

CHAPTER 1

1.0 INTRODUCTION

The background of the study will focus on the incidence and prevalence of Chronic Kidney Disease (CKD) leading to End Stage Renal Disease. When this stage in this disease is reached a person commences renal replacement therapy, such as Haemodialysis. The definition of Chronic Kidney Disease and its sequelae will also be addressed together with Haemodialysis and the effect it has on the family caregiver. This chapter will cover the problem, purpose of the study, objectives and the significance of the study to both family caregivers and health professionals.

1.1 BACKGROUND OF THE STUDY

Chronic Kidney Disease (CKD) has become a major health problem worldwide affecting all nations regardless of economic status or ethnicity. The impact of this major health problem eventually led to the development of the Kidney Disease Outcome Quality Initiative (K/DOQI) in 2002, its objective to set practice guidelines for the treatment and management of Chronic Kidney Disease and End Stage Renal Disease. The National Kidney Foundation Kidney Disease Outcomes Quality Initiative Clinical Practice Guidelines defined Chronic Kidney Disease, as kidney damage and a glomerular filtration rate lower than 60mls per 1.73 m² for 3 months or longer, resulting in End Stage Renal Disease (ESRD). Upon later analysis the Kidney Disease Improving Global Outcomes (KDIGO, 2012) revised this definition include albuminuria as a further indicator for ESRD. A 5 stage classification of increasing severity for this condition was initially established by the United States based National Kidney Foundation (NKF) and subsequently adopted by the Kidney Disease Improving Global outcomes in 2012 for international use. See table 1:

Table 1: Stages of Chronic Kidney Disease

Stage	Description	Glomerular filtration rate ml/min/1.73m ²
1	Slight kidney damage with normal or increased filtration	More than 90
2	Mild decrease in kidney function	60 – 89
3	Moderate decrease in kidney function	30 – 59
4	Severe decrease in kidney function	15 – 29
5	Kidney failure requiring dialysis or transplantation	Less than 15

Adapted from K/DOQI (2002)

It has been estimated that approximately 500 million individuals globally have some degree of Chronic Kidney Disease. This number translates to about 1 in every 10 adults suffering from Chronic Kidney Disease (Walli, 2010). The 2010 Global Burden of Disease study Chronic Kidney Disease was ranked 18th in 2012 with an annual mortality rate of 16.3 per 100 000 (Lozano, Naghavi, Foreman, Lim, Shibuya et al, 2010). Paraskevas, Bessias, Koupidus, Tziviskou, Mikhaidis and Oreopoulos (2010), state that the rate of Chronic Kidney Disease is increasing worldwide at an annual growth rate of 7% per annum which is evident in one of the private dialysis companies' global statistics. Fresenius Medical Care is an example of a private company which provides an integrated service in over 120 countries, treating a total of 257 916 patients at 3 160 dialysis clinics worldwide; a number which increased by 12% from 2011 (Fresenius- online Annual report-FMC, 2012). This clearly indicates an increase in the number of patients who are being diagnosed with Chronic Kidney Disease and who are on haemodialysis therapy.

The National Health and Nutrition Examination Survey (NHANES) data analysis from 2001 to 2010 deduced that 10.2% of the population in the United States, above the age of 20, were in stage 1 to 4 of Chronic Kidney Disease and 1% of this population will progress to stage 5 of Chronic Kidney Disease (Kuznik, Mardekian and Tarasenko, 2013). The number of Americans who were being treated for End Stage Renal Disease by the end of 2012, were 594 000 (United States Renal Data System, 2013). The population prevalence of Chronic Kidney Disease of varying severity in Australia is 11.5% an estimate of 1.4 million adults (White, Polkinghome, Atkins and Chadben, 2010). The annual report from the Korean registry showed the prevalence of patients undergoing renal replacement therapy was ranging

from 181.5 to 1.144.4 per million population (Jin, Ha, Kim, Lee, Lee, Yoon and Kim, 2012). In Sweden the prevalence of End Stage Renal Disease is more than 923 per million inhabitants and the incidence of renal replacement therapy was 125 per million inhabitants (Swedish Renal Registry Annual Report, 2012). A systematic review of 26 studies showed a prevalence rate of Chronic Kidney Disease of 7.2% in patients older than 30 years and a prevalence rate ranging from 23.4% to 35.8% in those older than 64 years (Zhang and Rottenbacher, 2008). A community based study in South Africa showed prevalence rate of Chronic Kidney Disease with advanced age which accelerated after 50 years of age (Matsha, Yako, Rensburg, Hassan, Kengne and Erasmus, 2013).

The treatment options for End Stage Renal Disease include haemodialysis, peritoneal dialysis, kidney transplantation and conservative management (Oxford Handbook of Dialysis, 2009). In-centre Haemodialysis is the most common renal replacement therapy in the world (United States Renal Data System, 2010). Haemodialysis is a process which accesses the patient's blood (haem) via an extracorporeal (outside the body) circuit and passes it through a filter (dialyser) where dialysis (diffusion across a semi permeable membrane) takes place (Oxford Handbook of Renal Nursing, 2009). The number of patients being treated for End Stage Renal Disease globally is estimated to be 3 010 000 at the end of 2012 with haemodialysis being the most common modality with approximately 2 106 000 persons on haemodialysis worldwide (Global Fresenius Medical Care Market Survey, 2012). The survey further states that more than 50% of the global dialysis patient population is being treated in just five countries, namely, the United States of America, Japan, China, Brazil and Germany. The dialysis population within Africa accounts for only 4.5% of the world's dialysis population, with a prevalence of 74 per million compared to a global average of 250 per million population (Abu-Aisha and Elamin, 2010).

According to the Centre for Disease Control and Prevention National Chronic Kidney Disease Fact Sheet (2010), African Americans with Chronic Kidney Disease are four times more likely to develop End Stage Renal Disease than the Caucasians, and Hispanics have 1.5 times the rate of developing Chronic Kidney Disease compared to non-Hispanic whites. Studies have shown that certain diseases are common among certain ethnic groups (Mbanya, Motala, Sobngwi, Assah and Enoru; 2010). Studies in the United States of America focused within certain ethnic groups such as African Americans, Hispanic Americans and Caucasians (Alves and Lewis, 2010). A higher prevalence of Chronic Kidney Disease is noted amongst Africans (Aktinson, Pierce, Zack, Barletta, Yadin, Menster, Warady and Furth, 2010). The

authors Alves and Lewis identified ethnicity as a determinant of health outcome though they suggest socio economic status also has a significant impact on health rather than ethnicity.

In South Africa, according to the statistics of the South African Dialysis and Transplant Registry (SADTR) reflect patients selected for renal replacement therapy only (Naicker, 2003). An estimated 430 000 South Africans are living with End Stage Renal Disease. Updated statistics will be available at the end of 2013, according to Naicker (see email Appendix H). The absence of reliable Chronic Kidney Disease registers within African countries has led to difficulties in estimating the extent of people with End Stage Renal Disease and the number of patients on haemodialysis. In developing countries the prevalence of Chronic Kidney Disease is expected to be higher due to the poor socioeconomic status of the population (Naicker, 2003). The number of patients on dialysis treatment rate ranges from 70 per million population in South Africa, compared to less than 20 per million population in most of sub Saharan Africa in 2009 (Naicker, 2009). Lower numbers of patients on dialysis treatment are reported in third world countries due to a lack of registries. However, where economies are growing, such as the economy of South Africa, the number of patients being accepted for renal replacement therapy is on the increase (Jha, 2009). The number of patients with Chronic Kidney Disease is presumed to increase in the poorest parts of the world, but a strong association is seen between low levels of economic development and reduced availability of renal replacement therapy (Vivekanand, Guillermo, Kunitoshi, Zuo, Saraldevi, Brett, Rajiv, Angela and Chih-weih; 2013).

Katz, Gernholtz and Naicker (2011), emphasise that the delivery of health care services within African countries has been classified as really challenging because of the ratio of nephrologists to the general population in Africa and it is likely to be the lowest in the world due to the exodus of skilled professionals and a lack of infrastructure. The primary challenge of combating the disease is to determine the prevalence of Chronic Kidney Disease leading to End Stage Renal Disease within a continent in order to provide evidence that Chronic Kidney Disease is a public health problem (Katz et al, 2011). According to the 2010 US Renal Data System Annual Report, the leading causes of Chronic Kidney Disease which result in End Stage Renal Disease (ESRD) in the United States is diabetes, hypertension and glomerulonephritis (Collins, Foley, Herzog, Chavers et al, 2010). The prevalence estimates by gender for End Stage Renal Disease were males 56.7% and females 43.3% (United States Renal Data System, 2012), showing that men are at a higher risk compared to females. Furthermore, the USRDS (2012) states that End Stage Renal Disease prevalence was greater

in persons with diabetes 37.8%, hypertension 25%, glomerulonephritis 14.6% and cystic kidney disease 4.8%.

In a study done by the South African Dialysis and Transplant Registry (SADTR), it was found that hypertension was reported to be the major cause of End Stage Renal Disease giving the figures of 34.6% of black South Africans, 20.9% mixed race group, 13.8% Indian descent and 4.3% white South Africans (Naicker, 2003). This study was conducted over a 6 year period. In a further study done by Naicker in 2010, it was noted that Chronic Kidney Disease affected a large number of young adults between the ages of 20 to 50. Naicker further states that, in sub Saharan Africa, Chronic Kidney Disease was primarily caused by hypertension and glomerulonephritis, unlike in developed countries where Chronic Kidney Disease presented in middle aged and elderly patients and was predominately due to diabetes mellitus and hypertension (Naicker, 2010). Human Immunodeficiency Virus can also cause Chronic Kidney Disease and can contribute significantly to the burden of patients requiring treatment such as haemodialysis. Human Immunodeficiency Virus associated nephropathy (HIVAN) is the third commonest cause of End Stage Renal Disease in black patients in the United States of America after hypertension and diabetes, and since the availability of antiretroviral therapy, HIVAN was in the 7th place (USRDS, 2006).

End Stage Renal Disease is 3 to 4 times more common in Africa than in developed countries (Naicker, 2009), as the presence of chronic dialysis services is low in Africa with the exception of North Africa and South Africa. It could be argued that the current dissemination of Chronic Kidney Disease awareness campaigns and information appears to favour mainly population groups in urban environments as they are exposed to media and have easy accessibility to health services and information especially patients who are dialysed in the private sector. The absolute reality is that there is not enough financial support and assistance for the delivery of health care services, coupled with the availability of skilled labour, for the provision of renal replacement therapy especially in sub Saharan Africa (Naicker, 2009). Chronic Kidney Disease, although no longer fatal, is a prevalent chronic condition requiring long term treatment.

It has been noted that renal replacement therapy is often unavailable or unaffordable. The availability of renal replacement therapy in Africa is largely due to donors and funding. The need for treatment of Chronic Kidney Disease with Haemodialysis and/or kidney transplantation arises in 1% of people with Chronic Kidney Disease; and it remains the most

expensive form of treatment (KDIGO, 2012). Nearly one million people die of End Stage Renal Disease each year in developing nations (Barsoum, 2006) due to lack of early detection and treatment of Chronic Kidney Disease. The high mortality rate associated with Chronic Kidney Disease in Africa is attributed to a number of factors, including infectious disease due to poor sanitation, late referrals due to location of medical centres, cultural perceptions of traditional methods and limited renal replacement therapy (Eastwood, Kerry, Plange-Rhule, Micah, Antwi, Boa, Banerjee, Emmett, Miller and Cappuccio, 2010; Madala, Nkwanyama, Dubula and Naicker, 2012). A study by Ulasi and Ijoma (2010) in the eastern part of Nigeria made the observation that 50% of patients in stage 5 kidney disease underwent dialysis; however, a majority of this group stopped dialysis after a few sessions due to financial constraints. Naicker (2009) further supports this by stating that in many African countries, haemodialysis treatment is mainly available in the private sector and patients are unable to afford dialysis beyond the first 2- 3months.

The public sector offers haemodialysis and peritoneal dialysis to patients who are eligible for kidney transplant (Naicker, 2003). An updated statistics of the number of patients diagnosed with Chronic Kidney Disease, End Stage Renal Disease and on Haemodialysis treatment will be available at the end of 2013, according to Naicker (see email Appendix H). Kidney transplantation has been limited to North African countries such as Egypt and also South Africa with little or no transplantation having been done in other countries (Katz et al 2011). In some third world countries such as Sudan and India, patients receive haemodialysis twice a week instead of three times per week due to cost of Haemodialysis treatment (Karopadi, Mason, Rettore and Ronco, 2013). According to the United States Renal Data System (2012), haemodialysis costs \$87 561 (US dollars) per year per patient, of which each patient requires two or three sessions a week per four hour session of haemodialysis. According to the Kidney Disease Outcome Initiative Guidelines (2002), this is in line with the recommended and preferred frequency for haemodialysis therapy. About 2-3 % of the health care expenditure in developed nations is used to provide treatment for patients with End Stage Renal Disease even though they account for only 0.1 to 0.2% of the total population. In 2010, treatment costs for End Stage Renal Disease accounted for 6.3% of the Medicare budget in the United States of America (United States Renal Data System, 2012), of which the annual cost of treatment was 47.5 billion US dollars.

In the South African private sector, the majority of patients on haemodialysis are covered by health insurance therefore this study is based on patients who are dialysing at private

Haemodialysis units. The unemployment rate in South Africa was 25.5% for the first quarter of 2012 (SA Department of Labour, 2013) and the ability to pay for medical insurance is reliant on the patient being able to remain gainfully employed or have a strong family support structure. Currently the priority of many countries is to develop, improve and strengthen their health systems in order to support, prevent and treat notable diseases such as Chronic Kidney Disease (Dye, Bogale, Hobden, Tilahun, Deressa, Bize and Reeler, 2010). There is a shortfall in the development of suitable health monitoring systems for Chronic Kidney Disease in Africa (Oviasu, 2012); therefore the condition is detected late leading to patients commencing treatment too late. Funding for renal replacement therapy is primarily private though much of Africa with the governments of only a few countries providing treatment for a small number of patients. In countries such as South Africa and Egypt, indigenous South Africans can access dialysis treatment at public institutions only if they are eligible for a kidney transplant Naicker (2009).

