EXPLORING THE EDUCATIONAL NEEDS OF DIABETIC PATIENTS REGARDING CHRONIC KIDNEY DISEASE.

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg in partial fulfilment of the requirements for the degree Of Master of Science in Nursing

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DECLARATION

I hereby declare that this research report is my own work. It is being submitted for the Degree Master of Science Nephrology (Nursing) to the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination to any other University.

Signature:

.....Lesemole.....

Mr C.SLesemola

Signed at:

.....Bethlehem.....

.....26... day of .....November..... year....2020.....

DEDICATION

I dedicate this research report affectionately to the following people:

My parents, Mr and Mrs Lesimola

My sister, Maureen Lesimola,

My sisters Son, Mpho Lesimola

My brothers, Moses and Rampai Lesimola

ABSTRACT

Background: An American study has supported that not much is known about educational experiences and needs on diabetes and its complications. Data using a qualitative approach is different from the actual surveys on the knowledge of diabetes and its complications and depth of information, such that the concept of how participants understand information is better explored (Monahan et al., 2007).

A systematic review of studies in 54 countries in sub-Saharan Africa supports that diabetic nephropathy with subsequent chronic kidney disease is very common (Noubiap, Naido and Kengne, 2015). The study included cross sectional, cohort, retrospective and prospective studies between 1994 and 2014 with 18 of the 32 studies coming from South Africa.

Objectives: The purpose of this study was to explore the educational needs of diabetic patients attending a Public hospital clinic in the Free State Province with regards to developing chronic kidney disease as a complication of diabetes. Two objectives exploring education on kidney disease and information of lifestyle changes required to prevent chronic kidney disease as a complication were stated.

Design: Twenty five diabetic patients participated in the study and agreed to be interviewed during their regular visits at the diabetic clinic. The researcher conducted face to face interviews in private rooms and data was recorded transcribed and analysed using thematic data analysis. Eight males participated in the study and seventeen females. They all had either type 1 diabetes mellitus or type 2 diabetes mellitus with other comorbidities such as hypertension, pain, asthma, arthritis and

tuberculosis. All races were represented with the majority being blacks and Sotho speaking.

Data analysis: Thematic data analysis was used for this study. Using the seven steps of thematic data analysis the researcher was able to focus on significant points and themes to elaborate the results clearly. A detailed discussion of the steps follows in chapter three of this report.

Results: The educational needs of diabetic patients regarding chronic kidney disease are not met by healthcare professionals and are a concern according to these study findings. There is a need to develop educational input across all means of communication that addresses the basic kidney physiology as well as the disease pattern of diabetes so that patients can understand the correlation between diabetes and kidney disease. Educational tools should be available in all eleven languages and information should be presented in simple terms. An explanation of blood and urine kidney function tests should also be outlined in the tool.

Key terms: Complications, Chronic kidney disease, Diabetes and Lifestyle.

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ABBREVIATIONS

ABREVIATION	EXPLANATION
1 CKD	Chronic kidney disease
2.BMI	Body mass index
3.WHO	World health organisation
4.ADA	American diabetic association
5.GFR	Glomerular filtration rate

CHAPTER ONE

OVERVIEW OF THE STUDY

1.0 INTRODUCTION

This chapter provides the overview of the study. It explains the background of the study, the problem statement, its purpose, and research question which was addressed and objectives that directed the study towards the aim or original purpose. The researcher has also emphasized the significance of the study and has provided a brief overview of the methodology used including the design, data collection methods, the population sample and sampling procedures and a data collection tool. The ethical considerations as well as the trustworthiness of the study have also been briefly outlined.

1.1 BACKGROUND OF THE STUDY

Diabetes mellitus can be defined as a metabolic disease with high blood glucose levels which results from low insulin (Type 2) or no insulin (Type 1) production by the pancreas (Monahan et al., 2007). It then affects the metabolism of proteins, carbohydrates and fats in the body. It is when diabetes is uncontrolled that it eventually leads to damage of other organs in the body. In the case of the kidneys, diabetes leads to the development of diabetic nephropathy in which a syndrome develops characteristic of damage to the

glomerulus, followed by presence of protein in urine, edema and hypertension, leading to Chronic Kidney Disease and End stage Renal Disease (Monahan et al., 2007).

It is now evident that diabetes is one of the leading causes of kidney disease in the world (Stanifer et al., 2014). The current statistics in South Africa from the 2011 South African Data Archives household survey included the use of health facilities and levels of selected conditions such as diabetes. About 4.7 percent of the population was diagnosed with diabetes. They were mostly above the age of 25, with about 94.5 percent of these taking medications for diabetes. The majority only started to take medication at the age of 55. Distribution of diabetes was highest amongst Indians, then Asians, Coloureds and Caucasians. The black population was recorded as having the least number of diagnosed diabetics. The Western Cape Province was the province with the largest number of diabetic patients taking medication (98.4%), followed by the Free-State province (96.5%). The least number of diabetic patients taking medication occurred in Mpumalanga at (90.4%). The gender pattern was mainly females (Statistics South Africa, 2013). These figures thus affirm the relevance of the proposed study which will be conducted in the Free-State province. The global prevalence of diabetes is rising rapidly and was 8.5 percent with a total number of 422 million cases in 2014 (WHO, 2018). Increasing numbers are especially concerning in developing countries like South Africa and among adults above the ages of 18 years. The World Health Organization (WHO) further notes that uncontrolled diabetes can lead to the development of diabetic nephropathy, making it one of the leading causes of chronic kidney disease world-wide (WHO, 2018).

People with end stage chronic kidney disease rely on dialysis therapy to sustain life while they await donors for kidney transplantation, however on a global scale an estimated 5-10 million people die annually whilst awaiting kidney transplantation and between 2.3 to 7.1 million died without treatment in 2010 due to limited space for dialysis (WHO, 2018).

A study of systematic reviews on awareness on chronic kidney disease in America has supported the view that educational levels regarding kidney disease remains low despite efforts to improve knowledge such as world kidney day, clinical policies and early evaluation programs (Platinga, Tout and Powe, 2010). In this review African Americans with uncontrolled blood pressure and diabetes were not fully educated about possible chronic kidney disease as a risk (Platinga et al., 2010). One third of the surveyed population already had chronic kidney disease but was not fully educated on it.

A Canadian study revealed in an intervention programme on kidney health and disease, that over 800 participants remained poorly informed of chronic kidney disease. The authors have argued that it will take the constant evaluation of education campaigns and multimedia platforms to reach the high risk groups like those with diabetes (Ryz et al., 2015). One would thus argue that it still remains appropriate to further investigate experience and behaviour in order to better understand patients' needs thus providing improved comprehension and articulation since interventions alone are not improving actual knowledge of chronic kidney disease as a complication of diabetes.

In an Iranian study 117 patients with Type 2 Diabetes mellitus on dialysis were evaluated for their knowledge, attitudes and practices concerning diabetes and its complications (Ghannadi et al., 2016). These authors reported that their knowledge remained poor despite the fact that the patients had been attending dialysis for a long period of time. Most patients still demonstrated unfavourable attitudes about their condition. The practice of self-care was linked to unfavourable attitudes. The greatest concern surfaced from the fact that few patients were well informed about chronic kidney disease as a complication that could arise from diabetes and how to asses for signs such as proteinuria and high blood pressure. Glycaemic control practices were also not adhered to (Ghannadi et al., 2016). This study surveyed and analysed data using descriptive statistics, however the depth of perceived education was not determined and needs further focus. According to these authors, studies that are explorative in nature need to be conducted in patients with diabetes before these patients develop chronic kidney disease. This is particularly true in developing countries like South Africa.

An American study has supported that one in three adults with diabetes is estimated to have chronic kidney disease (Burrows et al., 2017), however, many people with chronic kidney disease are poorly informed of it because of poor measures to educate them. Effective interventions to improve blood glucose levels and blood pressure control might prevent or delay the onset of kidney disease in adults with diabetes (Burrows et al., 2017). It is thus apparent that patient education needs improvement and thus needs to be explored. Measures are in place to address these issues but patient lifestyle changes remain low, possibly due to lack of understanding.

According to the South African Renal Registry, by the end of the year 2016, 10,257 patients with chronic kidney disease were receiving renal replacement therapy. This relates to a prevalence of 183 per million populations. One of the leading causes was attributed to diabetic nephropathy (15.2%) of the total patients with chronic kidney disease), second only to hypertension (34.7%).

Although the Western Cape and Gauteng lead with the highest prevalence of kidney disease (Davids et al., 2018), the Free State province had a significant number and held the third position with a prevalence rate of 202 per million population (Davids et al., 2018) with a total of 577 patients on dialysis by 2016. The age range of chronic kidney disease in this province is from 14 to 55 and occurs predominantly in males (60%).

The black population makes up the majority of patients on dialysis (54.1%). No kidney transplants were performed in Free State province during the time of that study (Davids et al., 2018). Limiting the incidence of Diabetic Nephropathy in the Free State is thus a priority and important for this specific study since the options for treatment in the Free State are limited.

Obadan, Walker, and Egede, (2015) found that in 345 patients from a primary care centre in the United States, the overall knowledge of kidney disease and associated risk factors was found to be poor. Thirty one percent of these patients were diabetic (Type 2) and were not fully educated about diabetic nephropathy as a complication. The study investigated clinical factors for correlation with awareness findings. The study also included health behaviour and self-care practices. This data was collected using self-administered questionnaires and the results were quantified and statistically analysed

(Obadan et al., 2015). These authors do however suggest that it will take qualitative studies to explore factors through probing patients' perspectives and experiences, to better understand the need for information resulting in change of lifestyle choices so that interventions have a comprehensive reach (Obadan et al., 2015).

A systematic review of studies in 54 countries in sub-Saharan Africa supports that diabetic nephropathy with subsequent chronic kidney disease is very common (Noubiap, Naido and Kengne, 2015). The study included cross sectional, cohort, retrospective and prospective studies between 1994 and 2014 with 18 of the 32 studies coming from South Africa.

The main risk factors and determinants of development of chronic kidney disease as a complication of diabetes are delayed diagnoses, limited screening tools, duration of both type 1 and type 2 diabetes, poor glucose control, high blood pressure, advanced age, and obesity (Noubiap et al., 2015). It is thus exploratory studies that will foster a surveillance system for education programmes on the disease patterns affecting the kidneys for subsequent early detection, proper screening and prevention of diabetic nephropathy as a complication of diabetes.

From the background discussion, information of the link between diabetes and chronic kidney disease remains an essential topic in patient education especially in developing countries like South Africa. Existing studies have not provided sufficient contribution in the advancing of practice screening and educational strategies to foster improved lifestyle changes of high risk groups such as diabetics, regarding chronic kidney disease.

In the Free State province there is no active kidney transplant programme due to shortage of surgeons and resources (South African Renal Registry, 2013). Organ donation programmes do not reach the vast rural communities. If the number of patients with chronic kidney disease increases due to diabetes, the number of patients exceeding the available facilities will become even more excessive. Patients will die before receiving dialysis treatment due to limited resources in the public sector. A qualitative study approach allows us to probe and explore the participants' understanding of the education programmes and the need for lifestyle changes required in Diabetes to avoid the development of chronic kidney disease.

An American study has supported that not much is known about educational experiences and needs on diabetes and its complications. Data using a qualitative approach is different from the actual surveys on the knowledge of diabetes and its complications and depth of information, such that the concept of how participants understand information is better explored (Monahan et al., 2007).

1.2 PROBLEM STATEMENT

The global increase in chronic kidney disease as a result of diabetes is well documented (WHO, 2018). This will contribute greatly to the disease burden and cost of treatment in a developing country where patients in the public sector are at present subjected to strict selection for renal replacement therapy.

On the African continent, a study of 454 residents in a Nigerian community supports that the lack of information of chronic kidney disease even among the high risk group with diabetes remains unacceptable (Oliyombo et al., 2016).

Currently the Free-State public health sector has no active transplant kidney unit due to shortage of surgeons, particularly Universitas Academic Hospital where the study took place , which also serves as the main referal center (South African renal registry report, 2013). The public sector dialysis units in Free-State do not have enough space to accommodate new patients with chronic kidney disease including those developing chronic kidney disease as a result of diabetes. There is a need to explore the educational needs of diabetic patients on Chronic kidney disease at this specific setting to help curb the complication of chronic kidney disease.

South Africa needs explorative studies on what information is given to newly diagnosed patients to prevent them from developing chronic kidney disease to be carried out especially amongst the diabetic patients who do not yet have Diabetic Nephropathy. Addressing this problem will add to the body of knowledge and thus improve information of chronic kidney disease in a group of patients whose disease may contribute significantly to the overall burden of disease in South Africa.

There remains a gap in the information and understanding of the possibility of developing CKD in diabetic nephropathy and what changes in lifestyle are required by patients who are at risk (Oliyombo et al., 2016).

1.3. RESEARCH QUESTION

The researcher sought to answer the following question:

What are the educational needs of diabetic patients about the possibility of developing chronic kidney disease as a complication of diabetes?

1.4 THE PURPOSE OF THE STUDY

The purpose of the study was to explore the educational needs of diabetic patients attending a Public hospital clinic in the Free State Province with regards to developing chronic kidney disease as a complication.

1.5 OBJECTIVES

The objectives of this study were:

To explore the educational needs in diabetic patients attending a clinic at a Public hospital in the Free State province regarding chronic kidney disease.

To explore lifestyle behaviour changes associated with preventing chronic kidney disease in the diabetic patients.

1.6 SIGNIFICANCE OF THE STUDY

Findings have fostered the need for promotion of information of chronic kidney disease amongst diabetics who are a high risk group for developing chronic kidney disease. This study has bridged the gap towards finding meaning and understanding of patient education experience, as they were asked to share their own understanding of their condition and chronic kidney disease as a complication. The overall educational experience of chronic kidney disease was poor as many participants did not know clinical symptoms and how they are treated. The findings have significantly raised the need to improve teaching tools to be more client focused so that information generated can encourage self-care practices amongst diabetic patients to prevent chronic kidney disease as a complication. As a result the increase in the number of diabetic patients with chronic kidney disease may be prevented, thus possibly reducing the socio economic burden of chronic kidney disease in the future.

