

**EXPLORING THE EXPERIENCES OF INDIVIDUALS DIAGNOSED WITH DIABETES
MELLITUS TYPE II, AND THEIR SIGNIFICANT OTHERS' CARING FOR THEM**

Elnéri Koegelenberg

3302553



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WESTERN CAPE**

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MASTER OF SOCIAL WORK**

**Department of Social Work
Faculty of Community and Health Sciences**

University of the Western Cape

Supervisor: Dr C J Erasmus

Supervisor: Dr R Davids

Date: 25 November 2022

DECLARATION

I declare that the work in this thesis titled “*Exploring the experiences of individuals diagnosed with diabetes mellitus type II, and their significant others’ caring for them*” is my original work. I declare that I have not plagiarised, all the sources of information used in this study were acknowledged.

Name: Elnéri Koegelenberg

Student Signature:



Date: 15 November 2022



ABSTRACT

Diabetes Mellitus (DM) is a non-communicable disease (NCD) with an increase in prevalence. The debilitating consequences of this disease include mortality, morbidity, a decrease in quality of life, with an enormous financial and social burden on the diagnosed person and their significant others. The global prevalence of Diabetes Mellitus type II (DMII) is escalating with similar consequences on individuals and families. Individuals find the acceptance of the disease and necessary lifestyle changes challenging which result in poor health decisions with non-adherence to treatment, financial limitations, emotional, physiological, and psychosocial discomfort. The aim of this research was to gain an in-depth understanding of the lived experiences of those living with DMII and their significant others caring for them.

The researcher used a qualitative research approach with a phenomenological strategy of inquiry and an explorative, descriptive design to attain the goal of the study. The sample consisted of ten participants recruited from the Diabetes Wellness/Support group in Mitchell's Plain through purposive sampling. Unstructured in-depth phenomenological interviews were used to collect data. Interviews were analysed using phenomenological data analysis that focused on the lived experience (textural) and the context in which it was experienced (structural). The biopsychosocial model (BPS) was employed as the theoretical framework.

The study's findings on the person diagnosed with DMII indicated that holistic support is of utmost importance in the management, and adherence to the treatment plan of DMII, and a lack thereof resulted in various challenges experienced by participants. Social factors such as their socio-economic status affected the individuals' health, management of the disease, and adherence to the treatment plan. Findings on the significant others concluded that caregivers experienced a lack of support, which result in a decline of their mental, emotional, and physical well-being. A recommendation would be for social workers with a Bachelor of Social Work and Master of Social Work to require additional information and skills to practice effectively within a multidisciplinary

team (MDT), in a medical and clinical setting and this can be accomplished in a dual-degree program.



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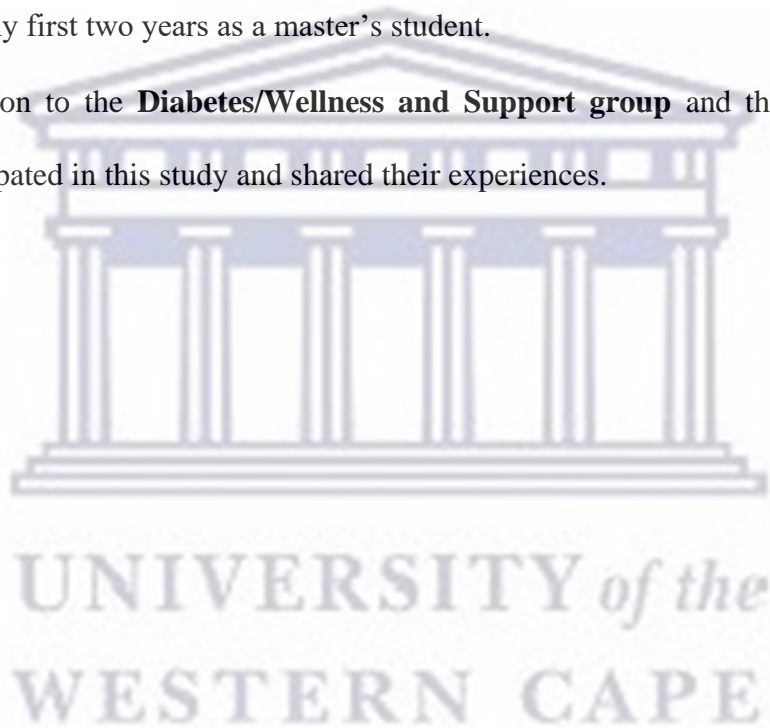


TABLE OF CONTENTS

DECLARATION	i
ABSTRACT	ii
ACKNOWLEDGEMENTS	iv
LIST OF ABBREVIATIONS	xiv

CHAPTER ONE

OVERVIEW TO THE STUDY

1.1	INTRODUCTION TO THE STUDY	1
1.2	THEORETICAL FRAMEWORK	2
1.3	PROBLEM STATEMENT	3
1.4	RESEARCH QUESTION	4
1.5	AIMS AND OBJECTIVES	4
1.5.1	Aim of the study	4
1.5.2	Objectives of the study	4
1.6	RESEARCH METHODOLOGY	4
1.6.1	Research approach and design	4
1.6.2	Research setting	5
1.6.3	Population and sampling	5
1.7	Pilot study	6
1.8	DATA COLLECTION	6
1.9	DATA ANALYSIS	7

1.10	ETHICAL CONSIDERATIONS	7
1.11	CHAPTERS TO FOLLOW	8
1.12	DEFENITION OF KEYCONCEPTS	8
1.13	CHAPTER CONCLUSION	10

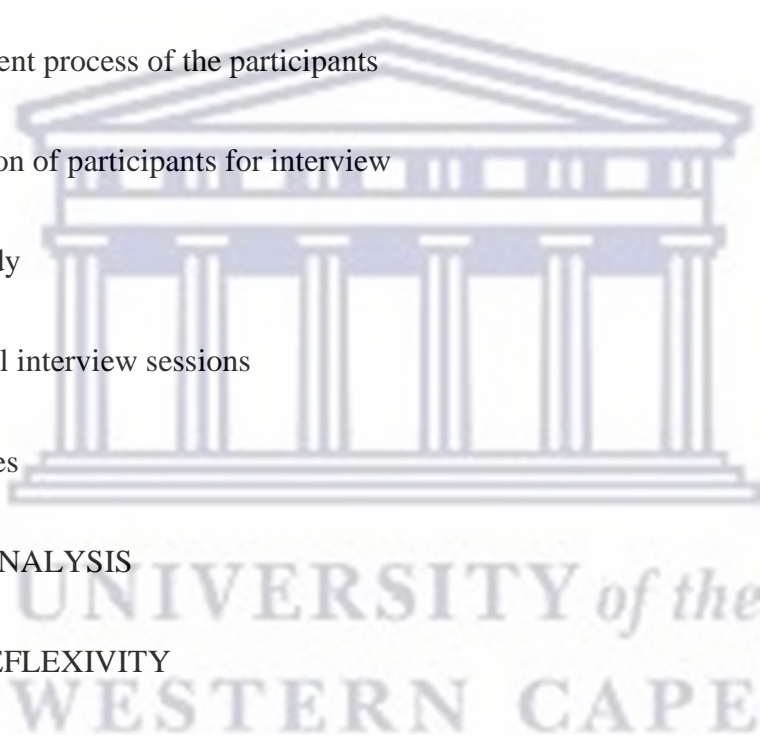
CHAPTER 2

LITERATURE REVIEW

2.1	INTRODUCTION	11
2.2	DIABETES MELLITUS	11
2.3	DIABETES MELLITUS PREVALENCY	13
2.3.1	DIABETES MELLITUS TYPE II PREVALENCY	14
2.4	FACTORS ASSOCIATED WITH DIABETES MELLITUS TYPE II	17
2.4.1	BIOLOGICAL FACTORS	17
2.4.1.1	Biological factors contributing to diabetes mellitus type II	18
2.4.1.2	Biological complications of diabetes mellitus type II	19
2.4.2	PSYCHOLOGICAL FACTORS	20
2.4.3	SOCIAL FACTORS	24
2.4.3.1	Financial burden of diabetes mellitus type II	25
2.4.3.2	Physical activity, diet, and obesity	27

2.5	EXPERIENCE OF INDIVIDUALS DIAGNOSED WITH DIABETES MELLITUS TYPE II	28
2.5.1	Experience after diagnosis	28
2.5.2	Physical illnesses	29
2.5.3	Engagement with health care workers	30
2.5.4	Family support	31
2.6	EXPERIENCES OF SIGNIFICANT OTHERS	34
2.7	THE BIOPSYCHOSOCIAL MODEL (BPS)	37
2.8	CHAPTER SUMMARY	38
CHAPTER 3		
RESEARCH METHODOLOGY		
3.1	INTRODUCTION	39
3.2	RESEARCH QUESTION	39
3.3	RESEARCH AIM AND OBJECTIVES	39
3.3.1	AIM	39
3.3.2	OBJECTIVES	39
3.4	RESEARCH METHODOLOGY	40
3.4.1	Research approach	40

3.4.2	Research design	41
3.4.3	Phenomenology as a strategy of inquiry	42
3.4.4	Research setting	43
3.4.5	Population	43
3.4.6	Sampling	43
3.5	DATA COLLECTION	44
3.5.1	Recruitment process of the participants	45
3.5.2	Preparation of participants for interview	48
3.5.3	Pilot Study	48
3.5.4	Individual interview sessions	49
3.5.5	Field notes	50
3.6	DATA ANALYSIS	50
3.7	SELF-REFLEXIVITY	52
3.8	TRUSTWORTHINESS	53
3.9	ETHICAL CONSIDERATIONS	54
3.9.1	Informed consent and voluntary participation	55
3.9.2	Anonymity and confidentiality	55
3.9.3	Avoidance of harm	56
3.9.4	Deceiving of participants	57



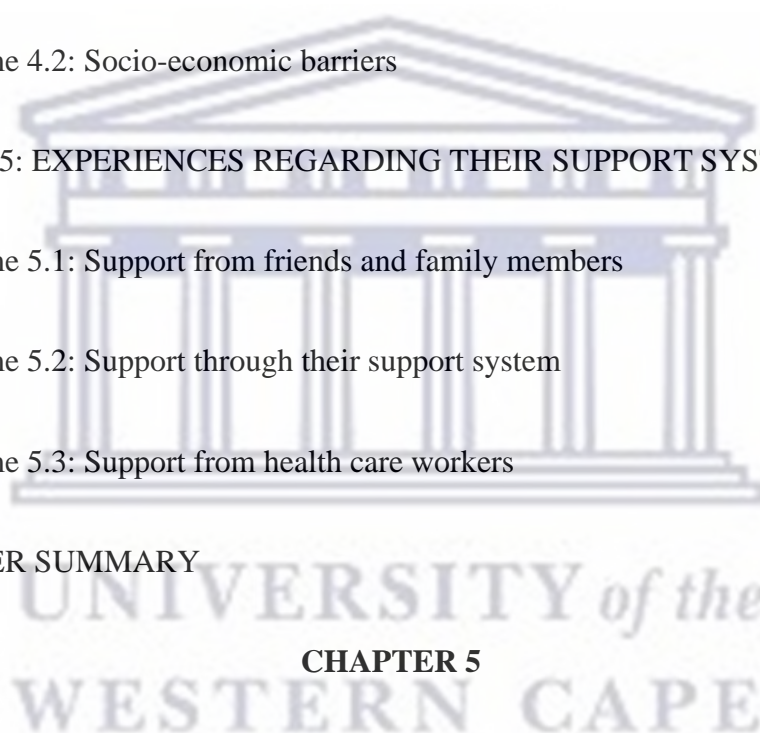
3.10	LIMITATIONS OF THE STUDY	57
3.11	CHAPTER SUMMARY	57

CHAPTER 4

PRESENTATION AND DISCUSSION OF THE FINDINGS PERSON DIAGNOSED WITHG DIABETES MELLITUS TYPE II

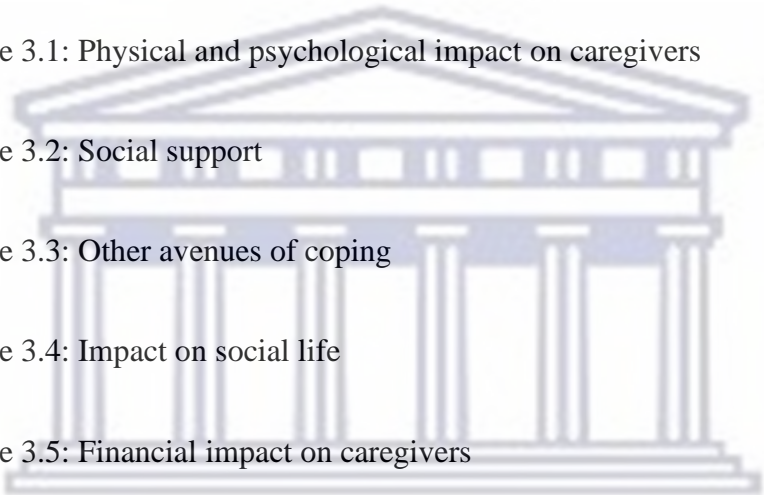
4.1	INTRODUCTION	59
4.2	DEMOGRAPHIC PROFILE OF PARTICIPANTS	60
4.2.1	Gender	60
4.2.2	Age	60
4.2.3	Race	60
4.2.4	Home language	61
4.2.5	Employment/Income status	61
4.2.6	Relation status	61
4.3	PRESENTATION AND DISCUSSION OF THE FINDINGS	61
4.3.1	THEME 1: UNDERSTANDING THEIR DIAGNOSIS	62
4.3.1.1	Sub-theme 1.1: Causes, symptoms and/or triggers that led to the diagnosis	63
4.3.1.2	Sub-theme 1.2: Family history of diabetes mellitus type II	66
4.3.1.3	Sub-theme 1.3: Complications as a result of their disease	67
4.3.2	THEME 2: EMOTIONAL AND MENTAL CHALLENGES EXPERIENCED	69

4.3.3	THEME 3: MANAGEMENT OF DIABETES MELLITUS TYPE II	72
4.3.3.1	Sub-theme 3.1: Dietary adherence	72
4.3.3.2	Sub-theme 3.2: Medication adherence	74
4.3.4	THEME 4: EXPERIENCES WITH BARRIERS IN MANAGING DIABETES MELLITUS TYPE II	75
4.3.4.1	Sub-theme 4.1: Health system-related barriers	76
4.3.4.2	Sub-theme 4.2: Socio-economic barriers	77
4.3.5	THEME 5: EXPERIENCES REGARDING THEIR SUPPORT SYSTEM	80
4.3.5.1	Sub-theme 5.1: Support from friends and family members	81
4.3.5.2	Sub-theme 5.2: Support through their support system	83
4.3.5.3	Sub-theme 5.3: Support from health care workers	84
4.4	CHAPTER SUMMARY	86



CHAPTER 5
**PRESENTATION AND DISCUSSION OF THE FINDINGS ON THE SIGNIFICANT
OTHERS'**

5.1	INTRODUCTION	87
5.2	DEMOGRAPHIC PROFILE OF PARTICIPANTS	87
5.3	PRESENTATION AND DISCUSSION OF THE FINDINGS	89

5.3.1	THEME 1: CAREGIVERS' UNDERSTANDING OF THE CONTRIBUTING FACTORS OF DIABETES MELLITUS TYPE II	89
5.3.2	THEME 2: CHALLENGES CAREGIVERS EXPERIENCE DURING MONITORING ADHERENCE TO PRESCRIBED MEDICATION	90
5.3.3	THEME 3: THE EFFECT OF CARING FOR SIGNIFICANT OTHERS DIAGNOSED WITH DIABETES MELLITUS TYPE II	93
5.3.3.1	Sub-theme 3.1: Physical and psychological impact on caregivers	94
5.3.3.2	Sub-theme 3.2: Social support	97
5.3.3.3	Sub-theme 3.3: Other avenues of coping	98
5.3.3.4	Sub-theme 3.4: Impact on social life	99
5.3.3.5	Sub-theme 3.5: Financial impact on caregivers	101
5.4	CHAPTER SUMMARY	104
 <p>CHAPTER SIX</p> <p>CONCLUSION AND RECOMMENDATIONS</p>		
6.1	INTRODUCTION	105
6.2	CONCLUSION	106
6.2.1	THEME 1: UNDERSTANDING THEIR DIAGNOSIS	106
6.2.2	THEME 2: EMOTIONAL AND MENTAL CHALLENGES EXPERIENCED	107
6.2.3	THEME 3: MANAGEMENT OF DIABETES MELLITUS TYPE II	107

6.2.4	THEME 4: EXPERIENCES WITH BARRIERS IN MANAGING DIABETES MELLITUS TYPE II	109
6.2.5	THEME 5: EXPERIENCES REGARDING THEIR SUPPORT SYSTEM	109
6.3	CONCLUSION	111
6.3.1	THEME 1: CAREGIVERS UNDERSTANDING OF THE CONTRIBUTING FACTORS OF DIABETES MELLITUS TYPE II	111
6.3.2	THEME 2: CHALLENGES CAREGIVERS EXPERIENCED DURING MONITORING ADHERENCE TO PRESCRIBED MEDICATION	111
6.3.3	THEME 3: THE EFFECTS OF CARING FOR SIGNIFICANT OTHERS DIAGNOSED WITH DIABETES MELLITUS TYPE II	112
6.4	RECOMMENDATIONS	114
6.4.1	Recommendations to the multi-disciplinary team (MDT)	114
6.4.2	Recommendations to the government	115
6.4.3	Recommendations to individuals/families/caregivers	116
6.5	RECOMMENDATION FOR HIGHER EDUCATION AND TRAINING	117
6.6	SUGGESTIONS FOR FUTURE RESEARCH	117
6.7	CONCLUSION	118
	BIBLIOGRAPHY	119

LIST OF APPENDICES

APPENDIX A: PERMISSION LETTER	145
APPENDIX B: INFORMATION SHEET	147
APPENDIX C: CONSENT FORM	150
APPENDIX D: TRANSCRIPT OF INTERVIEW	157

LIST OF FIGURES

Figure 2.1	Psychological factors in Diabetes Mellitus type II	22
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LIST OF TABLES

Table 4.2.	Demographic details of participants living with DMII	60
Table 4.3	Themes and Sub-themes	62
Table 5.1	Demographic details of the significant other	88
Table 5.2	Themes and Sub-Themes	89



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LIST OF ABBREVIATIONS

ADA	American Diabetes Association
APA	American Psychology Association
BMI	Body Mass Index
BPS	Biopsychosocial model
CDA	The Canadian Diabetes Association
CDC	Centres for Disease Control and Prevention
CDE	Cardiovascular Diabetes Education
DM	Diabetes Mellitus
DMI	Diabetes mellitus type I
DMII	Diabetes mellitus type II
IDF	International Diabetes Federation
MDT	Multidisciplinary team
NAC	National Alliance for Caregiving
NACDD	National Association of Chronic Disease Directors
NCD	Non-communicable diseases
NDEP	National Diabetes Educational Programme
TB	Tuberculosis
WHO	World Health Organisation

CHAPTER ONE

OVERVIEW OF THE STUDY

1.1 INTRODUCTION TO THE STUDY

Diabetes mellitus (DM) is a chronic disease that influences the body's ability to manage blood sugar or glucose (World Health Organization [WHO], 2020). DM is a non-communicable disease (NCD), which is a medical condition which cannot be transmitted because it is a non-infectious disease that cannot be transmitted from one person to the next (WHO, 2020). The two main types of DM are insulin-dependent, also referred to as diabetes mellitus type I (DMI), and non-insulin dependent, also referred to as diabetes mellitus type II [DMII] (Goayl & Jialal, 2021).

Behavior, environmental, genetic, and physiological variables all contribute to chronic/long-term disorders (Kengne, Kidzero & Shey, 2019). Diabetes, chronic respiratory illnesses (e.g., asthma, chronic obstructive lung disease), cancer, and cardiovascular diseases (e.g., strokes and heart attacks) are the four primary categories of NCDs (Kengne, *et al.*, 2019; WHO, 2020). The global prevalence of DM was 108 million in 1980 and escalated to an estimated 382 million people in 2013 (Shi & Hu, 2014). The projection is that the tendency of increasing numbers of people with DM will persist. The global prevalence of DM encompassed 10.5 percent in adults in 2021 with an increase of more than 12 percent by 2045. The prevalence of this disease will increase by 134 percent in Africa between 2021 and 2045, with only 24 percent in North America and the Caribbean (Elfein, 2021). The projection is that China will have the greatest percentage of diabetes, followed by the United States in 2045 (Standl, Khunti, Hansen & Schnell, 2019). Data from the International Diabetes Federation's (IDF) indicated that there is a mortality every seven seconds because of complications associated with DM, and half of these deaths occur in those younger than of 60 years old (Standl *et al.*, 2019).

A diagnosis of DMI is possible at any age, including infancy, childhood, adolescence, and adulthood (Goyal & Jialal, 2021). The cause of DMI is the inability of the pancreas to produce insulin, resulting in uncontrolled blood glucose levels. A diagnosis of DMII in adults is a result of the body's inability to utilize insulin appropriately (Goyal & Jialal, 2021; Standl *et al.*, 2019). DMII account for 90% of DM cases and physical inactivity and excess weight contribute to the disease (Elfein, 2021; Standl *et al.*, 2019). A study by the Center for Disease Control and Prevention (CDC) in the United States also indicated that DMII has become more common in children and adolescents, which is a concern and clinical trials have revealed that adolescents with DMII had a higher chance of developing health problems than adults with DMII (Xu & Verra, 2018).

1.2 THEORETICAL FRAMEWORK

This study is based on the Biopsychosocial (BPS) model as theoretical framework for this study. This model, with its holistic approach, considers the biological- for example genetic predisposition, psychological- for example emotions, feelings, and behavior, and social characteristics for example social support, cultural influences, family relationships, class) of each patient, and recognizes the interaction between the various systems (Gentry, Snyder, Barstow & Hamson-Utley, 2018; Engel, 1977).

The BPS model of health argues that health and disease are the result of numerous variables that include psychological and social characteristics and not just biological factors (Wade & Halligan, 2017). This model suggests that feelings, thoughts, and behavior can influence one's physical state and that the social and psychological factors affect the biological functioning of the person (Kusnanto, Agustian & Hilmanto, 2018; Engel, 1977). Therefore, the BPS model is significant in medical care because it expands the scope with which health and illness can be examined in clinical practice (Wade & Halligan, 2017). Medical practitioners should not only be aware of the biological factors but also the social and behavioral conditions that are associated with health risks (Kusnanto *et al.*, 2018). This study on DMII was based on the BPS model because it recognizes the importance of the biological, psychological, and social factors and the impact of these on those living with the

disease. A detailed discussion of this model follows in the theoretical chapter, chapter two of this study.

1.3 PROBLEM STATEMENT

DM is a chronic metabolic condition in which the body is unable to utilize glucose fully or partly (WHO, 2020). DMII with a high global prevalence is a critical public health concern (Standl *et al.*, 2019). This disease was responsible for almost one million deaths in 2017, which were the ninth highest cause of mortality (Khan, Hashim, King, Govender, Mustafa & Al Kaabi, 2020). Another concern is that DM is the seventh most common disease with regards to morbidity and is more prevalent in children and adolescents than in adults. Evidence showed that one out of three children and adolescents have a diagnosis of DMII in the United States (Xu & Verra, 2018). Furthermore, the quality of life is at greater risk because of reduced physical, emotional, and social well-being in persons diagnosed with DM (Gupta, Bhadada, Shah, & Mattoo, 2015). Coping and adherence to treatment in people with DM and family members caring for them are dependent on social and psychological factors (Gonzalez-Zacarias, Mavarez-Martinez, Arias-Morales, Stoicea & Rogers, 2016; Gupta *et al.*, 2015). Socio-demographic factors such as age, gender, employment, and income play a significant role in the care, prevalence, and treatment adherence of DM. DM also has adverse emotional, psychological, mental, physical, and financial effects on the person diagnosed with DM and on the members in a family caring for them (Gonzalez-Zacarias *et al.*, 2016). These challenges on various levels experienced by the person diagnosed with DMII and a significant other caring for them must be considered in the daily routine of diabetes management (Bennich, Roder, Overgaard, Egerod, Munch, Knop, Vilsbol & Konradsen, 2017). Consequently, the researcher wanted to answer the research question outlined below: *What are the lived experiences of the person diagnosed with diabetes mellitus type II, and their significant others' caring for them?*

1.4 RESEARCH QUESTION

The research question was: *What are the lived experiences of the person diagnosed with DMII, and their significant others' caring for them?*

1.5 AIM AND OBJECTIVES

1.5.1 Aim of the study

The aim of this research was to gain an in-depth understanding of the lived experiences of those living with DMII and their significant others caring for them.

1.5.2 Objectives of the study

The objectives of the study were:

- To explore the lived experiences of adults living with DMII.
- To explore and describe the reason adults living with DMII do not adhere to treatment and medication.
- To explore and describe the lived experiences and effects of significant others caring for individuals with DMII.
- To describe significant others' understanding of the contributing factors of the diagnosis, treatment and medication on the person taking the medication.

1.6 RESEARCH METHODOLOGY

1.6.1 Research approach and design

The researcher used a qualitative research approach using an explorative and descriptive research design to address the study's research question. The qualitative approach was used because it offered an in-depth and rich understanding of the participants' experiences (Creswell & Creswell, 2018). An explorative research design focuses on knowledge about unknown issues and it provides new perceptions, discovers fresh concepts, and increases the understanding of the specific phenomenon (De Vos, Strydom, Fouché & Delpont, 2011). The descriptive design provided a

deeper understanding of the phenomenon and endorsed detailed descriptions of participants' feelings and emotions (Strydom, 2011). In this study, a detailed description of the experiences and the context in which these experiences occur in the finding's chapters, chapters four and five.

The researcher selected phenomenology as a strategy of inquiry for this study as the study seeks to gain an in-depth understanding of the lived experiences of the participants living with DMII and those of their significant others. A phenomenological study outlines the shared importance of a notion or phenomenon for multiple people (Creswell & Creswell, 2018; Creswell, 2013). A phenomenological study was employed to gain a thorough understanding and description of the participants' lived experiences as a person diagnosed with DMII and their significant others' caring for them. The researcher achieved the research goal as a result of using a phenomenological strategy of inquiry.

1.6.2 Research setting

The study was conducted with members of a Diabetes Wellness/Support Group for individuals diagnosed with DMII and, their significant others caring for them. The support group is facilitated by a community member who is also diagnosed with this disease and established the need for support and education regarding DMII in the community. Therefore, she joined the Diabetes Wellness/Support Group as a facilitator to the community members who are diagnosed with DMII.

1.6.3 Population and sampling

The study population was individuals diagnosed with DMII and their significant others caring for them. The individuals diagnosed with DMII are members of the Diabetes Wellness/Support Group situated in Mitchell's Plain area, known as the Cape Flats in the City of Cape Town. The significant others are family/ spouses/or live-in friends who act as caregivers to those diagnosed with DMII but who are not part of the support group they however are allowed to attend.

Purposeful sampling was employed for this study, which is commonly employed to identify and select information-rich cases that are relevant to the phenomenon investigated (Creswell & Plano Clark, 2011; Patton, 2002). Purposeful sampling intentionally selects participants who shared similar features to provide an in-depth understanding that enabled the researcher to explore and explain the key concepts (Creswell & Plano Clark, 2011). Phenomenology utilizes smaller samples that are purposefully chosen to collect detailed information. The researcher, therefore, purposefully selects participants and the research setting because the selected participants can purposefully provide an in-depth understanding and rich information as they comprehend the research phenomenon under investigation (Patton, 2002). The sample selection of this study consisted of ten participants of which five participants were diagnosed with DMII and the other five were the significant others caring for them.

The inclusion requirements for the sample were: 1) Participants must have a diagnosis of DMII; 2) They must attend the Diabetes Wellness and Support Group; 3) They must be older than 18 years; and 4) Must have a significant other who lives with them and cares for them.

1.7 Pilot study

A pilot study is a crucial stage in any research project because it allows the researcher to identify possible areas of concern and provides the researcher with the opportunity to improve these areas and make changes accordingly (De Vos *et al.*, 2011). A pilot study was completed with a member that was part of the Diabetes/Wellness Support Group and diagnosed with DMII, however, the participant's data was not included in the final study. The goal of the pilot study was to see if the approach intended to be employed would be feasible in a larger-scale study (Strydom & Delpont, 2011).

1.8 DATA COLLECTION

The researcher used phenomenological in-depth interviews as the primary method of data collection because the goal of the research was to comprehend people's lived experiences (Creswell

& Creswell, 2018; Patton, 2002). The phenomenological strategy of inquiry obtains in-depth, contextualized, and open-ended responses from the participants on their views, feelings, understanding, and experiences on the phenomenon being studied by using interviews (Greeff, 2011). The researcher asked one general open-ended question to the participant to elicit as much data as possible. The question asked for the person diagnosed with DMII was: “You have been diagnosed with DMII. What has been the experience for you?” And the question asked for the significant other was: “You are taking care of a family member diagnosed with DMII. What has the experience been for you?” The researcher and participants followed Covid-19 safety protocols during the support group meetings and the individual interviews. These protocols included maintaining physical distance throughout the data collection process, wearing masks, everyone sanitized their hands, and the researcher met with the participants in an air-conditioned area. The researcher also provided each participant with an extra two masks and brought sanitizer to the interviews.

1.9 DATA ANALYSIS

The researcher employed phenomenological data analysis which extracted meaning from the themes revealed through initial manual coding (Creswell, 2013; Patton, 2002). The researcher followed the six steps of phenomenological data analysis as described by Creswell (2013). The researcher created a list of statements that described what and how the participants experienced the phenomena. Significant statements were organized into themes and sub-themes. The process to execute these steps are substantiated in chapter three of this document.

1.10 ETHICAL CONSIDERATIONS

Ethical permission was obtained from the Human and Social Sciences Research Ethics Committee of the University of the Western Cape and permission to do the study from the management of the Diabetes Wellness/Support group. Ethical considerations in research include informed consent and voluntary participation, anonymity and confidentiality, avoidance of harm, and deceiving of

participants (De Vos *et al.*, 2011). The application of the ethical considerations during the research study will be discussed in more detail in chapter three of this document.

1.11 CHAPTERS OUTLINE

Chapter One provided an overview of the research study.

Chapter Two offers a review of relevant literature on DM, DMI, and DMII. The BPS is also discussed in terms of the biological, psychological, and social factors that contribute to DMII. This chapter also include relevant literature on the experiences of persons diagnosed with DMII, the experiences of their significant others caring for them, and how it has affected their lifestyle and emotional well-being.

Chapter Three provides an in-depth discussion on the research methodology employed throughout the research process. The research aim, objectives, the research approach, and design are explicated. Furthermore, the research setting, population, and sampling are also presented. The chapter resumes with the methods of data collection and analysis which were utilized. It concludes with how data verification and trustworthiness, and ethical considerations were ensured throughout the research process.

Chapter Four presents the demographic profile, findings, and a discussion on the persons diagnosed with DMII, which originated from the data collected on the persons diagnosed with DMII.

Chapter Five presents the demographic profile, findings, and a discussion on the significant others who care for those diagnosed with DMII. The data collected on the significant others led to the findings in this chapter.

Chapter Six presents' conclusions and recommendations of this study.

1.12 DEFINITION OF KEY CONCEPTS

This section defines the key words used in this study:

Diabetes mellitus – A chronic disease because of the body being unable to effectively use the insulin produced, or the pancreas produces too little insulin (WHO, 2016).

Diabetes mellitus type I – A lack of insulin production in the body which required daily management of insulin to control the quantity of glucose in the blood (WHO, 2016).

Diabetes mellitus type II – This condition is the result of the body's unproductive use of insulin (WHO, 2016).

Diabetes distress – It is a concept suggested to describe emotional response which is a normal consequence of DM. (Young-Hyman, De Groot, Hill-Briggs, Gonzalez, Hood & Peyrot, 2016).

Emotional distress – This concept is diabetes-specific and distinguished by developing a fear of complications or concern about the direct impact it can have on a person's day-to-day life (Snoek, Bremmer & Hermanns, 2015).

Experience/s – Something one has directly experienced or lived through (Merriam-Webster, n.d)

Adherence – Adherence refers to the degree to which a patient carries on with an agreed-upon treatment without close supervision (Merriam-Webster, n.d).

Non-adherence – non-adherence is a concept used when patients throughout separate phases of their treatment do not use their treatment as prescribed and/or do not use their treatment at all due to several reasons (Merriam-Webster, n.d).

