EXPERIENCES OF THE XHOSA DIABETIC PATIENT

by

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Isinikezelo

Olu phando- nzulu lunikezelwa ku mama wam u Mercy Mamtembu, utata wam ongasekhoyo u James Radebe Dukuza, odade: Nomfundiso, Ntombovuyo, Lungiswa, Nomfusi, no- Nocwaka.

Dedication

This study is dedicated to my mother Mercy Mamtembu, my late father James Radebe Dukuza and my sisters: Nomfundiso, Ntombovuyo, Lungiswa, Nomfusi and Nocwaka.

Sing to the Lord, for he has done glorious things;
let this be known to all the world

(Isaiah 12:5)

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OVERVIEW OF STUDY

1.1 INTRODUCTION AND PROBLEM STATEMENT

Diabetes mellitus (DM) is one of the most challenging public health problems of the 21st century. The number of people with DM, particularly type 2 diabetes, is rapidly expanding throughout the world. According to Rotchford and Rotchford (2002:60), in 1985 an estimated 30 million people worldwide had DM. In 2000 the figure had risen to over 150 million people. According to World Health Organization (WHO) estimations (Rotchford and Rotchford, 2002:60) this figure is expected to double by the year 2025. This increase is also confirmed by Wild, Roglie, Green, Sicree and King (2004:1047), who project the total number of people with DM to rise from 171 million in 2000 to 366 million in 2030. Doctor Hillary King, of the WHO division of non-communicable diseases, also predicted in 1998 that by 2025 the worldwide adult population of 20 years and above, affected by DM will reach 300 million people. Of this figure 228 million patients with DM will be in developing countries and 72 million will be in the developed world (Jones, 1999:425). In 1995 the countries with the largest numbers of people with DM were India with 9 million, China with 16 million and the USA with 14 million diabetic patients (Jones, 1999:425).

In America there is an estimated 16 million people affected by this disease, with the incidence of diabetes having risen by more than 600 percent in the past 50 years (Safran, Mukhtar & Murphy, 2003:58), which is an increase of 61% from 1999 to 2001. An estimated 1 million overweight Americans aged 45-74 years have impaired glucose tolerance (Satterfield, Lofton, May, Bowman, Alfaro-Correa, Benjamin & Stankus, 2003:S56). This increase in people suffering from DM is due to population growth, aging of the population, urbanisation and the increased prevalence of obesity, physical inactivity, an altered diet, and other factors such as stress (Wild, et al., 2004:1049). According to the British Diabetes Association (cited in Gillibrand and Fynn, 2001:5010) DM is a common and chronic disease affecting at least 2% of people in the United Kingdom.

In developing countries the majority of people with DM is in the 45 to 65 year age range (Erasmus, Blanco, Okesina, Matsha, Mesa & Gqweta, 2001:157). In contrast, the majority of people with DM in developed countries is older than 64 years of age. It is estimated that by 2030 the number of people with DM who are older than 64 years of age will be more than 82 million in developing countries and more than 48 million in developed countries (Wild, et al., 2004:1050). A recent report by Erasmus, et al., (2001:157) also demonstrates that DM is very prevalent in developing countries.

In Africa, the prevalence of DM is low in some rural communities, but in others there is a moderate prevalence, comparable with that found in developed countries (Rotchford & Rotchford, 2002:60). Until recently DM was considered to be rare in Sub–Saharan Africa, but as a result of demographic and lifestyle changes, it is now recognized as a major health problem. Recent surveys estimate the prevalence of diabetes among the urbanised black population in South Africa to be around 8% in people over 30 years of age (Rotchford & Rotchford, 2002:60).

Ethnicity has been shown to be a factor in the development of DM in America. Members of minority groups in America, for example, African Americans, Hispanic Americans and Pacific Islanders are more likely than White Americans to have poor health (Safran, et al., 2003:59). This trend is also evident in South African statistics, as the black population has been shown to have a higher incidence of DM compared to white people. According to a study on diabetic management by Boschmans & McCartney (cited in O’Brien, 2005:5) 64.6% of the study population with DM was black, 23.7% were coloured, 2.9% were Indian and 8.7% were white.