1.7 PARADIGMATIC ASSUMPTIONS

1.7.1 Meta Theoretical Assumptions

A paradigm is a world view, and provides a general perspective on the complexities of the real world and the relationship between these complexities as well as methods used to generate theories from them (Brink, Van der walt and van Rensburg, 2018). All nursing research needs to be founded on a nursing paradigm as this guides the researcher in her research methodology. This research was based on the following meta-theoretical, theoretical and methodological assumptions.

- Person

People establish the nature of their reality based on the process of how the knowledge is communicated to them or how they acquire it (Adil and Khalid, 2016). In this study diabetic patients at high risk of developing chronic kidney disease needed to be given basic and understandable education on the physiology of kidney function, kidney health and how to prevent chronic kidney disease by identifying the link between the two diseases at an early stage.

- Environment:

In this study the setting is at a diabetic clinic in an academic hospital. Patients undergo individual consultations in private rooms to ensure comfort and confidentiality. The patients also wait in hallways with adequate lighting where posters on diabetes and its complications are mounted to the walls. However these posters lack attractive details on chronic kidney disease as complication of diabetes and how it can be prevented. The environment has not included audio visuals to stimulate learning the visual clinical picture of chronic kidney disease and the resultant dialysis treatment may offer stimulation of self-care measures.

- Health:

Health is defined by World Health Organisation (WHO) as the state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity (WHO, 2018). Diabetes is a chronic disease however it does lead to chronic kidney disease as a complication. The education of diabetic patients who have not yet developed chronic kidney disease has not been adequate enough to eliminate the

double burden of these two chronic conditions which can be physicaly, mentally and socially debilitating (Sakraida and Weber 2016). Self-care and lifestyle changes are empirical to managing diabetes and preventing complications (American Diabetes Association, 2014).

- Nursing:

Nursing is defined by the International Council of Nurses (ICN, 2019) as “autonomous and collaborative care of individuals of all ages, families, groups and communities, sick or well and in all settings. It includes health promotion, prevention of illness, and the care of the ill, disabled and dying people.” This emphasizes the importance of independent decision-making in nursing while working as a team with other health care professionals for the best outcome of care given to patients. It also clarifies the fact that access to health care is a universal right of every person not only the sick. This includes health promotion services, those services aimed at prevention of illnesses, caring for the sick, people with disabilities and those who need end of the life care. (International Council of Nurses, 2019). At the setting of this study the professional nurses have not specialised in endocrinology which limits their ability to educate patients on diabetes and chronic kidney disease as a complication.

Enrolled nurses do urine tests and vital signs and lack the ability to teach patients about interpretations of results such as proteinuria and high blood pressure which could indicate chronic kidney disease. Blood results are referred for interpretation by doctors however professional nurses should be playing a role in identifying key kidney function markers that patients can take note off.

1.7.2 Theoretical Assumptions

Theoretical assumptions reflect what the researcher believes regarding the research process. These beliefs are influenced by the nature of the specific research topic or research problem.

1.7.3 Definitions of concepts

- Diabetes: Medical disorder in which the body is not producing insulin or is producing it at low levels resulting in elevated blood glucose levels which damage small blood vessels in the kidneys causing protein loss and chronic kidney disease (WHO, 2018).
- Hypertension: Hypertension causes damage to blood vessels resulting in damage to the intrarenal capillaries and glomerulus. This causes chronic kidney disease over time. (WHO, 2018).
- Chronic kidney disease: Refers to progressive decline in kidney function in which the kidneys lose their ability to concentrate urine and regulate fluid output. Elevated blood sugar levels with diabetes contributes to the decline in kidney function (Oliyombo et al., 2016). The participants in this study had been diagnosed with Diabetes for a minimum period of two years.
- Lifestyle: The habits, attitudes, preferences, value standards, financial level, that together make up the mode of living of an individual or group (American Diabetes Association, 2014). The study participants were mostly rural dwelllers on social grants and could not afford to be compliant with dietary requirements for diabetes.

- Complication: A pathology or resulting disease which makes the original disease worse (Marieb and Keller, 2018). Diabetes can cause CKD as a complication.

1.7.4 Methodological Assumptions

Methodological assumptions refer to how the inquirer obtains knowledge or information about their reality (Brink et al., 2018). This is how the researcher responds to questions. The following section explains how the educational needs of diabetic patients were explored.

1.8 RESEARCH METHODS

Research methods are the tools used by the researcher to collect data and analyse it in a particular manner (Clarke and Braun, 2013). An outline of the methods used in this study follows.

1.8.1 Research Design:

This study made use of a descriptive exploratory qualitative design. In-depth interviews were conducted. In-depth Interviews offered the participants an opportunity to describe their own experiences however information on chronic kidney disease was very superficial.

1.8.2 Setting:

The setting was a Public sector clinic in a hospital in the Free State Province. This is an outpatient clinic and diabetic patients were seen by the researcher on Monday to Friday

during their monthly follow-up. This hospital is an academic hospital with tertiary services. The training programmes are accredited for Nursing, Medical and other Allied Health Science courses as regulated by bodies such as South African Nursing Council, Health Profession Council of South Africa and the Free State Health Department. Most diabetic patients are referred to this hospital from the district hospitals and primary health care centres for further management at the clinic and some are diagnosed at the hospital and managed at this clinic.

1.8.3 Population and sample:

The study population included all diabetic patients attending the clinic. The number of patients was 200 in total per month. In this case the whole population was representative of the study topic and thus relevant for the information required. The sample was selected by purposive sampling and continued until saturation had been established at 25 participants. Saturation refers to a point where data surfacing does not provide new information (Clarke et al., 2013). The sample was selected and recruited by the researcher at a diabetic clinic on the days of their regular visits from Monday to Friday. Purposive sampling allows for inclusion of participants who are most likely to provide information rich data for the topic of interest (Clarke et al., 2013). Twenty five participants were included and interviewed. Inclusion criteria were all patients age 18 and above, diagnosed with Type 1 or Type 2 diabetes mellitus, with or without other illnesses, who attended the clinic at the selected hospital on the days of data collection, and who had been seen at the clinic for at least 3 months. Exclusion criteria included patients who fell outside the age group, and patients who were newly diagnosed with Diabetes.

1.8.4 Data collection:

After permission was granted by the relevant bodies, data was collected through interviews using open ended questions. Below are examples of three questions put to each participant.

Tell me what you were told about diabetes when you were diagnosed as a diabetic?

Who gave you the information?

Tell me about how your lifestyle will change with diabetes in order to avoid complications?

An audio tape recording of the interview and the researcher's field notes were used to analyse data. Participants were interviewed face to face by the researcher while attending the clinic. Cresswell (2018) highlights the benefit of face to face interviews and states that it is valuable in obtaining in-depth information. This approach also helped to get real information, however due to insufficient education on chronic kidney disease in depth information was compromised. The interview took approximately 60 minutes. Open ended questions were asked of the respondents. Interviews were conducted in English. A Sotho expert was available for translations of those participants with Sotho expressions if there was a need. Data was collected weekly for two months as per clinic schedule. Interviews were conducted in a private room at the diabetic clinic during regular visits.

The researchers role in the setting was to conduct the interviews.The researcher was not employed by that facility but the setting was the best diabetic out patient department

targeting the population required. No pilot interview was conducted but the researcher was trained in interviewing by the supervisor and psychology members of staff in the department.

1.9 RESEARCH RIGOR

Trustworthiness was maintained in keeping with the model of Lincoln and Guba (1985) which proposed four aspects: credibility, dependability, conformability and transferability.

Credibility alludes to confidence in the truth of data. The in depth interviews that were conducted by the researcher were recorded on an audio tape recorder and kept as proof. The recorded interviews were also verified and by member checks or participants at the end of the interviews, and prolonged engagements or discussions with the participants to verify their views.

Dependability refers to stability of the data and was achieved by making use of purposive sampling which allowed inclusion of members that are mainly representative of the research topic.

Conformability establishes if data represents information provided by participants. Verbatim transcripts were used to ensure conformability. This ensured that the researcher's personal views did not influence the information provided by the participants.

Transferability refers to the ability to apply the findings to other studies or settings. This was done by using dense thick description of the information provided by participants.

1.10 ETHICAL CONSIDERATIONS:

Approval to conduct the study was sought and obtained from the following committees:

The University of the Witwatersrand, Faculty of Health Sciences Post-graduate Assessors Committee

Human Research Ethics committee (Medical) of the University of Witwatersrand.

Permission from hospital management via Free-state Health Department Research Committee.

An Information letter explaining the study was given to participants.

Informed consent was obtained for the face to face interviews and the audio recordings.

The researcher ensured confidentiality by keeping respondents details secure. Only the researcher and supervisor knew the details. Participants were assured that although complete anonymity was not possible due to face to face interviews, the findings were anonymous and no real names of participants were used during publication.

Emphasis on the right of withdrawal from the study at any given time was outlined for respondents on the information sheet. The participants were also assured that the information gathered will be kept in a password protected computer folder known only by the researcher and the supervisor and that the recorded interviews and documents

will also be kept in a code protected safe known only by the researcher and the supervisor.

1.11 OUTLINE OF THE REPORT

The chapters of this report are outlined as follows

Chapter one: Overview of the study

Chapter two: Literature review

Chapter three: Methods

Chapter four: Findings

Chapter five: Discussion, recommendations, limitations and conclusions

1.12 SUMMARY

The chapter has provided a framework of the study. It described a brief background of the study, the problem statement, and research question, purpose of the study, research objectives and the significance of the study. A brief overview has been given of the research methodology, trustworthiness of the study and the ethical procedures adhered to during the course of this study.

The following chapters will provide a review of the literature, the methods, data analysis, the description and interpretation of research findings. The final chapter will state

limitations of the study, summary of the study findings, conclusions and recommendations for future research.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter introduces the literature reviewed for this study. Literature review is aimed at exploring and clarifying key concepts or objectives that have been identified so that the nature and meaning of the problem or the research question is better understood (Brink et al., 2018). This study explores the educational needs of diabetic patients about their possibility of developing chronic kidney disease as a complication. The study further integrates the understanding of diabetic patients about the possible lifestyle changes needed for optimal health with diabetes as it refers to how they manage their condition. Literature pertaining to the education of diabetic patients, their understanding of chronic kidney disease as a complication and associated lifestyle changes required is reviewed.

Both type 1 and 2 diabetes mellitus are becoming leading causes of chronic kidney disease in sub-Saharan Africa while being number one in developed countries such as the United States of America (Sakraida et al., 2016). Diabetes mellitus is a complex vascular disease which affects not only the kidneys but other vital organs in the body such as the eyes and the brain. Diabetes is explained by the body's inability to metabolise carbohydrates due to lack of insulin (type 1) or suboptimal insulin (type2) from the pancreas (Marieb and Keller, 2018). Globally 5 million adults died in 2015 from diabetes, 29.6% from high income countries and 72.7 per cent from low income

countries like South Africa. If the patients are not fully educated on disease management especially with regards to making lifestyle changes, we can anticipate a global crisis with many complications from this disease.

2.2 DIABETES OVERVIEW

Type 1 diabetes mellitus is characterized by complete immune destruction of the beta cells in the pancreas with subsequent loss of insulin production (Monahan, Sand, Neighbors, Marek et al., 2007). Type 1 Diabetes mellitus usually occurs in younger people less than 30 years of age and the actual cause is still not known (Zaheer, Ankia, Coetzee, Dave et al., 2017).

Type 2 diabetes mellitus is characterized by the poor production of insulin by the beta cells of the pancreas due to some damage or defect and also by increased insulin resistance in some tissues across the body (Zaheer et al., 2017). Type 2 diabetes mellitus is mainly caused by inherited beta cells abnormality, but may result from certain infections such as CMV virus, medications and diseases of the pancreas such as pancreatitis (Monahan et al., 2007). Type 2 diabetes mellitus is common in older people, especially if obesity is present, alcohol abuse and heavy smoking. Classical symptoms of diabetes include excessive thirst, excessive urination and weight loss with increased hunger and blurred vision (WHO, 2018).

Diabetes is diagnosed based on the following criteria as proposed by endocrinology experts (Zaheer et al., 2017).

A blood test of the patient is repeated every two weeks if there are no symptoms.

- Presence of symptoms (excessive thirst, excessive urination, poor vision and Weight loss)
- Random blood glucose greater than 11 mmol/L
- Fasting glucose level greater than 7 mmol/L
- Glycosylated hemoglobin greater than 6.5%
- 2 hour post glucose load level greater than 11 mmol/L

2.3 DIABETES AND CHRONIC KIDNEY DISEASE

Chronic kidney disease (CKD) is characterized by slow loss of kidney function which occurs over years. It is defined by the National Kidney Foundation Kidney Disease Quality Outcome Initiative (KIDOQI) as loss of kidney injury for 3 months with a decline of the glomerular filtration rate (GFR) to <60ml/min/1.73m2 (Thomas, 2014). Common causes of chronic kidney disease have been attributed to Diabetes mellitus, glomerulonephritis, pyelonephritis, polycystic kidney disease, renal vascular disease and hypertension. Once the GFR has dropped to between 15-29ml/min/1.73m2 patients are then started on dialysis therapy and prepared for possible kidney transplant (Marieb et al., 2018).

CKD is very debilitating once it progresses to end stage renal disease. Diabetic nephropathy occurs over years in patients with diabetes particularly when it is uncontrolled diabetes. Diabetic nephropathy is characterized by protein and albumin in

urine with levels between 30 to 300 mg per day. At this point the patient needs urgent referral to a nephrologist before they progress to renal failure. Kidney biopsy results for diabetic nephropathy reveal that the glomerulus is thickened and the surrounding mesangial cells are expanded with a presence of Kimmelstiel lesions (Lloyd and Komenda, 2014). Diabetic patients who are at risk for diabetic nephropathy are generally males, who already have hypertension and those that are overweight and smoking, with noncompliance to diabetic treatment. It is recommended that education of diabetic patients centres around changing how they lead their life such as not smoking, losing weight (BMI<25kg/m2),not adding too much salt to meals, and eating less fatty meals (Lloyd et al., 2014).

Among other diabetic patients who are prone to get chronic kidney disease are the elderly above 50 years who have had diabetes for longer than 10 to 20 years as well as those with anaemia with haemoglobin <13g/dl (Lee and Chung, 2013). It is important to note that even excessive alcohol consumption amongst diabetics poses a high risk for the development of chronic kidney disease as it has been postulated to injure the glomerulus and cause high blood pressure which results in hypertensive nephro-sclerosis and high blood glucose levels (Lee et al., 2013). Diabetes also has an effect on the heart and circulation causing patients to develop heart attacks, strokes and cardiac failure which further compromise kidney perfusion increasing the risk for renal failure development (Lee et al., 2013). Evidence supports a reduction of HbA1c by only 1% from just lifestyle change and the correct self-care techniques in diabetes can reduce diabetic complications by 37% and chronic kidney disease by 50% (Lee et al., 2013).

