

**Knowledge, attitudes and adapted behaviours of adults with Type 2
Diabetes Mellitus, attending a private clinic in the Western Cape: A mixed-
method study.**

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**Research assignment in partial fulfilment of the requirements of
Masters in Human Rehabilitation Studies (by Coursework)**



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Declaration

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the authorship owner thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Loreen Winton

March 2020

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Abstract

Introduction: Diabetes is a worldwide epidemic. It is one of the top ten causes of death globally. Insulin resistance and deficiency are the main causes of type 2 Diabetes Mellitus (T2DM). Without proper control of blood glucose levels, tissue damage takes place within the body, causing diabetes-related complications. These include possible loss of vision, renal failure, peripheral and autonomic neuropathy, sexual dysfunction, cardiovascular disease, and symptoms of hypertension and lipoprotein abnormalities. Studies done in South Africa have demonstrated relatively poor knowledge, attitudes and practices of individuals with T2DM. Most of these studies have been conducted in state hospitals or rural areas in Southern Africa.

The current study aimed to describe the diabetes-related knowledge, attitudes and self-reported adapted behaviours of persons diagnosed for at least one year with T2DM, and attending a private clinic in Cape Town, South Africa.

Methods: A mixed method design was applied using a phased approach; quantitative data were collected using a structured questionnaire, followed by qualitative interviews. Sixty-seven consecutively sampled participants, attending the Diabetes Life Clinic, formed the study population and completed the questionnaire. Six participants were interviewed via telephone for the qualitative phase. Descriptive statistics have been used for quantitative data, as well as basic inferential statistics, with $P < 0.05$ considered statistically significant. Thematic analysis was applied to qualitative data.

Results: A knowledge score of 60.6% was found. A significant correlation was found between less favourable attitude and behaviour. The behaviour scores of female participants was significantly lower than that of males ($p = .16$). There was a positive significant association between behaviour and higher levels of education ($p = .049$), and a significant association between depression ($p < .001$) and stress/anxiety ($p = .026$) and quality of life. Qualitative data elicited three themes; 'Where it all started - How the diagnosis changed my life'; 'The diabetes journey – A daily choice'; 'It takes a

village...support is key!

Conclusion: Despite a reasonable knowledge score, this study sample demonstrated less than favourable behaviour and attitudes. The qualitative findings illustrated the stress and difficulty of managing diabetes daily.

Recommendations were for healthcare professionals and their role in collaborating in empowering-partnerships with patients, NGO's and their role in support groups and programmes, patients and their families, and the need to assume ownership of their DM.

Keywords: Type 2 Diabetes Mellitus, diabetes management, complications, knowledge, attitude, behaviour

Abstrak

Inleiding: Diabetes is 'n wêreldwye epidemie. Dit is een van die top tien oorsake van dood wêreldwyd. Insulienweerstandigheid en tekort is die belangrikste oorsake van tipe 2 Diabetes Mellitus (T2DM). Sonder behoorlike beheer van bloedglukosevlakke vind weefselskade binne die liggaam plaas, wat diabetes- verwante komplikasies veroorsaak. Dit sluit in moontlike verlies aan visie, nierversaking, perifere en outonome neuropatie, seksuele disfunksie, kardiovaskulêre siektes, en simptome van hipertensie en lipoproteïne abnormaliteite. Studies wat in Suid-Afrika gedoen is, het getoon relatief swak kennis, houdings en praktyke van individue met T2DM. Die meeste van hierdie studies is in staatshospitale of landelike gebiede in Suider-Afrika gedoen.

Die huidige studie het ten doel gehad om die diabetes- verwante kennis, gesindhede en selfgerapporteerde gedrag van persone wat ten minste een jaar met T2DM gediagnoseer is, en 'n privaat kliniek in Kaapstad, Suid-Afrika bywoon, te beskryf.

Metodes: 'n Gemengde metode is met behulp van 'n gefaseerde benadering toegepas; kwantitatiewe data is met behulp van 'n gestruktureerde vraelys versamel, gevolg deur kwalitatiewe onderhoude. Sewe-en-sestig opeenvolgende steekproefnemers wat die Diabetes Life Clinic bygewoon het, het die studiepopulasie gevorm en die vraelys voltooi. Ses deelnemers is telefonies ondervra vir die kwalitatiewe fase. Beskrywende statistieke is gebruik vir kwantitatiewe gegewens, sowel as basiese afleidende statistieke, met $P < 0,05$ as statisties beduidend. Tematiese analise is toegepas op kwalitatiewe data.

Resultate: 'n Kennis telling van 60.6 was gevind. 'n Beduidende verband is gevind tussen minder ongunstige houding en gedrag. Die gedragsyfers van vroulike deelnemers was beduidend laer as dié van mans ($p = .16$). Daar was 'n positiewe betekenisvolle assosiasie tussen gedrag en hoër opvoedingsvlakke ($p = .049$), en 'n beduidende assosiasie tussen depressie ($p = < .001$) en stres / angs ($p = .026$) en lewensgehalte. Kwalitatiewe data het drie temas ontlok; 'Waar

dit alles begin het - hoe die diagnose my lewe verander het'; 'Die diabetesreis - 'n daaglikse keuse'; 'Dit verg 'n dorp ... ondersteuning is die belangrikste!'.

Gevolgtrekking: Ondanks n redelike kennistelling, het hierdie studiemonster minder as gunstige gedrag en houdings getoon. Die kwalitatiewe bevindings illustreer die stres en probleme om daagliks diabetes te hanteer.

Aanbevelings was vir professionele persone in die gesondheidsorg en hul rol in die bemagtiging van vennootskappe met pasiënte, NRO's en hul rol in ondersteuningsgroepe en -programme, pasiënte en hul gesinne, en die behoefte om eienaarskap van hul DM te aanvaar.

Sleutelwoorde: Tipe 2 Diabetes Mellitus, hantering van diabetes, komplikasies, kennis, houding, gedrag

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ACRONYMS USED:

| | |
|---------------|--|
| ADA: | American Diabetes Association |
| BMI: | Body Mass Index |
| CDC: | Centre for Disease Control |
| CDE: | Centre for Diabetes and Endocrinology |
| DESSA: | Diabetes Education Society of South Africa |
| DM: | Diabetes Mellitus |
| IDF: | International Diabetes Federation |
| KAB: | Knowledge, Attitude and Behaviour |
| SA: | South Africa |
| T1DM: | Type 1 Diabetes Mellitus |
| T2DM: | Type 2 Diabetes Mellitus. |
| QOL: | Quality of life |
| WC: | Western Cape |
| WHO: | World Health Organisation |

DEFINITION OF CONCEPTS

A1C: “HbA1C is a blood test which reflects average exposure to blood glucose over the last 2-3 months.” (CDE, 2018)

Adapted behaviour: Behaviour that is changed in order to deal with a new situation successfully, i.e. behaviour adapted in response to a health concern or disease, with the purpose of managing it and reducing associated risk (Collins, 2019).

Attitude: “This refers to the thinking or feeling of a person towards a healthy lifestyle including causes and prevention of diabetes” (Kambinda, 2016: vi).

Body Mass Index: “BMI is a number calculated from a person’s weight and height – weight in kilograms divided by the square of height in meters. BMI is a reliable indicator of body fatness for people” (CDC, 2017).

Diabetes distress: “An emotional state where people experience feelings such as stress, guilt, or denial that arise from living with diabetes and the burden of self-management” (Kreider, 2017:1).

Diabetes Mellitus: “A chronic disease that occurs when the pancreas is no longer able to make insulin, or when the body cannot make good use of the insulin it produces” (IDF, 2018).

Diabetic Neuropathy: Damage to the nerves throughout the body caused by high blood glucose, altering autonomic, motor and sensory functions. Peripheral neuropathy, being the most common form of diabetic neuropathy, is a facilitator in the development of diabetic foot - a common, severe, diabetes-related complication (IDF, 2018).

Gestational Diabetes (GDM): A type of diabetes caused high blood glucose levels during pregnancy. GDM poses an increased risk of developing Type 2 diabetes later in life, for both women with GDM and their children (IDF, 2018).

Health literacy: An individual's ability to acquire and understand basic health information, to make suitable health decisions (Kindig, Panzer, & Nielsen-Bohlman, 2004:xi).

Hyperglycemia: “High blood glucose level” (IDF, 2017).

Insulin: “A hormone secreted by the pancreas that enables the metabolism of carbohydrates, fats, and proteins” (CDE, 2018).

Knowledge: This refers to what is known by an individual regarding diabetes mellitus, such as signs and symptoms, prevention, complications and treatment of diabetes (Kambinda, 2016:vi).

Obesity: “Excess adiposity” (fat composition) that is unhealthy (IDF, 2017)

Risk factors: Contributory risks that lead to diabetes mellitus developing such as a family history of diabetes, obesity, and overweight, inactive lifestyles, poor nutrition (Kambinda, 2016:vi).

Type 1 Diabetes: “An autoimmune reaction, where the body attacks the insulin-producing beta cells in the pancreas”, i.e. the body does not produce enough insulin (IDF, 2018).

Type 2 Diabetes: “A disorder of a person's metabolism, characterised by high blood glucose levels”. The main causes are insulin resistance and relative insulin deficiency. It is precipitated by obesity, lack of physical activity and poor diet” (CDE, 2018).

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Chapter 1

Overview of the Study

1.1 Introduction

This chapter provides an overview of the research assignment. It presents a brief background and problem statement, puts forward the rationale and motivation for the study and describes the study aim and objectives, as well as the potential significance.

1.2 Brief background

Type 2 Diabetes Mellitus (T2DM) results from a combination of factors, including resistance to the action of insulin and inadequate insulin response. Glucose levels may be chronically elevated without manifesting clinical symptoms. This chronic hyper-glycaemia causes pathological changes, before clinical diagnosis, leading to the development of disabling and life-threatening health complications. These include possible loss of vision, renal failure, peripheral and autonomic neuropathy, sexual dysfunction, cardiovascular disease, and symptoms of hypertension and lipoprotein abnormalities (ADA, 2010: S62; IDF, 2017:16). The aetiology of T2DM is complex. A strong link, however, exists between genetic disposition and the augmenting risk factors of increased age, obesity, little/insufficient activity or inactivity (ADA, 2010: S64).

Diabetes has been labeled a "societal catastrophe" (IDF, 2017: 6). It is a worldwide epidemic and one of the top10 causes of death globally, with 1 in 11 adults having diabetes, two-thirds of which are of working age (IDF, 2017). This poses a significant threat to economic systems. Moodley and Rambiritch (2007: 16a), noted an increased prevalence of diabetes mellitus in Africa with increasing age, sedentary lifestyles, rapid urbanization and 'modern diets', and predicted a tripling of the prevalence in 25 years. Closer to home, Rheeder (2006:10) showed prevalence estimates ranging from 3 to 28.7%, for South Africa (SA), with a high prevalence of "13% in the Indian community of Durban, and 28.7% in the elderly community of Cape Town". SA ranks highly in the African region, and

worldwide, with a national diabetes prevalence of 5,4% (IDF, 2017) - this despite a large percentage of cases still undiagnosed (Matsha, Hassan, Kidd & Erasmus, 2012; Okonta, Ikombele, & Ogunbanjo, 2014). IDF (2017) estimates a total health expenditure, related to diabetes, over 1,7 billion US dollars in SA.

1.3 Rationale and Motivation

As a biokineticist who works predominantly in the rehabilitation of persons with chronic disease, injury or disability, I see many clients diagnosed and living with T2DM. In my private capacity, I am familiar with a woman named Sarah (not her real name), who has been diagnosed with T2DM for approximately four years. Sarah has made negligible attempts to adapt her lifestyle, and her mobility has deteriorated to the point where she experiences disability, struggling to keep up with the physical demands of her job as a domestic worker. I am alarmed by how many individuals appear to have very little understanding of the disease, its progression, associated risks, and the necessary lifestyle adjustments. The nature of diabetes-related complications and the potential for limitation of full participation in all aspects of life highlights the danger of unawareness (WPRPD, 2015).

The reality of Sarah's story, together with my daily interactions with clients, has motivated a desire to understand the apparent lack of necessary lifestyle adjustments. As a researcher, therefore, I would like to investigate the current knowledge, attitudes and adapted behaviours of persons diagnosed and living with T2DM, in the area where I work. A connection between knowledge, attitude, and behaviour, is often assumed and it is suggested that knowledge and attitude may impact on adapted behaviours. As this is not always the case, an understanding of human behaviour when affected by the disease may be helpful in impacting patient health outcomes (Rav-Marathe, Wan & Rav-Marathe, 2016).

Apart from a study carried out by Phillips, Mashige and Clarke-Farr (2012) on the knowledge of diabetes mellitus amongst privately funded diabetes patients in Malmesbury, there is an apparent lack of knowledge, attitude and behaviour (KAB) data about persons with diabetes in the Western Cape. In terms of

behaviour, specifically, individual perceptions of disease and healthcare, and the resulting choice of self-care behaviour (or lack thereof) is an area that needs further investigation to fully understand the behaviours of persons with diabetes in Cape Town. The hope is to gain insight into this behaviour, to inform current diabetes treatment and/or management, and subsequently aid in managing the risk of complications leading to disability.

1.4 Aim and Objectives

1.4.1 Study Aim

The aim was to describe the diabetes-related knowledge, attitudes and self-reported adapted behaviours of persons diagnosed for at least one year with T2DM, and attending a private clinic in Cape Town, South Africa.

1.4.2 Objectives

The objectives of the study were to explore:

- The diabetes-related knowledge of persons diagnosed with T2DM for at least one year and attending the Diabetes Life Clinic in Cape Town, SA
- The diabetes-related attitudes of persons diagnosed with T2DM for at least one year and attending the Diabetes Life Clinic in Cape Town, SA
- The self-reported diabetes-related adapted behaviours of persons diagnosed with T2DM for at least one year and attending the Diabetes Life Clinic in Cape Town, SA

1.5 Significance

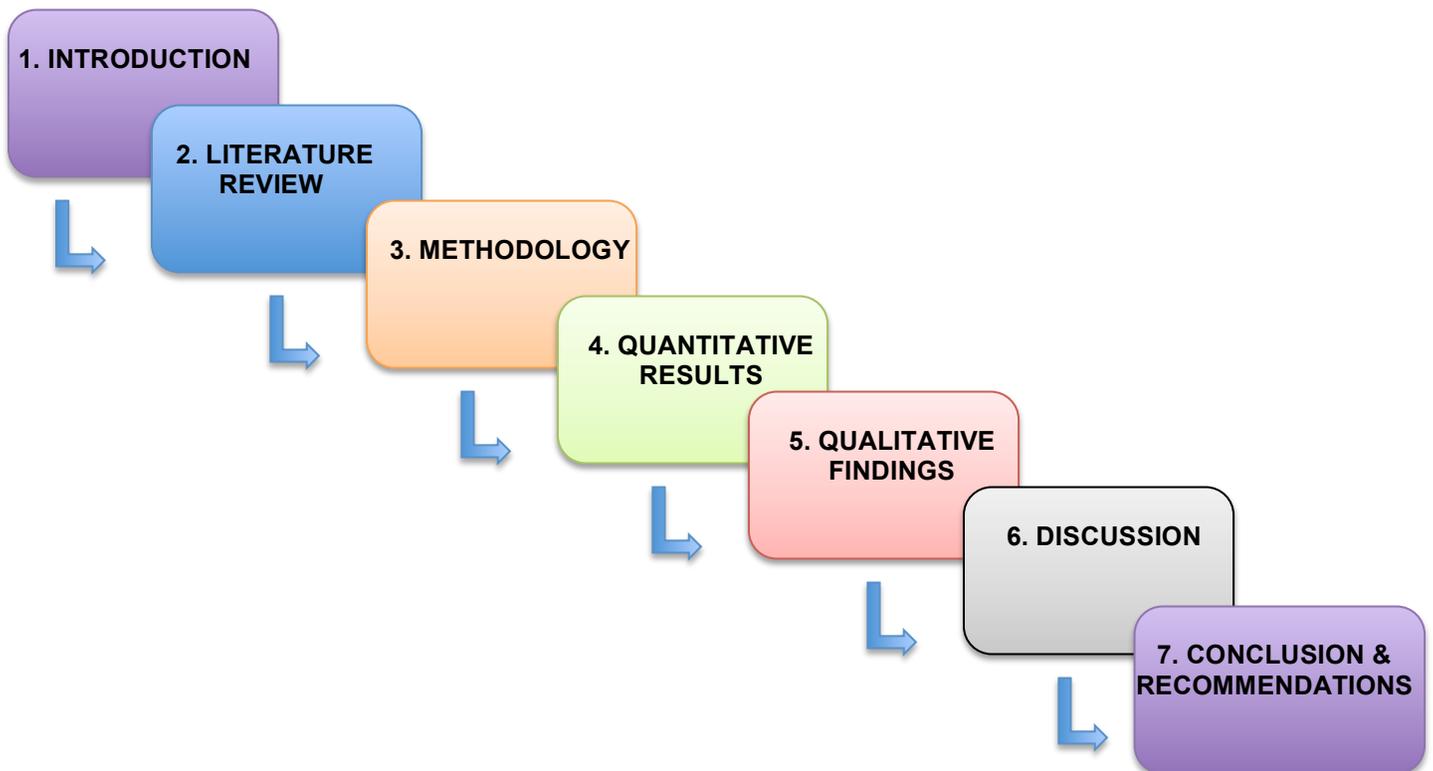
Due to the nature of T2DM, individuals who are unable to effectively manage this condition are at risk of developing complications, which may result in disabilities that not only affect the quality of life (QOL), but also the ability to earn an income and productively participate in society (WPRPD, 2015). While there are a few KAP studies relating to Type 2 diabetes worldwide, including some in the Free

State (Le Roux, 2016), Limpopo (Ralineba, Netshikweta & Shilubane, 2015; Shilubane, Netshikweta & Ralineba, 2016), Kwazulu Natal (Mashige, Notshweleka, Moodley, Rahmtoola, Sayed, Singh and Sardiwalla (2008) and Mamelodi (Okonta et al, 2014), there appears to be a lack of data on the Western Cape population. It is, therefore, imperative to establish the current knowledge, attitudes and behaviours of individuals with T2DM in the Western Cape, in an attempt to mitigate any adverse outcomes. While not looking at the entire Western Cape population this study does make a small contribution to the body of knowledge through adding qualitative explanations of behaviours to the usually collected quantitative KAB data.

1.6 Outline of the research assignment

This research assignment is divided into seven chapters as illustrated in Figure 1.1.

Figure 1.1: Outline of the research assignment



- Chapter 1 introduces a brief background and problem statement, and describes the motivation and rationale for the study, together with the study aim and objectives.
- Chapter 2 presents the literature review.
- Chapter 3 provides an overview of the methodology employed, including the study design, sampling, study procedures and ethical considerations.
- In chapters 4 and 5 the quantitative results (phase one) of the study and the qualitative findings (phase two) are presented.
- Chapter 6 provides a discussion of the results.
- Chapter 7 describes conclusions drawn from the study, and puts forward recommendations for practice and further research.

