CHAPTER 1

INTRODUCTION

1.1 INTRODUCTION

Diabetes mellitus is a chronic disease that is globally spread. The most frequent form is type 2 with about 85% of all diabetes cases according to WHO report WHO 2007). The global prevalence is projected to rise from 171 million in 2007 to 366 million in 2030 if no action is taken (Roglic G *et al*, 2004, Wild S *et al*, 2004).

The burden of this disease in sub-Saharan Africa is very high where in some countries a mortality rate as high as 40 per 10 000 inhabitants (WHO 2004). Such figures show that diabetes in no longer rare in Africa (Sobngwi E *et al*, 2001).

The challenge is for African countries to implement the WHO resolution to take measures that focuses on the population and are adapted to their local situation, and create a model for an integrated approach in the fight against diabetes at community level (WHO 1989).

At an individual level the problem of poor compliance and adherence to strict medical prescription and life style modification is widely recognized (Galanti GA, 2000).

1.2 MOTIVATION

Diabetes is one of the most common clinical conditions seen by family physicians in their daily practice (Gearheart JG *et al*, 1998). They are constantly confronted with the burden of caring for poorly controlled and poorly adherent patients presenting with, yet preventable debilitating, disabling and mutilating complications.

These complications are preventable, the WHO declared in the June 2007 diabetes prevention and control strategy report for the African region, 80% of type 2 diabetic cases could be prevented by simple measures but the efforts to fight diabetes in Africa are far below the expected results (WHO/AFR/RC57, 2007).

The researcher was confronted with this reality at his daily clinical practice and failed to comprehend the "mystery" behind the clinical presentation of patients with diabetic complications.

As far as the researcher could recall, this research was actually triggered by such a traumatic experience at the very beginning of his residency in family medicine with his very first patient study.

The researcher met this male patient institutionalized for complications post diabetic foot amputation. Certainly, a limb or foot amputation was not unknown to the researcher as a complication of uncontrolled diabetes but having first hand experience to deal with such a thorny daily experience of pain, grief and lamenting of the patient over his life made the researcher realize the impact of poor glycaemic control and mostly wondered how could one get to such mutilating complications when effective recommended control measures and medication are known and available.

Why is it that people do not get their sugar levels under control? What is it that the researcher was missing to see out there? Is it us or them to blame? Having no answers to the above questions the researcher decided to investigate what could be the reasons unknown to the medical professionals that patients with diabetes were doing that their sugar levels were uncontrolled.

Overall, diabetes requires a life long commitment and can be life threatening if not well controlled due to its complications.

To ensure a successful ongoing management process, both health care providers and patients need to be involved in a more patient-centred intervention that understands: patient's health care beliefs, healing philosophy, educational

level, cultural background and the whole social network in which they live (Greenhalgh T et al, 1998, Samuel - Hodge CD et al, 2000)

McWhinney rightly quoted William James concerning a more patient-centred approach and greatly elaborated on the second principle of family medicine that stipulates how the family physician should seek to understand the context of all illnesses (McWhinney IR, 1997). He further demonstrated the relevance for family physicians to see their patients both in and out of their environment, taking time to explore their lay beliefs, personal expectations, attitudes, the family, social and cultural context. Moreover, health care providers at any level should enquire about and grasp a fair understanding of the above social dynamics (Greenhalgh T *et al*, 1998). Furthermore it has been demonstrated that patients' trust in their physician appear to be enhanced when the physician makes and an effort to understand their experiences, communicate clearly and competently, build partnerships, obtain referrals, and share power with their patients (Fiscella *et al*, 2004).

Patients and their health care providers may greatly differ in their disease perceptions; either with regards to the perceived severity, management plan or therapeutic goals. They may have different priorities in assessing the success in diabetes management (Saultz J W, 2001). A patient could greatly be satisfied with the remission of his initial symptoms such as thirst, tiredness and urinary frequency while his physician is concerned with protein in his urine and some blood sugar target levels. How would a newly diagnosed type 2 diabetic patient fully comprehend complex concepts; short-term and long-term therapeutic goals compared to the spectacular symptom alleviation on treatment initiation? Therefore the family physician who begins with assessing patients owns perspective and expectations will improve communication efficiency, the patient-physician relationship will then acquire a better comprehension of the illness background often obscured at the initial encounter in a clinical setting (McWhinney, 1997).

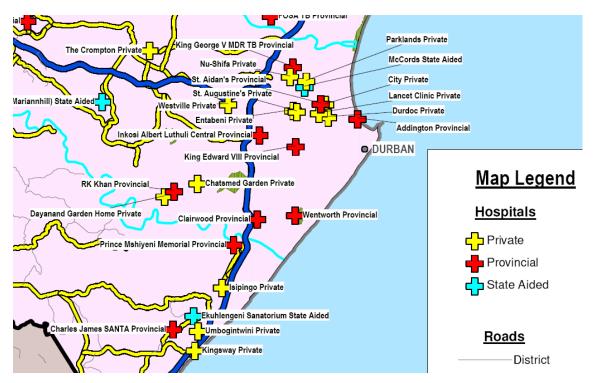
The purpose of this research was to explore lay beliefs of patients in the management of type 2 diabetes at Prince Mshiyeni Memorial Hospital (PMMH). The researcher sought to understand what the rationale was for patient's choices and decisions with regards to their therapeutic model. Why do they struggle to adhere to prescribed remedies?

1.3 SETTING OF THE STUDY

Prince Mshiyeni Memorial Hospital known as PMMH named after His Royal Highness Prince Arthur Mshiyeni ka Dinuzulu was established in 1980 and officially opened on 20th May 1987. The hospital is currently designated as a level 2 hospital but functions as both district and regional hospital in the eThekwini district servicing a population estimated at approximately 2 million (www.kznhealth.gov.za/princemshiyenihospital.htm).

The hospital has 1200 beds and attends to an average of 1500 patients per day in outpatients' clinics. In the area there is no other district hospital under PMMH along the south cost up to GJ Crookes Hospital of Scottburgh in the neighbouring district.

Figure 1: Hospitals around PMMH in the eThekwini District



Source: www.kznhealth.gov.za/princemshiyenihospital/htm/map

1.3.1 Health Care Facilities

1.3.1.1 Public Sector

At present, there are 17 clinics operating under the PMMH servicing area. Seven of these clinics are across Umlazi, the township where the hospital is located with an escalating population because of the mushrooming informal settlements and the remaining ten other are located outside the greater Umlazi area.

Two state-owned institution provincial institutions and one state-aided sanatorium hospital are located in the PMMH servicing area respectively: Clairwood Provincial Hospital, North-East of PMMH, Charles James SANTA Hospital southwest of PMMH and Ekuhlengeni Sanatorium located in the south- west. These hospitals fall under PMMH as their regional referral hospital

(Figure 1: Hospitals around PMMH in eThekwini Health District).

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At PMMH, there is a specific ward D3 where all chronic clinic patients are seen at the family medicine department. The diabetic clinic, located in D3, operates every Thursday from 8:00 to 16:00 where about 250 to 300 patients are seen. Once glycaemic control is achieved within 3 to 6 months of follow-up at the chronic clinic, the patient is down-referred to his local clinic for continuation of care. Patients are reviewed either after 6 months or at yearly intervals. The Diabetic clinic has the highest turn-over of patients in D3 compared to all the other chronic clinics.

1.3.1.2 Private Sector

The implementation of private medical institutions in South Africa ought to be considered in the context of racial division of the past. As all communities where divided on racial basis, the previously disadvantaged racial groups did not have access to better health facilities especially to private hospitals. Hence the current distribution of private institutions parallels the former racially based apartheid medical system. Private hospitals are mainly located in former white areas and upmarket suburbs.

The community in Umlazi is predominantly African, mainly Zulu from Umlazi and the surrounding rural areas. None of the major private hospital holdings in Durban namely NETCARE, LIFE Healthcare and the emerging Indian group JOINT MEDICAL HOLDINDS are operating in the greater Umlazi area. General Practitioners are well involved in the primary health care system in the greater Umlazi, mostly located in business centres and shopping malls. Their well known scarcity in the rural outskirts of Umlazi needs no comment; the community relies essentially on state clinics and the few operational private doctor rooms. Private medical centres are on a small scale but are now blossoming with the upcoming African elite but the injustices of the past will take long to reverse, if not beyond the point of no return.

The Indian community is mostly located south-easterly of the hospital in the Isipingo-Prospectus area and Adams mission area, where a private hospital,

Isipingo Medical Towers is operational. This private hospital renders services to all the south-eastern Durban suburbs.

The white community is predominantly located southerly of the area towards Amanzimtoti, up to Scottburgh. General practitioners as well as other private institutions such as Kingsway hospital, Umbongitwini private hospital are at services to the community in these areas. These institutions are jointly working for these communities in collaboration with PMMH as their referring district and regional hospital.

1.3.1.3 Traditional Healers

There are no official data regarding traditional healers in the hospital servicing area, nevertheless traditional healers in South Africa known as *Inyangas or Sangomas* are an integral component of the health practice and cultural practices in this predominantly underdeveloped and rural KwaZulu-Natal community. They are referred to as the first health provider to be consulted by up to 80% of cases, especially in rural areas (Clarke E, 1998). It is estimated that 1500 tons of traditional medicines are sold in medicine markets in Durban alone every year (WHO 2001).

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

In this section the researcher presents a review and synthesis of an elaborate search and appraisal of the available literature and electronic database examining various aspects of lay experiences and beliefs on diabetes.

Most articles were retrieved from the resource centre of the Department of Family Medicine at Medunsa Campus.

The researcher made extensive use of resources such as national and international diabetes management guidelines; prescribed books in family medicine, medical text books; internal and general medicine text books and manuals.

Literature from the journal of endocrinology, metabolism and diabetes of South Africa and other South African medical journal such as SAMJ, CME, and SAFPJ, added great value to access local data.

The following electronic databases were used through their provided search link: MEDLINE, PUBMED, SCIENCE DIRECT, SUM SERACH, TRIPDATABASE, GOOGLE SCHOOLAR, and GOOGLE CHROME. The researcher combined the following key words to generate related articles: "type 2 diabetes", "lay beliefs", "diabetes beliefs", "and cultural barrier", "behaviour", "experiences", "alternative remedies".

Additional free-text search was used with Google chrome, and Tripdatabase to yield more specific qualitative published articles.

2.2 DEFINITION

Diabetes mellitus can be defined as a disease complex characterized primarily by a relative or absolute insufficiency of insulin secretion and concomitant insensitivity or resistance to the metabolic action of insulin on target tissues (Garber AJ, 1998). Hyperglycaemia results as a consequence of the defects in the secretion of insulin by the pancreas and its action.

Another definition is that diabetes mellitus is a heterogeneous group of metabolic diseases that are characterized by chronic hyperglycaemia and disturbances in carbohydrate, lipid, and protein metabolism. These diseases result from a lack of insulin secretion, insulin action or both (Barnett P; Braunstein GD, 2005).

Although diabetes is merely a disease of inadequate insulin secretion and action, a variety of classifications and diagnostic criteria have been proposed over the years. Three major types of diabetes mellitus are now recognized based on their respective pathophysiology; two primary types namely type 1 and type 2, and the other as secondary diabetes (DOH/National Guidelines, 2005).

2.2.1 Type 1 diabetes

This form of diabetes is mostly common in the first two decades of life but can occur at any age. Type 1 diabetes is a disorder characterized by β -cell destruction resulting in an absolute insulin secretion deficiency (Garber AJ, 1998) The clinical onset of the disease is usually abrupt, with the classic clinical presentation: polyuria, polydipsia, polyphagia, weight loss and fatigue. Patients here are highly prone to ketoacidosis.

Patients with type 1 diabetes have little or no endogenous insulin secretion; as a result carbohydrate metabolism is severely affected and patients require insulin to survive (Clark C, 2006).

2.2.2 Type 2 Diabetes

In a more practical way patients are thought to have type 2 diabetes when they do not have type 1 diabetes (rapid onset, often in childhood, insulin-dependent, ketoacidosis if neglected), or other medical condition or medication suggestive of secondary diabetes (IDF,2006; NICE, 2008).

The South African national guidelines on management of diabetes defines type 2 diabetes as a condition resulting from predominantly insulin resistance with relative insulin deficiency (DOH, 2005). Others would argue that a primary relative insufficiency of insulin secretion is the pathologic essential for the clinical development of type 2 diabetes (DOH, 2005). Thus obesity being a major risk factor for the development of this type of diabetes, owing in part to the associated insulin resistance, and pancreatic cell function decline (Graber AJ, 1998; Mbokazi AJ 2006).

Nevertheless it is clear that the pathophysiology of type 2 diabetes is linked to obesity, insulin resistance and environmental factors such as inactivity, and abundance of food (Ogunbanjo GA, 2006).

In South Africa the prevalence is highest in the community of Indian descent 10%, and about 5 – 6% in the African community (Ogunbanjo GA, 2006). Type 2 diabetes accounts for 80- 90% of all forms of diabetes worldwide and its prevalence is increasing as the prevalence of obesity continues to increase (WHO, 2007).

Patients with type 2 diabetes do not depend on insulin for their survival although there can be limitations in the amount of endogenous insulin secretion coupled with the presence of insulin resistance.

The clinical presentation of patients with type 2 diabetes varies greatly. Generally for type 2 diabetes many patients are asymptomatic initially and at the time of diagnosis mild to marked obesity is present in 80% of type 2 diabetic patients (Ogunbanjo GA, 2006).

Mostly these patients may present for consultation only after the development of complications such as retinopathy and neuropathy, 20-21 % of patients with newly diagnosed type 2 diabetes have retinopathy (Fong *et al* 2004; Mbokazi AJ, 2006). At the time of diagnosis and that 10-15 % of type 2 diabetic patients will develop diabetic foot ulceration at some stage of their illness (Levin, 1997).

Considering such a devastating disease progress for the sufferer it is critical for the family physician and all primary health care providers to have a high index of suspicion and initiate relevant investigations for any patient presenting with risk factors of obesity, increasing age, positive family history of diabetes, unexplained recurrent infections, visual difficulties, unexplained peripheral neuropathy and others such as the metabolic syndrome X (Ogunbanjo GA, 2006).

2.3 EPIDEMIOLOGY

Worldwide the prevalence of diabetes was estimated at 2.8 % in 2000 with a projection of increasing to 4.8% by 2030. These figures indicate that the number of persons affected will rise from 171 million in 2000 to 366 million in 2030 if no action is taken (Roglic G *et al* 2004).

In a different report of 2004 compiled by the health of population in transition research group in Cameroon, they estimated that 190 million suffer worldwide from diabetes and 330 million will be affected by 2025 (CamBod 2004). However, it was not possible to present data separately for the different sub-types of diabetes amongst adults in Africa as most data sources do not distinguish between the type 1 and type 2 diabetes prevalence (Wild S *et al* 2004).

In Africa diabetes is no longer a rare condition. The burden of the disease is very high with unknown cases of diabetes escalating in the order of 60 % to 80% prevalence rate of diabetes in these countries; Cameroon, Ghana and Tanzania as reported by the International Diabetic Foundation (IDF 2003). Meta-analytic

estimates and recent investigations indicate a wide discrepancy amongst African countries and regions (figure 2). The prevalence rate ranges between 1% and 20 % as in Mauritius for instance (WHO 2006).

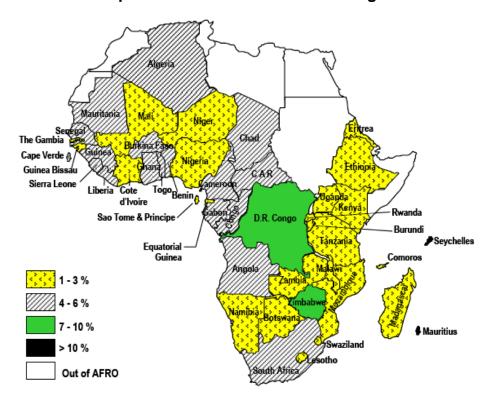


Figure 2: Diabetes prevalence rate in WHO Africa region

Sources: Sobngwi E *et al*, Diabetes in Africans: Part1: epidemiology and clinical specificities, *Diabetes and Metabolism* 27(6): 628-634, 2001.

In South Africa the diabetic statistics are quiet alarming; about 4 million are known to have diabetes mellitus (Clack C, 2006). An earlier South-African study had estimated diabetes to have caused 4.3% of all deaths in 2000 (Bradshaw D et al 2003).

A recent study conducted in 2007 estimated the large percentage of burden disease in South Africa as attributable to diabetes (Procor 2008). Indicators such as the disability-adjusted life years (DALY) rate for diabetes in South Africa ranks second highest in the world after the American region (Clark C, 2006). Therefore, any study that undertakes to investigate this phenomenon in a South African

context patients' perspective of living with type 2 diabetes and/or to understand the lay beliefs that drives their health model and health seeking behaviour in the management of type 2 diabetes will be more than relevant to the family medicine field.

2.4 PSYCHOSOCIAL DIMENSION OF DIABETES CARE

Eminent clinical trials such as the Diabetes Control and Complications Trial (DCCT, 1993) and the UK Prospective Diabetes Study (UKPDS, 1998) have provided strong evidence that most diabetic-related pathologies are potentially avoidable if optimum metabolic control is achieved in people with diabetes (Rafigue G *et al,* 2006). However, scientific analysts have raised questions as to whether the improvement of patients' metabolic control in the DCCT study was attributable primarily to the intensive insulin regimen, to the intensive psychosocial support provided by the research care teams, or merely by a combination of both strategies (Chas Skinner T & Hampson SE, 2001). A study published in the *Diabetic Care* on adolescent diabetic patients showed that an intensive insulin regimen is not the only key to improve diabetes control (Dorchy H *et al,* 1997). Therefore other significant factors, influential to achieving a more sustainable glycaemic control such as psychosocial support (Glasgow RE *et al* 2001), cultural and health beliefs (Tripper-Reimer R *et al,* 2001) ought to be considered for better glucose control (Zgibor J C & Simmons D, 2002).

Diabetes is a prototypical disease in which responsibility for day-to-day management of the illness falls directly on the patient as cited by Rodriguez GS & Bayley KB (Saultz JW, 2001). Dr Anderson would agree with the above statement as he wrote in their article in *Clinical Diabetes:* "self-management is a crucial element of good diabetic care" (Anderson D & Christon-Lagay J, 2008). Hence, the management of diabetes depends to a great extent on the patient's ability to carry out self-care and healthy behaviour in their daily lives (Rafigue G *et al, 2006*). This calls for very high level of patients' participation in setting of

goals as substantial adjustment is required of them. Unavoidably such changes will affect numerous aspects of their lives. Their emotional, personal, familial, professional lives are confronted with the sudden need to change many basic daily life patterns. They now face the challenge of living with a chronic illness, including adherence to chronic medication.