2.3.1 Psychological impact of chronic kidney disease and diabetes on lifestyle change.

Once diabetic patients develop chronic kidney disease they are confronted with more than one condition that requires lifestyle adjustment. Studies have highlighted that depression is a common mental ailment amongst diabetic patients. It is an ailment which worsens when they have to adjust to living with chronic kidney disease and having to prepare for dialysis (Sakraida and Weber 2016). The burden of having to balance both conditions was reported as a stumbling block and very stressful. The patients lose internal drive and physical strength. They complain of feeling tired and not sleeping properly. The diabetic patients with chronic kidney disease also feel helpless and have poor mental and physical power so they don't take care of themselves nor do they cooperate with the treatment plan for diabetes and health education (Sakraida et al., 2016). The body's defence mechanisms are also depleted by depression and it can cause severe dysfunction of glucose metabolism in the body thus potentiating the progression to renal failure (Sakraida et al., 2016). Psychologists and social support are important for these patients and their depression and must be treated early so that they are able to change their lifestyles.

The American Diabetes Association has proposed that psychosocial screening is important for diabetic patients to pick up stress, fears and depression by using a distress scale that is locally available in any health care settings (American Diabetes Association, 2014).

Evidence suggests that diabetic patients need to change their lifestyles in order to prevent chronic kidney disease and its terminal complications. This is achieved mainly through education.

2.4 EDUCATING DIABETIC PATIENTS

Education of diabetic patients should be culture sensitive in addressing social classes equally. Individual characteristics and aspects patients also need attention. Studies propose that health care policies be drafted for preventative health talks on diabetes and its potential complications (Cheng, Wang, Lim and Wu, 2019). Some Americans still believe that diabetes is caused by fate or stress and Europeans consider that it is genetic or due to overweight, Arabs believe Allah is punishing them (Hjelm, Bard, and Apelquist, 2011). The Arabs choose not to consider the danger of diabetes and they don't know much about it (Hjelm et al., 2011). This evidence supports the theory that explains that change of lifestyle will only be possible once the disease is perceived as a threat (Choukem et al, 2018). It has also been discovered that if the diabetic patients have lost trust in the care giver the information they provide they will not change their lifestyles nor cooperate with treatment plans (Okop et al., 2016). Lifestyle and behaviour are learned and not genetic so it is the responsibility of the care giver to tell the patients the truth about diabetes this will facilitate self-drive and freedom to choose right lifestyles amongst diabetics (Hjelm et al., 2011).

The American diabetes association has together with the National Standards and International Diabetes Federation and International Standards for Diabetes Education

outlined that diabetic patients are given the freedom and the will to exercise self-care (American Diabetes Association, 2014). ADA has proposed that education for diabetic patients should be arranged in group sessions to allow interaction and that the education must be consistent and continuous. The ADA has proposed the following key areas for care givers to outline in diabetic education programmes which include exercises and food planning, addressing loosing body weight to normal levels, managing blood glucose levels using treatment the right way and complying with it, addressing stress and emotional burden, smoking dangers and peer and family support (American Diabetes Association, 2014).

One can thus argue that it is in this regard that best lifestyle choices will be attained and the ability of patients to be accountable for the condition. Literature provides the following aspects to consider.

2.4.1 Knowledge and social status

Diabetic patients that are well informed and come from stable economic backgrounds are easily educated about control of their blood sugar levels. These patients have better access to all platforms of learning about their condition such as the internet. They can also better understand that there are complications related to diabetes such as chronic kidney disease and that these can be prevented by good lifestyle choices. They are have less anxiety, stress and are more encouraged to make the decisions such as choosing and learning about the best diet plans to foster wellbeing (Cheng et al., 2019).

2.4.2 Exercising self-control

Diabetic patients need to be allowed to make their own choices for an effective education plan regarding their care (Lansing, Berg, Butner, and Wiebe, 2016). They need to make their own objectives and feasible outcomes with regard to disease management strategies they have been taught such as diet plans and other lifestyle modifications they deem best practice. This practice has enhanced good glycaemic control (Lansing et al., 2016). The face to face teaching and evaluation tests have been noted to have improved glucose control worldwide (WHO, 2018). Self-management education has been linked to saving health sector budgets on hospitalisations and even better is that diabetic patients developed good quality of life and mental stability (Chatterjie, Davis, Heller, Speight et al., 2018).

Self-management on diabetic education should not only emphasise glucose control as the only factor leading to complications that have been already outlined but rather include that having hypertension as a coexisting disease and an elevated lipid profile could also potentially lead to complications such as nephropathy (Mehravar, Mansournia, Holakouie-Naieni, Nasli-Esfahani et al., 2016). This approach allows diabetic patients to have a holistic perspective when changing their life style patterns. Self-management is a notion which implies that a diabetic patient uses all the information they've been provided with together with the skills and tools to transform their lives such that they exercise a more independent control of their disease (Mehravar et al., 2016).

Glucose control is not the only factor leading to complications. Having hypertension as a coexisting disease and an elevated lipid profile could also potentially lead to complications such as nephropathy (Mehravar, et al., 2016). This approach allows diabetic patients to have a holistic perspective when changing their life style patterns. Self-management is a notion which implies that a diabetic patient uses all the information they've been provided with together with the skills and tools to transform their lives such that they exercise a more independent control of their disease (Mehravar et al., 2016)

2.4.3 Self-motivation and empowerment

Diabetic patients need these positive fundamental concepts as a drive for effective self-care. Diabetic patients who are demotivated tend to regard their condition as being beyond their control and they have lost the ability to make decisions (Lambrinou, Hansen and Beulens, 2019). The lack of these attributes leads to ineffective coping mechanism and conflicts with health care professionals during education procedures (Cheng et al., 2019). It is evident that education of diabetic patients must include empowerment sessions to lay the foundation for autonomy and self-will (Lambrinou et al., 2019).

2.4.4 Time frame and age

The newly diagnosed diabetic patients demonstrate poor adherence to glycaemic control. This is due to frustrations of the required lifestyle changes and the early stages of denial while having to cooperate with education programmes about the disease (Amankwah-Poku, 2019). Young adults (20-40) are more concerned about money and

employment goals and their orientation to self-care is not a top priority (Amankwah-Poku, 2019). The young and newly diagnosed are to be prioritised for effective education on diabetic complications. .

2.4.5 Body mass index and race

Studies have indicated that Indians and whites practice good glycaemic control possibly due to better educational facilities (Cheng et al., 2019). Priority education needs to focus on the black population who still demonstrate poor control of diabetes (Gujral and Narayan, 2019). Body training will induce insulin secretion and increase sensitivity to allow good glucose control. Teaching diabetic patients to exercise and burn fat is a priority as is effective lifestyle changes to prevent complications associated with high blood glucose level (Gujral et al., 2019).

Self-management on diabetic education must not emphasise glucose control as the only factor leading to complications but also include coexisting diseases and an elevated lipid profile could also potentially lead to complications such as nephropathy (Mehravar, et al., 2016). This approach allows diabetic patients to have a holistic perspective when changing their life style patterns. Self-management is a notion which implies that a diabetic patient uses all the information they’ve been provided with together with the skills and tools to transform their lives such that they exercise a more independent control of their disease (Mehravar et al., 2016)

China, who has the highest number of diabetic patients in the world (92.4 million), further emphasises a holistic education plan for especially the aged who have been shown to have poor literacy and skills to manage diabetes because they are weak, and

confused and usually have other diseases (Hu, Gruber, Liu, Zhao, and Garcia, 2012). The more informed diabetic patients are the ones who regularly attend education classes, they check their glucose well and consult with their dieticians implying that information gives a positive will power. It is these patients who also managed to control their body size well and maintain normal blood pressure requirements. In addition to that, the Chinese still practice mind training techniques like Tai Chi which intensifies self-care and discipline (Hu et al., 2012). Some studies maintain it boils down to individual choices. Some diabetic patients were well informed and still did not exercise, stop smoking, take care of their feet or drink their medication as prescribed (Goie et al., 2016). The care givers are requested to tailor education focusing more on the aged with poor information and the programme should be holistic to address self-will and include families (Roland et., 2015)

Electronic education of using messages, emails and phone calls is also a growing fundamental need for diabetic patients especially in developed countries (Moattari, Hashemi, and Dabbaghmanesh, 2012) and could prove to be useful in developing countries. It has been noted to save a lot of time since it is readily available. Patients get enough information on diabetes (complications and lab results) as well as their follow up dates, feedback and education on how to change their lifestyle, and use of treatment as well as being counselled by the psychologist. Electronic education becomes relevant for the 21st century. There have been complaints that doctors and nurses don't have time to give health talks anymore due to the growing population of patients (Moattari et al., 2012). Studies highlight that electronic education has had good outcomes in controlling blood glucose (Moattari et al., 2012).

2.5 DIABETES IN AFRICA

Over 40 million people in Sub-Saharan Africa will suffer from diabetes especially Type 2 by 2035 (Mufunda , Ernersson, and Hjelm, 2018). Sub-Saharan Africa is still developing but also becoming more and more modernised. People are adjusting to Western lifestyle and thus, they eat fast foods and do not exercise. They often fail to go for regular check-ups. There is a concern that diabetic patients in Africa still do not have the correct education or knowledge about diabetes and this lack of understanding causes poor compliance. This poor communication will make it impossible to manage diabetes and prevent complications like chronic kidney disease in the future (Mufunda et al., 2018).

The call on the African continent to educate diabetic patients does not undermine the limited resources like technological advancements of access to internet services and the limited training of the general public to use these facilities. However certain authors support that it is best for the African health system to use what they have and can afford to enrich their diabetic education facilities. This includes layman's terms in group sessions, hallway posters, television and radio stations (Mufunda et al., 2018).

Education on diabetes should be an on-going process and appropriate measures to engage with patients for discussions that illustrate their understanding becomes a key step in the African health sectors. They also need to understand the effects of the treatment they receive and how to use it. Choukem and Mbanya (2018) suggest that physical activities conducive to optimal health should also be amalgamated into the education as well as the food and drinks they should adopt into their daily plans.

Particular reference about beliefs on illness still needs to be taken into account especially in rural and traditional Africa which views disease as a curse by the Gods or witchcraft.

There is a growing concern of the low output of diabetic research in Africa. Perhaps this is one of the key reasons why it is difficult to influence change of lifestyle amongst diabetics or even prevent the disease because publications do not address effective remedies (Choukem et al, 2018).

Diabetes consumes billons of rands from health sector budgets. Even so, the budget is insufficient to meet the demands of the disease and its complications (Atun, Davies, Gale, Bärnighausen et al., 2017). Some African diabetics still go undiagnosed due to poor resources such as the use of urine dipsticks and HGT machines, lack of guidelines and wrong diagnostic tests.

Countries of highest concern with health resource depletion are Tanzania, Kenya, Nigeria and Uganda (Atun et al., 2017). Rural clinics in South Africa are frequently situated a distance from laboratories and this delays diagnoses of diabetes. Metformin is readily available but in some clinics there is no Insulin available. The high prevalence of chronic kidney disease has already been underpinned with subsequent lack of spaces for dialysis and transplant. There is one nephrologist per two million population in Kenya and one per million in South Africa (Atun et al., 2017).

The World Health Organisation proposes that African campaigns should target education of lifestyle changes required of diabetic patients and non-diabetics to prevent complications and manage the disease. The plan should include campaigns to promote

healthy lifestyles in ways that the impact reaches across all borders of socioeconomic standards (WHO, 2018).

2.6 DIABETES IN SOUTH AFRICA

With other developing countries South Africa faces scarce health care resources and remains burdened with other infectious diseases such as HIV (Baleta and Mitchell, 2014). Over 2 million South Africans are reported to have diabetes and many are guilty of unhealthy lifestyle choices. They are often sedentary and may be heavy tobacco smokers with an estimated overweight in the population of 61% (Umeh and Nkombua, 2018). Without a doubt diabetes is becoming critical in this nation.

The number of doctors and nurses in sub-Saharan Africa estimated to only be 2-4 million will result in an excessive burden that will be unbearable (Baleta et al., 2014). The South African health department outlines that efforts to prevent diabetes and its complications is better than the attempts to cure and for those who already have the disease education is important to manage the disease by healthy living. The Health Department's plan is to equip and use primary health care centres as starting points for this education plan in order to reach the less privileged. Regular check-ups to identify those patients that are likely to develop complications like chronic kidney disease will also be done (Umeh et al., 2018).

Many diabetic patients in South Africa are reported to have a low quality of life probably due to the fact that many family relationships are broken and rural dwellers do not

receive enough education opportunities. Poverty is still high and chronic conditions such as heart disease, bone disease and lung diseases are on the rise.

Diabetes is the fourth leading cause of death in South Africa (Werfalli , Kassanjee, Kalula, and Levitt, 2018). The prevalence of diabetes is greater in urban areas than rural areas however people in rural areas need to be prioritised in diabetic education programmes due to their long distance from specialised services. They could potentially die from complications that could arise needing referral to hospitals in urban areas (Werfalli et al., 2018). These authors highlight that there is a need for qualitative research in this field and for an in-depth approach to the diabetic education plan regarding lifestyle and how patients and health care professionals outline the facilitation of the disease management (Werfalli et al., 2018).

The WHO has developed creative plans for managing chronic diseases especially for developing countries like South Africa. One of those is called the Cumulative Complexity model (CCM). This plan can be integrated into the diabetic education plan and can serve as an evaluation tool because it addresses patients' experience of the disease and education plans (Matima, Murphy, Levitt, BeLue et al., 2018).

Cumulative Complex Model

- Patients' burden: Diabetic patients wait in long lines in public hospitals and clinics in South Africa waiting for services. Some miss work and time with families and are sometimes excluded and judged by their families making it hard to manage diabetes. The plan suggests taking the services to communities and homes where they are with their loved ones. Educate them and give them treatment

with their families involved to safe them time and allow their families to understand them for moral support (Matima et al., 2018)

- Improve patient support: It has been supported that putting diabetic patients on social grants will assist them to buy food required for healthy living (Lambrinou, Hansen, and Beulens, 2019). The information and treatment resources of South African clinics need renovation and upgrading and the health care givers including dieticians should show compassion and do regular follow ups this will boost patient moral and trust in service (Lambrinou et al., 2019).

