leech and Collins (2008:2), the researcher is considered as the main instrument for data collection, data analysis and data interpretation. Since the key instrument in qualitative research is the human being, the researcher has personal biases which must be acknowledged and identified. Biases can enter the study at any stage of the research process. Researcher biases can inhibit the participants from feeling free to share their experiences of the phenomenon of interest in the study and can influence the researcher in the data analysis process, thereby affecting the credibility of the findings of the study.

To limit researcher biases, intuiting and bracketing was applied to enhance the credibility of this study. The following aspects will be described in relation to the "researcher as instrument", namely, (a) intuiting, (b) bracketing, (c) facilitative communication skills (listening skills, paraphrasing, summarising, probing, reflecting feelings), and (d) reasoning strategies.

#### a) Intuiting

Speziale and Carpenter (2007:85) report that intuiting requires the researcher to become "totally immersed in the phenomenon under investigation". Intuiting is the step whereby the researcher begins to know about the phenomenon as described by the participants. The researcher avoids criticism, evaluation or personal opinion and pays strict attention to the phenomenon under investigation as it is being described. In intuiting the researcher becomes the tool for data collection and listens to individual descriptions of the participants' experiences of the phenomenon through the interview process. The researcher then studies the data as it is transcribed and repeatedly reviews what the participants have described concerning the influence the phenomenon had on their lives.

For Moustakes (1990:23), intuiting is where "the researcher utilises an internal capacity to make inferences and arrive at knowledge of underlying structures or dynamics". The researcher perceives things as a whole by connecting the parts and sub-parts into patterns and relationships. At every step along the way the heuristic researcher makes a necessary shift in method, procedure, direction and understanding which will add depth, substance and



essential meaning to the discovery process. Polit and Beck (2006:220) add "the researcher must remain receptive throughout the research process to the meanings attributed to the phenomenon by those who have experienced it".

During the conducting of phenomenological interviews I listened to the participants' experiences of erectile dysfunction with an open, objective mind. Being female made it easier to remain unbiased and withhold personal opinions. I then studied the transcribed data and proceeded with the data analysis and clustered themes simultaneously to get the whole picture of the participants' experiences of erectile dysfunction.

## b) Bracketing

Rolls and Relf (2006:288) note that at "every point in the research study – observing, interpreting, reporting and everything else the researcher does – he or she injects a host of assumptions about human knowledge and realities encountered in the human world". The same authors contend that a "major challenge for researchers using qualitative methods is to explore how their assumptions and experiences may be influencing the construction of knowledge" (Rolls & Relf, 2006:286).

Hamil and Sinclair (2010:16) refer to bracketing as "a fundamental methodological principle of Husserlian phenomenology". The researcher's preconceptions are held in abeyance to ensure they do not follow their assumptions to shape the data collection or impose their understanding and construction on the data. By bracketing the researcher does not influence the participants' understanding of the phenomenon; thus it is the participants' own reality which is reflected. Essentially, each participant can present new knowledge and new understanding in the search for the essence of things through the identification of essential themes.

According to Rolls and Relf (2006:286; 291), bracketing interviews provides an important research-focused relationship that adapts the skill of clinical supervision to the context of research. These authors are of the opinion that the "presence of a skilled "bracketer" contributes to the production of knowledge by increasing objectivity and amplifying the researcher's own reflexive capacity". Bracketing interviews therefore enables the researcher to investigate the participants' experiences and at the same time "hold in abeyance his or her own experience and suppositions" (Rolls & Relf, 2006:302).



In line with Rolls and Relf (2006:286), bracketing was applied to this study in the various ways. During one of my visits in 2009 to meet with my two supervisors at the University of Pretoria, I was engaged in a bracketing interview by them regarding my thoughts and feelings about erectile dysfunction. I also described my views of living with erectile dysfunction and bracketed these views in reflexive notes before proceeding with the experiences of the participants in this study (see Annexure J). This was done to ensure that my preconceived thoughts and feelings on erectile dysfunction were set aside.

My preconceived thoughts and feelings on erectile dysfunction that were described in my reflexive notes are set out below.

## Bracketing (Epoch): April 2007

Bednall (2006:1) explains that an "epoch indicates a particular period of time marked by distinctive events. Within qualitative research an epoch can reasonably be interpreted as highlighting a particular period and significant events in the experiences of a researcher, but it is vital to put aside any impact from the memory during data collecting. An epoch implies a continuous dynamic setting aside of unexplained assumptions".

My initial assumptions of erectile dysfunction were that any male experiencing erectile dysfunction would be embarrassed and disappointed with himself for his sexual non-performance. This would result in loss of self-esteem because he would not feel as if he was a "man". My view on this was to a certain extent influenced by the considerably wide span of publicity given in the media to promoting treatments such as taking Viagra for erectile dysfunction. Currently, the order of the day is also to distribute pamphlets on how to increase the size of the male genital on the streets and at intersections. I therefore believed that men measured their manliness by their ability to engage in sexual by having an erection and by the size of their genital organ.

However, at the same time it was my interpretation that experiencing erectile dysfunction was and should not be a major problem as I viewed happiness in a relationship as more than just sexual intercourse. My first experiences with the patients on haemodialysis who were experiencing erectile dysfunction was when I observed two patients informally disclosing their experiences regarding this with the care workers and other patients rather than with the professional nurse practitioners as discussed in Chapter 1, section 1.3. I wondered why they shared their experiences with the care workers and assumed that patients have difficulty in disclosing their experiences of erectile dysfunction to the professional nurse practitioners.



## • Bracketing (Epoch): November 2009

While I was conducting the individual phenomenological interviews my perspective on erectile dysfunction changed. This was due to the data collected through the phenomenological interviews, naïve sketches and my field notes. I began to view erectile dysfunction as a major problem that challenged the stability of the relationship between the participants and their partners and the identity of the self. It became clear to me that happiness in a relationship included having successful sexual intercourse with one's partner.

### c) Facilitative communication skills

The following facilitative communication skills implemented in this study included listening skills, paraphrasing, summarising, probing, and reflecting feelings.

## · Listening skills

According to Ivey, Ivey and Zalaquett (2010:149,153), one of the perceptual processes in communication is the ability to "listen efficiently". Listening is an active process which requires a purposeful and systematic response to messages; it includes being silent. Encouragers used during the listening process included head nods, open gestures, and positive facial expressions that encouraged the participant to keep talking. Minimal verbal responses such as "Umm" and "Uh-hhh", silences and non-verbal communication by the interviewer are also types of encouragers that can be used in an interview.

During each of the in-depth phenomenological interviews, I consciously tried to listen to the participant's words; I watched his body language and became perceptive to his communication in order to foster open communication between the participant and myself. I remained silent when the participant spoke. When I was silent I gave the participant the opportunity to collect and organise his thoughts and increase his awareness of his experiences of erectile dysfunction. Listening then became an active process in which I had to respond to the communication of the participant. Listening also involved me orientating myself to the participant in the manner in which I responded to him. I encouraged him through maintaining eye contact and the sensitive use of non-verbal communication (Evans, et al. 2008:23). By making use of minimal verbal responses such as "Umm" and "Uh-hhh", head nods, open gestures, and silences, I encouraged the participants to describe their lived experiences of erectile dysfunction.



### Paraphrasing

Du Plooy-Cilliers and Olivier (2000:216) state paraphrasing is a "summarised interpretation that includes underlying feelings and meanings". Ivey, Ivey and Zalaquett (2010:1580) note that paraphrasing can be used to "gain clarification and understanding", but it is also a powerful ingredient in a supportive or an empathetic response.

I paraphrased the participant's description of his lived experiences of erectile dysfunction in my own words to clarify the meaning as I interpreted it from his descriptions.

## Summarising

Ivey, Ivey and Zalaquett (2010:152) reflect that "summarising encompasses a longer period of conversation"; it may cover one interview or several interviews. The main purpose of summarising is to give the interviewee a feeling of progress in exploring feelings, solve problems, focus on ideas, and clear the way for new ideas. Summarising is used to show the interviewee that the interviewer is tuned in to the former's messages and has formed the correct perception of the messages that the interviewee has communicated to the interviewer.

Summarising in this study meant I attended to the participants' verbal and non-verbal comments, including their feelings. Subsequently, I selectively attended to key concepts and dimensions and restating them to the participant at the end of the phenomenological interview as accurately as possible. The participants' thoughts and emotions were included in the summary to the participant.

## Probing

Baxter and Babbie (2004:192) stated that probes are more "frequently required in eliciting responses to open-ended questions". The probe can be either a question or a statement with the aim of getting the interviewee to clarify or elaborate on a previous response. The probe is the interviewer's tool for rectifying inadequacies in the initial response to a question, thus motivating the interviewee to give additional information that is needed.

I probed to get additional information from the participants on their lived experiences of erectile dysfunction. I made use of both verbal and non-verbal probes and used silences



when the participants were required to think and gather their thoughts as a response to my probes. An example of a probe used by me was: "Tell me more about your experiences of erectile dysfunction".

## Reflecting feelings

Evans <u>et al</u>. (2008:77) explain reflecting feelings involves "identifying interviewee's emotions and then rephrasing this component effectively back to the interviewee". The feelings may be inferred from the interviewee's verbal communication or non-verbal behaviour. This reflects to the interviewee that the she or he is being understood.

Using reflection in this study had two advantages; indicating understanding of what was being said by the participant, and trying to facilitate a context for open communication during interviewing. I realised that the participants could experience emotional discomfort during the phenomenological interview as they explored their experiences with erectile dysfunction. I responded to the participants' emotional discomfort by reflecting their feelings thus indicating to them that I had empathy for them in their circumstances and was able to identify with their feelings.

## d) Reasoning strategies

According to Leighton and Sternberg (2004:3), reasoning is broadly defined as the process of drawing conclusions. In research these conclusions are the outcome of the data collection and data analysis processes. For these processes to occur logical thought it must be implemented in the form of reasoning strategies. The reasoning strategies that were implemented in this study were inductive reasoning, deductive reasoning, analysis, and critical thinking.

## Inductive reasoning

According to Polit and Beck (2006:501), inductive reasoning is the "process of reasoning from the specific observations to more general rules" (described in section 2.3.1.1). This is where conclusions are developed from specific observations, a sample of participants is observed and then conclusions are drawn about the population from which the sample has been selected (Leedy & Ormrod, 2005:32).



I followed an inductive approach in this study. Within this approach I applied inductive reasoning whereby the conclusions that developed through the phenomenological interviews, naïve sketches and the observations in the field notes were drawn from the participants' shared experiences of the phenomenon and then re-contextualised to the population (patients on a haemodialysis programme and experiencing erectile dysfunction) through the use of a literature control.

## · Deductive reasoning

Leedy and Ormrod (2005:31) note that deductive reasoning "begins with one of more premises". These premises are statements or assumptions that are accepted as true, and from these premises reasoning proceeds logically towards conclusions. Therefore, deductive reasoning is "the process of developing specific predictions from general principles" (Polit & Beck, 2006:40).

I applied deductive reasoning to this study by interpreting the data collected through the phenomenological interviews, naïve sketches and field notes on the participants' experiences of erectile dysfunction. I then proceeded by identifying and categorising the themes and arriving at conclusions that served as the basis for the recommendations with reference to nursing practice, education and research. The independent coder for analysing the data and the literature control served to counter distortions and biases that might have occurred in this study.

#### Analysis and synthesis

Polit and Beck (2006:495) state analysis is the "process of organising and synthesising data so as to answer research questions".

The participants' experiences of the phenomenon of erectile dysfunction were investigated, the data collected through phenomenological interviews, naïve sketches and field notes. The data were then analysed (taken apart) and classified in themes and sub-themes to provide an in-depth understanding of the participants' experiences with the phenomenon. Thus the objective of the study, namely to explore and describe the lived experiences of patients with erectile dysfunction who were on a haemodialysis programme, was met through the analysis of the data collected.



## Critical thinking

According to Leedy and Ormrod (2005:33), before beginning a research an effective researcher looks at other research studies and the theoretical perspectives in them that are related to the topic of interest. Effective researchers therefore do not simply accept the research findings and theories at face value, but they analyse them by engaging in critical thinking.

To learn about qualitative research with a phenomenological design, I critically analysed some qualitative studies with a phenomenological design to evaluate the methods used to obtain and analyse data, identify whether the sampling was relevant and adequate and, finally, what were the conclusions derived from these studies. It assisted me in the selection of the research design and methods implemented in this study. I applied critical thinking in the discussion of the findings. I identified the similarities and differences in the findings of other studies on erectile dysfunction in relation to this study in the literature control as described in Chapter 3, section 3.3.

#### 2.3.2.5 Data collection

Data collection refers to all the pieces of information obtained in the course of a study (Polit & Beck, 2006:498). According to Henning (2005:60), the methods for data gathering may also be termed "data sources", meaning that the source is the method or the way in which the data "travels". Creswell (2007:129) states data are grouped into four basic types of information, namely observations, interviews, documents and audiovisual material. Henning (2005:60) assesses that in most studies the researcher would make use of at least two – but preferably three – sources (known as data triangulation) to ensure that the phenomenon has been investigated by means of different sources of information, thus giving the data variety. The aim of triangulation is to overcome the intrinsic biases that come from a single method of study; it further helps to capture a more complete and contextualised portrait of the phenomenon under study (Polit & Beck, 2006:333). The data collection methods utilised in this study was phenomenological interviews, naïve sketches and field notes.

## a) Phenomenological interviews

Creswell (2007:131) explains that in order to undertake a phenomenological study, the process of collecting information involves primarily in-depth interviews. Collecting data through interviews brings to the researcher's attention what the individuals think, feel and do



and what they have to say about the phenomenon. This provides the researcher with the participants' subjective reality of their experience of the phenomenon (Henning, 2005:52).

In this study I conducted phenomenological interviews with the participants to elicit in-depth information and understanding of their experiences of erectile dysfunction through the use of unstructured and open-ended questions. The phenomenological interview involves unstructured and generally open-ended questions on the phenomenon of interest to elicit an in-depth understanding of the participants' experiences of the phenomenon (Creswell, 2007:132).

Polit and Beck (2006: 56) state the first interview serves as a "pilot interview" to verify the information obtained from the questions and to adapt the interviewing process if needed. Many researchers prefer audiotaping the interviews for later transcription to ensure the accuracy of the data collected (Polit & Beck, 2006:294). For Henning (2005:53), the interviewer should guide the interview and not ask leading questions which could contaminate the data. The interview should be conducted in an atmosphere of trust between the interviewer and the interviewee. Ultimately the researcher should accept accountability for the data that is gathered from the interviews (Henning, 2005:53).

I made use of the facilitative communication skills as described in section 2.3.2.4(c) to elicit in-depth information. To ensure privacy and confidentiality the phenomenological interviews were conducted in the office at the renal unit where the participant received his treatment.

The phenomenological interview lasted for 30 to 45 minutes each. Every phenomenological interview was digitally recorded with the permission of the participants for verification of the verbatim transcriptions from it to ensure accuracy of the data collected (see Annexure I).

The central question I asked was: "How is it for you to live with erectile dysfunction?" I paid attention and responded to the statements and themes that emerged from the participants' lived experiences with erectile dysfunction. It was clear from the pilot phenomenological interview that no changes needed to be made to the research question as it elicited rich data during the interviewing process.

I started the phenomenological interview by introducing myself to each participant, thanking the participant for his time and participation. I then debriefed the participant on the background and the objectives of the study.



I applied the facilitative communication skills as described in section 2.3.2.4(c) when conducting each phenomenological interview. I was formally prepared on the use of these skills by my two supervisors who engaged me in a practice interview to improve my facilitative communication skills.

I tried to be a neutral facilitator who elicited the information from the participant by the use of open-ended questions and prompts. I encouraged the participants to speak freely, at the same time exuding trust and empathy whilst controlling the process of not letting the participant deviate from exploring the phenomenon of erectile dysfunction. I also accepted accountability for the data that was gathered by ensuring that the data elicited from the participants regarding their experiences of erectile dysfunction were exposed to minimal bias. This was achieved by applying intuiting and bracketing as described in this chapter, sections 2.3.2.4(a) and 2.3.2.4(b).

### b) Naïve sketches

According to Giorgi (1985:9), naïve sketches as a method of data collection emerged from a phenomenological orientation and means "going back to the phenomenon itself." A naïve sketch refers to a candid description such as an essay, short story or notes (Giorgi, 1985:48).

Naïve sketches were used in this study. Participants were requested to answer the central question, "Write a story on living with erectile dysfunction", in the form of a short story or essay. They were asked to write about their lived experiences of erectile dysfunction within the context of the study. The naïve sketch of each participant as a method of collecting data was used for triangulation to enhance the credibility of the study (see Annexure K).

## c) Field notes

Mouton (2001:108) explains that keeping extensive field notes of observations and other forms of data collection is essential in order to capture the context of such an observation. Polit and Beck (2006:306) define field notes as being objective descriptive and observational notes made by the researcher of events and conversations in the study. Field notes represent the observer's efforts to record information and also to synthesise and understand the data. The objective descriptions must include enough contextual information about the time, place and actors to fully portray the situation. The field notes of this study included observational, methodological, theoretical and personal notes (Polit & Beck, 2006:500).



#### Observational notes

Polit and Beck (2006:306) describe observational notes as objective descriptions of events and conversations. The focus of the observation can be broadly defined events or highly specific behaviours. These include the observations from verbal communication (tone, pitch and fluency of speech), non-verbal communication (body language such as gestures, eye contact, posture and facial expressions), activities, and the environmental conditions.

Skilful unstructured observation of the participants' verbal and non-verbal communication during the phenomenological interviews permitted me to develop a rich understanding and appreciation of the phenomenon of interest and how it affected the participants. In discussing their experiences of erectile dysfunction I observed participants' emotions specific to the issue that was being discussed. These included sadness in facial expressions, a soft tone of voice, tearfulness, and gestures with their hands like hammering on the table. Some participants verbalised that they did experience a change in behaviour and that their home environment with their partners also underwent change due to their experiences of erectile dysfunction. I have included a copy of my observational notes as part of the audit trail (see Annexure L).

### Methodological notes

According to Polit and Beck (2006:307), methodological notes are kept by the researcher regarding the methods used in collecting the data.

Methodological notes included instructions or reminders to me on how I made subsequent observations. During this study I recorded reminders of the dates, times and interview venue with each participant in my diary. After each phenomenological interview I made notes on my observations concerning the participants' behaviour during the interview (observational notes). This is also related to notes in terms of what worked effectively during the interviews and what did not.

#### Theoretical notes

Polit and Beck (2006:307) state theoretical notes are "interpretive attempts by the researcher to attach meaning to observations". The researcher observes the participants' behaviour and then interprets this behaviour. According to Henning (2005:83), the researcher aims to



capture the "insider's view" and not to impose exterior knowledge categories on what was observed. This is the "etic" and "emic" way of categorising knowledge (data). The "etic" categorisation of knowledge is according to the categories of social science where the elements of the category come from the "outside". Here the researcher designs an observational schedule where to locate what must be observed according to the headings of the schedule. An "emic" categorisation of knowledge is where the researcher makes field notes and then locates the knowledge in categories that he or she builds up inductively from what has been learnt from the participants, thus giving space for the participants voicing their experiences with the phenomenon of interest.

The emic (the insider's view) approach was utilised in this study. Emic categorisation of data meant that I made field notes, then located the data and constructed it into categories that I built up inductively from what I had learnt from the participants through the data collecting methods. This included the phenomenological interviews where the participants were encouraged to voice their experiences of erectile dysfunction to me.

#### Personal notes

Polit and Beck (2006:307) explain personal notes are comments about the researcher's own feelings during the research process. This includes the researcher's personal experiences, reflections and progress in the field. This is reflected by the epoch.

I evaluated myself continuously and was sensitive towards my biases, judgements and feelings regarding the phenomenon of erectile dysfunction. I applied intuiting and bracketing as described in sections 2.3.2.4(a) and 2.3.2.4(b) in this chapter. In this study the field notes described above were taken during and after the interviews with the participants to describe underlying themes and statements.

## 2.3.2.6 Data analysis

Polit and Beck (2006:397) maintain that data analysis denotes organising, providing structure to, and eliciting the meanings from the data into themes. For Creswell (2007:101), "the true test of a competent qualitative researcher lies in the analysis of the data".

The recorded phenomenological interviews were transcribed and analysed using Creswell's method of analysing phenomenological interviews (Creswell, 2007:156). Firstly, I managed the data by manually filing all the data obtained in a file. These included the transcripts of the



phenomenological interviews, the written naïve sketches and the field notes. The data were then read by me, margin notes were made and initial codes formed. My personal experiences over time were described in the epoch, section 2.3.2.4(b). By applying personal bracketing, described in section 2.3.2.4(b), I tried to set aside my opinions about the phenomenon of erectile dysfunction so that the focus could be directed to the participants in the study.

The next step was to develop and classify significant statements about how the participants experienced erectile dysfunction into themes. The essence of the phenomenon of erectile dysfunction was then described. The "essence" of the experience of erectile dysfunction represented the culminating aspect of a phenomenological study. This was my analysis of the data from the phenomenological interviews, naïve sketches and field notes (see Annexure M).

In line with Creswell (2007:156), I implemented my knowledge of data analysis. In the analysis of the data I showed my understanding of design logic. I was able to fit the analysis procedures with the methodological position of the study and consistently managed the analysis process according to the principles of the study design.

To ensure the credibility of my interpretation of the data, I made use of an independent coder to analyse and interpret the data (see Annexure F). She is experienced in qualitative research. I gave the raw data in the form of the transcribed phenomenological interviews, field notes and naïve sketches to the independent coder for data analysis. I discussed the data analysis method that I had implemented in this study, namely Creswell's (2007:159) method of data analysis, telephonically and via emails with the independent coder. I also referred her to Creswell's textbook, Qualitative inquiry and research design – choosing among five approaches, which guided me through the coding process.

After the independent coder had analysed the data, we met and discussed the categorising of the findings. The independent coder did not follow the data analysis method that I had originally discussed with her - she made use of content analysis rather than thematic analysis which I had used. It was recognised that this could have placed a limitation on the study (see discussion in Chapter 4, section 4.3). The independent coder and I had identified similar themes and sub-themes. We were, however, unable to reach consensus on the essence of the participants' experiences of the phenomenon as the independent coder had not conceptualised the essence. To counteract the fact that the independent coder had not used the same data analysis method, my two supervisors compared and verified the two



findings as well as some of the raw data to prevent bias emanating from my own views intruding. In addition, my supervisors assisted me in verifying the essence of the phenomenon of erectile dysfunction as experienced by the participants in this study. This added to the credibility of the findings.

According to Henning (2005:27), a literature control is important to show the relevance of the researcher's findings in relation to the existing body of knowledge. Therefore, in this study a literature control was conducted to re-contextualise findings in order to identify any similarities and differences between the current study and the previous related studies.

### 2.4 MEASURES TO ENSURE TRUSTWORTHINESS

Polit and Beck (2006:511) posit that trustworthiness refers to the "degree of confidence qualitative researchers have in their data". Polit and Beck (2006:332) describe Lincoln and Guba's model as the "gold standard" for qualitative research.

This model was used in this study to ensure the trustworthiness of the study findings. This model refers to the criteria of credibility, dependability, confirmability and transferability in assessing trustworthiness. The criterion of authenticity is another measure to ensure trustworthiness of the study findings (Bryman, 2004:276)

### 2.4.1 Credibility

According to Polit and Beck (2006:332), credibility refers to confidence in the truth of the data and its interpretations. Tobin and Begley's (2004:391) stance is that credibility addresses the issue of "fit" between the participants' views and the researcher's representation of these views. It poses the question on whether the explanation fits the description and whether the description is credible.

The credibility of an inquiry involves two aspects. Firstly, carrying out the investigation in a way that believability is enhanced and, secondly, taking steps to demonstrate credibility (Polit & Beck, 2006:332). Smyth (2006:8) contends that credibility requires a researcher to remain aware that personal beliefs might influence the research.

Credibility is enhanced by pre-briefing and debriefing the participants, prolonged engagement with the participants, triangulation (method, investigator, communication, interdisciplinary, collaborative, and theoretical), purposive sampling, conducting a literature



control, bracketing, and intuition. These criteria and its application in this study are described below. Onwuegbuzie, Leech and Collins (2008:2) report that pre-briefing involves interviewing or informing persons in the study about the study and its progress. Pre-briefing contributes to the credibility of the study as the participants are cognisant of what the study will involve. Pre-briefing of participants involves the researcher interviewing the participants and informing them of the aim, objectives and purpose of the study, the outcomes of the study as well as to answer any questions that the participants may have. Onwuegbuzie, Leech and Collins (2008:5) describe debriefing as informing the participants of some or all of the findings of the study.

In this study I pre-briefed the participants prior to the commencement of the study and informed them of the aim, objectives and purpose of the study, the procedures to be followed and the risks and benefits of the study. The participant information leaflet (see Annexure D) and informed consent (see Annexure E) were explained and given to the participants. Any questions that the participants had were dealt with. At the end of the study I debriefed the participants on the findings of the study. The findings were presented in a letter and given to each of the participants (see Annexure N).

For Polit and Beck (2006:507), "prolonged engagement is the investment of sufficient time during data collection to have an in-depth understanding of the phenomenon under study, thereby enhancing data credibility".

I prolonged the time spent with the participants prior to the interviews and after the interviews to build rapport with them. Before each interview I talked informally to the participants about their haemodialysis and how they were coping with the treatment. I then explained the aim and objectives of this study and went through the participant information leaflet with them. Next I proceeded with conducting the phenomenological interviews which lasted between 45 and 60 minutes each. Afterwards, I spent time with each of the participants; this gave them time to think about and discuss issues that they might have been concerned about, with me.

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Henning (2005:103) defines triangulation as coming from various points or angles towards a "measured position" where the true position is found. In this study the method, investigator, communication, and interdisciplinary and theoretical triangulation methods were used to enhance credibility.



Method triangulation is the use of multiple methods of data collection pertaining to the same phenomenon to enhance the credibility of the findings (Polit & Beck, 2006:504). Method triangulation was used in this study to draw conclusions about what constituted the truth from the multiple data collection methods. This included conducting phenomenological interviews with the participants, naïve sketches and field notes.

Investigator triangulation refers the use of more than one person to collect, analyse or interpret a set of data (Polit & Beck, 2006:333). Investor triangulation in this study was insured by the use of an independent coder to analyse and interpret a set of all the data obtained, the supervisors of the study, and myself as the researcher. I presented a holistic picture of the participants' experiences of erectile dysfunction in a logical and structured report as well as a description of the essence of their experiences (see Chapter 3).

Huber-Warring (2010:424) describes communication triangulation as the communication skills that the researcher uses through throughout the interview process. I applied different communication skills during the phenomenological interviews to elicit data from the participants to gain an in-depth understanding of their experiences of erectile dysfunction as discussed in section 2.3.2.4(c).

I am a nurse with a psychiatric qualification and have a post basic qualification as a nephrology nurse. These qualifications enhanced my credibility as a researcher in this study. The psychiatric qualification made me aware that erectile dysfunction negatively impacts on the mental health of the patients on the haemodialysis programme. Consequently, I identified a need to address the patients' experiences of the phenomenon of erectile dysfunction to enhance the mental health of these patients. My knowledge of chronic renal failure and the complications thereof, including includes erectile dysfunction, is attributable to my nephrology qualification. Additionally, I have completed a module in research methodology on master's level.

Denzin and Lincoln (2005:7) refer to qualitative research as "an interdisciplinary field. It crosscuts the humanities, social and physical sciences. Interdisciplinary triangulation is the utilisation of other disciplines during the research process to broaden understanding of method and substance". Huber-Warring (2010:426) adds that collaborative triangulation is to work jointly on an activity or project; "collaborative triangulation enables the recognition of the diversity of roles and the interplay and interdependence of health care professionals".



Interdisciplinary triangulation was facilitated in this study through the transcriber (with transcribing experience), the independent coder (with coding experience) and my two supervisors (with experience in qualitative research). The transcriber was an independent member and not part of the research team thus preventing bias in the transcription of the digitally recorded phenomenological interviews (see Annexure I). All the members of the interdisciplinary team collaborated well and shared their knowledge, decisions and responsibilities. My supervisors shared their knowledge with me, guided me through the research process, and provided me with feedback. As members of the interdisciplinary team the transcriber and the independent coder completed their tasks on time.

Thurmond (2001:254) describes theoretical triangulation as the use of multiple theories when examining a phenomenon. It is the use of all possible theoretical interpretations as the background for a study (Huber-Warring, 2010:423).

For the purpose of theoretical triangulation I applied the Theory of Health Promotion in Nursing (UJ, 2009:1) in this study as discussed in Chapter 1, section 1.6.2. Before commencing with this study, I read extensively regarding the different theories in order to connect participants' lived experiences of the phenomenon of erectile dysfunction to a relevant theory. The Theory of Health Promotion in Nursing (UJ, 2009:1-8) was chosen for this study because it is aimed at the promotion of health of the individual and family (participant and partner). It also proposes that the promotion of the individual's (participant's) health must be seen holistically, in interaction with the environment. The professional nurse practitioners in the haemodialysis unit must implement holistic nursing care through the mobilisation of resources to promote the participants' health. Holistic nursing care aims to promote the health of the participants (patients) and includes the facilitation of mental health.

Purposive sampling identifies people who fit the criteria for desirable participants (Henning, 2005:71). The inclusion and exclusion criteria used in the selection of participants for this study are discussed in section 2.3.2.3.

In a phenomenological study there is a need to know more about a particular phenomenon and the common experiences of individuals involved with it (Creswell, 2007:103). Hence, a literature control was conducted to verify the findings as well as to create a chain of evidence by identifying the similarities and differences of the findings in literature and comparing it to the findings of this study. I aimed to include references that were current and relevant to the study. I also made sure that references were accounted for in the list of references.



To ensure referential adequacy relevant documents were attached to this report in the form of an appendix (see List of Annexures).

Bracketing is where the researcher sets aside all preconceived experiences to best understand the experiences of the participants in the study (Creswell, 2007:234). I applied bracketing to close off my preconceived ideas on erectile dysfunction as described in section 2.3.2.4(b) of this chapter. This was to ensure the truth of the data and its interpretations. My two supervisors engaged me in a bracketing interview regarding my thoughts and feelings of erectile dysfunction as discussed in section 2.3.2.4(b).

Reflexivity refers to critical self-reflection concerning the researcher's own biases, preferences and preconceptions (Polit & Beck, 2006:502). As described in the epoch, section 2.3.24(b), I critically reflected on my own biases and preconceptions on the participants' experiences of erectile dysfunction. I described my thoughts and feelings on erectile dysfunction in reflexive notes (see Annexure J).

Polit and Beck (2006:502) defines intuiting as the researcher being required to remain open to the meanings attributed to the phenomenon by those who experienced it. I became immersed in the participants' experiences of the phenomenon of erectile dysfunction and remained open to their experiences as described by them.

Credibility was enhanced with my two supervisors having doctoral qualifications in psychiatric nursing science and experience in qualitative research. The independent coder had coding experience.

### 2.4.2 Dependability

Polit and Beck (2006:335) state dependability refers to data stability spanning time periods and diverse conditions. Tobin and Begley (2004:392) confirm that researchers are responsible for ensuring that the process of research is logical, traceable and clearly documented. Smyth (2006:8) notes that the planning and process of the research include the justification of a researcher's decisions and actions.

Dependability was enhanced by prolonged engagement, investigator triangulation, supervision and independent checking by my supervisors, the description of the research process and the storage of the research documents.



Prolonged engagement was implemented when I prolonged my contact with the participants before and after the phenomenological interviews. Prolonged engagement is described under the sub-section Credibility, section 2.4.1. In investigator triangulation an independent coder was used to determine whether the data analysis process followed in the study was acceptable. A consensus discussion was held between the independent coder and me for the placing of themes and identification inferences. Dependability in this study was further enhanced by having an independent checking process and supervision by the two supervisors concerned. The description of the research process involved all the aspects of the study being fully described in the research design and methods, including the sample and the data analysis.

Storage of research documents entailed that the important documents in the research process such as the documents on the data collection and data analysis, and reflexive notes as well as other relevant documents, for example my notes on the decisions I made, were kept in a file and will be stored under lock and key in the Department of Nursing Science of the University of Pretoria for 15 years to allow for a dependability audit.

# 2.4.3 Confirmability

According to Polit and Beck (2006:336), confirmability refers to the neutrality of the data, indicating the potential for congruence between two or more independent people about the data's accuracy, relevance or meaning. Tobin and Begley (2004:392) define confirmability as being "concerned with establishing that data and interpretations of the findings are not figments of the researcher's imagination but are clearly derived from the data". Confirmability was enhanced by bracketing, method and theoretical triangulation, and reflexivity; these measures to ensure confirmability are discussed in section 2.4.1.

## 2.4.4 Transferability

Transferability refers to the generalisability of inquiry (Tobin & Begley, 2004: 392). According to Polit and Beck (2006:336), transferability refers "to the extent to which the findings from the data can be transferred to other settings or groups". This is ensured by selecting the sample in a context which will enhance the understanding about the phenomenon of interest. Transferability is also enhanced when the theoretical basis for the study is substantiated (Huber-Warring, 2010:423), and by purposive sampling, dense description of the demographics of the participants and the research setting, transferring of findings and peer review.



A purposive sample was used to ensure that rich data was gathered from the participants on their lived experiences of erectile dysfunction as described in section 2.3.2.2. To further enhance transferability a dense description was provided of the demographics of the participants (see section 3.2.1 of Chapter 3) and the research setting as presented in section 2.3.2.1. The transactions and processes observed during the enquiry were specified. The findings were described in depth with direct quotations from the participants.

Transferability will take place when the findings of this study are transferred to other haemodialysis settings or patients with chronic renal failure who experience erectile dysfunction by other researchers who are interested in conducting a similar study.

I conducted a peer review, showing the findings of the study to a number of professional nurse practitioners in other haemodialysis units in KwaZulu-Natal with the intention of them evaluating the applicability of the data and results in their haemodialysis programmes.

# 2.4.5 Authenticity

The criteria of authenticity emerged as a result of critique against the other four measures of trustworthiness, namely credibility, dependability, confirmability and transferability (Bryman, 2004:276). Bryman (2004:276) describes Guba and Lincoln's criteria of authenticity as a measure of trustworthiness. According to Bryman (2004:276), "authenticity raises issues concerning the wider political impact of research". The criteria for authenticity as described by Bryman (2004:276) are: fairness, ontological authenticity, educative authenticity, catalytic authenticity and tactical authenticity. According to Onwuegbuzie, Leech and Collins (2008:8), fairness embodies a quality of balance. Fairness relates to the thoughts, perceptions, feelings, concerns, assertions and experiences of all stakeholders being represented in the text; in other words, the voice of all the stakeholders.