It is known that various studies have been conducted to analyze the difficulties in diabetes regimen adherence and to explore the psychosocial factors related to self-management, mostly focusing on the individual in their assessment of barriers to diabetes care (Glasgow RE *et al,* 1997).

Schoenberg and colleagues in a study on lay perspectives on origin and management of type 2 diabetes also elaborated on how researchers have sought to explain non-adherence to standard medical regimens by investigating varieties of socio-demographic variables but these studies lacked to explore variations between health perspectives and life circumstances of the individual and the psychosocial dimension. They demonstrated that previous studies have ignored to acknowledge the influential role of explanatory models of illness or health beliefs in diabetes while they was emerging evidence that an individual's beliefs about illness influences his or her health behaviour (Schoenberg NE et al, 1998). Another study a leading team of psychosocial research in diabetes selfmanagement later on conducted a review of existing research on psychosocial and interpersonal barriers to diabetes self-management and the quality of life and has also undertaken to explore the patients "internal environment" and socialenvironmental barriers to self-management, the "external system". These two factors were considered to be the most important factors to influence diabetes care in this study (Glasgow RE et al, 2001). Patient's "internal environment" would include specifically his personal-model cognition about diabetes and its treatment (Glasgow RE et al, 1997).

An individual personal-model is known as one's representation of their illness, including disease beliefs, emotions, knowledge, and experiences. It includes the representation of emotional response to disease and treatment, which guides the

processing and merging of all incoming information with the individual's past experiences (Glasgow RE *et al* 1997, Skinner TC *et al*, 2001).

An individual's personal-model of diabetes is seen as his or her emotional and behavioural response to the illness and like other social cognition schema, personal-model beliefs will change in response to experiences, as one is learning

responsibility in their own diabetes management it is a patient-generated phenomenon (Skinner TC *et al*, 2001).

2.5 KNOWLEDGE AND EDUCATION ABOUT DIABETES

It is established that people with diabetes often have inadequate knowledge of their condition, risk factors and associated complications (Sivaganam G *et al*, 2002). This lack of awareness is the driving factor of their careless attitude and behaviour towards appropriate diabetic care (Rafigue G *et al*, 2006). Another study showed that research on personal barriers to diabetes care that knowledge itself does not necessarily create an ability to enhance self-care if other priorities and barriers exist. He therefore suggested that providing counselling, guidance and support should have a higher priority, along with the traditional clinical and educational patients' session (Simmons D, 2001). Many patients require medical supervision, training and social support to achieve their therapeutic goals. Others will need to feel that they have more to gain than to loose before they can change their previous lifestyle. The aim is to help them towards changing their current life pattern by stirring in a sense of "ownership" of the achievement and changes, hence build self-worth through accomplished success (Saultz JW, 2001).

In a recent randomized controlled trial on the effectiveness of the diabetes education and self-management on both ongoing and newly diagnosed type 2 diabetic patients at primary care level in the United Kingdom, they concluded that a well structured group education program for newly diagnosed type 2 diabetic patients resulted in a greater improvement in weight loss, smoking cessation, and positive improvements in beliefs about the disease but did not result in any

difference in their HbA_{1c} levels up to 12 months after diagnosis (Davies MJ *et al*, 2008).

A previous similar study among Mexican Americans aimed at assessing the effectiveness of a culturally competent self-management education intervention. This study showed on the contrary significantly low levels of HbA_{1c} and fasting blood sugar at 6 months and at 12 months and a high diabetes knowledge score in the experimental group to the control group. However, the mean of HbA_{1c} level of the experimental group was still high. A close analysis to the study's results showed no clinically significant difference between the experimental and the control group. The HbA_{1c} remained over 10% despite their statistically significant improvement of 1.4% below the mean of the control group. Although the authors have concluded that the intervention was beneficial only for patients with an initial high HbA_{1c} levels, it does not provide a clinical significance as these levels remained far beyond the recommended preventive threshold (Brown SA, *et al*, 2002).

The UKDPS recommends a tight glycaemic control lowering the HbA_{1c} below 7% to prevent diabetes microvascular complications (UKDPS, 1998). Therefore achieving and maintaining clinically significant improvement in HbA_{1c} levels for any ethnic or racial group would require more comprehensive strategies rather than a unifocal educational intervention (Simmons D, 2001; Anderson D *et al*, 2006). These studies have highlighted that patients' practices, attitudes and behaviours are not solely influenced by a rational cognitive component alone.

A parallel with the recent HIV/AIDS pandemic illustrates eloquently the complexity of implementing policies and practices of HIV prevention strategies targeting health related behaviour at population level; therefore it is not a matter of educating the masses only. It was sufficiently demonstrated that this construct in the context of HIV prevention by exposing erroneous beliefs and the fallacies of the assumption that health education was merely a matter of identifying deficiencies and gaps in "people's knowledge" and addressing them with educational materials such as leaflets, teaching seminars, or mass media

programs (Airhinhenbuwa CO *et al*, 1992). International bodies and scientific authorities recommend that educational strategies rather be centralized on the cultural experience of the recipient to be successful (Airhinhenbuwa CO, 1995; WHO, 2007).

Nevertheless it is widely accepted that any adequately integrated diabetes educational program, will consequently result in improvements of patients' knowledge, attitudes and practices; therefore improve patients' skills, hence better disease control (Nicolucci A, 2000). Moreover for these educational programs to be effective there ought to be culturally sensitivity (Brown SA, *et al*, 2002; Rafigue G, 2006).

Associations that patients' education with family support as identification of complications and signs of hypo/hyperglycaemia should be known by both patient and family (Ogunbanjo GA, 2006).

A family physician should help the family through motivational interviews and family conference sessions to gain more insight acceptance of the illness, to regulate issues over family adjustment and coping mechanisms with the advent of chronic disease in the home that brings about changes in attitudes, behaviours and practices of family members. It is essential for the family physician to comprehend the broader cultural context of his practice population.

A better understanding of the context in which families are enmeshed will provide a useful background data for proper assessment and planning of culturally competent intervention strategies (Tripp-Reimer T *et al*, 2001; Brown SA *et al*, 2002).

The family as a whole must learn to appreciate the value of compliance to medication; dietary advice and all relevant recommendations about diabetes care despite either their collective or individual grounded health beliefs for the sake of the sufferer. Research on families and health demonstrated the powerful influence of the family on both health and illness.

2.6 LAY BELIEFS, ATTITUDES, BEHAVIOURS AND PRACTICES

Over decades researchers have sought to explain the phenomenon of non-adherence or compliance to standard medical regimen in diabetes. Despite numerous amounts of earlier studies conducted, researchers remained thwarted in their potential to understand and furnish a clear explanation of why between one-quarter and three-quarter of all patients do not follow medical recommendations (Haynes 1979).

The persistent and escalating tuberculosis in public health services during the first half of the 20th century in the United States of America led the federal government to involve leading social psychologist to investigate the phenomenon from a perspective that differed from the classic epidemiology and biomedical approach. Pioneer social psychologists endeavoured to understand the reasons behind the failure to a free tuberculosis screening services despite screening policies and preventative strategies implemented to curb down the epidemic. They developed a framework known as the *Health Belief Model* (HBM) which is a psychological model that attempted to explain and predict health behaviour by focusing on the attitudes and beliefs of individuals (Rosenstocks, Hochbaun & Kegels, 1966).

The HBM theory as evolved from the original constructs with the works. Subsequent to that emerged evidence to accommodate the role that knowledge and perceptions play in personal responsibility (Becker MH *at* al, 1975). It is argued that in those early research phases, the emphasis in many of these research approaches was focused on socio-demographic factors or psychosocial issues and has ignored the influential role of the explanatory model of illness or health beliefs (Schoenberg NE *et al*, 1998). On the contrary the well-known theory on health behaviour models such as Health Belief Model, Social Cognition Theory, and the theory of reasoned action (Ajzen I & Fishbein M, 1980).

All acknowledge that an individual's beliefs about illness undoubtedly influence his or her health behaviour (Schoenberg N E *et al*, 1998).

The theory of the HBM is based on the understanding that a patient or any person in general, will embark on health-related action plan in the context of the following assumptions:

- If that person feels that a negative health condition or outcome can be avoided,
- If that person has a positive expectation that by taking a recommended action, he/she will avoid the negative condition, and
- 3. If that person believes that he/she can successfully take a recommended health action.

These statements as originally constructed are summed into four constructs of the "core belief" of the individual, representing the "perceived threat" and the "net benefit", respectively: the perceived *susceptibility*, perceived *severity*, perceived *barriers* and perceived *benefit* (Rosenstocks, 1966).

- <u>Perceived susceptibility</u>: refers to the individual's assessment of the risk of him getting a condition.
- <u>Perceived severity</u>: refers to an individual's assessment of the seriousness of the condition and its potential consequences.
- <u>Perceived benefits</u>: refers to an individual's assessment of the positive consequences of taking action and adopting the behaviour.
- <u>Perceived barriers</u>: refers to an individual assessment of the influences that facilitates or discourages the adoption of the promoted behaviour.

The hallmark of the HBM conceptual model (see figure 3 below) is about how psychosocial, demographic and educational modifying factors interact with the

individual's_perception of his/her susceptibility of getting a disease and to develop a serious illness thereafter; hence the person comes to acknowledge the actual threat of the disease over his/her life. Thus, prompting decisive action plan for change.

INDIVIDUAL PERCEPTION MODIFYING FACTORS LIKELIHOOD OF ACTION Perceived benefits Age, sex, ethnicity Personality barriers to behavioural Socio-economics knowledge change Perceived susceptibility seriousness of disease Perceived threat of Likelihood of disease behaviour change Cue to action: 1.Education 2.Symptoms 3. Media information

Figure 3: HBM Conceptual Model

Sources: Glanz K et al, 2002

The likelihood of action that a person decides to carry out and change his/her behaviour has been found to be influenced by factors not accounted for in the original conceptual model proposed by Rosenstocks. The model was further developed by Becker and colleagues in the 70's and 80's. Subsequent amendments were made to include the *perceived costs* of adhering to the prescribed intervention as part of the "core beliefs" of the individual (Becker MH *et al*, 1975).

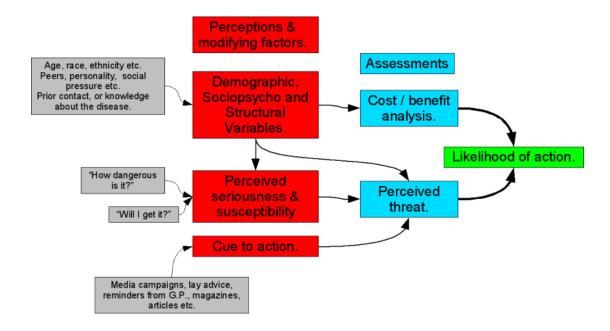
Constructs of mediating factors were also later added to connect the various types of perceptions described above with the predicted health behaviour.

Originally, the HBM theory was generated in order to predict patient's behavioural response to treatment regardless of the fact that the patient is

acutely or chronically ill; it is now used to predict a more general type of health behaviours. These added constructs as listed below were incorporated to the body of the conceptual model; they enable the model to predict in a more comprehensive approach the likelihood of the individual concerned to carry out the prescribed health action such as preventive and curative measures.

- Demographic variables (age, gender, ethnicity, occupation)
- Perceived efficacy (an individual's self-assessment of his/her ability to successfully adopt the desired behaviour)
- Socio-psychological variables (such as social economic status, personality, coping strategies)
- Cues to action (external influences promoting the desired behaviour, they
 may include information provided or sought, reminders by powerful others,
 persuasive communication, and personal experiences)
- Health motivation (individual driven to stick to a given health goal)
- Perceived control (a measure of level of self-efficacy)
- Perceived threat (whether the danger imposed by not undertaking a certain health action recommended is great).

The integrated HBM conceptual model is shown in the diagram below:



Sources: Health Belief Model-wikipedia (2009)

Health beliefs about diabetes from a marital perspective amongst middle-aged and older couples living with type 2 diabetes was shown that diabetes management is heavily influenced by the above mediating psychosocial factors such as diabetes beliefs and spousal beliefs in their particular research (Beverly EA *et* al, 2007).

Over the past decades a substantial body of evidence has emerged from empirical research examining patient's beliefs about illness and how these belief system influences their cognitive, emotional and behavioural responses to their condition (Searle A et al, 2008). Such investigations to be comprehensive have been guided by wide-ranging theoretical framework extending from social and behavioural medicine to psychology, anthropology, sociology and other social sciences. The most common theory approach being the "Common Sense Model of illness Behaviour" as developed in a handbook of psychology and health (Leventhal H et al, 1984) referred to as CSM hereafter.

Explanatory models of illness by Kleinman or CSM and Leventhal involve a profound comprehension of concepts such as symptom identifying and labelling for an individual or a particular ethnic group, their perspectives on origin, consequences of diseases, illness time-line and lay treatment strategies of diseases (Lau RR & Hartman KA, 1983).

The CSM hypothesizes that an individual experiencing an illness may perceive a range of problems that are pertinent only to that individual. In response to this interior conflict and in order to make sense of these problems patients create their own lay beliefs about their illness, which then influence their coping faculty and drives their care-seeking behaviour (Cameron L *et al*, 1993). It is relevant in this context to understand that lay beliefs can greatly differ from one individual to another based on their illness beliefs, experiences and practices (Skinner T C *et al*, 2001).

To understand illness beliefs better, it is proposed that an individual formulates his illness beliefs around five "core" dimensions regarding the following disease aspect: the *cause*, *control*, *timeline* (course of the disease), *consequences* and *identity* (the perceived symptoms) of the condition (Searle A *et al*, 2008). The *time-line* dimension is a measure of the perceived duration of the illness. The *consequence* dimension is a measure of the perceived impact that the illness has on a patient's life. The *control* dimension measures the patient's perceived control of their illness in two different sub-scales. Firstly the *treatment control* which measures the patient's perception that the treatment is effective in controlling the illness. Secondly the *personal control* sub-scale measures the patient's perceived efficacy in controlling their illness.

In a meta-analysis of studies adopting the CSM framework have concluded that a predictable relationship exists between illness beliefs, coping, and outcomes (Hagger MS & Orbell S, 2003). It is therefore believed that illness beliefs provide a coherent and empirical based framework for assessing patient's responses to their chronic diseases (Searle A *et al*, 2008).

Investigations conducted in the context of diabetes have showed that *control* beliefs have been shown to be more important in predicting self-management behaviour, including exercises and diet (Griva K *et al*, 2000) as well as clinic attendance (Lawson VL *et al*, 2004).

It was also shown that key self-management behaviour in diabetes was particularly associated with beliefs regarding *treatment* and *control* of the condition (Skinner TC *et al*, 2002). In a study exploring foot ulceration and retinopathy complications in diabetes, differences were also found in diabetic patient's beliefs according to their complications (Searle A *et al*, 2008).

The assessment of these illness beliefs is done by means of tested questionnaires such as the *Illness Perception Questionnaire* and others, *designed* to assess patient's beliefs about a particular condition by exploring the above dimensions (Moss-Morris *et al.*, 2002). This assessment merely serves to

predict the patient's attitude and subsequent behaviour towards the prescribed medication, the recommended lifestyle modification and health related behavioural change to carry out for a sustained illness management. From a patient's perspective the definition of illness in this context would be a perception that he/she has of the condition at hand, which is part of a belief system and is undoubtedly largely determined by cultural factors (Searle A *et al*, 2008). It has been unquestionably demonstrated that these cultural factors mediate ways in which symptoms are identified and interpreted in any ethnic group (Tripp-Reimer T *et al*, 2001).

Ethnic characteristics such as values, beliefs, customs, and family patterns are therefore important in gathering information about an individual affected by a chronic illness. For example, research on adolescent diabetic patients has demonstrated that the family environment may influence the development of their illness beliefs (Skinner TC *et al*, 2001).

Ethnicity is a critical variable in how people with diabetes are perceived and treated by their family and how their family in turn is viewed by the community at large as part of a macroscopic belief system.

Lay beliefs appears to be of tremendous significance in any given ethnic group or cultural system and they have a major impact on how an individual views his or her presenting medical condition, hence his/her care-seeking behaviour and lastly how the physicians manage it (Mhlongo SWP, 2002). Similar investigations on hypertensive patients have shown that individual beliefs on high blood pressure have been linked to compliance and blood pressure control (Blumhagen D, 1980).

In view of the significant role that lay beliefs play in a person's response to an acute or chronic illness as demonstrated in the above paragraph; it is critical to consider that beliefs are part of the fabric of a society, they stem out of a cultural system that moulds and shapes our social behaviour. A cultural assessment of any community would help family physicians to gain a better understanding of the

prominent lay health beliefs and endeavour to deliver an appropriate culturally sensitive and competent diabetic care plan (Brown SA, et al, 2001; WHO, 2007).

2.7 CULTURE AND BELIEFS BARRIERS IN DIABETIC CARE

Culture is a very broad concept that is defined as a set of beliefs, values, artistic, historical, religious characteristics, customs, etc common to a community or a nation (Stetman, 2001). In Collins (2001), culture is described as a "total of the inherited ideas, beliefs, values and knowledge, which constitute the shared basis of social action." It is "a total range of activities and ideas of a people, a particular civilization at a particular period.' Furthermore it is also defined as "the attitudes and general behaviour of a particular social group or profession." From these elaborated definitions, culture may be seen as a concept that encompasses all attributes and attitudes that defines who we are and how we relate and interact as individuals, from the perspective of the nuclear family setting to the world and the universe at large.

Throughout centuries of patient care in general and particularly in diabetes management, the need to consider cultural factors in the care of people living with this condition has been identified for years regardless of their origin (Tripp-Reimer T *et al*, 2001).

Common health beliefs and behaviour can be found across different ethnic groups. For example, it is common that health is seen as a state of equilibrium, and illness caused by either excess or deficiencies. Diabetes is often believed to be caused by excessive ingestion of sugar or sweets in turn brought on by stress or worry of some sort of internal imbalance, or a form of punishment for immoral behaviour (Tripp-Reimer T *et al*, 2001).

Cultural beliefs can be a barrier to effective diabetic care as they greatly influence the perceptions of patient's body image, value system, symptom identification, and interpretation in response to an acute or chronic body dysfunction, hence the subsequent care seeking behaviour that they would

embark on (van Houtum WH, 2005). For example a heavier body is indicative of health and happiness amongst some Native American tribes: Navajo and Ute's in (Tom-Orme L, 1993). Some Chinese perceive extra weight as a sign of blessing related to wealth and prosperity (Wong C, 1992). The Native American Indians as reported by Hickey would often judge the severity of an illness by the amount of pain, disability, and discomfort it inflicts on a person (Hickey ME & Carter JS, 1993). Hence, anything asymptomatic such as the first asymptomatic years of type 2 diabetes, would often not be of concern, remain hidden, unnoticed and will evolve leaving ravaging damages of chronic untreated hyperglycaemia.