- Access: Diabetic patients can benefit from mobile clinics and home visits by trusted health care providers especially the aged and rural dwellers (Shaheen , Sanderlin, and Schrode, 2020)

- Use of health care services: If access is maintained and patient's burdens are eased they can have a better experience of health care services.

- Best results: If the above mentioned areas are addressed patients will co-operate better and have better disease management (Shaheen et al., 2020).

Authors support that even though Diabetes in South Africa is common amongst the more highly educated urban dwellers who lead more sedentary lifestyles and engage in unhealthy habits, it is possible that a majority of rural dwellers are clueless about the diabetes and are dying undiagnosed (Mutyambizi, Chola, Groot, Pavlova et al., 2017). It should be noted that it would be wise to prioritise Indians in diabetic education as they have a greater genetic risk for diabetes (Mutyambizi et al., 2017)

There are more men than women reported to have type 2 diabetes mellitus in South Africa possibly due to the fact that men don't regard health as a priority until they become symptomatic and ill enough to seek medical attention (Goie, and Naidoo, 2016). WHO has reported that in the next decade diabetes will be the seventh leading cause of death in the world (WHO, 2018). South Africa is at a critical state of managing this disease and the emphasis of education and prevention is further highlighted as the key to survive the coming crises of diabetes (Goie et al., 2016). It has been outlined in South Africa that group education programmes together with one on one sessions for diabetic patients have had a good results, this is coupled with evaluations of the impact of the health talks on lifestyle and also getting feedback from the diabetic patients about their challenges and how they experience the education sessions (Popkin and Kenan Jr, 2016).

Diabetes is the 6th leading cause of death in South Africa and South Africa has the second highest in the number of diabetic patients in Sub-Saharan Africa (Adegbola, Marincowitz, Govender and Ogunbanjo, 2016). One can thus deduce how alarming this is to the South African health facilities. Studies have also outlined issues around poor compliance to diabetic medication even amongst people who have the opportunity to get medications and health care education. Adegbola et al., (2016) suggest education programmes on life style change are not properly evaluated and diabetic patients are not engaged enough to demonstrate how they perceive information. Diabetic patients should be taught to keep set times and take their medication with food. A close family member can be involved to assist the patient in that regard (Popkin et al., 2016). In order for diabetic patients to change their lives in a way

that promotes good quality of life care givers can teach them to manage time and other diseases such as high blood pressure. Health Care Professionals should take into account where the people come from and their living environment so that regular follow ups can be arranged for the care service and education programme according to their situations especially in rural South Africa (Adegbola et al., 2016).

South African National Health Department has pledged to promote good health for all South Africans but with the current state of affairs one would argue that the nation is not ready to deal with diabetes and its complications especially chronic kidney disease which is very expensive to manage. The global budget for diabetes management is already not enough (Adeniyi, Yogeswaran, Longo-Mbenza, Ter Goon, et al., 2016). Diabetes is still uncontrolled in South Africa and propositions are that records must be kept on where the gap is in terms of treatment availability, glucose control and the number of the undiagnosed population so that the primary targets for campaigns on lifestyle change and disease management have a clear focus in overcoming the disease spreading (Adeniyi et al., 2016). It has been evident that provinces needing attention for diabetic disease management in South Africa include Kwazulu Natal, Western Cape and North-West, these provinces were all reported to have a prevalence rate of 83.8% for uncontrolled diabetes (Adeniyi et al., 2016)

Studies outline that obese people in South Africa still don't consider it a high risk for developing diabetes mellitus especially the black traditional women (Okop, Mukumbang, Mathole, Levitt, 2016). This finding is concerning since about 87% of type 2 diabetes mellitus is attributed to obesity in South Africa (Okop et al., 2016). Rural dwellers like the ones in Kwazulu Natal regard their obese bodies as a sign of being real mothers.

Others report that they eat cheap unhealthy food high in fat because they don't have money to buy the food required. It has been reported that many South Africans not willing to lose weight are also not informed about the risks (Erzse, Stacey, Chola, Tugendhaft et al., 2019).

South Africa is attempting to strengthen the wheel of primary health care, and education on the importance of lifestyle changes in such rural communities with strong body perceptions and cultural influences that would be detrimental to health (Erzse et al., 2019). Food security is also fundamental role of the South African health sector to promote lifestyle change. It has been suggested that communities should plant their own vegetable gardens, attend healthy food gatherings and seminars at community halls and make use of exercise programmes for all age groups (Erzse et al., 2019). The farmers and food markets are also urged to facilitate the provision of healthy food that the communities can afford (Okop et al., 2016).

The burden of the South African health sector comes from the fact that about 64% of South Africans depend on the public health sector (Mendenhall, and Norris, 2015). Diabetic patients in low income areas don't trust the health care system and they seek advice from their peers, television and family about lifestyle changes. It has been reported that community outreach activities for diabetics in low income areas in South Africa, have the sole aim of delivering treatment and offering information on self-management and lifestyle changes in places of residence. However this approach needs resources, funding and material to be effective (Mendenhall et al., 2015)

It is reported that if diabetic education is done by a well-trained health care worker patients exercise better glucose control and blood pressure and this reduces the already overwhelming cost of care on the South African health sector (Roland, Gaziano, and Levitt, 2015). Overcoming diabetes in South Africa requires a collective approach on treatment, information and continuous follow ups for diabetic patients (Sechabe , Mothiba, and Bastiaens, 2019). It has been reported that one of the challenges leading to poor diabetic education and poor lifestyle change amongst South Africans is the poor teaching methods and counselling skills of the health care professionals, who constantly complain about lack of time and unbearable working conditions (Roland et ., 2015)

Educating diabetic patients should be a multidisciplinary approach in South Africa (Pillay and Aldou, 2016). Diabetic information could be displayed in hall ways and given to diabetics as talks and in information booklets. Staff should be given in service training about available guidelines and policies (Sechabe et al., 2019). A well trained team will allow diabetic patients will make better informed lifestyle choices and it is the role of government to build and provide this (Mohammed, and Sharew, 2019).

In South Africa the guidelines on the management of diabetes stipulate the key need areas for patients with diabetes to take better care for themselves. The key needs for diabetic persons have been outlined (Zaheer, Ankia, Coetzee, and Pirie, 2017) (Appendix G).

If the recommended education system is implemented in South African health system concerning diabetic patients, it will foster their ability to maintain blood sugar levels

compatible with sustaining their wellbeing. The cost of caring for diabetic related complications will also be reduced when patients demonstrate self-will and power (Zaheer et al., 2017). Optimal education on diabetes will boost confidence with the facilities provided (Sabrina, Gupta and Rosalie, 2018). Diabetic patients will be better equipped with the necessary skills needed to manage diabetes and become less dependent on care givers such that compliance will no longer be a stumbling block (Zaheer et al., 2017).

Evidence supports that 75% of the total of diabetic patients around the world come from low and middle income countries where there's and urgent need on self-directed management education of this disease (Flood, Hawkins, and Rohloff, 2017). In low income areas care givers and diabetic patients are faced with difficulties for lifestyle changes conducive to sustain wellbeing such as poorly schooled minority groups, poverty and poor peer and family support, integrating such issues into the education programme for diabetics requires multi team approach as it is costly and the care givers are to be aware of such (Flood et al., 2017)

Authors have outlined that the care givers need to also be wise counsellors and patient because to produce best diabetes management education outcomes they will be faced with patients with different attitudes, information perceptions and different behaviours (Gautam, Bhatta, and Aryal, 2015). In poor countries like rural South Africa one would be faced with people with less information about diabetes (Mutyambizi et al., 2017). Diabetes has a mortality rate of 4 million per year around the world (WHO 2018). Although technology has become a positive driving force behind diabetic education there remains some rural dwellers around the world that don't have easy access to

computers, laboratories and the use of smart phones (Jenks, 2018). In these situations health care providers need to assist in driving the educational programs.

Life style is about food choices and the physical activities in accordance with the diabetic patient's preferences (Jenks, 2018). Useful education strategies have been 30 minutes aerobic exercise per day five times per week if patient is able to walk, some patients are advised to do chores at home like cleaning and gardening and go for brisk walking. ADA has recommended the exclusion of straight sugar in meals and that patients must eat lots of vegetables and fruits particularly the green leafy vegetables apples and pears (Jenks, 2018).

CHAPTER THREE

RESEARCH METHODS

3.1 INTRODUCTION:

This chapter elaborates the research methods of this study**.** It begins with the description of the aims and objectives guiding the study followed by the application of the research design. It further explains population and sampling methods used as well as the setting of the study and how data was collected. Methods of data analysis and maintenance of research rigor are also explained. The chapter ends with ethical considerations concerning the study.

3.2 PURPOSE

The purpose is what sets the intention of a study whereas the objectives are more solid and serve as measurable components or steps leading to the intention of the study (Clarke and Braun, 2013). A study of residents in a Nigerian community supports that the information on chronic kidney disease even among the high risk group with diabetes remains low (Oliyombo et al., 2016).

3.3 RESEARCH DESIGN:

Qualitative research methodology allows us to explore how people establish views of their daily experiences (Clarke et al., 2013). This approach provides understanding of key areas of interest that can be arranged into a well fashioned and an organised story. The advantage of qualitative research design is that the researchers are intimate with the subjects while they withhold their own personal views to allow the subjects to lead the flow of events that the researcher seeks to understand (Yates and Legget, 2016).

3.3.1 Research design

This study made use of a descriptive exploratory qualitative design. Coupled to the exploratory nature of qualitative design the descriptive component also allows a full description of the events or information gathered and being explored by the researchers so that this information becomes a full representation of the sample being studied (Kim, Sefcik and Bradway, 2017). The researcher gains a better understanding of experiences of the participants regarding the topic being explored (Kim et al., 2017).

3.3.2 Qualitative research

Qualitative research methods tend to make use of a population that is mainly representative of the topic under study (Boddy, 2016). This approach produces a wealth of information that is very meaningful for that group of subjects or sample which are at times the entire population (Boddy, 2016). However because the population is

homogeneous the probability of reaching data saturation or a point at which Information becomes repetitive is approximately 12-25 of the sample number (Braun et al., 2013).

3.3.3 Descriptive

A descriptive design describes peoples' views clearly as they are being presented. It is especially useful in a study where the participants are selected using purposeful sampling so that the information gathered is adequate.

3.3.4 Exploratory

An exploratory research design seeks to get more details on the topic that is not well understood. More information can be generated from the data collected. Other researchers can get topics from the results that are used this approach.

3.4 RESEARCH METHODS

Research methods are strategies used by researchers to arrange, assemble and resolve the findings that relate to the research questions. The research methods used in this study include selection of the target population, data collection and data analysis.

3.4.1 Population and Sample

The study population is defined as the entire number of subjects that the researcher is interested in and that meet the inclusion criteria for the topic of the study (Brink, van der Walt and van Rensburg, 2018). A sample is the fraction of that entire population that the researcher has chosen to represent the entire population (Brink et al., 2018). In this

study the population was a total of about 200 diabetic patients attending a clinic and the sample was the population in its entirety until saturation was reached. Sampling in qualitative studies continues until saturation is reached and at which no new information surfaces from additional participants (Boddy, 2016). Inclusion and exclusion criteria for the study were outlined in chapter one of this report.

A purposive sampling method was used to select the participants for the study. Purposeful sampling involves the selection of information rich cases to provide the depth, relevance and clarity of the study findings (Charles, Ploeg and McKibbon, 2015). The selected participants are usually very informed and vocal about the study topic (Charles et al., 2015). Purposive sampling provides better insight of the study topic (Braun et al., 2013).

3.4.2 Setting

Setting for the study refers to the location where data will be collected (Brink et al., 2018). For this study the setting was the diabetic clinic in a public sector hospital in the Free State. The setting must be comfortable and as private as possible without disturbances for participants (Braun et al., 2013).The setting was a private room at a diabetic clinic with comfortable chairs and with no disturbance signs on the doors.The researchers role within the setting of a qualitative study is to listen attentively and objectively while conducting interviews and to build rapport with participants(Charles et al., 2015).

3.4.3 Data Collection

Data collection refers to a process by which the researcher accumulates findings of the study based on the information needed to address the research question (Brink et al., 2018). Cresswell (2018) states that face to face interviews allow better engagement between the interviewer and interviewee, as it promotes discussion and in-depth information that is recorded by an audio tape from which the recordings can be transcribed. These face to face interviews in this study were conducted using a series of open ended questions.

The researcher conducted the interviews at this specific setting. Open ended questions are encouraged because participants use their own words to provide the details of their views. The answers of participants are comprehensive and usually contain more in depth (Braun et al., 2013). The researcher obtains many views and probes are used together with questions that were not planned. The participants may even share sensitive issues. Data that is gathered with face to face interviews is very useful. An audio tape recording of the interview and the researcher's field notes were used to collect data.

- Planning the interview

Participants were given written and verbal explanation of the study and when they understood a letter of consent for recording, participation and use of findings for publication was requested.

- Conducting the interview

Participants were interviewed face to face by the researcher while attending the clinic. Each interview session took approximately 60 minutes. No pilot interviews were

conducted. Interviews were conducted in English. Any responses in Sotho were translated by the researcher. The expert in Sotho from the University of Witwatersrand confirmed the translation. Data was collected weekly for two months as per clinic schedule. Interviews were conducted in a private room at the diabetic clinic during regular visits.

The participants within the interview location were made to feel comfortable (Braun et al., 2013). The interview contained open ended questions with probes. Examples of questions are found below.

1. Tell me about the education you were given about diabetes when you were diagnosed as a diabetic?
2. Who gave you the information?
3. Tell me about how your lifestyle will change with diabetes in order to avoid complications?

3.5 DATA ANALYSIS:

Qualitative data analysis is concerned with the information that is either spoken or recorded and then documented (Brink et al., 2018). The researcher reflects deeply upon this information by finding patterns that can be concluded upon or by subdividing the information into groups that explain what the participants meant about the information they rendered on a specific topic of discussion (Creswell, 2018). There are many

examples of qualitative data analysis methods in literature but for this study we focused on thematic analysis as the best choice.