1.7 Chapter Summary

T2DM is a condition that is complex in aetiology, and one that is exacerbated by lifestyle factors including obesity and insufficient exercise or physical activity. While some research on the knowledge attitudes and behaviours of persons living with T2DM has been done in South Africa, data specific to the Western Cape appears to be lacking.

Chapter 2

Literature Review

2.1 Introduction

Databases such as Pubmed, Science Direct and Google Scholar were searched. Search words included, 'KAB AND Type 2 Diabetes Mellitus', 'KAB AND Diabetes AND South Africa', 'Knowledge, attitude, behaviour AND Diabetes', 'Cultural beliefs AND Diabetes AND South Africa'. Article reference lists were further scrutinized for relevant sources in a pearl growing search strategy.

The literature review begins with a brief explanation of the nature and importance of diabetes management. A brief rationale for using a KAB survey questionnaire as a tool for gathering knowledge about persons with T2DM in a specific setting is offered, followed by a brief discussion of the diabetes-related evidence of knowledge, attitudes, and behaviours (KAB), and possible factors impacting on the KAB of people diagnosed with T2DM.

2.2 The nature of diabetes management

Diabetes self-management is dependent on factors such as patient-centeredness, improved disease-related knowledge, feelings about having the disease, and acquired behaviour modification skills (Krichbaum, Aarestad & Bueth, 2003). The ADA (2018a: S38) highlights the importance of nutrition therapy, physical activity, smoking cessation counselling, and psychosocial care in diabetes management. Similarly, Gul (2010:128) emphasises a multifactorial approach achieved through "good glycaemic control, control of risk factors, lifestyle modification, prevention of complications and diabetes education". Dessa (2018) corroborates the above-mentioned views. The goal of diabetes management is put forward as improving and maintaining quality of life through improving patient knowledge and skills, and facilitating changes in attitudes, values, and beliefs. The role of diet, exercise, and medication in successful diabetes management are also confirmed.

2.3 The KAB survey questionnaire

A KAB survey is a useful tool for gathering information about what is 'known, believed and done in relation to a specific topic'. It highlights gaps in knowledge and cultural beliefs, providing potentially new insight into behaviours or attitudes of a specific population (World Health Organization, 2008:6). A survey questionnaire, therefore, would be a useful tool in exploring the current level of knowledge, attitude and behaviours of a particular group, within the diabetes context, with the goal of informing improved diabetes management strategies.

2.4 Knowledge, attitude and behaviour

2.4.1 Knowledge

Knowledge is the 'greatest weapon in the fight against diabetes mellitus' (Berhe, Gebru, Kahsay, & Kahsay, 2014:1). Unfortunately, most studies show poor knowledge among persons diagnosed with T2DM (Ahmad & Ahmad, 2015; Berhe et al, 2014; Gul, 2010; Konduru, Ranjan, Karthik, Shaik & Vakkapatla, 2017; Le Roux, 2016; Mabaso & Oduntan, 2016; Mshunqane, Stewart & Rothberg, 2012; Powell, Hill & Clancy, 2007). Locally, a study by Ralineba et al (2015) shows more than 78% (n=78) of respondents in Limpopo, with no awareness of DM, and negligible knowledge of complications and blood glucose control. Contrastingly, Mashige et al (2008), report sufficient knowledge in 76% (n=81) of a study sample in Durban. Mabaso and Oduntan (2016) attribute the varying levels of knowledge in SA to the inequalities of education and health services, and health education continuing to exist from the apartheid era.

Interestingly, while Guatum, Bhatta, and Aryal (2015) associated increased knowledge with improved behaviour in Nepal, Le Roux (2016) suggests that improved knowledge does not translate into improved behaviour in SA. Phillips et al (2012) concur, demonstrating acceptable knowledge of management protocols but poor practices among a group of patients at a private facility in the WC. Similarly, Shilubane et al (2016) propose that higher education does not guarantee favourable KAB; this being evident in a predominantly educated study

sample in Limpopo, SA, who were unaware of the benefits of exercise and conveyed the belief that traditional medicine can cure diabetes.

2.4.2 Attitudes

Attitude is “the thinking or feeling of a person towards a healthy lifestyle including causes and prevention of diabetes” (Kambinda, 2016: vi). A significant correlation between attitude and education, as demonstrated by Kheir, Greer, Yousif, Al Geed and Al Okkah (2011), among Qatari patients, implies that general literacy levels impact on attitude. In agreement, Le Roux (2016) attributes negative attitudes in SA to a lack of understanding of a particular behaviour. Here, the high level of general illiteracy could be a factor in the predominantly negative attitudes towards DM reported by Le Roux (2016) and Ralineba et al (2015). More specific to adapted behaviour, Okonta et al (2014), report mostly positive attitudes (84,3%; n=183) towards lifestyle modification in Mamelodi, SA, despite recording poor lifestyle practices, and highlighted poverty as a causal factor.

2.4.3 Behaviours

Disease management behaviours are shaped by more than just knowledge and attitude (Ng, Waseem & Kadirvelu, 2012:728). Internationally, Ng et al (2012) propose older age as a causal factor of the dissociation discovered between adequate KAB scores and insufficient diabetes management. Self-care behaviours were also negatively impacted by poor education in India, according to Konduru et al (2017). In SA, behaviours reported were generally poor with regards to levels of physical activity, dietary habits and monitoring of BG levels (Le Roux, 2016; Mabaso & Oduntan, 2016; Okonta, et al 2014; Phillips et al, 2012). Poor adherence to medication was highlighted together with the impact of cultural beliefs about illness and treatment, lack of resources and incomprehensible patient education. (Ralineba et al, 2015; Roux, 2016; Shilubane et al, 2016; Mshunqane et al, 2012). Contrastingly, Mashige et al (2008) reported regular BG monitoring and positive lifestyle changes.

2.4.4 Related demographic factors

Globally, research portrays the general Type 2 diabetic population as individuals who are within the age-range of 40-69 years old, low-income earners, poorly educated, predominantly female, and present with complications (Ahmad & Ahmad, 2015; Berhe et al, 2014; Gul, 2010; IDF, 2017; Le Roux, 2016; Mabaso & Oduntan, 2016; Okonta et al, 2014; Phillips et al, 2012; Powell et al, 2007; Ralineba et al, 2015; Shilubane et al, 2016). The low-income trend noted above, particularly in SA, might be related to most participants having been sourced from public healthcare facilities, which are generally believed to service poorer individuals.

Internationally, Guatum et al (2015) show a positive association of knowledge to age, that is, increased knowledge with age. They also suggested females as more likely to have satisfactory knowledge and behaviours in Nepal. Mufunda, Wikby, Björn and Hjelm (2012:2) describe females as being more 'information-seeking and active in self-care', however, they demonstrate limited knowledge and self-care in Zimbabwe, for both genders.

Berhe et al (2014) suggest that one's culturally determined beliefs about health and illness affect self-care behaviour. This is echoed locally, by Ralineba et al (2015), who further suggest that these beliefs should inform specific, realistic and patient-centered recommendations. Shilubane et al (2016) caution that cultural beliefs may be barriers to effective diabetes management, with religious individuals more likely to believe in cure through prayer or other belief-based rituals and less likely to adhere to medication and treatment regimes. Similarly, Ralineba et al (2015) note 76,7% (n=76), of their participants reporting a belief that DM is the result of bewitchment. Le Roux (2016), however, disagrees and suggests that prayer and religious faith may strengthen an individual's belief of control, and positively influence 'intention' towards positive behaviour.

International research shows dissociation between knowledge and years of diagnosis (Berhe et al, 2014; Gul, 2010; Mufunda et al, 2012). Here in SA, Le Roux (2016) is in agreement and notes participants diagnosed for as long as 7

years with poor knowledge and behaviour. Moodley and Rambiritch (2007), however, found increased diabetes knowledge with increased years post-diagnosis. This increased knowledge may be explained by the increased awareness of DM among the Indian population, resulting from the high prevalence of diabetes in the Indian community for many years (Moodley and Rambiritch (2007).

Local research suggests that the diabetes pre-diagnosis period is extended due to the mildness of symptoms, thereby, increasing the incidence of complications (Ralineba et al, 2015; Mshunqane et al, 2012). Further, Mshunqane et al (2012) believe that a lack of resources affects behaviour negatively, using the cost of diabetic-friendly food as an example. This idea of limited resources is supported by the deceleration in the rate of economic growth in South Africa due to the global recession, with an average growth just above two percent for the period 2008-2012 (Statssa, 2019).

2.5 Conclusion

Diabetes is a worldwide epidemic. The high prevalence rates in South Africa emphasize the urgency of effective self-management. While research demonstrates mostly limited knowledge around diabetes and the associated complications, the results are conflicting in terms of feelings towards diabetes and associated self-care behaviours, and the relationship between knowledge and positive behaviour. Several variables, including poverty, poor health literacy and cultural beliefs are introduced as factors that might impact health and health behaviour. Confoundingly, while KAB studies have been carried out in some provinces around SA, the available KAB data is limited for the Western Cape. The researcher would, therefore, like to address the gap in research in Cape Town and explore the diabetes-related knowledge, attitudes and adapted behaviours of persons diagnosed with T2DM for at least one year and attending a private clinic in Cape Town, SA.

Chapter 3

Methodology and Methods

3.1 Introduction

This chapter describes the methodology implemented to explore the knowledge, attitudes and adapted behaviours of the study population. I motivate the choice of a mixed-methods design, describe the setting, and indicate the inclusion criteria as well as the specific procedures followed during sampling, data collection and analysis. The methods are described in two phases with phase 1 the quantitative component and phase 2 the qualitative component.

3.2 Research Design

Based on the synergistic value of both quantitative and qualitative research, a mixed-methods methodology has been selected (O' Leary, 2017). Ozawa and Pongpirul (2013:323) highlight the importance of mixed-method studies in low – and middle-income settings, like South Africa, where exploratory insight into social, economic and cultural contexts is vital to successful healthcare. The study design and methods are illustrated in Table 3.1.

Table 3.1 Overview of research design and methods

| | PHASE 1: QUANTITATIVE | PHASE 2: QUALITATIVE |
|-----------------------------------|--|---------------------------------|
| Data collection strategies | QUESTIONNAIRE | INTERVIEWS |
| Tools | Self-administered questionnaire | Interview Schedule |
| Sampling | Consecutive | Purposive |
| Participants | 67 | 6 |
| Nature of data | i. Short questions - quantitative | Open-ended - qualitative |
| Data analysis strategies | Descriptive statistics (means, standard deviations, frequencies, p) | Thematic content analysis |
| Data analysis procedures | Spearman correlations, Chi-2, Kruskal-Wallis test | Immersion categorisation |
| Software | SPSS | none |

A KAB survey/questionnaire was implemented to gather information about the current diabetes-related knowledge, attitudes and behaviours of a particular group, within a particular setting. The hope being that this information will provide insight into the relationships between knowledge, attitude, and adapted behaviour, and highlight associations between KAB and socio-demographic factors (Rav-Marathe et al, 2016:7). It may also infer the success of current diabetes management through a general indication of the quality of life. An adapted version of the South African diabetes KAP Questionnaire was selected as it had been used previously by Le Roux (2016) and was specific to South Africa. Reviews of existing and validated instruments were used to adapt the

South African- Diabetes KAP questionnaire and the validity of questions assessed by a multidisciplinary expert team Le Roux (2017:57).

As the majority of KAB studies already conducted appeared to be quantitative, I believed a quantitative component was necessary to produce knowledge that is comparable to other KAB studies. Additionally, it demonstrates the extent of the diabetes dilemma and illustrates how representative the findings are (Ozawa & Pongpirul, 2013:324). On the other hand, Phillips et al (2012) demonstrate that good knowledge does not guarantee good behaviour practices. The role of culture and belief systems in behaviour is highlighted (Berhe et al, 2014; Shilubane et al, 2016). I, therefore, included a qualitative component to further explain the quantitative findings and draw meaning for the particular study population, i.e. identify some of the cultural and social influences affecting them. (Goutille, 2009:18).

Quantitative and qualitative components are weighted equally, allowing for triangulation of the data. A phased approach was used; quantitative followed by qualitative. Data collected during the first phase was used to purposively sample participants for the second phase. While quantitative and qualitative data were analyzed separately, results were combined at an interpretation level of the research in the discussion (Sandelowski, 2000:252).

3.3 Setting

The setting is the Diabetes Life clinic, situated in the Life Kingsbury Hospital Suites, in Claremont, Cape Town. It is a private clinic offering the professional services of a general practitioner specialising in diabetes; a clinic assistant helping with data downloads and education; a foot-care nurse and dietician consulting at the clinic; and a biokineticist, ophthalmologist and endocrinologist consulting externally. These services cover all aspects of diabetes management, including screening, lifestyle management (nutrition and physical activity), glucose management, and monitoring and referral for complications and co-morbidities (SEMDSA, 2017). The services are paid for, either personally by the client, or by medical insurance benefits, i.e. some patients are registered as

having diabetes with their medical aid, affording specific cover for much of the related costs.

This population is privileged when compared to the majority of South Africans ($\pm 84\%$) being serviced by the public health sector, especially when one compares the per-capita health spending, i.e. annual per capita expenditure is $\pm R1200$ in the public sector and $\pm R12000$ in the private sector (Benatar, 2013:2).

According to the socio-economic profile of Cape Town (Western Cape Government, 2016), 39,3% of people in the City of Cape Town live below the poverty line, with households falling under the low-income bracket of R4166 per month. As I already work with many of the clinic's patients, I wanted to collect data that may inform my clinical practice. Insight gained from the research results, I believe, will enhance my understanding of these clients and positively affect my approach to their treatment. While this privileged population limits the generalisability of the results, the study will add to the body of knowledge and produce insight that might inform possible further research into improving diabetes management in the wider Western Cape.

3.4 Phase 1: Quantitative Component

3.4.1 Population

All adults (> 18 years) with T2DM, diagnosed for at least one year and attending the Diabetes Life Clinic in Claremont, Western Cape, during the period of data collection (22 October 2018 - 02 July 2019) formed the study population.

3.4.2 Selection Criteria

The researcher briefly discussed the inclusion and exclusion criteria with the office manager and clinic nurse prior to data collection. The office manager managed the practice diary and only offered the questionnaire to patients who met both inclusion and exclusion criteria – this was confirmed in patient files if uncertain. In addition, patients were asked to indicate the type of diabetes and any complications on the questionnaire. Any patients who indicated or alluded to any of the exclusion criteria were checked with the office manager and data was

not used if the exclusion proved valid.

3.4.2.1 Inclusion criteria:

The following participants were included in the study population:

- Male and female adults (> 18 years) with T2DM
 - Reason: T2DM, the most common form of diabetes, is mostly seen in adults older than 30 years (Mabaso & Oduntan 2016; Ralineba et al, 2015). The South African law declares an adult at 18 years of age (Legal Aid SA, 2015).
- Clinically diagnosed with T2DM
 - Reason: T2DM is diagnosed through clinical testing. Tests and blood glucose limits commonly used (ADA, 2018b):
 - o *HbA1c* (average glucose over 2-3 months) - 6.5% or higher
 - o *Fasting Plasma Glucose (FPG)* - 26mg/dl or higher
 - o *Oral Glucose Tolerance Test (OGTT)*: Checks glucose before and 2hours after a sweet drink - 200mg/dl or higher
 - o *Random Plasma Glucose Test*: Casual testing with severe symptoms of diabetes - \geq 200mg/dl
- Diagnosed for at least one year
 - Reason: Presumably one year affords the time and lived experience to acquire the necessary skills and knowledge to manage diabetes.
- Attending Diabetes Life Clinic during the data collection period
 - Reason: Limited time available for data collection

- Must be able to read and write
 - Reason: Data will be self-reported. Understanding what is read to communicate written answers is, therefore, important.

3.4.2.2 Exclusion criteria:

- Patients with gestational diabetes, T1DM or mixed diabetes
 - Reason: The focus of this study is T2DM.
- Patients with additional severe illnesses such as cardiac failure or renal failure (Gul, 2010)
 - Reason: The inability to participate due to illness, and/or the effect of illness on the individual's attitude and adapted behaviour (Le Roux, 2016).
- Participants with intellectual disability and/or communication disability, precluding their ability to participate in responding to the written questionnaire and the verbal interview.
 - Reason: Participants must be able to give informed consent (Berhe et al, 2014; Mufunda et al, 2012). It is not within the scope of such a small, focused study to explore further and include persons with intellectual disability and/or communication disability in this study population.

3.4.3 Sampling

A list of patients attending the clinic was not available, therefore, the exact population size was not known. A feasibility study was conducted to determine project viability, i.e. the number of patients booked over an 8week period at the clinic was used to determine an estimate number of potential participants in a month (n=178) and ensure a valid sample size. Non-probability, consecutive sampling allowed all available potential participants that met the study criteria,

the opportunity to participate in the KAB survey (Omair, 2014). This choice was motivated by time and budget constraints of the study while realizing that it would negatively affect the randomness of the sample and thus the generalisability of the findings.

All clients attending the clinic during the study period, and meeting the study criteria, were asked if they wanted to participate in the study. Those that consented completed the questionnaire. Seventy-five individuals completed the questionnaire, however, three were Type 1DM, one has been diagnosed for less than one year, one was duplicated, another failed to sign the consent form, and another withdrew from the study. The remaining 67 participants formed the sample for this study. It is not clear how many individuals refused participation, as the person handing out the questionnaires did not record this information.

3.4.4 Pilot study

The questionnaire was piloted with five adults with T2DM from the clinic, who did not form part of the sample - covering both genders and all official languages in the WC, namely, Afrikaans, English and IsiXhosa. Subsequent changes included: the print of the questionnaire was found to be too small and was enlarged for easier reading. An additional exclusion criterion was added, being that of patients with 'mixed diabetes'. Spelling errors were corrected before printing.

3.4.5 Recruitment

I, the researcher, scheduled an information session with the office manager to cover details around obtaining informed consent, aims and objectives of the study, and specific requirements for answering survey questions.

A flyer was put up in the clinic one month before data collection, to advertise the study. [ADDENDUM A]

During the data collection period, due to the researcher being employed full-time and budgetary constraints, the office manager identified patients that fitted the

selection criteria and informed them of the study. The completion of a questionnaire before or after the consultation was mentioned. Those who agreed to participate were asked to sign an informed consent for both the questionnaire and the potential telephonic interview, in their language of preference (ANHMRC, 2012; Goutille, 2009; OHRPP, 2012; Teddlie & Yu, 2007). The aims and objectives, as well as the procedure of completing the questionnaire, were explained in the informed consent document. [ADDENDUM B]

3.4.6 Data Collection

3.4.6.1 Tools

An adapted South African Diabetes KAP-questionnaire, used previously by Le Roux (2016), was modified according to the current research aim and objectives. [ADDENDUM C]

The questionnaire is structured, with closed and open-ended questions. Questions asked were not leading and were carefully ordered to avoid influence on subsequent questions. The questionnaire is brief to avoid fatigue and distraction, limiting unreliable data. It has four parts, namely, a respondent profile (including demographic details and associated factors), knowledge about diabetes, associated risks and management, attitudes towards diabetes, and specific behaviours followed to avoid or prevent progression of diabetes (Rav-Marathe et al, 2016). Included in the respondent profile were a few questions aimed at establishing a measure of the quality of life of the respondent. While I am aware that there are more precise and reliable tools for measuring quality of life, I followed Le Roux's lead on this, for comparative purposes.

