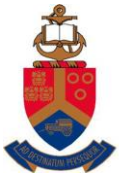

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THE INFLUENCE OF POPULATION-BASED FACTORS ON SELF-CARE OF PATIENTS WITH DIABETES MELLITUS

by

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Consult not your fears, but your hopes

and your dreams.

Pope John xxiii

THE INFLUENCE OF POPULATION-BASED FACTORS ON SELF-CARE OF PATIENTS WITH DIABETES MELLITUS

"Diabetes poses a special challenge because it is possibly under-diagnosed, and subjected to the 'rule of halves' – only half of all cases of diabetes are diagnosed, only half of those diagnosed treated, and only half of those having treatment are managed effectively" (McKinlay & Marceau, 2000: 758). Globally, diabetes is a leading cause of death and a major source of morbidity. Clinical investigations of diabetes are fundamentally limited because they do not address the socially-constructed patterns of consumption, lifestyle, and its manifestation in individual behaviour as well as the differences between social groups, while the traditional sociological study of diabetes as an experiential phenomenon provides limited insight into material processes by which the social world is formed (Timmermans & Haas, 2008).

This qualitative population-based study explored the influence of selected population-based factors on self-care of patients with diabetes mellitus. The study was conducted at seven primary health care clinics in the district of Tshwane, Gauteng Province, South Africa. Fifteen focus groups, seven full and eight small or mini groups, were facilitated, with an average size of five participants per group at the seven selected clinics. Seventy two adults with diabetes mellitus participated in the study; 20 males and 52 females with ages ranging from 30 to 87. The development of the topics for the focus group discussion schedule was informed by the literature, the conceptual framework and the theories. The final topics emerged from the pre-testing of the focus group discussion schedule during a pilot study. The study explored the population-based factors that might determine sustainable diabetes self-care management. The focus was on the role of social integration and its interrelationship with demographic and social changes. These factors were utilised to facilitate the empirical research process by means of the focus groups, while other possible related factors were identified from the responses.

The ethical clearance process for the study was four-fold: the research proposal was approved by the Faculty of Humanities; the research instruments of this qualitative study were approved by the Ethics Committee of the Faculty of Health Sciences at the University of Pretoria as part of the research protocol for the Diabetes Lifestyle Research study at the Kalafong Academic Hospital; the written preliminary permission was required from the clinic managers of each of the seven primary health care district clinics; and the ethical clearance of the combined Ethical Committee of the Tshwane District Health and Gauteng Provincial Health Authorities.

The focus groups discussions were mainly conducted in English and Afrikaans; and recorded, transcribed, coded, and analysed by the researcher. In the analysis the researcher maintained an emphatic stance of seeking an understanding through the eyes of the research participants that indicated the study was in tune with interpretivism. A three-pronged theoretical approach was followed, namely a multi-level heuristic framework, a health behavioural model and a social theory. The rich text data provided multiple observations and possible meanings. The experiences viewed by the participants reflect the difficulty of persons with diabetes to accept the diagnosis as a lifelong condition. The emotional and psychological burden of diabetes is reflected in the complexity of the socio-geographic networks that include all their relationships, as well as home and living environments. The findings suggest that knowledge about diabetes and the empowerment through social support are predictors of sustained self-care management. The perceptions about diabetes in particular and health beliefs in general are determining factors regarding the participants' reasoning about their present quality of life and future life with diabetes. The complexity of diabetes self-care management is reflected in the Trinity of the three themes namely 'Diabetes Health Beliefs', the 'Socialising' patterns of persons living with diabetes and the 'Experiencing of Diabetes'. The Trinity of Themes is the final strategic outcome that prioritises the multiple observations and the essential meanings in the data and strategically focuses the parameters of this study. The Trinity of Themes also serves as the pathway towards sustainable diabetes self-care management.

The main limitation of the study is that the findings cannot be generalised to the rest of the South African population because the study included only people with diabetes who live in the district of Tshwane in Pretoria and who make use of public primary health care facilities. The main significance of this study is the theoretical engagement of sociology with the discipline of social epidemiology; as well as the clinical complications of ineffective self-care management of diabetes. The population-based perspective rather than an individual perspective towards diabetes self-care management distinguishes this study from previous studies done in either sociology or the health sciences.

Keywords: Sociology; qualitative; Diabetes Mellitus; diabetes self-care management; diabetes self-care; Tshwane; primary health care clinic; social integration; population-based.

DIE INVLOED VAN BEVOLKINGS-GEBASEERDE FAKTORE OP SELF-SORG VAN PASIËNTE MET DIABETES MELLITUS

"Diabetes bied 'n spesiale uitdaging omdat dit moontlik onder gediagnoseer, en onderhewing aan die 'reel van halwes' is – slegs die helfte van alle diabetes gevalle word gediagnoseer, slegs die helfte van diegene wat gediagnoseer word ontvang behandeling, en slegs die helfte van diegene wat behandeling ontvang word effektief bestuur" (McKinlay & Marceau, 2000:758). Diabetes is wêreldwyd 'n hoof oorsaak van sterftes en 'n groot oorsaak van morbiditeit. Kliniese ondersoeke oor diabetes is fundamenteel beperk omdat dit nie die sosiaal-gekonstrueërde patrone van verbruiking, lewensstyl, en die manifestering daarvan in persoonlike gedrag sowel as die verskille tussen sosiale groepe aanspreek nie, terwyl tradisionele sosiologiese studies van diabetes as 'n ervaringsleer fenomeen 'n beperkte insig bied tot die materiële prosesse waardeur die sosiale wêreld gevorm is (Timmermans & Haas, 2008).

Hierdie kwalitatiewe bevolkings-gebaseerde sosiale navorsingstudie het die invloed van geselekteerde bevolkings-gebaseerde faktore op self-sorg van pasiënte met diabetes-mellitus ondersoek. Die studie is uitgevoer by sewe primêre gesondheidsdiens klinieke in die Tshwane distrik, Gauteng Provinsie, Suid Afrika. Vyftien fokusgroepe, waarvan sewe vol en agt klein of mini-groepe was, met 'n gemiddelde grootte van vyf deelnemers per groep is by die sewe gekose klinieke gefasiliteer. Twee-en-sewentig volwassenes met diabetes mellitus het deelgeneem aan die studie; 20 mans en 52 vrouens wie se ouderdomme gewissel het vanaf 30 tot 87 jaar. Die ontwikkeling van die onderwerpe vir die fokus-groep bespreking-skedule is toegelig deur die literatuur, die konsepsuele raamwerk en die teorieë. Die finale onderwerpe het voortgekom uit die voortoetsing van die fokusgroep bespreking-skedule tydens die loods-studie. Die studie het die bevolkings-gebaseerde faktore wat volhoubare diabetes self-sorg bestuur bepaal ondersoek. Die fokus was op die rol van sosial integrasie en die interverwantskap daarvan met demografiese en sosiale veranderinge. Hierdie faktore is gebruik om die empiriese

navorsingsproses by wyse van fokusgroepe te fasiliteer, terwyl ander faktore wat moontlik verband hou, het uit die response na vore gekom het.

Die etiese klaringsproses vir die studie was vierledig: die navorsingsvoorstel is goedgekeur deur die Fakulteit Geesteswetenskappe; die navorsings-instrumente vir die kwalitatiewe studie is goedgekeur deur die Etiese Komitee van die Fakulteit Gesondheidswetenskappe by die Universiteit van Pretoria as deel van die Diabetes Lewenstyl Navorsingstudie by die Kalafong Akademiese Hospitaal; die voorlopige skriftelike goedkeuring is verkry van die kliniekbestuurders van elk van die sewe primêre gesondheidsorg distriksklinieke; en die etiese klaring van die gekombineerde Etiese Komitee van die Tshwane Gesondheidsdistrik en Gauteng Provinsiale Gesondheids Owerhede is verkry.

Die fokusgroep besprekings was merendeels in Engels en Afrikaans gevoer; en opgeneem, getranskribeer, gekodeer, en analiseer deur die navorser. Gedurende die analise het die navorser ‘n empatiese houding gehandhaaf ten opsigte die soeke na ‘n begrip deur die oë van die navorsingsdeelnemers – dit het bevestig dat die studie in lyn is met interpretivisme. ‘n Drieledige teoretiese benadering is gevolg, naamlik ‘n multi-vlak heuristiese raamwerk, ‘n gesondheidsgedrag model en ‘n sosiale teorie. Die ryk teksdata het veelvoudige waarnemings en moontlike betekenisse verskaf. Die ervarings beskou deur die deelnemers reflekteer die stryd van persone met diabetes om die diagnose as ‘n lewenslange toestand te aanvaar. Die emosionele en sielkundige las van diabetes word gereflekteer in die kompleksiteit van die sosio-geografiese netwerke wat al die verhoudinge van die deelnemers, sowel as hul huishoudelike- en lewensomgewings insluit. Die resultate dui daarop dat kennis van diabetes en bemagtiging deur sosiale ondersteuning voorspellers is vir volhoubare self-sorg bestuur. Die persepsies oor diabetes in besonder, en gesondheidsoortuigings oor die algemeen is bepalende faktore met betrekking tot die pasiënt se redenering oor hul huidige lewenskwaliteit en hul toekoms met diabetes. Die kompleksiteit van diabetes self-sorg bestuur word gereflekteer in die drie-eenheid van die drie temas, naamlik ‘Diabetes Gesondheidsoortuigings’, die ‘Sosialisering’ patrone van persone wat met

diabetes saamleef, en die ‘Ervaring van Diabetes’. Die Drie-eenheid van Temas is die finale strategiese uitkoms wat die veelvoudige waarnemings en die essensiële betekenis in die data prioritiseer, en die parameters van die studie strategies fokus. Die Drie-eenheid van die Temas dien ook as die deurgang na volhoubare diabetes self-sorg bestuur.

Die hoof beperking van die studie is dat die bevindinge nie veralgemeen kan word vir die res van die Suid-Afrikaanse bevolking nie, aangesien die studies slegs mense met diabetes ingesluit het in die Tshwane distrik wat gebruik maak van die openbare primêre gesondheidsorg fasiliteite. Die belangrikste betekenis van die studie is die teoretiese interaksie van sosiologie met sosiale epidemiologie as dissipline; sowel as met die kliniese komplikasies van oneffektiewe self-sorg bestuur van diabetes. Die bevolkings-gebaseerde perspektief eerder as ‘n individuele perspektief met betrekking tot diabetes self-sorg bestuur onderskei hierdie studie van vorige studies wat in beide sosiologie en die gesondheidswetenskappe gedoen is.

Sleutelwoorde: Sosiologie; kwalitatief; Diabetes mellitus; diabetes self-sorg bestuur; diabetes self-sorg; Tshwane; primêre gesondheidsorg kliniek; sosiale integrasie; bevolkings-gebaseerd.

Dedication

To the 72 individuals who are living with Diabetes Mellitus - who opened their hearts and shared their experiences with me and the group.

To my late father, Kosie Pietersen – your dedication to Mamma and our family, your youthful spirit, sense of humour and faith in God will forever be part of my memories.

To my mother, Raaitjie Pietersen – you are a remarkable woman and an inspiration of hope and dedication for me.

In loving memory

of

my colleague and dear friend,

Lizette Schoeman

who passed away on the 3rd of November 2014

'Montani Semper Liberty'

Mountaineers are always free

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'Soli Deo Gloria' - To God all the glory

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List of acronyms

AIDS:	Acquired Immune Deficiency Syndrome
DALY's:	Disability-adjusted life-years
DM:	Diabetes Mellitus
DPPRP:	Diabetes Prevention Program Research Group
GDM:	Gestational Diabetes Mellitus
HBM:	Health Belief Model
HIV:	Human Immunodeficiency Virus
HLCP:	Healthy Lifestyle Change Program
IDP:	Integrated Development Plan
IDF:	International Diabetes Federation
MDG's:	Millennium Development Goals
NCD's:	Non-communicable diseases
NGT:	Nominal Group Technique
RSA:	Republic of South Africa
SEMDSA:	Society for Endocrinology, Metabolism and Diabetes of South Africa
SSKN's:	Socio-spatial knowledge networks
UK:	United Kingdom
UN:	United Nations
USA:	United States of America
WHO:	World Health Organization

CHAPTER 1
Perspectives on Diabetes Mellitus

1.1 INTRODUCTION AND BACKGROUND

"Diabetes poses a special challenge because it is possibly under-diagnosed, and subjected to the 'rule of halves' – only half of all cases of diabetes are diagnosed, only half of those diagnosed treated, and only half of those having treatment are managed effectively" (McKinlay & Marceau, 2000: 758). The International Diabetes Federation (IDF) estimates that as many as 175 million people worldwide, or close to half of all people with diabetes are unaware of their condition; most of these people have type 2 diabetes[1] (IDF, 2013: 38). According to the Centers for Disease Control (CDC) prevalence estimates indicate that as much as 27.8% of diabetes cases in the United States of America (USA) remain undiagnosed (CDC, 2014).

Diabetes mellitus is a complex metabolic disorder that remains poorly understood and managed. Type 2 diabetes is a degenerative, life-style disease and can, like a large number of present-day chronic diseases, sometimes referred to as non-communicable diseases (NCDs) be contextualised in the late phase of the classical model of the epidemiological transition[2]. The disease is also one of the most common chronic conditions in nearly all countries, and its prevalence continues to increase as lifestyles change. Diabetes has a major impact on the health system, and on community resources, and poses a life-long burden on the quality of life of individuals living with diabetes. Sustainable self-care management of a chronic condition such as diabetes may prevent the onset of clinical complications and delay the progression of the disease.

[1] Type 2 diabetes results from the body's ineffective use of insulin (Section 1.2.2) (WHO, 2011a:1)
[2] The epidemiological transition reflects various shifts in demographic and disease profiles (Omran, 1971; Bradshaw et al. 2003)

Health and disease patterns worldwide have changed over the last two centuries from acute, infectious diseases to chronic, lifestyle-related health conditions. As the leading cause of death globally, NCDs were responsible for 38 million (68%) of the world's 56 million deaths in 2012. More than 40% of them (16 million) were premature deaths under 70 years of age. Almost three quarters of all chronic disease deaths (28 million), and the majority of premature deaths (82%), occur in low- and middle-income countries. In terms of the burden of disease, measured in disability adjusted life years[3] (DALYs) diabetes was directly responsible for 1.5 million deaths in 2012 and 89 million DALYs (WHO, 2014).

According to the United Nations (2012) some progress has been made in addressing NCDs since the adoption of the Political Declaration of the High-level Meeting of the [United Nations] General Assembly in 2011. However, progress remains uneven and the response does not match growing needs, particularly in low- and middle-income countries. The adverse human, social and economic consequences of NCDs are felt by all societies and economies, but they are particularly devastating in poor and vulnerable populations. Addressing NCDs is now recognised as a priority not only for health but also for social development and investments in people (WHO, 2014: xi).

In 2005, Strong, Mathers, Leeder and Beaglehole (2005: 1581) argued that the serious consequences of NCDs and their risk factors are not recognised by the international community. In particular, the view that chronic conditions are often characterised as "problems of affluent, ageing communities that acquired them through risk factors such as tobacco use, unhealthy diets and physical inactivity, is inaccurate because chronic disease is a bigger problem in low-income countries where people do not have the resources to pursue healthy choices easily". The cost of treating chronic health conditions, together with, in some instances, the inability to work can lead to continued expenditures that trap poor households in cycles of debt and illness. Ten years later (2015) the

[3] Disability-adjusted life-years (DALYs) are a summary metric of population health. DALYs represent a health gap; they measure the state of a population's health compared to a normative goal (Murray et al. 2012: 2199)

status quo remains in many developing countries. People with diabetes require at least two to three times the health care resources compared to those who do not have the condition, while diabetes care may account for only up to 15% of national health care budgets (Zhang et al. 2010; Guariguata, Whiting, Hambleton, Beagley, Linnenkamp and Shaw, 2014). In September 2011, world leaders agreed on a roadmap of concrete commitments to address the global burden of NCDs, including a commitment to establish multisectoral action plans and policies for the prevention and control of NCDs (WHO, 2014: xi).

1.1.1 Global overview of diabetes

Globally, diabetes is a leading cause of death and a major source of morbidity. Systematic analyses of the work of a wide spectrum of scientists working and publishing in the field of diabetes vary in terms of diabetes prevalence and incidence estimates. According to Danaei et al. (2011: 37), the differences between estimates could be explained *inter alia* by the application of various inclusion and exclusion criteria; the number of studies analysed; different patient age ranges of diabetes estimates; different methods applied to deal with missing data; the year of data collection; rural and urban data; and national versus subnational and community data. Scientists acquire diabetes epidemiological data mostly from the IDF (Prof. D Van Zyl, Head of the Diabetes Clinic at Kalafong Provincial Academic Hospital, University of Pretoria, personal communication, October 3, 2014), the World Health Organization (WHO), and country-specific expert diabetes organisations such as the Society for Endocrinology Metabolism and Diabetes of South Africa (SEMDSA).

According to Wild, Roglic, Green, Sicree and King (2004:1047), in 2000 the number of adult diabetes sufferers (20 years and older) worldwide was estimated at 171 million, which is 11% higher than the previous estimate of 154 million. Wild et al. (2004: 1050) estimated the worldwide prevalence of diabetes among all age groups at 2.8% in 2000 and projected that it will be 4.4% by 2030. On the occasion of World Diabetes Day 2010, the Regional Director of WHO (2010:1) estimated that 220 million people worldwide suffer from

diabetes, and that by the year 2030 this number is likely to more than double if effective interventions are not undertaken. Shaw, Sicree and Zimmet (2010: 5, 9-10) produced estimates that updated the previous IDF estimates for 2003 and 2006, and include all 216 countries that are member states of the United Nations (UN). These estimates indicate that the world prevalence of diabetes among adults (aged 20 to 79 years) was 6.4% in 2010, affecting 285 million adults, and will increase to 7.7% by 2030 (439 million adults).

A systematic analysis of global patterns of glycaemia and diabetes by Danaei et al. (2011: 37) shows that diabetes is a rising global hazard, with the number of adults living with diabetes having more than doubled over nearly three decades to an estimated 347 million people for 2010. This estimate is in contrast with the estimate of 285 million for 2010 by Shaw et al. (2010: 12). The IDF (2013: 34), in its sixth edition of the Diabetes Atlas, reports an even higher estimate of 382 million people in 2013 worldwide, or 8.3% of adults having diabetes, of whom about 80% live in low- and middle-income countries. The IDF (2013: 34) estimates that by 2025, if these trends continue, some 592 million people, or one adult in 10, will have diabetes – equating to approximately three new cases every 10 seconds, or almost 10 million per year.

Most of the population growth between 2000 and 2030 is expected to be in urban areas, while the major demographic change will be an increase in the proportion of the population older than 65 years (Wild et al. 2004: 1049). Population growth, aging, urbanisation, and the increasing prevalence of obesity and physical inactivity are the most important determinants for the worldwide increase in the incidence of diabetes. Based solely on urbanisation and population ageing, even if the prevalence rate of obesity remains stable until 2030 (which seems unlikely), the number of people with diabetes in the world is expected to double between 2000 and 2030 (Wild et al. 2004: 1047-1051).

In 2004, Wild et al. (1047, 1050-1051) estimated that the greatest relative increases in the number of people with diabetes were expected in the Middle

Eastern Crescent, sub-Saharan Africa, and India. The highest regional prevalence rates for 2010 (after age-standardisation to the world population) were for North America, followed by the Eastern Mediterranean and Middle-East (EMME) and South Asia. “The African region is expected to have the largest proportional increase in adult diabetes numbers by 2030, followed by the EMME, while North America will continue to have the world’s highest diabetes prevalence” (Shaw et al. 2010: 9). The WHO Global status report (WHO, 2011b: 24) on NCD’s states that the high rate of urbanisation, combined with a high prevalence of obesity, is one of the most important determinants for the increase in the incidence of diabetes in developing countries, including the African region.

The 2013 global numbers of people with diabetes reflect a small gender difference, with 14 million more men (198 million) than women (184 million); the difference is expected to increase by 2035 to 15 million more men with diabetes than women (IDF, 2013: 34). However, while diabetes prevalence is higher among men than in women, in actual numbers, more women than men have diabetes. The increasing prevalence of diabetes with age, combined with the greater number of elderly women than men, is a possible explanation for the gender discrepancies. According to the IDF (2013: 34-35), almost half of all adults with diabetes are between the ages of 40 and 59 years old. More people with diabetes live in urban (246 million) than in rural (136 million) areas, although the figures for rural areas are on the increase IDF (2013: 35).

It is difficult to obtain accurate estimates of mortality attributable to diabetes with the currently available data, and any attempt to do so is based on a set of assumptions (Roglic & Unwin, 2010: 18). The WHO (2008:1-2) estimated that 1.1 million people died in 2005 from diabetes. Almost 80% of diabetic deaths occur in low and middle-income countries, and almost half of diabetes deaths occur among people under the age of 70 years. These mortality figures underestimate the true burden of diabetes − although people may live with diabetes for many years, their immediate cause of death is usually recorded as heart disease or kidney failure (WHO, 2008). Taking into account deaths in which diabetes was a contributory condition, approximately 3.4 million deaths

per year (as at 2004) could be attributable to the consequences of high blood glucose levels (WHO, 2011a). Diabetes and its complications are a major cause of mortality; while cardiovascular disease is one of the leading causes of death among people with diabetes, accounting for 50% or more of deaths due to diabetes in some populations (Roglic & Unwin, 2010: 19; IDF, 2013: 46). The overall risk of dying among people with diabetes is at least double the risk of their peers without diabetes (Roglic & Unwin, 2010; IDF, 2013). Furthermore, diabetes and its complications impose significant economic consequences on individuals, families, health systems and countries (Zhang et al. 2010).

Worldwide, the increase in diabetes is linked to an increase in obesity. The WHO (2011c:1) reports that "in 2008 more than 1.5 billion adults, 20 years and older were overweight – and of these more than 200 million men and 300 million women were clinically obese. Current obesity levels range from below 5% in China, Japan and certain African nations, to over 75% in urban Samoa. But even in relatively low prevalence countries like China, rates are almost 20% in some cities. Childhood obesity has already assumed epidemic proportions in some areas and is on the rise in others. An estimated 17.6 million children under five are estimated to be overweight worldwide". There is increasing evidence that the nature and structure of dietary intake and the prevalence of obesity around the developing world have been changing at an increasingly rapid pace over a period of time; at a much faster pace than in higher-income countries.

According to WHO (2014), obesity has been increasing in all countries. In 2014, 39% of adults aged 18 years and older (38% of men and 40% of women) were overweight. The worldwide prevalence of obesity nearly doubled between 1980 and 2014. In 2014, 11% of men and 15% of women worldwide were obese. Thus, more than half a billion adults worldwide are classed as obese. The prevalence of overweight and obesity is highest in the Region of the Americas (61% overweight or obese in both sexes, and 27% obese) and lowest in the South-East Asia Region (22% overweight in both sexes, and 5% obese). In the European and Eastern Mediterranean Regions and Region of the Americas, over 50% of women are overweight, and in all three regions roughly half of

overweight women are obese (25% in the European region, 24% in the Eastern Mediterranean Region, 30% in the Region of the Americas). In all WHO regions, women are more likely to be obese than men. In the African, South-East Asia and Eastern Mediterranean regions, women have roughly double the obesity prevalence of men.

Given these alarming figures, of the increasing burden of obesity and number of people with diabetes, the overall goal of the Diabetes Unit of the WHO is to improve health through stimulating and supporting the adoption of effective measures for surveillance, prevention and control of diabetes and its complications, particularly in low and middle-income countries (WHO, 2014).

1.1.2 Overview of diabetes in Africa

Although Africa is the second largest continent, with an estimated population of 1.033 billion people (Haub & Kaneda, 2013; StatsSA, 2013), epidemiological data on diabetes in Africa using WHO standardised criteria, is scanty (Levitt, 2008; Danaei et al. 2011; Hall, Thomsen, Henriksen & Lohse, 2011). In a review of health examination surveys and epidemiological studies that included 370 country-years and 2.7 million participants, Danaei et al. (2011: 35) could not identify any population-based data for 92 countries, with central Asia, central and eastern Europe, and sub-Saharan Africa having the largest proportion of countries without data.

Selected studies done in Africa before the 1980/1989 WHO criteria were introduced, showed diabetes prevalence rates ranging between 0% and 1% of the population; while six studies have reported prevalence rates of more than 1% (Motala, Omar & Pirie, 2001: 225). Another review by the same authors found that the prevalence of type 2 diabetes mellitus on the continent has increased since 1993, with reported rates varying from low (in some rural areas) to moderate (some countries in north and north east Africa, and South Africa) and high (among urban communities in Cairo and populations of mixed Egyptian ancestry in northern Sudan) (Motala, Omar & Pirie, 2003: 78-80). Hall

et al. (2011: 1), state that the prevalence of diabetes in Africa among adults aged 25 to 64 years ranges from 3% to 14.5%. They further report that an estimated 12.1 million people in Africa were living with diabetes in 2010, which is projected to increase by 98% to 23.9 million by 2030. The Diabetes Atlas (IDF, 2013: 56) reported an estimate of 19.8 million adults with diabetes in 2013, with a prevalence of 4.9% for the Africa Region.

Some of Africa's most populated countries have the highest numbers of people with diabetes, including Nigeria (3.9 million); South Africa (2.6 million); Ethiopia (1.9 million); and Tanzania (1.7 million), with more than half of all people with diabetes in Africa living in just these four highly-populated countries (IDF, 2013: 56). Furthermore, the Regional Director, WHO Africa Region (2010:1) stated: "A high proportion of diabetes cases remain undiagnosed and many cases are diagnosed late, usually after complications became evident". According to the IDF (2013: 39) the proportion of undiagnosed cases in middle-income African countries is 46.0%, while for low-income African countries it is 75.1% (IDF, 2013: 56).

As the rate of urbanisation increases in Africa, lifestyles change in both urban and rural areas, and both obesity and diabetes become more prevalent (Mbanya & Ramiaya, 2006). According to Shaw et al. (2010: 9), the Africa Region is expected to have the largest proportional increase in adult diabetes by 2030. Multi-faceted multi-disciplinary research is vital to identify the root causes and trends in the epidemiological transition to an increasing prevalence of diabetes in Africa (Mbanya, Motala, Sobngwi, Assah & Enoru, 2010: 2263). In 2013 an estimated 522 600 people in the Africa Region died from diabetes-related causes (IDF, 2013: 56). Although only 8.6% of all deaths in Africa can be attributed to diabetes, 76.4% of those deaths occurred in people under the age of 60 years (IDF, 2013: 56). Diabetes-related deaths in women were more than 50% higher than such deaths in men (IDF, 2013: 56).

According to Webb, Rheeder and Van Zyl (2014: 2), the burden of NCD's in sub-Saharan countries is already proportionally greater than that found in developed countries. The prevalence of diabetes and other NCD's in sub-

Saharan Africa is increasing rapidly; as a result of changes in lifestyle, urbanisation and population aging, and diabetes together with other NCD's is predicted to double within the next 20 years (Levitt, 2008: 1377). The available estimates for sub-Saharan Africa in 2000 attributed 2.2% of all male deaths and 2.5% of all female deaths to diabetes (Levitt, 2008: 1380). Mbanya et al. (2010: 2254) reported the projected growth for sub-Saharan Africa to be the same as the estimates reported by Hall et al. (2011: 1) for the African region, namely an increase from 12.1 million people in 2010 to 23.9 million in 2030 (growth of 98%).

1.1.3 Overview of diabetes in South Africa

In South Africa disease patterns have not only moved back to infectious diseases, but according to Bradshaw et al. (2003), and Mayosi, Flisher, Lalloo, Sitas, Tollman and Bradshaw (2009), the country is experiencing a quadruple burden of disease, namely infections like HIV and AIDS, emerging chronic diseases, violence and injury, as well as poverty-related conditions, thus creating new challenges for health care and the epidemiology[4] of disease. Chronic diseases such as heart disease, stroke and diabetes mellitus are, among the most common, costly and preventable of all the health problems in South Africa (Steyn, Fourie & Temple, 2006). According to a burden of disease analysis by Day, Groenewald, Laubscher, Chaudhry, Van Schaik and Bradshaw (2014: 682) NCDs have become the largest broad cause of years of life lost (YLLs) in South Africa. In 2009, YLLs due to NCDs exceeded those from communicable and related causes; with cerebrovascular, hypertensive and ischaemic heart disease in the leading ten age standardised causes of death in all South African metropolitan areas (Day et al. 2014: 685).

According to Bradshaw, Norman, Pieterse, Levitt and the South African Comparative Risk Assessment Collaborating Group (2007: 702), the

[4] Epidemiology as a systematic scientific investigation derives from the work of John Snow (1854). Epidemiology is concerned with the distribution of disease anddeath, together with their determinants and consequences within population groups (Krieger, 2001).

prevalence of diabetes was estimated in 2000 at 5.5% of the population of South African adults 30 years and older, and varied by age and sex. The IDF Diabetes Atlas (2003) reported a prevalence figure of 3.4% among the 24 million South Africans between the ages 20 and 79, with an expected increase to 3.9% by 2025. Information on diabetes prevalence and incidence is lacking, but based on available epidemiological data (as at 2011), approximately 1 to 1.9 million South Africans were considered to have diabetes (IDF, 2011). However, the 2009 estimates of Levitt (2009: 53) indicate that approximately 2 million people in South Africa were living with diabetes. Levitt (2008: 1378) indicated that the number of people with diabetes can be expected to grow as a consequence of population growth and ageing. According to a study by Motala et al. (2012: S4) the Society for Endocrinology, Metabolism and Diabetes of South Africa (SEMDSA), estimated the South African diabetes prevalence in 2011 for adults aged 20 to 79 years at 6.5%. The most recent IDF Diabetes Atlas (2013: 124) reports that in 2013 an estimated 2.65 million among the 24 million adults 20 to 79 years old in South Africa had diabetes, with a national prevalence of 8.27%. Guariguata et al. (2014: 137) confirm the large burden of diabetes, especially in developing countries, including South Africa. Guariguata et al. (2014: 139) estimated the South African national prevalence for 2035 adjusted to the national population at 9.9%. While these data are available for South Africa as a whole, there is no recent data by the four main population groups.

A study conducted in 2008 in rural South Africa found that only 15.2% of the people with diabetes were known to have the condition (Motala, Esterhuizen, Gouws, Pirie & Omar, 2008: 1786). Motala et al. (2008: 1786) in their previous studies in urban South Africa found that more than 50% of people with diabetes were known to have the condition, which is comparable with developed countries. These authors are of the opinion that the lower percentage of people with diabetes in rural South Africa, who know about their condition compared to the higher urban awareness, reflects better access to health care facilities in urban areas (Motala et al. 2008: 1786). According to Harris et al. (2011) this view posits an indication that there is a disparity between the urban and rural

areas in South Africa in terms of health care facilities and health care access. Marten, McIntyre, Travassos, Shishkin, Longde, Reddy and Vega (2014: 2168) in an assessment of progress towards universal health coverage in Brazil, Russia, India, China, and South Africa, confirm that there is an absolute shortage of health workers and an unequal distribution between the public and private sectors and the urban-rural distribution of resources in South Africa. The South African health system is inequitable and inaccessible for a substantial part of the South African population (SouthAfrica.info, 2015).

A 1996 analysis of mortality patterns in South Africa by MRC, reported that 41% of reported mortality was due to NCD's. In 1996, 487 people died per day due to NCD's, rising to 536 deaths per day in 2001 (MRC, 2001). An estimated 20 000 deaths (that is 4.3% of all deaths in 2000), could be attributed to diabetes (Bradshaw et al. 2007: 703). According to Bradshaw, Schneider, Norman and Bourne (2006: 13) studies of mortality trends (*chronic diseases of lifestyle)* have been "restricted to selected population groups as a result of the limited available data". South Africa might be further along the epidemiological transition than many other sub-Saharan countries when excess mortality due to diabetes was taken into account (Bradshaw et al. 2007). This places diabetes as the seventh most common cause of death in South Africa, compared to the fifth place of diabetes in a global study of the same year – with the South African estimate falling between the lowest mortality (2.4%) reported for the poorest African and Western Pacific countries, and the highest mortality (9%) in the Arabian Peninsula, East Mediterranean region, Canada and the USA (Bradshaw et al. 2007: 703). These estimates reflect deaths where diabetes was the underlying cause, but excludes the many deaths resulting from cardiovascular disease or renal failure associated with diabetes (Bradshaw et al. 2007). Analyses by Statistics South Africa (STATSSA) (2014: 27) indicate that diabetes mellitus was the firth leading cause of death in South Africa, with 26104 (4,1%) deaths in 2011; 21820 (4,4%) in 2012; and 22196 (4,8%) deaths in 2013. These analyses indicate a clear increasing gradient of death due to diabetes.

The lack of information about the prevalence of diabetes is exacerbated by the fact that there is also inadequate data on diabetes risk factors and complications; thus the urgent need for studies to determine the outcomes and determinants of diabetes in South Africa (Rheeder, 2003: 88). According to Motala et al. (2012: S4) the lack of accurate diabetes prevalence statistics and the worldwide tendency of underreporting, as well as the masking by other co-morbid factors mean that at the time of eventual diagnosis, approximately 20% of patients will already have clinical complications due to their previously undiagnosed condition. The burden of disease analysis by Day et al. (2014: 682) provides some perspective about the contribution of NCDs to YLLs in South Africa. According to Day et al. (2014: 686) the South African National Health and Nutrition Examination Survey conducted by Shisana et al. (2014) is expected to provide rich data for the evaluation of NCDs.

The effects of the rapid increase in urbanisation and unhealthy lifestyles, combined with high levels of hypertension and obesity, contribute to an increase in the prevalence of diabetes amongst Black South Africans – this increase in the prevalence of diabetes amongst Black people needs to be seen within the context of a lack of sufficient prevalence statistics for all population groups (Westaway, Seager, Rheeder & Van Zyl, 2003: 75). A recent study among urban-dwelling Black South Africans by Peer, Steyn, Lombard, Lambert, Vythilingum and Levitt (2012) posits that the high prevalence of diabetes and impaired glucose tolerance (IGT) may be attributed to the high rate of some of the diabetes risk factors such as obesity. Peer et al. (2012) found that raised adiposity, the most potent of the risk factors, was present in ≥50% of the total study sample, and in over 80% of participants with diabetes. The present high prevalence of diabetes in urban-residing South Africans, and the probability of further rises given the high rates of IGT and obesity, is alarming (Peer et al. 2012). Guariguata et al. (2014: 145) confirm that increases in obesity and other risk factors for diabetes could push the prevalence even higher over the next 20 years.

In general, the discrepancies in various estimates of diabetes statistics suggest an indication of the lack of standardised epidemiological data available globally,

but more specifically for the African and sub-Saharan regions, including South Africa.

1.1.4 Brief introduction to diabetes health care management

This section only briefly introduces the topic of diabetes health care management; an extensive discussion about the role of health care systems in diabetes self-care management is presented in Chapter 2 (Section 2.5). The growing public health burden of the diabetes epidemic across the world, which has resulted in increasing numbers of deaths from cardiovascular disease as well as associated complications, generates substantial human and economic costs. The prevailing public health care service provision model across most of the sub-Saharan African region focuses mainly on acute illnesses, and episodic interaction between the patient and the health care provider – a model that does not provide adequate care for patients with chronic health conditions (Steyn & Damasceno, 2006: 261; Bloom et al. 2011).

The human and economic costs of the diabetes epidemic, quantified within the context of the rapid urbanisation of the South African population pose major challenges to programme managers, health care staff and human and financial resources. The current health system in South Africa is based on a multi-level service structure with a public sector and a private sector; with the public health sector structured on national, provincial and local levels. The public sector provides services for the majority of the population, while the private sector provides services for the privately-insured minority (Coovadia, Jewkes, Barron, Sanders & McIntyre, 2009: 826-827). According to Coovadia et al. (2009: 327) there is a significant disparity in resource availability between public and private sectors; less than 15% of the population are members of private medical schemes, yet 46% of all health-care expenditure is attributable to these schemes. A further 21% of the population use the private sector on an out-of pocket basis mainly for primary level care, but are generally dependent on the public sector for hospital care. The remaining 64% of the population are entirely dependent on the public sector for all their health-care services (Coovadia et al.

2009: 327). A more recent study by Mayosi and Benatar (2014: 1345 & 1346) in a special report on 'Health and Health Care in South Africa – 20 Years after Mandela', posits that approximately 84% of the population are uninsured and make use of the national public health sector, while up to 25% of these uninsured people pay out of pocket for private-sector health care. The public sector is stretched and under-resourced in places, while the growing private sector, runs largely on commercial lines, provides for 18% of the population, mainly from the middle- and high-income groups who tend to be members of medical schemes (SouthAfrica.info, 2015).

Health care policies in South Africa are formulated at the national level while the nine provincial health care systems are responsible for the execution of the policies, which includes the provision of curative care, and in some regions also primary health care. At the local level, the District Health System is the direct service provider through the primary health care clinics (Coovadia et al. 2009). Chronic conditions in developing countries are usually managed at the primary health care level (Webb et al. 2014: 2). However, in South Africa, public primary health care services are provided by both provincial and local government health systems. The current policy guidelines in South Africa for the management and treatment of diabetes at primary health care level include recommendations for annual blood tests for both glycaemic and lipid control, as well as screening for complications linked to the feet, eyes, kidneys and heart (Department of Health, 2005; Webb et al. 2014: 2). However, limited data is available on the quality of diabetes care in South Africa (Webb et al. 2014: 2). Available statistical data provides an indication that diabetes has become not only a worldwide health burden, but a specific problem in sub-Saharan Africa; South Africa provides opportunities to conduct social epidemiologic research in order to investigate some of the challenges of diabetes health care management.

1.2 THE CONDITION DIABETES MELLITUS

The term *diabetes* is derived from the Ionian Greek meaning 'to pass through', while *mellitus* refers to the sweet honey-taste nature of the urine, to distinguish it from other polyuric states, where the urine is tasteless (Ekoe' & Zimmet, 2001: 7). Diabetes mellitus (DM) is defined by SEMDSA (Motala et al. 2012: S5) as "a metabolic disorder with heterogeneous aetiologies which is characterised by chronic hyperglycaemia[5] and disturbances of carbohydrate, fat and protein metabolism resulting from defects in insulin secretion, insulin action or both. The long-term relatively specific effects of diabetes include development of retinopathy, nephropathy and neuropathy. People with diabetes are also at increased risk of other diseases, including cardiac, peripheral arterial and cerebrovascular disease".

The WHO (2008:1) describes diabetes mellitus as a chronic disease that occurs when the pancreas does not produce enough insulin, or when the body cannot respond to the insulin it produces, a condition described as insulin resistance, or a combination thereof. Insulin is a hormone that regulates blood glucoes levels. As a metabolic disorder, diabetes is characterised by elevated blood glucose levels (hyperglycaemia), which is a common effect. Uncontrolled blood glucose levels can lead to serious damage to many of the body systems, especially the peripheral nerves and blood vessels (WHO, 2008:1). Diabetes mellitus is classified into three principal types, namely type 1, type 2, and gestational diabetes. However, various other types of diabetes also exist (Mbanya & Ramiaya, 2006: 267; WHO, 2008:1). For the purposes of this study, only the first three types of diabetes are briefly discussed. Most data sources do not distinguish between type 1 and type 2 diabetes in adults; thus it is not possible to present systematic data on global, African or South African prevalence rates separately for the subtypes. The following sections present selected available data to indicate the broad differences between the prevalence rates, demographic characteristics and treatment methods related to the three subtypes of diabetes.

[5] The term *hyperglycaemia* refers to elevated blood glucose levels (Motala et al. 2012)

1.2.1 Type 1 diabetes

Type 1 diabetes mellitus, previously known as insulin-dependent or childhood-onset diabetes mellitus is characterised by a lack of insulin production and without the daily administration of insulin, is rapidly fatal. Type 1 diabetes, which accounts for 5% of cases, is usually caused by beta-cell destruction, leading to an absolute insulin deficiency (Motala et al. 2012: S6). The onset of type 1 diabetes is usually acute and the diagnosis is unequivocal hyperglycaemia (Motala et al. 2012: S6). According to the WHO (2014), the cause of type 1 diabetes is unknown and it is not preventable with current knowledge about the condition. The standard medical treatment for patients with type 1 diabetes consists of insulin therapy, namely the injection of exogenous insulin (Timmermans & Haas: 2008: 667; Motala et al. 2012: S76). Patients diagnosed with type 1 diabetes mellitus are usually younger than thirty years, have a lean body weight, and are otherwise healthy (Motala et al. 2012: S6).

It is widely believed that classical type 1 diabetes is less common in Africa than in Europe or North America (Gill, Mbanya, Ramiaya & Tesfaye, 2009: 11). Nevertheless, data for the epidemiology of type 1 diabetes in sub-Saharan Africa is scarce and estimation of the prevalence is an unanswered research question (Motala, Omar & Pirie, 2003: 82; Levitt, 2008: 1378, 1381; Hall et al. 2011: 2). An unexplained aspect of African type 1 diabetes is that the age of onset is about 10 years later than elsewhere in the world (Gill et al. 2009: 11). In a long-term follow-up study of a type 1 diabetes cohort in Johannesburg, South Africa, it was found that the mean age at presentation was 23 years for Black South African type 1 patients, in comparison to 13 years for White South African patients (Kalk, Huddle & Raal, 1993: 553). In a recent clinical study in the Tshwane District, South Africa, the self-reported prevalence of type 1 diabetes was 3.7% (Webb et al. 2014: 2).

The management of type 1 diabetes is different from other chronic conditions because its successful treatment depends on self-care with family involvement and support, in terms of taking responsibility for the implementation of the

complex treatment regimen (Faulkner & Chang, 2007: 66; Dr L. Schoeman, Project Leader, Kalafong Diabetes Lifestyle Research Project, personal communication, August 9, 2014).

1.2.2 Type 2 diabetes

Type 2 diabetes mellitus, formerly called non-insulin-dependent or adult-onset diabetes mellitus, results from the body's ineffective use of insulin. About 90% of people with diabetes around the world have type 2 diabetes, which is largely the result of excess body weight and physical inactivity (WHO, 2011a: 1). Of all patients with diabetes worldwide, about 90% have type 2 diabetes and it is also the predominant form of diabetes in sub-Saharan Africa (Levitt, 2008: 1376). Type 2 diabetes is associated with obesity, in particular the concentration of adipose tissue around the abdomen, therefore weight loss and physical activity are encouraged (Timmermans & Haas: 2008: 667; CDC, 2014). The IDF (Mbanya et al. 2010: 2258) estimated that the peak onset in 2010 for type 2 diabetes was in the 40 to 59 year age group. However, it is predicted that by 2030 the highest prevalence will be in the oldest age group of 60 to 79 years old (Mbanya et al. 2010: 2258). In sub-Saharan Africa, diabetes prevalence increases with age and most reports indicate a peak at either 55 to 64 years, or 65 years and older (Mbanya et al. 2010: 2258). "The link between urbanisation, sedentary lifestyles, unhealthy eating, rising levels of obesity and type 2 diabetes has been demonstrated universally" (Motala et al. 2012: S4). The same authors state that effective prevention of obesity and type 2 diabetes requires a paradigm shift from a patient-centred approach to a "whole of government" and a "whole of society" approach.

The prevention and management of type 2 diabetes mellitus poses major challenges to the health system. The medical treatment of type 2 diabetes mellitus consists of orally administered medication and injected insulin therapy (Motala et al. 2012). Metformin is well established as the primary 'anchor' oral anti-diabetic agent in the management of type 2 diabetes. Patients with type 2

diabetes mellitus often also require insulin based therapies to achieve glycaemic control (Motala et al. 2012).

In 2002 the Diabetes Prevention Program Research Group (DPPRG, 2002: 393) conducted a randomised control study comparing lifestyle intervention to Metformin in the prevention of type 2 diabetes. The results show that lifestyle changes and treatment with Metformin both reduced the onset of diabetes in persons at high risk, but that lifestyle intervention is more effective than Metformin. The DPPRG (2002: 393) study investigated the persistence of these effects over ten years and found that the prevention or delay of onset of diabetes with both lifestyle intervention and Metformin can be delayed for at least 10 years.

Katula et al. (2010: 79, 80) conducted a community-based diabetes intervention programme which consisted of mediated cognitive behavioural meetings occurring weekly for six months, and monthly thereafter for 18 months. The primary outcome was lower fasting blood glucose levels, with secondary outcomes related to cardiovascular risk factors, health-related quality of life, and social cognitive variables. The results show that a community-based programme that is administered through local community members may be a promising strategy for the widespread dissemination of interventions effective in preventing type 2 diabetes in high risk individuals (Katula et al. 2010).

1.2.3 Gestational diabetes

Gestational diabetes mellitus (GDM) refers to hyperglycaemia which is first recognised during pregnancy and the pregnant women are most often diagnosed through prenatal screening (WHO, 2013); the symptoms are similar to those of type 2 diabetes. GDM is a growing health concern with serious, long-term consequences for both baby and mother (Reece, Leguizamon & Wiznitzer, 2009: 1794). An accurate estimation of the global incidence of GDM in many countries does not exist because of the lack of uniform standards in glucose tolerance testing around the world (WHO, 2014). Maternal obesity and

postpartum factors such as breastfeeding may intensify the in-utero effects of GDM, while factors such as race and ethnic variation may also play a role (Page, Romero, Buchanan & Xiang, 2014: 807). GDM is more frequent in certain ethnic groups than in the general population (Reece et al. 2009: 1789). An example of this is a study conducted in the USA, in which an ethnically mixed population of women with diabetes who entered a prenatal care programme found that African American women had significantly poorer glycaemic control than did other racial groups (Lawrence, Contreras, Chen & Sacks, 2008: 903).

A systematic literature review of 28 GDM studies by Kim, Newton and Knopp (2002: 1862, 1866) found that the cumulative incidence of progression to type 2 diabetes varies widely – even though intervention in patients with impaired glucose tolerance has been demonstrated to delay the onset of type 2 diabetes. The targeting of women with GDM to engage in preventive behaviours may prove to have the greatest effect in preventing progression to type 2 diabetes (Kim, Newton & Knopp, 2002: 1866). Two studies from 1990 to 2011 in rural and urban South Africa, found a GDM prevalence of 1.5% and 3.8% respectively among women of child-bearing age (Hall et al. 2011: 5).

1.2.4 Self-care management of diabetes

This section only provides a brief overview about diabetes self-care management, since an extensive discussion about self-care management is presented in Chapter 2 (Section 2.4.1). Effective integrated diabetes self-care management programmes require comprehensive efforts from multiple stakeholders, including international organisations, academic institutions, civil society and the private sector (Hall et al. 2011: 9). The need for self-management support is well documented in most diabetes education studies, but it has taken place mostly in clinical settings and has targeted those with a high HbA1c[6] (usually ≥7%) (Lorig, Ritter, Villa & Armas, 2009: 641, 648-650). Both type 1 and type 2 diabetes mellitus (referred to in the rest of the text

[6] HbA1c is the ratio of glycosylated haemoglobin to total haemoglobin (Lorig et al. 2009).

mainly as *diabetes*) need to be managed effectively and sustainably[7] in order to prevent life-threatening clinical complications. The results of the Finnish "Diabetes Prevention Study" (Illane-Parikka et al. 2008: 806) assessing the effects of lifestyle intervention on metabolic syndrome and its components, indicate that, with a mean follow-up of 3.9 years, a significant reduction in the prevalence of both metabolic syndrome and abdominal obesity was achieved in the intervention group compared to the control group.

Several studies have been conducted to evaluate the translation of hospital-based lifestyle education programmes into community-based programmes. Van Dam, van der Horst, van den Borne, Ryckman and Crebolder (2003: 18) found in a systematic review of eight published studies of diabetes self-care, that improvement of type 2 diabetes outcomes is impossible without the improvement of patient self-care management. In a study with the purpose of evaluating the feasibility of translating the Diabetes Prevention Program lifestyle intervention into practice in the general community in Montana, USA, the results indicate that 70% of participants achieved the physical activity goal of ≥150 minutes per week, and there was a significant decrease in the weight of participants from baseline to week 16 (Amundson et al. 2009: 209). A systematic literature review of thirteen studies on diabetes self-care management by Gucciardi, Chan, Manuel and Sidani (2013: 243), indicates that there is little understanding of interventions that promote behaviour change resulting in improved clinical outcomes, particularly in ethnically diverse populations.

1.3 RATIONALE AND JUSTIFICATION OF THE STUDY

John Cassel (1976), in his seminal lecture on the social environment and host resistance, claimed that a similar set of social circumstances characterises people's settings, notably those who developed tuberculosis, who became alcoholics, or committed suicide, and that all of them had a marginal status in society. This argument was mainly based on Emile Durkheim's (1951)

[7] Sustainability refers to the capacity to endure (Krieger, 2001).

explanation of the association between social isolation and suicide that signified the use of social facts to explain causes and patterns of disease. In sociological terms, the marginal status of people can be described as the lack of social integration that refers to the strength of the attachment that individuals have to society (Ritzer & Goodman, 2004:176). Subsequent to John Cassel's 1976, study, numerous researchers have documented the association between social isolation and non-adherence to the desired health behaviour with the resulting increase in morbidity and mortality (House, Landis & Umberson, 1988; Lubben, Weiler & Chi, 1989; Krause, Herzog & Baker, 1992; Potts, Hurwicz, Goldstein & Berkanovic, 1992; Rook, 1994; Stuck, Walthert, Nikolaus, Bula, Hohmann & Beck, 1999; Ceria, Masaki, Rodriguez, Chen, Yano & Curb, 2001). According to Lubben, Gironda, Sabbath, Kong, and Johnson (2015: 4) as a result of this overwhelming body of evidence, a special committee at the USA National Institutes of Health (National Research Council: NRC, 2001) issued a report that identified an area of behavioural and social sciences research questions whose resolution could lead to major improvements in the health of the USA population. Since the publication of the NRC report, evidence regarding the influence of social isolation on several measures of morbidity and mortality has grown sturdier (Berkman, Melchior, Chastang, Niedhammer, Leclerc & Goldberg, 2004; Lubben, Blozik, Gillmann, Iliffe, von Renteln Kruse, Beck & Stucket, 2006; Schnittger, Wherton, Prendergast, & Lawlor, 2012; Berkman, 2014). There has also been increased evidence of the influence of social isolation on self-reported health and well-being (Chan, Malhotra, Malhotra, & Ostbye, 2011; McHugh & Lawlor, 2012; Schnittger, Wherton, Prendergast, & Lawlor, 2012; Kimura, M., Yamazaki Haga, & Yasumura, 2013). The majority of these studies focused on social networks and social ties that can be contextualised on either the micro-social level or meso-social level.

The broad impact that social network integration has on all-cause mortality is one of the robust findings in the literature on networks and health. Based on examination of the pathways linking social networks to health outcomes, the assumption follows that social isolation, disintegration and disconnectedness influence mortality and longevity or life expectancy (Berkman, Glass, Brisette and Seeman, 2000: 851-852; Berkman, 2014). However, besides this large

number of studies, literature on the larger macro-social context within which social networks are formed and sustained is lacking, and is almost completely absent in studies of macro-level social network influences on health (Berkman et al. 2000: 843 & 853). According to Tomaka, Thompson and Palacios (2006) belonging support (characterised by interaction with friends, family, and other groups) was a consistent predictor of self-reported disease outcomes (including diabetes, hypertension, arthritis and emphysema) in an elderly population, while social integration has been shown to affect mortality from diseases such as diabetes (Zhang, Norris, Gregg & Beckles, 2007).

The social determinants of health refer to the overall features and pathways that indicate the vulnerability of populations to diabetes (Kaplan, 2004). To quote George Kaplan (2004:132), of the Center for Social Epidemiology and Population Health, University of Michigan, Ann Arbor: “A few years ago, a report from the Hastings Center called for an expansion of research on social determinants of health equal to that devoted to the human genome effort”. Current research focuses more on the clear definition of related concepts, the explanation of how social factors can cause diseases and the mechanism of diseases, as well as the most appropriate interventions (Syme, 2005: 4). Despite the lack of scientific studies on literature on the larger macro-social or population-based context are lacking, there has been an explosion of interest in the social determinants of health over the past several decades, from both a health science and social science perspective, with the initial impetus for this growth that began in sociology (Link, 2008: 368).

Reeder (1972: 97) defined social epidemiology as the “study of the role of social factors in the aetiology of disease,” and then added that “social epidemiology seeks to extend the scope of investigation to include variables and concepts drawn from a theory”. Therefore, Reeder (1972: 98-99) called for a unison of epidemiology and sociology, with the contribution of sociology the postulation of the concepts that capture social phenomena and the theories that provide explanations as to how social factors influence the onset and course of diseases. Kaplan (2004: 132) defined the distribution of health

outcomes and their social determinants as the study of social epidemiology. Therefore, the social epidemiology of diabetes refers to the investigation of social determinants of health, health behaviours, self-care management and health outcomes of a person with diabetes. An extensive discussion of social epidemiology is presented in Section 2.3 of Chapter 2. Link (2008: 368) reasserts Reeder's call for a union of sociology and epidemiology with the emphasis on the role that sociology must play in that association. Link (2008: 368) proposes for an emphasis on the role of sociology in understanding social determinants of health, using the term "epidemiological sociology," therefore making sociology the subject and epidemiology the modifier.

In addition to the argument for a union between sociology and epidemiology Hawe and Shiell (2007) assess that there is also an increasing move worldwide to shift the emphasis of population health research away from purely descriptive and analytic studies and towards the study of interventions to reduce health problems and reduce health inequities. This approach requires an appreciation of the best of what has been learnt from the diverse settings in which both health and social scientists have been working. Hawe and Potvin (2009: 1-18) also call for an integration of this learning to assist in the development of the relatively new overarching field of population health intervention research. Kindig and Stoddart (2003: 380) defined population health as "an approach that focuses on interrelated conditions and factors that influence the health of populations over the life course, identifies systematic variations in their patterns of occurrence, and applies the resulting knowledge to develop and implement policies and actions to improve the health and well-being of those populations".

According to Timmermans and Haas (2008:662), sociologists often study health and illness in a broader context, instead of taking the 'disease' aspects of medicine into account, which results in analytical 'holes'. The diagnoses, or disease aspects, should therefore be the starting point, from which the focus should be directed to the way in which people experience and address their various health problems. Timmermans and Haas (2008: 663) confirm this lack in the literature in their evaluation of the number of articles in *Sociology of*

Health and Illness, between 1997 and 2006, that dealt with the sociological understanding of the biological basis of disease. Although they did not focus on disease as a biological phenomenon, they found that only 21% (82 out of 387) of the original articles investigated a specific disease. They went further and reduced the articles to those dealing with disease as a health issue for patients and/or clinicians, and found that only 16%, or 60 out of 387, dealt per definition with the sociology of disease[8].

According to (Reblin & Uchino, 2008) interdisciplinary research viewpoints about the association between social integration and health are increasing but are still in the early stages. Reblin and Uchino (2008) concur that future studies must be able to explain the contexts and mechanisms for the association between social integration and health. This gap in the literature provides a fundamental argument that gave direction to the present study on the role of macro-social or population-based factors, including social integration, on health outcomes, particularly for diabetes. Research that interlinks the complex pathways of biological, socio-psychological and macro-social factors with health self-care and health outcomes will contribute to alleviating the gap in the present body of knowledge. The argument for this is that, although a lot is known about the personal characteristics of individuals with non-infectious chronic diseases like diabetes, little is known about the social determinants of the population prevalence rate. Individual- and population-based factors are the specific variables that indicate the individual and population risks of people susceptible to diabetes.

This study is therefore an attempt to address elements regarding the need for integration and contributes to the knowledge base about population-based[9] diabetes health lifestyle interventions. This study focuses on selected factors that are based in the population, in contrast to an individual-based[10] focus. The

[8] The sociological focus on a specific disease is classified as the sociology of disease (Timmermans & Haas, 2008).
[9] Population-based factors refer to social structural and social factors, including cultural context, social capital, social integration, neighbourhood effects (Poundstone et al. 2004)
[10] Individual-based factors refer to micro-level factors, including inter alia social support, social engagement and person-to-person contact (Rose, 2001: 427)

argument for a focus on population-based factors is further elucidated in Section 2.3.2 of Chapter 2. In order to direct the investigation into which determinants in the broader social environment affect the prevalence of diabetes, and to make a substantial contribution to the body of knowledge, a theory-based conceptual model (Figure 2.1) was developed for this study. The heuristic framework (Section 2.7.1 in Chapter 2) of social epidemiology contributes to an understanding of the socio-environmental factors that determine the pathways by which societal conditions affect the health of populations. The heuristic framework of social epidemiology (Poundstone, Strathdee & Celentano, 2004) builds on the classic epidemiological triangle (model) of agent, host and environment, and focuses on the role of social determinants in the aetiology and progression of disease. The Health Belief Model (HBM) of Irwin Rosenstock (1966) contributes to an understanding of the psycho-social factors that determine the health behaviour of individuals. These various frameworks and models (Poundstone et al. 2004; Cockerham, 2005) have been well documented over the past few decades and are powerful tools that have contributed to improved understanding of health behaviour. The most relevant elements of these frameworks and models, which directed this study, were integrated into the multi-level conceptual framework (Figure 2.1) and the theoretical framework that are presented in Chapter 2; and the research design in Chapter 3 (Figure 3.1 in Chapter 3).

The goal to attain more effective and sustainable diabetes self-care management is what motivated this qualitative study to focus on selected population-based factors. Therefore, this present study focuses on those questions that might provide possible answers to the underlying causes of diabetes, in particular, the causes of hyperglycaemia and societal factors that are conducive to the development of diabetes. The study departs from the social context of individual patients and is concerned instead with the population-based social epidemiology of diabetes mellitus: the distribution and complex changes and mortality patterns, social determinants and consequences related to type 1 and type 2 diabetes.

The social epidemiology of diabetes, and more specifically, the sociology of diabetes, adds to the understanding and explanation of some of the pathways, processes and mechanisms of the dynamic interplay between the biological health and social life of the diabetes patient. This approach necessitated the attainment of a new set of knowledge, skills and expertise, including information about the biology of diabetes by the researcher. The significance of this study relates to the theoretical engagement of sociology with the biology of, and clinical complications resulting from the ineffective self-care management of diabetes. The theoretical engagement of sociology with the social epidemiological research paradigms (namely the psycho-social approach, the social production of disease approach, and the eco-social approach) is significant in terms of the scientific field of the sociology of disease. The lack of scientific information about the sociology of diabetes in relation to self-care management justified research in this field. In addition, the lack of a scientifically verified health-lifestyle theory justifies a qualitative study from a population-based perspective.

The arguments in the literature review (see Chapter 2) about the *sociology of disease* justify a study that focuses on population-based factors, and illustrate the importance of a study that utilises the macro-social context of social networks and social connectedness to contribute to an understanding of the interlinking mechanisms that affect the self-care management of diabetes. Both the review of the sociology of disease and the population-based focus of the study can play an important role in contributing to filling the research gap between the macro-social context and the specific health conditions of a population.

1.4 RESEARCH PROBLEM STATEMENT

The global, African and South African extent of diabetes prevalence necessitates a study of the influence of population-based factors on the self-care management of patients with diabetes mellitus. Research that

interconnects the complex pathways of biological, socio-psychological and population-based factors with diabetes self-care management and diabetes health outcomes necessitates a qualitative sociological study of diabetes is necessary in order to contribute to an understanding of the social dynamics of diabetes, thus forming the basis for further qualitative research. This study does not claim to be an extensive quantitative population-based study, but rather a study that focuses on the investigation of the dynamics of selected factors that are based in the population and not factors that are located in the individual. The argument for this approach is enlightened in the rationale and justification of the study. An exploration of the interrelationships between population-based social-structural and social factors and health outcomes may help to identify diabetes progression indicators that should be considered when developing programmes for diabetes self-care management. Research into the social and organisational dynamics of diabetes self-care management programmes in the initial phase of implementation is crucial in order to identify both positive and negative consequences of current processes and systems, with a view to sustaining and improving health care service delivery. Based on the main arguments given in the rationale for this study (Section 1.3), in particular the research of Berkman et al. (2000); Berkman (2014); and Lubben et al. (2015) social integration and self-care management were identified as the two central factors or variables to be investigated in the study, and this is reflected in the research problem statement.

The research problem statement of this study is manifested in the need for a better understanding of population-based factors on various levels, namely meta, macro, and meso that influence and shape the beliefs about diabetes, its experience and health outcomes based on the management of diabetes self-care. This research problem statement is reflected in and derived from the deficiency of scientific research related to population-based factors that may cause ineffective self-care management of diabetes, leading in turn to uncontrolled blood glucose levels and a set of physiological complications. The complexity of this research problem was addressed by subdividing it into four completely researchable sub-problems. The variables reflected in the research

problem statement and sub-problems are contextualised and discussed in Section 2.6.2 in Chapter 2, including the contested position of the concept of 'social capital'. These sub-problems clarify the entirety of the research problem statement, and are tied to the interpretation of the data:

- The influence of demographic variables like age, and social changes such as urbanisation, migration and mobility, on the degree of social integration of the diabetes patient.
- The influence of socio-geographic factors, including the contested variable of 'social capital'[11] and neighbourhood effects that create social conditions conducive to sustainable self-care management by diabetes patients.
- The influence of the level of social integration on sustainable self-care management by diabetes patients.
- The lack of an indicative and integrated population-based model of sustainable self-care management of diabetes mellitus in South Africa, specifically in the Tshwane District.

The research sub-problem statements directed the research methodology (Chapter 3) of the study. Demographic and social changes, social capital, and place of residence are, *inter alia,* causal population-based factors that are dynamically linked with social integration. Figure 1.1 illustrates the contextualisation of these selected population-based factors in the research problem statement that might influence sustainable self-care management of diabetes.

[11] Social capital is defined as active aspects of social structures that facilitate collective action that would not be possible in the absence of social capital (Bourdieu & Wacquant, 1992). The meaning of the concept of 'social capital' continues to be contested - there are also some ambiguities concerning where exactly social capital resides, while the common criticism concerns its measurement (Islam, Merlo, Kawachi, Lindström & Gerdtham, 2006).

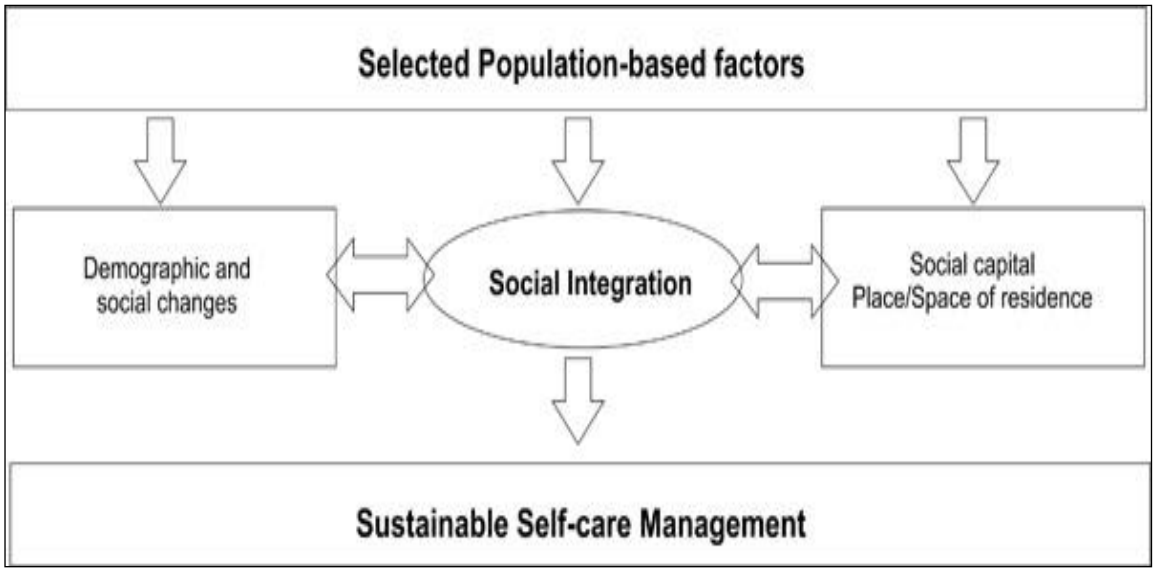


Figure 1.1: Contextualisation of the selected population-based factors
Source: The researcher's own construct

The figure shows that the focal point is social integration, with its interrelationship with demographic and social changes (such as age, gender, migration and urbanisation), as well as access to social capital and the effect of place of residence. These factors were utilised to direct the empirical research process in terms of the facilitation of the focus groups, while other possible related factors were identified from the responses of the participants. The same selected factors served as the variables to determine the nature and level of self-care management practised by diabetes patients.

1.5 RESEARCH QUESTIONS

The research questions emanate from the research problem statement and the sub-problems, and were formulated to precisely focus the thesis of the study. The overarching focus of the research questions relates to the population-based factors and characteristics that enhance vulnerability to diabetes and therefore place populations at risk of diabetes. The extensive and complex nature of the research problem statement and the overarching focus of the study were addressed by focusing on three research questions:

- How do socio-economic and socio-political determinants contribute to establishing and perpetuating inequalities in diabetes self-care management within populations?
- What population characteristics and social factors enhance the vulnerability of diabetes patients and place them at higher risk of ineffective self-care management, uncontrolled blood sugar levels, or clinical complications?
- What selected population-based factors influence resilience with regard to controlled blood sugar levels?

The research questions in combination with the research problem statement guided the research methodology of the study. The research problem and sub-problems, the aim and objectives, as well as the research questions were analysed through the lens of the multi-level conceptual framework (Section 2.6.1; Figure 2.1) formulated for the study.

1.6 AIM AND OBJECTIVES OF THE STUDY

1.6.1 Aim

The overall aim of this qualitative study was to explore selected population-based social determinants relevant to the implementation and sustainability of diabetes self-care management. The heuristic framework of social epidemiology, the classic epidemiological model, and the HBM referred to in the rationale and justification of the study (Section 1.3), were utilised to explore the interrelationships between socio-economic status and macro- and meso-level social factors in order to establish the critical transition to effective diabetes self-care management.

1.6.2 Objectives

The primary objective of the study was to identify the major upstream[12] population-based factors that may positively influence the sustainable self-care management[13] of diabetes.

The secondary objective of the study was to establish the social-structural and social factors that influence or play a major role in promoting sustainable diabetes self-care management.

1.7 DELINEATION AND LIMITATIONS OF THE STUDY

The study complements the related project referred to in the rationale (Section 1.3) for the study, and the study population discussed in Chapter 3; thus the scope is limited to primary health care clinics in the district of Tshwane. The delineation and scope of the study are restricted to the district of Tshwane, which determined the extent of scientific application of the findings. A number of limitations of the study emerged during the research process, which are summarised below. The limitations are outlined extensively in Chapter 6.

The main limitation of the study is that the findings cannot be generalised to the rest of the South African population. Ethnic diversity could not be attained, e.g. no participants from the Indian community participated, although the highest prevalence of diabetes in South Africa is amongst people of Indian descent. The female bias of the study population is another limitation – this is due to the substantially smaller number of male patients compared to females attending public primary health care facilities. The study is limited to people with diabetes that utilise public health care facilities – with an associated limited range of diabetes therapeutic opportunities and choices available to these participants.

[12] *Upstream* refers to the social and social-structural population factors in the community that have an influence on health, as opposed to the unique characteristics of the individual (Kumanyika et al. 2008)

[13] Sustainable self-care management refers to the activities that people with chronic illness may engage in to promote health, augment resources, and prevent clinical complications (Thorne & Paterson, 2001).

The low level of education and mainly low socio-economic status of participants in the study population limited the range of discussion of complex concepts. Time limitations at the clinics did not allow the researcher to apply the projective techniques used during the piloting and pre-testing of the research instruments.