3.5.1 Method of data analysis.

Thematic data analysis was used for this study. Thematic data analysis is also called a translator between researchers as a way to pass information to each other. It is described as a method for identifying, analysing, organizing, describing, and reporting on the themes found within the information gathered from participants (Nowell, Norris, White, and Moules, 2017). Thematic data analysis allows the researcher to explore similar and different views of participants which may yield unexpected results. Thematic data analysis has also been shown to offer a good solution of summarizing a large amount of findings so that when the final report is written the findings are well represented (Nowell et al., 2017). Deductive thematic analysis (Braun et al., 2013) was used in this study as the literature (Burrows et al., 2017; Ghannadi et al., 2016). Ryz et al., (2015) clearly indicates that often the education of the diabetic patient is lacking.

Audio tape interviews must be properly transcribed by a skilled researcher before undertaking thematic data analysis as the inability to do that may result in poor analysis (Chapman and Hartfield, 2015). Braun et al., (2013) have described seven steps of thematic data analysis detailed below. Braun et al., (2013) state that thematic data analysis is very dynamic and suitable for any study question without manipulating the way in which data is collected so that explanations are well pronounced**.**

3.5.1.1 Thematic Data Analysis

The first step is listening to the interviews on the audio tape recorder and transcribing the entire interview word for word.

The second step is reading and familiarisation: The researcher reads the transcribed data several times. Rereading data validates it. The researcher pays attention to areas that he or she finds to be of great value. It is important that the researcher's focus is not influenced by their own values, opinions or social standing.

Participant: "I was given a pamphlet by a doctor on foods to eat and to avoid and how much."

The third step is coding in which the researcher identifies statements from the participants responses that can be grouped together expressing the same meaning.

The fourth step is searching for themes. The researcher starts to put similar concepts into themes to represent their broader view. The themes organise the main view of the combined codes.

Table 3.1 Grouping of statements: Information

Statements	**Transcript number.**	**Page number.**	**Line number.**
"There was no information about how to avoid damage to kidneys, I would maybe ask a doctor about kidney health and he said just drink a lot of fluids".	4	116	31-33

“They did not talk much about kidney health to me they just told me that I should not eat a lot of salty food, they also told me about other things but I did not understand.”	9	126	6-9
“They take my urine and blood here but they do not discuss the results.”	8	124	38-39
“They never taught me much about how it causes damage to my kidneys They just said diabetes can damage my kidneys.”	2	112	3-5
“Not told about how diabetes affects the kidneys. [I] thought my kidneys need water.’’	25	156	5-6 32

The fifth step is reviewing themes. This is where the researcher develops a mind map of the main themes and their sub themes and clearly outlines how they come together as a fundamental idea. The researcher revises these themes in such a way that reliable evidence is produced about the information gathered.

The sixth step is defining and naming themes. This is where the researcher focuses on main themes for the full explanation of the data. This step is essential to establish

concise focus or the ability to narrow findings down to significant points that answer the research question and fully represent the data.

3.2 Extracting Themes and Sub-themes

EMERGENT THEMES	**SUB-THEMES**
3.2.1 Communication	• Information • Dietary information. • Incomplete education

The seventh step, writing and finalising data analysis, is the process during which the researcher takes points from the data and offers arguments to support his or her views.

3.6 RESEARCH RIGOR

Research rigor was maintained by using a model by Lincoln and Guba for maintaining trustworthiness in qualitative studies (Lincoln and Guba, 1985). The model seeks to underpin that the researchers should seek truth value in their findings, make sure that the findings can be applied with other respondents, and make sure that the same findings can be generated from the same group of participants (Lincoln et al., 1985). Key steps of the model were summarised in chapter one and are fully described below.

3.6.1 Credibility

This Alludes to confidence in the truth of data. This notion explains how well the findings represent what was actually said by the respondents. Credibility can be achieved in several ways. The first step is prolonged engagement with participants during data collection to form a bond and create a trusting atmosphere so that main issues of the participants are understood. In this study the researcher engaged with participants to create trust. Peer review of the findings by other researchers also helps the researcher to nurture their investigative skills. In this study the researcher referred findings for peer review by the supervisor and other members of the nursing department. Member checks are when participants are given the opportunity to confirm that the findings reflect their original views so that there's no unfairness. In this study the researcher confirmed the views of the participants by reiterating their recorded responses. With persistent observations the researcher learns a lot about the personalities of the participants and the influence of their setting on information delivery and tends to understand them better (Anney, 2014). In this study face to face contacts helped the researcher understand different personalities.

3.6.2 Dependability

Dependability refers to how stable the findings are over time. The respondents were given an opportunity to interpret the researcher's findings. The researcher can maintain dependability by keeping an audit trail in which the findings are supported by the main data such as recorded interviews or field notes and other records (Malley and Young, 2016). Code on recode strategy allows for coding of the same information twice to see if the pattern remains the same which makes the findings clear. To maintain honesty the researcher allowed the supervisor to also analyse the steps that were used to get the

findings (Malley et al., 2016). In this study the supervisor also helped to analyse the data.

3.6.3 Conformability

Conformability explains the objectivity of research during data collection and data analysis (Mandal, 2018). This notion establishes that the researcher did not draw his or her own conclusion about the findings. In this study conformability was adhered to by keeping a journal of all the activities that took place during collection of information.

3.6.4 Transferability

This concept is the same as generalising of the results. It refers to how well the findings can be transferred to other participants in a different setting (Malley et al., 2018). In this study the researcher achieved this through what is referred to as thick description of the findings from collection of information to the final report. The steps of research were clear and concise and well illuminated. Purposeful sampling that was implemented in this study has also been shown to support transferability because the relevant participants were selected by the researcher which allowed the better details of the information required and provided (Anney, 2014).

3.7 ETHICAL CONSIDERATIONS

These are the propositions that allow for safety of the participant through proper behaviour of the researcher in his interaction with them. The propositions serve to encourage and bind the researcher to be faithful when collecting the information for a

study and sharing it in the final report and publications (Brink et al., 2018). In this study the researcher maintained honesty throughout the study.

Permission to conduct research was provided by the Human Research ethics committee (Medical) from the University of the Witwatersrand. The study was approved unconditionally. Clearance certificate number**: M190727 (**Appendix A**).**

The first proposition of ethics states that people who participate in research have rights such that the researcher should allow them to make a self-informed decision about whether they would like to take part in a study or decline their participation at any moment. In this study the researcher asked for informed consent from participants with voluntary participation to respect their rights (Appendix D and E) . Ethics also includes beneficence, and anonymity (Dempsey, Dowling, Larkin and Murphy, 2016)

Informed Consent

An informed consent states what you are asking of the participants and gives them the opportunity to ask questions. This allows participants the freedom to engage in the study and protects that freedom so that they do not suffer any penalties. The particulars of an informed consent outline what the study is about and what it aims to achieve, what the participants will gain from the study and if there are unpleasant consequences anticipated from participation (Appendix F). The period of engagement of the study is also outlined as well as how anonymity and confidentiality will be maintained. The course of events to be expected are also clearly defined (Øye, Sørensen and Glasdam, 2015). Informed consent was obtained from participants at the diabetic clinic on the days of data collection. Participants were given an opportunity to read the study

information sheet and then given a form requesting informed consent for participation and for audio tape recording.

Anonymity and confidentiality

The factors around justice or the legal requirements supporting ethics the researcher must firstly ensure privacy of participants by not sharing their information without their agreement or even try to get information from the participants without their agreement. Although complete anonymity is not possible with qualitative interviews the researcher is advised to rather use numbers or labels instead of real names of participants when discussing the final findings are published (Dempsey et al., 2016). Confidentiality is another leg of legality that allows for assurance of the participant that the information generated from them will not be shared by other bodies except the researcher and the legalised institutions concerned upon request, this information includes recorded interviews and written documents. All these information sources gathered can be kept in a safe with lock pin known only by the researchers concerned or kept in a computer that has a password protection feature. It is also a legal requirement to protect human rights and this can be done by obtaining informed consent from participants (Dempsey et al., 2016).

Another important step of the informed consent is the declaration of free will, participation and the choice to decline participation. The contacts of researchers and ethics boards' chairperson are also included and the participant has a section to sign for and accept the invitation willingly.

Management of data.

Recorded data was locked away in a safe that is password protected. The password was only known by the researcher and supervisor. Transcribed data was also saved on a password protected computer programme known only by the researcher and supervisor.

The researchers are also held responsible by ethics to maintain a responsible attitude and protect the scientific process that research must be based upon. The ethics committee serves to scrutinise the research proposal to ensure that all matters pertaining to ethical principles are upheld and the bodies thus have the power to disapprove the research if the participants are not protected. This ensures the discipline and well-structured plan of action by the researcher (Roth, Wolff-Michael, von Unger and Hella, 2018).

3.8 SUMMARY

This chapter outlined the research methods of this study in details supported by literature and the scientific process of research. It began with a full description of the aims and objectives guiding the qualitative study followed by the applied qualitative research design and what it entails. It further explained population and sampling methods of a qualitative study used as well as the setting arrangements of the study and details of data collection methods employed. Methods of data analysis and maintenance of research rigor were also explained in detail. The chapter ended with ethical considerations that guided the study. In the next chapter the findings will be presented.

CHAPTER FOUR

FINDINGS

4.1 INTRODUCTION

This chapter presents the research findings. Description, explorative and interpretive methods were used to obtain these findings. Meaningful statements were first coded followed by the generation of sub-themes and Emergent themes from the face to face interviews using open ended questions which are now presented. The interviews were recorded with an audio tape recorder, transcribed and then analysed using Clarke and Braun (2013) thematic analysis described in chapter three. Discussion to substantiate the findings will be presented.

When considering the meaningful statements the researcher was guided by two objectives of the study.

4.2 DEMOGRAPHIC DATA OF PARTICIPANTS

The study population included all diabetic patients attending a clinic in the Free State. The number of patients was 200 in total per month. In this case the whole population was representative of the study topic and thus relevant for the information required. The sample was selected by purposive sampling and continued until saturation had been established. Saturation refers to a point where data surfacing does not provide new

information (Clarke et al., 2013). The sample was selected and recruited by the researcher at a diabetic clinic on the days of their regular visits from Monday to Friday. Purposive sampling allows for inclusion of participants who are most likely to provide information rich data for the topic of interest (Clarke et al., 2013).

Participants were interviewed in the study. Purposeful sampling allows for better clarity and relevance of study findings (Charles, Ploeg, and McKibbon, 2015). The study participants were actively involved and well informed.

Inclusion criteria were all diabetic patients aged18 and above, diagnosed with Type 1 or Type 2 diabetes mellitus, with or without other illnesses.

Table 4.2 Demographic data of participants.

DESCRIPTION AND DIAGNOSIS	**NUMBERS**	**OVERALL AGE GROUP**	**TOTAL NUMBER**
Males			8
Type 1 Diabetes	3	20-36	
Type 2 Diabetes	4	31-74	
Unknown	1	55	
Females			17
Type 1 Diabetes	9	31-70	

Type 2 Diabetes	8	39-80	

The researcher and supervisor worked together to analyse data. The categories were generated first followed by sub-themes and emergent themes. The themes are then supported by participants' quotes. These quotes are presented verbatim. English was not the home language of most of the participants and the grammar has been left in the verbatim format.

4.3 EMERGING THEMES

The interviews were conducted in a private room at the clinic in the public sector hospital. Each session of the interview was recorded by an audio tape and took approximately 60 minutes after obtaining written informed consent from the participants.

Emerging themes

The sub-themes and themes are presented as set out in the table below. These two categories addressed the important issues that were identified from the transcriptions recorded during the face to face interviews.

Table 4.3 Emergent themes and subthemes

EMERGENT THEMES	**SUB-THEMES**
4.3.1 Communication	• Information on link between Diabetes and CKD • Dietary information. • Incomplete education
4.3.2 Concerns	• Feelings of irritation and anger
4.3.3 Attitudes towards lifestyle change	• Acceptance • Resistance

Each of the themes identified will be detailed with supportive evidence from the participants' shared views as transcribed from the audio-recorded discussions. In presenting participants' shared views, anonymity was ensured by replacing their names with codes.

Theme one: Communication

Communication is the means for delivering and receiving information. Both parties should be clear and concise so that the information shared is understood well to have a positive effect. Educating diabetic patients also requires all communication means in a way that promotes self-care and wellbeing.

Some participants reported that the medical terms were difficult to understand whereas others reported that there was simply no effective communication. A few participants had the idea that if you did not ask the health care workers they would not educate you. Many patients would like getting information through other means such as pamphlets, radio stations internet and posters in hallways of the clinic.

Subthemes

- Information on link between CKD and diabetes.

Substantial physiological evidence has supported that one of the serious complications of diabetes is chronic kidney disease (Monahan et al., 2007). Diabetes leads to the development of diabetic nephropathy followed by presence of protein in urine, edema and hypertension, leading to Chronic Kidney Disease and End stage Renal Disease (Monahan et al., 2007). It is now evident that diabetes is one of the leading causes of kidney disease in the world (Stanifer et al., 2014).

It is the responsibility of health care professionals to explain the physiological impact of uncontrolled diabetes on kidneys to diabetic patients in primary health care clinics in order to minimise the development of chronic kidney disease as a complication. It is clear that patients who participated in this study felt poorly informed about the possibilities.

“They just said diabetes can damage my kidneys.” P 2

“Not told about how diabetes affects the kidneys. I thought my kidneys need water.” P 25

"….no information about how to avoid damage to kidneys." P 4

"They take my urine and blood here but they do not discuss the results." P 8

It was also worrying that some participants were only taught to check their blood glucose levels once a day and when not feeling well. This illustrates that there could be a lack of understanding amongst the health care professionals and how diabetes can be detrimental to kidneys if not closely monitored and sugar levels kept at normal levels. It was of interest to note that even with irregularities in terms of the times that the participants were taught to check their glucose levels they all knew the normal levels should range between 3.5 to 10mmol/l.

"I was taught to check my sugar levels once a day." P 4

"*To check the sugar levels twice a day in the morning and the evening." P 6*

"I only check my sugar when I am not feeling well and hear sounds." P 8

Participants stated that they did not receive information about how diabetes could affect their kidneys.