Bryman (2004:276) defines ontological authenticity as "a question of whether the research helps members to arrive at a better understanding of their social milieu". Educative authenticity refers to whether the research helps members to achieve a better appreciation of the perspectives of other members' social setting. Catalytic authenticity refers to how the research gave fresh impetus to members to engage in action to change their circumstances. Tactical authenticity refers to whether the research empowered the participants to take the steps necessary for engaging in action.



Fairness was applied by the selection of the participants, the method triangulation and investigator triangulation. The participants for this study were selected purposively from three different haemodialysis units and met the sampling inclusion criteria. The sampling inclusion criteria are described in section 2.3.2.2. Method triangulation included audiotaped phenomenological interviews, naïve sketches and field notes thereby preventing bias from a single method study. Method triangulation is described in section 2.3.2.5.

The independent coder's analysis of the data and the participation of the two supervisors contributed to meeting the criteria of fairness with regard to the analysis of the data (investigator triangulation). Investigator triangulation is described in section 2.3.2.6.

I applied bracketing by setting aside my preconceived beliefs and opinions of erectile dysfunction. Bracketing is described in section 2.3.2.4(b).

My supervisors additionally conducted a bracketing interview with me prior to me entering the field which is described in section 2.3.2.4(b).

Intuiting allowed me to remain open to the meanings attributed to the phenomenon of erectile dysfunction as experienced by the participants. Intuiting is described in section 2.3.2.4(a).

Regarding ontological and educative authenticity, this study may help the participants to increase their awareness of erectile dysfunction and the impact of erectile dysfunction on their lives. The pre-briefing interviews that were conducted at the beginning of the interviews also made induced the participants to take a closer look at their experiences of erectile dysfunction. The pre-briefing interviews are described in section 2.4.1.

The data collection methods, namely the phenomenological interviews and naïve sketches were chosen with the intent of facilitating empowerment of the participants by providing them with a voice to disclose their experiences of erectile dysfunction in a psychologically safe and non-threatening environment.

I envisioned that the participants in this study would realise the importance of disclosing their experiences of erectile dysfunction to the professional nurse practitioners in their dialysis units in order to get support and assistance from them. The goal was to facilitate the mental health of the participants.



I was motivated by the findings from the data collection on the influence of erectile dysfunction on the participants and their lives. I had known these participants for a long time because I worked in these haemodialysis units, but had not been aware of their experiences of erectile dysfunction and how this influenced their lives. When they were asked by the professional nurse practitioners whether they had had any problems, they replied, "No." By conducting this study, came to realise that, although the participants and patients in these haemodialysis units appeared to have no problems, they did in fact experience difficulties, but for some reason failed to disclose their negative experiences of erectile dysfunction to the professional nurse practitioners.

My supervisors involved in this study said in their feedback that they were empowered with knowledge gained from the study concerning the experiences of patients with erectile dysfunction. They also expressed their opinions that their engagement in this study enhanced their critical awareness of phenomenology as a research design. My presentation of the findings of the study to the participants was lauded by the supervisors; they appreciated the respect I displayed in honouring my obligation to the participants by providing information on the way in which I intended to provide them with feedback. As an emerging researcher I was impressed with phenomenology as a research design and its application to this study. It allowed me to gain insight into the participants' experiences of erectile dysfunction. Thus, as an advanced psychiatric nurse, I will be able to provide assistance and support to the professional nurse practitioners and the participants in order to facilitate the participants' mental health.

This study may help the professional nurse practitioners working in the haemodialysis units to understand and find a new perspective on the influence that lived experiences with erectile dysfunction have on patients' mental health. Thus the professional nurse practitioners may be able to assist these patients from a more holistic level by implementing holistic nursing care.

Regarding catalytically and tactical authenticity, the participants contacted me after reading the hand-outs given to them; thus taking action to participate in the study (see Annexure G). The participants then met with me on the appointed date and we engaged in a phenomenological interview. They also wrote a naïve sketch to describe their experiences of erectile dysfunction, as described in section 2.3.2.5(b).

From the findings it became evident that most of the participants were eager to describe their experiences of erectile dysfunction and wanted the problem to be treated. It was thus



obvious that the aim of some of the participants desired to change the circumstances caused by erectile dysfunction.

Recommendations were proposed to facilitate the mental health of patients with erectile dysfunction who are on a haemodialysis programme, with reference to nursing practice, education and research. These recommendations may empower the professional nurse practitioners to assist their patients in coping with erectile dysfunction from a holistic level. This will meet ontological authenticity as the study will help the professional nurse practitioners to better understand repercussions that may occur due to their patients' social milieu.

### 2.5 ETHICAL CONSIDERATIONS

There were several ethical issues that were considered in conducting this study. The ethical issues were articulated by the World Medical Association's Declaration of Helsinki and the Belmont Report. The World Medical Association (2010:1) developed the Declaration of Helsinki as a statement of ethical principles for medical research involving human participants, including research on identifiable human material and data. The Belmont Report (Polit & Beck, 2006:87) articulates three primary ethical principles that should be taken into account, namely beneficence, respect for human dignity and justice.

## 2.5.1 The Declaration of Helsinki

The Declaration of Helsinki (World Medical Association, 2010:1) states that "it is the duty of physicians who participate in medical research to protect the life, health, dignity, integrity, right to self-determination, privacy and confidentiality of personal information of research participants". Every medical research study involving human participants must be preceded by careful assessment of predictable risks and burdens to the participants involved in the research in comparison to the foreseeable benefits to them and others. Participation in the research must be voluntary and the privacy and confidentiality of the participants must be upheld. Participants must sign consent to participate in the study. The Declaration of Helsinki articulates that a research protocol must be submitted for consideration, comment, guidance and approval to a research ethics committee before the study begins. In this study the duty of the physicians will refer to the duties of the researcher to protect the life, health, dignity, integrity, right to self-determination, privacy and confidentiality of personal information of the research participants.



The Declaration of Helsinki for the principle investigator was completed and signed by me as part of the Ethics Committee application process at the University of Pretoria (see Annexure C). The submitting of my proposal and required documents to the Research Ethics Committee of the Faculty of Health Sciences at the University of Pretoria is discussed in section 2.5.2.1.

## 2.5.2 The Belmont Report

The three primary ethical principles articulated by the Belmont Report are described and discussed next.

### 2.5.2.1 Beneficence

Beneficence incorporates the principle of "first do no harm" (Sims, 2010:173).

The principle of beneficence imposes a duty on researchers to "minimise risks and to maximise potential benefits" by evaluating the risks and potential benefits of client participation in the study (Polit & Beck, 2006:87). Participants should not be subjected to unnecessary risks or harm. Before the commencement of this study my proposal was sent for permission to conduct this study to the Research Ethics Committee of the Faculty of Health Sciences at the University of Pretoria and the renal disease management organisation in KwaZulu-Natal that provided the haemodialysis programme. Permission was granted by both institutions. I enclosed the necessary documents for the permission and approval to conduct this study from both boards (see Annexure A and Annexure B).

The participants were provided with a participant information leaflet (see Annexure D) and informed consent forms (see Annexure E) prior to data collection. The participant's information leaflet included the nature and purpose of the study, the explanation of procedures to be followed, the risks and discomfort that might be involved and the possible benefits of this study. The participants signed consents that they were provided together with the information leaflets, indicating that they had read and fully understood contents of the information leaflet.

I did not envision that participation in this research would result in any permanent psychological risks for the participants. In the information leaflet I did explain that they might experience emotional discomfort while sharing their experiences of erectile dysfunction. If the participant did experience emotional discomfort while sharing his experiences of erectile



dysfunction, I planned to schedule an individual supportive interview with the particular participant. During this session the participant's emotional discomfort would have been explored and discussed in order to generate support for him. Some participants did experience emotional discomfort while sharing their lived experiences. I prolonged my time spent with these participants after the interview to alleviate their discomfort. I also offered the two participants who experienced emotional discomfort a planned individual supportive interview as follow-up, but they refused the supportive interview. Their refusal of an individual supportive interview raised certain questions for me as a researcher: Why did they refuse the supportive interview offered to them? Did they believe that there would be no change in the way they experienced and dealt with erectile dysfunction? Although I suggested to them that I could refer them to a professional for support or counselling, they also refused this offer. These recommendations are described in Chapter 4, section 4.4.1.

The benefits of this research were firstly to give patients an opportunity to share their experiences of living with erectile dysfunction in a safe environment where privacy and confidentiality was maintained. This is described in section 2.5.1. Secondly, I envisioned that the information obtained from this study would assist me to propose recommendations to facilitate the mental health of patients with erectile dysfunction who are on a haemodialysis programme with reference to nursing practice, education and research. The quality of the research was enhanced by the qualifications and experience of the researcher, the two supervisors, and the independent coder as described in section 2.4.1.

A summary of the findings and the outcome of this study were disseminated in the form of individual letters to the participants as discussed per the participants' information leaflet and informed consent (see Annexure N). Informing the participants of the findings and the outcomes, including the recommendations that I proposed, was intended to empower them to cope with their experiences of erectile dysfunction. I also wanted to uphold the agreement that the participants had signed, namely to be provided with the findings, the outcomes and recommendations of the study.

### 2.5.2.2 Respect for human dignity

Sims (2010:174) states people are "autonomous agents and have the right to decide for themselves whether they want to participate in a research study". According to Polit and Beck (2006:88), "respect for human dignity includes the right to self-determination and the right to full disclosure".



The principle of self-determination means that prospective participants have the right to decide voluntarily to participate in a study without the risk of incurring adverse consequences. It also means that participants have the right to ask questions, to refuse to give information or to withdraw from the study. A person's right to self-determination includes freedom from coercion of any type. Coercion involves threats of penalties for failing to participate in a study or excessive rewards for agreeing to participate (Polit & Beck, 2006:88).

The prospective participants were informed that their participation, non-participation or withdrawal from the study would not affect their haemodialysis treatment; it was emphasised that their treatment would continue as normal. No rewards were given to the participants for their participation in this study; therefore, their participation in this study did not result in any change in their haemodialysis treatment.

Even though I am employed by the renal disease management organisation in KwaZulu-Natal, I am not currently actively involved in the implementation of the haemodialysis process in the three haemodialysis units, neither was I involved in this capacity when the study was conducted. I am employed as the deputy operations manager at the renal disease management organisation in this province to assist and support the haemodialysis unit managers to ensure its units are efficiently operated. I held the same position at the time the study was conducted.

The patients in the three units were given handouts which requested them, if they were experiencing erectile dysfunction, to contact me if they wanted to participate in the study. (See Annexure G). Hence, the patients were given autonomy to decide whether to participate in the study or not without the risk of incurring adverse consequences. Those who were interested in participation contacted me and they were given a handout to inform them of the date, time and venue of the phenomenological interview as previously mentioned (see Annexure H).

According to Polit and Beck (2006:89), the right to full disclosure includes peoples' rights to make informed, voluntary decisions about participating in a study. Full disclosure means that the researcher has fully disclosed the nature of the study, the person's right to refuse participation, the researcher's responsibilities, and the likely risks and benefits that would be incurred.



In the pre-briefing process of the study, as described in section 2.4.1, the participants were provided with the participant information leaflet and informed consent (see Annexure D and Annexure E). The information leaflet provided information as regards the following: the purpose of the study, the procedure to be followed, the potential risks and benefits of the study, the researcher's responsibilities, permission to withdraw from the study, and the contact telephone numbers of the supervisors and myself. The participants were required to sign consent forms to voluntarily participate in the study (see Annexure E). No intentional coercion was used to force the participants to participate. They were further made aware that they had the right to withdraw from the study at any time without incurring any penalties. During the phenomenological interviews and after the interviews, participants had the opportunity to ask questions regarding the study and on the processes that were to follow. The prolonging of time with the participants before and after the phenomenological interviews gave them more time with me to ask questions.

According to Mouton (2001:244), anonymity is where the identity of the participant is not known and the data collected cannot be linked to a participant. During the recording of the phenomenological interviews with an audio recorder, I did not use the names of the participants. They did not write their names on their naïve sketches either. As a result, the data collected could not be linked to any participant. I ensured that confidentiality of the data collected during the phenomenological interviews was maintained by the specific people who were involved in the research process, namely the two supervisors, the independent coder, the transcriber of the audiotaped data, and myself.

When the recordings were transcribed, the transcriber could not identify the participants to the transcribed phenomenological interviews as there was no mention of the participants' names during the phenomenological interviews. Added to this I made use of patient numbers, for example, "Patient one", "Patient two" and so forth when referring to the individual phenomenological interviews. In the description of the findings in Chapter 3, section 3.2.2, pseudonyms were used to maintain the anonymity of the participants. The transcribers and the independent coder both signed a confidentiality agreement to ensure that confidentiality of the transcribing of the audiotaped phenomenological interviews and the coding of the data were maintained (see Annexure O and Annexure P respectively).

The participant's right to privacy was protected through anonymity and confidentiality procedures where I interviewed the participants in private without anyone present in the room. The data that were collected will be stored by the supervisor under lock and key for 15 years to allow verification of the findings if necessary.



### 2.5.2.3 Justice

The principle of justice includes efforts to describe the risks and benefits equally and to disseminate any research findings, both good and bad (Sims, 2010:173). To Polit and Beck (2006:90), "justice means being fair and equitable by the equitable distribution of benefits and burdens of research". The principle of fair treatment includes that the patients who refuse to participate or who withdraw from the study must be treated in a non-prejudicial manner.

I honoured all agreements I had made with the participants. They were informed of the possible risks and benefits of this study (see Annexure D). No participant withdrew from the study and all of them continued with their dialysis treatment. I provided the participants with a summary of the findings and the outcome of the study in paper per person after the study had been completed (see Annexure N).

# 2.6 CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

Based on the findings and the literature control recommendations were proposed to facilitate the mental health of patients with erectile dysfunction who were on a haemodialysis programme with reference to nursing practice, education and research

### 2.7 SUMMARY

Chapter 2 outlined the research design and methods that I followed during the fieldwork, the measures to ensure trustworthiness, and the ethical considerations. Chapter 3 provides a description of the findings and a literature control to re-contextualise the findings in existing literature.

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# **CHAPTER 3**

## DESCRIPTION OF THE FINDINGS AND LITERATURE CONTROL

"The process of human interaction with the environment influences behaviour, provides meaning to experience, and represents the individual's image of reality."

King (in George, 1990:195)

### 3.1 INTRODUCTION

Chapter 2 gave a description of the research design, research methods, measures to ensure trustworthiness and ethical considerations employed during the research process in the study. Chapter 3 presents the participants' demographic profile, their pseudonyms, the major themes and sub-themes. It includes a narrative description based on the major themes and sub-themes of the participants' lived experiences of erectile dysfunction while on the haemodialysis programme. These descriptions are the result of field work activities that included phenomenological interviews, naive sketches from the participants as well as field notes. A literature control is provided to re-contextualise the findings. Lastly, a final statement reflecting the essence of the participants' experiences is presented.

### 3.2 DESCRIPTION OF PARTICIPANTS

A demographic profile of the participants and their pseudonyms is given.

# 3.2.1 Participants' demographic profile

There were nine participants between the ages of 34 and 70 (average = 51.66). Five participants were Black and four were Indian. Seven of the nine participants were married (77.78%). The remaining two were single but both were in a sexually intimate relationship with their partners (22.22%). The duration of the haemodialysis treatment was from eight months to nine years (average = 38.89 months). The duration of experiencing erectile dysfunction was from eight months to five years (average = 26.22 months). Each participant was given a pseudo-name. To ensure that confidentiality is maintained, these names are used consistently when describing the participants' experiences of erectile dysfunction in this chapter.



# 3.2.2 Participants' pseudonyms

The names of the participants were replaced with pseudonyms to maintain confidentiality and anonymity as described in Chapter 2, section 2.5.

### **Gram**

Gram was a 34-year old Black male and was in a relationship with a partner. The duration of his haemodialysis was 18 months. The duration of his erectile dysfunction at the time the study was conducted had been 12 months.

### <u>Sam</u>

Sam was a 52-year old married Indian male. The duration of his haemodialysis had been 8 months. Equally, the duration of his erectile dysfunction had been 8 months when the study commenced.

## Ned

Ned, a 66-year old Indian male, was married. The duration of his haemodialysis was 72 months. He had been experiencing erectile dysfunction for 36 months.

## **Burt**

Burt was a 60-year old Indian male who was married. The duration of his haemodialysis was 24 months. The duration of his erectile dysfunction had also been 24 months.

## Mel

Mel was a 45-year old Black male. He was married. The duration of his haemodialysis was 12 months. He had also experienced erectile dysfunction for 12 months.

## **Clive**

Clive was a 69-year old Black male and was married. The duration of his haemodialysis was 60 months. Equally, the duration of his erectile dysfunction had been 60 months when the study commenced.

### Vic

Vic was a 56-year old Black male and married. The duration of his haemodialysis was 108 months. He had experienced erectile dysfunction for 48 months.



### Abe

Abe was 53 years old, Indian, male and married. The duration of his haemodialysis was 12 months. He had also experienced erectile dysfunction for 12 months.

### Newton

Newton was a 30-year old Black male and was in a sexual relationship with a partner. The duration of his haemodialysis was 36 months and the duration of his erectile dysfunction had been 24 months.

The pseudonyms of the participants will be used in the description of the findings which follows to reflect their voices in describing their experiences of the phenomenon of erectile dysfunction.

### 3.3 DESCRIPTION OF THE FINDINGS

Two major themes with supporting sub-themes emanated from the multiple data sources (phenomenological interviews, naïve sketches and field notes). The major themes and sub-themes are presented in the Table3.1below, followed by a narrative account of the participants' lived experiences of the phenomenon under study. Verbatim quotes of participants are reflected in italic writing and serves as evidence of the participants' experiences of erectile dysfunction as described by them. A literature control to recontextualise the findings will be presented at the end of each sub-theme. The experiences of the participants will be written as a narrative, reflecting the essence of the experience of erectile dysfunction. The verbatim quotes were carefully selected to become the voice of male persons experiencing erectile dysfunction.

Table 3.1: The major themes and sub-themes of the participants' lived experiences of erectile dysfunction

Major theme	Sub-theme
3.3.1 Participants' lived experiences of	3.3.1.1 Psychological loss:
erectile dysfunction reflected	(a) Loss of identity
psychological, physical and social	Loss of manhood
losses that seemingly negatively	
influenced their mental health	(b) Loss of self-worth



Major theme	Sub-theme
	(c) Loss of sexual fulfilment
	Longing to be with partner
	Loss of sexual desire
	3.3.1.2 Physical loss:
	a) Loss in erectile functioning
	Role of haemodialysis
	Loss in sexual performance
	Limited control over attaining and maintaining an erection
	3.3.1.3 Social loss:
	a) Loss in sharing and communicating
	experiences of erectile dysfunction
	Disclosing erectile dysfunction to
	intimate partner and others
	b) Loss of emotional closeness in the relationship
	Relational strain and interpersonal
	conflict
O O O Dantiniu autal accountance of living	
3.3.2 Participants' acceptance of living	3.3.2.1Acceptance of living with erectile
with erectile dysfunction positively influenced their mental health	dysfunction:
	"if you accept this [erectile dysfunction]
	and you can't do anything about it, so there
	is no point in worrying about it."

# 3.3.1 Participants' lived experiences of erectile dysfunction reflected psychological, physical and social losses that seemingly negatively influenced their mental health

The participants verbalised enduring multiple losses in their lives as a result of their experiences of erectile dysfunction. These losses were reflected in three dimensions,



namely psychological, physical and social. The classification of these losses (psychological, physical and social) was done to ensure conceptual clarity. The classification is further in line with the holistic underpinning of the Theory for Health Promotion in Nursing (UJ, 2009:1) which provided the meta-theoretical framework for the study. The findings from the data collected in these categories were linked to each other. The findings revealed that these losses resulted in severe emotional and mental discomfort for all the participants, seemingly negatively influencing their mental health.

### 3.3.1.1 Psychological loss

The South African pocket Oxford dictionary (2002) defines "psychological as relating to the mind with regard to the thinking processes and the emotions of a person". The Macmillan dictionary thesaurus (2010) defines "loss as the state of no longer having something because it has been taken from one or has been destroyed". The term "loss" can refer to a part of a person's body that one no longer has because of an illness.

According to the South African Pocket Oxford dictionary (2002), a feeling of sadness can occur in a person after the loss because of missing that which had been lost. Therefore the loss that the participant's experienced impaired their psychological functioning.

The psychological functioning reflecting in the mind and the emotions of the participants were seemingly impaired by their experiences of the phenomenon of erectile dysfunction. According to the meta-theoretical assumptions of this study which was described in Chapter 1, section 1.6.1, the mind and the emotions referred to the internal environment of the participants regarding their expressions of emotions and volitional abilities when they attempted to deal with the phenomenon of erectile dysfunction. The psychological (mind and emotions) losses include the loss in identity, self-worth and sexual fulfilment. Psychological losses in the context of this study therefore referred to how participants were internally making sense of the loss related to erectile dysfunction, with reference to the loss of identity, the loss of self-worth and the loss of sexual fulfilment. These losses affected the participants' thoughts, feelings and decision making processes.

In the following themes I describe how the participants experienced the loss of their identity, self-worth and sexual fulfilment which seemingly had a negative influence on their mental health based on the information obtained from them.



### a) Loss of identity

"Identity is the essential centre of a person's self" (Dison, 2004:85). Identity is seen "as an orientation in moral space, a space in which questions arise about what is good or bad, what has meaning and importance to one and what lacks importance. Identity is essentially tied up with what one is committed to and what one values highly and strives for" (Dison, 2004:86). Therefore, identity is an umbrella term used to describe an individual's understanding of him or herself as a unique individual with a separate entity

Conversely, since this study focused on male persons, all references to "identity" will denote the male sex. Thus, for the purpose of this study "identity" meant the participant's understanding of himself as a "man", and the concept of "a man's identity" referred to him as an intimate partner whose identity was intricately embedded in his ability to be an active and successful partner in sexual intercourse. The concept "loss of identity" referred to the impairment of the participant's selfhood. Selfhood refers to a "man's thoughts and feelings, his awareness of his existence and his functions as a man" (King in George, 1990:195). In this study the loss of selfhood was intrinsically linked to the loss of identity experienced by the participants in the context of their experiences with erectile dysfunction. Loss of identity formed part of these participants' internal environment. The loss of identity reflected in the loss of the self as a "man" and will be discussed in terms of the loss of manhood.

#### Loss of manhood

The term "manhood" refers to the various qualities and characteristics attributed to men such as masculinity, manliness, virility (manhood, vigour and lustfulness) and strength (Collins paperback thesaurus, 2008). In this study the term "manhood" referred to the loss of manliness, masculinity and virility that participants experienced because of their inability to engage in successful sexual intercourse with their partners. The South African Pocket Oxford dictionary (2002) defines "successful" as accomplishing an aim or purpose. In this study the term "successful" referred to accomplishing completed sexual intercourse. Successful sexual intercourse requires the male genital organ to have erectile functioning to attain and maintain an erection (EDPill Guide, 2009:para.2). The loss of manhood was embedded in the loss of identity for the participants since they experienced a change in how they perceived themselves as "men". (In the grammatical context, "men" is the plural of the common noun "man" where "man" indicates "an adult human male" [Concise Oxford English Dictionary, 2006]). This change in their perception was the result of the participants experiencing an inability to engage in sexual intercourse with their partners. Many of the



participants perceived themselves as "being not man enough" because they were unable to obtain and maintain an erection for successful sexual intercourse with their partners.

Most of the participants expressed "the loss of their manhood" and believed that they were "not a man at all" because their manhood and masculinity became challenged due to their inability to attain and maintain an erection for successful intercourse. The South African pocket Oxford dictionary (2002) defines "masculinity" as relating to men and having qualities associated with men. In this study the term "masculinity" alluded to the manly characteristic of the participant's ability to attain and maintain an erection for successful sexual intercourse with his partner. The loss of manhood was evidenced by Gram who said: "...it is challenging in terms of your manhood. The major stress that I am going through is the feeling that you are not man enough to function." The feeling of "not being man enough" was also expressed by Newton. To add to this theme Mel felt that he had "lost his manhood"; while Alvin felt that he was not a "full man" because of erectile dysfunction. Clive felt that he was "not a man at all" and Gram also described himself as being an "incomplete man".

One of Mel's concerns regarding his loss of manhood was other peoples' perception of him. He said: "...anyone else looking at me, he or she sees that this is not a man now". He stated that other people perceived him as "not a man" because they judged that "although he can talk like this but there are times in bed, this one is a failure". He further stated that a man must be "good in everything" including "being good in bed". He explained that people commented that even if he was good in one thing, ("he is singing nicely"), he was not good in bed as his "wife is complaining". This resulted in him losing confidence "in everything that I do." Mel's comments were linked to him experiencing the loss of self-worth which is described under the sub-theme Loss of self-worth, section 3.3.1(b). The inability to fulfil his partner's needs as a husband made Gram "feel less of a man" as his "manly duties are not being fulfilled". Gram went on to explain that he had lost his self as a man and said: "You are not man enough if you cannot take care of your woman." In my field notes I noted that Gram's facial expression reflected sadness, clearly indicating the feelings of sadness that he felt when he described his loss of being a "man".

Clive explained that "my body does not respond as a man should" when enticed by his partner. He further stated that his "penis does not wake up now even if I look at a woman naked; it just stays down like that..." This made him feel "not man enough and more like a woman." He associated himself with "being just like a woman" as he was unable to "fulfil his manly duties as a husband" in satisfying his wife's need for sexual intercourse. Clive described his partner as being more like "his sister and not like his wife". The loss of



manhood and the inability to satisfy their partners' sexual needs left some of the participants feeling sad. The expression of sadness as reflected in my field notes was seen on Clive's face; it seemed to me as if he wanted to cry. Clive stated: "If I am a man again I think and hope things will come to normality again with my wife." Vic mentioned that he was "very sad because I have failed my wife and I feel less of a man". Newton echoed the same sadness in the phenomenological interview as well in his naive sketch where he wrote that he "feels less the man that I was before and that is the one thing that makes me sad".

The data indicated that most of the participants had a longing to be a "man" again. Some participants expressed a loss of sexual identity in the bigger context of the loss of the self. They did not see themselves as the same person from before to after having been diagnosed with chronic renal failure in relation to their experiences of sexual intercourse. Therefore, the loss of continuity in sexual identity was intrinsically linked to the participants' experiences of the loss of their own identity. Ned explained: "...you are not the same person compared to somebody else who is not doing dialysis. Definitely not the same person."

Some of the participants expressed the desire to be a "man" again; to be the same "man" as the time before they went into chronic renal failure and had good erectile functioning. Their longing to be "men" again induced in them a consciousness to compare their experiences of their ability to have sexual intercourse and the size and the strength of their erection before and after chronic renal failure. Newton explained that "before I was perfectly alright. But after dialysis started then this thing [his experiencing erectile dysfunction] came about."

The discussion above reveals the theme of the loss of identity which was reflected in a loss of manhood by the participants due to living with erectile dysfunction after commencing haemodialysis.

According to Intili and Nier (1998:185), when a male is asked, "What things make you a man in your eyes?" It refers to the identity of a man; in other words, the same question can be changed to: "What makes a man to be a man for a man?" The authors argue the answer will always make some reference to the ability of the male to have an erection sufficient for sexual intercourse. Intili and Nier (1998:186) conclude that it is not possible for a male of any age to lose his erection function and still feel that he is a "real man". As described by these authors, the loss of identity as a "man" was found to be similar in the current study. The participants' experiences of erectile dysfunction left them with feelings of not being a 'real man' because of their loss of manhood and inability to perform sexually.



In a study done by Pontin, Porter and McDonagh (2002:264) with nine males experiencing erectile dysfunction who were referred by general practitioners to a general hospital in England, one of the themes these authors reported on was the loss of manhood. These participants were not in chronic renal failure. The authors believe it is commonly accepted that an evaluation of a male's "manhood" is defined by his sexual activities, especially sexual intercourse; therefore, if a man cannot engage in sexual intercourse, he can ask the question, "How may I be a man?" The theme that these authors report on, namely the loss of manhood was found to be similar in the current study where participants described their loss of manhood due to their experiences of erectile dysfunction and their resulting inability to engage in sexual intercourse.

Similarly, other authors like Low et al. (2006:175) and Williams (2010:1) concede that "loss of manhood" is experienced by males with erectile dysfunction. Williams (2010:1) states erectile dysfunction is essentially a loss of manhood, while Low et al. (2006:175) accept that erectile dysfunction is associated with the loss of manhood. Low et al. (2006:175) conducted a qualitative study with 17 males who reported experiencing erectile dysfunction. The authors report that the participants perceived erectile dysfunction as a loss of manhood and that the ability to perform sexually was an important component of manhood. According to these authors, one participant stated: "A man is no longer a man if he is not able to function. You are no longer a man if you are not able to do that (referring to sexual intercourse)."

Although the participants in the study done by Low et al. (2006:175) were not in chronic renal failure their statements were similar to the findings of the current study in which statements such as the following were made, "you are not man enough" or "lost my manhood" and "not man at all". From these studies and the findings of this study I deduced that males who experience erectile dysfunction feel that they have lost their manhood; they feel they are no longer a man regardless of whether they are in chronic renal failure or not.

A sense of loss of masculinity was described by the participants in this study. This theme is confirmed by the results from studies conducted by Fergus, Gray and Fitch (2002:303) and Tomlinson and Wright (2004:328). Fergus, Gray and Fitch (2002:303) support this finding by stating that the loss of sexual functioning posed a threat to the masculine identities of the participants in their study.

Tomlinson and Wright (2004:328) conducted a study with 40 participants who attended a health clinic for males in the Royal Hampshire County Hospital in the United Kingdomon the



impact of erectile dysfunction and the treatment thereof. The authors found that the most common initial reaction to erectile dysfunction was a sense of emasculation. Through conducting semi-structured interviews they discovered that the ability to perform sexually and to satisfy their partners was an important marker of the participants' masculinity. They concluded that there was a definite association between getting an erection and being a "man".

Although the participants in the study by Tomlinson and Wright (2004:328) were not in chronic renal failure and not on a haemodialysis programme they perceived erectile dysfunction as a threat to their masculinity. The same finding was reflected in the current study. The loss of their sexual performance after the commencement of haemodialysis threatened the participants' masculine identity in this study. There were thus obvious similarities as to how the participants in the current study and those in the other studies perceived erectile dysfunction despite the fact that the participants in the other studies were not in chronic renal failure.

Furthermore, the association of being able to get an erection and have sex and being masculine is described by Morrow (2010:1). In the article, The Psychology of Impotence, Morrow (2010:1) confirms that for a large number of males the ability to get an erection and have sex is viewed as an integral part of their masculinity. The author explains that the onsetof impotence even though triggered by an underlying physical condition, can produce psychological problems that further impact on impotence (erectile dysfunction).

In contrast to all the above mentioned views and findings, Hareyan (2005:1) perceives the loss of manhood in males experiencing erectile dysfunction as "a myth or a legend borne out of ignorance thousands of years ago". For Hareyan (2005:1), "the myths and legends about impotence still influence human being sexual culture". One of these fallacies is that "real men" don't experience impotence. The author argues that it is misconceptions to view impotence as a lack of manhood, and that manhood and the ability to perform sexually are linked. Hareyan's view, however, conflicts with the findings of the current study in which significant statements were made concerning the negative feelings of the participants about their erectile dysfunction: "an incomplete man", the "loss of manhood" and "less of a man and more like a woman". It provides evidence that feelings of having lost his manhood due to erectile dysfunction are not just myths for a male, but a conscious reality.

The encyclopaedia of mental disorder (2011:1) states traditional gender roles define masculinity as "having power and being in control in emotional situations, in the workplace,



and in sexual relationships". Situations that typically produce stress for males are those which challenge their self-identity and cause them to feel inadequate. Males will experience stress if they feel that they are not meeting expectations for physical strength and intellect and sexual performance. Therefore, males who strictly adhere to gender roles are at higher risk for mental disorders.

As the discussion above indicates, it was revealed that the loss of identity reflected in a loss of manhood and masculinity by the participants due to living with erectile dysfunction after commencing haemodialysis. The participants expressed feelings of sadness, the loss of confidence and also of self-worth. In addition, they experienced a feeling of being a failure by not meeting the expectations for sexual performance. Participants experienced a loss of identity as a 'man'. The participants' experiences of loss of identity seemingly influenced their mental health negatively.

### b) Loss of self-worth

The South African pocket Oxford dictionary (2002) defines self-worth as "being confident in one's own worth and abilities".

For the purpose of this discussion the concept "loss of self-worth" will relate to losing one's confidence in one's worth and abilities. In the study, the loss of self-worth referred predominantly to how the participants were feeling in relation to the loss of manhood and the loss of sexual performance as described above.

The participants described that they felt like failures with regard to their inability to satisfy their own and their partners' needs for sexual intercourse. The inability to satisfy both their needs for sexual intercourse seemingly left participants in a helpless situation where they did not know what to do, but desperately sought for a solution to correct their erectile dysfunction. The experience of feeling helpless impaired participants' self-confidence and self-worth.

Gram verbalised that he felt "incomplete, useless, you feel being problematic that you cannot fulfil all your manly duties at home which would really affect your relationship". Mel described himself as being a "sex man failure". Vic's statement and his repetition of the word "failure" were of significance: "...we know we are a failure. I am a failure because I can't satisfy my partner. I am a failure." The perception that a "man" must be "good in everything including sexual intercourse" made Newton to feel a failure as a "man" because he could not



satisfy his partner's sexual intercourse needs. Mel, who was married, said: "Maybe in 2010 I'll be a total failure. I don't know she'll [his partner] run away." He reasoned that the feelings of failure he experienced were as a result of him "not doing what I was doing before"; he therefore regarded the absence or decrease in sexual intercourse with his partner as a possible reason why she would leave him in the future and this created a fear in him of losing her.

Newton exposed his desperation when he said: "...my biggest problem is that I don't know how to fix it. I'm lost. I don't know what to do to make my life easier and happier. I want some help to make life easier." He felt helpless and lost, while Abe sometimes felt angry because he "can't do anything". Abe expressed that he was angry with himself because "I can't take it out on my wife." A plea for "quick treatment" from Clive so that "I can be a man again" and one for a "cure" from Vic further described their desperation with the situation that they were in. In the naïve sketch Vic wrote: "...if there is any help I really need it".

Considering the above descriptions, it became clear that erectile dysfunction was a painful experience reflecting psychological losses for most of the participants involved in this study. For two participants the only way out of this painful situation was to "not be in this world" - death became a way out for them. This is evidenced by Mel's words: "...you feel as if you are not supposed to be there. They are not supposed to be living in this world; he must not be there because if you are not there they won't say anything about you. You must leave this world, so that they don't have nothing to say about." During the time that Mel made these comments I noticed the sadness on his face. Clive's response was similarly despondent: "...sometimes I feel it is better that I am dead. I am not there. So if somebody can take my life maybe that will be alright." His sad facial expression and accompanying tears made it apparent that he experienced erectile dysfunction as extremely painful and traumatic.