Non-communicable diseases – non-communicable diseases are non-infectious and is not transferable from one person to the next (WHO, 2021).

Social support – It is certainty and awareness of care to a person where others help. These supportive resources can vary and include friendships with a sense of belonging; emotional support such as nurturance; information for example advice; tangible support for example, financial or intangible support which includes personal advice (American Psychological Association, n.d).

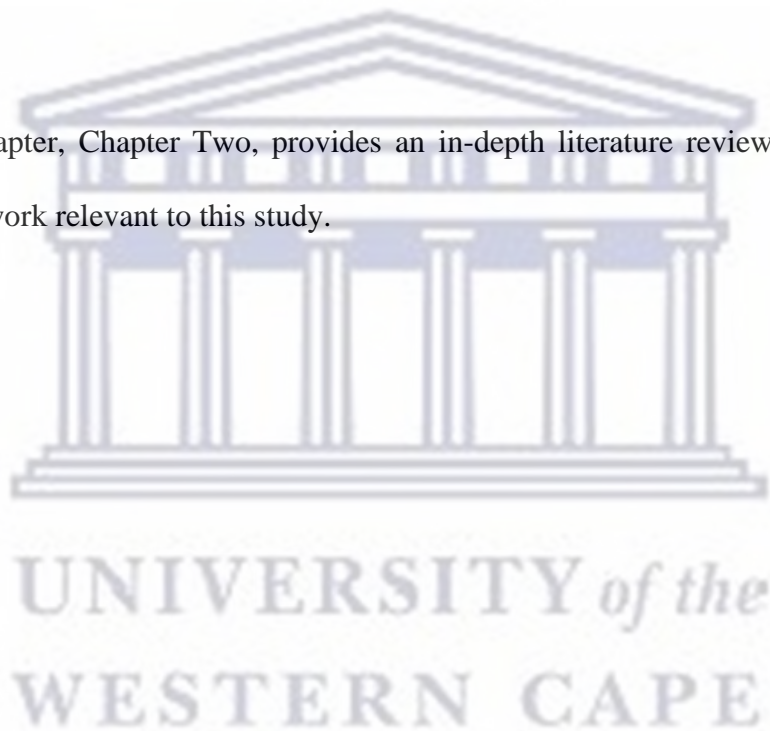
Diagnosis – An identification of a condition whereby an analysis and examination were conducted of the assumed or probable cause/s (Merriam-Webster. n.d).

People of color – people/persons of colour is a term used to refer to persons who is not considered white or who is mixed race (Merriam-Webster. (n.d).

1.13 CHAPTER SUMMARY

This chapter provided an overview of the research study and an introduction to the relevant literature to this study, the research methodology that was employed, and outlined the aim and objectives. This chapter furthermore provided the definitions of key concepts that are used during the research.

The following chapter, Chapter Two, provides an in-depth literature review and discussion of theoretical framework relevant to this study.



CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The previous chapter provided the foundation and overview of this study. This chapter provides a detailed understanding of DM, the types of DM, and an in-depth understanding of DMII. This chapter furthermore discusses the BPS model, which is the theoretical framework of this study. The discussion of the model is based on the three elements relevant to this model. The chapter will include also include literature on the experiences of persons diagnosed with this disease, the experiences of their significant others caring for them, and how this phenomenon has affected their lifestyle and emotional well-being.

2.2 DIABETES MELLITUS

DM is a disease and metabolic disorder in which blood glucose (sugar) levels are continuously elevated (American Diabetes Association [ADA], 2016) and the body's ability to use food for energy is impaired (International Diabetes Federation [IDF], 2019). The cells in the body either fail to respond to the released insulin or the pancreas fails to produce enough insulin, an essential hormone absorbed by the body, which consumes glucose as energy for the body's cells (WHO, 2020). In a case where there is a dysfunctional insulin signalling system, the dysfunction can lead to elevated blood glucose levels that will result in various metabolic defects, and the development of disabling difficulties (IDF, 2019).

The three most common types of diabetes are DMI, DMII, and gestational diabetes (Goyal & Jialal, 2021).

- DMI: The body no longer produces insulin in a person diagnosed with type IDM. As a result, an insulin pump provides insulin (Goayl & Jialal, 2021). DMI affects more than 8% of the South African population (IDF, 2019).

- DMII: A diagnosis with type IIDM in a person is the result of the body not absorbing and not producing enough insulin. The person must consider living a more balanced healthy lifestyle and may also be on medication (Goyal & Jialal, 2021; IDF, 2019).
- Gestational diabetes: A diagnosis of gestational diabetes is present only in pregnant women. This results in perinatal complications in the child and mother that might lead to caesarean section when the baby is born (Goyal & Jialal, 2021; IDF, 2019).
- Other, less common diagnosis of DM include congenital diabetes in neonates, and this is related to hereditary defects such as concealment of insulin, cystic fibrosis, steroid diabetes, and additional monogenic forms of the disease (WHO, 2020).

The origin of DMI is unknown and not easy detected, while an unhealthy lifestyle and obesity are characteristics of DMII. Both these types of DM are lifelong diseases with no cure (Serbis, Giapros, Kotanidou, Galli-Tsinopoulou & Siomou, 2021; Saeedi, Petersohn, Salpea, Bright & Williams, 2019). A regulated balanced diet that stabilizes glucose levels and frequent exercise will reduce the dependence on medication in persons diagnosed with DMII (Makgabutlane, 2018). While the causes of DMI and DMII are distinct, both illnesses require insulin (Goyal & Jialal, 2021; Saeedi *et al.*, 2019). A healthy lifestyle can prevent DMII but not DMI (Makgabutlane, 2018; ADA, 2016). The onset of DMI is usually instantaneous and if symptoms occur, immediate medical attention is a necessity (ADA, 2016).

The first stage of DM is prediabetes and during this preliminary stage there is no evident signs, although a regular blood test will reveal elevated blood glucose levels (WHO, 2020; ADA, 2016). DMI and DMII continue to be a leading cause of amputations, decreased vision, and renal failure due to physical problems despite maintaining a stable blood pressure and glycaemic control the (Serbis *et al.*, 2021; Pheiffer, Pillay-van Wyk, Joubert, Levitt, Nglazi, Mweete & Bradshaw, 2018). Furthermore, DM can develop serious clinical problems in adolescents if an excess of glucose (hyperglycaemia) in the bloodstream (Goyal & Jialal, 2021). These challenges comprise of not

being able to completely adjust to the disease and treatment but also experiencing challenges to continue a normal life as an individual and with family members. Children and adolescents with DM have an increased chance of developing a psychological disorder with a prevalence ranging between 12% and 83% (Onyiriuka & Ifebi, 2013).

DM remains a health challenge and is a more prevalent globally (Pheiffer *et al.*, 2018). The discussion will therefore focus on the prevalence of DM in the following section.

2.3 DIABETES MELLITUS PREVALENCY

There is an escalation in the prevalence of DM globally (Goyal & Jialal, 2021; Gupta *et al.*, 2015). An estimated diagnosis of DMI and DMII is prevalent in 537 million adults (20-79 years) globally and the number will rise to 783 million persons in 2045 (IDF, 2021). One in every five individuals above the age of 65 years and one in eleven adults below the age of 65 years have a DM diagnosis according to research (Goyal & Jialal, 2021; Zheng, Ley & Hu, 2018). Research furthermore indicates that one in two persons are not aware that they have the disease (IDF, 2021).

DM is one of the leading causes of mortality and morbidity globally in both developed and developing countries, continues to be an increasing problem (Khan *et al.*, 2020) and has caused 6.7 million deaths globally (IDF, 2021). Premature diabetes-related mortality increased with 5% between 2000 and 2016 and DM has caused an estimated 1.6 million deaths in 2016 (WHO, 2020). Fifty percent of all high blood glucose-related deaths occur before the age of 70 (Khan, Saba, Kausar & Siddiqui, 2019). DM is the ninth leading cause of death globally, with a 70% increase in prevalence since 2000, and is the leading cause of male deaths among the top ten diseases, with a staggering increase of 80% in mortality rates since 2000 (WHO, 2020).

Statistics furthermore indicate that DM is the tenth highest leading cause of mortality in high-income countries (Pheiffer *et al.*, 2021). An estimated 34.2 million people had a DM diagnosis in

the United States in 2018 (National Diabetes Statistics Report, 2020) and one in ten adult persons in China and one in twenty adults in the United Kingdom had DM (Elfein, 2021).

A similar trend is prevalent in Africa compared to globally where DM increase rapidly (IDF, 2021). The estimated prevalence of DM in Africa was 14.2 million people in 2015 and the projection was that there will be significant growth in DM numbers when compared with other regions globally (Sinclair, 2019; IDF, 2015). Africa recorded twenty-four million, which is one in twenty-two adults, which live with this disease and 416 000 deaths because of the disease occurred during 2021 (IDF, 2021). The prevalence of DM increased with 50% since 1980 and nine percent of men and 11.8% of women had DM in 2010 (Erzse, Stacey, Chola, Tugendhaft, Freeman & Hofman, 2019). The countries listed to have most people diagnosed with DM are Western Pacific with 206 million, Southeast Asia with ninety million, Middle East and North Africa with seventy-three million, Europe with sixty-one million, North America and the Caribbean with fifty-one million, South and Central America with thirty-two million, and Africa with twenty-four million (IDF, 2021).

2.3.1 DIABETES MELLITUS TYPE II PREVALENCY

The presence of DMII is one of the main challenges to human health in the twenty-first century (Khan *et al.*, 2020), and is a global pandemic (Unnikrishnan, Pradeepa, Joshi, Mohan, 2017). A diagnosis of DMII is prevalent in 90% of persons diagnosed with DM globally (Serbis *et al.*, 2021). India, China, and Asia are the epicentre of DMII diagnosis, and DMII developed into a global epidemic (Zheng *et al.*, 2018). A longitudinal study estimated that there will be more than five hundred million cases of DMII globally between 2018 and 2028 (Bradshaw Kaiser, Zhang & Van der Pluijm, 2018). The highest prevalence was amongst both low- and middle-income countries, and the prevalence will escalate in all countries with the highest growth in numbers in lower-income countries (Kader & Mohamed, 2020; Khan *et al.*, 2020). The living conditions in low-income countries contribute to this phenomenon (Bradshaw Kaiser *et al.*, 2018; Zheng *et al.*, 2018). Poor living conditions contribute to poor lifestyle choices such as no exercising, no or limited

intake of nutritional food, obesity, and smoking, which can result in the development of DMII (Zheng *et al.*, 2018; ADA, 2016). The vulnerability to DMII and obesity is greater in poorer sections of countries (Unnikrishnan *et al.*, 2017).

DMII are more prevalent in Africa and low-income countries (Kader & Mahomed, 2020; Pheiffer *et al.*, 2018) with an escalation in the prevalence in Sub-Saharan Africa in the last fifty years (Asmelash & Asmelash, 2019). There is a 77% mortality rate in people under the age of sixty years in Sub-Sahara Africa according to the eighth edition of the Diabetes Atlas (Dessie, Mulugeta, Amare, Negese, Wagnew, Getaneh, Endalamew, Adamu, Tadesse, Workineh & Leby, 2020).

There is a correlation between body mass index (BMI) and DM in both men and women (Pheiffer *et al.*, 2018). There was an increase in the BMI of persons from 1980 to 2014, which resulted in half of men being in the overweight risk group and half of the women in the obese risk group for developing DMII (Dessie *et al.*, 2020). BMI is however not an independent risk factor for this disease (Sinclair, 2019).

Women with a history of hyperglycaemia during pregnancy diagnosed with gestational diabetes mellitus, are seven times more vulnerable to develop DMII compared to women with no hyperglycaemia during pregnancy (Goyal & Jialal, 2021; Chivese, Norris & Levitt, 2019). These women and their children are therefore more likely to develop DMII later in life and diagnostic tests must be done regularly (Goyal & Jialal, 2021).

There was the highest proportional growth of people diagnosed with DMII, with 15.5 million people in 2017, and 69.2% of those were unaware of their DMII status (Pheiffer *et al.*, 2021). There is an increase in urbanisation and the associated lifestyle with this phenomenon as well as a genetic predisposition to DMII are all contributors to the high prevalence of the disease (Pheiffer *et al.*, 2021; Dessie *et al.*, 2020).

There are four African countries globally with the highest prevalence of DMII and South Africa is one of them (Boake, 2020). DMII is a leading cause of morbidity and mortality in South Africa, and these factors emphasize the importance of adequate self-management of the disease (Pheiffer *et al.*, 2018). An estimated two million individuals older than thirty-years of age had a DMII diagnosis in South Africa in 2009 which was 50% less in 2000 (Pheiffer *et al.*, 2021; Pheiffer *et al.*, 2018). The prevalence of DMII in South Africa was 4.5 % in 2010 but escalated with 155% in just six years (IDF, 2015). The IDF (2019) indicated that 4.5 million people in South Africa had DMII in 2019, which is an increase of 5.4% in 2017 (Kader & Mohamed, 2020). Makgabutlane (2018) states that five million people are at risk of developing the disease, and the majority of DMII patients in South Africa are undetected (Makgabutlane, 2018; Pheiffer *et al.*, 2018).

The age-standardised prevalence of DMII in South Africa is fifteen years and older, depending on the population group (Masupe, De Man, Onagbiye, Puoanie & Delobelle, 2021; Pheiffer *et al.*, 2021). Research initially indicated that the highest prevalence of DMII was amongst the Indian population, but studies have revealed that there is a high prevalence of DMII amongst people of colour () (Masupe *et al.*, 2021).

Makgabutlane (2018) states that the mortality rate of DM has surpassed heart disease and is the second leading cause of mortality in South Africa. DMII-related complications were the primary cause of mortality in women in South Africa in 2015, and the second most common cause of mortality in South Africa (Boake, 2020; Erzse *et al.*, 2019).

Statistics South Africa found that DMII is the leading cause of non-communicable mortality in persons over forty-five years of age in the Western Cape (Boake, 2020). Research on the prevalence, risk factors, diagnosis, and management, conducted in the Western Cape found that DMII was prevalent in 7.2% of 12,496 people (Baily, Ayles, Beyers, Godfrey-Faussett, Muyoyoeta, Du Toit, Yudkin & Floyd, 2016). Risk factors included people who were over the age of fifty and those who were obese, and 12.7% of the persons diagnosed with the disease were

unaware of their diagnosis (Baily *et al.*, 2016). A study conducted with a sample of 220 participants in Cape Town, South Africa found that people with a diagnosis of DMII in 48% and 47% of women who gave birth five-six years previously were unaware of their diagnosis. The study also found that women who were overweight with a higher glucose concentration were more susceptible to DMII (Chivese, *et al.*, 2019). In another study conducted with health care workers at Tygerberg Hospital in the Western Cape, Cape Town, 15% of their study sample were in the high-risk category, 27% in the moderate risk category, and 42% in the mild risk category. The prediction was that 11% of the study population will develop DMII in the following ten years (Coetzee, Beukes, Dreyer, Solomon, Du Toit, Mistry, Conradie & Van Der Vyver, 2019). Another study with 116 726 people on the database of people diagnosed with DMII in the Western Cape found that a 98.6% of those resided in the Cape Town metropole (Boake, 2020).

The above discussion emphasized the importance of DMII as topic, which is not only a global pandemic but evidence from literature indicated the high prevalence in South Africa. It is therefore important to focus on the biopsychosocial factors associated with DMII to address the phenomenon holistically.

2.4 FACTORS ASSOCIATED WITH DIABETES MELLITUS TYPE II

This section discusses the three factors associated with DMII. These factors are biological, psychological, and social factors.

2.4.1 BIOLOGICAL FACTORS

A biological factor encompasses anything that impacts a live organism's function and behaviour, and can be a physiological, physical, neurological, pharmacological, or genetic condition (Freeman & Pennings, 2021). Age, gender, family history/genetics, BMI, blood glucose, and the use of atypical antipsychotics are all biological influences associated with hereditary predispositions for DMII or treatment of other medical conditions (Freeman & Pennings, 2021; Khodaeian, Enayati,

Tabatabaei-Malazy & Amoli, 2015). The focus on the next section will be on a more detailed discussion of the biological factors related to DMII.

2.4.1.1 Biological factors contributing to diabetes mellitus type II

DMII can affect anyone regardless of their age and gender and risk factors can contribute to a DMII diagnosis (ADA, 2016). There are two interconnected problems which causes DMII, and these are the fat cells in the muscle, as well as the liver that become insulin resistant (Freeman & Pennings, 2021). The cells do not absorb enough sugar because they do not absorb insulin as expected, and the pancreas does not have enough insulin to regulate the blood sugar levels (Freeman & Pennings, 2021). It is difficult to distinguish between genetic and environmental risk factors contributing to this phenomenon and it is therefore important to follow healthy lifestyle habits such as a nutritional diet, and physical activities in daily routines (Kolb & Martin, 2017). If family members follow healthy eating habits children will follow and it will benefit their BMI (Flannick & Florez, 2016; Biswas, Faulkner, Bajaj, Silver, Mitchell & Alter, 2015). Genetics however also have a significant role in BMI and DM (Andersen, Pederson, Moltke, Hansen, Albrechtsen & Grarup, 2016). Gene mutations and lifestyle habits are therefore related to an increased risk of DM (Kolb & Martin, 2017; Andersen *et al.*, 2016). In general, mutations in any gene involved in glucose regulation may raise the risk of developing DMII (Andersen *et al.*, 2016; Flannick & Florez, 2016). Other biological characteristics (BMI, high blood pressure, history of gestational diabetes, prediabetes, and family history) are also predictors of a DMII diagnosis (Kolb & Martin, 2017; Andersen *et al.*, 2016).

Impaired fasting glycaemia and DMII are more common with age (Habtewold, Islam, Radie, 2016). In the United States, there was a staggering increase in cases diagnosed with DMII within the age group 20 years and older and an additional 38% of the population have a substantial risk to develop DMII (Pal, Horsfall, Sharma, Nazareth & Petersen, 2021; National Diabetes Statistic Report, 2020). A similar trend prevails in prevalence of DMII within this age range with an increase of

20% between 2000 and 2009 and 30% between 2009 to 2018 in England. The risk of a DMII diagnosis in individuals between the ages of 40 and 49 increased especially when poverty was present and was highest in those between the ages of 70 and 79. The incidence of prediabetes increased by 52% where age and hardship were present in comparison with people in less deprived areas (Pal *et al.*, 2021).

Obesity is the result of having an excessive amount of body fat (Parmar, 2018). It affects your entire body from your joints to your heart, blood pressure, blood sugar, and other processes (Parmar, 2018; Habtewold *et al.*, 2016). Excess weight has a variety of negative consequences on health and the most severe is DMII. Persons classified as being ‘overweight’ are three times more likely to develop DMII in comparison with persons being of ‘average weight’ (Parmar, 2018). Fat cells in the abdomen can release pro-inflammatory chemicals that disrupt the role of insulin-responsive cells and their ability to respond to insulin and the body is less receptive to the insulin it produces, which increases the chances of developing DMII (Habtewold *et al.*, 2016).

2.4.1.2 Biological complications of diabetes mellitus type II

Over time, poorly regulated blood glucose can result in various health complications (Su, Zhao, Wang, Wang, Zhang, Li, Liu, Yang, Li & Hou, 2019). Symptoms of DMII is often mild and the progress of the disease slow and people are unaware that they have the disease. (Makgabutlane, 2018; Pheiffer *et al.*, 2018). Persons diagnosed with DMII already developed complications (Makgabutlane, 2018), and it is essential for long-term supervision for patients to improve their treatment and glycaemic regulation due to the chronic nature of DMII (Gomes, Coelho, Dos Santos Gomides, Fos-Freitas, Foss & Pace, 2017).

The longer the period with DMII, the more likely to experience complications (Ghavami, Radfar, Soheily, Shamsi & Khalkhali, 2018; Gomes *et al.*, 2017). The complications of DMII are serious and biological characteristics include poor blood glucose levels, obesity, genetics, and age (Pheiffer *et al.*, 2018). Signs and symptoms of a diagnosis with DMII include thirst, frequent vaginal

infection, exhaustion, weight loss, polyuria which is a condition where a person urinates more than usual, and a history of blurred vision (Ghavami *et al.*, 2018). Complications due to DMII include retinopathy (eye damage), neuropathy (nerve damage), nephropathy (kidney damage), erectile dysfunction and high blood pressure, foot damage, skin conditions, hearing deficiency and heart and blood vessel disease with a risk of strokes and heart disease (IDF, 2021; Masupe *et al.*, 2021). Other complications include gastroparesis which is a condition where food remains in the abdomen for longer than necessary, depression, tooth decay, and more recently scientists discovered a correlation between DMII and dementia (Kosiborod, Gomes, Nicolucci, Pocock, Rathmann, Shestakova, Watada, Shimomura, Chen, Cid-Ruzafa, Fenici, Hammar, Surmont, Tang & Khunti, 2018).

Poor management of DMII results in diabetic neuropathy which exists in approximately 50% of people with the disease (Lin & Jiaying 2019). Diabetic sensory neuropathy affects various nerves in the body, but most commonly the feet (WHO, 2020; Lin & Jiaying, 2019). It affects the sensation and symptoms include stinging discomfort and a burning sensation in the feet (Lin & Jiaying, 2019). Neuropathy in the feet combined with reduced blood flow is the leading cause of foot ulcers and as a result limb amputation (Kosiborod *et al.*, 2018). Signs of damaged nerves include weakness, tingling, and pain in the hands and feet (WHO, 2020). Furthermore, uncontrolled DM results in elevated blood glucose and causes damage to the kidneys, nerves, heart, eyes, and blood vessels (WHO, 2020; Pheiffer *et al.*, 2018). People with DMII also suffer from diabetic retinopathy which affects the eyes, and they are more vulnerable to develop severe visual impairment after 15 years of diagnosis (Lin & Jiaying, 2019; Kosiborod *et al.*, 2018).

2.4.2 PSYCHOLOGICAL FACTORS

DMII not only affects people physically but also their social, and psychological well-being (Kalra, Verma & Balhara, 2018). Prevailing psychosocial factors have an adverse impact on the social life and well-being of people diagnosed with DMII when disregarded (Dong, Qu, Gong, Pang, Yan,

Wei, 2019; Kalra *et al.*, 2018). The purpose of DMII treatment must also focus on the psychosocial barriers such as inadequate support, misinformation, inaccurate beliefs about the disease or treatment, emotional distress and depressive symptoms which can contribute to address the psychological problems related to self-care and treatment adherence (Kalra *et al.*, 2018; Young-Hyman, De Groot, Hill-Briggs, Gonzalez, Hood & Peyrot, 2016).

Psychological responses in vulnerable people are the result of the ongoing struggle to cope with triggers related to elevated levels of chronic stress (Kalra *et al.*, 2018). Persistent stress can lead to signs and symptoms of depression, anxiety, as well as poor self-esteem, as well as lack of ambition, and enthusiasm. These increase the risk for adverse behaviour such as smoking, disproportionate use of alcohol, not monitoring glycaemic and glucose levels, and indulging on junk food. Chronic stress has negative repercussions such as increased blood pressure and high blood glucose levels which result in the inability to react to potential stressors effectively (Dong *et al.*, 2019; Kalra *et al.*, 2018). There is a relationship between psychological issues such as depression, eating disorders, anxiety and DMII (Dong *et al.*, 2019). When there are fulfilment of psychological needs regulation and decrease of psychological comorbidities follow (Kalra *et al.*, 2018; Young-Hyman *et al.*, 2016).

Figure 2.1 from Kalra *et al.*, 2018 explains the psychological factors related to DM.

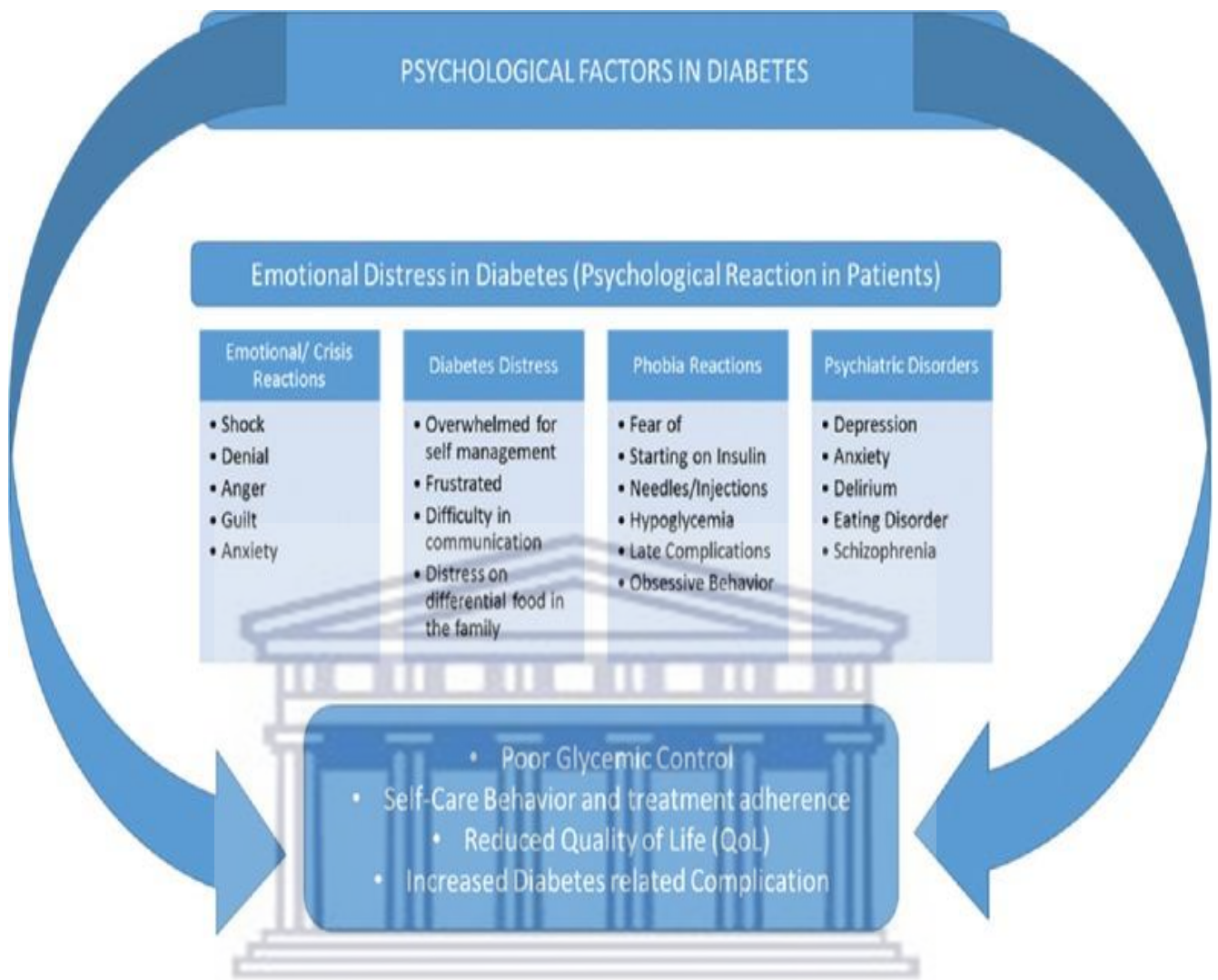


Figure 2.1: Psychological factors in Diabetes Mellitus type II (Kalra *et al.*, 2018)

Emotional distress is common among persons diagnosed with DM (Hamed, Ibrahim, Ali & Kheir, 2019; Snoek., Bremmer & Hermanns, 2015) and result in a lower quality of life, reduced monitoring of glycaemic levels, and higher rates of mortality (Hamed *et al.*, 2019; Kalra *et al.*, 2018). Emotional distress can be generic, or diabetes-specific, and is evident when fear of complications or concern about the direct impact which DMII can have on a person's day to day life developed (Snoek *et al.*, 2015).

Diabetes distress is a normal emotional response to DMII, and not classified as a mental illness (Young-Hyman *et al.*, 2016). Diabetes distress comprises of emotional pressure and concern that a person faces during the treatment of a severe chronic disease like DMII which is also frequently masked (Kalra *et al.*, 2018; Young-Hyman *et al.*, 2016). It is however not a complication of DMII

(Hamed *et al.*, 2019). People experience discomfort, remorse, or denial because of the diagnosis DMII and the responsibility of self-management of the disease during diabetes distress (Hamed *et al.*, 2019; Young-Hyman *et al.*, 2016) A person may experience diabetes distress on some occasions but might be anxious and distressed in other when a complication, change in treatment, or a change in their healthcare provider occur (Hamed *et al.*, 2019; Young-Hyman *et al.*, 2016). Indications of diabetes distress are related to the constant behavioural demands of diabetes self-management and the realisation of the progression of this disease (Young-Hyman *et al.*, 2016). This phenomenon can affect up to 40% of persons diagnosed with DM and there is an increase in diabetes distress in persons diagnosed with DMII (Hamed *et al.*, 2019; Snoek *et al.*, 2015). Patient specific interventions must monitor diabetes distress on a regular basis (Young-Hyman *et al.*, 2016). Referral for diabetes education to discuss diabetes self-care is important to achieve better outcomes during the detection of diabetes distress (Hamed *et al.*, 2019).

Individuals having DM are more likely to become depressed (ADA, 2016; Vancampfort, Correll, Gallinger, Probst, De Hert, Ward, Rosenbaum, Gaughran, Lally & Stubbs, 2016). Depression can also result in the development of DMII (ADA, 2016; Vancampfort *et al.*, 2016). Young-Hyman *et al.* (2016) found in a study that one in every four patients with DMII demonstrated depressive symptoms and depressive disorders. Depression may contribute to poor lifestyle decisions such as unhealthy eating habits, insufficient exercise, smoking, and weight gain, which are risk factors for DMII (De Groot, Hill & Wagner, 2016). Depression has a negative influence on the ability to communicate, logical reasoning, and the execution of daily activities (ADA, 2016; De Groot *et al.*, 2016). This contributes to strain in effective self-management of DM (Vancampfort *et al.*, 2016); Current depression, a history of depression, and the use of antidepressant drugs are all risk factors for DMII, particularly when related with another risk factor causing DMII (De Groot *et al.*, 2016; Vancampfort *et al.*, 2016). There is therefore a relationship between diabetes and depression which may be biological, and this has an influence on better care and outcomes for the disease (Badescu, Tataru, Kobylinska, Geogescu, Zahiu, Zagrean & Zagrean, 2016).

Anxiety has adverse outcomes in people with DM (Badescu *et al.*, 2016). Anxious people are less likely to adhere to self-care guidelines of DM and are more likely to be physically inactive and smoke, both behaviours which contribute to inadequate diabetes management and increased risk of emotional and physical complications (ADA, 2016). Anxiety is a result of general diabetes related concerns such as fear of hyperglycaemia, not reaching blood glucose thresholds, and insulin injections or infusions (De Groot *et al.*, 2016). Hypoglycaemia, or low blood sugar, is a risk factor for people with diabetes (ADA, 2016). Hypoglycaemia and anxiety have similar signs (Badescu *et al.*, 2016) and anxiety can complicate hypoglycaemia control (Young-Hyman *et al.*, 2016).

People diagnosed with DM have concerns about the perception of peers family and co-workers towards their condition (De Groot *et al.*, 2016). They are also concerned about the long-term consequences of their disease (Badescu *et al.*, 2016).

2.4.3 SOCIAL FACTORS

DMII and the challenges related to this disease contribute to social and environmental risk factors. Clinical approaches to assist people with DMII in the management of the disease progressed because more health care professionals recognize the significance of the social determinants of health that include income, access to resources, education, nutritional food, and housing. These variables have a considerable influence on DM and are predictors of health outcomes in the person with the disease and population ((Dendup, Feng, Clingan, Astell-Burt, 2018). Global and national research found that social determinants are significant in the development and progression of DMII, (Wang, Cao, Wu, Yang, Song, Tian, Wang, Wu & Hu, 2019).