Some concerns raised about information were as follows:

"I want to know how sugar diabetes affects the kidneys." P 3

"How will I recognise that I am starting to have chronic kidney disease." P 6

The above statements are the general overview of the main points on information of diabetic patients with regards to their need to know more about chronic kidney disease. There is evidence of little to no information given.

- Dietary information.

Diabetes is the 6th leading cause of death in South Africa and South Africa has the second highest in the number of diabetic patients in sub Saharan Africa. The need to provide diabetic diet information thus remains the cornerstone to prevent complications (Adegbola, Marincowitz, Govender, Ogunbanjo, 2016). Electronic and printed education becomes relevant for the 21st century. Studies highlight that electronic education had good outcomes in controlling blood glucose (Moattari et al., 2012). Printed information can have limitations with understanding for the illiterate rural dwellers (Adegbola et al., 2016). Other participants reported getting satisfactory printed information on diabetic diets.

Some statements on dietary information were as follows:

> *"I also Googled how to change my lifestyle." P 15*
>
> [I was] *"Given a pamphlet by a doctor on foods to eat and to avoid and how much to avoid." P 1*
>
> *"Gave me a big book written in Afrikaans and English but I do not remember the contents that much." P 11* [Patient was not English or Afrikaans speaking]
>
> *"It was a lot of things in that booklet. Even the pap I eat they said you should not eat it while it's hot to reduce the starch." P 11*

Many of the patients in this study have reported good education on diet.

Some statements to support good dietary information include:

"Can't eat more than 8 pieces of grapes to avoid high sugar. Eat pears and apples and oranges because they have less sugar." P 3

"To protect your kidneys one must eat healthy food like vegetables, low fat diet and fruits." P 9

"Stop drinking alcohol, avoid fatty diet, avoid salt, and avoid sugar." P 16

None of the respondents highlighted the value of food planning in order to avoid weight gain. Many participants have gained weight after being diagnosed with diabetes due to increased appetite. Health care workers are not addressing the issue of patients gaining weight in their information sessions.

- Incomplete Education

Many people with chronic kidney disease including high risk groups with diabetes are poorly informed about CKD because of lack of early detection and thus early patient education. Effective interventions to improve blood glucose levels and blood pressure control might prevent or delay the onset of kidney disease in adults with diabetes (Burrows et al., 2017). In this study the education given on diabetes and its complications was very superficial.

The following statements support the incomplete education given to participants.

"They never taught me much about how it causes damage to my kidneys." P 21

"I want to know a lot of things." P 18

The few patients who had some education on kidney disease expressed it as a dreadful disease. They did not seem to be empowered by the information to prevent the disease but rather threatened and doomed for death if they got it.

> *"I am scared of it* [chronic kidney disease]. [I] *would like to know about the specific signs and symptoms." P 5*
>
> "*Is very dangerous and painful, those people are like the walking dead, they can't walk too long. I really don't want to get that illness, they are very weak." P 9*
>
> *"People get kidney failure. I just know that they have to come for check-up frequently. I just know that I can die from renal failure." P 8*
>
> *"I know kidney disease is dangerous, I think about it all the time. You do not drink alcohol and you have to eat healthy." P 10*
>
> *"Peoples with kidney diseases… bodies swell a lot. I heard that sometimes they put tubes in their bodies, their bodies have a lot of toxins and some put water in their tummies to clean their body and some use machines." P 12*

Summary of Theme one

It is evident that many participants were satisfied with the dietary information they received for diabetes and to the multidisciplinary approach and discussion session of different healthcare providers. Dietary information remains the cornerstone of the management of diabetes. Some participants felt differently. The information was discussed in depth however there remains a challenge with the fact that printed

information on diabetes and its complications may not be as effective due to possible illiteracy of rural dwellers in Free State who were mostly blacks in this group of participants. The elderly participants struggle to read. Participants report that they gained more information on diet from other means such as reading, radio and television than what they were told by their health care providers.

The general overview of the link between diabetes and kidney disease was lacking according to these findings. The information given to participants about kidney disease is superficial and without emphasis on recognising early signs and symptoms.

Some participants have presented with typical signs and symptoms that can be attributed to underlying early symptoms of chronic kidney disease but because they are not aware they could not identify the possibility of chronic kidney disease. None of these participants knew about kidney function tests and this raises a concern since they are all high risk and need to be tested regularly. Creatinine and estimated glomerular filtration ratio are fundamental tests that diabetic patients need to understand in order to prevent deterioration of their kidney function.

Theme two: Concerns

Diabetes is a vascular disease with other complications that are as detrimental as chronic kidney disease. The participants had a lot of concerns about the disease and the potential complications which triggered a lot of negative emotions which may have eventually hindered their ability to manage the disease.

Subthemes

- Feelings of Irritation and anger

Lack of knowledge and understanding in diabetic patients in Africa is causing frustrations and poor cooperation with health care workers. Mufunda , Ernersson, and Hjelm, (2018) suggest that this will make it impossible to manage diabetes and prevent complications such as chronic kidney disease in the future.There is evidence that the patients who participated in this study showed significant irritation about what they still need to know for their own wellbeing concerning diabetes. The researcher attests that the tone in their voices and facial expressions reflected anger. Anger is a negative emotion which stimulates stress hormones that can eventually cause sugar levels in the blood to rise.

The following statements underpin the emotive power of irritation and anger:

> *"Told I have diabetes but I do not know which type, my blood results have never been discussed with me regarding kidney health but I ask for my blood results copy and I interpret the results myself". P 25*

> *"They never taught me much about how it causes damage to my kidneys. They just said diabetes can damage my kidneys." P 2*

> *"If I did not ask the doctor about my results, he would not have told me." P 19*

> *"Am I at risk of getting chronic kidney disease as a diabetic patient?" P 24*

Summary of Theme two

Participants in the study have expressed concern of not being educated enough about either diabetes or kidney disease. The general response highlights the fact that there's little initiative from health care professionals to eliminate these concerns. This population is chronic patients who had been coming for follow up visits for many years at the clinic. Their irritation and frustration was understandable. The participants were understandably angry however there are health concerns with this emotional robustness that can lead to uncontrolled blood glucose levels from stress (Sagoo and Gnudi, 2018) which can be debilitating.

Theme three: Attitudes towards lifestyle change.

Life style in this context is about food choices and the physical activities in accordance with the diabetic patient's preferences (Jenks, 2018). Useful activity strategies have been 30 minutes aerobic exercise per day 5 times per week if the patient is able to manage this. Some patients are advised to do chores at home like cleaning and gardening and go for brisk walks (Jenks, 2018).

Diabetic patients need to know about their meal plans, the exercise routines, the use and impact of therapy modalities on their wellbeing and how to build a good relationship with their care givers to facilitate cooperation. Diabetic patients also need to understand how they can balance their lifestyle at work and enjoy recreational facilities with friends and families while coping with the disease (Pet et al., 2018).

Subthemes

- Acceptance

Acceptance was achieved when the participants made peace with having diabetes as a chronic condition. This is supported by their ability to cope better with the disease having less to worry about and complying with the use of treatment (Schmitt, Reimer, Kulzer, and Icks, 2018).

At the top of the list to effectively manage their lifestyles the diabetic patients need a feasible plan. Health care professionals can assist with motivating the diabetic patients. The plan for the correct diet comprising of low carbohydrates and fats should be presented (Sanchez et al., 2018). Almost all Participants in this study demonstrated a fair amount of confidence in the information they received concerning diabetic diet.

Physical activities conducive for optimal health should be integrated with the food and drinks that should be adopted in the daily plans of diabetic patients (Mufanda et al., 2018). Exercise promotes cardiovascular fitness and circulation (Thomas, 2018). Exercise also burns fat and stimulates insulin sensitivity on cell walls so that blood glucose levels remain well controlled.

Most of these patients were not given a specific exercise routine, however they had come up with creative though less demanding ways to exercise.

Acceptance was supported by the following statements

“you actually become conditioned to living like this” “doing my work outs in my house” ” lot of things to calm my emotions.” P 10

“Exercise as well by going to the gym and running on the tread mill.” P 21

“Not very good with exercises. Walk a lot and do house chores.” P 17

“Exercise to avoid gaining too much weight.” P 15

“Exercise comes first, and then the food I eat selectively.” P 9

“For exercise I work at my house, clean the house, laundry and clean the fields.” P 6

“My exercise program, I do jogging for about 10 - 12 kilometres.” P 5

A few statements to support acceptance of diet change were shared and are as follows.

“I do not eat a lot anymore. I used to [have] *a few shots every night and have a bottle of whiskey. But now we only drink alcohol during the weekend.*” P 4

“*Not have fatty foods, eat brown bread and vegetables and fruits. My main fruits are apple and banana.”* P 25

“*They said I must not eat a lot of fat and all sorts of things but basically it’s not what you eat but it’s about the quantity. I eat everything in small quantities and avoid sugar.*” P 1

“*I have mainly focused on the food that I must eat. Avoid high salt diet and fatty meals*.” P 5

"*Shy away from junk food.*" P 8

"*I don't have to eat spices and salt. I eat veggies. Avoid fizzy drinks but I drink juice with less percentage of sugar. My diabetes is well controlled.*" P 10

"*Take good care of myself and change my lifestyle. Eat small meal portions avoid food high in sugar and fat and salt."* P 12

"*I do not drink caffeinated drinks, I drink hundred per cent juice and I drink a lot of water."* P 13

From the above statements participants demonstrated a good effort towards self-care as an indicator of acceptance of diabetes as a chronic disease. Information on diet change has given diabetic patients who participated in this study the confidence to accept and change their lifestyles accordingly in order to manage the disease. Finding creative ways to keep fit was also a good indicator of acceptance. Acceptance of a chronic disease optimises wellbeing (Schmitt et al., 2018).

- Resistance

There wasn't enough effort to stick to the diet by many of the participants due to confounding factors mentioned by some of them such as not having enough money to buy vegetables and fruits every day, others just decided that the diet recommendations were too strict so they cheated a lot with sweets and chips coke and beer, some just believed that they could still eat everything in small amounts. There were some patients that said they were too busy for a healthy diet of eating 6 times a day. They had not been properly trained to integrate meal plans with their daily duties.

"*I don't usually stick to my diet. Even though it was wrong but I ate it, other days I am naughty*." P 2

"*We do not have food. End up eating anything. Sometimes I just have cabbage and maize meal.*" P 7

"*I really haven't changed much* [elderly patient 80 years old]. *When I cook my pap I cook it with salt, I eat my pap with milk or vegetables. I also eat bread and tea with milk and sugar, I do not apply margarine on the bread. I like my pap, rice and stamp mealies but mainly pap*."P.6

Sub-Saharan Africa is still developing but also becoming more and more modernised. People are becoming more pressured. They eat fast foods and do not exercise let alone go for regular check-ups (Mufanda et al., 2018**)**

In this study some patients reported to have gained weight after being diagnosed with diabetes which can be attributed to sedentary lifestyles and the fact that even if they were given exercise health talks there was no guide or plan.

Some of the participants admitted that they were not as compliant as they should have been statements are as follows.

"*My sugar level is always around 27 to 28 then I just sleep the whole time."*
P 20

"*Difficult (diabetes) to manage*."P15

"*Not necessary to eat 6 times a day if I am not hungry. I have my own way of doing things*." P 25

"*My weight has increased by 3 kg in the last 6 months*." P 4

Summary of Theme three

The last theme discussed the attitudes around lifestyle changes. Generally there was not enough effort to change lifestyle amongst this group of participants. The participants were given information but often because of their limited circumstances they were unable to stick to their diet. Physical activity is a well-known requirement amongst diabetic patients however there was no clear guideline within this clinical setting where the study was done. Participants developed their own creative ways to keep fit.

The participants were informed about their best dietary changes required to manage their disease. Others had financial problems like having to share their South African social security agency grant with their family members thus it was not enough to buy the right food. For others there was still resistance towards recommended lifestyle changes. Others did value diet plans and stuck to it. They were pleased to benefit from results such as less hospital admissions from complications such as high blood sugar levels. One participant indirectly testified that diabetes simply means diet control as its core value for management.

These diabetic participants are educated to change their lifestyles and many of them have reported compliance, however a significant number of them are still choosing to ignore the interventions.

4.4 SUMMARY OF FINDINGS

This chapter presented the findings of this study under three themes and six sub-themes that emerged from the use of a thematic approach to data analysis developed by Clarke and Braun (2013).

The first theme that addressed the communication of participants with regards to their educational experience on diabetes and chronic kidney disease addressed the first objective mentioned in chapter one. The first theme had three subthemes which were elaborated further to explain the theme in more detail. The participants sometimes received good information on diabetes but many did not understand. There was also lack of information about chronic kidney disease as a result of diabetes.

The second theme was explained by one subtheme as feelings of irritation and anger. These concerns regarding feelings triggered by inadequate Information was being communicated inadequately and it was not well received by participants.

The third theme was more specific about attitudes towards change and it had two subthemes which were answering the first objective. All subthemes were supported by quotes from participants with substantial evidence from literature. The data served to address the study purpose which is mainly to explore the educational needs of diabetic patients regarding chronic kidney disease.

A detailed discussion of findings continues in the next chapter.

CHAPTER FIVE

DISCUSSION, RECOMMENDATIONS, LIMITATIONS AND CONCLUSIONS

5.1 INTRODUCTION

This chapter outlines the summary of the findings, recommendations and limitations and conclusions of the study based on the data analysed in the previous chapter. Some limitations have been identified. The significance of the study in light of educational needs of diabetic patients is also emphasised as well as recommendations for future researchers**.**

5.2 SUMMARY OF THE STUDY

The purpose of this study was to explore the educational needs of diabetic patients attending a Public hospital clinic in the Free State Province with regards to developing chronic kidney disease as a complication. This was further guided by the objectives on education on kidney disease and lifestyle changes required to prevent chronic kidney disease as a complication.

Diabetic patients participated in the study and agreed to be interviewed for approximately 60 minutes each during their regular visits at the diabetic clinic. The researcher conducted face to face interviews in private rooms and data was recorded

transcribed and analysed accordingly. Seven males participated in the study and 18 females. They all either had type 1 diabetes mellitus or type 2 diabetes mellitus and all had other comorbidities such as hypertension, pain, asthma, arthritis and tuberculosis. All races were represented significantly with the majority being blacks and Sotho speaking.

The two main objectives are outlined below:

To explore the educational needs regarding chronic kidney disease in diabetic patients attending a clinic at a Public hospital in the Free State province.