Kitayama and Cohen (2007:315) state the measurement of self-worth identifies four related components. These include the identity component (how important is the partner to the participant's self-worth), member worth (the participant's assessment of his value in his relationship with his partner), private worth (the participant's personal evaluation of his relationship with his partner), and public worth (the participant's assessment of how the partner evaluates their relationship).

Tomlinson and Wright (2004:328) endorse the findings of the current study by stating that impotence, or erectile dysfunction, has a considerable impact on males as their loss in masculinity affects their feelings of self-worth due to their inability to satisfy their partners'



sexual intercourse needs. Klinger (2007:1) and Williams (2010:1) add lowered self-esteem due to erectile dysfunction causes embarrassment for the male who is experiencing erectile dysfunction, thus affecting his self-esteem. DiMeo (2006a:442) claims that males who judge themselves solely on sexual performance may perceive themselves as failures. This author explains that a male loses confidence and experiences a decrease in his self-esteem because he feels that he is a failure. The fear of being a failure, in turn, causes a male to withdraw emotionally and physically from his partner thus affecting his relationship with her. (This is described in section 3.3.3.3).

The participants in this study reported a lowered self-esteem and feelings of failure due to them experiencing erectile dysfunction. Participants reported that they were not able to engage in sexual intercourse with their partners to satisfy their own and their partners' sexual intercourse needs. The findings of a lowered self-esteem as well as the loss of confidence in the males experiencing erectile dysfunction discussed by the authors above were experienced by most of the participants in this study.

According to Tomlinson and Wright (2004:328), the decline in confidence due to erectile dysfunction did not just affect the study participants' sexual relationships, but it also had an impact on their day-to-day relationships with their friends and work colleagues.

Morales <u>et al.</u> (2005:493-498) conducted a large scale study with 405 participants who were experiencing erectile dysfunction. These participants had to complete a self-esteem scale to evaluate their self-esteem and self-confidence related to their experiences of erectile dysfunction. The authors then compared the findings to those of a group of participants who were not experiencing erectile dysfunction. The findings indicated that the participants with erectile dysfunction obtained significantly lower scores in the self-esteem and self-confident scales than those who were not experiencing erectile dysfunction. The authors thus concluded that males with erectile dysfunction experience a loss of self-esteem and self-confidence.

In Chapter 1, section 1.6.6, the meta-theoretical assumptions for this study are described. In the assumptions the internal environment included the spirit of the participants which reflected the participant's identity as a "man". The loss of identity seemingly influenced the participant's meaning in life in a negative way. Two participants in the current study experienced the loss of the meaning of life; they admitted they had lost their enjoyment for life, favouring death above the type of life they were leading due to erectile dysfunction.



The loss of enjoyment for life is supported by DiMeo (2006:b442) who report that not only does the male lose his confidence but also his enjoyment in life and his morale. The author states that the males who experience erectile dysfunction may experience a decrease in quality of life. Having negative thoughts about sexual behaviours can increase anxiety pertaining to sexual performance, resulting in poor sexual function. Therefore, any kind of sexual activity is avoided.

The findings of the current study correspond with those of Rosen et al. (2004:334) in that erectile dysfunction is associated with a decreased quality of life and a lowered self-esteem. Rosen et al. (2004:334) conducted a study with a sample of depressed males who were experiencing erectile dysfunction. The findings revealed a reduced life satisfaction for them. The authors concluded that a change in the males' quality of life may be mediated by changes in sexual function and family relationships. There was also a decrease in the quality of life of the participants in the current study due to the seemingly negative influence of erectile dysfunction in the lives of them and their partners. This finding is verified by Unger (2004:28) who states that erectile dysfunction has a negative impact on the quality of life for males which often results in the loss of self-image, low sexual satisfaction, and depression.

The participants in this study expressed feelings of helplessness and hopelessness in dealing with erectile dysfunction and requested help from me in my role as a professional nurse practitioner. According to Barnes (2010:1), erectile dysfunction can affect one in 10 males and can cause feelings of inadequacy, helplessness and inferiority in them. Orth, Robins and Meier (2009:307) suggest that low self-esteem and stressful events jointly influence the development of depressive effects. Individuals with low self-esteem are prone to depression because they lack sufficient coping resources. The authors based their suggestions on a study conducted with 359 participants that showed that low self-esteem and stressful events were risk factors for depression.

The above discussion above reveals the theme of the loss of self-worth reflected by the participants expressing their feelings of uselessness and helplessness, and their loss of self-worth and confidence. They believed they were failures because they could not satisfy their partners' needs for sexual intercourse. The feelings expressed by the participants are closely related to the symptoms of depression and mental illness. Therefore, the participants' experiences of the loss of their self-worth seemingly had a negative influence on their mental health.



### c) Loss of sexual fulfilment

For the purpose of this discussion, the concept "loss of sexual fulfilment" will refer to the psychological consequences of the participant's as well as his partner's perceived unmet needs for sexual intercourse. Within the context of unmet needs for sexual intercourse, participants described a longing to be with their partners on the one hand, while on the other hand they experienced a loss of sexual desire situated in a perceived inability to satisfy their own and their partners' sexual intercourse needs. The loss of sexual fulfilment is closely related to the loss of identity as the participant longed to be with his partner as a "man" and to satisfy his own and his partner's sexual intercourse needs, but failed in this process. It fed into the loss of self-worth and an experience of losing his manhood as described in section 3.3.1.1. Therefore the loss of sexual fulfilment was experienced more on an individual level transpiring to the social world of the individual resulting in a disruption of his relationship with his partner as described in section 3.3.1.3.

In the phenomenological interview Vic explained that because of his "decrease in erection arousal and short time of erection" his partner "does not like this" and therefore "she refuses to give me because she knows that I'm not going to finish her". Clive's partner has "stopped all the advances that she used to do when I was well. She just sleeps." Clive reported that he perceived his partner as being "different" towards him because of his loss of interest and initiative for sexual intercourse with her. According to Clive, his partner "displays everything to me now yet before she used to hide herself when she went for a bath so as to provoke me or stimulate me but it does not happen".

In this study most of the participants reported being concerned that their partners' needs for sexual intercourse were not being met because of their erectile dysfunction and loss of sexual desire. According to Vic, "ladies want satisfaction" but he is "not satisfying" his partner. Clive wrote in his naive sketch not satisfying the partner made him "feel bad my wife was never satisfied anymore". The inability to satisfy his partner made Newton to feel that "his function to satisfy a woman is gone". He commented that "if she wants satisfaction, then you can't give her that. You can do everything for her but for that part, no." For Gram erectile dysfunction "affects you dealing with your partner." He reasoned that "sometimes she will see that this is your intention [to have sexual intercourse with her]" but because of erectile dysfunction "you cannot have sexual intercourse with her and fulfil her needs for sex". In his naïve sketch Gram wrote that the most frustrating scenario for him was "when your partner is craving for intercourse then she starts touching you but it [male genital organ] does not function and get hard enough for intercourse". The result for Gram was that he was not able



to satisfy his partner's need for sexual intercourse. Vic felt that he "always leave her on all the time" without satisfying his partner's sexual intercourse needs. He explained that "when I am with my partner it is two minutes and I'm finished with the job".

Not satisfying their partners' needs for sexual intercourse and not fulfilling them (the partners) sexually, evoked reactions of anger, frustration, sadness and guilt in some of the participants. They experienced a loss of control to satisfy their own and their partner's sexual intercourse needs. Clive stated he became frustrated "when I come to my wife because she didn't understand me like this". He explained that he was "frustrated with myself because I cannot go to her, cannot do anything to her". Abe had a similar response and voiced that he also got "angry with me because I can't do anything". Newton was also "angry" with himself as he "wants to make someone [his partner] happy and you can't". Clive's frustration resulted in anger: "I feel angry because I cannot jump the rope that I used to jump, feel very angry. I feel very angry with myself because I cannot function well."

Mel stated that "when I look with my eyes at my partner my body does not respond, so it makes me even more angrier, angry with myself". The anger made him want to "fight with yourself because you can't perform but there is nothing that you can do about it". Another concern Vic had was that "even though he leads her on, there is nothing that he can do". When this study was conducted, Vic had experienced erectile dysfunction for four years. He stated that, in all of that time, he had not been able to satisfy his partner and this caused him to feel "sad about this and this is my fourth year with this [erectile dysfunction]". He voiced that he "feels sad all the time". I observed in my field notes that Vic did not maintain eye contact when he expressed his feelings of sadness. I perceived this as him experiencing feelings of guilt for not being able to satisfy his partner's needs for sexual intercourse. He stated: "I am leading her on and it is very difficult. There is nothing I can do. I get upset because I know the problem is with me."

The discussion above reveals the theme of loss of sexual fulfilment experienced by the participants because of erectile dysfunction. Loss of sexual fulfilment will be further discussed in terms of longing to be with the partner and loss of sexual desire.

### Longing to be with partner

Some of the participants described a longing to be with their partners and to have sexual intercourse with them. Sexual intercourse is achieved by either of the partners (the



participant or his partner) initiating sex and engaging in sexual intercourse with each other (Harvey, Wenzel & Sprecher, 2004:213).

According to some participants they had the desire for sexual intercourse and wanted to have it with their partners, but there was lack from their side to initiate sexual intercourse, which resulted in the loss of sexual fulfilment. This was due to the participants not being able to attain or not maintain an erection. This was evidenced by Gram's concern that the "major issue is when you happen to start the intercourse and for one reason or the other you don't do well". It frustrated Gram when sexual intercourse "becomes impossible, it doesn't start, doesn't function".

Vic said that as a man he "always touches her [his partner] and leads her on". But he found it "difficult" to continue doing this because he could not satisfy her as his partner. He voiced he had a "fear to touch her [his partner]". He concluded that he "likes to be with her [his partner] but it is difficult to satisfy her". It was evident that Vic did not want to touch his partner as this would lead to them both wanting to engage in sexual intercourse and it was impossible because of his erectile dysfunction. In my field notes I noted that Vic appeared unhappy when he spoke about how he liked to be with his partner and have sexual intercourse with her, but failed in the process.

Mel's naïve sketch depicted clearly that he had a need to be with his partner but he did not get what he wanted (an erection) to satisfy himself and her. Abe explained his "wife is young and maybe she wants to have sex" with him. He stated that "sometimes when I want to make love to her I can't; my penis doesn't wake up". He reasoned that he had "this problem [erectile dysfunction] because I am a dialysis patient". Because he could not have sexual intercourse with his partner Abe felt "bad". Gram described sexual intercourse with his partner "even in the morning you say you want to ...your making of love in the morning" because his partner "loves the morning one". For Gram it was especially embarrassing not to "function in the morning" because he knew his partner expected it then; he said there was no sexual fulfilment for him and his partner in the morning because "it doesn't come up at all, it doesn't work at all when it comes to the morning". Most of the participants expressed feeling frustrated and angry with their situation and with themselves. For Gram the "worst frustrating scenario" was when he was unable to respond appropriately to his partner's initiation of sexual intercourse. This made him become "irritated" while Sam shared that it was "frustrating that I am not able to sleep with her [his partner]".



Participants evidently had a deep longing to be with their partners sexually but experiencing a loss of sexual desire prevented some of them from engaging in sexual intercourse with their partners.

### Loss of sexual desire

The Merck manual of medical information (2003:1206) defines 'desire' "as the wish to engage in sexual activity. Desire leads to the first stage of the sexual response cycle namely sexual arousal".

The different data sources (phenomenological interviews, naïve sketches and field notes) revealed that meeting the sexual intercourse needs of their partners were important to the participants. According to their descriptions, it seemed as if most of them dealt with the compromised sexual desire by losing interest in sexual intercourse, thus losing their sexual desire or experiencing a fluctuating sexual desire.

Mel stated that "you completely lose feeling of ever having any sexual thing or anything" and Abe commented that erectile dysfunction "makes you lose interest in intercourse". Newton explained that "you want to perform and make your partner happy, but you can't make her happy". For Vic, there was "little erection arousal" when he was with his partner. Ned described his "loss of feeling of having sex" as due to the loss of sexual fulfilment, while Gram agreed that he experienced "loss of interest" in sexual intercourse with his partner. Desire for sexual intercourse may be present on one day and there may be no desire on the next day. This was confirmed by Vic who said: "I have met her on Monday, then now the whole week I'm not interested." He added "I do not want to do it daily, but when there is an interest I must do it correctly." Mel agreed with the loss of sexual desire. He described how it fluctuated one day he would have a desire for sexual intercourse but "the following day I do not have any desire, maybe for 2 to 3 days". In my field notes I noted that Mel was open and expressive in his description of his experiences of erectile dysfunction. It was my perception that Mel had needed to share his experiences and was thankful for having been given the opportunity in this study to talk about it. He was comfortable with describing his experiences of erectile dysfunction to me.

In the naïve sketch Clive wrote that "it started with quick ejaculation and poor erection and it gave me not to wish for a woman". In my field notes I noted that Clive banged his fist on the table to indicate his frustration. He was angry because he had lost his ability to achieve and maintain an erection for successful sexual intercourse. His anger seemed to intensify when



he spoke about him being attracted to her but being unable to satisfy her need for sexual intercourse. It seemed as if Clive's coping mechanism in this situation was to suppress his own sexual desire; it also appeared to be some form of protection against his own embarrassment in the situation.

The findings of this study revealed that some partners displayed coping strategies similar to those of the participants. The partners lost interest in sexual intercourse due the participants' experiences with erectile dysfunction.

The discussion above revealed the theme of loss of sexual fulfilment of the participants and their partners which reflected the participants' longing to be with their partners and their experiencing a loss in their sexual desire. Both of the sub-themes, longing to be with their partners and experiencing loss in sexual desire are, re-contextualised next.

The American Psychiatry Association (DSM-IV-TR, 2000:535) defines 'sexual dysfunction' "as a disturbance in the sexual response cycle with sexual intercourse". In the discussion above the participants expressed feelings of anger, frustration, sadness and guilt caused by their inability to engage in sexual intercourse with their partners. This resulted in them not fulfilling their partners' needs for sexual intercourse; the participants therefore perceived themselves as failures. The inability to engage in sexual intercourse with their partners resulted in distress and interpersonal difficulty (as discussed in section 3.3.1.3) for the participants, thus seemingly negatively influencing their mental health.

DiMeo (2006b:442-446) supports the finding of this study, namely that there is a decrease in initiation of sexual intercourse by males who experience erectile dysfunction. In the context of erectile dysfunction literature indicates that males have a tendency to withdraw emotionally and physically from their partners because they fear that physical affection will precipitate a desire for sexual intercourse and remind them of their inability to achieve an erection (DiMeo, 2006b:442). It was found in this study that participants emotionally and physically withdrew from their partners because of their inability to engage in sexual intercourse with their partners. The participants wanted to protect themselves from the embarrassment of not satisfying their partners.

Yilmaz et al. (2009:405) conducted a study on male and female patients who were on a haemodialysis programme. They reported that the male patients experienced a higher incidence of problematic arousal and attaining and maintaining an erection to initiate sexual intercourse. This negatively affected the sexual life of their intimate partners because the



decrease in arousal and the limited control in attaining and maintaining an erection resulted in a decrease in sexual intercourse between the patients and their intimate partners. More than 50% of the participants complained of a reduction in libido and a marked reduction in the frequency of sexual relations with their intimate partners, while 60% of the participants experienced erectile dysfunction.

Similarly, Fryckstedt and Hylander (2008:466) found that there was a decrease in sexual desire and sexual function due to erectile dysfunction in patients with chronic renal failure. These authors conducted a study to determine the desire and sexual functioning of male and female patients before and after being diagnosed with chronic renal failure. An overall decrease was seen in sexual desire (46%) and initiative (68%). A decrease in sexual function was also recorded. In the current study the participants' experiences of erectile dysfunction resulted in a loss in sexual desire and initiative after starting haemodialysis because of the diagnosis of chronic renal failure. A loss of sexual desire by both the male and his partner is also reported by Dunn (2004:7) who states that this is due to erection difficulties and the result is a cessation of all sexual activity. The cessation of all sexual activity including sexual intercourse was confirmed by the participants in this study who were experiencing erectile dysfunction. DiMeo (2006b:442) adds the failure of sexual advances made by the male makes the female partner believe that the he is losing interest in her, thereby also lowering her self-esteem and making her to feel less attractive.

Not being able to satisfy their partners' needs resulted in emotional reactions from the participants in this study as mentioned earlier. DiMeo (2006a:442) confirms that the male may be manifesting signs of frustration and humiliation for not being able to complete the set act to satisfy his partner's needs. This leaves him devastated and very much alone even though his interest in his partner is not diminishing. The author reports that the inability to meet the partners' sexual intercourse needs resulted in participants being dissatisfied with their sex life because there was no of sexual fulfilment. These findings are similar to the findings of the current study; because the participants were not able to satisfy their own and their partners' sexual intercourse needs, it left both parties with feelings of dissatisfaction with their sex life.

The fact that erectile dysfunction can be the cause of dissatisfaction with one's sex life is supported by Braun et al. (2000:305). These authors based their findings from a study they conducted on a representative population sample of 4,489 participants to determine the epidemiology of erectile dysfunction in Germany. The findings revealed that 44% of the participants experienced dissatisfaction with their current sex life due to erectile dysfunction.



These findings are confirmed by Mallis <u>et al.</u> (2006:442) and Neto <u>et al.</u> (2002:19) (2002:19). Neto <u>et al.</u> (2002:19) found that erectile dysfunction lowered the sexual activity and satisfaction with one's sex life with a partner in the context of patients who were on a haemodialysis programme in southern Brazil. According to Dunn (2004:7), the impact of erectile dysfunction on relationships is that a diminished sexual desire is experienced by both the participant and his partner leading to withdrawal of affection from both parties. The loss of sexual fulfilment as experienced by participants in these studies led to them having feelings of dissatisfaction with their sex life – this finding was the same in the current study.

To explore the life satisfaction of patients with erectile dysfunction and to determine the relation between severity of erectile dysfunction and life satisfaction, Mallis <u>et al.</u> (2006:442) conducted a study with 69 patients in an outpatient clinic who complained of erectile dysfunction. The authors report that males who experienced erectile dysfunction had a loss of sexual fulfilment and expressed dissatisfaction with their overall quality of life. These findings were consistent with the findings of the current study which showed that erectile dysfunction reflected losses in the psychological dimension that seemingly negatively influenced the mental health of the participants. The participants experienced a loss of their identity as a "man"; there was a significant decrease in their self-worth resulting from the loss of sexual fulfilment to satisfy their partners' as well as their own sexual needs.

The discussion above and the literature control revealed the negative influence of erectile dysfunction on the psychological dimension. The psychological losses reflected losses in identity, self-worth and sexual fulfilment as a result of the loss in erectile functioning which seemingly negatively influenced the participants' sexual performance in the physical dimension.

### 3.3.1.2 Physical loss

As stated in the themes and sub-themes of the participants' lived experiences of erectile dysfunction (Table 3.1), the participants' lived experiences of erectile dysfunction reflected physical losses.

The South African pocket Oxford dictionary (2002) defines 'physical' as "pertaining to the human body and its functions as opposed to the mind". According to the Theory of Health Promotion in Nursing (UJ, 2009:3-7), the body (a dimension of the internal environment) includes all the anatomical structures and physiological processes pertaining to the individual/family/group/community. In this study the participants experienced a dysfunction



with their genital organ relating to erectile dysfunction. Their experiences of erectile dysfunction influenced the physiological functioning of their bodies with regard to sexual functioning. Therefore, the participants' experiences of erectile dysfunction resulted in physical losses as part of the internal environment.

For the purpose of this discussion the term "physical" will refer to the functioning ability to attain, control and maintain an erection for sexual intercourse. "Physical losses" will refer to the loss in erectile functioning resulting in loss in sexual performance and the limited control over attaining and maintaining an erection for sexual intercourse. In this study participants described that their experiences with erectile dysfunction commenced after haemodialysis had been started as a treatment for chronic renal failure. The literature control for physical losses focused more on quantitative data (percentages and statistics) rather than a narrative style in qualitative data.

In the following themes I describe the participants' physical losses with specific reference to loss in erectile functioning. Loss in erectile functioning was discussed with reference to the role of haemodialysis, loss in sexual performance, and limited control over attaining and maintaining an erection.

## a) Loss in erectile functioning

The Merck manual of medical information (2003:1193; 1206) explains that during sexual activity the penis (male genital organ) becomes erect, enabling penetration during sexual intercourse. The inability to achieve or maintain an erection for sexual intercourse is defined as erectile dysfunction. Males with erectile dysfunction have difficulty engaging in intercourse either because the erect penis is not sufficiently hard, long or elevated for penetration or because the erection cannot be sustained.

In the current study the loss in erectile functioning for the participants started after haemodialysis had commenced. It was experienced as a loss in sexual performance. Participants also experienced a loss of control in attaining and maintaining an erection for successful sexual intercourse with their partners. Experiences also reflected the participants' inability to have an erection as well as experiences of premature ejaculation.

Loss in erectile functioning was closely related to the role of haemodialysis as the treatment modality for chronic renal failure.



### Role of haemodialysis

According to the participant demographic profile (as described in section 3.2.1), all participants agreed that their experiences with erectile dysfunction started after they had commenced with haemodialysis as a treatment for chronic renal failure. Gram confirmed this by stating: "It started shortly after dialysis which is almost two weeks after that, and it has been my life since then." Ned voiced that "before haemodialysis I was perfectly alright. But after the dialysis started then this thing [erectile dysfunction] came about." Vic wrote in his naïve sketch that after commencing haemodialysis he "felt himself deteriorating in my sexual intercourse with my partner". For Vic the loss of control over erectile functioning affected his sexual functioning in his relationship with his partner.

Newton, who had had erectile dysfunction for two years before this study was conducted, verbalised that his erectile dysfunction was caused by renal failure. He blamed himself for not taking care of his physical well-being in order to prevent renal failure: "you have to blame yourself. If you think that what caused your renal failure then maybe if you were the part of it. Like me, the BP [blood pressure] and hypertension was the main cause but now, that thing is ... if I lived my life well at that time or I look to myself more carefully, I would not get this renal failure. But now I've got it." Newton expressed the same feelings in his naïve sketch, namely that the loss in his sexual performance was due to renal failure when he wrote: "...since starting with renal failure my life [sex] has changed as performing [sexual intercourse] is low and the morale is gone".

Haemodialysis was viewed as a point of departure for the experience of loss in sexual performance and limited control over erectile functioning within the physical dimension.

## Loss in sexual performance

All participants reported that they had had successful sexual performance before haemodialysis but that their performance decreased after the commencement of haemodialysis.

Gram's statement of comparing his past sexual performance as opposed to that he experienced at the time of the study represented the experience of all the participants when he said: "So you look at yourself, how you are functioning before it [erectile dysfunction] and you look at what is currently happening. Then you think back before this thing didn't use to happen." His statement about comparing his sexual functioning before and after renal failure



was also reflected in Gram's naive sketch. He wrote: "When you look at your current state with renal failure you always tempted to compare yourself before the renal failure. You look at your erection." Newton further explained: "Before I'll go easy three [times of having sexual intercourse with his partner] but now one per week is a lot of job." The decrease experienced in sexual performance after haemodialysis had commenced was also supported by Mel who said: "You see the difference is, those years when I was – let's start from fifteen – I mean five rooms and we were proud to say I've done it, you see."

From the above it was noted that there was a decrease in sexual performance experienced by these participants after haemodialysis had commenced. Their ability to have successful sexual intercourse diminished. Data revealed that participants linked their loss in sexual performance to sexual immaturity and being "young." This was evidenced when Mel, who was 45 years old, described himself as being "young and not an adult" as he was unable to achieve and maintain an erection as an adult. For him experiencing erectile dysfunction while at the young age of 34 was difficult to accept. Also Newton, 30 years old, had a "hard time" with the fact that he was "still young" and is experiencing erectile dysfunction. He regretted: "I am still young; I should be enjoying my life. For me it is hard as I am still young, most of the patients that have the same problem are twice my age. It is not a big thing for them but for me it is. We are young, we should be enjoying this part but now we can't." Ned, who was 66 years old, voiced that he was sad because "there is a part missing in you, that part in normal life". Regardless of their different ages, all participants experienced the inability to have sexual intercourse and/or a decrease in sexual performance due to erectile dysfunction as a physical loss. The loss in sexual performance reflected in the limited control over attaining and maintaining an erection.

### Limited control over attaining and maintaining an erection

The South African pocket Oxford dictionary (2002) defines 'control' as "having power over something and be able to limit or regulate something".

For the purpose of this study the term "loss of control over erectile functioning" will mean the inability of the participants to control (to be in charge of, to attain and maintain) erectile functioning for successful sexual intercourse with their partners.

In this study all the participants expressed their experiences of loss in erectile functioning leaving them with limited control over erectile functioning. The limited control manifested in the participants' inability to attain and maintain a sufficient erection in order to engage in



sexual intercourse with their partners. The limited control seemingly ranged from no control to inefficient erectile control.

Gram describes his lived experiences with erectile dysfunction as "a major challenge that I experience ... it becomes an impossible situation that you engage in, mainly to control it [male genital organ]". This seemingly left him in a stressful and challenging situation. In the naïve sketch, he noted that" one of the major noticeable thing is that you cannot control it [male genital organ]". He goes on to say "...it [male genital organ] normally gets hard on its own and you don't know how long that is going to last". Gram further explained that "one of the problems that actually happens is that it [male genital organ] gets hard sometimes on its own, sometimes it doesn't when you want it to ... an efficient erection within the process becomes so impossible .... managing it is an issue as it does not get hard enough, it leaves you on the way and it never came up".

Gram noted in both the phenomenological interview and his naïve sketch that when intercourse is started and "for some reason you don't do well, you want to quickly start it again, it always doesn't come up at all". He wrote that even when at the times he managed to obtain an erection, the erection was over in a few minutes before ejaculation because the erection was "not effective enough." He then tried to "start again but it does not come up at all ... this worries me". He continued by writing that, even if he had asked his partner for assistance, "still nothing happens". In his view, even if he had to have a "threesome [with two partners] it is impossible as it can fall and never get up". Most of the time during the phenomenological interview Gram rubbed his head. I wrote in my field notes that this gesture indicated to me Gram's inability to deal with his problem; his erectile dysfunction left him in a helpless situation.

Mel described his limited control over erectile functioning as "it is off and on, works then it doesn't work". He explained that it would "not work and then maybe after 3 days it comes back again." I detected a sense of hopelessness when he asked me whether his control over erectile functioning was "going to last or end".

Burt stated that "he tried to have an erection but it did not work". Clive described himself as "not functioning well" because of erectile dysfunction where the "penis does not wake up now". This happened even if he "looks at a woman naked"; his male genital organ "stays down". Newton commented that his "performance is gone". He predicted that his "standard that I am performing is going to drop because I don't see it improving. After 3 years it is still the same." Both Clive and Newton linked the physical dimension (erectile dysfunction and



the loss of performance) to the psychological dimension – Clive found that even female nudity failed to stimulate an erection and Newton had negative thoughts on a further decrease in future sexual performance.

Vic complained that his male genital organ was not "getting hard enough to actually engage in intercourse, it becomes impossible; it doesn't start". For Abe, when he "sleeps with my wife ... my penis don't wake up, it just sleeps flat. When I want to have sex or something, my penis just dies off." It was thus perceived that the participants had no control over sexual intercourse with their partners. Mel explained when he was with his wife "it works and then doesn't work". For Clive the troublesome thing was that "his penis does not wake up now. It just stays down. It is the most worrying thing". Abe voiced his concern as follows: "...bad when I want to have sex, my penis just dies off". In the naïve sketch Sam wrote when he wanted to have sexual intercourse with his partner his erection was not "full" and therefore sexual intercourse was not possible.

Premature ejaculation seemed to form an integral part of the participants' experiences of limited control over their attaining and maintaining an erection for successful sexual intercourse with their partners.

Some participants stated that when they did attain an erection they experienced "quick ejaculation." In his phenomenological interview Clive voiced that he had "quick ejaculation and the poor erection give me not enough for a woman anymore. It does not rise anymore." Vic also mentioned that he experienced "little erection arousal" and "early ejaculation"; he described how "when I'm doing the work, it just takes two minutes and I'm finished with the job". His statement is supported by his naïve sketch where he wrote about the "little erection and early ejaculation which takes only two minutes and I am sad about this". Gram acknowledged in his naïve sketch that for him the "worst embarrassing situation is when you have managed to be erect and start your first round and it does not go well, you get quick ejaculation".

It is clear that the loss of control over their erectile functioning and the limited control to attain and maintain an erection for successful sexual intercourse was difficult to accept for some of the participants. The physical loss associated with the lived experiences of erectile dysfunction was linked very strongly to limited control over attaining and maintaining an erection as well as an experience of premature ejaculation. Erectile functioning of participants was experienced as dysfunctional because the quality of the erection was influenced and ejaculation was untimely. The limited control over attaining and maintaining



an erection resulted in the inability of the participants to engage in sexual intercourse with their partners.

The discussion above revealed the theme of loss in erectile functioning which started after the commencement of haemodialysis and was reflected in the participants' limited control over attaining and maintaining an erection. The participants revealed their sadness and the embarrassment in their limited control over attaining and maintaining an erection thereby resulting in the loss of sexual performance.

Zamd et al. (2005:33) conducted a study on 86 patients to determine the sexual dysfunction in male patients undergoing haemodialysis in Morocco. They reported 94.2% of the participants had sexual activity before the start of haemodialysis, but the study participants experienced a loss of erectile functioning after commencing haemodialysis. They reported that 81.4% of the participants suffered from a decrease in sexual activity (decrease in sexual functioning) after the onset of haemodialysis. A decrease or loss of libido was noted in 59.3% of the participants. The authors noted that 36% of the participants experienced an incomplete erection while 24% experienced an absence of an erection. The inability to ejaculate was experienced by 14% of the participants. Similar to the finding of the current study that sexual functioning had decreased or become non-existent after haemodialysis, these authors concluded that haemodialysis was one of the factors that caused sexual dysfunction in participants who underwent haemodialysis treatment. In a study by Zamd et al. (2005:33) the authors describe themes of loss in sexual performance, loss in sexual desire and loss in attaining and maintaining an erection for sexual intercourse. These themes are similar to the themes that have been described in this study; participants in both studies had similar experiences of living with erectile dysfunction.

In support of the findings that there is a decrease in sexual functioning after haemodialysis, Yilmaz et al. (2009:405) confirm the theme loss of sexual fulfilment which is presented in section 3.3.3.1. These authors note that a higher rate of male and female participants in their study reported that their sexual functioning decreased after commencement of haemodialysis: 65% of the participants were dissatisfied with their sexual life since starting haemodialysis and 40% had stopped having sexual intercourse. The authors found that the male participants had problems of maintaining an erection and to maintain arousal for the initiation of sexual intercourse. Yilmaz et al. (2009:405) concluded that sexual problems were common in haemodialysis patients.



Tsai et al. (2008:36) as well as Diaz, Reig-Ferrer and Ferrer-Cascales (2006:458) conducted studies to determine the number of male patients experiencing erectile dysfunction while on a haemodialysis programme. The results of these studies weret hat 86.8% and 60% of the participants experienced erectile dysfunction respectively. The authors agreed that erectile dysfunction started after the commencement of haemodialysis and that the participants' sexual functioning deteriorated. Diaz, Reig-Ferrer and Ferrer-Cascales (2006:458) found that 47% of the 103 male patients who were on a haemodialysis programme reported having no sexual activity at all.

A study to determine sexual functioning in 117 patients (male and female) with end stage renal failure (chronic renal failure) was conducted by Fryckstedt and Hylander (2008:466). These authors noted that there was a pronounced decrease in sexual function with regard to erection/lubrication (68%) while 64% of the participants reported a decrease in the frequency of intercourse. The study was not specifically focused on the male patients on the haemodialysis programme but included male and female patients with chronic renal failure. However, the authors concluded that most of the participants experienced a decrease in sexual desire, initiative and ability to engage in sexual intercourse due to chronic renal failure. The themes decrease in sexual desire and initiative in the study were found to be similar to the themes in the current study.

The participants' lived experiences of limited control over attaining and maintaining an erection in the current study was supported by different authors. Juergensen et al. (2001:355) found that over 50% of the patients on a renal treatment modality (haemodialysis or continuous peritoneal dialysis) had difficulty in getting and maintaining an erection for intercourse, concluding that there was a high prevalence of sexual and erectile dysfunction in patients with chronic renal failure. Neto et al. (2002:19) agree that erectile dysfunction reflected a higher frequency of difficulty to get and maintain an erection during intercourse. They report that 25.4% of the 118 participants in their study had complete erectile dysfunction while 60% had moderate or minimal erectile dysfunction. Erectile dysfunction was perceived to be a higher frequency of difficulty to get an erection or maintain an erection during sexual intercourse, a lower monthly rate of sexual activity, and a lower satisfaction with sex life.

A symptom of sexual dysfunction in male patients is premature or delayed ejaculation (Levy, et al. 2004:762). Gokce and Ekmekcioglu (2010:251) define premature ejaculation as "a male sexual dysfunction characterised by ejaculation that always or nearly occurs before or within approximately one minute of vaginal penetration". According to Ringold (2010:para.



2), premature ejaculation causes distress to both the male and his partner. These findings are similar to the findings of the current study in which the participants complained about quick ejaculation when they were with their partners.

An analysis of premature ejaculation in haemodialysis patients was conducted by Aslan et al. (2003:59) on 98 patients on a haemodialysis programme. Premature ejaculation was determined in 31.6% of the participants with a lower satisfaction score on sexual life and sexual relationship with partners. The authors therefore concluded that premature ejaculation was a prevalent disorder in haemodialysis patients and seemed to affect their sexual fulfilment. Similarly, in the current study some of the participants complained about "quick ejaculation" and "early ejaculation", thus describing premature ejaculation.

The discussion above and the literature control revealed the negative influence of erectile dysfunction on the physical dimension. The participants' loss in erectile functioning which started after the commencement of haemodialysis reflected in limited control over attaining and maintaining an erection and loss in sexual performance. The loss in sexual performance seemingly had a negative influence on the relationship between the participants and their partners. This is discussed in the next sub-theme, namely the social loss experienced by the participants.

