Challenges and coping strategies of caregivers caring for elderly people living with diabetes mellitus in a selected village of the Vhembe district, Limpopo province

BY

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DECLARATION

I, Patience Ipfi Mamatsharaga, hereby declare that this mini-dissertation titled: **“Challenges and coping strategies of caregivers caring for elderly people living with diabetes mellitus in a selected village of the Vhembe district, Limpopo province”,** for the degree, Masters of Public Health in the School of Health Sciences at the University of Venda, hereby submitted by me, has not been previously submitted for any degree at this university or any other university and that it is my own work in design and execution; and that all reference materials contained therein have been duly acknowledged.

Signature: Mamatsharaga P.I

Date: 08 July 2020

DEDICATION

I would like to dedicate this mini-dissertation to my parents Thinawanga David and Naledzani Agnes Mamatsharaga for their love and support.

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I am grateful for the grace of the Almighty God, who granted me life, strength, knowledge and wisdom to complete this mini-dissertation. I would like to direct my sincere gratitude to the following people, whose effort and support made it possible for me to reach my goals:

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LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	:	Acquired immune Deficiency Syndrome
CHD	:	Coronary Heart Diseases
DM	:	Diabetes mellitus
DOH	:	Department of Health
EPLWDM	:	Elderly People living with Diabetes Mellitus
HbA1c	:	Hemoglobin A1C
HBC	:	Home-Based Care
HIV	:	Human Immunodeficiency Virus
NA	:	National Alliance
NCD	:	Non-Communicable Disease
SANCO	:	South African National Civil Organization
T1DM	:	Type 1 Diabetes Mellitus
WHO	:	World Health Organization

ABSTRACT

Most elderly people with diabetes mellitus are community dwelling and cared for by local healthcare providers and frequently by caregivers within the elders' homes. Care for these elders is often suboptimal compared with that of elderly people without diabetes. the purpose of this study was to investigate the challenges experienced by caregivers of elderly people living with diabetes mellitus in a selected village of the Vhembe district in the Limpopo province. The study adopted a qualitative research approach using an exploratory design to provide insights into the challenges experienced by caregivers of elderly people living with diabetes mellitus. This research used purposive sampling to ensure that the empirical evidence retrieved is detailed and objective. Before data collection, the researcher applied for ethical clearance to the University of Venda Research Ethics Committee. Ethical considerations adhered to include anonymity, informed consent and voluntary participation. Data was collected using a semi-structured interview method, using an interview guide. Interviews and discussions with caregivers were audio-taped with permission from participants. Data saturation occurred after interviewing 17 participants. Data were transcribed verbatim and later translated into English by an English language expert. Data was coded into larger themes and categories by means of a thematic analytical approach. Measurements of trustworthiness such as conformability, dependability, transferability and credibility were ensured.

The findings of the study revealed that caregivers of elderly people living with diabetes mellitus experience financial challenges when caring for diabetes mellitus patients. It was also revealed by the study findings that caregivers of elderly people living with diabetes mellitus suffer from physical, psychological psychosocial and psych spiritual stress. Time management and poor performance at work were also revealed by the study findings as challenges for the caregivers who are working.

Keywords: Caregivers, Challenges, Diabetes Mellitus, Elderly People, Experiences

TABLE OF CONTENT

DECLARATION ii

DEDICATION iii

ACKNOWLEDGEMENT iv

LIST OF ABBREVIATIONS AND ACRONYMS v

ABSTRACT vi

TABLE OF CONTENT vii

CHAPTER ONE: INTRODUCTION 1

1.1 INTRODUCTION AND BACKGROUND TO THE STUDY 1

1.2. PROBLEM STATEMENT 4

1.3 RATIONALE OF THE STUDY 4

1.4 SIGNIFICANCE OF THE STUDY 5

1.5 AIM OF THE STUDY 5

1.6 RESEARCH QUESTIONS 5

1.7 DEFINITION OF CONCEPTS 6

1.8 ARRANGEMENT OF CHAPTERS 6

Chapter 2: Literature review 7

2.1 INTRODUCTION 8

2.2 GLOBAL OVERVIEW OF FAMILY CAREGIVING 8

2.3 FAMILY CAREGIVING IN SOUTH AFRICA 9

2.4. CHALLENGES EXPERIENCED BY CAREGIVERS OF ELDERLY PEOPLE LIVING WITH DIABETES MELLITUS 9

  2.4.1. Physical health challenges experienced by caregivers of people living with diabetes. 12

  2.4.2. Psychological challenges experienced by caregivers 13

  2.4.3. Socio-economic challenges experienced by caregivers when managing diabetes patients. ... 14

2.4 COPING STRATEGIES 15

  2.4.1 Prayers 16

  2.4.2 Family, relative, friends and neighbour support 16

  2.4.3 Take Time Out 17

  2.4.4 Quality Time 17

2.5 SUMMARY OF THE CHAPTER 17

CHAPTER THREE: RESEARCH METHODS 19

3.1 INTRODUCTION 19

3.2 RESEARCH APPROACH 19

3.2 RESEARCH DESIGN 19

3.3. STUDY SETTING 19

Figure 1: A selected village in the Vhembe district village (source: Vhembe GIS section) 20

3.4. POPULATION, SAMPLE AND SAMPLING METHOD 20

3.4.1 Study Population 20

3.4.2. Sampling Method 21

3.5. DATA COLLECTION METHOD 22

3.6. PRE-TEST 22

3.7. DATA COLLECTION PROCEDURE 22

3.8. DATA ANALYSIS METHOD 23

3.8.1 Becoming familiar with the data 23

3.8.2 Transcription of verbal data 23

3.8.3 Generating initial codes 23

3.8.4 Reviewing themes 24

3.8.5 Defining and naming themes 24

3.8.6 Producing the report 24

3.8.7 Measures to ensure Trustworthiness 24

3.8.8 Credibility 24

3.8.9 Dependability 25

3.8.10 Conformability 25

3.8.11 Transferability 25

3.9. ETHICAL CONSIDERATIONS 25

3.9.1 Permission to conduct the study 26

3.9.2 Informed consent 26

3.9.4 Voluntary participation 26

3.9.5 Confidentiality and privacy 26

3.9.6 Anonymity 27

3.10. DISSEMINATION OF RESULTS 27

3.11 SUMMARY 27

CHAPTER FOUR: PRESENTATION AND DISCUSSION OF FINDINGS 28

4.1 INTRODUCTION 28

4.2 RESEARCH FINDINGS ANALYSIS AND DISCUSSION 28

4.3 DEMOGRAPHIC PROFILE OF THE PARTICIPANTS 28
    Table 1: Participants Demography 29
4.4 SUMMARY OF THE STUDY FINDINGS 30
    Table 2: Themes emerged from findings 30
4.4.1 THEME 1: SOCIO-ECONOMIC CHALLENGES 31
    4.4.1.1 Caregiver related problems 31
    4.4.1.2 Time-Management. 31
    4.4.1.3 Financial Problems 32
    4.4.1.4. Lack of resources 35
    4.4.1.5 Inadequate family support. 37
4.4.2 THEME 2: HEALTH-RELATED CHALLENGES 38
    4.4.2.1 Physical health 38
4.4.3 THEME 3: CHALLENGES RELATED TO THE HEALTH SYSTEM 40
    4.4.3.1 Shortage of Medication in the clinic 40
    4.4.3.2 Inadequate Government Support 41
    4.4.3.3 Unavailability of counselling sessions. 42
4.4.4 THEME 4: COPING STRATEGIES 42
    4.4.4.1 Acceptance 42
    4.4.4.2 Prayers. 43
    4.4.4.3 Support visits by Community Home Based Care. 44
    4.4.4.4 Support from close friends and relatives. 44
4.5 SUMMARY OF THE CHAPTER 45
CHAPTER FIVE: CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS OF THE STUDY 46
5.1 INTRODUCTION 46
5.2 LIMITATIONS OF THE STUDY 46
5.3 CONCLUSIONS DRAWN FROM THE STUDY 46
5.4 RECOMMENDATIONS 47
    5.4.1 Recommendations for the Community Home Based care 48
    5.4.2 Recommendation for the Department of Health 48
    5.4.3 Recommendations for further research 48
5.5 SUMMARY OF THE CHAPTER 49
REFERENCES 50
APPENDICES 55

APPENDIX A: INTERVIEW GUIDE 55
APPENDIX B: INFORMATION SHEET 56
APPENDIX C: CONSENT FORM 57
APPENDIX D: INTERVIEW TRANSCRIPT 59
APPENDIX E: ETHICAL CLEARANCE CERTIFICATE 62

CHAPTER ONE: INTRODUCTION

1.1 INTRODUCTION AND BACKGROUND TO THE STUDY

Worldwide, the prevalence of chronic non-communicable diseases is increasing at an alarming rate; chronic non-communicable diseases account for one of the leading causes of death globally, and in South Africa. Diabetes mellitus is one of the most common non-communicable diseases that is causing a burden in most developed and developing countries. It is a condition in which the body's ability to produce or respond to the hormone insulin is impaired, resulting in abnormal metabolism of carbohydrates and elevated levels of glucose in the blood (World Health Organization, 2017). According to Zhou, Lu, Hajifathalian, Bentham, Di Cesare, Danaei, Bixby, Cowan, Ali, Taddei, and Lo (2016: 45), "It is the fourth or fifth leading cause of death in most high-income countries and there is substantial evidence that it is epidemic in many economically developing and newly industrialized countries". Joshi (2015: 12) indicates that "in 2014, 387 million people had been reported as having diabetes in South Africa, and without effective prevention and management programmes, this number is expected to rise to 592 million by 2035". The majority of the people with diabetes mellitus are located in low- and middle-income countries (WHO, 2017). Furthermore, WHO (2017: 56) state that "Statistics reveal that almost 80% of the total elderly people living with diabetes mellitus are in developing countries".

In the United Kingdom, diabetes has been established as a burden affecting millions of people. According to the WHO (2017), in 2015, one in 17 elderly people in the United Kingdom was diagnosed with diabetes mellitus. According to the same report, it is estimated that 400 people per day are being diagnosed with diabetes mellitus in the United Kingdom, and this translates to approximately three people every 10 minutes (WHO, 2017). According to WHO (2016), in 2015, 9.4% of the population in America was diagnosed with diabetes mellitus. It is estimated that approximately 1.25 million American children and elderly people are living with type 1 diabetes. Diabetes remains the seventh leading cause of death in the United States, with 79,535 death certificates listing it as the underlying cause of death, and a total of 252,806 death certificates listing diabetes as an underlying or contributing cause of death (WHO, 2015).

The estimated prevalence of diabetes mellitus in Africa is 1% in rural areas and ranges from 5% to 7% in urban sub-Saharan Africa (Okwaraji, Onyebueke, Nduanya, and Nwokpoku, 2017). Nigeria is said to have the highest incidence of diabetes in sub-Saharan Africa, with about five million people currently living with the condition, and much more, about 50 per cent of the cases, still undetected (Bertram, Jaswal, Van Wyk, Levitt, and Hoffman, 2018). In South Africa, 2.3 million people are estimated to be living with diabetes, with 1.39 million people who have not yet been diagnosed (IDF, 2015). In 2015, diabetes was among the first of three leading causes of death in South Africa (WHO, 2016).

A study by Baig, Benitez, Quinn & Burnet (2017: 99) states, “Currently, there is no cure for diabetes and treatment is limited to disease management approaches, therefore, people living with diabetes mellitus need to take insulin periodically throughout the day and maintain a healthy diet to maintain healthy blood glucose levels”. Moreover, Baig, et al (2017: 87) state that “Frequent and close monitoring of blood glucose levels is very important”. Therefore, the elderly who are living with diabetes mellitus need close caregiving from professionals or family caregivers to manage the condition. Family caregivers around the globe are faced with many various challenges that may include the burden of monitoring sugar levels, controlling haemoglobin A1C (HbA1c), managing medications, and medical compliance issues. Baig, et al (2017: 102) assert that “serious complications of diabetes such as mobility, heart-related problems, vision loss, wound care, hypoglycemia, kidney disease, loss of limb, and neuropathy, are among other challenges faced by family caregivers”.

Gregg, Beckles, Williamson, Leveille, Langlois, Engelgau and Narayan (2017: 76) claim, “Diabetes mellitus is also associated with greater risks of disabilities related to mobility and daily tasks among elderly people. The findings from the National Health, Nutrition and Examination Surveys indicate that people with diabetes have about two to three times the prevalence of inability to walk 400 metres, do housework, prepare meals, and manage money. Their inability to be mobile increases the need for a full-time caregiver”.

Beutel, Klein, Brahler, Reiner, Junger, Michal, Wiltink, Wild, Munzel, Lackner, and Tibubos (2017: 65) explain that, “Globally, families and friends who give care to elderly people living with diabetes mellitus are affected in a variety of ways and degrees. The interplay of caregiving consequences are poverty, discrimination and stigma. Lack of support from others, diminished social relationships, depression, emotional trauma and poor or interrupted sleep are also associated with caregivers’ challenges. Family caregivers experience challenges in balancing their occupational demands associated with their caregiving position, own family, and profession”. Previous studies by Mthembu (2016: 64) indicate that “the effect of presenting care for family caregivers in terms of their physical health, psychological well-being, social life, financial situation and quality of life which appeared to form part of their burden”. These studies found that the family caregivers’ social life, such as going on holiday, engaging in social activities, maintaining telephone contacts, visiting friends and attending recreational and social clubs were negatively influenced by providing care to elderly people with chronic diseases (Mthembu, 2016; Schulz and Eden, 2016).