1.8 ORGANISATION OF THE THESIS

The study is presented in the next five chapters. The first part of Chapter 2 reviews the literature on the sociology of diabetes mellitus and the social epidemiological research paradigms; the second part presents the literature review on diabetes self-care management and the role of health systems; and the last two parts present the conceptual and theoretical frameworks for the study. The methodology applied, in particular the qualitative methods, and the data analysis are described in Chapter 3. The findings are presented as main trends and patterns in Chapter 4, with the interpretation and discussion of the findings given in Chapter 5. Chapter 6 presents the conclusions and recommendations of the study.

1.9 SUMMARY

In the introduction and background to the study, a brief overview about diabetes was given with regard to the world, Africa, and South Africa. An overview about the concept of Diabetes Mellitus and self-care management was given in the second section of the chapter. The subject of 'The influence of population-based factors on self-care of patients with Diabetes Mellitus' was introduced with the rationale and justification of the study. The research problem statement and sub-problems were outlined; where after the research questions to the study were presented; and the aim and objectives of the study given. A delineation of the study and a brief summary of the limitations of the study were provided. Finally, the arrangement of the rest of the chapters of the study was given.

CHAPTER 2
Literature Review, Conceptual and Theoretical Frameworks Underpinning the Study

2.1 INTRODUCTION

The literature in chapter 1 provided a background on the global extent of the diabetes epidemic, the concept of diabetes, and outlined the rationale and justification for this qualitative study. The purpose of this chapter is to extend the literature review to the sociology of disease; the social epidemiological research paradigms; and diabetes self-care management; and to present the conceptual and theoretical frameworks of the study. The literature review relates and feeds into the conceptual framework; while also laying the foundation for the theoretical framework. The conceptual framework is used to explain the diabetes mellitus self-care management and health outcomes of diabetes patients at macro social-structural level and meso-social level. The theoretical framework is used to analyse and elucidate the social phenomena to diabetes self-care management that emerge from the findings of the study as they relate diabetes self-care management.

The 'funnel method' of structuring a literature review was applied to assist with the grouping of research areas and relevant scientific publications, and to make sure that all the objectives of the literature search were met (Hofstee, 2006: 94). As a first step to establish a structure for the literature review, the literature was perused to identify different ways in which the social epidemiology of diabetes and sociology of disease have been studied. Most of the research on diabetes and diabetes self-care management is quantitative in nature focusing on clinical aspects, treatment adherence and psychological factors relevant to the disease (Norris, Lau, Smith, Schmid & Engelgau, 2002; Heisler, Smith, Hayward, Krein & Kerr, 2003; Heisler, Piette, Spencer, Kieffer & Vijan, 2005). Furthermore, studies on diabetes patient satisfaction are limited (Westaway, Rheeder, Van Zyl & Seager, 2003). A number of researchers focus a great deal

on the psychological variables *inter alia,* the personal characteristics of the individuals with non-infectious chronic diseases such as diabetes, but not on the social determinants of the prevalence rate of the diseases (Berkman, 2004; Kaplan, 2004: 125; Liburd, Jack, Williams & Tucker, 2005). The sociology of disease, specifically the sociology of diabetes (Section 1.3 in chapter 1), holds a marginal position in terms of the number of scientific articles published confirming the gap in the literature. The literature review highlights the information gap in the field of study between the macro-social context and the specific health conditions of a population. The dearth of information in the literature from a population-based perspective and specifically the sociology of diabetes confirm the lack of a multi-level theory that can explain the complex pathways of biological, socio-psychological and macro-social factors to health. An argument is made for the qualitative social enquiry of disease, and in particular diabetes self-care management from a population-based perspective.

The first three sections of the chapter provide the scope, structure and broad theory base through the review of the literature on the sociology of disease - the case of diabetes mellitus; and the different epidemiological research paradigms. An overview of diabetes self-care management and the role of health care systems in diabetes self-care are discussed in the next two sections. The specific conceptual framework and the theoretical framework of the study are discussed in the last two sections.

2.2 THE SOCIOLOGY OF DISEASE – THE CASE OF DIABETES MELLITUS

Medical sociology as a specialised field in sociology evolved through a number of stages since its establishment during the 1940's. The most significant reorientation of medical sociology came in 1951, with the publication of The Social System of Talcott Parsons (1951). Parsons' explanation of a relatively complex structural-functionalist model of society in which social systems are linked to corresponding systems of personality and culture played a major role

in the development of the theoretical base of medical sociology. During the fifties there was already a clear distinction between the sociology in medicine, and the sociology of medicine. Medical sociology evolved into the sociology of health and illness, because earlier medical sociology implied a mere focus on the medical profession, hospitals and the health system (Timmermans & Haas, 2008). The change indicated recognition that illness also included family, work, school, and other life terrains, while social scientists would also look at how health problems can be prevented and how people's health improved. The exclusion of biology and disease as research areas within the context of the social study of health and illness however created a research gap for fundamental research questions about specific diseases. The sociology of disease does not replace the rich scholarship on medical sociology and the sociology of health and illness, but rather adds to it (Timmermans & Haas, 2008:661). A merger of a clinical and social explanation is needed, as will be explained in the following paragraphs.

Diabetes requires monitoring of the blood-glucose, in many cases several times a day, and controlling of the intake of carbohydrates based on specific standards. The clinical description does not provide a good explanation of the causal processes by which an individual becomes diabetic, why large differences in prevalence rates exist between social groups or why some diabetic patients cannot effectively manage their blood-glucose levels. At the individual-based micro-level, the risk of diabetes incidence is strongly linked to socio-demographic characteristics, large disparities in risk by income, education levels, and across racial-ethnic groups (Maty, Everson-Rose, Haan, Raghunathan & Kaplan, 2005: 1275 & 1279). Group patterns of diet and physical activity can explain some of these differences, but lifestyles and behavioural factors do not fully explain health disparities. Lifestyles and behavioural factors sometimes ignore the ways in which these factors are themselves products of the social environment. The increased risk associated with individual-level social characteristics is structured by larger social forces, such as patterns of consumption, residential and commercial development, and public policy (Timmermans & Haas, 2008: 667).

Clinical investigations of diabetes are fundamentally limited because they do not address the socially-constructed patterns of consumption, lifestyle, and its manifestation in individual behaviour as well as the differences between social groups. Whereas, the traditional sociological study of diabetes as an experiential phenomenon provides limited insight into material processes by which the social world is formed (Timmermans & Haas, 2008). Disparities in diabetes can only be understood through a sociology that includes the study of disease and its proximate pathways, and one that integrates the study of human wellbeing as both a biological and social phenomenon (Timmermans & Haas, 2008: 667).

With diabetes, like other health conditions, there are several advantages to collecting proximate biomarkers (Krieger, 2001b; Timmermans & Haas, 2008). Biomarkers are indicators of normal biological and pathogenic processes, or pharmacologic responses to a therapeutic intervention Krieger, 2001b; Timmermans & Haas, 2008). Firstly, it is critical to understand social inequalities in health to be able to map out the pathways, like societal arrangements of power and social capital, and constraints and possibilities of human biology, by which the social world comes to be embodied within the biological dimension (Krieger, 2001b: 672). Individuals' experiences in the social context determine the trajectories for later life – deficit in sleep and post-work relaxation, a blue-collar shift worker, as possible pathways for socio-economic (SES)-related stress (Adler & Stewart, 1999: xiv). Secondly, from a methodological perspective a large number of diabetes cases are undiagnosed (see estimates in the introduction to the study). The collection of biomarkers may also provide information about the interaction between the larger structural factors that predispose individuals and communities to risk; the more proximate behavioural and lifestyle pathways; the role of access to and utilisation of health services in the management of diabetes; the minimisation of co-morbid factors, as well as how individual and social factors both positively and negatively influence the management of diabetes (Timmermans & Haas, 2008). The aim with the biomarkers is not to reduce diabetes to a biological entity, but to bring the same critical sociological focus to 'social efficacy', as with clinical efficacy

(Rosenberg, 2007). Biomarkers for diabetes usually involve the measure of glycosylated haemoglobin, a measure of glucose circulating in the blood by means of small drop of blood from a finger prick (Danaei et al. 2011: 31). The HbAc1 measure is used to measure the blood glucose control over a period of three months (IDF, 2013: 108). Sociological studies can utilise these biomarkers to establish how social factors influence compliance with self-care management regimens.

2.3 THE SOCIAL EPIDEMIOLOGICAL PARADIGM

2.3.1 Introduction

The focus of this study is on selected population-based factors. This focus necessitated the scientific engagement of sociology with the discipline of social epidemiology and an investigation of the most relevant social epidemiological research paradigms relevant to this study. This investigation of the research paradigms informed the researcher and served as a lens to extend the scientific understanding of a qualitative study with a focus on population-based factors as reflected in the rationale of the study and the research problem statement. The purpose of this section is threefold: i) to theoretically engage with social epidemiology, contributing to the body of knowledge in search of a multi-disciplinary and comprehensive health lifestyle theory; ii) to contextualise the argument for a focus on population-based factors versus individual-based factors; and iii) to inform and add to the literature on the heuristic framework of social epidemiology that forms part of the theoretical framework of this study. Thus, this section of the literature review is not intended to extensively apply the literature to the interpretation of the data and findings of the study.

2.3.2 Social epidemiology

A prominent social epidemiologist, Nancy Krieger (2001a), localises the first reference of the term “social epidemiology” in the American Sociological

Review in a paper by Alfred Yankauer (1950) titled “The Relationship of Fetal and Infant Mortality to Residential Segregation: An Inquiry into Social Epidemiology”. According to Link (2008: 368) by 1969 there was enough accumulated substance in this area for Leo Reeder (1972) to give a talk at the American Sociological Association meetings in San Francisco entitled, “Social Epidemiology: An Appraisal”. Krieger (2001a: 693) distinguishes social epidemiology by its insistence on explicitly investigating social determinants of population distributions of health, disease, and wellbeing, rather than treating such determinants as mere background to biomedical phenomena. Epidemiologists are trained to establish the occurrence of disease in populations, and these trends inform planners and policy makers. Social epidemiologists depart from other epidemiologists on the level of causal thinking, e.g. instead of asking the question “Why did this individual get sick?” they will ask “Why is this society unhealthy?” (Kawachi, 2002:1739). Geoffrey Rose (1985: 32-34) in his seminal research brought to light the crucial insight that “the determinants of individual health are often different from the determinants of population health, and therefore it is imperative to study the characteristics of populations”

The spectrum of scientific studies done with regard to the most appropriate social epidemiological research paradigms in the study of diabetes clearly indicated that researchers can either use an individual or a population-based focus. The individually-based, case-control method or high risk strategy is concerned with why a specific patient got a disease at a certain time, therefore identifying certain individuals as being more susceptible, or at higher risk to a disease (Rose, 2001: 427). An example of this strategy is illustrated by the data derived from the occurrence of Down’s syndrome births by maternal age. Mothers under 30 years are individually at minimal risk; but because they are so numerous, they generate half of the cases. High risk individuals aged 40 and above generate only 13% of the cases. Therefore a large number of people at a small risk may give rise to more cases of disease than the small number who are at a high risk. This strategy seeks the causes of cases and will for example in the case of diabetes ask “Why do some individuals suffer from diabetes and

others do not?" Lifestyle characteristics are constrained by social norms, therefore individuals in a population will for example, eat according to their social norms. When individuals try to eat differently from their friends, this behaviour will be inconvenient and they run the risk of being identified as deviant (Rose, 2001: 431). For example, the individually focused risk factor epidemiological approach concentrates on what places individuals at risk of acquiring diabetes, and what individual characteristics are associated with the development of diabetes and the progression of the disease. The risk factor epidemiological approach therefore focuses on individual behaviour changes and access to clinical diabetes care and the interpretation of diabetes risk which manifests at the individual micro level. Cockerham (2005: 62) argues that the theoretical conceptualisation of health lifestyles is affected by the individual-versus population-based focus that implicates also the agency-structure debate. Arguments about the lack of a health-lifestyle theory and the agency-structure debate are central to the theoretical discussions of health and health lifestyles (Cockerham, 2005: 51, 52, 54 & 64). This debate is more extensively addressed in Section 2.5.3 of this chapter.

The focus on population-based factors or population incidence rate strategy attempts to control the determinants of incidence, to lower the mean level of risk factors and to shift the whole distribution of population exposure in a favourable direction (Rose, 2001: 431). A question related to this strategy will be "Why do some populations have larger numbers of diabetes sufferers, whilst in others it is rare?" In terms of population mass control and prevention of the onset of a disease or spectrum of diseases well known examples in South Africa are the addition of fluoride to the water to prevent dental problems, and the anti-tobacco control policy. With regard to the latter, the prohibition of smoking in public spaces, including restaurants, created an opportunity to develop a norm of non-smoking, which makes it less necessary to keep on persuading individuals not to smoke. In the USA, the guidelines developed for the fast food industry, will inter alia lessen the fat and refined carbohydrate intake of that part of the population who eat fast-food, and should have a

positive effect on the levels of obesity (Departments of Agriculture and Human Services as cited in Popkin, Siega-Riz, Haines & Jahns, 2001: 245).

The above discussion underscored the necessity to discuss the three main theories applied in social epidemiology. These are: i) the psychosocial theory, ii) the social production of disease and/or political economy of health, and iii) the eco-social theory and related multi-level frameworks. These research paradigms contributed to the context, not only for the research problem statement, but also for the theoretical framework and specific research methodology used in this study.

2.3.3 Psychosocial theory

The psychosocial theory developed out of problems or experiences that prior paradigms could not explain, e.g. why is it that not all people exposed to a specific germ become infected, and not all people infected develop the disease? In the classic paper by John Cassel (1976:111-119) 'The contribution of the social environment to host resistance', his central hypothesis is that "the social environment alters host susceptibility by affecting neuro-endocrine function." His list of psychosocial factors includes: "dominance hierarchies, social disorganisation, rapid social change, marginal status in society, including social isolation, bereavement, and the psychosocial asset of social support." Cassel (1976:120). Cassel (1976:121) argued: "… we should focus efforts more directly on attempts at further identification and subsequent modification of these categories of psychosocial factors rather than on screening and early detection." Social isolation, disintegration and disconnectedness influence mortality and therefore longevity or life expectancy by influencing the rate of aging of the organism (Berkman et al. 2000: 851-852; Berkman, 2014).

The psychosocial theory focuses therefore on response to 'stress' and on stressed people in need of psychosocial resources. Comparatively less attention is accorded to: i) who and what generates psychosocial insults and buffers, and ii) how their distribution is shaped by social, political and economic

policies (Krieger, 2001b: 670). The psychosocial factors, that mediate the effects of social structural factors on individual risk, and that are conditioned and modified by the larger social context in which they occur facilitate better understanding of diabetes risk. Interventions therefore focus on modifying personal or individual behaviour to enable diabetes prevention or to improve health outcomes for persons with diabetes.

2.3.4 Social production of disease and/or political economy of health theory

The social production of disease theory introduces agency to the 'upstream-downstream' metaphors, and explicitly addresses economic and political determinants of health and disease, including structural barriers to people living healthy lives. The 'upstream-downstream' argument reflects the analogy of a situation in which a continuing number of people are struggling in the water downstream, about to drown. "Going upstream to find out why people keep falling into the river, e.g. a bridge might have collapsed, is as critical as working downstream to pull the people out of the river one at a time" (Kumanyika et al. 2008: 443). The underlying hypothesis is that policies and decisions of economic and political institutions, create economic and social privilege and inequality, and are the fundamental causes of social inequalities in health (Krieger, 2001b: 670).

Worldwide there is a call for action to address these inequalities, especially policies that will ensure the reduction of poverty and income inequality. There are four implications for actions that flow from this approach that require focused attention of decision-makers (Wilkinson, 1996; Reid, 1998; Krieger, 2001b). The first is the development of a strategy of social justice that facilitates change of unjust policies. A second implication is that economic growth and health interventions might, like in Britain after World War II when the health system was expanded, sustain the gap, and in certain communities, increase the gap between the health status of the poor and the wealthy (Wilkinson, 1996; Reid, 1998). The third implication for action that flows from the approach

is that greater familiarity with health and human rights, supplemented by analyses of who gains from violating these rights, will improve the real-world efficacy of the work of the social epidemiologists. The last implication is that social epidemiologists must be key actors in ensuring viability of monitoring social inequalities in health (Krieger, 2001b: 671). The risk of diabetes might be higher for persons with limited access to resources, therefore to be able to understand the sequence of causality involved in diabetes, its epidemiology and the population health implications of the rise in the prevalence of obesity requires an approach that focuses on the role of social institutions and other aspects of the social structure. Changes to the structure of the social environment through legal, political or economic intervention might be necessary to empower vulnerable groups. (Timmermans & Haas, 2008: 667). These changes necessitate the extension of the research agenda on living with diabetes towards the systematic examination of the social production of diabetes and the political economy of self-care management of diabetes (Hinder & Greenhalgh, 2012). The inclusion of elements of the social production of disease and political economy of health theory in the literature can assist with the contextualisation of the macro-structural factors that influence diabetes self-care.

2.3.5 Eco-social theory and related multi-level frameworks

The eco-social theory and other multi-level epidemiological frameworks focus on the integration of social and biological reasoning, as well as a historical and ecological perspective to develop insight in social determinants of health (Krieger, 2001a). It considers how the health of a population is generated by both social conditions and biological processes (Krieger, 2001a: 694). Great epidemiological discoveries stemmed from multi-level thinking, e.g. the work of John Snow on the cholera epidemic during 1854 in London and Peter Ludwig Panum on the outbreak of measles in the Faroe Islands in 1846 (Susser, 1999; Brown, 2000). Snow (Beaglehole, Bonita & Kjellstrom, 1994:1) plotted all reported cholera cases in London according to geographic location, and inquired about the day-to-day behaviour of these victims. With this information,

he suspected that the cholera was transmitted by water, and closed down the source of the water with positive effects. This investigation demonstrated that research could lead to positive action and that social behaviour and the physical environment were both important in the transmission of disease (Brown, 2000). Panum (1858) in 1846 did a remarkable multi-level field investigation about the whole way of life of the 7 782 people scattered across the several Faroe Islands in the conviction that he would find clues to the nature of the deadly measles epidemic. Firstly, Panum deduced the transmissible nature of the disease, and its incubation period; secondly he noticed the greater mortality of attacks with increasing age only after age 20; and thirdly he understood the individual immunity conferred by infection, which he inferred from the history of a previous epidemic (Susser, 1999: S1021).

Krieger (2001b: 671) distinguishes between three frameworks within the context of the eco-social and multi-level paradigm, namely eco-social theory; eco-epidemiology; and the social-ecological systems perspective. Eco-social theory was introduced in 1994 by Krieger (2001b: 671), and refers to life that is intertwined on a micro and macro scale, with the different core social groups in society. Eco-epidemiology was proposed by Mervyn Susser (1998:610), with his metaphor of the ‘Chinese Boxes’ that illustrates a conjurer’s nest of boxes, each containing a succession of smaller ones. This ‘nest of boxes’ represents localised structures with successive levels of organisation, each of which encompasses the next and simpler level, all functioning as interactive systems in society (Susser & Susser, 1996: 675). The social-ecological systems perspective of Anthony McMichael (1999: 890 & 896) moves away from the mind-set and methods of modern epidemiology that entail four types of proximate constraints. The constraints are the preoccupation with proximate risk factors, the focus on individual-level versus population-level influences on health, the modular view of how individuals undergo changes in risk status, and the challenge of scenario-based forecasting of health consequences of future, large-scale, social and environmental changes (McMichael, 1999: 896). The social-ecological perspective focuses more on population health in ecologic terms, and extends the spatial-temporal framework. Social scientists have

started to play a dynamic role with diverse contributions and perspectives that include understanding of social processes such as social learning and social memory, mental models and knowledge-system integration, visioning and scenario building, leadership, agents and actor groups, social networks, institutional and organizational inertia and change (Folke, 2006: 262-263). However, according to Folke (2006: 263); and Golden and Earp (2012: 364) research on social-ecological theory and related multi-level frameworks is still in the explorative phase.

The focus of eco-social theory and other related multi-level frameworks is on the multi-level determinants of disease, from the microscopic to the societal level, and the challenges to social epidemiologists are to acquire or establish data sets that contain multi-level information, linking the most macro and micro-level phenomena (Kaplan, 2004: 125; Golden & Earp, 2012: 367). The social, behavioural and physiological pathways from socio-economic position to the development of diabetes mellitus will be differently distributed, and need to be analysed from a multi-level perspective, identifying the causes of the causes (Schwartz & Diez-Roux, 2001; Golden & Earp, 2012: 368). The understanding of diabetes risk is 'embodied' among persons over lifetime exposures to numerous biologic and social factors (Schwartz & Diez-Roux, 2001). According to McMichael (2006: 580) three types of research are required, namely empirical studies that clarify how variations in environmental and ecological systems affect health risks, secondly how global environmental changes are already affecting health, and thirdly the need to make credible estimates of future changes in the health risks due to changes in large-scale environmental systems. Responsibility for factors that enhance vulnerability maybe located at multiple levels, as such interventions might be targeted to the level specified through eco-social studies.

2.4 DIABETES SELF-CARE MANAGEMENT

An overview of diabetes self-care management; the factors that influence diabetes self-care; views about diabetes; social effects of diabetes; and behaviour of persons with diabetes are presented below.

2.4.1 Overview of sustainable diabetes self-care management

Self-care management (commonly referred to as self-care) has traditionally been considered as the product of the individual characteristics and skills that the individual brings to the illness situation, and not a consequence of his or her social context (Thorne & Paterson, 2001: 82). The majority of reviews on diabetes self-care management focused on clinical self-care interventions and some patient challenges rather than population-based factors that might be contributing factors on self-care in persons with diabetes. A wide spectrum of research instruments are used to evaluate different elements of self-care, namely the Self-Care Inventory[i], the health belief survey of Given[14], the Diabetes Social Support Questionnaire[ii], the Problem Areas Diabetes in Scale [iii](PAID), a Diabetes knowledge scale[iv], and questions integrated in other instruments with regard to screening of depression, excessive alcohol intake and patient-physician communication (Given, Given, Gallin & Condon, 1983; Greco et al. 1990; Garay-Sevilla et al. 1995; Polonsky et al. 1995; Whooley, Avins, Mirnada & Browner, 1997; Bautista, Aguilar-Salinas & Lerman, 1999; Williams, Mulrow & Kroen, 1999; Ciechanowski, Katon, Russo & Walker, 2001; Brown, Becker, Garcia, Barton & Hanis, 2002; La Greca, 2004; Lerman et al. 2004).

As indicated in chapter 1, the need for self-care management support is well documented, but it has mostly taken place in clinical settings and targeted those who have a high HbA1c. A number of community-level, peer-led, small-group diabetes self-management programmes however, have after a 12-month

[14] The Given Health Belief Instrument has been developed by C.W. Given and B.A. Given to measure diabetes-related health beliefs (Given, Given, Gallin & Condon, 1983)

intervention period shown significant improvements of participants regarding depression, symptoms of hypoglycaemia, communication with physicians, healthy eating, reading of food labels, patient activation and self-efficacy (Lorig, Ritter, Villa & Armas, 2009: 641 & 648-650). A study that was conducted in the USA on a single group, the Healthy Lifestyle Change Program (HLCP) demonstration project in the Los Angelos county during 2005 and 2006 by Bazzano et al. (2009: S201) indicated the positive value of community-based health interventions. This HLCP was developed and implemented using community-based participatory research methods by members of the developmental disabilities community, in collaboration with academic researchers. The HLCP was a 7-month, twice-weekly education and exercise program to increase knowledge, skills, and self-efficacy regarding health, nutrition, and fitness among adults with developmental disabilities. Peer mentors served as participant leaders and primary motivators. The HLCP resulted in improved lifestyles, weight loss success, and increased community capacity, indicating that a community-based programme with significant participation of those with developmental disabilities is feasible (Bazzano et al. 2009: S206).

Norris et al. (2002: 1167-1168) found that lifestyle and knowledge-focused diabetes education interventions for type 2 diabetes adults with multiple age and ethnic groups is effective at the community level. A study by Spenceley and Williams (2006) focused on barriers to and facilitators of diabetes self-care management from the perspective of the person with diabetes. The findings of a meta-analysis of four studies by Cardona-Morrell, Rychetnik, Morrell, Espinel and Bauman (2010: 13-14) revealed that lifestyle interventions in routine clinical care positively contribute to the reduction of diabetes related risks.

Wagner, Austin and Von Korff (1996: 511) found that successful chronic illness intervention programmes share common characteristics which they organised in a heurist model for improvement of chronic care. The original evidence upon which this heuristic model, known as the Chronic Care Model (CCM), was based came from a review of interventions to improve care for various

chronically ill populations (Wagner, Austin & Von Korff, 1996; Wagner, 1998). The CCM consists of six elements: Health care organization; Community resources; Self-management support; Delivery system design; Decision support; and Clinical information system (Wagner, Austin, Davis, Hindmarsh, Schaefer & Bonomi, 2001: 73-75). The CCM portrays the health system as part of the larger community and the practice as a part of a health organisation, while effective self-management support and links to patient-oriented community resources help to activate and inform patients and families to better manage the challenges of living with chronic illness (Wagner et al. 2001: 69). Further, conventional patient education within this model underlines knowledge acquisition and educational counselling (Wagner et al. 2001: 69). Lastly, the model requires the organisation to ensure that the health teams have the proficiency to provide suitable clinical and behavioural management, as well as standardised approaches to collect, summarise, and review individual or cumulative patient data to facilitate care (Wagner et al. 2001: 70). According to Berenson et al. (2008) and Iglehart (2008) the CCM is an extensively accepted approach in the USA to ambulatory care improvement where it guides national quality improvement initiatives involving groups of primary care practices, and also forms an integral part of patient-centred medical home models. The characteristics of the model mainly reflect the elements that relates to the health care system and its interaction with the patient. The reference to community resources resonates with this study's population-based paradigm, but does not specifically outlines the variables involved.

Diabetes self-care requires individual skills to manage the physical and psychological symptoms of the condition; the prescribed regimen; the lifestyle adjustments; and the possible clinical complications of uncontrolled blood glucose levels (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002: 181-183). Self-care management education prepares individuals to be adequately equipped and empowered to change their health behaviour (Gary, Genkinger, Guallar, Peyrot & Brancati, 2003: 1495). Diabetes health education programmes are therefore imperative to enable persons with diabetes to better

participate in the intensive treatment and facilitate sustainable diabetes self-care management (Norris, Engelgau & Venkat, 2001: 580; Norris et al. 2002: 1164).

2.4.2 Factors that influence diabetes self-care

In a literature review on diabetes self-management by Glasgow, Toobert and Gillette (2001), the researchers evaluated 35 studies in terms of psychosocial barriers, examining each barrier. The spectrum of variables focused mainly on the internal psychosocial factors, with six studies that evaluated amongst others, variables on health beliefs and ten on social support. The assessment instruments and reviewed studies blend the different types of barriers, while the focus of the majority of the studies lies in the second level, namely more proximal than systems barriers, such as the health system, and community or cultural influences (Glasgow et al. 2001: 33). The psychosocial factors relate mainly to the individually-based research strategy referred to in Section 2.3.1, and therefore do not adequately explain diabetes self-care management from a sociological perspective.

In addition to biological and psychological factors, many factors such as interactions within the family system, the social and cultural community, and socioeconomic and healthcare system factors, can directly or indirectly influence the patient's self-care behaviour of the disease. In a study about the psychosocial factors associated with poor self-care management, adherence to the three main recommendations of the diabetic treatment programme was observed only in 26,1% of the patients (Lerman et al. 2004: 566). These patients were characterised by higher knowledge levels about the disease, routine home blood-glucose monitoring, an inner perception of better diabetes control, good health and better patient-physician communication (Lerman et al. 2004: 566 & 568). Adherence to treatment with oral agents and/or insulin was observed in 78% of the patients and was more common in patients with longer diabetes duration and increased diabetes knowledge, while lower adherence rates were mostly observed in primary care settings, in insulin users and

patients with depression (Cramer, 1995; Cramer, 2004). Depression has been shown to adversely impact on self-care of diabetes, and predicts an increased incidence of adverse health outcomes (Black, Kyriakos, Markides & Ray, 2003: 2826).

Research and theoretical formulations accounting for adherence to medical regimens and the management of other chronic conditions are extensive, e.g. studies on arthritis; cancer; cardiovascular conditions; asthma; and HIV and AIDS (Ho, Bryson & Rumsfeld, 2009; Jansa et al. 2010). Earlier studies (Chesler & Barbarin, 1987; Toljamo & Hentinen, 2001; Dunbar-Jacob & Mortimer-Stephens, 2001; DiMatteo, 2004) explored the experiences, attitudes and life chances of survivors of *inter alia* childhood cancer, HIV, arthritis, gastrointestinal disorders, adult cancer, pulmonary diseases, diabetes, as well as persons with sleep disorders. These studies contain similar elements to the conceptual framework used in this study, namely the exploring of the experiences, perceptions and attitudes of persons with diabetes. However these studies mainly focused on the individual micro-level contextualisation of these health conditions and clinical regimen, and did not focus on the macro- and meso-level population-based factors that might influence self-care management of these conditions.

Another study about the adherence to the diabetes therapeutic regimen broadly categorised the reasons for non-compliance into six themes, namely the course of diabetes; information about diabetes; the context of the person with diabetes; the relationship to the health care provider; and the provision of health care (Vermeire, Van Royen, Coenen, Wens & Denekens, 2003: 29-31). The complexity of diabetes requires specialised knowledge and a specific set of skills to manage it effectively. Persons with diabetes may have barriers to self-care management that vary from beliefs about the cause and seriousness of the condition and the effectiveness of treatments; and the spiritual and social context of coping with and adjusting to the condition (Hampson, Glasgow & Toobert, 1990: ; Samuel-Hodge et al. 2000: 930).

2.4.3 Views about diabetes

Michael Bury (1982: 169) developed the classic sociological formulation of the notion of chronic illness as a 'biographical disruption', suggesting that chronic illness is an experience in which the structures of everyday life, its taken-for-granted features, and the unspoken frameworks of knowledge that they rest upon, are severely disrupted. Bury based his notion of 'biographical disruption' mainly on the work of Giddens (1979) who first used the term 'critical situation' in the context of chronic illness. Giddens (1979: 123) argued that a good deal can be learnt about the day-to-day situations in 'radically disturbed' routine settings by analysing the 'critical situations' in these circumstances. Chronic illness "involves recognition of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others" (Bury, 1982: 169). The notion of biographical disruption brings into account the sociological focus that meaning and the social context, including *inter alia* the physical, social, cultural and medical resources available to individuals and their families in the face of their adversity, cannot be separated (Bury, 1991: 543). Kelly and Field (1996: 251) argued for a more bodily approach to chronic illness, noting the sociological importance of biological and physical facts because they: i) impinge directly on the self; ii) provide the signals for identity reconstruction; and iii) act as limiting factors on social action and social interaction.

In a longitudinal qualitative study, involving type 2 diabetes patients, Lawton, Peel, Parry and Douglas (2008: 47) observed the perceptions and understandings why these patients had developed diabetes and how, and why, their causality versions had changed or remained stable over time. The interpretations and explanations of earlier expectations and hopes by persons with diabetes may be revised in conjunction with their present in order to reconcile a present painful recognition that one is faced with the lifelong burden of a chronic condition (Lawton et al. 2008: 54). Lawton et al. (2008: 54) found that the highlighted contexts and experiences that inform persons with diabetes indicated to be in essence more 'exterior' to the individual. These include the

social and cultural contexts into which people are socialized; their exposure to neighbourhood effects; the presence or absence of intimate and other social networks with a specific disease; and information from health care professionals and other media resources (Fagerli, Lien & Wandel, 2005; Lawton, Ahmad, Peel & Hallowell, 2007: 895; Gomersall, Madill, & Summers, 2011).

2.4.4 Social effects of diabetes

As the state of health shifts from a mild chronic state to a state of severe chronic disease, such as with diabetes clinical complications, interpersonal self-efficiency may increasingly become an obstacle to collaborate with family and the medical system for successful disease self-care (Ciechanowski et al. 2004: 726). In a complex condition such as diabetes, high self-efficiency may interfere with critical interpersonal interactions that would facilitate disease self-care like negotiation with the spouse and the family regarding the spectrum of the diabetes regimen (Ciechanowski et al. 2004: 726). Williams (2000: 43 & 44) distinguishes between two types of meanings that persons with a chronic illness can attach to the condition, firstly the practical consequences or effects for individuals and their families, and secondly symbolic significance. The effects of the disruptive symptoms on everyday life, including the time spent on the self-care management of the symptoms and the application of the medical regimens, and the socio-economic costs associated with long-term illness, are according to Bury (1991: 453) the primary social effects. The symbolic significance reflects the symbolic connotations and imagery that different conditions carry with them within different social and cultural contexts that can have a profound effect upon how individuals regard and think about themselves (Bury, 1991: 453).

The perception of individuals about themselves and the perceptions of other people about the condition and them, relates to their identity and in some instances these perceptions are attributed to their condition. These perceptions are reflected in the concept of stigma, defined by Erving Goffman (1963: 3) as

"an attribute that is deeply discrediting" and the stigmatised person is reduced "from a whole and usual person to a tainted, discounted one". Goffman (1963: 15) explained three main forms of stigma: i) physical stigma such as visible types of physical deformities; ii) personal or character stigma aspects below the surface that blemishes the individual character; and iii) social or tribal stigmas related to a particular group or ethnic minority. Another aspect of Goffman's notion of stigma is that it is highly relational, socially constructed in and through social relationships depending on the situation, representing a rupture between an individual's virtual and actual social identity that is regarded in some way as failing (Goffman, 1963: 2 & 4; Pescosolido, Martin, Lang & Olafsdottir, 2008: 432). Even though stigma is imposed on the individual by other people it can have a negative effect on the self-concepts of those stigmatised. The problem is not the person with the chronic illness but the societal attitudes and the way in which the physical environment is shaped (Goffman, 1963: 32; Crocker, Major & Steele, 1998: 505).

Stigma is a universal phenomenon that has received substantial research attention for conditions such as HIV and AIDS, epilepsy and obesity, but in diabetes it is relatively under-researched (Schabert, Browne, Mosely & Speight, 2013: 2). Persons with diabetes report that stigma is a significant concern that they experience across many life domains for example in the workplace, and in relationships (Schabert et al. 2013: 1). Link and Phelan (2006: 528) merge social psychological and sociological explanations in their interactionist conceptualisation of stigma, which enables the examination of stigma more holistically. They distinguish and label human differences according to salient characteristics and attributes (Link & Phelan, 2006: 528). In diabetes these characteristics and attributes include the observable behaviour usually required to manage the condition such as food choices, injecting insulin, or taking medication, or physical characteristics associated with the condition for example obesity in the case of type 2 diabetes (Schabert et al. 2013: 2). A common theme of perceptions about social stigma and its influence on diabetes self-management emerged from the findings of two qualitative studies conducted in Hong Kong (Shiu, Kwan & Wong, 2003: 149). Participants

described their negative experience during self-administration of insulin in public places, with the public looking strangely at them, relating the procedure to ‘intravenous drug addiction’, or ‘self-inflicting the condition as a result of food over-indulgence’ (Shiu et al. 2003: 149).

The notion of chronic illness as a ‘biographical disruption’, that not only disrupts the physical body but also the social contexts of individuals closely relates to the specific meaning that is given to the health condition. In one social context a certain health condition would be perceived as normal while in another it would be seen as abnormal and regarded as labelling. The labelling perspective is rooted in the thoughts of George Herbert Mead and Herbert Blumer, and has been one of the most influential in the field of deviance (Dotter & Roebuck, 1988: 19). Labelling theory is based on the concept that what is regarded as deviant by one person or social group may be regarded as normal by other persons or social groups (Cockerham, 2004: 158). The position of Howard Becker (1973), as one of the leading proponents of labelling theory, is that deviance is created by social groups who make the rules and norms (Cockerham, 2004: 158). Illness is seen by labelling theorists as a condition treated by human beings in accordance with their understanding of the situation, while judgements concerning what is sickness and deviant behaviour are relative and cannot be separated from the social situations in which people live, such as in parts of Africa mild malaria may not be considered abnormal because of its prevalence (Cockerham, 2004: 159). The application of deviant labels to individuals can lead to changed self-perceptions, identities and changed social opportunities. The mere fact that a person with diabetes is called a ‘diabetic’ implies an altered status and in some instances becomes the ‘master status’ of an individual or group. The label of being a ‘diabetic’ that is attached a person with the condition is one of the reasons why the researcher preferred to use the concept of a ‘person with diabetes’, describing the condition in relation to the person, and not referring to the identity of the person.

2.4.5 Behaviour of persons with diabetes

The treatment of diabetes involves complex changes in the basic behaviour of persons with diabetes, and adherence to complicated clinical and dietary regimens (Vermeire et al. 2003: 210). Diabetes self-care behaviours stretch over the continuum from more relationship-dependent to relatively less relationship-dependent. Diet and exercise for example are more dependent on the guidance from a health care provider, meal preparation in a family context, and exercising with a partner or group, while glucose monitoring is a quick and straightforward procedure (Ciechanowski et al. 2004: 726). The process to integrate behaviour and lifestyle changes by persons with diabetes is multifaceted and complex with numerous challenges. According to Whittemore, Chase, Mandle and Roy (2002: 23) the experiences that facilitate the integration process are i) the acknowledgement of their own vulnerability toward morbidity and mortality; ii) knowledge to prevent clinical complications; and iii) hope that the enacting of new knowledge would maintain a good quality of life. The challenges include the inability to reconcile their emotions and create a new set of health behaviours; while the lack of symptoms, glycaemic control through their medication regimen, and a lack of perceived seriousness of diabetes are factors that contribute to reduced feelings of a possible threat or vulnerability (Whittemore et al. 2002: 23).

Seminal work by Bury (1982: 167 & 180; 1991: 460 & 461) in the area of chronic illness such as diabetes has demonstrated the impact of diagnosis on people's identity. In an analysis about the perceptions, views and experiences of diabetes education in people with type 2 diabetes, Ockleford, Shaw, Willars and Dixon-Woods (2008: 28 & 30) identified four principal orientations towards diabetes and its management, namely 'resisters'; 'identity resisters, consequence accepters'; 'identity accepters, consequence resisters'; and 'accepters'. Persons with diabetes who were categorised as 'accepters' reported that they had "fully incorporated the diabetic identity as they perceived it had been defined for them by medicine, and they were enthusiastic or committed to change their behaviour in response" (Ockleford et al. 2008: 30).

Although 'accepters' did accept the need for change, not all reported that they consistently adhered to what they understood to be best practice in managing their diabetes (Ockleford et al. 2008: 31). 'Identity accepters, consequence resisters' accepted that they had diabetes, but reported that they "had difficulties in embracing the full consequences of the new identity, at least as specified for them by medical orthodoxy. They produced accounts in which they argued that other aspects of their lives had higher priority than managing diabetes, and that their approach to managing their diabetes had to be understood within a broader context" (Ockleford et al. 2008: 31). 'Identity resisters, consequence accepters' reported that they found it difficult to accept that they had diabetes, but nonetheless described making changes to diet and lifestyle in response to the diagnosis (Ockleford et al. 2008: 31). Persons with diabetes whom Ockleford et al. (2008: 31) classified as 'resisters' found it difficult to accept that they had diabetes, reporting that they did not feel any different from how they had felt before diagnosis. These participants described themselves as not making any changes either to their identity or to their lifestyle (Ockleford et al. 2008).

Finally, self-care behaviours need to be understood in terms of the meanings attached to them, the socio-economic and cultural contexts in which they take place, the norms that they are subjected to, the decision-making power available to the individuals, and the social and emotional aspects of living with a chronic condition (Hunt, Jordan & Irwin, 1989: 325 & 329; May, 2005: 15).

2.5 THE ROLE OF HEALTH SYSTEMS IN DIABETES SELF-CARE

2.5.1 The policy framework

The World Health Organization Report 2000 (WHO, 2000: 5) defines a health system as follows: "… a health system to include all the activities whose primary purpose is to promote, restore or maintain health. Formal health

services, including the professional delivery of personal medical attention, are clearly within these boundaries. So are actions by traditional leaders, and all use of medication, whether prescribed by a provider or not. So is home care of the sick, which is how somewhere between 70% and 90% of all sickness is managed. Such traditional public health activities as health promotion and disease prevention, and other health-enhancing interventions like road and environmental safety improvement, are also part of the system".

Health systems have a responsibility to improve people's health and to treat them with dignity – focussing on three fundamental objectives (WHO, 2000: 8):

- Improving the health of the people they serve;
- Responding to people's expectations; and
- Providing financial protection against costs of ill-health.

The Declaration of Alma-Ata (1978: 1-3) states that effective management of disease should include a promotive aspect (which includes policy and inter-sectoral local actions), a preventive aspect (which includes personal and behavioural actions), as well as curative and rehabilitative services that focus on individuals who are already diagnosed to prevent complications. The development of innovative health care systems in all countries which meet the needs of persons with chronic conditions is a priority for the WHO (2010). According to Epping-Jordan, Pruitt, Bengoa and Wagner (2004: 300) the WHO analysed numerous programme alternatives in response to the increasing prevalence of chronic conditions and the subsequent need to help countries transform their healthcare systems.

The South African Constitution states that every person has the right to achieve optimal health and it is the responsibility of the government to create the conditions to achieve this. Progress has been made since 1994 to integrate the different segregated health structures that characterised the health system during the Apartheid years. The health system in South Africa is based on a two-pronged strategy: a public sector providing services for the majority of the population and a private sector providing services for the privately-insured

minority (Coovadia, Jewkes, Barron, Sanders & McIntyre, 2009: 10 & 11). The multi-level service of the public sector consists of the National Department of Health that is mainly responsible for policy formulation, guidelines for standards of care and the budget allocation to provinces. The provincial departments in each of the nine provinces form the next level of care, and are mainly responsible for the execution of the policies and provision of curative care through the various types of hospitals and primary health care clinics. There are three tiers of public hospital service delivery, namely tertiary, regional and district hospitals (Coovadia et al. 2009: 13). The lowest level of service provision is situated in the District Health System, where local municipal authorities are the direct service providers through the primary health care clinics.

According to Mayosi, Lawn, Van Niekerk, Bradshaw, Abdool-Karim & Coovadia (2012: 2029-2037) four important changes have occurred since 2009 with regard to the South African health care system towards attaining the Millennium Development Goals (MDG's) of 2015, namely i) the change in leadership of the Ministry of Health as a key driver; ii) specific policy and programme changes are evident for all four of the so-called colliding epidemics and some advances have been made in the health system responses; iii) a system of national health insurance and re-engineering of primary health care to be phased in over 14 years to enable universal coverage; and iv) national consensus on about seven priorities for health research with a commitment to increase the health research budget. Mayosi et al. (2012: 2037-2040) recognise that four major challenges remain towards attaining the MDG's, namely i) large racial differentials in the social determinants of health; ii) integration of the private and public sectors and coordination of services; iii) improvement of the surveillance and information systems; and iv) scaling up of innovative interventions.

In South Africa, it is expected that the public-sector primary health care clinics should be able to deal with 90% of minor ailments. The management of chronic illnesses, like diabetes, forms part of the responsibilities of these clinics. The essential medicines list with the relevant treatment protocol for each of the

stipulated health conditions, serves as a guideline for the biomedical treatment of *inter alia* diabetes. The standards of care for diabetes patients make provision for an annual blood-glucose test, an eye test, monitoring of the heart and an assessment of the condition of the feet of the patient (Webb, Rheeder & Van Zyl, 2014: 1).

It is however not uncommon that the standards of care are not being adhered to at the primary health care level. Prevention programmes and self-care management programme implementation pose challenges to programme managers, health care staff and human and financial resources. The failure in adherence causes major clinical complications for diabetes patients, thus the main reason for the clinical trial study by the Faculty of Health Sciences at the University of Pretoria. This recent study in the Tshwane district found that diabetes care and screening for complications at primary level is sub-optimal (Webb et al. 2014: 1). The primary health care clinics are characterised by nursing-staff-initiated care and the large number of patients does not allow nurses to spend more than the minimum time with each patient, especially those patients with chronic illnesses like diabetes. The public sector has been transformed into a comprehensive, integrated national service, but defects in leadership and stewardship, as well as managerial weaknesses have led to inadequate implementation of good policies. Essential aspects of primary health care are not in place and there is a substantial human resources crisis within the health system (Coovadia et al. 2009: 1). The complexity of a condition such as diabetes requires specialised health care therefore the lack of adequate human resources is significant within the context of this study.

Another major deficiency in the standards of care and a biomedical barrier to effective self-care management by insulin-dependent diabetes patients in the public sector is the lack of individual glucose-meters to monitor their insulin levels (Prof D van Zyl, Head of Kalafong Diabetes Clinic, University of Pretoria, personal communication, March 14, 2013). The latter directly increases the burden for injectable insulin on the primary, secondary as well as tertiary level, resulting in many more patients with uncontrolled blood glucose levels and

serious clinical complications (Webb et al. 2014). Poor management of diabetes results in upward referral in the health system with a concomitant cost of care. Only a limited number of public sector patients have access to some form of private health care. The result is inequalities between health care provision to the poor and the rich (Coovadia et al. 2009; HSRC, undated).

While health-care access for all South African citizens is constitutionally protected, considerable inequities remain, largely due to distortions in resource allocation (Gilson & McIntyre, 2007; Coovadia et al. 2009). The achievement of equitable universal health coverage requires the provision of accessible, essential services for the whole population without imposing an unreasonable financial burden on individuals or households (Harris et al. 2011: S102). According to Harris et al. (2011: S102) little is known in South Africa about access barriers to health care for the general population. In 2008, a national household survey was conducted in South Africa to collect information about health status; utilisation of outpatient and inpatient services; health insurance status; and reasons for delaying care when someone was ill and then the illness worsened in the previous year (McIntyre, Goudge, Harris, Nxumalo & Nkosi, 2009; Nxumalo, Alaba, Harris, Cherish & Goudge, 2011). Based on this survey's results Harris et al. (2011: S102) examined health care access barriers and found that the affordability, availability and acceptability of health care services are closely associated with socio-economic status, race, health insurance status, and urban-rural location. They also established that vulnerable social groups have limited power to "claim and use entitlements and opportunities" to access health care. Harris et al. (2011: S119) suggest that "to achieve equitable universal health care, the right to access health care requires a comprehensive approach to universal health care which considers the 'breath', 'depth' and 'height' of access across society, rather than financing alone."

Persons who live with a chronic condition such as diabetes, have to make decisions daily and therefore need to increase their knowledge and skills to cope with a variety of uncertainties since they have limited immediate

assistance from a health care professional (Bruce, Davis, Cull & Davis, 2003: 87-88). A qualitative review of diabetes self-management education stresses the need for assistance by a health care professional and concludes that patient education is more effective when combined with health care provider medication and reinforcement of information and practical support by such professionals (Norris et al. 2001: 582). Moreover, proper communication between patients and health professional is essential for effective diabetes self-care. Bradley and Gamsu (1994: 510) argue that successful diabetes management requires that health care providers understand the lifestyle, beliefs and attitudes of patients being treated: "Diabetes team members need to develop an understanding of what having and coping with diabetes means to individuals". However, weaknesses may persist despite the intervention of a health care professional. After receiving guidelines for diabetes self-care from the primary health care clinic or hospital diabetes clinic, a large number of persons with diabetes still present with serious clinical complications (Funnell & Anderson, 2004: 123 & 127). This view also resonates with the assessment of the Regional Director of the WHO African Region (2010:1) that a high proportion of diabetes cases remain undiagnosed or diagnosed only after complications.

2.5.2 The position of government in health care

According to Kernick (2002: 123), internationally, governments have been seen as standing outside public health institutions, focussing on a mainly rational approach underpinned by the principles of science in areas where there is likely to be a high degree of predictability, e.g. undertaking cardiac resuscitation or hip replacement operations. However, diabetes health care focuses mainly on the primary level where effects are less predictable with uncertainty over how outputs can be measured and how inputs can be converted to outputs. Complexity theory can contribute to facilitate understanding of what creates emerging patterns of order and behaviour, and how these patterns evolve to assist in the redesigning of health care systems (Kernick, 2002). Two of the features of complexity theory are environmental determinism and non-linearity

(Stapleton, 2008: 9 & 20). Environmental determinism takes the view that environmental forces are beyond the institution's control, while non-linearity implies that inputs and interactions between the environment and the institution do not achieve predictable outcomes, therefore the system never reaches equilibrium (Stapleton, 2008: 9 & 20). Complexity theory changes the accent away from analysis, prediction and control of the arrangement of relationships amongst the systems' components towards the understanding of what generates patterns of order and behaviour among the systems (Kernick, 2002: 123 & 124). Health care systems are complex social entities operating in a challenging social environment, especially public primary health care systems in developing countries such as South Africa. Thus the complexity theory can facilitate understanding of the role and position of government in relation to public and private health care, as well as between the public and private health care systems on the primary care level.

The above view links up with Foucault's (Lemke, 2002: 50-53) concept of 'governmentality[15]' which recognises a re-conceptualisation of government from the concept of a master institution to an agency that oversees and facilitates a population that flourishes. The latter implies that governments shape and guide people's health care and lifestyle, so that they do what is best for themselves and society as a whole. The eco-social research paradigm (or theory) discussed under Section 2.3.6 complements this approach. It suggests an ecosystem as a useful multi-level model to view health care. In this model hierarchies of enduring relationships and informal networks are embedded with the focus on the relationship between agents, long-term agreements, trust and mutual responsibility (Royston & Dick, 1998: 238).

2.5.3 Promoting healthy lifestyles and population health

Cockerham (2005: 51) argues that an important but undeveloped area of theoretical discourse in medical sociology pertains to the comparative

[15] Governmentality refers *inter alia* to the individual's capacity for self-control and the link to forms of political rule and economic exploitation (Lemke, 2002: 50-53).

contributions of structure and agency in determining health lifestyles. Theorists who support social-structural approaches emphasize the power of structural conditions in contouring individual dispositions and behaviour along socially arranged lines, while advocates of agency accentuate the capacity of individual actors to choose their behaviour regardless of structural influences (Cockerham, 2005: 51). William Sewell (1992: 19) defines structures in his classic essay as "sets of mutually sustaining schemas and resources" that enable or restrict social action and incline to be replicated by that social action. Schemas are exchangeable rules or procedures applied to the depiction of social life, with resources that can either be human (e.g. physical strength, knowledge) or non-human (naturally occurring or manufactured) that can be utilised to increase or sustain power (Sewell, 1992: 12, 13 &16).

According to a review of health behaviour and health education theory use in published research between 2000 and 2005, Glanz, Rimer and Viswanath (2008: 31) found that dozens of theories and models were applied, though only a few of them were utilised in multiple publications, with the most often used theories, the Trans Theoretical Model (TTM), Social Cognitive Theory (SCT), and the HBM. Glanz, Rimer and Viswanath (2008: 31 & 35) argue that no single theory or conceptual framework dominates research or practice in health promotion and education. According to Kegler and Glanz (2008: 400) societal, community, and institutional structural factors are critical to promoting health behaviour modifications, with macro-level population-based approaches that complement intrapersonal and interpersonal methods of health education and health behaviour. Kegler and Glanz (2008: 400 & 401) posit that the most challenging public health problems require increased attention to organisational and environmental factors, because behaviour is highly influenced by settings, rules, organisational policy, community norms, and opportunities for action. These authors argue that health education and health behavioural change strategies will achieve greater success through informed application of frameworks for social-structural activation and community attitude and behaviour change, with individual agency that will follow successful organisational and environmental changes (Kegler & Glanz, 2008: 401). The

lack of a comprehensive theoretical approach to understand health behaviour and health lifestyle, as well as the concomitant debate about structure and agency resonate with the rationale and research problem statement of this study.

The bridge from agency to structure for Weber was the 'ideal type', consisting of structural entities, such as bureaucracy or processes, like formal rationality, whose construction allowed him to make general statements about collective forms of collective behaviour (Kalberg, 1994: 9 & 46). In *The Protestant Ethic and the Spirit of Capitalism* Weber (1968) emphasises macro-structure as an essentially 'top-down' approach showing how social institutions, such as Calvinist religion and widespread belief systems, such as capitalism are powerful forces in shaping the thoughts and behaviour of individuals (Sibeon, 2004: 38). Agency can be considered a process in which individuals recall their past, imagine their future actions, critically evaluate their present circumstances, and choose their behaviour based upon their assessment of the situation (Emirbayer and Mische, 1998: 975; Cockerham, 2010: 162). Cockerham's (2005: 51, 52, 54 & 64) arguments regarding the lack of a health lifestyle theory, the agency-structure problem as central to the theoretical discussions of health and lifestyles, and his initial theoretical representation of the health lifestyle phenomenon confirms the gap in the literature. Cockerham (2005: 62) argues that the theoretical conceptualisation of health lifestyles is affected by the agency-structure debate. The discourse about structure and agency in relation to population health and health behaviour of persons with a chronic condition such as diabetes is imperative towards the understanding and interpretation of the population-based factors that influence diabetes self-care. The agency-structure debate can in combination with the other theoretical arguments contribute to the advancement of the towards a comprehensive health lifestyle theory.

2.6 CONCEPTUAL FRAMEWORK FOR THE ANALYSIS OF SUSTAINABLE DIABETES SELF-CARE MANAGEMENT

2.6.1 Introduction

This section of the chapter briefly explores the links between social integration, social capital, the socio-geographic context, external systems barriers and cultural context barriers to diabetes self-care management, it also explains the multi-level nature of the conceptual framework; and diabetes self-care management and health outcomes. The multi-level interactive conceptual framework brings conceptual coherence to the study and simplifies the understanding of the selected population-based factors in relation to sustainable self-care management. It also provides the direction for critical examination of the influencing factors, the development of the research methods, the analysis of the empirical results, and forms the basis for possible problem-solving assertions.

A large number of macro[16]- and meso[17]-level population-based factors might determine the level and quality of diabetes self-care management, but for purposes of this study only selected related elements and variables form part of the final conceptual framework. The research problem statement and sub-problems discussed in Chapter 1 reflect these selected population-based factors that might determine or influence sustainable self-care management, with the role of social integration as the focal point reflecting its interrelationship with demographic variables such as age, gender, migration and urbanisation, as well as the access to social capital and place of residence. These population-based factors have been further modified for purposes of the conceptual framework and reflect an integration of the main relevant elements from the research problem statement and research sub-problems. Figure 2.1

[16] Macro-level population-based factors are *inter alia* social integration, socio-economic factors, the policy environment, demographic and social change (Berkman et al. 2000: 847).
[17] Meso-level population-based factors are *inter alia* social capital, social network structures, socio-geographic networks, and neighbourhood effects, e.g. place of residence (Berkman et al. 2000: 847).

presents the conceptual framework at two levels of social aggregation, namely the macro social-structural level and the meso-social level. The factors at both the macro social-structural and meso-social levels are societal or area related, in contrast with micro-social level factors that pertain to the individual. The diagrammatic presentation of the conceptual framework illustrates how the selected up-stream population-based factors (variables) might serve as predictors and/or barriers for sustainable self-care management of diabetes. The framework outlines a process that begins at the macro social-structural and meso-social levels, and incorporates the selected up-stream population-based factors. Social capital; the socio-geographic context; the cultural contexts barriers; the external systems barriers are *inter alia* population-based factors that are dynamically linked with social integration.

Figure 2.1: Conceptual framework of the study

Source: The researcher's own construct

These factors are linked together to establish the processes by which social integration affects the self-care management of diabetes. These factors are interrelated and some can fit into either the macro social-structural or meso-

social level, serving as the variables that determine the nature of self-care management practised by persons with diabetes. The selected factors were utilised to facilitate the empirical research process through focus groups, while other possibly related factors were identified from the responses.

The conceptual synthesis derived from the framework illustrates the integration of the interactive relationship of the main relevant factors or variables, and reflects how the self-care management health outcomes of persons with diabetes relate to the macro social-structural and meso-social level upstream population-based factors. The description of the relationship of the characteristics of the main elements or factors as it pertains to diabetes self-care management, and reflected within the conceptual framework are briefly explained.

2.6.2 Description of the relationship of characteristics within the framework

Broadly speaking, the main argument underpinning this study is that; firstly, social integration forms the focal point that dynamically links and interacts with social capital, socio-geographic networks, the external systems barriers, and the cultural context barriers. Thereafter, the structural multi-levelled nature of the conceptual framework, comprising the upstream population-based factors, the macro social-structural level, and the meso-social level is explored. Lastly, the interrelationship of sustainable diabetes self-care management and health outcomes that produces different health outcomes in people with diabetes mellitus is explained.

The discussion of the characteristics within the conceptual framework is approached from the centrally positioned factors, reflecting the interactive, multi-levelled nature of the factors, and signifying the dynamic interrelationship towards the external characteristics. A number of the population-based factors or variables intersect with more than one framework characteristic, but each factor is explained only once within the first related context.

2.6.2.1 Social integration

The concepts ‘social integration’ and ‘social capital’ and its inhibiting factors are not clearly distinguished in the literature. Wakefield and Poland (2005: 2823) suggest that the social capital literature represents the ‘norms and networks’ aspect of social capital as essentially synonymous with social integration, emphasising the importance of social integration. The interrelated nature of these concepts as illustrated by Kawachi, Kennedy and Glass (1999: 1187) is that an important distinction must be drawn between social integration measured as an individual characteristic, which is how most epidemiological studies measure social networks, and social integration measured as a collective characteristic, which is how social capital is conceptualised by social scientists. A general description of social integration by (Ritzer & Goodman, 2004: 176) refers to the strength of the attachment that individuals have to society, while social regulation refers to the degree of external constraints of society on people. A more specific definition explaining social isolation is given by Seeman (1996: 442) who describes social isolation as the disengagement from social ties, institutional connections and/or community participation.

The relationship between ‘social integration’ or ‘social capital’ to health and disease is ambiguously defined. In this respect the contribution of Berkman et al. (2000: 844) highlights that when scientists refer to the term social integration in relation to health, a spectrum of related terms are loosely and interchangeably used including social relationships, social networks, social support, and social ties. This use of these terms, in some instances in combination with the term social capital, as interchangeable concepts in relation to health, is confirmed by a number of publications (Lin, 1999; Macinko & Starfield, 2001: 387 & 399; Kritsotakis & Gamarnikow, 2004; Stephens, 2008). Michael, Berkman, Colditz and Kawachi (2001: 123) state that social integration can be divided into informal networks, such as involvement with friends and relatives, and formal engagement, for example participation in paid employment, clubs, and other organisations.

The relationship between social integration and social isolation culminating in suicide is signified in Emile Durkheim's (1951) use of social facts to explain causes and patterns of suicide with his study of suicide, alienation and anomie. This study contributes to the understanding of the influence of social integration and social cohesion on mortality (Berkman et al. 2000; Syme, 2005). Furthermore, a systematic review of 10 studies in the USA, Sweden and Finland by Seeman, (1996: 443) provides evidence of a significant association between social integration and lower mortality. The strongest indication for the effects of social integration on 'health' broadly defined is the evidence of the protective effects of social integration in reducing mortality risks. The evidence suggests that the quality of the social environment may have beneficial or negative effects (Seeman, 1996: 449). The use of 'social integration' as the central factor or characteristic of the conceptual framework for this study in relation to the ambiguous concept of 'social capital' is an endeavour to consider the significance of the concept from the perspective of persons with diabetes.

- Social capital

The concept of 'social capital' has drawn extensive attention in the social sciences and public health literature over the last 15 years (Kawachi, Kennedy & Glass, 1999; Lochner, Kawachi & Kennedy, 1999; Dasgupta, 2000; Kawachi & Berkman, 2000; Glaeser, Laibson & Sacerdote, 2002; Kawachi, Kim, Coutts & Subramanian, 2004). The notion of 'social capital' is a multifaceted phenomenon (Dasgupta, 2000) and is based on the work of James Coleman (1988), Bourdieu and Wacquant (1992), and Robert Putnam (1995). Coleman (1988: S98) describes social capital as active aspects of social structures that facilitate collective action that would be impossible in its absence, it is therefore a function of social structure that produces advantage. Bourdieu and Wacquant (1992) define social capital as "the sum of the resources, actual or virtual", that accumulate to an individual or group by virtue of having a sustainable network of more or less institutionalised affiliations of shared acquaintance and recollection. Social capital contextually supplements human capital, and can be described as a community-level variable that contains the characteristics of social organisation, such as civic involvement, norms of reciprocity, and trust in

others that enables collaboration for the advantage of everybody in the community (Kawachi, Kennedy, Lochner &, Prothrow-Stith, 1997: 1491). Thus, social capital refers to the collective mobilisation of virtues such as knowledge, trust, norms and values, attitudes, levels of involvement that are inherently part of a specific community.

Putnam (1993: 167) based his influential work on social capital on Coleman's argument that social capital denotes to features of social organization, such as trust, norms, and networks that can improve the efficiency of society by facilitating coordinated action. Putnam (1995: 2) in his 1995 seminal publication *'Bowling Alone: America's Declining Social Capital'*, argues that the mechanisms through which civic engagement and social connectedness produce better results are multiple and complex. Life in a community with a substantial reserve of social capital is easier for a variety of reasons: i) networks of civic engagement foster sturdy norms of generalised reciprocity and encourage the emergence of social trust; ii) such networks facilitate coordination and communication, and thus allow dilemmas of collective actions to be resolved; iii) networks of civic engagement embody past success at collaboration, serving as a cultural template for future collaboration; and iv) dense networks of interaction probably broaden the participant's sense of self, from the 'I' to the 'we' (Putnam, 1995: 2).

Social scientists have long pondered over why some communities flourish, have effective political institutions and law-abiding, healthy citizens while other communities do not. Since the middle eighties, researchers began to turn to the concept of social capital as a possible explanation (Kawachi et al. 1999: 1187). According to Burt (2000: 347) the social capital metaphor is that people who do better are somehow better connected, e.g. certain people or groups are connected to certain others, trusting certain others, and dependent on exchange with certain others. In a contextual analysis of social capital Kawachi et al. (1999: 1190 & 1191) found that neighbourhood social capital may influence health behaviour in three ways by i) promoting more rapid diffusion of health information, increasing the likelihood of the adoption of healthy norms of

behaviour, and exerting social control over deviant health-related behaviour; ii) increasing access to local services and amenities; and iii) psychosocial processes by providing affective support and acting as a source of self-esteem and mutual respect. An emergent body of empirical research has been conducted on the associations between individual micro and area macro/meso level of social capital and population health (Kamrul Islam, Merlo, Kawachi, Lindstrom & Gerdtham, 2006: 5). Macinko and Starfield (2001: 410 & 411) argue that social capital can be analysed at four different levels, namely i) the macro level, such as countries and regions; ii) the meso level, like neighbourhoods; iii) the micro level, like social networks of individuals; and iv) the individual attitudinal and psychological level, that refers to an aspect like trust. This multi-level analytic approach towards the assessment of social capital is suggestive of the interaction between external health and other systems, and the challenge posed to persons with diabetes to access these resources in order to enable sustainable self-care management.

The meaning of the concept of ‘social capital’ continues to be contested - there are also some ambiguities concerning where exactly social capital resides, while the common criticism concerns its measurement (Islam, Merlo, Kawachi, Lindström & Gerdtham, 2006). Baum (1999) finds that the concepts that describe social capital are "vague, slippery, and poorly specified, and in danger of 'meaning all things to all people' on both the right and left of the political spectrum". Economists (Dasgupta, 2000; Manaski, 2000; Narayan, 2002) have also criticised the definitions of social capital, pointing out the vagueness and inconsistency of various definitions. Nearly all methods to the measurement and conceptualisation of social capital obscure the differences between social capital as a collective social resource, as a combined social product, or as an individual response (Macinko & Starfield, 2001). The ambiguous and contested nature of ‘social capital’ in relation to social integration necessitates the inclusion in the conceptual framework of the study as an attempt to assess the meaning and understanding of the concept within the context of diabetes self-care.

- Socio-geographic networks

Wallace (1991: 847) first described the concept of socio-geographic networks referring to the intersection of the spatial location of people with their social networks as socio-geographic networks. The maintenance of these networks requires relative geographic stability among the participants who reside within walking distance of family and friends (Wallace, 1991: 850). The socio-geographic networks describe a social-spatial arrangement where the spatial patterns of information flow overlap with other social relationships, for example the primary source of information for an individual may be within the longstanding membership of a faith-based group (Cravey, Washburn, Gesler, Arcury & Skelly, 2001: 1766). Backstrom, Sun and Marlow (2010) reviewed the empirical and theoretical work that informs the relationship between geography and social structure, as well as the ways that this relationship can inform location prediction. They find that at medium to long-range distances, the likelihood of friendship is crudely related to the opposite of distance, with individual experiences of geography and social environment that largely dictates the people and information that individuals have access to (Backstrom, Sun & Marlow, 2010). Thus, the geography and social relationships are inseparably intertwined, which influence their acces to resources with the concomitant impact on their knowledge levels, attitudes and perceptions with regard health and health lifestyle.

According to Gatrell, Popay and Thomas (2004: 245) extensive research effort has been devoted since the late 1990's to describing, and seeking to understand, place-to-place variations in health outcomes. At present there is a sizable literature (Curtis & Jones, 1998; Cravey et al. 2001; Gatrell, 2002; Shaw, Dorling & Mitchell, 2002; Eberhardt & Pamuk, 2004; Cummins, Curtis, Diez-Roux & Macintyre, 2007; Carpiano, 2009) that represents health inequalities in the developed world at a variety of spatial scales. Cravey et al. (2001: 1765) in a geographical analysis of the concept of socio-spatial knowledge networks (SSKN's) determined which sites might be best characterised as SSKN nodes for sharing diabetes information and which sites

might be less suited to such an exchange of information. They found that a socio-spatial approach can improve the effectiveness of chronic disease prevention and the improvement of self-care management of existing conditions within communities.

The application of this approach allows health professionals to know precisely what the people in a community understand about a chronic condition, its treatment or prevention, where people go within the community to share that information, and helps to i) identify strategic locations within a community for future interventions; and ii) evaluate the effectiveness of existing interventions (Cravey et al. 2001: 1773). In addition to this approach Gatrell, Popay and Thomas (2004: 256) argue for more focus on the context of social space and less on 'context' in a geographical sense (the local environment) emphasising the need to examine more fully the health and lived experiences of people located in similar regions of social space. Berkman et al. (2000: 846 & 847) propose that the 'upstream' macro-social forces related to the political economy of health can be integrated with social networks as mediating structures between the largest and smallest scale social forms if social networks are embedded in a larger chain of causation. The socio-geographic networks of the population in this study are complex; the population is spread from rural to informal residential areas to urban environments with the result that an effective mediating structure is of utmost importance to the study.

- External systems barriers

External systems barriers refer *inter alia* to the socio-economic status of the population; health policy; physical access to health care services; the availability of health care personnel; transportation to and from health care facilities and other related resources; and attitudes of health care personnel toward treating diabetes (Zgibor & Songer, 2001: 24-26). The majority of studies investigating barriers to diabetes self-care focus on health care system

factors, while relatively few studies have attempted to understand barriers from the patient perspective (Zgibor & Songer, 2001: 23). According to Aljasem, Peyrot, Wissow and Rubin (2001: 402) diabetes treatment adherence is adversely affected if treatment barriers to diabetes self-care management are underestimated or not identified.

The results of two studies on the barriers to diabetes self-care that included the patient's perspective are consistent in terms of the broad categories of barriers. Nam, Chesla, Stotts, Kroon and Janson (2011: 2-5) conducted a systematic review of 80 studies to establish the existing knowledge regarding various barriers of diabetes management from the perspectives of both patients and clinicians. The results of this review reported the following patient factors to be barriers: i) adherence; ii) attitudes and beliefs; iii) knowledge; iv) culture, ethnicity, and language; v) financial resources; vi) co-morbidities; and vii) social support. Coupled with these were provider factor barriers: i) beliefs, attitudes, and knowledge; ii) patient-provider interaction and communication; and iii) the health care system (Nam et al. 2011:2-5).