### 3.3.1.3 Social loss

In Table 3.3 the participants' expression of social losses emanating from their lived experiences of erectile dysfunction are presented. The South African pocket Oxford dictionary (2002) defines 'social' as being "companionable meaning that there is a need to be in the company of others. People are social beings as well as individuals and as social beings people meet each other for companionship". According to the Theory of Health Promotion in Nursing (UJ, 2009:3-7), the social dimension refers to the human resources in the external environment of the individual/family/group/community. In this study the human resources related to the participants' relationship with their partners, friends and health care practitioners (doctors and professional nurse practitioners) with regard to sharing and communicating their experiences of erectile dysfunction to them. The participants' non-disclosure of their experiences of erectile dysfunction resulted in a social loss.

For the purpose of this study the term "social" will refer to the companionship between the participants and their partners – where their need for sexual intercourse is expected to be met as constructed by societal norms. The participants and their partners were companions,



in a relationship and had a desire to engage in sexual intercourse. As stated under the theme psychological loss (section 3.3.3.1), loss is when impairment occurs and in this context the impairment was in the companionship and emotional closeness between the participant and his partner. Therefore, social loss referred to the impairment in the companionship and social closeness between the participant and his partner. In the context of this study social losses resulted from, firstly, the loss of sharing and communicating (verbal and non-verbal) by the participants and their partners regarding the participants' experiences of erectile dysfunction and, secondly, the participants' experiences of erectile dysfunction resulted in no or minimal sexual intercourse with their partners, thus negatively affecting their relationships.

In the following themes I describe how the participants experienced social losses as reflected by the loss in sharing and communicating experiences of erectile dysfunction and the loss of emotional closeness in the relationship with their partners.

## a) Loss in sharing and communicating experiences of erectile dysfunction

The loss in sharing and communicating experiences on erectile dysfunction referred to no or limited verbal communication between the participant and his partner regarding his experiences of erectile dysfunction. There was a silence from the participants with reference to communication with their partners on their experiences thereof. Most of the participants found it difficult to disclose their experiencing erectile dysfunction to their partners.

Losses in sharing experiences and emotions and communicating experiences on erectile dysfunction resulted from non-disclosure of erectile dysfunction by the participant to his intimate partner and others.

### Disclosing erectile dysfunction to intimate partner and others

The South African pocket Oxford dictionary (2002) defines 'intimate' as "having a sexual relationship". In this study the term "intimate partners" referred to the person with whom the participants had sexual intercourse and the term "others" included friends and health care practitioners. The latter were the doctors and professional nurse practitioners working in the haemodialysis units.

Many of the participants seemingly did not disclose the fact that they were experiencing erectile dysfunction with their intimate partners and others. This was evidenced by Gram



who verbalised that "you are so trapped emotionally to actually communicate that it [erection of the genital organ] doesn't function".

When I inquired whether Gram discussed his experiences of erectile dysfunction with his intimate partner, his response was: "No, not yet." Alvin's response to the same question was: "No, maybe she's [the partner] caught on, I don't know." Later on he again said: "I don't think my wife knows what's going on." In my field notes I noted that Alvin was very soft-spoken and battled to express himself at times. He refused to write a naive sketch. It seemed as if Alvin had difficulty in communicating verbally or in writing about his experiences of erectile dysfunction. The truth of the perception was reflected by the fact that he calmly stated that he does not "talk to anyone". Mel's response to the question of whether he had spoken to his intimate partner about his experience of erectile dysfunction was "No." His inability to share and communicate his feelings with his partner made him feeling "sick if I keep all inside and not talk about it [his experiences of erectile dysfunction]". Mel has received support from his intimate partner and stated that she "has accepted" his experiencing erectile dysfunction and therefore she was "supportive" of him. His intimate partner was patient as she would say "...ok, never mind we will see tomorrow". Vic voiced that the fact that be kept everything "all bottled up inside" made him "feels as if I am sick".

Two participants were unsure of what their intimate partners thought and felt. Gram kept "guessing of exactly what might be going through your partner's mind within this whole period". He "hopes for the right time we'll be able to discuss the issue". He coped by rationalising that his intimate partner "is waiting for me to start discussing it". Gram did state that his intimate partner is "accommodative on the issue, she is understanding; she does not put pressure on me". He disclosed that he would, however, like to discuss his experiences of erectile dysfunction with his intimate partner. I mentioned in my field notes that Gram had a sad expression on his face while talking about sharing his experiences with his partner. I perceived this as indicative of his unhappiness. Ned was 66 and had been married for 40 years. He stated that he "does not know how my wife takes it. But she does not speak about it. I do not know my wife's feelings. She does not discuss her feelings."

Some of the participants reasoned that they could only share their experiences of erectile dysfunction with others (friends and professional nurse practitioners) if they knew they could trust the latter. When asked if he had told anyone about his experiences of erectile dysfunction Mel's response was that "I can tell this to no one else but someone to trust." The same feelings were echoed by Newton who stated that he could only talk to people that "I can trust but other people, no." He did not trust people who "go behind my back and talk".



about me". Newton reasoned that "the people that I trust, like here the patients, we know each other and we are on the same trouble. We will speak around. 'This is the problem, can you fix it?' and they say, 'No, this thing is always happening." It became evident that the participants preferred to talk to others who were also experiencing erectile dysfunction.

The embarrassment of being a "sex man failure" inhibited Mel's communication to someone else. Abe also did not tell anyone about his experiences of erectile dysfunction as he "feels ashamed". Newton, on the other hand explained, that he "does not like people going behind my back and talking about me". He explained for him "it is hard to go and talk about your private life outside". He justified his explanation by adding "it is very hard to talk to someone outside [anyone who does not experience erectile dysfunction] because they will not understand". Newton found it hard "as men to go out and just talk about it ... someone else may think that this guy is lying, maybe it is something that he is doing". He reasoned that this response from others could be because" most people don't understand renal failure". Vic verbalised that "there is no one I am talking to" and added that he "can't talk openly" to his wife the way that "I talk to you [the researcher]". Ned stated that he had approached his doctor and discussed his experiences with erectile dysfunction with him (the doctor). This was evidenced in his naïve sketch in which he wrote that he "went to the doctor and I spoke to him concerning this [erectile dysfunction], but the doctors can't help you". He felt that the doctors "are afraid to give you any kind of tablet or anything like that because it might affect the kidneys or something".

Some of the participants were able to discuss their experiences of erectile dysfunction with their intimate partners. In spite of Ned, Clive, and Newton having discussed their experiences of erectile dysfunction with their intimate partners they felt that their intimate partners did not understand their experiences of erectile dysfunction as evidenced by their partners' unresponsiveness and behaviour. Newton stated: "I have tried to explain to her that it's because of the problem [erectile dysfunction], but she don't understand." Clive's response to discussing erectile dysfunction with his intimate partner was "what could she say. She never said anything." He became frustrated "when I come to my wife because she didn't understand me like this". Ned suggested that "the main thing is to discuss with your partner, and I think if the partner understands then its ok". He claimed that "there must be a mutual understanding between the two and when we spoke about it, and then she understood that". Ned explained in the naïve sketch that his intimate partner understood that he was experiencing erectile dysfunction. Sam's intimate partner was also understanding of his situation. He stated: "I think it's quiet hard but my wife is very understanding of the situation that I am in." This is also confirmed in the naïve sketch where



he wrote that his intimate partner was very understanding; she realised he had a problem and that he was sick, and she therefore would stand by him all the time.

The participants expressed a feeling of freedom and relief after having shared their stories of losses related to erectile dysfunction within the context of this research. Ned explained that "we are all just waiting for someone to talk about this. So when the letter [letter from researcher to patients to participate in the study [see Annexure A] came about I replied to the letter." Vic explained that he "feels much better because I could voice out what is always in me alone". He went on to say that "he feels happy that I have told this to someone else, everything that's in me". Newton as well was "happy now because there is someone that I'm talking to". It was clear to me that most of the participants were grateful that there was someone who was prepared to listen to them disclosing their experiences of erectile dysfunction. They had not disclosed their experiences of erectile dysfunction to their intimate partners or others.

The discussion above reveals that some of the participants did not share and communicate their experiences of erectile dysfunction to their intimate partners while others who did communicate their experiences with their intimate partners felt that it did not help them.

The findings of this study regarding the participants finding it difficult to disclose their experiences of erectile dysfunction to their intimate partners were similar to the findings of studies done by DiMeo (2006b:442) and Lakin (2000:1). According to DiMeo (2006b:442), a male can feel embarrassed and even guilty. This makes it difficult for him to talk to his intimate partner about his experiences with erectile dysfunction. Lakin (2000:1) agrees that many males with erectile dysfunction are reluctant or embarrassed to discuss their experiences with erectile dysfunction with a significant other. Tomlinson and Wright (2004:1038) report it was revealed in their study that some of the participants felt belittled by their experiences of erectile dysfunction. It is therefore not unusual for the male to experience feelings of loneliness and isolation due to the fact that he cannot (or will not) share or disclose his experiences of erectile dysfunction with or to anyone (DiMeo, 2006a:442).

The lack of communication between the participants and their intimate partners is also reported by Fisher <u>et al.</u> (2005:64-78). In a study conducted by these authors in an erectile dysfunction helpline in Italy, 41% of the participants had not spoken to their intimate partners about their experiences of erectile dysfunction. The authors report that males with erectile dysfunction may have poor communication skills when it comes to sharing their problems



and experiences with their intimate partners because of the embarrassment that this may cause them. The findings in the current study were similar.

In a study conducted by Messina et al. (2007:673) to determine the prevalence of erectile dysfunction on 58 patients undergoing haemodialysis, 91% of them did not discuss their experiences of erectile dysfunction with their physicians. The study by Messina et al. (2007: 673) supports the findings of the current study in which only one participant verbalised that he had disclosed his experiencing erectile dysfunction to his doctor. In contrast Pontin, Porter and McDonagh (2002:264) report that most of the participants in their study were comfortable to disclose their experiences of erectile dysfunction to the health care professionals regardless of whether the health care professionals were male or female. The participants spoke of receiving professionalism and confidentiality from the health care professionals.

Participants experienced a loss in the social dimension arising from the loss of sharing and communicating their experiences on erectile dysfunction to their intimate partners and others. The participants' difficulty in disclosing their experiences of erectile dysfunction to their intimate partners and to others was viewed as a point of departure for the loss of emotional closeness in the relationship between the participant and his intimate partner.

#### b) Loss of emotional closeness in the relationship

For the purpose of this discussion, The South African pocket Oxford dictionary's (2002) definitions of the terms 'emotional', 'closeness' and 'relationship' will be adopted. 'Emotional' is defined "as readily showing emotion (a strong instinctive feeling)". 'Closeness' is defined as "being affectionate or intimate and part of a person's immediate family. 'Relationship' is defined as a "loving and sexual association between two people".

In this study the affectionate association referred to the physical and emotional bond between the participant and his partner. The loss of sexual intercourse affecting the relationship referred to the changing nature of the couple's affectionate relationship in relation to their engaging in sexual intercourse and how the changes in sexual intercourse influenced their relationship. Relational changes were evident in an absence or decrease in sexual intercourse between the participant and his partner, thus impairing their relationship. The loss of intercourse within the relationship seemingly placed strain on the relationship, reflected as interpersonal conflict between the participant and his partner.



#### b.i) Relational strain and interpersonal conflict

As described under loss of sexual fulfilment section 3.3.1.1(c) participants verbalised a decrease or absence of sexual intercourse with their partners due to their experience of erectile dysfunction. It became clear that when the participants' needs for sexual intercourse were not met they became frustrated and angry. This in turn made their partners to reciprocate and also become frustrated and angry within the relationship. This became evident when Gram explained that his loss of interest in sexual intercourse with his partner would "affect your partner negatively which will actually be a problem in your relationship". For Gram, when his partner's needs were not met "she will have a problem with that".

Clive explained that if his partner "gets no sex from me, it's bad then she's angry with me sometimes and very frustrated. It's terrible." For Clive the anger that he had with regard to his not satisfying his partner was "causing a lot of problems at home. Because the relationship between us now is not so good."

Some of the participants were worried about the effects of erectile dysfunction on their relationship with their partners. Two participants were constantly worrying and ruminating about what will happen, what must they do and when will this (erectile dysfunction) stop. Mel stated that "I won't just fall asleep at that moment; I just lie thinking what will happen? What should I do? Why?" while Vic responded with: "In your mind there is worry and worry and I don't even know when I slept because I'm always thinking when it will stop. I feel tired and restless. I am brooding on this problem [the problem of erectile dysfunction]."

From the loss in sharing and communicating experiences on erectile dysfunction as discussed section 3.3.1.3(a) there appeared to be diminished trust within the relationship between the participant and his partner. According to Newton "this is like you are cheating; there is something that you are doing on the side". He added that his partner "is thinking that there is something that you are doing because you are not performing now at home therefore the relationship is not strong". For Newton the result of this was "a lot of tension in the house. A lot of tension in the relationship." In Newton's home "there are lot of fights, small fights because of the problems of erectile dysfunction". His reasoning was "if you can't perform you will be in fights". For him this resulted in the relationship "suffering". In the naïve sketch Newton described "erectile dysfunction is causing much tension in our lives and that if it is not fixed, it will break our lives". Therefore he found it "hard to go home because she [the partner] will expect something from you [sexual intercourse] and you can't give her that. Then she will end up fighting. It's hard." Clive stated that "it [erectile dysfunction] is



causing a lot of problems at home because the relationship between us [his partner and him] now is not so good". He acknowledged that there was a "strain in the relationship". Vic explained that "erectile dysfunction is causing a problem with me and my partner".

The conflict within their relationship resulted in the participants fearing that they might lose their partners. Some of the participants were worried that their partners would leave them because they regarded erectile dysfunction as a "life-long term problem" that they cannot be resolved. Thoughts of their partner's possible infidelity resulted in the some participants anticipating that they would lose their partner to someone else. This was evidenced when Sam stated that "in today's life if a man is not satisfying his wife, the wife goes and looks for somebody else to satisfy her and that worries me because one day I may just lose her because of not satisfying her". In the interview and naïve sketch Sam's biggest fear appeared to be to "lose her [his partner]". Mel echoed the same words, thinking that his partner would "think of somebody else who is going to satisfy her". He described his thoughts of his partner's anticipated infidelity and unfaithfulness as follows: "It's like I'm in the hospital now, my wife she is going to town, she meets someone asking for love, now that she knows that I cannot, she will meet a man who is driving a car, go to a certain hotel and sleep with the man and it will mean something good." Mel worried about "being left by his wife". This was Mel's "big concern". During this time in the interview I noted Mel was tearful reflecting feelings of sadness due to his loss of his intimate relationship with his wife. Vic also had thoughts of his partner's infidelity when he stated "when you see your wife hiking from town, you think maybe she has got someone else. Maybe they are eloping." He feared that "my wife will leave me and go to another man". Newton stated that the relationship between him and his partner could culminate in "she can leave you. You can break up any time." He feared that his partner would leave him because she was "still young". The breakup of the relationship between the participant and his partner emerged as a possibility that could result in divorce. For 69-year old Clive, who was married, the thoughts of a divorce crept in: "If we were not Christians I'm sure she would have divorced me by now. It will come to a point where my wife will divorce me." This was an immense worry for Clive; he stated that "I don't know what to do about it."

From the data presented above it became evident that the external environment, in particular the social dimension of the participant's relationship with his partner was negatively affected by his experiences of erectile dysfunction, indicating the interweaving internal and external dimensions depicted by The Theory for Health Promotion in Nursing as described in Chapter 1, section 1.6.2.



The discussion above reveals the social loss due to the loss of sexual intercourse between some of the participants and their partners. The loss of sexual intercourse negatively affected their relationship resulting in strain and conflict within their relationship.

Yilmaz et al. (2009: 405) report that the loss of sharing and communicating experiences of erectile dysfunction by the participants and their partners resulted in their withdrawal from each other. This then resulted in a strain within their relationship. The loss of sharing and communicating experiences of erectile dysfunction led to a strain in the relationship between the participant and his partner as discussed in this study concurs with that of the findings of these authors.

Neto <u>et al</u>. (2002:19) also support the findings of the current study in their report that erectile dysfunction can have a strong negative effect on a couple's life. This is evident in the findings of the current study where erectile dysfunction resulted in a strain in the relationship between some of the participants' and their partners.

Low et al. (2006:175) reported that erectile dysfunction had a significant impact on relationships with the participants' partners. The participants felt insecure in maintaining a stable and satisfying relationship with their partners. The strain and conflict in the relationship between the participant and his partner in the current study was reflected in the behaviour of the partners when their sexual intercourse needs were not met. The partners became angry and frustrated with the participants. Nelson (2007:37) is of the similar opinion that male sexual dysfunction increases distress in many female partners.

According to the findings of this study, the loss of sexual fulfilment resulted in some of the participants not trusting their partners due to their experiencing thoughts of anticipated infidelity from their his partners. This is confirmed by DiMeo (2006b:442) who found that erectile dysfunction had an effect on issues of trust, intimacy and closeness between the male and his partner. The partner may worry that the man may not be sexually intimate with her but may be sexually intimate with another person, leaving her with anticipated thoughts of betrayal and infidelity. Because of erectile dysfunction a male's partner may leave him ending their relationship. This was a major concern for some of the participants in the current study. DiMeo (2006b:442) states that the misconceptions and fears caused by the loss of sharing and communication between the man and his partner regarding his experiences of erectile dysfunction can drive a couple apart.



Tomlinson and Wright (2004:1037) report that the reaction to erectile dysfunction displayed by participants in their study was that relationships with their partners were badly affected. The authors report that 25% of the participants felt that they were "letting down their partners" by not being able to satisfy their partners' sexual intercourse needs. Some of the participants were worried that their partners would go elsewhere or that they would lose their partners.

These findings were similar to the findings of the current study in that the consequences arising from the difficulties between the participant and partner with regard to the participants' experiences with erectile dysfunction could end the relationship. Tomlinson and Wright (2004:1039) conclude that erectile dysfunction has a major psychosocial impact on males.

The termination of the relationship between the participant and his partner is possible as reported by Rosen <u>et al</u>. (2004:234). They found that 28% of the participants in a UK-based survey believed that erectile dysfunction was directly responsible for the termination of their last relationship. In the data discussed above some of the participants disclosed that they were afraid that their partners would leave them and thus terminate their relationship.

DiMeo (2006b:442) supports the findings of the current study that not only does erectile dysfunction affect the male's identity (his relationship with himself) but also that with his partner. The author further states that erectile dysfunction has a direct impact on a male's life and marriage and is involved in one in five failed marriages.

Adequate sexual expression is essential in many human relationships and provides a sense of physical, psychological and social well-being (Baldwin & Mayers, 2003:202). A loss in the social dimension is reflected by the loss in sharing and communicating experiences of erectile dysfunction and the loss of emotional closeness in the relationship as reflected by relational strain and interpersonal conflict between the participant and his intimate partner.

Conflict between the intimate partners affects their mental health. The mental health of males and females showed signs of anxiety when faced with abandonment and rejection. The Mental health relief (2009:1) states that enduring relationships were associated with good mental health and breakups with poor mental health. If conflict between partners (a male and female) is not resolved then mental health is affected (Mental health relief, 2009:1).



For two participants, despite experiences of erectile dysfunction, their relationships with their partners remained intact. The following are the alternative stories of acceptance of the experiences of erectile dysfunction by the two participants and their partners. This had a positive influence on the participants' mental health.

# 3.3.2 Participants' acceptance of living with erectile dysfunction contributed to their mental health

Two of the participants verbalised acceptance of their experiences of erectile dysfunction by themselves and their partners. This formed part of the alternative story of acceptance which seemingly positively influenced these specific two participants' mental health. Even though in the second theme only two of the participants reflected on their acceptance of living with erectile dysfunction, their significant statements had worth equal to that of the statements made by the other participants that were reflected in the first major theme. Added to this is the fact that the second major theme contributed towards the recommendations that is presented in Chapter 4, section 4.4.1. Therefore, the two participants' voices were honoured in providing hope and alternative ways of coping with their experiences of erectile dysfunction.

### 3.3.2.1 Acceptance of living with erectile dysfunction

The South African pocket Oxford dictionary (2002) defines 'acceptance' as "to agree upon, to believe and to receive as correct". In this discussion the term 'acceptance' will refer to the acceptance of erectile dysfunction or of the experiences thereof by participants and partners. Two of the participants, Ned and Burt, accepted their experiences of erectile dysfunction. This forms part of the alternative story of acceptance. Even though Ned, who was 66 years old, was experiencing erectile dysfunction like all the other participants, he had accepted it. He had been married for 40 years and had accepted that the "dialysis and age" contributed to the way in which he experienced erectile dysfunction. He accepted having erectile dysfunction because "I'm older I have to accept it". He asserted that "since you are old now, this happens to a lot of people regardless if they come for dialysis or not". He did acknowledge though that "if I was younger then it should affect me quite badly. But not at this age." He explained that "so many of them [males] even at the age of fifty are going through it"; therefore it was "okay" for him.

In the naïve sketch Burt explained that he had accepted erectile dysfunction as being due to his old age. Ned asserted that the reason that he participated in this study was for altruistic



reasons to assist the younger patients: "I'm doing this because I don't like this kind of thing happening to younger chaps who are in their thirties and forties. Now that is very bad." Burt suggested that "younger patients should be in the study so as to benefit them".

Ned and Burt gained emotional intimacy in their relationship with their partners. They accepted having erectile dysfunction therefore their relationships with their partners were healthy. According to Ned, erectile dysfunction "will have an impact on anyone. But you know, if you accept this and you can't do anything about it, so there is no point in worrying about it." Burt and his partner also accepted his experiencing erectile dysfunction. He stated: "I accept the dysfunction. My wife accepts it and I'm happy with it. She is fine with it". In the naïve sketch he wrote that his wife had accepted his experiencing erectile dysfunction as due to old age.

Burt's life went on as "normal as husband and wife." He described the relationship he had with his partner where "we sleep together, we cuddle, we kiss we hold each other and sleep but the erection is not there. There is no such thing that we have to have sex." To him "love is more important than sex". Burt explained: "We don't have a negative attitude. Because she doesn't think of having an affair somewhere else, we don't think of looking at someone else. We've reached an old age and I think we're quite happy with it."

The alternative story of acceptance revealed that two participants and their partners accepted the participants' experiences of erectile dysfunction. The factors that contributed to their acceptance of erectile dysfunction were that the two participants were unable to do anything about their experiencing erectile dysfunction and that they were in an older age group (age related).

In a study conducted by Pontin, Porter and McDonagh (2002:264) the authors found that some of the participants accepted their experiences of erectile dysfunction, and were still in love with their partners. The authors explain that some of the participants in their study discussed their experiences of erectile dysfunction with their partners and also the ways of managing the situation. However, although they did get support from their partners, the participants still felt that their partners did not telling them (the participants) how they really felt purely to spare their (the participants') feelings. Participants in the study by Pontin, Porter and McDonagh (2002:264) hoped for a resolution but did not expect to find one. Consequently, they decided to accept their experiences of erectile dysfunction.



In the data presented in the current study, one of the participants explained that his experience with erectile dysfunction was due to two factors, namely his older in age and his chronic renal failure. He further stated that he could not do anything about his erectile dysfunction so he had accepted it.

According to Bortolotti et al. (2003:323), the influence of age and several medical conditions such as chronic renal failure and dialysis can cause erectile dysfunction. Lyngdorf and Hemmingsen (2004:105) agree that erectile dysfunction increases with age. Neto et al. (2002:524) add that among men on dialysis they found erectile dysfunction to be an age-dependent disorder with a prevalence of 52.6% at younger than 50, and 70.5% at 50 and older. The two participants in the current study who accepted erectile dysfunction as being part of their ageing process were both older than 59.

# 3.4 ESSENCE OF THE PARTICIPANTS' EXPERIENCES OF ERECTILE DYSFUNCTION

The essence (meaning) of the participants' experiences of erectile dysfunction was reflected by losses in the psychological, physical and social dimensions that seemingly negatively influenced their mental health.

The participants in this study were in chronic renal failure, on a haemodialysis programme and experiencing erectile dysfunction. The themes that were generated from the data collection (phenomenological interviews, naïve sketches and field notes) described their experiences of living with erectile dysfunction which was embedded within and emanating in multiple losses - psychological, physical and social. Losses emanating from the psychological dimension were the loss of identity, the loss of self-worth and the loss of sexual fulfilment. In the physical dimension participants experienced a loss in erectile functioning which resulted in a loss of sexual performance and a loss in the ability to control and maintain an erection for successful sexual intercourse with their partners. The loss of sharing and communicating experiences on erectile dysfunction and the loss of emotional closeness in the relationship between the participant and his partner were experienced in the social dimension. However, two participants embraced the challenges of erectile dysfunction and had managed to deal with the losses in the psychological and social dimensions.



#### 3.5 CONCLUSION OF THE FINDINGS

This chapter described the demographic profile and pseudonyms of the participants followed by a description of the findings and a literature control. In the literature control my search for studies from a South African perspective on the phenomenon of erectile dysfunction was limited. I made use of the search engines as such LINAHL and Ebscohost as well as the key words to search for studies from a South African perspective. However, I found there were limited researches conducted on erectile dysfunction in South Africa.

The findings revealed that the participants' lived experiences of erectile dysfunction reflected losses in the psychological, physical and social dimensions that seemingly negatively influenced their mental health. However, there were participants who had accepted living with erectile dysfunction; this contributed to the psychological and social dimensions of their mental health because they maintained a healthy relationship with their partners. This chapter concludes with the essence of the participants' experiences of the phenomenon of erectile dysfunction.



## **CHAPTER 4**

# DISCUSSION OF CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

"Body and soul cannot be separated for purposes of treatment, for they are one and indivisible. Sick minds must be healed as well as sick bodies."

(Miller 2010:para.4)

#### 4.1 INTRODUCTION

Chapter 3 gave a description of the findings of the study and a literature control to recontextualise the findings. Chapter 4 presents a discussion of the conclusions, limitations and the recommendations drawn from this study.

#### 4.2 CONCLUSIONS

This study focused on the lived experiences of patients with erectile dysfunction who were on a haemodialysis programme in three national renal care haemodialysis units in KwaZulu-Natal. The study resulted from the observation by me that the patients disclosed their experiences of erectile dysfunction to the care workers or to other patients rather than to the professional nurse practitioners. This study emanated from my realisation that the professional nurse practitioners working in these haemodialysis units might not have had the necessary training and skills to facilitate mental health as an integral part of holistic nursing care in cases of patients experiencing erectile dysfunction.

Two research questions were posed.

- What are the lived experiences of male patients with erectile dysfunction who are on a haemodialysis programme in three units of a renal disease management organisation in KwaZulu-Natal?
- What can be done by the professional nurse practitioners to facilitate the mental health of
  male patients who are on a haemodialysis programme in three units of a renal disease
  management organisation in KwaZulu-Natal?



The overall aim of this study was to generate an in-depth understanding of the lived experiences of patients with erectile dysfunction who were on a haemodialysis programme in three national renal care units in KwaZulu-Natal. The aim of the study was achieved as represented in the findings in Chapter 3 which reflected the participants' lived experiences of erectile dysfunction.

The objectives of the study were:

- to explore and describe the lived experiences of patients with erectile dysfunction who
  were on a haemodialysis programme in three units of a renal disease management
  organisation in KwaZulu-Natal, and
- to propose recommendations for professional nurse practitioners to facilitate the mental health of patients with erectile dysfunction on a haemodialysis programme in three units of a renal disease management organisation in KwaZulu-Natal with reference to nursing practice, education and research.

In this study a phenomenological research design that was qualitative, explorative and contextual was utilised to achieve the aim and objectives of the study. The multiple data collection methods that were utilised to ensure data triangulation were phenomenological interviews, naïve sketches and field notes. The recorded phenomenological interviews were transcribed and analysed using Creswell's method of analysing phenomenological interviews (Creswell, 2007:156), integrated with a literature control to re-contextualise data, as presented in Chapter 3. Based on the findings in Chapter 3, recommendations were proposed on nursing practice, nursing education and future research to be conducted. These recommendations focused on the training and assistance of the professional nurse practitioners working in haemodialysis units to enable them to render holistic nursing care to patients experiencing erectile dysfunction. Promotion (facilitation) of health implicates the mobilisation of resources (UJ, 2009:1). Erectile dysfunction had a negative influence on the mental health of the participants in this study The goal was to provide the patients within the context under study with holistic nursing care by mobilising these patients' internal and external resources in order to facilitate their mental health (UJ, 2009:1).

All the participants (patients with erectile dysfunction who were on a haemodialysis programme) reported that their experiences of erectile dysfunction started when they commenced haemodialysis as a treatment modality for chronic renal failure. An analysis of the participants' description of their lived experiences of erectile dysfunction through



phenomenological interviews, naïve sketches and field notes reflected two major themes. The first major theme reflected multiple losses (psychological, physical and social) that negatively influenced the mental health of the participants. The second major theme was the alternative story of acceptance of living with erectile dysfunction that contributed positively to two participants' mental health. Even though in the second theme only two of the participants reflected on their acceptance of living with erectile dysfunction, their significant statements contributed information with as much intrinsic value as that of the participants reflected in the first major theme, as well as to the recommendations presented in section 4.4.1.

Within the psychological dimension most of the participants experienced erectile dysfunction as a loss of identity in the form of loss of manhood and loss of sexual performance. Most of the participants expressed that they felt "less of a man," "not man enough" or an "incomplete man" because they were unable to engage in sexual intercourse with their partners and thereby satisfy their partners and their own needs for sexual intercourse. All the participants reported having had satisfactory experiences of sexual intercourse prior to the commencement of haemodialysis; but after haemodialysis had commenced their engaging in sexual intercourse decreased or became non-existent. The perceived loss of manhood, the inability to satisfy their partners' and their own sexual needs made them feel like failures. This has resulted in a loss of their self-worth.

However, the participants were not the only people who were affected by the experiences of living with erectile dysfunction, there were also their partners. The inability to engage in sexual intercourse with their partners has resulted in frustration and anger in both the participants and their partners. Participants had a longing to be with their partners and to satisfy their partners' sexual intercourse needs but they experienced a loss in sexual desire. This resulted in the loss of sexual fulfilment for both the participants and his partners.

Within the physical dimension, all the participants experienced a loss in erectile functioning after the commencement of haemodialysis due to chronic renal failure. They experienced limited control over attaining and maintaining an erection for successful intercourse with their partners. The participants complained of premature ejaculation which caused them much distress.

Within the social dimension most of the participants withdrew from their relationship with their partners because of their experiences of erectile dysfunction. Subsequently, a loss in sharing and communicating experiences of erectile dysfunction by the participants with their partners and others – the latter included friends, doctors and the professional nurse



practitioners – emerged. The participants' inability to engage in sexual intercourse with their partners negatively affected their relationship with their partners resulting in terms of loss of emotional closeness and relational strain causing interpersonal conflict. Some of the participants experienced fear of their partners leaving them or having affairs with men who could "satisfy her".

The losses within the psychological, physical and social dimensions resulting from the participants' lived experiences of erectile dysfunction had a negative effect on their mental health.

An alternative story uncovered in this study was two of the participants' acceptance of living with erectile dysfunction which positively influenced their mental health in the psychological and social dimensions. These two participants seemingly accepted their experiences of erectile dysfunction linking the causes of erectile dysfunction to their "old age" and "haemodialysis". Although all the participants in the study, irrespective of their ages, were negatively influenced by erectile dysfunction, these two were able to cope with their experiences differently. They implemented alternative coping methods to deal with their experiences of erectile dysfunction which did not include sexual intercourse with their partners. Their ability to cope with their experiences of erectile dysfunction might have been be due to age or developing and implementing better coping skills. These two participants perceived showing love to their partners in other ways as more important than engaging in sexual intercourse. Therefore, they managed to maintain a healthy relationship with their partners regardless of their experiences of erectile dysfunction.

As the researcher I was sensitive regarding any undue risks that the participants may have experienced as a result of participating in this study. Some of the participants did experience emotional discomfort while sharing their experiences of erectile dysfunction with me. These participants had sad facial expressions, were tearful and some appeared angry. I prolonged my time with these participants after the interview to contain their emotional discomfort and to make them feel comfortable. After the interviews, I sat with the patients and gave them time to think and to discuss any issues that they were concerned about.

I also did offer the participants who experienced emotional discomfort a planned individual supportive interview as follow-up but they refused the supportive interview. Their refusal of individual supportive interviews raised certain questions in my mind as a researcher, namely why were these participants refusing the supportive interview offered to them, and did they believe or accept that there would be no change to their experiencing erectile dysfunction?



#### 4.3 LIMITATIONS

During the process of conducting this study there were some limitations that were identified. It is discussed next.

• The coding process created a challenge. The independent coder and I did not use the same method in coding. The independent coder made use of content analysis instead of thematic analysis. In the outcome of the coding process I generated themes while the independent coder generated codes. I did inform the independent coder prior to the data analysis that I would be using Creswell's method of data analysis (Creswell, 2007:159). This resulted in two different coding methods being used which made the analysis process more time consuming and difficult for me as a novice researcher in qualitative research.

I realised that clearer communication between myself and the independent coder with regard to the coding process and coding method was required for this study and would have eliminated this problem. The independent coder and I should have met face-to-face to discuss the coding process and method rather than to rely on electronic communication. I attempted to manage this limitation by the assistance of my two supervisors in verifying the essence of the phenomenon under study thereby adding to the credibility of the findings.

- I live in Durban, KwaZulu-Natal and therefore face-to-face supervision with my two supervisors was very limited. This posed a problem for me in conducting the study. I had three face-to-face meetings with my supervisors during the course of my study. I came to the conclusion that these meetings, which included feedback on my progress, was more positive and enlightening; I gained a better understanding of what was required of me in my development as a qualitative researcher from these contact sessions as opposed to the electronic communication we utilised.
- During the phenomenological interviews I experienced difficulties in bracketing my preconceived notions of erectile dysfunction. This is evident in the leading questions that I posed to the participants to gather more in-depth information on their experiences of erectile dysfunction. Leading questions were asked when the participants were unable to express their feelings; for example, when participants stated that they "feel bad." They were unable to explain what they meant by "bad". It was my perception that the



participants associated negative feelings with the word "bad" because in my field notes I wrote that their facial expressions depicted emotional discomfort congruent with their expression of "bad". The participants were not able to be specific in expressing their negative feelings. Therefore, I used a leading question to probe further as to what "bad" meant. I asked: "When you say 'bad', do you mean that you are angry or sad?" According to Creswell (2007:62), an interpretive approach to phenomenology would signal bracketing as an impossibility. However, the researcher still needs to decide how and in what way his or her personal understandings will be introduced into the study (Creswell 2007:62). Therefore, for me to understand the participants' experiences of erectile dysfunction I deduced that I had to ask the leading questions.