Rotchford and Rotchford (2002:60) estimate that there are at least 1 million known diabetics in South Africa, 8% of whom are black, over 30 years of age and residing in urban areas. The difference in the prevalence of diabetes between Indians and black people in South Africa is estimated at 10% and 6% respectively (Van Huyssteen, 2003:2). Panz and Jaffe (cited in Van Huyssteen, 2003:3) predict that South Africa will have 106 million type 2 diabetics by 2010, with the highest prevalence being among the black population.

DM is divided into type 1, formally referred to as insulin-dependent diabetes mellitus (IDDM), and type 2, formally referred to as non-insulin-dependent diabetes mellitus (NIDDM). Type 1 diabetes occurs when the beta cells in the pancreas stop producing insulin. This is an autoimmune disease in which the beta cells of the islets of Langerhans in the pancreas are destroyed. It usually starts in younger people under 30 years of age and may occur in very young children and in infants (Smeltzer & Bare, 2002:974). Type 1 diabetes is treated with daily insulin injections to maintain a blood glucose level within the acceptable range. Insulin, a protein given subcutaneous to a diabetic patient, cannot be given orally as it is destroyed by the digestive juices in the stomach (Khare, 2003:66).

According to Waugh and Grant (2001:235) type 2 diabetes is a metabolic disorder, characterised by the relative deficiency of insulin production and a decrease in insulin action. The prevalence of type 2 DM that classically occurs in adults over 30 years of age is increasing rapidly as compared to type 1 DM. According to Smeltzer and Bare (2002:975) 90-95% of people with DM have type 2 diabetes, 80% of whom are obese. Many people who have the disease go undiagnosed, as there are no early symptoms. People with type 2 diabetes are only diagnosed several years after the onset of the condition, when various diabetic complications have already set in. These people are usually overweight and do not exercise. Reducing weight and modifying one's lifestyle may reduce blood glucose levels, but if this management fails, anti-diabetic treatment including tablets and/or insulin will be prescribed to improve the control of glucose levels (Smeltzer & Bare, 2002:975).

Most studies ascribe the prevalence of type 2 DM to the following factors: poor eating habits, the reduction of physical activity levels, obesity, a family history of DM, smoking and stress (Satterfield, et al., 2003:58). According to Van Huyssteen (2003:1) the effects of urbanisation and westernisation in South Africa are contributing to unhealthy lifestyles. Urban life is associated with a sedentary lifestyle and poor eating habits (Van Huyssteen, et al., 2004:28). The latter is characterised by the intake of high amounts of fat and increased carbohydrates and refined food, the consequence of which is the development of obesity, which may be difficult to control.

According to Brown, Lee and Ganda (cited in Gillibrand & Flynn, 2001:501) DM is also the cause of a number of long-term complications, which can lead to serious debilitating effects and even death. Some of these complications are cardio–vascular problems, renal diseases, central and peripheral nerve damage, infections, gangrene and visual impairment. According to Motala, Pierie, Gouws, Amond and Omar (2001:90) there is increased morbidity and mortality associated with diabetic complications, both micro-vascular and macro-vascular. Erasmus, et al., (2001:158) state that the highest prevalence of diabetes was observed in Xhosa patients between the ages of 50 – 59, in a study of factory workers in Umtata. Ongoing quality care is therefore necessary to prevent serious diabetic complications, especially in rural areas where major socioeconomic, cultural and geographical difficulties exist (Rotchford & Rotchford, 2002:60).

This study was conducted in the western region of the Eastern Cape, in the Nelson Mandela Metropole Municipality (NMMM). Public health care is mainly provided at 3 hospitals, namely Dora Nginza Hospital, Provincial

Hospital and Livingstone Hospital, which have amalgamated to form one hospital complex. In these government hospitals diabetic patients are attended to in the Out-Patient Departments (OPD) by registered nurses and medical practitioners. In addition there are several state-funded clinics providing primary health care to patients in the NMMM. These clinics are mainly staffed by registered nurses, many of whom are trained in primary health care. Some clinics are visited by medical practitioners on a weekly basis. Registered nurses in South Africa form more than 60% of human health resources, with a nurse-population ratio of 43:10 000. A significant number of nurses work in the private sector (Muller, 2002:95). The bulk of patients in the NMMM make use of public health care facilities, where they are seen by registered nurses who only refer complications to medical practitioners. Most black patients in this area make use of public health care facilities because they cannot afford the medical care and treatment provided by medical aid schemes, nor can they use the private health care facilities available to people belonging to medical aid schemes. According to Leuner (2000:410) 78% of the population in South Africa makes use of the state-funded medical care system, while the rest of the population uses private care. This results in an increased workload on the part of nursing staff in the public health sector, which can affect the quality of health care delivery. According to statistics obtained in one of the NMMM hospitals, staff in this particular hospital's OPD treats, amongst many other conditions, an average of 500 diabetics per month (see Figure 1 below).