Chronic Kidney Disease imposes a substantial economic burden on the patient and families tend to experience a loss in income and changes in lifestyle because of diverting household finances to care and welfare costs (Vivekanand et al, 2013). As a result of income and lifestyle adjustments, a growing number of patients with Chronic Kidney Disease rely on non-professional health care providers, mainly their relatives, to assist and manage their condition throughout their life. Relatives are often the primary caregivers for people with chronic illness such as patients on haemodialysis (Smith, Greenberg and Seltzer, 2007). Relatives have to cope with the patient's emotional feelings, low acceptance of the disease and loss of personal control over their lives (Tong, Sainsbury, Walker, Harris, Carter, Hull, Hawley and Craig, 2009). Since Chronic Kidney Disease is not curable, it is important that relatives understand that chronic illness not only affects the patient but also the inter relationship between the patient and themselves (Ellenwood and Jenkins, 2007). A study done by the World Health Organisation (WHO) estimates that in many developing countries the need for caregivers will increase by as much as 400% in the coming decades (WHO, 2002a), therefore, long term care for people with chronic illness presents an urgent challenge. In South Africa the number of patients on haemodialysis is increasing with an annual growth of 7% (Paraskevas et al, 2010). In Africa this increase is expected to be much higher due to the poor socio-economic environment (Naicker, 2003).

Research regarding relatives living with a person who suffers from a Chronic Kidney Disease reveals a reduced sense of individual freedom arising from the responsibility for the care of

the patient who is on haemodialysis treatment (Esbensen and Thome, 2010). Hickman and Douglas (2010), state that an episode of chronic illness exposes the relatives to the reality of future critical illness which includes recurrent infections, hospital readmissions and diminishment of a patient's health overtime. These comorbidities compromise the patients overall ability to function and the acquisition of knowledge increasing the caregivers burden (Gayomeli, Sutherland and Finklestein, 2008). Hickman and Douglas (2010) agree that an episode of chronic illness exposes the relatives to the reality of future critical illness which includes recurrent infections, hospital readmissions and diminishment in the patient's health overtime and say that this eventually depletes the coping resources of the family and renders the family susceptible to psychological health problems such as depression. This study therefore explores the perceived benefits and burdens encountered by relatives caring for persons on long term haemodialysis, Johannesburg.

1.2 PROBLEM STATEMENT

Patients with Chronic Kidney Disease are dependent on family caregivers due to the chronicity of the illness. Haemodialysis is a long term treatment which is very expensive, as patients need to spend the prescribed hours, which can amount to 12 hours per week, on haemodialysis (KDOQI, 2002). This time commitment to treatment can eventually lead to unemployment leading to financial difficulty resulting in the financial burden being transferred to the family caregivers. This requires a lifestyle modification for the family caregivers to suit the requirements of treatment. Although benefits of being a family caregiver are noted, these arise from being able to give back to someone who has cared for them and the satisfaction of knowing that their loved one is getting excellent care. This incurs challenges for the family caregivers as they have minimal support from the health care system and government financial support to aid them in caring for their relatives on haemodialysis. In this study, the researcher attempts to identify the perceived benefits and burdens of caring for a patient on haemodialysis by family caregivers in a South African context. Several countries such as America, Australia and England have researched this topic but no research has been done in South Africa, despite the growing extent of the problem.

1.3 PURPOSE OF THE STUDY

The purpose of the study is to explore and describe the perceived benefits and burdens encountered by relatives caring for persons on long term haemodialysis who are being treated in a private haemodialysis unit in an urban area in Johannesburg.

1.4 AIM AND OBJECTIVES OF THE STUDY

The objectives of the study are to:

1. Explore the perceived benefits and burdens of caring for a patient on haemodialysis by the family caregivers.
2. Describe the family caregivers perspectives on factors which challenge the process of caring.
3. Identify, from the caregivers, the perceived shortfalls in the health care system relating to caregiving by relatives.

1.5 SIGNIFICANCE OF THE STUDY

The study elicits the benefits and burdens of caring for a patient on haemodialysis as perceived by the family caregiver. The findings from this study will identify possible shortfalls in the education of family caregivers of patients on haemodialysis by understanding their perceived benefits and burdens involved in caregiving. Perceived shortfalls in the health care system will be identified relating to the support provided to the family caregivers who are caring for haemodialysis patients. The study will explore the benefits that the family caregivers have experienced in caring for their relative on haemodialysis. The challenges encountered by the family caregivers will be identified and possible recommendations for the improvement of support provided for the family caregiver will be posited.

1.6 OPERATIONAL DEFINITIONS

1.6.1 Caregiving

It is the act of providing unpaid assistance and support to relatives or friends who have physical, psychological or developmental challenges (The National Alliance for Caregiving, 2004). In this study, caregiving is considered to be the caring of persons on long term haemodialysis by family caregivers.

1.6.2. Family caregiver

Defined as any member of the family nominated by the patient on haemodialysis; this person could be a spouse, adult child, a relative, partner or friend over the age of 18 who provides assistance with at least one activity of daily living over a long period of time (National Alliance for Caregiving, 2004).

1.6.3. Caregiver burden

The burden caregivers experience may be understood as the need for work and lifestyle adjustment experienced by a family with a chronically ill patient, it is a multidimensional event that includes the requirement for constant care for the patient, financial worries and coping with the disruption of the family routine and changes in the roles in the family. Miyazaki, Dos Santos, Miyazaki, Domingos, Felicio, Rocha, Arroyor, Duca, Silva and Silva (2010).

1.6.4. Burdens

Defined as the observable costs to the family caregiver that results from the disease and its management, (such as disruption to everyday life) and includes the burden experienced by the family caregiver's perception of the situation as burdensome (Jungbauer, Wittmund, Dietrich and Angermeyer, 2004).

1.6.5 Benefits

Benefit finding may be a product of the ability to find meaning through positive reappraisals or other adaptive coping mechanisms in the face of stress (Haley, LaMonde, Han, Burton and Schonwetter, 2003).

1.6.6 Factors Affecting Family Caregivers Caring For A Patient on Haemodialysis

The Caregiver Burden Scale by Elmastahl, Malmeberg and Annestedtl (1996) subjectively assesses the caregiver burden of family caregivers caring for chronically disabled persons. In this study the Caregiver Burden Scale was used to assess the caregiver burden of the family caregivers of persons on long term haemodialysis. The Caregiver Burden Scale comprises of the factors General strain, Isolation, Disappointment, Emotional Involvement and Environment. Further definitions are given of the factors impacting on the caregiver in Caregiver Burden Scale and for further explication included on page 21 Chapter 3.

1.6.7 Chronic Kidney Disease

Defined as either kidney damage or glomerular filtrate rate less than 60mls per hour for three months or more. It is a progressive process that results in End Stage Renal Disease, National Kidney Foundation Disease Outcome Initiative classification of Chronic Kidney Disease (K/DOQI, 2002).

1.6.8 End Stage Renal Disease

Defined as an irreversible decline in kidney function which is severe enough to be fatal in the absence of dialysis or transplantation. End Stage Renal Disease is included under stage 5 of the National Kidney Foundation Disease Outcome Quality Initiative classification of Chronic Kidney disease (2002).

1.6.9 Haemodialysis

Is a process which accesses the patient's blood (haem) via an extracorporeal (outside the body) circuit and passes it through a filter (dialyser) where dialysis (diffusion across a semi permeable membrane) takes place, Oxford Handbook of Renal Nursing (2009).

1.7 CONCLUSION

In chapter one, the researcher focused on the background to the study, problem statement, objectives, significance of the study and operational definitions. The objectives will be used to guide the study through the literature review, data collection, data analysis, conclusion and recommendations. Acquiring the knowledge and problems encountered by family caregivers caring for family members who require Haemodialysis therapy, will assist family caregivers

to cope with their relatives on haemodialysis. In the following chapter, the literature regarding the renal dialysis and caring for persons with end stage renal disease by family members will be discussed.

CHAPTER 2: LITERATURE REVIEW

2.0 INTRODUCTION

The literature review in this chapter will include a discussion of the perceived benefits and burdens of caring for a patient on Haemodialysis by a family caregiver. Factors which challenge the process of caring and the perceived shortfalls in the health care system relating to caregiving by relatives will be reviewed. Recommendations by other researchers may address the shortfalls and to improve the care of patients on haemodialysis by health professionals and family caregivers are discussed.

2.1 LITERATURE REVIEW

Literature on family caregiving abounds particularly in the western countries such as the United States and in Europe (Suri, Larive, Garg, Hall, Pierratas, Chertouw, Gorodetsekeya and Kliger, 2011; Schipper and Abma, 2011). In Africa, particularly South Africa, there is a dearth of studies on the subject but there is a need for more research on the perceived benefits and burdens of caring for a patient on long term haemodialysis by family caregivers. Prolonged Haemodialysis treatment and the chronicity of the condition increases patient dependency on and a change in roles amongst the members in the family (Harillal and Kasiram, 2011). Patients tend to feel as if they are not worthy as they are unable to manage activities they could perform before they were ill. This eventually leads to their relatives gradually taking over the major roles in the family. Having a relative with Chronic Kidney Disease and on haemodialysis treatment brings with it a variety of emotions and financial obligations many of which are a strain for the family caregivers to meet. Continuous and repeated visits to the haemodialysis unit, which is the greater part of their care, lie solely with the relatives to ensure they attend treatment (Pourebrahimi, Rahimi, Tayebi, Ali and Ebrahimi, 2013). The frequency of the treatment results in strain on the family and their social lives (Calvey and Mee, 2011). Consequently, relatives are less free to plan their own personal daily activities (Ziergert, Fridlund and Lidell, 2009).

The patient's relatives basically take over the role of provider and face daunting financial challenges over the years as Haemodialysis is a treatment which stretches over a period of

time and is very expensive. Sources of income may shrink and many patients are overwhelmed by the cost of health insurance premiums (Burton, 2011). Finances are affected by the high cost of weekly treatments for Haemodialysis and occasional admissions to hospital due to complications arising from the End Stage Renal Disease (Theofilou, Synodinou and Panagiotaki, 2013) as most of the patients are managed in the private sector. A study done in Nigeria by Alasia et al (2012) analysed the sources of funding for End Stage Renal Disease care, the study showed that 65% of the patients funded their dialysis treatment from direct “out of pocket payment” for haemodialysis. This form of direct payment for Haemodialysis treatment, in many African countries, is not sustainable; hence most patients cannot afford to pay beyond 2 to 3 months (Naicker, 2009) eventually withdraw treatment.

Conversely, one of the main factors associated with patients discontinuing dialysis is they perceive that they have become a “burden” to close relatives (Ashby, Hoog, Kellelear, Kerr, Brooks, Nicholls and Forrest, 2005). The daily management of Haemodialysis inevitably leads to family caregivers and patients being unable to fulfil their personal and professional goals within the context of living with chronic illness (Theofilou, 2013b). Ziergert et al (2009), state that family caregivers of patients undergoing haemodialysis struggle to maintain control over their daily lives and have a constant concern about their relative’s condition. Family caregivers experience a fragmented existence by constantly feeling they must be available to support the patient’s medical situation. Ziergert et al (2009), they further mention that, relatives have a feeling of frustration and powerlessness associated with lack of awareness of the diseases prognosis. The most difficult caregiving tasks were those dealing with patient’s behaviour, problems and the most negative outcomes of caregiving was having less time for activities with other relatives and friends (Pressler, Gradus-Pizlo, Chubinski, Smith, Wheeler, Wu and Sloan, 2009).

In many instances being diagnosed with Chronic Kidney Disease and the necessity for implementation of haemodialysis are a cause of concern for the patient and the family caregiver and will ultimately lead to major changes in their lifestyle (Brunner et al 2010). Haemodialysis therapy does improve the patient’s quality of life and reduces the mortality rate of patients suffering from end stage renal disease. Before dialysis was available, patients with end stage renal disease faced imminent death. However since the development of haemodialysis and other forms of dialysis therapy, the life of patients with End Stage Renal Disease has improved and been prolonged (Theofilou, 2011a). Patients need to be compliant with treatment so as to avoid relapse, but due to costly implications of treatment, compliancy

can be a challenge, as observed by the researcher in her practice, some patients are unable to continue working due to the debilitating effects of the chronic illness. Relatives need to manage the consequences of the patients decline in bodily functions (reduced urine output leading to fluid overload), loss of energy and diet restrictions (low sodium diet) resulting from the disease (Tong et al 2009). The result being that patients on haemodialysis often end up being forced into early retirement due to multiple reasons including the employer's preference to keep an able bodied person in employment, lack of personal well-being, a reduced ability to concentrate and perform adequately (Karkar, 2011). Having a job for a patient on haemodialysis certainly creates a sense of meaningfulness, but a normal working life is complicated for the patients on haemodialysis due to frequent and regular absences from work to attend treatment sessions (Schipper and Abma, 2011).

Family caregivers of patients with Chronic Kidney Disease may risk losing their jobs due to absenteeism which further compounds their economic burden. A 2012 study by the American Association of Retired Persons (AARP) Public Policy Institute and the United Hospitals Fund reported that nearly half of the caregivers in their study performed complex medical and nursing care at home. Tasks included managing multiple medications, preparing meals to adhere to a specific diet and blood pressure monitoring. It can be a stressful experience to juggle caregiving with work and other family responsibilities, especially for those working caregivers (Reinhard, Levine and Sarris, 2012). In a recent study done by Reinhard, Levine and Sarris (2013), 57% of family caregivers had no say in becoming caregivers of their relatives it was a role that was thrust upon them due to the situation. Caring for a relative on haemodialysis is an activity that cuts across most demographic groups , though it seems to be more prevalent among adults between the ages of 30 to 64, spanning an of age group who is in the workforce (Fox, Duggan and Purcell, 2013).

End Stage Renal Disease sufferers in sub Saharan African countries have very reduced access to optimal management and care as a result of poverty, very little or no end stage renal disease care and the absence of government assistance for renal care (Alasia et al 2012). This incurs challenges for the family caregivers as they have minimal support from the health care systems, poor or no government financial support, government funding of specialist facilities and reduced access to health care. To receive government financial support for haemodialysis treatment, the single most important criterion determining selection for Haemodialysis in the public sector, is suitability for kidney transplantation (Moosa and Kidd, 2006). Hence only those earning an income can afford medical insurance for Haemodialysis treatment if they are

not considered potential transplant candidates. In South Africa, approximately one out of every five patients diagnosed with End Stage Renal Disease and on Haemodialysis therapy has a form of health insurance (Fink, 2010). Illustrating this is the fact that Limpopo province has one public dialysis unit available to the public sector and it serves a population of 6 million. Most of the patients reside in rural areas with some living up to 300km from the dialysis unit (Zaldivar, Rozumik, Yudina and Hale, 2012).