#### 4.4 RECOMMENDATIONS

The recommendations that are proposed originated from the empirical findings of this study (Chapter 3, section 3.3) and by the Theory of Health Promotion in Nursing from the University of Johannesburg (2009:1) as discussed in Chapter 1, section 1.6. This theory strives to promote (facilitate) the health of individuals, groups, families and communities (UJ, 2009:1). I used this theory as a frame of reference to propose recommendations to facilitate the mental health of patients experiencing erectile dysfunction while on a haemodialysis programme with reference to nursing practice, education and research.

#### 4.4.1 Nursing practice

Nursing practice incorporates the application of the nurses' knowledge, skills and attitudes towards alleviating, supporting or enhancing actual or potential responses of individuals or groups to health issues. It focuses on the facilitation and maintenance of health and the provision of care to people with identified nursing needs so that they may maintain or attain optimal well being (The Royal College of Nursing, 2003:9). The recommendations to nursing practice in this study will include the implementation of holistic nursing care by the professional nurse practitioners in combination with the support and assistance of the advanced psychiatric nurse practitioner to patients experiencing erectile dysfunction and who are on the haemodialysis programme in order to facilitate their mental health.

As discussed in the background and rationale in Chapter 1, section 1.2, 70% of the professional nurse practitioners working in the twelve haemodialysis units of the renal disease management organisation did not have psychiatric qualifications because they qualified prior to the commencement of the four year comprehensive training course for



professional nurse practitioners in 1985. Added to this some of them bridged from enrolled nurses to professional nurse practitioners and therefore they did not have a psychiatric qualification. The number of professional nurse practitioners without a psychiatric qualification might have added to the lack of holistic nursing care rendered to the patients who were experiencing erectile dysfunction and who were on the haemodialysis programme. Therefore, the need for the advanced psychiatric nurse practitioner, as a "sensitive therapeutic professional" (UJ, 2009:4) with a consultative and developmental role has been identified.

In relation to the course in clinical nursing science for registration of an additional qualification, the South African Nursing Council (SANC, 1997:3) describes the 'consultative role' as meaningful "co-operation and collaboration with the multi-disciplinary team with the view to achieve a common goal". In this study the consultative role pertains to the referrals that will be made to the multidisciplinary team.

The 'developmental role' is described as effective interaction to facilitate growth in individuals and groups (SANC, 1997:3). The development of individuals and groups refer to the development of the professional nurse practitioners in the haemodialysis units.

Through the use of the Theory for Health Promotion (facilitation) in Nursing (UJ, 2009:1) the advanced psychiatric nurse practitioner should support and assist the professional nurse practitioners in the haemodialysis units to facilitate the mental health of the patients who are experiencing erectile dysfunction as well as their partners by mobilising their internal and external resources (developmental role). The internal and external environments of the patients are affected by their experiences of erectile dysfunction. The internal environment is the patient's body, mind and spirit while the external environment refers to the physical, social and spiritual dimensions.

Participants experienced multiple losses on physical, psychological and social levels. As a result of chronic renal failure haemodialysis was commenced; this led to the loss in the physical functioning of the male genital organ (loss of erectile functioning). The participants' experiences of erectile dysfunction resulted in psychological losses evidenced by the loss of identity, the loss of self-worth and the loss of sexual fulfilment. The social losses comprised loss in sharing and communicating experiences of erectile dysfunction between the participants and their partners. This resulted in the loss of emotional closeness in their relationship.



In nursing the function of the professional nurse practitioner is to facilitate the promotion of holistic health through the mobilisation of internal and external resources (UJ, 2009:7). The mobilisation of internal and external resources is required to assist the patients to overcome the psychological, physical and social losses (as discussed in Chapter 3, section 3.3) and thus facilitate their mental health. The need for holistic nursing care to enable the patients to deal with their losses and to move towards acceptance of their experiences of erectile dysfunction was identified.

It was determined in this study that the resources which can be mobilised to facilitate the mental health of the participants include internal resources (insight and coping skills through education on erectile dysfunction, psycho-education, therapeutic groups and supportive sessions) and external resources (partners, professional nurse practitioners, advanced psychiatric nurse practitioners, doctor and referrals to professionals including the psychologists, psychiatrists and sexologists).

The advanced psychiatric nurse practitioner can conduct workshops and render support services for the professional nurse practitioners to teach them to mobilise the internal and external resources of patients who experience erectile dysfunction with the goal of facilitating these patients' mental health within the context of holistic nursing care (UJ, 2009:7). The internal resources are closely related to their experiences of psychological and physical losses, while the external resources focus on their social losses. (The losses are discussed in Chapter 3, section 3.3). The workshops and support services can empower the professional nurse practitioners working in the haemodialysis units with knowledge and confidence to encourage the patients who are on the haemodialysis programme to discuss their experiences of erectile dysfunction with them.

According to Algier and Kav (2008:136), sexual function is an important aspect for quality of life; therefore the professional nurse practitioners should find out if a patient is experiencing sexual problems. However, these authors ascertain that one of the reasons why professional nurse practitioners do not discuss issues on sexual functioning with the patients is because the professional nurse practitioners feel uncomfortable to talk about sexual functioning with the patients. According to the authors, it results in the sexual concerns of the patients often being neglected when holistic nursing care is implemented. Added to this is the fact that professional nurse practitioners must be comfortable to address the problem of erectile dysfunction with the patients in a confidential and professional manner to encourage the patients to disclose their concerns in order to collaboratively explore options to manage their living with erectile dysfunction. The workshops conducted by the advanced psychiatric



nurse practitioner can support and assist the professional nurse practitioner to assess and implement a plan of care based on the patients' experiences of erectile dysfunction; in this way the patients' mental health care needs can be met which, in turn, will allow for attending to their needs on a holistic level. The plan of care should incorporate the major themes and sub-themes from the findings (as discussed in section 3.3) as reflected by the losses in the psychological, physical and social dimensions.

Since I am an employee in the renal disease management organisation I am aware that in the haemodialysis units where the participants in this study are dialysed, the professional nurse practitioners are expected to implement follow-up interviews and assessments of the patients during the patients' scheduling for haemodialysis. The scheduling for haemodialysis may be 2 to 3 times a week as prescribed by the patients' doctors. The aim of the interviews and assessments of the patients is to identity problems and thereby implement a plan of care. In spite of the fact that, as part of the patient's initial assessment, the sexual functioning of the patient is currently recorded there is a lack of follow-up assessments of the patients' sexual functioning by professional nurse practitioners while they are on the haemodialysis programme. For this reason, I propose a policy for weekly comprehensive assessments on the psychological (the mental state, mood and mental stability), physical (bodily functioning including sexual functioning), and social (relationship with partners) dimensions of the patients while they are on the haemodialysis programme.

With reference to the scope of a professional nurse practitioner the SANC (1984:2) stipulates that the professional nurse practitioner should make provision for effective patient advocacy to enable the patient to obtain health care needs. This includes the diagnosing of a health need, prescribing, provision and execution of a nursing regimen to meet the need of a patient or a group of patients, and making referrals to a registered person where necessary. As an advocate for the patient and on behalf of the patient, the professional nurse practitioner should therefore consult with the patient's doctor as regards the plan of care to assist the patient to cope with his experiences of erectile dysfunction. From the findings of this study (discussed in Chapter 3, section 3.3) it is evident that erectile dysfunction is closely related to the mental health of the patient receiving haemodialysis. The professional nurse practitioner must thus firstly evaluate the patients' mental health and identify the risk for depression and anxiety related to their experiences of erectile dysfunction based on a depression and anxiety scale. It is clear that there is the need for the advanced psychiatric professional nurse to assist in developing professional nurse practitioners in each haemodialysis unit to facilitate the patients' mental health.



In facilitating the patients' mental health the professional nurse practitioner, with the support and assistance of the advanced psychiatric nurse practitioner, can conduct relationship supportive sessions for the patients and their partners to prevent disruption in their relationship. The mobilisation of external resources through referrals can also be made to psychologists, psychiatrists and sexologists by the professional nurse practitioner with the assistance of the advanced psychiatric nurse practitioner and in consultation with the patients' doctors (consultative role of the advanced psychiatric nurse practitioner). Hareyan (2005:2) reports that talking to a specialist counsellor or therapist will clear up any misconceptions and help individuals to deal with the problems that develop as a result of their lack of knowledge.

Psycho-education and group therapy can be implemented as resources to provide support for the patients and their partners as well as to provide a platform for them to voice their experiences and the impact of living with erectile dysfunction on in their lives. I propose that the advanced psychiatric nurse practitioner educates the professional nurse practitioners to conduct psycho-educational groups for patients who are in chronic renal failure and on the haemodialysis programme. The patients experiencing erectile dysfunction and their partners must be encouraged to attend the psycho-educational groups where erectile dysfunction can be addressed to assist them to cope with erectile dysfunction. Psycho-educational is an approach used with patients and family care givers (partners of the participants) which emphasises the goal of increasing family stability by increasing knowledge and coping strategies (Van Reenen, et al. 2010:258).

Group therapy is a structured or semi-structured process of therapeutic intervention in which the behaviour and emotional responses of the individual members of a group towards one another are used to improve the mental health and combat the mental illness of the group members (Van Reenen, et al. 2010:246). The advanced psychiatric nurse practitioner can conduct the group therapy in the haemodialysis units or referrals can be made to outside resources for group therapy.

The professional nurse practitioners can offer supportive group sessions in the haemodialysis units and patients should be encouraged to attend these sessions where they can voice their own experiences of erectile dysfunction. The professional nurse practitioner with the support of the advanced psychiatric nurse practitioner can offer supportive sessions for the patients and their partners. The individual supportive sessions might be helpful to promote understanding of erectile dysfunction and to provide the patient and his partner with



relationship support. In this supportive relationship session the patient may feel comfortable to disclose his experiences of erectile dysfunction to his partner.

The patients and their partners can be referred to professional counselling if the need arises. Van Reenen <u>et al.</u> (2010:266) defines counselling as "helping a person to analyse interpersonal and intrapersonal patterns in order to understand and improve them". It is an interpersonal process in which one person (the counsellor) facilitates the exploration of a feeling or situation that another person (the counselee) is experiencing.

Morrow (2010:4) is of the opinion that good communication is the key to a satisfying and healthy sexual relationship. The author suggests that when couples are experiencing communication problems they should seek the help of a mediator or sex therapist. The presence of a third party in such situations can help diffuse tension and ease any difficulties the partners may have communicating their feelings to each other. Dunn's (2004:10) stance is that physicians must take into account the significance and the complexity of the couple's dynamics in the development of a treatment plan. This includes strategies to restore intimacy between the couple. The patient must include romance, time spent together outside the bedroom, foreplay and mutual caressing as these are important in restoring satisfying sexual activity. The author further states that psychological counselling has a positive effect on treatment.

In this study the alternative stories of acceptance by the two participants indicates that the implementation of some of these strategies such as kissing and hugging each other helped them to maintain a healthy relationship with their partners. In other words, the patients can be assisted to deal with their losses in an optimal way and to grow towards acceptance of their experiences of erectile dysfunction. The acceptance of living with erectile dysfunction contributed positively towards the two participants' mental health (as discussed in Chapter 3, section 3.3.2.1). Holistic nursing care provided by the professional nurse practitioner is thus required to assist the patient to maintain healthy internal and external environments (UJ, 2009:4). This will allow him to function as a human being in a relationship with himself, his family (partner), and friends.

I recommend that the recruitment of professional nurse practitioners should focus on employing nurses who have been comprehensively trained (general, psychiatry, community nursing and midwifery) for the haemodialysis units.



The renal disease management organisation that provides the haemodialysis programme has a Wellness Programme. This programme identifies people with a high risk for chronic renal failure and monitors people who are in the early stages of renal failure but do not require haemodialysis. I propose that the Wellness Programme practitioner (professional nurse practitioner) educates and encourages the patients to disclose their experiences with erectile dysfunction to the professional nurse practitioners in the haemodialysis units when they are on the haemodialysis programme. I propose a policy that a criteria for the recruitment of a Wellness Programme practitioner should include a psychiatric nursing qualification to ensure that the patients receive holistic care. The Wellness programme practitioner can facilitate the patients' mental health through identifying the patients' experiences of erectile dysfunction and providing education, support and counselling to them accordingly. The Wellness Programme is the first contact and commencement of treatment that the patient receives from the renal care provider.

As a psychiatric nurse practitioner and the deputy operations manager in KwaZulu-Natal I plan to utilise these recommendations to achieve buy-in from top management of the renal disease management organisation for implementing these recommendations for the mental health promotion of patients on the haemodialysis programme. I intend advising that the findings and recommendations be presented to top management as the organisation always strives to improve the patients' quality of lives on haemodialysis.

#### 4.4.2 Nursing education

Nursing education refers to formal learning and training in the science of nursing. This includes the functions and duties involved with the physical care of patients, and a combination of different disciplines that both accelerates the patient's return to health and helps maintain it (Nursing Education Encyclopaedia of Nursing and Allied Health, 2011:1). In this study the recommendation for nursing education pertains to professional nurse practitioners receiving training in the mental health care aspects of nursing. Nursing education will refer to the development of the professional nurse practitioners by the advanced psychiatric nurse practitioner as well as the incorporation of mental health programmes in a specific discipline, namely nephrology nursing.

Regarding nursing education, I propose a protocol that the professional nurse practitioners who are enrolled for the nephrology course in nursing must have a psychiatric nursing qualification so that the patients' mental health can be facilitated and nursing care be provided on a holistic level. However, if this suggestion is not accepted by the renal disease



management organisation training department, I propose that the advanced psychiatric nurse practitioners that are employed in the renal disease management organisation must educate the nephrology nurse practitioner to assist and support the patients experiencing erectile dysfunction with the goal of attaining holistic nursing care.

It is apparent from the findings of this study that erectile dysfunction has a negative influence on the mental health of the patients on the haemodialysis programme. Therefore I propose that the curriculum of the nephrology course must include a module on the facilitation of mental health in patients who are in chronic renal failure. This module should incorporate a plan of care to patients experiencing erectile dysfunction. The curriculum should not only focus on the physical impact of chronic renal failure, but also the psychological and social impact of the complications of chronic renal failure needs to be addressed thereby attaining holistic nursing care. Attending this course will empower professional nurse practitioners by enabling them to have a better understanding of how to implement a plan of care for patients experiencing erectile dysfunction with the aim of facilitating their mental health. This can be achieved by training the professional nurse practitioners to conduct supportive groups for the patients and their partners and implementing supportive individual sessions for them. The underlying assumption is that the professional nurse practitioners should be knowledgeable and competent in educating and assessing the patients with regard to their experiences of erectile dysfunction and take the necessary action to facilitate their mental health as an integral part of holistic nursing care.

During the orientation phase of their training the new professional nurse practitioners in the renal disease management organisation are provided with an orientation manual as a guide for their training in haemodialysis. I propose that this manual should have a module on the assessment and management of erectile dysfunction with the aim of educating the new professional nurse practitioners on erectile dysfunction. This module should be compiled by the training manager of the renal disease management organisation in liaison with me. The training manager is responsible for the compilation of the training materials for new staff and my knowledge, skills and training as an advanced psychiatric professional nurse would be required and be advantageous in this respect.

Patient education prior to experiencing erectile dysfunction and early identification of erectile dysfunction is important to enable the patients to cope with the problem. This can be achieved by educating the patients on the causes, symptoms, impact on their lives, and management of erectile dysfunction. The responsibility of educating the patients lies with the professional nurse practitioners working in the haemodialysis units. Algier and Kav



(2008:136) opine that the professional nurse practitioners can acquire the skills to deal with sexual functioning issues and thereby make appropriate referrals. I propose that the professional nurse practitioners in the haemodialysis units must firstly be educated on the impact of erectile dysfunction on the mental health of the patients who are on the haemodialysis programme and the management thereof. I therefore propose a policy on the assessment of the experiences and management of erectile dysfunction experienced by the patients on the haemodialysis programme. This should include education about the implementation of positive coping strategies by the patients with regard to their experiences of erectile dysfunction. In this study two participants and their partners accepted the participants' experiences of erectile dysfunction. The coping strategies that were implemented in this study by one participant included sleeping with his partner, cuddling, kissing and holding his partner when sleeping. These participants felt that love was more important than sex.

The education of professional nurse practitioners on managing erectile dysfunction can also be achieved through in-service education and journal clubs. The South African Pocket Oxford dictionary (2002) defines 'in-service education' as "training intended to take place during the course of employment". A journal club is when "a group of people meet to discuss and critique research reports appearing in journals and sometimes to assess the potential use of the findings in practice" (Polit & Beck, 2006:502). The advanced psychiatric nurse practitioner can play an important role in the facilitation of these two educational interventions based on her consultative and developmental roles. The professional nurse practitioners can develop an understanding regarding the importance of providing psychological support to patients as part of holistic nursing care through the attendance of the in-service education meetings and journal clubs.

Prior to the commencement of haemodialysis, patients should be educated on erectile dysfunction to encourage a comfortable relationship between the patient and the professional nurse practitioner. The aim is to encourage the patient to be comfortable in disclosing his experiences of erectile dysfunction to the professional nurse practitioner. The renal disease management organisation has undertaken to provide patients with education pamphlets on how to cope with their illness (chronic renal failure) and on dealing with the complications of haemodialysis in the three haemodialysis units included in this study. The patients should be provided with these education pamphlets. The pamphlets should contain information on the causes of erectile dysfunction, the symptoms, the impact of erectile dysfunction on their lives, and how to cope with their experiences on the physical, psychological and social dimensions. Dunn (2004:10) reports that educational pamphlets on



how to maintain an intimate relationship for the couple (patient and his partner) are needed. This includes how to communicate experiences of erectile dysfunction to each other and thus cope with erectile dysfunction. The advanced psychiatric nurse practitioner should be involved in the writing and compilation of these educational pamphlets. The advanced psychiatric nurse practitioner has the necessary training and skills to facilitate the mental health of patients who experience erectile dysfunction as an integral part of holistic nursing care.

The findings of this study and the recommendations will be presented at a National and International Renal Conference to educate professional nurse practitioners on erectile dysfunction so that they can improve the quality of the life of patients who are on a haemodialysis programme and thus facilitate the patients' mental health. This study will also be published in a relevant scientific journal as a resource for education on erectile dysfunction.

## 4.4.3 Nursing research

Polit and Beck (2006:4) defines nursing research as "a systematic inquiry designed to develop knowledge about issues of importance to nurses, including nursing practice and nursing education". In this study recommendations in nursing research will relate to further research on the patients' lived experiences of erectile dysfunction and on the haemodialysis programme.

This study was conducted in three haemodialysis units in KwaZulu-Natal. The units are managed by one total renal disease management organisation in the province. The findings revealed that the participants experienced multiple losses in their lives as a result of their experiences of erectile dysfunction. These losses were reflected in the psychological, physical and social dimensions. Studies to determine the lived experiences of the partners living with patients who are experiencing erectile dysfunction and are on the haemodialysis programme are encouraged with the aim of generating an understanding of their experiences.

The study sample consisted of nine participants. Five of the participants were Black and four were Indian. The other racial groups such as Coloureds and Whites were not included because they did not respond to the invitation to participate in this study. In this arena I suggest further studies on how race or culture affects patients' perception of erectile dysfunction.



Research is required to determine the professional nurse practitioner's skills, attitude and ability to support and assist the patients with their experiences of erectile dysfunction on the psychological, physical and social dimensions. This would identify whether the professional nurse practitioner is professionally developed to support and assist the patients who experience erectile dysfunction thereby facilitating their mental health.

Another study that is recommended is to determine the reasons why patients on the haemodialysis programme do not disclose their experiences of erectile dysfunction to the professional nurse practitioners.

In addition, the use of medications and other forms of treatment to safely assist the haemodialysis patients to attain and maintain an erection for successful intercourse needs to be addressed in a study. This will be of help to the participants in this study and accordingly patients who experience erectile dysfunction and who are on the haemodialysis programme.

I am of the opinion that this study has undeniably revealed the need for more studies to be conducted in the future related to the patients' experiences of erectile dysfunction while on the haemodialysis programme.

#### 4.5 CONCLUSION

The aim of this study was to generate an in-depth understanding of the lived experiences of patients with erectile dysfunction who were on a haemodialysis programme in three units of a renal disease management organisation KwaZulu-Natal. The research objectives, namely to explore and describe the lived experiences of patients with erectile dysfunction who were on a haemodialysis programme in three haemodialysis units of a renal disease management organisation in, and to propose recommendations to facilitate the mental health of patients with erectile dysfunction who were on a haemodialysis programme with reference to nursing practice, education and research, were met. I conducted a phenomenological study that was qualitative, explorative and contextual in nature to achieve the aim and objectives of this study.

From the findings of this study it became evident that the patients who were experiencing erectile dysfunction and who were on a haemodialysis programme endured multiple losses in the psychological, physical and social dimensions. It was thus found that the phenomenon of erectile dysfunction negatively impacts on the patients' mental health.



Although some of the participants encountered emotional discomfort when discussing their experiences of erectile dysfunction they showed great courage in disclosing their experiences of erectile dysfunction to me. This has contributed positively to this study. Moreover, there were some patients who, regardless of experiencing erectile dysfunction, had empowered themselves to cope positively with erectile dysfunction and thus maintain a healthy social relationship with their partners.



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# **ANNEXURE A**

# ETHICAL CLEARANCE FROM THE RESEARCH ETHICS COMMITTEE OF THE UNIVERSITY OF PRETORIA







## Faculty of Health Sciences Research Ethics Committee

#### 27/05/2009

Number S38/2009 Title Lived experiences of haemodialysis patients with erectile dysfunction: A

phenomenological study

Soundalay Govender, Department of Nursing Science, University of Pretoria (SUPERVISORS: Mrs E.S. Janse van Rensburg / Mrs R.G. Visagle) Investigator :

Sponsor None

Study Degree M.Cur (Psychiatric Nursing Science)

This Student Protocol has been considered by the Faculty of Health Sciences Research Ethics Committee, University of Pretoria on 26/05/2009 and found to be acceptable.

Prof AG Nienaber (female) BA (Hons) (Wits); LLB (Pretoria); LLM (Pretoria); LLD (Pretoria); Diploma in Datametrics (UNISA) Prof V.O.L. Karusseit

MBChB; MFGP (SA); M.Med (Chir); FCS (SA)
Deputy Dean: MBChB (Pretoria); MMed (Int) (Pretoria); MD (Pretoria) Prof J A Ker

Prof M Kruger

(female) MBChB.(Pretoria) M. Med.Paed.(Pretoria) M. Phil. (Applied Ethics) (Stell) PhD.(Leuven)

(Special Advisory Member)

Dr N K Likibi MBChB.; Med.Adviser (Gauteng Dept. of Health) Dr T S Marcus (female) BSc (LSE), PhD (University of Lodz, Poland) Mrs M C Nzeku (female) BSc (NUL); MSc Biochem (UCL,UK) Snr Sr J. Phatoli (female) BCur (Et.Al); BTech Oncology

Mr Y M Sikweyiya MPH (Umea University Umea, Sweden); Master Level Fellowship (Research Ethics) (Pretoria and UKZN); Post

Grad. Diploma in Health Promotion (Unitra); BSc in Health Promotion (Unitra)

Dr L Schoeman (female) BPharm (North West); BAHons (Psychology)(Pretoria); PhD (KwaZulu-Natal); International Diploma in

Research Ethics (UCT)

Dr R Sommers Deputy Chairperson: (female) MBChB; M.Med (Int); MPhar.Med Prof C W van Staden

CHAIRPERSON: MBChB (Pretoria); MMed(Psych) (Pretoria); MD (Warwick,UK); FCPsych (SA); FTCL (London);

UPLM (UNISA)

Prof TJP Swart BChD, MSc (Odont), MChD (Oral Path)

Dr AP van der Walt BChD, DGA (Pretoria)

## Student Ethics Sub-Committee

Prof R S K Apatu MBChB (Legon, UG); PhD (Cantab); PGDip International Research Ethics (UCT)

Dr A M Bergh (female) BA (RAU); BA (Hons) (Linguistics) (Stell); BA (Hons) (German) (UNISA); BEd (Pretoria); PhD (Pretoria);

Mrs N Briers (female) BSc (Stell); BSc Hons (Pretoria); MSc (Pretoria); DHETP (Pretoria)

Dr S I Cronje BA (Pretoria); BD (Pretoria); DD (Pretoria)

(female) MBChB (Pretoria); BSc (Computer Science)(Pretoria); BSc Hons (Pharm) (Potchefstroom); MpraxMed Dr M M Geyser

(Pretoria); MSc (Clinical Epidemiology) (Pretoria); FCEM (SA); Dip PEC (SA)

Prof D Millard (female) B.lur (Pretoria); LLB (Pretoria); LLM (Pretoria); AIPSA Diploma in Insolvency Law (Pretoria); LLD (UJ) BSc (Hons). Stats (Ahmadu Bello University -Nigeria); MSc (Applied Statistics (UKC United Kingdom); PhD Dr S A S Oloruniu

(Ahmadu Bello University - Nigeria)

CHAIRPERSON: (female) BPharm (North West); BAHons (Psychology)(Pretoria); PhD (KwaZulu-Natal); Dr L Schoeman

International Diploma in Research Ethics (UCT)

Dr R Sommers Deputy Chairperson (female) MBChB; M.Med (Int); MPhar.Med

DR L SCHOEMAN; BPharm, BA Hons (Psy), PhD; Dip. International Research Ethics

www

CHAIRPERSON of the Faculty of Health Sciences

Student Research Ethics Committee, University of Pretoria

DR R SOMMERS; MBChB; M.Med (Int); MPhar.Med. DEPUTY CHAIRPERSON of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

**2** 012 354 1677 P O Box 667, Pretoria, 0001

0866516047

deepeka.behari@up.ac.za

cunar

http://www.healthethics-up.co.za 31 Bophelo Road, HW Snyman South Building, Level 2, Room 2.33, Gezina, Pretoria



P O Box 256
Park Rynie
Kwa-Zulu Natal
4182

Faculty of Health Sciences Research Ethics Committee University of Pretoria 0001

Sir / Madam

## **Approval from Ethics Committee to conduct research**

I, Miss S Govender am applying for ethical approval to conduct research for Masters Degree. The topic for research is "Lived experiences of haemodialysis patients with erectile dysfunction: A phenomenological study".

The research will be conducted in three renal dialysis of a renal disease management organisation in Kwa-Zulu Natal. The participants will be the patients who are dialysing and also are experiencing erectile dysfunction.

Consent for participation will be obtained from the participants. Permission has been obtained from the renal disease management organisation. Permission is subject to the University ethical approval and approval from renal disease management organisation's medical advisor. The research policy has been signed and sent to the renal disease management organisation.



All the necessary documents and proposal are submitted to the Ethical Committee as requested.

My supervisors are: Mrs E Janse Van Rensburg Mrs R Visagie

Thanking You

Yours Sincerely

S Govender

Email-tilly.govender@mwebbiz.co.za

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# **ANNEXURE B**

# ETHICAL CLEARANCE FROM THE RENAL DISEASE MANAGEMENT ORGANISATION



### 1. POLICY RESEARCH PROJECTS

#### 1.1 Introduction

This policy will apply to all students registering for the following courses:

- B-Tech Clinical Technology
- M-Tech Clinical Technology
- D-Tech Clinical Technology

..... belief that Scientific co-operation within the company should be encouraged. Mutual research projects between the company and its employees should ensure the required transfer and gain of knowledge and expertise. The practical application of existing and new theoretical knowledge is important to solve the industrial and technological problems inherent to the industry.

This policy will also apply to employees registering for any other course that requires that research be done in the working environment.

## 1.2 Objectives

- To encourage and promote access to appropriate research opportunities.
- To ensure that all research projects are beneficial to both the individual and the company.
- To facilitate consultation, communication and co-operation between managers/supervisors and staff in identifying and addressing research needs.

### 1.3 General conditions

In considering applications for research, the Research Committee shall satisfy itself that all of the following requirements are fulfilled:

- candidates are suitably qualified to undertake research;
- candidates are embarking on viable research programmes;
- supervision is adequate and likely to be sustained;
- the research environment and facilities are suitable;
- ethical clearance will be available where appropriate.

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## 1.4 Application process

In order for the employee's research project to be considered by the company the employee must follow the following process:

- The employee must apply in writing to the research committee one (1) month prior to registering for a course that requires that a research project be submitted.
- The employee must select a topic in consultation with the study supervisor.
   The company will provide a list of approved topics to the employee.
- The employee must submit a research proposal to the committee for approval.
   The research proposal must meet the requirements of the research committee and the academic institution where the employee is registered for the course.
- The employee must submit a budget for approval by the research committee.

Any employee who fail to comply with the above requirements and procedure will not be allowed to conduct research within the company and will not be allowed access to or to utilise the companies resources and or any information sources controlled by the company.

## 1.5 Approval

Once 1.3 and 1.4 above have been complied with, registration for the course can only take place following approval of the research proposal by the Companies Research Committee. This approval requires appropriate academic judgement to be brought to bear on the viability of each research proposal. For this purpose the Research Committee is composed of persons who are or have engaged in research and who have appropriate experience of successful research degree supervision.

## 1.6 Intellectual Property

All research will remain the intellectual property of the company. Research projects and results may not be copied, duplicated in any way, presented and or published without the research committee's written approval. Such approval must be signed by all the members of the committee.

### 1.7 Confidentiality

Should you be in possession of any copies of documents which are of a confidential or otherwise sensitive nature pertaining to the Company, Products, Procedures, Systems, Facilities, Plans, etc, these must be kept confidential and must be returned to the responsible Manager on the completion of your research.



## 1.8 Information

- In terms of legal requirements in this regard, the company will makes available any records controlled by or in the possession of the company to the researcher after approval form the committee.
- Patient records will only be made available if the patient has consented to its disclosure.
- The company ensures reasonable protection of privacy (information about people), commercial confidentiality, research information, the security of the company's computer network and the company in general as well as any other information for which protection is justifiable.
- The company protects third parties (people or organizations) about whom information is requested or that are affected by information that is requested.
- The company does not provide information that could endanger the life or physical safety of an individual.
- If the provision of information could result in a material transgression of the law or an environmental risk, public interest would outweigh any damage that could be caused through the disclosure of information.
- The company maintains only relevant information that is necessary for its functioning or that must be maintained by law.
- The company reserves the right to refuse access to information in terms of existing legislation, taking into account subparagraphs above.
- The company may attach a condition of confidentiality to the disclosure of information, provided that such disclosure is in keeping with legal requirements.
- The company establishes procedures for the handling of requests for access to information.
- No one may destroy or remove information in possession of the company or have it removed, damaged, concealed or falsified with the intent of denying another individual or institution the right to access to such information.

## Agreement

I SCUNDACAY CONTROL understand and accept all conditions as outlined in the Research Policy:

Employee Signature

Date

## KWAZULU NATAL APPLICATION TO CONDUCT A STUDY

Faculty of Health Sciences Research Ethics Committee University of Pretoria Pretoria Academic Hospital Tel: 012 354 1330 / 012 354 1677

Fax: 012 3541367

E Mail: <a href="mailto:manda@med.up.ac.za">manda@med.up.ac.za</a> - Main Committee

E Mail: <a href="mailto:deepeka.behari@up.ac.za">deepeka.behari@up.ac.za</a> - Student Committee

31 Bonhelo Road, HW Snyman South Building Level 2 - Rooms 2.33 & 2.34 P O Box 667, Pretoria, 0001

RENAL DISEASE MANAGEMENT ORGANISATION	
DATE RECEIVED	
PROTOCOL NUMBER	
REPORT DUE DATE	
FILE REFERENCE	

### GENERAL INFORMATION AND AGREEMENT BY APPLICANT

APPLICANT INVESTIGATOR : Soundalay (Tilly) Govender

RENAL DISEASE MANAGEMENT ORGANISATION ETHICS

COMMITTEE INVESTIGATOR :

DESIGNATION / RANK :

TELEPHONE NO :

FAX NO :

E MAIL ADDRESS :

NAME OF COMPANY : Renal Disease Management Organisation

ADDRESS OF COMPANY :

FULL TITLE OF DISSERTATION: Lived experiences of haemodialysis patients with erectile dysfunction: A Phenomenological study.

INDICATE DATE OF COMMENCEMENT

OF STUDY :

DAY	MONTH	YEAR
	March	2008



INDICATE NUMBER	OF PATIE	:NTS IN\	VOLVED:

## AGREEMENT BY APPLICANT

- The applicant agree as follows
- To conduct the study recorded in and under the conditions set out in this application form.
- To conduct this study at no additional expense to the Renal Disease Management Organization whatsoever.
- To inform the C.E.O of the Renal Disease Management organisation should it be deemed necessary to deviate from protocol or stop this study?
- To make available without delay all the results of this study to the C.E.O of the Renal Disease Management Organization.
- I understand that the C.E.O of the Renal Disease Management Organization having allowed this study to be conducted places himself or herself or the Renal Disease Management Organization under no obligation whatsoever.

#### THE APPLICANT MUST SIGN HERE

APPLICANT- INVESTIGATOR				DATE	
Signature	Initial(s)	Surname	Day	Month	Year
	S	GOVENDER			

Designation/Rank: Registered Nurse.

## INITIAL CONSENT BY DEPARTMENTAL HEAD

Ihead of	
department of	_ in consultation with
the Chief Executive Officer of the Renal Disease Management Organ	ization grant
permission to submit an application to conduct a study to the Chairpe	rson (s) of the relevant
Ethics, Research and Therapeutic Committees of the Renal Disease	Management
Organization	



		TONIBEST	THE TA PRETORIA			
The officer conducting t	the trial/eval	uation will	l be		_	
Designation / Rank					_	
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Signature	Initial(s)		Surname	Day	Month	Year
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		THE AP	PLICANT MUST SIGN	HERE		
	INVESTIGA	ATOR			DATE	
6"	In	itial(s)	Surname	Day	Month	Year
Signature	s		Govender			
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ORGANISA HONC	HIEF EXECC	TIVE OFF	TICER.			
I	Ch	ief Execut	ive Officer of the Re	enal Diseas	e	
			e that this study be			
Haemodialysis u			<b>,</b> -		-	
•	•					
The officer condu	ucting the tria	l will be: S	Govender			
RENAL DISEASE MANAGEMENT ORGANISATION C.E.O.				DAT	_	
ORGA			SCIVICIN I		DAT	E
Signature	ANISATION		Surname	Day	Month	

ORGA	NISATION C.E.O.				
Signature	Initial(s)	Surname	Day	Month	Year



# **ANNEXURE C**

## **DECLARATION OF HELSINKI**



## WORLD MEDICAL ASSOCIATION DECLARATION OF HELSINKI Ethical Principles for Medical Research Involving Human Subjects

Adopted by the 18th WMA General Assembly, Helsinki, Finland, June 1964, and amended by the:

29th WMA General Assembly, Tokyo, Japan, October 1975

35th WMA General Assembly, Venice, Italy, October 1983

41st WMA General Assembly, Hong Kong, September 1989

48th WMA General Assembly, Somerset West, Republic of South Africa, October 1996

52nd WMA General Assembly, Edinburgh, Scotland, October 2000

53rd WMA General Assembly, Washington 2002 (Note of Clarification on paragraph 29 added)

55th WMA General Assembly, Tokyo 2004 (Note of Clarification on Paragraph 30 added)

59th WMA General Assembly, Seoul, October 2008

#### A. INTRODUCTION

 The World Medical Association (WMA) has developed the Declaration of Helsinki as a statement of ethical principles for medical research involving human subjects, including research on identifiable human material and data.