To explore lifestyle behaviour changes associated with chronic kidney disease in the diabetic patients.

Open ended questions and probes were used (Appendix F) to guide the interview sessions towards the aim of the study as well as the objectives needed. The next section discusses the research findings that were analysed in the previous chapter.

5.3 DISCUSSION OF FINDINGS

Educational needs are a concern for diabetic patients. Studies propose that health care policies be drafted for preventative health talks on diabetes and its potential complications (Cheng, Wang, Lim and Wu, 2019). It is a concern to note that diabetic patients participating in this study have been attending the clinic for longer than three months and still lack the basic understanding of the disease patterns. However

complications such as chronic kidney disease were dreaded by those with minimal information.

Education for diabetic patients should include lay terms and demonstrations including flash cards to stimulate learning and the ability to develop self-drive and take the right steps towards your best life (Chatterjie, Davis, Heller, Speight et al, 2018). In this study doctors also played a big role in educating patients regarding their diet. This face to face teaching and evaluation tests have been noted to have improved glucose control worldwide especially concerning diabetic diet plans (Chattejie et al., 2018).

Secondary to dietary education the study also engaged participants on chronic kidney disease as a complication of diabetes. Some participants were frustrated by typical early signs of kidney disease such as nausea and vomiting, headaches, extreme fatigue, constipation and loss of appetite, swollen feet foam in urine .The participants were not educated on these signs and the typical tests that they should be aware of. The participants attributed these signs to poorly controlled blood sugar levels when essentially they could have been showing early stages of chronic kidney disease. Signs and symptoms of uncontrolled sugar levels and chronic kidney disease are similar however patients must be educated about kidney function tests and the physiology of kidney functions in order to consult doctors if symptoms persist even when sugar levels are rectified (Adegbola et al., 2016).

The lack of sufficient education was demonstrated in the face to face interviews during data collection.

Three themes and six subthemes were identified and their discussion follows.

Theme one: Communication

Diabetic patients that are well informed are easily educated about control of their blood sugar levels (Cheng et al., 2019). In the study by Cheng et al., (2019) patients had better access to all platforms of learning about their condition such as the internet. They could also better understand that complications related to diabetes such as chronic kidney disease could be prevented by good lifestyle choices. They were less stressed and more encouraged to make the decisions such as choosing and learning about the best diet plans to foster wellbeing (Cheng et al., 2019).

Information on chronic kidney disease was very superficial. Most participants were just informed to drink water to flush kidneys as way to keep them healthy. Others had typical early signs of chronic kidney disease such as flank pain around kidneys which they never reported to doctors because of being poorly informed and not making the association. Few participants had an idea about chronic kidney disease. They understood it as a deadly disease which they feared because in their view it could not be managed. Participants wanted to know about chronic kidney disease, how it presents clinically and how it is managed. None of the participants were on dialysis.

Even though the Free State province is able to cater for renal replacement therapy for a number of renal failure patients. This province has no active kidney transplant facility and reported that there were no transplants done from January to the end of December, 2016 according to the renal registry report (Davis et al., 2018). This information supports the need to educate diabetic patients about the link between diabetes and chronic kidney disease in order to prevent increased demand for dialysis therapy which

is already strained. There was little or no emphasis on chronic kidney disease as a complication of diabetes highlighted during education, in this study findings. Participants reported that they knew diabetes can damage kidneys but none of them knew how.

It is documented that uncontrolled diabetes causes diabetic nephropathy with subsequent chronic kidney disease which can further result in end stage renal disease if blood glucose levels remain elevated and unmonitored (Monahan et al., 2007). That link is not emphasised according to participants. This is evident by the fact that despite being able to check blood glucose levels some participants still presented with high blood glucose levels on consultation. Some of the participants were taught to check the glucose levels from once a day to just when they are not feeling well. This is one factor that can fast track complications including chronic kidney disease.

This study has identified potential communication barriers. A few factors that have to be taken into account with regards to how information is rendered to diabetic patients include using layman terms and avoiding medical terminology. Using the patients mother tongue in all platforms of communication such as the pamphlets, radio, TV, internet and posters and one on one sessions is advised (Schmitt et al., 2018) .The reinforcement or on-going education concerning Diabetes is also needed especially with regards to chronic kidney disease. Participants in this study only had memories of education from a period long ago concerning diabetic education. The participants in this study were predominantly black Sotho and Tswana speaking people. Some of them were elderly and they could not read English well nor could they comprehend medical terminology. It is worth recognising that a multidisciplinary team of Doctors, Dieticians and Nurses were involved in educating these participants on diabetes.

The American Diabetic Association (ADA) has recommended the exclusion of straight sugar and fat in meals and that patients should eat lots of vegetables and fruits particularly the green leafy vegetables, apples and pears (Jenks, 2018). Most participants in this study were well informed about the diabetic diet and when to eat and how to prepare their meals. The importance of complications like chronic kidney disease was not emphasised. The dietician plays an important role with diet information (Sanchez et al., 2018). According to all participants, the renal diet was not incorporated in the education of these participants even though similar to a diabetic diet.

The ADA has proposed the key areas for care givers to outline in diabetic education programs which include food planning and addressing loosing body weight to normal levels (American Diabetes Association, 2014).

Summary of Theme one

It is evident that many participants were satisfied with the dietary information they received for diabetes and to the multidisciplinary approach and discussion session of different healthcare providers. They understood the diet and felt able to follow the Dietary information remains the cornerstone of the management of diabetes. Some participants felt differently. The information was discussed in depth however there remains a challenge with the fact that printed information on diabetes and its complications may not be as effective due to possible illiteracy of rural dwellers in Free State who were mostly blacks in this group of participants. The elderly participants struggle to read. Participants reported that they gained more information on diet from

other means such as reading, radio and television than what they were told by their health care providers.

The general overview of the link between diabetes and kidney disease was lacking according to these findings. The information given to participants about kidney disease is superficial and without emphasis on recognising early signs and symptoms.

Some participants have presented with typical signs and symptoms that can be attributed to underlying early symptoms of chronic kidney disease but because they are not aware they could not identify the possibility of chronic kidney disease. None of these participants knew about kidney function tests and this raises a concern since they are all high risk and need to be tested regularly. Creatinine and estimated glomerular filtration ratio are fundamental tests that diabetic patients need to understand in order to prevent deterioration of their kidney function.

Theme two: Concerns

Concerns of lack of information on chronic kidney disease and diabetes escalated the stress and negative emotions in participants. This was because of the inadequate information on complications that could result from diabetes.

Fear and anger will lead to uncontrolled diabetes by initiating the physiological stress response and stress hormones such as adrenaline and glucagon which increase blood glucose levels (Thomas, 2018). Chronic kidney disease and worse complications such as loss of sight and limb amputations can result from uncontrolled glucose levels. The

tone in the participants voices and facial expressions indicated that they were not happy about minimal information on kidney health that they had been given.

Summary of theme two

Participants in the study have expressed concern of not being educated enough about either diabetes or kidney disease. The general response highlights the fact that there's little initiative from health care professionals to eliminate these concerns. This population is chronic patients who had been coming for follow up visits for many years at the clinic.

Theme three: Attitudes towards lifestyle change

Participants had mostly made peace with having diabetes and were complying with medication use. This was an indication of acceptance. Exercise is also an essential component around lifestyle change that was explored as it promotes cardiovascular fitness and circulation (Thomas, 2018). Exercise is also essential to burn fat and promotes glucose control in the blood by stimulating insulin sensitivity and cellular uptake. The participants in this study reported their own exercise routines like doing home chores, taking walks and going to gym, however guidelines on exercise programmes suitable for their condition as diabetic patients were not available. They were simply told to exercise. It was also recognised that when participants developed their own creative ways of exercising to optimise management of diabetes this was an

indication of acceptance (Sanchez et al., 2018). Some participants demonstrated some confidence in the information they received on dietary changes to optimise well-being. This attitude indicated acceptance of diabetes as a chronic disease.

Reluctance to changing lifestyle was also noted amongst these participants. Other participants reported gaining weight after being diagnosed with diabetes which could imply that they are were none compliant and eating large meal portions with high fat even though they report to knowing about healthy diabetic diet .This is further supported by the fact that they have mostly admitted to cheating on their diet sometimes and creating their own rules. Changing human behaviour is thus a complex field.

Relaxation was also pointed out as key to maintaining glycaemic control in diabetic patients. Only one patient reported to have been educated on implementing coping mechanisms to deal with negative emotions like listening to music and writing. Diabetic patients may develop feelings like guilt, excitement anger and sadness of having brought the disease on themselves. It is the psychologist's duty to give exercises in this regard so that the patients can better cooperate with the education proposals and minimise the potential for complications such as chronic kidney disease (Pal et al., 2018).

Summary of theme three

Generally there was not enough effort to change lifestyle amongst this group of participants. The participants were given information but often because of their limited circumstances they were unable to stick to their diet. Physical activity is a well-known

requirement amongst diabetic patients however there was no clear guideline within this clinical setting where the study was done. Participants developed their own creative ways to keep fit.

The participants were informed about their best dietary changes required to manage their disease. Others had financial problems like having to share their South African social security agency grant with their family members thus it was not enough to buy the right food. For others there was still resistance towards recommended lifestyle changes. Others did value diet plans and stuck to it. They were pleased to benefit from results such as less hospital admissions from complications such as high blood sugar levels. One participant indirectly testified that diabetes simply means diet control as its core value for management.

These diabetic participants are educated to change their lifestyles and many of them have reported compliance, however a significant number of them are still choosing to ignore the interventions.

5.4 LIMITATIONS

The following limitations of the study were identified

The study focused on exploring the educational needs of diabetic patients regarding chronic kidney disease and the lifestyle behaviour changes required to prevent chronic disease as a complication. More time to conduct interviews would have been advantageous in order to get in-depth views of participants.

- The sample size was 25 out of the 200 population that visits the clinic in a month and this one clinic finding may not be representative of other clinics in South Africa.

5.5 RECOMMENDATIONS

Recommendations for Nursing Practice

It would be best to have qualified professional nurses with a speciality in nephrology working in diabetic clinics. This initiative would drive education on diabetes and chronic kidney disease as a complication so that clients are constantly informed with adequate information. Nephrologists should also be involved in educating diabetic patients about the chronic kidney disease and lifestyle changes.

Recommendations for Nursing Management

Nursing managers can use these study findings to draft patient education policies addressing key areas that have been highlighted and inviting primary health nurses for in service training. This can be achieved by a liaison with the National department of health which can provide advanced details on kidney health and diabetes.

Recommendations for nursing research

The views of the healthcare workers in the same institution were not included and this would have added more depth to the data. Evidence based practice research approach

can be integrated as part of an on-going effort to find information on diabetes and chronic kidney disease that can keep patients and professionals updated and informed.

A qualitative inquiry of how health care workers implement the education of the diabetic patients regarding complications could be integrated with that of the patients to identify the missing link.

Patients that are still aware of potential complications of diabetes find it difficult to be compliant. More studies are needed on how to positively impact human behaviour.

World kidney day is celebrated each year with the target to prevent chronic kidney disease amongst high risk groups but its impact needs to be measured as to where it is lacking.

What does this study add?

The study discovered lack of on-going reinforcement and education of diabetic patients. There are factors that need to be explored as to why there is no on-going education of diabetic patients. Qualitative research methodology is still proving to offer depth understanding of how participants understand concepts in their daily lives and interactions. More qualitative research is needed around educational aspects (Clarke et al., 2013).

Patients have reported that they are seen by different doctors all the time. Perhaps it would be wise to identify how the changing of health care workers affects education of diabetic patients.

5.6 CONCLUSIONS

The educational needs of diabetic patients regarding chronic kidney disease were found to be lacking and this is a big concern according to this study's findings. There's a need to develop educational tools across all methods of communication that addresses the basic kidney physiology as well as the disease pattern so that diabetic patients can understand the correlation between diabetes and kidney disease. Educational tools should be in languages that are mainly understood by patients and information presented in local terms. Typical kidney function tests should also be outlined in the tool as to what is being checked in urine and in the blood Diabetic patients can be taught to do urine tests at home to promote reinforcement.

Lifestyle changes suitable for diabetic patients should also be included in the tool and there needs to be an input to assist with exercise programmes suitable for diabetic patients so that they avoid injuries and wounds. Renal diet discussion should also be included in the education tool because some of the diabetic patients could be in the early stages of chronic kidney disease thus needing to slow the progression of the disease by avoiding foods such as those high in protein. The psychologist can make a contribution to the education tool on relaxation exercises and how to address matters hindering compliance such as negative attitudes towards behaviour change.

5.7. SUMMARY

This chapter has outlined the summary of the study findings, conclusions, recommendations and limitations based on the data analysed in the previous chapter. It has met both the objectives set out. Some limitations were also outlined. The significance of the study in light of educational needs of diabetic patients was also emphasised as well as recommendations for future researchers**.**

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APPENDIX A

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Chere Lesemola

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M190727

NAME: (Principal Investigator)	Chere Lesemola
DEPARTMENT:	Nursing Education Univesitas Academic Hospital
PROJECT TITLE:	Exploring the educational needs of diabetic patients regarding chronic kidney disease
DATE CONSIDERED:	26/07/2019
DECISION:	Approved Uncondtionally
CONDITIONS:	
SUPERVISOR:	Andrea Hayward
APPROVED BY:	Dr. C Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	11/11/2019

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in **October** and will therefore be due in the month of **October** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX B

University of Witwatersrand
Department of Nursing Education
Faculty of Health Sciences
7 York Road
Park town 2193
Johannesburg

The Chief Executive Officer

Universitas Academic Hospital,

Private Bag X20660

Bloemfontein

Dear Mrs M.C Mabitle.

REQUEST FOR PERMISSION TO CONDUCT A RESEARCH STUDY IN THE DIABETIC CLINIC AT UNIVERSITAS ACADEMIC HOSPITAL.

I am currently a registered postgraduate student at the University of the Witwatersrand in the department of Nursing Education (Nephrology Nursing)). I hereby request your permission to undertake research at the Universitas Academic Hospital. The title of my research is “Exploring the educational needs of diabetic patients regarding chronic kidney disease”.

I hope to undertake this research project with objectives outlined to explore the educational needs regarding chronic kidney disease in diabetic patients attending a diabetic clinic at Universitas Academic Hospital.