It is not only important to consider biological and social factors but also include behavioural factors in the treatment of DMII (Dendup *et al.*, 2018). This necessitates the use of a combination of traditional medical and therapeutic approaches in the absence of a cure for DMII to control the disease or alleviate symptoms with lifestyle changes such as dietary changes, improved physical movement, and controlled drug regimens (Dong *et al.*, 2019; Dendup *et al.*, 2018). The purpose of

these combined therapeutic approaches is to maintain blood glucose levels, and prevent morbidity, and premature complications linked to DMII (Dong *et al.*, 2019). DMII as a multifaceted long-lasting disease requires immediate and radical adjustment to a person's lifestyle when diagnosed (Low, Tong & Low, 2014). Specific aspects complicate the treatment of a chronic disease and adherence to a routine can result in emotional responses which result in the development of mood and anxiety disorders. The relationship between DMII and obesity is multifaceted and can have a negative impact on the treatment of the disease. Adherence by the patient to a diabetic diet is another problem in the treatment of DMII (Khodaeian *et al.*, 2015). Patients with DMII adhere less to treatment than with other chronic diseases and minor behavioural changes aggravate this (IDF, 2019; ADA, 2016). Adherence to prescribed treatment is a problem in most chronic illnesses but is especially problematic with DMII due to the complex nature of the disease, risk of non-compliance, and the benefits of compliance (IDF, 2019; ADA, 2016). People with DMII does not only have trouble to adhere to the treatment but also experiences problems with the lifestyle changes (IDF, 2019).

2.4.3.1 Financial burden of diabetes mellitus type II

DM is a condition that affects more than just one's physical well-being it also include a financial burden (Manyema, *et al.*, 2015), with direct and indirect costs for patients, which escalate as DM progresses (Erzse *et al.*, 2019). The continuous medical treatment and management of DMII are costly and influence the health care budget (Manyema, Veerman, Chola, Tugendhaft, Labadarios & Hofman, 2015). Middle and low-income countries do not always consider this in planning for treatment and management of DMII (Erzse *et al.*, 2019). Income is a significant yet often ignored factor in DMII (Bird, Lemstra, Rogers & Moraros, 2015).

Individuals with DMII often rely on family members for financial support because disease influences their functioning when employed (Manyema *et al.*, 2015; Bird *et al.*, 2015). The daily routine during the treatment of DMII consume family time and resources (Erzse *et al.*, 2019). These

routines include transport to and from doctor appointments, supplies, and health insurance in addition to routine medical care (Erzse *et al.*, 2019; Kengne, Motala, Mbanya & Peer, 2016). Furthermore, the person diagnosed with DM must buy prescription medication which include insulin, cholesterol medication, and high blood pressure medication, vitamins and over-the-counter medications, glucose tablets/water, insulin device, and blood glucose strips (Erzse *et al.*, 2019). This contributes to financial difficulties in families because governmental health facilities do not provide all of these (Kengne *et al.*, 2016).

DMII is therefore a challenging health problem (Berenguera, Molló-Inesta, Mata-Cases, Franch-Nadal, Bolívar, Rubinat, & Mauricio, 2016). Socioeconomic factors such as income, employment status and education contribute to the fact that it is now more vital than ever to address DM as a public health concern and acknowledge that the disease has an impact not only on persons diagnosed but also on families, communities, and society (Erzse *et al.*, 2019; Kalra *et al.*, 2018). It is important to focus on each of these areas (persons, families, communities, and society) if the goal is to stop or significantly decrease the DMII epidemic (Erzse *et al.*, 2019). Additionally, the financial consequences will become more widespread on a global scale with the increase of the prevalence of DMII (Afroz, Alramadan, Hossain, Romero, Alam, Maliano & Billah, 2018). The occurrence of DM with South Africa's HIV/AIDS and tuberculosis (TB) co-pandemics, contribute to additional pressure on an already unstable public health care structure that assists and renders health care services to over 80% of South Africa's population. The estimation is that 80.6% of the population in South Africa with DM, both diagnosed and undiagnosed experience constraints in their treatment (Erzse *et al.*, 2019). The health care rate for DM is 19.4% which is far lower than the recommended rate of 80% proposed by the WHO and World Bank Group's for countries with Universal Health Coverage [UHC] (Bird *et al.*, 2015).

2.4.3.2 Physical activity, diet, and obesity

Minor lifestyle modifications are beneficial in the prevention or delay in the onset of DMII (WHO, 2021). A combination of physical inactivity, overindulging, and unhealthy eating habits contribute to DMII (Wilmot & Idris, 2014). An individual diagnosed with DMII, must adjust their lifestyle to include moderate-intensity physical activities or high-intensity workouts, work towards a healthier BMI by gradually losing weight, substitute refined carbohydrates with whole-grain foods, and reduce stress and anxiety levels (IDF, 2015). These factors will decrease insulin sensitivity and glycaemic management (IDF, 2019; Wilmot & Idris, 2014). Exercise, with calorie restrictions, is one of the most effective tools in the prevention and treatment of obesity and DMII (Wilmot & Idris, 2014). People must acquire and maintain a healthy body weight, consume a nutritious diet, low in sugar and saturated fats, and be physically active where they engage in at least 30 minutes of regular, moderate-intensity activity, at least every second day to avoid DMII and consequent risks factors because of the disease (WHO, 2021). Improvement in a patient's nutritional knowledge, attitudes, and habits can assist in the treatment of DMII (Sami, Ansari, Butt & Hamid, 2017).

Implementation of the dietary and physical activity can be difficult in the treatment of DMII (Wang *et al.*, 2019; Low *et al.*, 2014). Patients have poor awareness on the role of nutrition in diabetes care despite the high prevalence of DMII (Sami *et al.*, 2017). Persons living in poverty are frequently forced to purchase unhealthy food products (Bekele, Asefa, Getachew & Muche, 2020). People living in poverty with a lack of education are more likely to consume food that is high in fats and low in fibre compared to persons that are more affluent and educated. They experience a high rate of food insecurity, less access to nutritional food and food is expensive, which contribute to DMII (Bekele *et al.*, 2020).

2.5 EXPERIENCES OF INDIVIDUALS DIAGNOSED WITH DIABETES MELLITUS TYPE II

The aim of the research and consideration of the previous factors discussed in this section necessitate cognizance on the experiences of individuals diagnosed with DMII.

2.5.1 Experience after diagnosis

Persons diagnosed with DMII have a greater risk of reduced physical, emotional, and social well-being (Gupta *et al.*, 2015). A study conducted at the University Teaching Hospital in Lusaka, Zambia, on the experiences of persons diagnosed with DMII, found that persons often experience physical illnesses, mental challenges, poor family support, and insufficient information (Mwila, Bwembya & Jacobs, 2019).

DMII influences various aspects of a person's life, which necessitates lifestyle changes to benefit of their health and the future (Sebire, Toumpakari, Turner, Cooper, Page, Malpass & Andrews 2018). However, Low *et al.* (2014) found that due to the lifetime commitment to lifestyle changes persons diagnosed was not keen to make immediate healthier changes. People found lifestyle changes challenging because they were familiar with their current lifestyle (Sebire *et al.*, 2018). Help-seeking behaviour in people with DMII demonstrates motivation to lifestyle changes and motivates persons to experiment and examine various treatment options (Low *et al.*, 2014; Davies, McGale, Humphries, Hirani, Beaney, Bappa, McCabe, Newman, 2015). However, people recognize that the change do not only comprise of dietary intake but also psychological and physical adjustment (Low *et al.*, 2014).

The emotions related to DMII include fear, unhappiness, apprehension, denial, and regret (Berenguaera *et al.*, 2016). Persons experience mixed feelings towards the needed changes which encompass restrictions where they desire a sense of personal and dietary independence (Cunningham, Gentsch, Doty, Mills, LaNoue, Carr, Hollander & Rising, 2020). The motivation to make the necessary lifestyle changes but also the acknowledgement of the difficulty to stay

disciplined contribute to experiences of mixed emotions (Davies *et al.*, 2015). Positive emotions in people with DMII signify that they anticipate healthier lifestyle changes which will have an impact on their future life (Davies *et al.*, 2015). Positive feelings also indicate acceptance of the disease and lifestyle changes (Davies *et al.*, 2015; Low *et al.*, 2014).

Negative emotions are an indication that the person with DMII experiences fear of complications due to the disease and will not be able to adhere to a healthier lifestyle (Davies *et al.*, 2015; Low *et al.*, 2014). Sebire *et al.* (2018) reported that persons who experience negative feelings find the diagnosis unpleasant and usually have difficulty to accept the disease. The constant decline in health also contributes to constant fear in people with DMII (Cunningham *et al.*, 2020). Feelings of frustration are evident because people with DMII must monitor their glucose levels regularly (Low *et al.*, 2014). Patients experience more negative feelings when they realize that they need insulin injections due to the fear towards injections (Davies *et al.*, 2015; Low *et al.*, 2014). There is a relationship between the range of mixed emotions experienced with the diagnosis of DMII, the adjustment towards the disease and lifestyle management (Low *et al.*, 2014).

2.5.2 Physical illnesses

Persons diagnosed with DMII often change their unhealthy lifestyle to a healthier lifestyle but however experience that they are more vulnerable to illness because of a weak immune system which makes them more susceptible to diseases (Mwila *et al.*, 2019). People diagnosed with DMII must have constant and not elevated blood glucose levels because elevated levels will result in hospital admissions and frequent doctor visits (Mwila *et al.*, 2019). Glycaemic targets are based on the individual's age, period of diabetes, the absenteeism or existence of the cardiac disease, and risk of severe hypoglycaemia/ hyperglycaemia (IDF, 2015). Hyperglycaemia occurs when the blood sugar exceeds 180 to 200 milligrams per decilitre (mg/dL) and can result in kidney, heart, nerve, and vision complications and even result in a coma or death (IDF, 2015). Hypoglycaemia is present when the blood sugar is below 70 mg/dL, and can result in accidents, a coma, and death

(IDF, 2015). Physical illnesses which can develop as the disease progresses include difficulty in breathing, constant headaches, fatigue, bloating, intestinal pain, and piercing pains, mostly in the hands and feet, loss of eyesight and sexual dysfunction (Mwila *et al.*, 2019; Pheiffer *et al.*, 2018). Depression, high blood pressure, cholesterol, and foot problems are also present in persons diagnosed with DMII. These physical illnesses in people with DMII result from inadequate treatment because they do not have access to resources, are not financially able to afford the necessary medication and medical care, or because they experience depressive symptoms that lead to non-compliance (Gopisetty, Levine, Liu, Younge, Brown, Close & Wood, 2018).

A diagnosis with DMII and treatment, which include exercising; deciding what to eat, and measuring blood glucose is demanding and influence the persons' daily quality of life (Gopisetty *et al.*, 2018). High (hyperglycaemia) or low (hypoglycaemia) blood sugar can occur at any time whether it is during the night or during the day (IDF, 2015). The person with DMII experiences stress and fear which are complicated because there is another doctor's appointment and a need to take time from work (Gopisetty *et al.*, 2018; ADA, 2016). Daily use of medication is necessary for all the various illnesses caused by DMII (Masupe *et al.*, 2021). Uncertainty about the physical and emotional health affect future planning, self-confidence, and intimate/sexual relationships of people with DMII (Gopisetty *et al.*, 2018). The most frequently ranked factors that influence the daily life of those with DMII are uncertainty about future planning of diet and weight management, followed by blood glucose control, and the time and commitment to manage this disease (Masupe *et al.*, 2021; Gopisetty *et al.*, 2018).

2.5.3 Engagement with health care workers

Patient involvement is a critical component of high-quality healthcare, especially with chronic diseases. It is important for patients to participate during doctor visits because it improves the efficacy and reliability of the treatment and thus prevent a risk of poor health outcomes and does not contribute to a waste of health care resources (Bombard, Baker, Orlando, Fancott, Bhatia,

Casalino, Onate, Dennis & Pomey, 2018). It is important for each patient to advocate for themselves, fully understand their health condition, get more information on their treatment, and the reason they follow it (Bombard *et al.*, 2018; WHO, 2016).

Poor communication and relations between the patient and health care workers contribute to lower rates in treatment adherence. The need to establish rapport and conveying a genuine interest in patients is therefore important (Lin & Jiyaing, 2019; Mwila *et al.*, 2019). Nonadherence to treatment is the result of insufficient patient education on their diagnosis or prescribed medication (Lin & Jiyaing, 2019; Pheiffer *et al.*, 2018). A study of Pheiffer *et al.* (2018) found that the majority individuals reported that the doctor and nurse do not spend enough time with them; they do not see the same doctor or nurse for their follow-up sessions, and this consequently result in different treatment plans and confusing information. The doctor-patient relationship is significant in the provision of emotional support to the patient (Lin & Jiyaing, 2019). Patients experience dissatisfaction with their doctors, and they perceive appointments as a lost opportunity to obtain support because doctors are too stressed (West & Coia, 2019). Patients also state that doctors give them abstract, theoretical guidelines about their care and lifestyle changes, which they found difficult to integrate in their daily routine and they therefore experience limited education in the required health skills needed to deal with this disease (West & Coia, 2019).

Various consultations with specialists including nutritionists are imperative if diagnosed with DMII. The nutritionist educates the person with DMII on their dietary consumption. Nutritional therapy is however expensive and there is limited access to this service when provided by public health care facilities (Mwila *et al.*, 2019).

2.5.4 Family support

A diagnosis of DMII and the treatment affect the patient and their immediate family, which may result in psychological distress or an increased sense of duty and support because the self-management and self-care occur in a family context (Bennich *et al.*, 2017). The family is primary

source of social support for the person with DMII and plays a significant role in the facilitation of DM self-care (Gomes *et al.*, 2017).

In most households the first person/s responsible for a person diagnosed with DMII is a family member and not necessarily because they are related but because they feel socially obliged to do so (Gomes *et al.*, 2017). The management of the diagnosis is dependent on the support which patients receive from family members. Limited support to the spouse or significant other result in feelings of loneliness and difficulty in the adaptation to their new role with a person diagnosed with DMII. (Lin & Jiayang, 2019). Persons diagnosed with DMII reported that family members tend to mock them because of their diagnosis which causes sadness and irritation. Family members do not support them emotionally but humiliate them by accusing them as weak and blame them for having the disease (Mwila *et al.*, 2019; Low *et al.*, 2014). The diagnosis of DM affects every family directly and it is important to know if family members can identify the warning signs of the disease and assist the person diagnosed with DMII (Bennich *et al.*, 2017). Family members are co-dependent and influence one another and a discussion on the intra-familial perspective towards supportive and non-supportive relationships during DMII is therefore necessary (Kristiangrum, Wiarsih & Nursai, 2018; Bennich *et al.*, 2017).

Spouses or significant others provide support (Lin & Jiaying, 2019). Support includes meal preparations, reminding patients to take their medication, exercise, and assistance with monitoring of glucose (Bennich *et al.*, 2017). Children also play a vital part in supporting their parents diagnosed with DMII especially when they provide health information and assist with therapy (Lin & Jiaying, 2019). Family support can play a positive role in assistance of persons diagnosed with DMII with better disease management by decreasing the risk of elevated blood glucose levels, anxiety, depression, and motivation to adapt to a healthier lifestyle which will result in better control of the disease and to delay DM related complications related (Kalra *et al.*, 2018; Bennich *et al.*, 2017). The physical and emotional situation of the person with DMII can improve with the

inclusion of family member/s in diabetes interventions and when dealing with challenging behaviour from the family carer (Mayberry, Harper & Osborn, 2016).

The support which the person with DMII receives in their environmental and social contexts motivates self-care activities (Mayberry *et al.*, 2016), limits any stress-related factors and allowing the person to successfully self-manage the disease (Pesantes *et al.*, 2017; Mayberry *et al.*, 2016). Constant positive social support affects the psychological well-being of the person with DMII and will result in improved quality of life and less diabetes distress (Mayberry *et al.*, 2016). Exposure to negative, uncontrollable incidents that jeopardise one's sense of agency will result in stress (Kalra *et al.*, 2018; Mayberry *et al.*, 2016). Social factors such as income, education, employment, social status, social mobility, and household composition influence psychological stress (Kalra *et al.*, 2018; Young-Hyman *et al.*, 2016). Social support enhances the psychological well-being of the person with DM and limits stress-related biological reactivity which causes inflammatory responses, social distresses and an increasing the risk of various health problems (Sinclair, 2019; Snoek *et al.*, 2015).

Certain behaviours and beliefs in the family contribute to experiences of safety and trust to depend on family members for information and advice (Gomes *et al.*, 2017). When a person with DMII initiates healthy behaviour which includes regular physical exercise, adherence to medication, a healthier eating plan and consistent follow-up treatment with health care providers, the person is more likely to sustain self-care (Mayberry *et al.*, 2016; Pesantes, Del Valle, Diez-Canseco, Bernabe-Ortiz, Portocarrero, Trujillo, Cornejo, Manrique, Miranda, 2017).

The previous discussion focused on the experiences of people diagnosed with DMII, but it is imperative to focus also on the experiences of the spouses'/family members who care for people diagnosed with DMII especially when considering the previous content.

2.6 EXPERIENCES OF SIGNIFICANT OTHERS

The diagnosis of DMII does not only affect the person diagnosed but also the significant others of the person which include a family member, spouse, or social support structures (Justus, 2020; Kristianingrum *et al.*, 2018).

DMII has various effects on family members, ranging from improved family stability to causation of psychological distress (Mlaba, Ginindza & Hlongwana, 2021; Bennich *et al.*, 2017). Families may experience a burden of care when caring for the patient with DMII (Mlaba *et al.*, 2021). Changes in the health of patients with DMII and the necessity to acquire the necessary knowledge to assist the patient affect close family members especially partners (Mlaba *et al.*, 2021; Maree, Moshima, Ngubeni & Zondi, 2017). Their willingness and enthusiasm to assist the person with DMII may lead to signs and symptoms of anxiety and stress because of their involvement the person perceives them as persistent and controlling (Johansen, Cvancarova & Ruland, 2018).

Emotions for both the person diagnosed with DMII and the significant other caring for them are overwhelming (Kristianingrum *et al.*, 2018; Pesantes *et al.*, 2017). Anxiety, stress, and frustration are present due to the unexpected and sudden changes from the onset of the disease not only for the person diagnosed with DMII but also for the ones caring for them (Gomes *et al.*, 2017; Pesantes *et al.*, 2017). Confusion arises to the new adjustments and acceptance of the new lifestyle, and they must determine the demands of new arrangements and how they should comply with their new roles (Justus, 2020; Berenguaera *et al.*, 2016). The concerns of family members include the influence of the disease on employment, hypoglycaemia/hyperglycaemia levels, the adverse effects of DM on relationships, and the support from family members to enhance meaningful life changes to benefit the persons' health (Berenguera *et al.*, 2016). Dysfunctional family behaviours such as bickering over food, exercise, or medication complicate the patient's ability to control their condition effectively and adversely affect the spouse/family members (Bennich *et al.*, 2017).

Families have reported that they can also experience emotional, psychological, and financial challenges as those diagnosed with DMII but do not receive the same support as the person diagnosed with DMII (Mlaba *et al.*, 2021; Berenguera *et al.*, 2016). Support to the one diagnosed with DMII includes physical and emotional guidance, financial sponsorship, assistance with daily tasks, reminding them to take their medication, and preparation of healthy food (Johnson & Melton, 2015). These types of support are time consuming for family members and they often experience emotional distress and physical exhaustion due to constantly monitoring of the person and repeating themselves (Justus, 2020; Berenguera *et al.*, 2016). Mechanisms to assist significant others in dealing with the burden of diabetes care include communication about the life changes, adaptation of both parties to the diagnosis, negotiation on the caregiver position, and setting of specific boundaries (Justus, 2020; Kristianingrum *et al.*, 2018).

Support from significant others, whether expected or not, is a motivating factor in DMII self-management (Baig, Benitaz, Quinn & Burnet, 2015; Justus, 2020). The role of spouses and family members are crucial to influence the diagnosed person to follow a healthy diet and self-care regimes; however, their efforts often result in resistance and increased interpersonal conflict (Mlaba *et al.*, 2021; Johansen *et al.*, 2018;). Increased stress of the family member is the disadvantage which result from guidance on healthy meals preparation, exercising, or social control by attempting to directly influence behaviour is (Maree *et al.*, 2017). Involvement in the well-being and diabetes self-care habits of the person with DMII result in increased stress and pressure for the care giver (Maree *et al.*, 2017; Johnson & Melton, 2015).

A partner of a person diagnosed with DMII experience daily emotional strain (Maree *et al.*, 2017; Johnson & Melton, 2015). Family members often experience anxiety due to limited knowledge of the disease and will be willing to get added information in a recently diagnosed person with DMII, but too much information at once can causes anxiety which can result in stress and burnout (Snoek *et al.*, 2015). The family member also experiences pressure and stress because they must change

their lifestyle to conform to the new lifestyle of the person with DMII. They perceive this as an invasion in their personal space (Maree *et al.*, 2017).

The treatment of DMII creates long-term stressors for spouses, which influence their perception of daily living and the relationship with the person diagnosed with DMII (Nissen, 2016). They experience disagreements and tension in their partnership, which affects their well-being and the diabetes management of the person diagnosed with this disease (Maree *et al.*, 2017; Nissen, 2016). Daily experiences of diabetes distress increase the chances of conflict, and as symptoms progress, partners display less satisfaction in the relationship (Nissen, 2016).

The family members experience fear related to the possible complications of DMII (Chrvala, Sherr & Lipman, 2016). The caregiver frequently fears emergency treatment during episodes of hypoglycaemia or hyperglycaemia, experiences anxiety concerning the long-term complications and distress and the possibility of a limited lifespan for the person diagnosed with DMII (Mlaba *et al.*, 2021; ADA, 2016). Family members think that complications of DMII will influence their potential future choices (Baig *et al.*, 2015). Family members experience elevated levels of anxiety due to the possibility that the person can develop complications such as kidney or heart disease, problems with sight and feet (Chrvala *et al.*, 2016; ADA, 2016). They also feel powerless and worried due to the daily experiences and effects of complications in the person diagnosed with DMII (Johansen *et al.*, 2018; Johnson & Melton, 2015). They experience a sense of burden because of these intensified short and long-term fears (Baig *et al.*, 2015). Caregivers also experience trauma when they witness their partner with DMII having an episode of hypoglycaemia or hyperglycaemia (Mlaba *et al.*, 2021; Baig *et al.*, 2015). The sense of burden intensified because they are terrified when an emergency occurs, and do not have the knowledge to assist the person with DMII (ADA, 2016). Family members can become physically ill due to the amount of stress they carry as a result of the sudden changes in their life (Mlaba *et al.*, 2021; Johansen *et al.*, 2018).

2.7 THE BIOPSYCHOSOCIAL MODEL (BPS)

The BPS model is the conceptual framework on which this study is based. The BPS model, as a theoretical approach in health care, explains the continuous interaction between the biological characteristics of illness and disease with psychological and social factors (Wade & Halligan, 2017). This is an integrated approach which include the biological factors such as a genetic predisposition, psychological factors which include emotions, feelings, and behaviour and social characteristics for example social support, cultural influences, family relationships, class of each patient, and recognises the interaction between these a range of factors (Gentry *et al.*, 2018; Engel, 1977). The BPS model of health argues that health and disease are the results of a variety of variables which do not only include biological factors but also include psychological and social factors (Wade & Halligan, 2017). Farre and Rapley (2017) argue that the original biomedical model considered the biological characteristics of a disease but neglected to consider the significance of the social, psychological, and behavioural factors necessary for the treatment of the patient. Health care professionals implementing the BPS model during the treatment of DMII acknowledge the significance of social, psychological, behavioural, and not only biological factors which have a substantial impact on a patients' outcomes (Kalra *et al.*, 2018; Farre & Rapley, 2017). Therefore, the suitability of the BPS model for this study enables the researcher to focus not only on the biological characteristics of the person diagnosed with DMII, but also on their psychological experiences, feelings and values, and the social influences, such as their interaction with their families and the wider community (Engel, 1977). The BPS model emphasized that thoughts, feelings, and behaviours can affect one's physical state and recognises the uniqueness of each patient, as well as the influence of their social, psychological, and behavioural characteristics on their biological functioning (Farre & Rapley, 2017; Engel, 1977).

Biological, psychological, and social characteristics play a vital role in causation and treatment of DMII (Babalola, Noel & White, 2017). Biological factors which trigger DMII are overweight/obesity and a predisposition to DMII (Bababola *et al.*, 2017). Social factors

contributing to the high prevalence of DMII include a sedentary lifestyle with lack of exercise as well as nutritional food, excessive eating of junk food, high-fat diets, and high stress levels. A study with two major randomized cohorts of overweight adults found that there was a 58% decrease in the incidence of DMII after a reduction of glucose tolerance and application of lifestyle interventions such as exercise, dietary changes, and weight loss implemented (Babalola *et al.*, 2017). These findings demonstrate that healthy lifestyle modifications that can significantly minimise triggers and/or contribute to better management of DMII (Wade & Halligan, 2017).

DMII is a complicated and demanding disease which causes significant psychological stress and exacerbates self-management (Babalola *et al.*, 2017). Stress which influences the stress hormones combined with other biological factors also affects glycaemic regulation in people with DMII. The individual coping skills of a person with DMII however also affects their of stress levels (Young-Hyman *et al.*, 2016). Chronic harmful stressors often contribute to deliberate impairment of healthy habits and disease management (WHO, 2020). It is therefore important to deal with the psychological effects of the disease timeously to ensure that DMII does not contribute to other health problems (Babalola *et al.*, 2017; Wade & Halligan, 2017). The BPS model proposes that a person's subjective experience during DMII significantly contributes to reliable health outcomes and treatment (Wade & Halligan, 2017). The key aim of the BPS models is to develop the capacity of people through the provision of psychological and social support.

2.8 CHAPTER SUMMARY

This chapter provided an overview of the literature within the framework of the BPS model. The focus was therefore on a detailed explanation of DM, the diverse types of DM, and an in-depth understanding of the clinical features and prevalence of DMII. The chapter also focused on the experiences of a person diagnosed with DMII and their significant others caring for them within the framework of the BPS model which include the psychological and social factors.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

Chapter one, presented an introduction to the thesis, focusing on the research problem, the research question, aim, and objectives. This served as an orientation of the research methodology used to implement this study. Chapter three explains the implementation of the research methodology during this study which focus on the research approach and design, population and sampling, data collection, and data analysis. The chapter also include the research ethics that guided the research, a discussion of the limitations of the study, and a conclusion of the chapter.

3.2 RESEARCH QUESTION

The creation of a research question is a crucial component of a study; and is a significant aspect of a research study (Fouché & De Vos, 2011). The current study, therefore, asked the question: *What are the experiences of individuals living with diabetes type II and their significant others caring for them?*

3.3 RESEARCH AIM AND OBJECTIVES

3.3.1 AIM

The research aims to understand how participants develop meaning from their situations, and how their meaning influences their behaviour (Fouché & De Vos, 2011). The aim of this research was to gain an in-depth understanding of the lived experiences of those living with DMII and their significant others caring for them.

3.3.2 OBJECTIVES

Objectives are the steps which the researcher follows to reach the goal (Fouché & De Vos, 2011). The content and presentation of data presented to the researcher, participants, and reader of the research are based on the research objectives (De Vos, Strydom, Fouché & Delpont, 2005). The

objectives must be an extension of the aim and must be closely related to the aim (De Vos et al., 2005).

The following research objectives result from the aim of this study:

- To explore the lived experiences of adults living with DMII.
- To explore and describe the reason why adults living with DMII do not adhere to treatment and medication.
- To explore and describe the lived experiences and effects of significant others caring for individuals with DMII.
- To describe significant others' understanding of the contributing factors of the diagnosis, treatment and medication on the person taking the medication.

3.4 RESEARCH METHODOLOGY

The research methodology of a study includes the data collection methods and approaches, as well as their underlying assumptions, used during the specific research (Babbie & Mouton, 2010). Research methodology uses a detailed approach that classifies, selects, processes, and discusses knowledge based on a subject chosen (Babbie & Mouton, 2007) to assist with goal attainment of the research and determines the credibility and validity of the study (Van Den Heever, 2011).

3.4.1 Research approach

This research employed a qualitative research approach to provide in-depth, rich data to the readers (Babbie & Mouton, 2010; Henning, Van Rensburg & Smith, 2004). Qualitative research is “first hand” interaction with the social environment, where “first hand” refer to the context of the research and the “involvement” referring to the participation of the participants in the research study (Henning *et al.*, 2004). Researchers using quantitative research pursue to control the outcome of the research by specifically designed instruments, whereas qualitative researchers do not pursue to control their research components (Henning *et al.*, 2004). The qualitative approach was employed during this study because it would have been difficult to get an in-depth understanding

from a closed-question survey. Participants in this study could freely share their experiences, opinions, and feelings without fear (Creswell, 2013; Babbie & Mouton, 2010), which resulted in a true reflection of their experiences and not from the perspective of the researcher. The qualitative research approach was therefore suitable for this study to explore and describe the lived experiences of those living with DMII and their significant others (Creswell, 2013).

3.4.2 Research design

A research design refers to an entire approach and planning of a scientific inquiry (Babbie & Mouton, 2007). Explorative and descriptive research designs were employed for this study. An explorative research design focuses on unknown topics, creates preliminary perceptions on the nature of a problem, and develops questions which require further in more in-depth studies. An exploratory research design provides new perceptions, discovers fresh concepts, and increases the understanding of the specific phenomenon (De Vos *et al.*, 2011). The researcher used an exploratory research design during this study to understand the lived experiences of participants' diagnosed with DMII, the experiences of their significant others' living with them and the contexts, in which these experiences occur (Babbie & Mouton, 2010). Exploratory studies resolve the 'what' questions of the phenomenon and aim to generate information and are preliminary studies into an unknown phenomenon (De Vos *et al.*, 2011). This was consistent with this study which asked the research question: "What are the lived experiences of individuals diagnosed with DMII, and their significant others living with them." This also corresponds with the objectives of the study which seek to explore the lived experiences and the contexts in which these experiences occur for individuals diagnosed with DMII and their significant others

A descriptive research design provides a deeper understanding of a phenomenon provide detailed descriptions of participants' feelings and emotions (De Vos *et al.*, 2011; Babbie & Mouton, 2010). The goal of descriptive research is not to determine "cause-and-effect" connotations, but accurately describe conditions and events (Creswell & Creswell, 2018). A detailed description of the

experiences and the context in which these experiences will follow in the findings chapters, in chapter four and five of this study.

3.4.3 Phenomenology as a strategy of inquiry

Qualitative research includes five strategies of inquiry namely grounded theory, narrative, ethnography, case study, and phenomenology (Creswell & Creswell, 2018; Creswell, 2013). This study is based on phenomenology as a strategy of inquiry because the focus of the study was on the exploration of the lived experiences of the participants living with DMII and that of their significant others. A phenomenological approach outlines the shared meaning of a notion or phenomenon for multiple people (Creswell & Creswell, 2018; Creswell, 2013). Phenomenologists emphasize and describe the common experiences of people on a phenomenon (Creswell, 2013; Fouché & Schurink, 2011). Phenomenology therefore is a study exploring people's perceptions, viewpoints, and understanding of specific circumstances as it occurs in their daily lives (Creswell, 2013; Fouché & Schurink, 2011). The focus is not so much on the interpretations of the experiences, but more on the exploration and describing of the experiences of the individuals (Creswell, 2013). Phenomenology seeks the truth of individual experiences through individuals (Moustakas, 1994). Therefore, this strategy of inquiry was suitable for this study because it allowed the participants to participate in an open, deep, and sensitive discussion about their experiences, allowing for a deep and rich understanding of their lived experiences (Creswell, 2007). The research question in phenomenology is general and attempts to answer the "what" (lived experiences) in the research question which is: "What are the experiences of people living with DMII and their significant other's caring for them?" The researcher used textural language that describes what they see, including both the external qualities and internal consciousness, and leave the experience without tempering (Moustakas, 1994).

3.4.4 Research setting

The researcher collected data in a physical research setting (Creswell, 2013). The researcher collected data in the Mitchells Plain area, which is approximately twenty kilometres west of Langa in Cape Town. Mitchell's Plain is well-known for gangsterism and abuse of illegal substances amongst its youth and is one of fifteen places listed as a high priority for action against crime and substance abuse. Sub-areas in Mitchell's Plain include Beacon Valley, Eastridge, Lentegeur, London Village, Lost City, New Tafelsig, Portlands (eastern suburbs) and Bayview, Colorado, Pelikan Heights, Rondevlei, Strandfontein, Wavecrest, Weltevreden Glen, Westridge, also West Gate or western suburbs (Western Cape Government, 2020). The population of Mitchell's Plain's sub-district ranged between the ages of 0-85; comprised of 311 366, males and 314 188 females during 2021. This was a combined population of 625 554 (Western Cape Government, 2020). Data estimates that the population in the Mitchells Plain district would rise to 716 386 by the year 2030 (Western Cape Government, 2020).