A statistician provided input into the questionnaire by advising on the addition of another question, and clarifying the scoring process.

The questionnaire was made available in English, Afrikaans and isiXhosa, i.e. the official languages of the WC according to the language policy of Western Cape Government (2018), to allow participants to answer questions in their first language (Le Roux, 2016). As English and Afrikaans versions already existed,

the questionnaire was further translated into isiXhosa, and back-translated to confirm accuracy. Individuals who are fully bilingual in both written English and isiXhosa did the translation and the back-translation.

3.4.6.2 Logistics

The questionnaire was completed before or after the respondent's clinic appointment. The office manager was available to answer any related questions. Additionally, the researcher was available for assistance by telephone or email. On completion, the questionnaire was placed into a sealed, unmarked box, which was collected from the clinic by the researcher. In exceptional cases where participants were not able to stay longer, questionnaires were completed at home and emailed or faxed directly to the researcher. Three questionnaires were collected from the participants' homes, upon their request.

3.4.6.3 Rigour

3.4.6.3.1 Reliability: The questionnaire was not tested for reliability.

3.4.6.3.2 Validity: The pilot and the use of a questionnaire already developed for a KAB study in T2DM, aimed to improve construct, content and cross-cultural validity (Mokkink, Terwee, Patrick, Alonso, Stratford, Knol, Bouter & de Vet, 2010). The questionnaire was not tested for concurrent validity.

3.4.7 Quantitative Data Analysis

Data were coded and captured by the researcher. The researcher was assisted by the Biostatistics Department at the University of Stellenbosch. SPSS software was used to analyse the data obtained through the questionnaires.

Knowledge scores were calculated by allocating a point for each correct answer, with a maximum score of 32. For questions where the participant offered more than one answer, each answer was coded. In the case where one option was correct and the other incorrect, the participant was awarded half a point.

Attitude and behaviour scores were adapted as the participant could select

options that were scored as positive, negative or neutral (ADDENDUM D). Participants were awarded one point for answers relating to positive attitude or behaviour, they lost a point for answers relating to negative behaviour or attitude and were rewarded zero points for answers relating to neutral attitudes or behaviour. While subtracting points for a personal perception seems punitive/harsh, this method of scoring was replicated from Le Roux (2016) and for purposes of comparison.

Descriptive statistics were used, and are presented as frequencies with percentages and means with standard deviations for continuous data (Le Roux, 2016; O' Leary, 2017; Konduru et al, 2017). Nominal and ordinal data are presented in tables. A Spearman correlation between the knowledge, attitude and practice scores is reported, as data is not evenly distributed

KAB variables and QOL were further classified into three categories for statistical comparison, namely negative, average/neutral and positive. While there appears to be no set evidence of what level of knowledge, attitude or behaviour is required to adequately manage T2DM, classification was based on the premise that individuals would run into complications with less than an average knowledge and predominantly negative attitude or behaviour (Perera, De Silva & Perera, 2013). Knowledge and QOL scores for the relevant categories were <50%, 50-65% and >65%, respectively. Attitude and behaviours scores were <0, zero and >0 (for mostly negative, average or mostly positive behaviour), respectively.

The Chi-square test was used to identify a possible association between KAB categories for knowledge, attitudes and behaviours (KABC), and associated, categorical variables, while the Kruskal Wallis was used to identify associations with between KABC and continuous variables such as age. P-values <0.05 were considered statistically significant.

3.5 Phase 2: Qualitative Component

3.5.1 Population

All 67 respondents who participated in phase 1 formed the population for phase 2.

3.5.2 Sampling

Provisional analysis of the quantitative data informed purposive sampling of information-rich participants for Phase 2 (Sandelowski, 2000), i.e. participants with either good or poor KAB scores, or those offering interesting information. Due to the focused nature of the study and the time-constraints of this study for degree purposes, six participants were selected for the telephonic interviews (Daniel, 2012).

3.5.3 Recruitment

Potential participants were contacted on the telephone number provided and invited to participate in a telephonic interview. Both parties agreed on a suitable date and time. The language of choice, as indicated on the questionnaire, was confirmed. An external interviewer was not needed as none of the respondents requested to be interviewed in isiXhosa.

3.5.4 Informed Consent

I explained the purpose of the interview and requested verbal consent for participation and for the recording of the interview. Once the recording was started, the request for verbal consent was repeated, to ensure a record of the participant's verbal consent.

3.5.5 Pilot

The interview was piloted with two individuals from different cultural groups, one English -speaking and one isiXhosa-speaking. The isiXhosa-speaking individual requested to be interviewed in English. One participant noted that no mention

was made of the fact that all data will be destroyed once the project has been finalized and submitted. The interview schedule was adapted to include the statement -- it is noted that the de-identified data will be kept safe and secure for a period of five years, for auditing purposes, before being destroyed. The data from the pilot interviews was included in the qualitative data analysis (Van Teijlingen & Hundley, 2001). There is less of a concern for contamination of results with qualitative studies, as qualitative data collection and analysis is often more progressive in that researchers use insight and experience gained, from earlier interviews, to improve schedules and questions for subsequent interviews (Van Teijlingen & Hundley, 2001).

3.5.6 Data Collection

Telephonic interviews were done as they decrease the cost of data collection, but also increase privacy, and allow the participant to feel more comfortable (Novick, 2008). I explained the confidentiality of all shared information, and freedom to withdraw at any time (O' Leary, 2017) – as per information in the informed consent form. Participant-narrated experiences, elicited through probing questions, provided raw data. I conducted the interviews from a private office/venue. The interview was kept informal and I used small talk to create rapport with the participant. The phone was placed on loudspeaker, and an external, audio-recording device was used to record the conversation.

Interview recordings were transferred from the recording device to a file on a password-protected computer for analysis

A semi-structured interview was used. An interview schedule noted important points to be discussed, i.e. the experience of having diabetes, adapted behaviours following the diabetes diagnosis, and social and cultural influences (Miles & Gilbert, 2005). [ADDENDUM E]

Additionally, pertinent answers or comments in the questionnaire from phase 1 were used to probe further. All participants requested the telephonic interview to be in English.

The interview lasted approximately 20 minutes - keeping it short enough to limit distraction and cost due to a limited research budget (Novick, 2008).

3.5.7 Qualitative Data Analysis

Data was narrative, and interviews were transcribed by myself. Thematic analysis was done according to the six steps, as offered by Braun and Clarke (2006:87): “Once familiar with the data, the researcher will generate initial codes. Themes will be explored, reviewed, and then named and defined. Finally, the report will be produced.”

During each interview, notes were made and a mind-map was drawn up for each participant, highlighting important comments. Each interview was later transcribed. Auditory cues such as anger, sarcasm, and rapid speech, also informed data analysis (Novick, 2008), i.e. during the transcription of the interviews, any change in tone, volume or 'speech speed' was noted as indicative of important narrative data.

Transcriptions were then reread to highlight further important comments, quotes or ideas. Codes were identified during reading. Transcripts were submitted for peer verification by the study supervisor.

Once familiar with all the data, interviews were compared, common ideas were explored, and themes named. Once themes had been identified and named, relevant data was extracted and used to report the findings under each theme.

Results were reported using both deductive and inductive reasoning (O' Leary, 2017). While a theory-driven/KAB-objective driven perspective allowed for the identification of abstract concepts and relationships among them, a data-driven perspective was used to derive insights from patterns that were extracted from the data analysis (Maass, Parsons, Puroo, Storey & Woo, 2018)

3.5.8 Trustworthiness

3.5.8.1 Transferability and Dependability

A detailed description of the study setting, participants and methods used, allows for judgement of transferability (O’Leary, 2017). Records of raw data, transcripts, field notes and reflexivity provide an audit trail, which demonstrates dependability (Nowell, Norris, White & Moules, 2017:3). Limitations will also be discussed.

3.5.8.2 Confirmability

Reasons for theoretical, methodological and analytical choices have been documented throughout the study, providing clarification for various decisions (Nowell et al, 2017). I acknowledge that my role as a healthcare practitioner working with clients with diabetes may have influenced interpretations.

3.5.8.3 Credibility

The mixed-method design allows for the triangulation of data. This together with regular debriefing with supervisors and purposive sampling will improve both credibility and dependability (Mabuza, Govender, Ogunbanjo & Mash, 2014). Regular peer debriefing provided an “external check on the research process”, and an opportunity to check preliminary findings against the raw data/transcripts (Nowell et al, 2017:3). Also, data saturation was achieved.

3.6. Ethical Considerations

3.6.1 Beneficence and non-maleficence

While there were no direct benefits to the participant, the opportunity was granted to have their voice heard. The insight gained will not only inform better clinical practice for the researcher but also hopefully, encourage future research into improving diabetes management. Assistance with completing the questionnaire was available if needed. Clinic staff was also available for emotional support if needed. Clinic clients use the paid parking area at the hospital and receive a

waiver if they have attended an appointment at the clinic, or in this case, have stayed longer to complete the questionnaire.

3.6.2 Respect for persons (dignity and autonomy)

Participants were informed that participation was completely voluntary and consent to participate could be withdrawn at any time. The participant had the right to refuse to answer any question (s) that caused discomfort. The participant was also free to not disclose personal information and ask for additional clarification (Le Roux, 2016). Each participant was approached and presented with an informed consent document, which explained the details of the study - ensuring the potential participants' right to full disclosure. Informed consent was obtained for both phases of the study. Additional consent was verbally confirmed before the telephonic interview. Participants were allowed to complete the questionnaire at home if they preferred, and email it directly to the researcher. Consent forms and de-identified questionnaires were separated to ensure anonymity. All data was kept anonymous, confidential, and used for research purposes only. All results were entered into a password-protected computer (Kambinda, 2016).

3.6.3 Approval and permission

Ethical clearance was received through the University of Stellenbosch. (Reference no: S18/05/113) (ADDENDUM F). Once obtained, written permission was obtained from the clinic (setting) for questionnaires to be completed at the clinic, and for selected participants to be approached for telephonic interviews (ADDENDUM G). Due to the slow process of data collection, approval for an extension of the initial ethics clearance was applied for and granted by the HREC (HREC2-2019-7377).

3.6.4 Distributive justice (or equality)

All participants that met inclusion criteria were invited to participate; there was no favouritism or partiality (Le Roux, 2016). Potential participants were able to choose any of the three official languages in the WC, in which to give their

consent, complete the questionnaire and participate in a telephonic interview. While the study sample is limited to one clinic, the insights gained from the research project will benefit this population directly through my dealings with individual clients (in my role as a biokineticist) or indirectly through further, potential research.

3.6.5 Researcher roles and responsibilities

The researcher acknowledges her role as healthcare professional and a vested interest in the clinic (setting) as many of her clients are living with T2DM and attend the clinic. The researcher further acknowledges that this may impact on the conclusions drawn. Transparency will be key in managing subjectivities and building trust with participants.

The researcher also acknowledges that her role as researcher may add to already existing power imbalance. The use of medical jargon will be avoided as far as possible and telephonic interviews will be informal and geared towards the 'respondent as the expert'. Reflexivity will be practiced to facilitate more equitable interaction.

The researcher will keep a 'research diary' of any notable changes to the research process, participant reactions, emotions experienced, and any obstacles that may impact on the research process or results.

The researcher will communicate regularly with her supervisors, sharing ethical concerns or dilemmas and maintaining accountability.

3.7 Conclusion

A mixed-methods methodology was used to explore the knowledge, attitudes and behaviours of persons with T2DM in a private clinic in the Western Cape. Participation was voluntary, and no compensation was offered from the researcher. Phase 1 made use of a self-reported questionnaire. Participants were sampled consecutively from the consultations booked within the data collection period - all patients who met the criteria were allowed to participate.

Assistance to complete the questionnaire and counselling support was available for participants at the clinic if they so required. Data was coded and analysed using SPSS software. Descriptive statistics were used to present data as frequencies with standard deviations, and test for correlations and associations. Of these initial participants (phase 1), six respondents were purposively sampled for phase 2 - a telephonic interview. Interview transcripts were thematically analysed - codes were identified while reading the raw data, interviews were compared, themes were named and relevant data was extracted to develop and describe the themes. The interview allowed the researcher an opportunity to get more insight into some of the behaviour patterns reported and explore the potential influence of cultural context. In both phases, participants were assured of confidentiality and were free to withdraw from participation at any point.

Chapter 4

Phase 1: Quantitative Results

4.1 Introduction

This chapter reports the results of the quantitative phase of the research project. It displays the frequencies and percentages of data in tables and presents the associations between the three KAB components as well as KAB and demographic and quality of life related variables.

4.2. Demographic Profile

Of the participants in this study, 61,2% (n=41) were male and 38,8% (n=26) were female. The majority (n= 61; 91%) indicated English as their home language. While a small percentage of participants (15,2%; n=10) completed some high school, 29,4% (n=20) fully completed high school and 47% (n=31) obtained a degree or diploma. A total of 64,4% (n=38) of the participants indicated that they earned R10, 000 per month (or more), and 74,2% (n=49) indicated that they were spiritual or religious (Table 4.1).

| Table 4.1: Demographic Profile | |
|--|--------------|
| Variable | n (%) |
| Gender (n = 67) | |
| <i>Male</i> | 41 (61,2) |
| <i>Female</i> | 26 (38,8) |
| Home Language (n = 67)...fourteen participants included more than one language | |
| <i>Afrikaans</i> | 18 (26,9) |
| <i>English</i> | 61 (91) |
| <i>Xhosa</i> | 1 (1,5) |
| <i>Other (French)</i> | 1 (1,5) |
| Level of Education (n = 66)...one participant selected “some high school” and “other” | |
| <i>No Schooling</i> | 0 (0) |
| <i>ABET (Adult based education training)</i> | 1 (1,5) |
| <i>Some primary school</i> | 0 (0) |
| <i>Completed primary school</i> | 0 (0) |
| <i>Some high school</i> | 10 (15,2) |
| <i>Completed high school</i> | 20 (29,4) |
| <i>Diploma/degree</i> | 31 (47) |
| <i>Other</i> | 5 (7,6) |

| Average monthly income (n = 59) | |
|--|-----------|
| < R3500 | 2 (3,4) |
| R3500 - R7000 | 8 (13,6) |
| R7100 - R10, 000 | 11 (18,6) |
| > R10, 000 | 38 (64,4) |
| Religious/ Spiritual (n = 66) | |
| Yes | 49 (74,2) |

The mean age of the participants was 59,2 years (sd 12,7). They were diagnosed with diabetes at a mean age of 47,3 years (sd 36,77), with mean years of being diagnosed (living with diabetes) of 11,3 (sd 7,5) years (Table 4.2).

| Table 4.2: Age Distribution | | | | | |
|------------------------------------|----------|----------------|----------------|-------------|----------------------|
| Variable | n | Minimum | Maximum | Mean | Std Deviation |
| Age | 66 | 35 | 84 | 59,15 | 12,711 |
| Years diagnosed (yrs) | 65 | 1 | 35 | 11,25 | 7,504 |
| Age diagnosed (yrs) | 64 | 24 | 76 | 47,34 | 36,77 |

4.3 Quality of life

There were 30,3% (n=20) of the participants that considered themselves ill at the time of data collection, 33,3% (n=22) of which listed symptoms related to metabolic syndrome and 12,1% (n=8) other symptoms, i.e. stress or anxiety (Table 4.3). This is relevant as persons with T2DM are at risk of developing complications, and many of the associated symptoms related to metabolic syndrome are risk factors for heart disease or stroke, i.e. high levels of cholesterol or high blood pressure. Some participants listed more than one illness/condition, highlighting the risk of developing co-morbidities. A small percentage of participants experienced problems with self-care (3%, n=2) or activities such as work, study, housework or leisure (17,9%; n=12). Almost half the participants experienced stress or anxiety (46,3%; n=31) while 34,3% (n=23) admitted to recently feeling depressed. The quality of life score was calculated by allocating one point for every "yes" answer related to problems with activities of daily life, physical and mental health. The mean QOL score was 69,7% (sd 23,7), with a minimum of 16,7% and a maximum of 100%.

| Table 4.3: Quality of life | |
|---|--------------|
| Variable | n (%) |
| Currently ill? (n= 66) | |
| Yes | 20 (30,3) |
| Condition / Co-morbidity (n=66)...some participants indicated more than one condition | |
| <i>Metabolic Illness</i> | 22 (33,3) |
| <i>Non-health/Lifestyle, i.e. stress</i> | 8 (12,1) |
| <i>Other health</i> | 1 (1,5) |
| Pain or loss of sensation/feeling in feet? (n=67) | |
| Yes | 23 (34,3) |
| A physical problem with walking (n=67) | |
| Yes | 14 (20,9) |
| Problems with self-care, i.e. dressing and washing (n=67) | |
| Yes | 2 (3) |
| Problems with activities such as work, study, housework, family or leisure activities (n=67) | |
| Yes | 12 (17,9) |
| Recent stress or anxiety (n=67) | |
| Yes | 31 (46,3) |
| <i>Unsure</i> | 7 (10,4) |

| Felt depressed recently? (n=67) | | | | | |
|--|----------|--------------|--------------|---------------|-----------|
| Yes | | | | | 23 (34,3) |
| Unsure | | | | | 10 (14,9) |
| | n | Min % | Max % | Mean % | Sd |
| Quality of Life Average % | 67 | 16,7 | 100 | 69,7 | 23,7 |

4.4 History of diagnosis

Twenty-six participants (41,3%) indicated experiencing symptoms related to metabolic syndrome before being diagnosed (Table 4.4).

More than half the participants (59,7%, n=37) were being treated by oral diabetes medication, 11,3% (n=7) were on insulin and 24,2% (n=15) were being treated with a combination of insulin and oral medication. Fifty-percent of the participants were also on medication for metabolic syndrome-related conditions.

| Table 4.4: History of diagnosis | |
|---|--------------|
| Variable | n (%) |
| Diagnosis process? (n = 63)... One participant mentioned multiple symptoms | |
| <i>Metabolic syndrome-related symptoms</i> | 26 (41,3) |
| <i>Other health-related symptoms</i> | 8 (12,7) |
| <i>Provider screening/testing</i> | 18 (28,6) |
| <i>Pregnancy</i> | 6 (9,5) |
| <i>Cannot remember/Irrelevant</i> | 6 (9,5) |
| Medication (n = 62)... 11 participants listed 3 or more medications | |
| <i>Insulin</i> | 7 (11,3) |
| <i>Diabetes tablets</i> | 37 (59,7) |
| <i>Insulin and tablets</i> | 15 (24,2) |
| <i>Pain</i> | 4 (6,5) |
| <i>Metabolic</i> | 31 (50,0) |
| <i>Psychological</i> | 5 (8,1) |
| <i>Other</i> | 11 (17,7) |
| <i>Arthritis</i> | 2 (3,2) |
| <i>Epilepsy</i> | 1 (1,6) |
| <i>Cannot remember</i> | 1 (1,6) |

4.5 Knowledge, attitudes and adapted behaviours related to T2DM

The mean scores for knowledge, attitude and adapted behaviour were 19.4, 6.9 and 2.6 respectively (Table 4.5).

| Table 4.5: Scores on Knowledge, Attitude and adapted Behaviour related to T2DM | | | | | |
|---|----------|-------------|------------|------------|----------------------------|
| Variable | n | Mean | Min | Max | Max. Possible Score |
| Knowledge | 66 | 19.4 | 5.0 | 26.5 | 32 |
| Attitude | 65 | 6.9 | -13 | 19 | 19 |
| Adapted Behaviour | 67 | 2.6 | -7 | 9 | 11 |

A breakdown of individual knowledge scores shows that the majority of knowledge scores are almost evenly distributed in the average (n=27) and positive (high knowledge scores) (n=30) scoring categories. (Table 4.6)

Attitude and adapted behaviour were scored differently, i.e. one point was added for a positive response, a point was deducted for a negative response and the score remained unchanged for a neutral answer. The distribution, therefore, of attitude (n=54) and adapted behaviour (n=48) scores mostly in the positive category, simply indicates that more positive than negative attitude and behaviour responses were recorded.