The Declaration is intended to be read as a whole and each of its constituent paragraphs should not be applied without consideration of all other relevant paragraphs.

- Although the Declaration is addressed primarily to physicians, the WMA encourages
  other participants in medical research involving human subjects to adopt these
  principles.
- It is the duty of the physician to promote and safeguard the health of patients, including
  those who are involved in medical research. The physician's knowledge and conscience
  are dedicated to the fulfilment of this duty.
- 4. The Declaration of Geneva of the WMA binds the physician with the words, "The health of my patient will be my first consideration," and the International Code of Medical Ethics declares that, "A physician shall act in the patient's best interest when providing medical care."
- Medical progress is based on research that ultimately must include studies involving human subjects. Populations that are underrepresented in medical research should be provided appropriate access to participation in research.
- 6. In medical research involving human subjects, the well-being of the individual research subject must take precedence over all other interests.
- 7. The primary purpose of medical research involving human subjects is to understand the causes, development and effects of diseases and improve preventive, diagnostic and therapeutic interventions (methods, procedures and treatments). Even the best current interventions must be evaluated continually through research for their safety, effectiveness, efficiency, accessibility and quality.
- In medical practice and in medical research, most interventions involve risks and burdens.



- 9. Medical research is subject to ethical standards that promote respect for all human subjects and protect their health and rights. Some research populations are particularly vulnerable and need special protection. These include those who cannot give or refuse consent for themselves and those who may be vulnerable to coercion or undue influence.
- 10. Physicians should consider the ethical, legal and regulatory norms and standards for research involving human subjects in their own countries as well as applicable international norms and standards. No national or international ethical, legal or regulatory requirement should reduce or eliminate any of the protections for research subjects set forth in this Declaration.

#### B. PRINCIPLES FOR ALL MEDICAL RESEARCH

- 11. It is the duty of physicians who participate in medical research to protect the life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information of research subjects.
- 12. Medical research involving human subjects must conform to generally accepted scientific principles, be based on a thorough knowledge of the scientific literature, other relevant sources of information, and adequate laboratory and, as appropriate, animal experimentation. The welfare of animals used for research must be respected.
- 13. Appropriate caution must be exercised in the conduct of medical research that may harm the environment.
- 14. The design and performance of each research study involving human subjects must be clearly described in a research protocol. The protocol should contain a statement of the ethical considerations involved and should indicate how the principles in this Declaration have been addressed. The protocol should include information regarding funding, sponsors, institutional affiliations, other potential conflicts of interest, incentives for subjects and provisions for treating and/or compensating subjects who are harmed as a consequence of participation in the research study. The protocol should describe arrangements for post-study access by study subjects to interventions identified as beneficial in the study or access to other appropriate care or benefits.
- 15. The research protocol must be submitted for consideration, comment, guidance and approval to a research ethics committee before the study begins. This committee must be independent of the researcher, the sponsor and any other undue influence. It must take into consideration the laws and regulations of the country or countries in which the research is to be performed as well as applicable international norms and standards but these must not be allowed to reduce or eliminate any of the protections for research subjects set forth in this Declaration. The committee must have the right to monitor ongoing studies. The researcher must provide monitoring information to the committee, especially information about any serious adverse events. No change to the protocol may be made without consideration and approval by the committee.
- 16. Medical research involving human subjects must be conducted only by individuals with the appropriate scientific training and qualifications. Research on patients or healthy



volunteers requires the supervision of a competent and appropriately qualified physician or other health care professional. The responsibility for the protection of research subjects must always rest with the physician or other health care professional and never the research subjects, even though they have given consent.

- 17. Medical research involving a disadvantaged or vulnerable population or community is only justified if the research is responsive to the health needs and priorities of this population or community and if there is a reasonable likelihood that this population or community stands to benefit from the results of the research.
- 18. Every medical research study involving human subjects must be preceded by careful assessment of predictable risks and burdens to the individuals and communities involved in the research in comparison with foreseeable benefits to them and to other individuals or communities affected by the condition under investigation.
- 19. Every clinical trial must be registered in a publicly accessible database before recruitment of the first subject.
- 20. Physicians may not participate in a research study involving human subjects unless they are confident that the risks involved have been adequately assessed and can be satisfactorily managed. Physicians must immediately stop a study when the risks are found to outweigh the potential benefits or when there is conclusive proof of positive and beneficial results.
- Medical research involving human subjects may only be conducted if the importance of the objective outweighs the inherent risks and burdens to the research subjects.
- 22. Participation by competent individuals as subjects in medical research must be voluntary. Although it may be appropriate to consult family members or community leaders, no competent individual may be enrolled in a research study unless he or she freely agrees.
- 23. Every precaution must be taken to protect the privacy of research subjects and the confidentiality of their personal information and to minimize the impact of the study on their physical, mental and social integrity.
- 24. In medical research involving competent human subjects, each potential subject must be adequately informed of the aims, methods, sources of funding, any possible conflicts of interest, institutional affiliations of the researcher, the anticipated benefits and potential risks of the study and the discomfort it may entail, and any other relevant aspects of the study. The potential subject must be informed of the right to refuse to participate in the study or to withdraw consent to participate at any time without reprisal. Special attention should be given to the specific information needs of individual potential subjects as well as to the methods used to deliver the information. After ensuring that the potential subject has understood the information, the physician or another appropriately qualified individual must then seek the potential subject's freely-given informed consent, preferably in writing. If the consent cannot be expressed in writing, the non-written consent must be formally documented and witnessed.



- 25. For medical research using identifiable human material or data, physicians must normally seek consent for the collection, analysis, storage and/or reuse. There may be situations where consent would be impossible or impractical to obtain for such research or would pose a threat to the validity of the research. In such situations the research may be done only after consideration and approval of a research ethics committee.
- 26. When seeking informed consent for participation in a research study the physician should be particularly cautious if the potential subject is in a dependent relationship with the physician or may consent under duress. In such situations the informed consent should be sought by an appropriately qualified individual who is completely independent of this relationship.
- 27. For a potential research subject who is incompetent, the physician must seek informed consent from the legally authorized representative. These individuals must not be included in a research study that has no likelihood of benefit for them unless it is intended to promote the health of the population represented by the potential subject, the research cannot instead be performed with competent persons, and the research entails only minimal risk and minimal burden.
- 28. When a potential research subject who is deemed incompetent is able to give assent to decisions about participation in research, the physician must seek that assent in addition to the consent of the legally authorized representative. The potential subject's dissent should be respected.
- 29. Research involving subjects who are physically or mentally incapable of giving consent, for example, unconscious patients, may be done only if the physical or mental condition that prevents giving informed consent is a necessary characteristic of the research population. In such circumstances the physician should seek informed consent from the legally authorized representative. If no such representative is available and if the research cannot be delayed, the study may proceed without informed consent provided that the specific reasons for involving subjects with a condition that renders them unable to give informed consent have been stated in the research protocol and the study has been approved by a research ethics committee. Consent to remain in the research should be obtained as soon as possible from the subject or a legally authorized representative.
- 30. Authors, editors and publishers all have ethical obligations with regard to the publication of the results of research. Authors have a duty to make publicly available the results of their research on human subjects and are accountable for the completeness and accuracy of their reports. They should adhere to accepted guidelines for ethical reporting. Negative and inconclusive as well as positive results should be published or otherwise made publicly available. Sources of funding, institutional affiliations and conflicts of interest should be declared in the publication. Reports of research not in accordance with the principles of this Declaration should not be accepted for publication.



# C. ADDITIONAL PRINCIPLES FOR MEDICAL RESEARCH COMBINED WITH MEDICAL CARE

- 31. The physician may combine medical research with medical care only to the extent that the research is justified by its potential preventive, diagnostic or therapeutic value and if the physician has good reason to believe that participation in the research study will not adversely affect the health of the patients who serve as research subjects.
- 32. The benefits, risks, burdens and effectiveness of a new intervention must be tested against those of the best current proven intervention, except in the following circumstances:
  - The use of placebo, or no treatment, is acceptable in studies where no current proven intervention exists; or
  - Where for compelling and scientifically sound methodological reasons the use of placebo is necessary to determine the efficacy or safety of an intervention and the patients who receive placebo or no treatment will not be subject to any risk of serious or irreversible harm. Extreme care must be taken to avoid abuse of this option.
- 33. At the conclusion of the study, patients entered into the study are entitled to be informed about the outcome of the study and to share any benefits that result from it, for example, access to interventions identified as beneficial in the study or to other appropriate care or benefits.
- 34. The physician must fully inform the patient which aspects of the care are related to the research. The refusal of a patient to participate in a study or the patient's decision to withdraw from the study must never interfere with the patient-physician relationship.
- 35. In the treatment of a patient, where proven interventions do not exist or have been ineffective, the physician, after seeking expert advice, with informed consent from the patient or a legally authorized representative, may use an unproven intervention if in the physician's judgement it offers hope of saving life, re-establishing health or alleviating suffering. Where possible, this intervention should be made the object of research, designed to evaluate its safety and efficacy. In all cases, new information should be recorded and, where appropriate, made publicly available.



# **ANNEXURE D**

## PARTICIPANT INFORMATION LEAFLET



## PARTICIPANT'S INFORMATION LEAFLET AND INFORMED CONSENT FORM FOR CLINICAL STUDY

TITLE OF STUDY: The lived experiences of haemodialysis patients with erectile dysfunction: A phenomenological study.

**Dear participant** 

## 1. INTRODUCTION

You are invited to volunteer for a research study. This information leaflet is to help you to decide if you would like to participate in the study. Before you agree to take part in this study you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the researcher. You should not agree to take part unless you are completely happy about all the procedures involved.

### 2. THE NATURE AND PURPOSE OF THIS STUDY

The goals of this study are to explore and describe your thoughts and feelings about your experiences with erectile dysfunction which is the inability to have and maintain an erection while you are on the haemodialysis programme in Kwa-Zulu Natal. Haemodialysis is the procedure to remove the waste materials from your body through an artificial kidney. The researcher wishes to learn more about your experiences of living with erectile dysfunction. A deeper understanding of your experience will result in knowledge to propose recommendations to assist in maintaining the mental health of patients with erectile dysfunction who are on a haemodialysis programme in Kwa-Zulu Natal with reference to nursing practice, education and research. You have specifically been selected for participation in this research study based on the contribution that is received from you about your experience of living with erectile dysfunction.

## 3. EXPLANATION OF PROCEDURES TO BE FOLLOWED

This study involves participating in an interview, describing your experiences of living with erectile dysfunction, as well as writing a brief story on your experience. This interview will last for approximately 60 minutes and will be audio taped with your consent for verification of the transcriptions from the interviews. The two broad questions that will be asked are:



- 1. What are your thoughts and feelings about your experiences with erectile dysfunction?
- 2. What is the overall essence of this experience?

You will also be requested to answer the central question in the form of a short story or essay, namely: Write a story on living with erectile dysfunction.

## 4. RISKS AND DISCOMFORT INVOLVED

No permanent risks are foreseen. It is possible that you might experience emotional discomfort while sharing your experiences of living with erectile dysfunction. Should you experience emotional discomfort while sharing your experiences; the researcher will schedule an individual supportive interview with you. During this session your emotional discomfort will be explored and discussed in order to generate emotional support for yourself. If required, the researcher will make appropriate referrals to specialists including nephrologists, mental health care practitioners, urologists and other support groups and men's health clinics to facilitate your mental health.

#### 5. POSSIBLE BENEFITS OF THIS STUDY

Participation in this study will give you the opportunity to share your experiences of living with erectile dysfunction in a safe environment. Your contribution can benefit yourself and other patients on the haemodialysis programme by the implementation of the proposed recommendations. A long term advantage is that your contribution might help to facilitate the mental health of haemodialysis patients with erectile dysfunction who are on the haemodialysis programme. I undertake to provide you with a summary of the results and outcome of the study once the study is completed.

#### 6. 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 study / interview / activity without giving any reason. Your withdrawal will not affect you or your treatment in any way.

### 7. 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 University of Pretoria and National Renal care. A copy of the approved letters are available if you wish to have them. The study has been structured in accordance with the Declaration of Helsinki (last update: October 2008), which deals with the recommendations guiding doctors in biomedical research involving human / subjects. A copy of the Declaration may be obtained from the researcher should you wish to review it.



### 8. INFORMATION AND CONTACT PERSON

The contact persons for the study are:

The researcher – Ms S Govender at 083 XXX XXX

The supervisor – Mrs E Janse Van Rensburg at 082 XXX XXX

The co-supervisor – Mrs R Visagie at 082 XXX XXX

If you have any questions about the study please contact any of the above persons.

### 9. COMPENSATION

Your participation is voluntary. No compensation will be given for your participation in the study.

### 10. CONFIDENTIALITY

All records obtained whilst in this study will be regarded as confidential. Once we have analysed the information no one will be able to identify you. Additionally, the person transcribing the interviews and the independent research coder will both sign confidentiality clauses to ensure that information remains strictly confidential. Research reports and articles in scientific journals will not include any information that may identify you or your dialysis unit.



## PARTICIPANT INFORMED CONSENT

## **CONSENT TO PARTICIPATE IN THIS STUDY**

I confirm that the person asking my consent to take part in this study has told me about the nature, process, risks, discomforts and benefits 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 objections 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 my treatment in any way.

I have received a signed copy of this informed cons	ent agreement.
Participant's name :	.(Please print)
Participant's signature:	Date
Investigator's name	. (Please print)
Investigator's signature	Date
Witness's Name:	(Please print)
Witness's signatures	.Date

## **VERBAL INFORMED CONSENT**

I, the undersigned, have read and have fully explained the participant information leaflet, which explains the nature, process, risks, discomforts and benefits of the study to the participant whom I have asked to participate in the study. The participant indicates that he understands that the results of the study, including personal details regarding the interview will be anonymously processed into a research report. The participant indicates that he has had time to ask questions and has no objection to participate in the interview. He understands that there is no penalty should he wish to discontinue with the study and his withdrawal will not affect any treatment in any way.

I hereby certify that the patient has agreed to p	articipate in this study.
Participant's Name :	(Please print)
Person seeking consent :	(Please print)
Signature:	Date
Witness's name :	(Please print)
Signature:	Date



# **ANNEXURE F**

## LIST OF CODES BY INDEPENDENT CODER



## **Analysis:**

# Lived experiences of haemodialysis patients with erectile dysfunction: a phenomenological study by T Govender Independent coder: Charlotte Engelbrecht 28 Jan 2010

RELATIONSHIP	IDENTITY	CULTURE	PHYSICAL EXPERIENCE	PSYCHOLOGICAL EXPERIENCE	COPING
Intimacy: Intimacy: Initiating sex with partner (Part 2 p 2 line 14-19) Initiating sex by partner (Part 2 p 2 line 25-26) Loss of sexual fulfillment Intimacy: Intitating sex by partner (Part 2 p 2 line 25-26) Loss of sexual fulfillment Intitating sex by partner (Part 2 p 2 line 30-32) Intitating partners needs Intitating partner	Being man  incompleteness (part.2 p 3 line 26)  imanly duties' (part.2 p 3 line 28)  Not man enough (part.2 p5 line 9) (part.8p4 line 25) (part.11p2 line 22)  failure (part.6p 1 line 1) (part.6p3 line 19-20) (part.6p9 line 21) (part.6p10 line 26) (part.8p4 line 18)  manhood (part.6p10 line 18, 20-21) (part.7p2 line 16-17)  not a man at all (part.7p2 line 13) (part.7p2 line 21)  being just like a woman (part.7p2 line 28)	Taboo  Talking about sexual functioning with partner / outsider (part.2 p 2 line 12-13) (part.11p4 line 30)  Traditional healing/medication  Muties (part.6p 1 line 12-14)  rectifying unfaithfulness in relationship (part.6p6 line 3-8)  Danger (part.6p 1 line 14-19) (part.8p4 line 9-11)  Communial relationships  Stigma (part.6p11 line 12-14) (part.6p11 line 19-21)  she can't experience relating to other women	Before  • high sexual activity	PSYCHOLOGICAL EXPERIENCE  THOUGHTS  Understanding self (part.2 p 3 line 10-12)  Questioning (part.6 p4 line 29-30) (part.6p9 line 27) brooding (part.8p3 line 22-23) guessing (part.2 p 5 line 9-11) Age influence acceptance (part.4 p4 line 22-24) (part.4 p5 line 15-26) (part.5 p1 line 19-21) (part.5 p2 line 13-14, 18) not thinking of sex (part.4 p8 line 23-27) Altruism (part.4 p8 line 23-27) will be right again (part.6p2 line 29-31)	Emotional coping mechanisms  Anger management (part.3 p 2 line 4-6)  got used to it (part.4 p2 line 20)  insight (part.4 p3 line 17)  hope of treatment (part.4 p3 line 18) (part.4 p5 line 28) (part.4 p5 line 28) (part.4 p8 line 1-3) (part.6p 1 line 22-23) (part.7p5 line 1-2) (part.8p1 line 20-21) (part.11p2 line 16-17)  Acceptance (part.4 p6 line 23-25)  not looking for sex (part.5 p3 line 15)  Need to talk to someone knowing confidentiality is honoured (part.6p7 line 14-16)
<ul> <li>Art of sexual efficiency (part.6p9 line 9-10,11-13)</li> <li>deteriorating relationship</li> </ul>	Personhood  Not the same person	(part.7p2 line 21-24) World view/assumption	• no control (part.10 p1 line 13-15)	Verbal expression (Discussion)	Appreciating suggestion to go for couple



(part.7p5 line 17-19)	(part.3 p 3 line21-25)	Sexuality	results in conflict	With partner	therapy/counceling
<ul> <li>strain in relationship</li> </ul>	<ul> <li>right to be seen</li> </ul>	<ul> <li>intercourse is eighty</li> </ul>	(part.11p4 line 18-19)	See communication in relationship	(part.7p9 line 17)
(part.7p6 line 8-12)	as adult	percent psychological		Health professional	(part.8p6 line 18-19)
<ul> <li>not setting it right</li> </ul>	(part.6p11 line 19-21)	(part.2 p 4 line 12)	Effects of dialysis	o doctor	<ul> <li>Kindness</li> </ul>
(part.8p1 line 15)		<ul> <li>she will look someone</li> </ul>	very tired	(part.3 p 5 line 13)	(part.8p3 line 3)
leaving her on	Husband and wife	else if I cannot fulfil in	(part.3 p 3 line 19)	(part.4 p2 line6)	Men's clinic(support
(part.8p1 line 15)	(part.5 p1 line 26-28)	her needs	(part.8p2 line 22)	(part.6p3 line 21)	group)
like to be with her	(part.6p3 line 10-11)	(part.3 p 2 line 17-18)	<ul> <li>restlessness</li> </ul>		(part.11p5 line 1-3)
(part.8p1 line 26)		<ul> <li>Old age don't need</li> </ul>	(part.8p2 line 22)	o nurse	
• touch	Note: where couple	the sex	drained out	(part.6p3 line 21)	Intimate alternatives
(part.8p3 line 13)	discussed condition	(part.5 p1 line 26-28)	(part.3 p 3 line 19)	(part.6p6 line 226-28)	to intercourse
making apologies	and the relationship is	(part.5 p2 line 13-14, 18)	,	Friend	<ul> <li>Sleeping together</li> </ul>
(part.8p4 line 4-5)	loving, there is very	<ul> <li>love is more</li> </ul>	Permanent	<ul> <li>gossiping</li> </ul>	(part.3 p 2 line 10-
The relationship is suffering	little identity issues by	important than sex	<ul> <li>problem as renal patient</li> </ul>	(part.6p4 line 6-9)	11)
(part.11p4 line 12-13)	the male partner	(part.5 p2 line 4-5)	(part.2 p 4 line 2)	Other patients	(part.5 p21 line2)
,,		(part.5 p3 line 29-31)		(part.11p5 line 6-10)	<ul> <li>Holding</li> </ul>
Gender roles and responsibilities		<ul> <li>Dysfunctional</li> </ul>	Other physical problems related	(part.11p5line 13-19)	(part.3 p 2 line 10)
<ul> <li>not fulfilling manly duties</li> </ul>		erection part of a	to	None	(part.5 p2 line 4)
(part.2 p 3 line 27-28)		natural course	Blood pressure problem	(part.2 p 4 line 5)	<ul> <li>Cuddle</li> </ul>
, ,		(part.5 p3 line 23)	(part.2 p 3 line 11)	(part.8p8 line 9)	(part.5 p2 line 4)
Communication:		<ul> <li>a man must be good</li> </ul>	<ul> <li>psychological state of mind</li> </ul>	(part.10p2 line 27)	Family relationship
<ul> <li>Emotional reaction limits</li> </ul>		in everything	(part.2 p 4 line 8-11, 17)	(part.11p4 line 30)	<ul> <li>Support from</li> </ul>
communication		(part.6p11line 1-6)	<ul> <li>work stress/financial worry</li> </ul>	<ul><li>keep it to myself</li></ul>	children
(part.2 p 2 line 27-28)		<ul> <li>women are married</li> </ul>	(part.3 p 1 line 22-25)	(part.3 p 3 line 28-31)	(part.3 p 4 line 13-15)
<ul> <li>erectyle functioning dicussed</li> </ul>		because of sex	stent	o no one I can trust	<ul> <li>Family members</li> </ul>
with partner		(part.7p1 line 24)	(part.3 p 4 line 27)	(part.6p3 line 20-21,22)	supporting each
(part.4 p3 line 19-23)		<ul> <li>erectyle disfunction is</li> </ul>	• pain	(part.11p5line 22-24)	other
(part.4 p4line 2-3)		related to	(part.3 p 4 line 27-28)		(part.3 p 4 line 15-17)
(part.7p3 line 5)		unfaithfulness	<ul> <li>disurea</li> </ul>	FEELINGS	Self
(part.8p3 line 8-11)		(part.11p1 line 7-8, 10-11)	(part.3 p 5 line 1)	Physical performance/illness	Care
(part.8p7 line 1)		(part.11p5 line 14-17)	Age	worried	(part.3 p5 line 8)
(part.11p2 line 13-14)		<ul> <li>sex important for</li> </ul>	(part.4 p4 line 22-23)	(part 2,p2,line 23)	Healthy life style
<ul> <li>hope for right time</li> </ul>		quality of life	(part.4 p5 line 2-3)	(part.3 p 3 line 3)	(part.5 p3 line 27-28)
(part.2 p 3 line 20)		(part.11p3 line 23)	Diabetes	(part.3 p 4 line 28)	<ul> <li>Avoid creating a</li> </ul>
<ul> <li>not discussed</li> </ul>			(part.4 p8 line 18-19)	(part.6 p1 line 11)	problem
(part.2 p 3 line 21-22)				(part.6p2 line 6-7, 12)	(part.4 p7 line 18-20)
(part.10p3 line 28-29)			Medication	(part.6p3 line 3-4)	• console
			<ul> <li>Influence kidneys</li> </ul>	(part.7p4 line 1-3)	(part.6p2 line 18-21)



Partner behaviour:	(part.4 p2 line 7)	(part.8p2 line 14)	Medicating
Accomodative	Not working	(part.8p2 line 24-25)	(part.5 p1 line 20)
(part.2 p 3 line 18)	(part.4 p3 line 4)	(part.8p3 line 17-19)	(part.5 p3 line 15-17)
understanding	<ul> <li>possible danger</li> </ul>	(part.11p2 line 12-13)	(part.6p2 line 8-10)
(part.2 p 3 line 19)	(part.5 p3 line 24-27)	<ul> <li>losing feeling</li> </ul>	(part.8p5 line 17-19)
(part.3 p 1 line 18)	, ,	(part.4 p3 line 3)	(part.11p1 line 26-27, p2
Support	Libido	<ul> <li>frustration</li> </ul>	line 1)
(part.3 p 1 line 119-20)	• lost	(part 2,p2,line 25)	
(part.6p4 line 19-20)	(part.4 p3 line 5-6)	(part.3 p 2 line 3)	
working(providing income)		(part.7p1 line 10-11)	
(part.3 p 1 line 26)		<ul> <li>Calming down</li> </ul>	
no pressure		(part.2 p 3 line 7)	
(part.2 p 3 line 19)		<ul> <li>Irritated</li> </ul>	
Waiting for him to discuss		(part.2 p 3 line 10)	
(part.2 p 5 line 15-17)		<ul> <li>stressful</li> </ul>	
potential finding someone else		(part.2 p 3 line 14-15)	
to satisfy her		<ul> <li>unhappy</li> </ul>	
(part.3 p 2 line 19-20)		(part.3 p 1 line 27)	
(part.5 p2 line 11-12)		(part.8p4 line 3-4)	
(part.6p5 line 21-25)		<ul><li>anger</li></ul>	
Worries		(part.3 p 2 line 4)	
(part.3 p 5 line 10-11)		(part.7p1 line 16-17)	
Not speaking		(part.7p2 line 4)	
(part.4 p2 line 12)		(part.8p3 line 5)	
(part.4 p6 line 4-5)		(part.10p2 line 3)	
Accepts		(part.11p 6line 18-19)	
(part.5 p1 line 21)		o selfdirected	
(part.6p2 line 17)		(part.7p1 line 19-20)	
• Fine		(part.7p2 line 4)	
(part.5 p2 line 7-8)		(part.11p3 line 11-12,16)	
posibility to run away		• fear	
(part.6p 1 line 12-14)		o loosing her	
patience		(part.3 p 2 line 18)	
(part.6p2 line 3-4)		(part.3 p 4 line 6)	
like a sister		(part.6 p 1 line 11-12)	
(part.7p1 line 20)		(part.6p3 line 3-4)	
Not feeling well		(part.6p5 line 21-25)	
(part.7p1 line 21)		(part.8p2 line 1-2)	



angn/	(nort 11n2 line 10 01)
o angry	(part.11p3 line 19-21)
(part.7p2 line 24)	o divorce
for elected	(part.7p6 line 1-3)
o frustrated	o driving her away
(part.7p1 line 25-26)	(part.3 p 2 line 22)
changed behaviour	o touching her
(displaying)	(part.8p1 line 25-27)
(part.7p7 line 21-23)	Scared
upset	(part.3 p 4 line 26)
(part.8p5 line 6)	● Bad
distrust	(part.4 p2 line 1)
(part.11p1 line 7-8, 10-11)	(part.7p2 line 4)
<ul> <li>not understanding</li> </ul>	(part.10p1 line 19)
(part.11p2 line 14)	● Happy
(part.11p7 line 30)	(part.5 p1 line 21)
expecting something	Embarrased
(part.11p7 line 27-28)	(part.6p3 line 19-20)
,	(part.6p4 line 9)
Quality of relationship	• Upset
Good	(part.6p5 line 20-30)
(part.4 p4 line 27-31)	• distrust
Understanding	(part.6p6 line 19-23)
(part.2 p 3 line 19)	young (inadequate)
(part.3 p 1 line 18)	(part.6p11 line 19)
(part.3 p 2 line 20-21)	Desperation
(part.4 p2 line 2)	(part.7p3 line 5-8)
o mutual	(part.7p7 line 1)
(part.4 p2 line 20)	• rejection
length of marriage	(part.7p4 line 6)
(part.4 p2 line 1)	• hopeless
(part.4 p6 line 8-9)	(part.7p6 line 5)
Age of both pt and partner	• suicidal
(part.4 p4 line 14-20,23)	(part.7p8 line 8-9)
(part.10p1 line 21-24)	
(part.11p3 line21- 22)	● pain (part.7p8line 11-19)
(part.11p4 line 24-26)	
Maturity	• sad
(part.4 p3 line 25-27)	(part.8p1 line 18)
(part. + po line 20-21)	(part.8p3 line 22-23)



(part.5 p1 line 26-28)	ashamed
(part.5 p2 line 13-14, 18)	(part.10p2 line 13-18)
(part.5 p3 line 1-5)	• selfblame
Waiting	
(part.2 p 5 line 15-17)	(part.11p3 line 30-31, p4 line 1-3)
Previous	Loss
relationships/marriages	part of normal life
(part.3 p 2 line 25-31)	
	(part.4 p7 3-4)
• communication	berievement
(part.3 p 2 line 24-25)	o sadness
(part.3 p 3 line 29-31)	(part.4 p6 line 27-28)
(part.4 p3 line 2)	o stage-acceptance
o uncertainty	(part.2 p 3 line 5-6)
(part.4 p2 line 11-12)	(part.4 p2 line 23-24)
together and in peace	(part.4 p2 line 20)
(part.6p 1 line 20-21)	(part.4 p5 line 2-11)
Trust	manhood
(part.6 p 5 line 21-25)	o anger
(part.8p2 line 5-7,10-12)	(part.7p2 line 29-30)
Satisfying my wifes needs	(part.7p3 line 1)
(part.7p3 line 19-21)\	lost intimacy
• faithfulness	(part.7p4 line 5-6)
(part.7p3 line 23-26)	(part.7p4 line 13-15)
Relationship not strong	
(part.11p1 line 16-17)	Identity
• conflict	incompleteness
(part.11p2 line 6-9)	(part.2 p 3 line 26)
• tension	• useless
(part.11p6line 3-4)	(part.2 p 3 line 27)
(part. 1 pointe 3-4)	• longing to a man again
	(part.7p6 line 29-30)
	WILL
	loss of control
	(part 2,p2,line5-9)
	(part 2,p2,line14-16)
	• loosing interest
	(part.2 p 5 line 21-22)
	lost confidence



		/nort Cn10 line 01 0C)	
		(part.6p10 line 21-26)	
		11 /	

Saturation was reached in the data collected.



# **ANNEXURE G**

## PATIENT HANDOUT FOR PARTICIPATION



## **Dear Patient**

Renal Failure can cause erectile dysfunction.

A study will be conducted to identify the effects of erectile dysfunction on you and your partner.

If you have experienced erectile dysfunction or are experiencing erectile dysfunction, please contact Tilly Govender.

There will be no cost incurred to you and this will be handled in confidence.

Thank You

Tilly Govender 083 XXX XXX



# **ANNEXURE H**

## PATIENT HANDOUT FOR APPOINTMENT DATE AND TIME



## Dear Mr

# Re: Research on LIVED EXPERIENCES OF HAEMODIALYSIS PATIENTS WITH ERECTILE DYSFUNCTION: A PHENOMENOLOGICAL STUDY

I have scheduled your interview with me for the 17<sup>th</sup> November, after your dialysis session.

I hope that this is not an inconvenience to you as this is the date that I could take leave to do the interview.

Thank you for your time. Much appreciated.

Yours truly Tilly Govender 16/10/2009



# **ANNEXURE I**

# **EXAMPLE OF TRANSCRIBED PHENOMENOLOGICAL INTERVIEW**



# PATIENT 6

# **Duration: 28:04 minutes**

Interviewer	Good afternoon. I'm interviewing patient number six for the research of		
	the lived experiences of haemodialysis patients with erectile dysfunction.		
	I have explained to you about the patient information leaflet and informed		
	consent for clinical study. The entire leaflet was explained to you about		
	the reason why we're doing the research, to the time for the interview and		
	also for the outcome of the interview, how will it benefit you. What I		
	basically want to find out is when you are unablewhen you have		
	erectile dysfunction, how does it affect you? What are your feelings and		
	your experiences during that time? If you can explain that for me.		
Participant	I feel so worried. I think that she will be thinking about somebody else		
	who is going to satisfy her. So, according to our culture there are some		
	muties we use todrink to make us strong. I think about that; going to		
	those people. But as far as I'm concerned or as far as I know, that will		
	lead to having a lot of fluid in my body which is not desirable for dialysis –		
	for somebody who's having this problem. Because it's called 'imbiza';		
imbiza you must take about two-hundred mills sometimes.			
	works, it will make you strong, but for this reason I'm saying that I have		
	renal failure and I can't do that. I don't do it. That's the only thing. But		
	for now I've got a wife who knows my problem, we are still together and		
	we are in peace. I don't know what will happen when time goes on.		
	Because maybe, as I've said to you, it's a matter of one to three days, the		
	fourth-fifth day I become all right. Maybe by 2010 I'll be a total failure. I		
	don't know, she'll run away.		
Interviewer	Ok, you mean that sometimes when you are with your wife it works and		
	then it doesn't work?		
Participant	Yes, it's off and on.		
Interviewer	Ok, so when it doesn't work, how do you feel? Because now your wife is		
	waiting for you, how does it make you feel?		
Participant By that particular one, she knows. She will say: "Ok, never m			
	see tomorrow".		
Interviewer	And then that happens?		
Participant	But I won't just fall asleep at that moment, I will just lie thinking 'what will		
	happen? What should I do?' Ok, to tell you the truth, there are times		
	•		

	when I will go to the chemist and buy those tablets - special ones - I			
	think you know them. Even though I don't like them. I was not born with			
	it			
Interviewer	Have you used it?			
Participant	Yes. But I don't want to depend on them.			
Interviewer	Ok, so when you find that you are unable to satisfy your wife, how does it			
	make you feel? You said that you will lie there and you think, what do			
	you think about?			
Participant	I don't know what to say if she didn't admit that it'sor accepted that it is			
	a problem. But now, because she knows and have accepted it, I don't			
	think further. I just console myself and say that as it is coming from her to			
	say: "Ok, we will see tomorrow" I get satisfied and then comfortable. And			
	then I know really that tomorrow or the other tomorrow I will be all right			
	and then she will get satisfied and I'm happy.			
Interviewer	Ok, so the next day when it doesn't work again, how do you feel?			
Participant	Nothing much to say. It will go back to the same thoughts.			
Interviewer	What thoughts? What thoughts?			
Participant	To say maybe after three days it will come back again.			
Interviewer Ok, do you have any negative feelings, or are you comfortal				
	what's happening at that time?			
Participant	I'm not comfortable.			
Interviewer	What goes through your mind at that time?			
Participant Steps to be taken. I think what should I do but at that time there				
	any solution.			
Interviewer	So what is yourwhat are you worried about the most with this - what			
you are suffering from – the problem that you have; what are y				
	about most?			
Participant	To be left by my wife.			
Interviewer	er Ok, so that worries you?			
Participant	Yes.			
Interviewer	It's a big concern?			
Participant	Yes.			
Interviewer	Ok, and anything else that worries you about the problem?			
Participant	We are talking about something which is for two persons in bed at night,			
	that is me and my wife, no one else. It ends there. Apart from that			
	nothing else worries me. So I want, if there are some ways to help me to			

	satisfy her, that will be the thing and it will end there. Really, if I don't give			
	you what you wanted, it will be because I didn't know what you want.			
Interviewer	Ok, is there any other feelings that go through your mind or any			
	experiences when you want to try and satisfy your wife but you can't,			
	goes through your mind? Is there anything?			
Participant	I will say yes, but no. Because to be a sex-man failure is embarrassing. I			
	could feel that I can tell this to no one else but someone to trust; a nurse			
	first of all or a doctor if I want to be assisted. But for the time being I			
	couldn't ask for any assistance.			
Interviewer	You never asked for assistance?			
Participant	No.			
Interviewer	Ok. And have you spoken to your wife about it?			
Participant	To do what?			
Interviewer	Have you spoken to your wife about when you have the problem?			
Participant	No.			
Interviewer	No?			
Participant	No.			
Interviewer Ok. When you say you feel embarrassed, you feel embarrassed				
the fact that you are not able to satisfy your wife; do				
	embarrassed from your wife? Do you feel embarrassed to talk to			
	someone about it?			
Participant	First it was to my wife, but after she has accepted it, I could feel			
	comfortable there, but this one I couldn't even tell my friend because she			
	or he having another closest friend, you will say 'this is confidential, don't			
	do' the other one will do and say 'don't do'. That's when I feel			
	embarrassed.			
Interviewer	Ok, so you are embarrassed that people will talk about it?			
Participant	Yes.			
Interviewer	Ok, and besides people talking about it, is there anything else that			
	embarrasses you about having the problem? Besides that people are			
	going to talk that you've got this problem, does it affect you and make you			
	feel embarrassed about yourself?			
Participant	For the time being no.			
Interviewer	ewer No?			
Participant	icipant No.			
Interviewer	Ok, because your wife is supportive for now?			