3.4.5 Population

The population consists of people, communities, objects, and events that meet the criteria of the related research project (Babbie & Mouton, 2010). The population for this study consisted of the Diabetes Wellness/Support Group in the Mitchells Plain area. The Diabetes Wellness/Support Group consists of various sub-groups that are all area dependent, and the estimated population size is 12 per group. This study had two population targets. The first population target for this study was individuals diagnosed with DMII residing in Mitchells Plain, and who were also participants of the Diabetes Wellness/Support Group. The second population target was the significant others of those diagnosed with DMII who performed the role of their caregiver.

3.4.6 Sampling

A sample includes participants with certain characteristics, relevant to the study (Creswell & Plano Clark, 2011). The researcher employed purposeful sampling for this study. This sampling identifies

and selects information-rich cases relevant to the phenomenon (Creswell & Plano Clark, 2011; Patton, 2002). Purposeful sampling intentionally selects participants which share similar features that enabled the researcher to explore and explain the key concepts and provides an in-depth understanding into the phenomenon (Creswell & Plano Clark, 2011). Information-rich cases yields insights and in-depth understanding rather than empirical generalisations in a study (Patton, 2002). Phenomenology focuses on purposeful smaller samples to collect detailed information (Patton, 2002). The researcher purposeful selects participants and the research setting because the selected participants can provide an in-depth understanding and rich information as they comprehend the research phenomenon (Patton, 2002). The researcher selected a purposeful sample during this research by including individuals living with DMII which attended a support group weekly and their significant others' caring for them from the Mitchells Plain area in the Western Cape (Creswell, 2013). Most participants attended their group weekly, however those who were not able to attend weekly were due to financial challenges as some had to take public transport to the group. In certain cases, family members also joined their significant other to the group. The sample consisted of ten participants which included five participants with a DMII diagnosis, and five participants were the significant others caring for them. Interviews continued until the researcher reached data saturation. Data saturation transpired after there was sufficient information and when no added information transpired after data analysis, and further coding was no longer feasible (Fusch & Ness, 2015).

3.5 DATA COLLECTION

This study employed unstructured in-depth phenomenological individual interviews to explore the daily lived experiences of participants diagnosed with DMII and the experiences of their significant others' caring for them. The purpose of a phenomenological study is to elicit more descriptive data, which is why the researcher asked questions to get the additional data which required to achieve the study's aim and objectives (Groenewald, 2004). The researcher and the participants had

dialogues during this research and the lived experiences, questions and time used for interviews varied depending on their lived experiences of participants.

The researcher used two questions, which are relevant to a phenomenological study during the study. These questions for the participants living with DMII the two questions were as follows:

- Tell me what your experience is living with DMII?
- In what situations did you experience this?

The questions for the significant other caring for the person diagnosed with DMII were as follows:

- Tell me your experience of taking care of a person diagnosed with DMII?
- In what situations did you experience this?

3.5.1 Recruitment process of the participants

The researcher emailed a support group manager from the Diabetes Wellness/Support Group to introduce and outline the research topic and inquire about group members' interest in participation in the research (See **Appendix A: Permission Letter**). The support group manager provided the researcher with the contact details of a facilitator who managed one of the support groups. The researcher phoned the facilitator of the support group to inform her of the goal and objectives of the study and requested her to explain the research study to the group members and discussed their willingness to participate in the study. The researcher also explained that she was willing to meet with the group members to explain the research study further. The facilitator notified the researcher that the group members agreed that the researcher joined the group to explain the research study. The facilitator, with the permission of the group members, arranged with the researcher to meet with the group members during one of their group sessions. The researcher introduced herself, explained the reason for her attendance, and introduced the research topic. She provided and discussed an information sheet about the research and a consent form to each group member. The researcher explained that the purpose of the interview was to gather information on their experience and understanding and that there is no right or wrong answer (Doody & Noonan, 2013). The

researcher also explained that only the participants who have a significant other caring for them will be able to participate in the research study. The significant others were not part of the support groups therefore the participants diagnosed with DMII had to discuss the research with their significant others who would be willing to participate. The group members indicated that they would speak to their significant others and inform them of the purpose of the study, and they would contact the researcher if both agreed to volunteer to participate in this study. Once the group members informed the researcher that their significant others were interested, the researcher had telephonic contact with each of the significant other persons, with permission from the person with DMII, to explain the purpose of the study. The researcher deemed it necessary to provide detailed information on the research goal, objectives, and process to get informed consent for the research. The researcher provided her phone number to the group members who were interested in voluntary participation in this study. Participants, which included the person with DMII and a significant other of that person, who were interested in this study contacted the researcher and agreed to a meeting after the next support group session. The researcher shared the purpose of the research again with the support group members and their significant others and explained the ethical requirements which included confidentiality, the right to withdraw at any time and referral to appropriate resources when they experienced any potential discomfort. The researcher also provided an information sheet with details about their participation and the research project. The researcher responded to any concerns from potential participants. These concerns included whether the prospective participants had to pay a fee to participate in this study, if they must travel to meet with the researcher, and if they had to participate according to the availability of the researcher or if the researcher will be available when they had time to participate. The information sheets presented to the participants contained sufficient information on the study and interview, and the researcher discussed these with all the participants individually (Doody & Noonan, 2013; Nnebue, 2010). (See **Appendix B: Information Sheet** and **Appendix C: Consent form**). Everybody agreed that the interviews would take place at each participant's home where participants feel most

comfortable (Creswell, 2013; Strydom, 2011). However, due to the Covid-19 epidemic four of the participants decided to have telephonic interviews because they did not want to have a face-to-face meeting.

The Human and Social Sciences Research and Ethics Committee of the University of the Western Cape provided permission to proceed with online data collection during the Covid-19 epidemic. Telephonic interviews can be a very productive and cost-effective technique to do data collection when a phone is available to the sample (Fox, 2009). The telephonic interviews with the four participants were successful and the researcher could collect the necessary data.

The researcher explained voluntary participation at the beginning of the study (De Vos *et al.*, 2011) and participants were aware that they could terminate participation at any time if they wish to do so (Doody & Noonan, 2013; Nnebue, 2010). The researcher obtained written and telephonic consent with the consent forms after the participants volunteered to participate in the study (De Vos *et al.*, 2011). The participants were aware that an audio-recorder will be used during the interviews therefore, consented to be recorded during the recruitment process (Greeff, 2011). The researcher provided assurance that all information shared will be confidential as indicated in the information sheet and each participant will have an assigned special code, for example, 'Participant A' (Groenewald, 2004). This also assisted with confidentiality and anonymity. The researcher ensured that the recording equipment were operational before the interview started. The recording of the interview provided the researcher with an opportunity to focus on the interview and build rapport, where note taking throughout the interview can be a hindrance. The recordings also assisted the researcher with verbatim transcriptions of the interviews (Greeff, 2011).

The researcher ensured that she followed all the prescribed Covid-19 safety protocols during the meeting with the participants when they attended their support group and when she conducted the interviews. These protocols included the maintenance of physical distance throughout the data collection process, wearing masks, everyone sanitized their hands, and the researcher met with the

participants in an air-conditioned area. The researcher also provided each participant with an extra two masks and brought sanitiser with to the interviews.

3.5.2 Preparation of participants for interviews

The researcher provided a brief explanation of the research study before the interviewees started to remind them of the process and she emphasized that they would not be deceived during the process. It is important to remind participants of the research aim to avoid deceiving of participants (Creswell & Creswell, 2018). The researcher repeated the consent/agreement process, the rationale for this interview, the agenda, and the interview structure (Greeff, 2011). The researcher also started with an icebreaker for introduction purposes and to discuss interests to establish cohesion, build rapport and trust (Patton, 2002).

3.5.3 Pilot Study

A pilot study is a study with a small sample to review research procedures, data collection instruments, sample recruitment strategies, and other research techniques in preparation for a larger study (Strydom & Delpont, 2011). A pilot study is a crucial stage in any research project because it allows researchers to identify problematic areas in the research process, which provides the researcher with the opportunity to improve these areas and to make changes accordingly (Strydom & Delpont, 2011).

The pilot interview allowed the researcher to evaluate and improve her interviewing skills and ensured that the interview question would generate rich data. During the interview the researcher asked the main research question and based on the information provided by the participant, the researcher probed, which resulted in valuable and rich information on the experiences of the participants.

The researcher established during the pilot study that probing after the interview question, in a phenomenological study is essential to ensure rich data. Even though the researcher thought the pilot interview was successful, the study supervisors provided comments that were extremely

valuable to the researcher in subsequent interviews. The comments from the study supervisors reminded the interviewer of what a phenomenological study is and to only focus on one main/central open-ended question before probing, as suggested by phenomenological studies. During the pilot study, the researcher did not ask a single main/central question, but a series of main questions. The following comments from the study supervisors assisted with the next interviews to gain rich data:

- 1) The researcher needed to focus on the central question of the study - allowing the participant to tell their story (Creswell, 2013).
- 2) A phenomenological study focuses on questions like "How did you feel?" and "What did you thinking?" which will elicit the desired descriptive information (Creswell, 2013).
- 3) The researcher must use probing in combination with the participant's story and the participant must do ninety percent of the talking (Bernard, 2000).
- 4) The researcher must ensure that participants must reflect and share their personal journey explaining their lived experiences (Creswell, 2013).

As a result, the researcher followed the advice and guidance from the supervisors and implemented it in the interviews that followed. The researcher did not include the pilot study in the study findings.

3.5.4 Individual interview sessions

The researcher conducted interviews in each participant's first language or preferred language, either English or Afrikaans, but the participants used a combination of these languages. The interviews lasted from 30 - 50 minutes and was dependent on what the participants wanted to share. The interviews were conducted at the participants home or the venue where the group meet. The chosen interview venue was solely the decision of the interviewees. There were no medical constraints or barriers during the interview process with the participants.

Throughout the interviews, the researcher maintained a polite and non-judgemental demeanour and a friendly and conversational tone, instead of a "question-answer" attitude (Doody & Noonan,

2013; Greeff, 2011). The researcher also observed the non-verbal communication of the participants which included the tone of voice, body language, motions, and modulation during the face-to-face interviews and these enhanced the participants' verbal responses and researchers' responses (Patton, 2002). The researcher also utilized field notes during and after the interviews.

3.5.5 Field notes

In qualitative research, uses field notes as secondary data. Field notes are essential in qualitative research because the human mind forgets rapidly, and these notes assisted with data analysis. This entails that the researcher diligently record data after each interview (Groenewald, 2004). The researcher must read field notes after the initial interview process to access additional information about the phenomenon (Creswell, 2013). The purpose of field notes is to note and remember incidents, attitudes, activities, and other observational features, and to critique and reflect on you as a researcher (Creswell, 2013). The researcher utilized a notebook specifically created for field notes, what she observed with each participant during the interviews. The notes included observations of participants' body language, tone of voice, reactions to certain questions, and reactions toward one another when they shared their experiences. During telephonic interviews, this process did not occur. However, the researcher was able to observe participants' tone of voice when they described their experiences of certain events and that was noted in the field notes.

3.6 DATA ANALYSIS

The researcher reduces a large amount of data during the data into smaller fragments during analysis process which enhance data interpretation (Henning *et al.*, 2004). The primary goal of phenomenological analysis is to derive meaning by identifying themes identified through manual coding (Creswell & Creswell, 2018). The researcher transcribed and thematically analysed all the interviews. Transcribing the interview recordings allowed the researcher to organise the data and execute the phenomenological analysis process (Henning *et al.*, 2004). A discussion on the main themes and sub-themes with relevant literature that supported the statements of the participants

follows in chapters four and five which are the findings chapters of this document. The researcher used the six steps of phenomenological data analysis of Creswell (2013) simplified from Moustakas (1994) which encompass:

Step 1: The first step for the researcher is to reflect on their own personal experience with the phenomenon as an attempt to focus solely on the participant and not the researchers' own experiences (Creswell, 2013). The researcher did not experience any subjective experiences during the study and was, therefore, able to immediately focus on the participants.

Step 2: The focus during the second step is to study the transcriptions and depict a list of significant statements that the researcher thinks is valuable. These statements should describe how the participants experience the phenomenon (Creswell, 2013). The researcher read all the scripts more than once, which known as the holistic reading approach, and selected statements with similar views and ideas, as well as statements with different views and ideas, and then clustered them together (Creswell, 2013). The aim and objectives of the study are key elements to remember during this process and the researcher must extract statements that focus on these (Creswell, 2013). To organise the data, the researcher highlighted/colour-coded prominent statements. This simplified the process to see the repetitive patterns of action, uniformities and to identify different themes (Creswell, 2013). The researcher did the labelling, organization, and coding of the data.

Step 3: The third step includes the creation of themes using larger chunks of information with valuable statements (Creswell, 2013). The statements contribute to themes and sub-themes and allocated to relevant themes and sub-themes. The researcher created the storyline by recognizing and connecting the common themes and therefore determined the meaning that the participants associated with the phenomenon (Creswell, 2013).

Step 4: The researcher wrote a textual description which included the “what” which focused on the lived experience for the participants, and this includes verbatim examples, during stage four (Creswell, 2013).

Step 5: The structural description of “how” the experience happened followed (Creswell, 2013). The researcher thematically categorised the significant statements and provided a textual description on the experiences of people diagnosed with DMII and the caregiver (textural), and how they experienced those (structural).

Step 6: The last step includes a combination of the textual and structural descriptions to create a combined description of the phenomena (Creswell, 2013). It is an extended paragraph that describes to the reader "what" the participants went through and "how" they went through the phenomena (Creswell, 2013). The researcher applied this by comparing the findings with current literature and constructed complex descriptions that provided the core of what the participants experienced and how they experienced it.

3.7 SELF-REFLEXIVITY

The researcher is more aware and look through an analytical lens during reflexivity. The researcher recognises his/her personal role as a participant in the research process, and that he/she is not just an outsider-observer of a phenomenon during reflexivity (Patnaik, 2013). Self-reflexivity means that the researcher must be reflective and reflexive; learn more about him-/herself, keeping track of thinking processes and standards during decision-making, and be aware of prejudices, preconceptions, uncertainties, expectations, limitations, and forces (Patton, 2002). The researcher must think objectively about what and why he/she is doing something, challenging expectations, accepting feelings, behaviour, decisions and how these influence the research and how the researcher perceive these. A reflective journal is a traditional approach in bracketing (Patnaik, 2013). The researcher ensured reflexivity by using a daily diary during direct observations and when there were occurrences of subjective norms and desires that transpired during the research process. Bracketing offered a deeper sense of participation of participants and was used to exclude possible prejudices that could have flawed the study process (Patnaik, 2013). Bracketing during phenomenological research is essential and all possible preconceived notions by the researcher are

rejected to ensure that the attention is solely based on the experiences of participants (Moustakas, 1994).

3.8 TRUSTWORTHINESS

The researcher ensured trustworthiness in qualitative research by following specific processes that and transpires when there is an agreement between the findings and the participant's descriptions of meaning. It therefore demonstrates that the researcher was attentive towards the participants (De Vos *et al.*, 2005; Guba, 1981).

Guba (1981) states that there are four criteria to ensure trustworthiness, and these encompass credibility, transferability, reliability, and confirmability. Credibility signals trust in the truth of study findings. This implies whether the findings of the study represent credible information which derived from the original data or not and is a valid interpretation of the participants' original opinions (Anney, 2014). Information on the lived experiences from persons diagnosed with DMII and their significant others' that care for them ensured credibility of the study. Data saturation when the participants indicated similar statements/experiences, is an indication of credibility. The researcher continued with interviews until she reached data saturation. The researcher furthermore established credibility by demonstrating that the data collected from the ten participants and that the conclusions reflected the participants' interpretations (Babbie & Mouton, 2010). The researcher also established credibility by capturing the experiences of participants from an audio-recorder and then transcribed the interviews and analysed the data from the transcriptions (Babbie & Mouton, 2010).

Confirmability occurred when the findings of the research originated from participants and not the qualitative researcher. The researcher also ensured confirmability by an in-depth explanation and application of the research methodology (De Vos *et al.*, 2011). The researcher furthermore established confirmability throughout the research by ensuring that the correct techniques were used to verify the data. The researcher also ensured appropriate steps to confirm that the study's findings are rigorous and sufficient according to the participants' experiences and notions, rather

than the researcher's preferences (De Vos *et al.*, 2011). The researcher also used reflexive analysis which assisted the researcher to be conscious of her impact on the data (Patton, 2002).

In addition, the researcher increased **transferability** by providing a thorough explanation of the implementation of the research methodology. Transferability refers to the possibility to transfer research from one context to another when relevant. A thorough description of the research context and the core assumptions of the study enhance the transferability of the study (De Vos *et al.*, 2011). The researcher ensured transferability by explaining the relevance of the findings in a different context and by organizing the findings in a well-structured research document. The researcher provided a detailed description of the research methodology and included verbatim transcripts from the interviews and a literature review. The researcher used audio recordings, transcripts, field notes, and an interview guide to ensure reliability and to ensure that the results of the analysis were accurate.

Dependability is essential to trustworthiness because it ensures that the research data are dependable and consistent. It is also important for researchers to ensure that their conclusions concur with the raw data (De Vos *et al.*, 2011). An independent researcher performs an inquiry audit on the study to establish dependability. This is a researcher who was not involved in the data collection and data analysis review and validate the accuracy of the results and confirm the findings through the data collected (De Vos *et al.*, 2011). The researcher ensured dependability by submitting the findings to the researcher's co-supervisor.

Bracketing where the researcher sets aside subjective experiences, is vital in the phenomenological study. Bracketing furthermore provides a deeper sense of researchers' involvement and exclude potential biases that might have a negative effect on the research process (Creswell, 2013). During data collection, the researcher maintained a reflective journal based on the researcher's own experiences during the study, which ensured bracketing during the research process.

3.9 ETHICAL CONSIDERATIONS

Ethical considerations include a set of beliefs which refers to the social behaviour of a person or group and this pose a serious question on the authenticity and reliability of the research study (Creswell, 2013). Ethical approval was adhered to during this study by obtaining ethical clearance from the Human and Social Sciences Ethics committee of the University of the Western Cape and permission to do the study from the management of the Diabetes Wellness/Support group. Creswell & Creswell (2018) emphasize the importance of an application to the institutional review board to review the research plan, to ensure no violation of human rights, or any potential risk such as physical, psychological, social, economic, or legal harm, during the research (Creswell & Creswell, 2018). Ethical considerations in research include informed consent, voluntary participation, anonymity and confidentiality, avoidance of harm, deceiving participants, and storing of the information (De Vos *et al.*, 2011, Nnebue, 2010). The researcher followed the following ethical considerations during this research:

3.9.1 Informed consent and voluntary participation

An informed consent form must be in the preferred language of the participants, must minimise the risk of manipulation and allow the participant enough time to think about participating (Creswell & Creswell, 2018; Creswell, 2013). The researcher obtained informed consent from each participant prior to data collection and days before participation in the interview, and therefore provided them with sufficient time to consent to this research. The researcher explained to each of the participants the meaning of a consent form. The researcher did not minimize or manipulate the potential risks which might result from this study (Creswell & Creswell, 2018). Potential risk factors can include but are not limited to psychological risks that can include the development of negative emotions, loss of confidentiality, and/or social risks that involves adjustments in relationships that are detrimental to the participants. Participants were aware that participation was voluntary and that they may withdraw from this study at any time (Creswell & Creswell, 2018).

3.9.2 Anonymity and confidentiality

Anonymity and confidentiality are ethical practices necessary during data gathering, analyses, and documentation to ensure that each participant will remain anonymous and any identifying information remains confidential (Creswell & Creswell, 2018). The researcher ensured anonymity and the safeguarding of identifying information by saving all information and data gathered on the researcher's computer, to which no one else had access, and secured all interview notes by locking them in a cabinet. The information sheet and consent form informed participants of their anonymity and confidentiality during the research. Pseudonyms protected the participant's identities during the recording and coding process (Creswell & Creswell, 2018).

3.9.3 Avoidance of harm

Beneficence and no maleficence are basic ethical concepts that govern a research process. Researchers are bound by the principles to support the well-being and avoid or harm their participants during the research process. Researchers must avoid inflicting harm to the participants either accidentally or intentionally, and to reduce the risk of harm or discomfort in a research context (Beauchamp & Childress, 2001). The researcher was aware of the participants' potential emotional state and posed questions in a non-intrusive manner, alleviate pressure from the participants by explaining the study, ensured them of confidentiality and protected all identifying information and data. Furthermore, the researcher was conscious that participants might reveal sensitive information such as sensitive and personal information, for example, participants might disclose spousal abuse which might include sexual, physical, or emotional abuse (Creswell & Creswell, 2018). The ethical code for researchers emphasized respect and protection of the privacy of participants to all the individuals involved in this study (Creswell & Creswell, 2018). The researcher informed the participants that an appropriate referral will be done if they experience any emotional distress during the research process after revealing sensitive and personal information. The referral process did not occur as it was not necessary.

3.9.4 Deceiving of participant

Researchers can deceive participants when they deliberately provide false or misleading information regarding the study (Nnebue, 2010). The researcher ensured that the expectations of the study was clear to participants and each participant received an information sheet that clearly stipulated the goal and additional information for the study.

3.10 LIMITATIONS OF THE STUDY

The limitations of a study refer to potential defects that are beyond the researcher's control and can be as result of the research design, statistical model constraints, financial constraints, or other reasons (Theofanidis & Fountouki, 2018).

Time-consuming process: The interviewing process was time consuming and exceeded the time allocated because of the Covid-19 pandemic. More than a year was required to complete ten interviews as the Diabetes Wellness/Support Group temporarily terminated all groups during the COVID-19 period.

Online interviews: The researcher conducted four interviews via telephone because it was the personal choice of the participants as safety precautions due to the Covid-19 pandemic. The researcher experienced this as a limitation because she was not able to connect on a personal level, establish rapport, and observe non-verbal communication during data collection. The responses from these participants, in comparison with the face-to-face interviews, were also shorter and the researcher could only assume that their responses might have been longer if these were face-to-face interviews.

3.11 CHAPTER SUMMARY

This chapter focused on the implementation of the research methodology that was employed during this research study. This research study used the qualitative research approach with an explorative research design to achieve the aim and objectives. The researcher followed the phenomenological strategy of enquiry which resulted in in-depth interviews and rich data. The research methodology

employed during this study allowed each participant and their significant others caring for them to discuss their lived experiences with a diagnosis of DMII. The chapter continued to explain how the researcher applied the research design, population and sampling, data collection, and data analysis within an ethical framework. Data collection included in-depth interviews and participant observation. The researcher also explained credibility, transferability, dependability, and confirmability as measures of trustworthiness in qualitative research to ensure reliability of the research. The findings of this research on the experiences of people with DMII are presented in the following chapter.



CHAPTER 4

PRESENTATION AND DISCUSSION OF THE FINDINGS

PERSON DIAGNOSED WITH DIABETES MELLITUS TYPE II

4.1 INTRODUCTION

The aim of this research was to gain an in-depth understanding of the lived experiences of those living with DMII and their significant others caring for them. The researcher employed a qualitative research approach with a phenomenological strategy of inquiry during data collection, using unstructured in-depth interviews. The interviews focused on the “what” that was experienced by participants, with verbatim descriptions, followed by “how” the experiences occurred to attain the goal. The researcher presents the findings of the research in two sections, chapter four, and chapter five. This chapter focuses on the findings of the person diagnosed with DMII and chapter five will on the findings of the significant other caring for the person diagnosed with DMII.

The research process focused on the realization of the research aim and by implementing the four objectives as outlined in chapter one (Section 1.4) and chapter three (Section 3.3.2). This chapter focuses on two objectives and chapter five on the other two. The two objectives addressed in this chapter were:

- To explore the lived experiences of adults living with DMII.
- To explore and describe the reason adults living with DMII do not adhere to treatment and medication.

The researcher focused on the theoretical framework of this study, the BPS model, and how it is connected to various themes and sub-themes in the finding’s chapters. The findings emphasized the correlation between the biological, psychological, social factors and the development of DMII and subsequent care, and how these factors affect each individual experience diagnosed with DMII, and the significant others caring for them.

4.2 DEMOGRAPHIC PROFILE OF PARTICIPANTS

Table 4.1 illustrates the demographic details of the participants diagnosed with DMII. Ten participants participated in the study and five were adults living with DMII. Chapter five focuses on the other five participants which are the significant others' caring for individuals living with DMII.

Table 4.1 Demographic details of participants living with DMII

	Gender	Age	Race	Home Language	Employment/ Income status	Relation to significant other
A	Female	59	Coloured	Afrikaans	Medically boarded Disability grant (DG)	Wife
C	Male	60	Coloured	Afrikaans	Unemployed, SASSA Pensioner	Husband
E	Female	70	Coloured	Afrikaans	Housekeeper, SASSA Pensioner	Wife
G	Female	62	Coloured	Afrikaans	SASSA Pensioner/ Entrepreneur	Friend
I	Female	63	Coloured	English	SASSA Pensioner	Daughter

4.2.1 Gender

Four of the five participants with DMII were female as indicated in Table 4.1.

4.2.2 Age

The participants diagnosed with DMII were between 59 and 70 years of age. A biological factor such as age (45 or older) plays a vital role in the diagnosis of DMII because older persons are at a higher risk for developing this disease (Andersen *et al.*, 2016).

4.2.3 Race

Table 4.1 indicates that the participants diagnosed with DMII are of coloured descent. Literature suggests that there are considerable differences in the prevalence of diabetes among different population groups and people of color appear to be a high-risk category (Beckles & Chou, 2016). It is more prevalent in people of color due to their economic status, difficulty accessing care due

to their geographic location, educational and communication barriers, prejudice, racism, and discrimination.

4.2.4 Home language

Four of the five participants were Afrikaans speaking, and one participant was English speaking.

4.2.5 Employment/Income status

Four of the participants are recipients of the SASSA pension, and one is dependent on the monthly disability grant due to DMII-related complications. One pensioner generates an extra income by selling goods.

4.2.6 Relation status

Table 4.1 illustrates that two participants with DMII were wives of their caregivers; one was a husband, another was the mother of the caregiver, and one was a longtime female friend.

4.3 PRESENTATION AND DISCUSSION OF THE FINDINGS

The data analysis originated from verbatim transcriptions as a result of the one-on-one in-depth interviews with the five participants diagnosed with DMII. The researcher coded and developed themes and sub-themes from the data. There are five themes, which were subsequently subdivided into relevant sub-themes. The focus of this chapter will be on the discussion of five themes and their sub-themes with reference to relevant literature supported by direct quotes from the participants. Table 4.2 illustrated the five themes with their sub-themes.

Table 4.2: Themes and Sub-themes

THEMES	SUB-THEMES
Theme 1: Understanding their diagnosis	Sub-theme 1.1: Causes, symptoms, and/or triggers that contributes to the diagnosis
	Sub-theme 1.2: Family history of diabetes mellitus type II
	Sub-theme 1.3: Complications as a result of their disease
Theme 2: Emotional and mental challenges experienced	
Theme 3: Management of diabetes mellitus type II	Sub-theme 3.1: Dietary adherence
	Sub-theme 3.2: Medication adherence
Theme 4: Experiences with barriers in managing diabetes mellitus type II	Sub-theme 4.1: Health system-related barriers
	Sub-theme 4.2: Socio-economic barriers
Theme 5: Experiences of their support systems	Sub-theme 5.1: Support from friends and family members
	Sub-theme 5.2: Support through their support group
	Sub-theme 5.3: Support from health care workers

4.3.1 THEME 1: UNDERSTANDING THEIR DIAGNOSIS

The life of a person diagnosed with DM may change dramatically because there is a period of adjustment as they learn to live with this disease. Patients may start to seek information on DMII when they recognize that the body changes due to the condition and subsequently develop a new perspective as a diabetic (Johansson, Osterberg, Leksell & Berglund, 2018). The perceptions of patients' during the onset of the disease will influence how they integrate their illness into their daily lives (Johansson *et al.*, 2018; Johansson, Osterberg, Leksell & Berglund, 2015). Attention of the patient shift to experiences of existential doubt rather than the symptoms of the disease when they are aware of their personal stance towards the disease (Johansson *et al.*, 2015; Andersson, Svanström, Rosén & Berglund, 2015). It is important to challenge patients' knowledge on DMII because this contributes to an integration of the entire experience and understanding by patients

(Andersson *et al.*, 2015). The patient must reflect on their situation when living with DMII to enhance awareness and confidence (Johansson *et al.*, 2015; Andersson *et al.*, 2015). The reflection must focus on the individual patient's actions which will consequently determines the patients' acceptance of responsibility (Andersson *et al.*, 2015). Theme one consists of three sub-themes namely, Sub-theme 1.1: causes, symptoms, and/or triggers that contribute to the diagnosis; Sub-theme 1.2: family history of diabetes mellitus type II; Sub-theme 1.3: complications because of their disease describe and support this theme.

4.3.1.1 Sub-theme 1.1: Causes, symptoms and/or triggers that contribute to the diagnosis

Participants shared different perspectives during the interviews on the experiences of symptoms of the disease prior to their diagnosis. There is initially a suspicion that they may have DMII due to the symptoms, which is then confirmed by using a standard test at a doctor's office (Silva, Souza, Echazu Boschemeier, Costa, Bezerra & Feitosa, 2018; Chen, Ovbiagele & Feng, 2016). One of the participants admitted that she was prediabetic and therefore requested a standard diabetic test.

“So, I was diagnosed in February that was 18 years ago... asked my doctor if they couldn't test my sugar and the doctor was so mad with me because my sugar was 17 now I was on medication”. (Participant E)

Prediabetes occurs when the blood sugar levels are higher than the norm but not high enough to diagnose DMII (Kumar, Singh & Kumar, 2016). Genetics can contribute to the development of DMII but it is also important to consider lifestyle and clinical risk factors. Clinical risk factors such as high cholesterol, high blood pressure, and obesity are physiological characteristics, according to the biopsychosocial model, that contribute to an increased risk in the development of certain diseases such as DMII (Kumar *et al.*, 2016). One participant indicated that he had a physiological characteristic that eventually contributed to his diagnosis:

“You know in 2001 I had a stroke. I was never diabetic but I had high blood pressure. So, in 2001 I got the stroke. In 2009 then they discovered I am a diabetic”. (Participant C)

Three participants reported that they experienced signs and symptoms of this disease but chose to disregard them at first. They had to seek medical assistance eventually due to persistent symptoms such as thirst, dizziness, frequent infections, and fatigue (Lal, 2016).

“I just started to feel bad the morning at work that’s when I collapsed, on my way home then I just got dizzy at the bus stop when I got to the Dr she was now examining me and doing a blood test, doing a sugar test on me they will discover my sugar is 12.7 ... that was the day they diagnosed me that I had sugar and believe me lady I could not walk”. (Participant A)

“I was always tired. I shared with my friend the itchiness in my private parts. My mouth was constantly dry. Needed to drink water every time so I asked the doctor to test me. She asked me questions and tested me. My results came back 24.7 and she was very concerned and asked if I don’t feel sick and with such a result you can get a stroke. She prescribed medication for me and gave a referral letter for the day hospital. Since then I have been on medication” (Participant G)

Comments from participants illustrate that they eventually had to take care of their symptoms but they were initially unaware of the symptoms of DM. This is confirmed by literature where people are often surprised that they are diagnosed with DM (Widayanti, Heydon, Norris & Green, 2019; Agustina, Dartanto, Sitompul, Susiloretni, Suparmi, Achadi, Taher, Wirawan, Sungkar, Thabrany & Indonesia Health Systems Group, 2019) This could result in serious consequences such as a stroke and high levels of blood glucose (Widayanti *et al.*, 2020). Participants need to understand triggers which contribute to the onset of their disease and not only the causes and/or symptoms.

A healthy lifestyle consists of a balance of mental, physical, and social well-being and is based on sensible decisions (Caliskan, Arberk & Uner, 2017). Lifestyle and environmental factors influence the probability to develop a disease when there is a genetic predisposition towards that disease (Kalra *et al.*, 2018). It is therefore necessary to evaluate lifestyle factors such as physical activity, effective stress management, adequate rest, support from family, friends, and the community, as

well as emotional wellbeing to enhance a healthy lifestyle (Van Der Windt, Zundert, Schoenmaker, Jansen, Van Rossen & Steegrs-Theunissen, 2021; Calliskan *et al.*, 2017). A healthy lifestyle decreases the occurrence and effect of health disorders, and contributes to healing, coping with life stressors, and enhances quality of life (Van Der Windt *et al.*, 2021; Calliskan *et al.*, 2017). Certain lifestyle decisions, such as a sedentary lifestyle, can therefore cause or increase the risk of DMII.

