

**EXPERIENCES OF DIABETES MELLITUS PATIENTS WHO ARE ON  
TREATMENT AT THE PIGGS PEAK HOSPITAL IN SWAZILAND**

by

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**DEDICATION**

I dedicate this work to my mother, and my late father. I love you so much Mom. This project is just one of the products of the immense work and nurturing that you generously gave to us, your children. Dad, as educator and intellectual, your hard work in educating us bears testimony in what we are all achieving in our academic and career endeavours today. May your soul rest in peace.

**Student number: 43347002**

**DECLARATION**

I declare that “**Experiences of diabetes mellitus patients who are on treatment at the Piggs Peak Hospital in Swaziland**” is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

.....

Darlington Chikwanha

.....

Date

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**ABSTRACT**

The aim of this study was to explore and describe the experiences of diabetes mellitus patients at the Piggs Peak Hospital in Swaziland, from the time of diabetes diagnosis to living with diabetes, adherence to treatment and implementing diabetes self-care. A descriptive, exploratory, contextual qualitative research was conducted. Data was gathered through semi-structured interviews with 26 participants purposively selected on diabetes days at the hospital. Data was analysed qualitatively. Results revealed that patients present late for diagnosis. Being diagnosed causes psychological distress of varying intensity and duration. Hospital visits are burdensome due to financial and transport challenges, as well as service shortcomings. Self-care activities are difficult due to financial challenges and non-conducive social circumstances at home. Social support is lacking. Diabetes patients fear insulin use and prefer oral tablets. It is concluded that diabetes self-care is burdensome for most patients of the PPH in Swaziland. The service providers, stakeholders, and government need to explore strategies for mitigating effects of various barriers to self-care as revealed in this study.

**KEY CONCEPTS:**

Diabetes Mellitus; Experience; Adherence; Diabetes diagnosis; Diabetes self-care; Living with Diabetes

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**ABBREVIATIONS / ACRONYMS**

ADA	American Diabetes Association
AIDS	Acquired Immunodeficiency Syndrome
BMI	Body Mass Index
CMS	Central Medical Stores
DM	Diabetes Mellitus
DM1	Type 1 Diabetes Mellitus
DM2	Type 2 Diabetes Mellitus
FBS	Fasting Blood Sugar
Hb1c	Glycosylated Haemoglobin
HIV	Human Immunodeficiency Virus
IDF	International Diabetes Federation
MOH	Ministry of Health
NCD	Non-communicable Disease
OPD	Outpatients' Department
PEPFAR	President's Emergency Plan for AIDS Relief
PPH	Piggs Peak Hospital
PSP	Psychosocial Problem
SSA	Sub-Saharan Africa
TB	Tuberculosis
UN	United Nations

UNISA	University of South Africa
WHO	World Health Organization

# CHAPTER 1

## ORIENTATION TO THE STUDY

### 1.1 INTRODUCTION

This chapter introduces the subject of diabetes mellitus (DM) as a medical condition, its impact on individuals, society, and governments in general. The condition is described in the Swaziland context and more narrowly, the Piggs Peak Hospital (PPH) context. The description is done in terms of management and challenges experienced by patients. This is followed by the purpose and aim of the research, including its significance. The researcher then defines the key research terms, followed by a description of the theoretical foundations of the study, the research design, and research methods. The researcher further describes the ethical considerations and measures taken to ensure trustworthiness during the research. The chapter concludes with a summary of the structure of the dissertation, scope of the research, and some concluding remarks.

#### 1.1.1 Diabetes mellitus, world and African perspective

DM is a non-communicable disease (NCD) that affects human populations worldwide and it poses public health and socio-economic challenges. This condition has been proven through research and scientific projections to be increasing in world prevalence. The increase in the prevalence of this condition will be highest in the developing regions of the world, mainly due to factors like ageing populations, urbanisation, general westernisation of diet, and the adoption of more sedentary lifestyles (Bardsley & Resnick 2008:161; Gill, Mbanya, Ramaiya & Tesfaye 2009:8,9; Mbanya, Motala, Sobngwi, Assah & Enoru 2010:2260).

Sub-Saharan Africa (SSA) is particularly projected to suffer from this increasing prevalence threat, severe enough to be termed an epidemiologic transition. This emerging threat will also cause socio-economic and public health burdens in the face of the limited resources of this region (Mbanya *et al.* 2010:2254). Mortality attributable to DM in SSA increased from 2.2 – 2.5% in the year 2000 to about 6% in the year 2010 (Mbanya *et al.* 2010:2254). Most of the 48 least developed countries (LDC) as defined by the United Nations (UN) are in SSA. While communicable

diseases; such as the human immunodeficiency virus / acquired immune deficiency syndrome (HIV / AIDS), malaria, and tuberculosis (TB) continue to weigh heavily on the public health systems of this region; emerging threats from NCDs like DM are presenting newer health burdens (Gill *et al.* 2009:9; Mbanya *et al.* 2010:2254; Twei, Maiyoh & Ha 2010:433,434; UN 2011).

### **1.1.2 Diabetes mellitus, the medical perspective**

According to the World Health Organization (WHO), DM is described as a metabolic disorder of multiple aetiology characterised by chronic hyperglycaemia (above normal blood sugar levels), with disturbances of carbohydrate, fat, and protein metabolism resulting from defects in insulin secretion, insulin action, or both. The condition can be diagnosed by means of various criteria, but the commonly used is presence of fasting (not having consumed food during a period of 12 hours prior to the test) blood sugar levels above 7mmol/l (126mg/dl) (ADA 2011:13; WHO 2006). For the human body to function normally, it is vital that the internal body environment is kept in an optimal physiological and biochemical state, a process called homeostasis. Disruption to the optimal internal environment, as with persistent hyperglycaemia associated with DM, leads to various medical illnesses and complications.

Common presenting signs of DM include polyuria meaning excessive urination, polydipsia meaning excessive water intake or excessive thirst, polyphagia meaning abnormally increased appetite for and consumption of food. DM sufferers also present with other less specific symptoms like chronic lethargy, also known as persistent feeling of ill health and reduced body vitality, dizziness, blurred vision, and poor concentration (ADA 2010:62; Longmore, Wilkinson, Turmezei & Cheung 2007:190). Many diabetes sufferers, especially in less developed countries, particularly in Africa, may not be aware of their diabetic statuses for a long time, often up to a decade before the diagnosis is made. This is partly due to weak screening strategies in these countries. Such patients often present to hospital already with long term complications of the disease (Bardsley & Rensick 2008:161; Mbanya *et al.* 2010:2254,2256; Twei *et al.* 2010:433,434).

Diabetes complications can mainly be classified as long term and short term in nature. Long term complications, which can either be microvascular or macrovascular in nature, arise as a toxic effect of persistently raised glucose levels on the body tissues and systems. The high levels of glucose change the way nerves work, harden the blood vessels which should otherwise be elastic to allow normal blood flow and also affect the function of the vital organs of the body like the kidneys, heart, eyes, brain, and skin (Bardsley & Resnick 2008:161; Debono & Cachia 2007:547). The term macrovascular refers to the pathology that is associated with wide calibre blood vessels and microvascular describes the pathology that affects small calibre blood vessels. The macrovascular complications present as strokes, limb gangrene, or limb death; also known as diabetic foot and this often leads to foot and leg amputations. Microvascular complications present as diabetic retinopathy that leads to loss of eyesight, nephropathy that leads to kidney or renal failure, and neuropathies that lead to abnormal sensations of the peripheral extremes of the limbs and impotence with poor or weak penile erections in men (ADA 2011:27-38). As Campbell and Martin (2009:249) state, DM is the leading cause of blindness in the United States of America (USA). It is also the leading cause of kidney failure, being responsible for up to 44% of new kidney complications in the same country.

Short term diabetes complications include the diabetic coma, which invariably needs admission to hospital and urgent acute medical management, failure of which the comatose patient has a very high risk of dying (ADA 2011:27-41; Longmore *et al.* 2007:190). There are various forms and types of DM, but for the purposes of this research, this author will describe only two major forms of this condition, namely type 1 DM (DM1) and type 2 DM (DM2).

#### **1.1.2.1 Type 1 diabetes mellitus**

This form of DM constitutes about 5 – 10% of the total diabetic population. It was previously known as juvenile onset or early onset DM, or alternatively insulin dependent diabetes mellitus (IDDM) (Bardsley & Resnick 2008:161). These terms are currently obsolete because they were made on some assumptions that have since been proven to be inaccurate. DM1 results from a lack of the vital glucose regulating body hormone insulin. This situation results from destruction of the pancreatic beta cells responsible for insulin production. This form of DM tends to

present early in life, like in children and adolescents, and most of the patients tend to present in a wasted or emaciated state, although DM1 can still be diagnosed on obese patients. DM1 patients also commonly present with severe hyperglycaemia with extreme acute diabetic symptoms like extreme thirst, polyuria with some degree of dehydration and these patients invariably need insulin therapy. DM1 patients are quite prone to diabetic ketoacidosis comma, a condition which needs urgent hospitalisation and insulin therapy to avoid death (ADA 2010:62-63; Longmore *et al.* 2007:190; WHO 2006).

### **1.1.2.2 Type 2 diabetes mellitus**

This is the commonest form of DM worldwide. It was also once known as adult onset, mature onset, and non-insulin dependent diabetes mellitus (NIDDM). Again, these terms are obsolete because they terminologically convey inaccurate assumptions in view of current scientific evidence. For instance, it has since been observed that there is an increasing incidence of DM2 in children due to childhood obesity and other lifestyle related factors. DM2 patients may also need insulin therapy at a certain stage in their lives, and thus can also become insulin dependent (Bardsley & Rensick 2008:161; Mbanya *et al.* 2010:2255). This form of DM represents 90 – 95% of the total DM population (ADA 2010:63; Twei *et al.* 2010:433-434). DM2 and obesity are now described as ‘modern epidemics’, due to their evidently progressively increasing world prevalence as decades pass. DM2 has a genetic predisposition with an above 80% concordance in identical twins (Longmore *et al.* 2007:190).

Pathophysiology of the development of the disease is explained by a mixed pathology of a gradual decline in pancreatic beta cell insulin production, together with an increase in insulin resistance or decreased insulin sensitivity of target body tissues and organs like the muscles and the liver. This endocrine dysfunction gives rise to a persistently hyperglycaemic body state, which subsequently leads to microvascular and macrovascular complications (ADA 2010:62; Bardsley & Rensick 2008:161; Longmore *et al.* 2007:190; WHO 2014).

A significant proportion of DM2 sufferers tend to go for a long time without knowing their diabetic statuses, and thus without being treated. Patients can live for up to a decade with the untreated condition only to be diagnosed having presented to

hospital with chronic complications (Bardsley & Rensick 2008:161). Late diagnosis is most common in poor countries that have limited health resource allocations and poor or near absent DM screening and awareness programmes. The SSA is one such region. DM2 is a condition that has mainly been linked to certain lifestyles characterised by little or no exercise; fat, salt, and sugar rich diets; sedentary lifestyles; and obesity (Gill *et al.* 2009:8; Mbanya *et al.* 2010:2260). These issues will be discussed shortly.

### **1.1.2.3 Type 2 diabetes mellitus, overweight and obesity**

Obesity or increased body adiposity is the degree to which the body has an excess of stored fat. The WHO defines overweight and obesity as abnormal or excessive fat accumulation that may impair health. Clinically, it is measured by dividing the weight in kilograms by the height in metres squared. This index is called body mass index (BMI). One form of obesity, visceral obesity, is measured by the waist-to-hip ratio. According to the WHO, overweight is BMI greater than 25, whilst obesity is BMI above 30 (WHO 2013). The abnormal increase in the amount of fat tissue in the body leads to metabolic derangements through the stored fat acting as an endocrine organ on its own, with resulting general impairment of glucose metabolism and, in some cases, DM2. The contributing factors or causes of obesity are mainly lifestyle related. The reason why one ends up obese is a result of a positive energy balance, meaning one is accumulating more energy through food consumption than one utilises through metabolism. Energy rich foods and drinks, polyunsaturated fatty foods, and lack of exercise through sedentary lifestyles all contribute to this situation (Bardsley & Resnick 2008:161; Mbanya *et al.* 2010:2260; Motala, Esterhuizen, Gouws, Pirie & Omar 2008:1786-1787; WHO 2013). Globally, 44% of the DM burden and 23% of ischaemic heart disease (IHD) burden are attributable to overweight and obesity. Once considered a high income country problem, overweight and obesity are on the increase in low and medium income countries, especially in urban settings. About 30 million overweight children live in developing countries whilst only 10 million live in developed countries, overweight and obesity kill more people worldwide than underweight (WHO 2013).

In both rural and urban Africa, cultural and traditional beliefs, attitudes, and perceptions have a strong impact on managing obesity as a disease. In some African

populations, obesity still commands respect and influence, since it is perceived to demonstrate a well-fed and well-to-do socio-economic status. In many African communities, obesity and malnutrition exist side-by-side, mainly due to emerging socio-economic disparities born out of the rapid urbanisation, industrialisation, and general globalisation of poor nations. Stated otherwise, in the eyes of some African societies, malnutrition would be taken as a sign and disease of deprivation and low societal status whilst obesity would be perceived as an indicator of excess, affluence, and general societal superiority (Mbanya *et al.* 2010:2262; Awah, Kengne, Fezeu & Mbanya 2008:[612-620]; WHO 2013). Another risk factor for developing DM2 in SSA is old age with peak prevalence at 55 – 64 years (Christensen, Friis, Mwaniki, Kilonzo, Tetens, Boit, Omondi, Kaduka & Borch-Johnsen 2009:[303-310]; Motala *et al.* 2008:1785).

#### **1.1.2.4 Diabetes mellitus management**

As already discussed, a significant number of DM2 patients do present to hospital already with some diabetes complications. One then notes the importance of early risk identification, screening, public awareness of the risk factors and early interventional care to achieve normal blood sugar levels. Both the ADA and the International Diabetes Federation (IDF) do not support wide scale screening of populations for DM. Screening is recommended for those patients with diabetes risk factors; such as a positive DM family history, being obese, and the presence of other related illnesses like hypertension and dyslipidaemia (ADA 2011:13-14; IDF 2005).

Management of DM is executed in several simultaneous approaches. The process needs input from a multidisciplinary team of health professionals and support teams like dieticians, educators, and psychologists. There is growing evidence in Africa that a protocol-based care system can be implemented by nurses with good medium term glycaemic improvements and patient satisfaction, especially in environments with a shortage of qualified doctors (Gill, Price, Shandu, Dediccoat & Wilkinson 2008:[606-611]; Kengne, Fezeu, Sobngwi, Awah, Aspray, Unwin & Mbanya 2009:181-182). Considering that many of the risks associated with developing the commonest form of diabetes, DM2, are lifestyle related, one notes that drug management cannot singularly be a rational approach towards treatment. Regular exercise alone has been seen in some studies to prevent progression to DM2 of patients who are prone

to the condition. Weight loss of any degree, no matter how small, has been shown to improve DM2 control. Some DM2 patients can achieve a drug-free normoglycaemia when they manage to lose weight to acceptable levels and keep it within those normal levels. Dietary adjustments can help in preventing and controlling DM. Besides lifestyle adjustments and weight control, some DM2 patients may need drug treatment. DM2 patients may still eventually need insulin therapy, either temporarily in situations of stress due to illness, surgery, infections, and pregnancy; or permanently if the body reaches a stage when there is minimal or no more production of endogenous insulin (ADA 2011:21-27; IDF 2005). DM1 patients do need insulin injections for treatment and glycaemic control. DM treatment requires the patient to be educated and involved in the treatment decision making process, with the hope that the patient will competently take full responsibility for self-care.

DM patients need to be reviewed at frequencies determined by their level of control and competence level in self-care. The routine tests performed to assess glycaemic control include the glycosylated haemoglobin (Hb1c), a test that shows the average level of glucose control for up to three months prior to the day of the test. Another test, though less reliable but still quite commonly used, is the fasting blood sugar test. Disadvantages of monthly blood sugar tests for monitoring purposes are firstly that the result does not necessarily give an average picture of the level of glycaemic control for the period preceding the actual day of the consultation itself, and that the patients have to visit the hospital starved. Review monitoring procedures should help to watch for the development of microvascular, and macrovascular complications discussed earlier (Section 1.1.2). Kidney function is monitored by checking protein levels in urine, eyes should be checked by simple visual acuity and ophthalmoscopic tests, blood lipids should also be regularly checked, as well as body indices like the BMI and waist-to-hip ratios. Blood pressure should be monitored, considering that DM patients tend to be prone to hypertension. Foot examinations should be conducted to assess neuropathy and other risks for diabetic feet like ingrown nails and ill-fitting shoes (ADA 2011:19-37).

The 2011 ADA standards of care guidelines recommend psycho-social monitoring for the possible presence of problems like depression and anxiety, since these conditions are known to impact on self-care of patients on chronic disease

treatments. Most recent studies show that depression is common in patients on chronic disease treatments and that self-care is negatively affected by these psychological states. Patients should thus be managed or referred appropriately when found to have psychological or psychiatric problems. Effort should be made to ensure that patients assume the major role in their self-care in partnership with the multidisciplinary health care provider team (ADA 2011:21-27; IDF 2005; Mahbubur, Anisur, Meerjady & Muhammad 2011:65-66; Snoek & Skinner 2006:61-62; Zuberi, Syed & Bhatti 2011:27).

## **1.2 RESEARCH PROBLEM**

A research problem is an area of concern with a knowledge gap that needs to be filled. Research problems can be realised from clinical situations, interaction with colleagues, or can be borrowed from theories, broad topics and past research findings that may be inadequate and need further verification. Research is thus conducted to provide evidence-based knowledge to address the concern or knowledge gap (Burns & Grove 2009:68-69; Fouché & Delport 2011:108; Fouché & De Vos 2011:92; Polit & Beck 2012:73). In this section, the researcher presents the context and the background of the research problem. This is achieved by describing the presence, impact, and treatment of DM in Swaziland and more narrowly, at the PPH. Successes and challenges in providing DM services are also highlighted. The statement of the research problem concludes the section.

### **1.2.1 Source and background of the research problem**

Under this sub-section, the researcher describes the presence, impact and treatment of DM in Swaziland and particularly at the PPH. The researcher, as a practising general practitioner in the government health system, also provides experiential information about the situation in the Swaziland public health system concerning DM management.

#### **1.2.1.1 *Diabetes mellitus in Swaziland***

The WHO population estimates for 2010 put the Swaziland population at 1 186 056 (WHO 2011). The Swazi people live in a small landlocked country of 17 363 square kilometres, or 6 704 square miles (Encyclopaedia of the nations 2011). The WHO

(2011) states that Swaziland fits in the lower-middle income group. The country faces a double burden of infectious diseases like TB, HIV / AIDS and malaria, accompanied by an increasing threat of the NCDs, like DM. Estimates put the total DM burden projection of the country for 2030 at 21 000. The WHO put the 2010 DM proportional mortality of total deaths for all ages at 2% (WHO 2011). A local weekly paper, The Weekend Observer reported in January 2013, that diabetes amputation rates at the Mbabane referral government hospital, the highest government referral level, are too high (Vilakati a 2013:2-3) (Annexure K). The same paper reported in February 2013, that a significant proportion of the adult population in Swaziland are at risk of developing NCDs, including DM (Vilakati b 2013:3) (Annexure L).

### **1.2.1.2 Diabetes mellitus management in Swaziland and the PPH**

This researcher could not gather significant usable information from research databases and scholarly websites about the subject of DM or NCDs in Swaziland. Most country specific information was gathered from organisations like the WHO and the UN. In all, it seems the NCD subject is not well-researched and published in Swaziland. Some information under this subheading was also gathered through investigating the Swaziland government medical institutions and from the researcher's seven years of experience as a government employed medical officer. The researcher has worked as a doctor at health centre level for six years and currently practises at regional referral hospital level.

Swaziland is divided into four administrative regions; namely Manzini, Hhoho, Shiselweni, and Lubombo. Each region has a regional referral hospital. These hospitals offer 24-hour medical services, with routine outpatients' services being offered only during normal working hours, whilst emergencies are attended to after-hours. Each referral hospital caters for one or several feeder health centres, which on their own function as 24-hour small hospitals, though with limited scope. The country has three tertiary level referral hospitals and two of them are Christian mission run whilst one is run by government. This researcher works in one of the regional referral hospitals by the name of PPH as a medical doctor or general practitioner. The hospital caters for one health centre and various clinics in its catchment area, i.e. the Hhoho region of Swaziland. The hospital has a total of seven full time government employed doctors with one of them being a surgical specialist. Of the seven doctors,

the outpatients-cum-casualty department is allocated a minimum of three doctors on each working day.

Outpatient and inpatient diabetes care is offered both at health centre and hospital levels in Swaziland. Clinics do not normally cater for or monitor diabetic patients on treatment, since such cases are referred to the nearest health centre or hospital for chronic management. This, in a way contributes to the severe congestion experienced at the various hospitals on the selected diabetes treatment days. Due to high levels of poverty and unemployment on the countryside, most patients on chronic medical treatments do rely fully on the available and more affordable government hospitals, such as the PPH (Fakudze 2012; IFAD 2007). At these hospitals, one is only required to pay user fees for the health services provided, since the government subsidises public health care. There is a general shortage of health personnel in the government health system, and this prevents a complete multidisciplinary approach towards the management of DM in Swaziland. For example, there are inadequate full-time dieticians to properly educate and follow-up DM patients at the various DM treatment centres. There is a general shortage of adequate specialists to deal with diabetes complications if and when they occur. The country has a general shortage of ophthalmologists, nephrologists, and neurologists to professionally cater for eye, kidney, and nerve complications that commonly afflict chronic diabetes patients especially in the rural areas.

There are no approved standard guidelines for the management of DM in Swaziland. Individual doctors manage the disease with the skills and expertise they themselves attained during training and work experience. On a positive note, the Ministry of Health (MOH) has since tasked a working group comprising stakeholders and physicians to formulate DM standard management guidelines for Swaziland. These guidelines are at draft stage at the time of the writing of this document. The supply of DM drugs in the public health system of Swaziland is fully catered for by the government. This is done and co-ordinated by a central drug warehouse facility, namely the central medical stores (CMS), and this entity supplies on order to the various public health unit pharmacies. The DM medications are available at the government pharmacies most of the time, except for infrequent drug stock-outs that mostly affect the oral drugs availability. When such stock-outs happen, patients do

have to source the unavailable drugs from privately run pharmacies. Swaziland does not have a functional and separate diabetes management programme. DM treatment services are provided as part of provisions of the general public health system. This means there is no separate budget and logistical provision for the management of the disease, apart from the already functioning public health system.

Diabetic patients at the PPH are normally reviewed by the medical officers in charge of the outpatients department (OPD) on Wednesdays, and all DM patients are reviewed once monthly. Some patients may be reviewed more frequently as per doctor's discretion. All diabetic patients should be consulted before midday, mainly because they come starved and their management is mainly monitored by use of the fasting blood sugar (FBS) index. This often means that diabetes days are quite busy and congested to such an extent that the available time a health provider can spend with the patient becomes limited. When the pressure mounts, the physicians are pressured to attend to the dense queues faster so that the rural-based patients can catch their buses to their destinations in good time. Most of the DM patients seen at the PPH come from the rural countryside and some travel from hard-to-reach areas. These are areas with geographical remoteness in terms of limited road access and scarce motorised transport availability.

The local diabetes register at the PPH shows that an average of 110 diabetes patients are seen on a single diabetes day. Of the total DM patients in the PPH DM register, 90% are older than 30 years, while less than 10% of the registered DM patients are on insulin. Most of these patients come from poor backgrounds; some survive on minimal returns from self-sustenance projects whilst others do need some form of aid from government or non-governmental agencies to survive. The fee structure for DM outpatients at the PPH adds up to a total of R 13.00 for the whole review process. The review process consists of a blood sugar test, medical consultation, and the drug refill.

On a typical diabetes day at the PPH, most patients arrive very early to secure front positions at the various service points. Firstly, the patients pay the user fee, secure their treatment cards with an updated stamp, and wait for health education which is implemented by the OPD nursing staff before 8 o'clock. After health education and a morning prayer, patients queue for FBS tests, after which they may be allowed to eat.

Patients are also routinely examined for blood pressure and temperature. The patients then join the queue to see the medical officers for the review consultation. Hb1c is not routinely done as part of the DM review tests at either the PPH, or the Swaziland public health system in general. An investigation done by this researcher in collaboration with the central laboratory managers of the country could not yield a good explanation why this vital test for diabetes patients is not routinely conducted.

Indices like the BMI are not routinely checked at the PPH. Lipid profiles, routine eye examinations, and kidney profiles are not systematically conducted on DM patients at the PPH, except when they are ordered by the doctors for specific patients due to certain medical reasons. Depending on the DM patients' conditions during consultation, most do eventually go back home after acquiring their relevant medications, but some may be admitted for inpatient care, either due to the DM condition itself or other medical reasons.

- **The Piggs Peak Hospital experience**

“I am surely failing to defeat this disease, my child. They have just told me that my sugar is very high, but I have a confession to make. You see, I missed my three previous reviews because I am poor. Who will help me with money to honour my reviews? My last son amongst the eight, of whom seven are dead, is at home. He came back from the mines in South Africa because he is sick, he won't stop coughing. My boy can't support me anymore. I am tired and I am ill. I am old and I can do with some rest...”

This scenario is one amongst many events that clinicians often face and experience at the PPH-OPD during a typical diabetes day. DM is a prioritised NCD at the PPH due to the level of its burden in the midst of many other NCDs. Therefore, the DM reviews are scheduled for every Wednesday at the hospital. This researcher has noticed, despite the obvious effort made by the clinicians and other team players in the management of the condition, the continued prevalence of signs and complications of poor glycaemic control and lack of self-care amongst the DM patients. It is not uncommon to see specific individuals coming monthly for review with persistently high blood sugar readings. In some cases, the same poorly

controlled patients do achieve good glycaemic control once admitted to hospital, surprisingly still on the very same drug regimen that seems to fail at home.

Another observation is that clinicians do struggle to effect proper lifestyle changes amongst the diabetic patients, especially in relation to the aspects of optimal weight management and diet. Despite being on treatment, some patients develop renal failure, blindness, and sexual dysfunction as complications of DM. Other patients struggle to follow the whole treatment plan, and this often manifests in missed appointments, frank treatment defaulting, and non-adherence to the recommended diabetes lifestyle. In some extreme cases, patients do reach the doctors consultation table demonstrably still eating and drinking the mostly discouraged sugary foodstuffs, and consequently registering high blood sugar readings. From some patients' confessions and testimonies, they know very little about the disease, as some would often declare, *"I never knew I was not supposed to eat that stuff"*.