Patient's illness beliefs would determine his/her first therapeutic decision in the advent of a disease. In South Africa many people turn to the skills of traditional medicine to treat their chronic conditions (Maduna PMH, 2006). Amongst the rural Zulu people it was shown that out of ten patients would first consult a traditional healer before they attend any medical facility (Clarke E, 1998). Therefore the use of herbal medicine and alternative remedies is very popular in this part of Southern Africa (WHO 2001).

Another researcher has described some of the most popular African herbal remedies used for diabetes namely the Aloe ferox know as "*Ikhala*" and the popular African potato "*Ikomfe*" (Maduna PMH, 2006). Herbal medicines are also widely used in Southwest America and Mexico especially those known with hypoglycaemic activity (Tripp-Reimer T *et al*, 2001). Globally as reported by the World Health Organization (WHO, 2001), the lack of evidence and the hypoglycaemic risk of some herbal remedies remain a challenge for all health care providers (WHO, 2001; Ernst E, 2002; Gardiner P *et al*, 2008).

Religion and spiritual beliefs are an important aspect of life and people's culture as a regulator of social norms in the community. For example, in some religious communities namely; Jewish, Moslem or Hindus their food patterns are determined by what their respective creeds and doctrines prescribe (Tripp-Reimer T *et al*, 2001).

Spiritual issues are a key aspect that significantly influences people's care seeking patterns and their social behaviour. In a study conducted in America, Missouri 96% of family physicians considered spiritual well-being as important to health (Ellis MR *et al*, 1999). Nevertheless, it is not an easy topic to embark upon with most patients, often seen as an invasion of the patient's privacy (Ellis MR *et al*, 2004). However, cultural barriers to appropriate diabetic care should not be seen as a patient driven factor only as pointed out in an his article on personal barriers to diabetes care (Simmons D, 2001).

The biomedical culture trough which medical care is delivered is also a set of values, beliefs, norms, and patterns of behaviours that health care providers have learned, acquired, and abide by as a profession (Tripper-Reimer T *et al*, 2001, Simmons D, 2001). Quite often there are substantial discrepancies in these values, norms, and beliefs, and behaviours from the biomedical culture that stands in conflict with one's very own cultural identity. Studies on ethnic minorities, immigrants, and religious groups such British-Bangladeshi, Mexican-American, African-Caribbean are eloquent examples of these cultural discrepancies (Brown K, et al, 2007).

A barrier may be seen in this context as anything that is hindering access to proper diabetic care. From the health care provider perspective, their values, behaviours, and beliefs inherited from the health care system, and from the biomedical culture constitute what Tripp-Reimer calls "practitioner barrier" to care in this instance. She gives a non-exhaustive list of beliefs and skills that we need to respectively do away with and inculcate in order to provide culturally competent care. For example:

- Biomedical medicine is always right,
- Patients who do not practice prescribed health behaviour do not care about their health,
- Traditional beliefs should be changed rather built upon. (Tripper-Reimer T et al, 2001)

Beliefs in minority communities for instance as among the Hmong immigrants from Asia, where they often discuss beliefs about a potential health problem before it occurs drastically increases its likelihood. Such lay beliefs can be detrimental for preventable diseases and particularly for any person potentially at risk of developing diabetes by hindering preventative screening measures and implementing health promotion practices.

Patient's beliefs in the context of their culture will affect their health beliefs and behaviours, their illness beliefs and practices, as well as their dietary beliefs and practices (Bolt L & Bolt C, 1995).

Nevertheless, it is acknowledged that numerous barriers to the implementation of universal good-care exists across all communities, involving attitudes and beliefs of doctors, other health professionals, and patients, and the structure of the health care system itself (van Houtum WH, 2005). Tripp-Reimer T (1999) in her sturdy critical analysis of the American health system says how it is exceptionally difficult to describe or comprehend the extent to which ethnocentrism and racism have been woven into the fabrics of their health care system. The legacy of the apartheid era in our current health system in South Africa would be a similar situation where institutionalized health inequalities prevailed on racial and ethnic differences as elaborated by Gilbert and colleagues in health South Africa (Gilbert L *et al.*, 1996).

The uniqueness of the South African multiracial and multicultural heritage will require as highlighted in this section a diverse strategic approach in planning for a comprehensive diabetic care program. Clearly in the South African post apartheid context a cultural sensitive diabetic program would have to be as diverse and cultural specific as possible while avoiding cultural stereotypes and victim blaming and concepts like ethnic or culture supremacy as imposed in the past; ignoring the significant influential role of people's culture and lay beliefs in their health decisions and subsequent behaviour (Helman CG, 2001).

2.8 CONCLUSION

Thousands of researches on lay beliefs across various ethnic groups, minorities and immigrants, indigenous and religious communities have been conducted; all concluding that any intervention to be effective must acknowledge lay beliefs of the recipients and be culturally sensitive and competent as recommended by the World Heath Organization (WHO/AFR/RC, 2007).

For most ethnic minority groups, discussion around cultural dynamics in health care in general and particularly access to proper diabetic care is a very complex matter. This debate cannot take place without consideration of the ways in which culture enmeshes with issues of poverty and equity, individual and/or institutional racism, and lack of cultural competence of health programs and health providers (Tripper-Reimer T *et al*, 2001).

Multidisciplinary and multisectorial approaches are indispensable to the prevention and control of diabetes. In Africa they constitute the cornerstone of interventions which should focus on the patient and the community, within the framework of primary health care (WHO 2007).

CHAPTER 3

METHODS

3.1 INTRODUCTION

The researcher describes in this chapter the methods applied in this research. It was an exploratory study from a qualitative perspective using free attitude interviews as a data collection technique.

3.2 AIM & OBJECTIVES

3.2.1 Aim

The aim of the study was to explore the lay beliefs of type 2 diabetic patients seen at Prince Mshiyeni Memorial Hospital.

3.2.2 Objectives

The objectives of the study were as follows:

- 1. To understand lay beliefs of effective life long management of type 2 diabetes patients.
- 2. To make recommendations of improving management of type 2 diabetes in conjunction with the findings of the study.

3.3 STUDY DESIGN

3.3.1 Definition

Hoepfl (1997) defines qualitative research to be any sort of research that produces findings not arrived at by means of statistical procedures or other means of quantification.

Qualitative research studies phenomena in their natural settings; they attempt to describe and make sense of, or interpret phenomena in terms of the meanings people bring to them. Therefore it is seen as both inductive and naturalistic (Wood 1992).

In qualitative studies the researcher is interested in exploring and creating new ways of thinking about things or the matter at hand. The assumption here in this approach is that a better understanding or an improved knowledge of the phenomenon at hand would lead to the development and alternative perspective about the phenomenon thus, generating new theories about what is happening. The definition by Britten et al (1995) corroborates the above construct. She defines qualitative research as a "multi-method in focus, involving an interpretative, naturalistic approach to its subject matter"

The investigative method in this study was a descriptive qualitative study using free attitude interviews. The application of such a qualitative inquiry was most appropriate as we were interested in the beliefs, experiences, actions and behaviours of our diabetic patients.

Reid (1996) has stipulated that qualitative methods are the best study designs to explain beliefs of participants through exploratory methods and that they are the most suitable study approach to provide a basic understanding of an under explored and poorly understood complex situation.

3.4 METHODS

3.4.1 Study population

The study population comprised of all patients diagnosed with type 2 diabetes of 40 years of age or more attending our diabetic chronic clinic at Prince Mshiyeni Memorial Hospital (known as PMMH hereafter).

The research team (researcher and research assistant (A)) was assisted in the selection of "key informant" participants in the selection of the study population by the professional nurse in charge of the diabetic chronic clinic at PMMH, Sister Bhengu.

3.4.2 Sampling

Sample selection was purposive, participants in this method are deliberately chosen based on their capacity of being articulate and able to provide appropriate information - "key informants" (Patton M Q 1990, Reid AJ 1996) A total sample of 10 participants was interviewed. Identification criteria for participants were as follows:

1. Inclusive criteria:

- age of ≥ 40
- diagnosed with type 2 diabetes for ≥ 18 months
- attending the PMMH diabetic chronic clinic
- Volunteer to participate in the study

For all interviewees, maximum variation was by sex, occupation and level of education.

2. Exclusive criteria:

- patient who did no agree to participate
- patients with other chronic co-morbid diseases

3.5 DATA COLLECTION

In the qualitative research approach more than one method of data collection can be used simultaneously, thus increasing the confidence in the credibility and accuracy of data gathered; Hence, the validity of the study (Wood 1992, Reid 1996).

The researcher attended two different research training sessions at the Department of Family Medicine & PHC IN March 2005 and September 2007 respectively.

Free attitude interviews were conducted for data collection in the language of choice of the participant, in this study they were all conducted in IsiZulu. The researcher was assisted in this copious task by two assistants (A) and (B) who constituted the research team.

Research assistant (A) NH Malete is a professional nurse with extensive training and experience in qualitative research which is her field of expertise. She was involved from the preliminary stage of this project up to the completion phase. Her assessment of the pilot study was of paramount contribution in improving the further quality of data collection in the main research. Research assistant (B) Miss Omelga Mathiyane an IsiZulu speaking qualified professional journalist who assisted with professional equipment and skills for recording, verbatim transcription and translation from IsiZulu to English of all the interviews in the main study.

3.5.1 Pilot study

A pilot study was conducted prior to the commencement of the actual study where the researcher and Sister Bhengu interviewed purposively selected three diabetic patients fulfilling the inclusion criteria.

The pilot study afforded the researcher a crucial opportunity to test the following:

- The exploratory question whether it was understandable and easy to stimulate a fruitful discussion,
- To test time management during the interview process

These interviews were not included in the main study

3.5.2 Exploratory question

The exploratory question which was asked and discussed in each interview was the following in English: "What are your lay beliefs about the management of your illness?"

As most of the respondents were more comfortable in expressing their views in their local language IsiZulu, the exploratory question was administered in their vernacular as follows: "Sicela usichazele ukuthi ngokwenkolelo yakho, isifo lesi onaso singelapheka kanjani?"

3.5.3 Method of data collection

On the day set for interviews Sister Bhengu identified patients who were willing to participate in the study who qualified according to the inclusion criteria and had been diagnosed with Type 2 diabetes. Once agreement was reached the participant was explained what the research was about by the research team prior to signing the consent form and demographic data form (appendix 2). The participant was then moved to a more quiet side room for the actual interview. Research Assistant (A) was the moderator; she facilitated all interviews in IsiZulu while the researcher took field notes and closely observed the interview process.

The interview began with the above mentioned exploratory question in IsiZulu, the participants preferred language. Research Assistant (A) used reflective summaries and requested for clarification where necessary to facilitate all interviews. The researcher recorded noticeable non-verbal events and salient body language in the field notes (Lofland and Lofland 1984)

The interviews lasted approximately 30 – 45 minutes. The research team and the interviewees were seated in a triangular setting, in a quiet, friendly and conducive environment for such interviews without no external interference and distractions.

All tapes and corresponding field notes were labelled with the same code used on the consent and demographic form to avoid mixing of data.

The researcher also made use of a research diary for purposes of reflection during the research process.

Finally, all these data simultaneously gathered were integrated in a single model at the end of each interview as recommended by (Krueger, 1994). The research team had a debriefing session where they ascertained the quality and integrity of data collected.

3.6 DATA ANALYSIS

Thematic analysis was the method used for data analysis in this research project. This particular method describes the specific and distinctive meaning, characteristic, quality and the very subject of discourse or concerns expressed by the interviewees.

During the interview process a sequential analysis was used to enable the research team to ascertain when saturation had been reached. The content of the data gathered in the form of audiotapes, transcripts, observational field notes were systematically scrutinized, compiled and coded. As salient themes emerged these where then grouped into "colour coded" categories (Wood 1992, Krueger 1994).

The research team did a manual data analysis by the "cut and paste" technique of key-words, phrases and quotes after dividing them into themes, sub-themes and then assigned to relevant categories as recommended. (Mac Millan *et al*, 1993, Krueger 1994)

The researcher sought to corroborate the manually generated findings by processing all the integrated transcripts on computer-based software to further

validate the power of their findings. The computer program, N Vivo 8, was purchased via internet via Google web site.

Valuable findings were added and in some instances wording conciliated after member checks and integrated into the final body of constructs.

3.8 RELIABILITY & VALIDITY

In qualitative research a study is evaluated differently from quantitative research. Their criteria are different. A qualitative study is deemed trustworthy when the researcher has proven to maximize critical aspects of the study such as its credibility, reliability, validity, transferability etc.

The researcher has responded to this requirement by ensuring that the following steps were taken:

- Mechanization Audio tape recording of all interviews was done
- <u>Triangulation</u> More than one source of data was used (audio tapes, field notes and researcher diary)
- Respondent validation Interviewees validated the fidelity of transcripts
- Peer debriefing The researcher was interviewed by his academic and research supervisors along the research process and spot checking done to ensure conformability to approved protocol and other technicalities.
- Peer review feed back and input by colleague involved in research and similar study was done.

3.9 **BIAS**

Bias can be defined as any effect that at any stage of a research process or any other inferences that tend to produce results that depart systematically from the true value (Ogunbanjo 2001).

The research team minimized bias in this study by doing the following:

- To minimize <u>interview bias</u>, interviews were conducted by research assistant (A) who never interacted with any of the participants before.
- Selection bias partly inevitable due to purposive sampling nature was minimized by interviewing respondent only known to be a key informant and to actively participate in the discussion.
- Sampling bias was reduced by abiding to quota sampling principles therefore these conclusions cannot be generalized but only transferable to a similar context (Hamberg et al 1994)
- Interpretation bias can occur when the researcher omits interpreting all facts or to consider all aspects of the results leading to interpretation error. The researcher attempted to reduce this type of bias by diversifying the team by including research assistant (B) who shared the cultural background of all participants. She translated the verbatim transcriptions from vernacular to English. Reliability and validity requirement reduces this type of bias.

3.10 ETHICAL CONSIDERATIONS

The Family Medicine Departmental Research Committee granted the researcher permission to conduct this study. The University Research Ethics and

Publications Committee at Medunsa thereafter approved the research proposal and granted authorization for the study, a clearance certificate was issued under the following project number MP 37/2006 (appendix 3).

The hospital's Research and Ethics Committee gave permission to conduct interviews on patients seen on the hospital premises.

A written informed consent was obtained from each interviewee prior to all interviews using the Medunsa Consent Form (appendix 4). Prior to the actual interview a demographic questionnaire was completed; ethnicity, literacy background, occupation, medical history, life style, etc. The confidentiality of information was ensured by attributing an identification code number to each participant's demographic questionnaire and thus keeping all data safe.

CHAPTER 4

RESULTS

INTRODUCTION

In this chapter the researcher presents an analytic interpretation of the respondents' accounts of their lay beliefs about diabetes. The transcripts presented in italic below are quotes from the respondents' narration in support of themes emerging.

In this section interviews will be presented individually; thereafter an integration of themes will conclude the chapter with a combined thematic analysis of salient constructs that would have emerged from the interpretative data analysis.

INDIVIDUAL INTERVIEWS

INTERVIEW 1

Respondent's Profile

Mrs. N a 41 years old African female a resilient and honest person. Poor, uneducated single mother of five children who is living on government child grant allocated for her last two children. She collects around R190 per child per month. She was diagnosed with diabetes in 1999.

She gladly volunteered to be interviewed. She was comfortable, expressed herself well, she laughed at times and kept an appropriate body language.

A good reflective summary and clarification allowed the interview to progress and explore her perspective and beliefs about the subject at hand.

4.1 Lay Beliefs about diabetes

For Mrs. N leaving with diabetes was a very challenging situation given that she was poor. Her beliefs seem to stem from her own experience with regards to the effectiveness of life style modification measures and the use of the prescribed "western medicine". Interestingly, it transpired that her behaviour in managing diabetes and her therapeutic choices were strongly influenced by two major factors: her unfortunate poor situation and her spiritual beliefs.

She furnished sufficient information with regards to her beliefs around psychosocial factors and their influence on diabetes.

The following themes emerged from this interview:

4.1.1. Drinking water

She elaborated on how she often gets tempted to eat sweet stuff and cheats a lot on her prescribed diet; but she had a belief that drinking a lot of water stabilizes her blood sugar level.

"My sister in law who is a nurse suggested that since I get tempted I should stay away from sweet stuff; once I have indulged, it's good to drink a lot of water".

4.1.1.1 Purpose of drinking water

The reason she gave was that when she drinks water it stabilizes her blood therefore; sugar will not go high but remain low. She was advised to do so as she often gets tempted and fails to refrain from "sweet stuff".

"She said once I've drank water, the blood stabilizes; sugar won't go high but low. So every time I pinch I go and drink a lot of water".

4.1.2. Wrong Food

She acknowledged that she is guilty of eating wrong food, and believes that it is the cause of her poor sugar control.

"I get tempted, I'm struggling with that. I can resist but once I see someone else purchasing and eating food, this type of food I can't resist it. I just say let me steal a bit. But once I steal a bit it becomes my problem.

I don't know, like I said, I indulge in wrong food, so I might be wrong there, I might be wrong in a sense that I pinch, still eating the wrong stuff, I don't listen".

4.1.3. Drinking bitter stuff.

She elaborated on the use of alternative remedies for diabetes by sharing her beliefs about drinking bitter herbal mixture. "I don't know anything but I hear some say it's better to get some of the bitter stuff".

4.1.3.1. Effect of the bitter stuff

Her beliefs in this regard was that sugar fears "bitter stuff" or bitter concoctions therefore sugar in the blood will get what she called "a fright" and the levels will not go high. Despite this belief, she did not try herself for two reasons: poverty and fear of a bitter taste. She said she failed every time she wanted to try.

"They say you must drink bitter stuff, maybe so that the sugar will get a fright, but I dread anything bitter. I never purchased the bitter stuff maybe it's because I'm poor and can't afford a bottle, I don't know how to use it, when I try I fail.

They say sugar fears bitter stuff, but I never tried the bitter stuff."

4.1.4. Stress and emotional conflicts raises sugar levels

She briefly recounted under what stressful circumstances she found herself while trying to make some money by selling some goods and how her sugar level shoots up when she is anxious or when she had gone through a panic event. Her belief was that being in this state of being constantly strained and stressed out raises her blood sugar levels.

"I don't know; when I am working I get anxious and then I panic.

I panic and sugar level goes up and I get confused on what's happening".

"...Maybe the reason why my sugar levels are high is because inside I'm having many problems in my life".