Brown et al. (2004: 63 & 67-70) reviewed literature, that characterises the association between socio-economic position and the health outcomes of persons with diabetes. In this review they categorise the distal pathways or external mediators (factors) that have an influence on health behaviours or can be barriers towards effective self-care into individual-level pathways, provider characteristics, characteristics of communities or neighbourhoods, and health care organisations. These individual-level pathways include: i) patient and provider communication; ii) health literacy; iii) language barriers; iv) culture and acculturation; v) mental health; vi) social support, social integration, and competing demands (Brown et al. 2004: 67-70). The provider characteristics refer to: i) the decision-making style; ii) the speciality; and iii) the language concordance (Brown et al. 2004: 66 & 69). The characteristics of communities or neighbourhoods include factors such as the availability and accessibility of health care services; the availability and accessibility of healthy foods; access to places to work out and neighbourhood safety; availability and access to

transportation; and environmental exposures (Brown et al. 2004: 69). Several characteristics of health care organisations have been shown to influence diabetes outcomes namely: i) registries of health care providers; ii) guidelines for diabetes care; iii) patient education; iv) provider education; v) management of referral care; and vi) financial incentives for clinicians that are linked to the volume of referrals, or use of expensive procedures (Brown et al. 2004: 66 & 70).

A qualitative study about the perceived barriers to self-management by Nagelkerk, Reick and Meengs (2006: 153 & 154) found that despite participants having had at least one dietician consultation, the highest ranked barrier was lack of knowledge and understanding of the dietary regimen. The six highest ranked perceived barriers to diabetes self-care management found in their study are reflected in Table 2.1.

Table 2.1: Perceived barriers to self-management in rank order

Rank	Perceived barriers
1	Lack of knowledge and understanding of a specific diet plan
2	Lack of individualised and coordinated care
3	Helplessness and frustration from lack of glycaemic control despite adherence
4	Limited resources to obtain recommended equipment, medicines, laboratory tests and provider services
5	Inconvenient, costly and non-specific group education sessions
6	Difficulty in remembering to take medications, lack of knowledge about medication action, side effects, schedules and adjustments

Source: Nagelkerk et al. 2006: 153

Nagelkerk et al. (2006: 154) further found that coordination of care between primary care providers and hospitals was valued and important to participants. Helplessness and frustration with the lack of success in achieving optimal glycaemic control can lead to ineffective coping such as denial or indifference, while the lack of resources was a common and frustrating barrier for all the participants. The group education structure and delivery may not meet the needs of people with diabetes, while information provided was perceived as confusing. The recurring theme of difficulty in remembering to take their

medication was ranked the sixth barrier in this study (Nagelkerk et al. 2006: 154). This grouping of six barriers to self-management is suggestive of the interaction between the external health system and the ability to sustain diabetes self-care.

- Cultural context barriers

Cultural context barriers are intertwined with external systems barriers. However, for purposes of this study the two contexts are discussed separately, to keep the focus of the importance of prevailing cultural issues in the study population. The efficacy and sustainability of diabetes self-care management is interwoven with the socio-economic and cultural context of a person with diabetes. Psychological factors, and social and cultural norms influence the health beliefs and experiences of individuals and populations about illness; producing barriers that can influence the health behaviour of the individual with the health condition (Skaff, Mullan, Fisher & Chesla, 2003: 309). Cultural influences on individual beliefs, attitudes, knowledge, and behaviours can affect diabetes self-care management (Tripp-Reimer, Choi, Kelly & Enslein, 2001: 16; Holmstrom & Rosenqvist, 2005).

According to Nam et al. (2011: 3) to date, no research has been conducted that compares cultural beliefs in diabetes self-care management across different racial and ethnic groups. A number of selective studies have however been conducted among specific culturally and ethnically homogenous groups. Lipton, Losey, Giachello, Mendez and Girotti, (1998: 67) report that the misconception of insulin being potentially harmful is a common belief among traditional Mexican Americans and probably inhibits participation in insulin treatment. In many cases, the emotional barriers and cultural beliefs of Latinos are more important than financial barriers, while noting that because family needs are considered most important; adhering to a diabetes treatment regimen is viewed as being self-indulgent by Latino persons with diabetes. Based on the development and pilot feasibility testing of a culturally competent intervention of education and care for black American women with type 2 diabetes; D'Eramo-

Melkus et al. (2004: 11, 12 & 17), report that different ethnic groups present various values and attitudes about dietary arrangements, body shape, and weight that influence health behaviours. Rajaram and Vinson (1998: 242 & 243) recommend that more research is needed on the cultural meaning of food and the cultural sensitivity of lifestyle intervention programmes. Cultural sensitivity refers to "the extent to which ethnic and cultural characteristics, experiences, norms, values, behavioural patterns, and beliefs of a target population's relevant historical, environmental, and social forces are incorporated in the design, delivery, and evaluation of targeted health promotion materials and programs" (Resnicow, Baranowski, Ahluwalia & Braithwaite, 1999: 11). A systematic review on barriers to diabetes management from the perspectives of both patients and clinicians by Nam et al. (2011: 3) found that cultural factors to consider in diabetes self-care management include food and dietary preferences, lifestyles, traditional and religious beliefs, and beliefs about general health.

2.6.2.2 Upstream population-based factors

The upstream population-based factors refer to the social and social-structural population factors in the community that have an influence on health, in contrast to the unique characteristics of the individual. In relation to applied health science, the population-based approach is a proactive approach that focuses on what is best for all patients; maintenance of function and the prevention of clinical complications; compared to the individually focused acute clinical care approach (Glasgow, Wagner, Kaplan, Vinicor, Smith & Norman, 1999: 161 & 166). "Increasing the emphasis on population approaches that go 'upstream' to focus on environmental and policy change requires a shift in thinking for those trained in clinical or individually orientated interventions" (Kumanyika et al. 2008: 443). A population-based approach emphasizes behavioural and psychosocial interventions; functional, quality of life outcomes; and routine screening measures for early detection of an illness (Glasgow et al. 1999: 161).

The 'upstream-downstream' debate reflects the metaphor of upstream prevention of an illness rather than trying to solve the crisis downstream (Kumanyika et al. 2008: 443). Berkman et al. (2000: 846) recommend that in order to develop a comprehensive framework that explains poorer health outcomes or less adaptive behaviours, an 'upstream' focus and a return to a more Durkheimian orientation to network structure and social context is needed. Questions about the upstream conditions which influence the development and structure of social networks have been the focus of much social network research, especially in relation to urbanisation, social stratification and culture changes, but little of this work becomes integrated with health issues (Berkman et al. 2000: 853). The argument for this study to focus on the population-based factors is also supported by Bandura (1984), as well as by Frohlich, Corin and Potvin (2001: 783) and Cockerham (2005: 53) who argue that when health lifestyle is debated within the socio-medical discourse, there is a definite tendency to refer to individual behavioural patterns that affect disease status – this tendency reflects a disregard for its collective and macro social-structural characteristics. The focus of this study on selected population-based factors can contribute to the understanding of the association between the macro-social context and the health behaviour of persons with diabetes.

2.6.2.3 Macro social-structural level factors

Mirowsky and Ross (2003: 53 & 199) in their book 'Education, Social Status, and Health', suggest that neither individual choice nor structural limitations can be ignored in studies of health behaviour and health lifestyles. The macro social-structural level factors condition the extent, shape, structure and nature of the social factors in a population. These societal or population-based factors refer *inter alia* to the policy environment; the health system; the cultural context; the socio-economic factors of the population; the neighbourhood; and demographic and social changes (Berkman et al. 2000: 847; Kumanyika et al. 2008: 443). When contextualising the related variables, such as social integration on the macro social-structural level, it signifies the embedded nature of *inter alia* the connections between structures such as the state and the

society and the extent to which there is synergy between the actions of the state and the interests of the population (Hawe & Shiell, 2000: 873). This distinctive focus reviews one of the sociological questions regarding ways in which these macro social-structural level phenomena are manifested and actualized in the lived experiences of persons with diabetes and the day-to-day unfolding of their social life (Shim, 2010: 1).

2.6.2.4 Meso-social level factors

The meso-social level factors provide opportunities for the facilitation of psychosocial mechanisms on the micro level and refer *inter alia* to the societal factors of social capital, social network structures socio-geographic networks, and neighbourhood effects (Berkman et al. 2000: 847). Martikainen, Bartley and Lahelma (2002: 1092) classify psychosocial factors as meso-level concepts, contextualizing psychosocial factors on the same level as religious institutions; the family; the work and economy; and social clubs as meso-level social formations. Hertzman, Power, Matthews and Manor (2001: 1576) refer to the civil society as the meso-social level, and argue that there are a series of factors at this level, including voluntarism; social affiliation, trust, and cohesions; and the capacity of important social institutions that respond to current and changing human needs. In the context of health research meso-social level psychosocial concepts, such as social networks, work effort and reward balance, security and autonomy, and work-family conflict are all produced within the meso-social level social formations. A central constituent of a psychosocial explanation of health is that macro social-structural- and meso-social level processes lead to perceptions and psychological processes at the micro individual level (Martikainen et al. 2002: 1092).

2.6.2.5 Diabetes self-care management and health outcomes

The integrated interactive nature of the main relevant factors or variables reflects how the self-care management and health outcomes of persons with diabetes interact with and relate to the macro social-structural and meso-social

level upstream population-based factors. Sustainable diabetes self-care management includes all aspects of the treatment regimen, namely the full range of activities that persons with chronic illness may engage in to promote their health, augment their physical, social or emotional resources and thereby prevent adverse clinical complications from their illness. It is the outcome of these activities that is interrelated with the clinical health outcome of effective blood glucose control (Thorne & Paterson, 2001: 82).

A health outcome can be described as the result of an intervention or series of interventions that are intended to change the health of an individual, or a group of people. Health outcomes are *inter alia* measured by health status (self-rated health, disability, social/role activities limitations, energy/fatigue, and health distress), health care utilization (outpatient visits, times hospitalized, and days in hospital), and perceived self-efficacy (Lorig et al. 2001: 1217). The clinical health outcomes of the full spectrum of the prescribed clinical and self-care regimen are affected not only by how well patients take their medications and apply their self-care practices but also by how long they take their medications and apply the required self-care regimen (Cramer et al. 2008: 46). Successful health outcomes are dependent on the effective application of both the clinical and lifestyle regimen for the specific chronic condition. Van Dam, van der Horst, van den Borne, Ryckman and Crebolder (2003: 18) argue that the improvement of health outcomes of type 2 diabetes health care is impossible without the improvement of patient self-care management.

2.7 CONSTRUCTION OF THE THEORETICAL FRAMEWORK UNDERLYING THE STUDY

2.7.1 Introduction

The theoretical framework structures the theory base of the study; and directs and enables the logical interpretations and explanations of the findings. The link between upstream population-based factors which are the invisible central

predictor variables that have a bearing on sustainable diabetes mellitus self-care management is fully dealt with in Chapter 5. The theoretical framework draws on a multi-level heuristic framework, a health behavioural model and a social theory which are also fully explored in Chapter 5. The heuristic framework is applied in terms of its explanation of the social-structural and social factors, and the causal accounts of ineffective self-care management. The health behavioural model provides an explanation of the role of individual preventative health as it pertains to an existing health condition; while the sociological theory brings an understanding of the role of social structures in the social dynamics of disease.

Mouton (2001: 52) defines real-life problems as social, political, economic and health-related problems, which can only be solved through human action. Disease and illness are real-life problems, problems that are part of the everyday life and lay knowledge. These real-life problems were scientifically transformed into research problems, and contextualised by Mouton (1996) in his Three Worlds framework. According to Mouton (2001) the problems in World One represent the ordinary social and physical reality, and like other diseases, the diabetes epidemic and progression of the disease need to be solved through human action and intervention. World Two represents the world of science and scientific research where real-life problems in World One are transformed into objects of inquiry. Reflection is prevalent in the world of science therefore in World Three, the world of meta-science; scientists submit research decisions to critical reflection (Mouton, 2001: 138). This study reflects the interwovenness of the World Two and World Three of the Three Worlds Framework developed by Mouton (2001: 137, 139 & 142). It represents the world of science and scientific research where objects of inquiry have been transformed in terms of the real-life problems of diabetes self-care management, and is a reflection of the nature of the meta-discipline of sociology and scientific research.

The study was theoretically contextualised by utilising elements of structural-functionalism. The emphatic stance of seeking an understanding through the

eyes of the research participants indicated that the study is in tune with interpretivism. “Interpretivism is predicated upon the view that a strategy is required that respects the differences between people and the objects of the natural sciences and therefore requires the social scientist to grasp the subjective meaning of social action” (Bryman, 2012: 30). The latter demonstrates its intellectual historical foundations of phenomenology, symbolic interactionism, and *Verstehen* (Bryman, 2012: 30). This epistemological position required the researcher to grasp the subjective meaning of social action and directed the synthesizing of a three-pronged theoretical approach.

There are several theories that can explain specific elements of self-care management, health behaviour and health lifestyle, but no comprehensive, integrated theory has yet been developed that explains the social complexity of a chronic condition such as diabetes (Cockerham, 2005: 51, 52 & 64). Cockerham (2005: 64) developed an initial theoretical representation of the health lifestyle phenomenon and suggests that this representation be subjected to verification, change, or rejection through empirical application. The researcher decided to apply an eclectic combination of a multi-level heuristic framework, a health behavioural model and a social theory to explain the phenomenon of the dynamic interrelation of population-based factors and sustainable diabetes self-care management. The researcher does not ‘claim’ that any single one of these theories explains the whole phenomenon, however each theory explains elements of it. The application of this three-pronged theoretical framework forms part of the theoretical engagement with the disciplines of epidemiology and social epidemiology. The qualitative nature of the research process of this study, in combination with the lack of a health lifestyle theory, creates an opportunity for the emergence of new explanations and theoretical ideas out of the data. This process is reflected in Strauss and Corbin’s (1998: 12) definition of grounded theory: “Theory that was derived from data, systematically gathered and analyzed through the research process. In this method, data collection, analysis, and eventual theory stand in close relationship to one another.” The theoretical framework of this study, which consists of the multi-level heuristic framework of social epidemiology, the

Health Belief Model (HBM) of Rosenstock, and the structural-functionalist theory of Parsons, will be discussed in the next three sections.

2.7.2 The heuristic framework of social epidemiology

Social epidemiology builds on the classic epidemiologic triangle of agent, host and environment, and focuses on the role of social determinants in the aetiology and progression of disease, and these are the pathways by which societal conditions affect health (Krieger, 2001a: 697). Louis Pasteur and other medical scientists, during the late 19th century, revolutionised medical thought with the germ theory – arguing that bacteria are the source of infection. This school of thought and Snow's (1854) findings led to the recognition that people or the susceptible host, come into contact with a wide spectrum of bacteria or agents, while the social environment refers to the actual living conditions of the individual (Cockerham, 2004). The specific characteristics of each agent are important in determining the nature of the infection or disease, and can be biological, nutritional, chemical, physical or social. Human hosts are examined in terms of biological (sex, age, degree of immunity) and behavioural characteristics (habits, customs, and lifestyle) (Cockerham, 2004: 24). Environmental conditions, such as sanitation, air pollution, water quality, as well as socioeconomic factors such as poverty, overcrowding and population density play a critical role in the development of not only communicable diseases, but also lifestyle diseases such as type 2 diabetes. Diseases and complications of diseases occur as a result of the interaction between the agent, human host and social environment that form the three corner anchors of the classical epidemiological triangle (Beaglehole, Bonita & Kjellstrom, 1994: 100-102). Based on this, Poundstone, Strathdee and Celentano (2004: 22-29) developed the heuristic framework of the social epidemiology of human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS). The principles of the framework were adapted and applied in this chapter in relation to the social epidemiology of diabetes. The discussion mainly draws on the work of these authors, while other authors are specifically cited.

The framework was developed within the context of the present and projected increased incidence of diabetes. Patterns that enhance vulnerability for diabetes can be conceptualised at multiple levels, and the framework distinguishes determinants of diabetes at three levels, namely individual, social and structural. The individual factors include biologic, demographic, and behavioural risk factors that may influence the risk of acquiring diabetes and disease progression. The application of the life course[18] approach to chronic disease epidemiology has been found to be useful with regard to the assessment of the long-term effects on chronic disease risk of physical and social exposures during gestation, childhood, adolescence, young adulthood and later adult life (Kuh & Ben-Shlomo, 1997). The life course approach intertwines both biological and social transmission of risk factors across generations (Ben-Shlomo & Kuh, 2002: 288). The socio-demographic individual characteristics included are gender, age, race and ethnicity; while individual education level, occupation and income determine the socio-economic position. The behavioural factors include, diet, exercise, stress levels, and alcohol and drug use.

There are four categories of social-level factors that are of importance to diabetes epidemiology, namely the cultural context, social networks, neighbourhood effects and social capital. The cultural context includes factors such as the norm and value system; social cohesion and integration; race and ethnic inclinations; and elements of sexism in a society that narrate to gendered eating patterns and exercise (Bourdieu, 1986; D'Eramo-Melkus et al. 2004; Shim, 2010). The dynamics of social networks can influence health outcomes in direct and indirect ways, including social support, social influence, social engagement and participation, and access to material goods and informational resources. Neighbourhood effects represent the intersection of social networks and physical spatial locations, called the socio-geographic networks (Wallace, 1991: 847) that are associated with the environmental socio-economic factors. Social capital may affect health through the presence of health-promoting

[18]The life course perspective refers to how health status at any given age, for a given birth cohort, reflects not only contemporary conditions but embodiment of prior living circumstances, in utero onwards (Kuh & Ben-Shlomo, 1997).

behaviours, access to services and amenities, levels of mutual trust in a community, and greater political participation, leading to policies that are more likely to benefit all citizens (Kawachi & Berkman, 2000: 184).

Structural-level factors can be divided in three main categories: policy and legal environment, structural discrimination, and demographic change. Policies and legal structures guide decisions about the allocation and utilisation of resources, while macroeconomic policies affect health and development by altering absolute poverty levels and/or inequalities in the distribution of wealth (Subramanian, Belli & Kawachi, 2002). Contextual and structural factors play key roles in shaping socialisation patterns that contribute to racial, ethnic, and gender discrimination, and *inter alia* lead to residential segregation, impacting on available resources. Demographic changes, like population mobility and migration, urbanisation, and the age and gender structures of subpopulations, act as modifying variables that may influence the incidence of diabetes.

2.7.3 The Health Belief Model of Rosenstock

Several studies have investigated the relationship between health beliefs and self-care management of chronic conditions (Glasgow, Toobert, Hampson, Brown, Lewinsohn & Donnelly, 1992; Wooldridge, Wallston, Graber, Brown & Davidson, 1992; Assal, Jacquemet & Morel, 1997; Funnell & Anderson, 2007; Kartal & Ozsoy, 2007). A review of these studies by Funnell et al. (2011) found that the majority of these studies endorse the importance of attitudes and health beliefs in diabetes self-care outcomes. Poor adherence to treatment regimens observed amongst type 2 diabetes patients, even when patients are offered on-going support has encouraged interest in using social cognition theories to predict and understand adherence (Farmer, Kinmonth & Sutton, 2005: 266 & 270). “The nuances of these theories, which include the health belief model, the locus of control construct and the theory of planned behaviour are slightly different, however common to all of them is the notion that an individual’s illness beliefs can be mapped onto and/or used to predict his/her health behaviour(s)” (Lawton et al. 2008: 48). This applies to beliefs about the causal

factors; personal disease susceptibility, including susceptibility to complications; disease seriousness; and disease controllability, including the effectiveness of treatments (Hardeman, Johnston, Johnston, Bonetti, Wareham & Kinmonth, 2002: 146 & 148). A small, yet rich, cluster of social scientific studies have sought to critically assess the use of social cognition models in understanding, and promoting, diabetic adherence by examining patients' perspectives in depth (Lawton et al. 2008: 48). An example is the application of the validity and reliability of a version of the Health Belief Model Scale that was performed in a study of diabetic patients in Turkey. This study found that the HBM provides a useful framework for understanding how persons with diabetes live with the condition, the problems they encounter and its treatment (Kartal & Ozsoy, 2007: 1455).

The Health Belief Model (HBM) of Irwin Rosenstock (1966) is one of the best-known and influential social-psychological approaches that explain the ways in which healthy people seek to prevent illness. The principles of the model are to a large extent based on the psychological theories of Kurt Lewin (Lewin, Lippitt & White, 1939; Lewin, 1943: 128-130; Lewin, 1947: 147-153) who suggested that individuals exist in life spaces composed of positive and negative values. Despite the individual social cognition nature of the model, several researchers who studied diabetes treatment adherence have applied the HBM for the prediction of adherence to diabetes treatment guidelines (Greco et al. 1990; Glasgow et al. 2001). The model hypothesises that the application of preventative behaviour and adherence to disease treatment guidelines, increases as a function of the patients' perception of greater susceptibility to the illness, greater disease severity, greater perceived benefits of adherence, fewer emotional, physical or financial barriers to adherence, more social support and greater self-efficacy (Greco et al. 1990; Glasgow et al. 2001).

An illness is contextualised as a negative value, which an individual would like to avoid; on the other hand health is a positive value which individuals are attracted to (Rosenstock, 1966). Human health behaviour depends upon two primary variables: i) the value placed by a person upon a specific health

outcome, and ii) the person's belief that a given action will result in that outcome (Cockerham, 2004: 113-114). Research supports the view that in order to actively engage in behaviour change, individuals need to perceive that the illness or risk is serious, that they are susceptible to the illness and/or complications of the condition, and that they are able to implement a new behaviour that will be beneficial (Whittemore, Bak, D'Eramo-Melkus & Grey, 2003: 341). Additionally to the individual's perception about his or her own susceptibility to, and the seriousness of a disease, there are modifying factors such as demographic, socio-psychological and structural variables that can influence the outcome (Rosenstock, 1966). The combination of these variables will determine the perceived threat of a disease and the cues to take preventative action. The likelihood of action depends on the individual's perception about the benefits or effectiveness of necessary action, and the barriers (too expensive, unpleasant, painful, traumatic or inconvenient) to take action (Cockerham, 2004). Despite acknowledgment of the necessity for action, and adequate energy, there might still be a need for stimuli to facilitate appropriate behaviour. Stimuli can include the perception of internal bodily states, or external cues, like interpersonal interaction, mass media communication or personal knowledge of someone affected with the disease (Rosenstock, 1966).

Since Rosenstock's (1966) publication of the HBM scientists have been engaged in a debate about the usefulness and/or lack of relevance of the model to a chronic condition such as diabetes. Rosenstock's (1974) assertion is that the model was designed to predict the adoption of preventative measures rather than treatment for existing diseases and disorders. Janz and Becker (1984) present a critical review of 29 HBM-related investigations published during the period 1974-1984. This review provides substantial empirical support for the HBM: 'perceived barriers' proved to be the most powerful of the Health Belief Model components across the various study designs and behaviours, while 'perceived severity' produced the lowest overall significance ratios (Janz & Becker, 1984: 39-40). According to this review it is recommended that components of the Health Belief Model be considered as part of health

education programmes (Janz & Becker, 1984). The efficacy of the HBM in nutritional education to the diabetic patients was confirmed in a study by Sharifirad, Entezari, Kamran and Azadbakht (2009: 1). In this study the HBM improved the knowledge, attitude and practice of patients with the highest increase noted for the variables 'perceived susceptibility' and 'perceived severity' (Sharifirad et al., 2009: 5).

Contrary to these analyses, Armitage and Conner (2000: 173) established through use of a structured review of social cognition models, that narrative reviews have tended to criticise the HBM on the grounds that the components have been formulated without definition and without any rules of combination. For example, although 'threat' may be a function of severity and susceptibility, they are presented as separate predictors of behaviour (Stroebe & Stroebe, 1995; Sheeran & Abraham, 1996). Champion & Skinner (2008: 50) in their synthesis of the HBM assessed that overall; 'perceived severity' was the least powerful predictor of the dimensions and strongly related to the sick-role behaviour. The concept of 'perceived threat', defined as a combination of 'perceived susceptibility and severity' in the HBM, has great relevance for much health-related behaviour. However, the HBM does not consider the emotional component of behaviour and should with the cues to action be added to, or better incorporated in, HBM research (Champion & Skinner, 2008: 62). Finally an updated critical review of the research and findings based on the HBM is warranted and would help to map future directions for researchers and practitioners (Champion & Skinner, 2008: 62).

2.7.4 The structural-functionalist theory of Talcott Parsons

Talcott Parsons (1951: 5-6) define a social system as consisting of a range of individual actors interrelating with each other in a situation with at least a physical or environmental aspect; motivated in terms of a tendency to the 'optimization of gratification' and whose relation to their situations is defined and mediated in terms of a system of structured and shared symbols. This

definition conceived of in a middle class structure with an ideal health care system and provision of services is of great value as a benchmark or criterion for the efficacy of the functioning of the South African health system. For this reason Parson's structural-functionalist theory is used to highlight positive and negative factors in health care provision.

Parsons (1951: 42) argued in one of his most important works 'The Social System', that the integration of levels of social analysis is of central importance in the social world: "This integration of a set of common value patterns with the internalized need-disposition structure of the constituent personalities is the core phenomenon of the dynamics of social systems. That the stability of any social system except the most evanescent interaction process is dependent on a degree of such integration may be said to be the fundamental dynamic theorem of sociology." In modernity the macro-level social system of the nation-state can be divided into four subsystems. The economic subsystem is concerned with adaptation; the subsystem of the polity with goal-attainment; the subsystem of the social community with integration; and the cultural subsystem with latency or pattern-maintenance (Parsons, 1951). Adaptation is the functional prerequisite and is characterized by universalism while subsystems such as the social community, where integration is the functional prerequisite, are characterized by particularism, quality and affectivity (Scambler, 2002: 13).

Parsons' structural-functionalist theory conceptualized society as a social system with inter-related social structures, each with a specific function to ensure the integration and stability of the individuals and their social roles. The structural-functionalist perspective is reflected in the main focus on how the social system, including the health system and the family as a system, controls the individual, and not on how the individual creates and maintains the system (Ritzer, 2011: 243-245). Parsons (1951: 431) combined the functional and social aspects of the illness experience in the definition of the social study of medicine: "… we may say that illness is a state of disturbance in the 'normal' functioning of the total human individual, including both the state of the organism as a biological system and his personal and social adjustments.

Participation in the social system is always potentially relevant to the state of illness, to its etiology and to the conditions of successful therapy, as well as to other things." Post-modernist thought challenges Parsons' (cited by White, 2002) model of structural-functionalism, emphasising that while society lays down functions, the increased number of options open to individuals facilitates choices to shape their own lives, allowing them to become 'agents' for their own lives (White, 2002: 56). The bridge from agency to structure for Weber (cited by Kalberg, 1994) was the 'ideal type' of institution, consisting of structural entities such as bureaucracy, or processes like formal rationality, whose construction allowed him to make general statements about collective forms of collective behaviour (Kalberg, 1994: 9, 46).

The processes of internalisation and socialisation are of key importance in integration, namely the ways that norms and values of a system are transferred to the individual actors in society. Successful internalisation implies that the norms and values become part of individual's consciences: "The combination of value-orientation patterns which is acquired (by the actor in socialization) must in a very important degree be a function of the fundamental role structure and dominant values of the social system" (Parsons, 1951: 227). The importance of the social system, its inter-related social structures, and specific functions that ensure the integration and stability of the individuals are fundamental to the effective functioning of society, including the health care system. The focus of Parsons' theory of structural-functionalism on the role of social integration contributed largely to the direction of the research problem statement and thesis of this study. The health system as a subsystem of society represents the diverse influences upon health behaviour with human action as its point of reference that explain behaviour in terms of external influences upon it. The structural-functionalist theory of Parsons brings an understanding of the role of social structures in the social dynamics of disease.

2.8 SUMMARY

The funnel approach was applied to the literature review that provided the scope, structure and broad theory base to the study. The sociology of diabetes and the epidemiological research paradigms indicated the gap in the scientific field of population-based perspectives on the self-care management of diabetes. The overview of diabetes self-care management and the role of the health care system confirmed the complex nature of diabetes mellitus as a metabolic disorder. The study is contextualised in terms of the selected population-based factors that might determine sustainable self-care management, with the focal point being the role of social integration and its interrelationship with the other factors that might have a bearing on diabetes self-care management. The interactive multi-level conceptual framework reflects the integration of the main relevant factors, and brings conceptual coherence to the field of study of the selected population-based factors in relation to sustainable self-care management. The emphatic stance of seeking an understanding of the real-life problems that persons with diabetes experience is in tune with the meta-analytical theory of interpretivism. The three-pronged theoretical approach of the multi-level heuristic social epidemiological framework, the HBM and the social-structural theory of Parsons laid the final foundation for the development of the conceptual framework. The theoretical approach explains the social-structural and social factors, and the causal accounts of ineffective self-care management; it provides an explanation of the role of individual preventative health; and brings an understanding of the role of social structures in the social dynamics of disease. The methodology applied in the study will be discussed in the next chapter.

CHAPTER 3
Sources of data and methods of analysis

3.1 INTRODUCTION

Figure 1.1 in Chapter 1 and Figure 2.1 in Chapter 2 present respectively the contextual and conceptual frameworks that directed this study. From the starting point, the assumption was made that sustainable diabetes self-care management has a positive impact on controlling blood glucose levels in diabetes patients. The intention of this chapter is to discuss the sources of data used in the study and the methods of analysis applied to the data. The chapter outlines the research design; the sample design and sampling methods; the target population, unit of analysis and selection of cases; the data collection methods and fieldwork practices; the description and justification of the data analyses; the ethical considerations that governed the study; and some of the limitations to the study.

This qualitative study complements a cluster randomised control trial (also referred to as a clinical trial), conducted by researchers from the Faculty of Health Sciences, University of Pretoria. The primary objective of the clinical trial was to evaluate the effect of a mobile screening team on the number of patients diagnosed with diabetes complications, as well as the number of patients who warranted referral for management of complications in the Tshwane district in Pretoria. The secondary objective of the clinical trial was to determine the effect of mobile screening on HbA1c and lipid levels in the diabetic patients in the study district and to estimate the cost of intervention per complication detected. The first phase of the clinical trial was conducted between July 2010 and March 2011 and the second phase between September 2011 and June 2012. The clinical trial formed the basis of, and served as an enabler for the demarcation and identification of the study population for this qualitative population-based social research study.

The preliminary results of the clinical trial provided a basis for identifying clinics that form part of the population for this qualitative study. The Tshwane District Health Authority assisted in selecting the study population in the Tshwane district, namely the first level sample of the primary health care clinics, and the second level sample of diabetes patient cases, for this study. This qualitative study focuses on research questions that might provide possible answers to the underlying causes of diabetes, in particular the causes of hyperglycaemia and societal factors that are conducive to the causes of diabetes. The findings of this study will contribute to providing a knowledge base of interventions that might be the most successful in addressing societal problems associated with diabetes and specifically diabetes self-care management.

3.2 RESEARCH DESIGN

The nature of the research problem required an exploratory, interpretive, and in-depth qualitative study. Qualitative research involves studying phenomena in their complexity in natural settings in the 'real world'. In qualitative research, the researcher recognises that the research problem has many dimensions and layers that need to be portrayed in a multifaceted form, and not merely simplified (Leedy & Ormrod, 2010: 135).

Apart from the nature of the research problem, other reasons for the qualitative nature of the study are the limited scientific literature available in this field, and the multiple possible realities about the research problem that might be constructed by the target population. Qualitative research involves investigating characteristics, or qualities, that cannot be easily reduced to numerical values; rather "it facilitates a better understanding of complex situations, is more holistic and emergent, and therefore enables the researcher to build theory from the ground up" (Leedy & Ormrod, 2010: 94-96).

Furthermore, unlike experimental designs, surveys and other quantitative methods, in which the elements of the research design, such as the hypothesis, measurement methods, and sampling are clearly specified prior to data

collection, in qualitative research, design elements are developed mainly during the course of the study. At the start of a qualitative study, researchers can outline a tentative design, provisional measurements, formulate key research questions, and indicate the broad scope of case selection. In qualitative research the emergent ideas and provisional findings can lead to refocusing of the research, and to exploring sources of data such as previously unidentified participants (Rubin & Rubin, 1995: 42-43). The main elements of the research design for this qualitative study, the data collection and analysis of data are presented in Figure 3.1. A case-control research design was employed, featuring diabetics with controlled blood glucose (sugar) levels and those with uncontrolled blood glucose (sugar) levels.

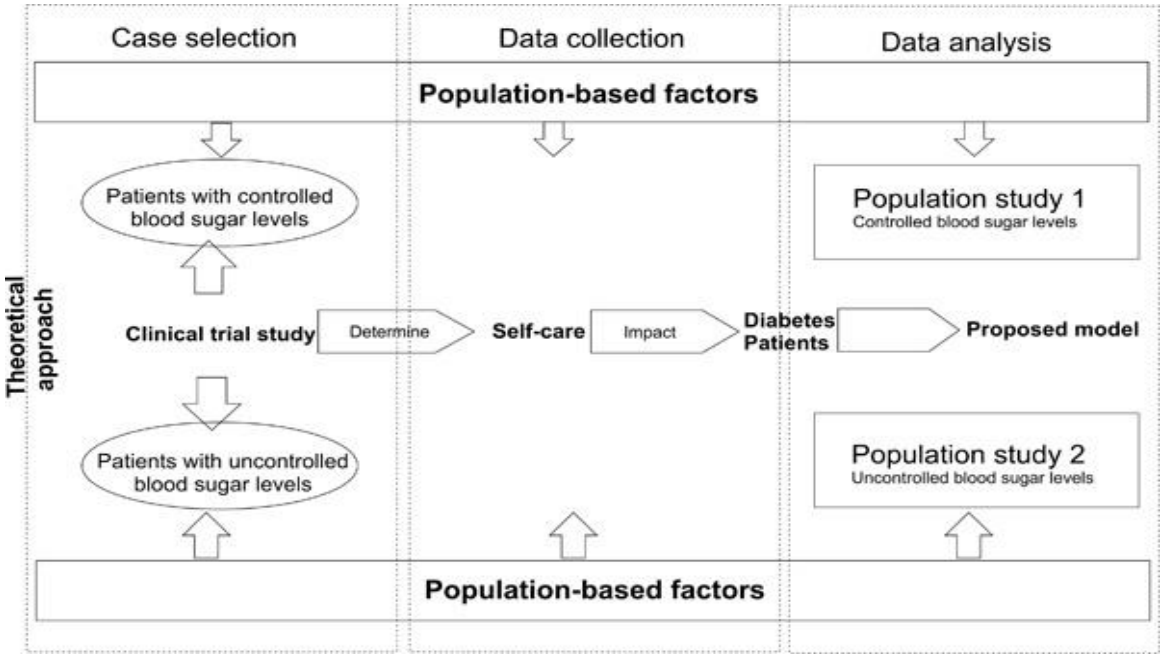


Figure 3.1: Research design

Source: The researcher's own construct

The research design reflects the interrelationship of all the elements and participants involved in the research process. The theoretical approach directed a qualitative social research study, complementing the completed clinical trial. Data was collected by means of focus groups, acquiring related population-based factors. Recommendations that emerged from the findings with regard to population-based factors that would be important in a diabetes self-care management model were made (Chapters 5 and 6). Correlations between the

preliminary clinical results and the population-based factors in the conceptual framework for this study partly informed the researcher about the socio-economic background of the study population.

Against this background, this study is based on an empirical research design, using primary data that is mainly textual in nature, with a low level of control by the researcher in the structure of the design. There was a low level of control because the researcher could not control the research process through experimental and control groups. The design is comparative[19], focusing on the similarities and differences between the units of analysis as outlined in Section 3.4.1 of this chapter. The grounded theory forms the basis of the research design. Grounded theory refers to the fact that the theory is derived from, and grounded in the data that is collected in the field, rather than taken from the literature (Leedy & Ormrod, 2010: 142). The grounded theory approach is used when current theories to explain phenomena are either inadequate or non-existent (Creswell, 2008). While grounded theory was applied in this study mainly during data collection, characteristics of a phenomenological[20] nature also emerged in the course of the data analysis. The complete data analysis approach is outlined in Section 3.6 of this chapter.

The key research questions were reformulated within the broad exploratory context of the study, and are descriptive, interpretive, and historical in nature. In the research proposal phase, no specific meta-theoretical tradition was followed, but the study was theoretically contextualised by utilising elements of structural-functionalism (Parsons, 1951). During the empirical phase of the study, the emphatic stance of seeking understanding through the eyes of the research participants indicated that the study is in tune with the interpretivist approach. Interpretivism demonstrates epistemological links with phenomenology, symbolic interactionism, and *Verstehen*[21] (Bryman, 2012: 401). This qualitative research design offered the potential to provide new

[19] "This entails studying two contrasting cases using more or less identical methods" (Bryman, 2012: 72).
[20] "Phenomenology is a philosophy that is concerned with the question of how individuals make sense of the world around them" (Bryman, 2012: 710).
[21] The approach that Weber (1947: 88) referred to in German as *Verstehen*, which means understanding.

insights, and re-orient current understanding of the complex nature of diabetes self-care management.

3.3 SAMPLE DESIGN AND SAMPLING METHODS

3.3.1 First level study sample of clinics

The 40 primary health care clinics in the Tshwane district contained the study population for both the clinical trial and this qualitative study. The sampling process for both the clinical trial and the qualitative study is reflected on two levels: the study sample of the clinics, and the sampling of the patients at the respective clinics. The clinical screening team identified 12 primary health care clinics from a total of 40 clinics in the Tshwane district that participated in the clinical trial. The first level study sample involved six of the clinics that were intervention clinics and six that were control clinics.

The final selection of clinics for this qualitative study differs from the initial clinical trial, for four main reasons. Firstly, not all the results from the clinical trial were available at the time of commencement of this study. Secondly, new district demarcations were introduced after the clinical trial. Thirdly, some of the clinics in the Tshwane district were closed due to renovations, and patients were forced to make use of alternative clinics in the district. Fourthly, after the pre-testing and piloting phase, the clinical endocrinology researchers in the Kalafong diabetes research team recommended an adapted sampling strategy. This recommendation was due to the three monthly changes seen in the clinical HbcA1 profiles of individual diabetes patients. The clinical trial provided the results of the HbcA1 profiles, but these tests were over a year old and were thus a poor indicator of recent blood glucose levels of diabetes patients.

Furthermore, certain specific circumstances had to be taken into account in selecting the final population and sample. The first was the researcher's involvement in a Lifestyle Research Project at the Kalafong Provincial Academic Hospital Diabetes Clinic, University of Pretoria, during the first half of

2013, which could have led to subjectivity. (See more details in Section 3.5.2 of this chapter.) This research and intervention project was not related to either the aforementioned clinical trial or the present qualitative study, except for the fact that it created an opportunity for the researcher to pre-test and pilot the research instruments for the present qualitative study. The patients in the primary feeding area for the Kalafong Diabetes Clinic, which includes the whole western region of the Tshwane district, had already been exposed to an extensive diabetes self-care intervention programme. The second circumstance was that some district clinics provide only one month's medicine supply, while the nearby provincial day hospital provides a three-month supply, and patients prefer the latter. The third circumstance was the fact that the Tshwane Health Authority gave ethical clearance specifically for these seven clinics, based on capacity and other clinical considerations.

The first level sample of clinics in this qualitative study comprises seven primary health care clinics in the district of Tshwane, including one intervention clinic, two control clinics, and four clinics that were not part of the clinical trial. A seventh clinic was included in the first level sample, after the manager indicated that they would like to be included in the study. A map of the district Tshwane district to indicate the area location of the clinics is provided in Appendix J. Two of the selected clinics are in close proximity to each other in the near-eastern region of the district of Tshwane, namely East Lynne and Silverton. The remaining five clinics are geographically well distributed: one is in the northern deep rural region of the Winterveldt, one is in a southern location in Rooihuiskraal, a third clinic is situated in the far-eastern region of Mamelodi in an informal housing area, a fourth clinic is in the mid-city area of Pretoria, and the fifth is in the far south-eastern region of Moreleta Park. The western region is the main feeding area for the Kalafong Diabetes Clinic; therefore clinics situated in this region had to be excluded. The clinics were selected based on their specific circumstances in terms of chronic patients and the willingness of clinic managers to participate in the qualitative study. In terms of demographics, the clinics do not reflect a good distribution, for example with regard to gender and race. The main reason for this is the fact that the majority of persons with

diabetes who attend primary health care clinics in the Tshwane district are mainly Black females.

3.3.2 Second level study sample of patients

The clinical trial research team compiled a record of specific patients with controlled blood glucose and those with uncontrolled blood glucose levels and clinical complications. The study sample of patients or unit of analysis of the clinical trial was 599 individuals with diabetes in the selected clinic cluster in the district of Tshwane.

The research design made provision for the inclusion of diabetes patients with controlled and uncontrolled blood glucose levels at a minimum of six clinics, but a seventh clinic was included. The final second level study sample of patients for this qualitative study included 72 persons with diabetes who make use of the seven primary health care service clinics.

3.3.3 Socio-economic context of the study population

The district of Tshwane is located in the north-western corner of the Gauteng Province and covers an area of 5 703 80 square kilometres, which is approximately 13% of the provincial geographical area. Tshwane and Metsweding have, in line with the new municipal demarcation, merged into one metropolitan municipality, namely the City of Tshwane. Unlike the other metropolitan cities in Gauteng, Tshwane comprises a significant amount of rural land and rural communities (City of Tshwane IDP, 2006: 12). Tshwane's human settlement pattern is characterised by inequitable low-income residential areas that are removed from economic opportunities and vital social amenities. Low-income, government assisted development occurs on the periphery of the urban areas, and is most dominant in the north, followed by the west. The northern areas of the district include GaRankuwa, Temba and the Winterveldt, while the western areas include Atteridgeville, Lotus Gardens and Olievenhoutbosch. However, Olievenhoutbosch attends to the southern areas of the district, like Centurion, while Mamelodi, the only settlement area to the

east, serves the eastern suburbs. Due to the city's eastward growth, Mamelodi experiences an overload in trying to manage the high influx of people who seek accommodation closer to their areas of employment (City of Tshwane IDP, 2006: 16).

The City of Tshwane has a total population of 2 708 702 people and a population density of 472,9 persons per square kilometre (City of Tshwane IDP, 2013/2014), of which 40,6% of the population falls within the 15 to 34 years of age category. According to the 2011 census, the annual population growth rate was 3.1% for the period between 2001 and 2011 (City of Tshwane IDP, 2013/2014:12). Statistics indicate that in 2001, 15,3% of households had no income, and the number of people living in poverty increased since 1996. The group that is hardest hit by unemployment is the youth, ages 20 to 24 years (City of Tshwane IDP, 2006: 17). The 2011 census reported the unemployment rate for Tshwane is 24.2% (City of Tshwane IDP, 2013/2014:12).

Social service delivery in the Tshwane district focuses on the provision of health, education and community development facilities. The Tshwane Health District has the same geographical boundaries as that of the metropolitan municipality and is demarcated into seven Health Sub-Districts which are aligned with the administrative demarcation of the metropolitan area (Tshwane District Health, 2013). Primary health care services offered by the Tshwane Health Department range from chronic and curative health services, to a comprehensive service package that focuses on the leading causes of mortality and morbidity. In the course of 2006, the Metropolitan authority launched an upgrading programme for district heath care facilities (City of Tshwane IDP, 2006: 21-22). Several of the health care facilities that are part of this programme are at present in the upgrading and improvement phase. Tshwane is one of the districts in the country with the highest percentage of the population having medical insurance coverage. However, according to the general household survey of 2007, only 24,6% of the population of Tshwane and 15,5% of the population of Metsweding has medical insurance coverage (Tshwane District Health Profile, 2013). These figures therefore indicate that

the majority of the Tshwane and Metsweding population is likely to depend on the public health care system.

The Tshwane Integrated Development Plan (IDP) (2006 and 2013/14: 14-16) reports reflect that a substantial percentage of the population does not have access to adequate housing and household services (see Table 3.1).

Table 3.1: Housing and household services in the Tshwane District

Housing and household services	Percentage %
Traditional and informal dwelling, shacks and squatter settlement (2006)	27,3
Households without access to improved sanitation (2013/14)	23,4
Households without access to piped water (2006)	2,5
Households without access to water inside their yards	35,8
Households without access to electricity for lighting (2013/2014)	11,4
Households without refuse removal by local authority/private company (2006)	11,4

Source: City of Tshwane IDP (2006 and 2013/2014: 14-16)

3.3.4 Methods of sampling and profile of the sample

Fifteen focus groups (seven full and eight small or mini groups) were facilitated, with an average size of five participants (patients with diagnosed diabetes) per group, across the seven selected clinics (See Table 3.2). In addition, individual discussions (individual interviews) were conducted with four patients with diagnosed diabetes. These individual discussions were facilitated with the patients who were very eager to partake in the study, but because of time constraints could not wait for the group discussions. Morgan (1998: 75) and Lupton (1996: 156) suggest smaller groups are effective when participants in the sample are very involved in – or emotionally preoccupied with – any topic that is about diet or health. The maximum group size for the full focus groups was eight participants. This implied a maximum of 96 potential diabetes patients as participants in the study, with 72 patients who formed part of the final second level sample (Table 3.2).

During the identification process of potential participants by the respective clinic managers, it became clear that the number of patients available per group would be less than eight. The final number of participants in the sample of 72 (22 more than the required number of 50 participants (Mouton, 2001) see Section 3.2) included 20 males and 52 females, ranging in age from 30 to 87 years. Table 3.2 provides a profile of the participating clinics (first level sample) and numbers of participants (second level sample).

Table 3.2: Profile of selected clinics

Clinic	Socio geographic position of clinic	Number of full or large focus groups	Number of mini focus groups	Number of individual discussions	Number of participants
Clinic 1	High income Upper class area	2	1	Nil	14
Clinic 2	Low to middle income Urban mid- city	Nil	2	2	8
Clinic 3	Low income Informal housing	2	Nil	Nil	13
Clinic 4	Low income Rural settlement	1	1	Nil	12
Clinic 5	Middle income	1	1	1	11
Clinic 6	Low income Semi-industrial area	1	2	Nil	11
Clinic 7	Low to middle income Light industrial area	Nil	1	1	3
Total	N/A	7	8	4	72

As Table 3.2 indicates, clinic 1 is located in a high income, high class residential area. The majority of patients, who make use of the services of this clinic, are low-educated, unskilled workers who work and live in the area during the week. The patients, who use the services of clinic 2 in the urban mid-city area, either work in the city, or travel from their place of residence to attend the clinic. Clinic 3 is situated in an informal housing area – patients who use the services of this clinic reside in this area. All patients who attend the rural clinic 4 live in the area surrounding the clinic. Clinic 5 reflects the same working and living context of patients who attend clinic 1. The difference is that clinic 5 is situated in a middle-income residential area. Clinics 6 and 7 are situated in

similar areas to each other, namely semi-industrial and light industrial areas respectively. Patients do not necessarily reside in these areas, but attend these clinics for reasons of proximity, work situation, or personal preference.

3.4 TARGET POPULATION AND SELECTION OF CASES

3.4.1 Study population and unit of analysis

The study population and unit of analysis were type 1 and type 2 diabetes patients, 18 years and older who receive primary health care at the seven clinics in the first level sample. The managers of the seven clinics assisted in identifying patients with controlled blood glucose levels, and those with uncontrolled blood glucose levels. It was therefore possible to adhere to the research design and establish the study population and unit of analysis for this research study.

3.4.2 Selection of patient cases

In this context, the selection of cases contained mainly elements of non-probability sampling. In non-probability sampling, the researcher cannot forecast or guarantee that each element of the study population will be represented in the sample (Leedy & Ormrod, 2010: 211). Purposive or judgemental sampling, as a form of non-probability sampling, is aimed at sampling participants in a strategic way so that those sampled are relevant to the research questions being investigated (Bryman, 2012: 418). Elements of two purposive sampling approaches were applied for the selection of the clinics, namely criterion and theoretical sampling. Criterion sampling refers to the sampling of all units that meet a particular criterion (Bryman, 2012: 418). The value of theoretical sampling is the use of theoretical reflection on data to establish whether more data are required (Bryman, 2012: 420). Theoretical sampling was applied in order to discover categories and their properties. The final selection of the diabetes patient cases was done on theoretical grounds

through judgemental sampling and with the assistance of the clinic managers; cases with either controlled or uncontrolled blood glucose levels were selected.

The research design made provision for the inclusion of diabetes patients with controlled and uncontrolled blood glucose levels in at least six district primary health care facilities. A seventh district primary health care clinic was during the research process added to the research design. The choice of participants with either controlled or uncontrolled blood glucose levels was partly informed by the preliminary results from the clinical trial. As mentioned earlier, after the pre-testing and piloting phase of the clinical trial study, the clinical endocrinology researchers of the Kalafong diabetes research team recommended an adapted sampling strategy.

3.5 DATA COLLECTION METHODS AND FIELDWORK

3.5.1 Introduction

Two main methods of data collection were used, namely a short biographical questionnaire consisting of close-ended questions that was completed by each patient and a focus group discussion schedule was the research instrument utilised to facilitate the focus group dynamics. The psycho-social factors of social disorganisation, rapid social change, marginal status in society, including social isolation, bereavement, and the psychosocial asset of social support devised by Cassel (1976:111-119) enabled the development of the topics for the focus group discussion schedule of this study. As mentioned, 15 focus groups and four individual discussions were conducted at the seven selected clinics. The fieldwork was conducted between 21 September and 30 November 2013. The language of preference for the focus groups was established beforehand by the participants in the focus groups. In cases where it seemed it would be difficult to conduct the focus groups in either English or Afrikaans, an appropriate mother tongue speaking interpreter assisted with the facilitation. The interpreter was a health educator and was knowledgeable about diabetes.

3.5.2 Pre-testing and piloting of research instruments

The research instruments of this qualitative study were pre-tested and piloted during the aforementioned Lifestyle Research project at the Kalafong Hospital Diabetes Clinic, University of Pretoria. The Lifestyle Research project was implemented during two research phases. The pre-testing and piloting of the research instruments of the present study was phased into the Lifestyle Research project and the following six steps were followed:

- Step 1: First drafts of the biographical questionnaire and focus group discussion schedule were submitted to the Kalafong Diabetes Lifestyle Multidisciplinary Research Team. The research team consisted of professionals from the following seven disciplines: Internal Medicine (Endocrinology), Dietetics, Psychology, Social work, Physiotherapy, Sociology and Health education. The changes recommended by the research team were integrated into the questionnaire.
- Step 2: During January 2013 the biographical questionnaire and the focus group discussion schedule were submitted as part of the first phase research protocol for the Kalafong Research Project to the Research Ethics Committee in the Faculty of Health Sciences. The committee approved the protocol and research instruments without changes.
- Step 3: The first phase of the Lifestyle Research project was conducted from 2 February to 9 March 2013. Each of the disciplines represented in the research team had a Saturday session specifically dedicated to their research field and a specific focus group allocated to them. The respective researchers were responsible for the facilitation of each group's session every Saturday. The participants in the six focus groups (an average of eight to 10 participants in each focus group) were asked to discuss the theme of the day. The researcher was responsible for the 'social integration' theme; she utilised the focus group discussion schedule and introduced a projective technique, namely each focus group created a 'collage' (See Section 3.5.3 for an explanation of the types of projective techniques). The required material such as paper, scissors, pictures, magazines, pens and glues was provided to each group to enable them to create their own

collage. The collages helped the groups to summarise and consolidate their discussions and they utilised them as the basis for their feedback to the large group. The six groups convened after their respective discussion sessions into one large group.

- Step 4: The researcher identified a number of gaps in the focus group discussion schedule during the first phase. The discussion schedule was submitted to the Kalafong research team again for comments. The researcher integrated the recommendations and changes, and included the updated schedule in the second phase research protocol that was submitted during April 2013 to the Research Ethics Committee in the Faculty of Health Sciences.
- Step 5: Phase two of the Lifestyle Research project was conducted from 4 May to 9 June 2013. The same application of the methodology was followed as for the first phase.
- Step 6: Both the experimental and control groups completed a combined questionnaire (the biographical questionnaire and focus group discussion schedule of the present study were integrated into the combined questionnaire) on the final day of the project (27 August 2013). The questionnaire included questions from the seven disciplines involved in the study, including Sociology that is the discipline of the present qualitative study. The sociological part of the questionnaire comprised five population-based themes with nine probing questions relating to diabetes self-care management. The themes included social integration and social networks; the nature of space and place of residence; social capital; demographic and social changes; and cultural context.

3.5.3 Types of projective techniques

Donoghue (2000: 49) categorised the projective techniques, based on a number of techniques described by other scientists, in terms of the type of response required of subjects. A combination of the construction technique and the choice or ordering technique was utilised during the focus group

discussions in this study. Construction techniques require research participants to construct a picture or story, and are loosely based on the clinical Thematic Apperception Test. Such techniques encourage the expression of imagination and creativity (Matthews, 1996). Choice or ordering techniques are where participants explain the importance of a concept or situation by selecting pictures or statements from a range of alternatives, and arranging them into some order, or grouping them into categories according to their similarities and dissimilarities (Gordon & Langmaid, 1988: 106).

These techniques enabled the groups to provide a reflection of their combined experiences, ideas and perceptions of the population-based factors involved in their diabetes self-care management. Each group developed their own unique reflection in the form of a picture or story collage. A wide range of pictures and magazines was provided for participants to page through and search for specific pictures to construct their collages. The groups pasted the pictures on an A2 size poster – some groups also provided a written reflection on their picture stories. The technique proved to be an effective tool which enabled each group to present a summary of their deliberations and reflections.

3.5.4 Questioning strategy

According to the literature, there are different questioning strategies and approaches for facilitating and moderating focus groups (Bryman, 2012: 512). The spectrum includes open-ended approaches as well as more structured strategies. This research study followed a combination strategy, using a structured focus group discussion schedule (Appendix I) containing certain ‘probes’, and an open-ended opportunity that departed from the schedule and allowed some discussion among participants. The latter strategy facilitated debate that provided new and unexpected insights about the topic under investigation.

The number of questions was kept within the range of 10 questions as recommended by Krueger (1988: 59). The probes served as further stimuli and were utilised only when the individuals/groups could not make progress in discussing a specific question. The probes served as reminders during the facilitation process, and were not formulated in terms of questions.

3.5.5 Focus group discussions

The research problem statement and the conceptual framework directed the construction of broad themes for the focus groups discussions, which were included in the discussion schedule. The 15 focus groups and four individual interviewees discussed the role of population-based factors in the diabetes self-care management of the patients. The topics for the focus group discussion were informed by the theories but mainly emerged from the pilot study and pre-testing of the focus group discussion schedule. The groups were given the following broad topics to facilitate the discussions: Perceptions about their socio-geographic context, demographic and social changes they had experienced recently that affected their self-care, the influence of their cultural environment, the role of their social networks, social capital in their communities, and lastly the level of social integration between community members and the role of this integration in self-care management of diabetes.

The focus group sessions began with an introduction, whereby the participants were welcomed and thanked for agreeing to participate in the study. The aim of the research was then briefly outlined; participant informed consent and the informed consent form were explained; the reasons for recording of the discussions were explained; and the format of the focus groups was outlined. The participants were invited to introduce themselves. The researcher moderated the first part of the discussion, making use of some elements of the nominal group technique (NGT) that created the opportunity for participants to share their ideas about diabetes and self-care management. The NGT was developed by Van de Ven and Delbecq (1972) in 1968, with the main purpose of generating and ranking ideas from members of a small group. The NGT is

used in health services research in a highly controlled, small group setting (Cantrill, Sibbald & Buetow, 1996: 67).

Selected population-based factors form the structure of the focus group discussion schedule (See Section 2.6 in Chapter 2). The population-based factors that constitute the themes of the discussion schedule are: the role of social integration; access to social capital; the socio-geographic context; the cultural contexts barriers; and the external systems barriers. In addition to these themes, probing questions are used to facilitate productive discussion in the focus groups. The focus group discussions aimed to enable participants to share common experiences and perceptions about their diabetes self-care. The group discussions lasted between 60 and 80 minutes and the individual discussions between 40 and 60 minutes, and both were audio recorded. Each focus group represents a single entity within the second level sample of groups from the selected clinics.

Rapport between the participants and the researcher, as moderator of a focus group, is very important. The researcher combined elements from the phases described by Rubin and Rubin (2005), and by Crabtree and Miller (1999):

- The *initial apprehension phase* is characterised by uncertainty, while the moderator's goal is to get the participants talking;
- The *exploration phase* is when the participants become engaged in an in-depth discussion, sharing and listening;
- The *co-operative phase* is when participants are not afraid to offend one another, and so share their feelings more openly; and
- The *participation phase* may occur within the time limit of the focus group discussion, depending on the degree of rapport already established within the group.

Varying characteristics of these stages of rapport were identified during the focus group discussions in this study. A positive and open discussion environment was quickly established within the respective groups that encouraged the participants to openly participate without the fear of judgement

about their views. The extent and depth of the data and the findings are a reflection of this.

3.5.6 Transcription

The researcher personally transcribed the deliberations of each of the 15 focus groups discussions and four individual discussions, directly after the completion of the discussions at each clinic. The transcribed text was imported from Word into ATLAS.ti version 7 (ATLAS.ti 7 Scientific Software Development GmbH, 2012). The biographical questionnaire provided additional information so that certain meanings and perspectives could be examined for association with the demographic variables. Data analysis could occur concurrently with the data collection, enabling the researcher to develop a deeper understanding of the research questions and their purpose. This iterative approach of repetitive interplay between the collection, transcription and analysis of the data shaped the next steps in the data collection process (Bryman, 2012: 566). The application of this approach contributed to the quality of the data in terms of consistency.

3.6 DESCRIPTION AND JUSTIFICATION OF DATA ANALYSES

3.6.1 Introduction

Grounded theory combined with elements of comparative research, and phenomenology (See research design in Section 3.2), were applied in this study. The unique combination of three research designs required a multi-pronged approach to the data analysis. There is no single correct way of analysing data from a qualitative study, because of the large body of information that the researcher has to transcribe, code, sort, organise and categorise, while making use of inductive reasoning (Leedy & Ormrod, 2010. Data analysis and interpretation are closely interwoven, and enmeshed within the data collection, usually culminating in a small set of abstract, underlying

themes (Leedy & Ormrod, 2010: 152-153). In particular, the role of the researcher is not to simply generate 'facts' but rather to engage actively in interpreting what happened (Schram, 2003: 11).

It became possible for the researcher to discover what was significant from the viewpoints of the participants who experience diabetes daily. This active involvement directed and shaped the final data analysis, since the construction of meaning was closely related to the actions that participants take to manage their diabetes. Herbert Blumer (1969) insists that social scientists should establish intimate familiarity with their studied phenomenon.

3.6.2 Coding strategy and procedures

The planning of the data analysis strategy was based on the principles of Creswell's qualitative data analysis spiral (cited in Leedy & Ormrod, 2010: 153):

- Listen to the transcripts on a daily basis to note important elements that were discussed in the focus group;
- Modify the data analysis procedure if need be. Participants might raise issues that the researcher had not thought of, which can be included in subsequent focus group discussions;
- Transcribe tapes, code the data, develop sub-themes and themes to guide the analysis; and
- Write field notes after each focus group session.

An interpretive, data analysis strategy (Figure 3.2; Table 3.3; Table 3.4) was developed that reflects the coding, organising, perusing and categorising of the data into themes. A process of synthesising prepared the appropriate basis for the formulation of research propositions (Leedy & Ormrod, 2010). Data analysis was performed using the computer database program ATLAS.ti (version 7). This program is designed for storing, segmenting and organising lengthy field notes in complex qualitative research studies. The entire transcribed text of each of the 15 focus groups and four individual discussions was – as a first

step – evaluated for broad issues and events related to diabetes self-care management. These issues can be defined as abstract propositions that unify subordinate statements relating to the topic. Thereafter, the text of each focus group was read in detail, identifying 'meaning units' that contained aspects related to the purpose of the study. Leedy and Ormrod (2013: 146) define 'meaning units' as the grouping of statements into various aspects or 'meanings' of the phenomenon as it is experienced. These units were then condensed, noting subordinate statements that could be assigned to Initial or First Cycle codes (Saldana, 2013) as they appear in the data. The coding approaches of Charmaz (2006) and Saldana (2013) are basically similar. However, because Saldana (2013) unpicks the phases and coding methods in more detail, the coding strategy for this study is essentially based on the principles described by Saldana (2013).

Charmaz (2006: 46) prefers to distinguish between two main forms or phases of coding, namely Initial Coding and Focused Coding. Initial Coding is very detailed, with multiple codes per line of text providing initial impressions of the data, while Focused Coding entails emphasising the most common codes (Charmaz, 2006:57). Initial Coding, as a First Cycle method, allows the researcher to remain open to all possible theoretical directions of the data. It provides an opportunity for the researcher to reflect on the nuances of the data (Charmaz, 2006: 46; Saldana, 2013: 100). "Focused Coding requires decisions about which Initial Codes make the most analytic sense in order to categorise the data incisively and completely" (Charmaz, 2006: 57-58).

According to Saldana (2013: 83), the First Cycle elemental coding method is a primary approach to data analysis and provides a foundation for all future coding cycles. As part of the First Cycle Coding phase, the meaning units referred to earlier were further condensed to assign *elemental* and *affective* codes. First Cycle elemental coding methods are primary approaches to qualitative data analysis and include coding such as In Vivo, Process and Initial Coding (Saldana, 2013: 83-84). First Cycle affective coding methods investigate the subjective qualities of human experiences by acknowledging and naming these experiences (Saldana, 2013: 105).

As a result of the First Cycle Coding phase, an adequate insight and understanding of the deeper nuances of the data was developed, in order to build a holistic coding strategy (according to Saldana, 2013: 59). A study-specific coding strategy was developed which directed the remaining coding and data analysis phases. Figure 3.2 presents the coding strategy for this study; details of the coding cycles and methods are discussed below the figure.

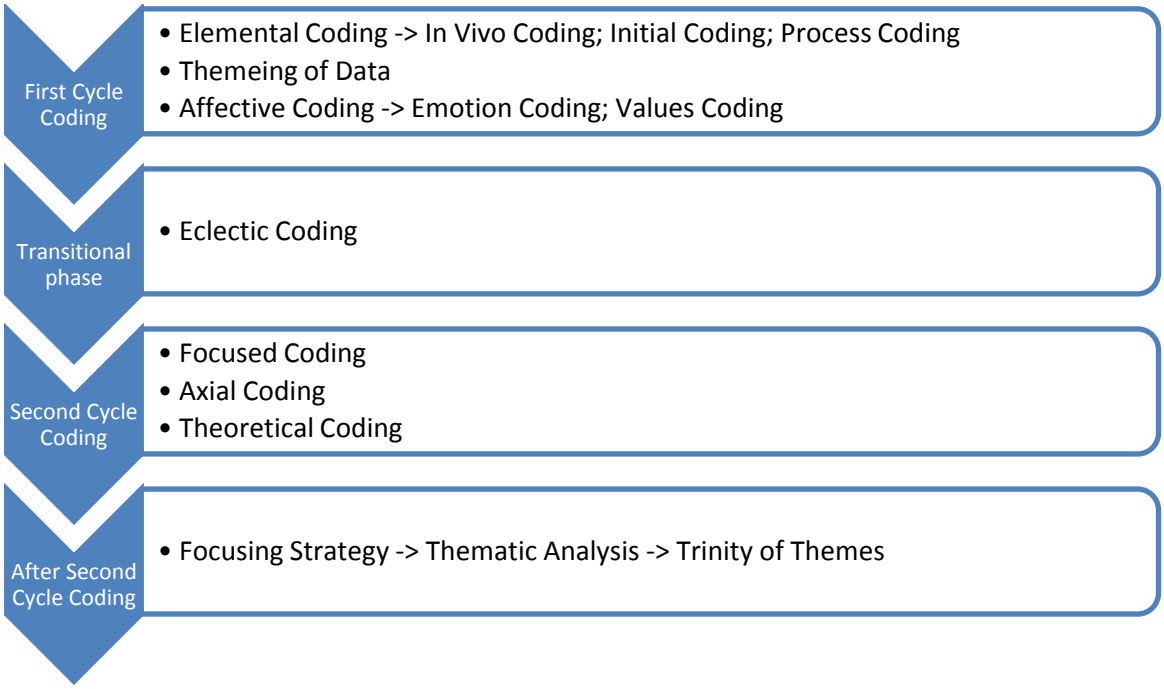


Figure 3.2: The coding strategy for this study

Source: The researcher's own construct

The elemental coding methods that the researcher applied are In Vivo Coding, Initial Coding and Process Coding. The root meaning of In Vivo is 'in that which is alive' and refers to the actual words, phrases or terms that the participants used themselves (Strauss, 1987: 33). The In Vivo coding method was included because of the prevalence in the data of action-orientated verbs, evocative word choices, similes and common use of the same words or phrases in the transcriptions. Process Coding refers to any actions intertwined with the dynamics of time, such as things that emerge, change or occur in particular sequences, or become strategically implemented over time (Saldana, 2013).

Such actions are described by a number of authors, and essentially embedded within ‘psychological concepts such as prejudice, identity, memory and trust’ (Saldana 2003: 90; Hennink, Hutter & Bailey, 2011: 253; Saldana, 2013: 96).

Two types of affective coding methods were used: Emotion Coding and Values Coding. Emotion Coding was applied due to the affective qualities that are core motives for human action, reaction and interaction (Saldana, 2013:105). The Emotion Codes tap into the inner cognitive systems of participants, labelling the feelings that they experienced. Values Coding, the second type of affective coding, was applied to the attitudes, beliefs and perspectives of participants about diabetes (Saldana, 2013:110). The selective application of Themeing the Data during the First Cycle Coding was guided mainly by the elements in the research design, the population-based factors reflected in the conceptual framework and the discussion themes in the focus group discussion schedule. DeSantis and Ugarizza (2000: 362) define a theme as “an abstract entity that brings meaning and identity to a recurrent (patterned) experience and its variant manifestations. As such a theme captures and unifies the nature or basis of the experience into a meaningful whole.”

The eclectic combination of the abovementioned coding methods served as the transitional phase to the Second Cycle Coding. The emotional and psychological stress that participants experience, and their awareness of self and their own identity introduced the second cycle of Focused Coding (Saldana, 2013: 213) and Axial Coding (Saldana, 2013: 218). Some qualitative researchers view Focused and Axial Coding as coding methods that are used After First Cycle Coding, but not part of Second Cycle Coding, namely as a transitional phase; while Saldana (2013: 206) views Focused and Axial Coding as second cycle coding methods. The researcher applied Focused Coding, Axial Coding and Theoretical Coding as the most appropriate Second Cycle coding methods. The purpose of Axial Coding is to determine which codes in the data are dominant and to reorganise the data set accordingly (Boeije, 2010: 108-109). ATLAS.ti allowed the researcher to apply Axial Coding to show how the codes and themes interact in a complex manner, creating networks, also called ‘models’. Theoretical Coding follows the First Cycle, Transitional and

Second Cycle coding methods and serves as an umbrella that covers and accounts for all other codes and categories formulated so far (Saldana, 2013: 223-224).

According to Saldana (2013: 247-248), focusing strategies that intentionally focus the parameters of an investigation are important as part of the After Second Cycle phase. A thematic analysis approach was applied to the Trinity of Themes as the final focusing strategy. Saldana (2013: 175) states that a theme is "an outcome of coding, categorisation or analytic reflection and may be identified at the manifest or latent level." The themes and sub-themes are essentially recurring motifs in the transcribed text applied to the data. The themes and sub-themes are a product of a thorough reading and rereading of the transcripts and field notes that make up the data (Bryman, 2012: 579). According to Saldana (2013: 247) a Trinity of Themes "reflects the three major codes, categories, themes and/or concepts generated up to a certain stage of the analysis process."