Chronic Kidney Disease is an illness which requires long term, integrated management. A well trained and experienced renal (multidisciplinary) team which includes nephrology nurses, a nephrologist, dieticians, community nurses and psychologists. As observed by the researcher, the availability of an integrated renal replacement therapy programme is vital to provide proper assistance and support to the relatives. This integrated approach helps alleviating psychological stress which is common with this illness. The integrated approach also aids the caregivers by, assisting with managing the side effects of haemodialysis with the eventual effect of improving compliance and the health of the patient on haemodialysis (Karkar, 2011). If a person reaches End Stage Renal Disease and is commenced on haemodialysis, but isn't psychologically prepared, the person will go through a stage of denial, shock, grief and anger and will not cope well with this stage of the disease, leading to psychological distress and depression (Mooney, Winterbottom and Bekker, 2009) and relatives are, unfortunately, often on the receiving end of the patients emotional behaviour.

Information on the South African Renal Society Guidelines is currently not been promulgated. However a study done in 2006, states that the patient, relatives and significant others should meet with a social worker to discuss treatment, gauge family dynamics and support structures. This is in agreement with the National Kidney Foundation Guideline of 2006 on the initiation of dialysis and preparation for potential kidney failure. They recommend that each patient be assessed prior to dialysis for assessment of their emotional, economic and social coping skills so that appropriate intervention can be determined. The family caregivers need to be involved in the diagnosis and management of their relative on haemodialysis in order for them to be well prepared for the challenges ahead. The researcher has observed that patients are often commenced on treatment without being briefed or counselled and consequently they do not understand their condition; this is true of their family caregivers as well. The guidelines in the South African Renal Society Chronic Guidelines (2006) appear not to heed the reality of scarce human resources, availability of human resources and haemodialysis units for patients.

Patients with End Stage Renal Disease and who are on haemodialysis often rely on their family caregivers to assist them with their daily living such as chauffeuring to and from the dialysis unit and medical needs such as medication administration. A high unemployment rate of 25.5% was noted for the first quarter of 2012 (Department of Labour, 2013), and as some family caregivers are willing to stay at home to assume a caregiving role for a patient on haemodialysis, this might add to the high employment rate. Moreover, if employed persons frequently absent themselves to care for relatives, they may well jeopardise their employment even if they are able to obtain work.

Many family caregivers derive positive benefits from caregiving including a sense of giving back to someone who has cared for them, the satisfaction of knowing that their loved one is getting excellent care, this might add to an increased meaning and purpose in their lives. A study by Rees, O'Boyle and Macdonagh, 2001, indicated that caregiving can be associated with increased self-esteem, pride, gratification and a closer relationship with the patient. In 2012, 60% of caregivers were employed and received a salary, 28% had children under the age of 18 years, yet despite these competing demands, 73% of the employed caregivers were content with their current balance between work and home life (Sonha, 2012). Patients on haemodialysis treatment value the assistance and support from their family caregivers (Harillal and Kasiram, 2011), allowing them to focus on their health.

The 2012 General Social Survey conducted a study in Canada, revealing that approximately 13 million Canadians aged 15 years and older, had provided some type of care such as assistance with activities of daily living or transportation to and from health facilities, for a relative who was chronically ill (Sonha, 2012). Consequences for employment were more long-term; possibly impacting the caregiver's career and /or benefits. Employed caregivers reported cutting down on their regular working hours to accommodate the caregiving needs of their relative on dialysis. A reduction in working hours can have consequences for the person's employee benefits, household income, availability of medical funds, life insurance and pension. Closely related to income is career development. In 2012 according to Sonha, 10 % of employed caregivers turned down or did not even pursue a new job as a result of their caregiving responsibilities. The more intensive caregiving responsibilities are, the higher the likelihood of the caregiver postponing or forgoing career opportunities. Reduced income may impact greatly on household income, while out of pocket expenses, such as purchasing medication, providing an ideal diet for a patient with End Stage Renal Disease and transportation costs increase. Consequently, family caregivers are less able to plan their own

activities (Ziegert et al 2009). Due to continuous and repeated visits by these patients to haemodialysis centres, the greater responsibilities for care of these patients is up to the relatives (Pourebrahim et al, 2013).

There have been various studies conducted which examined the levels of depressive symptoms among caregivers (Daly, O'Toole, Gordon, Hejal, Peerless, Rowbottom, Garland, Lilly, Wiencek and Hickman, 2010; Holstander and McMillan, 2011) and the majority of these studies indicate evidence of depression amongst caregivers. Other studies looked at the effects of participation in support groups on Alzheimer patient caregivers and their spiritual wellbeing (Mohammedi and Babaei, 2011) and a study on mental disorders on the effectiveness of family training on family caregivers (Navidan, Pahlavanzadeh and Yazdani, 2010). These are studies of other conditions which focus on the caregiving. Despite the growing recognition of the burden and adverse effects of caring for a patient on haemodialysis on the family caregiver, no studies have been conducted in a South African context which focuses on the growing extent of the caregiving role and all its related complications.

The importance of the caregiver situation has been recognised by an amendment to Swedish Law in 2009. This amendment emphasizes the need for caregiver support in order to minimise the caregivers' physical and, psychological strain, caregiver burden and financial constraints, thereby highlighting the need to focus on the caregivers' plight in Africa and more particularly, South Africa. Studies available focus on dialysis therapies in general which are inclusive of all forms of renal replacement therapies. In this study, the researcher's aim was to identify the perceived benefits and burdens of caring for persons on haemodialysis and identify possible shortfalls on the delivery of health care within a South African context and how it affects the family caregiver.

2.2 CONCLUSION

This chapter reviewed the current literature on Chronic Kidney Disease on the patient, their relatives, and the disease in the context of the South African health care system. The chapter discussed the effect of Chronic Kidney Disease and management on the family caregiver who provides care for the patient during the course of the disease and treatment. The following chapter deals with the research methodology used in the study. It gives information about the

research design, setting, sample, questionnaire used for data collection and data collection process.

CHAPTER 3: RESEARCH METHODOLOGY

3.0 INTRODUCTION

In the previous chapter, literature pertaining to the study was discussed. This chapter describes the methodology used in the study, the research approach chosen, the data collection instrument and the data collecting method. Included are discussions on the ethical considerations for this study.

3.1 RESEARCH DESIGN

A quantitative, descriptive survey was undertaken to provide a description of trends, attitudes or opinions of a population by studying a sample of the identified population (Creswell, 2009). The purpose of a descriptive design is to explore and describe the phenomenon in a real life situation (Burns and Grove, 2009). Throughout the descriptive study, research concepts were described and relationships were identified. No manipulation of variables took place.

3.2 SETTING AND POPULATION

The settings chosen for the study were three private Haemodialysis units which are located in the Johannesburg region. The selected Haemodialysis units comprise approximately fifty patients being dialysed per day as per register for each selected dialysis unit. The number of patients on haemodialysis fluctuates as patients are transferred, admitted in hospital or die. In this study, one hundred and fifty questionnaires were distributed amongst the three Haemodialysis units. Seventy-nine patients in total (N=79), responded to the invitation to participate in the study. The questionnaire consisted of a demographic section, the “Caregiver Burden Scale and a semi structured questionnaire with an option for elaboration. The number of participants’ responses to the questions as tabulated below in Table 3.2:

Table 3.2 Research Instrument Responses

Questionnaire	Total participant response
Demographic information	All participants N=79
Caregiver Burden scale	All participants N= 79
Semi structured questionnaire	“Yes of No” n = 41
Semi structured questionnaire	No response n= 38

3.3 THE SAMPLE

Sampling defines the process of selecting a group of people events, behaviours or other elements with which to conduct a study (Burns and Grove, 2009). The census method (total sampling) was used in this study, as information is collected from each and every member of the defined population (Medhi, 1992). In a census enquiry, all members within the defined population are purposely selected in order to get an in depth description of the perceived benefits and burdens, thereby reducing the risk of missing potential insights from the family caregivers. The total population in this study consisted of seventy nine family caregivers caring for the patients on haemodialysis at the three selected Haemodialysis units. They were informed about the study and assured that they or their relative on haemodialysis would not be disadvantaged in any way if they chose not to participate in the study. There were also informed they had the right to withdraw from the study at any time without incurring any penalty to themselves or their relative undergoing haemodialysis. The researcher eliminated family caregivers who did not meet the criteria set; these were:

Family caregivers who are below 18 years of age, as they are unable to give consent.

Family caregivers caring for patients on haemodialysis for less than one year as the researcher felt they did not have sufficient experience in caring for a patient on haemodialysis.

Relatives of family caregivers who have received a kidney transplant as they are unable to provide current information on their perceived benefits and burdens of caring for a person on haemodialysis.

3.3.1. Inclusion criteria:

All population groups and both genders.

The minimum age was eighteen years so that the family caregiver was able to give informed consent.

The family caregiver should have been caring for their relative on haemodialysis for more than one year, as the researcher was of the opinion that this was sufficient time to have been a carer for a relative on haemodialysis.

3.4 RESEARCH INSTRUMENT

A self-administered questionnaire, the Caregiver Burden Scale (used with permission) by Elmastahl et al (1996) was used for this study. The Caregiver Burden Scale is a 22 item Likert type scale that assesses subjectively the burden experienced by caregivers of chronically disabled persons. The instrument consisted of five factors: general strain, isolation, disappointment, emotional involvement and environment.

1. General strain- self-perception of exhaustion, responsibility, autonomy loss and health damage due to caregiving.
2. Isolation- perception of social network loss reduced social interaction and changes in living plans associated with the caregiving role.
3. Disappointment- change in plans, a sense of injustice and financial problems associated with the caregiving role.
4. Emotional involvement- perception of shame, embarrassment, anger or irritability with the patient's behaviour.
5. Environment- perception of limitations in performing household and personal chores because of ones role as a caregiver and problems associated with transportation, access to medication, health institutions and the community.

A previous study on reliability showed high internal consistency for the five factors found in a factor analysis with Cronbachs alpha values between 0.70 and 0.87, except for factor environment, Elmastahl et al (1996).

The factors were represented by the following questions:

For example the factor Isolation was represented by question 8, 12 and 22 in the Caregiver Burden Scale.

General strain	:1, 3, 4, 5, 7, 10, 14 and 19
Isolation	:8, 12 and 22
Disappointment	:2, 13, 18, 20 and 21
Emotional involvement	:6, 11 and 16
Environment	:9, 15 and 17

The family caregiver was asked to tick on anyone of the four boxes responding to the questions and the answers were graded from: 1 for “not at all” to and including 4 for “often.”

A demographic questionnaire was added to the caregiver burden scale to add richness and depth to the data. Further questions were added with opportunities provided for elaborating comments. There were:

3.4.1 Question 1

Describe any benefits you have encountered whilst caring for a patient on Haemodialysis?

Yes/ No

If yes would you kindly elaborate?

3.4.2 Question 2

Have you encountered any significant challenges whilst caring for your patient on Haemodialysis?

Yes/No

If yes would you kindly elaborate?

3.4.3 Question 3

Would health education prior to Haemodialysis treatment have better prepare you for the challenges ahead?

Yes/No

If yes would you kindly elaborate?

The semi structured questionnaire was also added to the original questionnaire allowing the relative to add their voice and be able to include their perceptions in a narrative format. Therefore the final questionnaire consisted of the following parts:

Part 1- consisted of the participants demographic data this included items such as sex, age, employment, level of education.

Part 2- Caregiver burden scale

Part 3- semi structured questionnaire with an option for elaboration

3.5 PILOT STUDY

A pilot study is commonly defined as a small study which accurately tests the proposed study and is conducted to refine the methodology (Grove, Burns and Gray, 2013).

The first stage of the study was a peer review which involved health professionals involved in the care of patients with end stage renal disease, with 3 to 5 years' experience in dialysis. They (n=5) were asked to comment on the suitability and applicability of the contents of the instrument prior to the scale being piloted on the family caregivers. Corrections were made on the semi structured question as they felt there was a repetition in the questions on part 3, and the questions were therefore reduced from 4 to 3.

Question 1

Describe any benefits you have encountered whilst caring for a patient on haemodialysis?

Yes/ No

If yes would kindly elaborate?

Question 2

Have you encountered any significant challenges whilst caring for a patient on haemodialysis?

Yes/No

If yes, please elaborate

Question 3

Have you encountered any significant challenges whilst caring for a patient on Haemodialysis?

Yes/No

If yes please elaborate

Question 4

Would health education prior to Haemodialysis treatment have better prepared you for the challenges ahead?

Yes/No

If yes please elaborate

The revised questionnaire:**Question 1**

Describe any benefits you have encountered whilst caring for a patient on Haemodialysis?

Yes/ No

If yes would you kindly elaborate?

Question 2

Have you encountered any significant challenges whilst caring for a Haemodialysis patient?

Yes/No

If yes would you kindly elaborate?

Question 3

Would health education prior to Haemodialysis treatment have better prepare you for the challenges ahead?

Yes/No

If yes would you kindly elaborate?

The second stage (targeting the family caregivers) of the pilot study was then carried out on 5 of the available participants who matched the inclusion criteria at one of the 3 selected Haemodialysis units. The researcher was unable to target a larger number of participants due to the limited number of participants at the unit on the day the pilot study was conducted. The aim was to test the extent of face validity of the questionnaire as the extent to which a method appears on face value to what it is intended to measure (Burns and Grove, 2009) as well as to establish if there were any ambiguous or difficult questions in the scale before it was issued to the research sample.

Each participant in the pilot study was issued with an information letter explaining the purpose of the study in detail, what was expected of the participants, their rights, the contact details of the researcher and a consent form. The participants were requested to complete the questionnaire whilst waiting for their relative being treated on haemodialysis. This procedure lasts for approximately 5 hours inclusive of connection, haemodialysis and disconnection of the patient. The participants were able to complete the questionnaire in full, no questions were left unanswered. There was no ambiguity or misunderstanding with the questionnaire. The answered questionnaires in this pilot study were excluded from the study.