There are those patients who believe the disease is curable and one does not necessarily need to take medication all the time. Some individuals also believe that they can accurately tell their blood sugar is high by the way they feel, and that obviously determines when they need to take their doses or visit hospital. Some patients admit resentment about clinicians for having put them on tough treatment regimens, especially insulin injections, and that they feel the treatment plans have been imposed on them. Clinicians often show frustration when DM patients repeatedly interrupt treatment and, in some cases, only seek medical attention when they develop some complications that often need admission and more rigorous medical or surgical interventions.

### **1.2.2 Statement of the research problem and research questions**

The statement of the research problem is meant to articulate the research problem; it describes the need for research by developing an argument (Polit & Beck 2012:73).

There are no standard treatment guidelines for DM in Swaziland. There also seems to be very little visible research work done so far in Swaziland about the subjects of NCDs, DM treatment and patients' experience. Despite reasonable availability of adequate DM medications and hospital-based diabetes care, some diabetic patients at PPH notably and constantly suffer from complications of poorly controlled DM.

Clinicians regularly admit patients into hospital with acute medical and surgical diabetes complications, despite them being on treatment. Some patients apparently struggle to adhere to DM treatment, implement, and maintain proper lifestyle changes as part of self-care recommended by health workers. Doctors seem not to understand the reason behind poor adherence and lack of self-care amongst the DM patients. Some health workers assume that such problems demonstrate lack of commitment by the patients. Under these circumstances, the patient's story about the whole experience of living with DM and treatments remains mainly untold. This situation prompted the researcher to conduct qualitative research with the purpose of affording the DM patients a platform for telling their life stories, in their own language, about living with DM in order to understand the patient better in a holistic and naturalistic way. In view of the research problem as explained, the researcher developed the following research questions.

#### **1.2.2.1 Research questions**

Research questions are the specific queries researchers want to answer in conducting the research to address the research problem (Polit & Beck:73). As Burns and Grove (2009:167) state, research questions are concise and interrogative statements stated in the present tense, and they include one or more variables. The research questions for this study are:

- What are the real life experiences of DM patients on treatment at the PPH in Swaziland?
- What factors in the PPH DM patients' life experiences seem to contribute to treatment failure or treatment success?

### **1.3 AIM OF THE STUDY**

The aim of this study was to explore and describe the experiences of DM patients at the PPH in Swaziland, from the moment of diagnosis to living with the condition on chronic treatments and self-care.

#### **1.3.1 Research purpose**

A research purpose is a statement that highlights the specific goal or aim of the study; it is generated from the research problem. This statement usually indicates the

research variables and the type of the study. The purpose of a study gives meaning, motivation, and direction to the research work (Burns & Grove 2009:69-70; Polit & Beck 2012:79; Saldana, Leavy & Beretvas 2011:32). The purpose of this research was twofold, namely to contribute to the scientific knowledge base on the subjects of DM and patients' experience in Swaziland, and to share the findings with hospital and government authorities in an effort to improve the treatment outcomes amongst diabetic patients in the PPH catchment area, and possibly the whole country.

### **1.3.2 Research objectives**

Research objectives are formulated to bridge the more abstractly stated research problem with the more detailed research design. They are declarative statements, concise, and presented in the present tense (Burns & Grove 2009:165). The objectives of this research were:

- To explore and describe the experiences of patients with DM, on treatment at the PPH in Swaziland; and
- To identify and describe the factors that contribute to treatment failure and treatment success amongst the DM patients at the PPH in Swaziland.

## **1.4 SIGNIFICANCE OF THE STUDY**

The significance of a study should convince the reader about the need of carrying out the research in the first place; it provides the justification, contribution, and importance of the study (Fouché & Delport 2011:107). If clinicians and health care workers at the PPH have a better understanding of how DM patients experience their treatment and self-care, patients at the PPH could directly and immediately benefit from improved treatment approaches. The research findings could possibly contribute to shaping and informing policies and guidelines for DM management, particularly in the rural settings of Swaziland, such as the Piggs Peak area. The research, being qualitative in nature, was aimed at contributing to the body of knowledge of DM management in a more patient-based and naturalistic way. Not enough such studies have been conducted in the Southern African region and almost none known have been done in Swaziland about experiences of patients on chronic NCD or DM management. This study would address the identified gap in research.

## 1.5 DEFINITION OF TERMS

### **Diabetes mellitus:**

According to the ADA (2010:62), DM is a group of metabolic diseases characterised by hyperglycaemia, resulting from defects in insulin secretion, action, or both. For the purposes of this study, DM is a medical diagnosis made by doctors by means of laboratory tests at the PPH in Swaziland.

### **Self-care:**

According to the Oxford Reference Online Premium (2012), self-care is the practice of activities necessary to sustain one's life and health. The activities are carried out by an individual for him- or herself. Self-care, in this research, means the activities carried out by the DM patients as part of their treatment plans. These activities include exercise, weight control, foot care, dietary management, hospital review visits, and medication use.

### **Experience:**

Along with consciousness, experience is the central focus of the philosophy of mind. It is a stream of private events known only to their possessor, and bearing at least a problematic relationship to any other events (Oxford Reference Online Premium 2012). For the purposes of this study, experience is what the diabetic patients report they go through physically, psychologically, socially, mentally, spiritually, and otherwise in their day-to-day life with the condition.

### **Adherence:**

Adherence has been defined as the "active, voluntary, and collaborative involvement of the patient in a mutually acceptable course of behaviour to produce a therapeutic result" (Delamater 2006:72). The WHO (2003) defines adherence as the extent to which a person's behaviour corresponds with the agreed recommendations from a health care provider. Adherence, in this research, is the degree to which the diabetic patients follow and comply with all activities of self-care, see above.

### **Treatment success:**

Treatment success in DM extends beyond reaching glycaemic targets. It needs to address durability of glycaemic control and favourable long-term clinical outcomes (Stolar 2010:50-51). For the purposes of this study, treatment success means that the diabetic patient is satisfactorily following and adhering to all the activities of self-care as defined (Section 1.5). Treatment success is thus alternatively referred to as self-care adherence.

## **1.6 FOUNDATIONS OF THE STUDY**

The philosophical base of the study is naturalistic, humanistic, and interpretive. This means the researcher seeks to understand the meanings of social interactions in their natural settings without any element of control (Burns & Grove 2009:23; Yin 2010:7; Stake 2010:15). As Denzin and Lincoln (1994:2) put it, it is “a multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural setting, attempting to make sense of, or interpret phenomena in terms of the meanings people bring to them”.

### **1.6.1 Assumptions**

Assumptions are statements that are considered true; they are assumed correct despite the fact that they may not have scientific proof. In a study, assumptions are embedded in the philosophical base of the framework, study design, and interpretation of the findings. These assumptions influence the development and implementation of the research process (Burns & Grove 2009:40; Polit & Beck 2012:12). This researcher carried out qualitative research with the assumptions described below.

#### **1.6.1.1 *Epistemological assumptions***

Epistemology is the theory of knowledge. It is our set of beliefs about the nature of knowledge, including the relationship between the knower and the known. Epistemology is what we believe constitutes legitimate knowledge, or justification of knowledge (Carter & Little 2007:1317,1319; Guba 1990:18; Pesut & Johnson 2008:117). Knowledge is internally constructed by the individual, rather than

something outside oneself (Saldana *et al.* 2011:32). In this research, epistemology, the nature of knowledge, was assumed to be interpretive, including the lived experience. It was assumed to be existential (non-deterministic) and constructivist (Stake 2010:31). The researcher assumed that legitimate knowledge about the experience of living with DM could be acquired by allowing the patients to present their life stories about their own perceptions and interpretations of living with DM. The approach was exploratory rather than the positivist quest for causality and explanation. There was thus a propensity towards inductive and dialectic reasoning (Burns & Grove 2009:23; Pascal, Johnson, Dore & Trainor 2011:174; VanderStoep & Johnson 2009:167).

### **1.6.1.2 *Ontological assumptions***

Ontology is our understanding of our existence or being in the world (Guba 1990:26-27). In this research, ontology as the nature of reality was assumed to be subjective, socially constructed and interpretive, internally and externally experienced, value laden, and meaningful (Pascal *et al.* 2011:174). It was assumed that reality is multiple, subjective, and mentally constructed (Polit & Beck 2012:13). This research was based on ontological assumptions of subjective idealism and critical realism. Subjective idealism assumes that there is no single or shared reality independent of multiple alternative human constructions. Reality is based on perception and is different for each individual. Critical realism assumes that knowledge of reality is mediated by human perceptions and beliefs. The research was concerned with the way people give meanings to the world, and it assumed that everyone is different. What we know has meaning only within a given situation and context (Burns & Grove 2009:51; Nicholls 2009:639; Stake 2010:62-63). The researcher allowed the DM patients to share the stories of their experiences in their own language; therefore, allowing them to present what they themselves interpret and believe is the real life experience of living with and managing their DM conditions.

### **1.6.1.3 *Methodological assumptions***

Research methodology encompasses the way in which knowledge and evidence are acquired. In this research, it was assumed that knowledge is gathered in an inductive process, with an emergent and flexible design that makes use of unstructured in-

depth approach (Polit & Beck 2012:13). The approach was idiographic rather than nomothetic; it was naturalistic, and iterative while seeking complexity rather than reduction, it sought to reveal hidden meaning rather than to control variables and it utilised a purposive rather than random sample. The researcher was not a neutral observer, but participated as the main research instrument. The researcher assumed an emic role, and thus was immersed (Pascal *et al.* 2011:174). The researcher utilised and relied mainly on transcribed verbal data rather than numerical data. The aim was to understand the meaning of human behaviour (Burns & Grove 2009:23; Carter & Little 2007:1318). The researcher assumed an insider or emic role and was thus immersed (Pascal *et al.* 2011:174). It was assumed that the researcher could bracket preconceived ideas and biases about the research phenomenon throughout the research process in order to allow the data to speak for itself (Yin 2010:17; VanderStoep & Johnson 2009:166-168,207). A systematic and subjective approach was used to describe life experiences of the participants with DM and to give meaning; it used a holistic framework for exploring depths, richness, and complexity of inherent phenomena (Burns & Grove 2009:51).

## **1.7 RESEARCH DESIGN**

A research design is the blueprint for the whole process of conducting the research, and it directs the essential steps like sampling, data collection, analysis, and interpretation (Burns & Grove 2009:41). The researcher used a descriptive, exploratory, contextual, and qualitative research design (Section 2.2).

### **1.7.1 Descriptive design**

Descriptive research concerns the description of the existing phenomena and discovering new information. The researcher observes and then describes what has been observed. This research approach is suited for building basic knowledge in a minimally researched area; it provides the groundwork for more rigorous predictive studies in future (Babbie 2007:89; Burns & Grove 2009:12, 45; Fouché & De Vos 2011:96). This research sought to describe the life experiences of diabetic patients on treatment at the PPH.

### **1.7.2 Exploratory design**

Exploratory research is carried out to gain insight into a situation or phenomenon. The approach is useful mainly when the phenomenon is little understood due to lack of basic information (Babbie 2007:88; Fouché & De Vos 2011:95; Polit & Beck 2012:18). Using an exploratory approach would ensure basic understanding of the phenomena of interest.

### **1.7.3 Contextual design**

The research was contextual, since DM patients were studied in their natural context of a routine hospital consultation in an unmodified OPD environment (Mongwe 2001:49).

### **1.7.4 Qualitative design**

The qualitative design explores and describes phenomena as they are consciously experienced by a group of people in their individual life situations (Burns & Grove 2009:23; Giorgi 2005:80; Stake 2010:15). Participants were interviewed in their natural pre-scheduled consultation environments without an element of manipulation of their routine treatment processes.

## **1.8 RESEARCH METHODS**

Research methods are the planned activities that will be carried out to gather the required data and to further analyse that data to attain useful and meaningful information from it (Fouché & Delpont 2011:75; Polit & Beck 2012:188-189). Under this section, the researcher discusses in brief how the research sample was selected, how the information was collected from that sample, and finally, the data analysis process.

### **1.8.1 Population and sample selection**

In this research, the target population was all diabetic patients in the PPH catchment area who were managed at the PPH, and who did meet the sampling criteria. The accessible population was the DM patients in the Pigg's Peak area being managed at the PPH who availed themselves at the hospital on the research days (Burns &

Grove 2009:343-344). Sampling is a process of selecting the sample from the population. Purposive or judgemental sampling was applied in this research. Due to its non-random nature, not every person in the population had an equal chance of being included in the study (Babbie 2007:184). The sample size was not pre-determined; the total number of participants was determined by data saturation. It is a common fact that qualitative research tends to use smaller sample sizes than the positivist quantitative research (Nicholls 2009:639). For more details about sampling and populations, refer to Section 2.3.1.

### **1.8.2 Setting**

The setting in qualitative research is the field where the phenomena under study can be observed or experienced. It is the actual place where data is gathered (Burns & Grove 2009:35; Polit & Beck 2012:49,183; Streubert & Carpenter 2011:27). The setting for this study was natural, since the researcher interacted with the participants in a place where, and at a time when, they would normally and routinely congregate for medical consultations and reviews. This was done in the OPD of the PPH. No attempt was made to interfere with the natural setting in terms of venue, timing of the hospital visit, or patient flow.

### **1.8.3 Data collection**

Firstly, the researcher ensured that all participants had read and understood the consent forms before signing prior to the data collection process. These consent forms were prepared in English and siSwati, the local vernacular. The researcher read the consent forms to the illiterate participants. Semi-structured interviews were conducted by the researcher at the PPH OPD in a quiet and private room, separate from the busy hospital sections (Burns & Grove 2009:510-511; Saldana *et al.* 2011:43-44). The interviews were audio-recorded, the participants had been informed about this arrangement on the consent forms that they agreed to sign on. Participants were interviewed only after concluding their consultations. The researcher initiated the interviews with four general questions on an interview schedule, prepared in both English and siSwati, Annexures E and F. The discussions were steered by means of relevant probes and the participants were allowed to do most of the talking (Babbie 2007:306; Burns & Grove 2009:510-511). Following each

interview, the researcher wrote observational notes about observed and intuitive data in order to record significant non-verbal clues from the participants', as well as the researcher's emotions, preconceptions, expectations and prejudices (Babbie 2007:309; Greeff 2011:342-346). For more details about data collection, refer to Section 2.3.3.

#### **1.8.4 Data analysis**

Data analysis in qualitative research begins during the interview and data gathering process. This is when the researcher notes what he observes and what he thinks he is observing. With empirical and interpretive note taking, analysis will already be under way (Burns & Grove 2009:510; Greeff 2011:342-343). Transcribing was done verbatim; the researcher used Microsoft Word to record the transcripts. The transcribed data constituted the researcher's raw data. The researcher read the transcripts repeatedly, immersing in the data, and recording analytic notes against vital statements that related to the research purpose and objectives. The narrative data was organised and analysed using the first five steps of the descriptive, existential phenomenological method of Colaizzi (Colaizzi 1978:48-71; Polit & Beck 2012:566-567); (Section 2.3.4).

### **1.9 MEASURES OF TRUSTWORTHINESS**

Lincoln and Guba (1985:290) refer to trustworthiness in research as the truth value of the research; its applicability, consistency, and neutrality. The researcher ensured trustworthiness through four processes; namely credibility, confirmability, transferability and dependability. For details about the strategies used, refer to Section 2.4.

### **1.10 ETHICAL CONSIDERATIONS**

The researcher ensured that the rights of the participants, in this case diabetic patients, were protected. This was achieved by observing participants' right to self-determination and autonomy, observation and protection of their privacy, their prevention from harm, as well as fair and just treatment during the research process. The rights of the institutions, in this case the PPH and the MOH Swaziland, were

protected and upheld by requesting permission before conducting the research and by avoiding disruption of services at these institutions during the research process.

The researcher also upheld high ethical and professional standards in the execution of the research. This was done through adequate acknowledgement of original work used during research, bracketing, and generally allowing the research process to unfold without biased interference towards certain interpretations (Babbie 2007:62-64; Burns & Grove 2009:189-207; Strydom 2011:115-129). For more details, refer to Section 2.5.

### **1.11 SCOPE OF THE STUDY**

This study was conducted in the catchment area of Piggs Peak, which is situated in the northern Hhoho Province of Swaziland. This implies that the results cannot necessarily be generalised to the generality of the Swaziland diabetes patients' population. More similar research in other areas of the country is needed to strengthen the level of evidence and overall scientific body of knowledge on this subject.

### **1.12 STRUCTURE OF THE DISSERTATION**

Chapter 1: Orientation to the study

Chapter 2: Research design and methodology

Chapter 3: Data management, analysis and literature control

Chapter 4: Research results, conclusions and recommendations.

### **1.13 CONCLUSION**

This chapter commences with an introduction to the subject of DM, the disease presence in the world, Africa, Southern Africa, and Swaziland. The presence, impact, and management of DM are explained; these form the background to the qualified research problem. Main concepts of the research are defined, followed by the research aim and the foundations of the study. The study design is described, followed by ethical and trustworthiness issues pertaining to the research. The scope of the research is provided, and the chapter concludes with an outline of the structure

of the dissertation. Chapter 2 follows with the detailed research design and methodology.

## **CHAPTER 2**

### **RESEARCH DESIGN AND METHODOLOGY**

#### **2.1 INTRODUCTION**

This chapter explains, in detail, the research design and methodology followed in executing the study. Sampling, data collection, data analysis, measures to enhance and ensure trustworthiness and truthfulness, and measures to ensure research ethics in the study process are explained. The researcher presents the actual research process and research methods used, integrated and supported by the research methodology theory.

#### **2.2 RESEARCH DESIGN**

A research design incorporates the major strategies adopted by the researcher in an effort to generate accurate and interpretable evidence. A research design is the blueprint for the whole process of conducting the research, and it directs the essential steps; like sampling, data collection, data analysis, and interpretation (Burns & Grove 2009:41; Polit & Beck 2012:180). The researcher used a descriptive, exploratory, contextual and qualitative research design.

##### **2.2.1 Descriptive design**

Descriptive research encompasses the observation and description of existing phenomena in their natural existence and the discovery of new information (Babbie 2007:89; Burns & Grove 2009:12; Fouché & De Vos 2011:96; Polit & Beck 2012:17,226). This research approach includes fact finding; it seeks to describe aspects and dimensions of the problem of inquiry. This approach does not seek to test or prove relationships and hypotheses, but it can expose possibilities of certain relationships that can be investigated with more analytical studies at a later stage (Krishnaswami & Ranganatham 2010:36). This research focuses on describing the life experiences of DM patients at the PPH, with regard to the diabetes condition itself, the treatment, and self-care.

### **2.2.2 Exploratory design**

Exploratory research is carried out to gain insight into a situation or phenomenon. The approach is useful mainly when the phenomenon is little understood due to lack of basic information. This design is also known as formulative research. It can serve as a predecessor to a series of more analytical research (Babbie 2007:88; Fouché & De Vos 2011:95-96; Krishnaswami & Ranganatham 2010:34-35; Polit & Beck:18). As mentioned in the research problem, DM patients' experiences are barely researched and published subjects in Swaziland. That calls for an exploratory approach to ensure a basic understanding of how patients with DM experience their condition and treatment.

### **2.2.3 Contextual design**

According to Mongwe (2001:49), a contextual study describes findings in terms of the time, space, and values in which the research is conducted. Diabetic patients are normally reviewed in the OPD at PPH on Wednesdays. Participants included in the sample participated in the natural, unmodified context of their regular consultations, hence contextual research was conducted, and the results would be relevant to the PPH setting.

### **2.2.4 Qualitative design**

Qualitative design explores and describes phenomena holistically as they are consciously experienced; it examines the real essence of how phenomena are experienced by a certain group of people or individuals in their unique life situations (Giorgi 2005:80; Polit & Beck 2012:487; Saldana *et al.* 2011:32; Stake 2010:15). The design is naturalistic, interpretive, broad, and humanistic. It uses unstructured interviews and observations; it values uniqueness, meaning, and understanding. It uses inductive and dialectic thinking and reasoning (Burns & Grove 2009:23). The design values and emphasises qualities of entities, processes, and meanings that are not experimentally examined. Qualitative researchers value the socially constructed nature of reality, and the intimate relationship between the researcher and what is researched (Denzin & Lincoln 2011:8). Qualitative research presents snapshots of life; including understandings, ideas, and experiences of participants that are rich in significance and meaning (Featherston 2007:[94-103]). Qualitative

research relies more, and uses textual rather than numerical data (Carter & Little 2007:1316). This approach is vital for exploring new phenomena, and to capture individuals' thoughts, feelings, and interpretations (Easterbrook & Given 2008:[828-833]). As Lahman and Geist (2008:[360-364]) state, this research design seeks to explore phenomena in their natural settings. The aim is to understand the meaning of human action and to tell the human story. This approach also provides holistic in-depth accounts and attempts to reflect the complicated, contextual, interactive, and interpretative nature of our social world (Staller 2010:[1159-1164]). The design also demands that the researcher disposes of all preconceived ideas and prejudices about the subject and allow the data to speak autonomously (VanderStoep & Johnson 2009:166-168,207; Yin 2010:38). In this research, the group of people referred to the diabetic patients attending the PPH, and the researcher was the main research instrument (Polit & Beck 2012:487). The research was executed in a non-intrusive way, in the routinely natural environment of scheduled diabetes consultations at the hospital. The individual life situations are to the way in which each of the participants experienced their diagnosis, and continue to experience their treatments and self-care. The researcher applied bracketing, self-reflection, and member checking during the research process, to allow the data to speak autonomously (Featherston 2007:[94-103]; Lahman & Geist 2008:[360-364]; Streubert & Carpenter 2011:48-49).

## **2.3 RESEARCH METHODS**

Research methods are the planned activities that are carried out to gather the required data and to analyse that data with the purpose of arriving at useful and meaningful conclusions (Fouché & Delport 2011:75; Polit & Beck 2012:188-189). Under this section, the researcher discusses how the research sample was selected, how the information was collected from that sample, and the way in which the data was analysed.

### **2.3.1 Sampling**

Sampling is the process of selecting elements or participants from the population that one eventually uses in the study process (Burns & Grove 2009:35,343; Strydom 2011:223-224; Mason 2002:120-121; Polit & Beck 2012:275). The researcher carried

out a qualitative study, and thus used a non-probability sampling approach appropriate for this research process.

### **2.3.1.1 Target population**

Target population in research is defined as all the elements in the general population who/which qualify to be included in the study. Stated otherwise, it is the total population to which the researcher may wish to generalise the research results. Elements in this definition mean the units of study, and these elements can either be people or objects, depending on the nature of the study (Burns & Grove 2009:343-344; Polit & Beck 2012:274). In this research, the target population was all living diabetic patients in the diabetes register at the PPH in Swaziland. On 30 July 2012, the total number of patients on the diabetes register at the PPH was 410.

### **2.3.1.2 Accessible population**

The accessible population is the subset of the target population, to which the researcher has reasonable access (Burns & Grove 2009:344; Polit & Beck 2012:274). In this research, the accessible population was all DM patients on the PPH register who reported as expected on Wednesdays at the PPH for routine monthly consultations, during the period of data collection, i.e. August and September 2012.

### **2.3.1.3 Purposive sampling**

Qualitative researchers do not attempt representative sampling. Instead, the sampling approaches are guided by the importance of involving participants who can offer rich descriptions of lived experiences, people who can represent a broad scope of human experience, and in this research, the life experiences of DM patients at the PPH. There is no intent of generalising the findings to the greater population, a quality characterising the positivist quantitative research approach (Nicholls 2009:639; Streubert & Carpenter 2011:28). Due to lack of impartiality, the qualitative sampling approaches are described as non-probability in nature, also known as non-random sampling. In non-probability sampling, samples are selected in some way not suggested by the probability theory. Not every element or person in the population

has an equal chance of being included in the study (Babbie 2007:183,187; Burns & Grove 2009:355).

The researcher used a non-probability sampling approach known as purposive or judgemental sampling to select participants who attended the OPD at the PPH on Wednesdays. Participants were selected based on the richness of their knowledge of the experiential phenomenon under study (Polit & Beck 2012:279; Streubert & Carpenter 2011:90). With this approach, the researcher chose participants most likely to give in-depth descriptions of the life experiences of patients living with DM (Babbie 2007:184; Staller 2010:[1159-1164]; Strydom 2011:232; VanderStoep & Johnson 2009:187). The sample selection process was based on particular inclusion and exclusion criteria.

#### **2.3.1.4 Inclusion criteria and justification**

Prior to the actual selection of the study sample, the eligibility characteristics should be spelt out, and these characteristics should be clear and specific (Polit & Beck 2012:286). They can be articulated in the format of inclusion and exclusion criteria. Inclusion criteria are those characteristics that the participants should have in order to be included in the research sample (Burns & Grove 2009:345; Polit & Beck 2012:274). For the purposes of this research, participants were considered for inclusion if they had the following characteristics:

- **The participants should be diabetic patients at the PPH and their names should appear in the hospital diabetes register**

The researcher had to be very sure that the participants selected were genuine diabetic patients who were being managed at the PPH. This could only be proven by verifying their names in the hospital diabetes register. The process was easy, considering that the diabetes register is always used and readily available on diabetes days.

- **The participants should have been diagnosed, and been on hospital-managed treatment for a minimum of six months prior to the day of the research**

The requirement that one should have been diagnosed and on hospital-based management for at least six months was important to ensure that the researcher got participants with significant life stories to tell.

- **The participants should be legally competent to participate in research of this nature**

The issue of autonomy and legal competence was observed in selecting participants. People with reduced legal competence like the mentally challenged and prisoners were not considered for participation (Burns & Grove 2009:189-194).

- **The participants should be eloquent in English, siSwati, or both languages**

SiSwati, an Nguni language very similar to the isiZulu language, is the predominantly spoken language in Swaziland. English is also quite commonly spoken since it is the language of business in the country; although rural people have less adequate linguistic competency in English compared to their urban counterparts (Swaziland Embassyhomepage.com 2012). The researcher is eloquent in English and siSwati and was comfortable in using either of these languages during the research processes. The participants needed to be reasonably eloquent in either or both of these languages to ensure adequate understanding and interpretation of the information gathered during the interviews.

- **The participants should be above 18 and below or equal to 65 years old**

Participants below 18 years old were not favoured due to age related legal competence issues. The researcher did not expect to secure the best in-depth and information-rich discussions from this age group. The elderly, also known to be above 65 years, were not considered for this research. This was due to the increased risk of diminished autonomy and legal competence of such participants due to higher prevalence of mental handicaps, like dementia and stroke related brain damage

(Longmore *et al.* 2007:478). Such handicaps, with their likelihood to cause memory and concentration problems, could possibly have compromised the value and quality of information to be gathered.