4.1.4.1 Cause of her stress

She describes herself as a struggling person who is constantly thinking on how to meet her daily survival needs. "...so about work, I try to put together small things and sell them at home. If I try to work I get tired on my knees, my feet, I fail to stand on my feet, and I get partially blind. If they (church people) come to my home, I don't have much;...see, I will offer you what I have at that particular time if there is anything, but there isn't because I don't have anyone supporting me. I'm usually a struggling person without anything, so I won't have a significant name, I'll stay just Ntombi".

4.1.5. Lack of Money

It appeared that she was a destitute person who wanted nothing more then to be helped by all means. She went to the extent of blaming the government for granting an insufficient child care grant.

Her belief about wealth was that if she was not as poor as she is, she would have lived a life peacefully in her soul that her sugar levels would be low.

"Yes I come to hospital; I don't miss my doctor's appointments. It's just that he (the doctor) doesn't want to give me some money, just a little to help me, just something for transport.

The government must provide, it's a problem since I'm unemployed...I'm poor, my Lord, maybe if I would be provided then my soul will rest and maybe my sugar levels will decrease".

4.1.6. Prayers Helps.

She had expressed her religious beliefs ambivalently. Although she believes that people do get help by prayer, she seams to exclude herself from those who would benefit from prayer because of her lack of patience.

"Yes, they pray for you, there is an open session for all those who are sick, some have BP only, some only arthritis, others both BP and diabetes.

No, they mix, all those who are sick.

People do get help.

My diabetes is not as bad as it was before. It's possible that I'm also healed; it's just that I want to see the results now, I'm impatient. Yes, maybe my problem is that I'm not patient enough for the healing process. I want to see speedy results".

4.1.7. It is better to loose weight

She had unquestionably experienced the benefit of shedding weight and her beliefs in this regard were very favourable for loosing weight.

"I saw its better I loose weight, ever since I lost some, I saw some difference.

When I was bigger my body took a lot of strain, it was heavy. Even if I think of
doing some work I would hesitate because I'll be thinking it will be strenuous...

It's not the same, its better, before when it was heavy, I would feel hot
everywhere, including under my breasts, but I'm better now".

Conclusion

Mrs. N shared her experience of leaving with diabetes as a very poor woman under difficult circumstances. Her beliefs on diabetes resulted from her own on life style modification measures and in the use of modern medications. It had transpired that her choices were strongly influenced by two major factors: her lack of money and her religious beliefs. She made a controversial statement when she pointed the fact that although her religious beliefs discourage her to use traditional medicine, she knows from hearsay that "sugar frightens the bitter stuff". Nevertheless, she never tried because she was so poor that she could not afford to buy the "bottle".

INTERVIEW 2

Respondent's Profile

Mrs. M a 51 year old married African woman, diagnosed with diabetes during a pregnancy in 1992. She was keen to participate in this interview and freely expressed her deepest feelings and concerns; literally an expression of grief was displayed at times.

She was not sure what to say from the start but she was very emotional about her personal experience of living with diabetes, she was weeping during the interview. Her opening statement was that she gets worried that she will die and leave her children alone. This lady was still haunted by the death of her beloved father who was diabetic.

Lay beliefs about diabetes

Mrs. M elaborated extensively on her most troubling symptoms, her beliefs and behaviour with regards to alternative remedies. She made an amazing parallel of diabetes and HIV. She cried about life for about a week at the diagnosis of diabetes as an immediate death sentence. She eventually adjusted her life over the past 15 years of leaving with this "HIV-like" disease. Her current daily struggle is with the visual complications and libidinal symptoms. Having a supportive church fellowship and an understanding partner eases her burden although the nagging reality of loosing her sight and the relationship strain remain her daily yoke.

The following themes emerged from this interview:

4.2.1. Alternative medicines are worth trying

She elaborated on her beliefs about diabetes by sharing with us how diabetes has affected intimacy in her marriage then she mentioned that despite the hope she has in her prayers for divine healing for such an incapacitating condition; she believes that she might try the common traditional remedies used for diabetes. "I get tired; when I'm in church I ask God to help me. I hope that one day I will get healed from diabetes. I have a belief that I should maybe try to treat it with traditional herbs".

4.2.1.1. Reasons for seeking alternative remedies

She sought alternative remedies for the reason she gave in her opening statement; fear of dying, eye symptoms, loss of libido with all the strain on her marriage. She said: "I usually get worried that I will die soon and leave my children behind. But I think my diabetes is not severe, it's just badly affecting my eyes. The main problem is that I can't entertain my husband, that's how it troubles me". "I usually get worried that I will die soon and leave my children behind"

4.2.1.2 Eye complications

The impairment of her sight was of great concern, as it affected her ability to do house work like thread a needle. This disabling complication really affected her. "I don't see much difference, and my eyes are getting worse.

They are really troubling me. The doctor gave me some treatment... and they gave me another appointment. I'm going there. Now I can't even work I'm not able to work at all because when I try to thread the needle, I can't see it. These are sunglasses. When there is light I get this powdery feeling in my eyes. I don't have spectacles yet, the doctor is still organizing them, and he said he can't

give me yet because my eyes are bleeding inside. He said I don't need them yet since I'm still bleeding, so he is still treating me.

On my appointments at St Aiden's Hospital (specialized hospital in Durban), they put me in this kind of machines for check ups. There is water that comes out of my eyes, but now this one is totally blind. When I close this one everything is totally dark. Yes my major problem is my eyes and that I get tired. Sometimes my body gets so tired I can't even do anything".

4.2.1.3 I cannot entertain my husband; I get tired in my blood

Her genital symptoms had caused strain in her relationship with regards to intimacy; she was feeling the distance between them and resorted to use alternative medicine to find a solution to the problem. She had a belief that the concoction would help in this regard. She elaborated on her belief about blood dysfunction when she said I get tired in my blood to express the reason why she does not enjoy intercourse with her husband anymore and to explain her menstruation problem. She had and understanding partner who was supportive in this matter.

"The main problem is that I can't entertain my husband, that's how it troubles me.

...I can't enjoy with my husband. Yes, I feel the distance between us.

I get tired, I get tired, tired in my blood.

I was really struggling with diabetes, after drinking it I got better.

Even the itchiness from my private part is gone; but the business with my husband, It's still a problem. It's a problem but he understands that I'm diabetic. It is not that much, except when he is drunk. It's a problem but I don't deny him, you know men, but I don't get excited, maybe it's because I'm 50 years old, my blood is tired and dysfunctional, that's what I think".

I don't get my period as well, yes I thought that's why I can't entertain my husband, I just think it's not just diabetes but also that I'm old".

4.2.2. The bitter concoction decreases sugar levels

Initially she presented this statement as a lay belief based on anecdotal evidence that she believed by hear say - "what people say"; then she started relating this belief to her personal daily experience as a diabetic patient. She specifically mentioned a mixture of leaves from some known medicinal herbs in the community and the famous "bitter bottle".

She elaborated on how the concoction is made and her personal experience of drinking the prescribed bitter herbal concoction. "They say it decreases the levels of diabetes...it decreases...

But others say if you take them after meals; you will get healed. I notice that if I am using it (Imbiza, the concoction from Jenna the herbalist) I am better by the time I get here... (at the hospital)

...It's this traditional crushed medicines that are mixed leaves called "Zambane" (African Potatoes), the "Ntshungu", then we also buy the bitter bottle from Jenna...

... I'm not sure of other ingredients, a mixture of green bitter leaves. She cooks it together, then people buy it and put in "Izipakupaku" (containers); it's a 5 litres or 2 litres container. I usually buy 2 litters maybe twice a month. I drink half in the morning and another half a cup in the afternoon".

4.2.3. Traditional versus Modern treatment

She attempted to compare alternative or traditional medicine to the western way of managing diabetes by presenting her own paradoxal perspective in order to justify her beliefs and subsequent therapeutic choices.

Her final take was that they complement each other in achieving diabetes control and improving symptoms. "They say the traditional crushed medicine decreases the levels of diabetes... I drink half in the morning and another half a cup in the afternoon. ...Others say it heals if you are persistent. But I like taking pills. Yes, the pills from here, at the hospital.

I take them frequently, because I take the concoction early in the morning. When I get to work I eat and then take them (diabetic tablets) around 09H00.

I also take it (Imbiza) first thing when I get home in the afternoon, and take more pills after supper.

...Yes, it works together. "Imbiza", it brings it down (the sugar level)...I was really struggling with diabetes, after drinking it I got better. Even itchiness is gone from my private parts".

4.2.4. Diabetes is like HIV

She gave an interesting parallel of these two conditions based on what she knew and believed about incurable conditions. "When I found out I've got diabetes I got sick and stressed out like a person who just got the results of an HIV positive status.

I cried the whole week thinking that I was going to die the following morning. In the hospital I was told that if I take my pills I will be fine, I won't die tomorrow. I have diabetes and my father died from it as well. I had no hope of living; I see it's been 15 years since living with diabetes, and I comfort myself with that. It scares me that HIV/AIDS is the same with diabetes"

4.2.4.1. Why HIV is like Diabetes

At the time of her diagnosis she said she was stressed out like a person who got an HIV positive result. This implied that her belief was that diabetes was incurable as HIV. But she believed that it is because the wounds in diabetic patients do not heal like sores in HIV patients.

"It scares me that HIV/AIDS is the same with diabetes...That's because they say when you get a sore it doesn't heal. I once got injured but the wound healed".

4.2.5. Eat right food and loose weight

Having been diagnosed with diabetes for 15 years, she strongly believes in eating the correct diet and not gaining weight as recommended by the doctor. "I eat food with no sugar, and boiled veggies, I also eat tripe, because I don't eat red meat, I don't buy it anymore. I eat fish and chicken; I buy vegetables and prepare them without oil and a little bit of salt. The Doctor encourages us to slim not to get fat…and, yes it helps, indeed".

Conclusion

Mrs. N shared her gave her experience of leaving with diabetes under very challenging circumstances. Her beliefs were over 15 years leaving with diabetes by life style modification measures and the use of modern medicine, within her cultural context. Her apparent controversial statement with regards to the combined usage of both traditional herbal medicine and diabetic medication was very informative of the behaviour pattern that we did not know from our patients. Her beliefs around HIV and diabetes, the reason of poor sugar control and blood dysfunction in relation to lack of libido were pertinent.

4.2.3 INTERVIEW 3

Respondent Profile

Miss J M 42 year old single mother who works in a child day care centre was diagnosed with diabetes in 2004, more than two years ago. She was very keen to participate in the interview; she openly expressed her experience of struggling with this condition.

Her initial symptoms were ocular and genital itchiness. She was in denial for a long time. Her opening statement was that she knows that she is suffering from diabetes and that her eyes will be affected and that she might even suffer a stroke. She was poorly controlled on oral agents until she almost became "blind".

Lay beliefs about diabetes

Ms J M presented a typical case of psychological reaction to a frightful chronic disease. Denial were highly prominent in her case, this had delayed her from seeking medical attention at an early stage of her symptoms.

She had elaborated a fair account of her beliefs with regards to how one's emotional status and stress levels could influence their blood sugar level.

The following emerged from this interview:

4.3.1. Body injuries could raise your sugar levels

She attempted to explain what beliefs she has regarding what she sees as the root cause of her unstable sugar levels. She said she thinks that it is related to that incident that occurred at work.

"With the injection it was slowly coming down, but it went up last month. But I think it's because I fell and broke my leg, I think it was caused by that, it went up

to 20. It's normalizing again now after I broke my leg at work, the following day I was supposed to come here for my treatment".

4.3.2. Stress and Sadness raises sugar levels

She did not have much to share her beliefs about how her emotional status and stress influence diabetes. "They say if you sad...! was sad.

- ... They say if you are stressing it goes up (blood sugar levels).
- ...Because if you become emotionally unwell, your sugar will go up".

4.3.3. Prayer Helps

She stated that she is a child of God (Christian) and does not believe in traditions and she knows that God can heal her but she has not experienced that divine healing herself. She elaborates nevertheless how by faith in God she could be healed. He helps by solving your problems and taking away your load and burdens, hence no stress and the sugar levels become normal.

"I'm a child of God, I don't believe in traditions. They say tell God about your problems, God will heal you. Yes, in my case not with diabetes, I haven't seen anything, but with other things like emotional issues He helps you...Yes ...What can I say? It happens, there was this person I had a problem with, we took each other to court...

God takes your load, that's when I discovered. I went to court and just sat, and the prosecutor did all the talking on my behalf. It was solved. I just sat and didn't talk, it just happened, they were talking. So in those difficult times I had... the sugar? It was normal".

4.3.4. Stay on right diet, but diabetes will progress

She strongly believes in complying with the right diet, but also showed a belief that the disease will still progress to worse symptoms.

"I know I have diabetes. I know my eyes will be affected and other things like stroke. I try my best to eat boiled foods, and stay on the right diet.

I eat lettuce, cucumber, I eat greens and boiled cabbage, I add veggies and I eat meat. When I eat red meat I cut out fats and add soup and add veggies, I do the same with the chicken, I remove the skin then boil it".

Conclusion

Mrs. J M was very knowledgeable about her condition and diabetes related complications. Her beliefs about physical and emotional stress were clearly expressed. She was determined to do her best to manage her life by keeping the prescribed recommendations despite the progressive nature of diabetes. She believes that one day she will be healed as she is a child of God, but this has not yet happened to her.

INTERVIEW 4

Respondent Profile

Mr. D is a 40 years old male leaving with girlfriend unemployed with 2 children who was diagnosed with diabetes more than one year ago.

He was comfortable, speaking freely. He is a young adult occasionally attending his church; he did not believe in prayers and had doubt in African traditions including herbal medicines.

He was literally worried about his initial symptoms of polyuria as he was urinating so frequently.

Lay beliefs about diabetes

Mr. D in this interview elaborated about his beliefs with regard to his trust in modern medicine, his state of spiritual beliefs, and how he believes diabetes can cause one to die from it.

The following themes emerged from this interview:

4.4.1. No need to go there

His had a very strong belief in the prescribed modern medicine that he is taking. He did not see the need to embark on any traditional therapy despite all what people say and all the advertisements in the public broadcast channels as his symptoms had improved.

"No I don't drink a lot of water anymore, don't get very thirsty anymore
I hear from the radio. They make announcements about the traditional medicines,
they suggest you drink this and that, but I never drink those.

The hospital medication helps me...so I don't see a need to go there".

4.4.2. Would prayers help?

This was quite a paradox for someone who purports to be Christian and who says that he does not believe that at church they can pray for him and he would get help. "We attend a Christian church...I don't go to church often, I go sometimes...you mean that I go and they pray for me?

I don't think they will help me. I don't believe".

4.4.3. African tradition? Maybe

It appeared at this stage that he believed that during the course of the disease it might get to a stage where even modern medicine would no longer help and African tradition might be considered; but he remained adamant and more obstinate in his belief towards his traditional medicine. "No, I don't believe in African traditions; it hasn't got to that level it hasn't reached that level but I can't say it won't. Maybe it can happen but I doubt it".

4.4.4. Diabetes is incurable

He was devastated by the diagnosis at his age because he believes that diabetes is an incurable condition. "I was hurt especially because I didn't expect it, plus I looked at my age and I thought at this age, they say there is no cure for this. That's what troubled me, I thought what would I do now, here in hospital the doctor explained that there is no cure for this condition, but you can control it".

4.4.5. All the water going out, I' am dying

He elaborated an interesting belief about how diabetes would lead to death. As you passing all the "water", you are also "going" meaning dying. "Yes, I figured out it was true because I was feeling weak. And I was going to the toilet 5 times at night. I was drinking a lot of water, drink water and it was going out at the

same time. That's what freaked me out and I thought I'm "going" (mean I'm dying). I was loosing hope...death".

Conclusion

Mr. D had a very interesting approach to his problem. From the beginning when asked about his spiritual beliefs, he wanted to know if we meant church. Clearly he was not a believer; he just occasionally attended church with his family. He had a strong belief that his medications were all that worked for him. The belief that he was going to die troubled him a lot. His hope was restored because the troubling symptoms of "passing all the water out" improved on medication.

INTERVIEW 5

Respondent profile

Mr. S was 52 years old, father of two children, unemployed who was a very energetic and smart kind of person. He was very open and spoke freely; his body language could show no hesitation in the way he expressed his mind. He was diagnosed with diabetes about 3 years prior to our interview and he openly shared the experience of his initial struggle until it was found that high sugar in the blood was the cause of all his symptoms.

Lay beliefs about diabetes

In this interview Mr. S shared his beliefs around various issues ranging from the use of both modern and traditional medicine, other alternative remedies and organic food and how they help to reduce sugar levels and keep healthy. He believed in the skills of traditional healers and that symptoms can be caused by evil forces.

The following themes emerged from the interview:

4.5.1. Combination Therapy

He acknowledged that taking the medicine given by the doctor really helped him but he is a man so rooted in cultural beliefs that he honestly confessed to the use of Zulu traditional medication at the same time, he combines both.

"These ones (tablets) are for diabetes, I take these pills, then the doctor changed me to these ones 5 in total. They really help me, I take them the way the doctor asked me to, but I also have my own traditional medicine that I use sometimes. I don't want to lie to you; I also use the Zulu traditional medication".

4.5.2 The "bitter stuff" reduces sugar levels

His believes in traditional medicine and natural remedies have become his life line. He has planted himself in his garden and cooks his concoction himself. It clearly transpires from him that he believes herbal medicine helps to reduce sugar levels because of its bitterness.

"I mix the bitter stuff, I don't want to lie to you, I also use the Zulu traditional medication. There is one called Inkalane; it's the Zulu bitter medicine.

I plant it; it's more like a flower. It helps to reduce the sugar levels because it's bitter. Yes I cook it...

I plant it back at home, in the rural area. I cook it then I get what is called "Isibibi samandiya" I mix it together, and then drink it. When I come here they say my sugar level is 5. My condition is improving, Life is good because I don't just sleep at home, and I wake at dawn and attend to my garden which I'm currently ploughing".

4.5.3. Vegetable and traditional food

Mr. S had a strong belief in the traditional way of planting your own vegetable in the back yard garden, what he calls the "traditional food". He believes that eating organic food helps his life. He actually says that he looks so healthy that none could tell that he his diabetic.

"I'm growing veggies at home. I get my green pepper, onions, and pumpkins from the garden; I eat traditional (organic) foods.

I eat veggies most of the time. I don't like rice anymore, I told my wife, and I eat veggies most of the time.

It helps my life, as you can see I'm quite healthy. You can't tell I'm diabetic.

You can't tell I'm diabetic by just looking at me. It's only when I tell people, I treat it. I don't want it to affect me further.

Since 2003, they are always impressed with my progress. They always say your condition is improving how do you do it?

Is it because of my garden? Yes...It gives me exercise, food as well

The vitamins needed by my body"

4.5.4. Traditional healer

He eloquently elaborated on how he uses and believes in the services of traditional healers called in IsiZulu "Inyanga". He does not hesitate to recommend the skills of his "Inyanga" who is in this instance his brother in law.