Caregivers play a fundamental role in the care for the terminally ill in many countries (International Diabetes Federation, 2015). Therefore, family members play important roles in caregiving, since old people need assistance. Being a caregiver has been associated with negative health impacts, psychological morbidity, social isolation, physical ill-health, and financial hardship (Musich, eWang, Kraemer, Hawkins and Wicker, 2017). Schulz, et al (2016) state that “caregiving for elderly chronic patients is associated with many challenges such as negative impacts on their physical health and well-being, increased depression, increased stress as well as social isolation”. A qualitative study by Ae-Ngibese, et al (2016) conducted in Ghana, explored the experiences of caregivers of people living with serious mental disorders. The results indicated that the caregivers, “prepared meals and fed their loved ones, as well as assisting their relatives during nature’s call”. Furthermore, the results of the study reported a variety of challenges related to the stress and burden experienced by caregivers such as financial difficulties, social isolation, emotional stress and depression.

Another study in China, by Leng (2019) also indicates that “caregivers had low quality of life in several domains including role-physical, role-emotional and mental health. Furthermore, caregivers rated themselves as having minimal levels of past support and little support seeking behaviour. These findings also suggest that the caregivers receiving good support from their colleagues, friends, neighbours and relatives have a better quality of life”. The findings of a study in the Western Cape province of South Africa reveal, “family caregivers lived a hectic life as they noticed that providing care to an older adult was a difficult occupation and that they were struggling to balance their caregiver role with work and social life” (Mthembu, et al., 2016).

As indicated by Puoane, Tsolekile, Egbujie, Lewy, and Sanders (2017), “there is a gross shortage of doctors, pharmacists, nurses, psychologists, rehabilitation therapists, oral hygienists and dental therapists in South Africa”. Mthembu, et al (2016) indicate that “as a result of the shortage of professional health workers, most of the diabetes mellitus elderly patients are taken care of by family caregivers and these are the non-professional people living with them. Many of them might face similar or unique challenges depending on various factors that might include socio-economic status, geographical location and psychological factors amongst others. Therefore, this study sought to investigate the challenges experienced by family caregivers of elderly people living with diabetes mellitus in selected villages of South Africa".

1.2. PROBLEM STATEMENT

As a community development practitioner, the researcher has observed during house-hold profiling that there is a high rate of people living with diabetes mellitus in some villages of the Vhembe district in the Limpopo province. Many family caregivers gave up their full-time jobs in order to provide care for elderly people living with diabetes mellitus at home. The researcher had observed the caregivers during the process of house-hold profiling that they seem to struggle to balance their daily duties which lead them to abandon their work activities. According to the Vhembe district 2018/2019 disease profile, the leading cause of death among elderly people aged 65 and above in the Vhembe district is diabetes mellitus, at 25.8 %.

Despite the efforts by the Department of Health (DOH) as well as Home-Based Cares (HBCs) in providing care and support, the majority of elderly people living with diabetes mellitus are being taken care of by untrained family caregivers in their households. Family members who are serving as caregivers are not trained to do this kind of job, hence, they face a lot of difficulties in caring for elderly people living with diabetes mellitus at home. "The benefits of diagnosed diabetes mellitus enable the patient to receive healthcare and family support" (Shamsaei, Cheraghi & Bashirian, 2017: 98). However, "… the extent of this burden is often difficult to assess and because of these measurement difficulties, it is frequently ignored" (Marimbe, Cowan, Kajawu, Muchirahondo and Lund, 2016). This study, therefore, investigated the challenges experienced by caregivers of elderly people living with diabetes mellitus at a selected village in the Vhembe district in the Limpopo province.

1.3 RATIONALE OF THE STUDY

In South Africa, there are few studies which seek to understand the challenges experienced by caregivers when taking care of elderly people living with diabetes mellitus. Literature in South Africa suggests that several studies focused on caregivers caring for patients with human immunodeficiency virus infection (HIV) and Acquired immune deficiency syndrome (AIDS) (Ralineba, Netshikweta and Shilubane, 2015). In the Vhembe district, a study by Mashau, Netshandama, & Mudau, (2016) focused on home-based carers (HBCs). Studies on the experiences of family caregivers, specifically caring for patients who are suffering from diabetes mellitus is limited and none focuses on the Vhembe district municipality. There is no known study conducted at the selected village that sought to understand the challenges experienced by caregivers of elderly people with diabetes mellitus. Therefore, this study sought to unravel the challenges experienced by caregivers of elderly people living with diabetes mellitus at a selected village, in the Vhembe district in the Limpopo province, South Africa.

1.4 SIGNIFICANCE OF THE STUDY

This study is important, as the results could add to the existing body of knowledge regarding the challenges experienced by caregivers of elderly people living with diabetes mellitus. This information might shed light for other caregivers, by uncapping the challenges faced by other families and how they cope with them. It may also help other caregivers to improve their caregiving competency and ability to ensure patient safety.

The study results might assist in providing information to the Department of Health (DOH) which will help them in improving the programmes which are aimed at helping caregivers of elderly people living with diabetes mellitus. The results of the study might also help the local traditional leaders at a selected village in the Vhembe district village to be aware of the challenges experienced by caregivers of elderly people living with diabetes mellitus so that they can offer support to the caregivers.

1.5 AIM OF THE STUDY

The study aimed to explore and describe the challenges experienced by caregivers and their coping strategies of elderly people living with diabetes mellitus in a selected village of the Vhembe district in the Limpopo province.

1.6 RESEARCH QUESTIONS

The followings questions were formulated to guide the study:

- What are the challenges experienced by caregivers of elderly people living with diabetes mellitus?
- What are the coping strategies of caregivers of elderly people living with diabetes mellitus?

1.7 DEFINITION OF CONCEPTS

Challenges

Challenges are difficulties faced or experienced by people in their daily lives (Mthembu, 2016). For this study, challenges are all the hurdles that are being faced by family caregivers when providing support to elderly people living with diabetes mellitus.

Diabetes Mellitus

"Diabetes mellitus is a condition in which the body's ability to produce or respond to the hormone insulin is impaired, resulting in abnormal metabolism of carbohydrates and elevated levels of glucose in the blood" (WHO, 2017).

Elderly people

"Elderly people are fully grown or developed people" (Yang, 2017). For this study, an elderly person refers to any older person diagnosed with diabetes mellitus who is at aged 50 years and above.

Experience

Mthembu, (2016) defines experience as, "the process of doing and seeing things and of having things happen to you, skill or knowledge that you get by doing something, the length of time you have spent doing something". For this study, experience refers to the unpleasant challenges undergone by family caregivers of elderly people living with diabetes mellitus.

Caregivers

"Caregivers refer to unpaid individuals such as family members, friends and neighbours who provide care" (Family Caregiver Alliance, 2016). For this study, caregivers are all the members who provide non-remunerated duties to diabetes mellitus patients at home.

1.8 ARRANGEMENT OF CHAPTERS

This study is made up of five chapters, each with specific subject matters as follows:

Chapter 1: Introduction

This chapter covered the introduction and background of the study, the problem statement, rationale of the study, the significance of the study, aim and objectives of the study, definitions of terms, and ends with the subsequent chapters.

Chapter 2: Literature review

This chapter focuses on the review and discussion of the relevant literature. In relation to the study. The researcher reviewed the literature from relevant sources such as journals, academic books and articles. This chapter helped the researcher to become aware of what other researchers have found in the same topic or related to it.

Chapter 3: Research methodology

This chapter includes an introduction, research design, target population, study setting, sampling method and sampling procedures that were used. This chapter also focuses on the data collection instrument, pre-test, data collection procedure, data analysis method, measures taken to ensure trustworthiness, dissemination of findings as well as a summary.

Chapter 4: Presentation and discussion

This chapter contains the presentation and discussion of the findings as presented by the participants.

Chapter 5: This chapter includes the limitations, conclusions, recommendations and ends with a summary.

Chapter summary

Chapter one presented the background of the study, problem statement, rationale, significance of the study, the aim of the study, the objectives of the study and definition of terms. The next chapter focuses on the literature that was reviewed for this study.

CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION

This chapter presents a literature review related to challenges experienced by caregivers of elderly people living with diabetes mellitus. Coping strategies of caregivers of elderly people living with diabetes mellitus also form part of this chapter. In this chapter, the researcher reviewed available literature from different schools of thoughts.

2.2 GLOBAL OVERVIEW OF FAMILY CAREGIVING

“Family caregivers refer to unpaid individuals such as family members, friends and neighbours who provide care” (Family Caregiver Alliance, 2016: 45). For this study, caregivers are all the members who provide non-remunerated duties to the diabetes mellitus patients within a family.

Globally, families and friends who give care to elderly people living with diabetes mellitus are affected in a variety of ways and degrees. The interplay of caregiving consequences are poverty, discrimination and stigma. Lack of support from others, diminished social relationships, depression, emotional trauma and poor or interrupted sleep are also associated with caregivers’ challenges. Family caregivers experience challenges in balancing their occupational demands associated with their caregiving position, own family, and profession. Previous studies by Mthembu (2016) and Schulz and Eden (2016) indicate that “the effect of presenting care for family caregivers in terms of their physical health, psychological well-being, social life, financial situation and quality of life which appeared to form part of their burden”. The study by Schulz and Eden (2016) found that “the family caregivers’ social life, such as going on holiday, engaging in social activities, maintaining telephone contacts, visiting friends and attending recreational and social clubs were negatively influenced by providing care to elderly people with chronic diseases” (Schulz & Eden,2016).

Caregivers play a fundamental role in the care for the terminally ill in many countries, (International Diabetes Federation, 2015). Therefore, family members play important roles in care-giving since old people need assistance. Being a caregiver has been associated with negative health impacts, psychological morbidity, social isolation, physical ill-health, and financial hardship (Musich, et al., 2017). A qualitative study by Ae-Ngibese, et al (2016), conducted in Ghana, explored the experiences of caregivers of people living with serious mental disorders. The results indicate, that “the caregivers prepared meals and fed their loved ones, as well as assisting their relatives during nature’s call. Moreover, the results of the study reported “a variety of challenges related to the stress and burden experienced by caregivers such as financial difficulties, social isolation, emotional stress and depression".

Another study in China by Leng, et al (2019) indicates that "caregivers had low quality of life in several domains including role-physical, role-emotional and mental health". Furthermore, the study indicates that "caregivers rated themselves as having minimal levels of past support and little support seeking behaviour". These findings also suggest that "the caregivers receiving good support from their colleagues, friends, neighbours and relatives have a better quality of life".

2.3 FAMILY CAREGIVING IN SOUTH AFRICA

As indicated by the Strategic Plan for the Prevention and Control of Non-Communicable Diseases (2013-17), in South Africa, "there is a gross shortage of doctors, pharmacists, nurses, psychologists, rehabilitation therapists, oral hygienists and dental therapists. As a result of the shortage of professional health workers, most of the diabetes mellitus elderly patients are taken care of by family caregivers and these are the non-professional people living with them. Many of them might face similar or unique challenges depending on various factors that might include socio-economic status, geographical location and psychological factors amongst others". The findings of the study in the Western Cape province of South Africa reveal that "family caregivers lived a hectic life as they noticed that providing care to an older adult was a difficult occupation and that they were struggling to balance their caregiver role with work and social life" (Mthembu, et al., 2016). Therefore, this study sought to investigate the challenges experienced by family caregivers of elderly people living with diabetes mellitus in selected villages, South Africa.

2.4. CHALLENGES EXPERIENCED BY CAREGIVERS OF ELDERLY PEOPLE LIVING WITH DIABETES MELLITUS

Challenges experienced by caregivers can also be understood when considering their occupational imbalance. According to Santos, et al (2019), "occupational imbalance is experienced by people who are un-occupied, under-occupied or over occupied. Regarding the literature that deals with the challenges faced by caregivers, it could be argued that they experience challenges in balancing their occupational demands related to their caregiver role, family, and career". Previous studies reported that caregivers seemed to experience caregiver burden, as they spent most of their time providing (or helping with) the selfcare activities of the older adult (Yerxa, 2017; Santos, et al., 2019). A qualitative study by AeNgibise, Doku, Asante, & Owusu-Agyei (2015: 33) conducted in Ghana, explored the experiences of caregivers of people living with serious mental disorders. The results indicate that, "the caregivers prepared meals and fed their loved ones, as well as assisting their relatives during nature's call. Furthermore, the results of the study reported a variety of challenges related to the stress and burden experienced by caregivers such as financial difficulties, social isolation, emotional stress and depression".

According to Bevans and Sternberg ((2017), the physical and emotional toll of caregiving is with high potential for symptom burden may negatively impact the physical health of the caregivers. Sjovall, et al (2018: 40), indicate that "Caregivers are concerned about disease progression and treatment outcomes while working with the practical demands of care. In a study regarding sick leave usage of spouses of diabetes patients, spouses of diabetes patients had the most sickleave episodes, which may correlate with higher physical and emotional burdens of care".