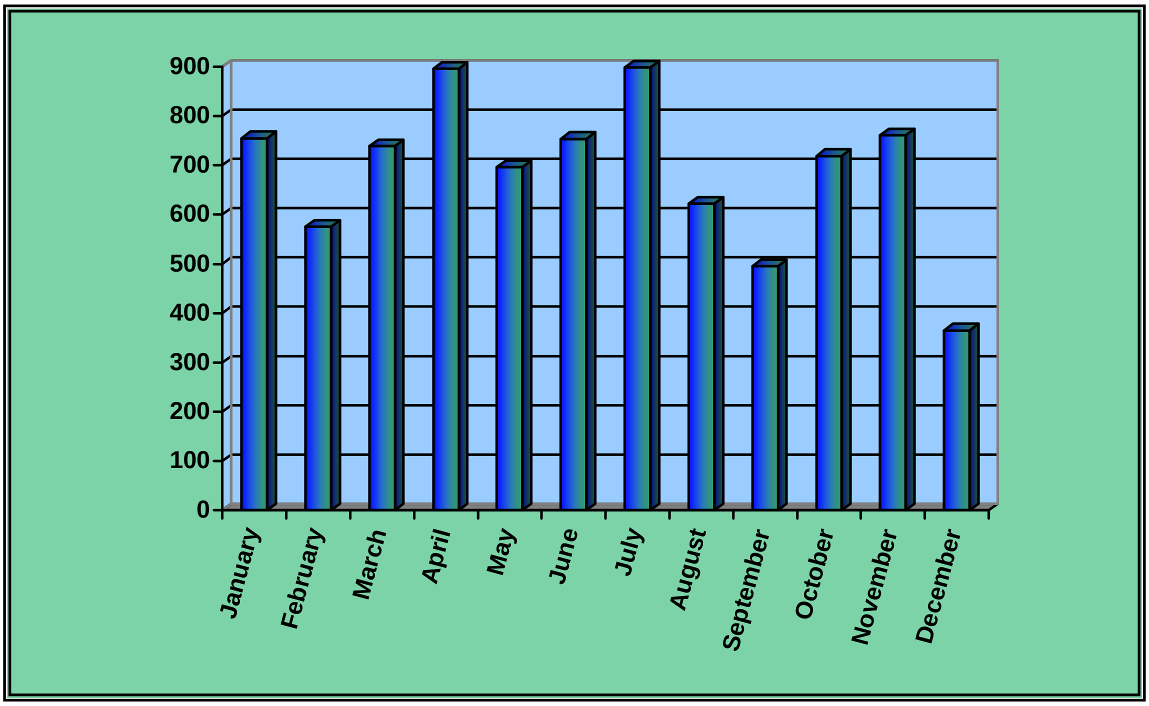

FIGURE 1 DIABETES MONTHLY STATISTICS FOR A LOCAL HOSPITAL - 2003

This study will be focussing on the experiences of Xhosa-speaking patients with DM utilising the NMMM public hospitals complex. In the OPD patients are assessed and treated for all chronic conditions including DM, and patients are seen at monthly intervals or when necessary. The OPD serves the neighbouring black population from the surrounding townships as well as the informal settlements. The effects of urbanisation have resulted in this area having a semi–rural, semi-urban population that is mostly Xhosa speaking. The bulk of the population is unemployed, while others are living on a minimal income. Unemployment in the Eastern Cape ranges from 40% in rural areas, rising to 50 - 60% in the urban areas (Proposed aluminium Pechiney smelter within the Coega IDZ, 2002:4-8). In some homes there is no or little money to buy food, and even less to make use of a health service. Some people live on either a social grant for the elderly, a grant for young children or a disability grant and most people in this area have an income below the level at which payment of taxes for contribution to the economy is possible.