Table 4.6: Overall Knowledge, Attitude and adapted Behaviour Scores

| Variable | n | Negative (<50%) | Average (50-65%) | Positive (>65%) |
|-------------------|----|--------------------|-------------------|--------------------|
| Knowledge | 66 | 9 | 27 | 30 |
| Variable | n | Negative (score<0) | Average (score=0) | Positive (score>0) |
| Attitude | 65 | 10 | 1 | 54 |
| Adapted Behaviour | 67 | 18 | 1 | 48 |

4.5.1 Knowledge related to T2DM

Forty participants (69%) correctly identified a cause for T2DM related to heredity, lifestyle and diet (Table 4.7). While 42,6% (n=26) of the participants knew the range for normal blood glucose levels, 57,6% (n=34) could correctly identify the common signs of high blood sugar and 52,5% (n=32) could identify health complications related to diabetes.

Participants were unsure about the classification of certain foods into food groups, particularly lentils (88,7%, n=55), baked beans (64,5%, n=40) and milk (50%, n=30), which were incorrectly classified as protein. Most participants understood that medication cannot cure diabetes (81,3%, n=52), while 57,6% (n=34) believed, incorrectly, that diabetes medication may cause feet to swell. All participants understood that uncontrolled diabetes is related to a greater risk of complications. There was apparent confusion around the understanding of weight loss, with 65,6% (n=42) believing that simply cutting bread out will reduce weight. Forty participants (60,6%) were unsure about the aggravating cause of epilepsy on diabetes.

| Table 4.7: Knowledge related to T2DM | |
|---|--------------|
| Variable | n (%) |
| Cause of diabetes (n=58)...16 participants selected more than one option | |
| <i>Genetic</i> | 15 (25,9) |
| <i>Lifestyle/Diet</i> | 36 (62,1) |
| <i>Correct cause listed</i> | 40 (68,97) |
| Normal BG range (n= 61) | |
| <i>4.0-7.0</i> | 26 (42,6) |
| Common signs of high blood sugar (n=59)...participants offered multiple suggestions | |
| <i>Correct</i> | 34 (57,6) |
| <i>Combined: Some correct / incorrect</i> | 18 |
| What to do when blood sugar is low? (n= 62)...some participants offered multiple suggestions | |
| <i>Correct</i> | 33 (53,2) |
| <i>Combined: Some correct / incorrect</i> | 7 |
| Associated health complications (n=61)...participants offered multiple suggestions | |
| <i>Correct</i> | 32 (52,5) |
| <i>Combined: Some correct / incorrect</i> | 20 |

| Food Classification | |
|--------------------------------------|-----------|
| Cooking oil/Fish oil (n = 60) | |
| <i>Fat</i> | 53 (88,3) |
| Pap (n = 57) | |
| <i>Carbohydrate</i> | 42 (73,7) |
| Bread (n = 62) | |
| <i>Carbohydrate</i> | 57 (91,9) |
| Lentils (n = 62) | |
| <i>Carbohydrate</i> | 7 (11,3) |
| Baked beans (n = 62) | |
| <i>Carbohydrate</i> | 19 (30,6) |
| Chicken feet (n = 60) | |
| <i>Protein</i> | 23 (38,3) |
| <i>Unsure</i> | 27 (45) |
| Organ meat (n = 61) | |
| <i>Protein</i> | 30 (49,2) |
| <i>Unsure</i> | 14 (23) |
| Vegetables (n = 59) | |
| <i>Carbohydrate</i> | 21 (35,6) |
| <i>Unsure</i> | 12 (20,3) |

| | |
|---|-----------|
| <i>Fruit (n = 58)</i> | |
| <i>Carbohydrate</i> | 27 (46,6) |
| <i>Unsure</i> | 11 |
| <i>Milk (n = 60)</i> | |
| <i>Carbohydrate</i> | 9 (15) |
| <i>Unsure</i> | 7 (11,7) |
| <i>Sardines in Tomato Sauce (n = 61)</i> | |
| <i>Protein</i> | 43 (70,5) |
| Medication Use | |
| <i>Diabetes medication can cure diabetes (n = 64)</i> | |
| <i>False</i> | 52 (81,3) |
| <i>Diabetes medication should be taken for life (n = 63)</i> | |
| <i>True</i> | 37 (58,7) |
| <i>You should stop taking your diabetic medication when you feel sick (n = 64)</i> | |
| <i>False</i> | 58 (90,6) |
| <i>Poor control of diabetes could result in a greater chance of complications (n = 64)</i> | |
| <i>True</i> | 64 (100) |
| <i>Eating less bread will make me lose weight (n = 64)</i> | |
| <i>False</i> | 16 (25) |

| | |
|--|-----------|
| <i>Salty food will prevent my sugar levels from dropping (n = 64)</i> | |
| <i>False</i> | 45 (70,3) |
| Diabetic foot health | |
| <i>Diabetic medication may cause swelling of the feet (n = 59)</i> | |
| <i>False</i> | 25 (42,4) |
| <i>Sore feet are common in people with diabetes (n = 60)</i> | |
| <i>True</i> | 43 (71,7) |
| <i>People with diabetes may have poor circulation of blood in the feet (n = 65)</i> | |
| <i>True</i> | 62 (95,4) |
| Importance of physical activity | |
| <i>Is physical work or exercise important for people with diabetes? (n = 65)</i> | |
| <i>Yes</i> | 63 (96,9) |
| Regular physical work/exercise help with... | |
| <i>Blood sugar control (n = 66)</i> | |
| <i>Yes</i> | 65 (98,5) |
| <i>Painful feet (n = 65)</i> | |
| <i>Yes (Correct)</i> | 37 (56,9) |
| <i>Weight loss (n = 65)</i> | |
| <i>Yes (Correct)</i> | 59 (90,8) |

| Aggravating factors | |
|--|------------------|
| <i>The following factors can make diabetes worse:</i> | |
| <i>High blood pressure (n = 65)</i> | |
| <i>Yes (Correct)</i> | <i>60 (92,3)</i> |
| <i>Epilepsy (n = 66)</i> | |
| <i>Yes (Correct)</i> | <i>19 (28,8)</i> |
| <i>Unsure</i> | <i>40 (60,6)</i> |
| <i>Overweight (n = 66)</i> | |
| <i>Yes (Correct)</i> | <i>62 (93,9)</i> |

4.5.2 Attitudes related to T2DM

A number of the questions relating to attitude were responded to positively, particularly those relating to feeling like diabetes is controllable (80%, n=52), being hopeful about living a normal life (86,2%, n=56), and feeling that something can be done if one has diabetes (82,5%, n=52) (Table 4.8). A few responses were rather negative and highlighted the belief that most people find it difficult to adjust to having diabetes (59,4%, n=38), that proper control of diabetes involves a lot of sacrifice and inconvenience (40%, n=26), and that participants felt that they would be different people if they did not have diabetes (38,7%, n=24).

Table 4.8: Attitudes related to T2DM

| Variable/Statement | n (%) | | | |
|---|--------------|-----------|-----------|--------------|
| | Disagree (%) | Neutral % | Agree % | % (Positive) |
| If I did not have diabetes I think I would be quite a different person (n = 62) | 24 (38,7) | 14 (22,6) | 24 (38,7) | 38,7 |
| I dislike being referred to as "A DIABETIC" (n = 64) | 27 (42,2) | 20 (31,3) | 17 (26,6) | 42,2 |
| Diabetes is the worst thing that has ever happened to me... (n=64) | 32 (50) | 14 (21,9) | 18 (28,1) | 50 |
| Most people would find it difficult to adjust to having diabetes (n=64) | 16 (25) | 10 (15,6) | 38 (59,4) | 25 |
| I often feel embarrassed about having diabetes (n=64) | 41 (64,1) | 13 (20,3) | 10 (15,6) | 64,1 |
| There is not much I seem to be able to do to control my diabetes (n=64) | 50 (78,1) | 6 (9,4) | 8 (12,5) | 78,1 |
| There is little hope of leading a normal life with diabetes (n=65) | 56 (86,2) | 4 (6,2) | 5 (7,7) | 86,2 |

| | | | | |
|--|-----------|-----------|-----------|------|
| The proper control of diabetes involves a lot of sacrifice and inconvenience (n=65) | 28 (43,1) | 11 (16,9) | 26 (40) | 43,1 |
| I avoid telling people I have diabetes (n=64) | 45 (70,3) | 10 (15,6) | 9 (14,1) | 70,3 |
| Being told you have diabetes is like being sentenced to a lifetime of illness (n=63) | 40 (63,5) | 9 (14,3) | 14 (22,2) | 63,5 |
| My diabetic diet spoils my social life (n=64) | 40 (62,5) | 12 (18,8) | 12 (18,8) | 62,5 |
| In general, nurses need to be more sympathetic in their treatment of people with diabetes (n=64) | 20 (31,3) | 21 (32,8) | 23 (35,9) | 31,3 |
| Having diabetes over a long period changes the personality (n=63) | 32 (50,8) | 18 (28,6) | 13 (20,6) | 50,8 |
| I often find it difficult to decide whether I feel sick or well (n=64) | 33 (51,6) | 16 (25,0) | 15 (23,4) | 51,6 |
| Diabetes can be controlled (n=65) | 10 (15,4) | 3 (4,6) | 52 (80) | 80 |

| | | | | |
|--|-----------|-----------|-----------|------|
| There is really nothing you can do if you have diabetes (n=63) | 52 (82,5) | 3 (4,8) | 8 (12,7) | 82,5 |
| There is really no-one I feel I can talk to openly about my diabetes (n=63) | 50 (79,4) | 6 (9,5) | 7 (11,1) | 79,4 |
| I believe I have adjusted well to having diabetes (n=63) | 14 (22,2) | 9 (14,3) | 40 (63,5) | 63,5 |
| I often think it is unfair that I should have diabetes when other people are so healthy (n=63) | 45 (71,4) | 11 (17,5) | 7 (11,1) | 71,4 |

4.5.3 Adapted behaviours related to T2DM

Most of the participants demonstrated desirable behaviour in terms of regularly taking medication (81,3%, n=52) and checking blood glucose levels (77,3%, n=51), regularly eating vegetables (75,8%, n=50) and fruit (78,8%, n=52), and avoiding alcohol (76,6%, n=49) (Table 4.9). The results showed little or no regular exercise or physical activity, with only 26,2% (n=17) active more than 3 x week, and regular consumption of refined starch (77,27%, n=51) (Table 4.9).

| Table 4.9: Adapted behaviours related to T2DM | |
|--|--------------|
| Variable | n (%) |
| Forgotten to take medication in the past week? (n=64) | |
| <i>Never /Less than once</i> | 52 (81,3) |
| How often have you done physical work or exercise in the last week? (n=65) | |
| <i>Nearly every day/Everyday</i> | 17 (26,2) |
| On the days when you do physical work or exercise: how long did it last on an average day? (n=61) | |
| <i>20-30 minutes/day /More the 30 mins/day</i> | 45 (73,8) |
| How often do you measure/check your blood glucose levels? (n=66) | |
| <i>3-5 times a week /Everyday</i> | 51 (77,3) |
| How often do you eat refined starch, such as white bread or cake? (n=66) | |
| <i>Never / Once a month</i> | 15 (22,7) |
| How often do you eat fatty food, like slap chips or vetkoek? (n=66) | |
| <i>Never / Once a month</i> | 31 (47) |
| How often do you eat food with lots of salt, like russians or polony or use stock cubes in food preparation? (n=66) | |
| <i>Never /Once a month</i> | 40 (60,6) |

| | |
|--|------------------|
| How often do you eat vegetables? (n=66) | |
| <i>Nearly every day / Everyday</i> | 50 (75,8) |
| How often do you eat fruit? (n=66) | |
| <i>Nearly every day / Everyday</i> | 52 (78,8) |
| What type of cold drink do you mostly drink? (n=63) | |
| <i>Water/ Diet/ Sugar-free (Good)</i> | 25 (39,7) |
| <i>Diluted juice (Good)</i> | 1 (1,6) |
| <i>Do not drink cold-drink (Good)</i> | 15 (23,8) |
| | 41 (65,1) |
| How often have you had an alcoholic drink in the last month? (n=64) | |
| <i>Never / Once a month /2-3 times per month</i> | 49 (76,6) |

4.6 Associations between variables

4.6.1 Knowledge, Attitude and Adapted behaviour Scores

Raw scores were used to explore whether any correlation existed between primary outcome variables. As previously explained, knowledge scores were calculated by allocating a point for each correct answer given, with a maximum total of 32. For open-ended questions, where several answers could be given, half a point was allocated for questions where the participant offered some correct and some incorrect answers. For closed questions, if the respondent selected more than one answer, they were given the benefit of the doubt and granted a point, as long as one of the answers offered was correct.

Attitude and behaviour were scored differently, giving one point for each positive answer, subtracting a point for each negative answer, and allocating no point for a neutral answer - with a maximum score of 19 and 11, respectively. While the researcher understands that a person cannot be penalised for having a negative view of /attitude towards something, the point system, as previously used by Le Roux (2016), was used for comparative purposes.

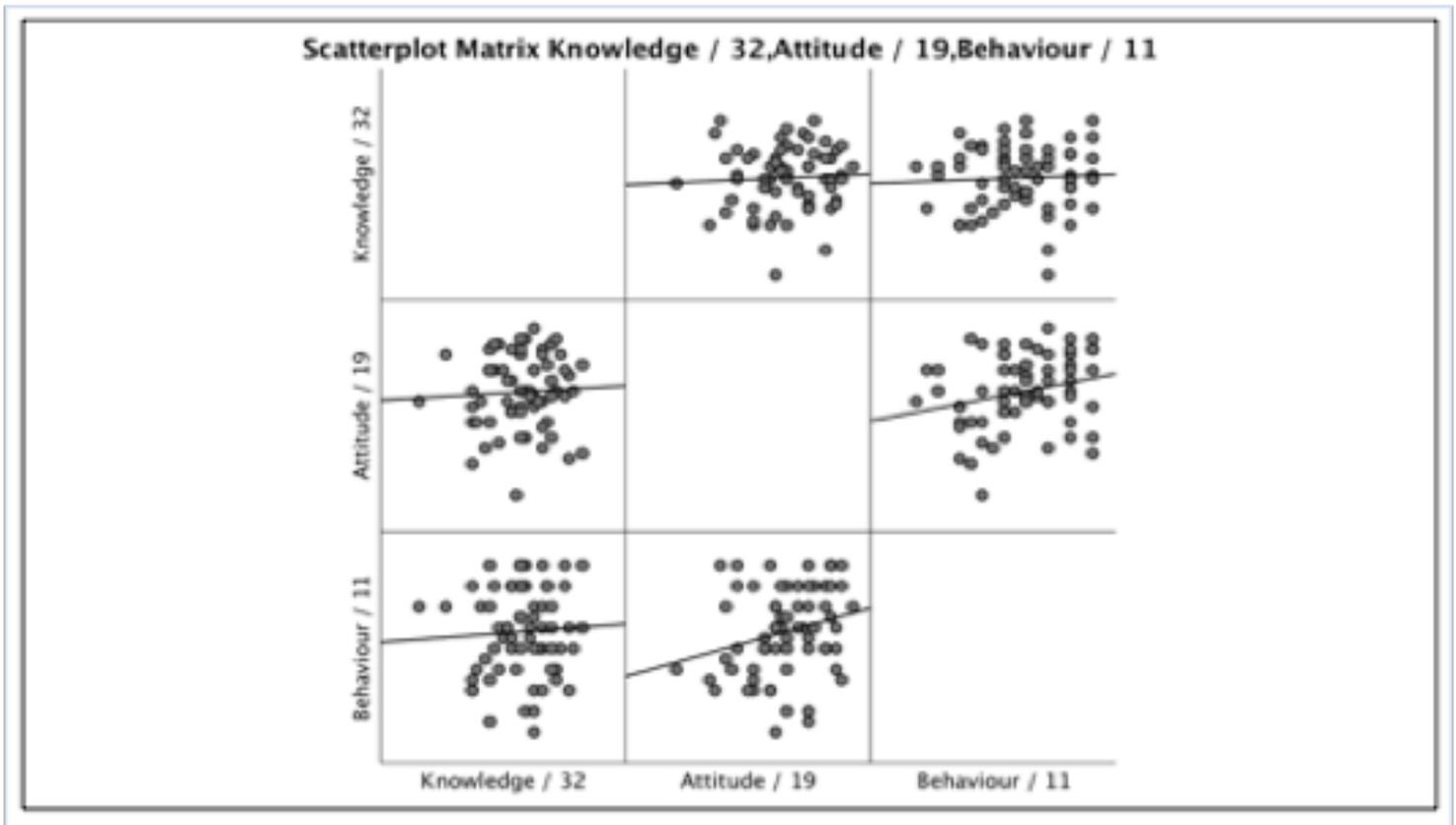
A Spearman's Correlation test was done with the raw, individual scores for knowledge, attitude and adapted behaviour. A correlation ($p=0.031$) was found between attitude and behaviour scores, indicating that positive attitude potentially results in or encourages positive behaviour (Table 4.10).

| Table 4.10: Correlations between Knowledge, Attitudes and Adapted Behaviours | | | | |
|---|--------------------------------|------------------|-----------------|------------------|
| | | Knowledge | Attitude | Behaviour |
| Knowledge | Correlation coefficient | 1 | .087 | 0.31 |
| | <i>p</i> | . | .489 | .804 |
| | <i>n</i> | 66 | 65 | 66 |
| Attitude | Correlation coefficient | .087 | 1 | .268* |
| | <i>p</i> | .489 | . | .031 |
| | <i>n</i> | 65 | 65 | 65 |
| Adapted Behaviour | Correlation coefficient | .031 | .268* | 1 |
| | <i>p</i> | .804 | .031 | . |
| | <i>n</i> | 66 | 65 | 67 |

*** Correlation is significant at the 0.05 level (2-tailed).**

A scatter plot graph similarly shows no strong correlations between knowledge, attitude and adapted behaviour, with also a possible trend of improved behaviour in response to a more positive attitude, as suggested by the Spearman correlation results above.