As the disease progresses, physical care and assisting the patient with daily activities may be necessary. "Added caregiver stress may result in sleep disturbance, fatigue, and unhealthy behaviours" (Bevans & Sternberg, 2017: 90). Furthermore, Bevans and Sternberg (2018) indicate that "sleep loss may result in changes in stress response, glucose regulation, and immune function". Bevans and Sternberg (2018: 8) also indicate that "Health behaviours and health changes of the caregivers may be negatively impacted following diabetes Mellitus diagnosis". Hackett, Moore, Steptoe, & Lassale (2018: 76), indicate that the above, "occurs when caregiving interferes with usual daily activities and is associated with negative lifestyle changes. Caregivers appear to prioritize the care of the patient and lose focus on self-care potentially resulting in the decline of quality of life".

According to Massey, Feig, Duque-Serrano, and Huffman (2017), "Caring for a loved one with Diabetes Mellitus is associated with both positive and negative psychological well-being. Caregivers who are in strong relationships with ample support may find that their relationship grows stronger through the intimacy of caregiving, while those for whom the relationship is more complicated and who lack adequate support for the intensity of this role may experience significant caregiver burden. Bevans and Sternberg (2018) state that "increased caregiver burden increases the risk for depression and anxiety".

Kim, Sun, Raz, Williams, Fujinami, Reckamp, Koczywas, Cristea, Hurria, & Ferrell, (2016: 54) show that "Caregivers often report a parallel roller-coaster of emotions mirroring the impact of the disease trajectory with the patient". Hackett, et al (2018)indicate that "Both caregivers and patient experience the uncertainties and fears associated with a new diagnosis, decisions about treatment choices, symptoms and loss of function. The potential for stress associated with the role of caregiver places those with a history of psychological challenges at increased risk for deepening depression or heightened anxiety". Massey, et al (2017) indicates that "those who rely upon alcohol or other substances to manage stress are at risk for increased usage and may benefit from additional education and support".

Adequate social support is critical to success in caregiving (Kim, et al., 2016). The responsibilities of the caregiving role vary and are influenced by gender, age, culture, and ethnicity (Hackett, et al., 2018). "The increased intimacy and vulnerability associated with caring for an increasingly debilitated loved one alters the roles of all involved. Strong relationships may find that bonds are tightened through the caregiving experience, while conflicted relationships or those with limited resources may be overwhelmed" (Hackett, et al., 2018).

Worsening illness places increasing burdens upon caregivers who become fatigued and lack the time to continue normal social activities. This loss of a social network increases a sense of isolation and is associated with worse psychological well-being (Massey, et al., 2017). The findings of Kim, et al (2016) study indicate that "the increasing demands of care for diabetes mellitus patients may lead to missed time from work, decreased productivity, and job resignation".

"Financial burden and social isolation are exacerbated by these changes. Increased caregiving responsibilities can alter sexual expression and increase tension between partners" (Hackett, et al., 2018). Massey, et al (2016) indicate that "partners can be challenged to maintain a loving intimate relationship when required to assist with wound care or worried about causing pain or symptom distress".

Additionally, Kim, et al (2016) found that "caregivers struggled to cope with the chronic stress and emotional disturbance related to caring for an older person with a chronic disease". Hackett, et al (2018), explains that "Most of the systematic reviews reported that family caregivers had 'no life anymore' and that they lacked the freedom to exercise their occupational rights to work, explore interests as well as engage in social participation with friends, relatives and partners".

According to a review by World Federation of Mental Health (2017), "caregivers suffer from poor health than non-caregivers and have more chronic illnesses such as high blood pressure, heart disease, diabetes, and arthritis than non-care giving peers. They may also suffer from poorer immune function and exhaustion". They may neglect their care and have higher mortality rates than non-caregivers of the same age (World Federation of Mental Health, 2016). "The effects of caregiving are both wide-ranging and highly individualized. Caregivers are potentially at increased risk for adverse effects on their wellbeing. In general caregiving for elderly chronic patients is associated with several challenges such as negative impacts on their physical health and wellbeing, increased depression, increased stress as well as social isolation" (Hackett, et al., 2018: 26). Hackett, et al (2018: 23) further indicate that "Caregiving literature in South Africa and beyond indicates that caregivers experience a range of social, physical and emotional costs in face of combined demands of care and paid employment".

2.4.1. Physical health challenges experienced by caregivers of people living with diabetes.

Caregivers are faced with the physical health challenge of High Blood Pressure, Physical Pain such as more likely to have recurring neck or back pain. Schulz, et al (2016) indicate that "the act of caregiving, perhaps in conjunction with caregivers' increases the likelihood to have physical ailments, also brings with it reduced energy and productivity levels. Caregivers in all age groups are more likely than non-caregivers to report that poor health keeps them from doing their usual activities and that they did not feel well-rested the prior day".

The study by Santos-Orlandi, Brito, Ottaviani, Rossetti, Zazzetta, and Pavarini (2017) indicates that, "caregiving for people with diabetes were likely to suffer from increased frailty, unintentional weight loss, self-reported exhaustion, weakness, slow walking speed, and low physical activity over time when compared to non-diabetes spousal caregivers". To confirm this, Massey, et al (2017) observed that, "among diabetes, caregivers experienced sleep disturbance, fatigue, pain, loss of physical strength, loss of appetite, and weight loss". Schulz and Eden (2016) reported similar results which linked caregiving and mortality risk as compared with non-caregivers. In contrast, Kim, et al (2016) concluded in their study that, "caregiving was associated with lower mortality risk, furthermore, the study also been confirmed that caregiving has an effect on health behaviours of caregivers". Santos (2019: 18) concluded in their study that, "caregiver neglect their health after taking caregiving role because of the relatively high rates of exhaustion, being overwhelmed, and not having enough time for themselves".

According to Santos, et al (2019: 22), "Caregiving, along with being stressful, oftentimes requires more physical activity than normal, including assisting in transfers into and out of wheelchairs, vehicles, and beds; physical therapy; and daily tasks such as bathing and dressing. Although the specific tasks involved in caregiving certainly differ from situation to situation, it is clear that what is involved is taking a toll on the physical health of those who fill this type of role".

The above means that caregivers experience physical exhaustion because of taking care of their diabetes mellitus patients. Therefore, caregiving can challenge long-standing family roles.

2.4.2. Psychological challenges experienced by caregivers

Although there are few studies which explored the experiences of caregivers about diabetes in the adult population there are studies which focused on the impact of caregiving for a child with diabetes. Kim, et al (2016) conducted a mixed-method study to describe the prevalence of psychological distress in parents of children with type 1 diabetes (T1DM), the relationship between parental psychological distress and health. The study concludes that, "parents suffered from parental psychological distress. Parental psychological distress in parents was associated with higher child self-report of stress and depressive symptoms, more problematic child behaviour, and lower child self-report of quality of life. Parental psychological distress also had negative effects on diabetes management. Themes form the qualitative synthesis indicated that parents perceived T1DM as a difficult diagnosis that contributed to significant family disruption. Adjustment occurred over time; however, ongoing stress was experienced" (Kim, et al., 2016).

The above means that being a carer of a patient with a chronic illness or disability is associated with psychological distress (Kim, et al., 2016). For instance, in a study that compared parents of children with cancer, asthma, cystic fibrosis, and type 1 diabetes, parents of children with type 1 diabetes and asthma reported greater parenting stress but less worry about their child's health compared to other parents (Santos, et al., 2019). Parents seem to report more stress in the area of social disruption, emotional strain, and financial strain when the child's condition is associated with unpredictable symptoms which is the case with diabetes.

Kim, et al (2016: 11) concluded in their study that, "a significant number of caregivers suffer from stress due to the diagnosis of patients with diabetes. The period after diagnosis appears to be the most stressful; many caregivers have psychological problems after the diagnosis, approximately one-third of caregivers showed significant levels of depression in the first few months. Usually, this was resolved by one year". Kim, et al (2016: 55) state that, "parents' long-term experiences of having a patient with diabetes. They concluded that after seven years, caregivers had adapted to the needs of diabetes management, but most had not come to terms with the diagnosis completely. Although they didn't feel sad most of the time, they experienced a resurgence of grief, anger and guilt during critical times, such as hospitalization, adolescence, injections and transitions. Family interactions also have a significant impact on how much tension is experienced concerning diabetes". Santos, et al (2018) indicate that, "families with high levels of conflict, diffusion of responsibility and regimen-related conflict had less success with glycemic control of the patients". The psychological burden of managing diabetes was often compounded with fear.

The life and death nature of fear associated with diabetes and insulin played a significant role here. Fear of hypoglycemia was especially prevalent in caregivers (Kim, et al., 2016).

With other chronic conditions, family and caregivers are known to succumb to mental health problems. For example, Santos, et al (2018) in their study concluded that, “caregivers for disabled older adults experienced emotional problems, depression, and anxiety”. In other studies, by Santos, et al (2018: 67), “cancer caregivers experienced depression two years after assuming caregiving role”. Kim, et al (2017) suggest that, “distress among caregivers is caused by lack of resources, communication difficulties, family conflict and difficulties in decision making regarding the sick older patients”.

Heckel, et al (2019: 43) conducted a descriptive study in an outpatient clinic in Nigeria examining the emotional and physical impact of providing care to a loved one with cancer. The results of this study show that “caregivers experience high levels of burden and psychological morbidity. This seems to be indicative of the unmet needs of the patient and caregiver, which primarily were lack of financial support, not having enough time for self, and the stress of caring for a loved one with cancer” (Heckel, et al., 2019).

2.4.3. Socio-economic challenges experienced by caregivers when managing diabetes patients.

2.4.3.1 Lack of resources

Barello, Castiglioni, Bonanomi, and Graffigna (2019: 72) indicate that, “caregivers experience physical and psychological distress due to lack of resources and information they need to care for their loved ones. Informal caregivers play an essential role in helping patients manage their pain, but often lack the necessary tools to do an effective job”.

Schulz, et al (2016: 121) indicate that, “caregivers who get support are less upset by a person's memory problems. It can also relieve depression and depression severity. In other words, when caregivers are happy with their social support, they feel less stressed. Lack of resources ultimately affects caregivers' health; whereas constant losses in resources may lead to stress and depression”.

2.4.3.2 Financial constraints

Caregivers of elderly people with diabetes mellitus suffer significant financial consequences with respect to both direct out-of-pocket costs and long-term economic and retirement security.

Spouses who are caregivers are especially at risk. Schulz and Eden (2016: 88) indicate that, “the economic effects of caregiving can be examined at individual, family, and societal levels, including reductions in available financial resources of the caregiver as a consequence of out of pocket expenses. Feelings of financial strain are a frequently used global measure of the economic costs of caregiving. The economic impact of intensive caregiving is likely related to the many hours of care and supervision that this population requires and the costs of hiring help”. Schulz and Eden (2016: 89) articulate that “caregivers are facing financial constraints because most family caregivers are unpaid, they can start to feel some financial strain, especially when caregiving takes them away from a paying job. The longer the family caregiver has been providing care, the more financial strain they feel”.

2.4.3.3 Time Management

Farhadi, Noroozian, Mohammadi, Foroughan, Rassouli, Sadeghmoghadam, and Nazari (2018: 53) state that “caregivers often find they have less time for themselves and other family members. They often spend so much time on caregiving duties that they end up sacrificing the things they enjoy, like hobbies or vacations, either they have trouble balancing work schedules around caregiving”.

The caregiving role impacts on their time in an economic sense. Caregiving is a role which consumes time depending on the disease, for example, Schulz and Eden (2016) found that, “caregivers who helped with dressing, bathing, and eating provided nearly three times the number of caregiving hours than caregivers who provided only household help. They were also more likely than household helpers to provide at least 1,000 hours of help annually”.

Evidence form longitudinal surveys indicate that there is a link between caring for elderly people and financial risk over time. To confirm this, Schulz and Eden (2016) linked caregiving and lower income later in life. In another similar study, Heckel, et al (2019) found that, “caregiving was associated with both reduced labour force participation and reduced net worth of family caregivers when compared with non-caregivers”. In short, these are significant links to caregiving and economics.

2.4 COPING STRATEGIES

Baqutayan (2015: 66) defines coping strategies as “the methods or mechanisms people use to deal with minor or major stress, trauma, pain and natural changes that they experience in life. Some of these strategies are unconscious, others are skills consciously mastered in order to reduce stress, while yet others learned behavioural patterns used to cope with the situation". Baqutayan (2015: 67) also defines coping strategies as "ongoing cognitive and behavioural efforts to manage specific external or internal demands that are appraised as taxing or exceeding the resources of the individual".

Baqutayan (2015: 68) adds that coping strategies are, "a process that addresses how the individual responds and acts both when experiencing stress and when the level of exposure to stress increases. According to their theory, coping strategies can be classier as emotion-focused vs. problem-focused. Emotion-focused coping involves effortful strategies that a person utilizes to minimize the negative emotional outcomes of stress. Problem-focused coping is aimed at resolving the stressful situation directly using problem-solving or removing the source of stress". Caregivers of elderly people living with Diabetes Mellitus are faced with numerous challenges when caring for Diabetes Mellitus patients. Baig, et al (2017) argue that the following can be strategies that can be adopted by caregivers to cope with the challenges of caregiving.