3.6 DATA COLLECTION

Data collection in a quantitative research is the process that involves obtaining numerical data to address the research objectives, questions or hypothesis (Burns and Grove, 2009). The process of data collection for this study involved the following:

Permission was granted by the relevant authorities of the Human Research Ethics Committee (Medical) of the University of Witwatersrand.

The Faculty of Health Sciences Postgraduate Committee.

Fresenius Medical Care Management, South Africa.

Unit managers and staff members were informed of the potential study by the researcher. Opportunities to ask questions about the study were provided by the researcher, telephonically, via email or in person. The possible effect on patient care was explained to the staff. Permission to conduct the research was then obtained from the unit managers through

verbal communication after securing consent from Fresenius Medical Care management. This was in order to establish rapport, understanding and to be introduced to the patients.

Once the researcher had received permission from the unit manager to approach the patients, she then approached the patients on haemodialysis to request their permission to approach their relative to participate in the study. The purpose, objective and procedures in the study were then explained to the patient on haemodialysis in the information letters (refer Appendix A). After written consent had been given by the patient together with the permission to invite family caregiver to participate in the study, she then informed the potential participant of the study. The researcher approached the accompanying relatives during the patient treatment appointment in the Haemodialysis unit and invited their participation. In the absence of the caregiver, the patient was asked to deliver the questionnaire to the family caregiver. The research questionnaire package contained an information letter (Appendix B), consent form (Appendix C), questionnaire (Appendix D) and an envelope that the family caregiver could insert and seal after completing the questionnaire. The sealed envelope was returned to the dialysis unit by the patient and left in the unit marked allocated boxes at all 3 research sites for the researcher to collect.

Data collection was done by the researcher purely to ensure confidentiality and privacy. An appropriate sample size was discussed with a statistician to ensure the representativeness of the population under the study. Taking into consideration possible refusal and sample mortality rates, sample inclusion and exclusion criteria were followed. The estimated population was approximately 150 patients from the registry of all patients receiving haemodialysis treatment. One hundred and fifty questionnaires were distributed amongst the 3 dialysis units. Patients were to give a questionnaire to one member of the family who had been taking care of them for more than one year and was above the age of 18 years. Only 79 questionnaires were returned.

3.7 APPROACH TO DATA ANALYSIS

The statistician was consulted prior to data collection and during data analysis to assist in the representation of the participants information.

3.7.1 Demographic Information of the Family Caregivers.

A table was constructed displaying the results in the study and were presented under the following categories; age, gender, relation to patient, highest educational level, employment, ethnicity and duration of care, see Table 4.1(Demographic Information of the Family Caregivers). The table shows the calculated frequencies and percentages of the responses from the participants under the demographic information provided by the participants. The STATA statistical programme version 12 was used to calculate frequencies and percentages and a table was constructed representing the demographic information. For example the category Age, from the age of 18 to 25 years there were 4 participants, the percentage was calculated from the total number of participants in the study (N= 79) the result being 5% representing ages 18 to 25 years. A verbatim description of the demographic information is documented in section 4.2.

3.7.2 Factors Affecting Family Caregivers Caring For a Patient on Haemodialysis.

The Caregiver Burden Scale by Elmastahl et al (1996) is a 22 item Likert scale that assesses subjectively the caregiver burden of family caregivers caring for persons on long term haemodialysis. The Caregiver Burden Scale was used to elicit the perceived, “Burden” encountered by the family caregivers. The family caregivers were asked to tick one of the four boxes (not at all, seldom, sometimes and often) a score of one to four for each question. The instrument comprises five factors: general strain, isolation, disappointment, emotional involvement and environment. A mean value was calculated for each participant’s response and the information represented in percentages. An overall caregiver burden score was also calculated to evaluate the overall burden score for the participants. The STATA statistical programme version 12 was used to calculate frequencies and percentages. The graphs were constructed to represent the factors of the Caregiver Burden Scale see section 4.3 in Chapter 4.

3.7.3 Relationship Between The Demographic Information and the Factors of the Caregiver Burden Scale.

Cross tabulation was conducted using the Fishers Exact test which is a statistical significance test used in the analysis of contingency tables (Agresti, 2002). It was employed for the study as the sample size was relatively suitable for the Fishers Exact Test as per advice from the statistician. Cross tabulation was conducted for the demographic information of participants and the factors of the Caregiver Burden Scale, so as to establish if there were any significant differences or associations between the variables. For example, the cross tabulation of the category Ethnicity of the family caregiver against the factor Isolation, in this example the researcher wanted to establish if there was a relationship between the ethnicity of the family caregiver and their environment and how it affects the manner in which the family caregiver cares for their relative on haemodialysis. A result of 0.05 or less shows a statistical significance between the variables hence a relationship exists between the variables.

3.7.4 Semi Structured Questionnaire

The semi structured questionnaire comprised a category which required yes or no responses see Table 3.2 represents the responses for the semi structured questionnaire.

Semi Structured Questionnaire Yes or No responses= 41.

Did not respond = 38

The responses were counted and graphs constructed to highlight which participants answered yes and those that answered no. The participants who answered yes where asked to elaborate further. Besides the Caregiver Burden Scale which focused on the “burden” encountered by the family caregivers. The Semi structured questionnaire provided the participants with the platform to provide more insight and depth on their role in caregiving for their relatives on haemodialysis. To elicit from the family caregiver the benefits their encounter as a product of their ability to find meaning through positive appraisal or other adaptive coping mechanisms in the face of the challenges they encounter (Haley, LaMonde, Han, Burton and Schonwetter, 2003). The participants’ responses would highlight and provide information on their perception of the factors which facilitate and challenge the process of caring including the perceived shortfalls in the health care system.

Content analysis was used for describing the caregivers' answers to open questions regarding their perception of the benefits and burdens of caring for a patient on haemodialysis. Content analysis classifies the words in a text according to categories or issues identified and provide a systematic means of measuring the frequency of words or sentences which occur in text as mentioned by Burns and Grove (2009), in order to find the common statement, issue or words in order to infer meaning. The researcher analysed each participants' responses looking for relationships among the ideas (Kelly and Sime, 1990). After careful analysis, a common meaning was deduced from the statements provided by the participants. These were read several times in order to ascertain a common meaning. A colleague was asked to read the same text and similar findings were established.

3.8 RELIABILITY AND VALIDITY

Reliability is the measure of the consistency of measures obtained in the use of a particular instrument and indicates the extent of random error in the measurement of the instrument (Burns and Grove, 2009). It is concerned with consistency, reliability and repeatability of the information (Brink, 1999). In this study reliability of the questionnaire was done by issuing the same questionnaire to all participants to ensure consistency in the information distributed to all participants. A study on reliability showed high internal consistency for the five factors of the Caregiver Burden Scale with a Cronbach's alpha values between 0.70 and 0.87, except for factor environment (Elmstahl et al, 1996).

Validity of the instrument determines the extent to which it actually reflects the abstract construct being examined (Burns and Grove, 2009: 377). The Caregiver Burden Scale had been validated by the original author (Elmstahl et al, 1996). Face validity is the extent to which a method appears on face value to measure the content it what is intended to measure, (Burns and Grove, 2009); it was achieved by having the Caregiver Burden Scale reviewed by my supervisors. In this study the face validity of the instrument is used to measure the perceived benefits and burdens of caring for persons on Haemodialysis. This was done in order to gauge the perception of the acceptance, appropriateness and precision of the instrument. The instrument was pre tested for face validity by the researcher in a pilot study on 5 family caregivers to ensure that questions were clear and understandable. Family caregivers who participated in the pilot study were excluded from the main study.

3.8.1 ETHICAL CONSIDERATIONS

Permission to conduct research was obtained from the following:

- The Human Research Ethics Committee (Medical) of the University of the Witwatersrand gave permission for the study to be undertaken on the 22nd of February 2013. The protocol number is M130217 (see appendix E).
- The Faculty of Health Sciences Postgraduate Committee certificate of permission to conduct the study was given on the 20 February 2013 (see appendix F).
- Fresenius Medical Care Management gave permission for the use of their dialysis units on the 4th February 2013 (appendix G).

All the participants were informed that it was a voluntary study and participants could withdraw from the study, refuse to participate or discontinue at any given time without incurring any penalty to themselves or their relatives on haemodialysis.

To ensure anonymity, all questionnaires had no identification to trace them back to the patient or participant.

In order to maintain confidentiality and privacy, all completed questionnaires were placed in a sealed box, in the unit manager's office and were stored safely away under lock and key by the researcher after the envelopes were opened. The total number of questionnaires was one hundred and fifty, distributed over the three days and the participants were given one month to return the completed questionnaires to the unit. Participants were reminded by email and telephonically. The questionnaires were collected every Friday from the respective units.

3.9 CONCLUSION

This chapter gives a description of the research methodology and data collection methods used in this study. The next chapter will look at the presentation and interpretation of data.

CHAPTER 4 ANALYSIS OF DATA

4.0 INTRODUCTION

In the previous chapter a description of the research methodology and data collection methods used in the study were explained. In this chapter data analysis will be conducted to reduce, organise and give meaning to data (Burns and Grove, 2009). This chapter presents the findings and analysis of the questionnaire of the Caregiver Burden Scale. The STATA statistical programme version 12 was used to calculate frequencies and percentages and graphs were constructed. Narrative and descriptive statistics such as percentages and frequencies were used to represent the data.

4.1 DEMOGRAPHIC INFORMATION OF THE FAMILY CAREGIVERS

The results in the study were presented under the following categories: age, gender, relation to patient, highest educational level, employment, ethnicity and duration of care. The table below shows the calculated frequencies and percentages of the responses from the participants:

TABLE 4.1 Demographic Information of the Family Caregivers

AGE	18 – 25	5%(4)
	26 – 45	41%(32)
	46 – 60	38%(30)
	ABOVE 60	16%(13)
GENDER	MALE	42%(33)
	FEMALE	58%(46)
RELATION TO PATIENT	WIFE	34.2%(27)
	HUSBAND	29.1%(23)
	SON	7.6%(6)
	DAUGHTER	10.1%(8)
	MOTHER	7.6%(6)
	FATHER	3.8%(3)
	BROTHER	1.3%(1)
	SISTER	5.1%(4)
HIGHEST EDUCATION LEVEL	GRANDMOTHER	1.3%(1)
	NONE	7.6%(6)
	PRIMARY	3.8%(3)
	SECONDARY	32.9%(26)
EMPLOYMENT	TERTIARY	55.7%(44)
	SELF EMPLOYED	19%(15)
	EMPLOYED	56.9%(45)
	UNEMPLOYED	24.1%(19)
ETHNICITY	AFRICAN	34.2%(27)
	WHITE	45.6%(36)
	COLOURED	7.6%(6)
	ASIAN	12.7%(10)
DURATION OF CARE	1 – 2 YEARS	17.7%(14)
	2 – 3	26.6%(21)
	3 – 4	40.5%(32)
	ABOVE 4	15.2%(12)

N.B all rounded to the last decimal place.

4.2 DESCRIPTION OF DEMOGRAPHIC INFORMATION OF FAMILY CAREGIVERS

The ages of the participants who are family caregivers were ranged between the ages 18 to 25 years of age were 5%, from ages 26 to 45 years of age were 41% who responded to the study. The next age group was 46 to 60 years of age made up 38% of the sample and the participant's age 60 years and above were 16% of the total sample. Thus the majority of the participants were in the age group 26 to 45 years with a percentage of 41% of the sample. This information is illustrated in table 4.1(Demographic Information of the Caregivers).

Female participants formed the larger group in the gender category with 58% of the total sample as compared to male participants who represented 42% of the total sample. In the category “relation to patient” the spouse either wife (34.2%) or husband (29.1%) of the total sample constituted the majority with 63.3% of the entire sample. Female caregivers in the sample constituted the wife (34.2%), daughter (10.1%), mother (7.6%), sister (5.1%) and grandmother (1.3%) and they were the majority with 58.3% of the total sample compared to male caregivers who constitute 41.85% of the total sample.

In the category, “highest level of education,” the majority of the participants went as far as tertiary education 55.7%, 32.9% had secondary education, and 3.8% participants were educated up to primary level and 7.6% had no education at all. On the whole, the majority of these participants were mainly made up of participants with higher education than participants with lower education. Participants who were employed constituted 56.9% of the total sample, 24.1% were unemployed and 19% of the participants in the total sample were self-employed.

When considering the participants’ ethnic distribution, white South Africans comprised 45.6% of the sample followed by black South Africans 34.2%, participants of Asian descent comprised 12.7% of the sample followed by “coloured” (persons of mixed racial descent) South African participants by 7.6% of the sample. The majority of participants had cared for the patient on haemodialysis for 3 to 4 years represented a percentage of 40.5% of the total sample, followed by 26.6% who cared for the patient for 2 to 3 years, 17.7% of the family caregivers had cared for the patient for 1 to 2 years and the fewest participants had cared for the patient for more than 4 years with 15.2%.

4.3 RESULTS: FACTORS AFFECTING FAMILY CAREGIVERS CARING FOR A PATIENT ON HAEMODIALYSIS

The caregiver burden scale by Elmastahl et al (1996) is a 22 item Likert scale that assesses subjectively the caregiver burden of family caregivers caring for chronically disabled persons. The caregivers were asked to tick one of the four boxes (not at all, seldom, sometimes and often) score 1 to 4 for each question. A mean value was calculated and the information represented in percentages. All rounded to the nearest 2 decimal places.

	score
Not at all	1
Seldom	2
Sometimes	3
Often	4

The instrument comprises five factors: general strain, isolation, disappointment, emotional involvement and environment. The questionnaire was organised under the following factors and were represented by the following questions:

General strain	:1, 3, 4, 5, 7, 10, 14 and 19
Isolation	:8, 12 and 22
Disappointment	:2, 13, 18, 20 and 21
Emotional involvement	:6, 11 and 16
Environment	:9, 15 and 17

Seventy nine responses were received to the one hundred and fifty questionnaires that were distributed. All participants answered the caregiver burden scale completely; no questions were left unanswered in this section.