### **2.3.1.5 Exclusion criteria and justification**

Criteria that lead a potential participant to be excluded from a study are called exclusion criteria (Burns & Grove 2009:345; Polit & Beck 2012:274). In this study, patients with the following were excluded:

- **The mentally impaired, i.e. patients with psychiatric illness and those under the influence of mind altering substances; such as alcohol, the brain damaged like patients with dementia, and the mentally retarded**

Mentally impaired patients were excluded, not only due to the challenges of getting legal consent, but also due to the potentially compromised quality of information likely to be sourced from such individuals. Qualitative research comprises harvesting the richest information from a few people (VanderStoep & Johnson 2009:188; Yin 2010:109). Including mentally challenged or intoxicated participants in the study would thus have been counter-productive. Chronic NCD patients at the PPH use patients' consultation cards stored at the hospital for all consultations and these cards contain all the patients' major diagnoses, therefore, those patients with dementia and psychiatric illness were easily excluded from taking part in the study. The researcher used his experience as a medical doctor to exclude persons under the influence of alcohol and those with questionable levels of sobriety (Burns & Grove 2009:189-194).

- **Diabetic patients considered to be very ill or in substantial physical or any other forms of discomfort**

The hospital casualty and outpatients area has a systematic triaging system to categorise people's conditions and states in a spectrum from stable to very ill. The triaging is done by experienced nursing staff before patients reach the doctors' consultation area. The very ill are identified in the triaging area and the responsible nurse ensures that such patients are prioritised. It is from this level that this researcher obtained guidance necessary to exclude the very ill from being part of the

research sample. Such exclusion was necessary for ethical and humanitarian reasons. One would not expect to gather reliable, in-depth and quality information from participants who were in substantial discomfort, distress, or pain.

### **2.3.1.6 Sample size**

Sample sizes are not predetermined in qualitative research and there are no rules to determine the size. The important principle is to generate enough in-depth data to illuminate the patterns, categories, and dimensions of the phenomenon under study (Polit & Beck 2012:521). Qualitative research tends to use smaller sample sizes than positivist quantitative research (Easterbrook & Given 2008:[828-833]; Nicholls 2009:639; VanderStoep & Johnson 2009:188). The researcher continued to collect data until data saturation occurred, and that determined the sample size. Data saturation, also known as redundancy, happens when one notices that no new information is forthcoming from any more interviews or observations. This is possible because the researcher begins to notice some familiarities and similarities between the already gathered information and the subsequently provided information (Burns & Grove 2009:361; Streubert & Carpenter 2011:30). The researcher noted saturation and stopped data gathering after a total of 26 interviews were conducted.

### **2.3.2 Ethical issues related to sampling**

In research, the selection of participants and their treatment should be fair and in accordance with the principles of justice and fairness. No potential deserving participants should be unnecessarily excluded from a study (Burns & Grove 2009:198). At a glance, the purposive nature of participant selection may suggest lack of fairness. Other potential participants might feel discriminated against when they are excluded (Yin 2010:67). This challenge was addressed by ensuring that every potential participant was made aware of the research process and that they could volunteer to take part. This information was announced to the patients during the morning education sessions at the PPH OPD on the diabetes days before data was gathered.

### **2.3.3 Data collection**

Qualitative research, unlike the more positivist quantitative research, tends to make use of non-numerical data (Lahman & Geist 2008:[360-364]; Saldana *et al.* 2011:12; Staller 2010:[1159-1164]). Observations and audio-visual data are thus converted to narrative data in preparation for the data analysis process. The researcher used a semi-structured interview schedule to conduct audio-recorded interviews with the selected participants. The information on the voice recordings had to be converted to a format that enables the researcher to analyse the data. The interviews were transcribed by the researcher to narrative format in Microsoft Word.

#### **2.3.3.1 Development and testing of the data collection instrument**

The researcher developed an interview schedule with broad questions as a general guide to each interview. These questions were perceived to initiate discussions and generally covered most aspects of the phenomenon under study. It is vital in research to test the data collection instrument prior to research with the aim of allowing for improvements and clarifications on the instrument. This testing also helps with identifying the most effective probing questions for the actual research process (Delpont & Roestenburg 2011:195). The interview schedule was pre-tested at the PPH OPD with one diabetic male patient on the 11th of July 2012. The schedule was found to be effective in sustaining a balanced and guided discussion about the various aspects of the experiential phenomenon under study. The entire interview took 40 minutes to complete and the participant understood and responded to all the broad questions. The English and siSwati interview schedule versions are attached as Annexures E and F.

#### **2.3.3.2 Characteristics and structure of the data collection instrument**

The interview schedule was designed to have different parts. The various parts served to set the ball rolling in a general sense to facilitate information-rich responses to the researcher's statements. Most information was to be gathered through relevant probing, once the broader topics had been introduced. The researcher remained prepared for the possibilities of otherwise unanticipated subtopics that might arise from the emerging discussions (Babbie 2007:306; Greeff 2011:352).

The introductory part of the interview schedule mainly continues from the pre-interview rapport building, at the same time capturing various demographic characteristics; like age, level of education, place of stay, and the distance of the participant's home from the hospital. Such information was vital for the analysis stage because one needed to know these characteristics of the sample, in order to establish whether certain characteristics would possibly be associated with certain analytic patterns. The interview schedule was arranged in a way that left the most sensitive part to the last stage of the discussion, i.e. information about challenges and coping (Greeff 2011:352).

The second part broadly interrogates the participant's experience of DM diagnosis, with further relevant probing to capture the circumstances in relation to the diagnosis and the psychological impact of the diagnosis. The third part investigates the life experiences of the DM patient, with regard to the actual tasks of treatment and self-care. The fourth part seeks discussion about the participant's coping with the DM condition and self-care in real life terms, the experience of being diabetic at family and community level, and the experience of diabetes complications. The last part seeks the participant's recommendations to the researcher, the hospital, the government, and every relevant stakeholder in the management of DM in Swaziland. An exit or conclusion part at the end of each interview allows the researcher to thank the participant for taking part in the interview and allows the participant to add any concluding comments (Yin 2010:161).

### **2.3.3.3 *Data collection method and process***

The researcher conducted one-to-one semi-structured interviews with the selected participants at the PPH on Wednesdays. On average, four interviews were conducted on each diabetes day. In total, the researcher utilised the eight Wednesdays to conduct a total of 26 interviews. Each interview took an average of 45 minutes. The data was audio-recorded and the researcher made use of observation notes in order to capture non-verbal data during the research process. The researcher was the main instrument in the research process (Featherston 2007:[94-103]; Stake 2010:20; Yin 2010:34).

- **Audio recorded semi-structured interviews**

Qualitative research studies rely on interviews with participants (Easterbrook & Given 2008:[828-833]; VanderStoep & Johnson 2009:224). The advantage of semi- or unstructured interviewing is that it is flexible and thus allows one to gather substantial amounts of information, which is the main purpose of this kind of research. As Saldana *et al.* (2011:41) put it "...the method is an effective way of soliciting and documenting, in their own words, an individual or group's perspectives, feelings, opinions, values, attitudes, and beliefs about their personal experiences and social world, in addition to factual information about their lives". The response rates during interviews are generally higher than with questionnaires because of the face to face contact between the researcher and participant, and data collection is easier even when dealing with participants who cannot read and / or write (Burns & Grove 2009:405).

One disadvantage with this data collection method can be the interruptions to the interview process (Polit & Beck 2012:543). Another disadvantage of interviews is that the participants may tell or inform the researcher what they think will impress or be perceived as acceptable to the researcher. Unanticipated turn of events can be a challenge, like when participants experience nervous or emotional breakdown during the interview process, or even plain participant stage fright (Burns & Grove 2009:511; Greeff 2011:342-347 ).

Audio-recording is advantageous, since it allows the researcher to concentrate on the observational and listening part of the data gathering process, without having to struggle with scribbling notes at the same time. Audio-recording also allows the interview tone and the actual discussion process to be replayed verbatim at a later stage, thus allowing the researcher an opportunity to capture a lot of interpretive data that would otherwise have been missed during the real interview session. Digital audio-recordings can also be easily transferred electronically onto a computer hard drive for future analysis. One challenge with audio-recording is that some participants may feel uncomfortable, or nervous about being recorded. Participants can generally be withdrawn during audio-recorded interviews, thus very little and calculated information might be provided (Greeff 2011:359-360; Polit & Beck 2012:542; Saldana *et al.* 2011:47). All challenges that accompany audio-recorded semi-structured

interviewing stated in this section were mitigated through strategies explained under the two bullet subsections below.

- **Preparation for the audio-recorded semi-structured interviews**

A quiet room was identified in the OPD of the PPH for the research interviews (Burns & Grove 2009:404-405; Saldana *et al.* 2011:43-44). The room had to be clean with adequate and moderate lighting, and sufficient ventilation. The stationery included the informed consent forms and interview schedules in vernacular siSwati and also in English (Annexures C, D, E & F), two working ink pens and a note pad for writing observational notes after each interview (Saldana *et al.* 2011:48). There were two chairs and a small table on the researcher's side for the audio-recorder. There was no physical barrier between the researcher and the participant. A notice was put on the outside of the door to encourage quiet and to avert unnecessary interruptions and disturbances (Saldana *et al.* 2011:44). Personal cell phones were switched off prior to each interview (Polit & Beck 2012:543; Yin 2010:193). The OPD hospital staff members were made aware of the on-going research interviews to ensure their cooperation.

The researcher took care not to overdress on the day of the interviews, but to look formal, un-intimidating, and down-to-earth (Burns & Grove 2009:405). Furthermore, he familiarised himself with the interview schedule to avoid overreliance on the interview schedule during the interview. The researcher was prepared for un-anticipated turn of events in the form of emotional crises like anger, fear, and grief. The researcher made prior arrangements with the psychiatry department that offers counselling services during daytime hours at the hospital to receive any participants who might need some counselling. The researcher also prepared for any unexpected and unanticipated new information that might arise during the interviews (Babbie 2007:306; Greeff 2011:352; Polit & Beck 2012:543).

To ensure the comfort of participants, unflavoured non-allergenic face and hand wipes and dry serviettes were made available. In view of the fact that the participants were patients who came starved for hospital consultations, it was necessary to prepare some light refreshments prior to the interview. Clear, unflavoured sealed mineral water, natural fruit juice with no added sugar, low calorie low-sugar biscuits

and brown bread, cheese, and lettuce sandwiches were available (Saldana *et al.* 2011:49).

Two audio-recording devices were available and tested for working order prior to the interviews to ensure good quality of the recorded voice. One of these devices was kept ready as backup. New spare batteries were always available (Saldana *et al.* 2011:47). The recording apparatus was positioned in an un-obtrusive way, away from the direct engagement line between the participants and the researcher (Schurink, Fouché & De Vos 2011:404; Yin 2010:193).

- **Conducting the interviews**

A qualitative interview is generally a conversation between the researcher and the participant, while the researcher is steering the conversation in a certain direction and the participant is adding related topics. In such conversational mode, the participant is also given an opportunity to query the researcher. The most important rule for a good interviewer is to be a good listener. One has to avoid leading, counselling, judging, and advising the interviewee (Polit & Beck 2012:543; Yin 2010:155).

Selected participants were considered for the interview process only after they had gone through the whole consultation and treatment process of the day. The researcher took time to build rapport and mutual trust with the participants; most of them knew the researcher as their doctor. This was done through small talk, greetings, and exchanging other pleasantries; this also assisted with putting the participants at ease (Streubert & Carpenter 2011:34-35). During this introduction, the researcher also selected the relevant language medium for conducting the rest of the interview. The participants were offered water and refreshments, and were invited to snack at any stage during the interview session. The researcher then read the informed consent (Annexures C and D) that explained the nature and process of the research, why the participant was chosen, the right to accept or decline participation without any consequent compromise to the quality of care the participant would receive as a patient at the PPH, and issues of privacy and protection of participants from harm (Burns & Grove 2009:189-190,202).

The participants were requested to show consent by co-signing the consent document with the researcher before the actual research interview started. The consent documents and interview files did not bear the participants' names but they would instead be identified by sequence-based codes. The researcher collected contact and hospital review date information from the participants and kept them against the code names for the purposes of validation and cross checking with the participants at any later stage of the research. This process is also known as member checking (Featherston 2007:[94-103]; Schurink *et al.* 2011:419-420; Streubert & Carpenter 2011:48-49). After the participant's consent, the researcher activated the audio recorder and then proceeded to the introductory part of the interview schedule (Saldana *et al.* 2011:49; Yin 2010:192-193).

The researcher avoided being rigidly stuck to the course and sequence of the interview schedule because most questions were determined by the natural, though guided, course of the discussion (Saldana *et al.* 2011:44). The wording of the questions was not identical either, including the non-verbal demeanour of the researcher during the interviews, since this was also determined by the dynamics of the particular interview (Yin 2010:155,160).

The participants were encouraged to do most of the talking. The researcher was prepared to think, talk, and listen at the same time. He applied verbal and non-verbal ways to demonstrate some interest, respect, appreciation, empathy, and acceptance with the purpose of encouraging the participants (Babbie 2007:306; Burns & Grove 2009:510; Greeff 2011:343-344; VanderStoep & Johnson 2009:226).

The researcher used the technique of probing to encourage the participants to elaborate whenever interesting information was forthcoming. The probing was, however, done in a neutral way to avoid biasing the whole discussion. Open-ended rather than close-ended questions were used to avoid limiting participants to predetermined areas. It encouraged the participants to use their own words to tell their own stories by structuring their narratives around their own emic issues (Polit & Beck 2012:537; Saldana *et al.* 2011:44; Stake 2010:95; VanderStoep & Johnson 2009:228).

Complex questions and yes or no questions were avoided. The researcher avoided verbal or non-verbal prompts likely to imply own biases and prejudices, thus preventing the risk of the participants pandering to the researcher (Yin 2010:156-158). Value-laden and “why” questions were avoided. The interviews were conducted with an attitude of courtesy and respect (Burns & Grove 2009:405; Saldana *et al.* 2011:48-49; Schurink *et al.* 2011:353). The researcher was always on guard not to overstep the boundary between self and other. The researcher had to establish an empathic but separate relationship with research participants and had to avoid posturing as someone willing and able to fix any problems, since it was not part of the original plan of the research (VanderStoep & Johnson 2009:228).

#### **2.3.3.4 Ethical considerations related to data collection**

The researcher only proceeded with data collection after permission had been granted by the University of South Africa (UNISA) Department of Health Sciences: Departmental Higher Degree Committee, and the Swaziland Government through the Ministry of Health (MOH), (Burns & Grove 2009:207; Strydom 2011:126) (Annexures A and B). Participants had to indicate by signing a consent form that they agreed with all aspects of the data collection process, including the research interviews being audio-recorded. Covert data collection is an unprofessional and unethical transgression to be avoided in research, and this was indeed avoided. The researcher ensured that the informed consent document contained full disclosure of the process of data collection and the consent form was available in both English and vernacular siSwati formats to ensure that consent would be secured after a well understood disclosure. The researcher made it clear during disclosure that participants would only be expected to answer questions that they were comfortable with, and that they could terminate the interview whenever they felt the need to do so (Burns & Grove 2009:190,201-206). The researcher took care not to unnecessarily prolong the interviews to avoid inconveniencing them considering that their main purpose of being at the hospital in the first place was medical consultation only (Yin 2010:173). Personal and private matters were not discussed during the interview, there was no use of trickery to get information from the participants, and the researcher avoided taking advantage of the power dynamics in the interview setting (Mason 2002:79-80).

The researcher observed due respect for the Swazi cultural values and avoided commenting on, and judging these values whenever they were raised in the interview context. The researcher ensured a smooth exit for participants from the interview by avoiding abrupt ends to discussions, and by allowing lighter brief small talk at the end of the interview, punctuated by good wishes for the rest of the day (Saldana *et al.* 2011:53; VanderStoep & Johnson 2009:227; Yin 2010:160). Interview scripts were coded, anonymised, and duly filed. Files with transcribed data were code named to correspond with the interviews and were electronically kept on the researcher's computer hard drive and on a back-up hard drive, both kept privately and securely by the researcher. All data documents were not to be shared with anyone else, and findings were eventually reported collectively, without identifying the participants (Yin 2010:193-194). No false promises were made during data collection and the researcher avoided raising false hopes during the whole interview process (VanderStoep & Johnson 2009:228).

#### **2.3.4 Data analysis**

It is vital to note that data management in qualitative research is reductionist, meaning taking masses of data and arranging them into manageable sections, whilst analysis is a constructionist and inductive process, involving putting sections together to form meaningful patterns (Polit & Beck 2012:562). Data analysis begins during the interview and data gathering process. From the first moment data is collected, analysis should be on-going and recursive; the researcher should take advantage of the emergent, flexible and data driven process of qualitative research. Through field note writing, interview transcribing, analytical memo writing and other documentation processes, one gets to assume cognitive ownership of the data. The intuitive, tacit, synthesising capabilities of the brain begin to sense patterns while starting to observe the bigger picture with greater clarity (Lahman & Geist 2008:[360-364]; Saldana *et al.* 2011:99). This is when the researcher notes what he perceives and what he thinks he is perceiving. Data collection occurred simultaneously with analysis, the researcher was totally involved by perceiving, reacting, interacting, reflecting, attaching meaning, and recording at the same time (Burns & Grove 2009:508; Greeff 2011:342-343). Considering that in qualitative research, data gathering and processing do happen simultaneously, the researcher continued to listen to the interviews whilst reflecting

and intuiting at the same time, and even arriving at naïve interpretations and writing them down as personal interpretive memos. With empirical and interpretive note making, analysis was already in swing (Burns & Grove 2009:508; Greeff 2011:359-360,342-343).

The researcher transcribed the audio-recorded interviews to a narrative format and the transcribing was done verbatim, using Microsoft Word. The researcher crosschecked whether what appeared on paper reflected what was indeed said and what had transpired during the interviews (Polit & Beck 2012:557). The transcribed interviews became the researcher's raw data, and the researcher went through all the data over and over again in a process of immersion in data. Data, in this situation, included the transcribed information, observational notes made by the researcher during the interview process (Burns & Grove 2009:521). The researcher then listened repeatedly to the interviews while checking the transcribed information, and putting down notes against vital statements that in a way related to the research purpose and objectives. The researcher immersed in the data, organising and checking for completeness of all forms of available data. Copies of the assembled data were backed up (Lahman & Geist 2008:[360-364]; Schurink *et al.* 2011:409-410). The researcher continued to read the notes over and over again, writing interpretive memos and reflective remarks in the margins of the transcripts. Every effort was made to continuously acknowledge unwanted biases imposed by the researcher's presuppositions and values while analysing data, during a process of bracketing (Polit & Beck 2012:495; Saldana *et al.* 2011:104; Schurink *et al.* 2011:409-410; Streubert & Carpenter 2011:26; Yin 2010:198). For the purposes of this study, the first five steps of the descriptive, existential phenomenological method of Colaizzi (Colaizzi 1978:48-71; Polit & Beck 2012:566-567) were used for manual data analysis.

### **Step 1:**

By reading and re-reading the transcribed data and all research entries, the researcher could totally immerse in the data to familiarise himself with the phenomenon.

**Step 2:**

The researcher extracted significant statements and phrases from the transcripts that related to the research purposes and objectives.

**Step 3:**

The researcher attached meaning to each significant statement.

**Step 4:**

The formulated meanings were organised into clusters of themes, and categories. The clusters of themes and categories were checked against the original transcripts to validate them.

**Step 5:**

Results yielded at that stage were integrated into an exhaustive description of the phenomenon under study.

The process produced three broad themes and a total of eleven categories under these themes, and these hierarchical interpretive structures helped to describe the whole experiential phenomenon under study (refer to sections 3.4 to 3.6).

**2.4 MEASURES OF TRUSTWORTHINESS**

Lincoln and Guba (1985:290) refer to trustworthiness in research as the truth value of the research, its applicability, consistency, and neutrality. It is measured in four aspects; namely credibility, transferability, dependability and confirmability (Polit & Beck 2012:584). According to Lahman and Geist (2008:[360-364]), trustworthiness is an overarching term for validity and reliability as commonly used in quantitative studies. Of vital importance is that research should be conducted in a transparent manner, and recorded in a way that allows professional scrutiny (Yin 2010:40). The researcher ensured trustworthiness through various strategies as explained below:

**2.4.1 Credibility**

Credibility, also known as authenticity, is the equivalent of internal validity in quantitative studies. It demonstrates the likelihood that the same results can be

acquired when the same sample and context were to be similar in a replication study. It confirms the believability of the study (Polit & Beck 2012:584-585; Schurink *et al.* 2011:419-420). The researcher carried out in-depth one-to-one interviews with the research participants, ensuring deep immersion in data. The researcher ensured in-depth descriptions of the analysed data, showing the complexities of the variables and interactions. The researcher kept a diary of the participants' subsequent review dates in order to arrange possible secondary confirmatory interviews in case there might be a need for further probing or validation of emerging meanings and themes during the data analysis process. This is also known as member checking (Featherston 2007:[94-103]; Schurink *et al.* 2011:419-420; Streubert & Carpenter 2011:48-49).

#### **2.4.2 Confirmability**

Confirmability, traditionally known as objectivity, is an equivalent of inter-rater reliability in quantitative studies. It is a measure of the degree of the researcher's objectivity (Polit & Beck 2012:584; Schurink *et al.* 2011:421). It represents the extent to which the research observations and results are a real reflection of the participants' perspectives rather than the researcher's own imagination or subjective thinking (Featherston 2007:[94-103]; Polit & Beck 2012:585). The researcher underwent peer debriefing by interacting with fellow doctors who had conducted qualitative research, especially on the process of data analysis (Polit & Beck 2012:594). The researcher employed the technique of rechecking the data throughout the study, and also kept an audit trail of the major steps and decisions made during course of the study. Audio recordings and data transcripts were retained as part of the audit trail (Burns & Grove 2009:546; Featherston 2007:[94-103]; Polit & Beck 2012:594-595; Streubert & Carpenter 2011:49). The researcher also made use of the technique of reflexivity throughout the research process to minimise the influence of pre-existing biases and prejudices (Lahman & Geist 2008:[360-364]).

#### **2.4.3 Transferability**

This aspect, also known as fittingness, is similar to generalisability or external validity in quantitative research (Polit & Beck 2012:584; Schurink *et al.* 2011:420). The researcher enhanced this aspect by a dense description of the research participants,

research setting and context, the total research process, and the detailed interaction between researcher and participants. The researcher also clarified the assumptions that guided the research (Featherston 2007:[94-103]; Polit & Beck 2012:525-526; Schurink *et al.* 2011:420; Streubert & Carpenter 2011:49).

#### **2.4.4 Dependability**

This aspect is similar to reliability in quantitative studies (Polit & Beck 2012:584; Schurink *et al.* 2011:420-421). It mainly involves the possibility that the same results or conclusions can be made with the same research process and context replicated, with everything being the same. It is also known as the stability of the research results. The researcher discussed the data analysis approach with an experienced researcher at a local research college and reached consensus. The independent expert also assisted to validate the interpretations of the data analysis process. The researcher further enhanced dependability by describing in detail the dynamic context in which the research occurred, which affected the way the research project was approached (Featherston 2007:[94-103]; Polit & Beck 2012:585).

### **2.5 ETHICAL CONSIDERATIONS**

This research was conducted by involving human participants who had been diagnosed with DM. The research was conducted at a government hospital, and the principal researcher is a government employed doctor. Therefore, the researcher had to ensure the rights of the participants, in this case diabetic patients, and the rights of the institutions, in this case PPH and the MOH of Swaziland, were fully protected and upheld. No unnecessary harm was to be imposed on any of these parties during the research process. The researcher also needed to uphold high ethical and professional standards during the execution of the research. Various steps were taken to achieve these standards.

#### **2.5.1 Protection of participants' rights**

It was vitally important that the rights of participants were protected during the entire research process. Aspects of participants' rights include the right to fair treatment through the principle of justice, the right to self-determination or autonomy, the right

to protection from harm or non-malevolence, and the right to privacy and confidentiality (Burns & Grove 2009:189-212; Strydom 2011:115-120).

### **2.5.1.1 *The right to self-determination / autonomy***

Every human being has a God-given right to do as they wish with their lives without external coercion or force. Participants in this research were made fully aware of the research processes prior to their voluntary consent. Participants were informed about their right to withdraw from the study at any point if they so wished, with assurance that they would still be treated with the same quality of care at the hospital (Babbie 2007:62). The researcher, through adherence to inclusion and exclusion criteria, ensured that all participants were legally and mentally competent to consent for the research (Sections 2.3.1.4 and 2.3.1.5). Every effort was made to avoid involving in the study the mentally challenged participants like the ones with dementia, stroke, anyone under the influence of intoxicating substances, children below 18 years, and the seriously ill (Burns & Grove 2009:189-212).

For those participants who were legally competent to consent and willing to take part in the study, a standard format of obtaining voluntary consent was followed. This involved the researcher reading and explaining the consent form in an appropriate language medium, and the participant either accepting to take part by co-signing with the researcher or declining. Deception was avoided in the process of securing consent from potential participants (Denzin & Lincoln 2011:65; Yin 2010:67). The consent form, as shown on Annexures C and D, contains all the vital information about the research, issues of data collection including audio-recording, freedom of participants to decline or opt out, and a guarantee of protection from breach of participants' privacy. The researcher avoided jeopardising the participant's right to self-determination by being transparent, avoiding deceptive and covert data gathering methods, and fully disclosing to the participants what the research was really about. Coercion was also excluded by not offering rewards to participation as an enticement (Burns & Grove 2009:189-212; Mason 2002:80-82; Polit & Beck 2012:154-155; Streubert & Carpenter 2011:61-62; Strydom 2011:115-120).

### **2.5.1.2 No maleficence, protection against harm**

The right of participants to protection from harm stems from the principle of beneficence that holds that one should do good, maximise benefits, and above all, do no harm (Burns & Grove 2009:198-199; Polit & Beck 2012:152). The participants have a right to be protected against unnecessary harm during the process of the study (Strydom 2011:115). Harm can present in the form of physical, social, psychological, legal, dignitary, financial, or any other discomforts to be suffered by the participant as a consequence of the research process (Yin 2010:67). Such harm can also present in various degrees, ranging from negligible or temporary to serious and long-term.

There was minimal harm due to the mere fact that participants were inconvenienced by being part of the interview process, but that discomfort was fully reversible on completion of the interview (Polit & Beck 2012:156). The researcher checked the travel arrangements with participants to ensure that the interviews would not interfere negatively with these arrangements. Financial harm was not inflicted, since the researcher conveniently selected patients who were at the research venue for treatment purposes in the first place. No participant was asked to come to the venue for the purposes of research only.