2.4.1 Prayers

The first thing that Caregivers mentioned when asked how they cope with the challenge they experience when taking care of elderly people living with diabetes mellitus is that they prayed and talk to God through the prayers. They read the Bible and they go to church (Baig, et al., 2017). They use prayer to seek divine intervention. They go to church for spiritual support as a strategy to ease their minds when experiencing challenges when caring for elderly people living with diabetes Mellitus.

2.4.2 Family, relative, friends and neighbour support

Schulz, et al (2016: 78) argue that "caregivers without family support can feel isolated and alone in the caregiving process. It could have resulted in higher levels of stress and family conflicts. Families who care for elderly people living with diabetes mellitus have to deal with a high level of burden and distress therefore caregivers with family support cope better than those without family support. Those with support from friends and relative experience less stress". They play a huge role in assisting caregiver to deal with the challenges they experience during the process of caregiving (Schulz, et al., 2016: 70).

2.4.3 Take Time Out

The first thing a caregiver needs to do is to stop and take stock of the situation. Sit down, lie in the tub, go out in the yard, take a walk, do whatever feels the most comfortable, and take a good hard look at what is happening. The reality is that a caregiver is not a superhuman. A caregiver is a loving, caring human being with many strengths, as well as limitations. According to Hinck and Scheffels (2015: 55), "there should be time for caregivers to take a time out because to continue pushing is dangerous, not just for caregivers, but for everyone around them". Furthermore, Hinck and Scheffels (2015: 56), indicate that, "there should be time for caregivers to step back when caregivers feel the beginnings of desperation, they should find a way to get some time to themselves".

2.4.4 Quality Time

According to Hinck and Scheffels (2015: 56), "quality time is an informal reference to time spent with close family, partners or friends that is in some way important, special, productive or profitable to one or everyone involved. It is time that is set aside for paying full and undivided attention to the person or matter at hand".

Hinck and Scheffels (2015: 57) further indicate that, "It is important to remember that caregivers are not in their situations alone. Others are involved. Beyond this, they have a life of their own and relationships with others. The important thing is the quality of time they spend with others. Ten minutes laughing with their spouses or children is far more therapeutic than an hour of arguing. More than this, just as they need time to rest and recover, they need time with others.

Sometimes the best "time out" is time spent with other members of the family. This gives them, and others, a sense of unity. Withdrawal, on the other hand, can increase caregivers' feelings of isolation and increase the risk of depression".

2.5 SUMMARY OF THE CHAPTER

In this chapter, the most relevant literature was reviewed in order to provide in-depth information to the topic titled "Challenges experienced by Caregivers of elderly people living with diabetes mellitus in a selected village of the Vhembe district". The literature revealed that caregivers of elderly people living with diabetes mellitus are facing so many challenges such as financial burden, social isolation, stress, lack of resources and support. It was also revealed by the literature that employed caregivers had to make some workplace accommodations, such as coming in late to work or leaving early, taking time off to manage care situations, reducing work hours or level of responsibility, and/or taking a leave of absence. Caregivers find that the increasing demands of care may lead to missed time from work, decreased productivity, and job resignation.

CHAPTER THREE: RESEARCH METHODS

3.1 INTRODUCTION

This chapter covers the following aspects: research design, outline the target population as well as the setting in which the study had been conducted; sampling method and sampling procedures that were used. Furthermore, this section also focuses on the instrument and method that the researcher used to collect data, as well as the measures that were taken to ensure the trustworthiness of the data collection instrument. It also covers the plan for data analysis and how ethical issues were observed to ensure the safety of the participants

3.2 RESEARCH APPROACH

This study used a qualitative research approach defined by Creswell & Poth (2017) as, "a systematic subjective approach used to describe experiences and give them meaning. This approach enabled the family caregivers to give an account of their experiences in their own context and to explore how they construct their worlds and the meaning they attribute to their experiences".

3.2 RESEARCH DESIGN

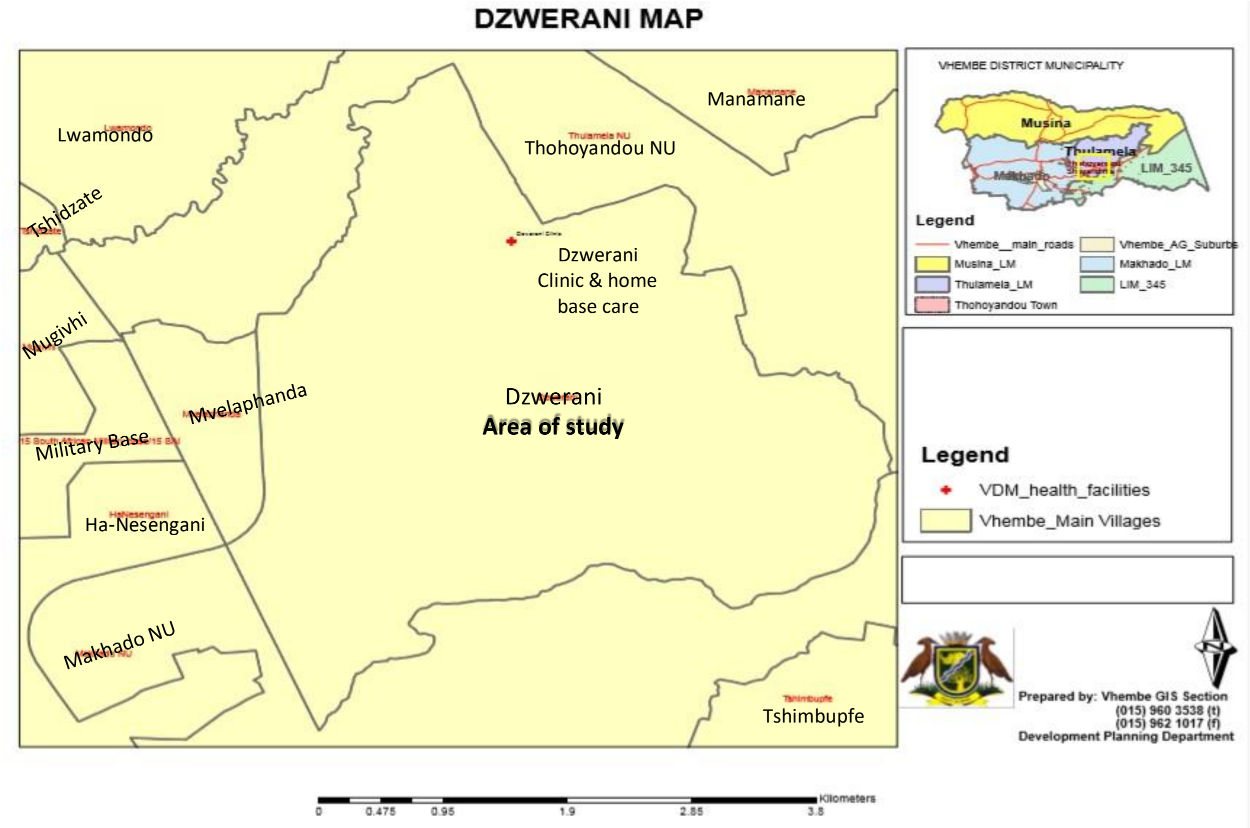
Research design is defined by Miller (2015) as, "a plan for conducting a study that maximizes the control over factors that could interfere with the validity of findings". The study used an exploratory-descriptive design to gain more information on caregivers' experiences. This design enabled the researcher to do an in-depth investigation of the challenges experienced by caregivers at a selected village in a natural setting. This explorative design also allowed the caregivers to express their feelings, emotions and experiences.

3.3. STUDY SETTING

The study was conducted at a village in the Thulamela municipality, in the Vhembe district, Limpopo province. The village is a deep rural area situated outside Thohoyandou, 32 kilometres away from the Thohoyandou Shopping complex, Limpopo province, South Africa. Most people in the area are illiterate and unemployed with a few having matric and post-matric qualifications. The main economic sector is agriculture and most people rely on farming. This village is under the leadership of a chief, with eight (8) sub-villages and each with its headman. There are 14000 households in this Vhembe district village.

There is a clinic and home-based care centre at the area and a nearby regional hospital. Its geographical coordinates are 23. 06 55 degrees South and 30. 42 14 East. The area has a total population of 20964. The majority of households in this village depend on the Child Support Grant, Old Age Grant, as well as the Disability Grant. Most households are women-headed. The dominant local language is Tshivenda. Many elderly people in this village are suffering from diabetes mellitus and are being taken care of by their families. There is a clinic where elderly diabetes mellitus patients receive medication. Currently, there are no recreational facilities for elderly people. There are only six sports grounds currently utilized by youth for football.

Figure 1: A selected village in the Vhembe district village (source: Vhembe GIS section)



3.4. POPULATION, SAMPLE AND SAMPLING METHOD

3.4.1 Study Population

According to Burns, Grove and Gray (2015), a study population is a group of individuals taken from a general population who share common characteristics such as age, gender and occupation, who may be studied for different reasons such as their response to a certain disease.

For this study, the population included all caregivers caring for people living with diabetes mellitus in the selected village.

3.4.2. Sampling Method

Sampling refers to the process used to select a portion of the population for the study (Bekele, 2017). Creswell and Poth (2017) non-probability sampling refers to the type of sampling that is used in qualitative research, where there is no generalization of information because it focuses on getting in-depth information. Therefore, this study employed a non-probability sampling method, which is also known as judgment sampling. This sampling method was adopted in order to select respondents based on their availability, ability to communicate, knowledge and understanding of the Diabetic Mellitus, and their willingness to participate and share their lived experiences within the context of caregiving for elderly people living with Diabetic Mellitus. The reason for selecting this sampling method was to ensure that the empirical evidence retrieved is detailed and objective.

Thus, purposive sampling is the appropriate method available if there are limited numbers of primary data sources who can contribute to the study (Bekele, 2017). In this case, elderly people living with Diabetic Mellitus were limited hence the purposive sampling method was the most appropriate method since the list of people living with Diabetes Mellitus were attained from the local clinic and homebased care centers. The researcher purposively selected caregivers caring for elderly people living with diabetes mellitus. In this study, the number of the participants was determined by data saturation which was reached on participant number 12 where the participants were no longer giving new information. However, the researcher continued to collect data and stopped at participant number 17.

Inclusion Criteria

In this study, for a participant, to be included in the sample, he or she was supposed to meet the following criteria:

- Providing care and support to people living with type 1 and type 2 diabetes mellitus.
- Residing at the selected village.
- Willing to participate in the study and have signed the consent form.
- Aged between 20 and 60 years.

3.5. DATA COLLECTION METHOD

The researcher collected data from the participants through an individual semi-structured face to face interviews with the aid of an interview guide. The interview guide was designed based on the specific objectives of the study. According to Creswell and Creswell (2017), “this type of interview guide gave the researcher opportunities to probe the lived experiences of the participants”. The interviews were conducted in Tshivenda and then translated to English.

3.6. PRE-TEST

This is a qualitative study and the researcher is an instrument for data collection, and therefore, the interviewing skills were tested and improved during data collection. The researcher conducted a pre-test with five caregivers from the population. The pretest assisted the researcher to check if the study questions helped to get the needed information. The pretest also assisted the researcher to rephrase some questions on the interview guide. The five participants selected for pretest also formed part of the main study as they have given reliable information

3.7. DATA COLLECTION PROCEDURE

After getting ethical clearance and permission to conduct the study from the Traditional leader, the researcher proceeded to make an appointment with the participants for data collection. The researcher made appointments with the participants and availed herself on the agreed time, date and venue convenient for the participants. The researcher used face to face semi-structured interviews to collect data in a private place and at times convenient to the participants. All the interview sessions were conducted in Tshivenda as it was the language preferred by the participants. The researcher developed a rapport with the participants beforehand, to make them comfortable.

The researcher asked probing questions in response to the information provided by the respondents. Asking furthermore information from the respondents is a way for the interviewer to get more information that may not have been given. Pseudo names were used to maintain confidentiality (Alston & Bowels, 2003). The participants were told of the main reason for the use of pseudo names. All the participants were asked open-ended questions. The interviews were conducted for approximately 45-60 minutes. The demographic information of the participants was also collected.

The researcher used various techniques such as taking field notes, observation and a voice recorder for data collection. The researcher used field notes and observation to record the nonverbal cues displayed by the participants during the interview. The voice recorder was tested to check if it is working properly before it is used for data collection and the participants were shown a stopping button so that they can stop the recording whenever they are no longer comfortable with it.

3.8. DATA ANALYSIS METHOD

The researcher used a thematic analytical approach to analyze the data. Creswell and Poth (2017) assert that the advantage of the thematic analytical approach is its flexibility which is well suited to large data sets, which allows researchers to expand a range of study participants' past individual experiences and interpretation of themes supported by data. Therefore, the researcher utilized a thematic analytical approach, since it applied to questions related to caregivers' experiences when caring for elderly people with diabetes mellitus.

3.8.1 Becoming familiar with the data

The researcher familiarized herself with the depth and breadth of the content. She listened to the voice recorder and read through the entire data set at least once before coding, as the ideas, as well as the identification of possible patterns, was shaped in the process of reading through.