In a study conducted by Mdolo (2005:45) on experiences of nursing students doing community-based learning in the NMMM region, the students were shocked to see the conditions in which the patients live as well as the needs of the residents. The large number of residents living below the poverty line overwhelmed these students. Clark (as cited in Mdolo, 2005:44) states that poverty affects the health status of the population because it contributes to poor health.

Professor Francis Wilson, a well-known poverty expert at the University of Cape Town, stated that poverty is a huge problem in South Africa. Wilson provided statistics from household surveys, which showed that an average monthly income of an African household was only R200 and further stated that inequality was rife in South Africa. The poorest of South African households earn 0.5% of the country's income while the richest 10% earn 45% of the country's income and unemployment is much higher in the black community than amongst white people. Health care professionals working in poor, underprivileged areas have to deal with not only their patients' health problems, but also with the effects of poverty on the health of their patients (De Vries & De Villiers, 2001:35). The challenge for all health care professionals is to understand the nature and extent of the problems faced by the poor.

Not only does poverty have an influence on the development and management of DM, but it is evident that DM also has serious economic consequences. When this disease affects the breadwinner in a poor family, it frequently has severe implications for the economically dependent children. Ill-health contributes to reduced productivity, and in some cases to loss of employment and poverty. People who could be contributing meaningfully to the national economy may be boarded from work because of diabetic complications and this adds to the already inflated pool of unemployment and poverty. Effective and accessible health services could prevent the problem from spiralling into an economic crisis (Heath & Haines, 2000:126).

Education of diabetic patients and their key family members is of fundamental importance in the management of DM. Management options in diabetic care include: diet modification, exercise, glycaemic control and lifestyle changes. In type 2 diabetes, which is more common amongst overweight people, an appropriate diet and increased physical activity are the corner stones in its management. Three regular meals should be taken at the same time every day with snacks in between to maintain the correct glucose level, and exercise should form a regular part of a diabetic patient's life (Mollentze, 2000:920). But these prescriptions may have cultural and socio-economic constraints in this study's identified population group, as the community views obese Xhosa women as physically attractive and healthy. Physical exercise for the reduction of weight may conflict with the woman's social norms and exercise can be impractical for them. Some of the hypoglycaemic medication should also be taken before or after regular meals, which in many homes is not possible. Thus western cultural ideals may not be realistic in the management of Xhosa diabetic patients.

Patient teaching should aim at preventing non-compliance to treatment. Health care professionals should be aware of cultural practices, values, ideas, observable behaviour, as well as attitudes of diabetic patients, for the cultural norms, beliefs and perceptions of patients may determine how patients manage their disease. Health and illness are strongly influenced by cultural aspects. Some clients of African origin, including Xhosa people, still consult a traditional healer before consulting a western doctor. This dual consultation can result in non-compliance to treatment. If western medication is discontinued, a diabetic patient can deteriorate into a hypo- or hyperglycaemic coma (Tjale in Tjale & De Villiers, 2004:5).

The question that the researcher wants to address in this study is how a Xhosa patient experiences living with DM and what culturally congruent guidelines should be developed to assist registered nurses with the management of DM in Xhosa patients. The problems faced by the target population are summarized in the following poem by Qaqamba Ngamlana (2005):

Sugar disease: Sweet urine

Living with this disease
No longer at ease
As it begins to devour your life
Restricting your lifestyle
Loss of quality health
Fear of premature death

Some say it's easy to manage
Will cause minimal damage
If you follow the correct diet and treatment plan
Just follow the medication
Give yourself the injection
Exercise as often as you can
See the doctor as often as you can

But on the other side of town
Which was plagued by previous government policies
Lives in a small space
An old woman black and proud
Chanting a monotonous drum beat
Too old to work, too strong to die
Living off government subsidies
She's poverty stricken, sells her wares on the street
Trying to provide for her grandchildren
But life is tough, when there's nothing but strife
Sleeping with an empty stomach at night

Diagnosed with sugar disease
This chronic sweet urine disease
Not knowing what it all really means
Shocked, angry, confused
Goes through all the steps of depression
As her world starts to crumble and fall

Hypoglycaemia or hyperglycaemia
That's what they call it
This sickness that might render her blind
This sickness that might leave her amputated
She can't keep it managed
She can't understand it
Since life hasn't offered her much

No way to afford it
No way to survive it
This sickness, which feeds on her soul
This "western" disease
Which will plague her existence
As she can't keep it under control

And all the while
All she thinks about
Is what will happen to her grandchildren
Should this disease rob her of her life?
What will happen?