Ryan and Bernard (2003) suggest eight guidelines of things to look for when searching for themes and sub-themes. In this study, the use of social scientific concepts, namely theory-related material, as a starting point for themes, was applied in constructing the focus group discussion schedule and related themes. The probing questions in the focus group discussion schedule directed the construction of sub-themes. Repetition of topics; indigenous expressions that are either unfamiliar or are used in an unfamiliar way; the way in which the participants present their thoughts in terms of metaphors and analogies; the ways in which topics shift in transcripts and other materials; the exploration of similarities and differences about the way participants discuss a topic; the examining of linguistic connectors, like 'because' or 'since' – these terms point to causal connections in the minds of the participants; and reflection on missing data, that is, when participants omit answers to specific questions (Ryan & Bernard, 2003) were utilised to construct the final thematic analysis. The thematic analysis approach used in this study provides a summary of the data and is classified as an outcome rather than as a coding strategy. The Trinity of Themes, as the final strategic outcome, served to prioritise the multiple

observations that emerged from the data, and to reflect on the essential meanings revealed by the data (Saldana, 2013; 247). The thematic analysis and the focusing strategy are presented in Sections 3.6.4 and 3.6.5 of this chapter.

3.6.3 The approach and nature of the analyses

The presentation of the qualitative data analysis in this section is based on the four practices of descriptive and interpretive inquiry described by Lindlof and Taylor (2002) namely: i) prolonged immersion; in this study, in the focus group discussions; ii) acknowledgement of the socially constitutive nature of reality; iii) claims to knowledge that preserves the subjective experiences of the participants; and iv) inductive understanding by the researcher achieved through reiterative analysis. Krueger (1988: 109) compares the qualitative data analysis process with an investigation by a detective, where the clues indicate the trends and patterns.

The data analysis in this study is theoretically contextualised by the heuristic framework of social epidemiology, the Health Belief Model (HBM) of Rosenstock (1966), and the structural-functionalist theory of Talcott Parsons (1951). The data analysis based on the coding strategy outlined in Section 3.6.2, included the identification of categories of codes composed from direct quotes made by the participants that are relevant to the self-care management of diabetes.

The focus group discussion schedule included six themes or topics that were introduced for discussion during each focus group, and individual discussion. During the focus group discussions and the data analysis process, nine new and unexpected main trends and patterns emerged. All the trends and patterns (Table 3.4) were prioritised in order of the decreasing coding frequencies: participant experiences of diabetes mellitus; self-care management practices; perceptions about diabetes; the emotional and psychological burden of diabetes; stressing; the role of their social networks in self-care; intimate

relationships and sexual health; external system barriers that have a bearing on self-care; perceptions of participants about their socio-geographic context, employment status and work environment; generational diabetes; the influence of participants' cultural environment; family relationships and the role of children; diabetes-related health problems; and lastly, demographic and social changes that affect their self-care. Exceptions and deviations from the decreasing hierarchical priority list (Table 3.3 & Table 3.4) are explained in the respective sections in Chapter 4. An example is where directly related topics form part of the 120 First Cycle codes, but with a lower frequency than a non-related topic. These topics were selectively integrated into the 15 categories of codes.

According to the research design, the researcher planned to use a combination of inductive and deductive approaches in the conceptualisation or mode of reasoning. Inductive reasoning begins with an observation, using specific occurrences to draw conclusions about entire classes of objects; in other words a sample is observed and then conclusions are drawn about the population from which the sample was taken. Deductive logic begins with one or more assumptions that the researcher initially takes to be true – reasoning proceeds logically from the assumptions toward conclusions. Deductive logic is valuable for generating research hypotheses and testing theories (Leedy & Ormrod, 2010: 32-33). The inductive approach was mainly used in this analysis, while the deductive approach was selectively used in terms of the application of conceptual frameworks or models.

Most of the first cycle and transitional phase analysis was inductive in nature, with the emerging trends and patterns exhibited by recurring or common words, phrases and ideas. Once a set of codes was created, additional trends and patterns emerged from the data. After this step, nodes or categories were created in ATLAS.ti. Deductive reasoning was used to complement the inductive approach, and to direct the After Second Cycle phase of the data analysis. The combination of inductive and deductive reasoning, and the need to utilise the empirical point of departure to understand the perspectives of the participants created the need for a better description of the analytical reasoning

approach. Charmaz (2006: 103-104) and Blaikie (2004: 57-58) describe abductive reasoning as being broadly the inductive approach, but distinguished by a research process grounded on a "theoretical understanding of the contexts of the research participants studied in the meanings and perspectives that form their worldview." In this study abductive reason therefore better describes the specific reasoning approach that was finally applied.

An iterative approach was applied to move between collecting and analysing the qualitative data. After collecting data at all seven clinics, the data appeared to be saturated, namely no new or relevant data emerged regarding the topics discussed in the focus groups. This point in qualitative data analysis is referred to as data saturation, indicating that data collection is complete (Crabtree & Miller, 1999). However, based on the geographical and demographic spread of the sample, the researcher decided to organise one additional focus group at two of the clinics. The additional data collected was integrated into the database. The iterative process of data collection and analysis eventually led to a point where no further trends and patterns emerged from the data.

The researcher applied triangulation or referential adequacy (Bryman, 2012) by using the research methodology, the theoretical perspectives, and the field notes to finally scrutinising the raw data in order to decide if saturation had occurred.

3.6.4 Practical application of the coding strategy

3.6.4.1 First Cycle and Second Cycle Coding

The researcher searched through the transcribed texts for evidence of repetition common in the majority of the focus groups. The First Cycle Coding (including the three elemental methods of Initial, Process and In Vivo Coding, and the two affective coding methods, namely Emotion and Values Coding) was done in ATLAS.ti and resulted in a total of 120 codes. Elements of Themeing the Data were selectively integrated during this phase. After this First

Cycle of detailed coding, the field notes were utilised to compare the codes with each other in order to identify similarities and differences related to the text, resulting in 50 more focused codes. These 50 codes were electronically prioritised through ATLAS.ti using the code frequencies. Codes with a frequency of 20 or more resulted in an eclectic combination of 25 priority codes. Table 3.3 presents the codes and their frequencies.

Table 3.3: Transitional phase Eclectic Coding list

Position of code	Code	Frequency *f*
1	Food	80
2	Emotions	52
3	First symptoms experienced	51
3	Experiences of diabetes	51
4	Compliance with medication	50
5	Intimate relationships	47
6	Stressing	46
7	Home and living environment	45
8	Talking	44
9	Support	39
10	Generational diabetes	38
11	Traditions and customs	37
12	Work type and nature	36
13	Role of children	34
14	Clinical complications	32
15	Changes in personal situation	31
16	Employer involvement	30
17	External systems	29
18	Perceptions about diabetes	28
19	Drinks – cold drinks, tea, coffee	27
19	Water	27
20	Sexual health	26
20	Supporting others	26
21	Exercising	25
22	Acknowledgement that stress is causing high blood glucose level	24
23	Lack of social integration	22
24	Depression	21
25	Death threat of diabetes	20
25	Denial	20

The transitional phase reflects an eclectic combination of codes and serves as a ‘bridge’ to the Second Cycle Coding phase during which the researcher

applied Focused, Axial and Theoretical Coding to look for evidence of repetition common in the majority of focus groups. During this process the researcher also revisited the list of 50 codes and applied the principles of Axial Coding. This process resulted in the combination and reduction of the 25 codes into 15 categories that represent the overall segments of conversations from within the focus groups. These 15 categories reflect the main trends and patterns in the data that are presented in Chapter 4. Table 3.4 shows the codes and categories.

Table 3.4: Second Cycle Coding: Categories

Number	Category	Codes
1	Experiences of diabetes	First symptoms; experiencing diabetes; awareness of self
2	Self-care management practices	Food/eating; drinks; medication; exercise
3	Perceptions about diabetes	Death threat; perceptions about susceptibility; perceptions about symptoms; HIV perceptions
4	Emotional and psychological burden	Emotions; depression; denial; loneliness
5	Stressing	Stress; acknowledging stress causing high blood glucose level; avoiding stress
6	Social networks	Support; talking
7	Intimate relationships and sexual health	Intimate relationships; sexual health
8	External systems	External systems; information and knowledge; lack of information
9	Socio-geographic context	Home environment; external living Environment
10	Employment status and work environment	Type and nature of work; employer involvement; unemployment
11	Generational diabetes	Generational diabetes
12	Cultural context	Traditions and customs
13	Family relationships and role of children	Family relationships and role of children
14	Diabetes health problems	Clinical complications
15	Demographic and social changes	Changes in personal situation

As Table 3.4 indicates, the 15 categories of codes or main trends and patterns are prioritised in terms of the coding frequencies (Table 3.3), with number 1 being the highest frequency.

3.6.4.2 After Second Cycle Coding

During the After Second Cycle Coding phase the researcher prioritised the multiple observations, and reflected on their essential meanings. This resulted in three Axial Codes which represent the final concepts or themes from the data, in terms of decreasing density (frequencies of codes) of the data in the following order: 'Experiencing diabetes', 'Socialising', and 'Diabetes Health Beliefs'. The researcher decided, based on theoretical reasoning in terms of the magnitude or dimensions of the respective themes, and the interactive causal sequence, to present the three themes in reverse order. The prevailing meta-level 'Diabetes Health Beliefs' determine the nature of the meso-level 'Socialising' patterns of participants, while the 'Experiencing of Diabetes' at the micro-level is determined by the meta- and meso-level factors. The Axial Codes that reflect the final themes revealed by the data are illustrated below through constellations of the relevant codes. The constellations for Diabetes Health Beliefs, Socialising, and Experiencing Diabetes are outlined in Figures 3.3, 3.4 and 3.5 respectively.

Diabetes Health Beliefs is the Axial Code and Theme 1 in the Trinity of Themes that serves as the axis or meeting point for attitudes and perceptions with regard to diabetes, perceived susceptibility to diabetes, attitudes about generational diabetes, the perceived seriousness of diabetes symptoms, and attitudes regarding the death threat of diabetes. This is illustrated with Figure 3.3.

Figure 3.3: Axial Code: Diabetes Health Beliefs

Source: The researcher's own construct

Socialising is the Axial Code and Theme 2 in the Trinity of Themes that indicates the on-going nature or process towards self-care management. The Socialising axis intersects with intimate relationships and sexual health; socio-geographic networks; the cultural context and the work environment. This interrelationship is illustrated in Figure 3.4.

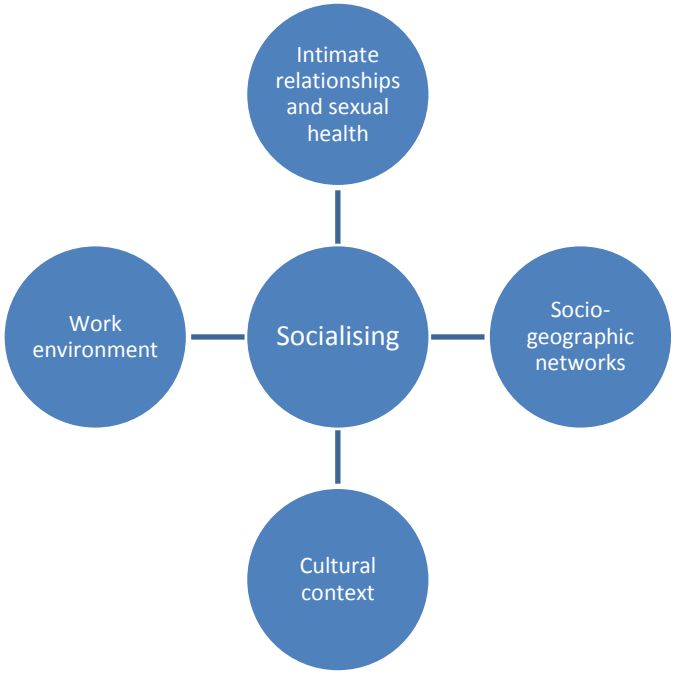


Figure 3.4: Axial Code: Socialising

Source: The researcher's own construct

Experiencing Diabetes, as one of the three Axial Codes and Theme 3 in the Trinity of Themes, is the axis that draws experiences of diabetes, the emotional and psychological burden, stressing, and demographic and social changes together. See Figure 3.5.

Figure 3.5: Axial Code: Experiencing Diabetes

Source: The researcher's own construct

The next section discusses the three Axial Codes that consolidate the final concepts or themes from the data, which are reflected in the final focussing strategic outcome of the Trinity of Themes

3.6.5 The Trinity of Themes

As the final themes, the Axial Codes are reflected in the Trinity of Themes, based on the Trinity of Concepts of Soklaridis (Saldana, 2013: 247). Soklaridis (cited by Saldana, 2013: 248) developed three themes from her qualitative study attributed dimensions to her trinity. The first theme of Soklaridis (Saldana, 2013: 248) is organisational at the macro-level; the second is contextualised as an intergroup theme at the meso-level; and the third is an individual theme at

the micro-level. The Trinity of Themes is the final strategic outcome that prioritises the multiple observations and the essential meanings in the data. The Trinity of Themes (illustrated in Figure 3.6) strategically focuses the parameters of this study. The rich textual data provided multiple observations and possible meanings. Through the application of triangulation, the researcher was able to cross-check the data for the essential meanings that emerged from the study. The complexity of diabetes self-care management is reflected in the Trinity of Themes that emerged, namely Diabetes Health Beliefs, the Socialising Patterns of persons living with diabetes, and Experiencing Diabetes. A Venn diagram has been used to illustrate the overlapping areas and the central area that represents the intersection of the three themes (Figure 3.6). A Venn diagram is a logic diagram invented by John Venn in 1869, with the aim of representing complex sets of logical propositions by inclusive and exclusive circles (Edwards, 2004). A Venn diagram directs the exploration and analysis of causal links, but does not reveal causal relationships between the themes (Lynam, De Jong, Sheil, Kusumanto & Evans, 2007: 7).

In theory, the interrelationship of the three concepts or themes in the Trinity can be unravelled and studied individually, but during the fieldwork and data analysis for this study it became clear that people living with diabetes experience life and living with diabetes as one integral experience. Dimensions or magnitude can thus be attributed to the Trinity of Themes as follows: the first theme forms part of the belief system at the meta level; the second is an intergroup[22] theme at the meso level; and the third is an individual theme at the micro level.

[22] Intergroup in this context represents the contact of the person with diabetes, with a person or groups who do not have diabetes. “Intergroup contact theory involves the meso-level of analysis” (Pettigrew,1998: 76).

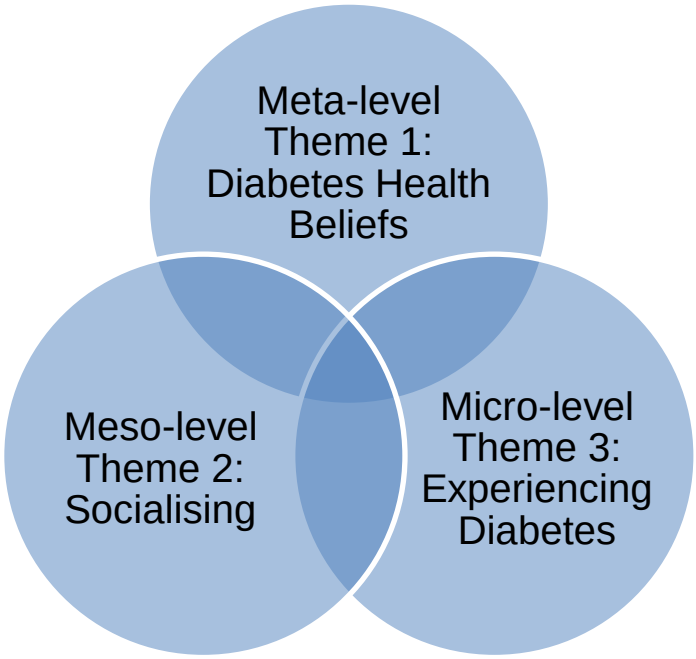


Figure 3.6: Focusing Strategy: Trinity of Themes

Source: The researcher's own construct, based on the trinity of Soklaridis (cited by Saldana, 2013: 247-248)

As a last step in the analysis process, a reflection on the Trinity of Themes was performed – Diabetes Health Beliefs, Socialising Patterns and Experiencing Diabetes were filtered through the viewpoints of participants to determine the extent and nature of their individual self-care management practices. This phenomenon is illustrated in Figure 3.7.

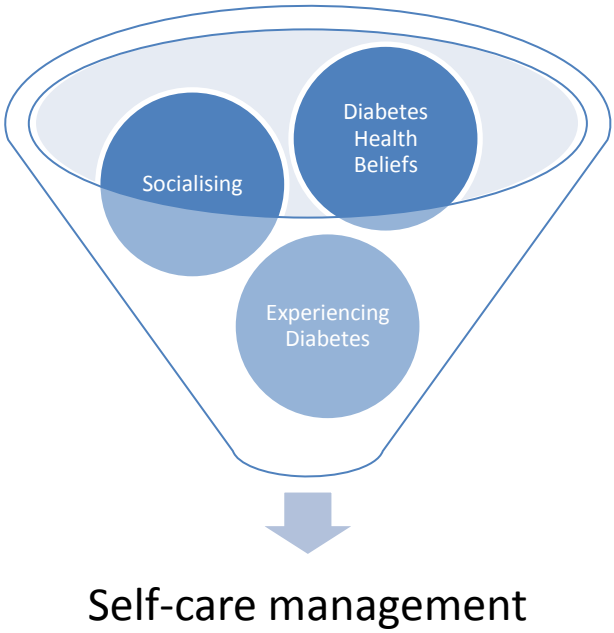


Figure 3.7: Outcome': Self-care management

The interpretation of the three themes that reflect the pathways towards the final outcome of self-care management is discussed in chapter 5.

3.7 ETHICAL CONSIDERATIONS

The study adhered to all the ethical principles outlined in the World Medical Association's Helsinki Declaration of June 1964 (2008) as well as with the ethical conventions of both the Faculty of Humanities and Faculty of Health Sciences at the University of Pretoria.

This qualitative study involved human beings and therefore the four basic ethical issues were taken into account, namely protection from harm, informed consent, the right to privacy, and honesty with professional colleagues. The ethical clearance process was four-fold; firstly the research proposal was

submitted to and approved by the Faculty of Humanities. The second step was the development, pre-testing and piloting of the research instruments, which formed part of the research protocol for the Diabetes Lifestyle Research study at the Kalafong Academic Hospital as outlined in sections 3.4.1 and 3.4.2. The research instruments of this qualitative study (part of aforementioned protocol) were approved by the Ethics Committee of the Faculty of Health Sciences at the University of Pretoria. The third step was to acquire written preliminary permission from the clinic managers of each of the seven primary health care district clinics in the sample for inclusion in the research proposal to the Ethical Committee of the Tshwane District Health and Gauteng Provincial Health Authorities. The fourth step was to submit the research proposal with the permission forms from the clinic managers to the combined Ethical Committee of the Tshwane District Health and Gauteng Provincial Health Authorities. Research activities began only after ethical clearance had been obtained from all these institutions.

The participants were identified through the process described in sections 3.4.1 and 3.4.2. Possible participants were invited to participate voluntarily, and no respondents were subjected to any form of coercion at any stage, nor did they feel compelled to participate in the activities and/or evidence collection for the study. Informed consent was obtained from every individual in the focus group discussions and the four individual interviewees.

Since the subject matter of the study is population-based factors of diabetes self-care management, participants were informed that it would touch on their own personal experience and perceptions about the disease. They were informed that they may feel uncomfortable discussing such matters in a group or in an individual setting, but that they did not have to participate in the discussion if it caused them discomfort. The participants were also assured that they would not be judged at any time on the basis of their responses. The researcher explained that their involvement in the study was to contribute to research findings that could influence policy decisions on diabetes self-care management. It was also suggested to them that their participation presented

an opportunity for them to gain knowledge and awareness about sustainable self-care management of diabetes.

The participants were assured that all information obtained during the course of this research is strictly confidential, and that any data that may be reported in diabetes or scientific journals will not include any information which identifies them as participants in this study. The biographical information was collected from the participants before the start of the focus group discussions. The participants were informed that none of their details would be disclosed to any third party without their written permission. The research did not harm participants in any way and does not foresee any later potential harm to the participants. An example of the informed consent form is attached as Appendix G.

3.8 DELINEATION AND LIMITATIONS RELATED TO THE METHODOLOY OF THE STUDY

A number of limitations of this qualitative study relate to the specific methodology applied. These limitations are more extensively discussed in Chapter 6.

- The sample of this study is limited to the district of Tshwane in Pretoria, South Africa. The sample includes only people already diagnosed with diabetes who utilise public primary health care facilities.
- The study does not reflect the ethnical diversity of either the district of Tshwane or the South African population. Comparisons that deal with ethnical differences are therefore not possible within the context of this study.
- The sample contains a female bias of the study population and therefore does not deal with comparisons based on gender.
- The study is limited to people with diabetes that utilise public health care facilities, therefore findings cannot be compared with people with diabetes who utilise the private health care sector.

- Comparative analyses based on age, marital status, race or gender is not possible.

3.9 SUMMARY

The methodology explained in this chapter reflects the qualitative research design; the sample design and sampling methods; the target population, that is the first level sample of the primary health care clinics; and the second level sample of the patient cases. The data collection and fieldwork practices are described as well as the description and justification of the data analyses conducted. The ethical considerations that were taken into account in the planning and execution of the research are presented. Finally, a brief summary of the delineation and limitations related to the methodology are given.

This qualitative study, through the methods of focus group discussions and individual discussions, focused on those questions that might provide possible answers to the underlying population-based causes of diabetes, thus providing a knowledge base for interventions to promote diabetes self-care management. Chapter 4 describes and summarises the findings of the research, reflecting the main trends and patterns in the data by means of focusing on the strategic Trinity of Themes outcome.

CHAPTER 4
Impact of population-based factors on the self-care management of diabetes mellitus

4.1 INTRODUCTION

Chapter 4 presents the findings derived from the analyses of the raw data, and reflects on the main trends and patterns in the data by means of the Trinity of Themes (Figure 3.6 in Chapter 3) based on the trinity of concepts of Soklaridis (cited by Saldana, 2013: 247-248). The interpretation of the findings and the meanings thereof are reflected in the discussion Chapter 5. The Trinity of Themes is the final strategic outcome that arranges the data and finally the findings of this study. The pathway towards self-care management practices and diabetes health outcomes is presented as a macro-social organisational theme. Access to, and the role of, external systems in diabetes self-care management is presented as a macro-structural organisational theme. This chapter is descriptive in nature and is organised according to the grounded theoretical nature of the study, the research objectives and the research design of the study.

The first two sections present the specific characteristics of the participants in the study sample and describe their biographical and diabetes profiles. The third section presents the findings, reflecting the main trends and patterns that emerged from the qualitative analyses of the focus group discussion data.

4.2 BIOGRAPHICAL PROFILE OF PARTICIPANTS

The individual biographical and diabetes information questionnaire (see Appendix H) was completed by all 72 participants in the study. The following variables: age, sex, level of education, marital status, employment status and type of work are included in the questionnaire. Table 4.1 and Table 4.2 present

respectively the biographical and diabetes information of the participants at the seven selected Tshwane district clinics.

The final sample size consisted of 20 males (27.8%) and 52 females (72.2%). Ages ranged from 30 to 87, with an average age of 51.1 years. Overall, this group has a low level of education; no education (22%), grade 5 or lower (12.5%), and grade 6 to 10 (44.4%). The education levels of the remaining participants are split broadly between those who completed grade 11 (11.1%), grade 12 (4.2%) and post-school (tertiary) education (4.2%). As Table 4.1 indicates, the majority of the participants (61.1%) perceive themselves to be in an intimate or romantic relationship and report having a primary romantic, sexual or intimate partner.

Table 4.1: Biographical profile of participants per clinic

Clinic number	1	2	3	4	5	6	7	Total
	n= (%)	n= (%)	n= (%)	n= (%)	n= (%)	n= (%)	n= (%)	
Sex: Male	2 (14,3)	3 (37,5)	4 (30,8)	4 (33,3)	1 (9,1)	3 (27,3)	3(100,0)	20
Female	12 (85,7)	5 (62,5)	9 (69,2)	8 (66,7)	10 (90,1)	8 (72,7)	0 (0,0)	52
Education:								
None	2 (14,3)	1(12,5)	3(23,1)	5 (41,7)	3 (27,3)	2 (18,2)	0 (0,0)	16
<3 years	1 (7,4)	0 (0,0)	0 (0,0)	0 (0,0)	0 (0,0)	0 (0,0)	0 (0,0)	1
Grade 3-5	1 (7,4)	0 (0,0)	2(15,4)	0 (0,0)	1 (9,1)	4 (36,4)	0 (0,0)	8
Grade 6-10	8 (57,1)	3(37,5)	5(38,5)	6 (50,0)	5 (45,5)	5 (45,5)	0 (0,0)	32
Grade 11	1 (7,4)	2(25,0)	3(23,1)	0 (0,0)	1 (9,1)	0 (0,0)	2 (66,7)	9
Grade 12	0 (0,0)	2(25,0)	0 (0,0)	1 (8,3)	0 (0,0)	0 (0,0)	0 (0,0)	3
Post-school education	1 (7,4)	0 (0,0)	0 (0,0)	0 (0,0)	1 (9,1)	0 (0,0)	1 (33,3)	3
Intimate partnership	10 (71,4)	5 (62,5)	4 (30,8)	10 (83,3)	6 (54,5)	8 (72,7)	1 (33,3)	44
Marital status:								
Married/Living with	10(71,4)	5 (62,5)	4 (30,8)	10 (83,3)	6 (54,5)	8 (72,7)	1 (33,3)	44
Divorced/Separated	2(14,3)	2 (25,0)	0 (0,0)	0 (0,0)	1 (9,1)	0 (0,0)	0 (0,0)	5
Single	0 (0,0)	1 (12,5)	7 (53,8)	0 (0,0)	1 (9,1)	0 (0,0)	2 (66,7)	11
Widowed	0 (0,0)	0 (0,0)	2 (15,4)	1 (8,3)	3 (27,3)	3 (27,3)	0 (0,0)	9
No response	2(14,3)	0 (0,0)	0 (0,0)	0 (0,0)	0 (0,0)	0 (0,0)	0 (0,0)	2
Employment status:								
Full time employed	11(78,6)	7(87,5)	3 (23,1)	0 (0,0)	11(100,0	4 (36,4)	2 (66,7)	38
Part time employed	3(21,4)	0 (0,0)	2 (15,4)	0 (0,0)	0 (0,0)	2 (18,2)	0 (0,0)	7
Unemployed	0 (0,0)	0 (0,0)	5 (38,5)	6 (50,0)	0 (0,0)	3 (27,3)	1 (33,3)	15
Self-employed	0 (0,0)	1(12,5)	0 (0,0)	0 (0,0)	0 (0,0)	0 (0,0)	0 (0,0)	1
Senior citizen grant	0 (0,0)	0 (0,0)	1 (7,7)	6 (50,0)	0 (0,0)	1 (9,1)	0 (0,0)	8
Disability grant	0 (0,0)	0 (0,0)	2 (15,4)	0 (0,0)	0 (0,0)	0 (0,0)	0 (0,0)	2
No response	0 (0,0)	0 (0,0)	0 (0,0)	0 (0,0)	0 (0,0)	1 (9,1)	0 (0,0)	1
Type of work:								
Driver	1 (7,4)	0 (0,0)	0 (0,0)		0 (0,0)	0 (0,0)	0 (0,0)	1
Domestic worker	12(85,7)	3(37,5)	3 (23,1)		8 (72,7)	4 (36,4)	0 (0,0)	30
Farm worker	1 (7,4)	0 (0,0)	0 (0,0)		0 (0,0)	0 (0,0)	0 (0,0)	1
VIP Driver	0 (0,0)	1(12,5)	0 (0,0)		0 (0,0)	0 (0,0)	0 (0,0)	1
Cleaning services	0 (0,0)	1(12,5)	1 (7,7)		2 (18,2)	0 (0,0)	0 (0,0)	4
Administration	0 (0,0)	1(12,5)	0 (0,0)		0 (0,0)	0 (0,0)	0 (0,0)	1
Assistant librarian	0 (0,0)	1(12,5)	0 (0,0)		0 (0,0)	0 (0,0)	0 (0,0)	1
Self-employed	0 (0,0)	1(12,5)	0 (0,0)		0 (0,0)	0 (0,0)	0 (0,0)	1
Car washing	0 (0,0)	0 (0,0)	1 (7,7)		0 (0,0)	0 (0,0)	0 (0,0)	1
Production worker	0 (0,0)	0 (0,0)	0 (0,0)	N/A	1 (9,1)	0 (0,0)	0 (0,0)	1
Security	0 (0,0)	0 (0,0)	0 (0,0)		0 (0,0)	1 (9,1)	0 (0,0)	1
Kitchen assistant	0 (0,0)	0 (0,0)	0 (0,0)		0 (0,0)	1 (9,1)	0 (0,0)	1
Forklift driver	0 (0,0)	0 (0,0)	0 (0,0)		0 (0,0)	0 (0,0)	1 (33,3)	1
Electrician assistant	0 (0,0)	0 (0,0)	0 (0,0)		0 (0,0)	0 (0,0)	1 (33,3)	1
Age range in years	43-61	43-59	30-87	43-70	34-69	44-61	37-45	30-87
Average age in years	51,21	51,63	50,85	58,5	50,0	54,18	41,33	51,1

More than half of the participants are in full-time employment (52.8%), with some employed part-time (9.7%) and the remaining substantial proportion (20.8%) being unemployed. The remaining participants consist of those who receive senior citizen grants (11.1%), disability grants (2.8%), one participant who is self-employed, and one non-response. The 46 participants, who reported that they are employed or self-employed, indicated that the main type of employment is domestic work (65.2%). If we combine the four participants who identified themselves as doing cleaning work, the one farmworker and the one car washer, with the domestic workers into a single category of unskilled workers, then 78.3% of the total of 46 participants who work for an income are

in unskilled positions. The remaining participants reported the following type of work: one driver and one VIP (Very Important Persons) driver, and one in each of the work categories: administrator, assistant librarian, self-employed, production worker, security guard, kitchen assistant, forklift driver and electrician assistant. The questionnaire did not include any question about race, but most of the participants self-identified as Black (95.8%) and three as White (4.2%).

4.3 DIABETES PROFILE OF PARTICIPANTS

The questions about diabetes that formed part of the individual biographical information and diabetes information questionnaire (See Section 3.5 in Chapter 3 and Appendix H) include: Type of diabetes, age when participant was diagnosed with diabetes, time since diagnosis, and a self-description of the participant's understanding of diabetes self-care management. All 72 participants in the study completed this part of the questionnaire. The diabetes profile in Table 4.2 presents a summary of the information collected from the participants at the seven selected Tshwane district clinics.

The majority (62.5%) of participants indicated that they were not aware of the type of diabetes they have. This is followed by 27.3% of the participants who indicated that they have type 2 diabetes mellitus and 9.7% who have type 1. Of those participants who know their Type, about 74.1% have type 2 diabetes mellitus. Their age of diabetes diagnosis ranges from 3 to 68 years, although only 5.9% were diagnosed before age 30, about 16.18% before age 40, and 38.2% before age 50. The number of patients diagnosed at, or after, 50 years of age is 27 or 39.7% of the total number of participants. The participants in the study share a total of 398.4 years living with diabetes, ranging from less than one year to 39 years each (average of 6.8 years per person). The participants thus reflect an extensive array of diabetes experiences.

Table 4.2: Diabetes profile of patients per clinic

Clinic number	1	2	3	4	5	6	7	Total
Type of diabetes:								
Type 1	4	1	0	1	0	0	1	7
Type 2	3	2	0	9	1	4	1	20
Don't know	7	5	13	2	10	7	1	45
Age range of diagnosis	32-57	40-59	23-67	22-68	30-57	30-60	3-37	3-68
No response	Nil	1	Nil	2	1	Nil	Nil	4
Mean age diagnosed in years	46,4	50,0	45,2	51,8	45,7	48,3	25,3	44,7
Total Number of years with diabetes	64,6	17,9	75,0	85,8	42,1	65,0	48,0	398,4
No response	Nil	1	Nil	2	1	Nil	Nil	4
Average number of years with diabetes	4,6	2,6	5,8	8,6	4,2	5,9	16,0	6,8
Self-care management								
Don't know	8	4	8	6	10	7	3	46
Meaningful comments	6	2	2	1	0	2	0	13
No sense	0	2	3	5	1	2	0	13

4.4 MAIN TRENDS AND PATTERNS IN THE DATA

This section presents an in-depth textual description of the main trends and patterns in the data according to the relevant themes, namely 'Experiencing diabetes', 'Socialising', and 'Diabetes Health Beliefs'. According to Saldana (2013: 175) a *theme* refers to a focusing strategy and that serves as an outcome. The researcher follows the summary descriptive style of focus group reporting according to Krueger (1988: 109), within the parameters of the Trinity of Themes. The descriptions of the trends and patterns are followed by illustrative quotations from the participants. As outlined in the methodology in Chapter 3, the researcher prioritised the multiple observations during the After Second Cycle Coding phase, reflecting on their essential meanings, which resulted in three Axial Codes. These Axial Codes represent the final concepts or themes from the data, and in terms of their density in the data, they emerged in the following descending order: Experiencing diabetes, Socialising, and Diabetes Health Beliefs. These themes are filtered through the viewpoints of participants in order to determine the extent and nature of their individual self-care management practices. Saldana (2013: 175) argues that a theme is rather an outcome of coding than a point of departure for qualitative data analysis.

The themes are presented in this section in the abovementioned order, while the 15 main trends and patterns constituting the themes are integrated appropriately as sub-headings. The majority of the sub-trends and patterns are part of the 120 first cycle codes; the researcher also makes selective use of additional sub-trends and patterns to order the data logically. The research will mainly use the term 'trend' or 'trends' in the text, when actually referring to both 'trends and patterns'. The research design included grounded theory but during the analysis of the data characteristics of a phenomenological nature also emerged. The presentation of the data therefore combines the reporting conventions of, grounded theory and phenomenology. The direct quotes of the participants are reflected in the vignettes and are not edited for grammar or language. The directional key in the text to a specific clinic and focus group is as follows: Clinic 1 group 2 is represented by the code (C1:2).

4.4.1 Experiencing diabetes

'Experiencing diabetes' (Figure 3.5 in Chapter 3), as a main theme, refers to the on-going nature of the life-long burden of living with diabetes, and serves as the intersection of the four main trends from the data, namely 'experiences of diabetes', the 'emotional and psychological burden', 'stressing', and 'demographic and social changes'. 'Experiencing diabetes' signifies the *process* whereby people with diabetes are trying to make sense of their condition, while 'Experiences of diabetes', relates to their internal and external *awareness* about the condition. The majority of categories and topics in the data have a direct or indirect bearing on the overall experiences of participants. The emotional and psychological stress that they experience, the continuous experiencing of other family members with diabetes (generational diabetes), the experience of diabetes health problems, and the demographic and social changes in personal situation were coded separately and are presented as complete main trends and patterns with sub-headings, in order to ensure that the qualitative value of these topics is not compromised. The experiences of the participants that relate to generational diabetes and experiences related to diabetes health problems

have been integrated into the Axial Code or Theme of 'Experiences of diabetes'.

The 'experiences of diabetes' emerged together with 'first symptoms experienced' by participants as the third most frequently discussed topic, but due to its overarching relevance it will be presented first. An integrated presentation (Section 4.4.1.1) of 'first symptoms experienced' and 'experiences of diabetes', followed by the 'experiences of awareness of self and their own identity' (Section 4.4.1.2) serves as the introduction to the in-depth textual description of the data in this section. This is followed by the description of the following main trends: emotional and psychological burden; experiences of generational diabetes; diabetes health problems or clinical complications; and demographic and social changes in personal situation.

4.4.1.1 First symptoms experiences

A spectrum of thirteen symptoms was experienced by participants before they were diagnosed with diabetes mellitus. These first symptoms included an exceptional thirst, tiredness, impairment of eyesight, sudden weight loss, dizziness, frequent urination, constipation, sweating, hearing difficulties, sore joints, swollen feet, changes in sleeping patterns and awareness of other bodily changes. Participants expressed themselves as follows about some of the early symptoms:

> Firstly I was so dizzy…; Each and every hour I had to urinate…but to release something (*faeces*) it was very difficult for me (C2:3); and

> With me it happened while I was driving – there was just darkness. It was suddenly totally dark in front of me…it was like a cloud…I opened the window to see what is on the window, but it was still dark. I had to go to the doctor, the doctor tested my blood and the sugar was 35 (*blood glucose level*) (C2:1).

Participants initially found it hard to accept the diagnosis and the reality that their symptoms were an indication of an illness that they will have to live with for the rest of their lives:

> I realised that if I do not accept I am not going to get help. I must try to accept, people they die because they do not accept and they don't take the medication. In my family, one of my brothers does not accept it, so he doesn't take the medication…he was very sick in hospital, but he does not go for help and get medication. Me, I must do the right thing (C1:2).

Some of the participants did not feel ill and therefore did not associate the symptoms of increased thirst, urination and vision problems with an illness:

> I did not feel anything...even after they told me about the sugar, I did not have any symptoms (C2:1).

4.4.1.2 Experience of self

Participants from two groups said that their experience of diabetes brought a sense of self – with diabetes being a part of the self, of their identity, of who they are. This realisation is seen as an opportunity to position themselves as individuals with specific needs, and who have specific roles to play in the family and community. Two of the participants stated:

> If somebody is looking strangely at you, then you look at the other person and you know that you will not look at yourself the way the other person is looking (C5:1); and
>
> Because I do not feel any pain, I don't feel anything. I just slept. Then I was starting to see myself (C7:1).

4.4.1.3 Emotional and psychological burden

The emotional and psychological burden of diabetes emerged overall as the fourth most frequently discussed topic in the focus groups, including the sub-topics of emotions experienced after diagnosis: denial, depression, the lifelong burden of diabetes, and loneliness. The main elements of the experiences of the emotions are presented as part of this section, while the fear of dying due to

diabetes and other illnesses is presented in Section 4.4.3 as part of the theme Diabetes Health Beliefs.

Based on the frequency in the focus group discussions, stress and related emotions emerged as the single main specific cause of uncontrolled blood glucose levels at the onset of diabetes. The concept of 'stressing' is a Process Code and refers to the on-going nature of stress. Stress has many permutations that relate not only to the emotional and psychological burden of diabetes, but also to family relationships and the role of children, intimate relationships and sexual health, and the complexities of self-care practices. These topics are presented as main trends and patterns under the 'Socialising' theme (Section 4.4.2). The sub-trends that substantiate stress-related issues are presented in this section, and include: emotions after diagnosis; denial; depression; lifelong burden of diabetes; loneliness; avoiding stress; stress and hyperglycaemia; and stress release and management.

Emotions after diagnosis: Emotions such as initial shock, uncertainty, sadness, fear, anger, loneliness and frustration, combined with the burden of tasks related to the clinical regimen, were indicated by all the groups:

> The first time I heard, I *eish*…I feel like I am going to die…something like…*eish*…I don't know…am I going to die or what, or maybe I will survive or is God going to take me while I am still young? I don't know. My heart was so sore, very, very sore…*Eish*, (*Participant experiencing deep emotional pain*) I feel the other way round, man. That was not nice for me to find out that the things that killed my mother are sugar diabetes, I am still to die from sugar diabetes…and maybe the one that is following me, my kids, is going to have sugar diabetes…(C2:3); and
>
> I was shocked, I was asking 'why me?' I just said 'why me?' (C2:4).

Denial: Despite experiencing symptoms for many years and suspecting diabetes participants still did not want to go to a doctor or to the clinic for a diagnosis. This behaviour suggests that the prevalence of undiagnosed diabetes cases could be high in the population. The following example illustrates the attitude of denial:

> My mother passed away at the age of 78 but when they diagnosed me with diabetes I went into denial, I denied it because I am a Christian…I had the denial…this disease is a 'devil' thing just to kill us (C2:4).

Depression: The trend of sadness, hopelessness and depression is exemplified by all the participants (13) of clinic 3 who were looking emotionally very tired. The first is the example of a 30-year-old male participant who was looking very depressed and hopeless:

> My wife is gone because I could not give her what she needed (*Demonstrating – directing to his groin area*)…I could not give it to her…it is a lot of stress because I don't know what is happening. I do not have work, with this diabetes I do not have a life…I just live (C3:1).

The same male participant later commented:

> My father and mother they feel the pain, they are feeling the pain for my life…because this thing it gives me stress. Maybe they get the stress about my life because of the fact that I stress so they also take the stress for my life…it is too difficult (C3:1).

A 57-year-old male participant confirmed the psychological burden of diabetes:

> I would like to go (*die*)…you see I live, but you see (*Participant showing his amputated leg, taking off his glasses and asking the moderator to look into his eyes*)…I cannot see. My eyes are closed, I cannot see anything. The one (*eye*) can only see a little bit, so I cannot see the road. So that is why I would like to go (C3:2). (*A very long quiet moment followed while the whole group sensed the very deep emotional pain of the participant*).

A female participant from another clinic confirmed the difficulties experienced by persons with diabetes:

> I talked to the nurse and she said I must talk to somebody, I must get it out. I was admitted to a psychiatric hospital because I was crying, crying all the time (C2:4).

A 34-year-old male participant, the only male at clinic 5, expressed the need for psychological assistance for persons with diabetes:

> …I was talking to…but it is difficult (Talking slowly with interruptions)…sometimes you won't have that knowledge to say 'I am stressed and what I can do to stress less'…if you do not have the resources…you come to the clinic for help…we get the medical attention but not for stress (C5:1).

Lifelong burden of diabetes: A 50-year-old male with a post-matric qualification and a full-time skilled position referred to the continual nature of diabetes:

> Yes, it is part of life, if I keep…it to my heart for a lifetime, then I will be unhappy for a lifetime…for the rest of my life…we must just try. I realised that this…I mean…disease, this is the type of disease that…it is like it strikes you in the emotions, so we must control our feelings and our emotions… (C2:1).

Loneliness: Participants feel that they are alone on their diabetes journey. Nobody else knows what they are going through, or wants to know about their process. The fear of being physically alone with the possibility of falling and nobody to help was expressed by one female participant whose husband had a stroke while alone at home:

> Sometimes I am just afraid that I can fall when I am alone and then there is nobody to help me…I am thinking a lot about it…one day when I fall 'who is going to help me?' (C1:2).

Avoiding stress: Participants do not want to hear about family problems, because it stresses them and causes high blood pressure and hyperglycaemia. The avoidance of stress-related events and increased sleep levels seem to be very important stress management or stress release mechanisms, and in many cases the only mechanisms available for a person with diabetes.

Stress and hyperglycaemia: Participants confirmed that the primary cause of uncontrolled blood glucose levels is stress:

> Stress is bad, it is like an accelerator…the more you are under pressure and experiencing problems, the more the stress comes up like an accelerator. Like with an accident…the more you drive high (*at high speed*), the higher the chances for an accident (C1:1); and

> When my grandchild is not coming back home at night, I worry and my sugar level is high the whole night (C4:2).

Stress release and management: These female participants shared their experiences of efforts to manage stress:

> And you also you must control yourself…I tell my husband the things…I was so cross, I was just sitting down, and I made myself sick, sick…myself sick… (C5:2); and
>
> The doctor told me not to think too much and I replied to the doctor 'I can't stop thinking' (C1:2).

Participants mentioned that they do gardening to release their stress, while others suggested that their religious beliefs assist them in coping with diabetes:

> I do not like my name to be connected to that (*to the perception that I am dying*)…I am a living testimony you understand…for us they like to keep things in secrecy and I don't like secrets, my God does not like secrets. So for other people to tell others that I am a diabetic and other people take you to a negative mind (*negative talking creating a negative mind set*) (C2:4).

4.4.1.4 Experiences of generational diabetes

Twenty nine of the 72 participants confirmed that their experiences of diabetes were shaped by other family members who have diabetes. In one of the focus groups, five of the six participants indicated that one or more of their family members also have, or had diabetes. The topics of denial and perceptions about susceptibility to diabetes emerged as sub-trends and patterns, and are presented in Sections 4.4.1.3 and 4.4.3.4 respectively. The attitudes of participants with regard to generational diabetes form part of the theme 'Diabetes Health Beliefs' (Section 4.4.3).

Some experiences of generational diabetes expressed by the participants are illustrated below:

> When I first heard about the fact that I have diabetes, I did not feel very bad. I did not think that is strange, because in my family, my mother also had

> diabetes and also my sister, she has diabetes, so I did not feel so bad, because in my family it is the generation to generation disease (C1:2); and
>
> My mother had it and our three sisters also, me and my eldest sister and my younger sister. I am not feeling bad…my mother always said that I mustn't worry…I do not feel bad, my mother lived long, and she is still living (C1:3).

In this one family the mother of the participant and six siblings have diabetes:

> I did not feel strange because it is in my family – my mother had it, my four sisters already had it and I was the last one to be diagnosed. I accepted it because my mother suffered a few years with it…my mother also had open sores on her feet but it never healed…my mother's never healed (*Female participant looking and sounding very sad because they could not help her diabetic mother*) (C6:1).

A male participant expressed his fears about his children's susceptibility:

> Now I want to know, because both of my parents died of diabetes, and I have five children and I want to know whether one of them can get it (C4:1).

4.4.1.5 Diabetes health problems or clinical complications

Diabetes health problems or clinical complications related to diabetes, is a main trend that emerged from the majority of group discussions. Diabetes health problems can be viewed as an outcome of uncontrolled blood glucose levels due to insufficient self-care management. The negative effects were specifically mentioned as a concern, namely the impact on their life expectancy, kidney failure, blindness and neurological symptoms in the legs that lead to amputations. The experience of diabetes-related clinical complications can be attributed to the number of years with undiagnosed diabetes, the number of years since diagnosed with diabetes, insufficient blood glucose management, and the progressive nature of the condition.

The ambiguity of the risk of health problems or complications – even when adhering to the clinical regimen – was reflected in the majority of the groups. A spectrum of fifteen complications was mentioned by the participants. The

majority of complications relate to the initial first symptoms experienced by the participants before diagnosis. These complications range from eyesight impairment, tiredness, dizziness, itching and burning feet and toes, sore joints, kidney stones, vaginal thrush, sexual problems, hearing impairment, cramping of legs, headaches, stomach problems, sores on heels and legs, sleepiness and sleeping difficulties, and a warm feeling in the body. Sexual health problems emerged as a major health problem or complication of diabetes – this theme is presented in relation to intimate relationships as a main trend in Section 4.4.2.3.

The relationship between diabetes health problems and uncontrolled blood glucose levels is a very complex concept for participants to understand. The uncertainty and complexity of these health problems or complications are revealed by these quotations from participants:

> Until now it was okay…but from this year I was getting tired…maybe they can change my medication…and then my eyesight is not good…every day, even on a clear day… (C2:2);
>
> What I can say now, I think that the more you are growing up, because I am 50 now…the age is going up, the more the sugar goes up….I, I think so, because to change the medication but it does not go better, I know there is something, I don't know what (C6:3); and
>
> Oh, I was rolling in my house, I was lying in the middle of the floor when I had those cramps in my legs and I could not get up…I had to kick against something so that it could disappear, so I had to roll through the whole house (C6:1).

The following deliberations between participants confirm similar symptoms:

> You feel a bit sleepy when it is going high. Sometimes you are passing out when the sugar is too high and so on…(*Other participant*) Your heart is getting 'loose', you cannot understand well…(*Other participant*) You are passing out, you are passing out because of the sugar…(*Other participant*) then you sleep, you sleep forever (C6:1).

4.4.1.6 Demographic and social changes in personal situation

Demographic and social changes in the participants' personal situation were identified by all the focus groups as major causes of stress and heightened levels of blood glucose levels, and, in some instances, also the primary cause of the onset of their diabetes. This main trend relates to the emotional and psychological burden presented in Section 4.4.1.3. Death and illness in the family and changes in their employment status were emphasised as events that brought about major changes in their condition, if not in the long term, then at least in the medium term. The sub-trends describe in this section are: death in the family; illness in the family; and job loss.

Death in the family: The death of a family member, especially the loss of a child, is attributed as the cause of elevated blood glucose levels. Some examples from the focus groups are:

> I am not alright because my brother passed away. I am not feeling okay, I am not alright (*Female participant was very emotional, distressed and was crying*) (C4:1);
>
> But I had a problem…my child died last year and my sugar went up. It was first my mother and after two months my daughter…I was very ill, I cried every day, every day, every night and every day I was crying. At the clinic they said: 'You cannot control, your 'high blood' is going high, the sugar also'. I told them that I was having a problem, I think it is my heart, I am heart-sore – also now my heart is very sore (C2:1); and
>
> As I came here, they said maybe I had major stress because they said that major stress is causing sugar diabetes. My children…my daughter suddenly became ill and she died within two weeks. She was 19 (*years old*) – then I felt at that time that I had major stress, then I believed them that it was the major stress that caused it (C5:2).

A male farmworker, who has been recently diagnosed with diabetes, expressed himself as follows:

> I am doing hard work…it is difficult, my sister is dead and I must now also take care of her five children, and must take care of my children, and of my wife...I am working hard,...and on this side I am ill (C1:3).

This female participant shared the experience of the hi-jacking and murder of her son-in-law:

> …my son-in-law…they killed him – they high-jacked him and killed him. I cried and I was angry the whole week. You can see in my file – last month when I came, my diabetes was high. I am having this problem. It is those things that hurt me. Yes, the sugar was really very high…nineteen (*blood glucose level*) (C6:3).

Illness in the family: This female participant's sister is ill due to diabetes complications:

> My sister…is ill with sugar, she says that she is not feeling well, she did not get up – then you start stressing about her, then it bothers you in your heart because you cannot handle it (C6:1).

Job loss: Two male participants confirmed that the loss of a job causes major stress:

> I lost my job in…2010…and I was in an accident, my car was written off. There is something coming out…now I am not working…that is the thing that is stressing me a lot, because financially I am experiencing a problem. *Eish*…when I speak about this, I feel I can cry (*Very emotional*)…I must just try to survive…it is difficult (C2:4); and

> I mean before I lost my job it (*blood glucose*) was so well-managed, it was as if it was not there when I was still in a job, but now the stress of not having a job and looking for a job, it is getting too much (*Looking very stressed and depressed, shared his experience about the loss of his job*) (C7:2).

4.4.2 Socialising

Socialising refers to the processes whereby participants meet and interact with other people. It involves on-going action and interaction that take place among

participants with the purpose of managing their diabetes self-care. The on-going nature of the socialising process defines this theme as a Process Code and in this context it serves as an Axial Code indicating the intersection of four main trends, as illustrated in Figure 3.4 (Chapter 3): intimate relationships and sexual health, socio-geographic networks, cultural context, and the work environment of participants.

4.4.2.1 Socio-geographic networks

Socio-geographic networks represent the intersection of social networks and physical spatial locations (Wallace, 1991: 847). The related trends of intimate relationships, family relationships, support and talking, integrated with socio-geographic networks, stand out as the trend or pattern with the highest frequency. The social networks uncovered in this research permeate into a spectrum of main trends, while family relationships emerged as a trend in all the group discussions.

Participants prefer not to hear about family problems because families are a source of stress for them, which in turn is associated with high blood pressure and hyperglycaemia. In particular, children, and in some instances grandchildren, emerged as the most important element in the social dynamics of the family, and the single aspect that causes high levels of stress for the participants who reported having children. Therefore the sub-trend *'*children as the main cause of stress' is presented in the first sub-section. The rest of the sub-trends described in this section are: support; talking; prefer not to talk; lack of support; support to others and the value of 'buddy' contact;

Children as the main cause of stress: This trend was suggested by several participants:

> …I must not get cross…you know children is always the case…it is difficult…(*Participant was very emotional and could for a few moments not find the words to express herself; then bowed her head with a sad and worried expression on her face*) (C5:2); and

> The grandchildren…their mother passed away and they are girls. She comes home at 10 o'clock at night, so from 6 until 10 the blood sugar is very high. If she does not come back home, the sugar level is high the whole night (*participant was banging loudly on the table in front of her*) (C4:2).

This trend is exemplified by a particular female participant who repeated the words 'those children' at least five times in one paragraph, thus emphasising the emotional pain that they are causing her. This is a short abstract from her deliberation about her children:

> Those children are stealing my money, those children are drinking beer, those children are not sleeping at home – the previous month there was a fight – I went…the police came to our house. Those children came to the clinic – those children took two packets of pills, she said that she wants to die (*commit suicide*)...now all these things, it causes my diabetes to go up – shock, the shock. Every day is difficult…now these things are the big heartache that I have (C3:1).

Support: A few participants shared their experiences of support from family members. They distinguished between talking to people and receiving support from other people. Support, talking, the lack of support and the support that participants provide to others are presented here as sub-trends. Husbands, wives, children, siblings, and in a limited number of cases, friends, were mentioned as people to whom participants talk. Two participants mentioned that their spouses also have either diabetes or high blood pressure, or both. Where there is already someone in the family who has diabetes, it seems that there is better understanding within the family of the condition, as well as better support. The involvement of employers emerged as a trend that is presented as part of employment status and work environment in Section 4.4.2.4. In some cases, examples of social support are presented as longer quotations to ensure the qualitative value of the analysis.

Men in a committed relationship feel that their wives or girlfriends are their primary support:

> If I feel a bit tired, my wife will bring an apple for me, and I sit there…she also has diabetes, we are the same (C1:1);
>
> Mostly the wife - it the same for me, you talk to your family, my wife is a person who is always next to me. It is she that can see that I am not all right, she sees and she helps me. She will ask me how I feel. In most cases I talk to her (C2:1); and
> Yes, and my girlfriend, she is very supportive, when I come to the clinic (C2:4).

In contrast, the female participants experience no or limited support from their spouses. The majority of female participants indicated that their family is their primary support network. These family members range from mothers, siblings and in some cases, children, who help them with practical support regarding their self-care management:

> Yes, she (*mother)*…she asks 'how are you today? You must take Aloe Vera, a teaspoon every day'…even my daughter…she is visiting us every weekend (C2:2);
>
> My children are bringing the pills and the water…they are saying: 'drink your pills – we know that when you go to your…you will forget your pills… (C6:2) (*All the participants from the group started laughing*); and
>
> I am going with many people to church, many people, you cannot expect these people to support you – everybody has his own illness…you…and then you talk to somebody…at home they are providing...it is the family with whom you are living – you are all the time with them. If they are supporting you – you cannot easily receive support from other people – it is only at home that they are supporting you – you can enjoy it at home. The one that you can always talk to is your husband – if your husband doesn't care then you can talk to your child (C5:1).

One participant mentioned the help of her neighbours:

> Most of the time the neighbours are helping me, because I only have one child who is working (C4:1).

At clinic 6 there was a husband, wife and sister in the same group who support each other:

> *Wife:* We talk with each other; *Husband:* We talk with each other…I talk with her about the sugar…see, the two of us we talk about the sugar and so on. If her sugar is a bit high, then we talk and then bring the sugar down. And she (*referring to his sister*) is with her mother…yes, there is communication between us. Because we are talking between us, it is helping for this, for the sugar, it is not that you become depressed and doing something different. The two of us (*pointing to himself and his wife*), we talk to each other and give advice to each other and things; my sister also, my mother also; *Sister commented:* Yes and we are together a lot; and *Brother echoing what his sister said:* Yes, we are together a lot (C6:1).

Talking: Participants indicated that they talk to their family or other people, but were not necessarily very clear about whether the familiy or others are supportive:

> I talk to my Mom and Dad, and my brother…my brother is also sugar diabetes (*Participant looking very worried and depressed*) (C3:1).

This 57-year-old man, with an amputated leg and blind, talks with his wife, but it does not seem helpful:

> I talk to my wife but she is now just waiting for me to go (*die*) (C3:2).

These participants at the rural clinic provided similar examples:

> I am talking to my husband…my husband also has high blood (C4:1); and
>
> I am sharing with my friends that I meet at the clinic – people with same or similar problem or other health problems (C4:1).

This female participant talks to her friend who also has diabetes:

> No, I talk a bit with my *tjommie* (*close friend*)….yes, it is helping…she also has the sugar (C5:1).

A 34-year-old male participant was looking very tired and depressed:

> I can talk to my wife about how I feel about it. Sometimes there is nothing to talk about and it is also exhausting to talk…now that we had the conversation here, I think I should speak to her (C5:1).

A female participant, who sat with a bowed head and a sad and worried expression on her face, was very emotional and struggled to express herself in words:

> I talk to my cousin…she is also sugar diabetes. She tells me about the food, which food I must eat…I must not get cross (C5:1).

One female participant makes an effort to contact her neighbours and other people, including children when she is feeling stressed or alone:

> But now you think that you should talk (*chat in this context*) to the people – I talk with my neighbours, they have small children – I enjoy playing with them, then I forget about it (*the condition*)…and then play outside with the children, then you forget a little bit, nearly. Not really, you do not really forget, but you imagine that you have forgotten…if you do not talk then you are carrying a heavy sack. I feel hundred per cent when I have talked (C6:3).

A male participant suggested that he has no secrets and talks with his children and other people:

> I do not create a secret (*about diabetes*) – I talk with my children – amongst our Black people…no, we do not keep a secret – so we are talking it out. That man has the same problem as me; this woman has the same problem as me. But if I do not talk, then I think that I am the only one with the problem (C6:3).

Prefer not to talk: A 37-year-old male participant commented that he does not talk to anybody, but has explained his condition to his sister – he distinguished between 'telling' and 'talking' (*support*). On the question of whether he is prepared to talk to other men about his condition, he said that he is scared to talk to people due to the risk of gossip and ridicule:

> No I am too scared;…now like today I can talk about my life…but outside this, it is very difficult to talk…because sometimes you want to talk to somebody, and tomorrow the person is talking about you, saying 'I see he is like this, like

> this'. So I also started to keep everything for myself. Eh, for some of the people – it is very difficult to understand that you are in this situation. They would laugh at you and say 'what is this? *Blah*, *blah*, *blah* (C7:1).

Lack of support: A male participant appeared to be in deep emotional pain while sharing his experience of no support when having to provide for his sister's five children, as she had recently died:

> No, I must cope alone. I live with the woman (*wife*) - my wife does not help me – this illness of mine, my…my wife she does not understand – we do not understand each other – because it started with me, we do not understand each other – we are trying, but we do not see eye-to-eye (*it is not working*). My family is far, I am nearly alone. My sister lives there on the other side of Pietersburg. Me, I am nearly alone. (*Repeating that he is alone three times*) My wife she, the children of my sister, my sister is dead…but this illness of mine, the illness…I am thinking a lot, the whole story of my family, it is a lot of pressure on me, it is pressuring me a lot – I am not sleeping – I am struggling to sleep, I worry a lot. I struggled (*due to lack of physical strength*) to dig the grave…then they created a lot of stories (*Observation: he explained how he struggled, due to his lack of strength, to dig the grave for his sister who died while his family commented about it – he is experiencing a lot of stress and deep emotional pain*) (C1:3).

The lack of support is exemplified by more examples given by the participants. The moderator directed a question about support to a female who was sitting with a bowed head, looking sad, lonely and shy:

> I am alone at home – I come to town and to the clinic but I am alone at home (C6:1); and

> Here I am on my own, but alone because there are people around, like the Nigerians they are tough, you…I don't say I am sick (C2:1).

Two female participants expressed their lack of support due to the fact they do not have daughters:

> I am with the children, I do not have daughters (C5:1); and

> But I have nobody to help me, I only have sons, I do not have daughters, the boys…they go everywhere (C1:2).

One female participant emphasised the fact that it is necessary to take responsibility for one's own self-care and not expect other people to become involved:

> If other people know that you are ill, it will not matter because they do not worry about you. You, you must worry about your own life (C5:1).

One participant indicated that the family understands the condition, but they are not involved:

> They (*family*) understand, but they do not worry (C6:3).

Non-verbal reactions of other people are described by a male participant:

> Many people, when I say that I am diabetic…they do not understand. Some people they look strangely at you…they just go the other way around (C6:3).

Support to others and the value of 'buddy' contact: Only two participants, a female and a male, shared their experience of intentionally supporting other people with diabetes.

> I say 'but if you (*aunty*) know that if you exercise, maybe it will be better'…she came every day to exercise. So the other day…they (*health care professionals*) said that those things (*kidney problems*) are gone. *The participant encouraged other patients at the clinic:* I said 'no that will kill you, you must exercise – why don't you exercise in the morning?' (*Some of the patients replied*) 'How?' I said 'give me your phone number…then I will wake you up every morning at 5 o'clock when I am starting to exercise (C5:3).

A 45-year-old single male participant, with two small children, indicated that although he does not have any support himself, he supports a male friend who also has diabetes:

> So we are sharing with each other, because we are in the same boat. I can tell you, *oeh*, *oeh*, mine is nothing compared to his…(*Smiling)* his values are going over 20 and so on – he has been admitted and so on. He does not have somebody to look after him, so he phones me and I go there and help him (C7:2).

4.4.2.2 Home and living environment

The home and living environment was one of the discussion themes in the focus group schedule and was viewed as an important topic by the participants. This main trend intersects with social networks, and forms part the sub-theme of socio-geographic networks as reflected in the relevant Axial Code (Figure 3.4 in Chapter 3). For purposes of interpretation, and to ensure that none of the qualitative value of the data is lost, it is presented as a separate trend. This section focuses on physical and spatial issues, and the intersecting social dynamics of the home and surrounding external living environments. The sub-trends described in this section are: home environment; external living environments; positive experiences of home and living environment; and retirement – need for routine in life to comply with the required lifestyle.

Home environment: Participants had long deliberations about their home environment; therefore the examples are presented in some instances as narratives to preserve the qualitative value of the data. The majority of employed participants prefer their working environment above their home environment, due to the high levels of stress that they experience at home. One female confirmed this circumstance:

> When I am at work I do not have stress, but when I am at home I am stressing…at work I do not have stress (C1:3).

This female participant made the following comment after having ejected the young adults from her home:

> This past two weeks…I am feeling much better – it feels as if I have 'swopped' (*exchanged*) what I have been carrying. I have picked up my life from the ground – now I can sleep – I do not have the headache that I had… now I feel that I will recover – my sugar will be back where it should be (C1:2).

These female participants, who live in an informal housing area, commented as follows about their home environment:

> No it is not nice…when you relax you feel the pain but when you work, you do something, you do not feel the pain, it is better. When you are at home you feel everything (C3:1).

This female participant shared that she has a very problematic and stressful home environment:

> I am not talking – at home there are ten people with me – my five children, and three of my sister, and me and my husband…the one of 26 (*years old*) she also has two children and she doesn't work…she is pregnant again. Then the other one is 16, my son, he is making me sad…he must go to school, but he doesn't go to school. Last month there was fighting…the police came to the house. Now all these things, it is causing the diabetes to go up – shock, the shock. Every day is difficult. That man, he is my husband, I am not intimate with him, and he is with somebody else there in Mpumalanga…now these things are causing big heartache for me. (*Repetition of the words 'those' and 'that' ('daai' in Afrikaans) four times seems to be an indication that she is trying to distance herself emotionally from the situation*) (C3:1).

This female participant referred to her husband who had a stroke nine years ago:

> At work I am fine. When I am arriving at home…my husband had a stroke…he is making me worry a lot (C6:1).

External living environment: Participants shared examples of how they are not able to relax and rest at home:

> You find that you have a wife, kids and grandchildren, you do not have enough time to rest, and the environment is not good for you but you cannot do anything to it. Like me where I am staying in the location in S (*name of residential area*) there is a lot of booze, a lot of children going up and down, there is lot of noise (C2:1); and

> If you want to be okay in the location and not be stressed…if they say you must fly, you must fly…so you must fit into the social environment. If you do not fit in or you get bored you will stress, you must fit in. If you put yourself in a different class, you experience negative reaction – it is a problem (C2:1).

Positive experiences of home and living environment: A number of participants have positive experiences of their home and living environment:

> I do not have problems at home – from the beginning of the year that I am sleeping at home I am feeling good at home…when I arrive at home I am playing with my grandchild (C1:2); and
>
> But when you are at home, my wife asks me 'How do you feel?' – 'I feel all right'. She is cooking the right food for me (*very softly saying this – 'food prepared with love'*) (C4:1).

Retirement – need for routine in life to comply with the required health lifestyle: This 63-year-old female, who is experiencing stress at home, is looking forward to retirement in a few months' time when she will go and live with her grandchildren:

> Yes, it will be very nice…I am going to live my children's children (*grandchildren*). Then, when I wake up, if I would like to get up, I can drink my pills (C5:2).

4.4.2.3 Intimate relationships and sexual health

The majority of the participants indicated that they are in an intimate relationship or a partnership. Intimate relationships emerged as a main trend from the beginning of the field work and are the fifth most important topic discussed. Sexual health problems emerged as a specific diabetes health complication, but due to the interrelationship between intimate relationships and sexual wellness, the two topics are presented as a single integrated main trend. The presentation of deliberations at the clinics or in specific groups follows a narrative approach in some instances, in order to preserve the qualitative value of the data.

A 45-year-old female participant opened the discussion by sharing issues about her intimate relationship with her husband. She was looking very stressed and depressed. She explained that she has lost her love for her husband, and she does not feel like making love with him. The following discussion took place amongst the members of the group and is presented as a narrative:

> It worries me a lot. How can I sleep with someone that I don't have feelings for? When my husband is asking me to go to the room, I am becoming even more upset, knowing that I will not feel anything.

A 61-year-old female participant shared her wisdom:

> But you must try, sometimes try to push yourself, do not run away. It is easy for you, it is not like men.

Then a 58- year-old female participant suggested:

> When you go to the room with your husband you must open your heart and be free and let him touch you wherever he wants to touch you. When you keep on ignoring him, he will get angry and go somewhere else.

The same female participant warned that:

> You will end up sleeping alone in bed and when he comes home at half past twelve or half past eleven at night he will not even bother to kiss you or touch you.

The distressed wife expressed her wish:

> This problem must go away; I want to give my husband love (C1:2).

This 43-year-old male participant said that his wife is very understanding and supportive with regard to his diabetes self-care management, but he expressed his concern about his sexual performance:

> But the only problem that I am coming across is when we are going to bed…sometimes I don't perform like a man and it worries me a lot…a lot, but…eh, but sometimes I am performing nicely, sometimes I am weak. *On the question whether his wife understands:* No she knows about it, we do not talk about it every time…I don't know what's happening now (C2:3).

Six of the seven participants in one group indicated that they are experiencing major sexual problems in their intimate relationships. The remaining participant prefers not to be in a relationship, in order to avoid the stress of a relationship. One of the female participants explained that her feelings inside did not change, and that she still loves her husband, but her body is different. She has a very complex and emotionally challenging home environment (see Section 4.4.2.2). The situation is traumatic for her – she was very emotional and crying, and although at first she did not want to talk about it, she was encouraged by the other participants to share her feelings.

The trend of sexual health problems experienced by participants is exacerbated by this discussion between these participants presented as a narrative:

> …and there at home I am still married, I have a husband but I am drinking the pills (*diabetes medication*); I do not sleep with that man. He has gotten another woman now. It is still the same inside of me (*feelings for her husband*). Now I don't know what those pills did…the body…I don't know, it is feeling different – I must lay down every day.

A 35-year-old female participant commented:

> I am not feeling for my husband, when I go home, I do not feel anything. When I am finished with drinking the tablet, I am sleeping.

One 30-year-old male participant's spouse left him:

> My wife is gone, because I could not give her what she needed (*Demonstrating – directing to his groin area*)…I could not give it to her…it is a lot of stress because I don't know what is happening. I do not have work, with this diabetes I do not have a life, I just live (*This male participant was looking much stressed, depressed and devastated*).

One 50-year-old female participant prefers not to have an intimate relationship:

> With me, I do not have the husband because I don't have the feelings, I do not want stress…it is suffering.