DMII develops when a person follows a poor diet and engages in limited or no physical activity (Brandt, Clemensen, Nielsen, and Sondergaard, 2018). Lifestyle factors such as weight, eating patterns, and physical activity are reliable predictors in the development of DMII (Flannick & Florez, 2016) as described in Chapter 2 (Section 2.5.1.1).

Participants indicated that their poor eating habits and unhealthy lifestyle triggered the development of their DMII diagnosis:

“Well like the doctor explained to me it could have been because I did not eat healthy and did not lead a healthy lifestyle. (Participant A)”

“...because we don't eat healthily... You know now. Obviously, it is not because of eating healthy. That is number one. (Participant C)”

There is a relationship between the development of DMII, a diet high carbohydrates, fat, and sugar (Sami *et al.*, 2017). There is also a correlation between weight gain and body mass index (BMI), specifically in the obesity range where the consumption of certain food, the quality of food influence weight (Sami *et al.*, 2017; Deshpande, Mapanga & Essop, 2017). The high consumption of deep-fried meals, red meat, and confectionaries increases the risk of insulin resistance and DMII (Sami *et al.*, 2017). Soft drinks contain glycated compounds that also increase insulin resistance significantly (Sami *et al.*, 2017; Deshpande *et al.*, 2017). A study published in the Journal of the Endocrine Society indicated that five in ten persons are at risk to develop DMII when they consume

only one can of soft drinks daily (Deshpande *et al.*, 2017). Three participants indicated that they consume a large amount of sugar and starch over time which result in their diagnosis of DM:

“...the things is I went overboard with the chocolates actually and the potato crisp. I think that was my downfall.” (Participant E).

“I loved cake, bread. You know the staple food. I loved coke”. (Participant G)

“I remember the sister asked me about my diet and what I eat. I know that I have always been a sweet tooth and looking back I think that is where I digged the hole for myself. I think through also eating a lot of starch because we were poor and had to eat food that would fill us”. (Participant I)

The quotations illustrate that all the participants acknowledged that their unhealthy eating habits contributed to the disease. The leading causes of the rapid increase in the prevalence of DMII in emerging countries are poor dietary habits and a sedentary lifestyle (Sami *et al.*, 2017; Beckles & Chou, 2016), which could be because of socioeconomic status which does not permit people to eat a healthier balanced diet.

4.3.1.3 Sub-theme 1.2: Family history of diabetes mellitus type II

A positive family history of DM is a significant risk factor in a diagnosis of DMII (Anthanont, Ramos, Jensen & Hames, 2017). First-degree relatives in families such as a parent, child, or sibling/s in a nuclear family, which do not include spouses of persons diagnosed with DMII, are more insulin resistant, due to their genetic predisposition. They also have increased metabolic and cardiovascular risks than persons with no family history of DMII (Abuelmadga, Osmana, Hakonsena, Jenumb & Toveruda, 2019; Anthanont *et al.*, 2017). Two participants shared that they had first degree relatives diagnosed with this disease:

“I know my mother had it but my father had the doctor diagnosed him when he was 71. That is when he became diabetic. But, in my ancestors is people that is diabetic type II and type I that I found out afterwards when I did my research that I did in the family that we found out that there was of our family”. (Participant A)

“...I didn’t know this new thing and I was the first to have it until I found out that my father was a diabetic. He passed away years ago”. (Participant I)

These participants have a family history of DM but were not aware of this and only discovered at a later stage that they had first-degree family members diagnosed with DM. The familial predisposition of both metabolic syndrome and DMII contribute to a probability of obesity, whether hereditary or related to the familial environment, as discussed in Chapter 2 (2.4.1.1). Individuals is more likely to gain weight than individuals who do not have a family history of DMII (Parmar, 2018). A participant with a genetic predisposition and with more than one family member diagnosed with DMII had an increased risk of DMII as illustrated in the following quotation.

“It is a family ailment. And mostly all my brothers and sisters as soon as we turn 40, we are diagnosed with it. My mother was a diabetic.” (Participant G)

Individuals living with DM II require knowledge on the complications relevant to DMII because they are more prone to develop complications (ADA, 2016). The following sub-theme with therefore focuses on these complications.

4.3.1.4 Sub-theme 1.3: Complications because of their disease

Biological factors which contribute to a DMII diagnosis include age, a lengthy history of diabetes, high BMI and blood glucose levels, comorbidities, and diabetic complications as emphasized from the BPS model (Amsah, Md Isa & Ahmad., 2022) DMII is associated with various physical health problems (ADA, 2016). Elevated blood glucose levels in people with DM which is not appropriately managed by diet, exercise, regular examinations, and monitoring can be dangerous and contribute to a variety and life-threatening complications, (ADA, 2016; Brownlee, Aiello, Sun, Cooper, Feldman, Plutzky & Boulton, 2020). As discussed in Chapter 2 (Section 2.4.1.2), these complications include retinopathy (eye damage), diabetic neuropathy (nerve damage), nephropathy (kidney damage), heart disease, gum disease, sexual and bladder problems, foot complications,

skin complications, amputations, and mental health disorders (Masupe *et al.*, 2021). Proper disease management can avoid diabetic complications (IDF, 2021). Symptoms can however be mild and unnoticed for approximately seven years during the onset of the disease and many people with DMII already developed complications when they are diagnosed (Makgabutlane, 2018; Pheiffer *et al.*, 2018).

Participants indicated that they developed more than one complication due to DMII in the following quotations:

“I sit with a leg problem. First it was the left leg and then it went over to the right leg. And the problem is underneath my foot. I told doctor that my foot is burning and it pains when I step on it even when I trap on my toes”. (Participant A)

“It affects my organs. I had a stroke, heart attack and now it affects my kidneys. My eyes are also affected through this”. (Participant G)

“My eyes has gotten worse over time and have been experiencing pain in my legs. I have also had a minor stroke about 7 years ago when I was alone at home. But what has me concerned is my eyes because I need my eyes. On top of this I also have high blood pressure but I had high blood shortly after I was diagnosed with diabetes”. (Participant I).

Only one participant reported no diabetes complications but had prior knowledge on the complications associated with DMII which generated attentiveness and worry. Patients with DMII potentially experience diabetes-related stress because it is a life-threatening disease that necessitates constant and extensive self-management and knowledge on topics such as medications and diet (Kalra *et al.*, 2018). Persons also experience fear to develop similar diabetes-related complications than family members with the disease (Abuelmagda *et al.*, 2019). Fear to develop complications as a result of DMII is related to the psychological factors explained in the BPS model

(Amsah *et al.*, 2022). This participant refers to his three brothers, who all deceased due to complications of diabetes, and expressed concern for his own health as follow:

“...I am very worried about my feet. Because why, I have lost three brothers already. They have amputated the one’s leg, the one got blind but okay it affects my eyes. It gives the cataracts on your eyes, it affects my eyes but not so much but I am very worried and about my eyes and scared. I have seen how people rot right in front of my eyes and I am worried...”

Complications from DM can be acute or chronic (Bhagavan & Ha, 2015; Stanley, Malamed & Daniel, 2015). Acute complications occur unexpectedly, are severe and life-threatening and include hypoglycemia which is low blood sugar levels and hyperglycemia which is high blood sugar levels (ADA, 2016; Stanley *et al.*, 2015). Chronic complications develop as the disease progresses and include kidney damage, nerve pain and damage, heart disease, gum disease, foot problems and eye damage, skin complications, and mental health complications (ADA, 2016; Bhagavan & Ha, 2015). It is evident from the quotes, that the participants developed chronic and acute complications because one participant had a stroke and a heart attack, while the other experienced a heart attack. Age, gender, family history/genes, BMI, blood glucose, are all biological genetic predispositions for DMII from a BPS perspective (Freeman & Pennings, 2021; Khodaeian *et al.*, 2015).

Chronic and acute DMII and predicted complications from the disease can cause mental health problems, which include negative thoughts, feelings, stress, anxiety, and excessive fear (Aduelmagda *et al.*, 2019). The next theme therefore demonstrates the participants’ experiences of these mental and emotional challenges as a result of DMII.

4.3.2 THEME 2: EMOTIONAL AND MENTAL CHALLENGES EXPERIENCED

Persons diagnosed with DMII experience shock and denial during the initial phase of diagnosis. It is also common for persons diagnosed with DMII to experience and display various emotional signs and symptoms such as stress, frustration, confusion, fear, anger and hurt (Abuelmagda *et al.*,

2019; Low *et al.*, 2014). The person diagnosed with DMII initially manage the shock of the diagnosis but then the daily struggles of living with this disease may contribute to other mental health challenges such as depression and anxiety (Abuelmagda *et al.*, 2019; Low *et al.*, 2014). A sense of defeat and grief is experienced by the loss of health and inability to be healthy again due to the fact that DMII is a permanent, life-long, and serious condition (Bhagavan & Ha, 2015). DM therefore does not only focus on physical consequences such as blood sugar levels, weight, blood pressure, or lipids (Kalra *et al.*, 2018) and it is also important to assess the emotional and social aspects of the patient's health. Stress, regret, and sadness are common emotional and psychological responses for persons who suffer from this disease (Abuelmagda *et al.*, 2019).

Participants expressed various emotional reactions after their diagnosis with DMII. The participants' voices illustrated that acceptance of their diagnosis was emotionally difficult and challenging for them, and they experienced shock, stress, disbelief, and/or denial.

"I was shocked" (Participant A)

*"To be diagnosed with diabetes was a shock because I am a lively person".
(Participant G)*

"When I found out I was a diabetic I couldn't believe that. It was really difficult to take in and to accept. Like I said before I was shocked. I think I was in denial for some time...". (Participant I)

It was evident that participants managed the information of their diagnosis differently. One participant indicated that she experienced denial towards the diagnosis which is a consequence of an inability to cope with emotional pain (McKay, Wood & Brantley, 2019).

"Uhm, I think that I was just that I am just being normal and that I don't focus on it. I don't focus on the diabetes. Like I said sometimes when I wake up in the morning I say oh yes I am diabetic. I forget most of the time that I am a diabetic". (Participant E)

Denial transpires after the diagnosis with an incurable and serious condition because a person wants to survive of an emotional incident without exacerbating the situation (McKay *et al.*, 2019). Biological factors can have a significant impact on a person's success to tolerate emotional distress (Kalra *et al.*, 2018; Jamilian, Malekirad, Farhadi, Habibi & Zamani, 2014). This participant furthermore implied that she coped with the disease by normalizing the condition (Widayanti *et al.*, 2019) and not by focusing on the problematic chronic diagnosis. People with DMII function as if the diagnosis never occurred when they are in denial. (Jamilian *et al.*, 2014). People also display behavior to avoid uncomfortable situations (Hoffman & Hay, 2018; Jamilian *et al.*, 2014). In this case, the participant did not experience emotional distress by avoiding the situation, ignoring the reality of the DMII diagnosis, not focusing on the diagnosis, and believing that it has caused no difficulty.

The quotations indicate that participants experienced overwhelming emotions when diagnosed with DMII. Denial and shock were the prominent emotions mentioned by participants. These emotions resulted in disturbing behavior due to their diagnosis. One participant stated that this disease did not affect her, which is a coping mechanism that assist with experiences of uncomfortable feelings such as shame, sadness, and fear (Amsah *et al.*, 2022; Hoffman & Hay, 2018). The BPS model is therefore significant in understanding the development of mental health conditions related to DMII.

The patient's perception of the seriousness of the disease will influence how they cope and manage it on an emotional and physical level. It is evident that a variety of factors influence the emotional and psychological well-being of a person with DMII. These factors include successful acceptance of the diagnosis, adjustment to the demands of self-care and their coping with the condition by following a healthy diet, being physically active, and adhering to medication (Kalra *et al.*, 2018). The following theme will illustrate the participants' management of their disease.

4.3.3 THEME 3: MANAGEMENT OF DIABETES MELLITUS TYPE II

Poor management of DMII could result in complications (ADA, 2016) as mentioned in sub-theme 1.3. Insufficient management of DMII can cause substantial variations in glucose levels which triggers a diabetic coma and can be fatal (ADA, 2020; Powers, Bardsley, Cypress, Duker, Funnell, Fischl, Maryniuk, Siminerio & Vivian, 2016). It is therefore important to adhere to a treatment plan which a healthcare professional provided and explained (Powers *et al.*, 2016), and to follow a diet, and/or implement lifestyle changes as prescribed by a healthcare professional (Nyirongo, Mukwato, Musenge & Kalusopa, 2021; ADA, 2020).

Social factors which influence management of DMII according to the BPS model include socio-economic status, educational attainment, marital status, and social support (Amsah *et al.*, 2022). Patients from low-income families are more likely to experience challenges to manage DMII due to their family's financial situation. One of the contributing factors to the prevalence of DMII and a low success rate in the self-management of the disease is low socio-economics status combined with poor education (Amsah *et al.*, 2022). There is a correlation between DMII and lower educational status because the latter results in limited awareness of DMII and consequently poor dietary control and non-compliance with medication (Amsah *et al.*, 2022; Nyirongo *et al.*, 2021).

This theme consists of two sub-themes which focus on adherence to the diet and medication when diagnosed with DMII. These sub-themes include Sub-theme 3.1: Dietary adherence; Sub-theme 3.2: Medication adherence.

4.3.3.1 Sub-theme 3.1: Dietary adherence

Better economic conditions improve the diets of people with DMII and develop healthy eating habits. However, research has found that low-income families receive limited support from their family, friends and community and do not have access to nutritious food necessary to follow a healthy diet (Ver Ploeg, Mancino, Todd, Clay & Scharadin, 2015). Access and support are vital to

adherence in diets and influence the individuals' food choices from the BPS perspective (Karami *et al.*, 2018).

Dietary modifications in people diagnosed with DMII focus on the consumption and maintenance of healthy meals (Nyirongo *et al.*, 2021; ADA, 2020). Dietary control is one of the most important characteristics in the treatment of DMII (Worku, Abebe & Wassie, 2015). It is important to endorse a diet that is low in saturated fat, unprocessed carbohydrates, fructose corn syrup, and high in fiber and monounsaturated fats (Nyirongo *et al.*, 2021; ADA, 2020). The focus should not only be on the type of food but also on the amount of food and the combination of the diverse types of food which the person with DMII consumes (ADA, 2020). The effort to adhere to the food quantities, and to follow the recommended guidelines of the 'diabetic diet' frequently result in unnecessary constraints, excessive, or repetitive intake of certain food items (Asif, 2014). Illiteracy, poverty, and cultural misconceptions about the role of nutrition in diabetes management contribute to this (ADA, 2020; Asif, 2014). The next two quotes highlight the dietary modifications to avoid salty and sugary snacks like beverages and cakes by participants:

"Your fruit, your drinks, your cooldrinks and that. Everything for me, there was nothing of sugar or such. But it is still going... it is not 100% yet but you try".
(Participant C)

"I had to also say no to cakes and chips especially on special occasions such as family gatherings. It was and still is not easy but I had to force myself to do it because my health would deteriorate if I decided not to look after myself.". (Participant I)

The participants reported that they experienced difficulty to manage a healthy and well-balanced diet (ADA, 2019; Asif, 2014). A well-balanced diet allows the person with DMII to maintain general health, improve blood glucose management, avoid, or reduce diabetes-related complications, attain blood fat levels, maintain a healthy BMI, and maintain the required blood glucose levels (Nyirongo *et al.*, 2021; Asif, 2014), Avoidance to follow a well-balanced diet is a

psychological consequence of DMII as indicated by the BPS model. However, it is not only a healthy diet but also adherence to prescribed medication that contribute to successful management of DMII (Nyirongo *et al.*, 2021). A discussion of the following sub-theme which includes adherence to medication follows in the next section.

4.3.3.2 Sub-theme 3.2: Medication adherence

Adherence to medication is crucial to have a positive outcome of the disease in people diagnosed with DMII (Nyirongo *et al.*, 2021; Kirkman, Rowan-Martin, Levin, Fonseca, Schmittziel, Herman & Aubert, 2015). Persons diagnosed with DMII must use various forms of prescribed medication to treat hyperglycemia, diabetes-related illnesses, and other comorbidities. Adherence to medication ensures better health outcomes, lower healthcare expenses, and limited admissions to the hospital (Kirkman *et al.*, 2015). Management of DMII with medication stabilizes blood glucose levels which lowers the chances of experiencing hypoglycemia or hyperglycemia (Papadakis, McPhee & Rabow, 2021). The relationship between the BPS model and adherence to medication includes factors such as age, employment status, socio-economic status, the duration of DM, health beliefs, acceptance of the disease, and lifestyle (Amsah *et al.*, 2022). Lifestyle satisfaction is essential to achieve a positive outcome in medication adherence.

The following quotations from two participants contribute to the notion that it is possible to live with this disease when medication is regulated.

“I need to inject myself every night with 22. For me it is a bit stressful but I am use to it now”. (Participant C)

“...you have a regular time when you take your tablets and to be consistent and not to miss out on any tablets. It was just another thing that you had to look after yourself and take your medication and go on living (Participant E)

Two participants reported that they do not adhere to the medication treatment because they were in denial which is a psychological defense mechanism. Age, information, perception, duration,

cost, and acceptability of the disease influence non-adherence to medication (Nyirongo *et al.*, 2021). The following quotations of participants with DMII illustrate that denial or non-acceptance of the disease can result in non-adherence to medication because they experienced this as a burden and this ultimately resulted in hospital admissions:

“I stopped using my medication for some time. Because I was in denial and so I ended up in hospital”. (Participant G)

“I think I was in denial for some time and that is why didn't take my medication because it felt like a burden to me”. (Participant I)

Denial of their diagnosis is a coping mechanism during the initial stages of the disease (Widayanti *et al.*, 2020). There is a similarity between a diagnosis with a chronic illness diagnosis and the phases of grief, and this impacts on disease management (Silva *et al.*, 2018).

The BPS perspective, which include social, economic, and psychological characteristics, is significant in the management of DMII. The management of the disease does not only depend on the adherence to medication but also on the control of external barriers that result in poor management of the disease. The following section focuses on theme four which comprises of these external barriers which influence the management of DMII.

4.3.4 THEME 4: EXPERIENCES OF BARRIERS IN MANAGEMENT OF DIABETES MELLITUS TYPE II

Barriers in the management of DMII vary from patient to patient, and social factors are barriers during the management according to the BPS model. These barriers include the financial status, poor education, unemployment, and social support (Amsah *et al.*, 2022). Health care providers can address and predict these barriers in the management of DMII if they are aware of the obstacles and how to cope with these. The WHO identifies five barriers which influence adherence to treatment which are patient-related, socio-economic, condition-related, healthcare system-related,

and medication-related factors (Hennessey & Peters, 2021). Patients with DMII may experience these barriers pertaining to the successful treatment of their disease.

This theme includes two sub-themes that focus on the two barriers which hamper successful adherence to the treatment plan. The sub-themes are Sub-theme 4.1: Health system-related barriers; and Sub-theme 4.2: Socio-economic barriers.

4.3.4.1 Sub-theme 4.1: Health system-related barriers

Health system-related barriers relate to follow-up care, doctor-patient affiliation, care that are provided by various medical professions, a lack or limited access to medication, the lack of information and the application of guidelines regarding the disease and treatment plan (Hennessey & Peters, 2021; Williams, Chastek, Sundquist, Barrera-Sierra, Leader, Weiss, Wang & Curtis, 2020). A major obstacle to effective care is malfunction in the service delivery system, which is evident from an inability to provide clinical information, duplication of services, and poor coordination in the administration of chronic diseases (Kini & Ho, 2018). Major obstacles to effective care in the health system in South Africa include a management and leadership crisis, poor record-keeping, delayed progress in re-organizing the health care system, prolonged waiting times, shortage of human resources and medical equipment, inadequate distribution of resources, insufficient time with a clinician, poor follow-up, and problems in the distribution of medication as a result of medication shortages, as well as the growing burden of disease (Maphumulo & Bhengu, 2019). Service providers need time to reinforce instructions and provide sufficient follow-up care in a complicated treatment plan such as with DMII (Kini & Ho, 2018). The development of the relationship between clinician and patient and effective communication is the first step to ensure treatment adherence (Hennessey & Peters, 2021; Kini & Ho, 2018). A clear explanation of adherence to treatment is an excellent approach to ensure that both the healthcare professional and the patient grasp the process (Hennessey & Peters, 2021).

Two participants reported poor treatment from the health care workers during a follow-up session. They report that they have limited time during the health care visits and therefore cannot ask the questions they desired as illustrated in the following quotations:

“At the clinic you may not even ask questions to the doctor because there is too many people.....They come and tell you there you are, there is your medication, use it. Further they give you no other information”. (Participant C)

“...I don't have questions that often but when I do I would ask them but I feel that most of the times they want me out so that they can help the next person so I feel that I don't get the information I need from them. (Participant I)

Participants experience limited time to ask the health care worker relevant questions or information regarding their disease (Pheiffer *et al.*, 2018). However, an open, welcoming environment contributes to the development of meaningful dialogue. It is essential to focus on specific questioning, as well as psychoeducation and assistance during the discussion (Hennessey & Peters, 2021).

4.3.4.2 Sub-theme 4.2: Socio-economic barriers

Socio-economic factors, such as low socio-economic status, out of pocket expenses related to the disease, and the distance to the clinic/hospital are barriers which affect the adherence in DMII treatment (Williams *et al.*, 2020; Suwannaphant, Loahasiriwong, Puttanapong, Saengsuwan & Phajan, 2017). The concept "socio-economic status" indicates that a comprehensive assessment of the financial and social circumstances of an individual's or family's is a necessity (Williams *et al.*, 2020; Suwannaphant, *et al.*, 2017). The socio-economic situation of a person influences the probability to develop DMII and socio-economic status, which include income, is also a risk factor for a DMII diagnosis (Suwannaphant *et al.*, 2017). A study found that even if risk factors such as behavior, diet and smoking are controlled the relationship between socio-economic status and DMII remained (Focus for Health Foundation, 2022). Persons diagnosed with DMII must follow a low-calorie diet, high in sources of energy, vitamins, minerals, and fiber during the treatment

plan (Nyirongo *et al.*, 2021; ADA, 2020). However, participants expressed that they were not able to follow the dietary recommendations due to their low socio-economic status and consequent financial constraints (Mutyambizi, Pavlova, Hongoro, Booysen & Groot, 2019).

The following quotations illustrate how the socio-economic and financial status affected DMII and emphasize the participants' financial concerns, which prevent them to follow the suggested dietary guidelines:

“...to eat our type of food is extremely expensive. I try my best to buy me like the future life porridge to eat and the bread as well. But this bread is R15, R16 – R15.99. So it is R16 to buy that bread for me every week or every second week. We are not allowed to eat white bread. So where are we going to get a cheaper, cheap bread other than a white bread because even the brown bread is more expensive than the white bread”. (Participant A)

“I know the other doctor said that we must eat the food that he told us to eat but we cannot afford it. When I and my wife need to go buy food and we get to the vegetables then we do not have any vegetable money left. We can't, we need to buy us meat and chicken and then the money is done. Now we need to eat healthy. How can we? And this is what caused it, now we must make this fast food” (Participant C)

One participant indicated that DMII had a limited financial impact on her because she did not purchase additional items but rather minimize her diet to specific food groups, which are more affordable.

“No, it was just cutting out. Not buying extra, just cutting out”. (Participant E)

Failure to adhere to a strict diet plan is one of the leading causes of complications in the management of DMII (Sami *et al.*, 2017). Dietary adjustments are important during self-management of DMII, however, dietary changes are particularly challenging for those in low socio-economic circumstances as demonstrated in the above quotations (Suwannaphant *et al.*, 2017). There is a correlation between low socio-economic status and poor health, where the lower the

socioeconomic status, the less likely to predict improvement of secure health (Suwannaphant *et al.*, 2017). Adherence to the treatment plan, such as the recommended diet is consequently impossible. A study conducted at Jimma University Specialized Hospital in south-west Ethiopia found that only 55.6% of persons diagnosed with DM had regular meals due to restricted access to vegetables and fruit and the excessive cost of foods (Worku *et al.*, 2015). Dietary recommendations are difficult to follow when the person does not have access to a decent income (Wilcox, Sharpe, Liese, Dunn & Hutto, 2020) especially in the South African context where participants primarily live on SASSA grants.

Expenses also include travelling to the health facility for follow-up consultations and collection of medication (Mtyambizi *et al.*, 2019). The person with DMII would not only have to spend more money on the recommended diet, but also have to spend a huge portion of their monthly income on travel expenses as demonstrated in the following quotations:

“If I have to go to the hospital then I need to pay someone to take me. A taxi, I have to pay traveling fair that costs me R50 of a R100 to just take me and come fetch me again” (Participant A)

“I have to spend more than a R100 to get to Groote Schuur Hospital. Here, I also need to take a taxi to get to the clinic” (Participant G)

It is evident that expenses, whether on food, visits for follow-up consultations, and/or buying of medication, and other healthcare payments can result in financial hardship. A study conducted in Tswane, South Africa, indicated that transportation costs could account for more than half of total health care costs (Mtyambizi *et al.*, 2019; Okoronkwo, Ekemiro, Okwor, Okpala & Adeyemo, 2015). Health expenditure can be catastrophic when health costs exceed the income of a family and reduce their ability to spend money on essential items and this can result in poverty (Mtyambizi *et al.*, 2019; Okoronkwo *et al.*, 2015). The study on DMII in Tswane also indicated that although all socio-economic groups experience catastrophic healthcare expenditure, the highest incidence are still within the low socio-economic group (Mtyambizi *et al.*, 2019; Okoronkwo *et al.*, 2015).

This is an indication of the imbalances in the distribution of expenditure across socio-economic groups (Mtyambizi *et al.*, 2019).

Social factors such as lack of support from healthcare workers and low economic status contribute to the barriers in the successful management of DMII according to the BPS model. Support, not only from health care workers but also from family, friends, and the community is critical in the treatment and management of DMII. The following theme will discuss the types of support experienced by participants.

4.3.5. THEME 5: EXPERIENCES OF THEIR SUPPORT SYSTEMS

Social relations are essential but the level and forms of social networks required vary from person to person according to the convoy model of social connections (Nguyen, Chatters, Taylor & Mouzon, 2016). The convoy of social relations refers to all these essential and meaningful relationships in a persons' life for example the social support network. The convoy consists of family, friends, colleagues, neighbors, and other individuals who provide significant and beneficial social support in the form of emotional support, aid, guidance, friendship, and caregiving to a person (Nguyen *et al.*, 2016). Social support is a critical element in strong relationships and recognition of psychological health and social support in human health is significant for BPS well-being (Brunelli, Murphy & Athanasou, 2016). The support which the person with DMII receives provides the strength to continue to thrive and cope with stress (Brunelli *et al.*, 2016). Social support includes the psychological and material resources available to the social network of the person with DMII, which assist them to deal with stress (Crookes, Shelton, Tehranifar, Aycinena, Gaffney, Koch, Contento & Greenlee, 2016). Social groups have a normative impact on behavior, which includes diet, physical activity, smoking, alcohol intake, and/or the use of illegal substances (Morelli, Lee, Arnn & Zaki, 2015). It is therefore important to understand how relationships and other social processes emerge and consequently assist people to value them and how these systems affect the health of the individual (Bolton & Gillett, 2019).

It is an emotional burden to live and control DMII. People with DMII experience a unique set of suppressed emotional burdens and concerns and the support from the health care providers and family influences their monitoring of the disease and how they manage the stressors (Ofstedal, 2014). The person with DMII experiences three types of support: individual, professional, and social (Johansson *et al.*, 2018). Caregivers provide support in the context of their practice guidelines and policies (Johansson *et al.*, 2018). Accountability, openness about the condition, introspection assisted by technology such as a blood glucose meter, and an open-minded attitude contribute to experiences of support in the patient (Johansson *et al.*, 2018; Andersson *et al.*, 2015). The goal of the support is to empower the patient to make informed decisions which lower the risk of diabetic complications (Johansson *et al.*, 2018).

The following sub-themes: Sub-theme 5.1: support from friends and family members; Sub-theme 5.2: Support through their support group; and Sub-theme 5.3: Support from health care workers illustrates the experiences of support by participants with DMII

4.3.5.1 Sub-theme 5.1: Support from friends and family members

Social support is one of the significant social factors in the BPS model which is crucial to maintain excellent physical and mental health (Amsah *et al.*, 2022). The BPS model further implies that stable psychosocial resources, such as being married and having positive coping mechanisms, contribute to better glycemic control. Social support originates from relationships with family members, friends, colleagues, and acquaintances (Koetsenruijter, Eikelenboom, Van Lieshout, Vassilev, Lionis, Todorova, Portillo, Foss, Serrano Gil, Roukova, Angelaki, Mujika, Knutsen, Rogers & Wensing, 2016). Patients with DMII can benefit from continuous support from friends and family in the management of their disease and during the execution of the required physical, emotional, and dietary changes (Ramkisson, Pillay & Sibanda, 2017; Koetsenruijter *et al.*, 2016). Family support is the most important source of assistance that contributes to lifestyle changes and

diabetes management (Ramkisson *et al.*, 2017). The following quotation illustrates the support provided by the participants' children:

My children have supported me so much through the years. Since they were still small and growing up knowing that I am sick even if no one really understood my sickness. They always ask me how I am doing and they make sure that they check in every morning and night. (Participant I)

Inadequate social support from friends has a negative impact on the patients' motivation and, as a result, reduces the commitment to diabetes self-management (Johansson *et al.*, 2015). The following participant received adequate support from his wife, but his circle of friends distanced themselves from him which affected his social life.

Where my wife is concerned, she helps me a lot. She is my right hand. She makes sure that I eat healthy. ... they came to fetch me at the house. Now they no longer worry about me. They do not worry. They are sitting there at home. No one comes to me. Ask her, no one comes to my house anymore. In the early mornings they were here and then they came for me and we will come. And if we go there and sit in the joint because we were young men. But now everything is done. It affected my whole social life, whole social life". (Participant C)

Spirituality is crucial when coping with health problems because religious and spiritual beliefs are coping strategies (Widayanti *et al.*, 2020). One participant experiences "God" and friends as a source of comfort and support as illustrated in her comment:

"The Lord...And dear friends" (Participant G).

The emphasis on the significance of family and peer support in achieving self-sufficiency is paramount (Ramkisson *et al.*, 2017). Adherence to recommended treatment in a timely and effective manner in DMII patients commonly occurs in a social context, which affects the family and social dynamics (Ramkisson *et al.*, 2017; Oftedal, 2014). The following sub-theme discusses the support through groups.

4.3.5.2 Sub-theme 5.2: Support through their support group

A lack of understanding of DMII, medication adherence, and dietary management is related to the social factor in the BPS model (Amsah *et al.*, 2022). ‘Self-help’ or ‘support groups’ are voluntary, small groups with the aim of mutual assistance to accomplish a common goal, such as resolving or minimizing a shared problem or condition that disrupts daily life, or attaining social change related to the shared problem (Brunelli *et al.*, 2016). Support from external sources, such as a support group is meaningful for persons diagnosed with DMII (Ramkisson *et al.*, 2017). ‘Self-help’ or ‘support groups’ may foster universality, hope, interpersonal learning, or therapeutic transformation (Brunelli *et al.*, 2016). Educational and counseling interventions occur in support groups to support behavioral change and improve self-management. Success rates in the treatment of chronic diseases also improved since the introduction of educational and behavior exchange programs (Koetsenruijter *et al.*, 2016). Two participants mentioned the importance of being a member of the support group because this allows them to receive information on food consumption, medication, and how to live with DMII as illustrated in the following quotations:

“...that’s why nowadays I go to my club for experience for diabetes what to eat and how to be. It is important to me. The information I received is mainly at the club at my group”. (Participant C)

“As far as information go, it’s, it’s important to belong to the club because we get a lot of information from the club. That is the best thing that could’ve happened for me to join up with uh C because from time to time she will get speakers there and uhm even how to take your medication... I have a machine now but I need to go back to C* so that she can show me how the machine work”. (Participant E)*

One participant indicated that she could seek support and assistance from the club manager at any time and not only when the group is functioning. This results from the positive relationship which this participant has with the support group manager and the fact that she is satisfied with the information received on disease management (Abuelmagda *et al.*, 2019).