Incidental reference to emotional topics that evoke past trauma can potentially cause emotional and psychological harm. The researcher steered clear of emotional inclinations to the discussions, and offered an empathic ear whenever participants verbalised emotional issues, especially during the questions about life and coping with DM. The researcher avoided abuse of the power dynamics during the interview by not forcing participants to provide information. The researcher made provisional plans with the counselling department at the hospital, in the event that participants might need counselling (Burns & Grove 2009:189-212; Mason 2002:79-80; Polit & Beck 2012:152-153; Strydom 2011:115-116).

Harm may also be inflicted when a participant's confidential information is divulged to the wrong recipients, since it breaches the person's right to privacy and confidentiality (Yin 2010:67). This researcher mitigated this by anonymising all participants' files and keeping them secured in a lockable drawer. The researcher

intended to publish the research results in a way that participants could neither be traced, nor identified in the findings (Babbie 2007:63-64). Participants were also discouraged from verbalising personally identifying information during the interviews, especially people's names and real addresses (Burns & Grove 2009:189-212; Polit & Beck 2012:162; Streubert & Carpenter 2011:63-64).

### **2.5.1.3 *The right to fair treatment / justice***

The right to fair treatment emanates from the principle of justice. There should be fairness in the way participants are selected, the way they are treated during the research process, and when there are benefits or discomforts during the study, such should be afforded fairly to the participants in the target population. The burdens and benefits of the research should be equitably distributed to all potential participants. The researcher did not compromise the chances of potential participants in the accessible population from participating in the study, except for adhering to the sampling criteria. Participants were promised equal treatment at the hospital, even if they declined participation in the study. Privacy and confidentiality were ensured for all participants throughout the whole study process; there was no way of identifying participants after the interviews or at any other later stage after the research process. No covert data collection took place and participants provided permission for the interviews to be audio-recorded (Burns & Grove 2009:198; Polit & Beck 2012:155-156; Yin 2010:67).

### **2.5.2 *Rights of the institutions***

The research was conducted at a government hospital. It is the right of both the hospital management and the parent MOH to give permission for the study to go ahead (Annexures A and B). No research activity was executed before these institutions had given permission. Participants were only interviewed after they had gone through the whole medical consultation process, as an effort not to disrupt the natural patient flow in the OPD at the PPH on the research days. The researcher carried out the research respectfully and professionally to avoid tarnishing the image of the hospital and the MOH in Swaziland. On conclusion of the research project, the hospital and the MOH of Swaziland would receive copies of the final report and recommendations (Strydom 2011:115-128).

### **2.5.3 Researcher, scientific integrity**

Part of research integrity requires that one and one's words can be trusted as representing truthful positions and statements (Yin 2010:62). It also involves one adhering to the ethical codes guiding the practice of research (Strydom 2011:123). Permission to carry out this research was sought from the Department of Health Studies: Departmental High Degrees Committee at UNISA. Permission to carry out the research was granted on the 26th of April 2012 (Annexure A). The researcher corresponded with the local Ministry of Health Scientific Research Ethics Committee (SEC) to seek permission for the research (Annexure G); permission was granted on the 3rd of July 2012 (Annexure B) (Babbie 2007:69-70; Polit & Beck 2012:165-166; Yin 2010:65). While conducting the study, the researcher ensured that all preconceptions and prejudices about the research subject were kept well-bracketed. Deception was avoided during the research process and reporting of findings. The researcher refrained from purposeful and intentional fabrication, manipulation, or falsification of research results (Polit & Beck 2012:168-169). The participants got exactly what they were promised and informed of prior to consent. All reports, data entries, and data management were done without researcher manipulation and thus with honesty (Babbie 2007:61-69; Burns & Grove 2009:189-212). Due acknowledgement was accorded to owners of original work whenever such was used at any stage of the research process, and this was done by means of adequate referencing and listing. The researcher, through the UNISA, committed to allowing publication of the research findings for the greater benefit of the public and the scientific world once the project had been finalised (Strydom 2011:126).

## **2.6 CONCLUSION**

This chapter describes in detail the research design and methodology. Measures to ensure trustworthiness of the research are covered, together with the ethical issues guiding the study. Chapter 3 provides details of the data analysis and literature control.

## **CHAPTER 3**

### **DATA ANALYSIS AND LITERATURE CONTROL**

#### **3.1 INTRODUCTION**

The second chapter discusses the design and methodology of the study. Chapter 3 discusses the data management, analysis, and the literature control. The researcher first presents the population-based biographical characteristics of the sample, followed by the data analysis; namely the various themes, categories, and subcategories that explain the phenomenon under study.

#### **3.2 DATA MANAGEMENT AND ANALYSIS**

Data was collected in the form of audio-recorded semi-structured individual interviews over a period of three months. The 26 interviews were transcribed verbatim into narrative text by the researcher, and the narrative transcripts became the raw data (Burns & Grove 2009:520-521). Data was then analysed using the first five steps of the descriptive, existential phenomenological method of Colaizzi (Colaizzi 1978:48-71; Polit & Beck 2012:566-567), as described under Section 2.3.4. The data management and interpretation process was verified and refined by an experienced researcher based at a local research college.

#### **3.3 RESEARCH RESULTS**

The biographical, treatment and location details of the 26 participants are presented in Table 3.1 below.

**Table 3.1: Biographical, treatment, and location details of the participants**

Participant	Age & gender		Marital status	Employment status	Education	Treatment period	Transport cost (2 way)
	Age	Gender					
A	60 years	M	Divorced	Unemployed	Standard 3	6 years	R 14.00
B	60 years	M	Married	Unemployed	No schooling	5 years	R 22.00
C	58 years	M	Married	Civil servant / Teacher	Diploma	6 months	R 20.00
D	60 years	F	Widowed	Unemployed	Standard 6	13 years	R 20.00
E	60 years	F	Widowed	Unemployed	Standard 2	5 years	R 14.00
F	64 years	M	Married	Unemployed	Standard 4	20 years	R 24.00
G	50 years	F	Married	Unemployed	Standard 6	3 years	R 16.00
H	62 years	F	Married	Unemployed	Standard 6	1 year	R 20.00
I	62 years	F	Widowed	Unemployed	No schooling	> 5 years	R 28.00
J	40 years	F	Single	Unemployed	Standard 6	2 years	Walking
K	64 years	F	Married	Unemployed	No schooling	> 5 years	R 20.00
L	52 years	M	Married	Truck driver / Pvt Co.	Standard 4	2.5 years	R 20.00
M	55 years	F	Widowed	Unemployed	Standard 5	6 years	R 40.00
N	60 years	F	Widowed	Unemployed	No schooling	2 years	R 14.00
O	45 years	M	Married	Unemployed	Standard 5	11 years	R 16.00
P	55 years	M	Married	Truck driver / Pvt Co.	Standard 4	14 years	R 10.00
Q	45 years	M	Married	Farm worker	Standard 6	7 years	R 32.00
R	55 years	F	Single	Unemployed	Standard 5	8 years	R 20.00
S	63 years	F	Widowed	Unemployed	No schooling	> 5 years	R 20.00
T	64 years	F	Divorced	Unemployed	No schooling	> 5 years	R 28.00

Participant	Age & gender		Marital status	Employment status	Education	Treatment period	Transport cost (2 way)
	Age	Gender					
U	55 years	F	Single	Unemployed	Standard 5	1 year	R 20.00
V	50 years	M	Married	Unemployed	Standard 5	4 years	R 30.00
W	63 years	F	Married	Unemployed	No schooling	4 years	R 24.00
X	55 years	F	Single	Unemployed	Standard 4	2 years	R 10.00
Y	64 years	F	Widowed	Unemployed	No schooling	1 year	R 32.00
Z	56 years	M	Married	Self-employed	Standard 6	7 years	R 16.00

### 3.3.1 Age characteristics

The participants' ages ranged from 40 years to 65 years. The majority of the participants were of the ages ranging between 50 and 65 years, with a total percentage of 88.5%. The higher availability of diabetes patients in the above 50 years age category at the research site in a way led to more research participants being selected from that age group. The state of much higher numbers of available older diabetic patients is supported by literature that states that mature onset or type 2 DM is more common, at 90 – 95% of the total diabetic population in the world (ADA 2010:62-63; Twei *et al.* 2010:433-434). The researcher endeavoured to include the few available participants in a younger age group in order to achieve a more complete grasp of the phenomenon under study. Three participants below the age of 50 years were included.

### 3.3.2 Gender and marital status characteristics

Of the 26 participants of the whole sample, 16 (61.5%) were women. Men represented 38.5% of the group. Fifty per cent (50%) of the participants were married and staying with their life partners and 26.9% were widows; none of the participants were widowers. The single and separated participants represented another 23%; almost all of these participants were women. The relevance of this information is described in Section 3.6.

### **3.3.3 Education, employment and income characteristics**

The level of education in the sample ranged from no schooling to a national diploma as the highest qualification. The majority of the participants had either little or no schooling at all. Most participants (96%) who had attended school did not progress beyond standard six. The majority of the participants (84.6%) were not gainfully employed and many amongst them survived on self-help menial jobs and sometimes had to sell their valuables, mainly in the form of livestock, when an urgent need for money arose. This observation concurs with the findings of the Sebenta Institute in the Swaziland Ministry of Education and Training that the majority of Swaziland peri-urban and rural population are disempowered due to low literacy levels (Ministry of Education and Training, Swaziland 2013). The Swaziland annual vulnerability assessment and analysis report for 2012 states that the unemployment rate in Swaziland rural areas is remarkably higher (51.2%) than the urban areas where it stands at 23.6 %. Unemployment is much higher in the rural areas mainly due to the factor of lower education levels and accompanying higher illiteracy in those areas (Fakudze 2012). In the year 2010, the rural poverty headcount was estimated at around 73 per cent, while at only 31 per cent in urban areas (WHO 2013).

Twenty one per cent (21%) of the sample cited government elderly grants as their major source of living income. In Swaziland, people of 60 years and older receive quarterly government grants in the form of money while the ones above 65 years are not expected to pay for health services provided by government (Help Age International 2010). These issues are relevant to the findings as described in Sections 3.5.1.2, 3.5.2.2, 3.5.3.1 and 3.5.3.2.

### **3.3.4 Location characteristics**

Most of the participants could not tell the actual distance of their homes from the hospital. The total cost of a return trip was used as a proxy indicator of the location distance. This was done for practical purposes, since the researcher had learnt from the interviews that the cost of the journeys was of more consequence to the participants than the actual distance itself. The cost of a return hospital trip ranged from zero cost, for those residing within walking distance from the hospital to a maximum of R 40.00. The average calculated cost of a return trip of the sample was

R 20.38, a high amount of money for a group mostly comprising unemployed people with no reliable sources of income. The impact of these factors is described in Section 3.5.1.2.

### 3.3.5 Analysis of data transcriptions

Through data management and analysis, as described in Chapter 2, three main themes emerged, with categories of the first and second hierarchy. The main themes are “experience of the process of diabetes mellitus diagnosis”, “experience of diabetes mellitus self-care”, and “living with diabetes mellitus”. The themes, categories and subcategories are presented in Table 3.2. Please note that the numbering in the table starts with 3.4 to correspond with the numbering of the sections in Chapter 3.

**Table 3.2: Identified themes, categories, and sub-categories**

Themes	Categories	Sub-categories
3.4 Experience of the the process of diabetes mellitus diagnosis	3.4.1 Pre-diagnosis experience	3.4.1.1 Diabetes symptomatology 3.4.1.2 Diabetes suspicion
	3.4.2 Experience of diabetes mellitus diagnosis	3.4.2.1 Shock 3.4.2.2 Hurt 3.4.2.3 Guilt 3.4.2.4 Sadness 3.4.2.5 Fear <ul style="list-style-type: none"> <li>• <i>Fear of uncertain future</i></li> <li>• <i>Fear of certain death</i></li> <li>• <i>Fear of the burden of diabetes self-care</i></li> </ul> 3.4.2.6 Relief

Themes	Categories	Sub-categories
	<b>3.4.3 Immediate post-diagnosis experience</b>	3.4.3.1 Coping with the new diagnosis <ul style="list-style-type: none"> <li>• <i>Denial</i></li> <li>• <i>Period of experiencing stress</i></li> <li>• <i>Acceptance</i></li> <li>• <i>Adjustment</i></li> </ul>
<b>3.5 Experience of diabetes mellitus self-care</b>	<b>3.5.1 Hospital visits</b>	3.5.1.1 Catch the queue early 3.5.1.2 Transport woes <ul style="list-style-type: none"> <li>• <i>Expensive</i></li> <li>• <i>Unreliable</i></li> </ul> 3.5.1.3 Hospital congestion <ul style="list-style-type: none"> <li>• <i>Physical discomfort</i></li> </ul> 3.5.1.4 Drug availability 3.5.1.5 Feeling short-changed 3.5.1.6 Self-care education
	<b>3.5.2 Dietary adherence</b>	3.5.2.1 Voluntary dietary non-adherence <ul style="list-style-type: none"> <li>• <i>Cravings</i></li> <li>• <i>Temptations</i></li> <li>• <i>Deliberate dietary non-adherence</i></li> </ul> 3.5.2.2 Involuntary dietary non-adherence <ul style="list-style-type: none"> <li>• <i>Cost of healthy food</i></li> <li>• <i>Role of food preparers</i></li> <li>• <i>Unfortunate circumstances</i></li> </ul>

Themes	Categories	Sub-categories
	<b>3.5.3 Drug adherence</b>	3.5.3.1 Involuntary drug non-adherence <ul style="list-style-type: none"> <li>• <i>Hospital drug shortages</i></li> <li>• <i>Financial shortcomings</i></li> <li>• <i>Forgetfulness</i></li> <li>• <i>Confusing prescriptions</i></li> </ul> 3.5.3.2 General drug non-adherence
	<b>3.5.4 Drug administration</b>	3.5.4.1 Daily drug taking 3.5.4.2 Self injection versus oral drugs
<b>3.6 Living with diabetes mellitus</b>	<b>3.6.1 Family involvement</b>	3.6.1.1 Family financial / material support 3.6.1.2 Family non-material support
	<b>3.6.2 Community involvement</b>	3.6.2.1 Community financial / material support 3.6.2.2 Community / peer non-material support
	<b>3.6.3 Diabetes control</b>	3.6.3.1 Good control 3.6.3.2 Poor control 3.6.3.3 Strength to persevere
	<b>3.6.4 Diabetes complications</b>	3.6.4.1 Poor eyesight 3.6.4.2 Hospital admissions 3.6.4.3 Sensory neuropathy

These themes, categories and sub-categories are henceforth described. Relevant data chunks from the transcripts are given. Where necessary, words have been added in [ ] to enhance the flow of the sentence or to add an explanation by the researcher. References are made to the literature that either confirm or contradict the findings of this study.

### **3.4 EXPERIENCE OF THE PROCESS OF DIABETES MELLITUS DIAGNOSIS**

Data analysis shows that the participants' experience of the DM diagnostic process contributes to their overall experience of being diabetic. It is also noted that the actual experience of diagnosis cannot be divorced from the immediate pre-diagnosis experience that forms part of the symptomatology, illness until the actual discovery of the condition itself. This point is made even more relevant, considering that all participants were diagnosed during and after medical illness rather than during routine screening. This observation is supported by literature which shows that the majority of diabetic patients in poor African countries are diagnosed with existing complications that would have taken up to a decade to develop due to either weak, or non-existent screening programmes in those countries (Mbanya *et al.* 2010:2254; Twei *et al.* 2010:433-434). This theme has three categories; namely "pre-diagnosis experience", "experience of diabetes mellitus diagnosis", and "immediate post-diagnosis experience".

#### **3.4.1 Pre-diagnosis experience**

The pre-diagnosis diabetes signs, symptoms, complaints, and in some cases disease suspicion all form part of the overall experience under study.

##### **3.4.1.1 Diabetes symptomatology**

The participants were asked about the circumstances that led to the diagnosis of DM. It is noted that most of the participants verbalised symptoms and signs that are quite similar.

"I was losing eyesight, I was always weak. I would drink litres of water per day, yet I would equally urinate all of it and still remain quite thirsty."

Participant G

"I was always hungry and could just not be satiated with food. I would drink and finish huge cups of water, which never seemed to stay because I would always rush to the toilet and pass so much urine, such that I would feel thirsty all over again. My privates [vagina and vulva] would always be itchy." Participant M

The symptoms reported in these statements are supported by medical and scientific literature. Diabetes symptoms may arise as a direct consequence of the raised blood sugar itself, as shown by excessive urination and intake of water, dry mouth, and non-specific lethargy. Symptoms may also arise as a result of short term and long term complications of the persistently raised blood sugar (Section 1.1.2). These symptoms can present in the form of deteriorating eyesight, as well as recurrent fungal genital and skin infections that often manifest in genital and skin rashes and itchiness (ADA 2010:62; Longmore *et al.* 2007:190; WHO 2013).

### **3.4.1.2 Diabetes suspicion**

The researcher notes that some of the participants suspected and sometimes believed that they were diabetic, even before they had been tested for the disease.

“I suspected that I should be having diabetes since my wife was already on treatment and I remembered her symptoms. I then came to hospital and my suspicions were confirmed.” Participant F

“I was always thirsty and my eyesight was deteriorating fast. Noticing this, my mother called me on a certain day [mother is diabetic], she told me to urinate on the ground and we looked at the urine residue, which appeared as if the urine was sugary. We [participant and her mother] were very sure it was diabetes and the reason we went to hospital thereafter was for mere confirmation and treatment.” Participant R

These statements suggest that undiagnosed diabetic patients who have prior exposure to DM life, and teachings by close diabetic relatives and acquaintances tend to understand and thus correctly suspect presence of the illness, even before the disease has been tested. This observation is supported by research done by Hörnsten, Jutterström, Audulv and Lundman (2011:46), which amongst other findings, shows that people who experience typical diabetes symptoms, and having been exposed to diabetes on family members, can be so convinced of their diagnoses prior to them being tested. As one of the participants in that research put it, “...and for me it was not about *if*, rather *when*, I am getting diabetes since all of my brothers have it. I understood it, but needed some confirmation...”

### **3.4.2 Experience of diabetes mellitus diagnosis**

The data shows that a lot of feelings and mental processes are triggered by the incident of the diagnosis itself, some of these processes do prevail for some time after the actual day of the diagnosis. The diagnosis of DM seemed to constitute a significant life changing event to most participants. The degree of psychological impact verbalised by the participants is not exactly similar in every case. The psychological events associated with the diagnosis consist of aspects similar to the adjustment process to grief, as illustrated by the Elizabeth Kubler-Ross grief model (Kessler 2013).

#### **3.4.2.1 Shock**

Some participants received the news of their diabetes diagnosis with shock and disbelief.

“I got seriously shocked to hear this [the diagnosis]. I got into a state whereby I could not even hear the doctor or any other person talking. The sounds [doctor talking] felt like far away echoes that did not make much sense to me.” Participant N

This and similar statements demonstrate the negative and traumatic effect of the event of being diagnosed with a chronic disease. This observation is supported by several published studies. According to literature, the diagnosis of a chronic condition has a crisis-like effect on the patient. It has a significant psychological impact which can result in various stages of a psychological adjustment process before one can accept and get used to being a chronic disease sufferer. The diagnosis itself can bring feelings of anxiety, anger, fear, irritability, guilt, shame, isolation, despair, shock, insecurity, and vulnerability (Gask, Macdonald, & Bower 2011:242; Penckofer, Ferrans, Velsor-Friedrich & Savoy 2007:[680-690]; Snoek & Skinner 2006:61).

#### **3.4.2.2 Hurt**

Some participants were hurt by the news of the diagnosis.

“I was really hurt, so much hurt [by the diagnosis]. I even refused to take medication.” Participant L

“It [the diagnosis] affected me so badly because I was not suspecting it... It seemed like I was the only one in the family tree to be diagnosed with diabetes.” Participant O

These statements suggest that the participants were hurt by the DM diagnosis; not having any known relatives with the DM diagnosis seemed to cause more hurt. The observation of participants being hurt by the DM diagnosis is supported by literature that confirms that a chronic disease diagnosis can hurt and cause shame to the diagnosed patient (Gask *et al.* 2011:242; Penckofer *et al.* 2007:[680-690]). The researcher could not find literature to support the observation that not having any known relatives with a chronic disease may be associated with a worse psychological effect of one being diagnosed with that chronic disease.

#### **3.4.2.3 Guilt**

Some participants felt guilty and suddenly blamed themselves for having caused the illness.

“...I felt this disease was a result of my years of taking too much alcohol. I blamed myself for the misfortune.” Participant B

“I thought maybe there was something I had been doing wrong all these years to result in me getting this terrible disease.” Participant K

The statements demonstrate a tendency towards self-blame upon one learning about one’s diabetic status. This observation is supported by research literature. Since the diagnosis of a chronic disease amounts to a significant traumatic event, guilt is one of the feelings that one may experience as part of the long process of adjusting to the new state of affairs (Gask *et al.* 2011:242; Hörnsten *et al.* 2011:45; Penckofer *et al.* 2007:[680-690]; Kessler 2013).

#### **3.4.2.4 Sadness**

Some participants reported feeling sad once being told of their diabetes diagnosis.

“It made me quite sad [the diagnosis], especially when they told me that it [the disease] was incurable and I had to live with it.” Participant M

“It [the diagnosis] made me so sad and afraid.” Participant C

Literature supports this observation. Sadness is one of the post-traumatic feelings that one may go through in the long process of adjusting to the traumatic event of a chronic disease diagnosis (Gask *et al.* 2011:242; Penckofer *et al.* 2007:[680-690]; Kessler 2013).

#### **3.4.2.5 Fear**

Some participants reported fear after learning about their diabetic statuses. The fear manifested in several forms, and for several reasons, as shown in the sub-headings below.

- **Fear of uncertain future**

Fear was apparently elicited by the sudden uncertainty prompted by the disease that at the point of diagnosis was not yet well-understood.

“It [the diagnosis] affected me badly because I thought I was in big trouble.” Participant H

“I was shocked and frightened [by the diagnosis] because I did not know what kind of a disease it was. They [clinicians] did not explain what kind of problem it was, they only told me about the treatment and diet plan. That made me even more scared.” Participant S

These statements show that the participants were mostly afraid because of a lack of knowledge and familiarity with the condition, and that triggered feelings of uncertainty about the future.

- **Fear of certain death**

One source of fear amongst the participants after learning about their diabetic diagnoses was fear of death. To some, being diabetic meant that they were on course to inevitable death.

“I was very scared and hurt too. I thought I was going to die.” Participant Q

“I was afraid, because I did not know how gravely it was [DM]. I even feared that this was the beginning of my end [death].” Participant K

The statements show that the participants feared the worst, in this case death. The researcher notes that lack of knowledge about the disease creates a gap that is immediately filled with the worst fears. Fear is one negative feeling that patients may live through after receiving news of their chronic disease diagnosis (Gask *et al.* 2011:242; Penckofer *et al.* 2007:[680-690]).

- **Fear of the burden of diabetes care**

Some participants reported fear of the burdens of diabetes treatments.

“I was not scared of the disease itself, but its requirements. Even at that point, I was aware that I would have to be on lifelong treatments, visit the hospital monthly like other diabetes patients in my neighbourhood, and to swallow pills every time daily. How would I cope with all this considering my predicament of poverty and loneliness? Who would support me, since I am the only one at home?” Participant N

“I was worried about the task of managing the disease. You see, the scariest thing about being diabetic is the amount of work you have to put into managing the disease. From then [after diagnosis], I had to depend on doctors all the time, take pills daily and be careful with food all the time. Diabetes is a bothersome and expensive disease in my opinion [his sister and mother were already on DM treatment].” Participant Z

These statements demonstrate that some participants perceived the need to accommodate life-long diabetic care as extra burdens that they might fail to fully accommodate and cope with. Diabetes self-care is perceived as quite burdensome in research literature. Some patients eventually fail to properly implement self-care and, as a result, suffer from serious complications besides being on treatment. Many diabetic patients fear losing control of their decision making power especially about dietary choices, meaning a deterioration of their quality of life. Such loss of control and the tasks of managing the condition can lead to pervasive emotional stress or

diabetes burnout. Such stressors can subsequently lead to clinical depression and poor self-care effort (Gask *et al.* 2011:242; Clark 2008:[113-120]).

#### **3.4.2.6 Relief**

Some participants reported a sense of relief especially that the cause of their apparently failing health had been diagnosed and could be managed.

“I was actually happy and relieved that finally the reason why I had been so weak had been discovered, meaning that I could finally be treated.”

Participant U

“I have to say I was very relieved to know [the diagnosis]...” Participant F

The statements demonstrate that the participants finally found some closure and relief in knowing the causes of their ill health. This observation is supported by research literature. In some cases, a DM diagnosis can result in a sense of relief. This happens due to persistent symptoms of ill health; patients might all along have been suspicious and scared of the possibility of worse diagnoses, like fatal cancer. The diagnosis does in a way relieve them of those worse fears (Gask *et al.* 2011:242; Snoek & Skinner 2006:61-62).

#### **3.4.3 Immediate post-diagnosis experience**

It is noted that the period immediately after the diagnosis of DM is characterised by some experiences, especially those of psychological nature. The psychological experiences are not similar in nature, sequence, and duration for everyone.

##### **3.4.3.1 Coping with the new diagnosis**

It is noted that the events on the day of the diabetes diagnosis amount to significant experiences to the individual patients. In most cases, these experiences present in form of psychological distress.

- **Denial**

Some participants could not accept and believe the news of their diabetes diagnosis on the very day.

“I could not accept it [the diagnosis] and I refused to take medication on the first day... but the illness continued... On the third visit, I had no choice but to accept the diagnosis and that is when I agreed to start medication.”

Participant L

“I did not accept this news well the very day. It was when I later interacted with other diabetic patients that I got calmer.” Participant C

The statements show that the participants were in immediate denial of their diagnoses on the first day. This observation is supported by literature. Denial is the first stage of dealing with a psychologically traumatic event, according to the Elisabeth Kubler-Ross grief model. It is a natural defence reaction for a person to avoid embracing more than one can process. It is important to allow the person time to absorb the unfolding reality at a manageable pace. Research shows that a chronic disease diagnosis can elicit a response of defensiveness and denial in some patients (Gask *et al.* 2011:242; Kessler 2013).

- **Period of experiencing stress**

The researcher notes that some participants went through stressful periods after having received the news of their diagnosis. These periods seem to vary in length for different individuals, with some of them struggling with the traumatic impact of their diagnoses long after the event of the diagnosis.

“The truth is that I have not yet gotten over it [stress of the DM diagnosis] up to now [2 years on]. Sometimes, I start to think about this diabetes so intensely such that I totally lose my mind and I begin to feel like blacking out.” Participant N

“It took me about two months to accept the diagnosis. In that period, I was suffering emotionally because I was thinking too much.” Participant W

“I think it took up to three months for me to accept the diagnosis. For that whole period, I was constantly stressed, thinking all the time.” Participant G

These statements demonstrate the varying periods of adjustment each participant had to go through whilst agonising to come to terms with the reality of being diabetic. The observation supports research that shows that a chronic disease diagnosis can be a psychologically stressful event with far reaching psychological consequences (Debono & Cachia 2007:546; Gask *et al.* 2011:242; Penckofer *et al.* 2007:[680-690]). Depending on different personalities and other confounding social circumstances, people neither take exactly the same period of time, nor do they follow the same psychological route while adjusting to a psychological stressor (Kessler 2013).