A 39-year-old male participant expressed his uncertainty about his future sexual wellness*:*

> I have my girlfriend, but it…this thing has started to affect me, the feelings…she is trying to understand, but I don't know as times goes on. Now she understands because I have told her that I am diabetic, but I don't know as times goes whether it will improve (*sexually*) what will happen…it is stressful to me (C3:1).

Two male participants, aged 62 and 69 years respectively, both experiencing sexual performance problems, expressed views about their intimate relationships:

> My wife does not have problems with my sexual performance, because she understands…but sometimes I feel so scared that my wife can get it from outside…having stress is another problem (C4:1); and

> She knows the sugar…and I do not feel like an old man, I must feel like a young man at home. She knows when we go to bed, we do not have sex. When the sugar is going high we must do other things, we must just be happy (C4:1).

At clinic 6 there were three members of one family in the same focus group session, namely a married couple and the husband's sister. Despite the possible difficulty for the married couple to openly discuss their intimate relationship in front of the sister, a spontaneous exchange of views took place. The 51-year-old male participant, who works night shifts, remarked:

> When I arrive at home from work I am drinking my pills and I go to bed and sleep. When I wake up I am preparing for work and leave for work. The wife, who was looking very distressed about the situation, agreed: We never see each other. Another female participant, who was looking very surprised about this, asked: Is it? The wife then responded: Only the three days that he is off-duty (C6:1).

Two male participants (37- and 42-years-old), in the same group, who both looked emotionally very tired and depressed, shared the following insights:

> It is problematic when I was sleeping with my wife (C7:1).

The moderator probing: And now that you are taking the medication? The participant replied:

> It is still the same…also early ejaculation (*This participant was quiet up to this stage in the group discussion about his experiences about diabetes, even reticent*) (C7:1).

The other male participant:

> What the other brother (*other participant*) was saying…I also cannot talk to somebody but I am also having the problem of early ejaculation…it is stressing me a lot because the other time I was ejaculating early and then she (*girlfriend*) was just turning back. She does not accept that it is difficult for me. She thinks that I have some sexual relationships outside – so I said no, it is not that, it is the sickness that is causing it. She knows that I am taking the medication…she knows your performance anyway but then she wonders what's happening. (*The participant is stressed about the lack of understanding and rejection by his girlfriend*). Some other ladies tried to explain it to her, but now I am at this stage…she was asking 'what's

> happening?' I said 'I don't know what's happening, but I tried to explain to her. I do not want myself to be like this. Sometimes it is a struggle…I don't, I don't understand, I do not understand…it is not something on the side. The other time I asked myself, 'if she was me, what would she have done if she was in my position? Maybe I will try to listen to her' (*Deep pain due to sexual problems*) (C7:1).

4.4.2.4 Work environment

In this section, the work environment is presented, including the type and nature of the work, and the role of employer involvement. The majority of the participants work full time or are employed on a part-time basis (See Section 4.2). The main type of work is unskilled, with 65.2% of them working as domestic workers in households. The work situation and work environment, even if it involves physical strenuous activities, seems to be an escape from pain (both physical and emotional) for the majority of employed participants. The sub-trends presented in this section include the experience of unemployment; the type and nature of work; and the role of employers.

Unemployment: All the participants at the rural clinic are either unemployed or receive a senior citizen's pension. The blood glucose levels of all eight participants in one of the groups are uncontrolled. The following examples are from two of the men, a 45- and 43-year-old male respectively:

> We cannot take pills without food – we are unemployed, we do not get the grants...(*Participant was looking very tired and depressed*) (C4:1); and

> Most of the time I am sitting with my brothers, because they all have diabetes, and we plan what to do…because sitting at home will not help us, because we are not working. I was working, but because of my illness they told me to resign (*Participant's right side of his body, right arm and hand are paralysed*) (C4:1).

This male participant, who lost his job, expressed the value of job security and private medical aid:

> I mean before I lost my job it was so well-managed, it was as if it was not there…but now the stress of not having a job and looking for a job, it is getting too much…ja, well…for me the best will be if I can get stability in my

> work situation. Things will without a doubt get back to normality (*Participant was looking very stressed and depressed*) (C7:1).

Type and nature of the work: The majority of employed participants are domestic workers. The type and nature of the work of participants plays an important role in their ability to control their blood glucose levels. The domestic workers prefer the work environment over their home environment:

> You know, any woman when you arrive at home, you will be scolding a bit…the children…did not tidy-up, then your 'high blood' is a bit high, because you will 'scold' a bit. I am happy when I am at work, because here at work I do not see anybody…*hee hee*, here (*demonstrating – showing that nobody can upset her heart at work*); here, no, my work is (*domestic*) and to look after their children (C5:3).

A male driver said that five other drivers, who work at the same company, also have diabetes:

> Where I work, there are five drivers who also have diabetes...here is a lot of sugar (*colleagues who have diabetes*)…we are always talking with each other. Moderator: And how are their blood glucose levels? Male participant: It is a bit high, but then they always go to the clinic in town (C1:1).

The role of the employer: The following four paragraphs present examples of employer involvement, an employer and/or their family members who have diabetes, an employer who does not want to be involved, and employers who do not understand the condition.

Employer involvement: Thirteen of the 14 participants at clinic 1 indicated that their employers are involved with their condition. Twelve of the participants at this clinic are domestic workers. The employers of these domestic workers are involved in their condition and form the primary support structure for the majority of the female participants. Employers assist the participants through a spectrum of actions such as: giving them time off to visit the clinic for check-ups; making sure that they eat well; talking to them about their condition; keeping the insulin in their fridge; and sometimes also helping them with their injections:

> It is only the people where I work – they are helping me a lot…I am doing domestic work…they will ask me 'did you drink your pills?' and whether I have eaten, and they are helping me to cook the food (C5:2); and
>
> At work I do not have problems. My people for whom I am working, they are helping me a lot, with everything I need…the medication that I need. I do not drink sugar, but they are buying those sweeteners instead of sugar...they are helping me like with the injection that is kept in her fridge. She is fetching it and assisting me with injecting it and then I go to sleep (C2:1).

The employer and/or their family members who have diabetes: Participants whose employer or their family members have diabetes, identify this as an important source of information and they find it valuable in terms of their own diabetes self-care management. A truck driver said that his employer and his employer's family are involved with the support of his condition, while a domestic worker's male employer himself has diabetes.

> My manager where I am working – his wife and his children also have diabetes – they are sitting and conversing with me; they say I must not stress a lot. They are saying that I have it now…I must accept that I have it (C1:1), and
>
> My boss, he has sugar – he said to me that I should not worry, because if I am eating properly and I am drinking the pills, and I must listen to what they are saying at the clinic – I will be fine (C5:1).

Employer not involved: One male participant (a farmworker) said that his employer only needs his physical power to do the work; he is not interested in the diabetes (quoting his employer):

> 'When you are working, then you must work…if you have a problem…I do not want to hear about your problem'. No, he doesn't want to hear about my problem, he is just requiring my strength to work – he only wants you to work, you are receiving your money and that is finish. I am doing hard work, I am earning a small amount…it is difficult (C1:3).

Employer not understanding: The employers of a few of the male participants do not understand their condition. The employers either want proof from the

clinics that their employees are being treated for diabetes, or they do not believe that they are experiencing hyperglycaemia:

> Then there was an HR officer…he insisted that every time I come here at the clinic that I should bring a medical certificate…this clinic do not give medical certificates… (C2:1); and

> They said 'no you are lying, you are lying, lying'. So I (*participant was a long-distance truck driver at the* time) off-loaded there until I parked the truck, and then I took the cell phone to the man so that he could talk, because I do not talk to the master anymore… (C6:3).

4.4.2.5 Cultural context – traditions and customs

The cultural context is complex, including, amongst other things: morals, customs, traditions, and habits of a society or a community. The topic of traditions and customs is not prominent amongst persons with diabetes. During the group discussions, only a few related issues were raised by the participants.

None of the participants at clinics 1, 3 and 7 indicated that traditions and customs have any role to play in their diabetes self-care. At clinic 2, one female participant mentioned that she uses 'Aloe Vera' produced from the aloe plants in her own garden as recommended by her mother. At another clinic, a male participant referred to traditional medicine that improves sexual performance but which he claims he refuses to use.

At the clinic located in the rural area of Tshwane, a few comments were made about traditional practices related to food that are presented in the sub-section 4.4.4.1 about diet. The participants in both focus groups at this clinic agreed that it is only the "*morogo* with the *half pap*" (*half a portion of maize meal porridge*) that works for them:

> The best thing is to eat *morogo* and *dinawa*. I am also eating *Mopani* worms. The doctors that were taking care of me in hospital told me that I must eat those worms. The 'cow leg' if you cook it - you must drink the 'cow leg' water and this is good for the joints (C4:1); and

> We use a plant that is growing everywhere in this area to make a tea – we drink it to help with the sugar diabetes (C4:2).

At clinic 5, only the male participant with a post-matric qualification made a comment about traditions:

> She (*wife*) does the cooking…sometimes…as Blacks we eat a lot of meat, and I know that is not healthy. As I have said… we must go back to the old ways of eating. Sometimes I say 'this is wrong' – I did it initially, but now less…the wife… she does the cooking, so when I come home from work and she has made a fatty steak, then I will eat it. In our culture the wife has to do the cooking (C2:1).

One male participant shared his experience with traditional or herbal medicine. An herbal medicine retailer created the perception that a specific mixture could cure diabetes, convincing him to stop his medication and take only the traditional herbal medicine. He promised that it would totally cure the diabetes:

> Herbs, yes…I experienced it…when you say you have high blood and diabetes, they say 'that is nothing, *ouh*'. They give you 2 litres - you drink it, it becomes worse, worse, worse…and it won't get out of you, it won't get better. They all promise that they are going to help you, but help…no, no, no. After I bought it, oh my sugar was going up – he told me not to take any tablets, 'but use this' (C6:3).

A female participant commented about traditional healers:

> Because we Africans, we have traditional healers…as a mother of a child who has diabetes, I took the child to a sangoma. So luckily at the sangoma I found the right person who advised me to go to the clinic, because the traditional healers they do not have the machine, so they cannot see the blood because everything is in the blood (C6:3).

4.4.3 Diabetes Health Beliefs

Diabetes Health Beliefs emerged as the theme that combines the main trend of perceptions about diabetes with the following three related main trends:

perceptions and attitudes with regard to the death threat of diabetes; perceptions about the possible symptoms of diabetes; and perceptions about susceptibility to diabetes. Due to its relation to perceptions about diabetes and susceptibility to diabetes, the trend 'attitudes about generational diabetes', is presented as part of this theme, while 'experiences of generational diabetes' was presented in Section 4.4.1.4. The following sub-trends are integrated into the relevant main trends: attitudes regarding undiagnosed diabetes, stigmatisation regarding symptoms and the diagnosis of diabetes, and perceptions that symptoms might be associated with HIV and AIDS.

4.4.3.1 Perceptions about diabetes

There are certain prevailing perceptions about diabetes in these communities. Participants indicated that they have to, in some instances, either correct the misconceptions of other people, or explain their condition. A 55-year-old female shared two misconceptions about diabetes.

> They (*people in the community*) do not believe me because they say that persons with sugar are very skinny and I am not (C2:1).

The perception that you cannot work when you have diabetes:

> And I work, now my other cousin said that I can get pension…I said 'from where'? I replied 'I still have a bit of strength' (C2:1).

A female participant shared her experience about another person with diabetes in the community where she lives, regarding the misconception that when your blood sugar is stabilised then you are healed from the disease (*Perception that illness has gone when taking the tablets*):

> …and they say maybe I will not have the sugar diabetes anymore in my body. I said 'No, it does not work that way, when you have it, if you do not exercise, you still have it…it is not going away, you must help it so that you do not develop problems (C5:3).

Participants described the attitudes, perceptions and reactions of other people about their illness (diabetes) and its complications. A female participant shared her experience regarding the reaction of other people:

> You know Black people − when you tell them you have diabetes or another sickness, they think you are going to die tomorrow or whatever. You do not think about anything else, you just think she is dying (C4:2).

A 50-year-old male participant shared the perception that people with diabetes are a problem for other people:

> When you go to visit other people, they forgot to cook the correct food for you, when they buy groceries, they do not think about you. Then you think…'Maybe I am a problem for this people' (C2:1).

A male participant commented about other people's reaction when they hear about his diagnosis:

> Many people − when I say that I am diabetic, they do not understand. Some people they look strangely to you…they just go the other way around (C6:3).

4.4.3.2 Perceived death threat of diabetes

These comments confirm the perception that the diagnosis of diabetes is equivalent to a death sentence:

> I will not forget, there was a big sister at 'S' Clinic – she said 'you will die, this thing is killing you' (C1:2);
>
> I was so scared, because I heard of somebody – hooe! That one has the sugar and she is dead now, she is dead now (*repeating the* statement) because she did not drink the medication. It is a big problem (C1:2); and
>
> The first time I heard, I *eish*…I feel like I am going to die…something like…*eish*…I don't know (C3:1).

4.4.3.3 Perceptions about symptoms

The sub-trends presented in this section include attitudes regarding undiagnosed diabetes, and attitudes regarding a possible HIV and AIDS diagnosis. The uncertainty and complexity of diabetes health complications and uncontrolled blood glucose levels were highlighted in Section 4.4.1.5. The

uncertainty and complexity of health complications are exemplified by the following example that illustrates the perceptions about symptoms:

> …the majority of us then do not know what are the symptoms…the majority of us then do not know what is the symptoms (*repeating his statement)*...most of us if you feel like this or this, you don't know that it is the sugar diabetes (C2:1).

Attitudes regarding undiagnosed diabetes: This participant referred to his mother who became blind before she was diagnosed:

> My mother became totally blind before she took action because she did not know about this story (*diabetes*) (C6:1).

Attitudes regarding possible HIV and AIDS diagnosis: The weight loss experienced by many participants is associated with a possible diagnosis of HIV, while one participant indicated that she would prefer to have HIV than diabetes. The following examples illustrate these attitudes:

> The sugar…I was worried…because the people…(*Saying that she has AIDS*) (C5:1);
>
> They (*community*)…when I first got diabetes I suddenly lost a lot of weight – …then they thought that I had HIV (C5:2); and
>
> She (*aunty of FP*) is saying 'I do not like sugar diabetes, I don't like the 'high blood'…maybe it is better to have HIV – with HIV you can live a lot, HIV is not dangerous because if you are drinking the pills you can live, but with this one (*diabetes*) you do not have control' (C5:3).

4.4.3.4 Perceptions about susceptibility to diabetes

Two male participants (50- and 43-years-old), referred to age:

> You think maybe it is just your age, over 40 or I am too much busy, I am doing several jobs and what I am doing is causing the tiredness. In most cases you will not know that you have the sugar diabetes (C2:1); and
>
> I realised it when I was 40…I listened to the radio one day and they were talking about sugar diabetes, they said when you reached 40, it is there where you will find out that you are sugar diabetes (C2:3);

Later the same man expressed his concern about whether his wife is also susceptible to diabetes:

> Now I have diabetes, is it possible that my wife can have diabetes as well? (C2:3).

One female participant echoed the earlier statements about age:

> I was shocked because this is the disease that people get when they are old…how can it be? (C3:1).

A father of five young children expressed his fear that his children might be susceptible to diabetes:

> Now that I am having children…is it possible that they could also have diabetes? Now I want to know, because both of my parents died of diabetes, and I have five children and I want to know whether one of them can get it (*Participant was looking very worried while expressing this fear*) (C4:1).

The example of this female participant, who is the guardian of her diabetic aunt, was presented in the main trend 'experiences of generational diabetes':

> I was the only one who took my aunty to the clinic for treatment. I had a medical failure…I was quickly admitted to hospital…I was there for three weeks. My sugar was 28.8…I was three weeks in hospital (C5:2).

A female participant (*sister of the male participant who was in the same group*), who for the last 20 years has been taking care of her diabetic mother, was unaware of her own condition:

> One day I was here, when I came the first time, my sugar was 43. The doctor could not believe that I could still stand upright…yes, it was then…(C6:1).

A female participant, whose mother experienced serious diabetic complications that led to the amputation of one leg, shared her perception about susceptibility to diabetes:

> But I cannot understand, she was not a lazy person, she worked, she moved, but then got this strange illness (C6:1).

4.4.3.5 Attitudes about generational diabetes

'Experiences of diabetes in the family' (generational diabetes) was presented as a main trend in Section 4.4.1.4. An attitude of fatalism emerged from the focus group discussions that are illustrated by this example of a female participant who assists her aunt:

> I wasn't shocked when I heard that I have diabetes…my aunty she was diabetes, I saw her, and so I knew about diabetes…that's why I wasn't shocked…but when I found out, it was very high (C5:2).

4.4.4 Self-care management practices

Self-care management implies taking care of oneself not only physically, but also mentally and emotionally. Good self-care depends on a positive and healthy mental status. Participants reported feelings of depression and lack of motivation, which were exacerbated by limited physical movement and 'wrong eating'. The sub-trends that emerged from the discussion about self-care management are: compliance with diet (eating and drinking); compliance with diabetes medication regimen; exercise; and the role of external systems: availability and accessibility. This combination of related sub-topics was discussed 209 times and is the most frequent main trend and pattern. Comments about traditional food are presented as a sub-topic under diet, while other aspects related to traditional health care practices were presented as part of the cultural context in Section 4.4.2.5.

4.4.4.1 Diet

Discussion about food was at the forefront for each of the individuals in the focus groups and interviews. Food received the highest frequency as a single code, namely 80. The dominance of the topic is substantial, taking into account that the researcher coded food only once per participant, unless the participant added a new perspective to the discussion. Food or eating was not part of the

focus group interview schedule, and was not used as a probing question during any of the interviews.

This sub-section utilises a logical approach instead of a priority sequence, by clustering the related elements into sub-codes or sub-trends and patterns. The following sub-trends are discussed: compliance with the correct food; confusing messages from clinical personnel about specific food and drinks; the debate about two types of porridge; portion sizes; social challenges of compliance with diet; side-effects of different food and food preparation; socio-economic status; supportive spouses; uncertainty about causes of uncontrolled blood glucose; waiting time between meals; traditional and alternative food; drinking water; soft drinks; tea and coffee; and alcohol.

Compliance with the correct food: A number of participants acknowledged that it is the food they eat that is causing hyperglycaemia. These are examples that they shared about what they are eating:

> I am no longer eating white pap, I am eating the brown pap and I am eating cabbage, but not overcooked. I also eat *morogo*. When I am eating meat I must add spinach. If I don't add the spinach the sugar is going high (C4:1); and
>
> I can see the mutton and beef and all that, you should not eat a lot of it. If I eat that I feel pain in my neck (*Demonstrating how it affects her body*) and here when I eat that. Then I am happy when I eat spinach or cabbage (C5:3).

Three members of one family, who were in the same focus group, had a discussion about the best food for a person with diabetes (*their 70-year-old mother who was not part of the group also has diabetes*):

> The male participant (*husband and brother*) said: The food…you must eat correctly. The sister reacted: The food is the most important. And on a probing question about what they perceive to be to correct, the male wanted to answer: I… The female participant (*sister*) continued (*Voice tone and words saying 'I know what is best'*): I am taking care of my mother (*diabetic*) for the past 20 years, so I give… This time the sister-in-law and wife of the brother interrupted: Lots of vegetables are good. The husband then said:

> What I cannot handle, I probably should handle (*laughing*), but I cannot handle it, meat, I like my meat, but I am not allowed to eat meat. The wife acknowledged that she also likes meat: I also like it (*laughing*) (C6:1).

Confusing messages about specific food and debate about porridge: Participants report receiving mixed messages from different health professionals, while there seems to be a debate amongst them about whether white maize meal porridge or the brown *mabela* (*sorghum*) porridge is the best for people with diabetes. Participants encouraged others to eat brown porridge:

> I am having a problem, because the clinic said that I must not eat brown porridge, because the porridge is not healthy, it makes the sugar go high. They said that the white porridge is fine (C4:1);
>
> (*Other participant commenting*): No you must eat the brown pap because it is healthy, you will get used to it (C4:1); and
>
> Brown pap is very good to eat when you have diabetes…you must just keep on eating it, it will get better (C1:3).

Portion size: Finding the correct portion size is problematic for participants:

> When you eat you must not eat a lot of food, you must eat just a little bit (C1:2).

This female participant's blood glucose level was 12 when measured before the interview:

> I ate a big bowl of porridge, I ate the… (C2:2).

Social challenges of compliance with diet: Participants are faced with challenges in cooking for themselves and the rest of the family and for visitors. Family and friends have certain expectations about food and sharing meals:

> If you are visiting, you must always take a tin of baked beans with you − so when they are starting to eat…then you open the tin of baked beans… (C1:3);
>
> I tell them 'you must know I have the sugar diabetes, I cannot eat all the food. I eat potato and cabbage, finish (*emphasis on finish),* and porridge with brown maize meal (*mabela*). If you do not have it, then you can rather leave it, that's all'…I, I take my own food with me when I am visiting other people –

> when they eat I take my food from my bag…and I eat my food. They will not ask me 'why do you eat this food?' (C5:2); and
>
> When my sister comes to eat then it is difficult (C6:1).

At the rural clinic there were several comments about social issues regarding the buying, preparation and eating of food:

> She (*wife*) cannot take care of me and take care of the children. She will buy whatever is needed for the whole family. I cannot blame her (C4:1); and
>
> *A comment from a very shy and softly-spoken male participant speaking in isiZulu*: Sometimes when I am going to my house they have cooked the wrong food and that is tempting, so I also eat the wrong food. When I go to bed, my legs are starting to itch again. When I am eating brown porridge then the sugar is getting level (C4:1).

A 43-year-old male participant, who is paralysed in the left half of his body, said the following:

> At home they are cooking for me, but when they put salt in my food, I will not eat it; and I am eating spinach with no salt. The only problem is that my children do not like the food without salt…I have to cook for myself only (C4:1).

Side-effects of different food and food preparation: Only a few comments were made about the possible physiological impact of eating and drinking according to the required regimen. This is one example of severe muscle cramping:

> It is just a bit difficult with the food because food without salt…I become paralysed and then the cramps…I experience severe cramps…my hands become like claws from the cramps and it gets me here (*Demonstrating how it is affecting her legs*) and then I cannot walk (C6:1).

Socio-economic status: Participants are challenged by difficult socio-economic conditions. A male participant with a post-matric qualification, who is employed full-time in a skilled position, expressed himself as follows:

> …sometimes it is difficult, you do not have money, and you do not eat the correct food. I am drinking medications but it does not help (C2:1).

Other participants commented:

> I am drinking tea without sugar, because I cannot afford the sweeteners, because I am not working (C4:1); and
>
> Sometimes I am eating the beans, then I am getting much better, because most of the things that I should eat, I cannot afford (C4:1).

Supportive spouses: Six male participants indicated that their spouses are supportive with regard to their dietary regimen. This example was given by a male participant:

> She is supporting me…eh…how can I put it…the food, the food, she cooks for me the correct food. She prepares the food without salt and without those rajas (curry) and all those stuff, soup…I don't eat them. If she cooks for example the chicken, she cooks it, cooks it until it is right, and when she wants to add all that stuff she is taking mine out and put it away without salt (C2:3).

Uncertainty about causes of uncontrolled blood glucose: One participant with uncontrolled blood glucose levels expressed her uncertainty:

> I don't know. We are eating the right food like raw vegetables, eating the *morogo* and cabbage, and then it is level. We are also eating fruits and carrots and green beans, and then it does not go up (C4:1).

Time between meals: Participants sometimes find it difficult to eat at particular times. Social circumstances like travelling or waiting in a queue at the clinic for their consultation opportunity are examples of challenges that they face:

> After two hours you must eat so that the stomach can get used to eating just small meals (C1:2); and
>
> Sometimes I sit the whole day (*at the clinic*)…and then I only eat tonight – then I eat a lot of pap (C1:3).

Traditional and alternative food: The role of traditional and alternative food in lowering blood glucose levels was a topic discussed amongst the participants. All those from one rural focus group agreed that it is only the *morogo* (*a*

traditional vegetable similar to spinach) with the half *pap* (*half a portion of porridge*) that works for them. Participants shared some examples about traditional food and traditions regarding food:

> When my sugar is high, high, high, I am eating the uncooked potato. I am also drinking water and then the sugar is going down (C4:1);
>
> Yes, the traditional foods, the food of the tradition, the tradition food is very good for the people (*repeating tradition three times*). They have planted and harvested *morogo* for a long time and were eating it. When you eat *morogo* you feel all right. We eat *pap* and *morogo* – that's right, we eat brown *pap* and *morogo* (C6:3); and
>
> Like at home there is a lot of activity, like slaughtering. Sometimes I do not do it because I am restricted to a specific diet (C7:2).

Drinking water: Water on its own was the most commonly cited drink, followed by soft drinks, tea, coffee and alcoholic drinks. The important role of water in lowering blood glucose levels was emphasised by the participants in most of the groups. All 14 participants in the first clinic indicated that they need to drink a lot of water, namely up to four litres per day. At clinic 6 all the participants indicated that drinking water is the most important way, after medication, to lower their blood glucose levels. Participants gave the following examples:

> I must drink water and then eat something, then it (*blood glucose*) goes level (C6:3); and
>
> …I drink water – 2 litres are enough per day – I am treating the sugar with the water. When I am drinking a lot of water, the sugar is coming level (C4:1).

Soft drinks: Seven of the participants indicated that the only drink that quenches their major thirst is Coca-Cola. Participants acknowledged that before and even after having been diagnosed with diabetes, when they are thirsty they drink a lot of cola and other cold drinks – at first it feels as if it is lessening their thirst, but after a few minutes, they feel lethargic and in some instances their eyes are affected:

> When I was thirsty, I could drink 2 litres of coke in…30 minutes was enough….I will finish it (C1:1); and
>
> my mouth was dry, very dry and then when I was drinking coke; I finished two litres of coke a day, in one day, so then when I drank coke I was feeling fine, I did not have to go to the bathroom, but when I drank water, two minutes I had to go to the bathroom…(C5:1).

Participants continue to drink soda soft drinks after their diabetes diagnosis:

> I drink cold drink and then I feel better (C3:1); and
>
> You are drinking the Stone *(soft drink)* when you feel weak, then I cannot see (C3:1).

Tea and coffee: A few comments were made about tea and coffee:

> I do not drink tea anymore – I now only drink…rooibos (*an indigenous South Africa herbal tea*) (C5:1); and
>
> If I drink coffee, or if I drink *Joko (Ceylon tea)* tea or if…my heart, my heart beat is very high, very, very, I cannot sleep at night. No, I will just sit like this the whole night (C6:1).

Alcohol: Less than a handful of participants referred to drinking alcohol:

> And something else is this drinking…alcohol…I had to stop (C7:1);
>
> One doctor said that I must drink one shot of whisky at night when I go to sleep…its very good; it's very good for sugar. No beer, no ciders or more (C5:2); and
>
> I was a person who liked to drink a lot…so I started to reduce the drinking to two. I do drink, but I don't…you know over weekends when you are watching a soccer match, you know, but I do not overdo it, I just use it moderately (C7:2).

4.4.4.2 Compliance with diabetes medication regimen

Compliance with the diabetes medication and blood glucose testing was the second most important topic related to the diabetes self-care management

regimen. The regimen of taking the medication at specific times is difficult because participants tend to forget about it when they are ill with related or other illnesses, or when working, especially when doing a work such as long-distance truck driving. The majority of the participants indicated that they do not have anybody to follow up and make sure that they take their medication. A contributing complication is that insulin-dependent patients cannot always eat at the right time after an injection. The following sub-trends are discussed: medication alone cannot ensure controlled blood glucose levels; perceptions about the role of medication in managing diabetes; perceived side-effects of the diabetes medication; reasons for not complying with the medication regimen; and routine with regard to diabetes medication regimen.

Medication alone cannot ensure controlled blood glucose levels: The following examples were mentioned by the participants:

> Until now it was okay… but from this year I was getting tired, nowadays I am feeling…maybe they can change my medication (C2:2).

Later this participant said that she had eaten a large bowl of maize meal porridge in the morning:

> …but…treatment…I do not jump my treatment…but this morning my blood sugar was high, 12 (C2:2).

One particular female did not eat prior to her clinic visit:

> I come here to the clinic – I drank the pills…and I drank water but I need food (C3:1).

Perceptions about the role of medication in managing diabetes: Two participants from one group shared the disbelief of two ladies who were not part of the group:

> Sometimes people do not believe in the pills. She (*also a diabetic*) must stop guiding people to throw away the pills; she is busy wasting the government pills…there is another lady – they went to her house and they found boxes that were not opened – so it meant that she was not drinking the medicine and now she is gone – passed away (C1:2); and

> I was so scared…that one has the sugar and she is dead now because she did not drink the medication. It is a big problem (C1:2).

Another female participant shared her own experience:

> At first they (*health care professionals*) said they will help me, I must get the pills. Then I said 'no I will come again'. Then when I walked…I was dizzy, I realised that I will fall. Then I came back but I wasn't happy to take the pills but now I am used to the pills (C5:3).

Perceived side-effects of the diabetes medication: There is a perception that the diabetes medication is negatively affecting sexual performance. After a short debate in Setswana (*indigenous language*) between the seven participants of the same group, one participant expressed her views as follows:

> All the people here are the same (*experiencing difficulties with sexual performance)*. I don't know whether it is the pills or whether it is the diabetes (C3:1).

Reasons for not complying with the medication regimen: Participants tend to forget to drink their medication when they are ill with a related or non-related illness:

> For the last two weeks I could not see because I was very ill – I was in and out of the hospital and I totally forgot about the injection and the pills, so I was blind, blind and could not see (C1:3).

One participant suggested their socio-economic conditions (*as a group*) as a reason why they do not comply:

> We are unemployed…you must eat if you are drinking the pills…that are the reason why the sugar is going up (C4:1).

A particular participant was without tablets for two weeks:

> As I speak now, it is 13 (*blood glucose level*) and I had two weeks that I did not drink the medication. The pills were finished and now I have to rush to clinic so that they can check me and give me the pills (C4:1).

One male participant explained his uncontrolled blood glucose level due to the fact that the clinic did not have insulin available:

> This year I am having problems with the sugar diabetes, it is always high – last month it was high and today it is also high. But I did not get some of the injection…they said it is finished…so I am two weeks without it. So they are looking for the right injections (C6:3).

This male participant stopped taking his medication because he started using traditional medication instead:

> After I bought it (*traditional medication*), oh, my sugar was going up – he (*traditional medicine retailer*) told me not to take any tablets…I left the tablets, I was just using this – at the end I could not even see, my eyes was otherwise, so I would never, never use it (C6:3).

Routine with regard to diabetes medication regimen: The routine required to comply with the use of the medication in combination with the rest of the regimen is a challenge for some participants:

> Last year, it was so high…28 (*blood glucose level*). I drank the medication at different times of the day; now I am taking the medication on a specific time every day (C1:2); and

> You see, that is another problem with managing diabetes…when you have a busy schedule, like I have been away this weekend, then it is difficult to drink the tablets at certain times (C7:2).

4.4.4.3 Exercise

Exercise as a self-care management practice is an important part of blood glucose control, but is a practice that received little attention from the participants during the group discussions.

One female participant at clinic 1 indicated that she is trying to walk as far as possible to release stress and keep the blood glucose level down, but none of the participants at clinic 2 gave any indication that they are exercising. At clinic 3 one male participant said that he uses his bicycle to go to work, while one female walks to the train station, and one young male participant plays soccer with his friends. One male participant at clinic 4 indicated that he exercises once a week with a group organised by a non-governmental organisation at the

clinic. None of the participants at clinic 6 gave any indication that they do exercise. One of the male participants at clinic 7 mentioned that he exercises. Only one participant at clinic 5 referred to her exercise:

> I exercise in the morning at 5 o'clock…(*giggling in between and demonstrating how she is exercising*) I switch on my radio – they talk about exercises on the radio…yes, I run and my job implies a lot of exercise you know, you sing, you clean the bathroom, you do ironing, you wash, the dishes, everything…Yes, and then I play with the children (she is looking after the employers' children)…the jumping castle…they have a jumping castle there…then I take off my shoes, I climb on and I jump with the children the whole day (C5:3).

4.4.4.4 The role of external systems: availability and accessibility

The availability and accessibility of external systems are closely related to the extent of compliance with the diabetes self-care regimen discussed in Sections 4.4.4.1 to 4.4.4.3. Although the health care clinics that the participants visit make provision for access every day of the week, participants do not see the same health care worker on each visit. They find it difficult to keep explaining their health problems to a new or different health care worker each time. Participants who live far from health care facilities have to travel long distances and the lack of, or irregular transport, especially during winter months, increases their stress levels. The lack of employment opportunities for some of the participants, and difficulties for those employed in gaining permission from their employers to attend the clinic, are some external barriers that have an influence on self-care management. The following sub-trends are discussed in this section: source of information in the community; lack of or insufficient information and assistance; expressed needs of participants with regard to services; lack of adequate clinical service; and preference for services at a specific clinic.

Source of information in the community: In most of the focus groups the participants indicated that the clinic is their only source of information about diabetes and other illnesses. The only exception is one participant at clinic 7

who initially received private medical care, as he was a full-time employee with private medical insurance at the time of diagnosis.

Lack of or insufficient information and assistance: Participants expressed the following views about the need for more focused and consistent care:

> Sometimes I have stress, like where I was at the…they could not explain. They did not talk to me nicely…that stresses me…most of our clinics, they don't explain to us what diabetes is...also they do not explain what type. You just take that medicine, they don't ask you whether that medication is good for you, does it make you strong, is it fit for you…they must take your medicine and your files and they must look at it and see whether it is making you better or not (C2:2); and
>
> Advice to patients to take care of their toes…they must also advise us on what type of shoes you must wear…and to check regularly…eye check-up – I expect them to check my eyes…(C2:2).

Expressed needs of participants with regard to services: One female participant referred to previous assistance she had received from the clinic nurses:

> Sometimes, but the nurses from the clinic, they used to come to our homes…the last time that they have come was in July (C3:2).

The narrative of this recently diagnosed 34-year-old male participant exemplifies the extent of the special needs of people with diabetes:

> I know what to eat and what not to eat, but if I could check it every day (*machine to measure*)…when it's high you can identify what caused it…I was talking to…but it is difficult (*Talking slowly with interruptions*)…sometimes you won't have that knowledge to say 'I am stressed and what I can do to stress less'…that becomes the problem, if you do not have the resources…you come to the clinic for help…we get the medical attention, but not for stress. Sometimes talking to people they even stress you more, like the other lady that was talking to other people who said that she is HIV positive…some of the things that you get out there stresses you more (*Participant confirmed to moderator that he has the need to talk to a psychologist*) (C5:1).

Lack of adequate clinical service: A few participants indicated that they do not receive adequate health care, such as the reference to the unavailability of medicine (Section 4.4.4.2). A participant, who was initially incorrectly diagnosed, remarked:

> But I always went to the doctor and told him that I have sugar – he said that I do not have it (*diabetes*)…later I fell and they (*employer*) took me to the doctor (C6:3).

Preference for services at a specific clinic: Three participants from the same group prefer the services at that clinic because they consider the services at other clinics to be inadequate. All three of them are prepared to travel further distances and pay more for transport to access proper services. The two male participants commented:

> I have to come here, because at home, sometimes they do not have the medications so...I rather once a month pay R100-00 to save my life, because they do not take good care of you. At home the sister…'*wha*, *wha*' at you…to go there is no guarantee. So I do not know what to do. Yes, the way that they are running the clinic, but also they talk to you nicely. They are a little bit fast…there are many more people here. At home you wait the whole day. Here it is not more than 2 hours (C6:3); and

> I know I get good care. I know the difference between here and (*name of clinic*). It is not good there in (*name of clinic*)…there are too many, like here the treatment is not the same…to handle the people, tell them to look after…, why it is too high – like you counselling us now. There they just say.... '*hey*, why is it too high?' 'Okay, I do not know why it is too high, you must tell me why it is too high'…the 'state' of not telling me nicely and they make me more worried (C6:3).

4.5 SUMMARY

The three Axial Codes, namely Experiencing Diabetes, Socialising, and Diabetes Health Beliefs that represent the final themes that emerged from the data, have been presented in this chapter by means of descriptions of the main trends and patterns in the data. The researcher introduced dimensions to the

themes in the Trinity of Theme, namely the belief system at the meta level; the intergroup theme at the meso level; and an individual level theme at the micro level. The themes that emerged from the data are reflected in the final strategic outcome of Trinity of Themes. The Trinity of Themes is applied as a method to prioritise the multiple observations and essential meanings in the data, and reflects the complexity of diabetes self-care management. Dimensions or magnitude can thus be attributed to the Trinity of Themes as follows: the first theme forms part of the belief system at the meta level; the second is an intergroup[23] theme at the meso level; and the third is an individual theme at the micro level.

For the researcher to be able to enter the phenomenon of living with diabetes, she had to be fully present during the focus group interviews and get deeply involved in analysing the data afterwards. The focused attention given during the group interviews validated the participants' humanity, not only as patients, but as individuals with a social context, trying to manage a challenging condition every minute of the day, seven days a week. The participants' experiences reflect the difficulty of people living with diabetes, particularly in accepting the diagnosis as a lifelong condition. The emotional and psychological burden of diabetes is reflected in the complexity of the socio-geographic networks that include all their relationships, as well as their home and living environments.

Participants conducted meaningful discussions about self-care management practices, including their everyday activities, such as dietary requirements and compliance with the medication regimen, as well as broader implications for their future health and life. Health care facilities are an important form of social capital that is available and accessible for all participants. However, the health care facilities are not always accessible in terms of transport and sometimes conflicting or insufficient information is provided. The pathway towards the outcome of sustainable self-care management is filtered through the three final

[23] Intergroup in this context represents the contact of the person with diabetes, with a person or groups who do not have diabetes. "Intergroup contact theory involves the meso level of analysis" (Pettigrew, 1998: 76).

themes of ‘Diabetes Health Beliefs’; the ‘Socialising’ patterns; and ‘Experiencing Diabetes’ by people with diabetes. Chapter 5 presents the interpretation of the findings and a discussion of the Trinity of Themes; and the organisational themes of ‘Self-care management and diabetes outcomes’, and ‘External systems and the role of the health care system’.

CHAPTER 5
Discussion of findings

5.1 INTRODUCTION

The analysis of the raw data and the main trends and patterns in the data were presented in Chapter 4, within the context of the Trinity of Themes. The Trinity prioritises the multiple observations and essential meanings in the data, thus reflecting the complexity of diabetes self-care management. In this chapter the main trends and patterns are interpreted and the meanings of the main findings are drawn together through the Trinity of Themes. The main findings with regard to diabetes self-care practices are filtered through the three themes which serve as a pathway towards the outcome of sustainable diabetes self-care management and diabetes health. The discussion opens by considering the main findings in relation to the meta, meso and micro levels reflected in the three themes that constitute the Trinity for this study. The discussion of the findings in relation to the macro-social level reflected in the organisational theme of self-care management practices and diabetes health outcomes follows the discussion of the Trinity. As the study is concerned with diabetes self-care management, the macro-structural level organisational theme of access to, and the role of external systems in diabetes self-care management will be discussed last. Macro-structural level factors are external elements to which self-care management is a reactive mechanism as people with diabetes have little control over factors on this level.

5.2 FOCUSING STRATEGY: THE TRINITY OF THEMES CONTEXTUALISED

5.2.1 Background to the Trinity

The findings signify that sustainable diabetes self-care management is shaped by meta-level viewpoints and beliefs about diabetes, meso-level socialising patterns, and micro-level experiencing of diabetes, with the macro-level being an organisational theme (organising of self-care management practices). The complexity of diabetes self-care management is reflected in the three themes: 'Diabetes Health Beliefs', 'Experiencing Diabetes' and the 'Socialising' patterns of people living with diabetes. The Trinity of Themes is the focusing strategy that serves to present the findings from the data analysis. The Trinity prioritises the multiple observations and essential meanings in the data. The discussion of the Trinity in this section introduces the interpretation of the main trends and patterns presented in Chapter 4, by theme and sub-theme. Chapter 3 outlines the combination of the three themes that strategically focuses the parameters of the study within the Trinity of Themes (Figure 3.6 in Chapter 3, is for contextual purposes again presented in this chapter).

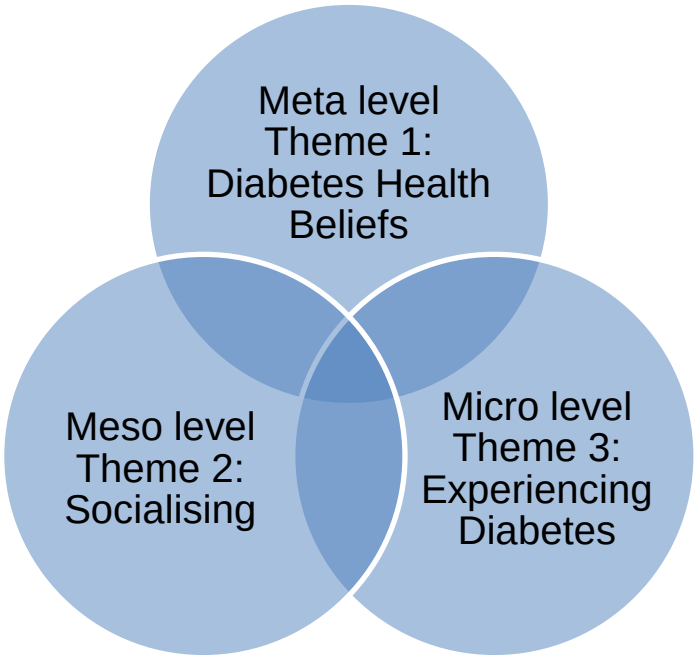


Figure 3.6: Focusing Strategy: Trinity of Themes

Source: The researcher's own construct

The Trinity of Themes represents three levels or dimensions: firstly, the meta level (the societal health belief system); secondly, the meso level (the intergroup theme of socialising); and thirdly, the micro level (the individual theme of experiencing diabetes). The distinction between the three levels is made for analytical purposes, but in reality the three levels are interwoven. The multi-level nature of the Trinity of Themes reflects the multi-level determinants of diabetes self-care, ranging from micro (individual) to meso (intergroup) and meta (societal) levels. According to the social-ecological systems perspective (McMichael, 1999: 890; Krieger, 2001a), the challenges to social epidemiologists are to acquire or build data sets that contain multi-level information, linking the macro- and micro-level phenomena (Kaplan, 2004: 125). The spatial-temporal nature of the eco-social systems approach towards population health is evident in the Trinity of Themes in this study. The multi-level Trinity of Themes moves away from a preoccupation with proximate

constraints and extends the scope to include social and environmental changes that influence population health.

The Trinity of Themes resonates with the interactive multi-level conceptual framework (Figure 2.1 in Chapter 2). The conceptual framework brought consistency to the field of study and simplified the understanding of the selected population-based factors in relation to sustainable diabetes self-care management. This framework outlines a process that begins on the macro social-structural and meso-social levels, and encloses the selected upstream population-based factors. A large number of macro- and meso-level population-based factors might determine the level and quality of diabetes self-care management, but for the purposes of this study, only the selected variables that pertain to diabetes self-care management form part of the final conceptual framework. The use of 'social' in some instances in the text in relation to the different levels is intentional to signify the link and relevance with the interactive multi-level conceptual framework, and to imply the actual interwovenness of the themes.

Diabetes self-care management practices are filtered through the pathway of the Trinity of Themes towards achieving desirable diabetes health outcomes. The discussion in this chapter is drawn together in Section 5.3 by highlighting a pathway towards self-care management and diabetes health outcomes. The multi-dimensional levels of the Trinity of Themes, namely the meta-, meso- and micro-social levels, are for purposes of completeness, briefly summarised in the next three sub-sections.

5.2.1.1 Meta-social level

The meta-social dimension encompasses both the population context and individual perspectives. The Diabetes Health Beliefs of an individual patient, as described in Section 5.2.2 are influenced by the health beliefs of the population about diabetes and/or related health conditions. For example, health beliefs are constructed through interaction with the health system, awareness created through the media, and observation of other people's illnesses. This theme

relates to the cues outlined in the Health Belief Model (HBM) of Rosenstock (1966). Diabetes Health Beliefs are the 'driver' for patients with regard to the extent and the 'way' they are prepared to talk about their condition. The willingness to talk is a pathway to the possibility of seeking support regarding diabetes self-care management. The action of social support is, however, situated in the meso-social dimension.

5.2.1.2 Meso-social level

In line with the purpose of this study and the focus group discussion questions, the moderator of the focus groups probed the participants about the population-based macro- and meso-level factors as contextualised in the conceptual framework of the study. However, regardless of the intentional line of questioning, the discussions reverted time and time again to issues closer to the participants' personal experiences. The majority of factors that emerged from the discussions relate to the meso- and individual levels. People with diabetes who are prepared to talk about their condition create opportunities to socialise with others. These individuals are prepared to share more about their condition and accept emotional and other support regarding diabetes self-care management.

5.2.1.3 Micro-social level

The micro-level psycho-social factors reflected in the Trinity of Themes mediate the effects of social-structural factors on individual attitudes and diabetes risk, and are conditioned and modified by the broader meso- and meta-social context in which they occur. These psycho-social factors are reflected as part of the theme 'Socialising' and are illustrated in Figure 3.4 (Chapter 3). This outcome of the study suggests that any interventions with regard to diabetes health behaviour need to focus on modifying personal or individual behaviour in order to improve the management of diabetes and health outcomes for people with the disease. This finding endorses the significance of the psycho-social

research paradigm, which in no way negates the prominence of the population-based approach used in this study.

These three levels of the Trinity of Themes that emerged from the findings correspond with the literature review by Brown et al. (2004: 63, 67-70). Those authors categorise the distal pathways or external mediators (factors) that have an influence on health behaviours, or can be barriers towards effective self-care, into individual-level pathways, health care provider characteristics, characteristics of communities or neighbourhoods, and health care policies. The literature review, the conceptual framework and the three-pronged theoretical framework of the study serve as the foundation for the discussion of the three themes.

5.2.2 Theme 1: Meta-level 'Diabetes Health Beliefs'

Human behaviour depends on the value placed by a person on a specific health outcome and their belief that a given action will result in that outcome (Rosenstock, Strecher & Becker, 1988: 176). This opinion implies that an individual's perception about his or her own susceptibility to, and seriousness of a disease, is influenced by demographic, socio-psychological and structural variables. These perceptions and variables, in combination with the available information stimuli about the disease, will determine the perceived threat of a disease (Rosenstock, 1966). The likelihood of taking preventative action or applying self-care management to prevent progression of the condition or clinical complications depends on the individual's perception about the benefits or effectiveness of necessary action, and the barriers to taking action (e.g. too expensive, unpleasant, painful, traumatic or inconvenient) (Rosenstock, 1966).

The perceived side effects of the medicine regimen and/or barriers to actions that prevent clinical complications resulting from diabetes are not included in this theme. However, because of the bearing on both the theme 'Diabetes Health Beliefs' and the outcome of 'Self-care management practices and diabetes health' the perceived side effects are reflected in the discussion of the

interrelated sub-themes. The topics of stigmatisation, labelling, denial, undiagnosed diabetes and perceptions about HIV and AIDS relate to more than one sub-theme and are therefore discussed within each of the relevant sub-themes.

The wide range of attitudes and perceptions related to diabetes health beliefs that emerged from the findings of this study are categorised into the following sub-themes, each of which is discussed in this section:

- Attitudes and perceptions about diabetes;
- Perceived susceptibility to diabetes;
- Attitudes about generational diabetes;
- Perceived seriousness of diabetes and the death threat of diabetes; and
- Attitudes and perceptions about diabetes symptoms and those associated with HIV and AIDS.

5.2.2.1 Attitudes and perceptions about diabetes

The attitudes and perceptions of not only people living with diabetes, but also of other people, including their family members, are important determinants of diabetes self-care practices. The perceptions about diabetes in particular, and health beliefs in general, are determining factors regarding the participants' reasoning about their present quality of life and future life in living with diabetes. The reactions of other people when they hear about the participants' (in this study) diabetes diagnosis can subsequently influence the likelihood of patients complying with their therapeutic regimen. The perception of individuals about themselves, and those of other people about both the condition and the person with diabetes, have an impact on their identity, and in some instances, these perceptions are attributed to their condition. Non-verbal reactions were reported, such as people 'looking strangely at you' or 'going the other way'. Subsequent avoidance of the topic of diabetes and/or the person diagnosed with diabetes, suggest stigmatisation of both the condition and the person with

diabetes. These perceptions are explained by the concept of stigma, defined by Erving Goffman (1963: 3).

Stigmatisation refers to the prejudice, discounting, discrediting, and discrimination that are directed towards people (Herek et al. 1998: 36). The findings of this study validate the experiences of discrediting and discrimination towards people with diabetes. The participants provided evidence of job loss, negative reactions of employers who do not understand or do not believe the circumstances related to their employee's chronic condition, and family and/or friends who neglect to buy or prepare the required food for the person with diabetes creating a perception that the person with diabetes 'is a problem'. The findings of the study validate the claim of Schabert, Browne, Mosely and Speight (2013: 1) that people with diabetes report that stigma is a significant concern that they experience across many life domains, such as in the workplace and in relationships. The findings validate this claim and challenge the perception (Schabert et al. 2013: 1) that diabetes and people living with diabetes are not stigmatised. Stigma is a universal phenomenon that has received substantial research attention for conditions such as HIV and AIDS, epilepsy and obesity, but it is relatively under-researched in relation to diabetes (Schabert et al. 2013: 2). This view is justified by the dearth in the literature that relates to research regarding diabetes-related stigma globally, as well as within the South African context.

The finding about the experience of stigma reflects another aspect of Goffman's (1963) notion of stigma, namely that it is highly relational, socially constructed in and through social relationships depending on the situation, and it represents a rupture between an individual's virtual and actual social identity that is regarded in some way as a failing (Goffman, 1963: 2, 4; Pescosolido, Martin, Lang & Olafsdottir, 2008: 432). Even though stigma is imposed on the individual by other people, it can have a negative effect on the self-concept of those stigmatised. The problem is not the person with the chronic illness, but societal attitudes and the way in which the physical environment is shaped (Goffman, 1963: 32; Crocker, Major & Steele, 1998: 505). These societal attitudes are confirmed by the participants.

The lack of knowledge and understanding about the implications of a chronic condition are suggested by four of the perceptions (and in some instances misconceptions or myths) about diabetes self-care that emerged from the findings. The first misconception is the perception that after a person has taken the medication for some time and the blood glucose level has been stabilised, then diabetes is healed and the medication can be discontinued. The second perception is that the blood glucose level rises with age and that individual lifestyle changes cannot influence the blood glucose level. This notion possibly relates to the emotional state or phase of denial that can be a barrier to compliance with the regimen and a capitulation of own responsibility. The third misconception is that a person with diabetes cannot work. The fourth misconception is that if an individual has been physically active then he or she is not susceptible to diabetes. Bury (1982: 169) offers an explanation for elements of these perceptions through his notion of chronic illness as a "biographical disruption" that involves recognition of pain and suffering, and possibly death, which are normally seen as distant possibilities and the plight of other people. The notion of biographical disruption confirms the sociological focus that the meaning that a person with diabetes gives to his or her condition cannot be separated from their social context (Bury, 1982: 169).

5.2.2.2 Perceived susceptibility to diabetes

Despite personal knowledge of someone with diabetes in the family or friendship circle, several participants did not perceive themselves to be susceptible to diabetes. Regardless of very high blood glucose levels themselves, namely an HbA1c of 28,8% and 43% measured by two of the participants (the guardian of a family member with diabetes and the primary carer of a diabetic mother respectively); these participants ignored their own symptoms. In both cases, the high blood glucose levels caused medical crises before the people were diagnosed, and in one case, hospitalisation for three weeks. The emotional state of both these participants prolonged the denial phase of their perceived non-susceptibility to diabetes. Notwithstanding their exposure to somebody living with diabetes and the experience of symptoms

themselves, these individuals seemed unwilling to face the reality of their own diagnosis.

The theoretical-conceptual level of the representation of the self is a product of the individual's perceptual managing of physical changes (Leventhal et al. 1998: 720). The notion of chronic illness as a 'biographical disruption', that disrupts not only the physical body but also the social contexts of individuals, relates closely to the specific meaning that is given, by patients and the society, to the health condition. In one social context, a certain health condition might be perceived as normal, while in another it could be seen as abnormal and regarded as labelling. The fear of being labelled with a particular health condition may cause individuals to deny possible susceptibility to the condition, delay or avoid seeking health care, or distance themselves from the possibility of a diagnosis (Link & Phelan, 2006: 529). Labelling is viewed by Leventhal, Leventhal and Contrada (1998: 720) as "an everyday event that refers to the experience of indicators or symptoms according to a symmetry rule." These symptoms require a label or labels, because the mind does not create constructs from something that does not exist, namely from "nothingness" (Hearst, 1991; Leventhal et al. 1998: 720). The phenomenon of perceived non-susceptibility within the context of familial or generational diabetes (which is discussed in the next sub-theme), is confirmed by labelling theory that is based on the concept that what is regarded as deviant by one person or social group may be regarded as normal by other people or social groups (Cockerham, 2004: 158).

5.2.2.3 Attitudes about generational diabetes

Forty per cent of the participants shared views about their experiences of diabetes being shaped by family members who had (or have) diabetes. Examples of family members with well-controlled blood glucose levels have a two-fold positive influence: they help with acceptance of the diagnosis and motivate participants to take better care of themselves and make lifestyle changes. However, a number of the participants either did not perceive themselves to be susceptible to diabetes, or were in denial about any

susceptibility. When there is already someone in the family who has diabetes, it seems that there is better understanding of the condition, participants experience more support, and they experience less discrimination and/or stigmatisation within the family context. Prior experiences of diabetes in their family influenced the participants' attitudes, perceptions and reactions to their own diagnosis. Interaction with someone with personal knowledge and experience of diabetes can be explained by the HBM of Rosenstock (1966), in which personal knowledge and experience can act as stimuli to take action on one's own behalf.

The finding of the emotional state of denial, or a prolonged denial phase of perceived non-susceptibility to diabetes when taking care of a family member, provides evidence of a possible life-long burden for the person with diabetes and the family members, as well as a complex set of challenges. The challenges include the inability to reconcile their emotions with a possible new set of required health behaviours for themselves. Two examples of female participants, as presented in the main trends 'perceptions about susceptibility to diabetes' and 'attitudes about generational diabetes' in Sections 4.4.3.4 and 4.4.3.5 (Chapter 4), suggest that these participants were both 'blind' to their own condition. The treatment of diabetes requires complex changes in behaviour and lifestyle of persons with diabetes. These challenges in combination with the psycho-social distress of the possible reality of a life-long burden with a chronic condition are barriers towards seeking competent help. This finding is explained by the tenet of the HBM, namely that an illness is experienced and contextualised as a negative value, which an individual would like to avoid (Rosenstock, 1966).

Consciously or unconsciously, these participants might have known that something was wrong with them, but either intentionally or unintentionally they chose not to know and avoided facing the reality of a possible diagnosis for themselves. This tendency relates to the view that diabetes is 'something that happens to others' but not to themselves. The shared experiences of 'blindness' to their own symptoms and an unwillingness of these participants to seek help until they experienced a medical crisis, are one of the possible

explanations for the high prevalence of undiagnosed diabetes cases around the world.

The finding described above illustrates the existence of a denial phase that people with diabetes may go through before they acknowledge that they might have a serious health condition. Participants' denial about their possible susceptibility to diabetes can be related to the experiences of taking care of, and/or living with a person with diabetes, with the result that they would avoid to be confronted with their own condition. The evidence of a possible denial phase postulates the relevance of the labelling theory. Labelling theorists (Tannenbaum, 1951; Erikson, 1964; Becker, 1973; Quicke & Winter, 1994) argue that deviance is created by social groups who make the rules and norms. This adverse attitude towards susceptibility within the social group of the family is further explained by the view of labelling theorists that a health condition is treated by human beings in accordance with their understanding of the situation. Judgements concerning what is sickness and deviant behaviour are relative and cannot be separated from the social situations in which people live (Lipowsky, 1970; Quicke & Winter, 1994; Cockerham, 2004: 159).

The emotional and physical burden and the continuous confrontation of supporting a person living with a chronic condition such as diabetes can be challenging. This reality may explain why people with diabetes who are also caregivers for family members with diabetes, can become emotionally detached and distant. Another example from the findings is where three family members with a diabetic mother participated in the same focus group. All these participants reflected verbal and non-verbal evidence of emotional indifference and detachment. The phenomenon of emotional indifference is confirmed by the findings of Nagelkerk et al. (2006: 154) who reported helplessness and frustration with the lack of success in achieving optimal glycaemic control, which in turn can lead to ineffective coping mechanisms such as denial or indifference of the person with diabetes and the caregiver. The same authors also found that the feeling of helplessness and frustration is perceived as the third highest ranked barrier to sustainable diabetes self-care management, after

the barriers of lack of understanding of the dietary plan and the need for individualised care.

5.2.2.4 Perceived seriousness of diabetes and death threat of diabetes

Several comments by participants consolidate the perception that diabetes poses a death threat and that the diagnosis of diabetes is equivalent to a death sentence. The phrases: ‘this thing is killing you’; ‘scared’; ‘she is dead now’; ‘I feel like I am going to die’ and ‘diabetes is a killer disease’ confirm the perceived death threat of diabetes. Despite acknowledgement of the seriousness of diabetes and it being a possible death threat, the majority of participants still have uncontrolled blood glucose levels. This contradiction suggests that knowledge about diabetes and an accompanying perception about the seriousness of the condition are not converted into health lifestyle changes and effective diabetes health outcomes. This finding is confirmed by the recent clinical study by Webb, Rheeder and Van Zyl (2014: 6) who found that glycaemic control as measured by the HbA1c test at primary health care clinics in the study district of Tshwane is poor, with less than 30% of patients with an HbA1c measure below 7%.

The prevalence of uncontrolled blood glucose levels and the subsequent clinical complications of diabetes health problems experienced by the majority of the participants suggest that there is inadequate orientation to sustainable self-care practices. This is confirmed by a study in Mexico City, Mexico about the psycho-social factors associated with poor self-care management, where adherence to the three main recommendations of the diabetic treatment programme was observed in only 26,1% of patients (Lerman et al. 2004: 566, 568). The same authors report that these patients had higher knowledge levels about the disease, conducted routine home blood-glucose monitoring, had an inner perception of better diabetes control, and enjoyed good health and better patient-physician communication. An optimistic outlook and positive reasoning may ultimately hold beneficial outcomes in terms of diabetes self-care management. A positive attitude (e.g., feeling hopeful or happy) has been

associated with a lower risk of death for people with diabetes, even after controlling for other predictors of mortality such as self-reported health status (Moskowitz, Epel & Acree, 2008).

The finding of the perceived seriousness of diabetes, in combination with the sub-theme 'perceived susceptibility to diabetes' can to a certain extent be explained by the view of Whittemore et al. (2002: 23). They argue that when there is a lack of perceived seriousness of diabetes it contributes to reduced feelings of a possible threat or vulnerability toward morbidity and mortality. A possible explanation for the inability of participants to convert the perceived death threat and seriousness of the condition into sustainable diabetes self-care management practises and favourable health outcomes could be the absence of internalised knowledge, and/or a lack in individuals' capacity to change their health behaviour. As stated, despite the perceived seriousness of the condition and possible death threat expressed, the majority of participants have uncontrolled blood glucose levels. This phenomenon demonstrates the value of considering the uncertainties of diabetes-related complications within the context of the individual perceptions and modifying factors exemplified in the HBM.

Hampson et al. (1990) and Samuel-Hodge et al. (2000: 930) confirm that people with diabetes may experience barriers to self-care management that vary from beliefs about the cause and seriousness of the condition, to the effectiveness of treatments. In the expanded explanatory formulation of the HBM, Rosenstock et al. (1988: 182) propose the inclusion of self-efficacy as a separate variable, with health motivation being added as a component of the model. The concepts of self-efficacy and health motivation are investigated predominantly within the field of psychology, and are not included in the scope of this study. The dearth in the literature regarding diabetes self-care from the viewpoint of the person with diabetes is evident. It is clear that there is a lack of a scientifically verified health lifestyle theory to explain the phenomenon of non-conversion of perceived seriousness of diabetes to lifestyle behavioural changes (Cockerham, 2005).

5.2.2.5 Attitudes and perceptions about diabetes symptoms and those associated with HIV and AIDS

Some of the participants did not feel ill and therefore did not associate the symptoms of increased thirst, urination and vision problems with an illness. Some of them initially found it hard to accept the diagnosis of diabetes and the reality that their symptoms were an indication of a lifelong illness. Participants from two groups declared that their experience of diabetes brought a sense of self – with diabetes being a part of the self – a sense of their identity, of who they are. This realisation was seen as an opportunity to position themselves as individuals with specific needs, but also that they have unique knowledge and skills, and specific roles to play within the family and community contexts. This observation is explained by Telford, Kralik and Koch (2006: 462), namely that a person with a chronic condition can view the illness as an opportunity for a change of focus, or growth of the inner-self as separate from the body. This sense of control and the body being distanced from the self, shifts the focus to the emotional, spiritual and social aspects of life (Telford et al. 2006: 462). Diabetes health problems or clinical complications are also related to diabetes health outcomes are discussed in Section 5.3.5.

A number of comments from participants suggest that some people who form part of their social network and/or living environment associate weight loss mainly with a possible diagnosis of tuberculosis or HIV and AIDS, or both, rather than diabetes. Participants who experience these attitudes from members of their community reported a lack of understanding and a lack of support with regard to their condition. The fear of stigmatisation and possible ridicule cause these people with diabetes to avoid talking about their condition. This finding emphasises the fact that the phenomenon of stigma associated with diabetes is underestimated and relatively under-researched, compared to the extent of such research on the topic of HIV and AIDS (Schabert et al. 2013: 2). Some of the participants revealed that they would prefer to rather have HIV because diabetes is such a complex condition to manage.

This finding validates the view that diabetes mellitus is a complex metabolic disorder that poses a life-long burden on the quality of life of individuals living with diabetes. The complexity of diabetes requires specialised knowledge and a specific set of skills to manage effectively, but it is still poorly understood and thus not effectively managed by sufferers. Vermeire et al. (2003: 210) confirm that the treatment of diabetes involves complex changes in the basic behaviour of people with diabetes, and adherence to complicated clinical and dietary regimens.

In concluding the theme 'Diabetes Health Beliefs', the findings about the attitudes and perceptions with regard to diabetes; the perceived susceptibility to diabetes; the attitudes about generational diabetes; the perceived seriousness of diabetes and the death threat of diabetes; and the attitudes and perceptions about diabetes symptoms and symptoms associated with HIV and AIDS, confirm the importance of the need to understand the attitudes and perceptions of people who live with diabetes and their difficulties in converting knowledge into compliance with the diabetes therapeutic regimen.

The theme 'Diabetes Health Beliefs' that is constituted at the meta-social level confirms the relevance of a social cognition theory such as the HBM of Rosenstock (1988). This study found that the model is not only relevant and applicable in terms of the prevention of the occurrence of an illness, but it also explains a number of the principles related to the management of a chronic illness such as diabetes. The application of the model within the context of diabetes relates to preventing the disease from progressing towards clinical complications. The application of the Turkish version of the HBM provides evidence that it is a useful framework for understanding how people with diabetes live with the condition, the problems they encounter, and its treatment (Kartal & Altug-Ozsoy, 2007: 1455). A number of other theorists (Bagozzi, 1993; Gollwitzer, 1993; Castle, Skinner & Hampson, 1999: 526; Pakenham, Pruss & Clutton, 2000) believe that the HBM cannot explain susceptibility and that it applies mainly to explanations of the prevention of illness. In contrast, the findings of this study provide evidence that the HBM contributes to an explanation of the health behaviour of people already diagnosed with a health

condition. Nevertheless, the researcher does not declare that the HBM can explain all the elements involved in diabetes health behaviour and diabetes self-care management.

The findings from this theme strongly suggest that the participants' concept of Diabetes Health Beliefs is very important for understanding and promoting sustainable diabetes self-care management. The prevailing diabetes health beliefs on the meta-social level determine the nature of the socialising patterns of people with diabetes that are constituted in the meso-social level.

5.2.3 Theme 2: Meso-level 'Socialising'

'Socialising' as a theme reflects the on-going nature of the social actions and interactions between the participants and other people who form part of their direct or indirect social networks. Corbin and Strauss (2008: 96-97) refer to this on-going process as a search for solutions to problems or achieving a goal. These social actions and interactions are reflected in response to the participants' social networks, with the purpose of managing their diabetes self-care. Furthermore, Willig (2008: 164) explains that processes of social interaction are embedded within "psychological concepts such as prejudice, identity, memory and trust" that refer to the things that people have rather than something that people do. Identity and trust determine the nature and extent of the socialising patterns of people with diabetes within their intimate relationships, social networks, cultural context and work environment. The theme 'Socialising' is a combination of the sub-themes: socio-geographic networks, intimate relationships and sexual health, the work environment and the cultural context, each of which is discussed in this section.

5.2.3.1 Socio-geographic networks

Socio-geographic networks were described in Chapter 4 (Section 4.4.2.1) as the complex intersection of social networks and the physical spatial location of the home environment (Section 4.4.2.2) and the external living environment. In

the discussion of this sub-theme, socio-geographic networks refer to the combination of social networks, family relationships, and home and external living environments. Social networks refer to relationships between people that include dyads or partnerships, personal networks and larger communities or 'sociometric' networks (Neaigus, 1998; Rothenberg, 2001; Poundstone, Strathdee & Celentano, 2004). The home and external environment refer to the physical and social-spatial characteristics of communities. The social environment is associated with disease and mortality risks independent of individual risk factors, and includes societal groups, the neighbourhoods that people live in, the workplace and the policies that order these societies.

Parents, spouses, children, siblings and, in some cases, friends represent the social networks of the participants in this study. The existence of a social network structure does not necessarily imply a support structure for people with diabetes. Participants made a distinction between talking with members of their social network and support with regard to their diabetes self-care management. Another finding from the study asserts that married men tend to receive their primary support mostly from their spouses, while in contrast; female participants experience none or very limited support from their husbands. Rosland et al. (2010: 27) found that overall, women (64%) report less family support compared to men (77%). Female participants in the present study receive their primary support mainly from their mothers, siblings and in some cases, their children. These family members encourage them to comply with their diabetes self-care regimen and sometimes assist them with practical support regarding the administration of medication. This finding is validated by Berkman and Glass (2000) who confirm that social networks can influence health outcomes in direct and indirect ways; such networks include social influence, social engagement and participation, access to material goods and informational resources, and social support. Nam et al. (2011: 2) and Brown et al. (2004: 69) infer that the lack of social support, the absence of social integration, and competing demands within a social group such as the family, are barriers to effective diabetes self-care management.

Social integration was one of the themes discussed in the focus group sessions and individual interviews in this study. The data reflect a very limited extent of social integration in the residential areas around the rural clinic, and a total absence of social integration in all the other residential areas of participants. This phenomenon of low levels of social integration and a lack of social cohesion can be understood as the absence of any attachment, or only weak attachments of individual participants to others within their immediate society. The lack of social integration has a broad impact on all-cause mortality, and is, according to Berkman et al. (2000: 851), one of the robust findings in the literature on networks and health. The assumption follows that social isolation, disintegration and disconnectedness influence mortality and longevity or life expectancy (Berkman et al. 2000: 851-852). Only two participants in this study mentioned that they receive support from a neighbour. The majority of participants reported that there is no support from other people in the communities where they reside. They emphasised the fact that everybody in the community has their own illness and that people with diabetes cannot expect to be helped by anyone outside their home environment.