"I have my Inyanga (traditional healer) I go to see when I'm sick.

... Yes, my brother-in-law is Inyanga, a healer, traditionally indeed.

I've just taken someone with high sugar level and he helped him.

... When I see that there is something wrong with my kidneys, I tell him there is something wrong and he prepares me a concoction.

I've done it only once...Yes when I had a pain.

Traditions and western medicine, it all comes together"

4.5.5. Other Alternative remedies

Mr S mentioned making use of some bitter concoction to help reduce sugar level. We were surprised to discover that he uses also other alternative remedies such as an enema and other mixture for his kidneys.

"I prepare my own concoction when I have a problem with my kidneys, to clean them. Yes when I have a kidney problem I prepare it myself, I cook it and fill the 2 litres. I put it in the fridge, when it cools down I drink a full cup.

He said he takes this concoction as an enema and then drink it.

I've done it only once; yes when I had a pain".

4.5.6. Bewitched or Cursed

While elaborating on the reason why he uses alternative remedies, he pointed out that he believed the pain that he could feel either in the kidneys or his feet were caused by some forces of darkness that bewitched or cursed him.

"I feel a sharp pain on the side here (on kidneys)...

Both sides here, then my feet feel painful. I told my brother (The Inyanga) that I suspect I've been bewitched because my feet are painful.

He said no it's not a curse your kidneys are dirty...

. He said take this concoction as an enema and then drink it".

4.5.7. Religious Beliefs

Mr S does not seem to have a clear cut position when it comes to Christian or spiritual beliefs, he have a tendency to lean on both sides at the same time. He is a church member but holds to his traditions.

"I'm a church member; I don't like preaching because people will start worshiping me instead of God. People are more interested in holding positions. I don't want promotion I just want a relationship with God.

We worship at church but we have our own tradition on the side, it depends on your beliefs, How you want to live your life, How you are managing Yes, in church they know that I have this condition that I see the doctor and that I use traditional ways...concoction. Yes, that I drink, and use enema, you see".

Conclusion

Traditional practices and cultural beliefs were dominant in his ways of life. He used a balanced approach between the use of both traditional and modern medicine. He was satisfied with his sugar control as his physical condition has

improved no one could tell that he has diabetes because he looks very healthy. Natural food and remedies were working for him.

INTERVIEW 6

Respondent profile

Mrs. Z 41 years old an employed married women, mother of a one child who was diagnosed about 2 years ago with diabetes. She is obese and struggling to control her sugar levels.

She spoke in a very soft voice but was expressive in narrating the shock of her life when she was diagnosed with diabetes. She was very honest when telling how poorly compliant she was with regards to diet and poorly adherent to medication.

Lay Beliefs about diabetes

Mrs. Z shared in this interview what was her beliefs regarding the causes of diabetes in diet and the use of herbal concoction. She also talked about her beliefs on others topics; exercise, fear of injections and traditional healing beliefs

The following themes emerged from the interview:

4.6.1. Sweet food causes diabetes

Mrs. Z was shocked when she was told that she has diabetes because she believed that this condition is caused by excessive consumption of sweet food. She said she hardly consume sweet foods, and was shocked to find out that she has diabetes. She translated her anger into denial and refused to start medication for a while but the sugar levels remained high.

"I didn't understand what causes diabetes, I thought you get it if you indulge in sweet stuff; I was disappointed to have diabetes because I don't like sweet stuff. I hardly consume sweet foods. I was shocked to find out I have diabetes.

I ignored taking treatment, and I didn't bother coming to get it. I got very sick and when they checked they found that my sugar levels were very high. I was asked to begin treatment unless I would get stroke. I came here in Mshiyeni and I started, but now what bothers me is that my sugar levels are slow to come down".

4.6.2. Eating wrong food

She honestly acknowledged that she is eating what was not prescribed for her at the dietician's counselling and educational session. Nevertheless she has a belief that it's just a weakness she has and she now tries to control herself.

"I was counselled on nutrition, I was asked not to drink coke, but diet coke, diet sprite or Zero% sprite, to take veggies, to boil food, on fruits, not to eat grapes, to eat a small portion of banana. Not to eat meat with skin, that I should eat three times a day, and that I should eat sandwiches should I get hungry. It's just that I love meat and especially the fat one.

I love coke, especially when it's very cold. I used to get very thirsty and I would consume the whole litre of coke at once.

Four hours wouldn't go by without me finishing two litres of coke. My husband found out I'm diabetic, when he finds something in the fridge he hides it outside. Yes, my husband he goes and throws it so when I hear his car engine outside I run and hide it. He once caught me and he said, listen girl, this is your life. Should you get sick I'm not a patient person and you know that, because you are killing yourself.

But now I try to control myself. But when I'm very thirsty I cheat on coke".

4.6.3. Lack of exercise

She does not exercise as she was advised to do but her belief is that walking up and down the stairs at work is worth to be accounted for body work out.

"They told me to exercise but I don't. I am exercising in a way because at work I take stairs instead of a lift. I work at the Port, South African Port Operations I use stairs, from ground floor to third floor...quite often because sometimes they call me to go get someone from ground floor. I don't count how many times".

4.6.4. Using Concoction

She believes that sometimes she should use traditional medicine to improve her sugar control despite all her wrong doing with regards to diet and lack of exercise. She told her husband the experience of someone else who apparently got better while using such a product.

"My husband doesn't approve of traditional medicine, he prefers I use only pills. ...No... I told him of someone who is using concoction, and he said let's see what the pills do".

4.6.5. Ancestor healing

She believes that she has a calling from her ancestors this came about after she was diagnosed with diabetes. That his why she wears beads, she is a chosen one. Among other reasons for this calling, they came to heal her.

"The beads means that I have ancestors on me (A calling)
Yes, but my husband doesn't like it, he just asked that I get healed.
He doesn't want me to start my calling.

Yes, the Ancestors ...they come to me...my husband didn't say anything because he could see what was happening. He allowed them to heal me".

4.6.6. Loosing weight

Although she is physically obese, she thinks that she has lost enough weight. To continue loosing was not on her agenda for now. Her belief in this regard was that she should loose more weight only at a stage where she becomes very sick.

"But I'm slimmer, I have lost some, I can see from my clothes".

4.6.6.1 Why loose more weight?

"Do I have to loose some more?

I thought that would be at a stage when I'm really sick".

Conclusion

This interview opened a perspective of a working class woman with a traditional background and a belief system that influences her daily struggle with diabetes in the context of marriage. She expressed her guilt in not abiding to prescribed diet and exercise recommendations. She was wearing beads on her which is a traditional sign of someone how has some kind of calling to be connected to the ancestors.

INTERVIEW 7

Respondent profile

Mrs. T 41 year old married mother of four children was diagnosed with diabetes about 2 years ago. She was very keen to participate in the interview and to share her views with us. She set in a comfortable position and used body language when the issue of skin rash was probed. At some stage she stood up to show us where she has a skin rash that she believes to be caused by a sorcerer's spell or witchcraft.

Lay beliefs about diabetes

In this interview Mrs.T elaborated her beliefs around the use of alternative remedies in diabetes. She talked about how she utilizes some mixture and used another traditional concoction to bring the sugar under control.

She also elaborated about witchcraft, how a spell was cast upon her, she then developed a burning rash and how she consulted traditional healer to help and cure the skin problem.

The following themes emerged from her interview:

4.7.1. Alternative remedies

She mentioned using a mixture named "Aloe Extra" that she purchased at the pharmacy. Her belief is that it helps to fight diabetes.

"I assist that with Aloe Extra, I take it only in the morning. I wake up from bed and drink it. It must take in on an empty tummy. They said it will help me, and now I see my sugar levels have subsided. I was here last month and it was 19, they said they can't discharge me because my levels were too high.

Just now it went to 17,5. I see the difference in using the aloe extra.

I get it from Sparksports chemist.

It's a one litre "muthi" mixture, with mixture that helps fight diabetes
It's got "unwele", it's mixed, all the ingredients are written on the bottle, it's got
aloe, and it will help me.

That's why I bought this one I'm using now. Aloe Extra, and only the pills. Yes I take Aloe only in the morning... it doesn't cause diarrhoea No, I just drink. I don't use anything else".

4.7.2. Traditional and modern medicine

She narrated how she takes her medication from the hospital and how she used to combine with herbal medication but was disappointed. She was given a concoction claimed to treat all diseases: "Uzifozonke" in IsiZulu.

"I woke up with a dry mouth; there was no saliva in my mouth. I told my neighbour and she advised me to go to uMshiyeni (the hospital) and check diabetes. They found out that my sugar levels are sixteen, they said it's high. They gave me pills and advised me to come get them every month. They give me the white ones...Yes, they gave me the big ones again, and I'm still taking them.

I use to take two in the morning, and one in the afternoon.

...but I don't I take them in the morning, I was advised to take only in the afternoon.

I used to take medication from Jeenah (the herbalist, the one from... a Boesman) concoction called 'Uzifozonke' (For all sicknesses/diseases)

I took it and saw that it doesn't help take my sugar levels down, the doctor would tell me that it's up (sugar levels).

The traditional concoction Uzifozonke (All sickness) I quit it.

I then bought this one (Aloe Extra) from the chemist because I didn't see the difference".

4.7.3. Diabetes is treatable

When asked to share her lay beliefs about diabetes she responded based on what people say.

"I don't know because my mother died long time ago, my father also passed away, I'm not sure who was diabetic.

They said diabetic is treatable, It does not suppose to be high or low, it's must be normal... That's what they say

But mine is always high, I will continue with pills (tablets)".

4.7.4. Witchcraft

She believed that the skin condition was not just an infection related to diabetes but caused by a kind of spell from a witch. She says she got it while hanging clothes on the line that is where the spell was cast by my neighbour.

"I got this when I was hanging the washing on the line, people from that side (neighbour) use "muthi" (They use witchcraft), I was rotting but I got better. I now apply some tissue oil. It erupted when I was hanging washing on the line.

I went to the skin doctor and he gave me some ointments. I bought the tissue oil to get rid of the marks".

5) Traditional healer

She consulted a traditional healer to understand where this strange decaying skin condition came from and how she got treated with tradition methods.

"I don't believe in witchcraft but when you see something that you don't understand and you consult and they tell you something. I consulted the "Inyanga";

He said I got it from the line...I was hanging the washing.

I felt itchy, it looked like rash, like burning, it broke up, I got the injection then I was better.

...There was water coming out... Yes, the blisters; when it healed it turned black and when I applied ointment the skin cleared.

The "Inyanga" gave me something to drink, he said I must drink and put an enema ...it never broke again.

...It was my neighbour from below my house Now, he moved to Kwamakhutha".

6) Eating together as family

She believed that it is important to eat the same food as a family, more particularly food cooked from the same pot; but her concern was mostly if her family would be affected by diabetes as they share the same food from the same pot.

"Yes I want to know... Is it important that we share the food from the same pot, should I be eating my own kind of food?

...Can they get it (diabetes)"?

Conclusion

Dissatisfied with her poor sugar control, she went shopping for alternative remedies until she started using Aloe extra and that she could finally see the difference.

She sought the skills of a traditional healer to find the origin of the skin infection she presented with. But she continued to see her doctor for the same problem. This showed that her beliefs were not only anchored in traditional medicine.

INTERVIEW 8

Respondent profile

Mr. S 59 year old married man father of 5 children was diagnosed with diabetes 2 years ago. He was very keen to participate in this study. He expressed himself with confidence; at times he laughed. He had a very expressive facial and body language; it was clear that he was pleased and also a humorous person. His figure of speech was very profound and his sense of humour facilitated to tap into very personal issues around intimacy in marital life.

Lay beliefs about diabetes

He movingly narrated his personal experience during this interview. His opening statement was that he agrees to speak to us otherwise we would not know what he does beyond what is prescribed to him from hospital; he said that it is better to hear it from "the horse's mouth".

He went at length on his beliefs around traditional means of healing and its practices in contrast to the so called modern or "western medicine" and where he stands. His lay beliefs about decreased libido or erectile dysfunction was narrated these symptoms metaphorically.

The following emerged from this interview:

4.8.1 Alternative versus Modern Medicine

He elaborated on how he believes that the tablets are more than the other things that he gets on the side. He said that they do not really help to bring down the sugar levels.

"Its better you hear it from the horse's mouth. I feel that the pills are really helping me towards my recovery, but we do use other stuff from the side. If they say it helps you then try it out but the pills are more important. The other stuff from the side doesn't really help bring down the sugar levels.

Even if it comes down you wouldn't know to what level because the doctors explain that if the sugar levels shoots up it's a problem.

...I can't complain now because I'm much better. I would be lying if I say anything else. I'm much better; it must be the pills...

You can drink... the concoction till you die without seeing any results. I have faith in pills, I truly rely on them".

4.8.1.1 Why modern better then traditional

He elaborated on why his belief is that traditional remedies are unreliable and that modern medicine is better than traditional.

"The other stuff from the side doesn't really help bring down the sugar levels.

Even if it comes down you wouldn't know to what level

I'm not criticizing what they make. It's a problem simply because you are drinking without any assessment. The doctor is able to evaluate".

4.8.2. Traditional healer "Inyanga"

He sought to understand what was going on in his life and was eager to find the reason behind this mysterious incident that was happening to him. He mentioned it all started when he collapsed and fell flat on the ground one day at home in the toilet.

He recounts his beliefs about traditional healers and what happened to him at the time of his diagnosis.

"I'll tell the truth, When it started I fell flat on the ground. I was on my way to work in the morning. I was trying to switch on the plug and I fell flat on the ground. I was thinking what is happening, I fainted, then I pee on my pants. I was shaking on the ground then the child found me...it was dark at dawn...

...I felt her touching my shoulders and I was already standing on my feet. She was shouting and I couldn't utter a word. She pulled me by my arm and I fell again. She was pulling and it was a problem.

You know us people if there is a problem we tend to go and consult the Inyanga for possible solutions.

He said what he thought, and gave us some things. It failed. He really tried what discouraged him is that I fell in front of him and it was the second time since he was checking on me. He was asking: "How is my patient"? I got sick and fell and my Inyanga took his bags and left.

He left me just like that, my wife said, but we have put out faith on this person and now he deserts us.

He realized there was nothing he could do to help me and he left. That's when I started to look for help here at the hospital, but I forget the name of the consultant, an Indian doctor... He really nursed me; I felt a little better from the pills he gave me.

The Inyanga took his bags and left... I said he is mocking me".

4.8.3. My blood is not fine

He explained his symptoms metaphorically about erectile dysfunction and said it was "unfinished business" and finally mentioned what the lay belief actually is with regard to this matter.

"Yes... something is bothering me in my body; when you have a house, you must make sure that you maintain it. Although the heart can be there but the body can fail you. It puzzles you and you think am I still functional? I'm not sure

what to do to fix my body again. Everything is fine except for my blood. As a man you have to function but I can't... Yes, a man's work, you do it and you discover that you have finished early.

We must all finish our food at home... like everyone must be satisfied in the end. Every plate with food must be eaten... We must all reach climax...

I am able to work but I can't finish, I don't go all the way.

I do get aroused, but once I get started and I'm active and then it just dies out. My wife...She is not happy though she doesn't say anything. She says there is something wrong with my blood. I tell her she is right".

4.8.3.1. Expectation from diabetes treatment

His beliefs was that his blood would get better with the treatment had his erectile dysfunction would have improved but it seams not to be the case that is why he was confused he was asking for help.

"I'm still confused...It's the first time I'm sharing this problem. I was hoping that if I take the pills I would get better. And my blood would be fine again.

... I just need something that would improve the state of my blood.

Since I know that my blood is not well. If I will find her plucking or harvesting the spinach, I will then chase her with my spear till she falls down flat.

Maybe I would hurt myself while chasing her, knowing very well that I'm the one with a problem... Yes, this is the matter, as when you found your wife there and you take your spear...

It's doesn't help to keep quite because she might figure out what is happening but you are not saying anything. She would wonder why you are not saying anything and you would wonder how she knows".

Conclusion

The advent of diabetes in his life came in a very dramatic scenario that he questioned the origin of the disease. The lay beliefs and cultural practices in his context led him to consult a traditional healer. His disappointment in traditional methods made him more objective with regards to choosing a healing method. His struggle with erectile dysfunction remained a burning issue that he even modern medicine had not satisfied.

INTERVIEW 9

Respondent Profile

Mr. ZN is a 63 year old male who was diagnosed with diabetes over 10 years ago. He was very enthusiastic in participating in this interview and willing to share his experience and beliefs about diabetes. He was knowledgeable of his condition and elaborated freely his views on the topic at hand. He expressed himself using body language and at times was would be emotional when he touched on issues around erectile dysfunction.

He described himself as a religious man, thus refraining from the tendency of seeking practices contrary to his spiritual beliefs.

Lay beliefs about diabetes

In this interview Mr. ZN mostly articulated on his beliefs around traditional medicine versus modern medication that he is now abiding to. He briefly shared the lay beliefs about diabetes seen an HIV-like disease and called the three letter plague.

His struggle with erectile dysfunction was expressed passionately; he said that his manhood is killed by diabetes.

The following themes emerged from his interview:

4.9.1. "Muthi" the traditional concoction

He elaborated on the lay beliefs about the use of traditional "Muthi" (the IsiZulu word for mixture or concoction) and he pointed out clearly where he stands based on his personal experience in the management of his condition. He said that it a wasted time while he was using the traditional concoction.

"There are people who suggest the bitter concoctions to help.

... I'm a church person. There was this person who came and offered to help with his medication, but in my heart I don't believe in it, it works on other people, but the bitter concoction doesn't work with me.

Some of it you can get from the chemist. They say it brings down the sugar levels. They say maybe two spoons in the morning, two more spoons in the afternoon".

4.9.1.1 "Muthi" does not work for me

The traditional remedies did not work for him despite the claimed healing effects. "I haven't seen any difference because all the time I come here after drinking the traditional "muthi" my sugar levels are up. I think I tried it for three weeks…

It wasted my time, the injection is better.

...There was someone at church who had the similar condition and he gave me the concoction, he said I must drink two spoons in the morning and two in the afternoon. I don't see the results of that.

... I use only the injection because it's effective".

4.9.2. Diabetes is like HIV

It is an interesting lay belief comparing diabetes is like HIV because of the wasting syndrome. In his attempt to explain how his symptoms got worse and he was not improving he pointed out that the tablets had really drained him and that he got so slim that he was labelled to have HIV.

"I was then given a date to get my medication. The pills really drained me I got so thin up to the point that people started to think I've got the three letter plague (HIV). People started to think I've got the three letter plague (HIV)".

"... My condition worsened and I almost died, my children thought I have the three letter plague (HIV)".