4.3.1 GENERAL STRAIN

A mean value was calculated for the factor General strain from the following questions from the Caregiver Burden Scale, questions 1, 3, 4, 5, 7, 10, 14 and 19. Percentages were used to construct a graph representing the participant's responses as shown below:

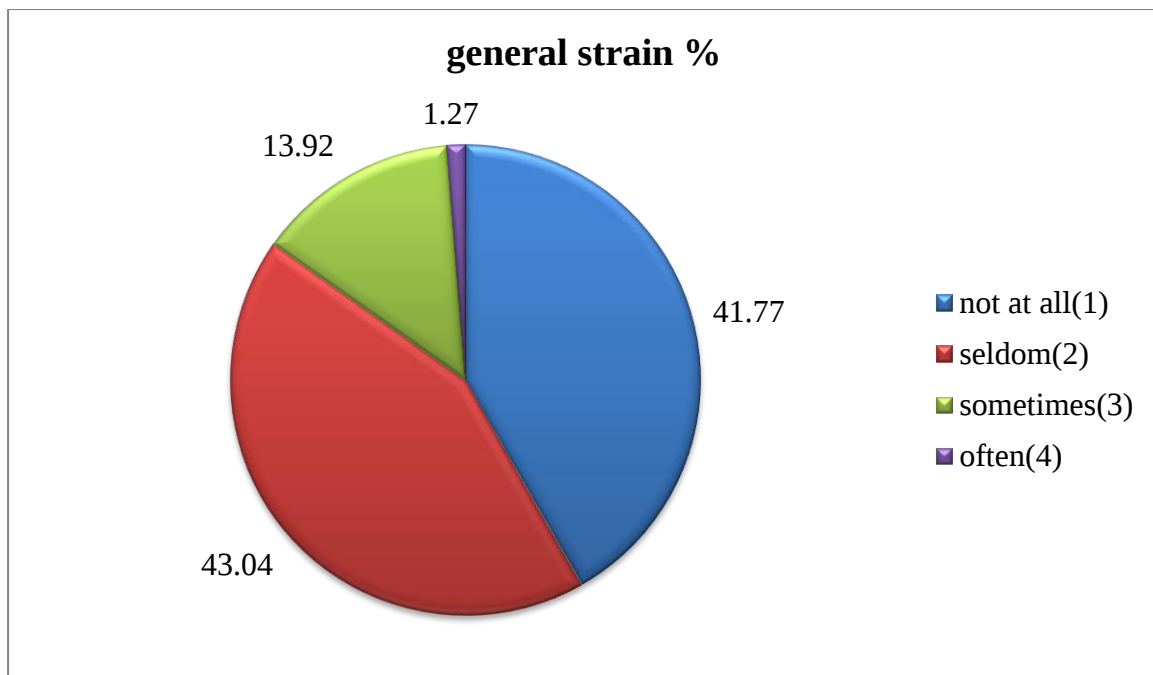


Figure 4.3.1 general strain%

NB all rounded off to 2 decimal places.

The participants responded as follows: 41.77% stated they experienced no strain at all from caregiving, 43.04% seldom experienced strain from caregiving, followed by 13.92% sometimes experienced strain from caregiving and 1.27% often experienced strain from caregiving. Thus the majority of the participants “seldom” experienced strain from caregiving and the least participants responded to “often” by 1.27% who least experienced strain from caregiving.

4.3.2 ISOLATION

A mean value was calculated for the factor Isolation from the following questions in the Caregiver Burden Scale, question 8, 12 and 22. Percentages were used to construct a graph to represent the participant's response:

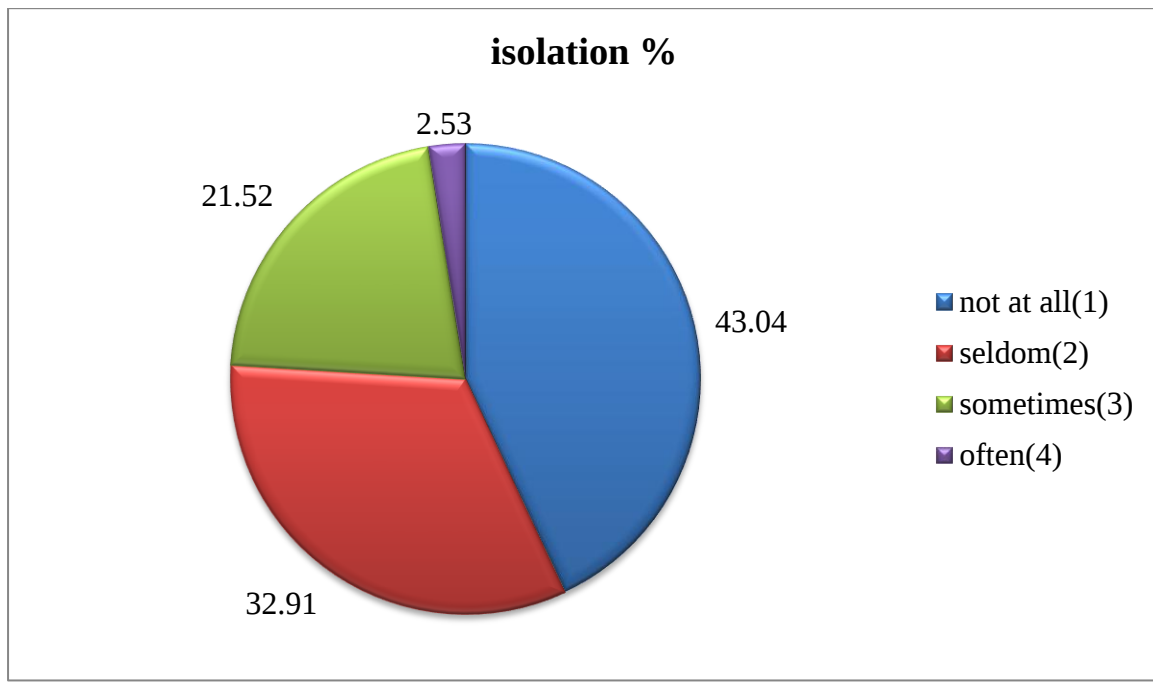


Figure 4.3.2 isolation %

NB: all rounded of to 2 decimal places.

The participants responded to the questions as follows: 43.04% stated that they experience no perception of isolation caused by caregiving, 32.91% seldom experienced isolation whilst caring for patient on haemodialysis followed by 21.52 who sometimes experienced isolation whilst providing care and 2.53% often experienced isolation from caregiving of their relative on haemodialysis. The majority of the participants did not experience any perception of isolation in caring for their relative on haemodialysis with a percentage of 43.04% and the least percentage of participants often experienced isolation in caring for their relative on haemodialysis with a percentage of 2.53% of the total sample.

4.3.3 DISAPPOINTMENT

A mean value was calculated for the factor Disappointment from the following questions of the Caregiver Burden Scale, questions 2, 13, 18, 20 and 21. Percentages were used to construct a graph to represent the participant's responses:

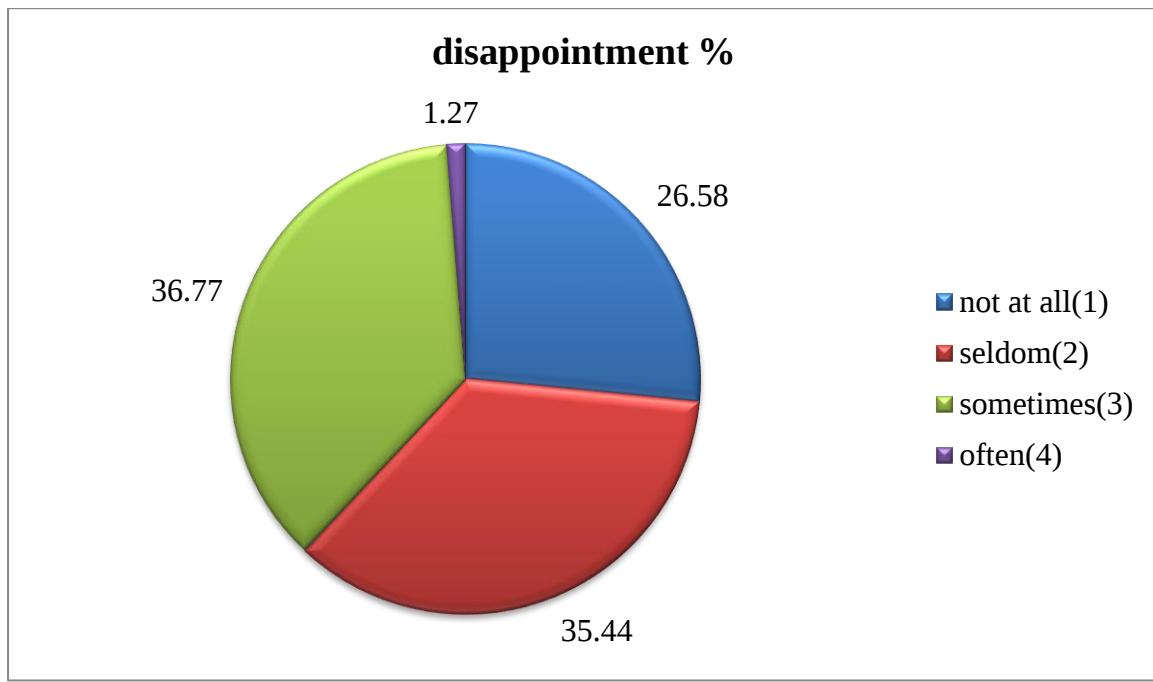


Figure 4.3.3 disappointment %

NB: all rounded of to 2 decimal places.

Participants responded to the factor disappointment as follows: 36.77% stated they “sometimes” experienced disappointment in caring for their relative on haemodialysis, 35.44% “seldom” experienced disappointment followed by 26.58% who did not experience any feelings of disappointment in caring for their relative and 1.27% who “often” experienced disappointment. The majority of the participants sometimes experienced disappointment in caring for their relative on haemodialysis with a percentage of 36.77% and the least responded with 1.27% often felt disappointed in caring for their relatives on haemodialysis.

4.3.4 EMOTIONAL INVOLVEMENT

A mean value was calculated for factor Emotional Involvement for the following questions of the Caregiver Burden Scale, questions 6, 11 and 16. Percentages were used to construct a graph representing the participant's response:

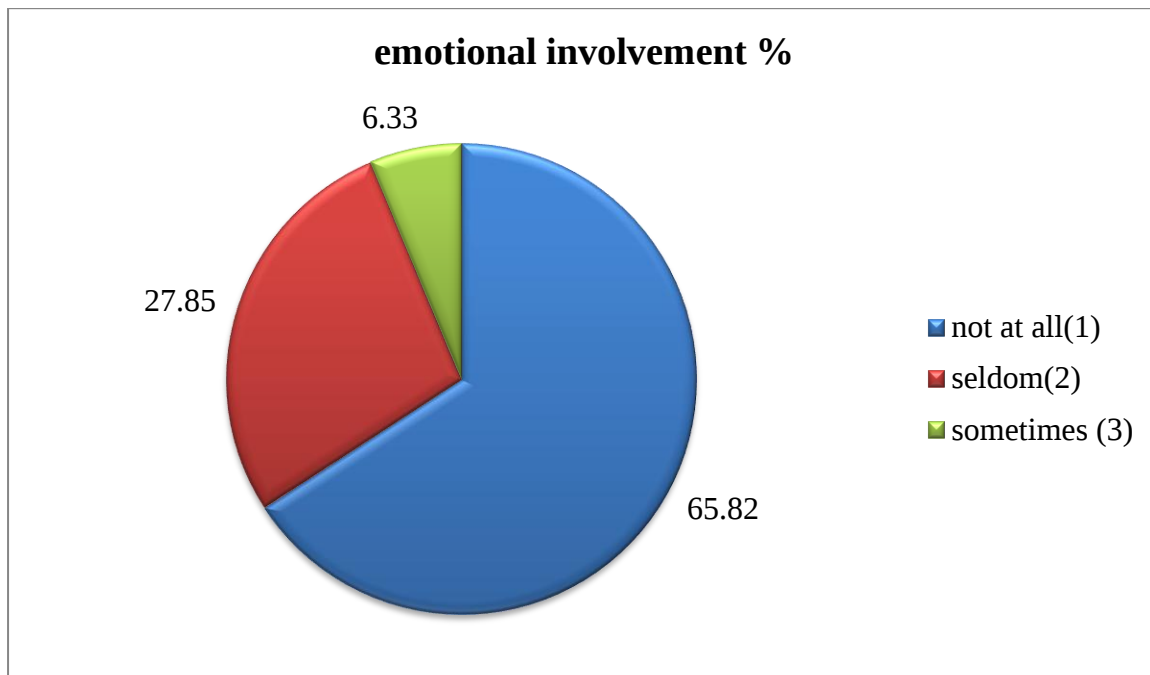


Figure 4.3.4 Emotional Involvement %

Participants responded to the factor emotional involvement as follows: 65.82% for the factor emotional involvement the participants responded to “not at all,” 27.85% “seldom” experienced emotional involvement whilst caring for a patient on haemodialysis and 6.33% “sometimes” experienced emotional involvement in caring for their relative on Haemodialysis. No participants responded to “often” in the factor emotional involvement. The majority of the participants were not affected emotionally by them caring for their family member on Haemodialysis with a percentage of 65.28% of the total population and the least affected emotionally responded “sometimes” with a percentage of 6.33% of the total sample.