- **Acceptance**

The researcher notes that participants accepted their diagnoses in different ways. Some did accept and embrace the diagnosis on the very day whilst some started in denial and went through stressful periods before finally accepting the diagnosis. The researcher presents different cases, starting with those participants who easily accepted their diagnoses, ending with the ones who struggled to accept.

“I was very relieved and happy to finally know...” Participant U

“I totally accepted my diagnosis without problems... Diabetes was not totally new to my family... I took the diagnosis seriously from the very first day.” Participant X

Participants who had relatives or close family members already diagnosed with DM seemed to accept and cope much better with the DM diagnosis. Research literature supports the observation that having close family members with DM can prepare one to correctly suspect presence of diabetes, to accept, and to cope better with the diabetes diagnosis (Hörnsten *et al.* 2011:45-46).

Other participants reported better competence in facing and accepting the DM diagnosis, mainly due to their belief in the protective power of God.

“I just said, God be with me and help me survive this predicament. That gave me some courage to accept it [DM diagnosis]. God helped me handle the whole situation, I was not that defeated.” Participant T

“Because I always pray to God, and I put this challenge [DM diagnosis] to his capable hands, God helped me accept the disease and I still fight it up to this day.” Participant Y

The statements above suggest that the participants applied their spirituality and belief in a higher power to help them absorb the impact of the diagnosis and thus coped better. They benefitted from their belief that a formidable power, in the form of God, was on their side, therefore, they could not be perturbed by a mere diagnosis. Spirituality has been known in research to play a vital role in helping patients accept and deal with life threatening diagnoses, illnesses, and to accept mortality (Albaugh 2003:[593-598]; Roberts, Brown, Elkins & Larson 1997:[166-172]; Vachon 2008:[218-225]).

Some participants however struggled to accept their new diagnoses.

“The news totally devastated me, in quite a bad way indeed. I just could not accept the diagnosis immediately...” Participant G

“The disease is not that common amongst my relatives... it was so difficult to accept [the diagnosis].” Participant C

“I could not accept it [the diagnosis] and I refused to take medication on the first day... On the third visit, I had no choice but to accept the diagnosis and that is when I agreed to start medication.” Participant L

These statements suggest that participants who least expected a diabetes diagnosis tended to struggle while coming to terms with such a diagnosis. Not having any known relatives with the disease seemed to make some participants deny and adjust with difficulty to a diabetes diagnosis. Such participants took varying time periods to finally accept the diagnosis, and they apparently suffered emotionally during that adjustment period. The transition from denial through stress as shown in the statements above can take varying durations for different individuals before they reach the equilibrium of total acceptance (Kessler 2013). The observation from these statements is supported by Hörnsten *et al.* (2011:48), who observed in their research that intense negative emotion on DM diagnosis is associated with participants least expecting the diagnosis. This same research also suggests that such patients

struggle to pass the turning point of adjustment to their diabetic statuses, and they do not easily take their self-care responsibilities.

- **Adjustment**

Following total acceptance of their diabetes diagnoses, participants reported a period of adjustment in their lives during a process of fully accommodating the tasks and routines of diabetes self-care. However, not all participants demonstrated full and healthy adjustment to the requirements of their diabetic statuses.

“These are tasks [dietary and treatment routines] I have now totally accepted and I take these as part of my new life. I, therefore, do not take these as extra burdens at all.” Participant D

“Following this routine has not been much of a task because I have totally adjusted to it as my own unique lifestyle.” Participant C

“But I was to be admitted again twice, with high sugar and feeling sick. I was not doing things well myself... I was not following the diet and medication as expected.” Participant J

The researcher notes that participants were in a much better space to implement the required adjustments and self-care routines when and after they had gone through the psychological process from the immediate psychological stress caused by the diagnosis to fully accepting their new diabetes statuses. This observation is supported by the Elisabeth Kubler-Ross grief model that states acceptance and adjustment to the new reality as the last and most balanced stage of coping after a traumatic event; the event in this research being the diabetes diagnosis (Kessler 2013). Hörnsten *et al.* (2011:46) support the same observation by stating that patients eventually pass through a turning point of adjustment to their diabetic statuses, and they cease to take self-care as burdensome, they begin to take self-care as familiar, routine, and well-integrated in their lives. According to other research, the newly diagnosed diabetic patients may take varying periods, from several months up to a year to reach the healthy emotional equilibrium following the shock of the diabetes diagnosis (Gask *et al.* 2011:242; Snoek & Skinner 2006:61-62).

### **3.5 EXPERIENCE OF DIABETES MELLITUS SELF-CARE**

Theme 3.5 represents four categories; namely “hospital visits”, “dietary adherence”, “drug adherence”, and “drug administration”.

#### **3.5.1 Hospital visits**

Hospital visits, as events, are a significant part of the whole diabetes self-care experience. Various activities and experiences are noted.

##### **3.5.1.1 *Catch the queue early***

Most participants reported that they left their homes quite early; in some cases as early as 2 a.m. in order to secure a front position in the anticipated long treatment queues. Some of them reported that they often had to finish off their sleep on the benches of the hospital after having arrived at night. Having arrived, they then had to secure positions by receiving numbered cards from the night staff in the OPD treatment area.

“We leave our homes as early as 5 a.m. to ensure we get front positions in the line.” Participant D

“Nowadays, we still arrive quite early, around 2 to 4 a.m., secure our numbers and some night nurses start to help us from around 5 a.m.”  
Participant J

The statements demonstrate that participants had to arrange to arrive at the hospital extraordinarily early and often had to finish their night sleep on the hospital benches with the comfort that they would be the first to be attended to when business starts. The occurrence of congestion was worsened not only by the hospital allocating only one diabetes day per week, but also by the fact that the treatment of diabetic and non-diabetic patients had to be completed before midday on Wednesdays. The researcher could not find scientific literature to corroborate the issues about hospital congestion in the Southern African setting, except for newspaper-based reports.

### **3.5.1.2 Transport woes**

The researcher notes that some patients experience transport challenges in their effort to honour their monthly reviews at the hospital.

- **Expensive transport**

Most of the participants were unemployed and, therefore, did not have a stable or reliable source of income (Section 3.3.3). They verbalised challenges in relation to transport fares.

“Transport money is very hard to come by because I do not work and I don’t have a husband. I have to do odd jobs in the neighbourhood to raise this money, or I have to borrow from neighbours.” Participant X

“It [monthly travels] is very hard, doctor, especially the money aspect. I fail to raise enough money for these visits, meaning I have to borrow from people, who in return expect to be paid back.” Participant R

“I sometimes find myself short [of transport money]... sometimes I fail to get it... meaning that I end up failing to come here.” Participant L

The researcher notes that the basic transport fares to visit the hospital monthly were often unaffordable for most participants, and some ended up failing to visit the hospital as scheduled. That partly contributed to involuntary drug defaulting (Section 3.5.3.1, Sub-category “Financial shortcomings”. Research literature shows that transport costs can contribute to missed reviews and in extreme circumstances may cause patients diagnosed with chronic diseases to fail maintaining chronic treatment after diagnosis (Nam, Chesla, Stotts, Kroon & Janson 2010:4). The catchment area covered by the PPH is mainly rural. In the rural areas, unemployment is high and the majority of the poor in the country reside in the rural areas (Section 3.3.3). This situation leaves the majority of the rural people unable to afford the most basic needs, like transport fares to and from hospital.

- **Unreliable transport**

Some participants reported difficulties in reaching the hospital, mainly because they resided in hard-to-reach areas where public transport is scarce. In some situations, public transporters reportedly avoided gravel roads, especially after heavy rains, leaving people in such areas stranded.

“Getting here becomes very difficult, especially when it rains because the roads are gravel surfaced and the buses stop coming.” Participant G

“The transport problems are worse when it rains because the roads get slippery and the buses don’t come. I have to walk along the gravel road until further off, where I can meet the buses.” Participant H

The challenges with transport seem to contribute to the whole self-care task being perceived as burdensome, and sometimes tedious. Some participants reported failing to reach the hospital in some instances, thus resulting in them temporarily defaulting treatment beyond their will (Section 3.5.3.1, Sub-category “Financial shortcomings”). This situation is supported by results of a South African study which shows that limited physical accessibility of the mainly rural populations to hospitals is a significant barrier to access to health care. This limited accessibility may be in form of unaffordable transport costs and geographical access factors (Harris, Goudge, Ataguba, McIntyre, Nxumalo, Jikwana & Chersich 2011:118).

### **3.5.1.3 Hospital congestion**

Participants reported crowding and congestion in the PPH OPD service area on diabetes days. There were reports of slow service. Despite patients arriving at the hospital very early, some service points only opened at 8 o’ clock or even later. The most reported service points in relation to this matter were the pay point and the pharmacy.

“We are often delayed a lot on trying to secure our treatment cards. And the hospital arrangement that all diabetic patients should be seen before midday puts us under too much pressure. I would be glad if we could be assisted for the whole day till 5 p.m.” Participant P

“And we want to be seen on all days of the week, not just on Wednesdays. That punishes us a lot because we have to crowd here and wait very long periods, and push and shove...” Participant J

“We arrive here before 8 o’ clock. The night nurses help us early, but all that effort is rendered useless because pharmacy only opens after 8 o’ clock .The same goes for the pay point, these services should also open early to allow for the busy diabetes day ahead...” Participant E

The statements illustrate the frustration that patients at the PPH experience on the designated diabetes days. The major problems are congestion in the OPD area, some vital service points opening late, the hospital arrangement of designating one day weekly for diabetes reviews, and the fact that on that same busy day, services are only offered until midday. All factors mentioned worsen the effect of patient congestion in the service areas, thus making the Wednesday diabetes days uniquely cumbersome to the patients and the health workers alike.

- **Physical discomfort**

Participants reported physical discomfort on the diabetes days, mainly in the form of exhaustion due to the waiting in queues and hunger pangs. They reported suffering from hunger, since they had to come starved and they could not be free to eat anything until their blood sugar had been checked. The process of these blood tests was reportedly congested and slow.

“We suffer hunger pangs whilst awaiting blood sugar checks.” Participant E

“One has to wait a long time before being checked for sugar, sometimes up to 10 a.m., and that punishes us with severe hunger.” Participant O

The PPH and Swaziland public health system in general do use FBS for the purposes of monitoring diabetes patients on treatment (Section 1.2.1.2). This index, however, requires patients to come starved. This single blood test can however not reflect the level of diabetes control for the whole month between reviews. The use of HbA1c, a more reliable blood index that does not require one to come to hospital

starved is not done for monitoring purposes in the government hospitals of Swaziland (ADA 2011:18-19; Sobngwi & Balde 2011:36-39).

#### **3.5.1.4 Drug availability**

Participants reported experiencing shortages of some of the vital drugs at the pharmacy on some days. Patients are sometimes advised to buy the relevant drugs from the nearest private pharmacies in town.

“There have been challenges recently in terms of drug shortages; they sometimes encourage us to buy certain drugs from private pharmacies if they are short.” Participant U

“Sometimes, you see that your medications are not there, and they tell you to buy from the pharmacy in town. And quite often, one doesn’t have that kind of money.” Participant I

The statements highlight the challenges faced by diabetic patients at the PPH in terms of drugs availability on some days. Most of the affected participants reported an inability to raise funds to buy their own stocks from private pharmacies. That situation left them vulnerable to involuntary drug non-adherence (Section 3.5.3.1).

#### **3.5.1.5 Feeling short-changed**

Participants reported disappointment with differential treatment given to other special groups of patients at the hospital. The researcher notes that diabetic participants felt that they, like the HIV and TB patients, should also be exempted from paying hospital fees. They also felt they should be served in a separate and different treatment area, like is done for HIV and TB patients.

“We do not want to be mixed with the rest of the patients. Look what they do for TB and HIV patients, those people have their clinics daily for the whole week, they don’t pay, their clinics are separate and they don’t mix with the rest of the patients. It is not fair on us [being made to pay] because we are also sick and don’t have money...” Participant X

“It would be preferable if diabetic patients were treated separate from the rest of the patients, just as they do with TB and HIV patients. We, as well should not pay for the services, as is done for TB and HIV patients.”

Participant P

Swaziland offers free treatment for HIV and TB. TB and HIV clinics are run in separate complexes from the rest of the hospital, with full complements of staff, including doctors. This is made possible mainly because TB and HIV treatments are to a large extent supported both in cash and in kind by non-governmental partners and stakeholders like the Global Fund, President’s Emergency Plan for AIDS Relief (PEPFAR), Medecins Sans Frontieres (MSF) and some of these partners assist in erecting separate structures in support of the fight against these two diseases (MSF 2012; PEPFAR [Sa]; The Global Fund 2013; WHO 2005).

### **3.5.1.6 Self-care education**

All participants communicated on being educated about some self-care activities. Participants reported attending combined health education sessions on the Wednesday mornings after the opening prayer. Some participants reported receiving brief educational talks by doctors at the consultation tables. Others reported not receiving adequate education on the day of the diagnosis, but rather on the subsequent days in combined groups on diabetes days.

“I was really not counselled well. I simply did not receive enough education on that day [day of diagnosis]. I, however, received some useful information during the public combined health talks given on Wednesday mornings on subsequent visits.” Participant G

“They said I was not supposed to eat too much porridge, and to minimise sweet fruits like apples and oranges.” Participant K

“I had been drinking too much sugary stuff like Coke before. The doctors told me to stop, and also to avoid red meat.” Participant C

From these statements, the researcher notes that some participants did not absorb enough educational information on the very day of diagnosis. Some participants perceive the first post-diagnosis health education package to be insufficient, though

most of them reported the usefulness of continued group education offered on subsequent diabetes days. The researcher also notes that two aspects of diabetes self-care are apparently not routinely promoted in the health education sessions given at the PPH, since none of the 26 participants mentioned foot care and regular exercise as being part of the promoted activities. The emphasis seems to be on diet, hospital reviews, and drug adherence. Foot care is one vital self-care activity which should be promoted by health workers through routine self-care education to mitigate the risk of developing limb threatening diabetic foot ulcers or gangrene (ADA 2011:22,24,33).

### **3.5.2 Dietary adherence**

Dietary adherence forms a separate aspect of the experience of diabetes self-care as gathered from the participants. Some participants reported success in adhering to their diet, mainly as a combined result of self-effort and positive family influence. Some reported good cooperation at home in terms of proper food preparation. In general, the researcher notes that food preparers, who most often happen to be women, are inclined to cooperate more with the dietary requirements of male diabetic patients, especially when the patient happens to be the breadwinner. Patients are more likely to ensure proper dietary adherence at home if they happen to be the cooks and shoppers too.

“Whilst at home, I have not faced any problems with diet because they always separate my food from the rest before adding ingredients [participant is a working male breadwinner]... I don't have problems in sourcing the required food because I am currently working.” Participant P

“I do not have a problem with kitchen food because I am the one who prepares the food.” Participant T

“They do understand and assist a lot [home food preparers]. For instance, they put my food aside, before they can add salt on the food... They do not [complain about his unique dietary needs] because I am the family head [he is also the breadwinner], and I give them instructions...” Participant Z

These statements highlight the role family plays in ensuring success of the diabetes dietary plans at home. They also demonstrate the apparent privileges of being the breadwinner, especially a male one, in determining the home menu plan suitable to oneself. Being the cook is also demonstrated as an advantage in determining the menu plan and thus dietary trends at home. Literature emphasises that the support from family plays a vital role in effecting and maintaining the required lifestyle changes and ensuring good diabetic self-management outcomes. It is vital that both the diabetic patient and the family practise healthy eating to ensure successful dietary adherence of the diabetic patient (Rintala, Jaatinen, Paavilainen, & Åstedt-Kurki 2013:4,15-16,20).

### **3.5.2.1 Voluntary dietary non-adherence**

Some participants often failed to adhere to the advised dietary rules due to reasons best described as voluntary.

- **Cravings**

Some participants reported succumbing to cravings for the wrong foods. Such cravings on their own contribute to them breaking the dietary rules.

“I feel strong cravings for certain good foods, and I end up eating these. I try most of the time to adhere to the dietary plan but I don’t always win.”

Participant X

“As for me, I love bananas a lot. When they say I should eat only two, I end up eating a dozen. Meat is very difficult to resist, I tend to eat a lot of it too.” Participant A

These statements show that participants often failed to adhere to the recommended diet, mainly because of their craving for those wrong foods, not because of a lack of knowledge. The researcher notes that the power of food cravings is strong and cannot be underestimated. Literature shows that diabetic patients consider dietary adherence as the most difficult component of self-care (Delamater 2006:71; Muchiri, Gericke & Rheeder 2009:156).

- **Temptations**

Some participants reported breaking dietary rules mainly due to failure to resist temptations of unhealthy food, especially if made available by circumstances. Some, however, reported victory in resisting the food temptations.

“It is my colleagues who sometimes tempt me especially on month-end when they gather socially to feast... But I politely excuse myself from such.” Participant C

“It is hard to resist *good* [sic] food, especially if someone makes it available at home. I end up eating it a lot too.” Participant J

The data above highlights the importance of family and close friends in influencing the eating habits of diabetic patients. Family members can undermine the patients' dietary plans by providing unsuitable foods or by simply eating unhealthy foods in the presence of the diabetic patients. Social contexts, like holidays and social gatherings, are often associated with poor dietary adherence due to the tempting availability of the mainly discouraged foods and the social circumstances of celebration and merrymaking (Chlebowy, Hood & LaJoie 2010:902-903; Vermeire, Hearnshaw, Råtsep, Levasseur, van Dam, van der Horst, Vinter-Repalust, Wens, Dale & Van Rooyen 2007:30).

- **Deliberate dietary non-adherence**

Some participants reported failing to adhere to dietary requirements, not because of any notable barriers.

“I have not been too good with dietary advice so far. I am still working on that issue though, I think with time maybe I will get used to the diet they always tell us to follow. I really need time to work on that issue [3 years on DM treatment].” Participant G

“Following the diet has not been easy, and I should say I have not really put much effort on that issue yet. I don't want to lie that I have been living with the recommended dietary rules; maybe it is time I took that issue

seriously... I don't know, but my sugar readings have been good so far.”

Participant U

With these statements, the researcher notes that some participants were somehow not totally committed to proper dietary adherence, without any appropriate obstacles verbalised. Diabetes fatalism is one known phenomenon that contributes to non-adherence to self-care, including diet and medication. It is a human trait that is associated with a tendency to give up, despair and generally to be inclined towards hopelessness. Such people, on being diagnosed are inclined to lose hope and assume that nothing can be done to change the future course of events if those events were already meant to be (Walker, Smalls, Hernandez-Tejada, Campbell, Davis, & Egede 2012:598,601-602). Other common reasons associated with poor dietary adherence amongst DM patients and NCD patients, in general, are explained in greater detail under Section 3.5.3.2.

### **3.5.2.2 *Involuntary dietary non-adherence***

Some participants would often fail to adhere to their dietary plans, mainly due to factors considered to be beyond their own will.

- **Cost of healthy food**

Participants reported that the recommended foods were often beyond their household budgets, such that they would end up eating whatever was available in order to live.

“The issue of availability and cost of the recommended healthy options comes too. You find that you don't have enough money to buy the recommended foods, and circumstances force you to eat whatever is available.” Participant J

“...I also fail to source the right foodstuffs for my condition due to lack of money. I, therefore, do not properly follow the proper diabetic diet.”

Participant R

These statements paint a picture of patients who are otherwise willing to follow dietary plans, but they are incapable due to their inability to source the food from the

groceries and other retail outlets. The study population in this research comprised rural-based participants of generally poor backgrounds and they mainly survived through subsistence agriculture and other self-help minimal returns ventures in their neighbourhoods. Ross and Geil (2010:120-123) support this observation by stating that in America, the cost of proper diabetic diet and medications are barriers to proper diabetes self-management, especially during challenging financial times. The researcher could not find literature to support this observation in the African context.

- **Role of food preparers**

Food preparation proves to be a controversial activity that can either aid, or totally undermine the dietary plans of the diabetic patients. Some participants reported poor or total lack of cooperation in the kitchen to ensure that their dietary requirements are adhered to. Non-diabetic food preparers were reported by some participants as less sympathetic and uncooperative when it comes to preparing separate and appropriate dishes for the participants.

“It is quite difficult [dietary adherence]. They [food preparers at home] often take it as a burden to prepare my food differently; in the end they just cook it anyhow for everybody... I also believe it is too hard for them to cater for me differently all the time... I have since accepted that they find it difficult to comply with my dietary requirements and I don't hold any grudges against them.” Participant O

“They [home food preparers] don't accept it at all, even when I complain that they should not put certain ingredients in my food. You hear them saying they can't all eat badly tasting food just because of me alone. I thus end up eating whatever is cooked...” Participant S

From these statements, the researcher notes how hard it can be for the individual diabetic patient to do it alone at family level, to ensure total dietary adherence without cooperation and a helping hand from family. According to literature, family plays a major role in influencing the extent to which diabetic patients stick to their dietary plans. Little or no family cooperation can, in a way, totally sabotage the dietary adherence efforts of the diabetic family member (Delamater 2006:72; Rintala *et al.* 2013:15-16). Instituting the various lifestyle changes required to properly manage DM

in the home environment has been known in literature to cause loved ones to rebel (Debono & Cachia 2007:548).

- **Unfortunate circumstances**

Some participants reported being forced by circumstances to eat wrong foods. Some cited eating from public facilities like kitchens at work, whilst some reported the inevitability of eating wrong foods at funerals and other often mandatory public gatherings.

“Being a long distance truck driver, it is not always possible to ensure one has the right foods at the right time all the time.” Participant L

“It becomes difficult though, when one has to attend mandatory public functions like church gatherings, funerals, and other cultural functions because the food preparation under such circumstances is done with common big pots. Nobody really can cater for your unique dietary specifications under such circumstances.” Participant F

These statements show that diabetic patients are often faced with difficult circumstances, such that they may be forced to either eat the only available food or starve. The researcher could not find literature to support this observation.

### **3.5.3 Drug adherence**

Data shows that drug adherence is another notable aspect of the experience of diabetes self-care.

#### **3.5.3.1 *Involuntary drug non-adherence***

Some participants reported failing to adhere to the drug regimens due to certain factors beyond their control.

- **Hospital drug shortages**

Drug shortages at the hospital pharmacy are noted to be a contributor to why some participants would not adhere to their drug regimens.

“Sometimes, some medicines are short at this hospital... I just take whatever is available at this hospital and hope that I can receive the missing medicines on my next review date.” Participant R

“...but there are instances when they tell us that certain medicines are not available, and it happened to me twice recently... It often means I have to go without the required medicines till the next review day.” Participant A

These statements illustrate that participants went for certain periods without the required medication because of failure to collect it from the hospital pharmacy. With the poverty and unemployment rate in the catchment area of the hospital, the majority of the patients cannot afford to buy their own medication from the private pharmacies if not supplied at the hospital. The researcher could not find literature about the link between hospital drug shortages and poor patient drug adherence.

- **Financial shortcomings**

Money matters seemed to contribute to some participants failing to adhere to their drug regimens. Failure to raise transport money meant that some participants would miss their review and drug refill visits at the hospital. As far as drugs that were unavailable at the hospital was concerned, most participants reported failure to buy stock from private pharmacies due to financial constraints. This situation led to inevitable drug non-adherence for the rest of the month until the next review date (Section 3.5.1.2, second bullet and Section 3.5.1.4).

“I have failed to collect my drugs from the hospital three times recently due to transport money problems.” Participant R

“I do buy the drugs [when there are shortages], but most of the time I don’t have enough money to buy adequate stock for the whole month. I just buy a little with the available money.” Participant V

These statements demonstrate how the financial shortcomings of the participants contributed to their failure to adhere to proper medication use. Obtaining refills and having to pay for drugs are factors known in literature to contribute to poor drug adherence. Transport costs are also known to cause missed reviews. Some patients

can totally abandon chronic treatment plans after being diagnosed with NCDs due to financial challenges (Delamater 2006:72; Nam *et al.* 2010:4).

- **Forgetfulness**

Some participants reported forgetting to take their drug doses, only to realise after the time for taking such doses had already passed. This often happened when one was preoccupied or busy with some chores.

“It happens that sometimes, one realises that time for a certain dose has already passed whilst busy with chores at home. That way, some doses are missed.” Participant G

“It has not been very easy [drug adherence] mainly because I sometimes forget to swallow my doses until it is too late.” Participant S

The researcher gathers from the statements that forgetfulness on its own can be a contributor to one failing to adhere to drug treatment. Research literature corroborates this observation. Forgetfulness is a known contributor to poor adherence to chronic disease medication, especially with patients of advanced age. Such patients can benefit from some kind of reminders such as alarms, cell phone messages or some form of reminder calendars (Chlebowy *et al.* 2010:903; Jimmy & Jose 2011:155; Odegard & Gray 2008:695).

- **Confusing prescriptions**

Some participants reported being confused by the several changes made to their drug regimens, mainly as a result of drug substitution in cases of drug shortages.

“I get confused with the treatment, especially when they [clinicians] continuously change the pills and the doses in events of shortages.” Participant N

“Yes, they usually change them because they know we cannot afford to buy the missing drugs with our own money. These new drugs may, however, not treat us well as I have experienced with my own body. They can be a bit too confusing because one has to suddenly learn and get use

to a new drug, with its own way of taking. I hope these drug shortages will end one day.” Participant Y

From these statements, the researcher notes that the participants could not cope with having to learn and adjust to the ever changing drug regimens. They would rather receive consistent and familiar drug regimens, which they could to some extent learn and mentally master in order to adhere well and avoid getting confused. According to literature, drug adherence is affected by the level to which the patient comprehends the treatment regime; it therefore, is affected by the health literacy of the patient. The majority of participants in this research and diabetic patients seen at the PPH in general have a low educational background, and are compromised on aspects of literacy and numeracy (Section 3.3.3). The practice of changing drug regimens according to availability implies that patients have to learn and grasp the new regimes every time substitutions are made, and these changes can pose comprehension challenges to an average PPH diabetic patient. Low literacy and health literacy are both associated with comprehension problems of verbal and written health information (Ngoh 2009:45-48).

Patients at the PPH receive their drugs in pill bags that double as the patient information leaflets (PILs) (Annexures I and J). These two different PILs are used interchangeably. The PIL in Annexure I does not have pictorial illustrations showing times of medication like the one in Annexure J. On pill bag I, patients need to be literate enough, with adequate numeracy and hour-reading skills for them to understand and follow the medication procedure. The textual part of both PILs is also likely to challenge the comprehension of the majority of the elderly PPH diabetic patients who cannot read (Sections 3.3.1, 3.3.3 and Table 3.1).