Wilkinson (1996) affirms that societies that exhibit high social cohesion are characterised by mutual aid, a low Gini Coefficient[24] (GI) (which means a small income gap amongst the members of the society), and a shared sense of purpose. Social cohesion refers to the experience of being part of a society with an emphasis on the group that is often expressed through helping others. Social cohesion helps people to be healthier, while the effects of poverty on an individual's health could be compounded by the lack of social integration (Cattell, 2001: 1512; Barry & Yuill, 2012: 112). The 1979 seminal research by Wolf and Bruhn (1993) provides evidence of the role that a strong sense of social cohesion played in an Italian 1880s migrant community in the United States of America. This particular community experienced a noticeably lower death rate compared to neighbouring towns. The research concluded that the uniformity between people, the emphasis on the family, and the help of

[24] The Gini coefficient is one of the most commonly used indicators of income inequality, now also applied in relation to health status (Atkinson & Micklewright, 1993; Wilkinson, 1996).

neighbours acted as strong protective factors against heart disease (Wolf & Bruhn, 1993).

A finding of this study is that the possibility of ridicule, gossip and stigmatisation of the person with diabetes induces a fear of talking with anybody about diabetes and its complications. This is particularly pertinent in the case of men, who definitely do not talk about it with other men. According to Charmaz (1994), and Wenzel, Utz, Steeves, Hinton and Jones (2005) chronically ill men experience identity dilemmas related to physical performance and levels of activity affected by their condition. The lack of understanding by other people of the condition and the association of weight loss with other diseases such as HIV and AIDS or tuberculosis, is a concern for the participants. Four participants reported a peculiar reaction from family and friends towards them, which is one of the reasons why they do not feel free to talk to other people about diabetes. This avoidance results in a lack of support from others. The overwhelming need to communicate and to talk in the focus groups proves that the participants welcomed the opportunity to talk with other people with diabetes in an emotionally safe environment. This observation is an illustration of the value of diabetes support groups.

Along with other family members and sometimes friends, children were mentioned as the primary support structure of participants. This is despite participants suggesting that children and even grown-up children can be a major liability and a main cause of stress. The latter experience is exemplified by the female participant who repeated the word ‘those children’ at least five times in one paragraph, emphasising the emotional pain that her children cause her. By using terms like ‘those children’ and ‘that man’ (*husband)*, she was trying to distance herself emotionally from the pain that her children, and in this instance also the rest of her family members, inflict on her. The evidence from the findings suggests that the social environment has important, although varied effects, on health, e.g. the lack of social integration may be associated with an increased risk of poorer health outcomes, while the quality of social ties appears to carry the potential for both positive and negative health effects (Seeman, 1996: 449).

A low level of social integration in relation to uncontrolled blood glucose levels for the majority of the participants in this study answers one of the research questions of the study, namely 'What population characteristics and social factors enhance the vulnerability of diabetes patients and place them at higher risk of ineffective self-care management, uncontrolled blood sugar levels, or clinical complications?'. In addition, this finding supports the research problem statement and more specifically the following sub-problems: 'The lack of understanding about the influence of demographic variables like age, and social changes like urbanisation, migration and mobility, on the degree of social integration of the diabetes patient' and 'The lack of understanding about the influence of the level of social integration on sustainable self-care management of diabetes patients.'

Social integration is reflected in the multi-level conceptual framework (Figure 2.1 in Chapter 2) as the central core population-based predictor with regard to sustainable diabetes self-care management. The findings of this study strongly suggest that the concept of social integration, in combination with socio-geographic networks in the form of social networks, family relationships, and home and external living environments; social capital; the socio-cultural context; as well as the broader external context of people with diabetes is important for an understanding of the health behaviour of people with diabetes. The intersection of these variables can be explained by elements of the multi-level nature of the eco-social theory, thus confirming the association with the meso social-level factors in the heuristic framework of social epidemiology. In relation to health, scientists use the term *social integration* interchangeably with concepts such as social relationships, social networks, social support, social ties, and social capital (Lin, 1999; Berkman et al., 2000: 844; Macinko & Starfield, 2001: 387, 399; Kritsotakis & Gamarnikow, 2004; Stephens, 2008). These multiple uses of similar meanings and terms provides evidence that the terminology and 'definitions' are contested.

5.2.3.2 Intimate relationships and sexual health

Intimate relationships and sexual health was not one of the topics that formed part of the focus group discussion schedule. However, the physical and emotional challenges that participants face regarding the relationship with their intimate partners emerged as a main trend from the beginning of the field work. This unexpected finding from the study that reflects the complexity of sexual wellness and blood glucose management is a major concern for all participants in an intimate relationship. All the participants who acknowledged that they experience problematic intimate relationships and/or sexual health difficulties have uncontrolled blood glucose levels, this is while relatively few studies have attempted to understand the side-effects of and barriers to adherence to the diabetes therapeutic regimen from the patient perspective (Zgibor & Songer, 2001: 23). According to Webb et al. (2014: 6), 88% of diabetic men in a recent clinical study in the Tshwane district reported a degree of erectile dysfunction, and 36% of these cases were considered to be severe. In a review article, Penson and Wessells (2004: 226) report a prevalence of between 26% and 64% of erectile dysfunction for different studies that included both type 1 and type 2 diabetes patients.

A problematic intimate relationship causes more stress for people with diabetes than for those without the condition, due to the emotional and physical burden of diabetes. This finding is justified by a cross-sectional study by Trief, Himes, Orendorff and Weinstock (2001: 1387) that assessed the association between marital quality and adaptation to diabetes the data indicate that marital quality does relate to an individual's adaptation to diabetes. Individuals who described a better overall marital adjustment and higher levels of perceived marital intimacy also reported that they were more satisfied with varied aspects of their own adaptation to the illness, felt diabetes has less of a negative impact, and experienced less diabetes-specific emotional distress (Trief et al. 2001: 1387). These individuals also reported better mental health–related quality of life, including better social and emotional functioning, mental health, and overall well-being (Trief et al. 2001: 1387). In a follow-up cross-sectional study by Trief, Wade, Britton and Weinstock (2002: 1157) the data provide prospective

evidence for the hypothesis that marital quality predicts diabetes-related quality of life.

In this study patients also indicated that their partners matter, with the quantitative data that support the cross-sectional findings confirming that marital relationships can be a major support or a significant source of stress (Trief et al. 2002: 1157). Although poor marriages may increase the likelihood of poor self-care, it is also likely that poor self-care will increase the likelihood of marital conflict (Trief, Ploutz-Snyder, Britton & Weinstock, 2004: 153). Even participants with very understanding and supportive spouses expressed their concern about their sexual performance and future life with the condition. They expressed experiences of deep emotional pain due to sexual health problems and difficulties in accepting themselves in this state. Avoidance of intimate contact was highlighted by a few participants, and in one case the choice of doing night shift work might be an indication of avoiding intimate contact. Male participants referred mostly to their lack of physical performance and how it impacts on their emotions. Female participants emphasised that they still feel emotional love for their spouses, but their bodies feel different. The view that the problem of sexual dysfunction due to diabetes can be more easily overcome by women than by men was expressed by three women (older than 54 years). These women encouraged a 45-year-old female to make sure that she does not lose her husband to another woman because of the sexual health problems that she experiences. The debate among these females hints at an underlying gender role and sexism element that invites further exploration.

In particular, male participants were very sensitive with regard to the impact of diabetes on their sexual performance, and specifically their masculinity. Schabert et al. (2013: 1) report that people with diabetes consider stigma as a significant concern that they experience *inter alia* in relationships. Stigma is imposed on the individual by societal attitudes but it can have a negative effect on the self-concepts of those stigmatised (Goffman, 1963: 32; Crocker, Major & Steele, 1998: 505). The above participants' comments could explain the reluctance of men to talk about their condition, due to possible stigmatisation of themselves as males who cannot perform sexually. The association of diabetes

with sexual problems and sexual health can lead, especially for men, to the perception that diabetes implies a lack of sexual performance (resulting in stigmatisation); this could result in non-disclosure of the symptoms.

As mentioned earlier, all the participants who experience problematic intimate relationships and or sexual health difficulties have uncontrolled blood glucose levels. The finding regarding the perceived negative effect of diabetes medication on these participants' sexual performance, rather than their uncontrolled blood glucose levels suggest a socio-cultural explanation for this phenomenon. According to a number of scientists (Tripp-Reimer, Choi, Kelly & Enslein, 2001: 16; Holmstrom & Rosenqvist, 2005) cultural influences on individual beliefs, attitudes, knowledge, and behaviours can affect diabetes self-care management. However, Nam et al. (2011: 3) report that no research has been done that compares cultural beliefs in diabetes self-care management across different racial and ethnic groups. A number of selective studies have, nevertheless, been conducted among specific culturally and ethnically homogenous groups. While cultural beliefs might be a possible explanation for this finding, this study did not investigate cultural beliefs directly, and this finding therefore poses an opportunity for further research. In addition, the evidence in this study that participants associate sexual problems with the administration of diabetes medication indicates potential problems in adhering to the diabetes clinical regimen. The burden of diabetes-relationship issues provides evidence of the importance of a qualitative investigation of the impact of diabetes on the quality of life, as proposed by other scientists (Rubin & Peyrot, 1999; Trief, Himes, Orendorff & Weinstock, 2001: 1388; Trief, Wade, Britton & Weinstock, 2002: 1157).

5.2.3.3 Work environment

More than half of the participants are employed either full-time or part-time, with nearly two-thirds of them working as domestic workers. The number of participants (20,8%) who are unemployed is consistent with the 16,5% unemployment rate in the Tshwane district according to the Community Survey

undertaken in South Africa in 2007 (Tshwane IDP, 2013/2014: 12). Two of the participants are drivers and two are former drivers. Four of the participants do skilled work, three are in semi-skilled positions, and one is self-employed. Most of the domestic workers and one driver indicated that their employers are involved with their diabetes self-care management. The participants who are employed, and indicated the involvement of their employers, have access to resources in their work environment, which can be explained as 'social capital'. Even if the nature of the work involves strenuous physical tasks, the work situation and work environment suggest an escape from physical and emotional pain for the majority of employed participants. The employers of the female domestic workers, who are involved in their employees' condition, form the primary support structure for the majority of these female participants. The female domestic workers indicated that their work environment is a positive experience and the majority of them reported a personal relationship with their employers. The intimate nature of the work in the private homes of their employers and executing tasks of a personal nature create opportunities for both the employer and employee to be more aware of each other's physical and emotional state. This close relationship is extended to providing practical support. These employers are involved in actions ranging from talking with the participants; preparing meals for them; and administering medication such as injections. This phenomenon therefore reflects characteristics of a social structure rather than purely a work environment (Parsons, 1951; Ritzer, 2011).

Those participants, whose employers or family members of the employer have diabetes, identified their place of employment as an important source of information which they find valuable in terms of their own diabetes self-care management. The combination of diabetes self-care support structures and a personal intimate employment environment, where the employer knows you and in some instances your family members by name, suggests a proxy and substitute for the lack of an adequate home and family support network. This finding suggests that a form of 'social capital' exists within the specific nature of the work and the work environment of these participants (Macinko & Starfield, 2001; Kamrul Islam, Merlo, Kawachi, Lindstrom & Gerdtham, 2006).

The findings suggest that male participants who are, or were, drivers of either short- or long-distance vehicles, might be at particular risk of either developing diabetes or, if already diagnosed, experiencing hyperglycaemia. At least three male participants reflected on experiencing one or more episodes of hyperglycaemia while driving, thereby severely affecting their eyesight. The specific nature of the work as a long-distance truck driver, e.g. sitting in the same position for hours, has an influence on blood circulation and can have a consequent effect on cardiovascular health, besides the visible complication of eyesight problems. In the majority of cases, long-distance truck drivers have limited or no control over their dietary regimen and depend mostly on fast-food outlets while on the road. One participant indicated that at least five of his driver colleagues also have diabetes, and that they do not have effective control over their blood glucose levels, despite the fact that all of them are on a medical treatment regimen. The work environment intersects with the specific type of work or occupation that suggests the relevance of elements of the social production of disease theory that reflects on possible structural barriers or opportunities to improve health lifestyle. This finding can be contextualised on respectively the meso social- and micro individual-levels of the heuristic framework of social epidemiology (D'Eramo-Melkus et al. 2004; Kaplan, 2004; Golden & Earp, 2012).

A number of male participants reported a lack of support and understanding by their employers. A particular farmworker's employer is concerned only about his physical strength required to do the work, while government employees' managers do not seem to understand, or they do not believe these participants when they experience episodes of either hyperglycaemia or hypoglycaemia, and they want proof from the clinics that these men are being treated for diabetes (Link & Phelan, 2006). Schabert et al. (2013: 1) confirm the evidence that people with diabetes report stigmatisation across many life domains. This finding supports the evidence of discrimination against people with diabetes and endorses the occurrence of stigmatisation within the workplace.

5.2.3.4 Cultural context

The efficacy and sustainability of diabetes self-care management is interwoven with both the socio-economic and the cultural contexts of a person with diabetes. The cultural context of individuals includes the complex entirety of the customary practices, traditions and habits of the community that they grew up in, and/or presently live in. In this study, the cultural environment's intersection with the socio-geographic context is more evident in the home environment and family networks than in the external living environment. Cultural factors that can have an effect on diabetes self-care management include food and dietary preferences, lifestyles, traditional and religious beliefs, and beliefs about general health (Tripp-Reimer et al. 2001: 16; Holmstrom & Rosenqvist, 2005; Nam et al. 2011: 3). The findings confirm the relevance of the meso social-level cultural context reflected in the heuristic framework of social epidemiology to interpret and understanding the on–going nature of the social actions and interactions of persons with diabetes.

The majority of participants referred to their childhood living environment and family homes that are located in more traditional, rural areas. Whether employed or unemployed, they are now based in the mainly urbanised regions of the Tshwane district for most of the year. A number of participants, mainly from the rural clinic, reported some traditional or customary practices that relate to specific types of food, food preparation, and the social occasion of meal times; one participant shared his perilous experience about the replacement of his medication regimen with a traditional herbal mixture for a period of time. Weddings and the traditional ritual of slaughtering a cow are examples of social events that were presented by the participants. They indicated that it is very difficult not to partake in such events; in particular, the refusal of certain food by the person with diabetes during these occasions is viewed as being offensive towards the host and/or family members. These participants reported episodes of hyperglycaemia during or after such social events. One of the participants who replaced his allopathic diabetes regimen with the traditional herbal mixture reported an episode of major hyperglycaemia while he was driving a long-distance truck.

There are a limited number of studies about diabetes self-care amongst culturally and ethnically homogenous groups. Lipton et al. (1998: 67) found that in many cases, the emotional barriers and cultural beliefs of Latinos are more significant than financial barriers, while family needs are prioritised, and adhering to a diabetes treatment regimen is viewed as being self-indulgent. D'Eramo-Melkus et al. (2004: 11, 12, 17) report that different ethnic groups present various values and attitudes about dietary arrangements, body shape, and weight, that all influence health behaviours. Rajaram and Vinson (1998: 242, 243) suggest that more research is needed on the cultural meaning of food, culturally specific information, and the cultural sensitivity of lifestyle intervention programmes. The argument for comparative research to investigate cultural practises and beliefs in relation to the diabetes dietary therapeutic regimen is supported by the findings of this study.

In concluding the theme 'Socialising', the findings reflect the significance of social integration in combination with socio-geographic networks; social capital; the socio-cultural context; as well as the broader external context of people with diabetes, in order to better understand the health behaviour and self-care practices of people with diabetes. The unexpected finding of the complex links between sexual wellness and blood glucose management supports the argument for qualitative studies to understand side-effects and barriers from the patient perspective. The phenomenon of stigma and discrimination that people with diabetes experience across many life domains suggests an area for further research. The meso-social level socialising patterns of people with diabetes influence the micro-social level experiencing of diabetes.

5.2.4 Theme 3: Micro-level 'Experiencing diabetes'

'Experiencing diabetes', as both a Process Code and Emotion Code, is the micro-level Theme 3 in the Trinity of Themes. 'Experiencing diabetes' indicates the on-going emotional response to the experiences of diabetes, the emotional and psychological burden, stress, and demographic and social changes. The difference between experiencing diabetes and experiences of diabetes is reflected in the nature of the two concepts. 'Experiencing diabetes' reflects the

on-going chronic nature of diabetes; the embeddedness within the person with diabetes; and reflects their own understanding, interpretation and meaning that they attach to diabetes (Telford et al. 2006: 462). 'Experiencing diabetes' signifies the process whereby people with diabetes are trying to make sense of their condition. On the other hand, 'experiences of diabetes' refers to the physical symptoms experienced, and the expressed thoughts and emotions of people with diabetes – it embodies the external stratum of the social dynamics that people with diabetes live through.

The sub-themes of experiences of diabetes; the emotional and psychological burden of diabetes; stressing as an on-going process; and demographic and social changes are interrelated and reflect the complexity of the continuing process of 'Experiencing diabetes'. Although closely related, each sub-theme is discussed separately in this section.

5.2.4.1 Experiences of diabetes

Two broad aspects were covered in the discussion about participants' experiences of diabetes as a chronic condition, namely the interpretation and understanding of diabetes, and the meanings that participants give to their condition. The wide range of experiences of diabetes expressed by the participants was reduced to experiences of the first symptoms, experiences after the diagnosis, and the awareness of self. The complexity of the condition is reflected in the long list of first symptoms reported by the participants. Any single symptom, or a combination of various symptoms, can also be attributed to a large number of other diseases or health conditions. This uncertainty could possibly be one of the reasons for the large number of undiagnosed cases or under reporting of diabetes, not only in South Africa, but also worldwide (Nagelkerk et al. 2006; Faulkner & Chang, 2007). The experiences as described by the participants reflect the difficulty of people with diabetes in accepting the diagnosis as a lifelong condition with an uncertain outcome.

Only 37,5% of the participants indicated that they know what type of diabetes they have. Webb et al. (2014: 4) report that 26% of the 599 participants in a recent clinical study in the Tshwane district do not know their type of diabetes. Participants do not have a clear understanding of what diabetes is, while the complexity of the condition creates a sense of uncertainty about self-care practices and blood glucose control. The use of the term 'sugar diabetes' is indicative of the perception that the condition is caused primarily by the intake of sugar or sugar-loaded products. None of the participants referred to any lay terminology or concepts that relate to the fact that diabetes mellitus is a chronic disease as a result of an organ that is dysfunctional.

Participants were quite willing, and in some instances, even eager to talk about diabetes and share their experiences during the focus group sessions. The majority of participants initially found it hard to accept their diagnosis. This reality was particularly evident amongst those who do not have any family member with diabetes. A sense of ownership regarding diabetes was reflected by the participants who indicated that the diabetes diagnosis and the reality of living with a chronic condition brought about increased awareness of themselves. These participants reflected a sense of pride and respect about what they perceive to be an empowered position − the challenge and opportunity of knowing and understanding something that their peers do not know about or understand. The opportunity positions them as individuals with specific knowledge and roles. This phenomenon can be explained by symbolic interactionism theory, whereby the meaning of human action can be interpreted by studying the meanings that people attach to their behaviour (Telford, Kralik & Koch, 2006: 458, 460; Barry & Yuill, 2012: 15). The notion of symbolic significance reflects the symbolic connotations and imagery that different conditions carry with them within different social and cultural contexts; this can have a profound effect upon how individuals regard and think about themselves (Bury, 1991: 453). The 'Looking Glass Self' theory of Cooley (1902) suggests that a person's ideas about the self are derived from imagining how other people see and judge them (Telford et al. 2006: 460). A quote from one of the participants is a classic example of self-awareness and interpretation by other

people, namely that people are looking in a strange way at the participant when finding out about the diabetes diagnosis.

Diabetes is a complex condition that requires an adequate level of literacy in order to understand the requirements for effective self-care management. Based on the findings in this sub-theme, the researcher argues that people with diabetes do not receive sufficient information about the conditions in the first place, and secondly they do not adequately understand the information provided to them.

5.2.4.2 Emotional and psychological burden of diabetes

Participants experienced a wide spectrum of emotions associated with the diagnosis of diabetes. These emotions ranged from intense shock, deep emotional pain, anger, and the fear of death. The denial phase of the diagnosis was acknowledged by the participants (discussed in section 5.2.2.3). Despite experiencing one or more symptoms for a number of years participants did not go for a medical check-up, either due to a lack of information, or not associating their symptoms with diabetes. Alternatively they were in denial about the possibility of a serious underlying health condition. This trend can be related to the main theme of Diabetes Health Beliefs, namely what participants believe and what they want to believe about their condition that can be partly explained by the HBM. A high incidence of denial could be one possible explanation for the prevalence of undiagnosed diabetes and/or under-reporting of diabetes. The emotional state of denial is a psychological phenomenon that needs further investigation within the broader social context of people with diabetes, and in relation to self-care management in particular.

Effective self-care management depends on a positive and healthy mental state. A number of the participants in the study experienced feelings of depression and a lack of motivation. These emotions were magnified by limited physical movement and ‘wrong eating’. Black, Kyriakos, Markides and Ray (2003: 2826) contend that depression has been shown to adversely impact on

the self-care of diabetes, and can lead to increased incidence of adverse health outcomes. Lower adherence rates to prescribed regimens were observed mostly in primary care settings, in insulin users, and patients with depression (Cramer, 1995; Cramer, 2004). Whittemore et al. (2002: 23) support the finding that the process of reconciling their emotions and integrating their emotions into a new set of health behaviours is a challenging experience for people diagnosed with diabetes.

5.2.4.3 Stressing

'Stressing' relates to the sub-themes of emotional and psychological burden of diabetes; socio-geographic networks; and demographic and social changes. Stressing as a sub-theme reflects the on-going fluctuations of emotions of people with diabetes in response to their lifelong condition. Stress refers to stressful events or experiences of people with diabetes, and the physiological and psychological responses to these experiences (Lloyd, Smith & Weinger, 2005: 121). Based on the frequency of the occurrence of the topic in the focus group discussions, stress or stressing emerged as the single main specific causal factor with regard to the onset of diabetes and episodes of hyperglycaemia. A number of research studies have shown that the manifestation of type 2 diabetes and/or hyperglycaemia may be stress-induced (Rubin & Peyrot, 1992; Polonsky & Welsch, 1996; Surwit et al. 2002; Lawton et al. 2008: 54). The findings of this study suggest that stress is one of the causes for the onset of diabetes and a major cause of uncontrolled blood glucose levels. This finding is closely related to the findings regarding the emotional and psychological burden of diabetes discussed in Section 5.2.4.2.

According to Spencer et al. (2006: 89), physical and environmental stressors are not the only source of stress for adults with type 2 diabetes. Illness-related emotional distress can arise from the often burdensome and continual diabetes self-care demands, such as administration of medication, testing and monitoring of blood glucose levels, monitoring the dietary regimen, and engaging in adequate physical activity (Polonsky, Anderson, Lohrer, Welch,

Jacobson, Aponte & Schwartz, 1995). The findings of this study suggest that family support is the most important for people with diabetes, but in several instances, family members, especially children, are also a major liability. Seeman (1996: 449) confirms that the quality of an individual's social networks also appears to carry the potential for positive and negative health effects.

According to Ingadottir and Haldorsdottir (2008: 615), support from others can easily become an interference and a source of criticism, which makes people with diabetes more vulnerable, threatens their autonomy, and might drive them into covert behaviour. The findings of this study indicate that problematic intimate relationships and grown-up children, combined with the complexities of diabetes self-care practices are major causes of stress for the majority of the participants. In a cross-sectional survey of 439 patients with diabetes or heart failure, Rosland et al. (2010: 29) found that approximately 25% of the respondents perceived significant family barriers to their self-care management. The challenges of diabetes health behaviour, combined with the challenges of their social conditions, create a situation that the majority of the participants in this study find difficult to cope with. Fischer, Glasgow, Mullan, Skaff and Polonsky (2008) found that diabetes-specific distress has a negative effect on self-care management, thus causing an increase in diabetes-related clinical complications.

A large number of the participants utilise the mechanism of avoidance of possible stress-causing problems, rather than applying problem-solving techniques and/or stress release mechanisms. As their state of health shifts from a mild chronic state to one of severe chronic disease, such as diabetes clinical complications, interpersonal self-efficiency may increasingly become an obstacle in collaborating with family and the medical system for successful disease self-care (Ciechanowski et al. 2004: 726; Telford et al. 2006: 458). The contribution of stress to uncontrolled blood glucose levels demonstrates the value of psycho-social theory in response to 'stress' and the need of stressed people for psycho-social resources. It underlines the importance of understanding the psycho-social factors that mediate the effects of social structural factors on individual risk (Krieger, 2001b: 670). These psycho-social

factors are conditioned and modified by the broader social context in which they occur; and facilitate and assist in a better understanding of the diabetes risk. The finding that stress is the major cause of uncontrolled blood glucose level for participants in this study supports the focus on individualised interventions that facilitate the modification of personal or individual behaviour to enable diabetes prevention or to improve health outcomes for people with diabetes.

5.2.4.4 Demographic and social changes

This sub-theme relates to the sub-theme of the emotional and psychological burden of diabetes. Type 2 diabetes mellitus is a classic example of a chronic condition related to a high level of urbanisation and rapid changes in lifestyle. Motala et al. (2012: S4) highlight the universally demonstrated link between type 2 diabetes and urbanisation, sedentary lifestyles, unhealthy eating and rising levels of obesity. As stated earlier, the majority of the participants' family networks and home environments are in rural areas, while they have migrated to the urban area in search of employment and other opportunities. These participants have either a low level of education, or no education at all, and they are faced with the challenges of an urban environment and continuous changes in their social environment. Seen against this background, they are challenged on a daily basis regarding their own personal and social conditions. For the majority of participants, the changes due to the urban nature of their work and/or living environment alienate them from their daily support structures and, in some instances, also from customs and traditions that they are familiar with. In addition, they face challenges of a lifestyle-related chronic condition with the core of the regimen rooted in modern medicine.

Death and illness in the family, the loss of a job, injuries incurred due to accidents, and other changes in the personal situation of participants were reported as social changes that either triggered the onset of diabetes or caused episodes of hyperglycaemia. Participants expressed their concern about the lack of income or the sudden loss of income. Two participants who lost their jobs during the past year related the value of job security to sustainable self-care management and well-controlled blood glucose levels. The onset of

diabetes or episodes of hyperglycaemia in these contexts can be attributed to the influence of psychological factors, and social and cultural norms, on the health and illness beliefs of people with diabetes, and by the experiences that eventually influence the health behaviour of individuals and populations (Skaff, Mullan, Fisher & Chesla, 2003: 309).

One of the social challenges that participants face in the heterogeneous multi-cultural urban social environment is the expectation that members of a community who live in a certain area should abide by the unwritten rules of that community. The requirement to accept the rules of the social environment that one lives in reflects the importance of a certain degree of social cohesion in a community that is necessary in order to be able to 'survive' within that community. The emergence of the social class situation as a stress-causing factor for people with diabetes relates to the high level of urbanisation and influx of people from neighbouring and other countries into residential areas. Kelly (1992: 391) reports that enormous effort is invested by people with a chronic health condition in order to appear 'normal', meet the required social norms, and avoid becoming marginalised in the society. Research about the social environment can capitalise on sociological research studies that have examined the urban environment, social areas, social disorganisation and social control, and bring an understanding of the social phenomena of diabetes (Yen & Syme, 1999).

In concluding this theme, the relationship between experiences of diabetes, the emotional and psychological burden of diabetes, stressing as an on-going process, and the demographic and social changes reported by the participants addresses the relevance of the research sub-problem statement: 'The lack of understanding about the influence of demographic variables such as gender, and social changes like urbanisation, migration and mobility, on the degree of social integration of the diabetes patient'. Further, the phenomenon of a low level of social integration that is prevalent in urban areas, combined with the lack of social capital, address the mentioned research sub-problem statement as well as a second sub-problem, namely: 'The lack of understanding about the influence of the level of social integration on sustainable self-care management

of diabetes patients'. Viewed within the context of the Trinity of Themes, symbolic interactionism and phenomenology can contribute to the explanation of micro level individual health behaviour, whether it is healthy lifestyles or irrational behaviour, of people with a chronic condition such as diabetes (White, 2002: 56, 57; Telford et al. 2006: 460; Barry & Yuill, 2012: 15).

Having outlined the meta level, how diabetes health beliefs impact on the meso level, how people with diabetes integrate into society, and the micro level, how they deal with experiences, the findings imply that diabetes self-care management is perceived from a distinct multi-level perspective by people with diabetes. The three themes, 'Diabetes Health Beliefs' on the meta-level, the meso-social level 'Socialising' patterns, and the micro-social level 'Experiencing diabetes' determine the self-care practices of people with diabetes and serve as a pathway towards diabetes self-care management and desirable diabetes health outcomes. The macro social-structural level pathway towards diabetes self-care management and diabetes health outcomes is discussed in the following section.

5.3 SELF-CARE MANAGEMENT PRACTICES AND DIABETES HEALTH OUTCOMES

5.2.5 Introduction

Diabetes self-care management practices and diabetes health outcomes emerged as an organisational theme at the macro-social level. As described in the literature review, self-care management includes the full range of activities that people with chronic illness engage in to promote their health, augment their physical, social, or emotional resources, and prevent adverse clinical complications arising from their disease (Thorne & Paterson, 2001: 82). Self-care management refers to the physical, mental and emotional attention required to care for oneself. Diabetes health outcomes are the result of diabetes self-care interventions that are intended to improve the diabetes-related health of an individual or a population. Although participants may

believe in the value of self-care, their orientation to the future is 'unknowable', which suggests a different orientation to beliefs about what can be known medically or personally (Vermeire et al. 2003; Nagelkerk et al. 2006; Nam et al. 2011).

The conceptual framework for this study reflects how the self-care management health outcomes of people with diabetes are linked to the macro social-structural and meso-social level upstream population-based factors (Figure 2.1 in Chapter 2). The findings confirm the macro-social nature of the outcome of self-care practices and diabetes health, and signify the relevance of elements of the heuristic framework of social epidemiology (Poundstone et al. 2004). Parsons' (1951: 431) definition of the social study of medicine is also relevant: "… we may say that illness is a state of disturbance…it is partly biologically and partly socially defined". The macro-social focus reviews one of the sociological questions regarding ways in which the phenomenon of diabetes self-care practices and diabetes health outcomes are manifested and actualised in the lived experiences of people with diabetes and the day-to-day unfolding of their social life (Shim, 2010: 1).

Upstream population-based and downstream social and psycho-social factors are predictors that influence the pathways to health behaviour and finally the self-care management of people with diabetes. The three themes 'Diabetes Health Beliefs', the 'Socialising' patterns, and 'Experiencing diabetes' determine the self-care practices of people with diabetes and serve as the pathway towards diabetes self-care management and diabetes health outcomes (See Figure 5.1).

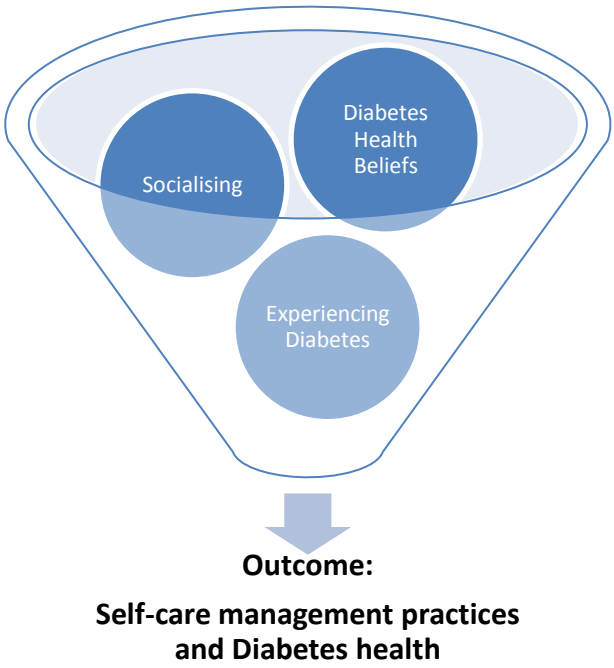


Figure 5.1 Pathway towards self-care management and diabetes health outcomes

Source: The researcher's own construct

The multi-level nature of the Trinity of Themes confirms the relevance of the social-ecological paradigm rationalised by Schwartz and Diez-Roux (2001). The social-ecological paradigm emphasises that the social, behavioural and physiological pathways from an individual's socio-economic position (Schwartz & Diez-Roux, 2001) to the development of diabetes mellitus are distributed in different ways, and need to be analysed from a multi-level perspective, in order to identify the causes of the disease. A number of elements of this paradigm are reflected in the conceptual framework (Figure 2.1 in chapter 1) of this study.

Participants in this study conducted meaningful discussions about self-care management practices, including everyday activities like compliance with dietary requirements and the medication regimen, as well as broader implications on their future health and life. The process of assimilating behaviour and lifestyle changes by people with diabetes is multi-faceted and complex, and poses numerous challenges. The continual and unrelenting nature of required diabetes self-care practices is complex and at times

burdensome. The extensiveness of the diabetes therapeutic regimen, the continual planning required, and the social environment of the participants are challenging when viewed individually, and together can become overwhelming. The findings confirm that diabetes is a complex condition to manage, especially within the social circumstances and specific challenges faced by all the participants in this study.

The findings related to the macro-social level organisational theme of self-care management are categorised according to the frequencies of the codes identified (see chapter 3) and refer to the basic therapeutic regimen categories (diet, medication, and exercise). A wide spectrum of reasons for non-compliance with the diabetes self-care regimen was offered by the participants. These reasons concur with the findings by Vermeire et al. (2003: 29-31) who broadly categorise the reasons for non-compliance into five themes, namely: the course of diabetes; information about diabetes; the context of the person with diabetes; the relationship to the health care provider; and the provision of health care. These reasons are discussed in the next three sections, where applicable, within the context of the respective diabetes therapeutic regimen categories, namely diet, medication, and exercise. The macro-social level organisational theme of 'Diabetes health outcomes' is linked with self-care management but for purposes of the discussion dealt with separately in the last section.

5.2.6 Dietary regimen

The dietary regimen, food in particular, was the foremost topic for each of the individuals in the focus groups and interviews. The dominance of the topic is substantial, while food as an item received the highest frequency as a single code. A number of participants acknowledged that compliance with the prescribed food is a major challenge. Despite awareness that deviation from the correct dietary regimen causes episodes of hyperglycaemia and/or hypoglycaemia, participants were unsure about the cause or causes of their uncontrolled blood glucose levels. This finding is supported by a qualitative study about the perceived barriers to self-management by Nagelkerk, Reick

and Meengs (2006: 153, 154). Those authors found that despite participants having had at least one consultation with a dietician, the highest ranked barrier was lack of knowledge and understanding of the dietary regimen.

People with diabetes also face several social challenges in attempting to comply with the diabetes dietary regimen. Participants in this study mentioned challenges in cooking for themselves, the rest of the family, and for visitors. They suggested that family and friends have certain expectations about food, preparation methods of food, and the social event of having a meal. Lifestyle characteristics are constrained by social norms; therefore individuals in a population will, for example, eat according to their social norms. When individuals try to eat differently from their friends, it is inconvenient and they also run the risk of being identified as deviant (Rose, 2001: 431). This phenomenon is confirmed by Lipton et al. (1998: 67) who report that in many cases, the emotional barriers and cultural beliefs of Latinos are more important than financial barriers; and further, that since family needs are considered most important, adherence to a treatment regimen by Latino people with diabetes is viewed as being self-indulgent. A study by Bopape and Peltzer (2002: 44) in a rural teaching hospital in South Africa found that the needs of a person with diabetes, particularly dietary needs, are frequently subordinated for the sake of the needs of the family.

Ethnographic research regarding the diabetes dietary practices of culturally homogeneous groups can contribute to understanding the social and group dynamics within specific groups. The discussion between three participants in this study (members of one family) about the best food to eat, offers some insight into the prevailing dynamics amongst people with diabetes and their family members. These family members interrupted each other several times, vented their views about their respective superior knowledge about diabetes dietary requirements, and at stages were brutally honest.

The majority of the participants are challenged by difficult socio-economic conditions that determine and limit their dietary options. Contradictory messages from different health professionals about specific food choices also

confuse the participants. The debate amongst participants about the best possible porridge for people with diabetes is one of a number of examples. A further difficulty is the complexity of establishing the correct portion size for individual participants. Nagelkerk et al. (2006: 154) maintain that information provided to the participants in their study was perceived as confusing.

Dieticians recommend more regular, smaller meals for people with diabetes; however, social circumstances of the participants make it difficult for them to eat at certain times. According to Bury (1991: 453), this phenomenon, in combination with the time spent on the self-care management of the symptoms, the application of the medical regimen, and the socio-economic costs associated with long-term illness is part of the primary social effects that disrupt everyday life. Married male participants suggested that supportive spouses are a positive indicator with regard to compliance with their dietary regimen. In comparison, female participants experience a lack of support, and they need to cook what their husbands want. According to Rosland et al. (2010: 27), women experience significantly more family barriers compared to men (30% and 21% respectively) with regard to healthy eating and exercise.

Participants confirmed that after medication, drinking water is the most important way to lower their blood glucose levels. Their acknowledgement that they drink cola and other soda drinks to lessen their thirst even after they have been diagnosed with diabetes, contributes to concerns regarding compliance with the dietary regimen. Traditional and alternative food plays a limited role in the dietary regimen of the participants who reside in the urban areas. In contrast, the participants who attend the rural clinic indicated that traditional food such as *morogo* (a traditional vegetable similar to spinach) works for them. This finding about ethnically specific food is non-significant within the predominantly urban and culturally heterogeneous context of the district of Tshwane (Holmstrom & Rosenqvist, 2005; Nam et al. 2011).

5.2.7 Medication regimen

Although this sub-theme also relates to Theme 1, it is discussed mainly in this section. The perceived side effects of diabetes medication are an important barrier to compliance with the medicine regimen; in particular, the perception that the medication has a negative effect on participants' sexual performance was evident. Several participants admitted that medication alone cannot ensure controlled blood glucose levels. Non-compliance should be viewed within the context of a number of reasons that participants posited for not complying with the medication regimen. These reasons are *inter alia*: forgetfulness when they are ill with a related or non-related illness; unavailability of the medication at the respective clinics; replacing allopathic medication with traditional medication; and socio-economic conditions that determine their access to medication and the required food. The evidence of forgetting to take their medication, lack of knowledge about the action of the medication, side effects, schedules and adjustments is affirmed in a study by Nagelkerk et al. (2006: 154); in that study the recurring theme of difficulty in remembering to take medication was the sixth highest ranked barrier to effective diabetes self-care.

The majority of participants reflected a positive attitude with regard to the importance of compliance with the medication regimen. Participants shared a narrative about people with diabetes who, due to their disbelief regarding medication efficacy, had discontinued the treatment and died because of diabetes-related clinical complications. This narrative strengthened these participants' apparent commitment to treatment compliance. However, in spite of their positive attitude and the illustration thereof by means of narrative examples, the majority of the participants continue to have uncontrolled blood glucose levels.

One can assume that the relationship between the level of education and diabetes literacy might be a possible explanation for the poor self-care management outcomes amongst people with diabetes in the district of Tshwane. Many aspects of diabetes self-care management require adequate numerical literacy for the purposes of: calculating medication dosages,

following prescribed dietary guidelines, calculating carbohydrate intake, reading the nutritional values on food labels, and reading and interpreting blood glucose values (Cavanaugh et al. 2008). Another matter of concern that emerged from the findings is the perception of a large number of participants that one of the side-effects of the diabetes medication is that it negatively affects sexual performance (see section 5.2.3.2). Lipton et al. (1998: 67) report that the misconception of insulin being potentially harmful is a common belief among traditional Mexican Americans and probably inhibits participation in insulin treatment. The effort to comply with the medication routine, in combination with the rest of the therapeutic regimen, presents a challenge for participants.

5.2.8 Exercise regimen

Exercise as a self-care therapeutic regimen is an important part of blood glucose control, but it is a practice that receives little attention from the participants, according to the group discussions. The topic of 'Exercise' did not form part of the questioning line during the focus group discussions, but it emerged as one of the sub-trends from a number of the groups. A few participants reported varying degrees of intentional physical activity related to their diabetes self-care, e.g. walking as far as possible en route to their workplace in order to release stress and keep blood glucose levels down; using a bicycle to go to work; exercising once a week with a non-governmental organisation; and one young male participant plays soccer with his friends. In addition, the unique example (playing with employer's children) of one of the female participants with a controlled blood glucose level gives some insight into the role of physical activity within the work context (Ciechanowski et al. 2004).

For the majority of the employed female participants, their type of work requires physical activity. A challenge for a number of the participants who travel far distances between their places of residence and work is that they arrive home just in time to prepare a meal before retiring for sleep. Thus their place of residence, together with their individual living arrangements, is a barrier to an exercise routine. The socio-economic conditions of the majority of participants,

in combination with the lack of evidence about an intentional exercise regimen, pose the possibility that opportunities for intentional physical activity do not exist (Whittemore, Chase, Mandle and Roy, 2002).

A large number of the participants do, however, expend physical energy on non-intentional physical activity that might be beneficial. Erickson (2013: 632) argues that "while physical activity is an important component of diabetes self-management used to improve control of blood glucose levels, it is often difficult for people with diabetes to start and maintain a physical activity program". According to Rosland et al. (2010: 29), approximately a quarter of people with diabetes or heart failure indicate the existence of family barriers to adherence to their exercise regimen.

5.2.9 Diabetes health outcomes

Diabetes health problems, or related clinical complications due to insufficient self-care management, were a main trend that emerged from the majority of focus group discussions. Major concerns for the participants are negative effects that impact on their life expectancy, such as kidney failure, blindness, and neurological symptoms in the legs that led, in some instances, to amputations. The experience of diabetes-related clinical complications can be attributed to the number of years with undiagnosed diabetes, the number of years since diagnosed with diabetes, insufficient blood glucose management and the progressive nature of the condition. The relationship between diabetes health problems and uncontrolled blood glucose levels is a very complex concept for people with diabetes to understand. The uncertainty and complexity of these health problems or complications were revealed by a large number of participants. The ambiguity of the risk of health problems or complications – even when adhering to the clinical regimen – was reflected in the majority of the groups. These complications included *inter alia* eyesight impairment, burning feet and toes, kidney stones, sexual problems, cramps in the legs, stomach problems, and sleeping difficulties. Sexual health problems emerged as a major health problem or complication of diabetes; this topic was discussed in section 5.2.3.2 in relation to intimate relationships and sexual health.

Aljasem, Peyrot, Wissow and Rubin (2001: 402) state that diabetes treatment adherence is adversely affected if barriers to diabetes self-care management are underestimated or unidentified. A large spectrum of barriers to diabetes self-care management, from the perspectives of the participants, emerged from the findings. A number of these barriers also relate to other sub-sections but for purposes of the discussion are reflected in this section. These barriers range from personal barriers such as emotional and psychological factors, demographic and social changes, and social networks, to external barriers such as the availability and accessibility of primary health care. Nam et al. (2011: 2) show in a global systematic review that a large number of barriers to sustainable diabetes self-care management enable the progression of diabetes to clinical complications; their stated barriers include: adherence to the diabetes therapeutic regimen; attitudes and beliefs; knowledge; culture, ethnicity and language; financial resources; co-morbidities; and social support. The same authors also found the following provider barriers in their study: beliefs, attitudes and knowledge of health care personnel; problematic patient-provider interaction and communication; and a number of problems related to health care systems (Nam et al. 2011).

The findings of a literature review by Brown et al. (2004: 66, 69) broadly correspond with these barriers. They found the following aspects to be important in enabling effective diabetes self-care management: individual-level pathway barriers include: patient-provider communication; health literacy; language barriers; culture and acculturation; mental health; social support, social integration, and competing demands; and provider characteristics include: decision-making style; the health-care speciality; and language concordance.

5.3 ACCESS TO EXTERNAL SYSTEMS AND THE ROLE OF HEALTH CARE SYSTEMS

In this study the macro-structural level, in particular the health care system emerged as having the most prominent influence on diabetes self-care. In

contrast the elements that directly relate to the individual were grouped either on the meta-social, meso-social or individually-based micro level; these include the cultural context, socio-economic factors of the population, health care policy, and demographic and social changes in the population. The findings do not associate a large number of self-care management practises to the macro social-structural level; however these findings do not imply that the health system does not have an influence on the diabetes self-care management of a population. Rather, people with diabetes 'struggle' daily to cope with their personal condition. As stated in the introduction macro-structural level factors are external elements to which self-care management is a reactive mechanism as people with diabetes have little control over factors on this level. The combination of the various macro social-structural level factors creates an environment that is either conducive for sustainable self-care management, or forms barriers to effective self-care.

The availability and accessibility of external systems such as health care facilities, schools and community structures are closely linked to the extent of compliance with the diabetes regimen described in Chapter 4 (section 4.4.4.2). Lawton et al. (2008: 54) found that the highlighted contexts and experiences that inform people with diabetes indicated to be in essence more 'exterior' to the individual. Influencing factors found by other researchers include the social and cultural contexts into which people are socialised; their exposure to neighbourhood effects; the presence or absence of intimate and other social networks of people with a specific disease; and information from health care professionals and other media resources (Glasgow, Strycker, Toobert & Eakin, 2000: 561; Hunt, Emslie & Watt, 2001: 1170; Horowitz, Colson, Herbert & Lancaster, 2004: 1553, 1554; Lawton, Ahmad, Peel & Hallowell, 2007: 895). Timmermans and Haas (2008: 667) argue that understanding the sequence of causality involved in diabetes, its epidemiology and the population health implications of the increased prevalence of obesity, requires an approach that focuses on the role of social institutions and other aspects of the social structure. They conclude by suggesting that the risk of diabetes might be higher for people with limited access to resources, and that changes to the structure of the social environment through legal, political or economic intervention might be

necessary to empower vulnerable groups (Timmermans & Haas, 2008). The participants in this study form part of the group that can be categorised as 'vulnerable', since they have access only to public sector facilities. With one exception (the participant who initially received private medical care), the participants confirmed that the clinic is their only source of information about diabetes. Reports of the Human Sciences Research Council (HSRC, undated report) in South Africa and Coovadia et al. (2009: 8) confirm the reality that only a limited number of public health patients in South Africa have access to some form of private health care, which results in inequalities between health care provision to the poor and the rich.

All the participants in this study have access to a health care facility. In the majority of the focus groups, the participants indicated that the primary health care clinics are their only source of information about diabetes self-care and other illnesses. The only exception is the participant who initially received private medical care, as he was a full-time employee with private medical insurance at the time of his diagnosis. As mentioned earlier, type 2 diabetes is a chronic condition associated with a high level of urbanisation and rapid changes in lifestyle. The high rate of urbanisation adds to the need for housing, infrastructure and services. Social systems and policies governing programmes such as education, welfare and health can directly affect people's access to resources and care. Although the primary health care clinics that the participants use make provision for access every day of the week, participants do not see the same health care worker with every visit. They thus find it difficult to keep explaining their health problems to a new or different health care worker on each visit.

The participants who indicated a preference for a specific primary health care clinic in the Tshwane district suggested the element of familiarity with a specific clinic as part of their motivation (Section 4.4.4.4 in Chapter 4). Another motivating factor was the quality of the service at a specific clinic compared to other clinics. They preferred the services of particular clinics because they consider those at other clinics to be inadequate. This finding is supported by a recent study in the Tshwane district that found that diabetes care and screening

for complications at primary level is sub-optimal (Webb et al. 2014: 1). Participants are prepared to travel further and pay more for transport costs in order to access satisfactory services. The primary health care clinics in the district of Tshwane are characterised by nursing staff-initiated care and the large number of patients does not allow nurses to spend more than the minimum time with each patient; this is particularly problematic for those patients with perceived 'stable' chronic conditions such as diabetes. This finding concurs with the view of Coovadia et al. (2009: 1) that the pivotal facets of primary health care in South Africa are not in place and there is a substantial human resources crisis facing the health sector.

A number of participants prefer certain clinics because they are treated with respect and dignity there. They described other clinics as being poorly managed with a lack of resources such as diabetes medication, and they perceived the health care professionals to be rude and a cause of stress for them. The majority of participants did not know what type of diabetes they have, neither could they explain diabetes in lay terms nor offer a good explanation and/or understanding of diabetes self-care management. In the discussion about the dietary regimen (Section 5.3.2), contradictory messages from different health professionals were highlighted as problematic for the participants. This systems barrier, namely that information provided was perceived as confusing, is confirmed by Nagelkerk et al. (2006: 154) and Coovadia et al. (2009: 1): "…failures in leadership and stewardship and weak management have led to inadequate implementation of what are often good policies (*in South Africa*)". There was agreement that there is insufficient information and a lack of assistance at public clinics in general. They expressed a need for more individually focused and consistent care, including home visits by health care professionals and psychological therapy. The narrative in Section 4.4.1.3 of a recently diagnosed 34-year-old male participant exemplifies the extent of special needs of people with diabetes, such as psychological services.

Another major deficiency in the standards of care that emerged from the findings of this study is the lack of individual glucose meters at clinics to monitor

the insulin levels of patients. This is a biomedical barrier to effective self-care management by insulin-dependent diabetes patients in the public sector and directly increases the burden for injectable insulin on all levels of health care provision. Nagelkerk et al. (2006: 154) found that the failure of the health care system to provide the recommended equipment, medicines, laboratory tests and other provider services is a common and frustrating barrier with regard to diabetes self-care management. The argument for a more individualised focus towards diabetes self-care management is made against the background that prevention and self-care programmes pose challenges for programme managers, health care staff and human and financial resources. The problem is that poor primary health level management of diabetes results in upward referral in the health system, with concomitant increases in the cost of care.

The overall low education level of the participants (34,5% of them either have no education or schooling lower than grade 5) is reflected in the mainly (78,2%) unskilled work positions they occupy. Despite their low education levels, the majority of participants rely on their self-care practices that take place outside the health system. Bruce et al. (2003: 87-88) confirm that people who live with a chronic condition such as diabetes, make decisions mostly outside the primary health care clinic. They are therefore required to acquire comparatively advanced knowledge and skills in order to cope with a variety of uncertainties, with limited immediate assistance from a health care professional. Their low education level aggravates the situation for these participants and limits the spectrum of diabetes information resources accessible to them; hence this restricts their capacity to fully understand the metabolic complexity of diabetes as a lifelong condition. The findings of this study suggest that diabetes self-care management interventions aimed at patients with a lower education level must also include personal communication methods. Dettori et al. (2005) confirm the importance of one-to-one diabetes education which can result in an improvement in patient management of the disease and prevention of diabetes-related complications. Based on this finding, a more individualised focus with regard to diabetes care and specifically diabetes self-care should be taken by health care professionals. Nagelkerk et al. (2006: 154) validate this view in their qualitative study which found that the lack of individualised and coordinated

care is a major barrier towards effective diabetes self-care. The same authors argue that the structure and delivery of group education may not meet the needs of people with diabetes (Nagelkerk et al. 2006). The individualised approach focuses on what places individuals at risk of acquiring diabetes, and what individual characteristics are associated with the development and progression of the disease. The understanding of diabetes risk manifests at the individual level and therefore interventions should focus on individual behaviour changes and access of individuals to clinical diabetes care (Rose, 2001: 431).

Contrary to these arguments for an individualised focus, Syme (1987) argues that the promotion of individualised information for disease prevention has attained limited success, due to the fact that individual risk studies focus mainly on individuals and exclude the social environment. This argument echoes two main limitations of the individually focused approach, namely that it is difficult for people to change their behaviour or their life situation, and even if some people do change their behaviour, others will enter the 'at risk' population because no action has been taken to change those forces in society that stimulated the problem in the first place (Syme, 1987). Researchers have been successful in identifying risk factors such as Type A behaviour, social isolation, stressful life events, and various psychological patterns that can put individuals at higher risk of developing a specific disease or diseases (Norris et al. 2002; Heisler et al. 2003).

Further major external system barriers that have an influence on self-care management relate to transport and employment. While all participants reported that they have access to some form of transport, long distances to health care facilities and irregular transport, especially during winter months, add to their stress levels. The lack of employment for 20,8% of the participants, and difficulties for those employed in obtaining permission from their employers to attend the clinic, add to the challenges they experience. These findings from the study about barriers to sustainable diabetes self-care management, and the view of Coovadia et al. (2009: 1) endorse the opinion of Harris et al. (2011: S102) that there are a substantial number of barriers.

However, according to Coovadia et al. (2009: 1) little is known in South Africa about these barriers to accessing health care for the general population, has been viewed from the perspective of the patient. Harris et al. (2011: S102) examined barriers to health care access and found that the affordability, availability and acceptability of health care services are closely associated with socio-economic status, race, health insurance status, and urban-rural location. The same authors also established that vulnerable social groups have limited power to "claim and use entitlements and opportunities" (Harris et al. 2011: S119) to access health care. These findings can be explained by the social production of disease theory that introduces agency to the 'upstream-downstream' metaphors, and explicitly addresses economic and political determinants of health and disease, including structural barriers to people living healthy lives. "The underlying hypothesis is that policies and decisions of economic and political institutions create economic and social privilege and inequality, and are the fundamental causes of social inequalities in health" (Krieger, 2001b: 670). The findings of this study validate the relevance of the social production of disease and/or political economy of health theory, and strongly suggest that the concept of 'social capital' is central to an understanding of the health behaviour patterns of people with diabetes.

Cockerham (2005: 51) argues that an important but undeveloped area of theoretical discourse in medical sociology pertains to the comparative contributions of structure and agency in determining health lifestyles: "Proponents of structure emphasize the power of structural conditions in contouring individual dispositions and behaviour along socially prescribed lines, while advocates of agency accentuate the capacity of individual actors to choose their behaviour regardless of structural influences". Post-modernist thought challenges Parsons' (cited by White, 2002) model of structural-functionalism, emphasising that while society lays down functions, the increased number of options open to individuals facilitates choices to shape their own lives, allowing them to become 'agents' for their own lives (White, 2002: 56). The findings of this study support the argument that individual biographies are becoming more important than social structures such as class, gender and ethnicity, resulting in a move towards agency rather than structure.

The bridge from agency to structure for Weber (cited by Kalberg, 1994) was the 'ideal type' of institution, consisting of structural entities such as bureaucracy, or processes like formal rationality, whose construction allowed him to make general statements about collective forms of collective behaviour (Kalberg, 1994: 9, 46). Cockerham (2005: 62) argues that the theoretical conceptualisation of health lifestyles is affected by the agency-structure debate. Cockerham's (2005: 51, 52, 54, 64) arguments regarding the lack of a health-lifestyle theory, and the agency-structure problem as being central to theoretical discussions of health and lifestyles, as well as the gap of a dearth in the literature on these topics is confirmed by the findings of this study.

5.4 SUMMARY

This study aimed to explore the major selected upstream population-based factors on the macro social-structural and meso-social levels that relate to diabetes self-care management. The majority of the factors or variables that emerged from the data and that constitute the sub-themes of the Trinity of Themes are rooted in the selected population-based factors. Socio-economic factors, socio-geographic networks, social capital, health policy and social integration are the population-based factors that emerged as the determining factors that place the population at risk of diabetes. Although the findings are mainly contextualised on the macro social-structural and meso-social levels, individual-based social context factors also emerged that are reflected on the micro-social level. The emergence of these micro-social level factors in the findings relates to and is an indication of the complex nature of this study.

The findings about the attitudes and perceptions with regard to diabetes; perceived susceptibility to diabetes; attitudes about generational diabetes; the perceived seriousness of diabetes and the death threat of diabetes; and the attitudes and perceptions about diabetes symptoms and symptoms associated with HIV and AIDS, confirm the importance of understanding the attitudes and perceptions of people who live with diabetes, and the difficulties of converting knowledge into compliance with the diabetes therapeutic regimen. The meta-level theme of 'Diabetes Health Beliefs' confirms the relevance of a social

cognition theory such as the HBM of Rosenstock (1988). The findings strongly suggest that the participants' concept of 'Diabetes Health Beliefs' is highly significant for an understanding of diabetes self-care management.

'Socialising' as a theme reflects the on-going nature of social actions and interactions between the participants and other people who form part of their direct or indirect social networks. The emotional and psychological burden of diabetes is reflected in the complexity of the socio-geographic networks that include all their relationships, as well as their home and living environments, and work environments. The findings suggest that internalised knowledge about diabetes and diabetes self-care management, and empowerment through social support networks are predictors of sustained self-care management.

The findings strongly suggest that the concept of social integration is important for an understanding of the health behaviour of people with diabetes. A low level of social integration or lack of social cohesion, low socio-economic status, high levels of poverty, a high rate of migration between residence and work place, lack of access to economic opportunities, housing and health care, and the lack of sustainable social networks structures are characteristics that enhance the study population's vulnerability to diabetes. The finding of a low level of social integration in relationship with the uncontrolled blood glucose levels of the majority of the participants in this study addresses the research problem statement and more specifically the following sub-problems: 'The lack of understanding about the influence of demographic variables like age, and social changes like urbanisation, migration and mobility, on the degree of social integration of the diabetes patient'; and 'The lack of understanding about the influence of the level of social integration on sustainable self-care management of diabetes patients'.

The experiences lived by the participants reflect the difficulty of people with diabetes in accepting the diagnosis as a lifelong condition. Upstream population-based and downstream social and psycho-social factors influence the pathways to health behaviour and the self-care management of people with

diabetes. The pathway towards diabetes self-care management and diabetes health outcomes is facilitated through the prevailing 'Diabetes Health Beliefs', the 'Socialising' patterns of persons with diabetes, and the 'Experiencing of diabetes' by persons with diabetes. The complex and multi-faceted diabetes regimen poses numerous behaviour and lifestyle challenges to persons with diabetes. The findings confirm that diabetes is a complex condition to manage; while social circumstances pose specific challenges for all the participants in this study.

The extent of compliance with the diabetes regimen is closely linked to the availability and accessibility of external systems such as health care facilities, schools, and community structures. The findings about barriers to sustainable diabetes self-care management endorse the opinion that there is a spectrum of access barriers to health care for the study population, while limited information is available from the patient's perspective about these types of barriers in South Africa (Coovadia et al. 2009). Health care access barriers include affordability, availability and acceptability of health care services and are closely associated with socio-economic status, race, health insurance status, and urban-rural location. "Vulnerable social groups have limited power to 'claim and use entitlements and opportunities' to access health care" (Harris et al. 2011: S102).

An undeveloped area of theoretical discourse in medical sociology pertains to the comparative contributions of structure and agency. These notions should form part of a multi-disciplinary theoretical debate in search of a scientifically verified health-lifestyle theory. The lack of a health-lifestyle theory confirms the dearth of knowledge in the literature about diabetes self-care management, specifically in relation to population-based factors.

Finally, the participants' perceptions about diabetes in particular and health beliefs in general are determining factors regarding their reasoning about their present quality of life and future life living with diabetes. It is clear from this research study that even if an individual might be able to modify their individual risk factors, only a society can modify population-based risk factors (Rose,

2001; Krieger, 2001a). The conclusions and recommendations of the study are discussed in the next chapter.

CHAPTER 6
Conclusion and recommendations

6.1 INTRODUCTION

In Chapter 5 the main findings from the study were drawn together through the discussion of the Trinity of Themes. A discussion of the findings in relation to the organisational theme of self-care management practices and diabetes health outcomes followed the discussion of the Trinity. Access to, and the role of, external systems in diabetes self-care management was discussed in the last section of the chapter. Chapter 6 briefly revisits the context of the study; provides a summary of the main findings of the study; and then focuses on conclusions about the findings. The chapter closes with a summary of the main scientific contributions of the study, the limitations of the study, recommendations for further research and concluding remarks.

6.2 REVISITING THE CONTEXT OF THE STUDY

The research problem statement of this study was manifested in the need for a better understanding of population-based factors on various levels, namely meta, macro, meso and micro, that influence and shape the beliefs about diabetes, its experience and health outcomes based on the management of diabetes self-care. The sub-problems reflected on the influences of variables such as social and demographic changes; social capital; and the level of social integration on sustainable self-care management. The overall aim of this qualitative study was to explore selected population-based social determinants relevant to the implementation and sustainability of diabetes self-care management. The supporting objectives of the study included the identification of the major upstream population-based factors and the socio-structural and social factors that influence or play a major role in the sustainable self-care management of diabetes.

The broad key research questions reflected on the population-based factors and characteristics that place populations at risk of diabetes and enhance vulnerability to the disease. Three specific research questions investigated the socio-economic and socio-political determinants that may help establish and perpetuate inequalities in populations and place patients at higher risk of ineffective self-care management, uncontrolled blood glucose levels, and clinical complications.

Against this background, the research design of the study reflected the interrelationship of grounded theory and phenomenological theoretical elements. The researcher theoretically contextualised the study by utilising elements of structural-functionalism, and adopted an emphatic stance in seeking an understanding through the eyes of the research participants. The interactive multi-level conceptual framework, combined with the three-pronged theoretical approach directed the exploration of the interrelationships between socio-economic status and the macro social-structural and meso-social level social factors, in order to establish the critical transition to effective self-care management.

The focus group discussions centred attention on the phenomenon of living with diabetes. The researcher made use of abductive reasoning, as an analytical approach. Deductive reasoning was used as a complementary method to the inductive approach, in order to direct the last phase of the data analysis. The research problem statement, the research objectives and research questions directed the data-collection process, which contained elements of theoretical sampling, shaping what the researcher did or did not look for. In exploring the research sub-problems and research questions, six of the initial themes that were part of the focus group discussion schedule and nine new trends and patterns emerged from the data.

6.3 SUMMARY OF THE MAIN FINDINGS

6.3.1 Brief background to the findings

The global, African, and South African overview regarding diabetes provides evidence of i) the extent of diabetes as a health condition; ii) discrepancies regarding estimates of diabetes prevalence; and iii) the lack of sufficient scientific information about the prevalence of diabetes. The discussion on the sociology of diabetes and the relevant epidemiological research paradigms emphasises the gap in the scientific field of population-based perspectives in relation to diabetes self-care management. The overview of diabetes self-care management affirms the complex nature of diabetes mellitus as a metabolic disorder and a chronic condition. The brief review about the role of the health care system regarding diabetes self-care infers that the pivotal facets of primary health care are not in place in South Africa and that there is a substantial human resources crisis facing the health sector.

The complexity of diabetes self-care management is reflected in the three themes, namely ‘Diabetes Health Beliefs’, ‘Socialising’ patterns and ‘Experiencing Diabetes’ that are evident for people living with diabetes. The Trinity of Themes is a model which can be used to prioritise the multiple observations and essential meanings in the data of this population-based study. In this study, the Trinity of Themes reflects three levels, firstly the health belief system at the meta-level; secondly the intergroup theme at the meso-level; and thirdly the individual theme at the micro-level. The main findings in relation to the macro-social level are reflected in the organisational theme of self-care management practices and diabetes health outcomes. The main findings related the macro-structural level concern access to, and the role of external systems in diabetes self-care management. The main findings are listed in the next five sections, and contextualised by a selection of only the most relevant literature.

6.3.2 Theme 1: Meta-level 'Diabetes Health Beliefs'

The findings reflected in the theme 'Diabetes Health Beliefs', relate to attitudes and perceptions with regard to diabetes; perceived susceptibility to diabetes; attitudes about generational diabetes; perceived seriousness of diabetes and the death threat of diabetes; and attitudes and perceptions about diabetes symptoms and symptoms associated with HIV and AIDS. The main findings that emerged as part of this meta-level theme confirm the importance of the need to understand the attitudes and perceptions of people who live with diabetes, and their difficulties in converting knowledge into compliance with the diabetes therapeutic regimen. The main findings in this theme are summarised in the following paragraphs below:

- The findings reveal the underlying notion of stigmatisation of the diabetes condition and people with diabetes. The experiences of discrediting and discrimination towards people with diabetes, in both the work context and the social environment, support the assertion of stigmatisation and challenge the perception that diabetes and people living with diabetes are not stigmatised. The findings of the study are validated by Schabert, Browne, Mosely and Speight (2013: 1) who claim that people with diabetes report that stigma is a significant concern experienced across many life domains. The finding about the experience of stigma reflects another aspect of Goffman's (1963) notion of stigma, namely that it is highly relational, socially constructed in and through social relationships, depending on the situation. This finding is confirmed by a number of scientists (Goffman, 1963; Pescosolido, Martin, Lang & Olafsdottir, 2008), namely that stigma represents a rupture between an individual's virtual and actual social identity, and that a disease is regarded in some way as a failing of the body, and the person. The fear of stigmatisation and possible ridicule that cause people with diabetes to avoid talking about their condition emerged in this study. This finding emphasises the fact that the phenomenon of stigma associated with diabetes is underestimated and relatively under-researched,

compared to the extent of research on other diseases such as HIV and AIDS (Schabert et al. 2013: 2).

- The emotional state of denial, or a prolonged denial phase of perceived non-susceptibility to diabetes when taking care of a family member with diabetes, provides evidence of a possible life-long burden for a person with diabetes and their family members, as well as a complex set of challenges. The findings illustrate the existence of a denial phase that people with diabetes may go through before they acknowledge that they might have a serious health condition. The evidence of a possible denial phase confirms the view of labelling theorists (Tannenbaum, 1951; Erikson, 1964; Becker, 1973; Quicke & Winter, 1994) who explain that deviance is created by social groups who establish rules and norms. Evidence of the emotional state of indifference and detachment of people with diabetes with one or more family members who also have diabetes, emerged from the data. This phenomenon of emotional indifference is confirmed by the findings of Nagelkerk et al. (2006: 154) who report helplessness and frustration with the lack of success in achieving optimal glycaemic control, which in turn can lead to ineffective coping mechanisms such as denial or indifference on the part of both of the person with diabetes and the caregiver.

- The inability to explain the phenomenon that knowledge about diabetes and the accompanying perception about the seriousness of the condition cannot be converted into health lifestyle changes confirms the lack of a health-lifestyle theory that can explain this phenomenon. The evidence of uncontrolled blood glucose levels that relate to this finding are confirmed by the recent clinical study by Webb, Rheeder and Van Zyl (2014: 6), who found that glycaemic control as measured by the HbA1c test at primary health care clinics in the study district of Tshwane is poor, with less than 30% of patients showing an HbA1c measure below 7%.

- The finding about the participants' preference of other diseases such as HIV and AIDS validates the view that diabetes mellitus is a complex metabolic

disorder that requires specialised knowledge and a specific set of skills to manage effectively. However, the condition is still poorly understood by both health professionals and people with diabetes, and thus not effectively managed on both macro-structural and macro-social level. Vermeire, Van Royen, Coenen, Wens and Deneken (2003: 210) confirm that the treatment of diabetes involves complex changes in the basic behaviour of people with diabetes, including adherence to complicated clinical and dietary regimens.

- Evidence from the findings reflected in the theme of 'Diabetes Health Beliefs' confirms the relevance of a social cognition theory such as the Health Belief Model (HBM) of Rosenstock (1966). A key finding of this study is that the model is not only relevant and applicable in terms of the prevention of the occurrence of an illness, but also explains a number of the principles related to the management of a chronic illness like diabetes. The application of the model within the context of diabetes relates to the prevention of the progression of diabetes towards clinical complications. Kartal and Altug-Ozsoy (2007: 1455) provide similar results in the application of the Turkish version of the Health Belief Model. On the contrary, a number of other theorists (Bagozzi, 1993; Gollwitzer, 1993; Castle, Skinner & Hampson, 1999: 526; Pakenham, Pruss & Clutton, 2000) believe that the HBM cannot explain susceptibility and that it applies mainly to explanations for the prevention of illness. The contribution of this study includes evidence that the HBM contributes to an explanation of the health behaviour of people already diagnosed with a health condition.

The diverse findings in this theme regarding stigma, labelling and denial confirm the importance of understanding the attitudes and perceptions of people who live with diabetes and their difficulties in converting knowledge into compliance with the diabetes therapeutic regimen. These notions are therefore closely related to the prevailing attitudes and perceptions about diabetes. These underlying attitudes can possibly explain the finding that people with diabetes, despite their understanding of the seriousness of diabetes and the death threat, are unable to change their health behaviour. The underlying

notions of stigma, labelling and denial confirm the importance of a multi-level approach to the investigation of diabetes self-care management.