Participant	Yes, that's the thing.			
Interviewer	Ok. Is there any other feelings that you go through when you have this			
	problem? Besides the embarrassment, you're worried, and you say the			
	relationship is ok with your wife, there's no problems?			
Participant	No problems.			
Interviewer	Ok, so you are worried because you know that your wife has saidyou			
	are worried that your wife may leave or go somewhere else because you			
	are unable to satisfy her, and you feel embarrassed to discuss it with			
	someone. Is there any other feelings that you experience?			
Participant	It's just a personal question that 'what is happening? What is wrong?' Or			
	is this going to last up to when? That is the question that I have. What			
	would be the solution?			
Interviewer	So you have lots of concerns as to whether this is going to be life-long for			
	you? Whether this problem is going to continue? Is that what you are			
	saying?			
Participant	I would say yes.			
Interviewer	Ok. And that is quite a big issue because if you are worried that it			
	isyou don't know whether it is going to continue, it is a big issue that is			
	worrying you?			
Participant	Yes.			
Interviewer	Ok. Is there anything else that you want to ask me or tell me about? Any			
	experiences that you have? Any feelings that you have? Any emotions			
	that you have that when you are with your wife and you can't satisfy her,			
	what goes through your mind?			
Participant	Apart from the thing that I told you, I would say for this time, nothing.			
Interviewer	Nothing, ok.			
Participant	When we are sleeping, there are many things we can think of but when			
	you are facing somebody and asking them some questions like these,			
	those things will run away.			
Interviewer	Ok. Can you remember when you are sleeping what things go through			
	your mind? Now you can't satisfy your wife, and nowwhat goes			
	through your mind at that time?			
Participant	It is the same like when I'm saying; ok, I'm in hospital now, my wife she's			
	going to town, she meets someone asking for love, now that she knows			
	that I cannot, "I want to get what I'm going to get now because this man is			
	driving a car, we are going to go to a certain hotel and sleep, and it will			

	mean something good".		
Interviewer	So that's your concern now? That your wife is going to find some		
	else?		
Participant	It is.		
Interviewer	That is a big concern, and I see it upsets as well when you think of that.		
Participant	Hm.		
Interviewer	Very upsetting. Ok, and when you have those thoughts, how do you feel		
	about yourself?		
Participant	That's when I think about what am I going to do? Then I go to those		
	people who are having some means to rectify that mistake. It's a		
	mistake; I'll put it that way.		
Interviewer	You're talking about the mutie?		
Participant	Yes.		
Interviewer	Ok. Is there anything you want to ask me?		
Participant	I wasn't so sure what was going to happen today, I didn't expect any		
	question, I really I did not prepare what to say, what to ask.		
Interviewer	But you know you are welcome whenever you see me, you are welcome		
	to ask me any questions? When you see me in the unit. And it will be		
	only me and you. Because whenever I come here, and you see me		
	want to ask me something, you are free to ask me. You know that?		
Participant	Hm.		
Interviewer	And it will be confidential like we discussed. Whatever you ask me is		
	between you and I. Ok?		
Participant	I know, I know, I know. But I know to say something is confidential sister,		
	the words mean it, but you are a human being. Something can bury		
	inside and then want to cough it out, you will call it confidentially but it will		
	be known that there is something which is happening that this and that		
	"People, it's confidential" but it's spreading confidentially.		
Interviewer	Ok.		
Participant Don't be afraid. I don't feel myselfI'm not scared of if what			
	you can be known by these nurses here or the staff, ja, it will end there		
	and nothing is going to be done because I will never ask any help from		
	one of them. What are they going to do with it?		
Interviewer	Ja, because you are with your wife.		
Participant If she – I mean one of them – wants to prove it, ok I will reserve			
	three to four days and on the fifth day I will come here and I will show her.		

Interviewer Ok. So because you have a good relationship with your w			
	between you and your wife as you said.		
Participant	Yes.		
Interviewer	Ok. Is there anything else that you want to tell me about the problem that you are experiencing? You said you haven't spoken to anyone about it because you feel embarrassed, you were saying that you concern is that it's your wife that may leave you if this continues and gets worse, and you feel embarrassed to talk to anybody about it; is there anything else that worries or concerns you or makes you feel? Because you have this problem.		
Participant	You see sister, really I can't tell you lies. If you have a shoulder to lie on when you are crying you feel comfortable and then you don't think about something else. I will put it that way. That is why I won't give you something else to sayI don't know what to say.		
Interviewer	Ok.		
Participant	I have nothing to say now.		
Interviewer	Ok.		
Participant	It's up to you to take what I've said to you. And then if you want me to say something, maybe you can give me some key points and say "What about this? What about this and this?" and maybe I will be having a light and then I will say something about it. For the time being nothing.		
Interviewer	All right, that's fine. Because what we will do, I may come back for more information from you, because maybe you can think about anything else you want to tell me and we can come back and we can discuss whatever more that you want us to discuss. Is that all right with you?		
Participant	Sometimes I may come with something same as the one we have talked about because I have nothing now and it's the same and you will say "You talked about this and this and this, you have given me nothing" so I will come maybe with the same problem and with the same comment or remarks. But I think as long as I come back. If you see or you hear this is the same story, you will take it as it is and know that maybe there's nothing more.		
Interviewer	Yes, ok. So basically what we've said as you were saying, is that if you have more information we can come back and we can discuss it. Is that fine?		
Participant	Yes. But these days I don't see you for the whole of a month.		



see you for more information and give you feedback on the research. Thanks for your time.  Participant I will be sorry if you didn't get what you wanted(Recording stopped)  Interviewer (Recording started) It's a continued interview with patient number six. Please continue.  Participant You see the difference now is, those years when I was – let's start from fifteen – from fifteen(Inaudible) I mean five rooms – and we were proud to say "I've done itt" you see. And then the problem started when I get married. I don't know whether it was because now I know that I will be having it with somebody for the whole of my life, because she's always there. Because that thing of five rooms was done by this girl today, one day it will pass. They will differ, these rounds and it will depend on how is she and how does she perform. Is she appetizing, you see? And even that erectile problem, it depends on how does your partner entice you or encourage you to do it. So at our age now, I think we are looking at having children so she knows that "ok, we want a baby girl now"it's called 'love-play' or 'play-before' you see? If those things are not there, I may become feeling sometimes. So now before sleeping, round one. Then you sleep. In the morning I think of what we were doing before we sleep, then it will come right and it will end there. It's now two rounds per night in my days. That's the thing that will make me become so different from the years before.  Interviewer Ok, so you said something about you're feeling like a failure  Participant Yes.  Interviewer What makes you feel like a failure?  Participant It's because I'm not doing what I was doing before. I was satisfied with that.  Interviewer Ok, so many times before you are not doing the same now?  Participant Hm.  Interviewer Ok. And when it makes you feel like a failure, what goes into your mind?	Interviewer (Laugh) Yes, I work in other units, that's why. But I will make it my d			
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Interviewer Ok. And when it makes you feel like a failure, what goes into your mind?	Interviewer	Ok, so many times before you are not doing the same now?		
	Participant	Hm.		
Double in and the the quantities "Miles O Miles the course 10"	Interviewer	Ok. And when it makes you feel like a failure, what goes into your mind?		
Participant It's the question "wny? what happened?"	Participant	It's the question "Why? What happened?"		



Interviewer	What happened to cause the problem?			
Participant	Yes.			
Interviewer	Ok. Are there any other emotions? Any other feelings besides being a			
	failure at that time?			
Participant	I would say no.			
Interviewer	Ok. So that must be upsetting when you feel that way?			
Participant	Yes.			
Interviewer	Because you are lying in bed and you feel "I'm a failure".			
Participant	Yes.			
Interviewer	It's upsetting?			
Participant	Yes.			
Interviewer	Ok. Do you go through emotions? When you are upset, what happens?			
Participant	I will take emotions.			
Interviewer	When you are upset, what happens? What happens to you?			
Participant	Maybe there are some things that I cannot explain but they are			
	happening.			
Interviewer	Ok. It's related to your relationship?			
Participant	If I could speak out, I couldn't to you.			
Interviewer	Ok, I'm going to pause (Recording stopped & started again) Continu			
	with the interview. So how else does it make you feel?			
Participant	I feel I have lost my manhood.			
Interviewer	When you say you've lost your manhood, what do you mean by that?			
Participant	I mean anyone else looking at me, she or he sees that this is not a man			
	now. So I feel so young and I lose confidence.			
Interviewer	Confidence?			
Participant	Hm.			
Interviewer	Confidence in what? What do you lose confidence in?			
Participant	In everything that I do. It seems as if I know that although he can talk like			
	this but there are times at bed, this one is a failure.			
Interviewer	Ok. Ok. And that is upsetting?			
Participant	Because me as far as I am concerned, I think he must be good in			
everything. When you are talking "Hey, this man is talking" when a musician "This man is singing" and then when you are there man everything goes well! This man in bed is good". They must be a single property of the single proper				
			"You see this man singing there, he is singing nicely but hey, his wife is	
			complaining." Those are the things.	

Interviewer	So that's what concerns you? That's why you don't wantyou feel		
	embarrassed to tell people because you feel like a failure, you would fe		
	embarrassed that people will think you are a failure		
Participant	Yes.		
Interviewer	You're not a man?		
Participant	Yes, more especially people when they are together theyyou are now		
	just passing by, they start remembering your problems; "Ah, there is he,		
	you know what" and they start talking about it.		
Interviewer	When you walk past? And you can hear them?		
Participant	Even if you won't hear.		
Interviewer	And that makes you feel? How does that make you feel when people		
	talk about it?		
Participant	You feel so young, you feel as if you are not supposed to be there. They		
	are notto be supposed to be living in this world, he must not be there.		
Interviewer	Ok, you feel upset?		
Participant	Because if you are not there they won't say anything about you. You		
	must leave this world, so that they don't have nothing to say about.		
Interviewer	So another fear that you have or worry that you have is people talking		
	about you and having that problem?		
Participant	Hm.		
Interviewer	Ok, and that's quite a big issue that you have to deal with.		
Participant	Hm.		
Interviewer	Ok. Is there anything else that you want to discuss?		
Participant	No.		
Interviewer	Ask me any questions?		
Participant	No.		
Interviewer Ok, what we will do is as I've said before; we will come together			
	can always get more information and ask you more information. Is that		
	all right?		
Participant	Yes.		
Interviewer	Ok, thank you so much for your time today. I know that you are rushing		
	off now, but thank you for your time.		
L	1		



# **ANNEXURE J**

# **REFLEXIVE NOTES**



## **Reflexive Notes**

### i) Bracketing (Epoch): April 2007

My initial assumptions of erectile dysfunction were that the person experiencing erectile dysfunction would be embarrassed and disappointed with himself for his sexual non performance. This would result in the decrease of his self esteem because he would not feel as if he is a man. I felt that men measure their manliness by their ability to engage in sexual intercourse successfully, by having an adequate erection and by the size of their genital organ. In the media, be it television, magazines and the radio there is constant referral to erectile dysfunction and the treatment that is available like Viagra. While on the streets and at some intersections where there are robots pamphlets are dispersed on how to increase the size of the male genital organ. Regardless of my above assumptions I perceived that experiencing erectile dysfunction was and should not be a major problem as I viewed happiness in a relationship as more than just sexual intercourse. My first experiences with the patients on haemodialysis who were experiencing erectile dysfunction was when I observed that two patients informally disclosed their experiences with erectile dysfunction with the care workers and other patients rather than with the professional nurse practitioners. I assumed that patients have difficulty in disclosing their experiences of erectile dysfunction to the professional nurse practitioners.

# ii) Bracketing (Epoch): November 2009

While I was conducting the individual phenomenological interviews my perspective on erectile dysfunction changed. This was due to the data collected through the phenomenological interviews, naive sketches and my field notes. I began to view erectile dysfunction as a major problem that challenges the stability of the relationship between the participants and their partners and the identity of the self. It became clear to me that happiness in a relationship entails having successful sexual intercourse with one's partner.

In the data analysis phase an independent coder was used to analyse and interpret a set of data. The two supervisors of the study additionally verified the findings by comparing my findings with the findings of the independent coder and some of the raw data thereby preventing bias emanating from my views being presented. The phenomenological interviews with the participants were audio taped and transcribed verbatim. The transcripts were transcribed by an independent transcriber who is not part of the research team thus preventing bias as the participants described their experiences of erectile dysfunction.



# **ANNEXURE K**

# **NAÏVE SKETCH OF PARTICIPANT**



When you look at you correct state will renal failure you always tempted to compare with your self before the renal failure how and how were you able to controll and manage it to prolong intercourse. One at the major naticable thing is that you can not controll it let alone to effectively control. It is alone to effectively control. It normally get haid on its own and you don't know how long that is gonna lost.

At some post when you want to have intercourse it just does not come up at all. You think of your best moments and there is no change at all.

It does occasionally become hard in its own and you feel tempeted to or use it there and then but life does not function like that

The worst embarrasing situation is attended when you have managed to be erect and start jour first cound and it does not go well eight of a could be for quickly wont to start over again it just does not come up int all low domittens thunking it might come up but mothering at



knowing your self you even ask your partner to go down, Hunking, if she start suckey then there will be a difference but nothing at all.

The other best where it embarrasses me is in the ment marriage knowing with the lovers they ephreciate the marriage gloray but there it does not furction at

There are worst frustating senarios when you bertner is craving for intercouse than ste start touching you. Many accassions it just does not final function. Sometimes it becomes hard but not hard enough for an intercourse.

There are also senancis when it is hard but there that edge bount is not then to start intercouse. Thank because you assess its hardness and sealise it would last you during the intercouse.

The idea of thereesen is just impossible becouse in the middle of that action it can fall and never get up. That would be the worst moment with two people there.

Managing it doing the process of intercourse is



a delicate process.

Sometimes the exection is not effective et all



# **ANNEXURE L**

# **OBSERVATIONAL NOTES**



## **OBSERVATIONAL NOTES**

## Patient 2

Date- 19/10/09

Time-17h00

Place- renal unit

Patient was on the haemodialysis machine but in an isolated room where he was the only patient in that room. The door to the room was closed and privacy maintained.

The researcher and the patient were the only persons in this interview.

The researcher had a meeting with the patient prior to the interview and a date was set for the interview to be conducted. At this stage the participant was keen to participate in the study. However the first appointment date was cancelled as the patient was haemodialysis in the open unit and not in the isolated room. The patient could not be interviewed post dialysis as he had transport problems. On the second appointment date the interview too place. The patient was open to the researcher and very comfortable to discuss his experiences with erectile dysfunction.

The patient is single and has a life partner. He is 34 years old.

## The interview

The patient was open, candid and descriptive about his experiences. He maintained minimal eye content. His facial expression was intense. At times he kept on moving one hand over his head in a rotational manner, indicating the inability to deal with erectile dysfunction, inability to help himself and the overwhelming impact of erectile dysfunction on him.

During the interview we were interrupted by a staff member, there was silence as the patient keeps quiet. The staff member apologises and leaves the unit.

The participant starts the interview describing erectile dysfunction as challenging and stressful. At times he is unable to achieve hardness of his penis and fails in getting an erection. He goes on to say that this has a negative impact on his partner. He verbalises that he feels incomplete and useless, unable to fulfil his manly duties at home.



Erectile dysfunction started after the commencement of haemodialysis. He has not discussed this issue with his partner or anyone else.

His naïve sketch was extensive in his description of living with erectile dysfunction.

#### Patient 3

Date- 16/11/09

Time-10h00

Place- renal unit

The participant was interviewed in the unit manager's office to maintain privacy. He was interviewed post dialysis.

The participant is married. He is 52 years old.

#### Interview

The participant had minimal eye contact. His facial expression was of sadness. At the beginning of the interview the participant the patient also mentions that not only is erectile dysfunction a problem that he is facing but also that he has financial problems as well. He is afraid that he will be boarded off from work with n income. He says that not only is the dialysis causing erectile dysfunction but also the financial worries that he has. He has feelings of frustration and anger that he is unable to sleep with his wife. His wife understands and he has spoken to her about the erectile dysfunction. However he is worried if his wife will go and look for someone else if he does not satisfy his wife and he will lose her. At this stage the sadness was greater with tears in his eyes. After talking about the impact of erectile dysfunction he mentions that he has three sons. The interview had to be directed to his thoughts and feelings on erectile dysfunction.

At this time the telephone in the office rings and there is a pause but the recording goes on as the telephone will be answered by someone else in the unit. The patient verbalises that he is also afraid of having sex as he has a stent insitu that causes him heavy pain at times when he passes urine.

The participant wanted to know if there is a solution to erectile dysfunction.



The participant lets the researcher know his dialysis schedule day and times if she needed to contact or see him again.

The researcher feels that the erectile dysfunction is multifactorial in this case, namely renal failure and dialysis, financial problems, having a stent insitu.

### Patient 4

Date- 16/11/09

Time-10h00

Place- renal unit

The participant was interviewed in the unit manager's office to maintain privacy. He was interviewed post dialysis.

He is 66 years old and is married.

This participant had contacted me per telephone after he had seen my letter on the study which was circulated in the unit. He was keen to be a part of the study and was happy that this study was being done as according to him no-one is helping the patients with the problem of erectile dysfunction. He said that he was waiting for someone to talk to about erectile dysfunction and then he saw my letter. He did mention in the interview that he did approach the doctor about the erectile dysfunction but he got no help from the doctor.

#### The interview

In the interview the participant says that he is participating in the study so that a solution can be found to help the younger males who experience erectile dysfunction. He does not like the effects of erectile dysfunction happening to the younger "chaps" and the effect that it will have on their marriages At this point he laughs. He states that he is old now and has accepted erectile dysfunction but if there is a solution then that is ok. According to him this will help him and his wife so that he can have an intimate relationship with her as this part is missing in a marriage. His wife understands the problem with erectile dysfunction. However he states that his wife is 10 years younger than him, and that she has not discussed her feelings with him. He is confident that the relationship with his wife is strong as the have been together for a long time, 40 years.



The participant said that he did not take erectile dysfunction seriously but if he were younger then it would affect him badly.

I had a difficulty at the beginning with participant responses as he said that he felt bad and when probed as to what bad means but he just replied that he felt bad. I did not want to lead him by influencing his responses.

His wife is understands his having erectile dysfunction. This participant had accepted erectile dysfunction as he did laugh throughout the interview therefore he was not subjected to the effects of erectile dysfunction at present but was subjected to the effects at the beginning when erectile dysfunction started.

#### Patient 5

Date- 17/11/09

Time-10h00

Place- renal unit

The participant was interviewed in the unit manager's office to maintain privacy. He was interviewed post dialysis.

He is 60 years old and is married.

The participant had to eat first before the interview commenced.

The participant did not want to make a naïve sketch but insisted that I write his experiences and that he will tell me what to write. This was very brief and the gist was that he has accepted having erectile dysfunction due to his "old age". He is also happy with his relationship with his wife. Throughout the interview he was relaxed and not troubled by discussing erectile dysfunction.

### <u>Interview</u>

In the interview the participant said that he and his wife have accepted erectile dysfunction due to his old age. At the beginning when he tried to have an erection and this failed him and his wife accepted the situation. They live as normal as husband and wife without sex, love each other and show their love for each other in other ways like kissing, hugging and



are happy in this relationship. At one point he does laugh saying that it is a dysfunction but it does not affect him.

### Patient 6

Date- 17/11/09

Time-17h00

Place- renal unit

The interview was in an office and the researcher and the participant were the only persons in the room.

The participant is 45 year old and is married.

This participant was interviewed on his non dialysis day as per his request. After dialysis he goes to work therefore he was not interviewed after dialysis. However he was prepared to come on a non dialysis day at 17h00. Most of the other participants wanted to be interviewed on the days of their dialysis as they did not want to come to the unit again on a non dialysis day. This did not pose a problem to him as he wanted to verbalise the impact of erectile dysfunction to the researcher. He was in the dialysis unit early, indicating his need to express his feelings and thoughts on erectile dysfunction. When I reminded him that the interview was confidential, he said that even if I disclose the information to others he is fine with that as he is not embarrassed to talk about his experiences with erectile dysfunction. And there is nothing that they cannot help him. He does say that he can talk about experiencing erectile dysfunction to someone that he trusts only.

#### Interview

Participant was open in expressing his thoughts and feelings on erectile dysfunction. Participant was very comfortable with the researcher. He started off by talking about his wife thinking about someone else who will satisfy her and this worries him. Therefore his biggest concern is that his wife will leave him, "run away" because of the erectile dysfunction. When he talks about his wife leaving him he becomes tearful and sad. He is so occupied with thoughts of his wife leaving him when he comes for dialysis and his wife "goes to tow, meets someone with a car , goes to a hotel and sleeps with the other man." He has not discussed this with his wife.



He has thought about taking "muti" or "ibiza" but has insight that this will cause complications as he is in renal failure and will be fluid overloaded. He did say that he has used the tablets from the chemist previously but does not want to depend on them. He has constant thoughts about what will happen and what he will do about his situation. He has thoughts that he will be able to have an erection the next day and consoles himself with this thought but if on the next day he does not have an erection then he thinks that maybe the following day he will have an erection. Therefore he has constant thoughts about having an erection. He has loss of self esteem as he has failed as a man in sex. He will be embarrassed if other people talk about his having erectile dysfunction.

There was an interruption in the recording as the interview was to be ended but the participant wanted to talk more about his experiences with erectile dysfunction. He describes himself as a failure as he is not performing as he used to.

The recording was stopped again as there was an interruption in the office and the interview was resumed. He has a low self esteem, failure, loss of manhood, loss of confidence. The ability to have a successful erection defines and gives the participant an identity regardless if he is successful in other areas of his life.

The participant has no told anyone about his erectile dysfunction because he feels that they will talk about him.

He indicates desperation to get out of this situation when he says that "they are not supposed to be living in this world, he must not be living in this world

The participant had minor difficulties with the probes used, and he said that he would prefer to be lead with questions or key points when he remarks ,"I do not know what you (researcher) want."

On my follow up visit to the unit post interview, I asked the participant if he has thought about anything else to say to me. He did not have any more information and was told that if he wanted to see me he must either contact me or inform the staff to contact me.



## Patient 7

Date- 17/11/09

Time-17h00

Place- renal unit

The interview was in an office and the researcher and the participant were the only persons in the room.

Participant is 69 years old and is married.

Participant became aware of the study in the dialysis unit. He approached me when I visited the unit to enquire if he can speak to me about his experiences with erectile dysfunction. His interview was conducted in another unit after hours. He did not have a problem being interviewed in another unit. The participant was happy to have someone who he can talk to about his experiences with erectile dysfunction.

#### <u>Interview</u>

The participant verbalises that he gets frustrated and angry as he cannot function well with erectile dysfunction. This is causing a problem with him and his wife. He feels that his wife is like a sister to him now as he cannot do anything to her, have sex with her. His wife is also angry with him and she does not understand his problem. He makes use of the metaphor of "cannot jump the ropes that I used to jump," indicating feeling uncomfortable with topic. He also verbalise that he has lost his manhood, feels like a woman to his wife indicting loss of identity as husband, gender. He verbalises that he has tried other treatments but they have not worked for him. He is afraid and worried that his wife will leave him, but being Christians they are together. However he is afraid that it will come to a point where his wife will divorce him. The participant's main concern is his now poor relationship with his wife caused by erectile dysfunction. Participant is desperate for a treatment, "as quick as possible."

The participant has a sad expression and pain is clearly visible on his face as if he wants to cry. When he discusses that he is angry and frustrated with himself, he hammers his fist on the table indicating his anger. The participant is in so much of pain that to alleviate the pain he would rather be dead and wonders if someone can kill him.



Because of the pain the participant was offered counselling together with his wife by the researcher. He has accepted the assistance but has not come given the researcher upon follow up of any feedback on what his wife's decision was.

The participant then calms down and relaxes at the end when he again says that the researcher must get the treatment as quickly as possible.

The researcher feels that the interview was therapeutic for the patient as he was angry at the beginning but relaxed at the end.

### Patient 8

Date- 18/11/09

Time-11h00

Place- renal unit

The interview was in an office and the researcher and the participant were the only persons in the room.

The participant was interviewed post dialysis session.

Participant is 56 years old and is married. Participant is quiet in the unit, does not talk much but during the interview he was open and unreserved.

### **Interview**

The participant's concern is that his experiencing erectile dysfunction is causing a problem with his partner. Therefore he wants help and a cure and that will please him. He fears touching his wife as he cannot satisfy her. He is afraid that his wife will leave him. He is preoccupied with this thought as he says, "When you see your wife is hiking from town, you just think sometimes maybe she has got someone else." This worries him and he is constantly thinking when this erectile dysfunction will stop, preoccupation. Participant has spoken to his wife, she does understand (according to the patient). However he is still afraid that she will leave him. Facial expression of sadness. The participant's phone rings and there is an interruption as he takes the call. The interview then continues. The participant says that he has suffered with erectile dysfunction for four years as there is no one to help him. According to the participant he does not know if the "things" sold by the people to solve the problem of erectile dysfunction are dangerous. The participant sees himself as a failure and not as a full man.



The participant asks me if I can get him something to use. I suggested that he and his wife get counselling and that he will get the results of the study after completion. The participant was interested in the counselling but has not yet followed up on this with his wife. He does say that he talks to his wife and that she does understand his experiencing erectile dysfunction.

This interview has been therapeutic for the participant as he says, "I'm happy that I have told this to someone else, everything that is in me." He says that when he keeps all bottled up inside then he feels sick, namely "brooding on the problems" that he has because of his experiencing erectile dysfunction.

The participant had a clenched fist hammered onto the table when he requested what treatment the researcher can get for him. He also wriggles his hands and is anxious. In his naïve sketch he writes, "...if there is any help, I really need it," indicating his desperation for treatment and resolving his situation.

#### Patient 10

Date - 28/11/2009

Time- 10h00

Place- renal unit

The participant was interviewed in the office. The participant and the researcher were the only persons in the room. The participant is 53 years old and is married.

The participant refused to write a naïve sketch. He was soft spoken and battled to express himself. His facial expression was of sadness.

#### Interview

The participant had difficulties expressing himself at the beginning and was uncomfortable. He was told to speak freely and openly as the interview is in confidential. He then settled and was open and comfortable. He refers to feeling "bad." The participant could not explain what feeling "bad" means, even when probed. He explains that erectile dysfunction has a negative impact on his relationship with his wife. He gets angry with himself. He is ashamed to tell anyone but wants to talk about his experiences with me so that I can help him. He has not discussed his experiences of erectile dysfunction with his wife. His biggest concern and



worry was that his relationship with his wife is affected by his experiences of erectile dysfunction.

### Patient 11

Date-28/11/2009

Time-10hoo

Place- renal unit

The participant was interviewed in the office. The participant and I were the only persons in the room. The participant is 30 years old and is single.

The first appointment date for the interview was cancelled due to the participant having to go to work post dialysis. He was apologetic.

The participant was open and comfortable in describing his experiences of erectile dysfunction to me.

#### <u>Interview</u>

Erectile dysfunction is stripping him of his confidence in himself, he feels like his partner is thinking that he is cheating as he is unable to perform. This is causing tension and fights in his home between himself and his partner. He is worried that the may break up. He talks about his previous performance before erectile dysfunction and that is what his partner is used to but now this has changed. He is not happy. He has tried the pills but they do not help. He has low self- esteem, not man enough to satisfy his partner and this makes him angry. He constantly fights with himself because he cannot perform and cannot help himself. He has thoughts and regrets that he is not enjoying his life as he is still young and that he did not take care of himself to prevent hypertension and renal failure. He has discussed his experiences of erectile dysfunction with his partner but according to the participant his partner does not understand as she is young. He did say that his partner is young so her leaving him is a big concern for him. He has not spoken to any medical professionals about his experiences of erectile dysfunction. He is now happy that he is talking to me. He has spoken to the other patients as it is easier for him to talk to the patients they share the same problems but he finds it hard to talk to someone else. If he talks to other people then he is afraid that they will talk about him. His thoughts, what is going to happen to him in 3 years from now and this worries him. He says that he feels less of a man, loss of manhood. He is lost, indicating helpless to make his life easier and happier. The disappointment of not



satisfying his partner makes it hard for him to go home. He ponders that it is better to have children to occupy his time with the children rather than with time spent with his partner. He is requesting help to make his life easier.

At times the participant uses his hand to tap the chair indicating his desperation in this situation and the need for help.



# **ANNEXURE M**

# **RESEACHER'S ANALYSIS OF THE DATA**



## **DATA ANALYSIS**

# 1. PATIENTS

SIGNIFICANT STATEMENTS	FORMULATED MEANINGS
1. Patient 2 "This has been challenging and stressing. The major challenge that I experience is actually controlling it and managing it. It becomes an impossible situation that you engage in, mainly to control it. You just have to accept the situation."  Patient 4 "It will have an impact on anyone. But you know, if you accept this and you can't do anything about it, so there is no point in worrying about it. You just have to live with it."  Patient 6 "When I'm with my wife it works and then doesn't work."  Patient 11 "Causes a lot of tension in the house because of it is like you are cheating, there is something that you are doing on the side."	Erectile dysfunction is stressful due to the sufferer being challenged by the inability to have, control and maintain a successful erection for intercourse with partner and be able to manage erectile dysfunction.
<ul> <li>2. "Patient 2 " when you dealing with this is actually comparing yourself with it and before it. So you look at yourself ,how are you functioning before it and you look at yourself at what is currently happening"</li> <li>Patient 6 "You see those years when I wasthat's the thing that will make me so different from the years before."</li> <li>Patient 7 "I feel very angry because I cannot jump the ropes that I used to jump."</li> <li>Patient 8 "It's not like we were before."</li> <li>Patient 11. "Your relationship is not strong, because we are not performing as what we were doing before.</li> <li>Some of the women are used to what you had and now you have changed. Before I'll go three times, but now one per week is a lot of job."</li> </ul>	Thoughts of how you functioned before onset of erectile dysfunction and how you are functioning at present with erectile dysfunction plays in your mind with feelings of loss of what the person once had and now miss.  Metaphors related to 'performance' eg. jump rope
3. Patient 2 "And the major problem is that it	The relationship between the sufferer with

always affects you dealing your partner. Well when you no longer satisfy her needs, she will have a problem with that. ....it is going to make you lose interest in intercourse. That would affect your partner negatively which will actually be a problem in your relationship."

Patient 3 "That's a big problem because I think in today's life is a man is not satisfying his wife, the wife goes and looks for somebody else. And this worries me as one day I might just lose her."

Patient 6 "I feel so worried .I think that she will be thinking about somebody who is going to satisfy her."

"It is a big concern that I may be left by my wife."

Patient 7 "And it's sad because my wife is like a sister now. I can't do anything to her. Of course it is causing a lot of problems at home. Because the relationship between us now is not so good, as I am like a woman. If we were not Christians, I'm sure she would have divorced me by now. Relationship has been hampered, it is a long time. There is a

have divorced me by now. Relationship has been hampered, it is a long time. There is a strain in the relationship. It will come to a point where my wife will divorce me. I do not know what to do."

Patient 8 "I got the problem of erectile dysfunction and it's causing a problem to me with my partner; there is no setting it right with my partner. She does not like this because I always leave her on all the time. Now she refuses to give me cos I am not going to finish her."

"When you see your wife hiking from town, you think maybe she has got someone else." Patient 11. "Your relationship is not strong, because we are not performing as what we were doing before.

There are a lot of fights, small fights in the house because of the problems of erectile dysfunction. This can cause a break up any time. It is a big problem in the relationship. You will be in fights. You are thinking that she

erectile dysfunction and his partner may be affected negatively, causing a breakdown in their relationship.

Sex central to fidelity and female satisfaction within the relationship

	can leave you. In the meantime the relationship is suffering, performance is gone. You can't perform, and then there is a fight."	
4.	Patient 2 "And mostly with us, culturally we are not good at communicating with this issue. you are so trapped emotionally to actually communicate that it just doesn't function. And thinking or guessing of exactly what might be going through your partner's mind within this whole period."  Patient 4 "I don't know how my wife takes it. But she does not speak about it. I do not know my wife's feelings. She does not discuss her feelings."  Patient 6 "I feel embarrassed to talk to my closest friend as people will think that I am a failure."  Patient 8 "It makes me feel sick, if I keep all inside and not talk about it."  Patient 10. "I don't think my wife knows what's going on. No, I have not spoken to my wife."  Patient 11. "There is a lot of tension in the house, because it is like you are cheating. Your partner is thinking that there is something that you are doing because you are not performing at home."  "But for men it is hard to go out and just talk about it Sometimes we talk patient to patient because he experience and knows about it but for someone outside it is very very hard to talk about it because they will not understand."	Person suffering with erectile dysfunction and partner have difficulty verbalizing his and partner's thoughts and feelings to each other resulting in lack of communication between them or with significant other.