The researcher sought a comment from the PPH resident pharmacist, Ms Sifundo Zwane on the 4th of July 2013 about how they selected one of the pill bags for different patients. The main reason determining choice is availability, as supplied by the government supplier from where the pharmacy orders. The pharmacy is forced to use the available pill bags, and the pharmacy cannot indicate a preference for one of the pill bags when ordering because the government stockists only supply what they have. On the same day of the discussion, pill bag I was much more visible on the dispensary shelves. The pharmacist concurred that pill bag J was by design more

relevant for the illiterate PPH clientele due to its pictorial illustrations, and that there was a chance that some patients might find pill bag I challenging to their comprehension. The pharmacist also pointed out a design zip-lock fault with pill bag J. The lock was prone to loosening and spilling contents, and that might have determined why some dispensers prefer to use pill bag I which has a better zip-lock.

According to literature, most of the health education information that is provided to patients, both oral instructions and written information, is presented in a format that is too complex for the average patient to understand. That communication incongruity is one of the causes of non-adherence. Health literacy is the degree to which patients possess the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions (Stiles 2011:36). Patients with low health literacy skills rely heavily on oral communication and they need assistance with remembering what they hear. Despite the widespread availability and benefits of written material, many such resources are of little value to patients with limited literacy and / or health literacy skills (Jimmy & Jose 2011:156; Ngoh 2009:51-53; Odegard & Gray 2008:695; Stiles 2011:38).

### **3.5.3.2 General drug non-adherence**

Some participants failed to follow their drug regimes, not because of factors beyond their own control. In some cases, the researcher realises the reason is that the newly diagnosed diabetic participants were struggling with accepting and adjusting to the new state of affairs, but in other cases, there are no clear reasons why the participants failed to adhere.

“I could not accept it [the diagnosis] and I refused to take medication on the first day... On the third visit, I had no choice but to accept the diagnosis and that is when I agreed to start medication.” Participant L

“But I was to be admitted again twice, with high sugar and feeling sick. I was not doing things well myself... I was not following the diet and medication as expected.” Participant J

These statements reinforce the researcher observation that the participants consciously and knowingly failed to follow drug treatment advice. Literature shows

that adherence to chronic disease medication is dependent on several factors. Patient factors include social, demographic, and psychological factors. There are also physician, health system, and disease factors (Delamater 2006:71-72; Jimmy & Jose 2011:156; Nam *et al.* 2010:2-5).

In the instance of demographic factors, low socio-economic status and low education levels are known to be associated with treatment adherence problems. Low education levels tend to be associated with low health literacy levels. Health literacy is the level to which patients comprehend their condition, ability to read prescription labels, and understand the treatment regimes in general. Lower health literacy levels can be associated with wrong medication use that results in poor adherence (Delamater 2006:72; Jimmy & Jose 2011:156; Odegard & Gray 2008:695; Osborn, Cavanaugh, Wallston, Kripalani, Elasy, Rothman & White 2011:274-275). The research sample and the client base of PPH in general, comprises people of low education levels and low socio-economic status (Section 3.3.3).

In relation to social factors, limited family support and the presence of family conflict are associated with treatment adherence problems. The majority of the sample in this research verbalised unsatisfactory, and sometimes non-existent, family support in their fight against the diabetes condition (Sections 3.6.1 and 3.5.2.2, second bullet). Psychological factors associated with poor drug adherence include stress, maladaptive coping with the disease, as well as negative beliefs and attitudes about the disease and treatment plans (Delamater 2006:72; Jimmy & Jose 2011:156; Nam *et al.* 2010:2-3). Some of the participants in this research reported persistent psychological stress due to the diabetes illness, in some cases for up to two years after the day of the diagnosis. The ones without adequate family and social support seemed to suffer more from stress and for longer periods after the day of diagnosis (Sections 3.4.3.1, bullet 2; and 3.6).

The physician factors affecting adherence include the approach towards treatment planning and the relationship between the physician and the patient. A prescriptive, compliance-seeking and authoritative approach by the physician is associated with poor patient adherence and poor treatment outcomes. A poor physician and patient relationship and poor communication are also known to cause poor patient adherence. A health system that provides psychological support and follow-up review

reminders to the patients achieves better medication compliance (Delamater 2006:72; Jimmy & Jose 2011:157; Nam *et al.* 2010:5). The PPH does not have a specific plan for psychological support of patients on chronic disease treatments, unless they are individually referred to the psychiatry department with notable symptomatic stress or other psychiatric illnesses. On the diabetes days, the physicians at the PPH have very limited time to attend to each patient due to severe patient congestion on those specific days (Section 3.5.1). There are no specific hospital-managed reminders for patients on chronic disease treatments at the PPH.

The disease factors affecting adherence include the chronicity of the disease, and a diagnosed disease without perceived symptoms. These two factors are associated with lower medical adherence. Diabetes mellitus may be mainly asymptomatic unless and until the long term complications start manifesting, or unless other acute diabetic illnesses also start appearing (Section 1.1.2). Treatment factors affecting adherence include the complexity of treatment regimes. Complex regimens are generally associated with poor adherence, especially for patients with lower health literacy and numeracy (Delamater 2006:72-73; Jimmy & Jose 2011:156-157; Miccoli, Penno & Prato 2011:234; Odegard & Gray 2008:695). Frequent drug substitution and confusing complex regimens were reported by participants in this research (Section 3.5.4.3).

The researcher also notes that the period immediately after the DM diagnosis seemed to present unique adherence challenges to the participants because of various factors; including the psychological challenges, and the need to fully adjust to the requirements of proper self-care. This observation is supported in research literature, which indicates that the first few months after commencing chronic disease medication can be fraught with adherence problems (Evans, Eurich, Remillard, Shevchuk & Blackburn 2012:[195-203]). This position is supported by other research that shows that adherence is associated with the duration of taking medication. Those patients who have been on medication for longer periods are seen to be more adherent to medication than the ones with shorter periods on medication, or those who were recently commenced on medication (Osborn *et al.* 2011:275).

### **3.5.4 Drug administration**

Drug administration is another notable aspect of the experience of diabetes self-care.

#### **3.5.4.1 Daily drug taking**

Participants reported that daily drug-taking is not an easy task, but one needs to fully commit and accept it as a lifestyle.

“It is hard [daily drug taking] but I am used to it. I am OK.” Participant I

“I have come to accept that [drug taking routines] as my new way of life, and I am quite used to it.” Participant G

The researcher notes that the participants had to commit to taking their drugs daily, and to not perceive this activity as a chore or an additional task. In their own words, they accepted this task as their own way of life, or as a lifestyle. Daily medication use as a component of self-care is recorded in literature as burdensome (Snoek & Skinner 2006:61-62).

#### **3.5.4.1 Self-injection versus oral drugs**

Participants expressed general preference for diabetic oral drugs compared to insulin injections. Some reported fear of having to inject themselves one day. Some of the participants on insulin injection wished they could take oral drugs instead. Some of the discomforts reported with insulin injections were pain and injection marks.

“I just pray that I don’t reach a stage whereby I have to use injection [insulin] for treatment.” Participant W

“It is quite difficult [use of insulin injections]. For example, for someone on injections like me, I have to take all necessary meals together with injections if I am to avoid fainting. Take situations where one is at gatherings and crowds, where does one get the food at the right time? And the task of injecting oneself in a clean and sterile way twice daily, it is all quite a task... Being very honest, Doctor, I don’t like to inject. If ever it

was possible to use pills, I would happily go that route. You see, it is too painful to inject all the time, *it's painful*. The pills are a better option... I used to inject on the abdomen until I started to notice unsightly black spots on the injection sites, and I had to stop and will never use the abdomen again." Participant J

These statements emphasise the observation that insulin use is less preferred, and even feared by diabetic patients. Most of them would rather live with daily oral medication than having to self-inject. Reported fears and discomforts include the physical pain of injections and the unsightly spots on the injection sites. The PPH provides patients with disposable insulin syringes and needles and the needles are generally bigger, longer, and more visible than the ones on insulin pens (Annexure M). They certainly cause more pain and possibly needle anxiety due to their size and visibility in comparison with insulin pens (Siminerio Kulkurni, Meece, Williams, Cypress, Haas, Pearson, Rodbard & Lavernia 2011). The researcher asked the resident pharmacist, Ms Sifundo Zwane, on the 23rd of August 2013 why the pharmacy orders and dispenses insulin syringes and needles instead of insulin pens. She responded that insulin pens would be generally more expensive for government to provide in the public health system, and also that insulin pens are not stocked by the government CMS.

Despite the fact that insulin use has been part of medical practice for many years, patients, and often doctors too, are apprehensive to use it, even when it is necessary. Psychological insulin resistance has been recorded in literature as a barrier to proper DM management, and also as a cause of treatment failure. Insulin fears, anxieties, and myths are recorded in literature, from both the patients' and the physicians' perspectives. Against this background, insulin use should always be viewed as an expected future adjustment for any diabetic on oral medication because with the progression of the disease, patients reach a stage of insulin deficiency, thus needing insulin supplementation (Section 1.1.2.2 ). In literature, the reasons for such insulin resistance and fear are mainly of a mythical nature, though sometimes real. Some of the common reasons include a perception of one having personally failed with the initial DM treatment plan and, therefore, deserving punishment by insulin use. Some perceive insulin use to imply that the disease is gravely worse. Some

perceive insulin use as incapacitating and restrictive. Others fear a compromise to their quality of life and stigmatisation. Some patients believe that insulin use is more expensive; some perceive it as an “end of the road” option, since insulin use is perceived as the last resort. Other patients fear blindness, tooth loss, and worsening of the disease. Some patients also have a needle phobia; a perception that daily injections are too painful to bear, more burdensome, and restrictive to one’s freedom than oral drug use, while some fear complications like hypoglycaemia. Except for hypoglycaemia and pain, most insulin fears discussed so far are more mythical than real (Benroubi 2011:97-98; Brunton, Davies & Renda 2006:19-26; Reid 2007:183-187).

### **3.6 LIVING WITH DIABETES MELLITUS**

The data analysis reveals this theme, mainly reflecting the participants’ daily lives as diabetic patients. This theme encompasses four categories; namely “family involvement”, “community involvement”, “diabetes control”, and “diabetes complications”.

#### **3.6.1 Family involvement**

The researcher notes that family plays a notable role in the comprehensive management of the diabetic patient through various mechanisms. The role of family is, however, not always positive.

##### **3.6.1.1 *Family financial / material support***

Participants reported some degree of financial support from close family, especially the elderly who were being assisted by their grown children. The kind of support reported mainly covers transport costs for hospital visits and sometimes money for purchasing drugs. This support was, however, not always consistent.

“I get it [transport money] from my children because they are working... I surely get it because they know about my reviews and they send the money in time.” Participant U

“Yes, I get money from my children. But sometimes they say they don’t have any money.” Participant W

The situation reported by other participants reflects a perception that their capable grown children didn't do enough to support them with money to make the expected visits and also purchase the required medicine for their conditions.

"...I have several boys but you know when these boys take a wife that is the last time you can expect of their assistance." Participant I

"I have grown children but their financial support is erratic..." Participant S

These statements indicate lack of financial support for the elderly by their able and grown children in assisting them with managing their diabetes conditions. The researcher could not find research literature on family material and financial support for diabetic or NCD patients in either the Swaziland, or the African context.

### **3.6.1.2 Family non-material support**

Participants reported aspects of family psychological and social support, quite often to highlight lack thereof.

"There is no notable support at home [social and psychological] because I stay with my equally old husband." Participant H

"With me, Doctor, it is quite hard [social support] ...I don't have anyone to share my troubles with since I am all alone [emotional]." Participant N

These statements highlight a lack of social support in the family context, thus leaving the diabetic patient in a lonesome battle with the emotionally draining diabetes condition. The sample comprised mainly women, and quite a significant proportion of the women participants were single, widowed, living alone or living with young grandchildren (Section 3.3.2). The researcher could not find literature about home- or family-based social support for diabetic or NCD patients in the African context.

### **3.6.2 Community involvement**

The community plays a role in the lives of diabetic participants through various support mechanisms.

### **3.6.2.1 Community financial, material support**

Some participants reported receiving a helping hand from neighbours in the form of money in order to pay taxi fares to the hospital. Most of them, however, reported that such money needed to be repaid at a later stage either in cash, or in kind through doing odd jobs for the lenders. Some participants reported receiving material support, especially in the form of food.

“...I borrow money from neighbours to foot the taxi fares.” Participant S

“...I try to borrow money from neighbours but they always expect me to repay it back somehow... I believe they try their best...” Participant N

“One day, my neighbour saw me without any food in my house; she was generous enough to give me half of the chicken that she had.” Participant G

These statements demonstrate the importance of community support and good neighbourliness in the lives of the socio-economically vulnerable diabetic participants, especially the elderly and the unemployed. The researcher could not find literature on community-based material and financial support for diabetic and NCD patients in Africa.

### **3.6.2.2 Community / peer non-material support**

The community and other diabetic peers were reported to play supportive roles in the lives of the diabetic participants, especially for the ones with little or no family structures to support them.

“Because of my lonely status, I often get some companionship and support from my neighbours and church whenever I feel stressed and overwhelmed with the burdens of life and illness.” Participant S

“This [coping] was made easier later when I met a lot of people at this hospital who are also diabetic. I met a certain old woman at this hospital, who told me that she had been diabetic for 11 years, that gave me a feeling that I would make it too.” Participant O

“...It was when I later interacted with other diabetic patients that I got calmer; as they comforted me that one can still live with the disease.”

Participant C

From these statements, the researcher notes that the participants benefited from, and also valued the comfort and the basic educational counselling they received from more experienced fellow diabetic patients and the community in general. As literature shows, peers can be more knowledgeable and open about the diabetic patient's condition than the family who may be too upset with the disease condition to such an extent that they cannot be openly proactive in its management. Peer and friendly community support can reduce the feeling of isolation and loneliness amongst diabetic patients, it can also promote more positive and healthy lifestyles and can generally assist diabetic patients to cope better with their conditions (Chlebowy *et al.* 2010:902; Dennis 2003:[321-332]).

### **3.6.3 Diabetes control**

The control of DM is notably a component of the experience under study.

#### **3.6.3.1 Good control**

Knowing that one's condition is well-controlled seemed to give some degree of psychological comfort, with a positive effect on the participant's adherence efforts during self-care.

“And I implemented those advices since that day till now, and my blood sugar is coming OK. You can even check on my record card...” Participant

G

“I have been implementing those changes [dietary changes] till now. That is why my control is very good, you can see for yourself on the card.”

Participant E

The statements show that participants were happy and somehow proud of the good levels of their diabetes control, and they took credit for successfully implementing the recommended lifestyle adjustments. They also appeared positively motivated to maintain the good level of adherence in order to maintain the good levels of disease

control. The researcher observed that good glycaemic control results help to build the self-efficacy of participants. Self-efficacy is defined as the confidence in one's capacity to perform certain behaviours, and it can be built on past successes (Lee & Lin 2009:1061). Good self-efficacy is known in literature to impact on self-care behaviours of diabetic patients. More self-efficacy is associated with better self-care adherence and thus better treatment outcomes (Mishali, Omer & Heymann 2011:85).

### **3.6.3.2 Poor control**

Poor diabetes control was noted to cause negative psychological effects on the participants, some strenuously sought to explain and possibly rationalise the presence of poor disease control.

“Problems are responsible [for high blood sugar reading]. This usually happens when I think too much. There are rumours that they want to do something against me at home, and I have been stressed about this.”

Participant K

“The only time it [blood sugar] went up is once recently when I had another stressful problem again.” Participant C

“Diabetes is a very fragile condition, it is easily thrown off balance if one gets worked up, for instance by stress in life. The sugar can also rise if people talk too much.” Participant H

These statements show that the participants were aware of, and are not happy with their poor levels of disease control. They also sought to cope with the undesirable state of affairs by attributing the problem to other triggers perceivably beyond their control. According to literature, diabetes treatment success or failure is dependent upon many factors; including the patient, health system, and physician factors (Section 3.5.3.2). Physicians at the PPH do work under excessive pressure on diabetes days, dealing with a lot of patients during a limited period of time (Section 3.5.1.3). There are no standard diabetes treatment guidelines in the Swaziland health system at the time of writing this document (Section 1.1.2).

As has been stated by the participants, there is indeed literature to support the notion that stress may negatively interfere with metabolic control in DM patients. This is

understood to occur through both physiological and behavioural mechanisms. Physiologically, stress causes an increase in the circulating body stress and catabolic hormones with a resulting increase in plasma glucose levels. Behaviourally, stressed patients may neglect self-care; they may engage in unhealthy comfort eating and generally default on self-care activities. There is evidence in literature to suggest that stress on its own may precipitate clinical DM2 for patients who are predisposed to the condition, and that stress can also cause persistent high blood sugar levels for established DM2 patients (Demers, Neale, Wenzloff, Gronsman & Jaber 2013:170; Lloyd, Smith & Weinger 2005:122-124; Pouwer, Kupper & Adriaanse 2010:[112-118]). This position is, however, contradicted by Riazi, Pickup & Bradley (2004:241-242) who in their research show no direct or causal link between stress and elevated blood glucose levels in diabetic patients.

### **3.6.3.2 *Strength to persevere***

The will to live was the most reported motivational factor in persevering with self-care. Some participants reported strength gathered from their intimate engagement with a higher power in the form of God, the Almighty.

“It is hard [daily medications] but what can one do? I have to continue because I also want to live.” Participant L

“I just said, God, be with me and help me survive this predicament. That gave me some courage... I was not that defeated.” Participant T

“I do pray and talk to God. That he can look after me and my illness. I pray with the Zionists [a very popular church in Swaziland]. I also pray for my doctors, that God can continue to empower them and give them wisdom to successfully treat my illness and keep me alive.” Participant Y

From these statements, the researcher notes that the will to live and the belief in God were the major factors empowering the participants to persevere with self-care. Diabetes self-care has been perceived as quite burdensome in some studies. Spirituality has been shown in literature to play a vital role in helping patients to accept serious illness, and to mobilise strength for dealing with life threatening diseases and facing death (Section 3.4.3.1, third bullet).

### **3.6.4 Diabetes complications**

Common complications associated with diabetes mellitus are another aspect of the whole diabetes experience.

#### **3.6.4.1 Poor eyesight**

Poor eyesight was one of the most reported diabetes complications.

“My eyesight is not good; I am booked to see the specialist in Mbabane.”

Participant W

“I have been having cloudy vision from the very time of diagnosis till now.”

Participant O

Poor eyesight of diabetic patients results from the long term toxic effects of the high blood sugar on the small vessels that nourish the retinal part of the eye. This pathological process is clinically known as diabetic retinopathy and its progression can eventually lead to blindness. Diabetic patients have a higher than normal tendency to develop cataracts of the eyes, and these can cause clouding of vision that may eventually lead to total blindness if not surgically managed. Glaucoma, a condition of sight threatening increase in the intraocular pressure, is more common amongst diabetic patients than the general population (ADA 2011:35; Debono & Cachia 2007:547; Longmore *et al.* 2007:194-195; Turner & Wass 2009:746-751).

#### **3.6.4.2 Hospital admissions**

In some cases, participants reported being admitted to hospital due to poor diabetes control.

“But I was to be admitted again twice, with high sugar and feeling sick.”

Participant J

Short term diabetes complications include hyperglycaemia and diabetic coma, which invariably require admission to hospital and urgent acute medical management, in the absence of which the comatose patient has a very high risk of dying (ADA 2011:11-61; Debono & Cachia 2007:547; Longmore *et al.* 2007:190).

### **3.6.4.3 Sensory neuropathy**

Hot feet and abnormal sensation of the peripheries were other commonly reported diabetes complications.

“I suffer from hot feet, and often, I have to sleep with them out of the blankets.” Participant X

“I have seen that my feet continue to be hot, with abnormal sensation despite me starting the treatment for diabetes...” Participant P

“It is difficult to feel my feet, lower legs and hands. It all feels a bit too numb and sometimes feels like pricking sensation.” Participant P

Abnormal peripheral sensation amongst diabetic patients is a result of a nerve condition called diabetic neuropathy. This is a disease of the nerves that results from both a direct toxic effect of the high blood sugar on the nerves, and the impaired efficiency of the small blood vessels that nourish the nerves of those peripheries. Diabetic neuropathy may present as feeling hot or reduced sensation of the toes, feet, the shin, or on the hands. It can also partially play a role in the pathogenesis of erectile dysfunction, or impotence through affecting the nerves that control erection and sexual stimulation. Sensation may be severely impaired, particularly on the feet to such an extent that patients sustain insensate injuries that heal poorly, and often get infected, a condition clinically known as diabetic foot. Diabetic foot is a limb-threatening surgical condition (ADA 2011:36-387; Debono & Cachia 2007:547; Longmore *et al.* 2007:196-197; Turner & Wass 2009:766-771).

## **3.7 CONCLUSION**

The researcher managed in Chapter 3 to report about the qualitative data analysis of the transcribed interviews. The findings were presented as themes, categories and sub-categories that all help to explain the phenomenon under study. The data analysis as interpreted by the researcher was substantiated by literature control. Chapter 4 presents the research conclusions, the implications of the research findings for clinical practice and for future research.

## CHAPTER 4

### CONCLUSIONS AND RECOMMENDATIONS

#### 4.1 INTRODUCTION

The previous chapter covered the data presentation, data management, data analysis, and literature control. This chapter presents the research objectives, research findings, conclusions and recommendations for clinical practice and for future research. The chapter also includes contributions of this research to the scientific world and to clinical practice. The chapter concludes with the reflections and experiences of the researcher, the limitations of the study, and some concluding remarks.

##### 4.1.1 Objectives of the study

The objectives of this study were met as follows:

**Objective 1: To explore and describe the experiences of patients with DM, on treatment at the PPH in Swaziland.**

The experiences of DM patients on treatment at the PPH in Swaziland were described by collecting their stories in their own language, in their natural environment with no element of control, and analysing the narrative information qualitatively, refer to Chapter3.

**Objective 2: To identify and describe the factors that contribute to treatment failure and treatment success amongst the DM patients at the PPH in Swaziland.**

Through qualitative analysis of the data, the researcher managed to describe the factors contributing to treatment failure and treatment success of patients being treated for DM at the PPH, refer to section 1.5 for the definitions of treatment failure and treatment success. The researcher will list the major findings shortly. The reader is advised to refer to section 4.2 for more contextually based details and substantiations for all these listed findings.

**Factors contributing to treatment failure.**

- The unaffordable costs of transport, unreliable public transport and geographical barriers all make monthly hospital visits difficult, and in some cases unachievable, thus contributing to poor self-care adherence, refer to section 1.5 for definitions of self-care and adherence.
- Hospital drug shortages contribute to poor drug adherence because most patients can't afford to privately buy the missing drugs, and for those drugs that get substituted, some patients fail to comprehend the rapidly changing drug regimens, thus leading to wrong drug taking.
- Forgetfulness leads to missed drug doses and thus contributes to poor drug adherence.
- Dietary education at the PPH is inflexible and most patients can't afford the recommended foodstuffs.
- Food cravings and situational food temptations may lead to poor dietary adherence.
- Public functions, work stations and gatherings present a dietary adherence challenge in that food can't be prepared for individuals separate from the common pot.
- Poor cooperation by home cooks undermines the DM patients' efforts to adhere with dietary requirements.
- Lacking family and social support may contribute to poor self-care adherence.

**Factors contributing to treatment success.**

- Good family support may contribute to better coping with the DM condition and thus better self-care adherence.
- Good cooperation at the home kitchen contributes to better dietary adherence.
- Community support helps DM patients cope with the DM disease and may enhance adhere to self-care activities.
- Peer support from more experienced diabetic patients helps newly diagnosed patients cope better and understand the condition better, and possibly adhere better to treatment and self-care.

## **4.2 RESEARCH FINDINGS AND CONCLUSIONS**

The data analysis process yielded three major themes, with categories and sub-categories under each theme. These themes, categories and sub-categories are covered in Sections 3.4, 3.5 and 3.6. The main conclusions of the study are described under each major theme by referring to categories and selected sub-categories.

#### **4.2.1 Experience of the process of diabetes mellitus diagnosis**

The first theme encompasses the process of diabetes mellitus diagnosis. Conclusions about the various categories are drawn.

##### **4.2.1.1 *Pre-diagnosis experience***

All participants were diagnosed as a result of medical illness or some symptoms. The most common pre-diagnosis symptoms were polyuria, polydipsia, deteriorating eyesight, and abnormal peripheral sensations (Section 3.4.1). These symptoms are known in medical practice to commonly present in diabetic patients (Section 1.1.2). None of the participants were diagnosed as a result of casual or routine medical screening.

The researcher, therefore, concludes that a DM diagnosis at the PPH is commonly a result of clinical complaints, in most cases being the manifestations of chronic complications afflicting the yet to be diagnosed diabetic patients. This also suggests a real possibility of presence of an undiagnosed diabetic population in the PPH patient catchment area, and possibly the Swaziland rural areas in general. Literature supports this conclusion by stating that the majority of diabetic patients in Africa and other developing countries are diagnosed long after the onset of the disease due to poor or non-existent diabetes awareness and screening programmes in those countries. Most of the patients, therefore, present to hospital as a result of chronic and acute diabetes complications (Section 1.1.2).

##### **4.2.1.2 *Diabetes mellitus diagnosis, immediate post diagnosis experiences***

Participants with prior suspicion of DM, and those with close family members and friends already with DM, demonstrated better capacity to accept their new DM diagnoses sooner than those ones without either prior exposure to or suspicion of the condition. Those participants without prior suspicion, exposure, or known family members with the condition also demonstrated more intense negative emotions accompanied by worse psychological effects. Some participants continued to suffer persistent post-diagnosis diabetes related stress long after the day of the diagnosis, in one case up to two years and still continuing. Some participants managed to

absorb the impact of their diagnosis through their belief in the protective power of God (Section 3.4.3.1).

The researcher concludes that having suspected that one could be diabetic, somehow prepares such an individual psychologically for the DM diagnosis, and such a patient is more likely to accept the diagnosis much earlier and in a more relaxed fashion. Not having suspected the condition, or not having known family members with the disease, seems to be associated with more negative psychological sequelae as a result of the diagnosis, and more difficulties with adjusting to, and coping with, the diagnosis. Some psychologically vulnerable individuals may continue to suffer from diabetes related stress for long periods after the day of the actual diagnosis, especially the ones with inadequate family and social support (Section 3.4.3.1, bullet 2). The researcher also concludes that spirituality can play a vital role in facilitating the process of coping with a chronic disease diagnosis, DM in particular. Literature confirms that individuals with a past intimate experience with DM, especially at family level, can correctly suspect their impending diagnoses before the actual diagnosis is made (Section 3.4.1.2). Literature also supports the conclusion that spirituality plays a vital role in coping with serious diseases, including impending death (Section 3.4.3.1).