Figure 4.1: Correlations between Knowledge, Attitude and Adapted behaviour



4.6.2 Association between KAB scores and diverse variables

4.6.2.1 KAB and Gender

A chi-square analysis suggested that males in this study had a more positive attitude towards T2DM than the females ($p=.016$) (Table 4.11).

| Table 4.11: Chi-Square: KAB categories in relation to gender | | | | | | |
|---|----------|------------------------------|--------------------------|------------------------------|------------------------|----------|
| Variable | n | Negative (<50%) | Average (50-65%) | Positive (>65%) | Chi² | p |
| Knowledge | 66 | 9 | 27 | 30 | 2.027 | .355 |
| <i>Male</i> | 40 | 7 | 14 | 19 | | |
| <i>Female</i> | 26 | 2 | 13 | 11 | | |
| Variable | n | Negative (score<0) | Average (score=0) | Positive (score>1) | Chi² | p |
| Attitude | 65 | 10 | 1 | 54 | 8.333 | .016 |
| <i>Male</i> | 39 | 2 | 1 | 36 | | |
| <i>Female</i> | 26 | 8 | 0 | 18 | | |
| Adapted Behaviour | 67 | 18 | 14 | 48 | 1.611 | .447 |
| <i>Male</i> | 41 | 11 | 0 | 30 | | |
| <i>Female</i> | 26 | 7 | 14 | 18 | | |

4.6.2.2 KAB and Age

A Kruskal-Wallis test was performed to compare age across the various KAB categories. There was no significant difference across any of the KAB categories (Table 4.12).

| Table 4.12a: Kruskal-Wallis Test: Age across KAB categories | | |
|--|------------|-----------------|
| Variable | Age | |
| | n | <i>p</i> |
| Knowledge (categories) | 65 | .145 |
| Attitude (categories) | 65 | .095 |
| Adapted Behaviour (categories) | 66 | .083 |

A closer look at particular age groups, i.e. 10-year cohorts, ranging from early adulthood to retirement age, compared to KAB is presented in table 4.12b. The Chi-square test similarly shows no association, however, there is an apparent clinical trend of more positive attitudes and adapted behaviours with increased age.

| Table 4.12b: Chi-Square: KAB categories within specific age groups | | | | | | | | |
|---|-----|-----|-----|------|------|------|------------------|------|
| Variable | Age | | | | | | Chi ² | p |
| | n | B | C | D | E | F | | |
| Knowledge | 65 | n=1 | n=7 | n=23 | n=15 | n=19 | 9.401 | .310 |
| <i>Negative (< 50%)</i> | 8 | 0 | 0 | 3 | 1 | 4 | | |
| <i>Average (50%-65%)</i> | 27 | 0 | 1 | 9 | 9 | 8 | | |
| <i>Positive (>65%)</i> | 30 | 1 | 6 | 11 | 5 | 7 | | |
| Attitude | 65 | n=1 | n=7 | n=23 | n=15 | n=19 | 8.802 | .359 |
| <i>Negative (score<0)</i> | 10 | 0 | 1 | 7 | 1 | 1 | | |
| <i>Average (score=0)</i> | 1 | 0 | 0 | 1 | 0 | 0 | | |
| <i>Positive (score>0)</i> | 54 | 2 | 6 | 15 | 14 | 18 | | |
| Adapted Behaviour | 66 | n=1 | n=7 | n=23 | n=15 | n=20 | 6.997 | .537 |
| <i>Negative (score<0)</i> | 18 | 1 | 2 | 8 | 4 | 3 | | |
| <i>Average (score=0)</i> | 1 | 0 | 0 | 1 | 0 | 0 | | |
| <i>Positive (score>0)</i> | 47 | 0 | 5 | 14 | 11 | 17 | | |
| <p>A: < 25 years B: 26-35 years C: 36-45 years D: 46-55 years E: 56-65 years F: > 65 years</p> | | | | | | | | |

4.6.2.3 KAB and level of Education

An association is visible between positive behaviour and higher education levels (Table 4.13). It is suggested by results below that behaviour improves significantly with higher levels of education ($p=.049$).

| Variable | Education | | | | | | Chi ² | p |
|--|-----------|-----|-----|------|------|-----|------------------|------|
| | n | 1 | 4 | 5 | 6 | 7 | | |
| Knowledge | 65 | n=1 | n=9 | n=19 | n=31 | n=5 | 11.392 | .180 |
| <i>Negative (< 50%)</i> | 9 | 0 | 3 | 4 | 2 | 0 | | |
| <i>Average (50%-65%)</i> | 26 | 0 | 4 | 7 | 11 | 4 | | |
| <i>Positive (>65%)</i> | 30 | 1 | 2 | 8 | 18 | 1 | | |
| Attitude | 64 | n=1 | n=9 | n=18 | n=31 | n=5 | 1.516 | .992 |
| <i>Negative (score<0)</i> | 10 | 0 | 1 | 3 | 5 | 1 | | |
| <i>Average (score=0)</i> | 1 | 0 | 0 | 0 | 1 | 0 | | |
| <i>Positive (score>0)</i> | 53 | 1 | 8 | 15 | 25 | 4 | | |
| Adapted Behaviour | 66 | n=1 | n=9 | n=20 | n=31 | n=5 | 15.592 | .049 |
| <i>Negative (score<0)</i> | 17 | 0 | 2 | 8 | 6 | 1 | | |
| <i>Average (score=0)</i> | 1 | 0 | 0 | 0 | 0 | 1 | | |
| <i>Positive (score>0)</i> | 48 | 1 | 7 | 12 | 25 | 3 | | |
| 1: ABET (Adult Based Education and Training) 4: Some high school 5: Completed high school 6: Tertiary qualification 7: Other | | | | | | | | |

4.6.2.4 KAB and Income

A Chi-square test was used to compare income groups across the three KAB categories (Table 4.14). Although there were no significant associations found, an upward trend of improved behaviour and attitudes is seen with higher income groups.

| Table 4.14: Chi-Square Test: KAB categories in relation to income | | | | | | | |
|--|--------|------|-----|------|------|------------------|------|
| Variable | Income | | | | | Chi ² | p |
| | n | 1 | 2 | 3 | 4 | | |
| Knowledge | 58 | n=2 | n=7 | n=11 | n=38 | 8.661 | .194 |
| <i>Negative (< 50%)</i> | 9 | 0 | 3 | 3 | 3 | | |
| <i>Average (50%-65%)</i> | 22 | 1 | 3 | 4 | 14 | | |
| <i>Positive (>65%)</i> | 27 | 1 | 1 | 4 | 21 | | |
| Attitude | 57 | n=2 | n=7 | n=11 | n=37 | 3.280 | .773 |
| <i>Negative (score<0)</i> | 10 | 0 | 0 | 3 | 7 | | |
| <i>Average (score=0)</i> | 1 | 0 | 0 | 0 | 1 | | |
| <i>Positive (score>0)</i> | 46 | 2 | 7 | 8 | 29 | | |
| Adapted Behaviour | 59 | n=14 | n=8 | n=11 | n=38 | 2.364 | .883 |
| <i>Negative (score<0)</i> | 16 | 0 | 3 | 4 | 9 | | |
| <i>Average (score=0)</i> | 1 | 0 | 0 | 0 | 1 | | |
| <i>Positive (score>0)</i> | 42 | 2 | 5 | 7 | 28 | | |
| 1: < R3500 2: R3500 – R7000 3: R7100 – R10,000 4: > R10,000 | | | | | | | |

4.6.2.5 KAB and Years of diagnosis

A Chi-square test was used to compare the years of diagnosis across the three KAB categories (Table 4.15). According to the test results, there was no significant difference across the various groups with more years of diagnosis, although one can see a clinical trend of improved knowledge and adapted behaviour scores with more than 5 years diagnosed.

| Table 4.15: Chi-Square Test: KAB Categories in relation to years of diagnosis | | | | | | |
|--|---------------------------|----------|----------|----------|------------------------|----------|
| Variable | Years of diagnosis | | | | Chi² | p |
| | n | A | B | C | | |
| Knowledge | 64 | n=13 | n=21 | n=30 | 1.565 | .815 |
| <i>Negative (< 50%)</i> | 9 | 3 | 2 | 4 | | |
| <i>Average (50%-65%)</i> | 26 | 5 | 8 | 13 | | |
| <i>Positive (>65%)</i> | 29 | 5 | 11 | 13 | | |
| Attitude | 63 | n=13 | n=20 | n=30 | 1.168 | .883 |
| <i>Negative (score<0)</i> | 10 | 2 | 3 | 5 | | |
| <i>Average (score=0)</i> | 1 | 0 | 0 | 1 | | |
| <i>Positive (score>0)</i> | 52 | 11 | 17 | 24 | | |
| Adapted Behaviour | 65 | n=14 | n=21 | n=30 | 3.824 | .430 |
| <i>Negative (score<0)</i> | 17 | 6 | 4 | 7 | | |
| <i>Average (score=0)</i> | 1 | 0 | 0 | 1 | | |
| <i>Positive (score>0)</i> | 47 | 8 | 17 | 22 | | |
| A: < 5 years B: 5-10 years C: >10 years | | | | | | |

4.6.2.6 KAB and Quality of life

There was no association between quality of life scores (QOL) and knowledge, attitude and adapted behaviour scores (Table 4.16a).

| Table 4.16a: Chi-Square Test: KAB categories in relation to QOL categories | | | | | | |
|--|-----------------------|-----|-----|------|------------------|------|
| Variable | Quality of Life (QOL) | | | | Chi ² | p |
| | n | A | B | C | | |
| Knowledge | 66 | n=8 | n=9 | n=49 | 1.219 | .875 |
| <i>Negative (< 50%)</i> | 9 | 1 | 1 | 7 | | |
| <i>Average (50%-65%)</i> | 27 | 2 | 4 | 21 | | |
| <i>Positive (>65%)</i> | 30 | 5 | 4 | 21 | | |
| Attitude | 65 | n=8 | n=9 | n=48 | .741 | .946 |
| <i>Negative (score<0)</i> | 10 | 1 | 2 | 7 | | |
| <i>Average (score=0)</i> | 1 | 0 | 0 | 1 | | |
| <i>Positive (score>0)</i> | 54 | 7 | 7 | 40 | | |
| Adapted Behaviour | 67 | n=9 | n=9 | n=49 | 7.054 | .133 |
| <i>Negative (score<0)</i> | 18 | 2 | 3 | 13 | | |
| <i>Average (score=0)</i> | 1 | 0 | 1 | 0 | | |
| <i>Positive (score>0)</i> | 48 | 7 | 5 | 36 | | |
| A: < 50% B: 50-60% C: > 65% | | | | | | |

Of possible clinical significance, however, is the trend of higher QOL scores across positive knowledge, attitude and behaviour scores. This may suggest that negative attitudes and behaviours towards T2DM are somehow linked to

diabetes-related complications, impacting negatively on one's quality of life.

A closer look at depression ($p < .001$) and stress/anxiety ($p = .026$), and QOL scores specifically, shows a significant association (Table 4.16b), suggesting that the presence of these two factors may have a significantly negative influence on one's quality of life.

Table 4.16b: Chi-Square: Anxiety and depression in relation to QOL categories

| Variable | Quality of Life Category | | | | Chi ² | p |
|-----------------------|--------------------------|-------|--------|-------|------------------|-------|
| | n | < 50% | 50-65% | > 65% | | |
| Anxiety/Stress | 67 | n=9 | n=9 | n=49 | 11.032 | .026 |
| No | 29 | 1 | 1 | 27 | | |
| Yes | 31 | 7 | 6 | 18 | | |
| Unsure | 7 | 1 | 2 | 4 | | |
| Depression | 67 | n=9 | n=9 | n=49 | 21.394 | <.001 |
| No | 34 | 1 | 1 | 32 | | |
| Yes | 23 | 7 | 7 | 9 | | |
| Unsure | 10 | 1 | 1 | 8 | | |

4.6.2.7 KAB and spirituality

There was no association between spirituality and knowledge, attitude and adapted behaviour scores (Table 4.17).

| Table 4.17: Chi-Square: KAB categories in relation to spirituality | | | | | | |
|---|---------------------|-----------|------------|-------|------------------------|----------|
| Variable | Spirituality | | | | Chi² | p |
| | n | No | Yes | | | |
| Knowledge | 65 | n=17 | n=48 | | | |
| <i>Negative (<50%)</i> | 9 | 2 | 7 | .302 | .860 | |
| <i>Average (50-65%)</i> | 27 | 8 | 19 | | | |
| <i>Positive (> 65%)</i> | 29 | 7 | 22 | | | |
| Attitude | 64 | n=17 | n=47 | | | |
| <i>Negative (score<0)</i> | 10 | 1 | 9 | 2.125 | .346 | |
| <i>Average (score=0)</i> | 1 | 0 | 1 | | | |
| <i>Positive (score>0)</i> | 53 | 16 | 37 | | | |
| Adapted Behaviour | 66 | n=17 | n=49 | | | |
| <i>Negative (score<0)</i> | 18 | 3 | 15 | 1.524 | .467 | |
| <i>Average (score=0)</i> | 1 | 0 | 1 | | | |
| <i>Positive (score>0)</i> | 47 | 14 | 33 | | | |

4.7 Summary

This study population looks different to many of the other populations that have been studied, previously, in South Africa, in that participants were mainly well educated, predominantly male, English speaking, and earning more than R7000 per month. The self-reported knowledge of the study population was average (63%), with the attitude and behaviour scores indicating more desirable than undesirable attitude and behaviour responses. There was a significant, but weak, correlation found between overall attitude and adapted behaviour scores. Associations were found between attitude and gender, behaviour and education, and behaviour and QOL (specifically anxiety and depression).

Chapter 5

Phase 2: Qualitative Findings

5.1 Introduction

The themes that emerged from the qualitative interviews are presented in Table 5.1. The main themes that emerged included the experiences related to the diabetes journey, the initial diagnosis and how it affected the status quo, and the important role of support along this journey.

Table 5.1: Themes developed from qualitative data

Theme 1 - Where it all started: How the diagnosis changed my life

Theme 2 - The diabetes journey: A daily choice

Theme 3 - It takes a village...support is key!

The details of the six participants who contributed to the qualitative findings are presented in Table 5.2.

Table 5.2: Participant Details - Qualitative Interviews

| Participant No. | Gender | Age (yrs) | Years since Diagnosis | Income | QOL% |
|-----------------|--------|-----------|-----------------------|-----------------|-------|
| PP0001 | M | 70 | 15 | > R10,000 | 50% |
| PP0005 | F | 54 | 14 | > R10,000 | 50% |
| P038 | F | 49 | 8 | R7100 - R10,000 | 33,3% |
| P039 | F | 47 | 2 | R3500 - R7000 | 83,3% |
| P057 | F | 71 | 3 | R3500 - R7000 | 66,7% |
| P061 | M | 40 | 16 | > R10,000 | 66,7% |

5.2 Theme 1: Where it all started - How the diagnosis changed my life

This theme explores how participants responded to the diagnosis of DM. As with many things in life the narratives showed varied responses, both to the initial diagnosis as well as processing what it all meant, i.e. the general weightiness of the diagnosis and the upcoming changes and what these meant for home-life.

“...um, and you know I realise that it was going to have an enormous effect upon me. I began to think, have I got to have a completely separate diet? How are we going to manage this?” (PP001)

Others were perturbed by the new regime of measuring their blood glucose.

“...I had to use those needles and I had to inject myself. I had to test myself with the sugar levels, the blood, and all these things. It was so new to me. Because I didn't know how to use the machine, I didn't know how to inject myself.” (P039)

Some participants weren't as shocked by the initial diagnosis, expressing an apparent lack of awareness and less certainty about what this diagnosis really meant, as illustrated by P038.

“No, no, not really because I suppose that time I wasn't as sure, as what it was related to, you know?” (P038)

Sometimes this lack of shock was attributed to participants growing up with family members who had T2DM.

“...but not actually shocked because my mommy had it. My mommy was a diabetic, so maybe it is in the family that is what I said to myself.” (P039)

One participant explained that knowing nothing about T2DM influenced the initial reality of the diagnosis.

“Yes, and my sugar it was 12...I thought in my mind, coz I didn't know anything about DB, I thought, ag, when you are sick the sugar must go up

anyway [laugh] I thought it's like that, but as I met Dr [Dr A] he said, "No, it's not like that". So I went again the following week, I went again to his rooms to test me again, yes, and my sugar was still high, but not '12', this time it was '10'...Yes, and then that's when he started giving me the tablet...At the clinic, I met Dr [Dr B], the eye Dr, Yes, I said to Dr [Dr B], um Dr [Dr A] said I'm diabetic but I don't believe him." (PP005)

And others were resigned.

"Man, if God comes HE must come." (P039)

Some participants, again, experienced an emotional response to something that felt unmanageable.

"I felt angry. I don't like to be sick, and if I'm sick I want to know that I'll get better. I've always been able to overcome an obstacle, but didn't feel like this was an obstacle that I would overcome." (P057)

A major worry for most participants was the complications related to T2DM.

"...I hear horrible things happening from people who don't look after themselves." (P057)

"Well, um there's the blindness and then, you know the amputations and that." (P038)

Being diagnosed with T2DM is often the precursor to both actual and needed lifestyle changes overall.

5.3 Theme 2: The Diabetes Journey - A daily choice

This theme explores the role of DM in the lives of participants. It shows the burden of the disease, but also how they dealt with it. It looks at the need for lifestyle changes and how that impact on participants, physically and emotionally. The narratives show that the participants understood that the disease was part of their lives and that with it came daily monitoring of blood glucose levels,

medication and lifestyle choices. Participants' narratives also show that T2DM is not a disease that one can forget about. It often challenges them and they would gladly be rid of it.

“Okay I got myself here, or my body, or my genetics, or whatever got me here. Is there not a way to reverse-gear it? So, ja you feel burdened. I manage it. It's a serious, conscious effort.” (P061)

They realise the serious nature of the disease and the negative consequences if not managed optimally.

“...this was not something that was going to be treated just by a few pills or something like that, this was something that was life-threatening and life-changing” (PP001)

The concept of optimal management was possibly being skewed by an uncertainty of what constitutes effective physical activity or exercise as seen from P038 who indicated that she doesn't exercise, but indeed walks briskly, 30mins a day, to and from work.

The management regime was a constant in their lives that required daily effort and discipline.

“I have to, I have to, I have to, I have to be, be the disciplined one. Ja, I have to, and I hate it, but I've learnt to say no so much. I practice, the word 'no' it has to become a serious part of your vocabulary. Like for example...there's a sweet cupboard...it's the biggest temptation in my life...it just sits there, but I can't deny them [his family] that...So you have a packet of chips, oh my word now I must have six glasses of water; it's a management issue. I'd love to live without this!” (P061)

However, following a 24-hour management regime for an infinite period was not always possible for everyone.

“...there are days when, or rather actually longer periods, when one feels absolutely committed to the idea of strict control on your diet and, you know,

making sure that you try to follow a very strict routine in terms of diet and one see's the beneficial results...But that doesn't last...So that from time to time, I really do drop off the rails, I'm overeating, I'm not doing as much exercise as I feel I should" (PP001)

Not being able to stick to the regime led to emotional torment as shown in the narrative of participant 038.