4.3.5 ENVIRONMENT

A mean value was calculated for the Environment factor for the following questions in the Caregiver Burden Scale, questions 9, 15 and 17. Percentages were used to construct the graph representing the participant's response:

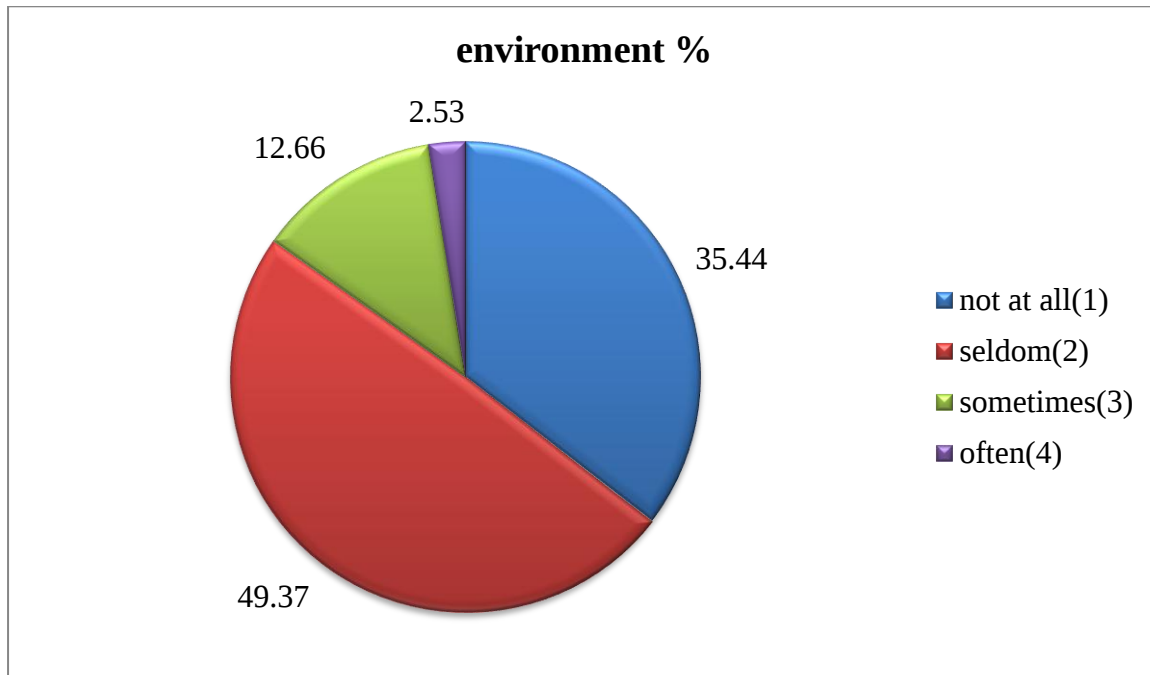


Figure 4.3.5 environment %

NB: all rounded of to 2 decimal places

Participants responded to the environmental factor as follows: 49.37% were “seldom” affected by the environment whilst caring for their family member on haemodialysis, 35.44% responded to “not at all,” meaning participants were not affected by the environment, followed by 12.66% of the participants who were “sometimes,” affected by the environment whilst caring for the patient and 2.53% were “often” affected by the environment. Thus a majority of the participants were “seldom” affected by the environment with a percentage of 49.37% of the total sample and the least were “often” affected by the environment with a percentage of 2.53% of the total sample.

4.3.6 OVERALL BURDEN SCORE

The Overall Burden Score inclusive of all the factors that is General Strain, isolation, Disappointment, Emotional Involvement and Environment. A median score overall of 46.59% with an interquartile ranges from 30.68% to 55.68%.

4.4 RELATIONSHIP BETWEEN THE DEMOGRAPHIC INFORMATION AND THE FACTORS OF THE CAREGIVER BURDEN SCALE

Cross tabulation was conducted using the fisher exact test, against the demographic information of the participants and the Factors of the Caregiver Burden Scale by Elmastahl et al (1996), so as to establish if there were any statistically significant differences or associations between the variables. This is illustrated in the table below:

p Value of less than or equal to 0.05 shows a statistical significance between the variables.

Table 4.4 Cross Tabulation of Demographic Information and the Caregiver Burden Scale

		p value
Highest education level	Employment	0.001
Gender	Relation to patient	0.000
Gender	Isolation	0.077
Gender	General strain	0.893
Gender	disappointment	0.730
Ethnicity	General strain	0.628
Ethnicity	Environment	0.231
General strain	Isolation	0.000
General strain	Environment	0.048
General strain	disappointment	0.000
Isolation	Environment	0.000

4.5 A description of the cross tabulation of demographic information and the factor of the caregiver burden scale.

Relationship between highest educational level and employment: Fishers exact = 0.001. There is a statistically significant relationship between highest educational level and employment as the result is less than 0.05.

Relationship between gender and relation to patient: Fishers exact =0.000. There is a statistically significance between gender and relation to patient as the result is 0.05.

Relationship isolation and gender: Fishers exact = 0.077. There is no statistical relationship between isolation and gender as the result is greater than 0.05.

Relationship between general strain and gender: Fishers exact = 0.893. There is no statistical relationship between the factor general strain and gender as the result is greater than 0.05.

Relationship between disappointment and gender: Fishers exact = 0.730. There is no statistical relationship between the factor disappointment and gender as the result is greater than 0.05.

Relationship between general strain and ethnicity: Fishers exact = 0.628. There is no statistical significance between factor general strain and ethnicity as the result is greater than 0.05.

Relationship between ethnicity and environment: Fishers exact = 0.231. There is no statistical relationship between ethnicity and environment as the result is greater than 0.05.

General strain and isolation: Fishers exact = 0.000. There is a statistical significance between general strain and isolation as the result is less than 0.05.

Isolation and environment: Fishers exact = 0.000. There is a statistical significance between isolation and environment as the result is less than 0.05.

Relationship between general strain and environment: Fishers exact = 0.048. There is a statistical relationship between general strain and environment as the result is less than 0.05.

Relationship between general strain and disappointment: Fishers exact = 0.000. There is a statistical relationship between general strain and disappointment as the result is less than 0.05.

4.6 SEMI STRUCTURED QUESTIONNAIRE

The semi structured questionnaire comprised a category which required yes or no responses see Table 3.2 represents the responses for the semi structured questionnaire.

Semi Structured Questionnaire Yes or No responses n= 41. Thirty eight of the participants did not attempt to answer the semi structured questionnaire out of a total sample of seventy nine (N= 79).

The responses were counted and graphs constructed to highlight which participants answered yes and those that answered no. All percentages were rounded off to the last two decimal places.

The participants who answered yes were asked to elaborate further. Besides the Caregiver Burden Scale which focused on the “burden” encountered by the family caregivers. The Semi Structured questionnaire provided the participants with the platform to provide more insight and depth on their role in caregiving for their relatives on haemodialysis by eliciting their view of benefits as a product of their ability to find meaning through positive appraisal or other adaptive coping mechanisms in the face of the challenges they encounter (Haley et al, 2003). The participants’ responses would highlight and provide information on their perception of the factors which challenge the process of caring including the perceived shortfalls in the health care delivery system.

Having answered ‘yes’ or ‘no’ to the question posed, an opportunity was afforded participants to expand on their answers. Content analysis was used for describing the family caregiver’s perception of the benefits and burdens of caring for a patient on Haemodialysis, words in the text were classified providing a systematic means of measuring the frequency of words or sentences which occur in text (Burns and Grove, 2009), in order to find the common statement or word to infer meaning in the text. The researcher analysed this section by looking for relationships among the ideas (Burns and Grove, 2009) as written by the participants. After careful analysis a common meaning was deduced from the statements provided by the participants. These were read several times in order to ascertain this common meaning. A colleague independent from the pilot study was asked to read the same text and similar findings were established.

These answers will be discussed below after the question posed is noted:

4.6.1. Question 1

Describe any benefits you have encountered whilst caring for a patient on Haemodialysis?

Yes/ No

If yes would you kindly elaborate?

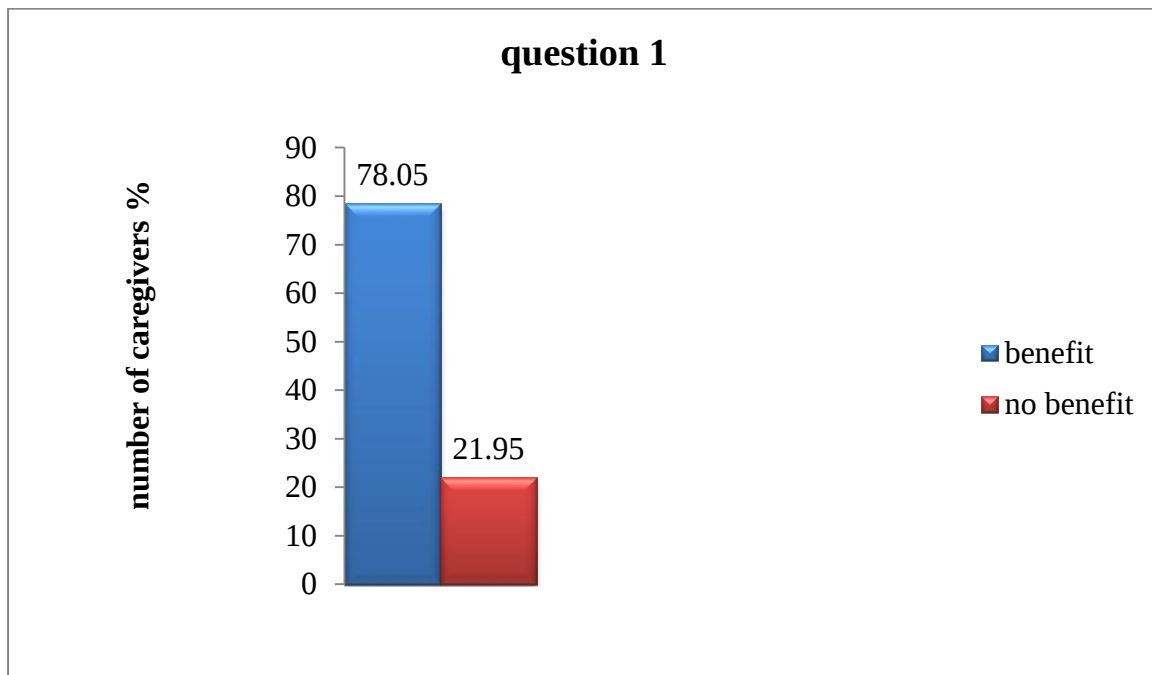


Figure 4.6.1: question 1

A majority of the respondents emphasised on the benefits of caring for their family members on Haemodialysis. This was expressed in the following narrative:

“The greatest benefit is that my husband’s quality of life between dialysis sessions is so improved and that he does not get admitted to hospital, which happened regularly before dialysis”

“I don’t know that there are any benefits to being on dialysis except prolonging her life but it is also restrictive to movement, ie if you want to go on holiday you have to make sure that you are near a dialysis unit.”

“Brought the family closer together”

“Our lives have been improved greatly; he is no longer always sick and this has brought us closer together.”

4.6.2 Question 2

Have you encountered any significant challenges whilst caring for a patient on haemodialysis?

Yes/ No

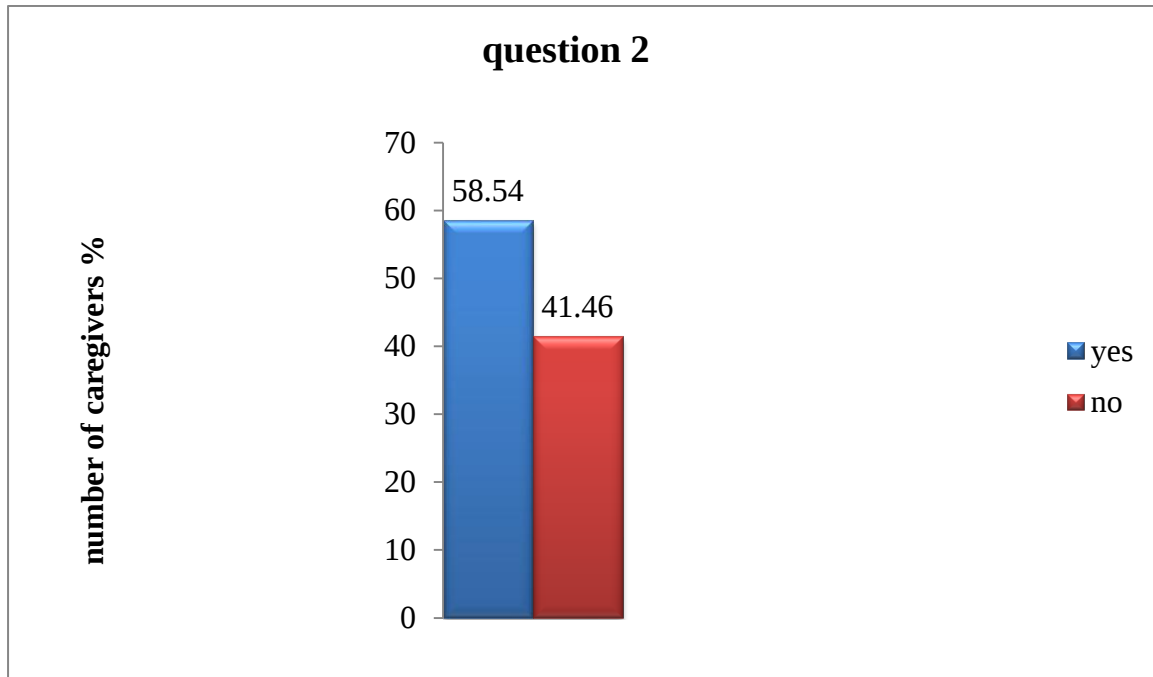


Figure 4.6.2: question 2

A majority of the participants encountered significant challenges whilst caring for a patient on haemodialysis. This was expressed in the following narrative:

“It has been very trying because of finances, social life, work and studies. I am more exhausted and emotionally drained.”

“When she is in hospital and I have to visit often. Money becomes a challenge.”