#### **4.2.2 Experience of diabetes mellitus self-care**

The second theme comprises the experience of self-caring. The tasks involved include exercise, weight control, foot care, dietary management, hospital review visits and medication use (Section 1.5).

##### **4.2.2.1 Hospital visits**

Most patients struggle to raise taxi fares for monthly diabetes visits. Living in hard to reach areas without reliable public transport contributes to the difficulty of attending hospital reviews (Section 3.5.1.2). In cases of drug shortages, most patients cannot afford to buy their drugs from private pharmacies (Section 3.5.3.1, the first two bullets).

The diabetes day is uniquely cumbersome due to patient congestion; four factors contribute to this state of affairs. The first factor is the designation of only one day

weekly for diabetes services despite the high demand for the diabetes service. Secondly is that these services are only available until midday on the designated Wednesday weekly. The third factor stems from the fact that all other outpatients and casualty medical services continue to be offered by the same personnel and department that also caters for diabetes patients (Section 3.5.1.3). The fourth factor is the requirement that all diabetic patients visit the hospital monthly; irrespective of their levels of disease control (Sections 1.2.1.2 and 3.5.1.2). The researcher concludes that monthly hospital visits, as part of self-care, are burdensome to the patients. The burdens are financial, logistical, and hospital service related in nature; they partly contribute to failure by some participants to attend scheduled review consultations and to adhere to drug treatment in general.

#### **4.2.2.2 Self-care education**

DM education may not be well-absorbed immediately after the DM diagnosis has been made, especially when the patient is taken by surprise and shock about the news of the diagnosis. Most participants manage to absorb self-care education advice in their subsequent hospital visits after the initial diabetes diagnosis. The self-care education package seems to exclude promotion of exercise and foot care, since these two activities were not mentioned by any of the 26 participants (Section 3.5.1.6). Patients fail to follow the diabetic diet, as educated due to the prohibitive costs of the recommended foodstuffs (Section 3.5.2.2, first bullet). Some patients benefit from peer education by more experienced diabetic patients (Section 3.6.2.2).

#### **4.2.2.3 Dietary adherence**

Following the recommended diabetes diet is a notably challenging task. The cost of the recommended foods is an unavoidable barrier to dietary adherence. Food cravings and situational food temptations also contribute to failure to adhere to the diabetes diet. The home kitchen plays a significant role in ensuring success or failure of the diabetes patients adhering to the proper diabetes diet at home (Section 3.5.2). Certain circumstances force DM patients to eat whatever is available, or starve; like at funerals and at work places where food is prepared in bulk. According to literature, dietary adherence- as a component of lifestyle adjustment and self-care – is known

to be difficult to implement. In other cases, patients fail to adhere as a consequence of diabetes fatalism (Sections 3.5.2 and 3.4.2.5, last bullet).

#### **4.2.2.4 *Drug adherence***

Drug adherence is another notable challenge, though of lesser magnitude than dietary adherence. Contributing factors to this situation include failure to raise transport money for hospital visits, drug shortages affecting the hospital, forgetfulness especially with the older patients, confusing prescriptions, and frequent drug regime changes. As part of self-care, drug taking is also reported in literature as burdensome, though less so than lifestyle adjustments. All factors reported to contribute to poor drug adherence (Section 3.5.3) and also diabetes fatalism (Section 3.5.2.1, last bullet) are supported by literature.

#### **4.2.2.5 *Drug administration***

Patients generally dislike and fear insulin injection use, as compared to oral drug administration. Reported fears include the pain of injections and the unsightly marks that follow on injection sites. The other possible origins of such fears were not thoroughly explored in this research because of its scope. Insulin fear is a well-documented phenomenon in medical literature. According to literature, this fear is mainly myth-based, but can also be a genuine phobia of needles and painful injections (Section 3.5.4.2).

### **4.2.3 *Living with diabetes mellitus***

The last theme deals with the life aspect of being diabetic. This theme focuses on the participants as diabetic individual human beings, as diabetic family members, and as diabetic community members.

#### **4.2.3.1 *Family involvement***

Family support is noted to be mainly lacking, especially for the elderly diabetic women. The researcher notes that family is a vital support structure for the diabetic patients, both materially and psychologically. Literature supports the notion that family is an important enabling, and in some cases disabling factor, to diabetic patients' self-care efforts (Sections 3.5.2.1, second bullet, 3.5.2.2, second bullet, and

3.6.1). Inadequate family support contributes to difficulties in coping with the diabetes diagnosis and illness, and can also contribute to poor self-care adherence. The need for psychological support both at diagnosis, and during follow up health care visits is demonstrated in this research.

#### **4.2.3.2 Community involvement**

Community support, of both material and financial nature, is evident in the lives of the patients, though such support is often accompanied by an expectation, at a later stage, to repay the assistance given (Section 3.6.2.1). Experienced diabetic peers play a vital role in counselling and educating the less experienced and the newly diagnosed DM patients (Section 3.6.2.2). Literature affirms that newly diagnosed DM patients who are struggling to come to terms with their diagnoses do well as a result of peer interaction with more experienced DM patients (Sections 3.4.3.1 and 3.6.2.2).

#### **4.2.3.3 Diabetes control**

Patients feel triumphant and motivated on taking note of good blood sugar level results. They feel that the researcher needs to acknowledge the tremendous effort they make to achieve such good results. A good blood sugar level, as a sign of good disease control, seems to positively motivate them to continue working hard on self-care with the aim of maintaining the situation. Poor blood sugar results, as a sign of poor disease control, seems to evoke defensiveness and an effort to rationalise the state of poor glycaemic control on the part of the patients (Section 3.6.3.2).

The researcher concludes that good glycaemic control and good follow up index values tend to have a positive feedback effect on the diabetic patients, spurring them on to maintain good self-care standards. Such results seem to build the self-efficacy of the diabetic patients. Literature confirms that such successes enable the building of self-efficacy of patients who are taking chronic disease treatments (Section 3.6.3.1).

### **4.3 RECOMMENDATIONS FOR CLINICAL PRACTICE**

Based on the research findings and conclusions in Section 4.2, the researcher presents some recommendations for the clinical practice of diabetes care at the PPH and, by extension, the entire public health system in Swaziland. Where appropriate, the recommendations are substantiated. Some recommendations may appear under more than one category and / or sub-category; such are mentioned again for emphasis purposes, as well as to demonstrate their unique importance.

#### **4.3.1 Diabetes mellitus diagnosis**

Under this section, the researcher explains the various recommendations made as a result of the conclusions in Section 4.2.1. Following the recommendations are detailed substantiations.

##### **4.3.1.1 *Early diabetes diagnosis in the communities***

- Effort should be made by government and stakeholders to diagnose DM early, especially in the rural areas.

This is based on the conclusion that most diabetic patients present late, already with complications of chronic illness.

##### **4.3.1.2 *Unique psychosocial vulnerabilities of newly diagnosed diabetic patients***

- Health workers need to assess newly diagnosed DM patients for psychosocial vulnerabilities; and
- When such vulnerabilities are discovered, they should be addressed appropriately in good time in order to enable and capacitate the newly diagnosed patients to accept and cope with self-care.

These recommendations are based on the conclusion that coping with the new diagnoses varies amongst patients, mainly based on either the presence, or absence of prior suspicion and family exposure. Care should be taken to acknowledge prior diabetes exposure, either through friends or family, and the presence of prior DM suspicion because these factors have demonstrated different and unique

psychological needs of the newly diagnosed DM patients (Sections 4.2.1.1, and 4.2.1.2).

### **4.3.2 Diabetes mellitus self-care**

Under this section, the researcher gives recommendations based on conclusions made in Section 4.2.2. The list of recommendations is followed by detailed substantiations.

#### **4.3.2.1 *The burden of hospital visits***

- The PPH must / should follow a flexible and demand-based approach in designating and fixing days for certain services.
- Authorities should consider rolling out diabetes services to the rural clinics, since these health care facilities are closer and more easily accessible to the majority of the rural-based patients.
- The PPH and the Swaziland public health system in general should move away from the apparently mandatory and rigid monthly DM reviews of all patients, but rather schedule reviews based on the unique individual patient's needs.

These recommendations are based on the observation that hospital visits, as part of self-care, are noted to be burdensome. They are burdensome in financial terms and also logistically in terms of unreliable transport and hospital congestion. At the time of writing this document, the number of diabetes days has been increased at the PPH to Tuesdays and Wednesdays. The change was effected in November 2012, after the researcher had completed the data collection process of this research project. The researcher, being one of the OPD-based doctors, has since noticed positive change through reduced patients' volume, increased speed of services, and reduced patients' waiting time. Clinicians should schedule patient reviews guided by individual-specific medical needs. Such a change is not only clinically justified (ADA 2011:17-19), but it can also save the stable patients from the burdens of unnecessary monthly hospital visits. The hospital can further reduce the diabetes patients' turnover while also reducing the element of congestion and crowding on diabetes days. Such change would also afford clinicians more time per patient, an element conducive for better quality diabetes services (Nam *et al.* 2010:5). Rolling

out diabetes services to the clinics could reduce, and in some cases eliminate, transport costs.

#### **4.3.2.2 Self-care education**

- Self-care education should be on-going.
- Self-care education should be made a family affair from the very start, after diagnosis.
- Self-care education should also be provided by expert diabetic patients at the PPH.
- Self-care education should be individualised according to the individual patient's needs and unique circumstances.
- Foot care and exercise should be promoted as part of self-care during the education group sessions for diabetic patients at the PPH.

Self-care education should be on-going, based on the conclusion that most diabetic patients cannot absorb this education immediately after the event of diagnosis, mainly due to the continuing psychological effects of the diagnosis itself (Section 4.2.2.2). This recommendation is also supported by literature (Debono & Cachia 2007:550). A need exists to involve the family and close significant others in this education, in the hope that adherence will be a family affair, rather than an individual's struggle (ADA 2011:22; Clark 2008:[113-120]; Gorter, Tuytel, De Leeuw, Van der Bijl, Bensing & Rutten 2010:88-90; Muchiri *et al.* 2009:158-159.) The observation that family members often play a negative role in the DM patients' efforts to stick to their diet at home further justifies this recommendation (Section 4.2.2.3).

Literature supports the use of expert diabetic patients for educational purposes because the rest of the patients find it easier to relate to an educator who walks the same path that they are walking. Such expert patients are also more likely to have more time at their disposal to offer thorough self-care education, in comparison with the busy health workers who are managing long queues (Phillis-Tsimikas, Fortmann, Lleva-ocana, Walker & Gallo 2011:1928-1929; Thom, Ghorob, Hessler, De Vore, Chen & Bodenheimer 2013:141-142).

Diabetes dietary education should be provided in a relevant format to the people in respect to their unique characteristics. These characteristics should include the

social, cultural, financial, and even religious elements (Funnel, Brown, Childs, Haas, Hosey, Jensen, Marynuik, Peyrot, Piette, Reader, Siminerio, Weinger & Weiss 2010:98-99; Orzech, Vivian, Torres, Armin, & Shaw 2013:62-64). This approach will assist the patients to stick to a proper diabetes diet irrespective of financial or cost based challenges (Sections 3.5.2.2, and 4.2.2.3). This approach will ensure that poor rural-based patients can be educated about feasible and practical dietary regimens, utilising the affordable foodstuffs at their disposal, as opposed to the more academic and standardised food regimens being promoted for every patient at the PPH, regardless of affordability. Foot care and exercise should be promoted as part of self-care during the education group sessions for diabetic patients at the PPH. This is based on the conclusion that these activities are not routinely promoted as part of self-care education at the PPH.

#### **4.3.2.3 Self-care adherence**

- Patients should be encouraged to use reminder strategies at home, like alarms on clocks or cell phones, to avoid forgetting drug doses.
- DM education and self-care training should be made a family affair.
- Government and other stakeholders should consider procedures and processes that can make diabetes devices and drugs more available in the public health system.
- Clinicians should avoid changing treatment regimens without thoroughly educating the patients about the intended changes, the reasons, and benefits of those changes.
- Patients should receive adequate and simplified oral and written health information about their treatment regimens.
- Effort should be made to assess the health literacy of the individual patients, and the health information provided should be of an appropriate format.
- The pharmacy department should assess the readability and comprehensibility of their PILs by conducting approved standard tests.
- The pharmacy department should be firm about choosing pill bag J when ordering from the government supplier and their reasons should be communicated and known to the supplier.

- The zip-lock problem on pill bag J should be reported to the supplier in order for the design fault to be rectified.

Drug shortages, forgetfulness, confusing prescriptions, financial constraints, transport challenges, cost of healthy diet, home social environment, food cravings, and social circumstances collectively affect the patients' adherence to drug and dietary requirements of self-care (Section 4.2.2). Clinicians should encourage use of reminder strategies for drug-taking at home, like alarms on clocks or cell phones (Section 3.5.3.1, bullet 3). Family members should be encouraged to share the responsibility of reminding the elderly DM patients to take their doses on time (Section 3.5.3.1, bullet 3). This further enhances the need for family involvement whenever a new DM diagnosis is made (Chlebowy *et al.* 2010:901-902; Rintala *et al.* 2013:16-18; Sandberg, Trief, Greenberg, Graff & Weinstock 2006:36-39; Shiøtz, Bøgeland, Almdal, Jensen & Willaing 2012:658-661), also see Sections 4.3.2.2 and 4.3.3.

Complicated and confusing drug regimens should be avoided, and patients should receive adequate and simplified oral and written health information about their treatment regimens (Lin & Ciechanowski 2008:17-18). Health workers should always be aware of the limited literacy, health literacy, and comprehension levels of the DM clientele at the PPH (Section 3.3.3 and 3.5.3.1, last bullet). Patients with low health literacy need the health worker to limit the amount of information given per consultation, the health worker should be slow and use classroom language rather than medical jargon, they need one to use a 'teach back' or 'show me' approach to assess understanding. One needs to avoid the 'do you understand me' attitude, but rather be sensitive, respectful and empowering to the patient (Jimmy & Jose 2011:156; Ngoh 2009:51-53; Odegard & Gray 2008:695; Stiles 2011:38).

Effort should also be made to enhance the health literacy of patients through continued education and self-management empowerment. The pharmacy department should assess the PIL readability and comprehensibility through recognised tests like the Fry Test (Ngoh 2009:47-53). Pill bag J is more user-friendly to the rural patients with literacy limitations and, therefore, it should be used as standard practice at the PPH and the zip-lock problem should be reported to the supplier in order for the design fault to be rectified (Section 3.5.3.1, last bullet).

### 4.3.3 Life with diabetes mellitus

Under this section, the researcher provides recommendations based on the conclusions made in Section 4.2.3. The list of recommendations is followed by detailed substantiations.

- Clinicians and health workers managing DM at the PPH should make the disease a family affair from the day of diagnosis.
- Clinicians should monitor their diabetic patients for psychological well-being as part of the routine medical consultations.
- Psychological problems should be attended to, if found to be present.
- The PPH should help establish DM expert patient groups.
- The PPH should help establish DM support groups, led and supported by specific and dedicated health workers at the hospital or by the expert DM patients.

Family plays a vital role, both positively and negatively, in the lives of DM patients. Dietary adherence, drug adherence, and general social well-being all occur in a family social context and these aspects are affected by the roles that family plays in the DM patients' lives (Sections 3.5.2.1, second bullet; 3.5.2.2, second bullet; and 3.6.1.2). The researcher encourages routine family diabetes education for all newly diagnosed diabetic patients in order to maximise cooperation at home; especially with food preparation, as well as dietary and drug adherence. Clinicians and health workers managing DM at the PPH should make the disease a family affair from the day of diagnosis (ADA 2011:22; Gorter *et al.* 2010:88-90; Muchiri *et al.* 2009:158-159), also refer to Sections 4.2.2.2, 4.3.2.2, and 4.3.2.3.

Family support is notably lacking amongst most DM patients. Social support is lacking amongst the DM patients and many suffer prolonged diabetes related stress (Sections 3.4.3.1, second bullet; and 3.6.1.2). Clinicians should monitor their diabetic patients for psychological well-being as part of the routine consultations (Debono & Cachia 2007:546), and if such problems are found, they should be attended to expeditiously to enhance coping and self-care adherence (Section 4.3.1.2). The PPH should facilitate the establishment of DM expert groups at the PPH. These groups can be utilised for the purposes of providing counselling to newly diagnosed DM

patients, and also for providing self-care peer format education. The hospital should also initiate the establishment of DM support groups, led and mentored by specific and dedicated health care workers at the hospital or by the expert DM patients as suggested earlier, with the purpose of providing support and assurance to those patients in diabetes related psychological distress and the newly diagnosed DM patients (Section 4.3.2.2).

#### **4.4 RECOMMENDATIONS FOR FUTURE RESEARCH**

From this study, the researcher suggests some recommendations for future research. These recommendations are explained below:

- **Replication of this research in other regions of the country**

This research was conducted at the PPH, which constitutes only a small part of the country of Swaziland. It provides a fraction of the required evidence about the research subject in the context of the whole country. The researcher recommends a replication of this study in other regions of Swaziland, especially the rural regions in order to strengthen the level of evidence on this topic.

- **Quantitative research to determine the prevalence of undiagnosed diabetes mellitus in Swaziland**

The researcher recommends research of a quantitative nature to determine the prevalence of undiagnosed DM in the rural population of Swaziland, in line with the conclusions in Section 4.2.1.1. Results of such a study can help equip government and other stakeholders with figures of the extent and magnitude of the burden of DM in Swaziland. With such knowledge, proper planning can be done with the purpose of tackling the condition, especially at national level.

- **Quantitative research on the prevalence of stress related illness amongst diabetic patients in Swaziland**

Patients apparently suffer from persistent stress, following the diagnosis of DM (Section 3.4.3, second bullet). Research shows that depression and stress related illnesses are more common amongst DM patients than the rest of the population; these conditions compromise proper self-care and should be treated accordingly

(Mahbubur *et al.* 2011:68-70; Snoek & Skinner 2006:61-62; Wu, Huang, Liang, Wang, Lee & Tung 2011:1381-1382; Zuberi *et al.* 2011:27). The researcher recommends that studies be conducted in Swaziland to estimate the prevalence of stress related, and depressive illness amongst DM patients and the NCD patients in general. Such results can assist to inform management approaches on DM and NCD patients, and possibly influence guidelines for their management in Swaziland.

- **Research on the Swazi beliefs and attitudes towards diabetes: Their effects on health seeking and treatment adherence**

As highlighted in Section 4.2.1.1, one can reasonably conclude that there are some undiagnosed diabetic patients in the population of Swaziland. As also noted in Section 4.2.2.4, some patients fail to adhere with treatment plans due to unclear, or yet to be discovered, reasons. The researcher is prompted to question the factors that drive the Swazi people to visit hospital if and when certain medical symptoms manifest, whether they report early or whether they tolerate such symptoms for some time, and also the reasons why some diabetic patients seem to knowingly fail to adhere to self-care. The researcher, therefore, recommends attitudes, beliefs, and knowledge studies amongst the Swaziland population about DM and its medical treatment. Results of such research can assist to explain population level traits; like health seeking behaviour, attitudes toward western methods of diabetes management.

- **The role of culture and spirituality in the well-being and coping mechanisms of Swaziland diabetic patients**

Some participants managed to absorb the shock of the DM diagnosis and the burden of self-care by using their spirituality and belief in God (Sections 3.4.3.1, third bullet; and 4.2.1.2). The researcher suggests more research about the role of spiritual and possibly cultural beliefs in accepting and coping with DM and chronic diseases in the Swaziland population. Such research can assist with demonstrating whether spiritual and cultural aspects of the Swazi people can be positively utilised in helping them cope with the stress and burdens of illness.

- **Research on the efficiency of the family unit as a social support pillar in the Swaziland rural context**

A lot of elderly DM participants implied a perception of disappointment and unmet expectations in relation to material and non-material support by their grown children. This deficiency mainly affected the elderly female participants, often living without their life partners due to widowhood, divorce, or spinsterhood (Section 3.6.1 and Table 3.1). This situation begs for qualitative research about the efficiency of the family unit as a social supporting pillar for the elderly diabetic patients, or any other elderly patients who are on any other chronic NCD treatments in Swaziland. Such research can assist the health planners to identify those social gaps that can possibly be closed by the community-based psychosocial services in Swaziland.

- **Research on the effect of poverty and unemployment as barriers to access to health care in Swaziland**

Patients fail to honour their review and drug refill consultations due to a lack of transport money, causing them to default on treatment beyond their will (Section 3.5.1.2). Some fail to buy prescribed medicine when it is out of stock at the hospital pharmacy. Most participants and diabetic patients in general, on treatment at the PPH are generally poor and mainly unemployed (Section 3.3.3). The researcher recommends research about the effects of poverty and unemployment on access to health care for the Swaziland rural population.

- **Geographical factors as barriers to access to health care in the rural areas of Swaziland**

Patients living in hard-to-reach areas often fail to reach the hospital due to the scarcity of public transport (Section 3.5.1.2). The researcher recommends research to determine the extent to which geographical factors are barriers to access to health care for people living in the hard-to-reach areas in Swaziland. Such research can also assist health planners and prompt them to be innovative in circumventing such barriers.

- **Comprehension as a factor to diabetes drugs non-adherence at the PPH**

Patients are confused by the new drug regimens penned by clinicians trying to manoeuvre around drug shortages. Patients fail to adhere to drug treatment due to the arising confusion (Section 3.5.3.1, last bullet). Such changes challenge the comprehension of the elderly DM patients with limited or no educational background. One or both of the available PILs (Section 3.5.3.1, last bullet; and Annexures I and J) may not be effective in directing the medication taking procedures for some patients, especially the elderly with low education and health literacy levels.

The researcher recommends research at the PPH to assess the extent to which poor comprehension leads to adherence problems among the patients, especially the elderly, on chronic disease treatments. The research should also focus on the suitability of the current PILs design for the PPH clientele. Such research can influence the clinicians, nurses, and pharmacy personnel to enhance effective communication with patients on chronic medications with the purpose of achieving good adherence. The results can also possibly lay ground for the design of a better and more appropriate PIL for the PPH clientele.

- **Beliefs and attitudes about insulin use among diabetes patients at the Piggs Peak Hospital or in Swaziland**

Insulin use is both feared and disliked by patients at the PPH (Section 3.5.4.2). From this conclusion, the researcher recommends research about the beliefs and attitudes of the Swazi diabetic patients to insulin use. Such information can be useful in informing guidelines about the best approach for initiating patients on insulin treatment at the PPH and possibly in Swaziland.

#### **4.5 CONTRIBUTIONS OF THE STUDY**

This study contributes to the meagre, if not non-existent qualitative scientific literature on the subjects of DM and NCDs and patients' experiences in Swaziland (Section 1.2.2). It also helps build patient-based evidence and thus suggestions that help improve the quality of diabetes care, especially at the PPH. The study also helps stimulate further research as highlighted in Section 4.4.

#### **4.6 LIMITATIONS OF THIS STUDY**

This research was conducted on one small area of the Swaziland nation, and, therefore, it presents limitations in its generalisability. A need exists to carry out such similar studies in the various regions of the country to strengthen the body of scientific evidence on the researched topic.

#### **4.7 THE RESEARCHER'S EXPERIENCES AND REFLECTIONS**

The researcher was to a little extent apprehensive about having to implement the research, mainly because his patients were the very people who had become research participants. This was an abrupt and big change of roles in the way the two parties were to relate. The first few interviews were also the researcher's practice sessions to shed the skin of the busy casualty doctor to being an attentive researcher, learner, interviewer, and listener. It was time to descend the power ladder; it was an opportunity for the researcher to be the one in need, to receive, and to listen more for a rare change.

Qualitative interviewing was a uniquely, and rather unexpectedly strange exercise, especially because of the unexpected events that the researcher was hardly prepared for. Some of the interviews progressively and unavoidably gathered rather higher than anticipated emotional inertia. The researcher had to learn fast to cope, steer, and intellectually process the interviews despite the often overwhelming avalanches of emotional content emerging. This was a result of the participants unabatedly disclosing a lot about the untold story of the real human being, mother, father, and grandparent in a real rural Swazi family set-up and, moreover, who were, in some cases, managed by educated professionals of a totally different socio-cultural and socio-economic status. It was strange, but also humbling and exciting, to suddenly be feeling the human side of the very people that the researcher had all along viewed as *the diabetic patients*. The researcher, and not the doctor, was suddenly observing upright human beings who were quite wise, reasonable, and most of all, people who deserved a respecting ear and some empathy. That time around, the participants were not wrong anymore if they failed in their self-care tasks, but were rather challenged by complex situations; both within and outside themselves. These situations present opportunities for the health system to work on,

mitigate, and remedy. These participants were quite intelligent people too, not passive recipients of pre-packaged advice. They were certainly not less intelligent than their health providers. They were people with great potential to excel, like any other highly educated person. Having a solid background of natural sciences, the researcher was walking the new and exciting path of humanistic, naturalistic, and holistic inquiry. The feeling was satisfying; it gave the researcher a totally new perspective of reality, evidence, and knowledge.

The data was voluminous in its textual format, and rather intimidating to a researcher of better experience and comfort with numbers and mathematical calculations. Numbers were not going to come handy, and equations were not going to make life easy that time around. The researcher had to apply a holistic method and route, apply inductive reasoning, and deal with linguistic patterns to make sense of the data. It helped to take a break of a week from the data pile, lock everything up, and to return later with new energy. Transcript by transcript, the researcher read and re-read, started colouring statements, phrases and paragraphs with different colours for different meanings, and theory became reality as meanings and patterns started to develop, and the data started speaking for itself (Sections 2.3.4 and 2.4). Identifying the themes, categories, and sub-categories naturally followed; all supported by and completely within, the content of the organised narrative data. That data analysis task made the researcher feel triumphant, mainly because it summarised the results of the whole research endeavour. It all felt good, as if the work had already been done, but as the researcher learned later, the task of the whole project was still far from completed.

The researcher has learnt some lessons. One lesson is that patients are sufficiently intelligent, despite their failing to follow supposedly simple self-care chores on their own. Reasons for failure to self-care are often complex, and not always patient-based; all patients wish to be well and live, but there are various and often unexplored opportunities for the health system to ensure proper self-care of the patients. Patients are whole human beings, autonomous; and intelligent; they are not simple instruction-following and totally needy entities. Their lives as diabetic patients are not known by anyone else except themselves, unless and until one makes time to explore and seriously listen to their real life stories, until one decides to mentally

walk in their shoes and view their real challenges with a neutral frame of mind. Only then, can health providers create working solutions to improve often failing treatment and self-management plans. At this point, a lot of work is still to be done. However, the researcher feels happy and satisfied with the whole eye-opening exercise of this research project.