According to research evidence Diabetes mellitus is one of the leading causes of chronic kidney disease in South Africa and around the world. This is as a result of Diabetic Nephropathy induced by poor glucose control. These patients will contribute to the millions of chronic kidney disease patients awaiting dialysis and kidney transplant as the only means to sustain their wellbeing. Predictions are that there will be increased socio economic burdens on the health sector due to this increasing epidemic.

In the Free State province there is no active kidney transplant programme in the Public sector due to shortage of surgeons and resources (South African Renal Registry, 2013). Organ donation programmes are also not reaching the vast rural communities. If the number of patients with chronic kidney disease increases due to diabetes, the number of patients needing dialysis will exceed the available facilities. Patients will die before receiving dialysis treatment due to limited resources in the public sector. This study is a qualitative study approach and allows us to probe and explore the participants' understanding of the education programmes and the need for lifestyle changes to avoid the development of chronic kidney disease.

The interview will be conducted with an audio-taped recorder with permission from the participants in order to obtain enough information from them. The audio-taped information will be locked away for safety and electronic information be protected by pass word after the transcription has been checked to ensure that no identification whatsoever is made to the participants and the institution. If the findings are published the names of participants will not be used, they will be given codes or numbers or labels. The transcribed information will be kept confidential and a copy of the report will be available to you if requested.

Necessary ethical measures regarding the study will be upheld to safeguard the dignity of the institution, personnel and participants. The study will be conducted after the proposed study has been critically reviewed by the research committee on Human subjects of the University of Witwatersrand and an approval has been received. Participation in the study will be voluntary and written consent will be provided.

I hope to conduct my research at the Diabetic clinic in the Universitas Academic Hospital once my proposal study has been approved by the Committee for Research on Human Subjects of the University of Witwatersrand.

Yours Sincerely,

Mr Chere Samuel Lesemola

MSc Nursing Postgraduate Student.

Supervisor: Mrs Andrea Hayward. Email:Andrea.Hayward@wits.ac.za

APPENDIX C

University of Witwatersrand
Department of Nursing Education
Faculty of Health Sciences
7 York Road
Park town 2193
Johannesburg

The Nursing director

Universitas Academic Hospital
Private Bag X20660
Bloemfontein

Dear Mrs B.E Modisapuli.

REQUEST FOR PERMISSION TO CONDUCT A RESEARCH STUDY IN THE DIABETIC CLINIC AT UNIVERSITAS ACADEMIC HOSPITAL.

I am currently a registered postgraduate student at the University of the Witwatersrand in the department of Nursing Education (Nephrology Nursing)). I hereby request your permission to undertake research at the Universitas Academic Hospital. The title of my research is “Exploring the educational needs of diabetic patients regarding chronic kidney disease”.

I hope to undertake this research project with objectives outlined to explore the educational needs regarding chronic kidney disease amongst diabetic patients attending a diabetic clinic at Universitas Academic Hospital.

According to research evidence Diabetes mellitus is one of the leading causes of chronic kidney disease in South Africa and around the world. This is as a result of Diabetic Nephropathy induced by poor glucose control. These patients will contribute to the millions of chronic kidney disease patients awaiting dialysis and kidney transplant as the only means to sustain their wellbeing. Predictions are that there will be increased socio economic burden on the health sector due to this increasing load.

In the Free State province there is no active kidney transplant programme in the Public sector due to shortage of surgeons and resources (South African Renal Registry, 2013).

Organ donation programmes are also not reaching the vast rural communities. If the number of patients with chronic kidney disease increases due to diabetes, the number of patients needing dialysis will exceed the available facilities. Patients will die before receiving dialysis treatment due to limited resources in the public sector. This study is a qualitative study approach and allows us to probe and explore the participants understanding of the education programmes and the need for lifestyle changes to avoid the development of chronic kidney disease as a complication.

The interview will be conducted with an audio-tape recorder with permission from the participants in order to obtain enough information from them. The audio-taped information will be locked away for safety and electronic information be protected by pass word after the transcription has been checked to ensure that no identification is made to the participants and the institution. If the findings are published the names of participants will not be used, they will be given codes or numbers or labels. The transcribed information will be kept confidential on computer protected by pass word and a copy of the report will be available to you if requested.

Necessary ethical measures regarding the study will be upheld to safeguard the dignity of the institution, personnel and participants. The study will be conducted after the proposed study has been critically reviewed by the research committee on Human subjects of the University of Witwatersrand and an approval has been received. Participation in the study will be voluntary and written consent will be provided.

I hope to conduct my research at the Diabetic clinic in the Universitas Academic Hospital once my proposal study has been approved by the Committee for Research on Human Subjects of the University of Witwatersrand.

Yours Sincerely,

Mr Chere Samuel Lesemola

MSc Nursing Postgraduate Student.

Supervisor: Mrs Andrea Hayward at email: Andrea.Hayward@wits.ac.za

APPENDIX D

Exploring the Educational Needs of Diabetic Patients Regarding Chronic Kidney Disease.

INFORMED CONSENT FOR PARTICIPATION:

I have been informed of the purpose of this study and understand that there is no risk to me by participating. I understand that my participation in this study is voluntary and I know that I can refuse to participate and or withdraw at any time without penalty.

Name of participant:

Signature of the participant:

Date:

Contact details of researcher: Please contact Sam Lesemola: 0762201950 if you need more information or have queries.

Contact details of supervisor: Please contact Mrs. Andrea Hayward: 011 488 4272 if you need more information or have queries.

Thank you for your assistance.

APPENDIX E

Exploring the Educational Needs of Diabetic Patients Regarding Chronic Kidney Disease.

INFORMED CONSENT FOR AUDIO RECORDING:

I understand that the interview between me and the researcher will be recorded to facilitate easy transcription and reviewing of my answers. I also understand that the recording will be kept in a secret and safe place that is pin code protected where no one other than the researcher and supervisor will have access to the recorded information. I understand that the recording will be typed and some of the words or information that I share will be written in the final research report, but my identifying information will not be shared. I understand that the recording will be kept for two years following any publications or for six years if no publications are made on the study. I understand that I may be quoted directly in the research report but then my identifying details will not be disclosed.

Name of participant:

Signature of the participant:

Date:

Contact details of researcher: Please contact Sam Lesemola: 0762201950 if you need more information or have queries.

Contact details of supervisor: Please contact Mrs. Andrea Hayward: 011 488 4272 if you need more information or have queries.

Thank you for your assistance.

APPENDIX F

PARTICIPANT INFORMATION DOCUMENT AND INFORMED CONSENT:

STUDY INFORMATION DOCUMENT

Study title: Exploring the Educational Needs of Diabetic Patients Regarding Chronic Kidney Disease

Greetings to you sir/madam

Introduction:

I, Chere Samuel Lesemola, am doing research on Diabetic patients and their knowledge of chronic kidney disease. Research is a process used in seeking new knowledge. In this study we want to learn what and how you understand chronic kidney disease by asking you a few questions. Chronic kidney disease is common in diabetic patients and is growing at a fast rate in South Africa and around the world. Research offers an opportunity to learn and improve the understanding and treatment of this condition the benefits of the study will be to provide evidence that will help us promote information and care of diabetic patients like you in order that you do not develop complications.

Invitation to Participate: I am inviting you to take part in this research study. Participation is voluntary. You may refuse to participate in the study without any penalties and at any given moment you may withdraw from the study should you wish to do so.

What is involved in the study:

1. The study is intended to gather information by asking you questions, and you sharing your own views and how you understand your condition.

2. This is done through interviews about the study topic.

3. I would like you to answer the questions as openly and freely as you can to the best of your understanding.

4. The interview will take about 60 minutes. With your permission, the interview will be recorded for transcribing after the interview.

5. Interview sessions are planned from October to December 2019 and an appointment will be made to fit in with your availability. The interviews will be conducted in a private room at the diabetic clinic at Universitas Academic Hospital in Bloemfontein.

Risks of being involved in the study: Although the researcher does not believe there are risks or discomfort foreseen for the Participant who agrees to participate in this study, a counselor will be available at the clinic if needed. The counselor will be available at no cost to the Participant.

Benefits of being in the study: There is no direct or immediate benefit to the Participant however in the longer term the information can be shared with all diabetic patients and this may assist in preventing the development of complications particularly chronic kidney disease. This is beneficial to all Diabetic patients. There will be no material benefits for participation in the study such as money or other goods.

You will be given pertinent information on the study while involved in the project and after the results are available.

Participation is voluntary. Refusal to participate will involve no penalty or loss of benefits to which you may be entitled. You may discontinue participation at any time without penalty, or loss of benefits to which you are otherwise entitled; there is no requirement to provide a reason for withdrawing and any data collected will be destroyed, unless you specifically consent to its retention.

Reimbursements for "out of pocket" expenses. Since the interview will take place whilst a routine clinic visit is planned, there is to be no payment or cost envisaged with participation,

Confidentiality: Personal information will be treated in the strictest confidence and will only be available to the Principal Investigator (PI) and his/her Supervisor. You are assured that personal information will be kept confidential as only codes will be used and not real names to maintain anonymity in the final report of the research.

The only exceptions - and all of them are rare - would be:

1. personal information may be disclosed if required by law
2. the Human Research Ethics Committees of the University may exceptionally require personal data to respond to a formal complaint, or for a compliance audit

All data collected in the course of the study will be securely retained for two (2) years, if a scientific publication arises from the study and six (6) years, if there is no publication.

Thereafter it will be destroyed accordingly. The audio recordings of the interviews will be transcribed by the researcher and verified by the supervisor. Confidentiality will be maintained by saving the information on a password protected computer and protecting the information that is only accessible by the supervisor and the researcher. The recordings will be kept in a safe locker that is pin code protected for 6 years before being destroyed. Only the supervisor and researcher will know the pin code for the safe.

Anonymity can usually only be guaranteed in questionnaires, whether in hard copy or online however the participants are likely unknown to both the investigator and the Supervisor

Contact details of researcher/s: Please feel free to contact Sam Lesemola: 0762201950. Supervisor Mrs. Andrea Hayward: 082 415 1872 if you need more information or have queries.

Outputs

The information obtained in the interviews will hopefully guide the researcher in understanding what information or assistance the Diabetic patient requires in order to improve their compliance and understanding of the risks associated with deteriorating diabetic disease. This information will be shared with the Participant on request after the study is completed.

Contact details of HREC administrator and chair

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee Professor Clement Penny, may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for agreeing to participate.

Date: 29.04.2019.

APPENDIX G

Zaheer, Ankia, Coetzee, and Pirie (2017) outline:

Key needs for diabetic persons.

- Choosing what is best (eating well, routine physical activities, none smoking, controlling BMI to remain less than 25kg/m^2 and counselling for stressors.
- Controlling diabetes (treatment compliance and correct use, self-checking of blood glucose and blood pressure).
- Knowing of preventable consequences (regular checks by podiatrist; regular check-ups for eye, and renal diseases).

APPENDIX H

PATIENT 4:

1. Tell me about the education you were given when you were diagnosed with diabetes?

I was taught to check my sugar levels once a day but since I've had it for more than 20 years I can always pick it up by feeling when it's high or low. I check it 2 to 3 times a week but only when I feel bad. I have accucheck active machine at home .They said the levels must vary between 4 to 7, I don't have regular times to eat some days my sugar is 6 and sometimes it's 10.Today morning when I checked my levels where 7.6 when I checked here at the hospital in about 30 minutes later it was 10.6, not all machines give the same reading.

2. Tell me more about the lifestyle changes you have made to avoid complications?

I used to eat a lot but I do not eat a lot anymore. I used to have a few shots every night and have a bottle of whiskey. But now we only drink alcohol during the weekend maybe a beer or two or a bottle of whiskey. The dietician wanted to make me a diet plan but I can't have a diet plan because there's a lot of running around at the farm after a quite week. We prepare lucerne, cut the sheep and take care of cattle. She can make me guidelines yes but it doesn't help to say 10 am eat a pear, 12 pm have lunch and 2 pm have a snack. You sometimes miss the morning meals such that by lunch time you eat double portions and they don't understand that.

(Probed about what he was told about protecting his kidneys): There was no information about how to avoid damage to kidneys. I would maybe ask a doctor about kidney health and he said just drink a lot of fluids .The blood results and urine specimens they took here at this hospital this morning is not discussed with regards to kidney health and disease. They would maybe tell me that some things like cholesterol are high but they would never say anything about avoiding kidney damage. There's no solid information given. (Probed about why he changed his lifestyle): We all want to live longer, nobody wants to die young, other people will say they want to live healthier but my definition of healthy could be a bowl of pap when yours is a good salad and I only eat salad when I want to.

Probed a bit more on his awareness of early and late signs of chronic kidney disease:

When I check my urine at home it's a bit concentrated but when my sugar levels are high I pass more than 3 litres of urine a day. My weight has increased by 3 kg in the last 6 months but it stays constant between 97 and 100kg.

PATIENT 6

1. Tell me about the lifestyle changes you made to avoid complications of diabetes?

I really haven't changed much. With my diet plan I eat pap but when I cook my pap I cook it with salt so that I don't eat raw salt, I eat my pap with milk or vegetables. I also eat bread and tea with milk and sugar but I do not apply margarine on the bread. I have a machine at home that I use it to check my sugar levels. They told me that the normal levels should range between 5 to 8. I was taught to check the sugar levels twice a day, in the morning and the evening. I have never had a specific exercise routine. I work at my house, I clean the house, do the laundry and clean the fields around my house, that is my form of exercise. I have already retired at the of sixty I am turning 80 years old in august this year. (Probed about the education she received about protecting her kidneys): I don't have any problems with my kidneys, even when they check my blood and urine specimens here at this hospital they never said that there was anything wrong with my kidneys based on those results, they never told me how to protect my kidneys.

All my vital signs are within normal limits when they check me here. I do not have kidney problems. Maybe I will start having problems with my kidneys now that I am old I have had diabetes for 20 years now. They never told me about the complications of diabetes I just live my life, I don't know whether it will kill me or what. I just live my life. I just avoid too much sugar and salt but I stick to my usual diet. (Probed about the reason and significance of change of lifestyle): Your body speaks to you when something does not agree with your body, your body will reject it and you will feel bad. I have never really changed my diet. The things that make me sick are pork. Amongst veggies I do not eat cabbage I like my pap, rice and stamp mealies but mainly pap.

Probe: what more would you like to know?

How will I recognise that I am starting to develop chronic kidney disease?