3.8.2 Transcription of verbal data

Transcription of verbal data informs the early stages of analysis, and the researcher developed a far more thorough understanding of the data through having transcribed it. The researcher transcribed the verbatim of the audiotape exactly it has been spoken by the participants during the interview.

3.8.3 Generating initial codes

The researcher coded and merged data and made a list of codes that were found. The researcher sorted the codes into themes and merged the relevant codes within the found themes.

3.8.4 Reviewing themes

The researcher devised themes and refined them. Some themes collapsed into each other during this phase.

3.8.5 Defining and naming themes

The researcher had a satisfactory thematic map of her data. At this point, the researcher defined and further refined the themes that were analyzed. The researcher identified the essence of what each theme is about and also determined the aspect of the data each theme captures.

3.8.6 Producing the report

The analysis must provide a concise, coherent, logical, non-repetitive, and interesting account of the story the data tell within and across themes. The write-up will provide sufficient evidence of the themes within the data.

3.8.7 Measures to ensure Trustworthiness

Trustworthiness is a method of establishing consistency in qualitative research without sacrificing relevance. According to Polit and Beck (2016), research findings must be evaluated concerning the procedures used to generate the findings to ensure trustworthiness. To ensure trustworthiness, the researcher used trustworthiness concepts that include credibility, dependability, transferability and conformability to describe various aspects of trustworthiness.

3.8.8 Credibility

“Credibility refers to confidence in the trust of the data and interpretation thereof” (Polit & Beck, 2016: 45). To ensure credibility, the researcher prolonged her engagement with the participants through building trust and rapport in their language and had actively participated in the collection of data. The researcher ensured that each interview took approximately 45-60 minutes. The researcher ensured credibility through triangulation wherein she made use of multiple methods of data collection such as interview guides, voice recorder, fields note and observation during the data collection process. The researcher also ensured credibility through member checking by confirming information with participants as a way of confirming the information that the participants shared during data collection.

3.8.9 Dependability

Dependability involves the provision of evidence in a way that if the study is to be done again with the same or similar participants in an analogous context, the findings would be similar (Brink, Van der Walt & Rensburg, 2016). In this study, the researcher ensured dependability by applying peer examination. The researcher requested an independent coder to examine the findings, interpretations, and recommendations; and attest that it is also supported by data. Member checking was conducted by doing a follow-up interview to confirm the responses given by the participants during data collection

3.8.10 Conformability

Conformability is when there is freedom from bias in the research procedures and results. The researcher ensured conformability by guarding herself against imposing his ideas on the participants in order to relevance meaning. The researcher also used flexibility by making use of field notes to identify the characteristics and elements relevant to the study. The researcher analyzed raw data and conclusion were formulated to ensure conformability.

3.8.11 Transferability

Brink, et al (2016) posit that "the description of data gathering must be inclusive enough to enable findings to be transferred to other situations". The descriptive interpretation resulting from the data analysis should apply to other areas. The researcher also provided a complete description of the research methods, findings and verbatim quotes from individual interviews to ensure applicability of the study to other contexts. The researcher requested the independent coder to randomly read through selected transcripts and identify major categories, so that readers may have a clear picture of the findings.

3.9. ETHICAL CONSIDERATIONS

Ethical considerations are the main principles to be observed in the study. According to Brink, et al (2016), "these principles are based on the human rights that need to be protected in research. The following aspects were applied to ensure adherence to ethical considerations.

3.9.1 Permission to conduct the study

For quality checking and approval, the researcher presented the proposal to the School of Health Sciences Higher Degrees Committee and thereafter submitted it to the University of Venda Higher Degrees Committee. After obtaining permission from the University of Venda Higher Degrees Committee, the researcher applied for ethical clearance (Appendix A) from the University of Venda Research Ethics Committee. After obtaining ethical clearance from the Ethics Committee, the researcher requested permission in writing to conduct the study from the traditional leader of the selected village, which was granted (Appendix B).

3.9.2 Informed consent

The researcher used an information sheet (Appendix E) to inform the participants about the nature of the study, the importance of the study and what is expected from them as the participants. The researcher also informed the participants about their rights to form part of the study as well as withdraw when they feel like they want to. The participants provided written informed consent (Appendix E) as an indicator that they agreed to form part of the study. The participants were also informed about the use of a voice recorder and were shown the stop button so that they can stop the recording if ever they feel uncomfortable with the questions.

3.9.4 Voluntary participation

The researcher explained the nature and importance of the study to the participants and informed them about their rights to or not to form part of the study, so that they could decide whether to participate or not, without forcing them. The participants were also informed that they could withdraw from the study at any time if they felt they were no longer comfortable with carrying on.

3.9.5 Confidentiality and privacy

Confidentiality means the ethical protection for those who are studied, it means holding research data in confidence or keeping them secret from the public (Kirilova & Karcher, 2017). To ensure confidentiality, the researcher ensured that whatever information she collected from the participants “will be kept confidential and only the researcher and the supervisors had access to the data. The voice recorder cassette was also placed in a safe place where no one can access it. The researcher also ensured privacy by asking for a separate space to be used during the interview process.

3.9.6 Anonymity

According to Brink, et al (2012), anonymity is the ethical principle of not providing the identifying details of the participants on any researcher conducted field notes without the use of personal identification information of the participants. The researcher ensured anonymity as an ethical principle for the study by making use of false names instead of the names of the participants so that the information remained anonymous. The findings were not displayed in public or in a way that can link specific individuals to it.

3.10. DISSEMINATION OF RESULTS

The final copy of the study will be submitted to the University of Venda library so that other researchers can use it for reference. A copy of the study will be submitted to the caregivers at the selected village in the Vhembe district village, and to the Department of Health.

3.11 SUMMARY

This chapter presented the research methods. It covered different key areas, including the research design, study setting, study population and the sampling method that was used in a selection of the participants. The data collection and data collection procedure were also discussed in this chapter. The method used to analyze data, measures to ensure trustworthiness and the ethical considerations are also covered in this chapter.

CHAPTER FOUR: PRESENTATION AND DISCUSSION OF FINDINGS

4.1 INTRODUCTION

This chapter of data analysis presents interprets, discusses and analyzes the research findings. This chapter focuses on the presentation of findings and analysis of the data. The data is presented and analyzed systematically using the thematic system of data analysis. In this respect, the data is presented in the form of major themes that emerged from the interviews in order to reflect the participant's views on the challenges they experience when taking care of elderly people living with diabetes mellitus in a selected village of the Vhembe district. It starts by presenting the participants' biographical data. This will be followed by the presentation and discussion of the research findings. The presentation of data is guided by the research objectives: to explore the challenges experienced by caregivers of elderly people living with diabetes mellitus, and to investigate the coping strategies of caregivers of elderly people living with diabetes, as described in chapter 3.

4.2 RESEARCH FINDINGS ANALYSIS AND DISCUSSION

The findings will be divided into five sections: biographical data, socio-economic challenges, health-related challenges, challenges related to the health system, and coping strategies.

4.3 DEMOGRAPHIC PROFILE OF THE PARTICIPANTS

The research consists of a sample of seventeen participants *(n=17)* from the Dzwerani village in the Vhembe district. Their ages range between 20 and 60. Table1 shows that the participant's educational levels are between grades 1-9. The majority of participants are married, and the majority of participants are unemployed.

Table 1: Participants Demography

Name	Age	Gender	Marital status	Educational status	Employment status	Relationship with the patient
Participants 1	39	F	Married	Grade 12	Employed	Mother
Participants 2	26	F	Single	Grade 12	Employed	Child
Participants 3	30	F	Married	Grade 12	Unemployed	Daughter in law
Participants 4	38	F	Married	Grade 10	Unemployed	Daughter in law
Participants 5	29	F	Single	Grade 12	Employed	Child
Participants 6	40	F	Single	Grade 7	Unemployed	Child
Participants 7	37	F	Married	Grade 12	Employed	Daughter in law
Participants 8	27	F	Single	Grade 10	Unemployed	Child
Participants 9	32	F	Married	Grade 11	Unemployed	Daughter in law
Participants 10	26	F	Married	Grade 12	Employed	Child
Participants 11	31	F	Single	Grade 11	Employed	Daughter in law
Participants 12	32	F	Single	Grade 10	Unemployed	Daughter in law
Participants 13	31	F	Married	Grade 7	Unemployed	Child
Participants 14	51	F	Single	Grade 12	Unemployed	Wife
Participants 15	60	F	Married	Grade 1	Pensioner	Wife
Participants 16	58	F	Married	Grade 10	Unemployed	Wife
Participants 17	30	F	Single	Grade 11	Unemployed	Child

4.4 SUMMARY OF THE STUDY FINDINGS

A detailed presentation of the identified themes and sub-themes that emerged during the analysis are supported by direct quotations of participants with regards to their challenges in taking care of elderly people living with diabetes mellitus has been presented in Table 2.

Table 2: Themes emerged from findings

Themes	**Sub-themes**
4.4.1. Socio-economic challenges	4.4.1.2 Time-Management 4.4.1.3 Financial Problems 4.4.1.4. Lack of resources 4.4.1.5 Inadequate family support.
4.4.2 Health-related challenges	4.4.2.1 Physical Health
4.4.3 Challenges related to the health system	4.4.3.1 Shortage of Medication in the clinic 4.4.3.2 Inadequate Government Support 4.4.3.3 Unavailability of counselling sessions.
4.4.4 Coping strategies	4.4.4.1 Acceptance 4.4.4.2 Prayers 4.4.4.3 Support Visit by Community Home Base care. 4.4.4.4 Support from close friends and relative.

4.4.1 THEME 1: SOCIO-ECONOMIC CHALLENGES

4.4.1.1 Caregiver related problems

The researcher sought to determine if participants have socio-economic challenges with regards to caring for elderly people living with diabetes mellitus. On this point, caregiver related problems are the problems that affect the person who is taking care of their loved ones. A caregiver is either a house helper, child, bother, wife or any close relative who is taking care of the diabetic patient. Their problems can vary according to the situation they are coming across, such as lack of resources, unemployment, financial constraints, time-management, high blood pressure, depression, stroke and stress. In what follows are the findings of the study.

4.4.1.2 Time-Management.

The study revealed that time-management is a serious problem for the caregivers as they have to spend time taking care of their loved ones, rather than taking care of themselves. Generally, participants believe that a diabetic patient needs much time and that consume the caregiver's time. The majority of participants have articulated that they cannot even go to work or church because they need to spend time with their patient. Participants postulated that they are forced to sacrifice their jobs and going to church for their loved ones because they cannot live them alone at home.

> Participant 1 said, "*Time management is also a challenge for me because I have got small kids here; therefore, I find it not easy to take care of my mom and for my three kids. I am pulling very hard to provide for this family (for my kids and for my diabetes mellitus patient, I no longer attend church services properly because there is no one who can take care of her".*
>
> Participant 2 said, *"With self-time yes, I try to balance everything, but I only lack self-time. I used to go to church, but time is no longer allowing me to attend church as I cannot go out and leave her alone because she really needs attention. My shopping also is very hard as I only use weekends because there will be at least someone watching over her at home and even if I manage to go for shopping, I don't spend much time at there as she needs me''*.

In addition, a minority of participants voiced a concern that ever since they started their caregiving role, their time for personal matters is being affected, especially in an economic sense. Caregiving is a role which consumes time depending on the disease, for example, Schulz et al., (2016) found that, “caregivers who helped with dressing, bathing, and eating provided nearly three times the number of caregiving hours than caregivers who provided only household help. They were also more likely than household helpers to provide at least 1,000 hours of help annually”. Evidence from longitudinal surveys indicates that there is a link between caring for an old adult and financial risk. In regards to time management, scholars such as Mthembu (2016), and Schulz and Eden (2016) reiterate that, “the participants revealed that they had to reduce the time they work some had to opt for part-time work. In line with the above statement, the majority of the women in this study had to retire early, missed work, lost their jobs and turn down promotion”. Fast, (2015) suggests, “the majority of employed caregivers had to make some workplace accommodations such as coming in late to work or leaving early, taking time off to manage care situations, reducing work hours or level of responsibility, and/or taking a leave of absence”. Furthermore, de Moor, Dowling, Ekwueme, Guy, Rodriguez, Virgo, Han, Kent, Li, Litzelman, and McNeel, (2017), state, “caregivers find that the increasing demands of care may lead to missed time from work, decreased productivity, and job resignation”.

4.4.1.3 Financial Problems

In addition to the above question, the researcher sought to determine the caregiver’s financial challenges. The majority of participants described how concerned they were about their household financial status. The data revealed that the caregivers of elderly people living with diabetes mellitus are not receiving anything when caring for their diabetes mellitus patients. Financial problem is one of the major challenges they are experiencing. According to the participants, it is impossible to take care of diabetes mellitus patients when you do not have enough money. The majority of participants demonstrate they do not have enough money to buy green leafy vegetables and fruits because they are expensive, and the Old Age grant is not enough to cater for all the needs of elderly people living with diabetes mellitus.