“The only person when I feel that I want to be calm then I tell him I am going for a walk so then I will go see V. She is the club woman so I will ask her then to test my blood and sugar levels when I get to her. And when I feel sad then I also go to her and talk to her”. (Participant A)

Social support is critical for preservation of physical and mental health. Support combined with psychosocial factors, such as the development of efficient coping strategies and the effect on other neurobiological factors alleviates the impact of hereditary and environmental vulnerabilities to mental illness. Findings suggest that self-help and support group interventions can improve chronic illness management and contribute to the targeted effective adaptation as outcome (Brunelli *et al.*, 2016).

4.3.5.3 Sub-theme 5.3: Support from health care workers

Management of DMII necessitates not just adherence to medicine, but also monitoring, follow-up, and self-care (Jutterstrom, Hornsten, Sandstrom, Stenlund, Isaksson, 2016; ADA, 2020). People with DMII do not only require medical treatment from their healthcare providers but also assistance in maintaining self-care behaviors which enable them to live as healthy as possible (Johansson *et al.*, 2018; Jutterström *et al.*, 2016). People with DMII may struggle to effectively manage their disease without ongoing care and psychoeducation and this will consequently result in poor health outcomes, including costly and severe complications (Johansson *et al.*, 2018; ADA, 2016). The goal of health care workers is to support and educate the patient, which result in the empowerment of the patient to make informed decisions that lower the risk of diabetic complications (ADA, 2016). Health care workers should therefore continue to educate their patients regarding their disease (Nikitara, Constantinou, Andreou & Diomidous, 2019). A descriptive exploratory study by Bostrom, Isaksson and Lundman cited in Nikitara *et al.*, (2019), found that ongoing patient education and support from health care workers resulted in improved glycemic control. Findings from a randomized trial study, by Wexxler, Veauharnais, Regan, Beauharnais, Nathan, Cagliero, and Larin also indicated that the patients who received care and education on their disease reported

lower levels of glucose and complications (Nikitara *et al.*, 2019). Health care workers acting as motivators by identifying psychosocial problems and referring the patient to other professionals perform a vital role in the psychological support for people with DMII (Nikitara *et al.*, 2019; Ramkisson *et al.*, 2017).

The following quotations however illustrate the lack of support that participants receive from their health care workers:

“The clinic don’t sit and chat with you on this and this and this. They give you a paper and say look here this is your diet, this is what you must do and that you must do here and here is your insulin and nothing further (Participant C)

“...that they don’t even tell you at the hospital. His colleague, uh he is a nurse, she didn’t even know how to take your medication. You take your glygone before you eat”. (Participant E)

“They don’t always deliver such a great service... After being diagnosed for years I feel that I still learn new things about my sickness that was never told by my clinic. So each day I learn and try to adapt. I stopped looking for support at my clinic. I don’t go look for support because I feel I don’t get it. (Participant I)

Health care workers must be self-critical and mindful not to accept responsibility for the patient's condition when they support the patient with DMII (Shiba, Kondo & Kondo, 2016; Worku *et al.*, 2015). However, healthcare workers should assist patients to comprehend DMII, display support, encouragement, and challenge their understanding of the disease and behaviors (Worku *et al.*, 2015). Health care workers must provide support by creatively providing information which is sensitively tailored to the needs of the individual patient (Jutterstrom *et al.*, 2016). Health care workers must encourage patients to learn by reflection on their experiences (Jutterstrom *et al.*, 2016). The goal of providing support is to increase the patient's readiness and capability to manage their disease independently (Jutterstorm *et al.*, 2016; Shiba *et al.*, 2016).

4.4 CHAPTER SUMMARY

This chapter presented the findings on the experiences of persons diagnosed with DMII. Adherence and management of diabetes care rely profoundly on family, social, and health care support. The findings clearly demonstrated the challenges experienced by the participants on a biological, psychological, and social level. The findings also suggest that the participants receive sufficient support from the support group, as well as family, but the support from health care workers was poor. Participants must however take responsibility for their own health because they have to follow the treatment plan. Furthermore, participants indicated that they were unaware of the symptoms of DMII and therefore did not pay attention to their symptoms which resulted in further complications. Moreover, participants described their difficulty to balance the management of the disease with their lifestyle and income especially when living on a social security grant. These experiences were consistent with available literature. It is evident that biopsychosocial factors are significant in the development and maintenance of DMII and that an integrated approach must be applied in the execution of a treatment plan. In conclusion, the experiences shared were congruent with the available literature.

The following chapter will present the findings of the significant others' caring for those diagnosed with DMII.

CHAPTER 5

PRESENTATION AND DISCUSSION OF THE FINDINGS ON THE SIGNIFICANT OTHERS'

5.1 INTRODUCTION

The previous chapter focuses on the findings on the experiences of the person diagnosed with DMII. This chapter focuses on the themes and sub-themes resulting from the lived experiences and the context in which these occurred for persons' caring for a person diagnosed with DMII. This chapter will also address two objectives outlined in chapter one (Section 1.4) and chapter three (Section 3.3.2) which is to:

- Explore and describe the lived experiences and effects of significant others caring for individuals with DMII.
- Describe significant others' understanding of the contributing factors of the diagnosis, treatment and medication on the person taking the medication.

5.2 DEMOGRAPHIC PROFILE OF PARTICIPANTS

Table 5.1 illustrates the demographic details of the participants caring for their significant others diagnosed with DMII. Five of the ten participants were parents/partners caring for individuals with DMII.

Table 5.1 Demographic details of the significant other

	Gender	Age	Race	Home Language	Employment/ Income status	Relation to the person diagnosed with diabetes II
B	Male	59	Coloured	English	Retrenched; Disability Grant (DG)	Husband
D	Female	59	Coloured	Afrikaans	Unemployed	Wife
F	Male	66	Coloured	English	Retired, SASSA Pensioner	Husband
H	Female	43	Coloured	English	Entrepreneur	Live in friend/ caregiver
J	Female	38	Coloured	English	Working mother	Daughter

It is evident from table 5.1 that both males and females can accept the role of caregiver for the person diagnosed with DMII. The participants identified as the significant other caring for the person diagnosed with DMII included three females and two males. Women in various countries are more likely to be caregivers, and a three-quarter of all caregivers are women. Women also devote significantly more time in caring for others than men and spend 50% more time with their care recipients than male caregivers (Sharma, Chakrabarti & Grover, 2016). The age of the caregivers in this study ranged from 38 to 66 years of age, and three participants were 59 years of age and older. Two participants were full-time employed and also performed the role of full-time caregivers. Two participants received a social support grant (SASSA) where one received a disability grant and the other received an old age pension grant. One of the participants was unemployed and has no source of income. Significant others are informal caregivers and they can be a spouse, partner, family member, friend, or neighbor that assist with various forms of care in daily living activities which also include medical care (National Alliance for Caregiving & AARP, 2015). Table 5.1 illustrates that three of the participants are spouses, one is a friend who lives with the patient, and another is a daughter who performs the role of caregiver.

5.3 PRESENTATION AND DISCUSSION OF THE FINDINGS

The findings of the research resulted from the data analysis of verbatim transcriptions from one-on-one in-depth interviews with the five participants that care for those diagnosed with DMII. Three themes with five sub-themes resulted from the analyzed data. This chapter focuses on these themes with reference to relevant literature which support the direct quotations of the participants. Table 5.2 illustrates the theme and sub-themes of the caregivers below.

Table 5.2: Themes and Sub-themes

THEMES	SUB-THEMES
Caregivers' understanding of the contributing factors of diabetes mellitus type II	Theme 1:
Challenges caregivers experienced during monitoring adherence to prescribed medication	Theme 2:
Theme 3: Effects of caring for significant others diagnosed with diabetes mellitus type II	Sub-theme 3.1: Physical and psychological impact on caregivers
	Sub-theme 3.2: Social support
	Sub-theme 3.3: Other avenues of coping
	Sub-theme 3.4: Financial impact on caregivers
	Sub-theme 3.5: Impact on social life

5.3.1. THEME 1: CAREGIVERS' UNDERSTANDING OF THE CONTRIBUTING FACTORS OF DIABETES MELLITUS TYPE II

The BPS model is an integrated approach that can assist healthcare workers, family members, and the patient to understand the contributing factors to DMII. Modifiable risk factors and non-modifiable risk factors are two distinct categories of risk factors that contribute to caregivers' understanding of causal factors in DMII (Galaviz, Narayan, Lobelo & Weber, 2015). Non-

modifiable risks factors are family history, race/ethnic origin, age, and gestational diabetes risk factors (Hill-Briggs, Adler, Berkowitz, Chin, Gary-Web, Navas-Acien, Thornton & Haire-Joshu, 2020; Hill-Briggs, 2019). Genetics or an individual's biology are non-modifiable risk factors. Weight, physical activity, sleeping habits, alcohol use, smoking, stress, blood pressure, cholesterol and general well-being levels are all modifiable social and environmental risk factors (Hill-Briggs *et al.*, 2020; Galaviz *et al.*, 2015). Control of modifiable risk factors is possible by health behavior modification to lower the risk or delay the onset in the development of DMII (Galaviz *et al.*, 2015). Two participants expressed their perception on the leading cause in the development of DMII in their spouses. Both participants referred to modifiable risk factors when they described their understanding of the development of DMII in the following quotations:

“...eating unhealthy food from young... Live either uh uh to live right with your food because most people die over diabetes and how do I try to make him live right”
(Participant D)

“...and her sweet tooth. You know what got her on it? Fudge. That is how she got on it...” (Participant F)

Participants could identify the circumstances which may resulted in their spouse's diagnosis but were not sure why a healthier diet was more difficult to follow. An unbalanced diet results in unhealthy blood glucose levels which is a risk factor for DMII. Restricted access to, and availability of better food choices, food affordability and food poverty, by not having adequate and quality food in the household, are however evident in some demographic groups and they can only adhere to a diet which is economically and general available to them. There is a relationship between adherence to a healthy lifestyle and a significantly lower risk of chronic diseases such as DMII.

The following theme focus on how caregivers experience the monitoring of medication adherence.

5.3.2 THEME 2: CHALLENGES CAREGIVERS EXPERIENCED DURING MONITORING ADHERENCE TO PRESCRIBED MEDICATION

The role of family caregivers is to assist the care recipient with a chronic disease in performing self-management tasks (Rahimi, Dastyar & Rafati, 2021). There is a relationship between self-management behavior and family functioning, cohesion, and conflict when adults care for someone with a chronic illness (Abuelmagda *et al.*, 2019). Home monitoring of the patients' adherence to medication improve diabetes control and care (Munshi, Amelung, Carter, James, Shah & Henderson, 2021). Non-adherence to medication may result in tension and frustration due to constantly monitoring of the person diagnosed with DMII (National Association of Chronic Disease Directors [NACDD], 2018). The following quotations serves as evidence that monitoring of adherence to medication in people with DMII often results in frustration and tension because of the non-adherence to the medication plan by the care recipient:

“She is forever forgetting. So I already told her “do what you want to”. If you don’t want to take your medication and don’t want to get healthy it is on you”.
(Participant B)

“Now in the evenings I ask him if he took his injection. No I am going to now. Then I say but no cannot take it so late because just look what your sugar will be tomorrow morning... then the two of us argue again”. (Participant D)

“...she is just being difficult and doesn’t want to take her medication at the prescribed times can get quite frustrating. It is easy to just take your medication. I put it out for her and always leave a bottle of water for her with the tablets...”.
(Participant J)

Fifty percent of the patients globally who require medicine to treat a chronic illness do not comply with their treatment plan which includes adherence to medication (Zullig, Blalock, Dougherty, Henderson, Ha, Oakes & Bosworth, 2018). This is evident in the previous quotations where caregivers reported their challenges with the non-adherence to medication by the care recipient.

Medication adherence also suggests that the patient uses medication daily according to a schedule (Umeda, Minami, Bartolomei & Summerhill, 2018). One participant reported that his wife adhered to her medication plan and there is therefore no tension between the caregiver and the care recipient. Literature illustrates that family caregivers play a significant role in the care of patients with chronic illnesses because they can influence the level of adherence to the treatment plan by the care recipients (Jadalla, Ginex, Coleman, Vrabel & Bevans, 2020).

“That is why I must say she is very consistent in her, in her uhm managing her medication and doing things the proper time and stuff every morning. I know she gets up and taking her tablet before she eats. You know that type of things so it is consistent. Every day, every day it is the same”. (Participant F)

Excellent communication, spousal support, knowledge, and awareness of the illness from both the patient and caregiver contribute to improved treatment management. Treatment management is however inadequate when family caregivers’ sense that they are unprepared to provide care due to a lack the knowledge and information, and because they receive limited or no assistance from formal health care providers (Jadalla *et al.*, 2020). The care recipient is then at risk to administer medication inaccurately (Tariq, Vashisht, Sinha & Scherbak, 2022). However, one participant reported that she assisted with administration of the medication to ensuring the correct medication is provided to the person with DMII:

*“Like I check her sugar level... Give her medication according to the reading”.
(Participant H)*

It is evident from the above content that most participants experienced challenges with medication adherence by the person with DMII. The following theme will discuss the effects of care on significant others diagnosed with DMII.

5.3.3 THEME 3: THE EFFECTS OF CARING FOR SIGNIFICANT OTHERS DIAGNOSED WITH DIABETES MELLITUS TYPE II

Family caregivers alleviate the rising demand on health and social care services (Rahimi *et al.*, 2021). Family caregivers are family members or close relations who offer care to patients at home on a voluntary basis (Rahimi *et al.*, 2021; Holt-Lunstead, Smith, Baker, Harris & Stephenson, 2015). Caregivers' which provide home-based care assist patients with daily activities, manage treatment-related diseases, communicate, teach, motivate, and enable patients to take care of them (Rahimi *et al.*, 2021; Tang, Jang, Lingler, Tamres & Erlen, 2015). They assist those with chronic diseases, impairments, or mental illnesses (NACDD, 2018; Holt-Lunstead *et al.*, 2015). Family members are more vulnerable to physical and psychological illness, including burnout and mental health distress when they accept the role of care provider (Longacre, Valdmanis, Handorf & Fang, 2017; Tang *et al.*, 2015). Caregiver distress result from limited freedom, physical and emotional support from other family members, poor care expertise, and guilt when they disregard the patient's symptoms (Lynch, Shuster & Lobo, 2018). The caregiver burden contributes to a higher prevalence of mental and physical illnesses (Lynch *et al.*, 2018). Family caregivers are also frequently affected on a biological and physiological level due to patient care (NACDD, 2018). They are likely to experience fewer or limited career opportunities, limited social activities, and damaged relationships with family and friends (Rahimi *et al.*, 2021; Lynch *et al.*, 2018). A lack of support from family, friends, neighbors, and the community contribute to imbalances on BPS level and has an impact on the general well-being and mental health of caregivers (Amsah *et al.*, 2022).

This theme described five sub-themes, namely, Sub-theme 3.1: Physical and psychological impact on caregivers; Sub-theme 3.2: Social support; Sub-theme 3.3: Other avenues of coping; Sub-theme 3.4: Financial impact on caregivers; and Sub-theme 3.5: Impact on social life.

5.3.3.1 Sub-theme 6.3.1: Physical and psychological impact on caregivers

Caring for others can be gratifying, but it can also be stressful and demanding (Al-Rawashdeh, Lennie & Chung, 2016). Caregivers ignore feelings of frustration and physical strain related to the care for a family member with a chronic disease and may be overwhelmed, exhausted and neglect their own needs (Kazemi, Azimian, Mafi, Allen & Motalebi, 2021; Al-Rawashdeh *et al.*, 2016). The patient and the caregiver are both stressed due to the chronic disease (NACDD, 2018). The type and amount of care provided to the family member, as well as the physical restrictions and behaviors, are all objective stressors (NACDD, 2018; Kazemi *et al.*, 2016). These objective stresses cause experiences of psychological distress and poor health habits, which activate physiological reactions which can result in illness and mortality in caregivers (NACDD, 2018; Kazemi *et al.*, 2016). A population-based study by The American Psychological Association [APA] (2015) however found that many caregivers do not report elevated levels of stress, succeed in the management of care, express numerous psychological advantages, and may even have enhanced health and lower mortality because of their caregiving experience. Conversely, there are subsections of caregivers who report elevated levels of stress, sadness, frustration, and poor health outcomes due to their caregiving roles (Kazemi *et al.*, 2016; APA, 2015). Lack of resources such as knowledge, skills, social support, respite, and community services exacerbate caregiver stress and they are overwhelmed (APA, 2015). This is an indication that biological markers can provide valuable information on the stressful processes involved in care and support of family members. It reveals the circumstances in which support and care provision are harmful to mental health and well-being by using a BPS approach (Amsah *et al.*, 2022).

Participants indicate their frustration and stress when caring for their significant other and that they are also affected by the mood swings from those for whom they care in the following quotations:

“He could not do anything for himself... ..” (Participant D)

“She’s fine but when the sugar levels are high then she’s very moody with people close to her like me... It makes me feel like I’m always the target. Her emotions only affect me. No one else. Cause we are always together. Sometimes I feel like leaving cause she stresses on me only”. (Participant H)

Conflict and arguments between participants and their significant others caring for them may eventually become stressful (Thomas, Liu & Umberson, 2017). Caregivers experience more complex feelings of burden with care-related stressors, which is likely to worsen during care (Thomas *et al.*, 2017). One participant indicated that he does not only care for his wife, but also for their son who is wheelchair-bound. He is consequently subjected to a lot of physical and psychological strain. While the participant described his responsibilities as a burden, he also contradicted this by explaining that they are not a burden, but rather two issues that he must attend to. The participant describes his experiences:

“So, where the diabetes stuff was concerned I am, I always ask her did you take your tablets? What time must you take your tablets? Did you eat? What did you eat? Yes, I did eat but I did not take my medication. Now that is her own fault... She takes tablets when she feels like taking it, 12 o’clock in the evening. So that works on me. .Or the frustrations there is times that I just want to walk to cool off,... then I go sit in my room then I don’t want to be bothered... I am the one that must struggle with her and with him, the one in the wheelchair. So I actually got two burdens on my shoulder. Not, I won’t say burdens. I won’t say burdens but I mean two parts that I need to see to. I need to see to her and I must see to him”. (Participant B)

While most family members expect to care for a parent or spouse during their lives, few anticipated this reality concurrently with their individual development, raising a family, or planning for retirement (Sullivan & Miller, 2015). One participant who is also a working mother of two children is also the primary caregiver of her mother. While the participant expressed her love for her mother, she also described her frustration as a caregiver as illustrated in the following quotation:

“It has not been easy to care for her because I am a full-time working mom and sometimes it feels that she is also my child because I constantly need to check on her. I feel that after all these years she still finds it difficult to understand and accept...I love my mother dearly and enjoy taking care of her and being around her daily but with having to care for my own two children and at times for her where she is just being difficult and doesn't want to take her medication on the prescribed times can get quite frustrating... It is just that it does take strain on you mentally especially if you have been caring for someone for many years”.
(Participant J)

The role of the caregivers often shifts from being a family member to being a caregiver, which results in a different type of relationships. The caregiver relationship is sometimes unpleasant because it is distant when they struggle with feelings of frustration, stress, isolation, grief, and anger (Sullivan & Miller, 2015). The most shared feeling between the participants was frustration. People are frustrated because they feel overwhelmed and insecure when dealing with situations and behaviors as a result of their circumstances, (Thomas *et al.*, 2017).

Furthermore, being the sole caregiver frequently entails other duties, such as work, parenting, and domestic chores (Sullivan & Miller, 2015). Most of the participants stated that they had other duties, in addition to being a caregiver, such as housework, employment, and attending to the needs of more than one person, which adds to the physical and emotional stress while caring for their significant other. Not one participant mentioned any type of support from other family members or friends. Human relations are only positive and healthy when shared and mutual (Amati, Meggiolaro, Rivellini & Zaccarin, 2018). The care receiver may require extensive support but needs of the caregiver's must also be fulfilled for the relationship to remain healthy (Amati *et al.*, 2018). Positive relationships and social support prevent hostile feelings and emotions, and those who receive adequate social support from friends and family are less likely to experience symptoms of depression (Nguyen *et al.*, 2016). Support for the caregivers is discussed in the following sub-theme.

5.3.3.2 Sub-theme 3.2: Social support

Relationships between family members are not necessarily close (Scharp & Hall, 2018; Thomas *et al.*, 2017). Although family bonds are obligatory due to cultural beliefs, countless families endure a degree of separation (Scharp & Hall, 2018; Scharp & Hall, 2017). Reasons which contribute to separation in families include the following: Families live far from each other, choose to spend less time together, family feud, or experiences a life-changing event such as the diagnosis of a chronic illness. This separation can be perceived as alienation during extreme circumstances (Scharp & Hall, 2018; Scharp & Hall, 2017).

The following quotations illustrate that the caregivers suffer significantly due to a lack of physical and emotional support from family and friends:

“To be honest with you, zero. No one. No one at all. No one at all... The eldest son ...Ask him for something, it takes two hours before he will do it. So his mother calls him, come help me here quickly and then he cannot do it. (Participant B)

“Wow, I will say now the day that he got the stroke and the day he became a diabetic, then the house was still full of people. Everyone came here but today you don't see anyone. Understand? What you might maybe need now, wait you can quickly phone the sisters and the brothers, give us this and that but it is not like that, it is not like that, it is not. All this things goes through your mind. His brothers come here. My sisters come here. No one is interested”. (Participant D)

Family relationships, both with the patient and with other family members, suffer with the patient's chronic diagnosis. Poor family ties are also harmful to chronic disease management, regardless of the disease, and family members struggle with relationships because they do not know how to provide emotional support to each other (Shiba *et al.*, 2016).

One participant reported that she does not have anyone to talk to, however, this is her decision as she prefers not to discuss her struggles as a caregiver. This participant voluntarily isolated her from support, which is also known as ‘pulling away’ and occurs when a member attempts to isolate

themselves from the rest of the family community. This phenomenon occurs in various forms such as by moving, communicating less with the family/community, or having an open discussion about severing ties with the family (Scharp & Hall, 2018).

“No one. I didn’t have anyone to talk to and I prefer not to talk about my personal struggles”. (Participant H)

Family ties can however also be strengthened because family members are closer when they work together to assist each other (NACDD, 2018). Two participants reported that they receive support from family members in the following quotations:

My support system is my children, what you put in you get out and I got a lot out”. (Participant F)

“I still go out and socialize because I have my other siblings that support me...”. (Participant J)

Care is both physically and emotionally demanding and the caregivers frequently do not receive support to prevent illness or burnout (Thomas *et al.*, 2017). It is important for caregivers to express frustrations and other feelings to other family members or close friends which they consider supportive (Irfan, Irfan, Ansari, Oidwai & Nanji, 2017). However, caregivers do not rely just on family and friends for support but also perceive their religion and spirituality as support and as a contributing factor to their sense of well-being (Widayanti *et al.*, 2020). This type of support is illustrated in the following sub-theme.

5.3.3.3 Sub-theme 3.3: Other avenues of coping

The concepts ‘caregiver burden’ and ‘caregiver strain’ refer to the multiple negative consequences when caring for another person (Jadalla *et al.*, 2020). Religion and spirituality can provide support when caregivers experience negative consequences such as stress, anxiety, loneliness, diseases, and emotional instability during care (Pearce, Medoff, Lawrence & Dixon, 2016). Spirituality and

religion are beneficial to health and caregivers who use religion and spirituality to cope with care have stronger relationships with the care recipient and are less stressed (Pearce *et al.*, 2016). Although no participant reported lower stress levels, they continued to pursue spiritual support, as supported by the following quotations:

“I mean what can one do without prayers. I said to myself the only thing that can help is pray and ask the Lord to help us.”. (Participant B)

“I am very spiritual and I am leaning on that uh uh my personal relationship with God helps me a lot because I know”. (Participant F)

“All we can do is to pray for her and pray that we make the best decision for her and her health”. (Participant J)

Literature indicates that participants used their religious and spiritual beliefs as a coping mechanism. Those with a lower or higher level of religious coping mechanisms are more vulnerable to depression (Aflakseir & Mahdiyar, 2016). The physical and mental health of people using religion and spirituality as coping mechanism are better and they perceive that God's involvement contribute to this. Experts are however unable to explain if religion and spirituality contribute to health or whether religious and spiritual groups attract people who are psychologically or physically healthier (Kaplan & Berkman, 2021).

The social life of participants remained affected by their caregiver role despite the possibility of greater physical and mental health which resulted from their spiritual beliefs. The following sub-theme focuses on the impact of caregiving on participants' social life.

5.3.3.5 Sub-theme 6.5: Impact on social life

The ability of family members to participate in activities that they enjoy is a vital aspect of family life. However, the stress when caring for a family member with a chronic illness has a significant impact on the social lives of families (Ghosh, Choi, Williams, Duggleby, Ploeg, Markle-Reid &

Peacock, 2020). Families experience constraints to enjoy social activities and have quality of life due to a lack of time when they care for a family member diagnosed with DMII (NACDD, 2018).

The voices of the participants illustrated how the role of family caregiver impacted on their social life, whether as a result of financial constraints, additional daily responsibilities/duties, or constant worry about the coping of the care receivers when they are absent.

“To me it is like I am in a prison. I am stuck at home. I can’t go out. Why? because I must think of this and think of this and I must do this and I must do that and then she nags on me, yes but you must still do this and you must do that. We have never been out, we have never been away. Never been away as husband and wife in our life for a weekend also. Because this is not here”. (Participant B)

“My biggest concern is that if I’m not with her. Will someone else know what to do or will she recover if she should be alone”. (Participant H)

In contrast, one participant experienced that caring had no impact on his social life. The participant applauded the excellent teamwork and support which he provided and received from his wife with DMII (Ghosh et al., 2020).

“I don’t care I am quite happy I go, we go, if we go out I put off what we do. I am a sportsman, right, I do sports. I love sports so I am into sports but the sports won’t interfere with our stuff. Tomorrow it would have hey? Because tomorrow I would have played golf but tomorrow there is no golf, it was postponed so I go with her then to the club”. (Participant F)

Another participant discussed her decision to be the primary caregiver and relocate to live with her mother diagnosed with DMII, irrespective of the limitation of freedom and privacy. The participant expressed she can socialize due to the support from her siblings and the time which she allocated for that. Families are more likely to succeed when a family caregiver takes the initiative to arrange

leisure activities with the support of family despite the limitations imposed by the relatives' illness (Ghosh *et al.*, 2020).

“I am divorced so the decision was not that hard however it does feel as if I gave up some freedom and privacy. I think once you are out of the house you grow fond of your own space and enjoy it. the moving in with my mother took some time to get use to and like I said it does get to me at times because I feel that I need to constantly check up on her”. (Participant J)

Friends often drift apart after a diagnosis with a chronic illness because they do not understand the family's situation. It is a common phenomenon, although the family would prefer to be in contact with their friends (Holt-Lunstad *et al.*, 2015). One participant stated that she and her husband used to socialize frequently and had friends, but since her husband's diagnosis, they have stopped to socialize and have not seen any of their friends.

“I have, we socialized a lot in life, I will not argue there. We have socialized a lot socialize and such friends, a lot came here but today what you see is no one, you don't see anyone coming, no one come any longer”. (Participant D)

Caregivers who socialize are less likely to experience feelings of helplessness and depression (Irfan *et al.*, 2017). There are a variety of explanations why caregiving affects the social life of caregivers. It could be because friends, family, and neighbors become drained when they hear about the hardships of care and they therefore gradually distanced themselves from the caregiver and the care situation (Irfan *et al.*, 2017). The caregiver's decreased socialization could also be due to too many responsibilities and chores, as well as the inability to enjoy themselves when they are not with the care receiver, but financial problems can also be a contributing factor. The financial impact on caregivers will be discussed in the last sub-theme.

5.3.3.4 Sub-theme 3.4: Financial impact on caregivers

Being a caregiver affects a person on a psychosocial level, based on the BPS model. Participants from low-income families are more likely to display signs and symptoms of anxiety and depression

depending on their family's socio-economic situation (Amsah *et al.*, 2022). Caregivers who care for family members and friends are more likely to experience financial hardship, with serious financial repercussions (Donovan & Muriel, 2021; National Alliance for Caregiving [NAC] and AARP Public Institute, 2015). A staggering 45% of caregivers in the United States experience at least one budgetary impact because of caregiving (Donovan & Muriel, 2021). These financial impacts are involuntarily and include influences on short- and long-term savings, default on basic bills, as well as additional debt, which include borrowing from relatives and friends (Donovan & Muriel, 2021; NAC & AARP Public Institute, 2015). These could have long-term consequences on the caregivers' financial and retirement security (NAC & AARP Public Institute, 2015).

Family caregivers face significant financial effects due to direct out-of-pocket expenditure (Schulz & Eden, 2016). Out-of-pocket expenditure refers to purchases made on behalf of the person for whom the caregiver is caring and include purchases of household goods, home modifications, medical equipment, co-payments for medical and pharmaceutical treatments, food and meals, transportation, and other products and services. The following quotation serves as evidence that caregivers experiences financial hardships due to the role of caregiver:

“How must we pay this, how must we pay that, we must buy food. We must do this and we must do that. Then we sit with no money by that time. Or we get sick, I must rush home from work. We have never been out, we have never been away. Never been away as husband and wife in our life for a weekend also. Because this (referring to money) is not here. Yeah, we cannot cope on saving to go away. With our money it comes in and it goes out. It is in this hand and out by that hand. We can't, it is pressurizing us. We can't do what we want to do. We have got so a lot of things that we have got to do here in this house but the financial thingies isn't there”. (Participant B)”

The quote also illustrates that it is challenging and demanding to balance work and caregiving obligations (Schulz & Eden, 2016). It can be challenging for those who do not have the option of taking paid time off work due to a lack of flexibility during employment and management of

employment and family commitments (Schulz & Eden, 2016). Employed caregivers can benefit from a flexible work environment since it gives them the time they need to deal with crises as well as everyday tasks such as doctor's appointments (NACDD, 2018; Schulz & Eden, 2016). This was however not evident in this participant's situation. One participant decided to leave her permanent employment to care for her daughter diagnosed with DMII, full-time due to the anxiety she experienced while being away from her daughter for extended periods. She could however not make ends meet and launched her own home-based business, which provided more flexibility and allowed her to continue to generate an income but she continues to worry about her income:

“I even gave up my job. Cause when I was at work I would really stress if she don't answer her phone. Like I wonder if something didn't maybe happen. And I can't work like that so I just left. Financially as I'm doing other things for an income.... Yes, I was worried about an income”. (Participant H)

Patients and their families may find it difficult to make decisions about health care due to the emotional, financial, and logistical consequences of a chronic diagnosis, the complexity of treatment options, as well as the limited health knowledge and lack of experience living with the chronic diagnosis (Schulz & Eben, 2016; Okoronkwo *et al.*, 2015). Families consequently prefer to employ a professional caregiver, but this is expensive (Schulz & Eden, 2016). One of the participants reported that the family considered to employ a caregiver but realized that it was not feasible due to the financial implications. This corresponds with the literature which states that family caregivers find it difficult to hire affordable caregivers (Schulz & Eden, 2016).

“Our family has come together and talked about getting a carer for my mother... but we have also looked at what it can cost to have someone look after her and it is not in our budget at the moment. I have tried to buy food in bulk because we had to change her diet and the type of food a diabetic requires is too expensive so we try to buy what we can and just monitor her eating”. (Participant J)

It is evident that the participants acknowledged that there are significant financial challenges involved in the care of a family member with a chronic disease. Caregivers face significant financial risks to care for elderly relatives (Schulz & Eden, 2016). All the care receivers in this study were older than 50 years of age and had limited financial resources.

5.4 CHAPTER SUMMARY

This chapter presented the findings of the significant others caring for a person diagnosed with DMII. The psycho-social experiences of these caregivers are evident in the chapter. Provision of adequate care from the caregiver to the care recipient caused strain on the emotional, mental, and physical well-being of caregivers and resulted in strained relationships with the care recipient. The evidence also highlighted those caregivers seldom received holistic support from their families and friends. The caregivers experienced lack of a social life and social support, which consequently influenced their emotional and psychological wellbeing. An integrated approach of care as proposed by the BPS model is therefore a necessity to focus on the emotional, psychological, social, financial wellbeing of both the care recipients, as discussed in the previous chapter, and the caregivers.