4.9.3. Injection better than tablets

As his was changed to insulin injection and got better, hence the belief that injections are better then pills.

"The injection has really helped me because they started by giving the pills, my condition worsened and I almost died, my children thought I have the three letter plague (HIV). The Doctor then changed me to the injection With the injection I felt better, Even my head stopped being dizzy.

My head would be dizzy and I would feel faint. So that stopped, after two weeks of starting the injection my body felt better.

Even my eye sight improved drastically. I still use my spectacles when I read a book".

4.9.4. Manhood killed

His belief about erectile dysfunction was that diabetes was the cause. Although he had hypertension and was on medication he was adamant and said "my manhood is killed by diabetes". He used a very touching way to express his problem.

"I'm not able to sustain even if I wish I fail.

I told him and he didn't answer me because he doesn't know whether it caused by diabetes, the blood pressure or arthritis because I have all of that. My manhood is killed by diabetes.

...She understands, I told her its diabetes, a lot of people experience the same problem".

Conclusion

The most difficult time was when his diabetes was not controlled by oral agents and he got so slim that he was labelled to have HIV. His family thought he was going to die. His medication was changed from oral agents to insulin and his blood glucose levels improved. He now strongly believes that the injection is better than anything else. He knows that diabetes is the cause of his erectile dysfunction as he said; "it killed my manhood."

INTERVIEW 10

Respondent profile

Mrs. A N 59 year old female widowed who was diagnosed with diabetes about 13 years ago in 1994. She was very keen to participate in this interview. She felt comfortable during the interview process, she had a very expressive body language, mainly when she talked about the disastrous loss she had in her family. She successively lost her first son a policeman killed in a shooting spree in 1990, her husband in 1996, another son died stabbed by his friend and finally her daughter died in 2004 of HIV-AIDS related condition. Her other daughter left home went on to live her life. She says that she is now left only with one son who is mentally challenged and two grand children. Although she is employed she is a poor woman with no family support to help her taking care for her traumatised family.

Lay beliefs about diabetes

In this interview she elaborated about her beliefs with regards to the concomitant use of traditional remedies with the prescribed medication in order to control her sugar levels as she saw that it was getting worse that she might need to get to hospital.

Her losses in the family through death left her distraught and traumatised emotionally.

The following themes emerged from this interview:

4.10.1 Combination therapy

She narrated how she was doing well for a while on her medication but for some non specified reason her sugar levels went up again; then she decided to

combine her medication with traditional concoctions as advised by her peers in view of her deteriorating condition.

"Life went on and it was 6.3, 6.7 as well as 4. On the 25th it went up to 18.8 but today its 10.3, but I was naughty because I purchased the bottles, advised by people.

I could see that I'm going to be admitted into the hospital and I went to buy the concoction from the coloured. I bought it at the taxi rank, from the very same coloured...The man...I don't know his name; I went there for the first time, I went last week...

I'm not sure what happened after that, but I didn't stop using the pills.
...The "Muthi" concoction's taste is bitter; the coloured man says it helps reduce
the progress of diabetes and blood pressure. I'm not sure about the blood
pressure because I haven't checked it".

4.10.2. "Muthi" restores your Energy

Although she was not sure about the concoction helping to reduce the sugar levels, she did not stop for a while drinking it as she believed it restores the energy of your body. She explained how she could now resume her house chores and able to walk for distances again.

"I consumed it without monitoring my progress. I felt my body was ready to do the washing. My body was fit to even clean the house after I used the concoction. My body was not tired and lazy anymore.

... I haven't stopped taking the pills. I have noticed that the coloured man concoction has granted me some energy to clean the house. I used to get tired before that.

I drink it, you can send me to Lamontville (about 5 km from here) and I'll come back. I mean on foot, walking... yes...

Yes, you feel your energy is back".

4.10.3. Stress raises sugar levels

She elaborated on what she calls her miserable life and how the whole situation affected her emotionally and mentally. The reasons of her uncontrolled diabetes as she said: "it must be the problems...I think it's related to stress...this is heavy in my heart."

"It must be the problems. My children died, do you understand. They were killed by these disease, and left me with grand children. This is heavy in my heart, I have worked backward, I don't rest. The children's mother ran away and I am up and down hospitals and clinics.

My son has passed away and left his wife behind. His wife ran away and left me with two children. My sugar levels jumped up and my life was miserable.

My child died on the 15th June 2004

One child is fine but the other one is on medication...

It's only her, the others died out of accidents. The police was killed in 1990 during the shooting spree on policemen. The other one was stabbed by his friend.

My sons, I'm left with only son Malkop... he is mentally handicapped, he is on medication.

My husband died in 1996; I'm the only one left at home with two grand children. If I die, it's over. Its affects me both emotionally and mentally.

I haven't told the doctor about this emotional state and why my sugar and blood levels are high, my life was miserable.

I am sick but I don't completely understand what's happening?

I don't understand what causes diabetes, was it the passing of my son? I was really shocked...The policeman... I was traumatized because I just spoke to him at three, instead of him coming home; the police came to report something else. I developed diarrhoea".

4.10.4. I was "bewitched"

The circumstances and events that unfolded with the symptoms that she presented of her diagnosis substantiated the belief that she was bewitched and that is how she got diabetes.

"I didn't know I was diabetic, I just lost energy, I felt faint while going to see my son. I was feeling faint and I felt extremely itchy underneath here, it was sore itchy more like I was bewitched. I didn't know about diabetic I thought I was bewitched. I fainted at work... what is happening with me... they took me to hospital. They asked me what is happening; I told them that I get thirsty.

My throat dried out as if I should add water. I was admitted to ward B here by a Chinese doctor, They nursed me well. My eye sight was not very good.

My eyes... I was extremely itchy".

Conclusion

The traumatic events in her family explained the stressful background in her life. She was consistent in her belief that it was so heavy in her heart that it caused her sugar to be uncontrolled. She believed that alternative remedies would help, but she emphasized more that it restored her energy level. The cultural belief of witchcraft was mentioned when talking about other diabetes symptoms like itchiness of eyes and genitalia.

COMBINED RESULTS

1. Combination Therapy

The commonest theme that emerged from all the respondents was about the combined use of both the prescribed medication and other means of treating diabetes that they will add on to achieve better control of their sugar levels. Everyone who added on any traditional remedy to the so called "modern" or "western" prescribed medication mentioned what were their lay beliefs around such practice, thus justifying their practice.

"It helps to bring down the sugar.

It helps reduce the progress of diabetes.

I mix the bitter concoction, I don't want to lie to you, and I also use the Zulu traditional medication.

They said it will help me, and now I see my sugar levels have subsided. I was here last month and it was 19, they said they can't discharge me because my levels were too high.

Just now it went to 17.5; I see the difference in using the aloe extra".

For those respondents who had an unsatisfactory outcome with the added concoction, they have either decided to go for a different formula or revert to and stick to their "modern" prescribed treatment. What was interesting was how they have expressed their beliefs in this regard and justify their therapeutic choices.

"I used to take medication from Jeenah (the herbalist) the concoction called 'Uzifozonke' (For all sicknesses/diseases). I took it and saw that it doesn't help take my sugar levels down, the doctor would tell me that it's up (sugar levels). The traditional concoction Uzifozonke (All sickness) I quit it.

I then bought this one, Aloe Extra from the chemist because I didn't see the

difference. The bitter concoction doesn't work with me.

Some of it you can get from the chemist. They say it brings down the sugar levels. They say maybe two spoons in the morning, two more spoons in the afternoon. I haven't seen any difference because all the time I come here after drinking the traditional "muthi" my sugar levels are up. I think I tried it for three weeks... It wasted my time, the injection is better".

2. Modern medicine versus traditional medicine

The most common theme that emerged from all interviewees in this regard was about a comparison of the two therapeutic models. Those in favour for the prescribed medication at the hospital or clinic will substantiate their beliefs by proving how their condition made them better or they would have achieved better sugar control by only adhering to the prescribed regimen and recommendations, or in some instances just because they did not believe in traditional means of treatment based on their religious beliefs.

Finally some have stopped using all types of mixture and claimed panacea and have reverted to their treatment because of the deceiving results yielded by these mixtures. On the other hand those using any of the traditional or alternative remedies had continued to do so based on either their strong cultural belief in their tradition or by their own experience with the product or simply by peer pressure or anecdotal evidence:

None of those using traditional medicine said that it was better or resorted exclusively to that mode of treatment. In all our respondents' case it was used as an adjunct method of care, as they said: "it helps to reduce, or it helps to decrease the progression".

"People talk in taxis at work as well when you sick, people make suggestions. I hear from the radio they make announcements about the traditional medicines, they suggest you drink this and that, but I never drink those things. The hospital medication helps me; so I don't see a need to go there".

"It brings the sugar level down, I was really struggling with diabetes, and after drinking it I got better".

"I haven't seen any difference because all the time I come here after drinking the traditional "muthi" my sugar levels are up. I think I tried it for three weeks...

It wasted my time, the injection is better".

Some respondents even said that there is no way to assess how to traditional medicine works.

"The other stuff from the side doesn't really help bring down the sugar levels.

Even if it comes down you wouldn't know to what level because the Doctors explain that if the sugar levels shoots up it's a problem.

I can't complain now because I'm much better. I would be lying if I say anything else. I'm much better; it must be the pills".

"You can drink... the concoction till you die without seeing any results.

I'm not criticizing what they make. It's a problem simply because you are drinking without any assessment. The Doctor is able to evaluate.

I have faith in pills, I truly rely on them".

3 The bitter concoction, the bitter "stuff", bitter "Muthi"

Most of the respondents expressed the reasons for the concurrent use of alternative therapy with orthodox medicine guided by their beliefs. The commonest lay belief shared were traditional remedies were that sugar in the blood is reduced or attacked by those herbal potions that had a bitter taste.

"It's this traditional crushed medicines that are mixed leaves called "Zambane" (African Potatoes), the "Ntshungu", then we also buy the bitter bottle from Jennah. They say it decreases the levels of diabetes.

I'm not sure of other ingredients, a mixture of green bitter leaves. He then just cooks it together, then people buy it and put in "Izipakupaku" (containers); it's a 5 litters or 2 litter's container, I usually buy 2 litters maybe twice a month. I drink half a cup in the morning and another half a cup in the afternoon".

"I mix the bitter stuff, I don't want to lie to you, I also use the IsiZulu traditional medication. There is one called Inkalane; it's the Zulu bitter medicine.

I plant it; it's more like a flower. It helps to reduce the sugar levels because it's bitter. I plant it back at home, in the rural area. I cook it then I get what is called "Isibibi samandiya" I mix it together, and then drink it.

When I come here they say my sugar level is 5. My condition is improving".

"I don't know anything but I hear some say it's better to get some of the bitter stuff. They say you must drink bitter stuff, maybe so the sugar will get a fright, but I dread anything bitter. I don't know how to use it, when I try I fail".

Even those who actually never gave it a try for one reason or other did not over look this well rooted lay belief of sugar frightening bitter herbal solutions.

One respondent did not use herbal medicine despite her struggle to control her sugar levels for the sole reason that she could not afford it as she was so poor.

"I never purchased the bitter stuff maybe it's because I'm poor and can't afford a bottle. They say sugar fears bitter stuff, but I never tried the bitter stuff.

The "Muthi" concoction's taste is bitter; the coloured man (Jeenah) says it helps reduce the progress of diabetes and blood pressure. I'm not sure about the blood pressure because I haven't checked it".

4. Traditional healers and Alternative remedies.

Seeking help from traditional healers and utilizing other alternating means of treatment in diabetes was one of the commonest themes that prevailed among most of the interviews.

The lay belief that was the most salient in this regard was that the traditional healer commonly called "Inyanga" was consulted when something went wrong in the spiritual or physical homeostasis of body functions and some unexplained symptoms were now noticed or experienced by the sufferer. Once an Inyanga was consulted, the prevailing belief was that he was capable of telling the cause or the origin of the body dysfunction and to explain the symptoms; and therefore he was able determine the remedy to cure and solve the problem.

The decision to consult a traditional healer was seen to be greatly influenced by one's cultural background. This belief was also seen in interviewee who confidently did not believe in African traditional healing ways. On the one hand it was on the basis of lack of measurable proof and on the other hand it was based on their religious beliefs.

"We attend a Christian church, I don't believe in African traditions; my diabetes it hasn't got to that level...to go to a traditional healer.

It hasn't reached that level but I can't say it won't

Maybe it can happen but I doubt it".

"Yes my brother in law is Inyanga, a healer, traditionally of course I've just taken someone with high sugar levels and he helped him. He is the same one, when I see that there is something wrong with my kidneys, I tell him there is something wrong and he prepares me a concoction. When I feel a sharp pain on the side here. Both sides here, then my feet feel painful. I told my brother that I suspect I've been bewitched because my feet are painful. He said no it's not a curse your kidneys are dirty. He said take this concoction as an enema and then drink it".

"I don't believe in witchcraft but when you see something that you don't understand and you consult and they tell you something. I consulted the "Inyanga"; He said I got it from the line...I was hanging the washing.

I felt itchy, it looked like rash, like burning, it broke up, I got the injection then I was better. There was water coming out... Yes, the blisters; when it healed it turned black and when I applied ointment the skin cleared.

The "Inyanga" gave me something to drink, he said I must drink and use an enema ...it never broke again. It was my neighbour from below my house".

Although this lay belief is well rooted in people's mind, thus influencing their decision to seek help, it does not guarantee the results or predicts the behaviour of a traditional healer facing a "difficult case"

"I'll tell the truth, When it started I fell flat on the ground. I was on my way to work in the morning. I was trying to switch on the plug and I fell flat on the ground. I was thinking what is happening, I fainted, then I pee on my pants. I was shaking on the ground then the child found me...it was dark at dawn...

...I felt her touching my shoulders and I was already standing on my feet. She was shouting and I couldn't utter a word. She pulled me by my arm and I fell again. She was pulling and it was a problem.

You know us people if there is a problem we tend to go and consult the Inyanga for possible solutions. He said what he thought, and gave us some things. It failed. He really tried what discouraged him is that I fell in front of him and it was the second time since he was checking on me. He was asking: "How is my patient"? I got sick and fell and my Inyanga took his bags and left.

He left me just like that, my wife said, but we have put out faith on this person and now he deserts us.

He realized there was nothing he could do to help me and he left. That's when I started to look for help here at the hospital".

5. Stress: Physical, Financial, Emotional, and Psychosocial strain

Another prominent theme was that which is associated with problems of living and traumatic events.

The variety of stressor factors that were mentioned by the respondents ranges from poverty, physical and emotional trauma, unresolved grief, to highly dysfunctional family with lack of social support.

"Yes I come to hospital; I don't miss my doctor's appointments. It's just that the doctor doesn't want to give me some money, just a little to help me, just something for transport. The government must provide, it's a problem since I'm unemployed..., I'm poor, my Lord, maybe if I would be provided then my soul will rest and maybe my sugar levels will decrease".

"But now the levels are not going down. No, not going down, it was up and down. With the injection it was slowly coming down, but it went up last month. But I think it's because I fell and broke my bone, I think it was caused by that, it went up to 20. It's normalizing again now after I broke my leg at work, the following day I was supposed to come here for my treatment".

"They say if you sad; I was sad; they say if you are stressing your blood sugar level goes up. Because if you become emotionally unwell, your sugar will go up".

"It must be the problems. My children died, do you understand. They were killed and my disease became worse and left me with grand children. This is heavy in my heart, I have worked backward, and I don't rest. The children's mother ran away and I am up and down hospitals and clinics.

My son has passed away and left his wife behind. His wife ran away and left me with two children. My sugar levels jumped up and my life was miserable.

My child died on the 15th June 2004

One child is fine but the other one is on medication...

It's only her, the others died from accidents. The police was killed in 1990 during the shooting spree on policemen. The other one was stabbed by his friend.

My sons, I'm left with only son Malkop... he is mentally handicapped, he is on medication.

My husband died in 1996; I'm the only one left at home with two grand children. If I die, it's over. Its affects me both emotionally and mentally

I haven't told the doctor about this emotional state and why my sugar and blood levels are high, my life was miserable.

I am sick but I don't completely understand what's happening?
I don't understand what causes diabetes, was it the passing of my son? I was really shocked...The policeman... I was traumatized because I just spoke to him at three, instead of him coming home; the police came to report something else. I developed diarrhoea".

6. Spiritual beliefs: Religious and Traditional

One of the most common themes that emerged from the respondents and that was discussed across all interviews was related to what beliefs they had about spirituality. Whether traditional or religious and how it influenced their therapeutic choices with regard to the management of diabetes.

From the religious perspective some interesting and ambiguous beliefs were expressed and from the traditional point of view beliefs varied from witchcraft, curse, to ancestral calling and healing.

"Yes, they pray for you in church, there is an open session for all those who are sick, some have BP only, some only arthritis, others both BP and diabetes.

No, they mix, all those who are sick. People do get help.

My diabetes is not as bad as it was before. It's possible that I'm also healed; it's just that I want to see the results now, I'm impatient. Yes, maybe my problem is that I'm not patient enough for the healing process. I want to see speedy results".

"I'm a child of God, I don't believe in traditions. They say tell God about your problems, God will heal you. Yes, in my case not with diabetes, I haven't seen anything, but with other things like emotional issues. He helps you...Yes ...What can I say? It happens, there was this person I had a problem with, we took each other to court. God takes your load, that's when I discovered. I went to court and just sat, and the prosecutor did all the talking on my behalf. It was solved. I just sat and didn't talk, it just happened, they were talking. So in that difficult time I had... the sugar, it was normal".

"I feel a sharp pain on the side here (on kidneys)...Both sides here, then my feet feel painful. I told my Inyanga that I suspect I've been bewitched because my feet are painful. He said no it's not a curse your kidneys are dirty".

"The beads mean that I have ancestors on me, I have a calling. Yes, but my husband doesn't like it, he just asked that I get healed. He doesn't want me to start my calling. Yes, the Ancestors ...they come to me...my husband didn't say anything because he could see what was happening. He allowed them to heal me".

"I didn't know I was diabetic, I just lost energy, I felt faint while going to see my son. I was feeling faint and I felt extremely itchy underneath here, it was sore itchy more like I was bewitched. I didn't know about diabetic I thought I was bewitched. I fainted at work... what is happening with me... they took me to hospital. They asked me what is happening; I told them that I get thirsty. My throat dried out as if I should add water. I was admitted to ward B here by a Chinese doctor, they nursed me well. My eye sight was not very good".

Other beliefs had an equal opportunity to be expressed in a non equivocal manner.

"I don't go to church often, I go sometimes; you mean that I go and they pray for me? I don't think they will help me. I don't believe. No, I don't believe in African traditions".