“Where you find that the fistula is sore or painful as a result of carelessness on nurses, not pricking it on the right direction and some nurses don’t have a heart, they are easily annoyed forgetting the pain associated with this”

“Trying to start a family”

“Getting him to adapt to new lifestyle, diet is challenging”

4.6.3. Question 3

Would health education prior to haemodialysis treatment, have better prepare you for the challenges ahead? Yes/ No

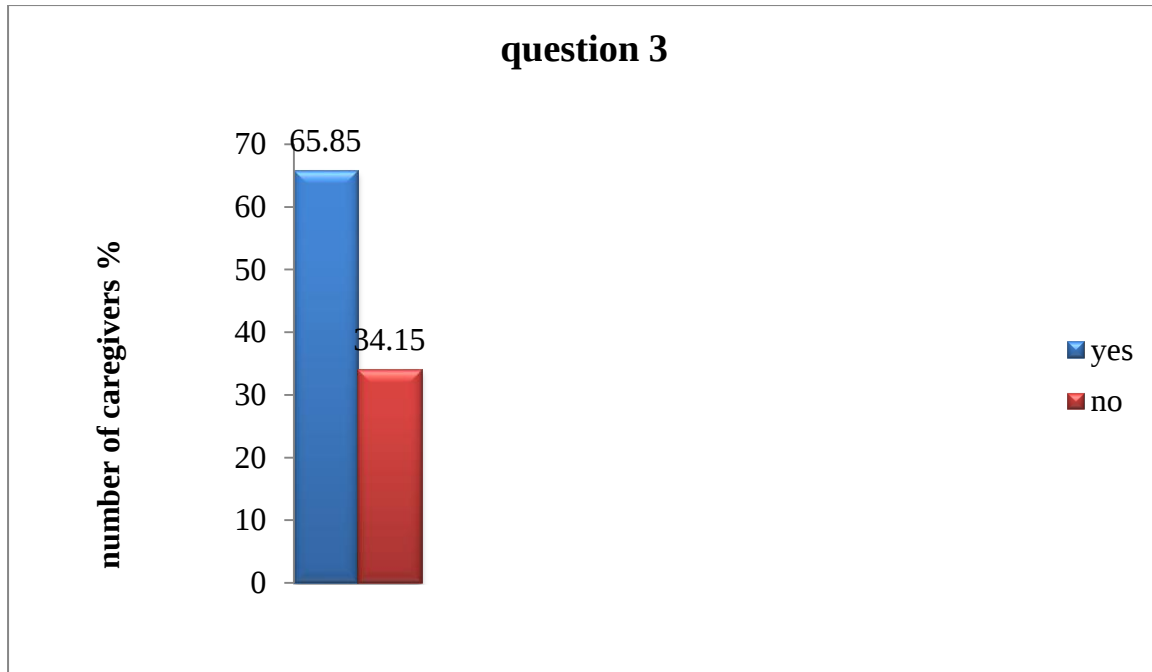


Figure 4.6.3: question 3

Health education prior to Haemodialysis treatment would have better prepared the family caregiver for the challenges ahead. This was expressed in the following narrative:

“Thanks to our health care professionals, we learned a lot and we knew what to expect”

“I think that the patient and the spouse should be more informed before the dialysis begins on what effects. Also a proper introductory tour of the centre, so that the spouse/partner/relative can envisage the patients environment during dialysis”

“Most of the information regarding the above I got from my own research and not from health education from doctors or nurses”

“It would have made it a bit easier to cope and it would have helped me to understand how to take care of the situation”

4.7 CONCLUSION

In this chapter the researcher analysed data using STATA version 12 and used graphs and tables to illustrate the results. In addition, verbatim excerpts were given to illustrate the answers received from participants expanding on yes/no answers. The next chapter contains a discussion of the findings as well as the limitations and recommendations of the study.

CHAPTER 5: DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.0 INTRODUCTION

In the previous chapter the researcher analysed data using STATA version 12 and used graphs and tables to illustrate the results. In this chapter the researcher discusses the findings in relation to the objectives of the study. The researcher further discusses the limitations and recommendations.

5.1 DISCUSSION OF THE RESULTS ILLUSTRATED IN CHAPTER 4

1. Explore the perceived benefits and burdens of caring for a patient on haemodialysis by the family caregivers.
2. Describe the family caregivers' perspective on factors which challenge the process of caring.
3. Identify, from the caregivers, the perceived shortfalls in the health care system relating to caregiving by relatives.

5.2 DEMOGRAPHIC INFORMATION OF FAMILY CAREGIVERS

In this section a discussion of the demographic information findings against the background of the literature is reviewed:

In the gender category, female caregivers represented the majority with 58% of the total sample compared to male participants who represented 42% of the total sample. Historically, caregivers have been disproportionally women (Cranswick and Dosman, 2008). A study in Turkish culture by Yurtsever, Ozge, Kara, Yandim, Kalav and Yessil (2013) state that, in many cultures around the world including Turkey, caregiving is a woman's role. Although the gap is slowly reducing in size as men slowly take up more caregiving roles. In 2009 according to the National Alliance for Caregiving, men accounted for 34% of the nearly 65 million family caregivers in the United States. In 2013 analysis by Fox et al found that men

may now represent 45% of all family caregivers. In the General Social Survey in 2012 the estimated number of female caregivers was 54% and men 46%. Hence the results of this study are similar to studies done previously.

The majority of family caregivers in this study were still employed. Results from the study indicated that 56.9% of family caregivers were employed, 19% were self-employed and 24.1% were unemployed see Table 4.1(Demographic Information of the Family Caregivers) in the previous chapter. The National Caregiving Alliance (2004) states that nearly two thirds of family caregivers are employed full or part time whilst caring for a relative with chronic illness. A National Survey in 2013 showed that 23% of family caregivers retired from work or left the work force earlier than planned, to care for an ill spouse or another relative (Helman, Adams, Copeland and Van Dei lei, 2013). Employed caregivers reported reducing the number of regular working hours to accommodate the caregiving need of their relative (in this case their relative on haemodialysis) (Sonha, 2012). Despite the competing demands, 73% of employed caregivers were satisfied with their current balance between work and caregiving (Sonha, 2012). The study results show that 75.9% of both self-employed and employed family caregivers are still able to earn an income despite providing care for a family member on Haemodialysis therapy.

5.3 FACTORS OF THE CAREGIVER BURDEN SCALE

In this section a discussion of the Caregiver burden factors against the background of the literature reviewed:

5.3.1 General Strain

In this factor General strain, focuses on the self-perception of exhaustion, responsibility, autonomy lost and health damage due to caregiving (Elmastahl et al, 1996). The results of the factor are illustrated in figure 4.3.1(General strain %), with a majority of the participants responding to “seldom” experiencing the strain of caregiving with a percentage of 43.04%. Psychosocial exhaustion forms an important element in the family caregivers’ life leading to the experience of burden as mentioned by Bahrami, Etemadifar, Shahrain and Farsani (2014). Due to continuous and repeated visits by these patients to Haemodialysis centres, the greater responsibilities for care of these patients is up to the family caregivers (Pourebrahimi et al, 2013). In a recent study done by Reinhard, Levine and Sarris (2013), 57% of family

caregivers had no say in becoming caregivers for their relatives, it was a role they undertook due to relationship they have with the patient on haemodialysis. It can be a stressful experience to juggle caregiving with work and other family responsibilities, especially for those working family caregivers who, in addition to working full time, have the burden of complex medical and nursing tasks like managing multiple medications and managing the patient's restrictive diet (Reinhard et al, 2012). The finding that forty per cent (40%) to 70% of family caregivers experience clinically significant symptoms of depression with a 1/4 to 1/2 of these caregivers meeting the diagnostics criteria for major depression (Zarit, 2006). This finding are not in support of the findings of this study as 43.04% of the participants seldom experience any strain in caring for their relative on haemodialysis.

5.3.2 Isolation

This factor "Isolation," focuses on the perception of social network loss, social interaction and changes in the living plans associated with the caregiving role. The results of the factor isolation (see figure 4.3.2) shows that 43.04% of the participants responded to "not at all," showing that caregivers had no perception of isolation whilst caring for their relative on Haemodialysis. This result does not support the finding by Beeson, Horton- Deutsch, Farran and Neundorfer (2000) who found that caregivers reported feelings of isolation from the community as well as a lack of companionship. The studies by Jeon, Kraus, Jowsey and Glasgow, 2010 and Bahrami et al, 2014, state most of the family caregivers, however, do experience sleep disturbances due to worrying about their relative's health, loss of hope, restriction in familial relationships and social isolation, of which the findings of the study are not consistent with. Chronic Kidney Disease and its management can restrict the family's daily activities, family life and social relationships; this can lead to feelings of isolation .The treatment of End Stage Renal Disease by haemodialysis creates considerable stress on patient including potential changes in family relations, social life and more specifically potential isolation (Theofilou, 2012e).

5.3.3 Disappointment

The factor "Disappointment," focuses on the change in plans, a sense of injustice experienced by the family caregiver and financial problems associated with the role of caregiving. The

results of the factor illustrated in figure 4.3.3(Disappointment %) show that 36.77% of the participants sometimes experienced disappointment in caring for their relative on haemodialysis. According to the General Social Survey 2012, 10% of employed caregivers turned down or did not even pursue a new career because of their caregiving responsibilities. In many instances a diagnosis of Chronic Kidney Disease and the necessity of implementing haemodialysis is a cause of concern for patients and their families and will lead to major changes in their lives (Brunner et al, 2010). The daily routine of management of haemodialysis will lead to patients being unable to fulfil their personal and professional goals within the context of living with a chronic illness (Theofilou, 2013b). This will consequently impact on their family relationships. A study in Nigeria by Alasia et al (2012) found that 65% of the participants funded their dialysis treatment from direct out of pocket payment hence the finances are redirected from the family needs to the health needs of their relative on haemodialysis. Relationships and independence are highly threatened by the role of caregiving as the family caregivers' movement and socialising is restricted and frequently revolves around patient care (Karamanidou, Theofilou, Gineri-Coccossis, Synodinou and Papadimitriou, 2009; Theofilou, 2011c). The restrictive treatment regime of Haemodialysis eventually leads to family caregivers and patients missing out on social events (Kaba, Bellou, Iordanou, Andrea, Kyritsi, Gerogianni., et al, 2007) leading to disappointment amongst the family caregivers. Hence the results of the study are in support of the studies highlighted above.

5.3.4 Emotional Involvement

The factor "Emotional Involvement," focuses on the perception of shame, embarrassment, anger or irritability with the patient's behaviour under their care. The results of the factor Emotional Involvement illustrated in figure 4.3.4(Emotional Involvement), indicate that 65.82% of the participants had no experience of fraught emotional involvement and responded to "not at all." This does not accord with the finding that family caregivers tend to experience high levels of emotional exhaustion, anger, social withdrawal, irritability, inability to concentrate and errors at work, supporting the need for more help in the work place (The Family Caregiver, 2008; Family Caregiving Alliance, 2009). Ziergert et al (2006) also state that family caregivers may feel they are caring for the family member on Haemodialysis at the expense of their own health. Moreover, they have to cope with the patient's emotional

feelings, low acceptance of the disease and loss of control over their condition (Tong et al, 2009).

5.3.5 Environment

The factor “Environment,” focuses on the perception of limitations in performing household chores as a result of one’s role as a caregiver and the problems associated with transportation, access to medication, health institutions and the community. Many of the participants (49.37%) stated that they were seldom affected by their environment in caring for their relatives on haemodialysis (see figure 4.3.5 in chapter 4). The pattern of renal disease and the disease management in any region or country is mainly determined by environmental factors such as accessibility to health care services, distribution of resources and of health care work force which entails the availability and brain drain of health professionals which affects the delivery of health care services to the patients and family caregivers (Moosa and Kidd, 2006). In the South African environment, the poor socio economic status of most patients with Chronic Kidney Disease (Naicker, 2003) affects the caring of and delivery of health service to the patients on haemodialysis. The majority of the participant’s responded to “seldom,” when asked whether they were affected by the environment which is not entirely in agreement with studies done by Naicker (2003) which show evidence that the environment does affect how family caregivers care for their relatives on haemodialysis. This may mean that participant do experience difficulty to an extent in caring for their relative on Haemodialysis in a South African environment but not to the extent they are unable to cope with caring for their relative on haemodialysis. In the Limpopo region, patients come from the rural areas and some travel as far as 300km to the dialysis unit (Zaldivar et al, 2012). Family caregivers in this situation are more likely to have negative feelings towards their relative on Haemodialysis especially if they have no experience or knowledge of the dialysis process. This problem is highlighted for those living in rural settings as they are far removed from health services, Blogg, O’ Shaughnessy and Cairns, (1999).

5.3.6 OVERALL BURDEN SCORE

The overall burden score, inclusive of all the factors: general strain, isolation, disappointment, emotional involvement and environment were obtained. A median score of

46.59% with an interquartile range of 30.68% to 55.68% applied. Hence, it can be stated many if not all family caregivers experience some degree of experiencing their caregiving as a source of burden. However, the majority in this small study (53.41%) experienced no burden in caring for the relatives on haemodialysis. This concurs with other studies which indicate that, despite the competing demands, 73% of employed caregivers were satisfied with their current balance between work and caregiving (Sonha, 2012). In another study done by the General Social Survey (2012), 95% of the family caregivers indicated they were coping with their caregiving responsibilities, with only 5% reporting that they were not coping well with their caregiving responsibilities. It would appear that, generally, caregivers were able to see their caregiving role as conferring more benefits than burdens.

5.4 CROSS TABULATION OF THE FACTORS OF THE CAREGIVER BURDEN SCALE AND DEMOGRAPHIC CATEGORY

In this section a discussion of the Cross Tabulation of the Caregiver Burden Factors and the Demographic Information Category against the back ground of the literature review:

Cross tabulation was done between the highest level of education and employment this is illustrated in table 4.4(Cross Tabulation of the Factors of the Caregiver Burden scale and Demographic Category). Participants with tertiary education equated to 55.7% of the total sample and 56.9% of the total sample were employed. The Fishers exact result was 0.001, shows there is a statistical significance between highest educational level and employment. The general consensus is that the educational level of a person is highly correlated with their socioeconomic status and that there is a significant association between the prevalence of Chronic Kidney Disease and those with low socioeconomic status (Crews, Charles, Evans, Zonderman and Powe, 2010). Bruce, Beech, Crook, Sims, Wyatt, Flessner, Taylor, Williams, Akylbekova and Ikizler(2010), found no significant associations between the prevalence of Chronic Kidney Disease and educational levels within their study of the Jackson area in Mississippi in the United States. While others suggest that there is a significant association between the levels of education and the prevalence of Chronic Kidney Disease (Young, 2010). Family caregivers with a higher education level may be engaged in more demanding employment resulting in a higher level of stress which in combination with caregiving reported a higher level of caregiver burden as stated by Stolley, Reed and Buckwater (2002). Reports from the National Alliance for Caregiving and American Association of Retired

Persons (2009) reports shows that there is a correlation between caregivers health on an income of less than 30 000 US dollars per annum: 34% reported poor health compared to 3% of caregivers earning 100 000 US dollars per annum or more. The same pattern is also found with a caregiver's level of education. This study was conducted in a private facility and the participants thus being placed in a higher socio-economic group than patients who are cared for in government hospitals. However, as this is a small study confined to private Health Care facilities, no conclusion can be drawn regarding socio economic status and the incidence of renal disease in this study.