"...the eating habits. Um, I am really just, I'm not disciplined with that...I'm sorry that I'm, I'm sorry that I, you know, that, this is now recorded and I need to put this on now...But the cost you now, it's a bit costly...the worrying part is I'm not taking care of myself. And I just need to be more disciplined on what I am told to do and how to follow the instructions...I'm living a stressful life basically. So, I tend to forget about these things. I need to put a reminder and I get distracted with something else and then I forget to take the insulin, and that is why my sugar levels is constantly high as well." (P038)

Some were successful in maintaining the lifestyle, but it was not easy and constantly required sacrifice.

"Yes, I do manage it well, because when I started on this programme, I love Kentucky, I love fatty foods...my balanced diet was a total mess, and when I got to diabetes I got the diet plan, I must do exercises. My entire life changed. I was a heavy smoker, I had to stop smoking or stop less smoking. So, it was hectic coz my whole life changed...very difficult because in the blink of an eye my entire life was twisted around. So to me, is a more disciplined life, because I loved Coke! Ooh, everyday, it was coke! Now, nothing, nothing, only water. Because I wasn't a person that drinks water; I could not get it into my body. But now I am forced to it - I had to drink water, I had to exercise, I had to smoke less." (P039)

The changes fostered a positive sense of well-being in some participants.

“...firstly it helped me to feel that I was actually doing something - I was making positive steps. I wasn't just pumping myself full of insulin at that time, or taking medication, I was actually doing something.” (PP001)

Emotionally T2DM forced participants to reassess priorities and sometimes put their bodies first even if it frustrated them. They had to adapt to the restraints of the disease.

“...for me personally, it's become a headache... in my previous years, I'm not the person for the Dr, I don't go easily to doctors and use pills easily. I'm just a person that's working...I'm into my work, I'm into my family, I don't have time to get sick, I don't have time to take pills. But for now, I have to. So I have to time myself; in the morning at 5 I have to take my Onglyza...” (P039)

When they did slip-up participants had to contend with guilt.

“I'm trying my darndest not to slip in the trap. I feel guilty um when I do, like on my birthday, I had a piece of cake, and I'm like ooh, there's my readings, but I must be forgiving of myself too, and accept that as well. Coz in the scheme of things, it won't be that bad.” (P061)

A possible uncertainty around what constitutes effective physical activity or exercise may cause unwarranted 'angst' amongst participants who feel that they are not meeting the exercise requirements.

The cost of medication was problematic for some participants.

“Dr [Name doctor] gave me some medication which really agreed with me for the months that I could afford, but because my medical aid doesn't cover it, so I do not have the R1000 to spend on this medication every month.” (P038)

Participants also found the required medical activities around diabetic management unpalatable.

“...even the testing of your sugar is so barbaric...coz you literally draw blood, there's got to be a better way. Every single day!!” (P061)

The daily monitoring was stressful.

“I've got the machine and I take my sugar levels, so when I see its high then I got a little bit worried, when I see its low, I am like “Oh thank God, it is not that high.” (P039)

They tried different avenues to maintain a healthy lifestyle but realised that whatever strategy they employ must be sustainable in the long run.

“I'm trying to do it differently to the way I've done it before. So I went from 140kg to 80kg in two years. Ja, with shakes and gym. Ja no, I was on a flippen, you know, macho man type of thing, but that's not sustainable because the minute you touch real food you pick up, and I picked up. I'm on equilibrium at the moment...slow, slow losses.” (P061)

Despite the stressors and daily requirements, they wanted to enjoy life and made the very best of it.

“But I live my life to the fullest. If anything happens, God forbid, then it must happen.” (P039)

The dream of life without DM remains.

“I would love one day to have this as a regular term - ‘my diabetes is in remission’.” (P061)

5.4 Theme 3: It takes a village - support is key!

This theme explores the role of support and the various representations thereof. It highlights the importance of not feeling that one is traversing such a challenge on one's own. The narratives showed a clear need for support and

encouragement. Many participants highlighted the importance of family and the need to be healthier and live better lives for them.

“Ja I’m doing it for my son; I want to still be around to play and that. And also I want to feel better.” (P061)

Others described the role of accountability attributed to loved ones or partners, and the ability to help keep them on track.

“...you know, I’m overeating, I’m not doing as much exercise as I feel I should, and, um, then I’ve really got to have the push from my family...to actually get back on the rails again.” (PP001)

“I got a daughter also, my daughter is energetic. She loves to run, then I will go with her...I will go with her, and she loves to exercise, and then I’ll try to do it with her although she will say ‘no not this way’, but I’ll try.” (PP005)

However, just being part of the normal doings of a family sometimes created its own challenges.

“People try to change their households to bend to them. I can’t deny them things because of me. And I had this discussion with somebody else as well and they said, no, no, no, it doesn’t need - he said, no, the whole family must all eat salad now or whatever. So I said, no, no, no that’s not right. Um, but I said, I get our challenge, I said because if your house isn’t on board with you, it’s difficult. It makes it hard for you. But I found a way around it.” (P061)

And often the actual experience of enjoying food with people or preparing food for people was a temptation and obstacle to healthy strategies.

“And that I think is one of the issues, definitely, um, a lot of the low GI stuff, um, is frankly pretty unattractive.” (PP001)

“I try to make interesting food for my husband to eat, and it’s hard to say no, especially in the winter.” (P057)

Sometimes the support comes in the form of peers who can share lived experiences and provide comfort and understanding.

“...of course I was joining people who were similarly affected and, I could talk to them, and find out more about how they coped with things like that. So, that was enormously important...many people are not so fortunate in actually having a kind of a group that they can talk to.” (PP001)

Other times the community where participants lived and worked provided a source of stress rather than encouragement. P061 was quite emotive when relaying the stress of openly sharing about one's diabetes.

“I'm not as embarrassed as I used to be in terms of to announce it, I'm a diabetic, but I don't freely give that information out...Coz you're judged!... So you have to deal with a lot and culturally is also um, you know, in the coloured communities it's, "Oh he has got sugar", that's how it's seen. I don't hide it, I just don't offer it out.” (P061)

The advice and support provided by health practitioners were seen as greatly valuable.

"I am having confidence in the doctors that I've got. They are stunning. They are genius." (PP005)

Scare-tactics, however, employed by some healthcare practitioners had the opposite effect.

“Doctors, when they say you are diabetic, if you don't this you'll be blind, like in that way, and quickly you feel afraid, and you don't want to discuss it with anyone, because one doctor said to me, since you are diabetic you know that diabetes is worse than HIV...to me, immediately when you say that, my chest closed because my nerves were on top. Because he said it as if I am now on the deathbed...instead of trying to let the person understand that you can overcome this by eating well and exercising.” (PP005)

Partnering with health professionals who share similar philosophies and approaches, as highlighted by participant 061, was also helpful.

"I wanted a Dr similar to my GP and at a similar philosophy, in terms of where my headspace is at, in terms of how diabetes, um, not how diabetes is seen...So, me and [Practitioner name], Dr [Doctor name]'s on that page, you know what I mean, and we're going to get ourselves there. And I have to put in the work, have to be committed, but she's onboard as well, so it makes a difference...and also just the whole ethos of the clinic." (P061)

5.5 Summary

From the interviews, one can surmise that whilst most interviewees were concerned about the complications related to diabetes, many admitted to not fully knowing what diabetes was about. Managing diabetes is a daily challenge, often accompanied by sacrifice and feelings of guilt. Stress, cost of medication and healthy food was highlighted as obstacles in managing diabetes well. Encouragement was experienced mostly through family, support from healthcare practitioners and camaraderie shared with individuals with similar experiences.

Chapter 6

Discussion

6.1 Introduction

The main objective of this study was to establish the KAB of a specific population with T2DM, attending a private health clinic in the Western Cape. In this chapter, the results that have emerged, along with possible reasons for the results and comparisons to other relevant studies, will be discussed. It must be noted that the researcher was not directly involved with data collection, and therefore cannot guarantee the correctness of the information as an accurate reflection of the situation. An attempt to encourage authentic data was made by including open-ended questions in the questionnaire, and the use of qualitative interviews included to provide some triangulation (O Leary, 2017).

6.2 Demographic Profile

The mean age of participants was 59 years, which falls in the 40-69 years range of the global diabetic population as suggested by Ahmad & Ahmad (2015), Berhe et al (2014), Gul (2010), IDF (2017), Le Roux (2016), Mabaso & Oduntan (2016), Okonta et al (2014), Phillips et al (2012), Powell et al (2007), Ralineba et al (2015), and Shilubane et al (2016). Contrary to prevalent findings in most of these preceding studies, this study population, was predominantly male, earning more than R10,000 per month and well educated. The predominantly male representation is interesting, but unfortunately, no information was collected on the demographic characteristics of the patients that refused participation in the study. Thus, it is not known if this trend was only present amongst study participants or in the bigger study population too. The higher income and education levels here were most probably due to the study setting as private health care is expensive.

6.3. Quality of life

While no significant association was found between QOL scores and KAB, a trend of higher QOL scores across positive knowledge, attitude and adapted behaviour scores suggested that negative attitudes and behaviours towards T2DM impact negatively on one's quality of life. The 34,3% of participants in the current study, who indicated feeling depressed, is less than the 54% reported by Le Roux (2016). Both studies reported most participants having no problems with walking, self-care and daily activities. This could be indicative of slower progression in terms of organ damage or complications, resulting from a healthy lifestyle and thus positive behaviour (Okonta et al, 2014). A notion supported by the fact that the current study population has been diagnosed with diabetes for a mean of 11,25 years, and the trend of adaptive behaviour scores improving post 5 years diagnosis.

Kreider (2017) puts forward that persons with diabetes and major depression disorder (MDD) are inclined to have poorer health outcomes, including uncontrolled sugar levels and diabetes-related complications. Some individuals, although not clinically diagnosed with MDD, experience an emotional state that causes emotional distress, similarly affecting health outcomes negatively - this condition is termed diabetes distress. It would thus be expected that persons experiencing symptoms of depression would find it more difficult to maintain the required lifestyle for effective diabetes management and demonstrate challenges to maintain the required behaviour. A closer look at the depression and anxiety scores for this study population and their association with QOL scores (categories), shows a much clearer reality of managing T2DM while experiencing symptoms of depression. The significant association found between QOL scoring categories and depression and stress/anxiety scores highlights the challenge of managing T2DM. Participant narratives, highlighting the daily burden of living with diabetes and the emotional impact of the required lifestyle changes, support this notion.

6.4. History of diabetes diagnosis

While this present study saw a small increase (7%) in the number of diagnoses through provider screening or testing, when compared to Le Roux (2016), the majority of diagnoses still resulted from patients presenting with metabolic symptoms (41,3%). This is higher than the 23% of patients who first presented for diagnosis with complications, as noted by Gul (2010) in Pakistan. Factors including poor health systems, lack of awareness and slow progression of T2DM, may contribute to high levels of diabetes (18,1%) still undiagnosed in South Africa (Asmelash & Asmelash, 2019). According to SEMDSA (2017), early detection of high-risk individuals and early intervention may help prevent the progression to diabetes and its associated health complications. Screening for overweight adults with at least one other risk factor for diabetes, or any adult over the age of 45 years is recommended. The above results are expanded by the qualitative interviews, which describe diagnoses due to illness or presenting with metabolic symptoms.

Half of the participants are being treated for metabolic-syndrome related conditions. This finding is similar to the 50% with hypertension reported by Shilubane et al (2016), and the 65% hypertension, 54% high cholesterol and 13% heart disease reported by Philips et al (2012). This treatment of co-morbidities is in line with the pharmacological management of T2DM, according to Cleveland Clinic Centre for Continuing Education (2018), which includes blood glucose control as well as the prevention and management of complications, i.e. blood pressure control, blood lipid control and anti-platelet or aspirin therapy, as well as regular screening and treatment for diabetic retinopathy and nephropathy. Both the current study and Le Roux (2016) showed 11% of participants being treated with insulin alone, and a greater proportion (24%) using both insulin and oral glucose-lowering medication in the Western Cape. Metformin (oral agent) is generally the initial pharmacological agent for T2DM, while insulin or dual therapy may be initiated for higher A1C levels, according to current trends (ADA, 2018c). The qualitative results showed that even in this relatively affluent group of participants sometimes the cost of medication prevented them from accessing

the first drug of choice.

6.5. Knowledge, attitude and behaviour related to T2DM

The KAB profile for this study is unexpected for various reasons. Despite the group being educated and having dedicated contact time and education with healthcare professionals at the clinic, and access, within a referral network, to dietary advice and exercise intervention, knowledge, attitude and adapted behaviour scores were still less favourable. In the current economic climate, discretionary funds are limited. The additional cost of professional, supplementary health services is, therefore, often a deterrent. While Mashige et al (2008) found a positive link between knowledge and / or behaviour in Durban, South Africa, this present study showed no such association between knowledge and behaviour. This was similarly demonstrated by Le Roux (2016), Phillips et al (2012) and Berhe et al (2014), highlighting that a reasonable amount of knowledge is not a guarantee of positive behaviour. Philips et al (2012) add, after studying a population visiting a private clinic with poor diabetes self-management, that management is better facilitated by a team approach. However, the current study participants did have access to a team and still knowledge scores were less than optimal and did not translate into positive behaviour.

The qualitative results showed the tension between knowledge and adapted behaviour very clearly. The narratives tell about periods of excellent adherence interspersed with periods of struggle. The participants knew what was right in terms of lifestyle choices but being human they could not maintain the required behaviour day in and day out for indefinite periods. On occasion they erred, they made unhealthy choices, they felt guilty about it. Failing to maintain an optimal lifestyle was not a willful act of self-negligence, it was the result of human frailty and of being real people instead of automatons.

A weak correlation was found between positive attitudes and improved behaviours, echoing the suggestion by Le Roux (2016) that attitude is a prerequisite for behaviour change. Le Roux (2016:103) frames her KAP study

around the Theory of planned behaviour, suggesting that the “probability of an individual to engage in specific health behaviour is correlated with the strength of his or her intention to engage in the behaviour, which is determined by subjective norms and perceived behavioural control”. While this present study did not investigate individual participant’s beliefs around their behaviour, one participant did share in her interview that diabetes felt like an obstacle she could not overcome. This lack of perceived control might contribute to the less favourable attitudes displayed.

6.5.1 Knowledge

The mean, knowledge score of 19,4 for this current study, was higher than the 8,9 reported by Le Roux (2016), who suggests that truly comparing knowledge across various studies is difficult, as different tools are used and contexts differ (Le Roux, 2016). Similar to Mufunda et al (2012), there were a few apparent knowledge gaps identified by scores of < 50%. These centered on certain food classifications, clearly indicating some confusion around food grouping. In part, this could be related to unfamiliarity with certain foods, indicated for example by the large percentage of participants who were unsure of the classification of chicken feet. Alternatively, it may also be due to previous education around food groups, which disconnected groups such as grains, fruits, vegetables and dairy, from the macronutrients (carbohydrates, proteins and fats). The reading of nutritional labels on foods may be a more effective way of distinguishing the main macronutrient components, thereby, allowing more informed choices. The extent to which participants do read labels was not assessed in this study.

During the qualitative interviews, a certain lack of awareness presented, mostly since some participants were not entirely sure what diabetes was all about, despite an awareness of certain symptoms and complications. Two participants confirmed this in mentioning that reading up and researching more about diabetes had helped them manage their condition. This could, similarly, explain the suboptimal behaviour responses, as suggested by Le Roux (2016).

It would seem, despite the appearance of reasonably good knowledge regarding

T2DM, that some patients still feel 'disempowered' to manage their condition. Either they have not understood the information provided; or they have been given only part thereof; or they feel their environment does not facilitate such management. This is likely to happen when behavioural change is prescribed without much consideration for the patient, their situation, needs, beliefs, and concerns. The information or advice often disseminated, by a practitioner, from a position of power rather than one of partnership. Patients should be motivated to become empowered, "promote autonomous self-regulation in order to maximise the individual's potential for health and wellness" (Meeto & Gopaul, 2005:29). The patient's expertise about their "priorities, concerns, goals, traditions, culture, values, and resources", is as important to effective self-management as the expertise of the healthcare professional, according to Anderson and Funnell (2010).

Patient-centered collaboration between patients and healthcare professionals with good social support are vital for patient empowerment (Delamater, 2006; Ng et al, 2012). In being person-centered, the empowerment approach encourages patients to select their own changes/goals related to weight, nutrition, and physical activity, facilitates and supports patients in reflecting on their lived diabetes-experience, and often leads to "enhanced awareness and understanding of the consequences of their self-management decisions" (Anderson & Funnell, 2010:8).

6.5.2. Attitude

The mean attitude score of this group (6.9), while fairly low in light of the maximum score of 19, still denotes more positive than negative behaviour. The apparent less favourable attitudes to having and living with diabetes agree with studies done by Le Roux (2016), Ralineba et al (2015) and Ahmad and Ahmad (2015). The qualitative narratives clarify the quantitative attitude scores in showing that coping with diabetes was not easy. Thus, one can begin to understand the few participants who believed themselves to be well adjusted to DM. At the same time, most participants felt they could do a lot to control their diabetes, but that doing this involved sacrifice and inconvenience. The constant

tension between the ideal and reality was highlighted. It is therefore important to note again that quantifying attitude is not ideal and probably not even possible as answers might change based on the participant's emotional status and how well they are coping with DM at the time when the questions were asked. This is illustrated to an extent in the reported health perception, where the majority of current participants did not perceive their diabetes as an illness. This may suggest a positive attitude in not seeing one's diagnosis as defining who you are. On the other hand, however, it may also suggest potential denial about the reality of diabetes and the management thereof.

This study did not investigate the cause of the anxiety or stress, which could be related to the many things including the current economic and social stress climate in South Africa, worrying about complications related to their diabetes or other stressors. Mshunqane et al (2012) suggested that diabetes complications are understood as fears, which would inherently drive anxiety or stress. It is important to acknowledge that patients may suffer from diabetes distress, with feelings arising in response to a diagnosis, the threat of complications, the burden of self-management and unsupportive social structures (Kreider, 2017).

The high proportion of neutral answers in the attitude section of the questionnaire might suggest an apathetic approach to diabetes or a possible disconnect in feelings about living with diabetes. Attitude scores are much lower for the female participants but improved with ages 45 years and above. This does not correspond to research reported by Le Roux (2016), suggesting that older individuals lose motivation to engage in recommended practices, as the attitude and behaviour scores show improvement in participants older than 65 years, in this study. On the positive side, more than 80% of participants believed diabetes could be controlled and there is the hope of living a normal life. This positivity could be linked to the support received from family, peers and / or health care professionals as shown through the qualitative findings. It must be noted, however, that the researcher was not involved in data collection and the high percentage of neutral answers might also be due to

6.5.3 Adapted Behaviour

As with attitude scores, while still more positive than negative, adapted-behaviour scores are low for this study. Participants of this study were adherent in taking their medication. This concurs with studies by Le Roux (2016), Mabaso & Oduntan (2016) and Phillips et al (2012). The majority of participants did check their BG regularly even if they described it as unpalatable and stressful in the qualitative results. The regular checking of BG levels is important as this process aid management. The readings are downloaded onto the clinic server with each follow-up consult, allowing the doctor an opportunity to augment prescriptions if need be, based on readings, to improve BG control and reduce the risk of complications. Gul (2010) and Mashige et al (2008), also reported regular blood glucose monitoring. Contrastingly, Phillips et al (2012) found that only 29,2% of the participants measured their blood glucose levels daily.