4.4.1.3.1 Lack of caregiver stipends

The researcher wanted to know whether the participants have any kind of funds for caring for their patients. In this regard, a caregiver stipend is a little money received by those who are taking care of the elderly people living with Diabetes Mellitus; it is not really a payment or salary but something that can motivate them to care for their loved one so that they can be able to take care of themselves. The majority of participants have articulated the importance of receiving such a stipend, as they can also be able to assist with some of the things their loved ones need.

> Participant 5 said, "*My mom is not receiving Grant and it's a challenge because she will say she wants fruits vegetables and I have to buy, where I am going to get the money because I am not working".*

> Participant 14 added, "*I also do not have a permanent job and is also a challenge because we do not afford to her healthy food every time and you find that there is no money at home she will have to make loans from neighbours so that we can buy food and repay back the money when I get paid and is not a lot".*

In addition, the findings of this study revealed that caregivers of elderly people with diabetes mellitus, experienced financial burdens because of transport costs needed to comply with followup dates and insufficient of money for food, clothing the child in need of care, pocket money for lunch boxes during school hours and time lost while waiting for consultations. Therefore, these difficulties included providing food, attending to hygiene needs, the lack of equipment, financial constraints as well as physical and psychological exhaustion.

4.4.1.3.2. Shortage of healthy food

Participants responded emotionally regarding the shortage of healthy food. To this point, healthy food to the people living with diabetes mellitus is very important as they do not eat anything except fruits, vegetables, meat with no fats and also milk so it is very important for those people to get those foods and if they don't get them is going to be challenging to the caregivers as they need to be provided.

> Participant 7 said, *"We also need food parcels from the government because we don't have enough money to buy a well-balanced diet for our elderly people living with diabetes mellitus".*

> Participant J said, *"Sometimes my mom prefers to eat different types of soft porridge, fruits and vegetables and I do not have enough money to buy all those things since we are not working".*

> Participant 12 said, *"My husband does not eat each and every food and he is very much selective. If I give him the food that we are eating here at home, without fruits and*

> *vegetables, he will experience burnout throughout the whole night, and we will also not go to sleep".*

> Participant 17 said: *"Yes My challenge is that my mother-in-law doesn't work and I don't work too, so she has to eat healthy food and you find that we have to buy those foods how it will be possible? So is challenging".*

Furthermore, Schulz and Eden, (2016) state, "caregivers of persons with type 2 diabetes often helped care recipients with meal planning, physical activity, medication, and blood glucose monitoring". Schulz and Eden, (2016) found that "almost half of the caregivers in their study had not been formally educated on dietary requirements". Two studies Schulz and Eden, (2016) and Heckel, et al., (2019) found that "Caregivers struggled with managing care recipients' blood glucose levels". For example, Heckel, et al., (2019) noted that, "American Indian caregivers had difficulty helping elders stabilize their blood glucose. One such caregiver expressed concerns about the care recipient's blood glucose fluctuating between extremely low levels and extremely high levels. This fluctuation in blood glucose levels is known to be very concerning to caregivers of persons with diabetes in general. Other demands that made caregiving difficult for the American Indian population, especially on reservations, were substandard living conditions such as the lack of central heating, washers or dryers, or even indoor plumbing" (Heckel, et al., 2019). In addition, there is a lack of knowledge about counting carbohydrates, recognizing healthy foods, and knowing what foods to limit. Baqutayan, (2015) studied the Latino population and found that caregivers were struggling with integrating the ADA recommendations into the typical Latino diet. In addition, Baig, et al., (2017) found that 39% of caregivers in their study wanted more information on local services.

4.4.1.3.3 High unemployment rate.

Research findings show that most of the caregivers are unemployed and have no source of income from anywhere. It comes as a problem for the caregivers to afford some of the things required by their loved once. They showed how concerned about been unemployed and caring for their loved once.

> Participant 4 said, *" Very hard, look now I have 3 children's and also my mother-in-law, I don't work she has no grant so if I was working and I was going to hire a person of her age who will help me and also taking care of my children".*

> Participant 10 said, "*I am not working, and she is also not working so where are we going to get healthy food, it's a big challenge my sister, she used to borrow money and make loans from the neighbours so that we can at least buy food".*

> Participant 17 said, *"Yes My challenge is that my mother in law doesn't work and I don't work too, so she has to eat healthy food and you find that we have to buy those foods how it will be possible? So is challenging".*

4.2.1.3.4. Insufficient Old Age grant.

Some participants reiterated mentioned the insufficient Old Age grant. Patients should get grants that can sustain them, as they are unable to do anything or work to buy fruit, food, medication, diapers. They said that if the patient gets a grant, they can use that money to take care of them. But only those who are old.

> Participant 15 said, *"My challenge is if she goes to the clinic and did not get treatments, we will have to buy the pills and she does not work or even a grant she will have to get the grant after 2 years from now and to think of it is very far from now. How will I get her medications is very bad hope government should do something. Sometimes will be transferred to Tshilidzini hospital and you find that we don't have transport we have to postpone the date and went on the other dates so is very hard for me".*

> Participant 9 said*, "My husband is receiving Old Age Grant, but I do not own the money because his brothers 'wife is the one who is taking the money and she is the one who is buying groceries here at home and the grant is not enough to buy all the needs. I do not own my husband's money, but I am the one who is taking care of him".*

> Respondent 10said, "My *mom is not receiving Grant and it's a challenge because she will say she wants fruits vegetables and I have to buy, where I am going to get the money because I am not working".*

4.4.1.4. Lack of resources

In this section, the researcher sought to determine whether participants have challenges regarding resources of taking care of patients with diabetes Mellitus. The majority of participants assert that there is a serious lack of resources in the clinics such as medications, transport and wheelchairs some of the patients who have diabetes Mellitus need wheelchairs. In this regard, this problem can affect a person in such an extent that he or she will not be able to walk or even see medical practitioners. Based on the participants' responses regarding lack of resources, they have to go and find something for them to eat, one of the respondents indicated that:

> *"My mother cannot see so on her way to the toilet we made a wire that she can use to hold on until she gets to the toilet then I will be coming home after work, so you see is very risky to have such patient and no one to help you taking care of them".*

According to Kim, et al., (2016), caregiving has been linked also to negative economic consequences. Economic challenges range from money employ related benefits, out of pocket expenditure and labour-related costs.

4.4.1.4.1 Lack of Transport

In addition, participants mentioned that within their community, getting transport is very difficult; you can wait for a taxi for about two hours. They further indicated that they are forced to hitchhike any car that passes by and if they are lucky, it has to be after an hour. Importantly, participants imply that the Department of Transport should consider that their roads need to be fixed so that will be able to have transport at any time like other villages.

> Participant 5 said, "*Yes! Sometimes we used to hire a car from those with cars and is very expensive at night, is like these diabetic attacks her mostly at night. "When it comes to food is not any food that she eats and their food are very much expensive, looking at our budget in the house, I don't work and my grandmother is the only one getting grant here at home, she has to buy food and also have money for transport to the hospital in case she will need to hire a car".*

> Participant 9 said, *"Remember we don't have reliable transport what if it happens at night that she has to go to the hospital and there is no Taxi? We will need someone with a car and give him/her money for petrol".*

4.4.1.4.2 Lack of Wheelchairs and crutches (Mobility)

In addition to the above challenge, the researcher sought to find out whether participants have access to wheelchairs and crutches. The majority of participants postulated that wheelchairs and crutches are very important in this case. Diabetes mellitus affects mostly the legs and eyes. Moreover, participants reiterated that patients have to be mobile and if they do not have wheelchairs, it is going to be hard for them. Participants suggested that the Hospital or clinic grant patients a wheelchair or even crutches.

> Participant 13 said, *"The other thing is freedom of movement, I wish she can get the wheelchair that can help her to move in the house because her legs sometimes can lock, and she will be unable to move to the kitchen and also toilet but if she has a wheelchair I think it can help a lot".*

Much of the literature points out that caregivers of persons endure psychosocial challenges associated with diabetes caregiving. For instance, according to a study conducted by Kim, et al., (2016), "the challenges which caregiver's faces involved instrumental care needs and concerns, physical care concerns and emotional care concerns. The Instrumental concerns of caregivers included those related to finances, transportation from one place to another, mobility and respite care. In relation to physical care needs and concerns caregivers expressed many concerns about providing physical care for care recipients, such as ensuring an adequate diet, helping them adhere to the plan of care, managing medication, monitoring blood glucose, and encouraging exercise". Furthermore, Kim, et al., (2016) indicates that, "the caregivers also described difficulties experienced when providing emotional support". Other studies that have looked at the needs and concerns of caregivers have had similar findings; however, caregivers of stroke survivors and home hemodialysis caregivers documented greater needs for instrumental care such as respite care (Kim, et al., 2016; Santos, et al., 2019). It is possible that caregivers of stroke survivors and those on home hemodialysis may require more physical care than caregivers of persons with type 2 diabetes.

4.4.1.5 Inadequate family support.

Importantly, the researcher also sought to determine from participants whether they receive adequate family support in taking care of elderly people living with diabetic mellitus. The majority of participants seem to have support from other relatives and friends. However, a minority of participants are struggling alone with the patients. In addition, participants reiterate that they receive warmly welcomed visits from Home Based care people, without family support their patients are easily prone to depression by their situations. Participants shared their experience while taking care of their patients in what follows:

> Participant 8 said, *"Once in a month my sister and other relatives can come to check how we are coping but from there you won't see anyone it depress a lot especially when you*

> *are married to the family and you have to take care of the elderly person with the diabetic problem and their families are not even visiting you will be affected by a lot of things".*
>
> Participant 13 said*, "Yes! Sometimes her sister comes and visits her, and she comforts us and also the pastor visits sometimes. When our pastor visit will be praying that feels better, we live by praying".*
>
> Participant 5 said*, "Yes! My older sister visits us when she is not working and also her friend visit us and sometimes people from home base care".*
>
> Participants 11 said*, "I do have support from my relatives they do give me the courage to continue taking care of my mom".*

According to Mthembu, et al., (2016), "families and friends who give care to elderly people living with diabetes mellitus are affected in a variety of ways and degrees. The interplay of caregiving consequences are poverty, discrimination isolation and stigma". "Literature entails that lack of family, government support, counselling, diminished social relationships, depression, emotional trauma and poor or interrupted sleep are also associated with caregivers' challenges. Participants experience challenges in balancing their occupational demands associated with their caregiving position, own family, and profession" (Mthembu, et al., 2016). Schulz and Eden (2016) show that, "the effect of presenting care for family caregivers in terms of their physical health, psychological well-being, social life, financial situation and quality of life which appeared to form part of their burden". These studies found that "the family caregivers' social life such as going on holiday, engaging in social activities, maintaining telephone contacts, visiting friends and attending recreational and social clubs were negatively influenced by providing care to elderly people with chronic diseases" (Mthembu, et al., 2016; Schulz & Eden, 2016).

4.4.2 THEME 2: HEALTH-RELATED CHALLENGES

4.4.2.1 Physical health

4.4.2.1.1 High blood pressure, depression, Stroke and stress

The study findings revealed that caregiving diabetic patients are affecting caregivers negatively because it leads them to have high blood pressure, depression, stroke and stress. It was revealed by the study findings that caregivers can spend sleepless nights due to their caregiving roles and responsibilities. Participant 11 indicated that they might not know what to do when a person wakes up during the night complaining about the pains in their legs,

> "*You have to wake up and give them medication, sometimes they need cold water from the fridge to put their legs inside and you end up not knowing what to do".*

Participants also indicated that diabetes mellitus patients are very dangerous to the caregivers and sometimes they are moody, and all these stresses depress them, sometimes leading to them having strokes themselves. Generally, it leads to physical, psychological as well as psychosocial stress.

> Participant 3 said**,** "*People say I am mentally disturbed, and I am not, it is just that I have got a lot of things to attend to. I am also suffering from Blood pressure due to the burden that I am having here at home and I have got no one to help me at least today we have got a visitor or a person that we can at least share our experiences with. I was thinking Uri maybe I am the only one who is having this problem, you must come back again. Today I feel so much relieved, I am no longer that much stressed".*

> Participant 8 said, "*Look at my eyes they were not like this, its stroke due to the problems that I am experiencing as a caregiver here at home, I am also having blood pressure as well. Sometimes her legs get swollen and it's my responsibility to see that she goes to the restroom, its tiring and stressing".*

> Participant 14 said: "*Sometimes she doesn't eat food with fats and she will be craving for vegetables and it is difficult for us to buy them so she will ask for uncooked onion for her to eat her medications as substitutes for vegetables and that also affect me as I will be thinking if I am failing her to be a good daughter in law or what is it that I can do and I am very broke, my B.P is always high and I will just look at her and when I get to bed I will cry alone."*

According to a review by World Federation of Mental Health (2017), caregivers suffer from poor health and have more chronic illnesses such as high blood pressure, heart disease, stroke, diabetes, and arthritis than non-care giving peers. They may also suffer from poorer immune function and exhaustion. They may neglect their care and have higher mortality rates than noncaregivers of the same age (World Federation of Mental Health, 2016). According to Fast, et al.