Finally, perceptions about diabetes in particular, and health beliefs in general, are determining factors regarding participants' reasoning about their present quality of life and their future life living with diabetes. The findings of this research confirm the view that an individual can modify their individual risk factors, but only a society can modify population-based risk factors (Rose, 2001; Krieger, 2001a).

6.3.3 Theme 2: Meso-level 'Socialising'

The findings reflected in the theme 'Socialising', relate to the significance of social integration, combined with socio-geographic networks; social capital; the socio-cultural context; as well as the broader external context of people with diabetes, in order to better understand the health behaviour and self-care practices of people with diabetes. The main findings in this theme are summarised in the following paragraphs below:

- The existence of a social network structure does not necessarily imply a support structure for people with diabetes. In this research, married men tend to receive their primary support mostly from their spouses, while in contrast; female participants experience none or very limited support from their husbands. Similar results were found by Rosland et al. (2010: 27), namely that overall, women (64%) report less family support compared to men (77%).

- The evidence from the findings suggests that the social environment has important, although varied effects on health, e.g. the lack of social integration may be associated with an increased risk of poorer health outcomes. This finding is validated by Berkman and Glass (2000), who confirm that social networks can influence health outcomes in direct and indirect ways. Nam et al. (2011: 2) and Brown et al. (2004: 69) infer that the

lack of social support, the absence of social integration, and competing demands within a social group such as the family, are barriers to effective diabetes self-care management.

- The finding of a low level of social integration and a lack of social cohesion reflects the absence of social attachments, or weak attachments within the residential areas of the participants in this study. The lack of social integration has a broad impact on all-cause mortality, and is, according to Berkman et al. (2000: 851), one of the robust findings in the literature on networks and health. The assumption follows that social isolation, disintegration and disconnectedness influence mortality and longevity or life expectancy (Berkman et al. 2000: 851-852).

- The lack of consistency with regard to the use in the literature of the concepts social integration, social relationships, social networks, social support, social ties, and social capital in relation to population health indicates a deficiency in conceptually dedicated investigations. A number of researchers confirm the use of these terms as interchangeable concepts in relation to health (Lin, 1999; Berkman et al. 2000: 844; Macinko & Starfield, 2001: 387; Kritsotakis & Gamarnikow, 2004; Stephens, 2008). This finding provides evidence that there exists a deficiency with regard to clear definitions and the application of these concepts in relation to health and disease, and specifically diabetes self-care management from a population-based perspective.

- Four perceptions and misconceptions emerged from the findings, namely that medication can heal diabetes and can therefore be discontinued; blood glucose level rises with age and individual lifestyle changes cannot influence it; a person with diabetes cannot work; and an individual who has been physically active is not susceptible to diabetes. These four perceptions and misconceptions about diabetes self-care management reflect a lack of knowledge and understanding about the implications of a chronic condition. Bury (1982: 169) offers an explanation for elements of these perceptions, through his notion of “chronic illness as a ‘biographical disruption’ that

involves recognition of pain and suffering, and possibly death, which are normally seen as distant possibilities and the plight of other people."

- The unexpected finding of the complexity of sexual wellness and blood glucose management supports the argument for qualitative studies to understand side-effects and barriers from the patient perspective. This finding supports the fact that relatively few studies have attempted to understand the side-effects of and barriers to adherence to the diabetes therapeutic regimen from the patient perspective (Zgibor & Songer, 2001: 23). According to Webb et al. (2014: 6), 88% of diabetic men in a recent clinical study in the Tshwane district reported a degree of erectile dysfunction, and 36% of these cases were considered to be severe. In a review article, Penson and Wessells (2004: 226) report a prevalence of between 26% and 64% of erectile dysfunction for different studies that included both type 1 and type 2 diabetes patients.

- A diabetes self-care support structure, combined with a personal intimate employment environment, where the employer knows the employee and in some instances, their family members, by name, suggests a proxy and substitute for an adequate home and family support network. Similar results found by Burt (2000: 347) confirm that the phenomenon of social capital reveals that people who do better are somehow better connected, e.g. certain people or groups are connected to certain others, trust certain others, and are dependent on exchanges with certain others. This finding of social support within the work environment suggests that a form of social capital exists within the specific nature of the work and the work environment of these participants. Macinko and Starfield (2001: 410, 411) concede that social capital can be analysed at more than one level, namely the micro level (for example, social networks of individuals); and the individual attitudinal and psychological level, that refers to an aspect like trust between various people and organisations.

The range of findings in this theme strongly suggest that the concept of social integration, in combination with socio-geographic networks; social capital; the socio-cultural context; as well as the broader external context of people with diabetes are significant for an understanding of the health behaviour of people with diabetes. The findings imply that a low level of social integration and lack of social cohesion; low socio-economic status of the population; high levels of poverty; a high rate of migration between residence and work place; lack of access to economic opportunities, housing and health care; and the lack of sustainable social network structures are population characteristics that enhance a population's vulnerability to diabetes. A number of scientists provide similar evidence of a significant association between the protective effects of social integration and reduced mortality risks (Seeman, 1996; Berkman et al. 2000; Syme, 2005). The findings contribute to answer the three specific research questions, namely 'How do socio-economic and socio-political determinants contribute to establishing and perpetuating inequalities in diabetes self-care management within populations?'; 'What population characteristics and social factors enhance the vulnerability of diabetes patients and place them at higher risk of ineffective self-care management, uncontrolled blood sugar levels, or clinical complications?'; and 'What population-based factors influence resilience with regard to controlled blood sugar levels?'

6.3.4 Theme 3: Micro-level 'Experiencing Diabetes'

The findings reflected in the theme 'Experiencing Diabetes' relate to the relationship between experiences of diabetes; the emotional and psychological burden of diabetes; stressing as an on-going process; and the demographic and social changes reported by the participants. The participants' experiences about diabetes reflect the difficulty that people with diabetes experience in accepting the diagnosis as a lifelong condition. The main findings that emerged from this theme confirm the relevance of two of the research sub-problem statements. These sub-problems refer to 'the lack of understanding about the influence of demographic variables such as gender and age and social changes like urbanisation, migration and mobility, on the degree of social

integration of the diabetes patient'. The main findings in this theme are summarised in the following paragraphs below:

- The finding of the emotional and psychological burden of diabetes is reflected in the complexity of the socio-geographic networks of the participants, including all their relationships, as well as home, living and work environments. The relationship between the emotional and psychological burden of diabetes, stressing as an on-going process, and the demographic and social changes reported by the participants validates the relevance of the research sub-problem expressed as: 'The lack of understanding about the influence of demographic variables such as gender and age, and social changes like urbanisation, migration and mobility, on the degree of social integration of the diabetes patient'.

- The occurrence of a low level of social integration prevalent in urban areas, combined with a lack of social capital in view of uncontrolled blood glucose levels of the majority of the participants in this study, supports the main research problem statement. These findings also validate two of the research sub-problem statements, namely: 'The lack of understanding about the influence of demographic variables such as gender and age, and social changes like urbanisation, migration and mobility, on the degree of social integration of the diabetes patient' and 'The lack of understanding about the influence of the level of social integration on sustainable self-care management of diabetes patients'.

- The findings in this theme indicate that problematic intimate relationships and grown-up children, combined with the complexities of diabetes self-care practices, are major causes of stress for the majority of the participants. Seeman (1996: 449) posits that the quality of social ties appears to carry the potential for both positive and negative health effects. In a cross-sectional survey of 439 patients with diabetes or heart failure, Rosland et al. (2010: 29) found that approximately 25% of the respondents perceived significant family barriers to their self-care management. Fischer, Glasgow, Mullan, Skaff and Polonsky (2008) found similar results about diabetes-specific

distress that have a negative effect on self-care management. The findings in this study suggest that the challenges of diabetes health behaviour, combined with those of their social conditions, create a situation that the majority of the participants find difficult to cope with.

These findings suggest that knowledge about diabetes and empowerment through social support are predictors of sustained self-care management. Similar results were found by Greco et al. (1990) and Glasgow et al. (2001). The findings contribute to answer two of the specific research questions, namely 'What population characteristics and social factors enhance the vulnerability of diabetes patients and place them at higher risk of ineffective self-care management, uncontrolled blood sugar levels, or clinical complications?', and 'What population-based factors influence resilience with regard to controlled blood sugar levels?

6.3.5 Self-care management practices and diabetes health outcomes

The themes 'Diabetes Health Beliefs', 'Socialising' patterns, and 'Experiencing of diabetes' determine the self-care practices of people with diabetes and serve as the pathway towards diabetes self-care management and diabetes health outcomes which emerged as an organisational theme at the macro-social level. The findings in this macro-social level theme relate to the dietary, medication, and exercise therapeutic regimens, as well as to participants' diabetes-related health outcomes. The findings reveal that upstream population-based and downstream social and psycho-social factors are predictors that influence the pathways to health behaviour and finally the self-care management of people with diabetes. The main findings in this theme are summarised in the following paragraphs below:

- Another key finding of this research is that diabetes self-care management involves complex changes in health behaviour; furthermore, diabetes health behaviour pathways and outcomes are determined by the prevailing diabetes health beliefs of people with diabetes, their socialising patterns and the interpretations and meanings that they give to diabetes, which reflect

their on-going internal experiencing of diabetes. Similar results were found by Vermeire et al. (2003: 210) who confirm that the process of integrating behaviour and lifestyle changes by people with diabetes is multi-faceted and complex, and presents numerous challenges.

- A main trend that emerged from the majority of the group discussions was diabetes health problems, or clinical complications related to diabetes due to insufficient self-care management. The relationship between diabetes health problems and uncontrolled blood glucose levels is a very complex concept for people with diabetes to understand. The uncertainty and complexity surrounding health problems or complications were revealed by a large number of participants. The complexity of the diabetes therapeutic regimen and resulting ambiguity of the risk of health problems or complications is confirmed by Vermeire et al. (2003) and Ciechanowski et al. (2004). In addition, the findings of this study suggest that the majority of participants reflect a positive attitude with regard to the importance of compliance with the medication regimen. Ockleford et al. (2008: 31) use the term ‘accepters’ to explain the phenomenon that despite their positive attitude, many people with diabetes continue to have uncontrolled blood glucose levels by calling them ‘accepters’. Ockleford et al. (2008: 31) report that although ‘accepters’ accept the need for change, not all of them consistently adhere to what they understand to be best practice in managing diabetes.

- Participants in this study tend to deviate from their prescribed dietary regimen, despite awareness that it can cause episodes of hyperglycaemia and/or hypoglycaemia. This finding confirms the lack of internalised knowledge and understanding of the complex interplay between their diabetes therapeutic regimen and uncontrolled blood glucose levels. This finding is supported by Nagelkerk et al. (2006: 153-154) in a qualitative study about perceived barriers to self-management. Those authors found that despite participants having had at least one consultation with a dietician, the highest ranked barrier to self-care management was the lack of knowledge and understanding of the dietary regimen.

- Cavanaugh et al. (2008) report that many aspects of diabetes self-care management require adequate numerical literacy. The findings of this study suggest that a low level of education and a lack of diabetes literacy might be a possible explanation for the poor self-care management outcomes amongst people with diabetes in the district of Tshwane.

The findings reflect the macro-social nature of self-care management practices of people with diabetes and their diabetes health outcomes; this gives an indication of how these variables relate to the macro social-structural and meso-social level upstream population-based factors. This finding signifies the relevance of elements of the heuristic framework of social epidemiology (Poundstone, Strathdee & Celentano, 2004).

6.3.6 Access to external systems and the role of health care systems

The findings do not relate a large number of self-care management practises to the macro-structural level; however this does not imply that external systems and the health system do not have an influence on the self-care management of a population. Macro-structural level factors are exterior to people with diabetes, thus factors that they have not much control over. The main findings that relate to the macro-structural level are summarised in the following paragraphs.

- The overall low level of education of the participants (34,5% of them either have no education or schooling lower than grade 5) is reflected in the mainly (78,2%) unskilled labour positions they occupy. Despite their low education levels, the majority of participants rely on self-care practices that take place outside the health system. Bruce et al. (2003: 87-88) confirm that people who live with a chronic condition such as diabetes, make decisions mostly outside the primary health care clinic. They are therefore required to acquire comparatively advanced knowledge and skills in order to cope with a variety of uncertainties, with limited immediate assistance from a health care professional. Their low level of education aggravates the situation for these participants and limits the spectrum of diabetes information resources

accessible to them; hence this restricts their capacity to fully understand the metabolic complexity of diabetes as a lifelong condition.

- Preference for specific primary health care clinics in the Tshwane district contains an element of familiarity with a specific clinic as part of their motivation. Another motivating factor that emerged from the findings is the quality of the service at a specific clinic compared to other clinics. Participants preferred the services of particular clinics because they consider those at other clinics to be inadequate. This finding is supported by a recent study in the Tshwane district that found that diabetes care and screening for complications at primary level is sub-optimal (Webb et al. 2014: 1).

- The participants in this study fall into a group that can be categorised as *vulnerable* in that they have access only to public health facilities. The majority of participants confirmed that primary health care clinics are their primary, and in some instances, only source of information about diabetes. Harris et al. (2011: S119) established that vulnerable social groups have limited power to "claim and use entitlements and opportunities" to access health care. The findings in this study posit that primary health care facilities are an important form of social capital for all participants. Furthermore, the findings suggest that a work environment of a personal nature, such as domestic service offers an opportunity for increased social capital for people with diabetes. Harris et al. (2011: S102) examined health care access barriers and found that the affordability, availability and acceptability of health care services are closely associated with socio-economic status, race, health insurance status, and urban-rural location.

- The barriers to effective self-care management that emerged from the findings range from personal barriers (such as emotional and psychological factors, demographic and social changes, and social networks), to external barriers (such as the availability and accessibility of primary health care). The availability and accessibility of external systems such as health care facilities, schools, and community structures are closely related to the extent

of compliance with the diabetes regimen. However, the participants in this study did not elaborate extensively about the availability and accessibility of the health system. The view of Coovadia et al. (2009: 1) endorses the opinion of Harris et al. (2011: S102), namely that little is known about access barriers to health care for the general population in South Africa.

Cockerham (2005: 51) argues that an important but undeveloped area of theoretical discourse in medical sociology pertains to the comparative contributions of structure and agency in determining health lifestyles. Post-modernist thought challenges Parsons' model (cited by White, 2002) of structural-functionalism, emphasising that while society lays down functions, the increased number of options open to individuals facilitates choices to shape their own lives, allowing them to become 'agents' for their own lives (White, 2002: 56). The findings in this theme support the argument that individual biographies are becoming more important than social structures such as class, gender and ethnicity, resulting in a move towards agency rather than structure. In addition, Cockerham (2005) argues that the theoretical conceptualisation of health lifestyles is affected by the agency-structure debate and should form part of the theoretical debate in search of a scientifically verified health-lifestyle theory. The dearth in the literature about diabetes self-care management in relation to population-based factors is further confirmed by the lack of a health-lifestyle theory. The findings in this study validate the research problem statement that is reflected in the need for a better understanding of population-based factors on various levels, which influence and shape the beliefs about diabetes, its experience and health outcomes based on the management of diabetes self-care.

6.4 CONCLUSIONS

On the basis of the findings generated by this study, the following conclusions may be drawn:

- This qualitative research study has demonstrated that understanding the themes 'Diabetes Health Beliefs', the 'Socialising' patterns, and

'Experiencing of diabetes' of people with diabetes is fundamental for the enablement of effective interventions towards sustainable diabetes self-care management and diabetes health outcomes.

- The findings have also demonstrated that the notions of stigmatisation and labelling, and the prevalence of denial of diabetes, as underlying causes of ineffective diabetes self-care management, are underestimated and under-researched from a sociological perspective. The notions of stigmatisation, labelling and denial are some possible explanations for the high prevalence of undiagnosed diabetes. Stigmatisation is a recurring issue within the social and work context, especially regarding the association of diabetes symptoms with diseases such as HIV and AIDS. Evidence was found in this study of discrimination against people with diabetes in the workplace, job losses due to diabetes, and/or lack of opportunities.

- Stress has been identified from the findings as the single major cause of uncontrolled blood glucose levels. The main causes of stressful conditions can be attributed to children, problematic intimate relationships and sexual dysfunction, and demographic and social changes. Social support is a proxy for sustainable diabetes self-care management, but the liability of adult children is a major cause of stress.

- Despite the findings that confirm the perceived seriousness of diabetes and its possible death threat, people with diabetes tend not to change their health behaviour. The lack of social support, social integration, social cohesion, and social capital negatively influences the translation of knowledge into health behaviour changes and sustainable diabetes self-care management. Social support, social integration, social cohesion, and social capital can provide a useful springboard for analysing the process to conversion of knowledge about diabetes health behaviour into effective diabetes self-care management.

- Ineffective diabetes self-care management and poor diabetes health outcomes can be explained *inter alia* by the following findings:
  - Participants demonstrated a lack of understanding of diabetes as a complex metabolic disorder and the complexity of the diabetes therapeutic regimen – this is one of the reasons why some of them verbalised a preference for other illnesses such as HIV and AIDS.
  - The availability and accessibility of the health care system is problematic, and participants do not receive adequate information. This finding illustrates that more attention should be given to individualised care with regard to diabetes self-care management. Based on the findings, a combination of the individually-based, case-control method or high risk strategy and the population-based or population incidence rate strategy can contribute to the development of a comprehensive multi-level, multi-disciplinary health-lifestyle and diabetes self-care management model.

- The concepts used in this study to research the influence of population-based factors on diabetes self-care management are relevant and appropriate within this context; however the concepts of social integration, social cohesion, social capital, social support, and social ties in relation to health tend to be used interchangeably by various scientists. According to Berkman et al. (2000: 844), when scientists refer to the term *social integration* in relation to health, a spectrum of related terms is used loosely and interchangeably. This use of these terms, in some instances in combination with the term *social capital*, as interchangeable concepts in relation to health, indicates a lack of conceptual clarity in the literature regarding population-based diabetes health and diabetes self-care management and contestation in the sociological literature.

The undeveloped area of theoretical discourse in medical sociology pertaining to the comparative contributions of structure and agency could form part of a multi-disciplinary theoretical debate in search of a scientifically verified health-lifestyle theory. The dearth of knowledge in the literature about diabetes self-

care management, specifically in relation to population-based factors is also confirmed by the lack of a health-lifestyle theory.

6.5 SUMMARY OF SCIENTIFIC CONTRIBUTIONS OF THE STUDY

The present study departed from the social context of individual patients and focuses instead on the population-based social epidemiology and sociology of diabetes: the distribution and complex changes and mortality patterns, social determinants and consequences related to type 1 and type 2 diabetes mellitus. The population-based perspective on diabetes self-care management distinguishes the study from previous studies done in either sociology or the health sciences.

The focus on the sociology of disease, and more specifically the social epidemiology of diabetes, adds to the understanding and explanation of some of the pathways, processes and mechanisms of the dynamic interplay between the biological health and the social life of the diabetes patient. This approach required a new set of knowledge, skills and expertise of the researcher, including on the topic of the biology of diabetes. The main significance of this study is the theoretical engagement of sociology with the biology of, and clinical complications resulting from ineffective self-care management of diabetes.

The theoretical engagement of sociology with the scientific field of social epidemiology, through the review of the social epidemiological research paradigms (namely the psychosocial approach, the social production of disease approach and the eco-social approach) is a significant contribution in terms of the scientific field of the sociology of disease, more specifically the sociology of diabetes.

The original data analysis strategy developed by the researcher is a unique contribution to the qualitative research process. A study-specific coding strategy was developed which directed the data analysis phases. Figure 3.2

(Chapter 3) presents the coding strategy of the study. The data analysis strategy is an eclectic combination of four phases of coding, namely First Cycle Coding, a Transitional phase, Second Cycle Coding, and After Second Cycle Coding. The First Cycle Coding phase reflects the application of three coding methods, namely Elemental Coding, Themeing of Data, and Affective Coding. The Transitional phase contains only the Eclectic Coding method. During the Second Cycle Coding phase, Focused Coding, Axial Coding and Theoretical Coding were applied. The final After Second Cycle Coding phase reflects the Focusing strategy that directed the Thematic Analysis towards the final outcome of the Trinity of Themes. This analysis strategy reflects the complex nature of an investigation such as this study, while it also encompasses the multi-level characteristics of the conceptual framework that forms the foundation of the study. A similar analysis strategy could be applied to the analysis of other qualitative data that requires the interpretation of complex phenomena on multiple levels.

6.6 LIMITATIONS OF THE STUDY

A number of limitations of this study were noted during the research process, and are discussed in this section.

- The main limitation of the study is that the findings cannot be generalised to the rest of the South African population because the study included only people with diabetes who live in the district of Tshwane in Pretoria and who make use of public primary health care facilities.
- Ethnical diversity could not be attained, e.g. no participants from the Indian community participated, in spite of the fact that the highest prevalence of diabetes in South Africa is amongst people of Indian descent. The mainly Indian residential area forms part of the western feeding area for the Kalafong Provincial Academic Hospital that has a well-established diabetes clinic that was not included in the study population.

- The female bias of the study population is another limitation – this is due to the substantially smaller number of male patients compared to females attending public primary health care facilities. The study population of the recent clinical study in the Tshwane district reflects a similar bias, namely 68% of the 599 participants were female (Webb et al. 2014: 4).

- The study is limited to people with diabetes that utilise public health care facilities – with an associated limited range of diabetes therapeutic opportunities and choices available to these participants. The findings cannot be compared with people with diabetes who make use of the private health care sector.

- The low education level and mainly low socio-economic status of participants in the study population limited the range of discussion of complex concepts. Thus the findings cannot be compared with people with higher education levels and a higher socio-economic status.

- The sample is limited to the higher end of the targeted age range, with the consequent limitation with regard to the generalisability of the conclusions to the higher end of the age range. However the sample is in line with the general population of the diabetes patients who attend the primary health care clinics in Tshwane. Due to the higher end age range of the sample the findings of this study are biased towards persons with diabetes who have lived longer with the condition, and who may be more successful in the self-care management of diabetes.

- The qualitative nature of the study required a limited sample of participants, namely 72 in this study. The thinly spread categories do not allow for inferences between the numbers in terms of the demographic variables such as of age, gender and race.

- Time limitations at the clinics did not allow the researcher to apply the projective techniques used during the piloting and pre-testing of the research instruments. An additional 45 to 60 minutes for similar focus group discussions is recommended in order to facilitate any form of projective technique. The application of picture story collages is especially, effective for groups with a low level of education.

- The conceptual challenge of the distinction between 'experiencing diabetes', 'socialising' and 'diabetes health beliefs' posed a specific challenge to the interpretation of the findings of the study.

- Although the findings are mainly contextualised on the macro social-structural and meso-social levels, individual-based social context factors also emerged that are reflected on the micro-social level. The emergence of these micro-social level factors in the findings relates to and is an indication of the challenge of the complex nature of this study and therefore presented as a limitation on the study.

6.7 RECOMMENDATIONS FOR FUTURE RESEARCH

The following recommendations are made with regard to future research:

- The findings emphasise that the phenomena of stigma and labelling associated with diabetes are underestimated and relatively under-researched compared to health conditions such as HIV and AIDS, epilepsy, and obesity. It is proposed that future research should concentrate on these innate phenomena that influence the extent of health behaviour changes in order to facilitate efficient and sustainable diabetes self-care management.

- The large number of participants who shared views about their experiences of diabetes, shaped by family members who have or had diabetes, posits the notion of labelling of the condition within the family context. The view of labelling theorists is that a health condition is treated by human beings in

accordance with their understanding of the situation and that judgements concerning sickness and deviant behaviour are relative and cannot be separated from the social situations in which people live. This suggests the necessity for an investigation within the relatively new scientific field of epi-genetics.

- The emotional state of denial is a psychological phenomenon that needs further investigation within the broader social context of people with diabetes, particularly in relation to diabetes self-care management.

- The phenomenon of stigma in relation to the sexual health of people with diabetes poses an argument for further research. There is also a need for culturally specific information regarding intimate relationships and sexual problems in relation to diabetes self-care management.

- The view that the problem of sexual dysfunction due to diabetes can be more easily overcome by women than by men was expressed during the study. The underlying elements of gender roles and sexism in the debate among these female participants suggest further exploration. This recommendation, together with the previous one, poses an argument for further research with regard to gender specific information regarding sexual problems in relation to diabetes self-care management.

- There are a limited number of studies about diabetes self-care amongst culturally and ethnically homogenous groups. There is a need for culturally specific information and comparative research including the investigation of cultural practices and beliefs in relation to the diabetes dietary regimen, especially the cultural meaning of food and cultural sensitivity of lifestyle intervention programmes. Ethnographic research regarding the diabetes dietary practices of culturally homogeneous groups would contribute to understanding the social and group dynamics within specific groups.

- The socio-economic environments of the place of residence, combined with individual living arrangements, are barriers to an exercise routine for a large

number of the participants in this study. Ethnographic research regarding the diabetes therapeutic regimen of exercise within culturally homogeneous groups would contribute to understanding barriers to compliance with prescribed physical activity.

- Scientists use the term *social integration* interchangeably with concepts such as social relationships, social networks, social support, social ties, and social capital in relation to health. This provides evidence of the gap in the body of knowledge and infers the need for the clarification of concepts, and the application of these concepts in relation to health and disease. These concepts can provide a useful springboard to investigate the role of population-based factors in diabetes self-care management. Research about the social environment would capitalise on sociological research studies that have examined the urban environment, social areas, social disorganisation and social control, and bring an understanding of the social phenomena linked to diabetes (Yen & Syme, 1999).

- The participants in this study fall into a group that can be categorised as vulnerable who have limited power to "claim and use entitlements and opportunities" Harris et al. (2011: S119) because they only have access to public health facilities. The necessity for further research regarding the accessibility of diabetes care at public primary health care facilities for vulnerable social groups is underscored by the findings of this study.

- The theoretical discourse in medical sociology regarding the comparative contributions of structure and agency in determining health lifestyles is according to Cockerham (2005: 51) an undeveloped, but significant to progress towards the development of a health lifestyle theory. The bridge from agency to structure for Weber (cited by Kalberg, 1994) is the 'ideal type', consisting of structural entities, such as bureaucracy or processes like formal rationality; this construction allowed him to make general statements about forms of collective behaviour (Kalberg, 1994: 9, 46). Cockerham (2005: 51, 52, 54, 62, 64) argues that the theoretical conceptualisation of

health lifestyles is affected by the agency-structure debate and should form part of the theoretical debate in search of a scientifically verified health lifestyle theory. The lack of a health-lifestyle theory confirms the dearth in the literature about diabetes self-care management in relation to population-based factors and reinforces the need for further research.

- It is clear from this research study that an individual can change their health lifestyle and moderates their individual risk factors, but only a society can modify the population-based risk factors (Rose, 2001; Krieger, 2001a). Research that combines the individually-based, case-control method or high risk strategy and the population-based or population incidence rate strategy can possibly result in a more in-depth and comprehensive understanding of all the social variables involved in diabetes self-care management.

6.8 CONCLUDING REMARKS

Scientists in the field of diabetes are in agreement that the ominous crisis with regard to diabetes mellitus seems to call for innovate approaches of thinking about and conveying research (Raphael, Anstice, Raine, McGannon, Rizvi & Yu, 2003: xvii).

In fact, the reality of diabetes is a far more complicated balance than the rule of halves. Possibly half of the population has a risk of diabetes and have probably half the likelihood of being diagnosed, but they also face living a half-life. The lack of substantial, consistent social support, low levels of social integration, and the lack of social cohesion in the multi-cultural heterogeneous nature of the mainly urbanised environment of the district of Tshwane reflect a society not fully whole, but a fractured society that is particularly vulnerable to the uncertainty of the rule of halves.

The hidden nature of the diabetes epidemic reflects the burden of a label in communities whose members become stigmatised when they become part of this half that is diagnosed. The emotional state of denial and perceived non-

susceptibility and the possible non-disclosure of the condition place individuals and populations at a higher risk of diabetes. Stigmatisation of the condition and of those with diabetes prevents open discussion, because those who live with diabetes do not want their identity and humanness to be inferior in any way. The complexity of balancing the lifelong burden of diabetes with a challenging therapeutic regimen multiplies the barriers to sustainable diabetes self-care management.

This research study contests the rule of halves and in its place posits an equation full of complexity. The sociologist and author of '*At the will of the body: Reflections on illness',* Arthur Frank (2004: 436), states that "Theory method needs to be useful to help people to *imagine themselves,* living as they do, in times that are part fate, part choice, and part opportunity". The same author claims that "…illness is an opportunity, though a dangerous one" Frank (1991: 1).

List of References

Adler, N.E., Boyce, T., Chesney, M.A., Cohen, S., Folkman, S., Kahn, R.L. & Syme, S.L. 1994. Socioeconomic status and health. The challenge of the gradient. *American Psychologist,* 49(1): 15-24. From social integration to health: Durkheim in the new millennium. *Social Science and Medicine,* 51: 843-857.

Aljasem, L.I., Peyrot, M., Wissow, L. & Rubin, R.R. 2001. The impact of barriers and self-efficacy on self-care behaviors in type 2 diabetes. *The Diabetes Educator,* 27: 393-404.

Amundson, H.A., Butcher, M.K., Gohdes, D., Hall, T.O., Harwell, T.S., Helgerson, S.D. & Vanderwood, K.K. 2012. Translating the Diabetes Prevention Program Into Practice in the General Community: Findings From the Montana Cardiovascular Disease and Diabetes Prevention Program. *The Diabetes Educator,* 35(2): 209-223.

Armitage, C.J. & Mark Conner, M. 2000. Social cognition models and health behaviour: A structured review. *Psychology & Health,* 15:2, 173-189.

Assal, J-P., Jacquemet, S. & Morel, Y. 1997. The added value of therapy in diabetes: The education of patients for self-management of their disease. *Metabolism,* 46(S1): 61-64.

Atkinson, A.B. & Micklewright, J. 1993. *Economic transformation in Eastern Europe and the distribution of income.* Cambridge: Cambridge University Press.

ATLAS.ti 7 Scientific Software Development GmbH. 2012. ATLAS.ti 7@. *ATLAS.ti 7 Scientific Software Development GmbH,* Germany: Berlin.

Backstrom, L., Sun, E. & Marlow, C. 2010. Find Me If You Can: Improving Geographical Prediction with Social and Spatial Proximity. World Wide Web Conference Committee (IW3C2). April 26–30, 2010, Raleigh, North Carolina, USA. Retrieved June 13, 2015 from: http://www.cameronmarlow.com/media/backstrom-geographical prediction_0.pdf

Bagozzi, R.P. 1993. On the neglect of volition in consumer research: A critique and proposal. *Psychology and Marketing,* 10: 215-237.

Bandura, B. 1984. Lifestyle and health: some remarks on different viewpoints. *Social Science and Medicine,* 19: 341-347.

Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. 2002. Self-management approaches for people with chronic conditions: A review. *Patient Education and Counseling,* 48(2): 177-187.

Barry, A. & Yuill, C. 2012. *Understanding the sociology of health: An introduction*. London: Sage Publications Ltd.

Baum, F. 1999. Social Capital: Is It Good for Your Health? Issues for a Public Health Agenda. *Journal of Epidemiology Community Health*, 53(1): 195-196.

Bautista, M.S., Aguilar-Salinas, C.A., Lerman, I. 1999. Diabetes knowledge and its determinants in a Mexican population. *Diabetes Education,* 25: 3-9.

Bazzano, A.T., Zeldin, A.S., Shihady Diab, I.R., Garro, N.M., Allevato, N.A., Lehrer, D. and the WRC Project Oversight Team. 2009. The healthy lifestyle change program a pilot of a community-based health promotion intervention for adults with developmental disabilities. *American Journal of Preventive Medicine,* 37(6S1): S201–S208.

Beaglehole, R., Bonita, R. & Kjellstrom, T. 1994. *Basic epidemiology*. World Health Organization, Geneva; England: Eastern Press.

Becker, H.S. 1973. *Outsiders: Studies in the sociology of deviance.* 2nd edition. New York: The Free Press.

Ben-Shlomo, Y. & Kuh, D. 2002. The life course approach to chronic disease epidemiology: conceptual models, empirical challenges and interdisciplinary perspectives. *International Journal of Epidemiology,* 31: 285-293.

Berenson, R.A., Hammons, T., Gans, D.N., Zuckerman, S., Merrell, K., Underwood, W.S. & Williams, A.F. 2008. A House Is Not a Home: Keeping Patients at the Center of Practice Redesign. *Health Affairs,* 27(5): 1219–1230.

Berkman, L.F. 2004. Introduction: Seeing the forest and the trees – from observation to experiments in social epidemiology. *Epidemiologic Reviews,* 26: 2-6.

Berkman, L. F., Kawachi, I., & Glymour, M. 2014. *Social Epidemiology* (Ed. 2). New York, NY: Oxford Press.

Berkman, L.F. & Glass, T. 2000. Social integration, networks and health. In L.F. Berkman & I. Kawachi (Eds.), *Social epidemiology* (pp. 137-173). New York, NY: Oxford University Press.

Berkman, L.F., Glass, T., Brisette, I. & Seeman, T.E. 2000. From social integration to health: Durkheim in the new millennium. *Social Science and Medicine,* 51: 843-857.

Berkman, L., Melchior, M., Chastang, J., Niedhammer, I., Leclerc, A., & Goldberg, M. 2004. Social integration and mortality: A prospective study of French employees of Electricity of France-Gas of France. *American Journal of Epidemiology,* 159(2): 167–174.

Black, S.A., Kyriakos, S., Markides, S.K. & Ray, L.A. 2003. Depression predicts increased incidence of adverse health outcomes in older Mexican Americans with type 2 diabetes. *Diabetes Care,* 26: 2822-2828.

Blaikie, N. 2004. Abduction. In M.S. Lewis-Beck, A. Bryman, & T.F. Liao (Eds.), *The Sage Encyclopaedia of Social Science Research Methods.* Three vols. Thousand Oaks, CA: Sage.

Bloom, D.E., Cafiero, E.T., Jané-Llopis, E., Abrahams-Gessel, S., Bloom, L.R., Fathima, S., Feigl, A.B., Gaziano, T., Mowafi, M., Pandya, A., Prettner, K., Rosenberg, L., Seligman, B., Stein, A.Z., & Weinstein, C. 2011.*The Global Economic Burden of Noncommunicable Diseases.* Geneva: World Economic Forum.

Boeije, H. 2010. *Analysis in Qualitative Research.* London: Sage Publication.

Bopape, M.W. & Peltzer, K. 2002. Health beliefs and stress among non-insulin dependent diabetes out-patients in a rural teaching hospital in South Africa. *Research: Health SA Gesondheid,* 7(4): 38-46.

Bourdieu, P. 1986. The Forms of Capital. (pp. 241-258). In J.G. Richardson (Eds.), *Handbook of Theory and Research for the Sociology of Education.* New York: Greenwood Press.

Bourdieu, P. & Wacquant, L. 1992. An invitation to reflexive sociology. Chicago: University of Chicago Press.

Bradley, C. & Gamsu, D.S. 1994. (for the Psychological Well-being Group of the WHO/IDF St Vincent Declaration Action Programme for Diabetes) Measures of psychological well-being and treatment satisfaction developed from the responses of people with tablet-treated diabetes. *Diabet Medicine,* 7: 510-516.

Bradshaw, D., Groenewald, P., Laubscher, R., Nannan, N., Nojilana, B., Norman, R., Pieterse, D. & Schneider, M. 2003. Initial estimates from the South African National Burden of Disease study, 2000. *MRC Policy Brief, No. 1, March 2003.* Cape Town: Medical Research Council.

Bradshaw, D., Schneider, M., Norman, R. & Bourne, D. 2006. Mortality Patterns of Chronic Diseases of Lifestyle in South Africa. In Steyn, K., Fourie, J., Temple, N. (Eds). *Chronic Diseases of Lifestyle in South Africa 1995-2005.* Technical Report. Cape Town: Medical Research Council.

Bradshaw, D., Norman, R., Pieterse, D., Levitt, N.S. & the South African Comparative Risk Assessment Collaborating Group. 2007. Estimating the burden of disease attributable to diabetes in South Africa in 2000. *South African Medical Journal.* 97(7): 700-706.

Brown, L.M. 2000. Helicobacter pylori: Epidemiology and routes of transmission. *Epidemiologic Reviews,* 22(2): 283- 297.

Brown, S., Becker, H.A., Garcia, A.A., Barton, S.A. & Hanis, C.L. 2002. Measuring health beliefs in Spanish speaking Mexican Americans with type 2 diabetes: adapting an existing instrument. *Research in Nursing & Health*, 25: 145-158.

Brown, A.F., Ettner, S.L., Piette, J., Weinberger, M., Gregg, E., Shapiro, M.F., Karter, A.J., Safford, M., Waitzfelder, B., Prata, P.A. & Beckles, G.L. 2004. Socioeconomic position and health among persons with diabetes Mellitus: A conceptual framework and review of the literature. *Epidemiologic Reviews,* 26: 63-77.

Bruce, D.G., Davis, W.A., Cull, C.A. & Davis, T.M.E. 2003. Diabetes education and knowledge in patients with type 2 diabetes from the community: The Fremantle Diabetes Study. *Journal of Diabetes and its Complications,* 17(2): 82-89.

Bryman, A. 2012. *Social research methods.* (4th edition). New York: Oxford University Press.

Burns, L.D. & Lennon, S.J. 1993. Social perception: methods for measuring our perception of others. *International Textile and Apparel Association Special Publication,* 5: 153-159.

Burt, R.S. 2000. The network structure of social capital. *Research in Organizational Behaviour,* 22: 345-423.

Bury, M.R. 1982. Chronic illness as biographical disruption. *Sociology of Health and Illness,* 4(2): 167-182.

Bury, M.R. 1991. The sociology of chronic illness: a review research and prospects. *Sociology of Health and Illness,* 13(4): 451-468.

Cantrill, J.A., Sibbald, B. & Buetow, S. 1996. The Delphi and nominal techniques in health services research. *The International Journal of Pharmacy Practice,* Review Articles, 4: 67-74.

Cardona-Morrell, M., Rychetnik, L., Morrell, S.L., Espinel, P.T. & Bauman, A. 2010. Reduction of diabetes risk in routine clinical practice: are physical activity and nutrition interventions feasible and are the outcomes from reference trials replicable? A systematic review and meta-analysis. *BioMed Central Public Health,* 10(653): 1-17.

Carpiano, R.M. 2009. Come take a walk with me: The ‘‘Go-Along’’ interview as a novel method for studying the implications of place for health and well-being. *Health & Place,* 15: 263–272.

Cassel, J. 1976. The contribution of the social environment to host resistance. The fourth Wade Hampton Frost lecture. *American Journal of Epidemiology,* 104(2): 107-123.

Castle, C.M., Skinner, T.C. & Hampson, S.E. 1999. Young women and sun tanning: An evaluation of a health education leaflet. *Psychology and Health,* 14: 517-527.

Cattell, V. 2001. Poor people, poor places, and poor health: the mediating role of social networks and social capital. *Social Science & Medicine,* 52: 1501-1516.

Cavanaugh, K., Huizinga, M., Wallston, K.A., Gebretsadik, T., Shintani, A., Davis, D., Gregory, R.P., Fuchs, L., Malone, R., Cherrington, A., Pignone, M., De Walt, D.A., Elasy, T.A. & Rothman, R.L. 2008. Association of numeracy and diabetes control. *Annals of Internal Medicine*, 148: 737-746.

Centers for Disease Control (CDC) 2014. National Diabetes Statistics Report. Retrieved June 18, 2015 from: http://www.cdc.gov/diabetes/pubs/statsreport14/national-diabetes-report-web.pdf

Ceria, C. D., Masaki, K. H., Rodriguez, B. L. Chen, R., Yano, K., & Curb, J. D. 2001. The relationship of psychosocial factors to total mortality among older Japanese American men: The Honolulu Heart Program. *Journal of the American Geriatrics Society,* 49: 725–731.

Champion, V.L. & Skinner, C.S. 2008. The Health Belief Model. In K. Glanz, B.K. Rimer & K. Viswanath, K. (Eds). *Health behavior and health education: theory, research, and practice*, 4th Edition, (pp. 45-65). John Wiley & Sons: Jossey-Bass, CA: San Francisco.

Chan, A., Malhotra, C., Malhotra, R. & Ostbye, T. 2011. Living arrangements, social networks and depressive symptoms among older men and women in Singapore. *International Journal of Geriatric Psychiatry,* 26: 630–639.

Charmaz, K. 1994. Identity dilemmas of chronically ill men. *The Sociological Quarter,* 35(2): 269-288.

Charmaz, K. 2006. *Constructing grounded theory: A practical guide through qualitative analysis.* London: Sage.

Chesler, M. & Barbarin, O. 1987. *Childhood cancer and the family.* New York: Brunner/Mazel.

Ciechanowski, P.S., Katon, W.J., Russo, J.E. & Walker, E.A. 2001. The patient-provider relationship: Attachment theory and adherence treatment in diabetes. *American Journal of Psychiatry,* 158: 29-35.

Ciechanowski, P., Russo, J., Katon, W., Von Korff, ScD., Ludman, E., Lin, E., Simon, G. & Bush, T. 2004. Influence of patient attachment style on self-care and outcomes in diabetes. *Psychosomatic Medicine,* 66: 720-728.

City of Tshwane. 2006. *Integrated Development Plan 2006-2016. April 2006.* Tshwane: City of Tshwane Metropolitan Municipality.

City of Tshwane. 2013. *Integrated Development Plan 2013/2014. April 2013.* Tshwane: City of Tshwane Metropolitan Municipality.

Cockerham, W.C. 2004. *Medical Sociology.* Upper Saddle River, New Jersey: Pearson Prentice Hall.

Cockerham, W.C. 2005. Health lifestyle theory and the convergence of agency and structure. *Journal of Health and Social Behavior,* 46: 51-67.

Cockerham, W.C (Ed.). 2010. *The New Blackwell companion to medical sociology,* West Sussex: Wiley-Blackwell Publishing.

Coleman, J.S. 1988. Social capital in the creation of human capital. *American Journal of Sociology,* 94: S95-S121.

Coovadia, H., Jewkes, R., Barron, P., Sanders, D. & McIntyre, D. 2009. Health in South Africa 1. The health and health system of South Africa: historical roots of current public health challenges. *The Lancet,* 374: 1-18.

Corbin, J. & Strauss, A. 2008. *Basics of Qualitative Research,* 3rd edition. Thousand Oaks, CA: Sage Publications.

Crabtree, B. & Miller, W. (Eds.). 1999. *Doing qualitative research.* 2nd edition. Thousand Oaks, California: Sage.

Cramer, J.A. 1995. Partial medication compliance. The enigma in poor medical outcomes. *American Journal of Managed Care,* 1: 45-52.

Cramer, J.A. 2004. A systematic review of adherence with medications for diabetes. *Diabetes Care,* 27: 1218-1224.

Cramer, J.A., Roy, A., Burrell, A., Fairchild, C.J., Fuldeore, M.J., Ollendorf, D.A. & Wong, P.K. 2008. Medication compliance and Persistence: Terminology and Definitions. *International Society for Pharmaco-economics and Outcomes Research (ISPOR), Value in Health,* 11(1): 44-47.

Cravey, A.J., Washburn, S.A., Gesler, W.M., Arcury, T.A. & Skelly, A.H. 2001. Developing socio-spatial knowledge networks: a qualitative methodology for chronic disease prevention. *Social Science & Medicine,* 52: 1763-1775.

Creswell, J.W. 2008. *Educational research: Planning, conducting, and evaluating quantitative and qualitative research,* 3rd edition. Upper Saddle River, NJ: Merrill/Prentice Hall.

Crocker, J., Major, B. & Steele, C. 1998. Social stigma. In S. Fiske, D. Gilbert, & G. Lindzey (Eds.), *Handbook of social psychology,* (pg. 504-553). Boston: McGraw-Hill.

Cummins, S., Curtis, S., Diez-Roux, A.V. & Macintyre, S. 2007. Understanding and representing 'place' in health research: A relational approach. *Social Science & Medicine,* 65: 1825–1838.

Curtis, S. & Jones, I.R. 1998. Is there a place for geography in the analysis of health inequality? In M. Bartley, D. Blane & G. Davey Smith (Eds.), *The Sociology of Health Inequalities*. Oxford: Blackwell.

Danaei, G., Finucane, M.M., Lu, Y., Singh, G.M., Cowan, M.J., Paciorek, C.J., Lin, J.K., Farzadfar, F., Khang, Y-H., Stevens, G.A., Rao, M., Ali, M.K., Riley, L.M., Robinson, C.A. & Ezzati, M. on behalf of the Global Burden of Metabolic Risk Factors of Chronic Diseases Collaborating Group (Blood Glucose). 2011. National, regional, and global trends in fasting plasma glucose and diabetes prevalence since 1980: systematic analysis of health examination surveys and epidemiological studies with 370 country-years and 2.7 million participants. *Lancet,* 378: 31-40.

Dasgupta, P. 2000. Economic Progress and the Idea of Social Capital. In *Social Capital: A Multifaceted Perspectives,* Edited by: Dasgupta, P. & Seragilden, I. Wasington DC: World Bank.

Day, C., Groenewald, P., Laubscher, R., Chaudhry, S., Van Schaik, N. & Bradshaw, D. 2014. Monitoring of non-communicable diseases such as hypertension in South Africa: Challenges for the post-2015 global development agenda. *South African Medical Journal,* 104 (10): 680-687.

Declaration of Alma-Ata. 1978. International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978. Retrieved May 7, 2012 from: http://www.who.int/hpr/NPH/docs/declaration_almaata.pdf

D'Eramo-Melkus, G., Spollett, G., Jefferson, V., Chyun, D., Tuohy, B., Robinson, T. & Kaisen, A. 2004. A culturally competent intervention of education and care for black women with type 2 diabetes. *Applied Nursing Research,* 17(1): 10-20.

Dettori, N., Flook, B.N., Pessl, E., Quesenberry, K., Loh, J., Harris, C., McDowall, J.M., Butcher, M.K., Helgerson, S.D., Gohdes, D. & Harwell, T.S. 2005. Improvements in care and reduced self-management barriers among rural patients with diabetes. *The Journal of Rural Health*, 21: 160-165.

DeSantis, L. & Ugarizza, D.N. 2000. The concept of theme as used in qualitative nursing research. *Western Journal of Nursing Research,* 22(3): 351-372.

Diabetes Prevention Program Research Group (DPPRG). 2002. Diabetes Prevention Program Research Group reduction in the incidence of type 2 diabetes with lifestyle intervention or Metformin. *New England Journal of Medicine,* 346(6): 393-402.

DiMatteo, M.R. 2004. Variations in Patients' Adherence to Medical Recommendations: A Quantitative Review of 50 Years of Research. *Medical Care,* 42(3): 200-209.

Donoghue, S. 2000. Projective techniques in consumer research. *Journal of Family Ecology and Consumer Sciences*, 28: 47-53.

Dotter, D.L & Roebuck, J.B. 1988. The labeling approach re-examined: Interactionism and the components of deviance. *Deviant Behavior,* 9(1): 19-32.

Dunbar-Jacob, J. & Mortimer-Stephens, M.K. 2001. Treatment adherence in chronic disease. *Journal of Clinical Epidemiology,* 54: S57–S60.

Durkheim, E. 1951. *Suicide.* New York: The Free Press.

Eberhardt, M.S. & Pamuk, E.R. 2004. The Importance of Place of Residence: Examining Health in Rural and Non rural Areas. Rural Health and Health Care Disparities. *American Journal of Public Health,* 94 (10): 1682-1686.

Edwards, A.W.F. 2004. *Cogwheels of the mind: the story of Venn diagrams.* Baltimore, Maryland: The Johns Hopkins University Press.

Ekoe', J-M. & Zimmet, P. 2001. The clinical syndrome and the biochemical definition. In J-M. Ekoe', P. Zimmet & R. Williams (Eds.), *The epidemiology of diabetes mellitus: and international perspective* (pp. 7-10). West Sussex, England: John Wiley & Sons Ltd.

Emirbayer, M. & Mische, A. 1998. What is agency? *American Journal of Sociology.* 103(4): 962-1023.

Epping-Jordan, J.E., Pruitt, S.D., Bengoa, R. & Wagner, E.H. 2004. Developing Research and Practice. Improving the quality of health care for chronic conditions. *British Medical Journal: Quality Safety of Health Care,* 13: 299-305.

Erikson, E. 1964. *Insight and responsibility: Lectures on the ethical implications of psychoanalytic insight.* New York: Norton.

Erickson, D. 2013. Barriers to physical activity in people with type 2 diabetes enrolled in a worksite diabetes disease management program. *The Diabetes Educator,* 39(5): 626-634.

Fagerli, R. A., Lien, M. E., & Wandel, M. 2005. Experience of dietary advice among Pakistani-born persons with type 2 diabetes in Oslo. *Appetite,* 45(3): 295-304.

Farmer, A., Kinmonth, A.L. & Sutton, S. 2005. Measuring beliefs about taking hypoglycaemic medication in people with type 2 diabetes. *Diabetic Medicine,* 23(8): 265-270.

Faulkner, M.Z. & Chang, L-I. 2007. Family influence on self-care, quality of life, and metabolic control in school-age children and adolescents with type 1 diabetes. *Journal of Pedriatic Nursing,* 22(1): 59-68.

Fischer, L., Glasgow, R.E., Mullan, J.T., Skaff, M.M. & Polonsky, W.H. 2008. Development of a brief diabetes distress screening instrument. *Annals of Family Medicine*, 6: 246-252.

Folke, C. 2006. Resilience: The emergence of a perspective for social–ecological systems analyses. *Global Environmental Change,* 16: 253–267

Frank, A.W. 1991. *At the will of the body: Reflections on Illness.* Boston: Houghton Mifflin.

Frank, A.W. 2004. After Methods, the Story: From Incongruity to Truth in Qualitative Research. *Qualitative Health Research,* 14: 430-440.

Freese, J., Li, J.-C.A.L. & Wade, L.D. 2003. The potential relevances of biology to social inquiry, *Annual Review of Sociology,* 29: 233-256.

Frohlich, K.L., Corin, E. & Potvin, L. 2001. A theoretical proposal for the relationship between context and disease. *Sociology of Health and Illness,* 23(6): 776-797.

Funnell, M.M. & Anderson, R.M. 2004. Empowerment and self-management education. *Clinical Diabetes,* 22: 123-127).

Funnell, M.M. & Anderson, R.M. 2007. AADE Position statement: individualization of diabetes self-management education. *Diabetes Educator,* 33: 45-49.

Funnell, M.M., Brown, T.L., Childs, B.P., Haas, L.B., Hosey, G.M., Jensen, B., Maryniuk, M., Peyrot, M., Piette, J.D., Reader, D., Siminerio, L.M., Weinger, K. & Weiss, M.A. 2011. National standards for diabetes self-management education. *Diabetes Care,* 34(1): S89-S96.

Garay-Sevilla, M.E., Nava, L.E., Malacara, J.M., Huerta, R., De Leon, J.D., Mena, A. & Fajardo, M.E. 1995. Adherence to treatment and social support in patients with non-insulin dependent diabetes mellitus. *Journal of Diabetes Complications,* 2: 81-86.

Gary, T. L., Genkinger, J. M., Guallar, E., Peyrot, M., & Brancati, F. L. 2003. Meta-analysis of randomized educational and behavioral interventions in type 2 diabetes. *Diabetes Educator,* 29(3): 488-501.

Gatrell, A.C., 2002. Geographies of Health: An Introduction. Blackwell, Oxford.

Gatrell, A.C., Popay, J & Thomas, C. 2004. Mapping the determinants of health inequalities in social space: can Bourdieu help us? *Health & Place,* 10: 245–257.

Gauteng Department of Health. 2008. *Health in Gauteng Status Report 2006/2007.* S98.

Geiss, L.S., Pan, L., Cadwell, B., Gregg, E.W., Benjamin, S.M. & Engelgau, M.M. 2006. Changes in incidence of diabetes in U.S. adults, 1997-2003. *American Journal of Preventative Medicine,* 30(5): 371-377.

Giddens, A. 1979. *Central problems in social theory.* London: Macmillan.

Gill, G.V., Mbanya, J.C., Ramaiya, K.L. & Tesfaye, S. 2009. A sub-Saharan African perspective of diabetes. *Diabetologia,* 52: 8-16.

Gilson, L. & McIntyre, D. 2007. Post-apartheid challenges: Household access and use of health care in South Africa. *International Journal of Health Services,* 37(4): 673-691.

Given, C.W.; Given, B.A., Gallin, R.S. & Condon, J.W. 1983. Development of scales to measure beliefs of diabetic patients. *Research in Nursing & Health,* 6: 127-141.

Glaeser, E.L., Laibson, D. & Sacerdote, B. 2002. An Economic Approach to Social Capital. *The Economic Journal*, 112(November): 437-458.

Glanz, K., Rimer, B.K. & Viswanath, K. 2008. Theory, Research, and Practice in health behavior and health education In K. Glanz, B.K. Rimer & K. Viswanath, K. (Eds). Health behavior and health education: theory, research, and practice, 4th Edition, (pp. 23-40). John Wiley & Sons: Jossey-Bass, CA: San Francisco.

Glasgow, R.E., Toobert, D.J., Hampson, S.E., Brown, J.E., Lewinsohn, P.M. & Donnelly, J. 1992. Improving self-care among older patients with type II diabetes: the "Sixty Something…" study. *Patient Education Counselling,* 19: 61-74.

Glasgow, R.E., Strycker, L.A., Toobert, D.J. & Eakin, E. 2000. A social-ecologic approach to assessing support for diabetes self-management: the Chronic Illness Resources Survey. *Journal of Behavioral Medicine,* 23(6): 559-583.

Glasgow, R.E., Toobert, D.J. & Gillette, C.D. 2001. Psychosocial barriers to diabetes self-management and quality of life. *Diabetes Spectrum,* 14(1): 33-41.

Glasgow, R.E., Wagner, E.H., Kaplan, R.M., Vinicor, F., Smith, L. & Norman, J. 1999. If diabetes is a public health problem, why not treat it as one? a population-based approach to chronic illness. *Annals of Behavioral Medicine,* 21(2): 159-170.

Goffman, E. 1963. *Stigma: Notes on the management of a spoiled identity.* Englewood Cliffs, New Jersey: Prentice-Hall.

Golden, S.D. & Earp, J.L. 2012. Social Ecological Approaches to Individuals and Their Contexts: Twenty Years of Health Education & Behavior Health Promotion Interventions. *Health Education & Behavior,* 39(3): 364–372.

Gollwitzer, P.M. 1993. Goal achievement: The role of intentions. *European Review of Social Psychology,* 4: 141-185.

Gordon, W. & Langmaid, R. 1988. *Qualitative market research: a practioner's and buyer's guide.* London: Gower.

Gomersall, T., Madill, A. & Summers, L.K. M. 2011. Evidence for Practice: A Metasynthesis of the Self Management of Type 2 Diabetes. *Qualitative Health Research,* 1-20.

Greco, P., La Greca, A.M., Ireland, S., Wick, P., Freeman, C., Agramonte, R., Gutt, M. & Skyler, J. 1990. Assessing adherence in IDDM: a comparison of two methods. *Diabetes,* 40(Suppl.1): A657, 1: 64.

Guariguata, L., Whiting, D.R., Hambleton, I., Beagley, J., Linnenkamp, U. & Shaw, J.E. 2014. Global estimates of diabetes prevalence for 2013 and projections for 2035. Diabetes Research and Clinical Practice, 103: 137-149.

Gucciardi, E., Chan, V.W-S., Manuel, L. & Sidani, S. 2013. A systematic literature review of diabetes self-management education features to improve diabetes education in women of Black African/Caribbean and Hispanic/Latin American ethnicity. *Patient Education and Couselling,* 92: 235-245.

Hall, V., Thomsen, R.W., Henriksen, O. & Lohse, N. 2011. Diabetes in sub-Saharan Africa 1999-2011: Epidemiology and public health implications: A systematic review. *BioMed Central, Public Health,* 11(564): 1-12.

Hampson, S. E., Glasgow, R. E., & Toobert, D. J. 1990. Personal models of diabetes and their relations to self-care activities. *Health Psychology,* 9(5): 632-646.

Hardeman, W., Johnston, M., Johnston, D.W., Bonetti, D., Wareham, N.J. & Kinmonth, A.L. 2002. Application of the theory of planned behaviour in behaviour change interventions: a systematic review. *Psychology & Health,* 17(2): 125-158.

Harris, B., Goudge, J., Ataguba, J.E., McIntyre, D., Nxumalo, N., Jikwanac, S. & Chersich, M. 2011. Inequities in access to health care in South Africa. *Journal of Public Health Policy,* 32(S1): S102-S123.

Haub, C. & Kaneda, T. 2013 *World Population Data Sheet.* Washington, DC: Population Reference Bureau, 2013.

Hawe, P. & Potvin, L. 2009. What is population health intervention? *Canadian Journal of Public Health,* 100(1): I-8-I-14.

Hawe, P. & Shiell, A. 2000. Social capital and health promotion: a review. *Social Science & Medicine,* 51: 871-885.

Health Systems Trust. 2007. Health statistics. Retrieved November 27, 2009 from: http://www.hst.org.za/healthstats/275/data

Hearst, E. 1991. Psychology and nothing. *American Scientist,* 79: 432-443.

Heisler, M., Smith, D.M., Hayward, R.A., Krein, S.L. & Kerr, E.A. 2003. How well do patients' assessments of their diabetes self-management correlate with actual glycaemia control and receipt of recommended diabetes services? *Diabetes Care,* 26(3): 738-743.

Heisler, M., Piette, J.D., Spencer, M., Kieffer, E. & Vijan, S. 2005. The relationship between knowledge of recent HbA1c values and diabetes care understanding and self-management. *Diabetes Care,* 28(4): 816-822.

Hennink, M., Hutter, I. & Bailey, A. 2011. *Qualitative research methods.* London: Sage.

Herek, G.M., Mitnick, L., Burris, S., Chesney, M., Devine, P., Fullilove, M.T., Fullilove, R., Gunther, H.C., Levi, J., Michaels, S., Novick, A., Pryor, J., Snyder, M. & Sweeney, T. 1998. AIDS and stigma: A conceptual framework and research agenda. *AIDS & Public Policy Journal,* 13: 36-47.

Hertzman, C., Power, C., Matthews, S. & Manor, O. 2001. Using an interactive framework of society and lifecourse to explain self-rated health in early adulthood. *Social Science & Medicine,* 53: 1575-1585.

Hinder, S. & Greenhalgh, T. 2012. This does my head in. Ethnographic study of self-management by people with diabetes. *Health Services Research,* 12:83 1472-1483.

Ho, P.M., Bryson, C.L. & Rumsfeld, J.S. 2009. Medication Adherence: It's Importance in Cardiovascular Outcomes. *Circulation,* 119: 3028-3035.

Hofstee, E. 2006. Constructing a Good Dissertation: A Practical Guide to Finishing a Masters, MBA or PhD on Schedule. South Africa, Sandton: EPE.

Holmstrom, I.M. & Rosenqvist, U. 2005. Misunderstandings about illness and treatment among patients with type 2 diabetes. *Journal of Advanced Nursing,* 49: 146-154.

Horowitz, C.R., Colson, K.A., Hebert, P.L. & Lancaster, K. 2004. Barriers to buying healthy foods for people with diabetes: evidence of environmental disparities. *American Journal of Public Health,* 94(9): 1549-1554.

House, J. S., Landis, K. R. & Umberson, D. 1988. Social relationships and health. *Science,* 241: 540–545.

Human Sciences Research Council (HSRC). Undated. A national health system - opportunities and challenges for South Africa. Presented by the CEO of the HSRC. Retrieved May 7, 2011 from: http://www.hsrc.ac.za/Document-2319.phtml

Hunt, K., Emslie, C. & Watt, G. 2001. Lay constructions of a family history of heart disease: potential for misunderstandings in the clinical encounter? *The Lancet,* 357: 1168-1171.

Hunt, L.M., Jordan, B. & Irwin, S. 1989. Views of what's wrong: diagnosis and patients' concepts of illness. *Social Science & Medicine,* 28: 945-956.

Ingadottir, B. & Halldorsdottir, S. 2008. To discipline a "dog": The essential structure of mastering diabetes. *Qualitative Health Research,* 18(5): 606-619.

Iglehart, J.K. 2008. No Place Like Home —Testing a New Model of Care Delivery. *New England Journal of Medicine,* 359 (12): 1200–1202.

Illane-Parikka, P., Eriksson, J.G., Lindstrom, J., Peltonen, M., Aunola, A., Hamalainen, H.H., Keinanen-Kiukaanniemi, S.K., Laakso, M., Valle, T.T, Lahtela, J., Uusitupa, M. & Tuomiletho, J. 2008. Effect of lifestyle intervention on the occurrence of metabolic syndrome and its components in the Finnish diabetes prevention study. *Diabetes care,* 31(4): 805-807.

International Diabetes Federation (IDF). 2003. *Diabetes Atlas,* 2nd edition, Brussels: International Diabetes Federation.

International Diabetes Federation (IDF). 2011. *IDF Diabetes Atlas 2011,* 5th edition*.* Retrieved May 8, 2011 from: http://www.idf.org/diabetesatlas/5e/africa

International Diabetes Federation (IDF). 2013. *IDF Diabetes Atlas 2013,* 6th edition*. Printed version.* Retrieved September 10, 2014 from: http://www.idf.org/diabetesatlas

Islam, M.K., Merlo, J., Kawachi, I., Lindström, M. & and Gerdtham, UG. 2006. Does egalitarianism matter? A literature review. *International Journal for Equity in Health*, 5:3.

Jansa, M., Hernandez, C., Vidal, M., Nunez, M., Bertran, M.J., Sanz, S., Castell, C. & Sanz, G. 2010. Medication Adherence. Multidimensional analysis of treatment adherence in patients with multiple chronic conditions. A cross-sectional study in a tertiary hospital. *Patient Education and Counseling*, 81: 161–168.

Janz, N.K. & Becker, M.H. 1984. The Health Belief Model: A Decade Later. *Journal of Research in Medical Sciences, Health Education Behavior,* 11 (1): 1-47.

Kalk, W.J., Huddle, K.R.L. & Raal, F.J. 1993. The age of onset of insulin-dependent diabetes mellitus in Africans in South Africa. *Postgraduate Medicine Journal,* 69: 552-556.

Kalberg, S. 1994. *Max Weber's Comparative-Historical Sociology,* Cambridge: Polity Press.

Kamrul Islam, M., Merlo, J., Kawachi, I., Lindstrom, M. & Gerdtham, Ulf-G. 2006. Social capital and health: Does egalitarianism matter? A literature review. *International Journal for Equity in Health,* 5(3): 5-39. Retrieved October 12, 2014 from: http://www.equityhealthj.com/content/5/1/3

Kaplan, G.A. 2004. What's wrong with social epidemiology, and how can we make it better? *Epidemiologic Reviews,* 26(1): 124-135.

Kartal, A. & Ozsoy, S.A. 2007. Validity and reliability study of the Turkish version of Health Belief Model Scale in diabetic patients. *International Journal of Nursing Studies,* 44(8): 1447-1458.

Katula J.,A., Vitolins, M.Z., Rosenberger, E.L., Blackwell, C., Espeland, M.A., Lawlor, M.S., Rejeski, W.J. & Goff, D.C. 2010. Healthy living partnerships to prevent diabetes (HELP PD): Design and methods. *Contemporary Clinical Trials,* 31: 71-81.

Kawachi, I. 2002. Social epidemiology. *Social Science and Medicine,* 54(12): 1739-1741. Editorial.

Kawachi, I. & Berkman, L. 2000. Social cohesion, social capital, and health. In L.F. Berkman & I. Kawachi (Eds.), *Social Epidemiology,* (pp. 174-190). New York: Oxford University Press.

Kawachi, I., Kennedy, B.P. & Glass, R. 1999. Social capital and self-rated health: A contextual analysis. *American Journal of Public Health,* 89(8): 1187-1193.

Kawachi, I., Kennedy, B.P., Lochner, K. & Prothrow-Stith, D. 1997. Social capital, income inequality, and mortality. *American Journal of Public Health,* 87(9): 1491-1498.

Kawachi, I., Kim, D., Coutts, A. & Subramanian, S.V. 2004. Reconciling the three accounts of social capital. *International Journal of Epidemiology*, 33: 682-690.

Kegler, M.C. & Glanz, K. 2008. Perspectives on group, organization, and community interventions. In K. Glanz, B.K. Rimer & K. Viswanath, K. (Eds). Health behavior and health education: theory, research, and practice, 4th Edition, (pp. 389-403). John Wiley & Sons: Jossey-Bass, CA: San Francisco.

Kelly, M. 1992. Self, identity and radical surgery. *Sociology of Health and Illness,* 14(3): 390-415.

Kelly, M. & Field, D. 1996. Medical sociology, chronic illness and the body. *Sociology of Health and Illness,* 19(3): 359-366.

Kernick, D. 2002. The demise of linearity in managing health services: a call for post normal health care. *Journal of Health Services & Policy,* 7(2): 121-124.

Kim, C., Newton, K.M. & Knopp, R.H. 2002. Gestational diabetes and the incidence of type 2 diabetes: A systematic review. *Diabetes Care,* 25(10): 1862-1868.

Kimura, M., Yamazaki, S., Haga, H., & Yasumura, S. 2013. The prevalence of social engagement in the disabled elderly and related factors. *ISRN Geriatrics, Article* ID 709823.

Kindig, D. & Stoddart, G.L. 2003. What is population health? *American Journal of Public Health,* 93: 380-383.

Krause, N., Herzog, A. R., & Baker, E. 1992. Providing support to others and well-being in later life. *Journal of Gerontology: Psychological Sciences,* 47: P300–P311.

Krieger, N. 2001a. A glossary for social epidemiology. *Journal of Epidemiology and Community Health,* 55: 693-700.

Krieger, N. 2001b. Theories for social epidemiology in the 21st century: An ecosocial perspective. *Journal for Epidemiology and Community Health,* 30(4): 668-677.

Krishna, A. 2007. For reducing poverty faster: Target reasons before people. *World Development,* 35(11): 1947-1960.

Kristsotakis, G. & Gamarnikow, E. 2004. What is social capital and how does it relate to health? *International Journal of Nursing Studies,* 41: 43-50.

Krueger, R.A. 1988. *Focus groups: A practical guide for applied research.* Newbury Park, California: Sage Publications, Inc.

Kuh, D.L. & Ben-Shlomo, Y. 1997. *A life course approach to chronic disease epidemiology: tracing the origins of ill-health from early to adult life.* Oxford: Oxford University Press.

Kumanyika, S.K., Obarzanek, E., Stettler, N., Bell, R., Field, A.E., Fortmann, S.P., Franklin, B.A., Gillman, M.W., Lewis, C.E., PostonII, W.C., Stevens, J. & Hong, Y. 2008. Population-based prevention of obesity: The need for comprehensive promotion of healthful eating, physical activity, and energy balance. A scientific statement from the American Heart Association Council on Epidemiology and Prevention, Interdisciplinary Committee for Prevention (formerly the Expert Panel on Population and Prevention Science). *Circulation: Journal of the American Heart Association,* 118: 428-464.

La Greca, A.M. 2004. *Manual for the Self Care Inventory*. Miami: University of Miami.

Lawrence, J.M., Contreras, R., Chen, W. & Sacks, D.A. 2008. Trends in the prevalence of pre-existing diabetes and gestational diabetes mellitus among a racially/ethnically diverse population of pregnant women, 1999-2005. *Diabetes Care,* 31(5): 899-904.

Lawton, J., Ahmad, N., Peel, E. & Hallowell, N. 2007. Contextualising accounts of illness: notions of responsibility and blame in white and South Asian respondents' accounts of diabetes causation. *Sociology of Health & Illness,* 29(6): 891-906.