In conclusion, the experiences shared were congruent with the available literature and the BPS model. The following chapter will present conclusions and recommendations of this research.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 INTRODUCTION

Chapters four and five presented the findings of this study in persons diagnosed with DMII and their significant others. The researcher was interested in the lived experiences of persons diagnosed with DMII and their significant others caring for them and therefore decided to embark on this study. The study aimed to gain an in-depth understanding of the lived experiences of those living with DMII and their significant others caring for them. This chapter will present the conclusion and recommendations for the persons diagnosed with DMII and for their significant others (chapters four and five). To achieve the research goal of the study, the research study aspired to achieve the following objectives:

- To explore the lived experiences of adults living with DMII.
- To explore and describe the reason adults living with DMII do not adhere to treatment and medication.
- To explore and describe the lived experiences and effects of significant others caring for individuals with DMII.
- To describe significant others' understanding of the contributing factors of the diagnosis, treatment and medication on the person taking the medication.

The study used a qualitative research approach with a phenomenological strategy of inquiry and an explorative and descriptive design to achieve the research goal and objectives. The researcher selected this methodological position because it allowed the researcher to explore the lived experiences of the participants. In-depth unstructured phenomenological interviews contributed to the successful attainment of the goal and objectives of this study. Unstructured interviews are useful in cases where the researcher wants to initiate an exploratory investigation (Creswell, 2013; De Vos *et al.*, 2011; Babbie & Mouton, 2010).

Chapters four and five provided detailed descriptions of the lived experiences and the contexts in which these experiences occurred in adults living with DMII and their significant caring for them. Phenomenology studies people's perceptions, positions, and understanding of specific circumstances as it occurs in their daily lives (Creswell, 2013; Fouché & Schurink, 2011). The researcher decided to use phenomenology because it allowed the participants to engage in an open, deep, and sensitive discussion that allowed for a deep and rich understanding of their lived experiences (Babbie, 2013; Creswell, 2007).

6.2 CONCLUSIONS

This section summarises the study's findings, draws conclusions, and makes recommendations based on these findings.

6.2.1 THEME 1: UNDERSTANDING THEIR DIAGNOSIS

Theme one includes three sub-themes as discussed below:

Sub-theme 1.1: Findings demonstrated that the participants experienced complications even before diagnosis with DMII. They indicated that their poor lifestyle choices, such as following a poor diet and unhealthy eating patterns, resulted in the diagnosis of DMII. One participant indicated that she was aware that she was prediabetic. Participants indicated that they initially ignored vital symptoms. It was only when they noticed complications that they seek medical attention and was diagnosed with DMII.

Sub-theme 1.2: Findings illustrated that most individuals had family members with a history of DMII. One participant specifically mentioned that all his siblings had DMII at the age of forty.

Sub-theme 1.3: Findings indicated that complications were already present during the diagnosis of DMII and participants reported experiences of complications. One participant mentioned the experiences of his sibling with DMII and the development of serious and debilitating complications. He was aware of the possible complications that might develop due to the diagnosis and consequently experienced fear.

The findings in sub-theme 1.1. and 1.2 highlighted that those adults diagnosed with DMII, did not necessarily understand the cause or symptoms or the management of DMII. Participants therefore ignored the symptoms, positive lifestyle habits and followed poor eating habits which are significant contributors to a DMII diagnosis. Participants were surprised when they discovered that they had DMII and described how they initially ignored the symptoms and eventually experienced complications/difficulties and ultimately requested medical help. Participants explained their experiences of the complications due to DMII which resulted in experiences of fear and anxiety. The findings also specified that participants were aware of unhealthy eating and lifestyle habits which triggered the onset of their disease.

In conclusion, theme one found that it is a prerequisite that the participants with DMII understand the risk factors and the causes of DMII, to recognize the signs and symptoms as early as possible, and to seek medical assistance when they experience any of the signs or symptoms. Knowledge is important and contributes to the prevention of DMII and related complications. Family members who are aware of a DMII diagnosis of another family member can consequently also monitor their own condition regarding DMII by having regular health assessments and tests.

6.2.2 THEME 2: EMOTIONAL AND MENTAL CHALLENGES EXPERIENCED

The study also found that participants expressed their feelings of shock, denial, and difficulty to accept their DMII diagnosis. There were however participants who managed the DMII diagnosis well and incorporate the diagnosis in their daily lives. The findings also suggest that the adjustment of the patients towards the demands during self-care, to cope with the disease, which include a healthy diet, being physically active, and adherence to medication depend on the patient's acceptance of their diagnosis (Kalra *et al.*, 2018) These factors will affect the persons emotional and mental adjustment towards the DMII diagnosis.

6.2.3 THEME 3: MANAGEMENT OF DIABETES MELLITUS TYPE II

The findings of the two sub-themes of theme three include the following:

Sub-theme 3.1: This sub-theme found that participants acknowledged problems with their lifestyle changes and selection of better lifestyle options which were important to their regular dietary intake. Participants struggled to make better food choices and to adhere to a healthier diet especially during family gatherings where tempting treats were available.

Sub-theme 3.2: The sub-theme indicated that there were several reasons why participants adhered to or did not adhere to their prescribed medication. Participants experienced the administration of their medication as stressful. Other participants however accepted the responsibility to manage their diagnosis and adhered to the medication daily. Participants which experienced challenges to accept their diagnosis did not adhere to their medication.

The findings also suggest that significant lifestyle adjustments are necessary when diagnosed with DMII. It was important to follow a recommended diet, take medications as prescribed, and follow a healthy lifestyle. If the person with DMII does not manage their diet and medication it can be fatal. Sub-theme 3.1 found that a healthy balanced diet contributed to maintenance of blood glucose levels, and therefore delays complications related to DMII. It was determined that people with DMII experienced difficulty to manage a healthy and well-balanced diet which is beneficial for their health (ADA, 2019; Asif, 2014). Participants also reported in sub-theme 3.2 that they experienced stress because they had to administer medication daily, some participants were in denial about their diagnosis and therefore did not take their medication as prescribed.

The findings of this theme emphasized that acceptance of the diagnosis by the person diagnosed with DMII is vital in treatment adherence and in making decisions to achieve optimal health.

6.2.4 THEME 4: EXPERIENCES WITH BARRIERS IN MANAGING DIABETES MELLITUS TYPE II

There are barriers towards successful control and treatment of DMII. This study found barriers in the management of DMII, which included health system-related and socio-economic barriers. Two sub-themes of theme four highlighted these barriers:

In *sub-theme 4.1*, the findings illustrated that health system-related barriers such as poor management of health care facilities, extended waiting times, a shortage of human resources and medical equipment and limited time with a clinician had profound adverse effects on the management of DMII by participants. Participants experienced follow-up sessions with the clinician as rushed. They were unable to ask any questions about their diagnosis in the time allocated to them, and experienced lack of information about their diagnosis to manage their treatment successfully. The conclusions of this sub-theme are that a comprehensive treatment plan for DMII, necessitates time by service providers to reinforce education to patients and to provide follow-up care to manage the diagnosis. These treatments included dietary plans, medication intake, therapy, and support groups within the community.

In *sub-theme 4.2*, the findings illustrated that the participants experienced social and economic barriers which contributed to difficulty with the maintenance and management of their disease. It was evident that participants experienced that the most basic food items were too expensive and therefore could not afford the dietary changes. The diagnosis also required more frequent visits to the hospital for follow-up sessions which then incurred transport costs. The conclusion is therefore that socio-economic status of a person has an impact on the management of DMII especially in the context of the study where the income of the participants were primarily SASSA grants.

6.2.5 THEME 5: EXPERIENCES OF THEIR SUPPORT SYSTEM

The findings of this study have demonstrated that a person diagnosed with DMII and their support system play a significant role in the management of their disease. It is also clear that support should

not only be from the significant others of a person with DMII but must also include external sources such as their support group, and the health care system. This theme consists of three sub-themes which are discussed in the following section.

In *sub-theme 5.1* participants experienced physical and emotional support from family members, which is consistent with the recommendation of the BPS model which recommends that people with chronic illnesses receive support from others. Participants did not experience the same level of support from friends, which resulted in feelings of dissatisfaction and frustration. However, one participant did not only experience support from others but also from God.

It is evident in *sub-theme 5.2* those participants had positive experiences from the support group. The support group did not only provide support, but also provided the participants with valuable information about their disease/treatment plan, which encourages their adherence to the treatment plan. In addition to the support from family and friends, the support group also provided individuals with individual support when needed, which assisted with their stress and frustration.

It is evident from *sub-theme 5.3* that participants' experienced stress due to a lack of information on DMII. Health care workers did not explain the information to the participants or did it in a manner where they could not comprehend and applied the information. Participants expressed their concerns and dissatisfaction about the lack of training among healthcare professionals and the lack of support from them. This resulted in demotivation and reluctance to visit the healthcare facility.

Some participants reported in *sub-themes 5.1 and 5.2*, that they experienced support from family members. However, other participants experienced disappointment and isolation when diagnosed with DMII because friends no longer demonstrated interest in their lives. The findings also suggested that religious and spiritual beliefs were coping strategies to support participants. In sub-theme 5.2, the findings suggest that support groups which provided support from fellow members with similar experiences and provided knowledge about DMII benefited participants.

It can be concluded that persons with DMII require holistic support as recommended by the BPS model. It is also evident that the emotional and physical health of participants are threatened due to their experiences with health care providers. It was evident that regular follow-up treatment and information are crucial for successful disease management and lack of support also contributed to frustration and ineffective disease management.

6.3 CONCLUSIONS

This section summarises the study's findings, draws conclusions, and makes recommendations based on these findings in chapter five.

6.3.1 THEME 1: CAREGIVERS' UNDERSTANDING OF THE CONTRIBUTING FACTORS OF DIABETES MELLITUS TYPE II

BPS factors contribute to the development of DMII, and it is, therefore, clear that the participants experienced those social factors such as that unhealthy lifestyles, financial status, social support, education, as well as following an unhealthy diet from an early age and overindulgence in sugary treats contribute to their partners DMII diagnosis.

6.3.2 THEME 2: CHALLENGES CAREGIVERS EXPERIENCED DURING MONITORING ADHERENCE TO PRESCRIBED MEDICATION

In theme two, caregivers expressed their frustrations during the monitoring of their spouse's medication adherence and they expressed that their spouse must take responsibility for their own health. Participants reported their fears and concerns due to the spouse's lack of routine when taking medication. They fear that the lack of routine might result in further complications such as hypoglycemia or hyperglycemia. The participants experienced that the person with DMII refused to take their medication even though they provided medication and water. Other participants on the contrary experienced no challenges with their spouse to follow their treatment routine and adhere to the prescribed medication. Another participant indicated that she preferred to administer the medication of the person with DMII.

In conclusion, most participants who monitor their partners' compliance with prescribed medication experienced adverse feelings. It is evident that the participants monitored the patient's adherence to medication and demonstrated support. The relationship between support and compliance is usually positive, but during this study the participants' unhappiness and other negative emotions minimized their supportive behavior. They just ensured that the person with DMII adhere to medication requirements.

6.3.3 THEME 3: THE EFFECTS OF CARING FOR SIGNIFICANT OTHERS DIAGNOSED WITH DMII

Theme three consists of five sub-themes which are discussed in the following section:

Sub-theme 3.1: The findings indicated that the patients' diagnosis of DMII affected the physical and psychological well-being of the participants. Participants perceived that they were frequently used as a punching bag when their partner experienced mood swings and was as a result reluctant to function as caregiver for the person with DMII. The participants were conscious of the effects when caring for a person with DMII. Their time was no longer their own since they must deal with their spouses' emotional and physical needs. They frequently experienced burden and frustration. The participants had to reconsider their own commitments, which were complicated by the fact that they had to care for their significant other. The participants also experienced that caring for a person with DMII affects their mental health.

Sub-theme 3.2 indicated that participants expressed dissatisfaction with their families' lack of support in fulfilling practical household responsibilities. Participants experienced a lack of support from family and friends and expressed frustration due to the lack of support and their inability to disclose their needs to their family and friends. The participants preferred not to request any kind of support because they experienced limited support in the past. However, participants experienced support when they participated in activities which they enjoy and when they had time to socialize.

It was clear in *sub-theme 3.3* that the participants pursued other support opportunities. Participants indicated that they pray and attended church services for support to ensure emotional stability when they experienced loneliness and when they were emotionally drained.

Sub-theme 3.4: Participants experienced financial challenges, disengagement, and burden. The participants had less opportunities for social interactions due to their financial challenges. It is also evident that participants had to take time from their employment or even quit duties when employed to manage their responsibilities as a caregiver. A family considered employment of a caregiver but abandoned the idea due to the cost involved. Families also altered the patient's diet because it was too expensive to buy diet specific meals for diabetic patients. When the person with DMII was the breadwinner and could not continue to generate a stable income, it had a detrimental effect on the household and specifically the caregiver. Participants indicated that they are not yet of retirement age and therefore cannot apply for a SASSA pension, which could alleviate the financial burden. Other participants indicated that they do not experience a financial burden because the day hospital provided the medication without costs.

In *sub-theme 3.5*, participants explained the effect of their spouse's diagnosis on them and expressed their frustrations, irritability, and anger due to their caregiver role. Participants indicated that they constantly worry when they leave the person with DMII at home. They also voiced their frustrations about the friends that no longer socialize with them. Other participants experienced mixed emotions about the changes in their lives as a caregiver and they socialized and engaged in activities which they enjoy.

The conclusion is that caregivers are an essential component to ensure and maintain outpatient care with DMII. Caregivers do not receive adequate support and their experiences were often disregarded which result in emotional and physical burden. The adverse effects when caring for a person with DMII are evident from the findings of the participants' experiences. Finances are a significant contributing factor in their well-being and the outcome of the significant others' DMII

diagnosis and treatment as illustrated in the findings. It is also clear that there is limited support from family and friends to caregivers and the health system disregard them as a group who also need access to support services and counselling sessions.

6.4 RECOMMENDATIONS

The researcher recommends the following based on the above conclusions and when the aim and objectives to understand the lived experiences of the participants diagnosed with DMII and their significant others caring for them are considered. Recommendations are relevant to multidisciplinary teams (MDT), the government, and individuals/families.

6.4.1 Recommendations to the multi-disciplinary team (MDT)

- A doctor must refer the patient to an MDT when the doctor suspects and did not confirm a DMII diagnosis during a consultation with patient. This will ensure a thorough assessment of the patient and education on this disease to prevent the development of DMII especially in high-risk patients or pre-diabetes.
- The MDT must focus on integrated management in people with DMII which includes various treatment goals such as stabilizing blood glucose levels, diet, lifestyle management, regular follow-up consultations with the team, and regular screening for the prevention and/or delay of DMII or co-morbidities.
- The patient and families/caregivers must always contribute and be considered as part of the MDT because they are the ones who provide the information and who are involved in diabetes management such as lifestyle changes and treatment adherence.
- Both primary and secondary health care professionals must have access to swift communication channels, precise record-keeping, information distribution, and appropriate referrals to specialist.

- Registered support and educational groups, facilitated by health care professionals, for patients and their families/caregivers, must be more regularly accessible in local communities.
- Patients and their families/caregivers must have immediate access to a physiotherapist, dietician, psychologist/social worker to provide the necessary support, guidance to ensure a more successful treatment plan and to educate both the patient and the family/caregivers.
- The MDT must also consider the biological and psychosocial elements which influenced the patient's diagnosis or the severity of the disease and must include and implement a plan based on the environmental and financial demands of the person with DMII and significant other. This will ensure successful implementation of the treatment program at home.
- The MDT must include the caregiver in discussions related to the patient's illness, with the consent of the patient. This will empower them with the necessary information and education to make informed decisions in the treatment of the person with DMII when necessary.
- Caregivers must be referred to appropriate resources such as registered support groups, and information sessions.

6.4.2 Recommendations to the government

- Vegetables and fruit are important in a balanced diet and is important to control blood sugar and insulin levels. Lowering taxes on these foods would be beneficial for families and thus encourage a healthier diet not only for the person with DMII but also to families.
- More affordable nutritional initiatives are necessary in low-income communities. The government can cooperate with private organizations through networking, coordinating, and by forming long-term alliances.
- Financial literacy and financial educational programs/courses are also a necessity for communities. These programs should be free and accessible to everyone. Education on

financial management will benefit families/individuals so that they purchase nourishing foods even with a limited budget.

- It is important to increase the awareness of NCD's such as DMII through awareness campaigns in the public and private sectors on a regular basis where patients and caregivers can form part of this delivery of awareness talks.
- Government must assist with the access to regular, affordable professional caregivers to alleviate potential financial and emotional stress in families by providing 24-hour care for a family member with DMII.
- Government must develop a program that provide caregivers access to relevant information, free support groups/services, as well as programs on a quarterly basis that would further encourage them and provide incentives such as food parcels to them to show appreciation to caregivers. This will decrease hospital admissions.
- It is also essential that government establish an easily accessible diabetes outpatient care program at health care facilities that supports families which provide care to those diagnosed with DMII.

6.4.3 Recommendations to individuals/families/caregivers

- Individuals, families, and caregivers must take responsibility for their health by exercising at home, by self-education on NCD's, as well as financial management to ensure a balanced diet.
- They must seek medical attention and attend follow-up appointments when they are aware of the symptoms of DMII.
- They must also establish a self-care routine and activities.
- They must monitor their emotional and mental well-being through reflection, journaling, and/or take part in regular supportive conversations with others in similar positions. This will assist patients and caregivers to identifying the risk for burn-out.

- It is important for them to ask for assistance from family, friends, and health care workers.
- Individuals, families, and caregivers must empower themselves through education, information, and by attending support groups, attending appointments with the patient, and asking questions.

6.5 RECOMMENDATION FOR HIGHER EDUCATION AND TRAINING

- Social work education needs to be reevaluated to address significant national health issues such as chronic diseases, and new emerging and reemerging disease/s. The social work profession must therefore broaden the scope of practice to focus on improved patient care and broaden the practice lens to include more health prevention and advocacy, population health, and promotion of health equity.
- Social work must include health policies in their training program. Every social worker will interact with elements that affect the social determinants of health on a micro, mezzo, and macro level and it is therefore crucial to have basic knowledge on health policies.
- Social workers with a Bachelor of Social Work and Master of Social Work require additional information and skills to practice effectively within an MDT, in a medical and clinical setting and this can be accomplished in a dual-degree program.

6.6 SUGGESTIONS FOR FUTURE RESEARCH

In order to address these recommendations, there is a need for further research as follows:

- There is a need for additional research to determine the psychosocial impact of illness on significant others in the role of caregivers.
- Further research is necessary to determine the psychosocial needs of patients diagnosed with DMII.
- Research is necessary to establish the different psychosocial needs of caregivers before and after the diagnosis of DMII.

- Research is recommended to establish the development of the psychosocial needs over time (over a period of 10 – 15 years) in those diagnosed with DMII. o

6.7 CHAPTER SUMMARY

In this chapter, the researcher summarized the conclusions and provided recommendations. The researcher established that DMII is a demanding disease to manage and maintain. The findings of the research also indicated that the diagnosis of DMII not only affect the patient but also the caregivers, specifically on a psychological and social level. The patient and the caregiver are therefore struggling psychologically and physically due to the DMII diagnosis. Environmental, social, and psychological factors affect the treatment and management of DMII and there is a need for holistic support to the patient and significant others. Research on the experiences of persons diagnosed with DMII and their significant others caring for them was imperative to grasp the holistic effects on the household. This study also highlighted the importance of internal and external support to the person diagnosed with DMII and the caregiver and how this contributes to the treatment and management plan of the disease.



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APPENDIX A: PERMISSION LETTER



UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa
Tel : +27 21-959-2821

07 July 2020

To whom it may concern

Subject: Permission Request Letter

Dear Sir/Madam,

I, Elnéri Koegelenberg, enrolled as a Master student in Social Work at the University of the Western Cape is writing this letter to you to kindly grant me permission to access members from your Diabetes Wellness/Support Group to conduct my research.

I am currently doing research around diabetes mellitus, mainly on diabetes mellitus type II. My topic is: *Exploring the experiences of individuals diagnosed with diabetes mellitus type II, and their significant others' caring for them.*

This research will employ a qualitative research approach, with the goal to collect in-depth, rich, and nuanced data.

The researcher will provide the participants with information letters that explains the study and what would be expected of them. Participants would be allowed to withdraw from the research at any time if they wish To.

The objectives of the research will be:

- To explore the lived experiences of adults living with diabetes mellitus type II.
- To describe the understanding what are the reasons why adult living with diabetes type II do not adhere to treatment and medication



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Private Bag X 17, Bellville 7535, South Africa
Tel : +27 21-959-2821

- explore and describe the lived experiences and effects of parents/partners living with individuals with diabetes mellitus type II,
- to describe their understanding of the contributing factors of the diagnose as well as the treatment and medication for the person taking the medication

I am hoping to receive a positive reply from your side.

Yours Sincerely,

Elnéri Koegelenberg

A handwritten signature in black ink, appearing to be the initials 'EK' or a stylized version of the name 'Elnéri Koegelenberg'.

APPENDIX B: INFORMATION SHEET



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel : +27 21-959-2821

INFORMATION SHEET

Project Title: Exploring the experiences of individuals diagnosed with diabetes mellitus type II, and their significant others' living with them.

What is this study about?

This is a research project being conducted by Elnéri Koegelenberg at the University of the Western Cape. We are inviting you to participate in this research project because you have experienced and have knowledge on type II diabetes mellitus. The purpose of this research is to obtain the experiences of individuals diagnosed with diabetes mellitus type II and their significant others living with them.

What will I be asked to do if I agree to participate?

You will be asked to share your experience/s of diabetes mellitus type II and how this has an impact on your life as an individual diagnosed with diabetes mellitus type II or as an individual living with an individual diagnosed with diabetes mellitus type II. The session will take approximately 60-120 minutes.

Would my participation in this study be kept confidential?

The researcher undertakes to protect your identity and the nature of your contribution at all times. To ensure your anonymity during the research process, you will get a number and will be at all times referred to as the number provided to you. Your name or surname will not be used during the research. All data collected during the research process will be locked in a cabinet where only the researcher has access to. The data stored on a computer will only be used by the researcher self, and only the researcher will have the password to access the data. Your identity will be protected at all times. In accordance with legal requirements and/or professional standards, information will be disclosed to the appropriate individuals and/or authorities if information comes to our attention that are of concern and might be harmful to you or others. In an event like this, you will be informed that we have to break confidentiality in order to fulfil our legal responsibility to report to the designated authorities.

What are the risks of this research?

There may be some risks from participating in this research study. You will give information which might contribute to you being emotional or which might influence the way you perceive these things. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention. Service delivery to you, your family or the person with diabetes mellitus type II will not be influenced by the participation in the research.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about persons diagnosed with diabetes mellitus type II, caring for them and living in a family with a member with a mental illness. We hope that, in the future, other people might benefit from this study through improved understanding of the experiences of diabetes mellitus type II.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time with no questions asked. Terminating your participation at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by *Elnéri Koegelenberg* from the *Social Work Department* at the University of the Western Cape. If you have any questions about the research study itself, please contact Elnéri Koegelenberg, at cellphone 079 281 7223 or at elnerikoegelenberg1@gmail.com. Should there be any questions regarding this study and your rights as a research participant or wishes to report any problems you experienced related to this study, please contact.

Head of Department: Dr. M. Londt

Social Work Department

Tel: (021) 959 2277

mlondt@uwc.ac.za

Dean of the Faculty of Community and Health Sciences: Prof. A. Rhoda

University of the Western Cape
Private Bag X17
Bellville 7535
Tel: (021) 959 3261
arhoda@uwc.ac.za

Biomedical Research Ethics Committee
University of the Western Cape
Private Bag X17
Bellville 7535
Tel: (021) 959 4111
research-ethics@uwc.ac.za

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.



UNIVERSITY *of the*
WESTERN CAPE

APPENDIX C: CONSENT FORM



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2821

CONSENT FORM

Project Title: Exploring the experiences of individuals diagnosed with diabetes mellitus type II, and their significant others' living with them.

The study has been described to me in a language that I understand and I volunteer to participate in this study. I fully understand the information sheet and my questions about the study has been answered. I understand that my identity will not be disclosed to anyone. I understand that I might withdraw from the study at any time without providing a reason and without fear or negative consequences or loss of benefits. I am furthermore consenting to being recorded for data collection and analysis purposes.

Participant's pseudonymous:

Participants signature:

Date:

INTERVIEW TRANSCRIPT: TRANSCRIPT

Interview transcript – Participant C & D

- **Researcher = Bold**
- Participant C = Normal text
- Participant D = Underlined

1 **Okay, you have been diagnosed with diabetes type II. How, or what has your**
2 **experience been since been diagnosed?**

3 Op die oomblik is dit met my, dit is baie stress. U weet uhh in 2001 het ek mos n
4 stroke gekry. Ek was nooit diabetes gewees nie, ek was high blood pressure gewees.
5 Toe kry ek mos die n in 2001 die stroke mos nou. In 2009 toe ontdek hulle ja ek is n
6 diabeet. Toe vra ek maar hoe bedoel hulle toe se hulle mar nee dit is van my pancreas.
7 Because why die stroke het mos nou my pancreas aangetas mos nou. Toe begin ek
8 met diabetes. Maar ek was nie geworried gewees in die begin nie because why ek
9 weet nie waaroor dit gaan nie. Maar met tyd toe se hulle vir my dis jou suiker, daar
10 is te veel suiker in jou bloed in se hulle vir my. Se hulle vir my ja ek moet aanpas.
11 maar net so se drie maande maar my suiker bly hoog ek moet nou op die diabeet II
12 en toe sit hulle vir my op insuline. Op die naald en toe.. maar vir my was dit n bietjie
13 stress gewees want ek moet elke oggend, elke aand ingespuut word. Dit was eers op
14 8 gewees toe gaan dit op na 12 toe, toe 18 en nou is ek op 22 insulin n dag in die aand
15 in. Maar die ding wat my nou pla nou. Ek het mos nie nog finance nie. Ek is net op
16 my pensioen mos nou. Elke maand, en U weet mos nou hoe min die geld is en U weet
17 mos nou ek moet met daai geld my brood koop wat ek nie kan bekostig nie. Die

18	brood is klaar R18 en R16 vir ee brood. En my rys, ek kan nie rys koop nie want dit
19	is te duur. N kilo rys, bruin rys amper R40 in die winkel. Ek wil dit koop maar ek
20	kan dit nie bekostig nie want dit is te veel. Toe moet ek maar net gewone rys eet en
21	dit het my suiker opgestoot elke dag. En vandag, party aande, een aande toe skrik ek
22	wakker toe is my suiker 1. Dit was 1 gewees toe moet ek onmiddelik eet want to
23	begin ek al bewe al van nie die regte kosse eet nie. Toe moes ek my vrou se en haar
24	wakker maak sodat sy vir my kan iets maak om tee eet. Dit was 2 uur die aand toe
25	moet sy opstaan. Wanneer ek iets makeer dan se ek vir haar ek makeer daai en daai
26	en dan doen sy dit vir my maar op die oombik cope ek myself maar okay help my
27	ook met brood en so. Maar vandag, ek het nou diabeet 2. Ek moet my elke aand
28	inspuit, elke aand inspuit 22. Vir my is dit bietjie stresvol maar ek is nou al so
29	gewoont aan dit, en dit is mooi nou mooi op die oomblik dit is nou onder 10. Dit is
30	nog bietjie te hoog maar ek gaan aan met my lewe want ons kan mos nie anders nie.
31	Hulle se mos one time a diabetes and all time a diabetes. Jy kan maak wat jy wil hy
32	is vir lewenslank met jou. Maar dit is hoe ek praat met haar. U moet vir my vrou vra
33	sys al verder praat daar van insulin. Vir insulin is dit vir my n groot probleem, n baie
34	groot probleem. Why, geld het ek gese. Sy kry nie pension nie sy het maar nou
35	aansoek gedoen vir pension. Ek kry nog pension. En ons twee op die geld is baie te
36	min vir ons. Ons kom te kort elke maand.
37	U het nou genoem van, wat het bygedra tot u se diagnose. Iets oor die pancreas.
38	Kan U vir my meer uitbrei oor dit, presies wat het gebeur en wat het gelei tot
39	dit. Wat was U se reaksie en wat het U gedink die dag toe hulle se u is nou
40	gediagnoseer.
41	

42	Jy weet mos nou. Obvious is dit mos nou nie van gesond eet nie. Dit is nommer een.
43	En ons kleurlinge het mos nie daai geld om dit te bekostig nie soos gesonde kos, ek
44	weet die ander dokter het gese ons moet nou eet die kos wat hy vir ons gese het ons
45	moet eet maar ons kan dit nie bekostog nie, ons kan nie. As ek... as ek en my vrou
46	moet gaan kos koop en ons kom by die groente dan het ons nie eers groente geld nie.
47	Ons kan nie, ons moet klaar vir ons vleis koop en hoende koop en dit dan is die geld
48	op. Nou moet ons gesond eet. Hoe kan ons? En dit is wat gedra het, nou moet ons die
49	fast food maak en hoe se hulle in Suid – Afrika, se hulle mos gemorskos. Ons moet
50	maar iet en dit is wat onse hoe bloedruk en dit veroorsaak dat ons vandag so is. Dat
51	ek diabetes is en ongesonde kos eet man, ons kan nie anders nie. (inaubable)
52	En wat is se fisiese, wat is U se fisiese komplikasies wat U tot dusver ontdek van
53	diabetes? Mens kry mos gesondheids komplikasies wat gepaard gaan met
54	diabetes tipe II. Het U tot dusver enige van dit ervaar?
55	Op die oomblik nog nie. Nog nie gekry, nog nie eitnlik fisiese uhh gekry nie maar ek
56	is baie besorgd oor my voete. Because why, ek het al 3 van broers verloor al. Hulle
57	het die een se been afgesit al, die een het blind geraak maar okay dit tas eintik my oe
58	aan. Dit gee mos die cataracts op jou oe, dit tas my oe aan maar nie so baie nie maar
59	ek is baie besorgd oor my oe, ek is bang Ek het al gesien al hoe mense vrot van die
60	diabetes voor my oe en ek is baie besorgd daaroor that's why deesdae gaan ek na my
61	klub toe vir ondervindings vi diabetes wat om te eet en hoe om te wees. Dis belangrik
62	vir my.
63	En hoe sal U se bestuur U die diagnose? As ek vra bestuur praat ek van manage
64	itv medikasie, leefstyle, gesond eet, fisiese oefeninge?
65	

66 Okay, U weet waar ek woon. Is, is oek mos nou loop in die oggende is dit baie
67 gevalik. Ons kan nie hier nie cause as die mens vir jou sien hie, hulle le sommer en
68 wag vir jou om die draai. So al tyd wat ek kan loop is miskien een oggend as ek nou
69 clinic toe gaan, veral as ek nou uit gaan. Ek loop baie. Ek loop, as ek taxi toe gaan
70 loop ekke, as ek gaan loop ekke, as eke na my club toe gaan dan loop ekke. Maar dis
71 gevalik vir ons maar ek manage dit cause ek ken baie van die ouens in die rondte en
72 hulle sali met my worry nie. Maar anner mense al seergemaak word en uh maar ek
73 manage ek manage somtyds maak ons die huis oep en maak oefeninge ek en my vrou
74 en ons kleinkinders. Dan maak ons oefening. Maar ons prober ook maar om gesond
75 te eet en gesond , gesond te lewe. Maar al wat ons try is probeer maar oefeninge ons
76 makeer dit, ons probeer baie hard. Ons probeer die afgelope tyd oefen maar ons
77 probeer maar.