SIGNIFICANT STATEMENTS		FORMULATED MEANINGS
	·	
5. Patient 2 "yo	u cannot fulfil all your manly	Loss of manhood and masculinity due to the
duties at home	. The major stress that I am	inability to have, maintain an erection and
actually going t	hrough is the feeling that you	satisfy one's partner is felt by the sufferer.

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are not man enough to function."

Patient 4"In the beginning it was affecting me."

Patient 6 "I feel I have lost my manhood, anyone looking at me sees that I am not a man now and I lose confidence."

Patient 7 "It's just worse because now seeing as I cannot satisfy my wife, it makes me not a man at all. I feel terrible.

My wife knows that I am just like a woman to her, which is bad. I am longing to be a man again. If I am a man again I think that things will come to normality again with my wife.

Now it is not normal."

Patient 8 "I feel that I am not a full man because this man part is not working right. This is upsetting."

Patient 10. "When I want to make love to my wife, my penis doesn't wake up."

Patient 11 "It's like you are not man enough. You cannot take care of your woman."

 Patient 2 "Obviously from a man's point of view you feel incomplete, you feel useless, you feel being problematic..."

Patient 4 "It makes you sad because there is a part missing in you; you know that part in normal life. The intimacy with wife is missing."

Patient 6 "May be by 2010 I'll be a total failure. I don't know she'll run away. To be a sex man failure is embarrassing. I feel a failure cos I'm not doing what I was doing before." "I lose confidence in everything that I do, even though he talks like this but there are times in bed one is a failure" (other people's perception of the participant).

Patient 7 "It's terrible not to be a man .I am just like a woman to her, which is bad." "Even if I can look at a woman naked, I can't. It just stays down like that .It is the most worrying thing. I am longing to be a man

Loss of self esteem as the person feels useless and that he is the one with the problem that he cannot control and it is not the partner to blame but him. again. My wife feels that I am not a man anymore as she displays everything to me yet before she used to hide herself when she went for a bath so as to provoke me or stimulate me but it does not happen."

Patient 8 "We know we are a failure. I am a failure because I can't satisfy my partner. I am the failure."

Patient 11 "It's like you are not man enough. You are not good enough for her. If she wants satisfaction, then you can't give her that."

 Patient 2 "...the worst frustrating scenario is when your partner initiates the intercourse, it becomes impossible...you feel so trapped emotionally. You get irritated. You worry will it get hard or not.."

Patient 3 "It is frustrating. To be honest it's very frustrating that I am not able to sleep with her. It makes me angry. If I get angry then I am driving her away from me"

Patient 4 "It made me feel bit bad right at the beginning. It is affecting you and you cannot do anything about it. Makes me sad as that part in normal life is missing in marriage."

Patient 6 "What worries me is to be left by my wife"

Patient 7 "It is sad because my wife is like a sister now, cannot do anything to her."
"I felt rather frustrated when I come to my wife because she didn't understand me like this. It's very very bad not to function well as far as this thing is concerned."I feel frustrated with myself because I cannot go to her, cannot do anything to her."

"I feel angry because I cannot jump the rope that I used to jump, feel very angry. I feel angry with myself because I cannot function well."

"It worries me very much" (referring to his wife can divorce him) "and that the penis does not wake up even if I look at a woman naked, it just stays down like that. It is the most worrying thing. I get angry with myself

Feelings of frustration, anger, worrying, irritation tends to overwhelm the person when intercourse is expected to occur but does not occur due to his experiencing erectile dysfunction. The person feels trapped in these emotions. Sadness for missing out on intimacy with wife.

when I look at my naked wife and my body does not respond."

Patient 8 "I am very sad about this and it has taken me..this is the fourth year with this. It worries me that she may elope with another guy."

"It is upsetting to not be a full man. I know ladies when they have got that time, they want satisfaction."

Patient 10. "I feel very bad when I want to have sex, my penis just dies off. Sometimes I feel angry with me because I can't do anything. It is a worry."

Patient 11. "I am not happy, I try the boosters sometimes but..no difference.
You are in a fight with yourself because you can't perform but there is nothing that you can do about it. You are angry to yourself, you want to make someone happy and you can't."

8. Patient 3. "My fear is that I may lose her"

Patient 6 "My wife will go to town, meet someone, and ask for love, go to a hotel and sleep and it will mean something good as she knows that I cannot."

Patient 7 "It seems as if I know that although he can talk like this but there are times at bed , this one is a failure. They mustn't say, you see this man singing there, he is singing nicely but hey, his wife is complaining."

Patient 8 "Fear to touch her. Because I know that I am not going to satisfy her. I always like to be with her and it's difficult to satisfy her, I've got that fear always with me. I'm afraid that maybe my wife will leave me and go to another man."

Patient 8 "I always think that she is with someone else, if I see her coming with another guy you see that causes a problem because I know that maybe they are eloping."

Patient 10. "I don't want to tell anyone because I can't. Because I feel ashamed."

The sufferer is fearful of the effects of erectile dysfunction on him and his partner. Fear that the partner will leave him for someone else , people talking about his problem



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	Patient 11. "She can leave me because she is	
	still young.	
	I don't like people going behind my back and talking about me."	
SIC	GNIFICANT STATEMENT	FORMULATED MEANING
-		
9.	Patient 3 "Is there is a solution to this?"	The sufferer's life and situation is so difficult to
		deal with due to erectile dysfunction that the
	Patient 4 "I will be grateful if a solution can be	only way to change the situation he faces is if
	found for this problem. I went to the doctor	there is a solution to overcome erectile
	and he can't help you. I don't think doctors	dysfunction.
	are concerned about it. My wife will	
	appreciate it if there is any help	
	on this part to rectify this problem"	
	Patient 6 "So in our culture there are some	
	muties we use to drink to make us strong, I	
	think about going to those people but this is	
	not desirable for dialysis. So I want, if there is	
	some ways to help me to satisfy her, that will	
	be the thing and it will end there."	
	Patient 7 "I have tried many things. I've tried	
	those other people who broadcast on the	
	streets, but it doesn't help.	
	What goes through my mind is that I'm just	
	hoping that I might get a doctor who will be	
	able to help me. It is getting worse. Is there a	
	doctor who can help me through this? Can I	
	ask if it is possible, can it be quick?"	
	"Do you think counselling will do anything for me?"	
	me:	
	Patient 8 "But if there is something you can	
	help me, I can be very pleased sister because I	
	want to cure it or to boost it.	
	Those things sold by those people, we don't	
	buy those things because we don't know how	
	dangerous they are.	
	The only thing that I can ask you is whether	
	you can try and get me something to use."	
	Patient 10 "I want to bring it out and maybe	
	you can help me. I see those tablets and I	
	think that I want to go take those tablets and	
	make myself happy, the tablets may affect	
	me, you see."	
	Patient 11. "I am happy now because there is	
	someone that I am talking to; maybe there is	
	something that will help after this."	



10. Patient 4 "Loss of feeling of having sex."	Erectile dysfunction results in loss of libido and loss of interest in sexual intercourse with
Patient 6 "The following day I do not have any desire, maybe for 2 to 3 days."	partner and by the partner.
Patient 7. "Even if I can look at a woman naked, I can't. It just stays down like that. She has stopped all the advances that she used to	
do when I was well. She just sleeps."	
Patient 8 "She does not like this because I always leave her on. Sometimes she refuses	
to give me because she knows I am not going to finish her.	
I have met her on Monday, then now the whole week I am not interested."	
11. Patient 6 "But I won't just fall asleep at that moment; I will just lie thinking what will happen? What should I do? Why?"	The inability to engage in successful intercourse results in the person ruminating about what will happen to him and what can he do to alleviate the problem
Patient 8 "In your mind there is worry and worry and I don't even know when I slept	
because I'm always thinking when it will stop.	
I feel tired and restless. I feel sad all the time.	
I am brooding on this problem."	
Patient 11 "Even if it is small talk, you will be like a fight because your thoughts are all over	
that she can leave you."	
Patient 11. "It is hard to go home and know	
you can't satisfy your partner. It's hard.	
Better to have kids around to play with the	
kids but if you are one on one just you and	
your partner then it is hard because she will	
expect something from you and you can't give	
her that thing. Then she will end up fighting. It is hard."	
12. Patient 6 " It seems as if I know that although	Stigma of being seen as a failure if experiencing
he can talk like this but there are times at bed	erectile dysfunction even though one is
, this one is a failure. They mustn't say, you see this man singing there, he is singing nicely	functioning well in the other areas in his life
but hey, his wife is complaining. People when	
they are together, they start remembering	
your problem, and they start talking about it.	
They are not supposed to be living in this	
world, you must leave this world so that they	
don't have nothing to say about you"	



Patient 8 "This one is good, will make you a man, we don't buy that thing. We know we are a failure. I am a failure because I can't satisfy my partner. I am the failure all the time"	
13. Patient 7 "My wife is not feeling well at all as far as this thing is concerned, she gets no sex from me, its bad then she is angry with me and very frustrated.  Because you see when you can think that I am not good to this woman, it's the worst, if I am a man I can satisfy her in bed and it is nice and she says it is good, now it is not like that anymore."	The sufferer is submerged in guilt as he feels that he is to blame for the lack of intimacy and intercourse between him and his partner caused by him having erectile dysfunction.
Patient 8 "I am a man and want to touch her, I'm leading her on and it is very difficult. I become worried as there is nothing I can do. Only to pass water. I also get upset because I know the problem is with me"	
Patient 11 "You can do everything for her but for that part, no.You cannot take care of your woman. You will leave it and she will need to be happy."	
Patient 11. "You have to blame yourself. The high blood pressure caused my renal failure, if I had lived my life well at that time or look after myself more carefully, I would not get this renal failure. But now I've got it."	
14. Patient 6 "They are not supposed to be living in this world; you must leave this world so that they don't have nothing to say about you."	The desire to be dead and away from this world are felt by sufferers with erectile dysfunction so as not to face the problems arising from having erectile dysfunction.
Patient 8 "Sometimes I feel it is better that I am dead. I'm not there. So if somebody can take my life, maybe that will be alright rather than staying with the bad. Nothing has been done so far and that is the only solution. It is very painful."	
15. Patient 7 "Because you see when you can think that I am not good to this woman, it's the worst, if I am a man I can satisfy her in bed and it is nice and she says it is good, now it is not like that anymore."	Erectile dysfunction erodes the satisfaction that is felt by the male in keeping one's partner happy and satisfied with their sexual life.



Patient 8 "I am sad because I am not satisfying my wife. I don't feel happy really, just apologise to each other. I must do it correctly and satisfactorily to satisfy my partner."  Patient 11. "You want to perform and make your partner happy, but you can't make her happy. It is hard."	
16. Patient 7 "She becomes frustrate with the situation. She is not in a good mood. It's difficult. It makes me feel terrible."	The negative reactions from the partner has a devastating emotional effect on the male.
Patient 8 "My wife gets upset when the part is not rising."	
Patient 11. "I've tried to explain to her but she doesn't understand."	
17. Patient 7 "Is there a doctor who can help me through this. If the treatment is possible, can it be quick? So that I can be a man again. I am longing to be a man again. Yes I am desperate. Just get the treatment quickly."  Patient 8 "But if there is something you can help me, I can be very pleased sister because I want to cure it or to boost it.  Four years is a long time with the problem cos we don't have someone to help us.  For four years I have been going through this and struggling with this."  "I want some help yes. When I got that interest to meet her, there should be something. I can't to do it correctly, satisfactorily."	Erectile dysfunction leaves the sufferer in a desperate and helpless situation.
Patient 11 "If I can get something to help it, I will be happy."  "First I thought it will go away, but the more and more the time is going, it's not going anywhere."  "My biggest problem is that I don't know how to fix it. I'm lost. I don't know what to do to make my life easier and happier. I want some help to make life easier."	
18. Patient 11. "I am still young; I should be enjoying my life. For me it is hard as I am still young, most of the patients that have same	The sufferer experiences a loss of a function or loss of his prime of life.



problem are twice my age.. It is not a big thing for them, but for me it is. I was thinking what will happen from now while I am performing like this and after three years how will the situation be.

We are still young. We should be enjoying this part but now we can't."

#### THEME CLUSTERS

#### 1. Lack of control

- Inability to control the physical functioning of the penis.
- Challenging to control the penis and maintain an erection
- The penis does not get hard enough
- No control of poor relationship with partner

#### 2. Loss of past life

- Grieve for past life before erectile dysfunction
- Comparison of strength and size of erection before and after erectile dysfunction started
- Anger at the decrease, poor or no performance
- · Confidence in spouses fidelity

#### 3. Devouring relationships

- Relationships with partners have been negatively affected
- No longer able to satisfy partner needs
- Problem if partner needs not satisfied
- Strained relationship
- Fights in the house
- Thoughts of divorce and infidelity
- Fear of losing partner to someone else
- Suspicious of partner's fidelity

#### 4. Loss of manhood

- · Loss of role as husband
- Challenge on manhood and masculinity
- · Perception of partner as lover changes
- No bodily response when with partner

#### 5. Hoping for treatment

- Seeking solution or treatment
- Lack of concern from doctors
- Awareness of prescription and non prescription treatments
- Fear of using prescription and non prescription treatments
- Need for quick treatment
- Hope that treatment available post research study

#### 6. Distorted thoughts

- Seen as failure
- · Uncertain what's going to happen to them
- · Ruminating about what to do
- Mood changes in partner and self
- Sadness and worry prevails



- Loss of self esteem
- Loss of confidence is self

#### 7. No way out resignation and acceptance

- Death is the solution
- Sense of defeat creeps in
- Uncertain what's going to happen in future
- Inability to enjoy prime of life

#### 8. Emotional trap

- Negative feelings due to unsuccessful intercourse
- Frustration and anger with self
- Sadness in failure to satisfy partner
- Part of normal life missing in marriage
- Divorce and desertion are worries
- Guilt caused by self blame
- Regret for not taking care of health

#### 9. Silent breakdown

- Difficulty in having open communication with partner
- Open communication hampered by embarrassment
- Uncertain of what is in partner's mind, misconceptions are made
- Communication between patients but not partners

#### 10. Intimacy lost

- Loss of interest in intercourse by participant and partner
- Lack of sexual arousal / stimulation by both parties
- Unable to make partner happy

#### THEME CLUSTERS

#### Theme1. Lack of control

In this theme the participants verbalised their inability to control the physical functioning of the penis. One participant, referring to the penis inability to get erected explained, "The major challenge that I experience is actually controlling it and managing it. It becomes an impossible situation that you engage in, mainly to control it. You just have to accept the situation." He explains that managing it is an issue, "the intercourse – it goes its own direction, it doesn't get hard enough, it leaves you on the way and it never came up." He goes on to say "And the major problem is that it always affects you dealing with your partner as sometimes she will see that this is your intention but you cannot fulfil them. Another participant verbalised that when he wants to make love to his wife, his penis doesn't wake up.

A 66 year old patient resided with the feeling that if you cannot do anything about it then you must accept it. He further states, "You just have to live with it."

#### Theme 2. Loss of past life

Some of the participants grieved for their past lives when they did not experience erectile dysfunction. A 34 year old participant described dealing with it as "comparing yourself with it and before it, how you functioned before it and what is currently happening. "A 69 year old participant stated, "I feel very angry because I cannot jump the ropes that I used to jump" A 30 year old



participant remarked ,"Your relationship is not strong because we are not performing as what we were doing before. Before I'll go three times but now one per week is a lot of job." These participants had normal erections that allowed successful intercourse, often many times. Now they miss their past performance in intercourse due to experiencing erectile dysfunction. Successful performance/s defined the person's sexuality but now that definition is changed negatively due to the inability in having an erection and intercourse.

#### Theme3. Devouring relationships

Participants verbalised that their relationship with their partners were significantly negatively affected by them experiencing erectile dysfunction. A 34 year old participant stated, "Well when you no longer satisfy her needs, she will have a problem with that. That will affect your partner negatively which will actually be a problem in your relationship." Relationships with partners have endured strains due to erectile dysfunction with the possible outcome of divorce. This is evidenced from the statement made by a 45 year old participant, "There is a strain in the relationship. It will come to a point where my wife will divorce me." Another participant who is 56 years old with erectile dysfunction for four years stated that erectile dysfunction is" causing a problem to me with my partner as she does not like this as I always leave her on all the time." Erectile dysfunction becomes a problem for the participant's partners and culminates in," lots of fights in the house because of the problems of erectile dysfunction," as stated by a 30 year old participant. Suspicions shadow the relationship with doubt when a 56 year old participant stated, "When you see your wife hiking from town, you think maybe she has got someone else." A 45 year old participant states," My wife will go to town, meet someone and ask for love, go to a hotel and sleep and it will mean something good as she knows that I cannot."

Participants verbalised their fears and worries that their partners will leave them and may look for someone else to satisfy them. This becomes evident in the statement of a participant," My fear is that I may lose her." A 52 year old who said," If a man is not satisfying his wife, the wife goes and looks for someone else." A similar view was expressed by a 45 year old participant, "I think that she will be thinking about somebody who is going to satisfy her." A 56 year old participant not only fears his wife leaving him but also fears sexually arousing his wife. He says, "Fear to touch her. Because I know that I am not going to satisfy her. I always like to be with her and it's difficult to satisfy her, I've got that fear always with me. "

#### Theme 4. Loss of Manhood

In this theme participants experienced loss of who they are as husbands and loss of their functioning in this role. Their manhood and masculinity have been challenged due to erectile dysfunction. A 34 year old states that the major stress that he is going through is the feeling that he is not man enough to function. While another patient said, "I feel I have lost my manhood, anyone looking at me sees that I am not a man now." These feelings are echoed by other participants who feel that they are not man enough or a full man because the "man part is not working right," as stated by a 56 year old participant.

A 69 year old participant referred to his wife as, "being like a sister now as I cannot do anything to her." He goes on to say, "I am like a woman." A 45 year old participant stated, It's terrible not to be a man. I am just like a woman to her, which is bad. Even if I look at a woman naked, I can't. It just stays down like that," (referring to his penis). The same feelings come across from a 53 year old who states, "When I want to make love to my wife, my penis doesn't wake up. I get angry with myself when I look at my naked wife and my body does not respond." A participant who is 30 years old states, "You want to make someone happy and you can't." One participant stated that even though you want to take care of your woman, you cannot.

#### Theme 5. Hoping for treatment

In this theme participants wanted to know from the researcher if there is a solution to erectile dysfunction. This is evidenced by a 53 year old participant who asked the researcher "Is there a solution to this?" A request was made from a participant to the researcher, "The only thing that I can ask you is whether you can try and get me something to use." The hope of finding a treatment was on the minds of many participants.

One participant verbalised that he did go to the doctor for treatment and stated, "I went to the doctor and he can't help you". He goes on to say that the doctors are not concerned about it. Some participants are aware of prescribed and non prescribed treatments that are available for erectile dysfunction. A participant who is 53 years old knows that there are tablets but feels that they will affect him negatively because of the renal failure. Participants have thought about the using non prescribed treatments (muties) that are sold on the streets but are afraid of using them because of they are in renal failure. A 45 year old participant verbalised that he did try to help himself but was unsuccessful, "I have tried many things. I've tried those other people who broadcast on the streets, but it doesn't help."

The desperation for the treatment of erectile dysfunction is evidenced by statements that were made like," Is there a doctor who can help me through this. Can I ask if it is possible, can it be quick? So that I can be a man again. I am longing to be a man again." The same participant responds, "Yes I am desperate. Just get the treatment quickly." Another participant stated, "I will be grateful if a solution can be found for this problem. My wife will appreciate it if there is any help on this part to rectify this problem." All the participants see a solution for erectile dysfunction as a way out of their problems that were caused by erectile dysfunction.

A participant verbalised that he thinks that him talking to the researcher may yield something to help him. He says," I am happy now because there is someone that I am talking to , maybe there is something that will help after this."

#### Theme 6. Distorted thoughts

Distorted thoughts and images occupy the participant's minds .According to the participants they are seen as failures by their partners and by significant others. Failure due to the inability to satisfy their partners despite being successful in other areas in their lives. This is evidenced by a 45 year old participant referring to other people talking about him as a failure. He says, "It seems as if I know that he can talk like this but there are times this one is a failure. They mustn't say, you see this man singing there , he is singing nicely but hey his wife is complaining." These thoughts result in the participants seeing themselves as failures. A 56 year old participant stated, "We know we are a failure. I am a failure because I can't satisfy my partner. I am the failure all the time." Participants also ruminated about what will happen to them and what can they do to alleviate the problem of erectile dysfunction. A participant said," But I won't just fall off to sleep at that moment, I just lie thinking what will happen? What should I do? Why?" Another participant remarked that this causes a mood change in him. He says, "In your mind there is worry and worry and I don't even know when I slept because I'm always tired and restless. I feel sad all the time. I am brooding on this problem." Loss of self esteem is evidenced by participants feeling of uselessness and helplessness in this situation. A participant remarked," Obviously from a man's point of view you feel incomplete, you feel useless you feel being problematic..." Another participant said that he loses confidence in everything that he does. "My biggest problem is that I don't know how to fix it. I'm lost. I don't know what to do to make my life easier and happier. I want some help to make life easier." These are statements made by one participant who is helplessly facing his painful situation.



#### Theme 7. No way out

In this theme participants have remarked that the only way out of this painful situation is for them to be dead. A sense of defeat was evident when a participant verbalised that he prefers to be dead than to be living with erectile dysfunction. This participant said," Sometimes I feel it is better that I am dead. I'm not there." He goes on to say," So if somebody can take my life, maybe that will be alright rather than staying with the bad." He sees death as the only solution, "nothing has been done so far and that is the only solution."

Another participant who is 45 years old supports this statement when he says, "They are not supposed to be living in this world, you must leave this world so that they don't have nothing to say about you." An unmarried 30 year old participant sees the problem of erectile dysfunction as ongoing and as a disruption in the prime of his life. He states," I am still young; I should be enjoying my life. For me it is hard as I am still young, most of the patients that have the problem are twice my age. It is not a big thing for them, but for me it is. I was thinking what will happen from now while I am performing like this and after three years how will the situation be. We are still young. We should be enjoying this part but now we can't."

#### Theme 8. Emotional trap

Participants were submerged in negative feelings and emotions. These feelings often occurred when intercourse is expected by both parties but was not successful due to erectile dysfunction. Feelings of frustration and anger descends on the participants. A 34 year old participant said, "the worst frustrating scenario is when your partner initiates the intercourse, it becomes impossible...you feel so trapped emotionally. You get irritated." Another participant was noted to have feelings of frustration, "It is frustrating. To be honest it's very frustrating that I am not able to sleep with her. It makes me angry. Participant's anger is directed to themselves as evidenced by a participant's statement, "I feel angry with myself because I cannot function well." Their anger serves as a further mechanism for distancing their partners from them. A participant concludes that," If I get angry then I am driving her away from me." Sadness prevails in participants because they fail to satisfy their partners. A participant who is experiencing erectile dysfunction for four years states," I am very sad about this and it has taken me ...this is the fourth year with this." A 66 year old participant states that he feels sad as that part in normal life is missing in marriage.

Compounded with the above emotions participants are also worried about the effect that their non performance will have on their partners. Some verbalised that they worry that their wives may divorce or leave them. One participant stated," It worries me that she may elope with another guy while another states," What worries me is to be left by my wife."

Guilt becomes an overwhelming emotion faced by participants. They see themselves as to be blamed for their situations. A 30 year old participant states" You have to blame yourself. The high blood pressure caused my renal failure, if I had lived my life well at that time or looked after myself more carefully, I would not get this renal failure. But now I've got it." Another participant who is experiencing erectile dysfunction for 4 years stated," I'm leading her on and it is very difficult. There is nothing I can do. I get upset because I know the problem is with me."

#### Theme 9. Silent breakdown

Difficulty in maintaining open communication between a participant and his partner or significant other is verbalised by most of the participants. These participants do not know how to approach their partners with this problem. One participant said," We are not good at communicating with this issue. You feel so trapped emotionally to actually communicate that it just doesn't function. A 45 year old participant said, "I feel embarrassed to talk to my closest friend as people will think that I

am a failure." While another participant explained the difficulty that he faces with communicating with his partner when he says," For men it is hard to go out and just talk about it." He verbalises that he would rather talk to other patients who are in the same situation as him," Sometimes we talk patient to patient because he experience and knows about it but for someone outside it is very very hard to talk about it because they will not understand." Not communicating with someone else regarding their concerns and fears caused by erectile dysfunction has left the participants in doubt and to guess what is going through the partner's mind. One participant said," Thinking or guessing of exactly what might be going through your partner's mind within this whole period." A 66 year old participant who has had erectile dysfunction for 3 years said," I don't know how my wife takes it. But she does not speak about it. I do not know my wife's feelings. She does not discuss her feelings." Another participant responded," I do not think my wife knows what's going on. No, I have not spoken to her."

One participant acknowledges that not communicating about his situation is unhealthy for him," It makes me feel sick, if I keep all inside and not talk about it."

#### Theme 10. Intimacy lost

In this theme participants have verbalised that they are experiencing loss of interest in intercourse due to their inability in satisfying their partner's sexual needs. Although the participants want to make their partners happy they are not successful in doing so. "You want to perform and make your partner happy, but you can't make her happy," a response from one participant. A participant noted that the partner has a problem if her needs are not satisfied therefore, "this makes you to lose interest in intercourse." Another participant noted that he has "loss of feeling of having sex". A 45 year old participant said that his desire for sex is for one day and for the next 2 to 3 days he has no desire for sex even though his wife expects it. Another participant had a similar comment," I have met her on Monday, then now the whole week I am not interested," (referring to having intercourse with his wife). Partners have also counter responded to the participants' inability to satisfy their needs .One participant responded that his partner has lost interest in intercourse," Now she refuses to give me cos I am not going to finish her." Added to this another participant said, "She has stopped all the advances that she used to do when I was well. She just sleeps." A participant explained that his wife has stopped making sexual advances to stimulate him prior to intercourse. He says," My wife displays everything to me yet before she used to hide herself when she went for a bath so as to provoke me or stimulate me but it does not happen."



# **ANNEXURE N**

## PARTICIPANT HANDOUT OF THE FINDINGS OF THE STUDY



#### **Dear Patient**

# Re: The study on the lived experiences of haemodialysis patients with erectile dysfunction

The overall aim of this study was to generate an in-depth understanding of the lived experiences of patients with erectile dysfunction who are on a haemodialysis programme in three renal units in Kwa-Zulu Natal. This understanding formed the basis for proposing recommendations to facilitate the mental health of patients with erectile dysfunction in the context of this study. The recommendations focused on nursing practice, education and research.

Below are the findings and recommendations on the study that was conducted by Tilly Govender.

## 1. The collection of data through the interviews with you and the naive sketch written by you presented the following findings:

All the participants (patients who participated in the study) revealed that erectile dysfunction started after the commencement of haemodialysis. In the interviews and written naive sketch, it was evident that you and the other participants had limited control over the attaining and maintaining of an erection for successful sexual intercourse with partner. Therefore this left you and the others with a loss in sexual performance.

Due to the loss in erectile functioning and the inability to engage in sexual intercourse with their partners, most of the participants experienced loss of identity because their manhood and masculinity were challenged. The result was a low self esteem expressed by the most of the participants. Some of the participants expressed a longing to be with their partners to engage in sexual intercourse but this longing is hampered by the loss of sexual desire and initiative. The outcome was the loss of sexual fulfilment experienced by these participants.

Erectile dysfunction evoked feelings of frustration and anger in the participants for not being able to engage in sexual intercourse with partner, thus some of the participants blamed themselves for the loss in sexual functioning. Feelings of sadness and guilt for not meeting partners' sexual intercourse needs were expressed by some of the participants. Added to this some of the participants were embarrassed to talk about their experiences of erectile dysfunction to others including the partner, professional nurse practitioner (nursing sister), doctor or friend resulting in a loss in sharing and communicating their experiences of erectile



dysfunction with their partner and others. Some participants were worried about the relationships with their partners, whether their relationships will break up or not.

Erectile dysfunction did not only affect the participants but also their partners as well. The loss in communicating their experiences of erectile dysfunction with their partners had a negative impact on the relationship between most of the participants and their partners. This resulted in the loss of emotional closeness between them. Relational and interpersonal conflict between most of the participants and their partners were experienced with expressions of potential break up of their relationships because of the participants' experiences of erectile dysfunction.

Two participants and their partners have accepted the participants' experiences of erectile dysfunction as due to their being of older age and the dialysis. They maintain a healthy relationship with their partners because of their acceptance of erectile dysfunction and their communication about their experiences of erectile dysfunction to their partners. They implement alternative strategies to maintain this healthy relationship like kissing, cuddling their partners, holding each other when sleeping together even though there is no sexual intercourse between them. One participant verbalised that love is more important than sex.

#### 2. The analysis of the findings produced the following recommendations:

The professional nurse practitioners in the haemodialysis units must provide holistic nursing care including care on the physical, psychological and social dimension. It is the responsibility of the advanced psychiatric nurse practitioner to provide workshops and support services to develop the professional nurse practitioners to provide holistic nursing care to the patients in the haemodialysis units. The professional nurse practitioners must encourage the patients to talk about their experiences of erectile dysfunction with a significant other, partner, professional nurse practitioner or their doctor. To be able to do so the professional nurse practitioners themselves must feel comfortable to address the patients concerns about their sexual functioning with them.

The professional nurse practitioners must work with the doctor and make appropriate referrals to psychologist, psychiatrist or a sexologist as required. The professional nurse practitioner and the advanced psychiatric nurse practitioners can facilitate psychoeducational and group therapy for the patients where their experiences of erectile dysfunction can be addressed. In the therapy group patients can learn how to communicate their experiences of erectile dysfunction to significant other and strategies to restore intimacy with their partner. Some of the strategies that can prevent conflict in their relationship with



partners are, romance, time spent with partner outside the bedroom, foreplay, mutual caressing, kissing, hugging, cuddling partner and holding partner when sleeping.

The curriculum of the nephrology course should include a module of mental health with the goal of the professional nurse practitioner to provide holistic nursing care to the patients on haemodialysis. With the orientation of the new professional nurse practitioner in the haemodialysis unit, the professional nurse practitioner is to receive an orientation manual that includes a module on the assessment of patients' sexual performances and the management of sexual dysfunction. Prior to the commencement of haemodialysis patients are to be given educated on erectile dysfunction by providing them with pamphlets thus allowing them to feel comfortable to communicate their experiences of erectile dysfunction to the professional nurse practitioners.

Future research on erectile dysfunction is recommended with emphasis on other areas regarding the experiences of erectile dysfunction.

Finally, I thank you for your participation in this study.

Tilly Govender



# **ANNEXURE O**

## **CONSENT OF CONFIDENTIALITY BY TRANSCRIBER**

## CONFIDENTIALITY AGREEMENT

# CONFIDENTIALITY AGREEMENT WITH REGARDS TO THE TRANSCRIPTION OF AUDIO RECORDINGS

- 1. I understand that all material received for the purposes of the transcribing audio taped records of the interviews with participants in the study are personal and confidential.
- 2. Lunderstand that the identity of participants as well as the content of the interviews must be
- kept confidential and may not be revealed unless according to the protocol for the study.
- 3. I undertake herewith to treat all material received and content to which I have access with appropriate professional confidentiality, ensuring this by storing all copied material securely and by returning all copies back to the investigator after completion of the transcription.

NAME:	LEATITIA PELSER
SIGNATURE	: As
DATE:	11/09/2009
PLACE:	MIDEANO
WITNESS:	A Sage



# **ANNEXURE P**

## CONSENT OF CONFIDENTIALITY BY INDEPENDENT CODER



# CONFIDENTIALITY CLAUSE REGARDING DATA COLLECTED FROM PARTICIPANT IN THE STUDY

TITLE OF STUDY: The lived experiences of haemodialysis patients with erectile dysfunction: A phenomenological study.

I, Charlotte Engelbrecht, 6309010148087 (include full name and ID number) hereby accept responsibility for maintaining confidentiality of the data (transcribed interviews, naïve sketches and field notes) that were submitted to me by Ms S Govender (researcher of the study) for the purpose of data analysis.

Charlotte Engelbrecht (M.Cur)

Name of independent coder

Signature of independent coder

26 07/2010



# **ANNEXURE Q**

## **LANGUAGE EDITING OF THESIS**

3 May 2011

#### TO WHOM IT MAY CONCERN

I, Suzette Marié Swart (ID 5211190101087), confirm that I have edited the following thesis:

Name of student:

#### **SOUNDALAY GOVENDER**

Title of thesis:

LIVED EXPERIENCES OF HAEMODIALYSIS PATIENTS WITH ERECTILE DYSFUNCTION: A PHENOMENOLOGICAL STUDY

Thank you

Suzette M Swart\* (not signed – sent electronically) 0825533302 smswart@vodamail.co.za

### LANGUAGE PRACTITIONER/EDITOR:

The Consortium for Language and Dimensional Dynamics (CLDD) University of Pretoria (UP) Tshwane University of Technology (TUT) University of Johannesburg (UJ) University of South Africa (UNISA)

#### The edit included the following:

- Spelling
- UK vs USA English
- Vocabulary
- Punctuation
- Grammar (tenses; pronoun matches; word choice etc.)
- Language tips
- Correct acronyms (please supply list)
- Consistency in terminology, italisation etc.
- Figure/Table numbers etc.
- Sentence construction
- Suggestions for text with unclear meaning
- References (consistency in text and against bibliography)
- Basic layout, font, numbering etc.
- Logic, relevance, clarity, consistency
- Style

<sup>\*</sup>Member of The Professional Editors' Group



#### The edit excluded:

- Correctness of crediting another's work PLAGIARISM.
- Content
- Correctness or truth of information (unless obvious)
- Correctness/spelling of specific technical terms and words (unless obvious)
- Correctness/spelling of unfamiliar names and proper nouns (unless obvious)
- Correctness of specific formulae or symbols, or illustrations
- Style
- Professional formatting

Suzette M Swart



# **ANNEXURE R**

## **TECHNICAL EDITING OF THESIS**



Leatitia Romero 083 236 4536 leatitia@ananzi.co.za



PO Box 8431 Halfway House 1685

Mirage Visions

TECHNICAL EDITING

September 2011

To whom it may concern

This letter serves to confirm that in September 2011 I, Leatitia Romero, ID 840322 0001 083 did the technical editing for the Dissertation of Soundalay Govender.

The technical editing process involves checking the conformity of the entire document with regards to headings, line spacing, page numbers, references, tables and figures. It does not involve any language editing or checking of content whatsoever. Annexures and appendices are also left unedited.

The author has been made aware that any changes to the document will result in the technical aspects of the work to change. Therefore it is strongly recommended that the document be converted to PDF before submission to the printers, since this will eliminate accidental errors occurring.

This confirmation refers only to technical editing work done up to the date of this letter and excludes any changes made by the author after this date.

Leatitia Romero