Lero, Duncan, Dunlop, Eales, Keating and Yoshino, (2017), "the effects of caregiving are both wide-ranging and highly individualized. Caregivers are potentially at increased risk for adverse effects on their wellbeing. In general caregiving for elderly chronic patients is associated with several challenges such as negative impacts on their physical health and well-being, increased depression, increased stress as well as social isolation".

Furthermore, Schulz, et al., (2016) concluded that "a significant number of caregivers suffer from stress due to the diagnosis of patients with diabetes. The period after diagnosis appears to be the most stressful; many caregivers have psychological problems after the diagnosis, approximately one-third of caregivers showed significant levels of depression in the first few months. Usually, this was resolved by one year". Santos, et al., (2019) explored parents' long-term experiences of having a patient with diabetes, the study concluded that, "after seven years, caregivers had adapted to the needs of diabetes management, but most had not come to terms with the diagnosis completely. Although they did not feel sad most of the time, they experienced a resurgence of grief, anger and guilt during critical times, such as hospitalization, adolescence, injections and transitions".

4.4.3 THEME 3: CHALLENGES RELATED TO THE HEALTH SYSTEM

4.4.3.1 Shortage of Medication in the clinic

This section seeks to explore challenges related to the health system. Here the research sought to determine if participants has the medication from their clinics. All respondents indicated that they do have a problem with the inadequate availability of medication in the clinic. Moreover, another challenge raised by participants was that of relevant resources while caring their diabetic patients such as gloves.

> Participant 2 said, "*My challenge is that if she goes to the clinic and does not get medication, we will have to buy the pills. Seriously the government need to do something. It is very much painful and disappointing. Sometimes we will be transferred to Tshilidzini hospital and it is not easy because we do not have enough funds*".

> Participant 6 said, "*Like now she has to go to the hospital as there are no medications in the clinic, I have to take her there because she cannot go alone, I don't even have time to see friends or to date as young as I am. All I can do is to sit at home waiting for her to request something then I will give her, and it ends there, that is how my life is".*

> Participant 14 added, "*(Mmmh) the last one is that their medications and also gloves to use when you're bathing them should be found in the clinic so that it can be simple for us to access them".*

The findings of the study by Santos, et al., (2019) revealed that, "participants, that are, caregivers of children on ART, experienced financial burdens because of transport costs needed to comply with follow-up dates and insufficient of money for food, clothing the child in need of care, pocket money for lunch boxes during school hours and time lost while waiting for consultations. Furthermore, participants reported some level of stigmatization against children on ART by family members, especially the husbands or in-laws of the secondary caregivers".

4.4.3.2 Inadequate Government Support

The researcher sought to determine whether participants have adequate government support for taking care of patients with diabetic Mellitus. Participants articulated that to resolve their challenges, the government should help them maybe once a month by giving them food parcels or by a little stipend that can help their loved ones with no problem, but now when they wake up they have to think of where to start so that they can help their loved ones, which is not good as some of them are young and they do not work and there are no funds coming in.

> Participant 11 said, *"My challenge is that if she goes to the clinic and does not get medication, we will have to buy the pills and she is not working. She will be getting Old Age Grant in two years from now. Tell me how am I going to get her medication? It is very bad is very bad. The government must do something about this situation. Sometimes we will be transferred to Tshilidzini hospital and you find that we don't have transport we have to postpone the date due to lack of funds and failure of the government to provide medicine".*

> Participant 8 said, *"(Mmm) we do not have gloves to use when bathing them and we were supposed to get this thing from the clinic where we get medications. the government must increase the grant of elderly people living with diabetes mellitus because we are experiencing financial constraints".*

4.4.3.3 Unavailability of counselling sessions.

Research findings show that caregivers need to be given counselling's, those people they see a lot and by looking at things some of the caregivers are still young to face such situations is like carrying a burden over their shoulders. Therefore, participants stated that if they can get counselling it can help them and also training on how to look after the diabetic person. They said they are not receiving any counselling from anyone even the social workers do not visit them just to give them comfort. There are home-based care people, but they said they do not think is enough they need people who are trained to comfort and console the situations such as the one there are facing.

> Participant 3 said, *"I can conclude by saying at least they should give us counselling and teach us how to take care of them".*
>
> Participant 13 said, "*I think we need to have a special counsellor whom we can talk to because today I feel more relieved that am talking to you because I don't have anyone to share my secrets with'.*
>
> Participants 16 said, *"You must also create platforms where diabetes mellitus caregivers can voice out or talk about their challenges because I feel like I am alone in this challenge and I think the Government has nothing to do with Diabetes mellitus patients but rather focus on People living with HIV and AIDS patients".*

4.4.4 THEME 4: COPING STRATEGIES

This section sought to find out possible coping strategies while caring for elderly people living with diabetes Mellitus. Research shows that coping strategies are mostly focusing on how they achieve all of this when living with a person who is diabetic in every day of their lives it is not simple to live a normal life when you have such people and it can easily change your character, so it gives the way they live and face the day to day work also.

4.4.4.1 Acceptance

Acceptance is a simple way of living with people that are diabetic as some of them get angry so simple they can be tempered by anything, they sometimes feel like you're taking advantage on her because they have a diabetic problem. The minority of participants asserts that their patients can sometimes get angry and refuse food and medication.

> Participant 12 said, “*tell you a lot of things and swearing at us but because we accepted, we just keep quiet and then she will be fine and eat afterwards so is very disturbing if you fail to accept*”.

> Participant 4 said, “*Yes she is old and a mother to my husband but now she is my mother I came here to be with her, and I will help her with no regret she is the one who defends me and also advise me…. We have accepted the situation and only God can heal our hearts”.*

> Participant 10 said, *“It is been Years with her, so we have accepted and give her what she need we have to support her”.*

> Participant 12 said, *“I have accepted but is not an easy job, I always pray for the Doctors to find a medication that can heal her. This people with diabetes are suffering they really need proper care”.*

4.4.4.2 Prayers

The majority of participants have alluded that they believe in prayers, as they are Christians.

> Participant 13 said, “*With prayers we pray a lot, it is normal to find people praying in the family but to stabilize the situation and our hearts we pray a lot. Sometimes we even invite our pastor to come and pray with us so that will feel culm by the situation*”.

Some participants demonstrated that their patients are prayer warriors if you can find them praying you might even join because you will love the way they enjoy praying and even if things are getting out of hand they will say let’s pray then you will take me to the clinic or hospital.

> Participant 15 said, *“When our pastor visit will be praying that is when will feel better, we live by praying”.*

> Participant 17 said, *“I have accepted at least my mother can sometimes when she is fine can go to her church”.*

> Participant 3 said*, “Her friend will come and be with her the whole day and sometimes the pastor will come to pray with her”.*

4.4.4.3 Support visits by Community Home Based Care.

The study findings revealed that some of the participants, as well as their patients living with Diabetes Mellitus, feel so relieved when they get support and visit from community home-based care. Participants demonstrate that the support visit from home-based care is very crucial as these people are well motivated and working very hard and they walk from their houses to come and visit their patient, and as trained workers, they can communicate with patients.

> Participant 14 said, "*We will feel very happy when they are going because they were here that means there are still people that care about us*".

> Participant 1 said, "*We spend much of time with them in a week so they are the hope of the community we are in as you see people are suffering".*

> Participant 5 said, "*Home base care people are the people who are working very hard and they make sure we are fine every time they come*".

> Participant 14 said, "*Home-based care is also helping a lot. They do come and visit their patient and sometimes they collect her medication from the clinic. The clinic provides us with medication even if sometimes there is a shortage of medication".*

4.4.4.4 Support from close friends and relatives.

The study findings revealed that some of the participants feel blessed especially when they receive support from close friends and relatives.

> Participant 3said, "*When a friend or a family member visit It is a great feeling, we need them at almost everything may be to talk to or just to see them*".

> Participant 4 said, "*My sister she is the one that can calm my mother down by just visiting her or talking to her through phone and the other participant said during the day my mother in law will be with her friend talking and having fun that reduces my workload for the day and I will be able to do the house chores and cook for her until her friend she is gone they are like sisters and I love their relationship".*

> Participant 9 said, *"Yes! Sometimes her sister and pastor do come and visit us. They give us counselling and console us as well as praying for us in order to cope with the situation".*

> Participant 11 said, “*We do get support from my husband and his brothers are always there for help*”.
>
> Participant 13F said: “*Yes! Her friend will come and be with her for the whole day and sometimes the pastor will come to pray with her”.*
>
> Participant 15 said, “*We do have our pastor; she will come and visit us and also her children too”*.

The findings also show that families who care for elderly people living with diabetes mellitus have to deal with a high level of burden and distress, therefore, caregivers with family support cope better than those without family support. As noted by Kim et al., (2016) caregivers without family support can feel isolated and alone in the caregiving process. In this regard, support from various people can increase hope to the elderly people living with diabetes Mellitus, and decrease depression, stroke as well as stress eventually caused by socio-economic challenges, health challenges, shortage of medication, and inadequate government support

4.5 SUMMARY OF THE CHAPTER

Chapter four analyzed the data collected from caregivers who are taking care of people living with diabetes Mellitus and the results were discussed with literature control. The data revealed that caregivers go through a lot of unfavourable situations which may affect the quality of personal lifestyle. The emergent themes, sub-themes and categories were discussed using literature control. Chapter five will discuss the conclusions, recommendations and limitations of the study.

CHAPTER FIVE: CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS OF THE STUDY

5.1 INTRODUCTION

The previous chapter presented the findings of the study under the themes that emerged during data analysis. The findings were complemented by literature. In the final chapter, the researcher deliberates on the conclusions and limitations of the study and makes recommendations pertaining to the study. The chapter also demonstrates how the objectives of the study were achieved.

5.2 LIMITATIONS OF THE STUDY

The following limitations on the study were faced as follows: the study was conducted in the Vhembe district, only focusing on the challenges experienced by caregivers of elderly people living with diabetes mellitus in a rural village. The researcher used snowball sampling to identify cases of interest from people rich with information. The researcher got hold of one participant who gave information of where others are or how they could be found. When the other participants were found, they explained where more people can be found, and the chain continued.

5.3 CONCLUSIONS DRAWN FROM THE STUDY

- The study concludes that caregivers of elderly people living with diabetes mellitus are facing so many challenges when taking care of the patients. Caregivers were concerned by the lack of resources such as funds which led to a shortage of food and transport.
- In this study, losing jobs due to caregiving responsibilities was another challenge faced by caregivers and this finding is in line with the studies that showed the caregivers who are unemployed having low incomes, suffered more distress because they had fewer resources to meet the caring demands.
- Furthermore, the chronicity of diabetes mellitus contributes to a greater financial burden on caregivers because financial problems induce a lot of stress on caregivers.
- Concurrently, constant caregiving itself seems to be affecting the caregivers themselves, which in turn, directly affect the care they provide to patients.
- The findings of the study revealed that caregivers of elderly people living with diabetes mellitus experienced various challenges, which have a negative impact on their personal life, physical and psychological well-being and all these have a negative impact on leisure and social activities and family relationships.

- This study also revealed that caregivers without support can feel isolated and alone in the caregiving process.
- The study findings also revealed that educational levels have a positive correlation with caregivers coping because the more highly educated caregiver could get better jobs, more support resources as well as higher salaries to help them deal with their problems.
- Again the study findings revealed that employed or working caregivers had to reduce the time they work, opt for part-time work, retire early, missed work, lost their jobs, turned down promotions, or make some workplace accommodations such as coming in late to work or leaving early, taking time off to manage care situations, reducing work hours or level of responsibility, and/or taking a leave of absence.
- In nutshell, the study findings revealed that proving care to elderly people living with diabetes mellitus is a persistent stressor and causes a high level of stress. Caregivers suffer from more poor health than non-caregivers and have more chronic illnesses such as high blood pressure, heart disease, diabetes, and arthritis than non-care giving peers

5.4 RECOMMENDATIONS

Based on the findings, the following recommendations are made:

- It is recommended that diabetes mellitus caregivers should get counselling from professional officials, such as social workers and psychologist, this is because they face so many traumatic events for their emotional and psychological wellbeing.
- It is also recommended that family, neighbours and relatives of caregivers of elderly people living with diabetes mellitus must start to give support to the caregivers, since they complain about lack of support.
- It is recommended that churches, pastors and church members must continue to give their support to caregivers of elderly people living with diabetes mellitus since the study revealed that prayers and the word of God are the best coping strategies, they are using in order to deal with the challenges they are experiencing when giving care to their patients.
- Diabetes mellitus caregivers must start to form teams/support groups and share/disclose their challenges, experiences, how they feel and advise each other on how best they can deal with the challenges they are encountering when giving care to elderly people living with diabetes mellitus.
- Professionals should plan programmes that support both patients and caregivers of people with diabetes mellitus

5.4.1 Recommendations for the Community Home Based care

- It is recommended that community Home-based care must continue to give support and pay special visits to both patient and caregiver since the study revealed that support from the local Home-based care keeps them going.
- The Home-based care should also organize the local clinic nursing professionals to provide workshop and training to caregivers to empower them about the new information regarding diabetes mellitus and skills on how they can cope better with certain challenges that they experience.
- Since the caregivers sometimes witness the death of elderly diabetes mellitus patients, it is also clear that the caregivers suffer emotionally and may need psychological support. It is recommended that the local community Home-based care organize a support programme that will assist the caregivers with counselling services. This will enable caregivers to provide quality care to their patients without the burden of psychological problems.