78 **En se vir my watter tipe ondersteuning kry U van se familie, U se vrou. Ek praat**
79 **nou van emosionele ondersteuning van die familie, vrou, gemeenskap en dalk**
80 **die klub.**

81 Jy sien nou die gemeenskap, hoe kan ek dit nou stel nou. Hoe kan ek dit nou se.. die
82 gemeenskap. Waar my vrou concern is help sy my baie. Sy is nou my regte hand. Sy
83 kyk nou dat ek gesond iet. Nie kyk nie ons probeer om gesond te iet nou. As ons gaan
84 na die winkels toe sorg ons dat met ons geld om een broed te koop want dit hou vir
85 ons amper een week vir ons twee want ons probeer maar nou vir mekaar met leefstyl
86 soos met een ding suiker uit te cut totaal. Ek gebruik nie suiker nie. Alles, niks suiker
87 nie. Die probleem is net onse brood. Ons kan mos nie (inaudable) eet nie. Baie mense
88 kan mos nie biscuits, die provita biscuits eet, dit is bo my vuur maak plek. Ek kan dit
89 nie bekostig nie. En, maar met die mense hier in die rondte by my as ek iets makeer

100	dan help hulle my, dan gee hulle my n lift of soe. Maar verder kan ek niks verder se
101	nie omdat al ons mense hier in die omgewing hierso is diabetes. Almal, (inadaibale).
102	Maar n.. maybe is hulle te bang of te skaam om saam te gaan. Maar ek, ek is al man
103	gaan. Ek is tussen klomp vroumense wat daar is. Ek is al man tussen die klomp
104	vroumense. Ek mind nie ek enjoy my want daar leer ek hoe om my..hoe ek my social
105	life, hoe ek my lewe reg te hou deur reg te eet, oefeninge en hoe ek my medikasie
106	moet gebruik en my inspuitings.
107	Se vir my is dit dieselfde ondersteuning wat U kry by die kliniek of hopsitaal op
108	n maandelikse basis of hoe?
109	By die clinic is uhm, al wat hulle vir jou se daarso.. jy mag nie eers vra vrae vir die
110	dokter nie want daar is te veel mense. En hulle se vir jou nou moet jy gaan 2 – 5
111	minutes. Jy kan nie vrae vra nie. Hulle kom vir jou se daar is jy daar is jou pille ,
112	gebruik dit. Verder kry jy niks informasie nie. Die informasie wat ek gekry het is
114	meeste by my club by my groep. Maar die clinic help nie vir jou nie. Die clinic sit en
115	gesels nie ook nie oor dis en dis en dis nie. Hulle gie nie vir jou n papier en se kykie
116	hier is jou dieet so moet jy maak en soe moet jy maak en hier is jou insulien en verder
117	niks meer nie.
118	En hoe laat dit vir U voel?
119	Ek... ek kan nie iets daaraan doen nie ek moet daarmee saam lewe. Dis al wat ek kan
120	doen ek moet daarmee saam lewe. Because why, but as jy wil langer ophou is jy dan
121	langer binne. Soos nou die dag toe was ek by die kliniek gewies toe maak een vrou
123	te lank daar binne toe skel die mense weer. Hoekom maak jy solank daar binne? Ons
124	het onse eie probleme oek maar die dokters, hulle help nie vir jou nie. Hulle pratie
125	met jou nie, hulle skryf net jou goed uit en there you go.

126 **Ek wil net weer terug kom by die finansiële situasie. U het vroer genoem van**
127 **voor ons begin record het wat dit kos om elke tweede week te gaan tot net by die**
128 **klub, wat so baie ondersteuning bied. Brei vir my net bietjie meer uit oor wat kos**
129 **dit en of U dit kan bekostig?**

130 Weet uhm, eerste het my vrou saam met my gegaan en dit was gewies R10. Om
131 na die club toe te kom en R10 terug van die club tot by die huis. Nou as ek met dink
132 nou ek alleenig is seker al klaar R20 n dag en dit is 2 keer maand en dit is R40. En
133 as my vrou moet saam dan is dit R80 n maand en dis hoekom sy eerder by die huis
134 bly en dat sy nie meer kan saam gaan nie. Want sy is die een wat eintlik saam kom
135 om die informasie te kry saam my maar dis te duur vir ons gewies. Te duur.

136 **En die dag toe U gediagnoseer was tot en met nou, watter emosies het U ervaar?**

137 Ek was n bietjie teleurgesteld gewies. Maar soos hulle se dis jou eie fout oek. Aan
138 die begin was dit maar bietjie hard vir my gewies want ek moes my hele leefstyl
139 gechange it. My whole life was changed. Ek magi meer daai ieti. Okay ek kon geet
140 het maar nie meer soos ek eens gedoen het nie. Ek moet alles uitgestel het, alles. Jou
141 vrugte, jou drinks jou, jou cooldrinks alles daai. Ek gebruik nou net zero als. Alles
142 vir my, daar is niks van suiker of goed nie. Maar dit gaan nog altyd... dis nie nog
143 hundred percent nie maar n mens probeer ma.

144 **Dink U dat U se social life is geaffekteer deur hierdie diagnose? Kan U nog gaan**
145 **en kom soos U wil?**

146 Ek sal nie se ek kan nie meer gaan soos ek wil nie want dit is nie meer dieselfde nie.
147 As ek moet gaan waar ek wil dan moet ek my medikasie saam vat. Eers het jy gegaan
148 waar jy wil maar nou dat ek siek is kan ek nie sonder my medikasie gan nie. Jou
149 suiker kan so gou daal en in die hoogte skiet en dit is gevaarlik vir os. Jy het al gesien

150 al, jy is nou reg dan is jy in n ander wereld in. Jy kan niks doen sonder jou medikasie
151 nie. Jou insulin en tablette baie belangrik vir jou soe dit het my hele lewe gechange.
152 Eers het ek baie, baie gesocial met vrinne en soe maar dit het totaal gestop. Totaal.
153 Ek gati meer na my vrinne toe nie cause as ek daar kom nou sit hulle en hulle en hulle
154 enjoy hulle self en ek kani meer daai doeni. Ek kani meer nie want ek moet onthou
155 oor my diabeet. Want daai laat jou suiker baie gou val en wat hy gevalit, jy is sommer
156 weg in n coma nou. Jy kan nie. Dis waar dit my social lewe, my lewe ge-affect. My
157 vrinne het totally, my vrou vra, ek het n klomp vrinne gehet. Ek het eers vis gevang
158 en n klomp vrine gehet, alles weg. Alles. Ek is maar alenig by die huis sit maar hier,
159 ek worry nie met my social life en vrinne nie. Ek bly by my huis. Okay but hulle prati
160 met my nie. En hulle vra nie meer vir my nie. Hulle worry nie meer nie.

161 **En hoe laat dit U voel dat hulle nie meer belangstel of vrae vra oor U se**
162 **gesondheid nie en dat U se social life nou heeltemal verander het? Hoe laat dit**
163 **U voel?**

164 Ek is, ek is baie... hulle het my kom haal by die huis. Nou worry hulle nie meer oor
165 my nie. Hulle worry nie. Hulle sit daar by die huis. Niemand kom na my toe nie. Vra
166 vir haar, niemand kom meer hier by my huis nie. In die oggende vroeg was hulle hier
167 gewies dan kom haal hulle vir my en se kom ons gaan daantoe. En as ons waantoe
168 gaan dan gaan sit ons in die joint want ons was mos jong manne. Maar nou is alles
169 klaar. Dit het my hele social life affect, hele social life.

170 **Is daar enige iets anders wat U nog wil bespreek van U se ervarign van diabetes,**
171 **vanaf U gediagnoseer is tot en met nou? Enige iets wat U nog wil byvoeg?**

172 Soos wat nou? Jy weet, baie van ons mense, van ons mense is diabetes en mevrou
173 moet n klomp mense kry en ek praat van klomp dan se hulle vir my hulle suiker is

174 soe en soe nou vra hulle my wat hulle moet maak. Nou wat moet ek maak as hulle
175 dit nie wil self doen nie. So ek wil net he.. ek sal likes dat die mense net moet nader
176 kom om meer informasie te kry want meeste van die mense wat vandag dood gaan
177 is diabetes. **Maar hulle.. my broers ook self, os is 7 broers en almal is diabetes van**
178 **nie gesond eet nie.** Miskien het hulle die geld, ek wiet self nie maar ek het nie die
179 geld nie.

180 **Wat sal U se dra by tot U se styging in bloed en suiker vlakke?**

181 Wat bydrae tot my is my etery. Ons iet, ek was se 7 dae in GSH gewies vir n operasie
182 en die kos wat hulle daar gee is meer gesonder as wat ons by die huis eet. Nie
183 gesonder nie, dis n belanced diet wat ons nie kan bekostig nie. So hulle iet net n
184 bietjie kos maar hulle iet, hulle het spesiale tye nou vertel hulle vir my ek moet sterk
185 wies. Wat moet ek maak? Ek kan nie biscuits koop nie. Biscuit met daai wit kaas..
186 Ek mag nie eers koek eet nie. Ek sal n stukkie eet ja maar alles is gesny, netso.

187 **My laaste punt wat ek net wil aanraak van my kant is, U het vroer genoem die**
188 **mense in hierdie straat wat ook diabete is. Hulle is te skaam om te gaan tot by**
189 **die klub? Is dit iets wat U self ook ervaar en hoekom dink U is hulle te skaam?**

190 Ek was 2001 gediagnose met uh, nie 2000 nie 20... **1998 was ek gediagnose met**
191 **high blood pressure. Drie jaar daarna toe kry ek n stroke toe was daar vir my gese ek**
192 **moet aan n club behoort daar by UWC in die Lentegur in.** Ek het daarvan afgegaan,
193 ek het nie geworry oor ander mense nie. Dit was my liewe gewies. Dit was my life.
194 Ek het daar gegaan vir ondervinding, ek het dit gekry. Vandag het ek lewe en die
195 dokter het vir my gese mmeer jy gaan weer n stroke kry en toe se ek vir myself no
196 ways. My hele lewe het gechange, my hele lewe. Ek praat van my hele lewe. Alles
197 het op my gekom.. Forty years old maar nie die jare toe kry ek n stroke nou. Maar

198	dis ook oor die life wat ek gehet het mos maar ek dink die mense vandag, ons is baie
199	skaam om te gaan. As ek vir hulle se kom ons gaan club toe vir informasie. Nie nou
200	nie man ons gaan more. Maybe is dit skaamgeit want dis mans. As jy kyk by enige
201	social club, enige groep wat daar is. Ou mense of by n diabetes of by n hoebloed
202	club, jy kan sien daar is meestal vroumense. Maar ons mans, maybe ons praat met
203	onself. Okay, dan pick hulle op my nou maar ek se ek worry nie ek worry nie. Want
204	dit is my lewe wat daarvan af hang. About 10 jaar, se 10 jaar in die diabetes club wat
205	ek bywoon. En hoebloed is oor die 20 jaar nou. Maar ek leer, ek hou...my bloed is
206	onder beheer. Ek moet nou net my suiker onder beheer kry maar suiker is baie swaar
207	om onder beheer te kry. My vrou weet als, drink maar pilletjie hier en pilletjie daar
208	en die inspuittings. En die broed. Ek het nou broed gekoep, ons het nou broed gekoep
209	vandag mar os nie het so ons die cheap een koep, cheap. Daai een kan os bekostig.
210	Os kan nie die anner een bekostig van R16 nie. Dan moet os gaan na die sentrum toe
211	en taxi vat dan is dit taxi fare en dit is R10 op en R10 af en die broed is R16/ R18.
212	Hoeveel is daai? Amoer R40. So verstaan jy nou, dis te veel vi os.
213	Okay is dit al wat U wil deel? Baie dankie. Okay, U as die versorger vir u se man
214	wat gediagnoseer is met tipe II diabetes. Wat is U se ervaring vanaf hy
215	gediagnoseer is tot en met nou? Wat is U se ervaring om na hom om te sien vanaf
216	hy gediagnoseer is met tipe II diabetes?
217	<u>Ek sal dat eintlik is dit nou net die probleem, die kos. Wat moet ek nou vir hom gie,</u>
218	<u>wat gaan ons nou vanaand het, wat gaan ons nou in die oggend eet. Daai is nou eintlik</u>
219	<u>die porbleem met die kos. Ek moet weet self want hy moet reg eet, hy moet reg eet.</u>
220	<u>Hy moet regte goeters mos nou kry dan beheer ek mos nou in die winkels wat kan ek</u>
221	<u>dan nou vir hom koop. Al wat ons meestal eet in die huis in is nou se maar hoender,</u>

222 nou en dan n stukkie vis. Hy is die een wat die meeste... hy sal mos nou hoender eet

223 want dit is mos nou gesond. Oek vi die maand mos nou.

224 **En hoe het U gevoel die dag toe U uitvind dat U se man gediagnoseer is met tipe**

225 **II diabetes? Wat het deur U gegaan, die emosies, wat het U gevoel en wat het U**

226 **gedink?**

227 Ek het sleg gevoel want ek wat dit mos nou soe nou dat hy het n stroke gekry, en nou

228 kry hy nou diabetes. Maar ek het altyd maar net gegloe alles sal regkom. Verstaan jy

229 nou? Ek het altyd maar net gegloe die vrou sal maar gloe ja. Ai jitte wat gaan die

230 doen en wat gaan die doen. En, maar ek het my bydrae mar gebring en gehelp en so

231 aan maar ek het maar gedink uh, daar sal n tyd kom wat alles sal regkom. Jy moet

232 mos gloe, jy moet mos gloe. Hy kan nie geloop het nie, hy kon nie gepraat het nie.

234 Vandag kan hy loep. Hy kan vir my tee maak en hy kan vir homself tee maak. So, so

235 is os in die huis in nou. Os help mekaar. Hy sit, sal tv sit en kyk en ek sal tee maak

236 of so maar so dink jy Here wat gaan jy nou vanaand eet. Da is nou n brood os vanand

237 kan eet want somtyds.. maar hy is die ene, as os nou niks in die huis het nie dan sal

238 hy nou die een wies wat nou sal loep en kyk sal ons nou iets kry en wat gat os nou

239 iet of soe. Hy is altyd die een wat daai sal doen. Ek is, ek is amper so ek is nie gewoont

240 aan dit nie because... by mense nou die gaan vra by die vrind en daai vrind. Maar hy

241 is die man in die huis. Hy sal mar nou moet loep, maar sukkel om te geloop het. Ek

242 het altyd gegloe dat dit sal regkom man. Dit sal regkom. Want ek het nou die dag, en

243 os kry mos net die tjek pension geld, 2 dae en 3dae as os nou os goeters betaal het,

244 die huis betaal het dan is daar maar nie meer geld oor nie. En dan glo os maar net en

245 dan dink ons, dan dink os alweer wat is die next payment. Os dink mos maar nou so

246

247	wat is die next payment want ai. Dan dink os ai, dis hoekom ek maar net dink os
248	moet maar net glo. Alles sal regkom. Dai was nou net my...
249	U het nou net genoem dat U het U se bydrae gebring toe hy gediagnoseer is. Brei
250	vir my bietjie uit oor die bydrae spesifiek? Wat bedoel U met die bydrae? Fisies
251	bydrae?
252	Ja, hy het gesit en hy kon niks vir homself gedoen het nie. Ek moes vir hom gebad
253	het in die badkamer. Ek moet altyd daai gedoenit. En uh dan sit hy maar daarso dan
254	gee ek vir hom kos of soe. Hy kon niks gedoen het nie maar vandag kan ek vir die
256	Here dankie se dat hy kan nou iets doen met sy hande. Hy kan nou nie eintlik lekker
257	sy hande, sy een hand gebruik nie maar hy kan dan nou as os nou se doen gou daai
258	dan staan hy op en doen daai. Nou daai is alles deel van ... nou hulle het vir my gese
259	by die dinges.. by die clinic dat die dinges, by die hospitaal dat ek hom maar net moet
260	help dat hy kan loop en so en uh, hy kon nie eers geloop het nie. Os moes hom uit
271	die kamer gehelp het en daar gesit het en so. Maar ek se nogal tyd vir die Here dankie
272	dat hy nou vandag so kan, soos n man kan geweest in die huis is. Som om hom te
273	need, sommige dae dan het man en vrou mos maar arguments waar hulle skel, jy
274	moet die kooi op maak en jy moet die doen en daai doen. So daai is mos dinge wat
275	mens moet doen. Maar uh dit is goed. Os kom, os kom nou uh n lank tyd saam. Dit
278	was n bietjie swaar gewees vir my omte.. toe hy nou die stroke kry. toe hy ingaan die
279	nag. Hy het toe heeltyd in die hospitaal gele en die dokter het toe gese ja hy gaan nou
280	weer n stroke kry maar toe glo ek in my in nee man hy het tog nie gese my man gaan
281	weer n stroke kry nie. Tot en met vandag toe het hy nog nooit weer n stroke gekry
282	nie. Want ek het geglo die medisyne en pilletjies en goed wat hy gedrink het gaan vir
283	hom nou gesond maak en so het os maar aangegaan en jare en jare en jare dat ons

284 nou vandag, toe ek nou 60 geraak het toe het ek ook maar nou aansoek gedoen ook
285 nou vir pension en ek het geglo dat ons moet saam bewerk.

286 **U het gese dat dit was swaar gewees vir U ook. Verduidelik vir my hoe is dit**
287 **swaar fisies en emotioneel?**

288 Dit was, dit was eintlik swaar gewees. Maar die kinders het eintlik vir ons baie
289 bygestaan. Dit was swaar gewees. Om vir hom te gehelp het uit die kamer uit en alles
290 daai goeters, en die bene. Dit was, dit almal was dinges gewies. Want ek vat dit so
291 as jy nou n stroke moes kry wat maak jy want ek maak mos nou die kos? Maar ek
292 wil, ek wil vandag, het ek nou geleer nou jy moenie sout in die kos ingooi nie. Nou
293 ek almal daai dinge, ek gebruik nie sout nie, hy gebruik nie suiker nie. Alles is daai
294 wat hy doen en drink. Maar somkeer as ek nou sien ja dat die wat ons eet kan hy nou
295 nie eet nie dan maak ek vir hom iets anders as daar is mos nou. Maar verder, maar
296 verder gat ons maar aan.

297 **Wat is U se main concern nou met die feit dat hy n diabeet leier is en wat was U**
298 **se main concern toe hy gediagnoseer was?**

299 Dit was n bietjie dinges gewies. Maar later het dit n gewoonte geraak en toe se os
300 mar os moet nou aangan met die wat hy gekry het, dat hy nou diabetes geraak het.
301 Maar sy hoogste punte is maar nou net die kos is die probleem, die geld is die
302 probleem. Maar my dogter bly oek hier maar sy is nou getroud maar sy help oek so
305 vir ons om te dinges, verstaan? Dit was n stres gewees. Dit was n hele stres gewees,
306 om te sukkel. Wat gaan os maak. Os het nie geld vir brood nie os het nie geld vir
307 krag nie. Dit is n stres. Maar by my was altyd gewees ek het geglo dit sal regkom.
308 Dit was ...
309

310 **Watter ondersteuning het U ontvang? Dit kan fisiese of emotionele**
311 **ondersteuning wees van die gemeenskap en familie. Watter ondersteuning**
312 **ontvang U?**

313 Jho, ek sal nou se die dag wat hy die stroke nou kry en wat hy n diabeet word toe was
314 die huis nou eintlik nog vol mense. Almal het nog hiernatoe gekom, almal het gekom
315 maar vandag sien jy nou net niemand nie. Verstaan? Wat jy nou meskien nodig het,
316 wag jy kan gou die sisters phone en die broers phone, gee vir ons die en daai maar
317 dit is nie so nie, dit is nie so nie. Al die dinge gaan deur jou mind. Sy broers kom
318 hiernatoe, sy sisters kom hiernatoe. Niemand stel belang nie. Os, os, toe die lock
319 down begin het toe sit ons maar net hier in die huis in, nogaltyd in die huis is. Dan is
320 die krag af. Maar ek sal se, ek weet nie ek sal sommer net se ons het gesukkel. Om
321 die waarheid te se ons het gesukkel. Ons het aangekom.

322 **En hoe laat dit U voel dat U nie die ondersteuning kry nie? Ons praat nou van**
323 **emotionele en fisiese ondersteuning. Hoe laat dit vir U voel omdat U nie daardie**
324 **ondersteuning ontvang nie?**

325 Dit was swaar gewies man, dit is... want jy dink in jou gedagte want die familie het
326 nou geld want hulle het karre maar daar is niks bydraes nie. Jy moet maar nou alleen
327 sukkel. Tot vandag toe. As os maar nou uit wil gaan dan moet ons die taxi vat, ons
328 kan nerens gani want ons het. Os het mar so gesukkel. Daar het baie dinge gebeur in
329 onse dinges in, in onse, vani tyd wat hy nou die stroke en diabetes het. Os het maar
330 geloep. Kom ons maar nou daar dan praat hulle iets aan wat jy dan maar nou self kon
331 gevra it. Het jy miskien net vir ons iets om te gee soos geld maar dan praat hulle iets
332 anders dan dink jy nou maar jy gaan nou nie vra nie want jy hoor nou ander goete

333

334 dan bly jy maar net stil en kom maar net weer huis toe. Maar verder gat ons maar nou
 335 so aan.

336 **En sal U se dit het n verandering gebring in U se social life?**

337 Ek het, ons het baie gesocial life daar sal ek nou nie stry nie, baie gesocial life. Maar
 338 ons was nie, daar was perke gewees. Ons behoort aan n kerk in, ons was nie uit dinges
 339 gewies nie ons het altyd maar alles net in toom gehou. Ons was nie, verstaan jy
 340 uitspatlik uit nie en deurmekaar nie. Ons was maar saam hier in die huis gewees en
 341 dit was maar voor hy die stroke gehad gekry het maar daar het hy gestop toe is ons
 342 sommer kant en klaar met die ook.. die verkeede goete.. die besigheid toe is ons
 343 sommer kant en klaar daarom sal my kinnere nie nog vir ons wys, vir osse wys nie.
 344 Os was amper gewies n voorbeeld vir die kinders verstaan jy? Soos vir kerk loep en
 345 sulke goed. Hulle kan dalk vir jou wys ja my ma en pa het nou wyn gedrink en die
 346 gedoen en soe.. os was eintlik n voorbeeldige stel vir hulle. Sorry vir die dat ek nou
 347 kan se wat ek nou dink nou verstaan jy. Socialise en sulke vrinne, het baie mense
 348 gekom maar vandag wat n .. sien jy niemand nie, niemand kom meer nie. Want os
 349 het nie geld nie, os het nie ander n n mense gesien nie, wat os kan gee, wat ons kan
 350 op die tafel sit en hulle kan nou tee of biscuit of so as jy na family toe gaan dan kom
 351 jy by hulle huise dan sien jy maar nou wag hulle haal uit hulle sit op die tafel en os
 352 iet en gaan te keure maar as hulle by my plek kom dan kan ek nie vir hulle die goeters
 353 vir hulle voorsit nie.

354 **En hoe laat dit vir U voel?**

355 Oeh dis terrible. Jy voel baie teleur teleurgesteld dan se ek vir hom, by hulle huis
 356 kom. ek wil nie eers gaan na hulle huise toe nie want ek wiet hulle gaan die goeters
 357 op die tafel sit en as jy by my huis kom dan kan ek, het ek nie om op die tafel te sit

359 nie. Dan se hulle oeh hulle het nou net tee gedrink en goete en ek kan nou nie vir
360 hulle voer nie. Hulle se dit nie in my gesig nie maar jy kan mos daai aanvoel, daai
361 gevoelens mos ne, jy ky mos daai. Wil nie .. die dinges vir family nie.

362 **Is daar enige ander ervaring wat U as die versorger vir U se man wat tipe II**
363 **diabetes het wil deel? Enige ander ervaring.**

364 Thinking...

365 **Gevoelens? Frustrasies? Enige iets, enige ervaring.**

366 Ek het mar net uh gewys ek is nou nie n .. hoe kan mens se.. ek kan nou nie uh.. ek
367 hou maar gesels as hy terug gesels. Ek sal nie nog dinges wys vir mense dat ek voel
368 nou so nie. Ek sal maar eithier maar nou gesels, ek sal nie .. hulle sal nie sien by my
369 .. op my dat ek kry swaar nie. Ek sal maar net voorgee dat ek kry nie swaar nie. Ek
370 sal nie nog hoe, hoe sal ek voel uh. Jy voel anders, jy voel.. ek het nou al n gewoonte,
371 ek weet nou al waaroor gaan dit. Ek is nou, ek is nou al gewoonte daaraan. Toe hy
372 nou uh, as ek hom moet help ek weet nou wat moet gedoen word en wat ek moet
373 doen. Maar somtyd dan gaan hy allien town centre toe dan sit ek nou by die huis en
374 dan moet ek nou na die kinders kyk en nou moet ek nou worry hoe maak hy by die
375 centre. Hy moet gaan pay en sy geld kry en ietsie koop vir ons om te eet dan gaan hy
376 nou en koop vir os iets om te eet maar os sal nou miskien daai dag iets lekker eet
377 maar na daai dag dan is daar niks weer nie.

378 **Is U se bekommernis dalk ook as hy alleen travel town centre toe dat iets kan**
379 **gebeur omdat hy n diabeet is?**

380 Jaaa, nou som keur dan loep hy dan wil hy nie sy phone saam vat nie nou kry ek..
381 nou moet ek maar dink by my mind mos nou hy n , hy n, hy het nou sonder sy phone

382

383 geloep en daar is nou nie airtime op nie of data op om nou vir my te laat dinges nie.

384 Hy het nou al n klomp dinge oorgekom..

385 Om die waarheid te se wat ek nou lank loop dan wil ek... (inaudable – child crying)..

386 Om n diabeet te wees is nie maklik nie, jou hele leefstyl is anders. Hoe djy moet

387 lewe. As jy opstaan, eerste ding jou bloed suiker moet jy check. As daai nie reg is

388 nie dan is die vrou geworried, dan is sy geworried.

389 **Okay so daar is bekommernis wat deurkom?**

390 Ja.

391 Nou is sy geworried, nou se sy ek moet water drink, ek moet pille drink. Dit is te

392 hoog. Want sy weet mos as dit te hoog is dan kan jy in n coma val. Ek wietie wat gan

393 sy maak as dit moet gebeur nie.

394 Dit het nog nie eintlik gebeur nie. Dit het nog nie maar as dit die dag moet gebeur

395 dan wat nou dan wat gaan gebeur as dit nou gebeur nou. Nou aande dan vra ek nou

396 so het jy jou inspuiting gevat.. Nee ek gaan nou eers.. Dan se ek nee jy moet dit nie

397 so laat vat nie want kyk nou more oggend hoeveel jou suiker is. Daai is eerste op

398 mense mind. Hoeveel is jou suiker en as sy suiker nou oor die 10 is dan is ek nou

399 geworried. Jy moet aande nie eet nie want kyk hoe hoog is jou suiker dan stry onse

400 tweetjies. Maar meantime dan is ek nou geworried want ek is mos nou die een wat

401 agter hom kyk as hy nou hier in n coma gaan dan wat dan, wat gaan ek doen? Maar

402 die meeste tyd is , meeste tyd wat ons nou kos maak dan maak ek groente. Soos

405 worrels en sukke butternut en sukke meeste tyd as ek nou geld het dan maak ek

406 meeste tyd van daai nou maar nou is daar nou eintlik nou niks om groente en sulke

407 goed, ons moet maar nou weer wag tot hy nou weer pay dan koop ek nou weer so

408 tipe kos. Hoe se as mens kom by butternut as os nou dit koep dan eet ons nou heelyd,

409 dan iet os nou heelyd. As dit nou op is dan is dit op dan kan ons nou nie weer gaan
410 nie. Dan moet ons nou weer wag maar die Here dra ons deur.
411 Ou kan nie elke aand groente eet nie sien jy, so vanaand en dan weer so eenkeer per
412 week kan ons groente eet. Ander tye dan eet os gewone kos.
413 Maar ek het nou al opgelet as ek nou die groente vir hom so maak, die kos en os
414 maak nou groente en die next dag dan kyk os nou sy suiker dan is sy suiker nogals
415 mooi by die 6 of 5 of 7 dan weet ek nou daai was nou die regte kos die regte meal
416 wat ek vir hom gegee het nou daai was nou dood reg gewees, dan weet ek nou elke
417 tyd ek kan nou so maak dan is sy suiker mooier maar sodra hy ander goetes eet dan
418 is sy suiker.. sy suiker was al 22 ne? Sy suiker was al 18 gewies en hoe stres ek nie
419 want ek is die een wat vir hom.. nou hy is baie lui om water te drink. Nou by die
420 hospital gee hulle die bottels water om te drink nou hy kan nie, lui vir water drink.
421 Ek skel hom baie keer uit somtyds en se hy moet water drink. Nou somtyd... nou ek
422 is ook die n uh die hoebloed nou ek raak ek weer dronk weer, nou my kop raak weer
423 dronk en soe. Ek het n hoebloed masjientjie maar die battery is mos nou pap en dit
424 kos mos nou n klomp geld nou moet ek maar wag om geld te he om die batteries te
425 koop. Nou vat ek sommer my suiker dan is dit so laag dan kan ek niks.. wag tot
426 wanneer ek nou, dan is my kop dronk dan sit ek hieso dan weet hulle nie my kop is
427 dronk nie. Ek hou vas hulle wietie dan se ek nou haai jinne die man sit nou hier en
428 wieti ek is nou ook nie lekker nie dan kry ek ook... nou se hulle ja dit is die hot
429 flushes dan later met tyd dan staan ek op dan moet ek maar nou weer aangaan. Dan
430 is my bloed net so laag dan drink ek nou nie baie water nie want water maak jou
431 bloed mos...dit lyk dit dun dit uit. Maar ek het mos hoebloed pille. Minstens het ek
432 nou nie suiker nie. Maar ek probeer maar nou dat ek nou nie daai kry nie want hulle

433 se die manne gee sommer vir die vrou oek diabetes. Maar my family hulle het nie
434 eintlik suiker nie. Hulle is meer arthirits. Hulle is nou meer hoebloed en suiker en
435 goete.
436 (inaudable).. dis in die gene. Maar ek dink ek dink ek dink by myself as jy gesond iet
437 dan is dit nie nodig om siek te raak nie. Se maar nou die ryk mense...
438 Ek raak som keer kwaad vir die mense as hulle nou soe, soe vet en soe en daai. Hy
439 was baie vet gewies weet jy, hy het n 40 iets gedra so vet was hy gewies vandag dra
440 hy nou n 32 maar ek mien hy was baie vet gewies. Maar as ek nou dink aan sy broers
441 dan kom hulle hier dan is hulle vet nou daai tyd dan het hulle hier gekom dan is hulle
442 dik nou jou mind gaan so jy se nie vir hulle nie maar jou mind se goetes vir jou dan
443 dink jy jho hulle het nou die geld om reg te eet hulle sien dan hoe gaan dit hier by
444 die stukkende huis, hulle het hulle broer verloor met die een been en die broer wat
445 blind gewiesit. Ek meen maar nou. Jy probeer, hulle het dan nou die geld hulle het
446 uh die geld hulle het gaan werk en hulle het die geld. Lewe either uh om reg te lewe
447 met jou iet want meeste mense gaan dood oor diabetes en hoe probeer ek dat hy reg
448 lewe en dat hy nie.. wie gaan nou sonder man sit. Hy kan mos nog nooit nou gaan
449 nie os moet saam lewe, os moet saam, verstaan jy. Os kan mos nie nou uh jy het geld
450 nie maar jy gati nou reg eti jy gaan nou niks vir jou koopi ek meen jy gaan. Ek se oek
451 vir hom os sal regkom, as os geld het sal is osse op daai level kom om reg te eet
452 verstan. Os kan nie.
453 **Maar om n diabetes te is, is nie is nie issie maklik nie. Jou hele leefstyl verander. Jou**
454 **hele social life en jou financial. Dit het vir my gerak.** (Inaudable)... **my een vrind se**
456 **tone het afgeval van diabetes. Eet lekkers eet lollipop. Ek het dit uitgecut, alles.** Ek
457 sal miskien n pakkie chips eet as ek nou pay miskien sal ek kope eenkeer n maand.

458	So het dit my lewe gechange. Ek het dit afgelos. You cant do nobody else will do it
459	for you.
460	Wel baie dankie vir julle storie of julle ervarign gedeel het met my. Ek weet nie
461	of julle enige laaste woorde het wat julle wil deel nie.
462	<u>Mens voel somtyds iemand moet met jou kom praat ne? Soos os nou, mens voel</u>
463	<u>sommer vry mens voel sommer mens wil met iemand praat maar dan is daar nie</u>
464	<u>iemand wat wil kom en gesels met jou nie. Verstaan? Maar ek se dankie ja vir die.</u>
465	<u>Soms hou mens die goeters in as jy weer kyk dan le jy op die grond.</u>
466	(Inaudable). In die ou dae het hulle gekom tot by die mense se huise maar nou kom
467	hulle nie meer nie.
468	<u>Ek het eenkeer aansoek gedoen en hulle se ja as jou man nou siek word dan kan jy</u>
469	<u>nou geld kry en hulle se wragtag vir my, vir os ne dan my man is nie bedleend nie ek</u>
470	<u>kan nie kom vir aansoek vir n grant ...</u>
471	Die care dependency grant
472	<u>Ja, mens kry nie. Dat ke nou eers aansoek gedoen het vir pension.</u>
473	Nou my pension, n R1800 is nie genoeg nie. Hy hou net vir 2 of 3 dae.
474	Okay baie dankie ek waardeer dit.