Notable is the lack of exercise or physical activity amongst current participants. This appears to be a common trend as noted by Ahmed & Ahmed (2015), Konduru et al (2017), Le Roux (2016), Mabaso & Oduntan (2016), Okonta et al (2014), Phillips et al (2012), and Ralineba et al (2015). The qualitative interviews reveal a bit more about the underlying understanding of activity. Individuals do not relate general activities such as walking to and from work, as physical activity or exercise - some participants who indicated no physical activity in fact walk at least 30 minutes a day. Thus an unclear understanding of what effective activity looks like for diabetes management may have exacerbated the results on inactivity

Participants of this study consumed refined starches, such a white bread (71,2%), and fatty, deep-fried foods (48,5%), at least once a week. While these behaviours appear defiant on the surface, they may be rooted in the less than optimal knowledge (i.e. the apparent lack of understanding around food groups and the physiology of healthy weight and weight loss), and cultural and social beliefs and practices around food and health, and the accessibility of affordable food and safe exercise options. The narratives also highlighted the relationship that participants have with food...not merely the eating of it, but the sharing of it,

the cultural importance of it, the expense of it – aspects that were echoed by Mshunqane et al, 2012. Current participants mentioned that their diabetic diet was compromised by their enjoyment of eating food and preparing interesting food for their spouses. Food is often shared as an expression of gratitude for a sense of belonging - "a daily reaffirmation of one's cultural identity" (Shipman & Durmus, 2017:93).

While participants indicated that lifestyle was a major cause for diabetes on the questionnaire, further discussion in the interviews revealed none of the participants openly accepting responsibility for the cause of their diabetes, i.e. their lifestyle as a possible contributing cause to their DM - it is important to fully understand and accept one's role, not only in precipitating the condition but also in the management of the condition to ensure effective management.

6.6. Associations between KAB and demographic variables

6.6.1 KAB and gender

While current male and female participants had similar knowledge scores there was a significant difference in attitude, with female participants scoring much lower. This finding appears to be in contrast with Guatum, Bhatta, & Aryal (2015), who found that females were more likely to have better knowledge and practice in Nepal. While this is an avenue that would need to be explored deeper, a possibility is that the traditional role of women, that being a domestic one, in the household, would augment the frustration and difficulty of instituting individual behavioural changes within the family set-up - resulting in a poorer attitude towards diabetes and the required lifestyle changes.

6.6.2 KAB and age

In this study, there was no association found between KAB and age, although a possible trend was visible with improved KAB results reported for ages 46 years and above. One would expect better KAB from younger participants who have it in their best interest to limit the progression of diabetes and the risk of complications. The improvement that was seen in the scores of the 'older'

groups could relate to the 'acceptance' that appears to develop over the years. These findings are in contrast with Ng et al (2012) who suggested that older age may compromise diabetes management due to factors such as the lack of self-interest, lack of motivation or social support, or possibly poor compliance to medications due to financial difficulties related to being closer to retirement or already retired.

6.6.3 KAB and education

Most studies conclude that the level of education influences the knowledge score of participants (Ahmed & Ahmed, 2015, Gul, 2010, Le Roux, 2016, Mabaso & Oduntan, 2016, Okonta et al, 2014, Ralineba et al, 2015). While the level of education in this study was similar to those reported by Philips et al (2012), both studies noted less favourable practices regarding diabetes management. Despite relatively high levels of education of the current participants, the knowledge scores were average. Similarly, Shilubane et al (2016) propose that higher education levels do not guarantee favourable KAB. Le Roux (2016) quotes Maina et al (2011:18) to support this argument in suggesting that social and cultural belief and good health care services influence practices more than education levels.

6.6.4 KAB and years of diagnosis

In this study, there was no association between KAB scores and time since diagnosis. An apparent trend shows slightly improved behaviour and knowledge scores post 5 years diagnosis. This is fairly consistent with Le Roux's (2016) findings, which saw a higher median practice score for participants diagnosed with T2DM for more than 10 years. Similarly, Guatum et al (2015) found that patients were more likely to employ required/adapted behaviour with increased duration of T2DM.

Interestingly in this study, while knowledge and adapted behaviour showed apparent improvement with years of diagnosis post 5 years, attitudes were fairly constant across diagnosis periods. A possible supporting argument could be found in the reality of managing diabetes, as illustrated by PP01 in his interview

The idea that living with diabetes is like a "rollercoaster", with periods of good behaviour and management, followed intermittently by periods of "falling of the rails", where it all just feels too much. So although time living with diabetes might allow one to improve knowledge and behavioural choices, there are periods where one might lose motivation and control, requiring encouragement to realign oneself to effective self-management goals.

Chapter 7

Conclusion and Recommendations

7.1 Conclusion

The study participants were well educated, living well above the poverty line, with access to dedicated, quality medical care, and fairly knowledgeable about diabetes and its associated complications, and the desired adapted behaviours. However, the knowledge did not result in positive behaviour. Many participants demonstrated both attitudes and adapted behaviours that could be viewed as negative and unhelpful in the management of diabetes.

When explored a little more deeply, it became clear that living with and managing diabetes was an intensely personal and often stressful experience. Participants felt judged by others, burdened by the cost of healthy food and medication, as well as the acts of monitoring blood glucose, regularly taking medication and daily denying themselves food that they previously enjoyed and that were still consumed by others in their households.

The participants spoke of T2DM as something that was done to them. This feeling of being a victim can make it potentially more difficult to take ownership of the condition and clearly see one's role in the process. Additionally, during the interviews, it became evident that while the participants demonstrated fairly good knowledge about diabetes and its complications, this knowledge might not extend to a clear understanding of the physiology of diabetes and its required adapted behaviours, i.e. Insufficient health literacy.

If one does not fully understand why certain behaviour is important then one is less likely to practice that behaviour. A clearer understanding of what happens when various foods enter the digestive system, or what happens when exercises are done, may result in a more authentic approach to lifestyle adaptations. This, in turn, placing the person with DM in the centre and equipping him/her with the knowledge to make more informed decisions, rather than just follow a list of prescriptive rules.

7.2 Limitations

7.2.1 General limitations

The available timeframe for this study demanded a small, focused study – limiting the scope of investigation from including the influence of the environment on KAB and quality of life.

Data was collected from only one private clinic in the WC, with a predominantly English study population, making the findings not generalizable to the WC.

7.2.2 Phase 1: Quantitative

Time limitations necessitated convenience (consecutive) sampling rather than random sampling. Using a non-random sampling strategy negatively impacted the generalisability of findings to the study population. An initial feasibility study suggested a sample size of 178 participants in a 4-week data collection period, which would provide sufficient data for statistical analysis. There were several administrative and staff complications that resulted in the data collection period starting a month later than planned. The clinic sister also resigned and data collection had to be halted while a replacement was found. This resulted in a very slow and limited inflow of data. The data collection period was extended as far as possible to maximise the number of available participants

It is not clear how many individuals refused participation as the person handing out the questionnaires and obtaining informed consent did not record this information. Additionally, no information was kept on the demographic details of those who declined to participate in the study. Thus there is no way of knowing what percentage of the population they were or if they differed from those who did consent and participate.

The tool was not tested for reliability and concurrent validity by the researcher. It was, however, adapted for a previous study in the Free State. The adaptation was based on reviews of existing and validated instruments, and a multidisciplinary expert team assessed the validity of questions.

Data were self-reported, introducing possible recall bias. Additionally, several questions were not answered by some participants, which reduced the total number of participants for each question during analysis.

This could be because questionnaires were not consistently checked for completeness once handed in, however, participants were free to not answer any questions that made them uncomfortable or caused any anxiety.

There were a few questions where it appeared that the participant might not have understood the question clearly - the answer given was not relevant to the question asked, i.e.

*Question: How did it happen that you were diagnosed with Type 2 diabetes?
(Describe the day and the circumstances)*

Answer: Job interview

Question: What is the most important thing to do when you feel the beginning of low blood sugar?

Answer: Weak, sweaty, legs feel wobbly

The language was also potentially a problem. While the questionnaires were available in English, Afrikaans and isiXhosa, most participants chose to complete the English questionnaire. When I enquired about this with an isiXhosa speaking participant during an interview, she explained that currently many mixed words are used during dialogue, "That was Xhosa "A"...Remember, now when we speak, you mix the words." (PP02)

7.2.3 Phase 2: Qualitative

As most of the interviewees had never done a telephonic interview before, it is possible that they were unable to confidently convey their responses. Similarly, although all the interviewees indicated that they would prefer their interview in English, a few struggled with vocabulary as English was not their first language.

7.3 Recommendations

Based on the outcomes of this research project, it is clear that the input from several stakeholders is required to achieve effective, patient-centered self-management.

Professionals could give consideration to:

Empowerment-based education - through online CEU courses or courses rolled out in local clinics, hospitals, and private practices. Education should empower patients to make better decisions - one example being dietary choices.

Individuals should be able to determine what effect a particular food will have on their BG levels, based on the nutritional value and macronutrient makeup of the particular food. To this end, the researcher suggests that healthcare professionals should educate patients in reading and understanding food labels, to improve knowledge related to food classification and potentially enhance food choices.

Building partnerships with patients, involving them in goal setting and behaviour modifications guidelines. Practitioners and patients need to collaborate, whilst maintaining a patient-centered approach, incorporating patient's needs and lived experiences. Individuals need to take ownership of their DM and make proactive rather than reactive choices, facilitating an enhanced awareness of the consequences of unfavourable behaviour.

Focusing energy and attention on developing positive, healthy attitudes towards DM, together with improving knowledge around diabetes and the required management. Attitude is vital in managing DM, and counseling for patients should be included as standard practice.

Implementing regular screening for high-risk individuals or patients over 45 years of age, in an attempt to mitigate the progression to DM, and simultaneously creating educational opportunities around DM and risk factors.

Persons with T2DM and their families:

Families have been highlighted as an integral part of the support system. For this reason, education for patients and their families is important, not only for patients to grow in knowledge and health literacy but their families/support systems as well. The partnership for self-management of the chronic disease needs to go beyond just the HCP and patient.

Persons living with T2DM must be equipped to acknowledge that T2DM is predominantly a lifestyle-related condition, to accept responsibility and to take control of their health management.

NGO's could become involved in:

Support groups led by persons living with diabetes with the support of a HCP (if needed). The aim being to provide a 'biopsychosocial' platform where clinical and health-related issues can be dealt with in light of emotional and personal concerns, with guidance and wisdom gained from shared experiences.

Self-management programmes which incorporate both the emotional and physiological aspects of living with diabetes, to develop better coping skills and behaviour, i.e. including tools to manage depression and anxiety as part of the existing behaviour modification required (diet, exercise and medication) for effective diabetes management.

Recommendations for further research

Further research into understanding the effect of cultural and social beliefs and systems on the adapted health behaviours of the communities of the Western Cape and South Africa, as well as the environmental barriers hindering or facilitating positive behavioural change.

Further research into the current health literacy and self-management initiatives available, and investigation into the possibility of technology-based interventions, As a large percentage of the population in Cape Town, according to Census 2011 by Statssa, already has access to a cellphone (91,3%) or television

(87,3%), mobile applications with dedicated knowledge sharing and support platforms could be a more effective means of enhancing patient engagement and involvement.

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ADDENDUM A: FLYER



ADDENDUM B: INFORMED CONSENT

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

Knowledge, attitudes and adapted behaviours of adults with Type 2 Diabetes Mellitus, attending a private clinic in the Western Cape: A mixed-method study

REFERENCE NUMBER: S18/05/113

PRINCIPAL INVESTIGATOR: Loreen Winton

ADDRESS: PO Box 23595, Claremont, Western Cape, 7735

CONTACT NUMBER: 084 701 6971

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the office manager any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research is about and how you could be involved. Also, your participation is entirely voluntary and you do not have to participate. If you say no, this will not affect you negatively in any way at all. You are also free to withdraw from the study at any point, even if at first you do agree to take part.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- The study is directed specifically at individuals who have been diagnosed with Type 2 Diabetes. The aim is to determine what is known about diabetes, its risks, and complications, what the feeling is about having diabetes, and what specific behaviours are practiced to manage diabetes. I am eager to gain insight and understanding around diabetes management from the perspective of the person with diabetes.
- The study will consist of two phases. Phase 1 of the study involves a questionnaire and will take place at Diabetes Life Clinic. Phase 2 will consist of a telephonic interview, at a time that suits you, should you be selected.
- As I already work with some of the clinic's patients, I believe that conducting my study in this particular setting may benefit the quality of my services. Your choice to participate or not, will not influence the current or any future treatment you receive at the clinic.
- Additionally, I am hoping to produce insight that leads to possible further research to improve diabetes management in the Western Cape.

Why have you been invited to participate?

- You have been invited to take part in the study because you have been diagnosed with Type 2 Diabetes, for at least one year, and currently attend Diabetes Life Clinic.

What will your responsibilities be?

- If you agree to take part in this study, you will be asked to complete a questionnaire (which may take \pm 20-30 minutes). The questionnaire will be completed, at the clinic, after your consultation. Based on the results, you may be invited to participate in a telephonic interview. In the interview I hope to get more insights and understanding of some of the responses in the questionnaire. The interview will be informal, on a date and at a time of your choice, and will take \pm 20 minutes.

Will you benefit from taking part in this research?

- While there may be no direct benefit to you, the participant, from participating in the study, you are being offered the opportunity to have your voice heard.
- Knowledge and insight gained in this study will hopefully lead to further research and improved diabetes care in the future.

Are there any risks involved in your taking part in this research?

- Fear of disclosing sensitive information
All information will be kept confidential. All names will be removed from questionnaires. Consent forms will be separate from questionnaires so that there can be no link. You have the freedom to not answer any questions that make you feel uncomfortable.
- Social stigmatisation related to participating in a diabetes study
All data will be anonymous and will be kept confidential.
- The indirect cost of time
I appreciate that your time is valuable, and therefore, have been careful to ensure that both the questionnaire and the planned interview are as brief as possible.
- The anxiety of being interviewed
Interviews will be telephonic, allowing you to be in the comfort of your own home, or another private space. Interviews will be conducted at a time convenient to you – that is: you choose
- Discomfort related to the inconvenience of filling out forms
The office manager will be available to offer assistance where needed. Alternatively, the researcher will be available by phone or email for any further assistance required.

If you do not agree to take part, what alternatives do you have?

- Important: If you decide not to take part, this will not affect your current or future treatment at the clinic.

Who will have access to your medical records?

- Your medical records will NOT be accessed during the study, and no information will be taken from your records.
- Any information you share with me during this study will be kept confidential. All names will be removed from questionnaires and a code will be used. Consent forms will be completely separated from questionnaires. Completed questionnaires will be placed into a sealed box, which will be collected from the clinic by the researcher. All information will be coded and entered into a password-protected computer.
- Telephonic interviews will be recorded, and only I will have access to these recordings. Study supervisors may have access to the coded data when analysis takes place, in order to assist me, but all data will be anonymous. Recordings will be erased once the study has been accepted for publication and all edits have been made. No names will be used in the publication, and any defining information that may lead to identification will be removed.

What will happen in the unlikely event of some form of injury occurring as a direct result of your taking part in this research study?

- The study is purely descriptive in nature and there will be no trial intervention or experimentation. Participation is completely voluntary and will carry no compensation for any injury occurring during the time taken to complete the questionnaire or participate in the telephonic interview.

Will you be paid to take part in this study and are there any costs involved?

- You will not be paid to take part in the study. You will be compensated for additional parking expenses if you do take part.

Is there anything else that you should know or do?

- You can contact me, Loreen Winton on tel: 084 701 6971 should you have any further queries or encounter any problems. Alternatively, my research supervisors can be contacted:

1) Martha Geiger at 082 440 8713 / mgeiger@sun.ac.za

2) Surona Visagie at surona@telkomsa.net
 - You can contact the Stellenbosch University Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
 - You may request a copy of this information and consent form for your own records and it will be sent directly to you via email or post. Please indicate a postal address or email address should you require a copy:
-

Declaration by participant

By signing below, I agree to take part in a research study entitled (Knowledge, attitudes and adapted behaviours of adults with Type 2 Diabetes Mellitus, attending a private clinic in the Western Cape: A mixed-method study)

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or

prejudiced in any way.

- I may be asked to leave the study before it has finished if the researcher feels it is in my best interests.

Signed at (place)on (date) 2018.

.....

Signature of participant

.....

Signature of witness

Declaration by office manager

I (name) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (If an interpreter is used then the interpreter must sign the declaration below.

Signed at (place) on (date) 2018.

.....

Signature of office manager

.....

Signature of witness

Declaration by interpreter

I (name) declare that:

- I assisted the investigator (name) to explain the in-formation in this document to (name of participant) using the language medium of Afrikaans/isiXhosa.
- We encouraged him/her to ask questions and took adequate time to answer them. I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (place) on (date)2018.

.....

Signature of interpreter

.....

Signature of witness

ADDENDUM C: KAB QUESTIONNAIRE

ADULT DIABETIC PATIENT QUESTIONNAIRE

18 years and older

Participants to complete questionnaire: Have signed consent
Older than 18 years
Have Type 2 Diabetes

For Office use

Instructions - Circle the appropriate number or write your answer in the space provided.

1-3 Interview No

If you have any questions, please ask the Clinic Office Manager. Alternatively, you can contact the researcher on: 084 701 6971.

1.1 Date questionnaire is completed / / (ddmmyy)

4-9
d d m m y y

1.2 Should you be invited to take part in a telephonic interview, please indicate your preferred language:

- 1 Afrikaans
- 2 English
- 3 Xhosa
- 4 Other, specify.....

10

1.3 Please indicate a telephone number you can be contacted on, should you be invited to take part in a telephonic interview:

PART I: RESPONDENT PROFILE

Demographic Information

2.1 Please indicate your gender

11

2.2 How old are you in years?

12-13

2.3 What is your home language? (If you speak more than one, please indicate ALL of them)

- 1 Afrikaans
- 2 English
- 3 Xhosa
- 4 Other, specify?.....

14

15

2.4 What is your highest level of education?

- 0 No schooling
- 1 ABET (Adult Based Education and Training)
- 2 Some primary school
- 3 Completed primary school
- 4 Some high school
- 5 Completed high school
- 6 Tertiary qualification
- 7 Other (Specify).....

16

17

2.5 What is your average monthly income?

- 1 < R3500
- 2 R3500 - R7000
- 3 R7100 - R10,000
- 4 > R10,000

18

2.6 Would you describe yourself as spiritual or religious?

- 1 No
- 2 Yes

19

Quality of Life

2.7 Do you consider yourself CURRENTLY ill?

- 1 No
- 2 Yes

If no, go to 2.9

20

2.8 If yes, what is wrong with you? (Please list all the things that come to mind)

.....
.....

21-22

23-24

.....

| |
|-------|
| 25-26 |
| 27-28 |
| 29-30 |
| 31-32 |

In the following section I want to ask about your GENERAL state of health.
 Please indicate which statement best describes your own state of health **TODAY**.