7. Eating right food and loose weight

The belief regarding issues pertaining to lifestyle such eating and weight loss where shared by most respondents and the following statements were some of the most prominent and commonest lay beliefs on diet and weight loss.

Loosing few kilos was believed to be sufficient for one of one obese patient who had the belief that she needs to loose more weight only when she becomes very sick. While other believed and has seen the benefit of loosing weight.

"But I'm slimmer, I have lost some, I can see from my clothes. Do I have to loose some more? I thought that would be at a stage when I'm really sick".

"I saw its better I loose weight, ever since I lost some, I saw some difference. When I was bigger my body took a lot of strain, it was heavy. Even if I think of doing some work I would hesitate because I'll be thinking it will be strenuous... It's not the same, it is better, before when it was heavy, I would feel hot everywhere, including under my breasts, but I'm better now".

One interviewee wrestled with the belief that it was important to eat the food cooked from the same pot as a family, but she wondered if other family member would get diabetes as they shared the same food.

"Is it important that we share the food from the same pot, should I be eating my own kind of food? Can they get it (diabetes)"?

A pertinent belief about organic food emerged on this topic. Food that was naturally processed just like in the olden days, traditionally, without chemicals no mechanics, no machinery were good for ones health.

"I plant it back at home, in the rural area. I cook it then I get what is called "Isibibi samandiya" I mix it together, and then drink it.

When I come here they say my sugar level is 5. My condition is improving, Life is good because I don't just sleep at home, I wake at dawn and attend to my garden which I'm currently ploughing. I'm growing veggies at home. I get my green pepper, onions, and pumpkins from the garden; I eat traditional (organic) foods. I eat veggies most of the time. I don't like rice anymore, I told my wife, and I eat veggies most of the time. It helps my life, as you can see I'm quite healthy. You can't tell I'm diabetic. You can't tell I'm diabetic by just looking at me. It's only when I tell people, I treat it. I don't want it to affect me further".

CHAPTER 5

DISCUSSION

5.1. INTRODUCTION

This section is a synoptic view of the entire process of the research project. The following subsections of this chapter will provide an overview of the methodology applied to this research and the subsequent results thereof.

The final subsection of this chapter will look into limitations of this research.

5.2. METHODS

Qualitative methods are the best study design to explore and explain beliefs of respondents when the phenomenon is unexplored and poorly understood (Reid AJ, 1996).

5.2.2 STUDY POPULATION AND SAMPLE

5.2.2.1. Study population

The study population comprised of all patients diagnosed with type 2 diabetes of 40 years of age or more attending our diabetic chronic clinic at Prince Mshiyeni Memorial Hospital for a minimum of 1 year and more.

These patients were well known by the team of nurses and doctors in charge of the chronic clinic and those attending the diabetic target group in particular.

The diabetic target group is a weekly specialised clinic by family physicians were uncontrolled diabetic patients are closely monitored and followed up until they achieve their target sugar levels after dosage adjustment and series educational sessions with dieticians. In the majority of cases patients achieve control within 3 to 6 months. The sample was selected from this study population.

5.2.2.2. Sampling

A purposive sampling was used for this study. In this method, participants are deliberately chosen based on their capacity of being articulate and able to provide appropriate information. They are called "key informants" (Patton M Q 1990, Reid AJ 1996).

After this process of selection, a total sample of 10 participants was interviewed. Ethical issues were duly complied with before they all signed a written consent form jointly with the researcher.

5.2.3. DATA COLLECTION

The researcher in this study conducted free attitude interviews for data collection in the language of choice of the respondent. All interviews were conducted at the hospital at patient's convenience on a day they come for their diabetic clinic. Interviews must be arranged at participant's convenience as recommended to avoid unnecessary travelling (Britten, 1995).

Data collection was conducted by research assistant (A). All the interviews were audio recorded. The principal researcher took field notes.

Research assistant (B) Miss O Mthiyane a isiZulu speaking qualified professional journalist who assisted with professional equipment and skills for recording, verbatim transcription and translation from IsiZulu to English of all the interviews in the main study.

5.2.4. DATA ANALYSIS

The raw data collected consisted of transcribed verbatim interviews and researcher's validated field notes. A member checking of the final English translation was done by the research team before the actual data analysis. Interviews were analyzed individually.

To ensure reliability and validity of data gathered member checking to validate all interviews. The researcher kept close monitoring contact with the research cosupervisor through all steps of data analysis and reporting.

The research team used the manual colour coding cut and paste thematic analysis method (Thomas J & Harden A, 2008).

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5.3. RESULTS

The following are the results of this research and corroborated with literature associated with the findings in this study.

5.3.1 Combination therapy

Many respondents made use of both therapeutic means namely their prescribed biomedical therapy from the hospital or their local clinic and added on natural preparations or mixtures to improve sugar level control. Some were of the belief that these herbal mixtures had properties to decrease the sugar levels and in some instances were that they helped to decrease the progress of diabetes. These beliefs were in keeping with what previous research on attitudes and beliefs of Mexican American diabetic patients in the United States of America. Participants generally agreed that natural therapies should be used as a complement to medicines that were prescribed by doctors (Cornado GD et al, 2004).

In another study on 525 elderly Hispanic, Asian, and non-Hispanic white respondents, it was shown that the majority of those using natural therapy (58%) consulted their physician for the same problem for which they sought natural therapy (Najm W *et al*, 2003). This finding was confirmed by the findings of this study of using combined therapy.

The belief among most of the participants who resorted to natural remedies was about its efficacy in lowering the levels of blood sugar. This belief was corroborated by an African study in Guinea. This study investigated herbal

medicine and treatment of diabetes in Africa; from a total of 397 participants, 33% declared they used herbal medicine and 74% believed in its efficacy (Baldé NM et al, 2007). This study has shown the same pattern of how patients were convinced to start using herbal medicine. Most of the respondents said it was either by hearsay in the community, advertisements on radio or after hearing about a positive experience of someone they knew. Hearing about a positive experience had convinced 78% of herbal medicine user in the study done in Conakry, Guinea (Baldé NM et al, 2007). Findings in this study were also corroborated by a previous study on the use of complementary and alternative medicine by American women. In this study it was reported that more informal networks such as family and friends were the most social influences to use complementary and alternative remedies among African, Mexican, and Chinese-American women while non-Hispanic white women cited formal media networks, family and friends were more likely to lead to natural remedy use (Chao M T et al, 2006).

A qualitative enquiry which aim was to understand similarities and differences in spouses' beliefs about diabetes and the effect of daily life and on the management of diabetes in the context of marriage. This study provided evidence that corroborates findings in this study that diabetes management in the context of marriage is greatly influenced by spouses' beliefs (Beverly EA *et al*, 2007).

In this study this was mostly the case of female diabetic partners where their therapeutic choice was greatly influenced by their husbands' beliefs. One respondent tried to convince her husband to use alternative remedies based on the alleged positive experience of her friend but her spouse was adamant and demanded that she continue with the prescribed biomedical treatment only.

5.3.2 Modern versus Traditional medicine

Although most respondents used both therapeutic methods a prevailing belief among them was that the biomedical therapy was better then the natural or traditional one. This finding was consistent with the results from the study on Latino American beliefs about diabetes. She pointed out that although Latin Americans often tend to use the pharmacist as source of health care, they believed that diabetes is best treated by doctors (Weller SC et al, 1999). To illustrate this further another respondent said: "I'm not criticizing what they make. It's a problem simply because you are drinking without any assessment. The doctor is able to evaluate".

These researchers showed that the prominent belief about type 2 diabetes treatments amongst Mexican Americans was that *many participants also identified natural therapy as effective treatments or cures for diabetes* (Cornado GD *et al*, 2004). None of the participants believed that herbal medicine could cure diabetes. In this regard findings in this study were different from the above mentioned study with regards to this particular construct. On the other hand most participants could substantiate their beliefs in herbal remedies. Most of them said that they got better, they could now see the difference and that their sugar levels had subsided. It was also reported that one third of a sample of Mexican American in Texas-Mexico border used home remedies to augment their diabetes therapy (Brown SA *et al*, 2002). Similarly it was shown that 58.1% of Hispanics living in America used natural therapies. They do consult their practitioners but the use of herbal remedies at their homes is common (Najm W *et al*, 2003).

5.3.3 The bitter "Stuff", bitter "Muthi", bitter "Concoction"

The belief that bitter herbs help to bring the sugar levels down was shared by all the respondents. In their attempt to explain how bitter herbs works, all they could say was that it is believed that sugar fears "bitter stuff" and that it gets a kind of fright and the blood levels drops down. Other respondents held the belief that natural remedies could bring sugar levels down only because they had a bitter taste; thus confirming the belief that sugar fears the "bitter stuff". The understanding was that "bitter stuff" referred to a broader range of natural remedies than "bitter Muthi". Muthi is the IsiZulu word for concoction or mixture referring to any preparation in the form of a solution to drink. Therefore anytime a respondent referred to "bitter stuff" it actually included any other form of alternative remedies meaning not only herbal solution to drink but enema preparations, roots, nuts, leaves, seeds, bitter food or even natural remedies tablets.

These findings were in line with the study that showed the same belief among British Bangladeshis (Grace C *et al*, 2008). They held a belief that bitter food could prevent diabetes by decreasing sugar levels in the body. The use of bitter gourd and banana tree sap to treat diabetes was reported in a study on Vietnamese patients (Culhane-Pera K, 2001).

5.3.4 Traditional healers and alternative remedies

The majority of the respondents believed in the skills of traditional healers. They consulted a traditional healer either to understand what is happening when they were faced with new problems or to find a cure for experiencing new symptoms in their bodies.

The findings on their beliefs in the skills of traditional healers corroborate earlier reports from the World Health Organization and previous researches. In South Africa traditional healers are known as *Inyangas or Sangomas* and are an integral component of the health practice and cultural practices in this predominantly underdeveloped and rural KwaZulu-Natal community (WHO, 2001). Traditional healers are the first health provider to be consulted in up to 80% of cases, especially in rural areas (Clarke E, 1998).

The use of alternative remedies and other herbal medicine is very popular in this part of Southern Africa (WHO 2001). In this study the commonest form of natural

or traditional medicine used was herbal concoctions called "*Muthi*", used in most cases orally but in some cases "Muthi" could be used as an enema for symptom relief associated with pain in the kidneys. This particular belief of kidneys affected by diabetes was corroborated in a Latino study by Weller (Weller SC *et al*, 1999). Aloe Vera, the most well-known species of aloe is used as a dried sap or gel as traditional remedy for diabetes in the Arabic peninsula (Yeh GY *et al*, 2003). Called "*Savila*" in Spanish, Aloe Vera was also cited by some of our respondents corroborating the findings by Cornado in his study on attitudes and beliefs of type 2 diabetes among Mexican-American (Cornado GD, et al, 2004).

Maduna described some of the most popular African herbal remedies used for diabetes namely the Aloe ferox know as "*Ikhala*" and the popular African potato "*Ikomfe*" (Maduna PMH, 2006). Herbal medicines are also widely used in Southwest America and Mexico especially those known with hypoglycaemic properties (Tripper-Reimer T *et al*, 2001) and globally as reported by the World Health Organization (WHO, 2001). Unfortunately, their lack of evidence and the hypoglycaemic risk of some herbal remedies remain a challenge for all health care providers (Ernst E, 2002; Gardiner P *et al*, 2008).

5.3.5 Stress: Physical, financial, emotional and psychosocial strain

The belief that stress and problems of living could cause body dysfunction that could either cause or destabilize diabetes was common among these respondents. They expressed stressful events which were quite diverse ranging from physical injuries, panic and anxiety, financial difficulties, and dysfunctional families with lack of social support, unresolved grief, poverty and unemployment. Most of the respondents did not explain the mechanisms by which emotions influence an individual's risk for diabetes or how it destabilizes blood sugar levels. It was shown that beliefs concerning this mechanism were reported in a previous study among Hispanic people who believed that having stress, experiencing other strong emotions or once a frightening event occurs. The body will develop symptoms such as agitation, nervousness, shaking, fear, diarrhoea, disrupted

sleep, and cold sweat. They believe that the treatment to this state called "susto" (Spanish for 'fright' or 'strong emotions') is prayer, seeing a herbalist and going to church. If the individual remains untreated then he could develop diabetes, die or see blood turning to water (Weller SC et al, 2002).

Adams reported in his study in a more urban setting that type 2 diabetic women would relate the onset of their illness to the emotional stress of witnessing a son being shot or seeing or child seriously injured on the playground (Adams CR, 2003). This belief was consistent with the findings in this study of one of the respondents where a woman after receiving the news of her child who was a policeman was shot and the death of her husband and another daughter through HIV. She associated these traumatic events to the onset of diabetes.

5.3.6 Spiritual beliefs: Religious and Traditional

Most respondents in this study expressed their religious beliefs during the interview. The commonest pattern of spirituality in this community was either Christian faith as religion, traditional, Ancestral or a combination of both. Only one respondent said he does not believe, but he sometimes went with his family to church. The belief shared among the respondents was that the Divine power of God could heal them, or help them as they said in most cases: "prayers do help".

These beliefs on religion were corroborated by patients with chronic disease using religion when coping with their problem (Koenig HG *et al*, 1997). Their faith sustains them as mentioned by an Asian Muslim woman: "I was in Ramadan. I used to eat buttered chapattis in the morning and was fine all the day. I think it was my faith. The doctor told me not to fast" (Brown K *et al*, 2007). The sample was predominantly Christian. The Christian faith has gained a significant influence in the practice population but did not interfere with their beliefs in the use of diabetes medication.

Brown corroborates the findings of this study on the influence of faith in a previous research were he reported on health beliefs of African-Caribbean in the

United Kingdom. He pointed out that participants in their study believed that faith was accompanied by a feeling that the outcome of their illness was in the hands of a higher power. He emphasised that this was not necessarily a barrier to keep control of their blood sugar (Brown K *et al*, 2007).

5.3.7 Eating right food and loosing weight

The belief concerning diabetes prevention by eating the prescribed food and weight loss was prominently shared by most of the respondents. Some acknowledged how much they fail to comply with dietary measures and others reported how they are trying their best to adhere to prescribed diet and life style modification measures. As one respondent said that he is trying his best to "keep the law".

It was shown in Latino beliefs about diabetes that also held the belief that diabetes could be controlled by eating the right food and loosing weight. The following beliefs were also found in her study: "Eat balanced diet; No sweet, no alcohol, and no fat; No "Yerbabuena" or lemon tea; Lose weight if overweight (Weller SC et al, 1999).

This belief concerning traditional food helping to prevent diabetes was also reported in a study that corroborated these findings on traditional food. Among British Bangladeshis they believed that traditional food and traditional vegetable like "kerela" and other bitter food could prevent diabetes. In the same study they have reported that British Bangladeshis believed that doing exercises and loosing weight were appropriate for good diabetes control but their cultural and religious constraints with regards to issues on revealing sport clothes for women, mixed sex exercise classes, running in public were all seen as inappropriate to their context (Grace C et al, 2008).

Many respondents believed in loosing weight by strict diet and exercising. It has been reported that people's exercise behaviour are associated with their exercise beliefs (Symons Downs D, Ulbrecht JS, 2006).

As Fisher pointed out clearly in his behavioural research on diabetes prevention, wherever an intervention is provided for diabetes prevention such as exercise and weight loss or any lifestyle modification measure, the implementation must be linked to the community, its culture, and its values (Fisher EB *et al*, 2002). The belief in weight loss over time appeared not to be consistent although many respondents experienced its benefit. This finding was corroborated by Polley et al study that pointed out that efforts to address patients' beliefs on weight loss did not yield effective long-term results (Polley BA *et al*, 1997).

5.4 LIMITATIONS & SHORTCOMINGS

In this section the researcher looked at possible flaws, bias and inherent study limitations that have occurred in the process of this research and how the actual findings would have been affected by the very context of the research process (Britten N *et al*, 1995).

From the preliminary stage of this research project, the researcher pointed out what was to be taken into account to enhance reliability and validity of this study and to reduce as much as possible any bias. The following areas are those that were of concern for the research team.

Sample Size: The small sample size in qualitative research does not allow for generalization, the reason being the study population was not representative, only specific participants were selected according to the inclusion criteria.

Sample selection: Although other ethnic groups do attend the diabetic chronic clinic at PMMH, the sample was largely selected by convenience where volunteering of key informants were purposively recruited to participate in the study. Therefore the study sample was not representative of all ethnic groups as it was totally made of African respondents. Moreover, other ethnocultural groups, their lay beliefs could not be explored.

Respondent's bias: The potential response bias in free attitude interview limits the interpretation of results in studies relying solely on exploratory open-ended questions. Respondents vary in detailed responses; they elaborated more on what they recalled most while responding as compared to perfunctory responses in a semi-structured interview were they are all asked a set questionnaire. This could have interfered with the interpretation on issues concerning symptoms and complications beliefs as all respondents did not elaborate uniformly on such topic. They could have had an equal chance to recognize all items with a structured questionnaire and narrate beliefs thereof.

The time factor: In qualitative research approach, data analysis is by far the most time consuming stage of the research process. The time lapse between data collection to the actual reporting of final data could have had an impact on the final study outcome; but the rigorous quality of mechanization in data capturing and a close collaboration of the researcher with experienced research co-facilitator and facilitator guaranteed the reliability and validity of data analysis and the study findings.

Lack of local research: The paucity of African and South African studies on the addressed subject made it difficult to compare these findings with previous studies in a more similar ethnographic and sociodemographic setting. This limits the inference of the findings to other similar settings and indicates the need for further local studies.

Language barriers: The use of a language of choice during the interview could affect the translation. In this study the interviews were in IsiZulu and translated to English, data collected could have been lost during the translation, for lack of appropriate concepts in any of the languages. None of the researchers were of English decent and that had an impact in the translation and interpretation.

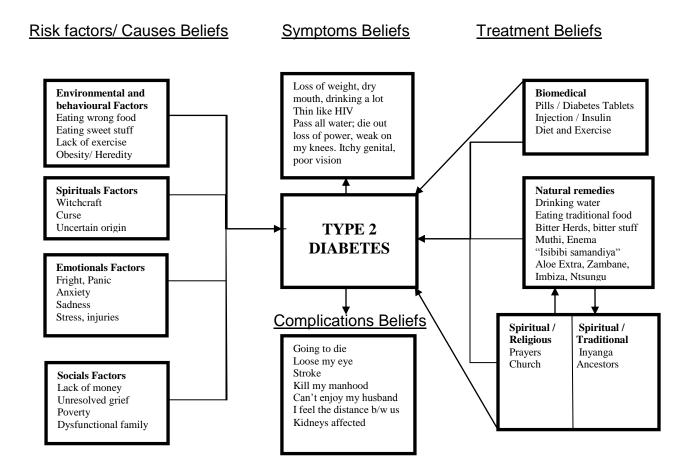
CHAPTER 6

CONCLUSIONS AND RECOMMENDATIONS

6.1. Conclusions

From the vast amount of data collected for this research emerged pertinent themes and subthemes from the interpretative analysis process; thus leading to this final stage of conclusion of this study.