5.4.2 Recommendation for the Department of Health

- Medication for people living with diabetes mellitus patients should always be made available in the local clinics because caregivers of elderly people living with diabetes mellitus complained about the shortage of the medications at the nearest or local clinic, this forces them to go to the nearest hospital and they ended up having a financial challenge. Caregivers complained about transport challenge to go to the hospital.
- It is also recommended that caregivers of elderly people living with diabetes mellitus should receive stipends so that they can afford all the required needs for the patients.
- The Department of Health should also start to create workshops and training more often so that caregivers can learn and understand how to handle certain issues when taking care of elderly people living with diabetes mellitus and also get a new update regarding diabetes mellitus.

5.4.3 Recommendations for further research

This study focused on the challenges experienced by caregivers of elderly people living with diabetes mellitus in a selected village of the Vhembe district. The findings of this study revealed that caregivers of elderly people living with diabetes mellitus face so many challenges on their daily basis when giving care and they were affected emotionally and physically by these challenges. The researcher, therefore, recommends that further research be conducted on the other areas in relations to this topic, so that the findings can be compared in order to improve the generalization.

5.5 SUMMARY OF THE CHAPTER

This was a qualitative study, it focused on challenges experienced by and coping strategies of caregivers of elderly people living with diabetes mellitus in a selected village in the Vhembe district. The objectives of the study were to explore the challenges experienced by caregivers of elderly people living with diabetes mellitus as well as investigating the coping strategies of caregivers of elderly people living with diabetes mellitus. The conclusions of this study are that the caregivers are experiencing various challenges when taking care of elderly people living with diabetes mellitus. The recommendations were also made based on the various challenges that the caregivers experience when taking care of elderly people living with diabetes mellitus. Recommendations for future researchers to further research in relation to this study were also discussed in this chapter

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APPENDICES

APPENDIX A: INTERVIEW GUIDE

Title: “***Challenges and coping strategies of caregivers caring for elderly people living with diabetes mellitus in a selected village of the Vhembe district, Limpopo province***”

Demographic information

1. How old are you?
2. Are you married?
3. What is your educational status?
4. What is your relationship with the patient?
5. How long have you being caring for your loved one living with diabetes mellitus?

Central question

What challenges do you experience when taking care of elderly people living with diabetes mellitus?

Guiding questions

1. Describe the challenges that you experience when taking care of elderly people living diabetes mellitus?
2. What do you think are the coping strategies to deal with challenges that you experience when caring for people with diabetes mellitus?

APPENDIX B: INFORMATION SHEET

Dear participants

I Patience Ipfi Mamatsharaga, I am a student at the University of Venda, registered for the master of Public Health degree (MPH). My research focuses on the Challenges experienced by Care givers of elderly people living with Diabetes Mellitus in Vhembe. You are kindly requested to take part in this study because your participation is very much important in improving your working condition as the care giver

Research data will be collected by the researcher, before data collection, I will explain the purpose and the ethical principles to be adhere to, Furthermore, you as the participants will also be required to give informed consent. I will use the interview guide as means of collecting information from those who meet the inclusion criteria. Data will be collected individually in private space, to maintain privacy and also use codes rather than participant real name to ensure anonymity.

In this research project participation is free and voluntary. You are allowed to withdraw from the project at any time should you feel uncomfortable or threatened I any way to continue participating in the study

During research I will ensure that the benefits surpass the risks. I will also ensure that no physical psychological or emotional harm is inflicted on you during the course of the study. Other possible dangers will be looked at and the researcher will do follow up and refer you to appropriate health workers for treatment. Your positive response to participate in this study will enable the researcher to draw conclusions from the findings and be able to give recommendations that may assist the Department of Health to come up with appropriate measures that may reduce challenges experienced by care givers of elderly people living with diabetes mellitus

For more information contact Mamatsharaga P.I (Researcher)

Cell: 079 4177 906

Email: patiemams@yahoo.com

APPENDIX C: CONSENT FORM

Statement of Agreement to Participate in the Research Study:

- I hereby confirm that I have been informed by the researcher, (name of researcher), about the nature, conduct, benefits and risks of this study - Research Ethics Clearance Number:
- I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.

- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.

- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerized system by the researcher.

- I may, at any stage, without prejudice, withdraw my consent and participation in the study.

- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

Full Name of Participant	Date	Time	Signature
I, ………………………….	……………	…………	………………………..

(Name of researcher) herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

Full Name of Researcher: ……………………. Date: ……………….
Signature: …………………

Full Name of Witness (If applicable): ……………………. Date ……………….
Signature………………….

Full Name of Legal Guardian (If applicable): ………………… Date: ………………
Signature: …………………….

Please note the following:

Research details must be provided in a clear, simple and culturally appropriate manner and prospective participants should be helped to arrive at an informed decision by use of appropriate language (grade 10 level- use Flesch Reading Ease Scores on Microsoft Word), selecting of a non-threatening environment for interaction and the availability of peer counselling (Department of Health, 2004).

If the potential participant is unable to read/illiterate, then a right thumbprint is required and an impartial witness, who is literate and knows the participant e.g. parent, sibling, friend, pastor, etc. should verify in writing, duly signed that informed verbal consent was obtained (Department of Health, 2004).

If anyone makes a mistake completing this document e.g. a wrong date or spelling mistake, a new document has to be completed. The incomplete original document has to be kept in the participant’s file and not thrown away, and copies thereof must be issued to the participant.

APPENDIX D: INTERVIEW TRANSCRIPT

Transcript from an in-depth individual interview

Researcher: Good morning and, how are you?

Participant 1: I am fine, thank you and, how are you? You are welcome

Researcher: We can start with our interviews

What are the challenges that you face when taking care of elderly people living with Diabetes Mellitus?

Participant 1 Said "The main challenge is that Sometimes my mom get angry to such an extent that she refuse to eat food, she cannot control her temper, sometimes she does not cooperate, because she refuse to take medication and it really stresses me .Am no longer performing at work, I always ask my supervisor to release me each and every time when she wants to go for check-up because she has problems with eyes, she is partially blind. Sometimes I don't ask for permission to be released at work, I used to abscond always. I am a bread winner here at home, I have got a daughter who has got epilepsy and she has an infant child. Time management is a serious challenge because I do not have time for myself anymore".

Researcher "Tjoh jah neh"

Participant 1 said "The other challenge is that I provide for my kids and the money that am receiving is not enough, I have got a serious financial challenge here at home. When her eyes are due for check-ups or operation, I used to take unpaid leave. A Person with diabetes mellitus must eat fruits and vegetables always and she must drink rooibos tea only and I am not affording to buy all those things. The other challenge is that when there is a shortage of medicine in the clinic we are referred to Tshilidzini hospital and we do not have money for the transport.

Researcher "I heard you say your mom is partially blind so how do you manage this situation"?

Participant 1 said "I used to bath her and accompany her to the toilet when am around and when am at work, I used to leave a bucket in her room so that she can use it .I have got a huge burden because all these things stresses me a lot and now Iam having blood pressure due to this situation. I feel burdened serious, I am emotionally, physically, psychological and financially stressed. I no longer attend church services properly because there is no one who can take care of her. I cannot leave her alone at home because she cannot take care of herself. I must also make sure that she is taking medication in time. Sometimes I will call the neighbour to give her medication”

Researcher ‘’Eish”

Participant 1 said “Eish it is not easy my sister. Sometimes I don’t eat food while am at work, thinking that maybe I will receive a call from my neighbour saying that my mom is no more I don’t have any relative for the support, I used to cry whenever I think of challenges that I am experiencing”.

Researcher “I heard you saying that you have no one who can give you support even the relatives so how do you cope with all these challenges that you are experiencing here at home”?

Participant 1 said “What do you mean when you say how do we cope?

Researcher “Please explain the coping strategies that you adopt when facing challenges when taking care of elderly people living with diabetes mellitus”?

Participant 1 said “Yoh” it is tough my sister but only God knows.

Researcher “true”

Participant 1 “I have accepted this situation because honestly speaking, there is nothing that I can do. The only support that am getting is from our local church members, pastors and my neighbour. I do pray for myself and the church leaders will come and pray for us as well”.

Researcher “ok I understand, so you mean those are the only coping strategies that you are using?

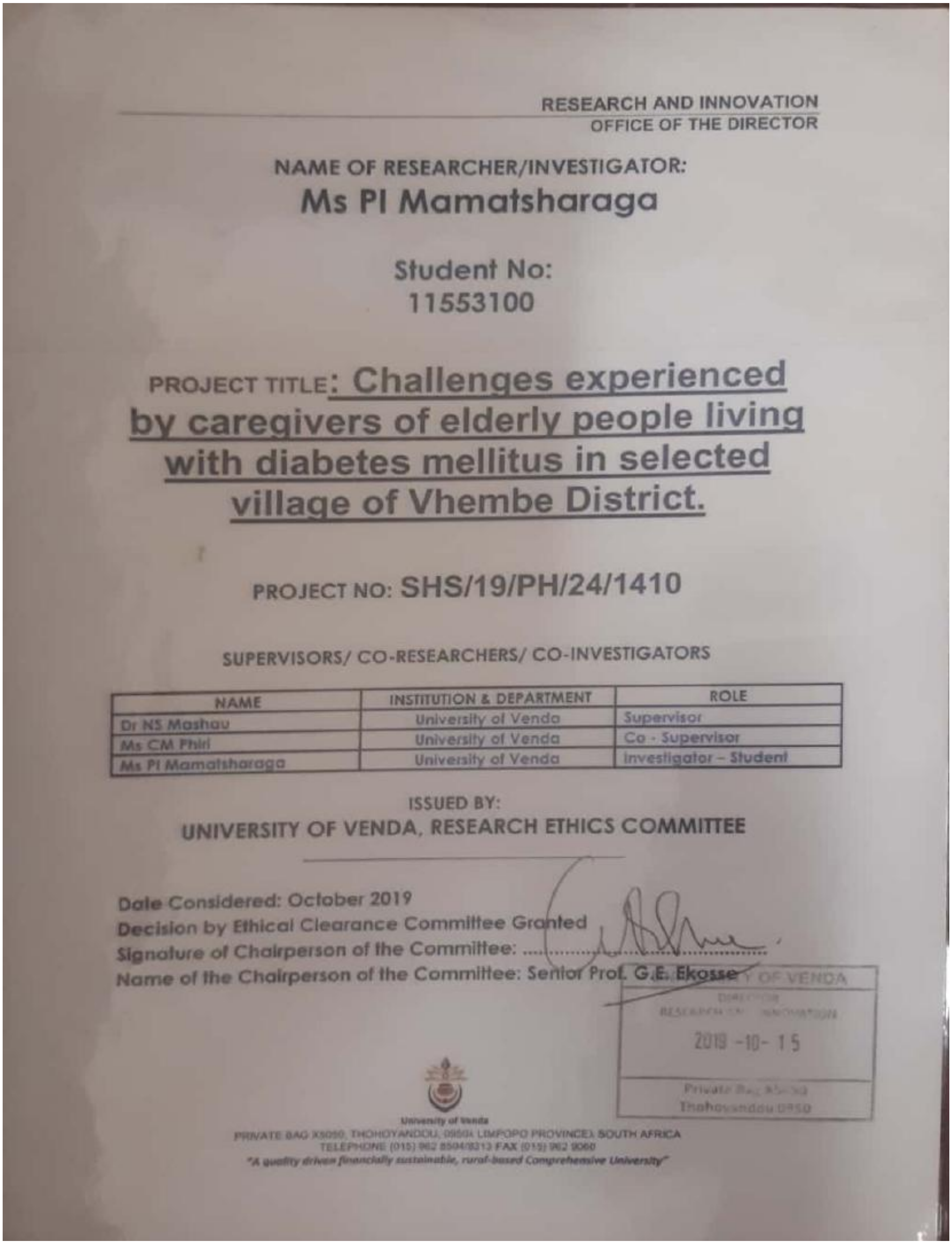
Participant 1 said “Jah’’ I think that’s all except the fact that we are also having our local Home Based Care here in the community .The Home-Based Cares used to come and visit us maybe twice a week. They sometimes give us counselling sessions so that we can cope with our challenges and even at the clinic they sometimes give us counselling”.

Researcher “Do you have anything to add”?

Participant 1 said “yah” today I feel much more relieved because I vented out .Thanks so much for coming and your time to listen to our problems and challenges .I think it’s always good to talk to other people when you experience problems. I was so depressed before you came here because I have got no one to tell my problems but now am feeling better”

Researcher “In that case I think we must end our discussion here. Thank you very much and have a great day’”.

APPENDIX E: ETHICAL CLEARANCE CERTIFICATE



RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:
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Student No:
11553100

PROJECT TITLE: **Challenges experienced by caregivers of elderly people living with diabetes mellitus in selected village of Vhembe District.**

PROJECT NO: **SHS/19/PH/24/1410**

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

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ISSUED BY:
UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE

Date Considered: October 2019
Decision by Ethical Clearance Committee Granted
Signature of Chairperson of the Committee: ....
Name of the Chairperson of the Committee: Senior Prof. G.E. Ekosse

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