STATEMENTS ARE RELATED SPECIFICALLY TO YOUR PHYSICAL HEALTH...

2.9 Do you experience pain or loss of sensation / feeling in your feet?

| | |
|---|-----|
| 1 | No |
| 2 | Yes |

| |
|----|
| 33 |
|----|

2.10 Do you physically have any problems walking about?

| | |
|---|-----|
| 1 | No |
| 2 | Yes |

| |
|----|
| 34 |
|----|

2.11 Do you have problems with selfcare such as dressing and washing?

| | |
|---|-----|
| 1 | No |
| 2 | Yes |

| |
|----|
| 35 |
|----|

2.12 Do you have problems with usual activities such as work, study, housework, family or leisure activities?

| | |
|---|-----|
| 1 | No |
| 2 | Yes |

| |
|----|
| 36 |
|----|

2.13 Did you have stress or anxiety recently?

| | |
|---|--------|
| 1 | No |
| 2 | Yes |
| 3 | Unsure |

| |
|----|
| 37 |
|----|

2.14 Have you felt depressed recently?

| | |
|---|--------|
| 1 | No |
| 2 | Yes |
| 3 | Unsure |

| |
|----|
| 38 |
|----|

History of Diabetes diagnosis

2.15 How long ago were you diagnosed with Diabetes?

..... Years

| |
|-------|
| years |
| 39-40 |

2.16 How did it happen that you were diagnosed with Type 2 diabetes? **(Describe the day and the circumstances)**

.....

| |
|-------|
| 41-42 |
| 43-44 |
| 45-46 |
| 47-48 |
| 49-50 |
| 51-52 |

2.17 Indicate which medication/therapy you currently use? **(I.e. condition and type of medication...list everything)**

.....

| |
|-------|
| 53-54 |
| 55-56 |
| 57-58 |
| 59-60 |
| 61-62 |
| 63-64 |
| 65-66 |

PART II: KNOWLEDGE REGARDING DIABETES

In the next few questions I will be asking you about your knowledge about diabetes.

3.1 What causes diabetes?

.....

| | | |
|--|--|------|
| | | 1-2 |
| | | 3-4 |
| | | 5-6 |
| | | 7-8 |
| | | 9-10 |

3.2 Many people don't know what the normal range of blood glucose is. Do you know? What is the normal range?

.....

| | | |
|--|--|-------|
| | | 11-12 |
|--|--|-------|

3.3 What do you think are the most common signs of high blood sugar? Mention as many signs as you want to.

.....

| | | |
|--|--|-------|
| | | 13-14 |
| | | 15-16 |
| | | 17-18 |
| | | 19-20 |
| | | 21-22 |
| | | 23-24 |
| | | 25-26 |

3.4 What is the most important thing to do when you feel the beginning of low blood sugar?

.....

| | | |
|--|--|-------|
| | | 27-28 |
| | | 29-30 |
| | | 31-32 |

3.5 What type of health complications are usually associated with diabetes?

.....

| | | |
|--|--|-------|
| | | 33-34 |
| | | 35-36 |
| | | 37-38 |
| | | 39-40 |
| | | 41-42 |
| | | 43-44 |
| | | 45-46 |

3.6 Many people find terminology like carbohydrates, protein and fat confusing. What about you? In which group would you place the following items?

| | 1 | 2 | 3 | 4 |
|--------------------------|--------------|---------|-----|--------|
| | Carbohydrate | Protein | Fat | Unsure |
| Cooking oil/Fish oil | | | | |
| Pap | | | | |
| Bread | | | | |
| Lentils | | | | |
| Baked Beans | | | | |
| Chicken feet | | | | |
| Organ meat | | | | |
| Vegetables | | | | |
| Fruit | | | | |
| Milk | | | | |
| Sardines in Tomato sauce | | | | |

| | |
|--|----|
| | 47 |
| | 48 |
| | 49 |
| | 50 |
| | 51 |
| | 52 |
| | 53 |
| | 54 |
| | 55 |
| | 56 |
| | 57 |

Indicate whether the following statements are true (T), false (F) or if you are unsure (U).

| | | | | |
|-----|---|---|---|--|
| 3.7 | T | F | U | Diabetic medication can cure diabetes |
| | T | F | U | Diabetic medication should be taken for life |
| | T | F | U | You should stop taking your diabetic medication when you feel sick |
| | T | F | U | Poor control of diabetes could result in a greater chance of complications |
| | T | F | U | Eating less bread will make me lose weight |
| | T | F | U | Salty food will prevent my sugar levels from dropping |

| | |
|--|----|
| | 58 |
| | 59 |
| | 60 |
| | 61 |
| | 62 |
| | 63 |

3.8 People with diabetes should take care of their feet because...

| | | |
|---|---|---|
| T | F | U |
| T | F | U |
| T | F | U |

Diabetic medication may cause swelling of the feet

Sore feet are common in people with diabetes

People with diabetes may have poor circulation of blood in the feet

| |
|----|
| 64 |
| 65 |
| 66 |

3.9 Is physical work or exercise important for people with diabetes?

| | |
|---|--------|
| 1 | Yes |
| 2 | No |
| 3 | Unsure |

| |
|----|
| 67 |
|----|

3.10 If you do physical work or exercise regularly, it will help with...

Blood sugar control

| | |
|---|--------|
| 1 | Yes |
| 2 | No |
| 3 | Unsure |

| |
|----|
| 68 |
|----|

3.11 Painful feet

| | |
|---|--------|
| 1 | Yes |
| 2 | No |
| 3 | Unsure |

| |
|----|
| 69 |
|----|

3.12 Weight loss

| | |
|---|--------|
| 1 | Yes |
| 2 | No |
| 3 | Unsure |

| |
|----|
| 70 |
|----|

3.13 The following factors can make diabetes worse:

High blood pressure

| | |
|---|--------|
| 1 | Yes |
| 2 | No |
| 3 | Unsure |

| |
|----|
| 71 |
|----|

3.14 Epilepsy

| | |
|---|--------|
| 1 | Yes |
| 2 | No |
| 3 | Unsure |

| |
|----|
| 72 |
|----|

3.15 Overweight

| | |
|---|--------|
| 1 | Yes |
| 2 | No |
| 3 | Unsure |

| |
|----|
| 73 |
|----|

PART III: ATTITUDE REGARDING DIABETES

4.1 This section consists of 19 statements to see how you feel about diabetes and its effect on your life. There is no "right" or "wrong" answer because everyone has the right to their own opinion. Give your first, natural answer as it occurs to you. There are 3 possible answers.

| | I DISAGREE | NEUTRAL | I AGREE |
|---|------------|---------|---------|
| 1 | 1 | 2 | 3 |
| 2 | 1 | 2 | 3 |
| 3 | 1 | 2 | 3 |
| 4 | 1 | 2 | 3 |
| 5 | 1 | 2 | 3 |
| 6 | 1 | 2 | 3 |
| 7 | 1 | 2 | 3 |
| 8 | 1 | 2 | 3 |

| | |
|---|---|
| 1 | 1 |
| 2 | 2 |
| 3 | 3 |
| 4 | 4 |
| 5 | 5 |
| 6 | 6 |
| 7 | 7 |
| 8 | 8 |

| | | | | |
|----|---|---|---|---|
| 9 | I avoid telling people I have diabetes | 1 | 2 | 3 |
| 10 | Being told you have diabetes is like being sentenced to a lifetime of illness | 1 | 2 | 3 |
| 11 | My diabetic diet spoils my social life | 1 | 2 | 3 |
| 12 | In general, nurses need to be more sympathetic in their treatment of people with diabetes | 1 | 2 | 3 |
| 13 | Having diabetes over a long period changes the personality | 1 | 2 | 3 |
| 14 | I often find it difficult to decide whether I feel sick or well | 1 | 2 | 3 |
| 15 | Diabetes can be controlled | 1 | 2 | 3 |
| 16 | There is really nothing you can do if you have diabetes | 1 | 2 | 3 |
| 17 | There is really no-one I feel I can talk to openly about my diabetes | 1 | 2 | 3 |
| 18 | I believe I have adjusted well to having diabetes | 1 | 2 | 3 |
| 19 | I often think it is unfair that I should have diabetes when other people are so healthy | 1 | 2 | 3 |

| | |
|----|----|
| 9 | 9 |
| 10 | 10 |
| 11 | 11 |
| 12 | 12 |
| 13 | 13 |
| 14 | 14 |
| 15 | 15 |
| 16 | 16 |
| 17 | 17 |
| 18 | 18 |
| 19 | 19 |

PART IV: PRACTICES REGARDING DIABETES

In the next few questions I would like to ask you about practices with regards to diabetes.

5.1 Many people tend to forget taking medication. How often have you forgotten to take your diabetic medication in the last week?

- 1 Never
- 2 Less than once
- 3 Once a week
- 4 2-3 times a week
- 5 Nearly everyday
- 6 Everyday

20

5.2 How often have you done physical work or exercise in the last week?

- 1 Never *If never, go to 5.4*
- 2 Less than once
- 3 Once a week
- 4 2-3 times a week
- 5 Nearly everyday
- 6 Everyday

21

5.3 On the days when you do physical work or exercise: how long did it last on an **average** day?

- 1 less than 10 minutes/day
- 2 10-20 minutes/day
- 3 20-30 minutes/day
- 4 More than 30 minutes/day

22

5.4 How often do you measure/check your blood glucose levels?

- 1 Never
- 2 Less than once per week
- 3 1-2 times a week
- 4 3-5 times a week
- 5 Everyday

23

5.5 How often do you eat refined starch, such as white bread or cake?

- 1 Never
- 2 Once a month
- 3 Nearly once a week
- 4 Nearly everyday
- 5 Everyday
- 6 Other.....(specify)

24

25

5.6 How often do you eat fatty food, like slap chips or vetkoek?

- 1 Never
- 2 Once a month
- 3 Nearly once a week
- 4 Nearly everyday
- 5 Everyday
- 6 Other.....(specify)

26

27

- 5.7 How often do you eat food with lots of salt, like russians or poloni or use stock cubes in food preparation? 28
- 1 Never
 - 2 Once a month
 - 3 Nearly once a week
 - 4 Nearly every day
 - 5 Every day
 - 6 Other.....(specify) 29
- 5.8 How often do you eat vegetables? 30
- 1 Never
 - 2 Once a month
 - 3 Nearly once a week
 - 4 Nearly every day
 - 5 Every day
 - 6 Other.....(specify) 31
- 5.9 How often do you eat fruit? 32
- 1 Never
 - 2 Once a month
 - 3 Nearly once a week
 - 4 Nearly every day
 - 5 Every day
 - 6 Other.....(specifiy) 33
- 5.10 What type of coldrink do you mostly drink? *If no, go to 5.12* 34
.....
- 5.11 How often do you drink these coldrinks? 35
- 1 Never
 - 2 Once a month
 - 3 2-3 times a month
 - 4 Weekly
 - 5 2-3 times a week
 - 6 Nearly every day
 - 7 Every day
- 5.12 How often have you had an alcoholic drink in the last month? 36
- 1 Never
 - 2 Once a month
 - 3 2-3 times a month
 - 4 Weekly
 - 5 2-3 times a week
 - 6 Nearly every day
 - 7 Every day

THANK YOU VERY MUCH FOR YOUR TIME

**Please place the questionnaire in the box at reception OR email it back to the researcher on:
loreenwinton@gmail.com OR Fax it on: 0867320347**

ADDENDUM D: SCORING OF ATTITUDE AND BEHAVIOUR

(Le Roux, 2016)

| 4 Attitude | | |
|---|----------|----------|
| 1. If I did not have diabetes I think I would be quite a different person | Disagree | Positive |
| | Agree | Negative |
| 2. I dislike being referred to as "a diabetic Disagree | Disagree | Positive |
| | Agree | Negative |
| 3. Diabetes is the worst thing that has ever happened to me.. | Disagree | Positive |
| | Agree | Negative |
| 4. Most people would find it difficult to adjust to having diabetes | Disagree | Positive |
| | Agree | Negative |
| 5. I often feel embarrassed about having diabetes | Disagree | Positive |
| | Agree | Negative |
| 6. There is not much I seem to be able to do to control my diabetes | Disagree | Positive |
| | Agree | Negative |
| 7. There is little hope of leading a normal life with diabetes | Disagree | Positive |
| | Agree | Negative |
| 8. The proper control of diabetes involves a lot of sacrifice and inconvenience | Disagree | Positive |
| | Agree | Negative |
| 9. I avoid telling people I have diabetes | Disagree | Positive |
| | Agree | Negative |
| 10. Being told you have diabetes is like being sentenced to a lifetime of illness | Disagree | Positive |
| | Agree | Negative |
| 11. My diabetic diet spoils my social life | Disagree | Positive |
| | Agree | Negative |
| 13. Having diabetes over a long period changes the personality | Disagree | Positive |
| | Agree | Negative |
| 14. I often find it difficult to decide whether I feel sick or well | Disagree | Positive |
| | Agree | Negative |
| 15. Diabetes can be | Disagree | Negative |

| | | |
|---|----------|----------|
| controlled | Agree | Positive |
| 16. There is really nothing you can do if you have diabetes | Disagree | Positive |
| | Agree | Negative |
| 17. There is really no-one I feel I can talk to openly about my diabetes | Disagree | Positive |
| | Agree | Negative |
| 18. I believe I have adjusted well to having diabetes | Disagree | Negative |
| | Agree | Positive |
| 19. I often think it is unfair that I should have diabetes when other people are so healthy | Disagree | Positive |
| | Agree | Negative |
| 5. Practices | | |
| 5.1 Many people tend to forget taking medication. How often have you forgotten | 1 | Good |
| | 2 | |
| | 3 | Poor |
| | 4 | |
| | 5 | |
| | 6 | |
| 5.2 How often have you done physical work or exercise in the last week | 5 | Good |
| | 6 | |
| | 1 | Poor |
| | 2 | |
| | 3 | |
| | 4 | |
| 5.3 On the days when you do physical work or exercise: How long did it last on average | 3 | Good |
| | 4 | |
| | 1 | Poor |
| | 2 | |
| 5.4 How often do you measure your BG levels | 4 | Good |
| | 5 | |
| | 1 | Poor |
| | 2 | |
| | 3 | |
| 5.4 How often do you eat refined starch, such as white bread or cake | 1 | Good |
| | 2 | |
| | 3 | Poor |
| | 4 | |
| | 5 | |
| | 6 | |

| | | |
|---|------------------|------|
| 5.5 How often do you eat fatty food like slap chips or vetkoek | 1 2 | Good |
| | 3 4 5 6 | Poor |
| 5.6 How often do you eat food with lots of salt, like russians or poloni or use stock cubes in food preparation | 1 2 | Good |
| | 3 4 5 6 | Poor |
| 5.7 How often do you eat vegetables | 4 5 | Good |
| | 1 2 3 6 | Poor |
| 5.8 How often do you eat fruit | 4 5 | Good |
| | 1 2 3 6 | Poor |
| 5.9 What type of cold drink do you mostly drink | 1 5 99 | Good |
| | 2 3 4 | Poor |
| 5.11 How often have you had an alcoholic drink in the last month | 1 2 3 | Good |
| | 4 5 6 7 | Poor |

ADDENDUM E: TELEPHONIC INTERVIEW SCHEDULE

1. Introduce myself (researcher) and thank the respondent for participating
2. Briefly discuss the purpose of the interview
 - a. *I am doing research on Type 2 diabetes*
 - b. *I am hoping to understand various attitudes and behaviours better*
 - c. *I am eager to learn from your own experience of having diabetes*
3. Discuss ethics and confidentiality:
 - a. *Ethics approval has been granted by the University of Stellenbosch*
 - b. *Everything we discuss will be confidential and anonymous*
 - c. *Would you mind if I record our conversation? The reason is so that I can give you my full attention.*
 - d. *The recordings will be deleted once the research has been finalised and accepted for publication.*
 - e. *Please don't hesitate to stop me if you feel uncomfortable. Please know that you may withdraw from this interview at any time.*
4. Create rapport: general conversation
 - a. *How has your day been?*
 - b. *Have you participated in a telephonic interview before?*
 - c. *How long have you been visiting the clinic?*
 - d. *How did you hear about the clinic?*
 - e. *How long have you had diabetes?*
5. Questions:
 - a. *How did you feel when you were diagnosed with diabetes? Why?*
 - b. *How would you describe living with diabetes?*
 - c. *Would you say that you manage your diabetes well?*
 - d. *Please describe what makes it easier or more difficult.*
 - e. *Does having diabetes worry you at all? Why? .*
 - f. *[Discuss interesting comments or responses on questionnaire]*
6. Debriefing: summarise the main points that were covered in the interview.
 - a. *Have I understood and interpreted your experiences correctly?*
 - b. *Is there anything else you would like to add?*
 - c. *Do you perhaps have any questions about the interview?*
7. Thank the respondent again for their time

ADDENDUM F: ETHICS APPROVAL LETTER



UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

Health Research Ethics Committee (HREC)

Approval Notice

New Application

03/07/2018

Project ID:7377

HREC Reference #: S18/05/113

Title: Knowledge, attitudes and adapted behaviours of adults with Type 2 Diabetes Mellitus, attending a private clinic in the Western Cape: A mixed method study.

Dear Miss Loreen Winton,

The **New Application** received on 29/05/2018 19:56 was reviewed by members of **Health Research Ethics Committee 2 (HREC2)** via **expedited** review procedures on 03/07/2018 and was approved.

Please note the following information about your approved research protocol:
Protocol Approval Period: **This project has approval for 12 months from the date of this letter.**

Please remember to use your **Project ID [7377]** on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further

questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review

Please note you can submit your progress report through the online ethics application process, available at: Links Application Form Direct Link and the application should be submitted to the HREC before the year has expired. Please see [Forms and Instructions](#) on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see:

<https://www.westerncape.gov.za/general-publication/health-research-approval-process>. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: [Forms and Instructions](#) on our HREC website <https://applyethics.sun.ac.za/ProjectView/Index/7377>

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,
Francis Masiye ,
HREC Coordinator,
Health Research Ethics Committee 2 (HREC2).

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)·REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372

Office of Human Research Protections (OHRP) Institutional Review Board (IRB)

Number: IRB0005240 (HREC1)·IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

ADDENDUM G: LETTER OF PERMISSION

- ❖ Diabetes education and counselling
- ❖ Healthy eating and exercise program
- ❖ Foot care
- ❖ Wound care
- ❖ Glucose monitoring
- ❖ Insulin pump management



Nurse Educator - Doctor - Dietician - Podiatrist - Affiliated biokineticist

3 AUGUST 2018

TO- WHOM IT MAY CONCERN

Dear Sir/ Madam

PERMISSION: CONSENT TO CONDUCT A MASTERS STUDY AT THE DIABETES LIFE CLINIC- KINGSBURY HOSPITAL: MS LOREEN WINTON

This letter hereby confirms that Ms Loreen Winton has my permission, as the clinical director of the Diabetes Life Clinic, to conduct her survey on Diabetes and Exercise at the Diabetes Life Clinic.

I am satisfied that I have reviewed her study protocol and have no objections to her questionnaire.

She has also applied for the necessary consent from the appropriate regulatory and ethics committees.

Sincerely

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