In this study it was identified through this research that the general illness perception of the study population regarding diabetes origin, risk factors, and initial symptom and management strategies was moulded by their prominent lay beliefs. The respondents reported their beliefs on the management of diabetes as summarized in the following diagram.



This descriptive study on lay beliefs of type 2 diabetic patients seen at Prince Mshiyeni Memorial Hospital has provided an important perspective in patients' beliefs about diabetes management in this population. The most salient of these lay beliefs are embedded in the community as a result of their cultural beliefs and spiritual belief system.

The researcher has been cautious in implying that the exploratory models of illness in this population drives the pattern of their health seeking behaviour based on their illness beliefs. Nevertheless, on the basis of the common sense model of illness behaviour (CSM) theory that hypothesizes that an individual experiencing an illness may perceive a range of problems that are pertinent only to that individual and that in response to this interior conflict and in order to make sense of these problems patients create their own lay beliefs about their illness, which then influences their coping faculties and drives their care-seeking behaviour (Cameron L *et al*, 1993). It can therefore be assumed that most prominent themes in this study have provided us with a constellation of beliefs that allowed the researcher to put into perspective a matrix list of lay beliefs and subsequent care-seeking behaviour of the respondents.

From the point of view of the "Explanatory models of illness" or "CSM" theory; all clinicians would have to invest in a more patient-centred approach and furnish more efforts to grasp a profound comprehension of concepts such as symptom identifying and labelling for an individual or a particular ethnic group, to know their perspectives on origin and consequences of diseases, their perception of illness time-line and lay treatment strategies of diseases (Lau RR & Hartman KA, 1983). Any clinician who would endeavour in such undertaking will gain great expertise in what is believed to be the substance matter driving any ethnocultural group lay beliefs and health related behaviours and practices.

This research has identified that patients in this series interrogate their initial symptoms or complications symptoms differently and that the subsequent search for their illness origin and treatment behaviour significantly differed based on their lay beliefs.

This explanatory model of illness (Kleinman 1980) or CSM (Leventhal *et al*, 1992) which involve a profound comprehension of concepts such as symptom identifying and labelling, their perspectives on illness origin and complication of diseases will determine their lay treatment strategies (Lau RR & Hartman KA, 1983). Therefore it is essential that the provider's exploratory models of illness must be in concordance with his patients' CSM (Kleinman A *et al*, 1978) to increase patients' satisfaction and in turn this may positively affect adherence to prescribed treatment. Cohen and colleagues have proven that were clinicians and patients' beliefs are discordant pairs; these patients have higher HbA1_c levels (Cohen MZ *et al*, 1994).

The strength of this study is that is has revealed how patients understand diabetes management and the effect of their beliefs on their therapeutic decision and how it affects their lives. These findings provided a great opportunity for family physicians, clinicians and all health care providers to maximize interaction with patients taking into account their ethnocultural background.

Diabetes management is significantly influenced by demographic, psychosocial factor and lay beliefs it is consequently necessary to understand patients in their social and cultural context and to acknowledge their individual beliefs (Schoenberg NE *et al*, 1998).

For couples living with diabetes effective management is a process that is greatly influenced by their lay diabetic beliefs and mainly by spouses' beliefs (Beverly EA et al, 2007). Family members, clinicians and social workers or educators should consider that the above factors influence their self-care behaviours, emotional well-being and ultimately their sugar control.

Many studies have shown the influential role of natural remedies in the management of diabetes. In this research traditional healers, traditional or natural remedies were commonly used as compared to the biomedical therapy among adult in rural areas as shown in international and local studies (Clarke E, 1998, Arcury TA *et al*, 2006). The lack of evidence and the deleterious hypoglycaemic effect of most herbal remedies make this one aspect of the patients lay beliefs and treatment behaviour a must to be investigated at any encounter with a diabetic patient. In this study few patients disclose to their clinicians using any alternative or complementary mode of therapy. This was in keeping with previous international studies (Caufield J.S 2000, Gardiner P *et al*, 2008), and locally in KwaZulu Natal, South Africa (Clarke E, 1998, WHO 2001).

6.2. Impact of the study

The strength of this study is that it has addressed a previously unexplored subject in this setting. This research has brought about findings that are a contribution to the body of knowledge that from now on stands as a light that will enable clinicians and all care providers to gain more insight into patients' own perspective for therapeutic choices, poor adherence, compliance to prescribed regimens.

This study has enabled the researcher to draw inferences on patients' poor glycaemic control by understanding some unexplained clinical presentation of the patients despite their supposed tight follow-up in their records. Their attendance rate at the clinic was very good but the success rate in terms of glycaemic control was poor for most patients. This behavioural pattern is unequivocally based on their illness and treatment belief. In order to alter this equation there is a need to shift from the doctors own illness beliefs and therapeutic perspective and gain a better understanding of the patients' lay beliefs and health related behaviour.

A parallel medical system has been identified. Although legal but informal, the tradition medical system is adhered to and very much utilized by most of patients

but only ignored by the biomedical tunnel vision culture and beliefs. Although the South African legislature has provided a legal framework for traditional medicine, the two systems are evolving in total mutual ignorance.

The reality from this study shows that doctors are bound to deliver care to the very same population. Whether it is a biomedical trained doctor, an "Inyanga" or an herbalist who is treating the patient, we are all committed to their greater good and not to harm them by our mutual ignorance and rejection. It is time for the WHO call for integrated medical system to deliver more culturally sensitive and medical competent health program for the management of diabetes in the communities and for all medical issues (Hsiao A *et al*, 2006).

Chronic diseases prevention and diagnosis must be listed as a high priority for key policy makers as the viability of any health care delivery system hinges on health promotion and disease prevention; "prevention is better than cure" (Mabuza LH, 2006).

6.3. Recommendations

- These research findings provide a great opportunity for family physicians, clinicians and all health care providers to maximize interaction with patients taking into account their socio-cultural backgrounds and their lay beliefs. All clinicians should embark upon such approach to deliver a more cultural sensitive and competent diabetes care that has proven to enhance patient satisfaction and adherence.
- All clinicians to invest in a more patient-centred approach and furnish
 more efforts to patients' beliefs of concepts such as symptom identifying
 and labelling, origin and consequences of diseases, illness time-line and
 treatment choices or strategies of diseases.
- To encourage a truly supportive relationship between partners in couples living with diabetes as identified in the great challenges of housewives to

adhere to dietary recommendations, the strain in relationship in the case of genital symptoms in the wife and erectile dysfunction in men.

- Policy makers to implement WHO resolutions to move towards an integrated medical system in order to deliver more culturally sensitive and scientifically competent medical care to the better satisfaction and greater good of our population in such a multicultural diverse nation.
- Recommend that all patients should be asked about the use of any complementary or alternative mode of therapy used concomitantly with their prescribed medications.
- A multidisciplinary approach among all health care stakeholders in the community when dealing with all chronic diseases.
- Transformation of the health care system in the light of the great influence of traditional medicine in rural areas in our country.
- Traditional healers, herbalist and therapist to collaborate with the formal biomedical system for the sake and safety of patients' and the health profession.

"If people believe things to be real, they are real in their consequences"

The Thomas Dictum.

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APPENDIX I

RESEARCH PROTOCOL

LAY BELIEFS OF TYPE 2 DIABETIC PATIENTS AT PRINCE MSHIYENI MEMORIAL HOSPITAL, DURBAN

As partial fulfilment for the M Med in Family Medicine

RESEARCHER: KABAMBA J. MBAYA, MD (UNIKIN)

Student number: 200390988

SUPERVISOR: Prof SW Mhlongo

CO-SUPERVISOR: Mrs NH MALETE

THE STUDY PROBLEM

Diabetes is a disease in which patients' compliance and adherence to medical advice and prescriptions are recommended. This requires the patients to be fully informed about the management and involved in the decision making process so that they can conduct themselves in a healthy lifestyle, carrying out more health-related behaviours. Diabetic patient history taking in practice offers us the opportunity to investigate the reason of poor compliance and adherence to medical prescription on the basis of a life long daily medication, life style and behaviours change. Behaviour is related to multiple social factors that mainly influence how people live. This influence extends to their underlying belief, healing philosophy, choice of therapeutic methods, the trust in their physician and ideas concerning concurrent use of different therapeutics modalities.

Successful management of such chronic common condition requires that health care providers at any level understand the lifestyle, beliefs, attitudes and the family and social network of the patient.³

The purpose of this study is to explore lay beliefs of patients in the management of type II diabetes at Prince Mshiyeni Memorial Hospital.

By understanding cultural barriers associated with diabetes, one can improve effective life long management of the condition.

LITERATURE REVIEW

Diabetes is one of the most common clinical conditions encountered by family physicians in their practice.⁴ Doctors often have the opportunity to make the initial diagnosis and plan for the management and follow-up. The problem of compliance and control in the treatment of diabetes is widely recognized and emphasized by the medical profession.⁵ Furthermore, to ensure a successful ongoing management process, the initial intervention must be more patient centred and should address the patient's health care beliefs, educational level, cultural background and the whole social network in which they live.^{3,4,6,7}

Misunderstanding patients' expectations can lead to failure of patient participation and non-adherence. Physicians must be in a situation of a better understanding of the system that drives their lay beliefs and behaviour.

Knowledge of a broad spectrum of behaviours and beliefs would give the physician and other health care providers a starting point to provide the appropriate care possible. The Thomas dictum demonstrates this construct, < *If people believe things* to be real, they are real in their consequences>

In the latter part of the 20th century, studies have shown that an increasing number of people are turning to alternative and complementary medicine to help manage or to prevent the onset diabetes, thereby competing with appropriate medical treatment.^{7,9} Their evolving consumption stands on anecdotal evidence, likely related to lay beliefs.⁷

Some of the issues rose in different studies on African American, Mexican American, British Bangladeshis and black South African, have noted the barriers associated with treatment. ^{3,6,9,10,11} For example among British Bangladeshis, Greenhalgh et al have found that high value is placed on a family's eating communally, increasing difficulties associated with managing diet³. Samuel-Hodge et al had concluded that spirituality was an important factor in general health, disease adjustment and cooping in African American type II diabetic women. ⁶

While these studies offer much insight into the understanding of cultural barriers as a means of more effectively managing diabetes disease, they are inherently specific to the culture where they were performed.

In light of the impact of cultural barriers in patient management of chronic conditions, we have found it necessary to explore local beliefs and mores specific to our locality in order to effectively manage patient care and promote health.

Research Question

What are the lay beliefs of type II diabetes patients in the management of their illness?

AIM OF THE STUDY

To explore the lay beliefs of type II diabetic patients about effective management at Prince Mshiyeni Memorial, PMMH.

OBJECTIVES

 To understand lay beliefs about effective life long management of type II diabetes. 2. To make recommendation toward improving management of type II diabetes in conjunction with the findings of the study.

METHODS

Study design

It will be an exploratory study from a qualitative perspective using free attitude interviews as a data collection technique.

Study Population/Sampling

All patients above 40 years of age and having been diagnosed with type II diabetes will be eligible to participate and have been on the treatment for 18 months and more. Maximum variation will be by; sex, occupation and level of education attending PMMH, Durban.

8-10 subjects will be purposively selected. This method will allow choice of subjects known to be articulate and able to provide appropriate information. Data collection will continue until no new information (saturation) is emerging from the interviews.

Inclusion criteria — Patients who agree to participate in this study and are receiving medication at PMMH with no other condition either than diabetes.

Exclusion criteria – Patients who do not agree to participate will be excluded and those with another condition e.g. hypertension.

Data collection

Exploratory Question

What are your beliefs about the management of your illness?

Pilot study

A pilot study will be conducted before the main study by interviewing purposively tree patients.

Method of Data collection

Prior to commencement of data collection each respondent will be explained the aim and objectives of the study and requested to sign a consent form (Appendix 1). Data will be collected by research assistant (A) using free attitude interviews in the language of choice of the participant (isiZulu, English and Africans) and will be audio taped as well. The researcher will take field notes during the interviews and will also keep a research diary for purposes of reflection during the research process.

Data analysis

will be integrated into a single model.

Data will be analysed sequentially, this will enable the researcher to ascertain when saturation has been reached. The researcher will take field notes and keep a research dairy to document and reflect on the process of the research. All the interviews will be transcribed verbatim. Interviews not in English will be first transcribe in the language they where conducted in and then translated to English by research assistant (B). The researcher will transcribe verbatim interviews conducted in English. Information from the field notes and the researcher diary will be incorporated with data from the interviews. All interviews will be analysed using thematic analysis method.¹² Colour coding and cut and past method will be used to identify themes. The interviews

Reliability, validity and objectivity

To enhance reliability and validity the following steps will be taken

<u>Mechanization</u> – Audio taping of all interviews

Triangulation – Using more than one source of data collection

(i.e. audio-taping and field notes and researcher dairy).

<u>Member checks / respondent validation</u> – transcribed data will be verified with the respondents.

<u>Peer debriefing</u> – the researcher will be interviewed on the topic under investigation by the supervisor or co-supervisor.

<u>Peers review</u> – will be done by a colleague.

Bias

To minimize bias the following steps will be taken: ¹³

<u>Interview bias</u> – to minimize this type of bias interviews will be conducted by an independent research assistant (A).

<u>Selection bias</u> – only those respondents known to be informed of the topic will be selected thus excluding those who could have had an equal opportunity for selection.

<u>Sampling bias</u> – the small sample size cannot be generalized due the size but can be transferred to a similar context.

<u>Interpretation bias</u> – this type of bias can occur when the researcher omits interpreting all facts or consider all aspects of the results.

Ethical considerations

Permission to the study will be sought from the Departmental Research Committee (DRC) Family Medicine and the medical superintendent of PMMH.

Approval will be obtained from the Research, Ethics and Publications Committee (REPC) MEDUNSA. All the respondents will be sign the consent form (Appendix 1) before participating in the study.

IMPLEMENTATION

Time Frame

The study will commence after approval from REPC.

Data collection and data analysis 3-6 months

Write – up 6-9 months

Budget

Stationery R 750.00

Audio recorder & Tapes R 750.00

Binding of dissertation R 1000.00

TOTAL R 2500.00

All costs for the conduction of this study will be borne by the researcher.

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 SA Fam Pract 2001;23(3)35

APPENDIX II

MEDUNSA CONSCENT FORM

CONSENT FORM

<u>Statement concerning participation in a Clinical Trial/Research Project*.</u>

Name of Project / Study / Trial*

LAY BELIEFS OF TYPE 2 DIABETIC PATIENTS AT PRINCE MSHIYENI MEMORIAL HOSPITAL, DURBAN / KWAZULU-NATAL

I have read the information on */heard the aims and objectives of* the proposed study and was provided the

opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurized to participate in any way.

I understand that participation in this Clinical Trial / Study / Project* is completely voluntary and that I may withdraw from it at any time and without supplying reasons. This will have no influence on the regular treatment that holds for my condition neither will it influence the care that I receive from my regular doctor.

I know that this Trial / Study / Project* has been approved by the Research, Ethics and Publications Committee of Medunsa / PMMH. I am fully aware that the results of this Trial / Study / Project* will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

I hereby give consent to participate in	<u>in this Trial / Study / Project*.</u>
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·······

Name of patient.		Signature of patie	ent or guardian.
Place.	Date.	<u>Witness</u>	······
Statement by the I	Doctor:		
<u>I provided verbal ar</u>	nd/or written in	nformation regarding this Tra	ail / Study / Project*
I agree to answer a	any future que	estions concerning the Trail	/ Study / Project* as
best as I am able.			
I will adhere to the a	approved prot	ocol.	
<u>Dr Kabamba Jo</u>	hn MBAYA	<u></u>	<u></u>
<u></u>			
Name of Doctor		<u>Signature</u>	<u>Date</u>
Place			

APPENDIX III

DEMOGRAPHIC QUESTIONNAIRE
Identification number
Gender: Female Male
Age (years) Diagnosed with diabetes since:
AfricanWhiteColoredAsian
Marital status: SingleMarriesDivorcedWidowed
Profession
Occupation
Level of education:
None elementary school Middle school High School
College Postgraduate
Language: Englishother to specify
Residency: Urban zone Rural zone
Lifestyle:
Diet Smoking Exercise Sedentary Alcohol

APPENDIX IV

UNIVERSITY OF LIMPOPO

Medunsa Campus



RESEARCH, ETHICS & PUBLICATIONS COMMITTEE

FACULTY OF MEDICINE

CLEARANCE CERTIFICATE

P O Medunsa Medunsa 0204 SOUTH AFRICA

Tel: 012 - 521 4000 Fax: 012 - 560 0086

MEETING:

03/2006

PROJECT NUMBER: MP 37/2006

PROJECT:

Title:

Lay beliefs of type 2 diabetic patients at

Prince Mshiyeni Hospital, Durban, KZN

Researcher:

Dr KJ Mbaya Prof SWP Mhlongo

Supervisor: Co-supervisor:

Ms N Malete

Hospital Superintendent:

Dr BH Janowski

Department: Degree:

Family Medicine & Primary Health Care)

M Med (Fam Med)

DATE CONSIDERED:

April 05, 2006

DECISION OF COMMITTEE:

REPC approved the project.

DATE:

April 11, 2006



PROF GA OGUNBANJO

CHAIRMAN (RESEARCH) REPC OF FBM

Should any departure be contemplated from the research procedure Note: i) as approved, the researcher(s) must re-submit the protocol to the committee.

The budget for the research will be considered separately from the ii) protocol, PLEASE QUOTE THE PROTOCOL NUMBER IN ALL **ENQUIRIES.**

APPENDIX V



DEPARTMENT OF HEALTH

PROVINCE OF KWAZULU-NATAL

PRINCE MSHIYENI MEMORIAL HOSPITAL DEPT: FAMILY MEDICINE

MANGOSUTU HIGHWAY Private Bag X07, MOBENI, 4060 Tel.:031-9078111, Fax.: 031: 9073334

AUTHORIZATION FOR RESEARCH AT PMMH

Project Title:

Lay beliefs of type 2 Diabetic Patients at Prince Mshiyeni

Memorial Hospital

University Clearance Certificate No. MP 37/2006

Researcher:

Dr K.J. Mbaya

Supervisor:

Dr Mabuza L H

Co-supervisor:

Mrs Malete NH

Hospital Manager:

Dr IMS Jajbhay BH Janowski

HOD: Dept:

Family Medicine

Decision of Hospital Committee: The above research was authorized to be conducted on patients attending PMMH

Dr ZA Gilani Acting HOD

Family Medicine

Prince Mshiyeni Memorial Hospital