Lawton, J., Peel, E., Parry, O. & Douglas, M. 2008. Shifting accountability: A longitudinal qualitative study of diabetes causation accounts. *Social Science & Medicine,* 67: 47-56.

Leedy, P.D. & Ormrod, J.E. 2010. *Practical research planning and design.* Upper Saddle River, New Jersey: Pearson Education.

Lemke, T. 2002. Foucault, governmentality, and critique, Rethinking Marxism. *A Journal of Economics, Culture & Society,* 14(3): 49-64.

Lerman, I., Lozano, L., Villa, A.R., Hernandez-Jimenez, S., Weinger, K., Caballero, A.E., Salinas, C.A., Velasco, M.L., Gomez-Perez, F.J. & Rull, J.A. 2004. Psychosocial factors associated with poor diabetes self-care management in a specialized Center in Mexico City. *Biomedicine and Pharmacotherapy,* 58: 566-570.

Leventhal, H., Leventhal, E.A. & Contrada, R.J. 1998. Self-regulation, health, and behavior: A perceptual cognitive approach. *Psychology & Health,* 13(4): 717-733.

Levitt, N.S. 2008. Diabetes in Africa: epidemiology, management and healthcare challenges. *British Medical Journal, Global burden of cardiovascular disease,* 94: 1376-1382.

Levitt, N. 2009. SEMDSA guidelines for type 2 diabetes 2009. *Journal of Endocrinology Metabolism and diabetes of South Africa,* 14(1).

Lewin, K. 1943. Psychology and the process of group living. *The Journal of Social Psychology, S.P.S.S.I. Bulletin,* 17: 113-131.

Lewin, K. 1947. Frontiers in group dynamics: II. Channels of group life; social planning and action research. *Human Relations,* 1: 143-153.

Liburd, L.C., Jack, L., Williams, S. & Tucker, P. 2005. Intervening on the Social Determinants of Cardiovascular Disease and Diabetes. *American Journal of Preventive Medicine,* 29(5S1): 18-24.

Lin, N. 1999. Building a network theory of social capital. *Connections,* 22 (1): 28-51.

Lindlof, T.R. & Taylor, B.C. 2002. *Qualitative communication research methods,* 2nd edition. Thousand Oaks, CA: Sage.

Link, B.G. 2008. Epidemiological Sociology and the Social Shaping of Population Health. *Journal of Health and Social Behavior,* 49 (December): 367–384.

Link, B.G. & Phelan, J.C. 2002. McKeown and the idea that social conditions are fundamental causes of disease. *Health Policy and Ethics,* 92(5): 730-732. Peer reviewed.

Link, B.G. & Phelan, J.C. 2006. Stigma and its public health implications. *The Lancet,* 367: 528-529.

Lipton, R.B., Losey, L.M., Giachello, A., Mendez, J. & Girotti, M.H. 1998. Attitudes and issues in treating Latino patients with type 2 diabetes: views of healthcare providers. *The Diabetes Educator,* 25: 67-71.

Lipowsky, Z.J. 1970. Physical illness, the individual and the coping process. *Psychiatry in Medicine,* 1: 91-101.

Lloyd, C., Smith, J. & Weinger, K. 2005. Stress and diabetes: a review of the links. *Diabetes Spectrum,* 18(2): 121-127.

Lochner, K., Kawachi, I. & Kennedy, B.P. 1999. Social capital: a guide to its measurement. *Health & Place*, 5: 259-270.

Lorig, K.R., Ritter, P., Stewart, A.L., Sobel, D.S., Brown Jr, B.W., Bandura, A., Gonzalez, V.M., Laurent, D.D. & Holman, H.R. 2001. Chronic disease self-management program: two-year health status and health care utilization outcomes. *Medical Care,* 39(11): 1217-1223.

Lorig, K., Ritter, P.L., Villa. F.J. & Armas J. 2009. Community-based peer-led diabetes self-management: a randomized trial. *Diabetes Education,* 35: 641–651.

Lubben, J. E., Weiler, P. G., & Chi, I. 1989. Health practices of the elderly poor. *American Journal of Public Health,* 79: 731–734.

Lubben, J., Blozik, E., Gillmann, G., Iliffe, S., von Renteln Kruse, W., Beck, J., & Stuck, A. 2006. Performance of an abbreviated version of the Lubben Social Network Scale among three European community-dwelling older adult populations. *The Gerontologist,* 46(4): 503-513.

Lubben, J., Gironda, M., Sabbath, E. Kong, J., & Johnson, C. 2015. Social isolation presents a grand challenge for social work (Grand Challenges for Social Work Initiative Working Paper No. 7). Cleveland, OH: *American Academy of Social Work and Social Welfare,* 1-20.

Lupton, D. 1996. *Food, the Body and the Self.* London: Sage.

Lynam, T., De Jong, W., Sheil, D., Kusumanto, T. & Evans, K. 2007. A review of tools for incorporating community knowledge, preferences and values into decision making in natural resources management. *Ecology and Society*, 12(1): 5: 1-15.

Macinko, J. & Starfield, B. 2001. The utility of social capital in research of health determinants. *The Milbank Quaterly,* 79(3): 387-427.

Manaski, C.F. 2000. Economic Analysis of social interactions. *Journal of Economic Perspectives*, 14: 115-136.

Marten, R., McIntyre, D., Travassos, C., Shishkin, S., Longde, W., Reddy, S. & Vega, J. 2014. An assessment of progress towards universal health coverage in Brazil, Russia, India, China, and South Africa (BRICS). *Lancet,* 384: 2164–71.

Martikainen, P., Bartley, M. & Lahelma, E. 2002. Psychosocial determinants of health in social epidemiology. *International Journal of Epidemiology,* 31: 1091-1093.

Matthews, B. 1996. Drawing scientists. *Gender and Education,* 8: 231-243.

Maty, S.C., Everson-Rose, S.A., Haan, M.N., Raghunathan, T.E. & Kaplan, G.A. 2005. Education, income, occupation, and the 34-year incidence (1965-99) of type 2 diabetes in the Almeda County study. *International Journal of Epidemiology,* 34: 1274-1281.

May, C. 2005. Chronic illness and intractability: professional-patient interactions in primary care. *Chronic Illness,* 1: 15-20.

Mayosi, B.M., Flisher, A.J., Lalloo, U.G., Sitas, F., Tollman, S.M. & Bradshaw, D. 2009. The burden of non-communicable diseases in South Africa. *The Lancet,* 374: 934–47.

Mayosi, B.M., Lawn, J.E., Van Niekerk, A., Bradshaw, D., Abdool-Karim, S.S. & Coovadia, H.M. 2012. Health in South Africa: changes and challenges since 2009. *The Lancet,* 380: 2029-2043.

Mayosi, B.M. & Benatar, S.R. 2014. Special Report: Health and Health Care in South Africa – 20 Years after Mandela. *The New England Journal of Medicine,* 371(14): 1344-1353.

Mbanya, J.C. & Ramiaya, K. 2006. Diabetes Mellitus. In D.T. Jamison, R.G. Feachem, M.W. Makgoba, E.R.Bos, F.K. Baingana, K.J. Hofman & K.O. Rogo (Eds), *Disease and Mortality in Sub-Saharan Africa, Second Edition* (pp. 267-287). Washington: The International Bank for Reconstruction and Development/ The World Bank.

Mbanya, J.C.N., Motala, A.A., Sobngwi, E., Assah, F.K. & Enoru, S.T. 2010. Diabetes in sub-Saharan Africa. *The Lancet,* 375: 2254-2266.

McHugh, J., & Lawlor, B. 2012. Social support differentially moderates the impact of neuroticism and extraversion on mental wellbeing among community-dwelling older adults. *Journal of Mental Health,* 21(5): 448–458.

McIntyre, D., Goudge, J., Harris, B., Nxumalo, N. & Nkosi, M. 2009. Prerequisites for national health insurance in South Africa: Results of a national household survey. *South African Medical Journal,* 99(10): 725-729.

McKinlay, J. & Marceau, L. 2000. US public health and the 21st century: diabetes mellitus. *The Lancet,* 356(9231): 757-761.

McMichael, A.J. 1999. Prisoners of the proximate: loosening the constraints on epidemiology in an age of change. *American Journal of Epidemiology,* 149(10): 887-897.

McMichael, A.J. 2006. Population health as the 'bottom line' of sustainability: a contemporary challenge for public health researchers. *European Journal of Public Health,* 16 (6): 579–582

Medical Research Council (MRC). 2001. *South African cause of death profile.* MRC Technical Report. MRC: Cape Town, September 2001. ISBN 1-919809. Retrieved September 10, 2010 from:
http://www.ac.za//bod/1996deathcause.pdf

Mendez, M.A., Monteiro, C.A. & Popkin, B.M. 2005. Overweight exceeds underweight among women in most developing countries. *American Journal of Clinical Nutrition,* 81: 714-721.

Michael, Y.L., Berkman, L.F., Colditz, G.A. & Kawachi, I. 2001. Living arrangements, social integration, and change in functional health status. *American Journal of Epidemiology,* 153(2): 123-131.

Mirowsky, J. & Ross, C.E. 2003. *Education, Social Status, and Health.* New York: Aldine de Gruyter.

Monteiro, C.A, Conde, W.L., Lu, B. & Popkin, B.M. 2004. Obesity and inequalities in health in the developing world. *International Journal of Obesity,* 27(9): 1181-1186.

Monteiro, C.A., Moura, E.C., Conde, W.L. & Popkin, B.M. 2004. Socioeconomic status and obesity in adult populations of developing countries: Public Health Reviews. *Bulletin of the World Health Organization,* 82(12): 940-946.

Morgan, D.L. 1998. *Planning focus groups.* Thousand Oaks, CA: Sage.

Moskowitz, J.T., Epel, E.S. & Acree, M. 2008. Positive affect uniquely predicts lower risk of mortality in people with diabetes. *Health Psychology,* 27(1 Suppl): S73-S82.

Motala, A.A., Omar, M.A.K. & Pirie, F.J. 2001. Africa. In J-M. Ekoe', P. Zimmet & R. Williams (Eds.), *The epidemiology of diabetes mellitus: An international perspective* (pp. 225-232). West Sussex, England: John Wiley & Sons Ltd.

Motala, A.A., Omar, M.A.K. & Pirie, F.J. 2003. Diabetes in Africa. Epidemiology of type 1 and type 2 diabetes in Africa. *European Journal of Cardiovascular Risk,* 10: 77-83.

Motala, A.A., Esterhuizen, T., Gouws, E., Pirie, F.J. & Omar, M.AK. 2008.Diabetes and other disorders of glycemia in a rural South African community: Prevalence and associated risk factors. *Diabetes Care,* 31(9): 1783-1788.

Motala, A.A., Levitt, N., Berg, J., Young, M., Grobler, N., Heilbrunn, A., Distiller, L., Pirie, F., Dave, J., Huddle, K., Jivan, D., Paruk, I., May, W., Raal, D., Blom, D., Ascott-Evans, B., Brown, S., Mollentze, W., Rheeder, P., Tudhope, L., Van Rensburg, G., Ganie, Y., Carrihill, M., Rauff, S., Van Zyl, D., Randeree, H., Khutsoane, D., Joshi, P., Raubenheimer, P. & Guideline Committee. 2012. The 2012 SEMDSA guideline for the management of type 2 diabetes. *Journal of Endocrinology, Metabolism and Diabetes of South Africa* (*JEMDSA*)*,* 17(1):S1-S94.

Mouton, J. 1996. *Understanding social research.* Pretoria: J.L. Van Schaik.

Mouton, J. 2001. *How to succeed in your Master's and Doctoral Studies: A South African guide and resource book.* Pretoria: Van Schaik Publishers.

Murray, C.J.L. et al. (more than 200 authors – all names not listed) 2012. Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990-2010: a systematic analysis for the Global Burden of Disease Study 2010. *The Lancet,* 380: 2197-2223.

Nagelkerk, J., Reick, K. & Meengs, L. 2006. Perceived barriers and effective strategies to diabetes self-management. *Journal of Advanced Nursing,* 54(2): 151-158.

Nam, S., Chesla, C., Stotts, N.A., Kroon, L. & Janson, S.L. 2011. Barriers to diabetes management: Patient and provider factors. *Diabetes Research and Clinical Practice,* 93: 1-9.

Narayan, D. 2002. Bonds and Bridges: Social Capital and Poverty. In *Social Capital and Economic Development: Well-Being in Developing Countries* Edited by: Jonathan Isham, Thomas Kelly, Sunder Ramaswamy. Northampton, MA: Edward Elgar; 58-81.

National Research Council. 2001. *New horizons in health: An integrative approach.* Washington, DC: National Academy Press.

Neaigus, A. 1998. The network approach and interventions to prevent HIV among injection drug users. *Public Health Reports June 1998,* 113 (suppl 1): 140-150.

Norman, R., Bradshaw, D., Schneider, M., Pieterse, D. & Groenewald, P. 2006. *Revised burden of disease estimates for the comparative risk factor assessment, South Africa 2000*. Cape Town: Medical Research Council.

Norris, S. L., Engelgau, M. M., & Venkat, N. K. M. 2001. Effectiveness of self-management training in type 2 diabetes. *Diabetes Care,* 24(3): 561-587.

Norris, S.L., Lau, J., Smith, S.J., Schmid, C.H. & Engelgau, M.M. 2002. Self-management education for adults with Type 2 diabetes. *Diabetes Care,* 25(7): 1159-1171.

Nxumalo, N., Alaba, O., Harris, B., Chersich, M. & Goudge, J. 2011. Utilization of traditional healers in South Africa and costs to patients: Findings from a national household survey. *Journal of Public Health Policy,* 32(Supp 1): S124-S136.

Ockleford, E., Shaw, R.L., Willars, J. & Dixon-Woods, M. 2008. Education and self-management for people newly diagnosed with type 2 diabetes; a qualitative study of patients' views. *Chronic Illness,* 4: 28-37.

Omran, A.R. 1971. The epidemiologic transition: A theory of the epidemiology of population change. *The Milbank Memorial Fund Quarterly,* 49(4): 509-538.

Page, K.A., Romero, A., Buchanan, T.A. & Xiang, A.H. 2014. Gestational diabetes mellitus, maternal obesity, and adiposity in offspring. *The Journal of Pediatrics,* 164: 807-810.

Pakenham, K.I., Pruss, M. & Clutton, S. 2000. The utility of socio-demographics, knowledge and health belief model variables in predicting re-attendance for mammography screening: A brief report. *Psychology and Health,* 15: 585-591.

Panum, P.L. 1858. *Physiologische untersuchungen uber das Sehen mit zwei augen.* Kiel: Schwerssche Buchhandlung.

Parsons, T. 1951. *The social system.* London: Mackays of Chatham PLC. New edition 1991.

Peer, N., Steyn, K., Lombard, C., Lambert, E.V., Vythilingum, B. & Levitt, N.S. Rising Diabetes Prevalence among Urban-Dwelling Black South Africans. Published online: September 4, 2012 DOI: 10.1371/journal.pone.0043336. Retrieved June 10, 2015 from: http://0journals.plos.org.innopac.up.ac.za/plosone/article?id=10.1371/journal.pone.0043336

Penson, D. & Wessells, H. 2004. Erectile dysfunction in diabetic patients. *Diabetes Spectrum,* 17 (4): 225-230.

Pescosolido, B.A., Martin, J.K., Lang, A. & Olafsdottir, S. 2008. Rethinking theoretical approaches to stigma: A framework integrating normative influences on stigma (FINIS). *Social Science & Medicine,* 67: 431-440.

Pettigrew, T.F. 1998. Intergroup Contact Theory. *Annual Review of Psychology,* 49: 65-85.

Pickett, K.E. & Pearl, M. 2001. Multilevel analyses of neighbourhood socioeconomic context and health outcomes: a critical review. *Journal of Epidemiological Community Health,* 55: 111-122.

Polonsky, W.H., Anderson, B.J., Lohrer, P.A., Welch, G., Jacobson, A.M., Aponte, J.E. & Schwartz, C.E. 1995. Assessment of diabetes related distress. *Diabetes Care,* 18 (6): 754-760.

Polonsky, W.H. & Welsch, G. 1996. Listening to our patients' concerns: understanding and addressing diabetes-specific emotional distress. *Diabetes Spectrum,* 9(8): 8-11.

Popkin, B.M. 2002. The shift in stages of the nutrition transition in the developing world differs from past experiences. *Public Health Nutrition,* 5(1A): 205-214.

Popkin, B.M., Siega-Riz, A.M., Haines, P.S. & Jahns, L. 2001. Where's the Fat? Trends in U.S. Diets 1965-1996. *Preventive Medicine,* 32: 245-254.

Potts, M. K., Hurwicz, M. L., Goldstein, M. S., & Berkanovic, E. 1992. Social support, health promotive beliefs, and preventive health behaviors among the elderly. *Journal of Applied Gerontology,* 11: 425–441.

Poundstone, K.E., Strathdee, S.A. & Celentano, D.D. 2004. The social epidemiology of Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome. *Epidemiologic Reviews,* 26: 22-35.

Putnam, R.D. 1993. *Making democracy work.* Princeton, NJ: Princeton University Press.

Putnam, R.D. 1995. Bowling alone: America's declining social capital. *Journal of Democracy,* January 1995: 65-78.

Quicke, J. & Winter, C. 1994. Labeling and learning: an interactionist perspective. *Support for Learning,* 9: 16-21.

Rajaram, S.S. & Vinson, V. 1998. African American women and diabetes: A sociocultural context. *Journal of Health Care for the Poor and Underserved,* 9(3): 236-247.

Reblin, M. & Uchino, B.N. 2008. Social and emotional support and its implication for health. *Current Opinion in Psychiatry*, 21:201–205

Reece, E.A., Leguizamon, G. & Wiznitzer, A. 2009. Gestational diabetes: the need for a common ground. *The Lancet,* 373: 1789-1797.

Reeder, L.G. 1972. Social epidemiology: an appraisal. (pp. 97-101). In: E.G. Jaco (Ed). *Patients, Physicians, and Illness.* 2nd Edition. New York: The Free Press.

Reid, I. 1998. *Social class differences in Britain.* Cambridge, United Kingdom: Polity Press.

Republic of South (RSA), Department of Health. 2005*. National guidelines for the management of diabetes type 1 and 2 in adults at hospital level.* Pretoria: Government Printers.

Republic of South Africa (RSA) Statistics South Africa (StatsSA). 2013. Mortality and causes of death in South Africa: Findings from death notification 2013. Statistical release P0309.3. Pretoria: Statistics South Africa.

Resnicow, K., Baranowski, T., Ahluwalia, J. & Braithwaite, R. 1999. Cultural sensitivity in public health: defined and demystified. *Ethnicity and Disease,* 9: 10-21.

Rheeder, P. 2003. *Obesity and diabetes related complications in South African Black women.* Unpublished doctoral thesis. Utrecht: University of Utrecht.

Rheeder, P. 2006. Type 2 diabetes: the emerging epidemic. *SA Family Practitioner,* 48(10): 20.

Ritzer, G. 2011. *The McDonaldization of Society6.* 6th edition. London: Sage Publications.

Ritzer, G. & Goodman, D.J. 2004. *Classical sociological theory.* New York: McGraw-Hill.

Rook, K. S. 1994. Assessing the health-related dimensions of older adults' social relationships. (pp. 142–181). In M. P. Lawton & J. Teresi (Eds.), *Annual review of gerontology and geriatrics New York,* NY: Springer.

Roglic, G. & Unwin, N. 2010. Mortality attributable to diabetes: Estimates for the year 2010. *Diabetes Research Clinical Practice,* 87: 15-19.

Roglic, G. & Unwin, N. 2013. Mortality attributable to diabetes: Estimates for the year 2011. *Diabetes Research Clinical Practice,* 100(2): 15-19.

Rose, G. 1985. Sick individuals and sick populations. *International Journal of Epidemiology,* 14(1): 32-38.

Rose, G. 2001. Sick individuals and sick populations. *International Journal of Epidemiology,* 30: 427-432. Reiteration − based on Rose's 1985 article in *International Journal of Epidemiology, International Epidemiological Association,* 14: 32-38.

Rosenberg, C.E. 2007. *Our Present Complaint: American Medicine, Then and Now.* Baltimore, MD: Johns Hopkins University Press.

Rosenstock, I. 1966. Why people use health services. *Milbank Memorial Fund Quarterly,* 44: 94-127.

Rosenstock, I. M. 1974. Historical origins of the health belief model. *Health Education Monographs,* 2: 328–335.

Rosenstock, I.M., Strecher, V.J. & Becker, M.H. 1988. Social learning theory and the Health Belief Model. *Health Education Quarterly,* 15(2): 175-183.

Rosland, A., Heisler, M., Choi, H., Silveira, M.J. & Piette, J.D. 2010. Family influences on self-care management among functionally independent adults with diabetes or heart failure: do family members hinder as much as they help? *Chronic Illness,* 6: 22-33.

Rothenberg, R. 2001. How a net works: implications of network structure for the persistence and control of sexually transmitted diseases and HIV. *Sexually Transmitted Diseases,* 28: 63-68.

Royston, G. & Dick, P. 1998. Health care ecology. *British Journal of Healthcare Management,* 4: 238-241.

Rubin, R.B. & Peyrot, M. 2001. Psychological issues and treatments for people with diabetes. *Journal of Clinical Psychology,* 57(4): 457-478.

Rubin, H.J. & Rubin, I.S. 1995. *Qualitative interviewing: The art of hearing data.* Chicago, IL: Nelson-Hall.

Rubin, H.J. & Rubin, I.S. 2005. *Listening, hearing and sharing social experiences. Qualitative interviewing: The art of hearing data.* Thousand Oaks, California: Sage.

Ryan, G.W. & Bernard, H.R. 2003. Techniques to Identify Themes, *Field Methods,* 15: 85-109.

Saldana, J. 2003. *Longitudinal qualitative research: Analyzing change through time.* Walnut Creek, CA: AltaMira Press.

Saldana, J. 2013. *The coding manual for qualitative researchers.* 2nd edition*.* London: Sage.

Samuel-Hodge, C. D., Headen, S. W., Skelly, A. H., Ingram, A. F., Keyserling, T. C., Jackson, E. J. & Elasy, T. A. 2000. Influences on day-to-day self-management of type 2 diabetes among African-American women: spirituality, the multi-caregiver role, and other social context factors. *Diabetes Care,* 23(7): 928-933.

Scambler, G. 2002. *Health and social change. A critical theory.* Buckingham, UK: Open University Press.

Schabert, J., Browne, J.L., Mosely, K. & Speight, J. 2013. Social stigma in diabetes. A framework to understand a growing problem for an increasing epidemic. *Patient, Springer International Publishing Switzerland.*

Schnittger, R., Wherton, J., Prendergast, D., & Lawlor, B. 2012. Risk factors and mediating pathways of loneliness and social support in community-dwelling older adults. *Aging & Mental Health,* 16(3): 335–346.

Schram, T.H. 2003. *Conceptualizing qualitative inquiry: Mindwork for fieldwork in education and the social sciences.* Upper Saddle River, NJ: Merrill/Prentice Hall.

Schwartz, S. & Diez-Roux, R. 2001. Commentary: Causes of incidence and causes of cases – a Durkheimian perspective on Rose. *International Journal of Epidemiology,* 30: 435-439.

Scully, T. 2012. Diabetes in numbers. *Nature,* 485: S2-S3.

Seeman, T.E. 1996. Social ties and health: the benefits of social integration. *Annals of Epidemiology,* 6: 442-451.

Sewell, Jr. W.H. 1992. A theory of structure: duality, agency, and transformation. *American Journal of Sociology,* 98(1): 1-29.

Sharifirad, G., Entezari, M.H., Kamran, A. & Azadbakht, L. 2009. The effectiveness of nutritional education on the knowledge of diabetic patients using the health belief model. *Journal of Research in Medical Sciences Jan-Feb,* 14(1): 1–6.

Shaw, M., Dorling, D. & Mitchell, R. 2002. *Health, Place and Society*. Harlow: Pearson Education.

Shaw, J.E., Sicree, R.A. & Zimmet, P.Z. 2010. Global estimates of the prevalence of diabetes for 2010 and 2030. *Diabetes Research and Clinical Practice,* 87: 4-14.

Sheeran, P. & Abraham, C. 1996. The health belief model. In M. Conner & P. Norman (Eds.), *Predicting health behaviour* (pp23-61). Buckingham, UK: Open University Press.

Shim, J.K. 2010. Cultural health capital: a theoretical approach to understanding health care interactions and the dynamics of unequal treatment. *Journal of Health and Social Behavior,* 51(1): 1-15.

Shisana, O., Labadarios, D., Rehle, T., Simbayi, L., Zuma, K.., Dhansay, A., Reddy, P., Parker, W., Hoosain, E., Naidoo, P., Hongoro, C., Mchiza, Z., Steyn, N.P., Dwane, N., Makoae, M., Maluleke, T., Ramlagan, S., Zungu, N., Evans, M.G., Jacobs, L., Faber, M. & the SANHANES-1 Team. 2014. South African National Health and Nutrition Examination Survey (SANHANES-1): 2014 Edition. Cape Town: HSRC Press.

Shiu, A.T-K., Kwan, J.J.Y-M. & Wong, R.Y-M. 2003. Social stigma as a barrier to diabetes self-management: implications for multi-level interventions. *Journal of Clinical Nursing,* 12: 149-150.

Sibeon, R. 2004. *Rethinking social theory.* London: Sage Publications Ltd.

Skaff, M.M., Mullan, J.T., Fisher, L. & Chesla, C.A. 2003. A contextual model of control beliefs, behavior, and health: Latino and European Americans with type 2 diabetes. *Psychology & Health,* 18(3): 295-312.

Snow, J. 1854. *Mode of communication of cholera.* London: John Churchhill, New Burlington Street.

South African Government Information. 2009. *Gauteng health and social development on World Diabetes Day.* Retrieved August 26, 2010 from: http://www.info.gov.za/speech/DynamicAction?pageid=461&sid=5360&tid=5505

SouthAfrica.info. 2015. Healthcare in South Africa. Retrieved June 15, 2015 from: http://www.southafrica.info/about/health/health.htm#.VYEmZPmqpHx

Spenceley, S.M. & Williams, B.A. 2006. Self-care from the perspective of people living with Diabetes. *Canadian Journal of Nursing Research,* 38(3): 124-145.

Spencer, M.S., Kieffer, E.C., Sinco, B.R., Palmisano, G., Guzman, J.R., James, S.A., Graddy-Dansby, G., Two Feathers, J. & Heisler, M. 2006. Diabetes-specific emotional distress among African Americans and Hispanics with type 2 diabetes. *Journal of Health Care for the Poor and Underserved,* 17(2): 88-105.

Stephens, C. 2008. Social capital in its place: Using social theory to understand social capital and inequalities in health. *Social Science & Medicine,* 66: 1174-1184.

Stapleton, T. 2008. Complexity: Study guide for MBA B825. Marketing in a complex world. Milton Keynes: The Open University.

Steyn, K., Fourie, J. & Temple, N. (Eds.). 2006. Chronic diseases of lifestyle in South Africa: 1995 – 2005. Technical Report. Cape Town: South African Medical Research Council.

Steyn, K. & Damasceno, A. 2006. In D.T. Jamison, R.G. Feachem, M.W. Makgoba, E.R.Bos, F.K. Baingana, K.J. Hofman & K.O. Rogo (Eds), *Disease and Mortality in Sub-Saharan Africa, Second Edition* (pp. 247-265). Washington: The International Bank for Reconstruction and Development/The World Bank.

Statistics South Africa (STATSSA). 2014. *Mortality and causes of death in South Africa, 2013: Findings from death notification*. Statistics South Africa. Pretoria: Statistics South Africa, i-viii; 1-126. Retrieved June 10, 2015 from: www.statssa.gov.za

Strauss, A.L. 1987. *Qualitative analysis for social scientists.* Cambridge: Cambridge University Press.

Strauss, A. & Corbin, J.M. 1998. *Basics of qualitative research: techniques and procedures for developing grounded theory.* Thousand Oaks, CA: Sage.

Stroebe, W. & Stroebe, M.S. 1995. *Social psychology and health*. Buckingham, UK. Open University Press.

Strong, K., Mathers, C., Leeder, S. & Beaglehole, R. 2005. Chronic Diseases 1. Preventing chronic diseases: how many lives can we save? *The Lancet,* 366: 1578-1582.

Stuck, A. E., Walthert, J. M., Nikolaus, T., Bula, C. J., Hohmann, C., & Beck, J. C. 1999. Risk factors for functional status decline in community-living elderly people: A systematic literature review. *Social Science & Medicine,* 48: 445–469.

Subramanian, S.V., Belli, P. & Kawachi, I. 2002. The macroeconomic determinants of health. *Annual Review of Public Health*, 23: 287-302.

Surwit, R.S., Van Tilburg, M.A.L., Zucker, N., McCaskil, C.C., Parekh, P., Feinglos, M.N., Edwards, C.L., Williams, P. & Lane, J.D. 2002. Stress management improves long-term glycemic control in type 2 diabetes. *Diabetes Care,* 25(1): 30-34.

Susser, M. 1998. Does risk factor epidemiology put epidemiology at risk? Peering into the future. *Journal of Epidemiology and Community Health,* 52: 608-611.

Susser, M. 1999. Should the epidemiologist be a social scientist or a molecular biologist? *International Journal of Epidemiology,* 28: S1019-S1021.

Susser, M. & Susser, E. 1996. Choosing a future for epidemiology: II. From Black Box to Chinese Boxes and eco-epidemiology. *American Journal of Public Health,* 86(5): 674-677.

Syme, S.L. 1987. Social determinants of disease. *Annals of Clinical Research,* 19(2): 44-52.

Syme, S.L. 2005. Historical perspective: The social determinants of disease – some roots of the movement. *Epidemiologic Perspectives and Innovations,* 2(2). Retrieved August 10, 2009 from: http://www.epi-perspectives.com/content/2/1/2

Tannenbaum, F. 1951. *Crime and the community.* New York: Ginn.

Telford, K., Kralik, D. & Koch, T. 2006. Acceptance and denial: implications for people adapting to chronic illness: literature review. *Journal of Advanced Nursing,* 55(4): 457-464.

Thorne, S.E. & Paterson, B.L. 2001. Health care professional support for self-care management in chronic illness: insights from diabetes research. *Patient Education and Counseling,* 42: 81-90.

Timmermans, S. & Haas, S. 2008. Towards a sociology of disease. *Sociology of Health and Illness,* 30(5): 659-676.

Toljamo, M. & Hentinen, M. 2001. Adherence to self-care and social support. *Journal of Clinical Nursing,* 10: 618-627.

Tomaka, J., Thompson, S. & Palacios, R. 2006. The relation of social isolation, loneliness, and social support to disease outcomes among the elderly. *Journal of Aging Health*, 18: 359–384.

Trief, P.M., Himes, C.L., Orendorff, R. & Weinstock, R.S. 2001. The marital relationship and psychosocial adaptation and glycemic control of individuals with diabetes. *Diabetes Care,* 24(8): 1384-1389.

Trief, P.M., Wade, M.J., Britton, K.D. & Weinstock, R.S. 2002. A prospective analysis of marital relationship factors and quality of life in diabetes. *Diabetes Care,* 25(7): 1154-1158.

Trief, P.M., Ploutz-Snyder, R. Britton, K.D. & Weinstock, R.S. 2004. The Relationship Between Marital Quality and Adherence to the Diabetes Care Regimen. *Annual Behavioral Medicine,* 27(3): 148–154.

Tripp-Reimer, T., Choi, E., Kelly, L.S. & Enslein, J.C. 2001. Cultural barriers to care: inverting the problem. *Diabetes Spectrum,* 14(1): 13-22.

Tshwane District Health. 2013. Tshwane District Health Profile. Retrieved September 27, 2013 from: www.health-e.org.za/wp-content/uploads/2013/06/Tshwane-District-Profile.pdf

United Kingdom Department of Health. 2005. *Departmental Report 2005 - The Health and Personal social services programme,* Department of Health, 1 June 2005. Retrieved August 30, 2010 from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/AnnualReports/DH_4

United Nations. 2012. United Nations General Assembly Resolution A/RES/66/2. Political Declaration of the High-level Meeting of the General Assembly on the Preventionand Control of Non-communicable Diseases. NewYork (NY): United Nations. Retrieved June 19, 2015 from: http://daccessdds-ny.un.org/doc/UNDOC/GEN/N11/458/94/PDF/N1145894.pdf?OpenElement

Vallee, J., Cadot, E., Grillo, F., Parizot, I. & Chauvin, P. 2010. The combined effects of space and neighbourhood of residence on participation in preventive health-care activities: The case of cervical screening in the Paris metropolitan area (France). *Health & Place,* 16(5): 838-852.

Van Dam, H.A., van der Horst, F., van den Borne, B., Ryckman, R. & Crebolder, H. 2003. Provider-patient interaction in diabetes care: effects on patient self-care and outcomes. A systematic review. *Patient Education and Counselling,* 51: 17-28.

Van de Ven, A.H. Delbecq, A.L. 1972. The nominal group as a research instrument for exploratory health studies. *American Journal of Public Health,* 62: 337-342.

Vermeire, E., Van Royen, P., Coenen, S., Wens, J., & Denekens, J. 2003. The adherence of type 2 diabetes patients to their therapeutic regimens: A qualitative study from the patient's perspective. *Practical Diabetes International,* 20(6): 209-214.

Wagner, E.H. 1998. Chronic Disease Management: What Will It Take to Improve Care for Chronic Illness? *Effective Clinical Practice,* 1(1): 2–4.

Wagner, E.H., Austin, B.T. & Von Korff, M. 1996. Organizing Care for Patients with Chronic Illness. *Milbank Quarterly,* 74(4): 511–544.

Wagner, E.H., Austin, B.T., Davis, C., Hindmarsh, M., Schaefer, J. & Bonomi, A. 2001. Improving Chronic Illness Care: Translating Evidence Into Action Interventions that encourage people to acquire self-management skills are essential in chronic illness care. *Health Affairs,* 20 (6): 64-78.

Wakefield, S.E.L. & Poland, B. 2005. Family, friend or foe? Critical reflections on the relevance and role of social capital in health promotion and community development. *Social Science & Medicine,* 60: 2819-2832.

Wallace, R. 1991. Travelling waves of HIV Infection on a low dimensional 'socio-geographic' network. *Social Science & Medicine*, 32(7): 847-852.

Webb, E.M., Rheeder, P. & Van Zyl, D.G. 2014. Diabetes care and complications in primary care in the Tshwane district of South Africa. *Primary Care Diabetes,* 1-8. Retrieved August 26, 2014 from: http://dx.doi.org/10.1016/j.pcd.2014.05.02

Weber, M. 1947. *The Theory of Social and Economic Organization.* Translation A.M. Henderson and T. Parsons. New York: Free Press.

Wenzel, J., Utz, S.W., Steeves, R., Hinton, I. & Jones, R.A. 2005. 'Plenty of Sickness': Descriptions by African Americans Living in Rural Areas with Type 2 Diabetes. *The Diabetes Educator,* 31(1): 98-107.

Westaway, M.S., Rheeder, P., Van Zyl, D.G. & Seager, J.R. 2003. Interpersonal and organizational dimensions of patient satisfaction: The moderating effects of health status. *International Journal for Quality in Health Care,* 15(4): 337-344.

Westaway, M.S., Seager, J.R., Rheeder, P. & Van Zyl, D. 2003. The effects of social support on health, well-being and management of diabetes mellitus: A black South African perspective. *Ethnicity and Health,* 10(1): 73-89.

White, K. 2002. *An Introduction to the Sociology of Health and Illness*. London: Sage Publications.

Whittemore, R., Chase, S.K., Mandle, C.L. & Roy, S.C. 2002. Lifestyle change in type 2 diabetes. A process model. *Nursing Research,* 51(1): 18-25.

Whittemore, R., Bak, P.S., D'Eramo-Melkus, G.D. & Grey, M. 2003. Promoting lifestyle change in the prevention and management of type 2 diabetes. *Journal of the American Academy of Nurse Practitioners,* 15(8): 341-349.

Whooley, M.A., Avins, A.L., Mirnada, J. & Browner, W.S. 1997. Case finding for depression. Two questions are as good as many. *Journal of General Internal Medicine,* 12: 439-445.

Wild, S., Roglic, G., Green, A., Sicree, R. & King, H. 2004. Global prevalence of diabetes – Estimates for the year 2000 and projections for 2030. *Diabetic care,* 27(5): 1047-1053.

Wilkinson, R.G. 1996. *Unhealthy societies.* London: Routledge.

Williams, S.J. 2000. Chronic illness as biographical disruption or biographical disruption as chronic illness? *Sociology of Health and Illness,* 22(1): 40-67.

Williams, J.W., Mulrow, C.D., Kroen, K. 1999. Case finding for depression in primary care. A randomized trial. *American Journal of Medicine,* 106: 36-43.

Willig, C. 2008. *Introducing qualitative research in psychology: Adventures in theory and method.* Buckingham, UK: Open University Press.

Wolf, S. & Bruhn, J.G. 1993. *The power of clan.* New Brunswick, New Jersey: Transaction.

Wooldridge, K.L., Wallston, K.A., Graber, A.L., Brown, A.W. & Davidson, P. 1992. The relationship between health beliefs, adherence, and metabolic control of diabetes. *The Diabetes Educator,* 18(6): 495-500.

World Health Organization (WHO). 2000. Health systems: improving performance. *The World Health Report 2000.* Geneva. Retrieved May 7, 2012 from: http://www.who.int/whr/2000/en/whr00_en.pdf

World Health Organization (WHO). 2008. Diabetes. *Fact sheet,* No 312: 1-3.

World Health Organization (WHO). 2009. Goal of the diabetes programme. Retrieved August 12, 2009 from: http://www.who.int/diabetes/goal/en/print.html

World Health Organization (WHO). 2010. Message from the Regional Director on the occasion of World Diabetes Day 2010. *World Diabetes Day, 14 November 2010.*

World Health Organization (WHO). 2011a. Obesity. *Fact sheet March 2011,* No 311. Retrieved August 30, 2011 from: http://www.who.int/mediacentre/factsheets/fs311/en/

World Health Organization (WHO). 2011b. Global status report on non-communicable diseases 2010. *World Health Organization,* ISBN: 9789241564229: i-176.

World Health Organization (WHO). 2011c. Diabetes. *Fact sheet August 2011,* No 312: 1-3. Retrieved November 30, 2011 from: http://www.who.int/mediacentre/factsheets/fs312/en/

World Health Organization (WHO). 2013. Diabetes. *Fact sheet, October 2013,* No 312. Retrieved November 30, 2013 from: http://www.who.int/mediacentre/factsheets/fs312/en/

World Health Organization (WHO). 2014. Diabetes. *Fact sheet, November 2014,* No 312. Retrieved November 30, 2014 from: http://www.who.int/mediacentre/factsheets/fs312/en/

World Health Organization (WHO). 2014. Global Status Report on non-communicable diseases 2014 “Attaining the nine global non-communicable diseases targets; a shared responsibility”. Retrieved June 20, 2015 from: http://www.who.int/global-coordination-mechanism/publications/global-status-report-ncds-2014-eng.pdf

World Medical Association. 2008. WMA Declaration of Helsinki – Ethical principles for medical research involving human subjects. Retrieved August 30, 2010 from: http://ww.wma.net/en/30publications/10policies/b3/index.html

Yankauer, A. 1950. The Relationship of Fetal and Infant Mortality to Residential Segregation: An Inquiry into Social Epidemiology. *American Sociological Review,* 15: 644-648.

Yen, I.H. & Syme, S.L. 1999. The social environment and health: A discussion of the epidemiologic literature. *Annual Review of Public Health,* 20: 287-308. Abstract.

Zgibor, J.C. & Songer, T.J. 2001. External barriers to diabetes care: addressing personal and health systems issues. *Diabetes Spectrum*, 14(1): 23-28.

Zhang, X., Norris, S.L., Gregg, E.W. & Beckles, G. 2007. Social support and mortality among older persons with diabetes. *Diabetes Educator*, 33: 273–281.

Zhang, P., Zhang, X., Brown, J., Vistisen, D., Sicree, R., Shaw, J. & Nichols, G. 2010. Global healthcare expenditure on diabetes for 2010 and 2030. *Diabetes Research and Clinical Practice,* 87: 293-301.

List of Appendices

Appendice A

Ethical approval of research proposal of this study

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

18 October 2013

Dear Dr Bomela

Project:	**The influence of population-based factors in self-care of patients with Diabetes Mellitus**
Researcher:	**MH Pietersen**
Supervisor:	**Dr N Bomela**
Department:	**Sociology**
Reference number:	**02487969**

Thank you for your response to the Committee's letter of 3 July 2013.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 17 October 2013. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

Sincerely

Prof. Sakhela Buhlungu
Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: sakhela.buhlungu@up.ac.za

Research Ethics Committee Members: Dr L Blokland; Prof S Buhlungu (Chair); Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris; Ms H Klopp
Prof A Mlambo; Dr C Panebianco-Warrens; Prof GM Spies; Prof E Taljard; Dr FG Wolvaardt; Dr P Wood

Appendix B

Approval of protocol for clinical trial

MS: dd 2010/09/02: C:\Documents and Settings\User\MyDocuments\PhD\Ethics\Permission letters\UP Ethics Committee permission 61b.doc

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

* **FWA** 00002567, Approved dd 22 May 2002 and Expires 13 Jan 2012.
* **IRB** 0000 2235 IORG0001762 Approved dd Jan 2006 and Expires 13 Aug 2011.

Faculty of Health Sciences Research Ethics Committee
Fakulteit Gesondheidswetenskappe Navorsingsetiekkomitee

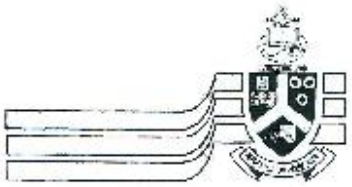
DATE: 27/05/2010 PROTOCOL NO.
PROTOCOL TITLE

61B/2010
The efficacy of primary and tertiary specialist care collaboration using a mobile diabetes complications screening team for improving the management of diabetes at primary health care level in Tshwane District.

Principal Investigator: Mrs E M Webb
Prof P Rheeder (Dept Internal Medicine; Steve Biko hospital)
Prof J Hugo (Dept Family Medicine jannie.hugo@up.ac.za)
Dept:School of Health Systems + Public Health Mobile: 0824203027
Phone: 012 354 1803 E-Mail: elize.webb@up.ac.za
PhD: Epidemiology
None
21/04/2010

Appendix C

Confirmation of pre-testing and piloting of the research instruments



University of Pretoria

Faculty of Health Sciences
Department Internal Medicine
Private Bag X395
PRETORIA 0001

5 August 2013

TO WHOM IT MAY CONCERN

This letter serves to confirm that **MARIA HELENA PIETERSEN** (University of Pretoria personnel number 2487969) is a member of the University of Pretoria's Kalafong Diabetes Lifestyle research team.

The University of Pretoria's Department of Internal Medicine at Kalafong Hospital embarked in January 2013 on a 14 week long research study to evaluate the impact of a lifestyle intervention on patients with diabetes mellitus Type 2. Ms Pietersen, was involved as medical sociologist, in the multidisciplinary research project. At the core of the research project was, *inter alia,* the facilitation of focus group discussions – Ms Pietersen's focus groups were exceptionally successful in terms of the internalization of diabetes lifestyle principles.

Ms Pietersen will conduct a qualitative research study with the title "The influence of population-based factors in self-care of patients with diabetes mellitus". This research will be conducted from August 2013 to January 2014 at selected clinics in the Tshwane district and will focus on those questions that might provide possible answers to the underlying causes of diabetes, and specifically the causes of hyperglycaemia (high blood sugar levels) and factors in society that are conducive to the causes, providing a knowledge base for interventions that might be the most successful in this regard. The methodology of the study, as part of a research protocol for the abovementioned research project at the Kalafong Diabetes Clinic, has also been approved by the Faculty of Health Sciences Ethics Committee. The research instruments of the study have also been pre-tested and piloted during the Lifestyle Research project.

As Head of the Department of Internal Medicine, University of Pretoria at Kalafong Hospital, I can confirm that Ms Pietersen is a mature, knowledgeable, well-skilled and very professional qualitative researcher. I shall greatly appreciate your assistance to Ms Pietersen to access selected Tshwane district clinics and diabetes patients who are willing to participate in this very important research project.

Yours sincerely

PROF J H RETIEF
HEAD: DEPT INTERNAL MEDICINE
KALAFONG HOSPITAL

Appendix D

Confirmation of status of researcher

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Office of the Dean

25 July 2103

TO WHOM IT MAY CONCERN

This letter serves to confirm that Maria Helena Pietersen (personnel number: 248/969) is a permanent full time lecturer and registered doctoral (DPhil) student in the Department of Sociology at the University of Pretoria.

As part of the requirements for the DPhil, Ms Pietersen has to do an empirical study. Her research proposal with the title 'The influence of population-based factors in self-care of patients with diabetes mellitus' has been approved by the Ethics Committee of the Faculty of Humanities. This study will complement and link up with a cluster randomised control trial, conducted by researchers from the Faculty of Health Sciences, University of Pretoria, assessing the efficacy of a mobile diabetes complications screening team in the Tshwane district, Pretoria. The results of the clinical trial will provide the basis for the researcher to identify the patients with controlled blood sugar levels, and those with uncontrolled blood sugar levels. The methodology of the study, as part of a research protocol for a research project at the Kalafong Diabetes Clinic, has also been approved by the Faculty of Health Sciences Ethics Committee.

This research will be conducted from August 2013 to January 2014 at selected clinics in the Tshwane district and will focus on those questions that might provide possible answers to the underlying causes of diabetes, and specifically the causes of hyperglycaemia (high blood sugar levels) and factors in society that are conducive to the causes, providing a knowledge base for interventions that might be the most successful in this regard.

As acting Head of the Department of Sociology and Vice Dean of Humanities I shall greatly appreciate your assistance to Ms Pietersen to access selected Tshwane district clinics and diabetics patients who are willing to participate in this very important research project.

Yours sincerely,

Prof Sakhela Buhlungu
Vice Dean: Faculty of Humanities and Acting Head: Department of Sociology
Sakhela.buhlungu@up.ac.za

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Appendix E

Approval by Ethical Committee of Tshwane District Authority and Gauteng Province

CITY OF TSHWANE
IGNITING EXCELLENCE

Health and Social Development Department

Room L2015 | 2nd Floor | Eskia Mphahlele Library | Cnr Van der Walt and Vermeulen Streets | Pretoria | 0002
PO Box 234 | Pretoria | 0001
Tel: 012 358 8605 | Fax: 012 324 5135
Email: elfredao@tshwane.gov.za | www.tshwane.gov.za | www.facebook.com/CityOf Tshwane

My ref:
Your ref:
Contact person: Dr E Oosthuizen
Section/Unit: Information, Training and Research

Tel: 012 358 8605
Fax: 012 324 5135
Email: Elfredao@tshwane.gov.za

Mariana Pietersen

Lecturer: Medical Sociology and Research

Department of Sociology

University of Pretoria

Tel; 012-4202707

Cell: 0722064878

14 October 2013

APPROVAL: DIABETES SOCIAL RESEARCH STUDY

Permission is herewith granted to Ms Mariana Pietersen to do the Diabetes Social Research Study in the City of Tshwane clinics.

Dr Elfreda Oosthuizen

DIRECTOR: RESEARCH AND INFORMATION SERVICES

Kgoro ya Dit Maphelo le Tlhabollo ya Setšhaba • Departement Gesondheid en Maatskaplike Ontwikkeling
Lefapha la Bophelo le Kgodiseho le Kgodiseho • Ndzawulo ya Rihanyo na Nhluvukiso wa Vanhu • UMnyango Wezempilo Nezempilo
Health and Social Development Department

Appendix F

Preliminary approval form by Clinic Managers to access seven clinics

5

NAME		SIGNATURE		DATE	

COMMISSIONER OF OATHS

Signed and sworn to before me at .....

on this the ..... day of 20

by the deponent, who has acknowledged that he or she knows and understands the contents of this affidavit, that it is true and correct to the best of his or her knowledge, that he or she has no objection to taking the prescribed oath and that the prescribed oath will be binding on his or her conscience.

COMMISSIONER OF OATHS

Annexure 1

Declaration of intent from the clinic manager or hospital CEO

I give preliminary permission to _____ (name of researcher) to do his or her

research on _____ (research topic) in

_____ (name of clinic) or

_____ (name of CHC) or

_____ (name of hospital).

I know that the final approval will be from the Tshwane/Metsweding Regional Research Ethics Committee and that this is only to indicate that the clinic/hospital is willing to assist.

Other comments or conditions prescribed by the clinic or CHC manager or hospital CEO:

Signature
Clinic Manager/CHC Manager/CEO

Date

See Research Proposal : Mariana Pietersen DPhil Sociology

Annexure 2

STRUCTURE OF RESEARCH PROPOSALS

1. Title and authors

The title should clearly describe the purpose of the study. The names of the researchers, the qualifications, and the address and name of the institution should be indicated in this section.

2. Abstract

The abstract should provide the aims and objectives of the study and the research methodology briefly and to the point.

3. Introduction

This comprises the summary of relevant literature around the problem. Gaps need to be identified in this section to draw hypotheses and justify the study.

4. Justification

This serves as a justification indicating the importance and benefits of conducting the study.

5. Aims

The aim needs to be clear and researchable and should be able to contribute new scientific findings to the school of knowledge.

6. Objectives

Objectives should describe specific and exact issues to be investigated by researchers to achieve the aim.

7. Methods

- The study design needs to be specified, for example descriptive, analytical or intervention.
- The study population should clearly state the age groups, gender, geographic location, etc of the participants.

Appendix G

Participant Informed consent form

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Dear Participant

Title of project: The influence of population-based factors on self-care of patients with diabetes

Introduction

You are invited to volunteer for a research study. This information will help you to decide if you would like to participate. Before you agree to take part in this study you should fully understand what is involved. If you have any questions, which are not fully explained in this document, do not hesitate to ask the researcher. You should not agree to take part unless you are completely happy about all the procedures involved.

What is the purpose of the study?

This study explores selected social determinants relevant to the implementation and sustainability of diabetes self-care management.

How will the study be conducted?

The methods of the research to be used for the study are individual questionnaires and focus group interviews.

When will the study be conducted?

The study will take place between August 2013 and December 2013.

Has the study received ethical approval?

This research protocol was submitted to the Faculty of Humanities Ethics Committee, University of Pretoria, and written approval has been granted by the Committee. The study has been structured in accordance with ethical considerations such as the protection of harm to participants, and the protection of the identity of all participants.

What are my rights as a research participant in this study?

Your participation in this research is entirely voluntary and you can refuse to participate or stop at any time without stating any reason. The researcher retains the right to withdraw you from the study if considered to be in your best interest.

Will any of the research procedures result in any discomfort?

The subject matter of the study is the population-based factors of diabetes self-care management, and will also touch on your own personal experience and perceptions about the disease. Some may feel uncomfortable discussing such matters in a group or in an individual setting. You do not have to participate in the discussion if it causes you discomfort although you can be assured that you will not be judged at any time on the basis of your response.

What are the benefits involved in the study?

Your involvement in the study will contribute to research that will be circulated worldwide that could influence policy decisions on diabetes self-care management. You will also gain knowledge and awareness about sustainable self-care management of diabetes.

Are there any restrictions concerning my participation in this study? No

Source of additional information

This study will be conducted by way of individual questionnaires and focus group discussions a member of the University if Pretoria. Should you have any questions, please contact the researcher, Ms Mariana Pietersen. The telephone number is 012-4202707.

Confidentiality

All information obtained during the course of this research is strictly confidential. Data that may be reported in diabetes or scientific journals will not include any information which identifies you as a participant in this study. Data/information will be published anonymously. No information will be disclosed to any third party without your written permission.

INFORMED CONSENT CLAUSE

I hereby confirm that I have been informed by the researcher _____ (state particulars) about the nature, conduct, benefits and risks of the proposed research. I have also received, read and understood the above written information (informed consent) regarding the study.

I am aware that the results of the study, including my personal details regarding sex, age, marital status, etc of myself will be anonymously processed into the research report. (See in particular the definition of “personal information” in the Promotion of Access to Information Act 2 of 2000).

I may at any stage, without prejudice, withdraw my consent and participation in the study. I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

Participant’s name: _____

Participant’s signature: _____

I, _____ hereby confirm that the above participant has been informed fully about the nature and scope of the above study.

Researcher’s / investigator’s name: _____

Researcher’s / investigator’s signature: _____

Supervisor name: _____

Appendix H

Research instrument 1: Biographical information

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Number :
DIABETES SOCIAL RESEARCH: August – November 2013
LEVEL OF SOCIAL INTEGRATION – INDIVIDUAL BIOGRAPHICAL INFORMATION AND INFORMATION ABOUT DIABETES

Dear Participant,

We are inviting people diagnosed with diabetes mellitus to share their experiences, ideas and opinions about their diabetes self-care. Everybody who will complete this biographical questionnaire has agreed in writing to participate. Thank you very much for your willingness to complete this.

Confidentiality

Your name will not be used on the questionnaire. We will keep your name secret when we report the results of the study. We will only use numbers and not names. The questionnaires will be kept in a safe place.

Participation

You can refuse to take part in the discussion or stop taking part at any time if you feel uncomfortable. Should any question make you feel uncomfortable, you will not have to answer that question. Your participation in this study will not affect your treatment in the clinic in any way.

Please answer the following questions or mark with an X

A. Your background information

1. What is your age? In years		
2. What is your sex?	Male	Female
3. What is your highest education level?	**Level**	
	None	
	Less than 3 years of school	

	3 to 5 years of school	
	Grade 6 to 10	
	Grade 11	
	Grade 12	
	Post-school education	
4. Are single or do you have a partner?	**Status**	
	Single	
	Married – legal/ traditional	
	Widowed	
	Divorced	
	Living with partner	
	Other – name	
5. Employment status	**Status**	
	Employed	
	Part-time/piece work	
	Unemployed	
	Pensioner	
	Illness / disability grant	
	Other – name	
6. If employed - What type of work do you do?		

B. DIABETES PROFILE

7. What type of Diabetes do you have?	Type 1	Type 2
8. How old were you when you were diagnosed with diabetes?		
9. How long since you have been diagnosed with diabetes?		
10. Describe how you understand diabetes self-care		

Thank you very much for your participation!

Appendix I

Research instrument 2: Focus group discussion schedule

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Number :

DIABETES SOCIAL RESEARCH: AUGUST – NOVEMBER 2013

LEVEL OF SOCIAL INTEGRATION: FOCUS GROUP DISCUSSION SCHEDULE

Dear Participant,

Good day and welcome to our group session today. Thank you very much for taking time to join our discussion of diabetes and self-care management. My name is Mariana Pietersen and I am from the University of Pretoria. Assisting me is “Name of student”, also from the University of Pretoria. We would like information about the self-care of diabetes. We have invited people with diabetes to share their experiences, ideas and opinions about their diabetes self-care. There are no right or wrong answers but rather different experiences and different points of view. Please feel free to share your experience and point of view even if it differs from what others have said.

Everybody who will be involved in this group discussion has agreed in writing to participate, but to help you to feel more at ease let me explain two ethical considerations to you, namely confidentiality and participation.

Confidentiality

Your name will not be used on any documents or reports of this study. We will only use numbers and not names. Today’s questions, notes, sound and/or video recordings, photos, picture collages and any other record of the group discussions will not be shared with anyone else.

Participation

You can refuse to take part or stop taking part at any time if you feel uncomfortable. Should any question make you feel uncomfortable, you will not have to answer that question. Your participation in this study will not affect your treatment in the clinic in any way.

The group must also agree to a few ground rules for the progress of the group discussion. It is important to speak up, but allow one person at a time to talk. As indicated on the ethical form, we are video- and tape-recording the session, because we do not want to miss any of your comments. Keep in mind that we are just as interested in negative comments as in positive comments, and at times the negative comments are the most helpful. Our session will last about two hours with a 10 minute break.

We have made name cards for you to help us to remember each other’s names. Let us find out more about each other by going around the room one at

a time. Tell us your name, where you're from and about the first time you became aware of your diabetes.

Thank you very much for sharing more about yourself.

A. Introduction – Let us first talk about your experience of diabetes.

1. How do you experience your diabetes?	**Probes:** - Condition that can be managed - Opportunity to improve my lifestyle - Tiredness, Anxiety, Sadness
2. How bad would you say is diabetes?	**Probes:** - Would you say that diabetes poses a threat to your quality of life? - Would you say that diabetes poses a threat to your life?
3. Tell us about what you have done to stop getting worse	**Probes:** - Prevent complications - Test: Eye problems - Test: Heart problems - Report: Problems with your feet

B. Space and place of residence – Please tell us where you stay and about your home

4. Tell us about the place where you live	**Probes:** - Permanent house - Informal home - Water – running taps in house/communal water resources - Electricity / gas/ wood / other fuel - Sanitation - Garden/s – flowers / vegetables - Parks - Clean / Polluted residential area - Near industrial area
5. Does the place where you live help you with your diabetes self-care? Explain to us how it helps you or not.	**Probes:** - Safe - Homely

	- Too many people in the house - Cold - Weather – different seasons

C. Demographic and social changes – Let us talk about possible recent changes that might have affected your life

6. Think about the last few weeks. Did you experience any changes in your family situation that changed the way you take care of yourself?	**Probes:** - New family member - Illness in the family - Death in the family - New work position - Became unemployed - Moving house - New friends
7. If there were any changes in your diabetes self-care, please describe how it affected taking care of yourself	**Probes:** - Routine of taking medication - Sleeping pattern - Exercise - Diet - Stress - Blood pressure - Blood sugar

D. Cultural context – Please, tell us about your traditions

8. Do you think that your traditions and customs affect your diabetes self-care?	**Probes:** - Traditional food - Traditional healer - Marital status - Gender power relations - Roles and responsibilities in the family
9. If traditions and customs affect your diabetes self-care, please describe how you think traditions and customs affect the way you take care of yourself.	**Probes:** - Traditional food - Traditional healer - Marital status - Gender power relations - Roles/responsibilities in the family

E. Social networks – nature of social contacts (family/friends) – Let us talk about you family and friends

10. Who do you talk to about your diabetes self-care?	**Probes:** - Husband / wife - Children – son / daughter - Sister / brother - Father / mother - Grandparents - Uncles / aunts - Cousins - Friends - Other: Doctor, Traditional healer, nurse, minister of religion
11. If your family/friends help with your diabetes self-care, please describe how they help you?	**Probes:** - Discuss your diabetic condition - Accompany to diabetes clinic - Healthy food preparation - Motivate you - Exercise with you

F. Social capital (resources in community that includes aspects of social organisation) Let us talk about resources of information and assistance in your community

12. When you need information and help related to your diabetes, where do you go?	**Probes:** - Health clinic - Community organisations (examples: support groups, religious groups, stokvels)
13. What comes to mind when you think about your clinic or community organisations?	**Probes:** - Trust - Helpfulness - Knowledgeable - Understanding - Acceptance

G. Social integration focus – this section relates to the previous discussion about community organisations. Let us talk about how you experience your community with regard to your diabetes self-care management.

14. If your community organisations are involved, please tell us about your community's involvement with your diabetes self-care.	**Probes:** - Assist you to go to the clinic - Consider your dietary requirements - Establish support groups - Community-based employment opportunities
15. Describe some of the qualities and abilities of your community that you find valuable with regard to your diabetes self-care	**Probes:** - Respect - Trust - Unselfishness - Sharing - Caring - Helpfulness

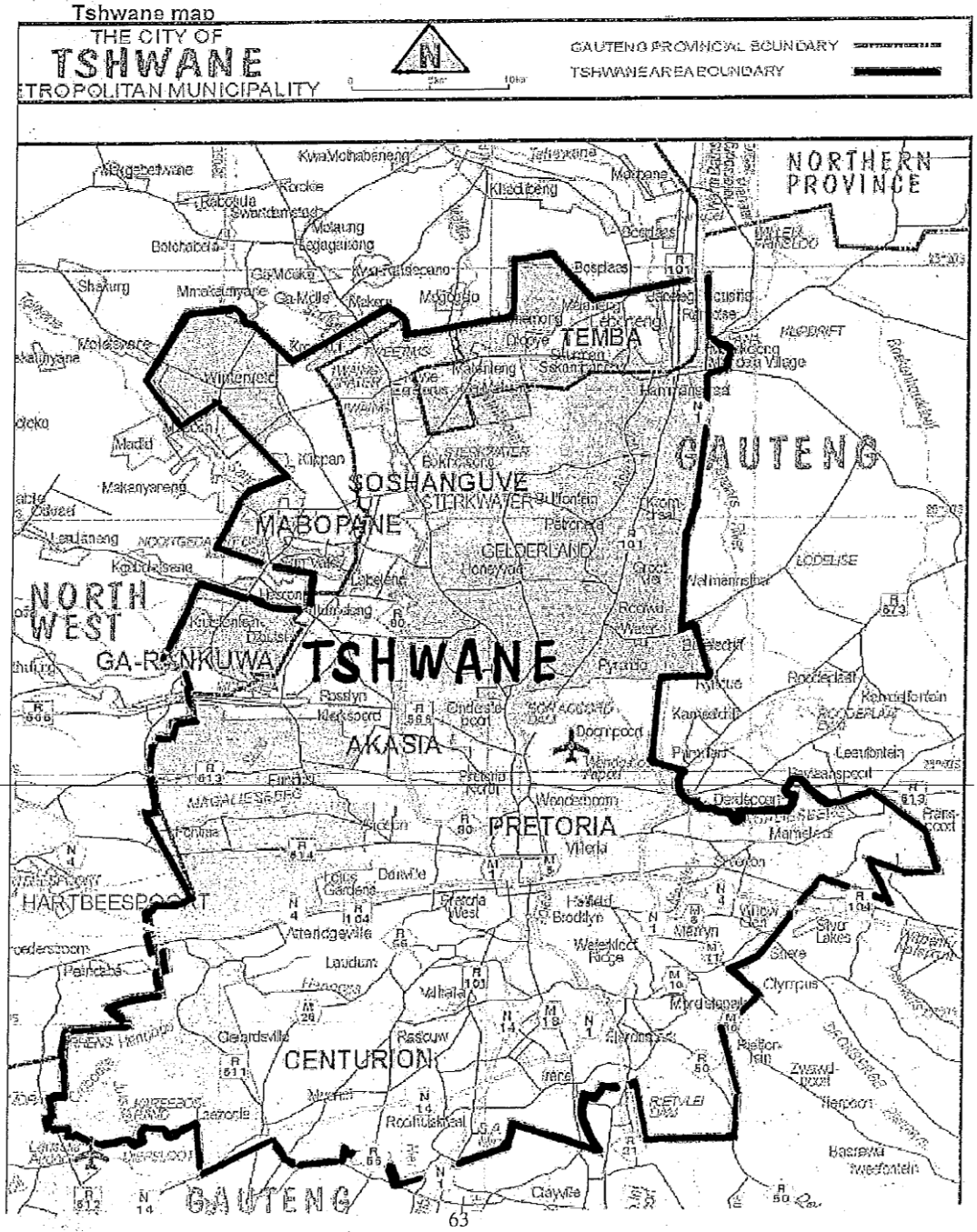
H. Any other information about the self-care of your diabetes that you would like to share with the group?

Thank you very much for your participation!

Appendix J

Map of Tshwane District

Tshwane map



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Appendix K

Key concepts

Diabetes mellitus

There are three main types of diabetes (WHO, 2008:1):

Type 1 diabetes, previously known as insulin-dependent or childhood-onset is characterized by a lack of insulin production and without daily administration of insulin, is rapidly fatal.

Type 2 diabetes, formerly called non-insulin-dependent or adult-onset; result from the body's ineffective use of insulin. Type 2 diabetes comprises 90% of people with diabetes around the world, and is largely the result of excess body weight and physical inactivity.

Gestational diabetes is hyperglycaemia which is first recognized during pregnancy.

Epidemiology

"Epidemiology is concerned with the distribution of disease and death, and with their determinants and consequences in populations groups. Conceptually, the theory of epidemiologic transition focuses on the complex change in patterns of health and disease and the interactions between these patterns and their demographic, economic and sociologic determinants and consequences" (Omran, 1971: 731-732). The primary focus of epidemiology is on diseases and health problems of social aggregates or large groups of people, and therefore not on the individual.

Social epidemiology

Social epidemiology is defined as the study of the distribution of health outcomes and their social determinants (Poundstone, Strathdee & Celentano, 2004: 22). Social epidemiology is distinguished by explicitly investigating social determinants of population distributions of health, disease, and wellbeing, and not only treating these determinants as mere background to biomedical phenomena (Krieger, 2001: 693).

Population-based factors

Population-based factors refer to social-structural and social factors, including *inter alia* the cultural context, social capital, social integration, neighbourhood effects, and the policy, demographical and socio-economic environment (Kaplan, 2004: 124-135).

Sustainable self-care management

Sustainable self-care management (also referred to as self-care or self-management) refers to the capacity to endure the prolonged full range of activities that persons with chronic illness may engage in to promote their health, augment their physical, social or emotional resources, preventing adverse clinical complications from their disease (Thorne & Paterson, 2001: 82).

Social integration and social regulation

Social integration refers to the strength of the attachment that individuals have to society, while social regulation refers to the degree of external constraints of society on people (Ritzer & Goodman, 2004: 176).

Social capital

Social capital is defined as active aspects of social structures that facilitate collective action that would be impossible in its absence (Coleman, 1988: S98).

Demographic and social changes

Demographic and social changes in this study refer *inter alia* to the urbanisation patterns of a population; labour migration; population growth due to natural births and immigration; mortality rates; male-to-female sex ratios; marital status; social relations and social policies.

Place and space of residence

The place of residence refers to the establishment that functions as the main habitat and centre of social interactions for the person/s involved, while the space of residence refers to the area where the concentration of daily activities in the perceived neighbourhood can be measured (Vallee, Cadot, Grillo, Parizot & Chauvin, 2010: 839).

Social system

Parsons (1951: 5-6) in his classic 'The Social System' defined the social system as follows: "A social system consists in a plurality of individual actors interacting with each other in a situation which has at least a physical or environmental aspect, actors who are motivated in terms of a tendency to 'optimization of gratification' and whose relation to their situations, including each other, is defined and mediated in terms of a system of culturally structured and shared symbols."

Social determinants of health

Social determinants of health refer to specific features of and pathways by which societal conditions affect health and can potentially be altered by informed action (Krieger, 2001: 697).

Prevention

Prevention is the controlling of causes and risk factors to limit the incidence of disease. Four levels of prevention can be identified, corresponding with the different phases in the development of the disease, namely primordial, primary, secondary and tertiary prevention (Beaglehole, Bonita & Kjellstrom, 1993: 85).

Incidence and prevalence

Incidence refers to the number of new cases of a specific disease or health disorder occurring within a given population during a stated period of time

(Cockerham, 2004: 20). Prevalence refers to the total number of cases of a disease or health disorder at any given time, and would therefore include new cases as well as previously existing cases (Cockerham, 2004: 20).

Patient satisfaction

Patient satisfaction can be explained by, *inter alia* interpersonal manner, technical quality, accessibility, cost efficacy, continuity, physical environment and availability of resources (Ware, Snyder, Wright & Davies, 1983: 262).

[i] Self-Care Inventory is a 13-item self-report measure to assess patient's perceptions of the degree to which they adhere to treatment recommendations for their diabetes self-care

[ii] Diabetes Social Support Questionnaire evaluates the patient's perception of the backing they receive from family and friends to comply with treatment

[iii] Problem Areas in Diabetes Scale (PAID) is a 20-item questionnaire in which each item represents a unique area of diabetes-related psychosocial distress

[iv] Diabetes knowledge scale evaluates general concepts evaluates general concepts of disease, diet, exercise, self-monitoring of blood glucose, diabetes-related medication, and foot care