#### **4.8 CONCLUDING REMARKS**

This research was successfully conducted and objectives were met as planned. The researcher would like the research findings to be published for use by the scientific community and all stakeholders, including the PPH and the government of Swaziland.

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**ANNEXURE B: PERMISSION, SWAZILAND RESEARCH ETHICS  
COMMITTEE**

*Telegrams:*  
*Telex:*  
*Telephone: (+268 404 2431)*  
*Fax: (+268 404 2092)*



**MINISTRY OF HEALTH**  
P.O. BOX 5  
MBABANE  
SWAZILAND

**THE KINGDOM OF SWAZILAND**

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**FROM:** The Chairman  
Scientific and Ethics Committee  
Ministry of Health  
P. O. Box 5  
Mbabane

**TO:** Dr D Chikwanha

**DATE:** 02<sup>nd</sup> July 2012

**REF:** MH/599C

**RE: EXPERIENCES OF DIABETES MELLITUS PATIENTS WHO ARE ON TREATMENT AT THE PIGGS  
PEAK HOSPITAL IN SWAZILAND.**

The committee thanks you for your submission to the Scientific and Ethics Committee

In view of the responses submitted after concerns raised and the fact that the study is in accordance with ethical and scientific standards, the committee therefore grants you authority to conduct the study. You are requested to adhere to the specific topic and inform the committee through the chairperson of any changes that might occur in the duration of the study which are not in this present arrangement.

The committee wishes you the best and is eagerly awaiting findings of the study to inform proper planning and programming to use for analysis

Yours Sincerely,

**Dr S.M. Zwane**  
DIRECTOR OF HEALTH SERVICES  
(THE CHAIRMAN)  
cc: SEC members



**ANNEXURE C: INFORMED CONSENT (ENGLISH VERSION)****Study title:**

Experiences of diabetes mellitus patients who are on treatment at the Piggs Peak Hospital in Swaziland

Investigator: Darlington Chikwanha

Good morning / afternoon, sir / madam. My name is **Darlington Chikwanha** and I am a Master's in public health student with the University of South Africa. I am carrying out a study about experiences of diabetic patients about long term medical treatment in Swaziland, Piggs Peak area. To qualify for the study, one has to be a diabetic patient on treatment at the Piggs Peak Hospital for at least the last six months. You qualify to be part of this study and I am requesting you to participate. Your participation is voluntary and declining participation will not in any way affect the way you will be treated at this hospital.

Through this study, I want to understand what diabetic patients of the Piggs Peak area in Swaziland go through in their daily efforts to achieve good health. Such understanding is necessary to improve the effectiveness of treating diabetes mellitus at the Piggs Peak Hospital and possibly Swaziland in general. Findings of this study will be communicated to government and other non-governmental partners, including health workers, in order for patients like you to benefit in the end. If you wish, you can also be informed of the study results when they become available.

In this study, information will be gathered through a one-on-one conversation between you and me about aspects of life with diabetes mellitus. The conversation will be audio-recorded. To protect the privacy of persons, you are asked not to use people's names and personal, identifying information during the interview. The recorded information will be stored in a secure place and only the researcher will have access to that information for research purposes only. There will be no way of identifying you at any later stage because the interviews will be stored without name labels.

You may answer only those questions you are comfortable with. You are also free to terminate the interview at any stage if you want to. If you agree to participate in the

study interview, please indicate your willingness by signing below, but if you are not comfortable to do so, thank you for your time.

Participants signature .....

Date .....

Researchers signature .....

Date .....

**ANNEXURE D: INFORMED CONSENT (SISWATI VERSION) (LIFOMU  
LESIVUMELWANO)**

**Sihloko Selucwaningo:**

Timo lengihlangene nano etigulaneni letinesifo sashukhela esibedlela Pigg's Peak eSwatini

Umcwaniqi: Ngu Dokodela Darlington Chikwanha

Kusile/lishonile mnuzane/medemu. Ligama lami ngingu Darlington Chikwanha phindze ngifundzela iMasters ku etifundweni Public Health yaseUnivesity of South Africa . Ngeta lucwaningo ngetimo lengihlangene nato kutigulane letelashwa sikhatsi lesidze letinashukela eSwatini Pigg's Peak. Kuze kukhone kungenele lelucwaningo kufute ubesigulane lesilaphelwa sifo sashukela Pigg's Peak Hospital , lokungenani tinyanga letisitfupha letedlulile. Uyaphumelela kubayincenye yalucwaningo phindze ngiyakucela kutsi ube yincenye. Uyatiketsela kungenela loluhlobo futsi nawungakhoni kungenela loluhlobo akunawutsikabeta indlela lotawulashwa ngayo kulesibhedlela.

Ngalelucwaningo ngifuna kwatisisa kabanti kutsi tigulane letinesifo sashukela lapha endzaweni yaseSipiki eSwatini tenta njani kuze tiphumelele ngalokusemandleni ngemphilo lehlantekile. Kuvisisa kahle kumcoka kuphakamisa lizinga lekwelashwa kwetigulane letinashukela esibhedlela eSipiki saHulumende nawo onkhe emaSwati ngebunyenti bawo. Kutfola kabanti ngalelinwaningo kungakhulumisana naHulumende wemaSwati kanye netikapane letingekho ngaphasi kwaHulumende kufaka ekhatsi tiSebenti teMphilo kuze tigulane letinjengawe tibesenhlanhleni. Uma ufisile ungatiswa ngemiphumela yalucwaningo nasewuphumile.

Kulolucwaningo lwati lutawutfolwa kumunye nanga munye kukhulumisane emkhatsisini wami nawe ngemphilo yashukela. Lenkhulumiswano itawutsetjulwa. Kuvikela timfihlo tebantfu, niyacelwa kutsi ningasebentisi emagama ebantfu kanye nendlela lwati lwakhe angabonakala ngalo kuloluhlobo. Lwati lolutsetjuliwe utawugcinwa endzaweni legadziwe kani Baseshi kuphela, kulesimo lebatoba

nendlela yekutfolwa lwati ne tihloso tekusesha kuphela. Kute indlela longabonakala ngayo esgabeni lesendlulile ngoba luhlolo batalugcina ngaphandle kwemagama.

Ungaphendvula kuphela imibuto lova unetiseka ngayo. Ukhululekile kuyekela luhlolo kunoma kusiphi sigaba losifunako. Uma uvuma ubayincenye yaloluhlolo, ngicela ukhombise ngakusayina ngentase kepha uma ungakakhululuki kwenta njalo, siyabonga sikhatsi sakho.

Kusayina kwalongenele loluhlolo .....

Lusuku .....

Kusayina kweMcwangingi .....

Lusuku .....

**ANNEXURE E: SEMI-STRUCTURED INTERVIEW SCHEDULE, ENGLISH VERSION**

**Title:**

Experiences of diabetes mellitus patients who are on treatment at the Piggs Peak Hospital in Swaziland

Researcher: Darlingtone Chikwanha

Question	Instruction
<p><b>Introduction</b></p> <p>I will start by asking you about general aspects of yourself.</p>	
<p>1 Which language of communication do you prefer to speak?</p>	<ul style="list-style-type: none"> <li>• <i>Select language best to gather most information.</i></li> </ul>
<p>2 How old are you?</p>	
<p>3 What level of education did you attain?</p>	<ul style="list-style-type: none"> <li>• <i>Probe, assess literacy level.</i></li> </ul>
<p>4 Where do you live?</p>	<ul style="list-style-type: none"> <li>• <i>Probe for actual location, how far from hospital, cost from home to hospital, accessibility and ease of transport.</i></li> </ul>
<p>5 Whom do you live with?</p>	<ul style="list-style-type: none"> <li>• <i>Probe for family, relatives, support systems and general home situation.</i></li> </ul>
<p>6 How long have you been on diabetes treatment?</p>	<ul style="list-style-type: none"> <li>• <i>Ensure at least six months on treatment (<b>inclusion criterion</b>).</i></li> </ul>
<p><b>Experience of diabetes mellitus diagnosis</b></p>	
<p>How did you feel or react when you were told that you have DM?</p>	<ul style="list-style-type: none"> <li>• <i>Probe for psychological impact of the diagnosis.</i></li> <li>• <i>Probe for hospital-based psychological support, education, client involvement in the plan for treatment.</i></li> </ul>
<p><b>Experience of life with diabetes mellitus (treatment and self-care)</b></p>	
<p>Can you explain how the diagnosis of DM</p>	<ul style="list-style-type: none"> <li>• <i>Probe for challenges of life with diabetes,</i></li> </ul>

Question	Instruction
changed your life so far?	<p><i>treatment and self-care; e.g. medical complications, financial, time constraints, etc.</i></p> <ul style="list-style-type: none"> <li>• <i>Probe for community / family support or lack thereof.</i></li> <li>• <i>Probe for continued hospital support, education, medical treatment, health promotion, and psychological support.</i></li> </ul>
<b>Coping</b>	
Can you tell me how you have been coping with the diabetes status and the burden of self-care up to now?	<ul style="list-style-type: none"> <li>• <i>Probe for coping strategies and competency, barriers to coping, vital support systems and their effect on coping, dampers to coping.</i></li> <li>• <i>Probe for adjustment and acceptance of diabetic status or lack of, reinforcers and dampeners in the adjustment process.</i></li> </ul>
<b>Recommendations</b>	
<p>1 Do you see any opportunity for improvement in the way diabetes mellitus is managed at the Piggs Peak hospital, and in Swaziland in general?</p> <p>2 Do you have general recommendations for the hospital, community and family, government to better the lives of diabetic patients?</p>	
<b>Conclusions</b>	
I appreciate your participation in this interview. Do you have anything else to say to me as a researcher and as a doctor at the Piggs Peak hospital about your diabetes condition?	

**ANNEXURE F: INTERVIEW SCHEDULE, SISWATI VERSION (LUHLA LWELUHLOLO)**

Sihloko :

Timo letihlangene nato tigulane letinesifo sashukela esibhelela lesikhulu saHulumende ePigg's Peak eSwatini .

Umcwaningi :Ngu Darlington Chikwanha

<b>Imibuto</b>	<b>Lendlela lokumele uyilandzele</b>
<b>Kwekucala / Singeniso</b> Ngitawucala ngekukubuta kabati ngawe.	
1 Nguluphi lulwini longatsadza kulukhuluma?	• <i>Khetsa lulwini lolucono lwekutfola lwati.</i>
2 Uneminyaka lemingaki?	
3 Wagcina ebangeni lesingakhi esikolweni?	• <i>Kutfola lwati kutsi ufundze kanganani.</i>
4 Uhlalaphi?	• <i>Lucwaningo kutsi uhlalaphi , ukhashane kanganani kunesibhedlela, tindleko kusuka ekhaya kuya esibhedlela, udvute kanganani nekwekugibela.</i>
5 Uhlala nabani?	• <i>Buta uvisise kabanti ngemndeni, tihlobo, kusekeleka nenhlala kahle yasekhaya.</i>
6 Une sikhatsi lesinganani welashwa lesisifo seshukela?	• <i>Kumele kwendlule tinyanga letingi 6.</i>
<b>Simo lohlangene naso ngekubanjwa sifo sashukela</b>	
Ngitjele ngesimo lohlangene naso ngekubanjwa nguShukela?	<ul style="list-style-type: none"> <li>• <i>Buta uvisise kutsi utfola kanjani umuntfu ngasengcondvweni lokutjelwa kutsi unaso lesi sifo.</i></li> <li>• <i>Buta uvisise ngelwati lolitfolo esibhedlela, ngekufundziseka, kunakekelwa encondweni, kubambisana ukukhetseni</i></li> </ul>

Imibuto	Lendlela lokumele uyilandzele
	<i>indlela yekulashwa.</i>
<b>Timo lohlangene nato ngemphilo ne kulashwa ne kutinakekela nge sifo sashukela</b>	
Yini timo lohlangene nato ekuphileni nesifo sashukela nekusinakekela?	<ul style="list-style-type: none"> <li>• <i>Buta uvisise tigcinamba, kabanti ngetemnotfo noma sikhatsi lanaso sekuya esibhedlela ekunakekelweni, ngumndeni, kanye nemango mayelana naletinkinga.</i></li> <li>• <i>Buta uvisise kutsi emangweni noma emndenini kutsi usekelekile noma awukasekeleki.</i></li> <li>• <i>Buta uvisise kutsi uya chubeka yini ngekusekeleka esibhedlela, ngekufundziseka, ngekuphakamisa lizinganga letemphilo kanye nekusekeleka engcondvweni.</i></li> </ul>
<b>Kuphila ne kuphumelela</b>	
Ungangitjela kutsi ukhone njani kuphila nale sifo sashukela ne bumatima bekutinakekela kuze kube ngumanje?	
<b>Imibono</b>	
<p>1 Kukhona yini litfuba lolibonako lenchubekela phambili ngendlela sifo sashukela leselashwa ngayo esibhendlela saHulumende eSipiki kanye nelive lonkhe laseSwatini?</p> <p>2 Kukhona yini longakusho mayelana nesibhedlela, nemango nemndeni, kanye naHulumende kuze tigulane letinesifo saShukela tiphile ncono?</p>	
<b>Tiphetfo</b>	
Ngijabulile kutsi ube yincenye yaloluhlolo, kukhona yini longakusho ngami nginguMcwangingi phindze nginguDokotela waseSipiki esibhedlela saHulumende malelano ngashukela?	

**ANNEXURE G: PERMISSION REQUEST FROM THE SWAZILAND  
RESEARCH ETHICS COMMITTEE**

Piggs Peak Hospital

Box 254

Piggs Peak

Swaziland

30 May 2012

The Research Ethics Review Committee

Swaziland Research Council

The Cooper Centre

Mbabane

Dear Sir / Madam

**Re: Permission to conduct a research project**

I am a student of the University of South Africa (Unisa), registered for a Master's Degree in Public Health. I hereby request permission to carry out a research project at Piggs Peak Hospital during the period of June 2012 – November 2012. The title of my research project is **“Experiences of diabetes mellitus patients who are on treatment at the Piggs Peak Hospital in Swaziland”**. The research proposal has been granted ethical clearance by the Department of Health Studies at UNISA,

Departmental Higher Degrees Committee, as evidenced by the approval certificate attached for your inspection. The proposal document is available for your perusal.

A qualitative approach will be followed and data collection will be through semi-structured interviews with patients on the hospital diabetes register. Refer to the attached interview schedule. The initial sample size will be 15, but it may change since data saturation will determine the final number of participants.

Measures will be taken to avoid disruption of services in the outpatients department during the research process. Interviews will be conducted in a separate office away from the busy floors and diabetic patients will be interviewed after their full consultations.

This research will be directly beneficial to patients at the Piggs Peak Hospital and may on a broader scale, contribute towards policies and guidelines for the management of diabetes mellitus in Swaziland. It will also help in building empirical scientific knowledge in the minimally researched area of non-communicable diseases in Swaziland.

Results of the study will be communicated to you.

I thank you in advance for your assistance.

Yours sincerely

Darlington Chikwanha(Dr)

MPH student

Phone: +26876614188

E-mail: cdarlington@yahoo.com

## ANNEXURE H: TRANSCRIPT 10, INTERVIEW 10, PARTICIPANT J

Informant

J

Informant characteristics:

Age : 40 years

Gender: Female

Employment status: Unemployed

Duration on DM treatment: 2 years

Education: Standard 6.

Race: Black African.

Nationality: Swazi.

RES: Thank you. Which language do you prefer to use, English or Swazi.

J: Siswati.

RES: That will be fine. How long have you been on DM treatment?

J: Ummm, I think about two years.

RES: I notice on your card that you are on treatment for both DM and hypertension (HPT).

J: That's right.

RES: What was diagnosed first, DM or HPT.

J: It was DM.

RES: May you tell me the reason why they checked your sugar in the first place, was it illness or other reasons?

J: I was not well. My mouth was always dry; I was always drinking water and then urinating a lot. I almost died.

RES: I see, and then you came to hospital with those complaints.

J: Yes doctor. I came here; they had to admit me and used injections to treat me.

RES: Uhuhh, so they discharged you to continue with the injections?

J: Yes until now. But I was to be admitted again twice, with high sugar and feeling sick. I was not doing things well myself.

↑  
poor adherence

← symptomsatology

← complications

RES: I see. When you say you were not doing well, do you speak about the injecting or...?

J: No, I was not following the diet and medication as expected.

← poor adherence - continued

RES: To your memory, did they properly teach you about the required diet during your first admission?

J: They did doctor. You see, there are situations that often make us eat wrongly at home. The first is cravings; you may end up eating certain things just because you crave for them too much. The issue of availability and cost of the recommended healthy options comes too. You find that you don't have enough money to buy the recommended foods, and circumstances force you to eat whatever is available.

• cost  
• availability  
• cravings

RES: Where do you stay?

↑ eat to live

J: I stay in Mangwaneni.

RES: How far is that place from here?

J: So near doctor, in Piggs Peak.

RES: I see. So it is a walkable distance?

J: Indeed doctor, it's a walkable distance, about 20 to 30 minutes on foot from here.

RES: Well put. May I then ask about the various tasks of treatments, hospital visits and diet adherence, how heavy are such burdens?

J: It is quite difficult. For example, for someone on injections like me, I have to take all necessary meals together with injections if I am to avoid fainting. Take situations where one is at gatherings and crowds, where does one get the food at the right time? And the task of injecting oneself in a clean and sterile way twice daily, it is all quite a task.

RES: Does it happen that sometimes you fail to achieve all these requirements.

J: *Laughs...*, yes it happens as I already confessed about food. You see, it is hard to resist good food especially if someone makes it available at home. I end up eating it a lot too. *Laughs.*

} dietary, self-care adherence  
① temptations  
② family influence

RES: I appreciate the honesty. Do you always get your injection at this hospital?

J: I have no memory of having problems in getting it.

RES: How do you find the technique of self-injection so far?

dietary adherence - cravings

drug administration

3

J: Being very honest doctor, I don't like to inject. If ever it was possible to use pills, I would happily go that route. You see, it is too painful to inject all the time, its painful. The pills are a better option.

1) Tablet preference  
2) Insulin diabetes  
3) Burden of injections  
4) Periods of injection

RES: Which areas do you use to inject?

J: I use the thighs.

RES: Did they say those are the only areas you can use?

J: They said I could also use the abdomen. I used to inject on the abdomen until I started to notice unsightly black spots on the injection sites, and I had to stop and will never use the abdomen again.

Burden of drug adminis-  
-estric  
challenges.

RES: You sound as if you really admire to be on pills rather than injections.

J: That's for sure. But I have noted that there happens to be more shortages with the DM pills than injections, meaning that I am somehow lucky so far.

shortages  
will  
know

RES: How do you judge the quality of our service on a diabetic day like this one? Tell me your experiences and views.

J: I think things have improved a lot. We used to arrive here around 2am, secure our numbers only to be helped from 8am onwards. Nowadays, we still arrive quite early, around 2 to 4am, secure our numbers and some night nurses (name verbalised but omitted) start to help us from around 5am. That is quite helpful and we appreciate it.

hospital work -  
come very early

But all the same, why can't they also separate us from the rest of the patients like they do for HIV and TB patients, we also want our own clinic. As it is now, there are some sick patients amongst us, sometimes they have to be prioritised first and we have to wait, despite that it is supposed to be a diabetic day.

Policy  
is hospital -  
me for ethical  
the defences

RES: Well put.

J: And we want to be seen on all days of the week, not just on Wednesdays. That punishes us a lot because we have to crowd here and wait very long periods, and push and shove. Why not treat us just like other clinics like TB and HIV clinics, they see their patients daily.

hospital users  
1) crowding  
2) slow  
3) long  
4) pushing  
and shoving  
5) one day weekly

Let me give you my own situation. I am a trader and I travel as far as Durban. Circumstances with business may make the recommended Wednesday impossible for me, lest I lose a business trip. It would be good if I were to be allowed to come any convenient day, but whenever I try to do so, it sounds like I am troubling the hospital system because they complain about the futile task of retrieving my card on an unanticipated day. They want everyone to go by their scheduled group.

ANNEXURE I: PILL BAG I, PATIENT INFORMATION LEAFLET

GAFIKELELEKI KUBANTWANA - HOU BUIE KINDERS SE BEREIK - BEA HOLE LE BANA .  
OU BUIE KINDERS SE BEREIK- BEKA KUDE EBANTWANENI - KEEP OUT OF CHILDREN'S RE

**TABLETS/CAPS - EMAPILISI**

Tablets  
Emaphilisi

Times a day  
Ngelilanga

Every  
Emahora

Hours

Name  
Lebito

Cont.  
Ekhatsi

Batch	Exp	No	Date
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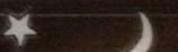
1172

ANNEXURE J: PILL BAG J, PATIENT INFORMATION LEAFLET

**KEEP OUT OF REACH OF CHILDREN!**

DRUG..... QTY.....

TAKE  TABLET(S) TIME(S) DAILY  
 TSATSA EMAPHILISI NGELILANGA

			
<b>TSATSA EKUSENI</b>	<b>EMINI</b>	<b>NTSAM BAMA</b>	<b>EBUSUKU</b>

**Patient's Name**.....

**Date**.....

**Instructions**.....

**Ministry of Health and Social Welfare  
Swaziland Government**

ANNEXURE K: NEWSPAPER CLIP (DIABETES SHOCKER)



## ANNEXURE L: NEWSPAPER CLIP (DIABETES REVELATIONS)

National News

Weekend OBSERVER

Saturday - Sunday February 2 - 3, 2013

More revelations on diabetes as ...

# 50% SWAZIS DIABETIC

**COVER STORY**

By Faith Vilakati

Half the country's population is diabetic. This is according to a survey conducted by the ministry of health in 2007, which catered for all the Non-Communicable Diseases (NCD).

The report is in possession of the ministry of health, which has been discussed at length in several meetings to curb the alarming situation.

In fact, it was gathered yesterday that the ministry is locked in several meetings discussing means of instituting a new survey considering that these statistics were now outdated and the latest figures could be even more shocking now.

It was stated in the 2007 report that failure by people to participate in different exercises contributed immensely to the alarming statistics.

During the survey it was also discovered that 55 percent of the country's population was at high risk of transmitting all the NCDs. These people were found with all the risk factors of getting all NCDs which include obesity, alcohol and cigarette consumption.

The survey was for chronic disease risk factors in Swaziland. It was carried out in October to November 2007.

Deputy Director of Health Surgical Dr Vusi Magagula could not commit himself on the statistics about half the country's population being diabetic, but he did confirm that over 50 percent of the population was living with one or more risk factors of NCDs. He named these risk factors as obesity, excessive use of alcohol and cigarettes. He added another factor as the lack of activities and exercises. "These figures are alarming and a cause for concern for the country."

...survey also reveals that 55 percent of the country's population is at high risk of all the Non-Communicable Diseases (NCDs).

Most people might think that the ministry is not doing anything to address this challenge yet we are doing everything to bring the situation to normal, even if maybe it's not that significant.

Even then we have decided to come up with awareness campaigns to teach people how to live and eat healthy food so they are safe," he said.

Dr Magagula further mentioned that as a ministry they were working on a law to restrict people from smoking anywhere and were waiting for parliament to pass that law. He said before the end of the year the ministry would host campaigns on the dangers of excessive alcohol consumption.

"I am not in a position to discuss the issue of the number of people who already have the NCDs because I do not have facts yet. It would be better if I have a report to substantiate those figures, then we would issue a comment," he said.

This report comes after this newspaper, a few weeks ago, published current statistics of people being amputated at the Mbabane Government Hospital.

It was revealed that at least seven people were amputated at the hospital every month, which Principal Secretary (PS) Dr Steven Shongwe said might be a tip of an iceberg. He said there were fears that more people were diabetic in the country.

Those statistics raised alarm among many commentators, including medical doctors, who felt diabetes was not given the proper attention it deserved.

During the survey three things were sampled, namely, the socio demographic and behavioural information, physical measurements such as height, weight and blood pressure and biochemical measurements to assess blood glucose and cholesterol levels.

The survey was population-based, of adults aged 25-64. A repeat survey was planned for last year but due to financial constraints the ministry could not conduct it.

Sources within the ministry of health lamented that the numbers might be even higher considering the fact that the survey was conducted five years ago.

"Diabetes is the most deadly disease, which is a silent killer in the country and it is now time for government to take control before the situation overcomes us.

It also brings a challenge to people to start acting and being careful of the type of food they eat, and make sure that they exercise at least once a day.

**Optimistic**

I am optimistic that if finances permitted, government would have started addressing issues of NCDs, mainly diabetes," said the source.

She further mentioned that in most countries the focus has been shifted from HIV and AIDS to NCDs because the leaders had observed and understood the dangers of such diseases.

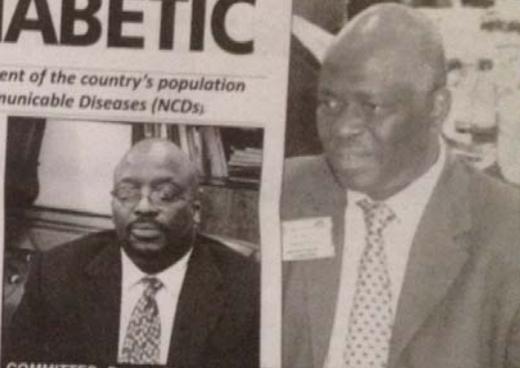
Risk factors of NCDs include sedentary lifestyle, unhealthy diet, heavy alcohol consumption and smoking. "There is a high prevalence of modifiable risk factors of non-communicable diseases in the country. Alcohol consumption and tobacco consumption is high, mainly amongst males. Other lifestyle factors such as being overweight and central obesity were noted to be high, especially in females," added the source.

"Training and capacity building is needed for all stakeholders, which should be reinforced with adequate logistical resources, with which to carry out these activities," reads part of a Swaziland NCDs risk factor surveillance report.

In the National NCD Strategic Plan 2011-2017, Minister of Health Benedict Xaba acknowledged that the country has not been spared by NCDs.

He mentioned that the World Health Organization (WHO) subscribes NCDs as a world's biggest killers. The annual status report from the ministry in 2009 indicated that amongst out-patients, hypertension and heart diseases were responsible for 33 54 and 3 146 cases respectively.

To respond to this situation, the minister said the ministry of health developed the NCD policy, which defines direction that the country shall take to minimize consequences of these diseases on the health of the Swazi population.



**COMMITTED: Deputy Director of Health Surgical Dr Vusi Magagula left and PS Dr Steven Shongwe.**

**Snip** Those statistics raised alarm among many commentators, including medical doctors, who felt diabetes was not given the proper attention it deserved.

**ANNEXURE M: INSULIN SYRINGE AND NEEDLE**