Cross tabulation was done between the factor isolation and category gender this is illustrated in table 4.4. The majority of the participants in the gender category were female with 58% see table 4.1(Demographic Information of The Family Caregivers) and in the factor isolation most of the participants responded to "not at all" with 43.04% see figure 4.3.2(Isolation). No statistical relationship was found between the factor isolation and the category gender, the fisher's exact result of 0.077 shows a borderline relationship between the factor isolation and the category gender. The woman's role of caregiving, coupled with other domestic responsibilities, lack of resources and support brings about an increased burden of caregiving (Yurtsever et al, 2013) may well apply but no firm conclusions may be made in this study.

Cross tabulation was done between the gender category and relation to patient as illustrated in table 4.4. In the gender category female participants formed the majority with 58% see table 4.1(. In the category relation to patient the majority of the participants who responded were spouses with a total of 63.3% inclusive of wives and husbands of the population see table 4.1. After cross tabulation the fishers exact was a 0.000 which shows a statistical significance between gender and relation to patient. In the category of relation to patient the spouse who could either be the wife constituted 34.2% compared to the husband with 29.1%. A study done by the General Social Survey in 2011 highlighted the comparison between male and female caregivers where 54% were female caregivers compared to 46% for male caregivers. The study result almost mimics the results of this study. Most family caregivers are traditionally women in society who handle tasks which form part of daily living, although male caregivers are becoming more involved in caregiving responsibilities. Male family caregivers handle such matters as managing finances as well as assisting with the activities of daily living (AARP, 2008).

Cross tabulation of general strain and disappointment table 4.4 yielded a Fishers exact of 0.000. Cross tabulation of the factor general strain and disappointment shows a statistical relationship between the factor general strain and disappointment. The daily routine of management of Haemodialysis will lead to family members being unable to fulfil their personal and professional goals resulting in a feeling of disappointment within the context of living with a chronic illness (Theofilou, 2013b). The continuous strain of repeated visits by these patients to Haemodialysis centres is in the hands of the family. Some family caregivers may feel they are caring for the patient on dialysis to the detriment of their own health (Ziergert et al, 2006).

Cross tabulation was done between disappointment and the category gender table 4.4. The majority of the participants in the category gender where female with 58% (46) see table 4.1. The factor disappointment had a majority of the participant's responding to "sometimes" with 36.77% see figure 4.3.3, the fisher's exact result was 0.730; hence no statistical relationship exists between the factor disappointment and gender. Cross tabulation was done between general strain and ethnicity table 4.4. The majority of the participants for the factor general strain category responded to 'seldom' 43.04% see figure 4.3.1 and in the category ethnicity majority of participants were white with 45.6% see table 4.1. No statistical significance exists between general strain and ethnicity fisher's exact result being 0.628. The factor environment was cross tabulated with ethnicity table 4.4. The participants in the category ethnicity were white South Africans with 45.6% see table 4.1 and in the factor environment a majority of the participants responded to 'seldom' with 49.37%. No statistical significance exists between the factor environment and the category ethnicity with a fisher's exact result of 0.231. There is some evidence of ethnicity differences in the appraisal of strain due to caregiving, as evidenced in a study conducted in the United States. African- American caregivers had a lower likelihood of viewing caregiving as stressful, compared with Caucasian caregivers (Pinquart and Sorenson, 2001). However much of the research on ethnicity is compounded by socio economic status and there is little information available on caregiver perspective from different socio economic strata within racial and ethnic groups (Gehlert and Browne, 2011). As the participants in this study were drawn from a private facility, no conclusions can be drawn about ethnicity or socio-economic status on the perspectives of caregivers in the general population.

Factor isolation and factor environment were cross tabulated table 4.4. The majority of participants responded to "not at all" with 43.04% see figure 4.3.2 for factor isolation and for

factor environment participants responded to “seldom” with 49.37% see figure 4.3.5. The fisher’s exact result was 0.000 shows a statistical significance between factor isolation and factor environment. Environments that are far such as rural settings or those that are not conducive to safety, such as areas with are high crime rate can contribute to social isolations (Klinenberg, 2001). Cross tabulation of the factor environment and factor general strain table 4.4. The fisher’s exact result was 0.048 which shows a statistical significance between the factors environment and general strain. This further supports the study conducted by the researcher that the patient and the relatives have to seek medical care further from home. This adds further strain on the relatives as they have to travel longer distances to seek medical care as most of the private haemodialysis units are located in the urban areas.

5.5 SEMI STRUCTURED QUESTIONS

5.5.1 Question 1

Describe any benefits you have encountered whilst caring for a patient on Haemodialysis?

Many family caregivers have positive experiences from caregiving including a sense of giving back to someone who has cared for them. The satisfaction of knowing that their loved one is getting excellent care, adds an increased meaning and purpose in their lives. Some family caregivers feel that they are passing on the tradition of care and that by modelling caregiving, their children will more likely care for them if necessary (Haley, LaMonde, Han, Burton and Schonwetter, 2003). This aids and supports the information in the study where a majority of the participants responded to this question had experienced the benefits of caring for a patient on Haemodialysis shown on figure4.6.1 (Question 1). One participant mentioned, *“Brought the family closer together,”* this is supported by Smith (2003), that when one spouse is chronically ill, married couples spend more time together. Another participant further supported the evidence from the studies stating that, *“the greatest benefit is that my husband’s quality of life between dialysis sessions is improved and that he does not get admitted to the hospital which happened regularly before dialysis.”* Despite these competing demands, a study by Sonha(2012), stated 73% of the employed caregivers were content with their current balance between work and home life.

5.5.2 Question 2

Have you encountered any significant challenges whilst caring for a Haemodialysis patient? Yes/ no

Families encounter challenges which are extensive, Fifty eight percent (58%) of the participants in this study encounter significant challenges in whilst caring for their relative on haemodialysis as evidenced by the study of Hickman and Douglas (2010) which states that an episode of chronic illness exposes the relatives to the reality of critical illness. Ziegert et al (2009) also state that relatives of patients undergoing haemodialysis struggle to maintain control over their daily lives.. A participant stated, *“It has been a very trying because of finances, social life, work and studies. I am more exhausted and emotionally drained.”* Haemodialysis is a treatment which stretches over a long period of time. Treatment is costly requiring 2 or 3 sessions a week for 4 hours, according to KDOQI (2001). This treatment regime affects the family caregiver as they have to ensure their relative attends treatment and have to deal with the side effects of treatment such as fatigue, nausea and vomiting. As emphasised further by one of the participants, *“Getting him to adapt to a new lifestyle, diet is challenging.”* Participants highlighted the challenges for their financial situation, social situation and dialysis complications (drowsiness, loss of energy and fatigue) hinders a person’s ability to perform activities such as working, socialising and travelling as commented upon by the study by Al- Arabi, (2006). Women and men both suffer fertility problems with men experiencing lowered fertility or no fertility at all. Women are advised against becoming pregnant due to the complications of pregnancy on the mother and the developing infant (National Kidney Foundation, 2013), this was highlighted by one of the participants, *“trying to start a family.”*

5.5.3 Question 3

Would health education prior to Haemodialysis treatment, have better prepare you for the challenges ahead? Yes/ no

Participants answering this question confirmed that health education prior to Haemodialysis treatment would better prepare the family caregivers to care for their relatives on haemodialysis with a percentage result of 65.85%. Participants responded affirmatively to the fact that it would be beneficial to have received health education such as information on

haemodialysis treatment and how to cope with chronic illness. The study findings are supported by Paulson, Norbeg and Soderberg (2003) who state a lack of insight into the disease and a lack of support from professionals make it difficult to live with a person with Chronic Kidney Disease. As mentioned by one participant, *“it would have made it easier to cope and it would have helped me to understand how to take care of the situation.”* Natterland and Istrom (1999) further support this study by stating that it is important for relatives to get the same information as the patients to facilitate their understanding of the situation. The South African Renal Society Chronic Dialysis Guidelines (2006) state that the patient, relatives and significant others should meet the social worker to discuss treatment, gauge family dynamics and support structures, then recommend that each patient be assessed prior to dialysis to assess their emotional, economic and social coping skills so that appropriate interventions can be given. As mentioned by one of the participants, *“I think that the patient and the spouse should be more informed before dialysis begins on what effects,”* a need for health workers who are well equipped with knowledge are able to adequately care for the needs of family caregivers. Support by a medical team appears to be very important for family caregiver’s wellbeing (Yurstev et al, 2013).

5.6 LIMITATIONS OF THE STUDY

- The results of this study cannot be generalised to all family caregivers caring for family members on haemodialysis as the study took place in three private facilities belonging to one private health care institution.
- The study was conducted over a limited time period.
- Only 3 centres were included in the study. Involving other centres might have yielded different results.
- The participants selected were limited to participants caring for the patient for longer than 1 year. Kidney transplanted patients were excluded.
- The researcher asked the patients on haemodialysis whose relatives were not present during the haemodialysis session to take the questionnaire to their place of residence for their relative to complete and return the completed questionnaire on their next Haemodialysis session. Of the 150 questionnaire distributed only 79 questionnaires were returned and completed. A poor response was noted on part 3 of the entire questionnaire which was the semi structured questionnaire, only 41 participants

answered the section completely. Resulting in a poor response for the semi structured section.

5.7 RECOMMENDATIONS

- The researcher feels that health education about haemodialysis therapy should not only be given to patients undergoing therapy but their families must also be included as they are involved in the care of the patient. As mentioned by the respondents in question 3 who emphasized on the need for the patient and family caregivers to be health educated on chronic kidney disease and its management. Multidisciplinary team dieticians, psychologists, social workers and the relevant members of the multidisciplinary team could be involved in the care of a patient who is on Haemodialysis therapy for Chronic Kidney Disease.
- The employment sector needs to be educated about Chronic Kidney Disease and Haemodialysis therapy so that they can be more accommodating to people who need time off to attend therapy sessions rather than aggravating unemployment rates, which are already high in South Africa. Unemployment is one of the stressors experienced by haemodialysis patients, more media publicity should be given to Chronic Kidney Disease and haemodialysis. In Chapter 5 under question 3, one of the respondents state they struggle to maintain control of their daily lives as they struggle to maintain a balance over their finances, social life, work and studies. The demographic information in table 4.1 of this study revealed 24.1% of the participants were unemployed. Caregiver health is a public health issue that requires attention from the health professionals, policy makers and caregivers themselves to ensure the health safety of those individuals dedicating their lives to the care of others.
- Nocturnal haemodialysis. While traditional haemodialysis provides effective treatment, nocturnal haemodialysis offers a longer slower treatment which allows for time to clear as much waste as possible from the blood stream, which allows the patient to work during the day and receive treatment at night. Hence patients may maintain gainful employment during the day which will maintain financial balance in the family. In Chapter 4 under question 2, some of the participants highlighted on financial challenges they encounter due to the management of the condition, as the patients are in private sector and are paying their treatment via the medical aide.

Hence gainfully employment and being able to attend normal working hours would improve the families' financial situation.

- Health education and its continuance should be a prerequisite for all family caregivers to aide them in coping with the daily challenges they encounter caring for their relatives on haemodialysis. Family caregivers in question 3 chapter 4 highlighted it would have been easier to cope with their relative on haemodialysis if they had received information pertaining to the condition and its management.

5.7.1 Recommendations for research

For the research it may be recommended that

- A qualitative study can be conducted on the perceived benefits and burdens of caring for a relative on haemodialysis.
- A study focusing on the role of the nurse as a patient and family educator.
- A study on the need for increased training of nephrology nurse specialists to provide specialist treatment for a growing End stage Renal disease population..

5.8 CONCLUSION

In this study the following aim and objectives were set as to explore the perceived benefits and burdens of caring for a patient on haemodialysis by the family caregivers. The description from the family caregivers, factors which challenge the process of caring and identification from the caregivers, the perceived shortfalls in the health care systems. The researcher was able to establish from the findings of the study. The factors surrounding the family caregiver whether good or poor are not always predictors of perceived benefits and burdens of caring for a haemodialysis patient. From the findings of this study the following factors emerged namely demographics which include age, gender, relation to patient, highest educational level, employment, ethnicity and duration of care and the factors surrounding general strain, isolation, disappointment, emotional involvement and environment.

The researcher was able to establish that the majority of the family caregivers in societies are female as seen by the results in table 4.1 (Demographic information of the Family Caregivers), the female caregivers represented the majority with 58% of the total population against the male caregivers who were 42% of the total population. It is the women who are

traditionally the caregivers but findings from the study indicate that the number of male caregivers is on the rise. Most of the family caregivers were either employed 56.9% or self-employed 19% see table 4.1 (Demographic Information of the Family Caregivers), which shows that despite caring for their relative on haemodialysis they are able to continue working despite the strain of caregiving. Overall burden score inclusive of all the factors, a median score of 46.59% of all family caregivers experience burden whilst caring for their relatives on haemodialysis and 53.41% experienced no burden in caring for their relatives on haemodialysis. After cross tabulation a relationship between the factors of the caregiver burden scale showed relationships between some of the variables for example gender and relation to patient see table are more likely to care for a spouse see Table 4.4 and a statistical significance with a fishers exact result of 0.000. Hence showing a relationship between gender of the family caregiver and relation to patient as evidenced by literature, a survey of older caregivers were more likely to care for a spouse or partner National Alliance for Caregiving and American Associated Retired Persons (2009). In the category relation to patient the majority of the participants who responded were spouses with a total population of 63.3% inclusive of wives and husbands of the population see Table 4.1 (Demographic Information of the Family Caregivers). The semi structured questionnaire with an option for elaboration, allowed for deeper understanding of the family caregivers perceived benefits, burdens and factors that facilitate and challenge the process of caring for a relative on haemodialysis. Family caregivers did however experience benefits when caring for a relative on haemodialysis as noted in Chapter 4 under Question 1, where the participants highlighted on positive experiences such as improving family relations and less need for hospitalisation. The significant challenges encountered by family caregivers were highlighted in Chapter 4 question 2, challenges encountered such as the basic inability to travel long distance due to unavailability of haemodialysis units in some areas, financial difficulties, emotional and social distress. Family caregivers need to adapt their lifestyle to the dietary recommendations prescribed for their relative on haemodialysis. In question 3, family caregivers emphasise the need for professional support, health education, follow up care and the need for involvement in the care of their relative on haemodialysis. In Summary it can be stated that in the Private sector in South Africa, most of the family caregivers who participated in the study encountered both benefits and burdens in caring for their family caregivers. However they did highlight on the need for social support from health professionals, community and the government.

CHAPTER 6

LIST OF SOURCES

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