1.2 RESEARCH OBJECTIVES

The objectives of this study are to:

- explore and describe the experiences of Xhosa diabetic patients related to living with DM; and
- develop culturally congruent guidelines for registered nurses in order to optimize the health care of Xhosa diabetic patients in the public health care sector.

1.3 CONCEPT CLARIFICATION

For the purpose of this study, certain key concepts will be defined as follows:

1.3.1 DIABETES MELLITUS (DM)

Diabetes Mellitus is a metabolic disorder, primarily characterised by the elevated level of glucose in the blood and urine resulting from defects in insulin secretion, insulin action or both and by micro vascular and cardiovascular complications that substantially increase the morbidity and mortality associated with the disease and reduce the quality of life (United Kingdom Prospective Diabetes Study, 2002).

1.3.2 INSULIN

Insulin is a hormone produced by the pancreas to control the level of glucose in the blood by regulating the production and storage of glucose (Smeltzer & Bare, 2002:973).

1.3.3 NURSING

Nursing is a profession based on a body of specialised knowledge, which is constantly being extended by research and transmitted to new practitioners through education programmes. It is a comprehensive interpersonal service to mankind at all stages of life, ill or well (Uys, 2002:160).

1.3.4 REGISTERED NURSE

The registered nurse is a person who has undergone training at an institution accredited by the South African Nursing Council (SANC) and thereafter registered as a nurse and a midwife. The person practices according to the scope of practice as set out by the SANC (South African Nursing Council, 1994:10).

1.3.5 ANCESTORS

The ancestral spirits are the spirits of deceased people who retain an important influence on the lives of their living descendants and for whom the common Xhosa term *izinyanya* is used (Pauw, 1975:59).

1.3.6 CULTURALLY CONGRUENT CARE

According to Leininger's theory (cited by De Villiers & Herselman in Tjale & De Villiers, 2002:22) culturally congruent care is the broadest holistic means to know, explain, interpret and predict nursing care phenomena in order to guide nursing care practices by focusing on the different ways of life of people, which include their values, beliefs, illnesses, handicaps and deaths.

1.3.7 GUIDELINES

Guidelines are systematically developed statements, meant to assist practitioner and patient decisions about appropriate health care for specific circumstances (Todd, Biskupiak & Weingarten, 1998:1).

1.3.8 PUBLIC HEALTH CARE

For the purpose of this study the term public health care institution refers to the three state hospitals, which have amalgamated to form one hospital complex, in the NMMM. This includes the several comprehensive primary health care clinics in the NMMM.

1.4 PARADIGMATIC PERSPECTIVE

The research is based on an anthropological nursing science, namely nursing accompaniment theory, which was developed by WJ Kotzé in 1998. It provides an understanding of man, world, health and nursing as well as the accompaniment of patients, (the accompanee) and the nurse, (the accompanier) (Kotzé, 1998:3-14). "Man" in this context is used in a generic sense to indicate both genders, that is, women are implied in the term and not excluded.

1.4.1 METAPARADIGMS

Kotzé (1998:4) defines the metaparadigms of man, world, health and nursing as follows:

1.4.1.1 Man/human being/person

Man in this study is a diabetic patient who is a unique total being, consisting of body, mind and spirit and has an inseparable dynamic relationship with the world, time, fellow-beings and God. According to Kotzé (1998:4) the world in which man exists consists of the personal world and the interpersonal world of co-existence. The psyche is the center of man's perceptions and experiences. The external world includes, *inter alia*, ecology and microorganisms, which cause diseases. Each person with a disease will have his or her own way of perceiving and coming to terms with their condition (Kotzé, 1998:4).

1.4.1.2 Health

Health refers to a diabetic patient's state of wellness or illness as well as the ability or inability of a patient to maintain him/herself optimally especially during illness (Kotzé, 1998:4). It is a dynamic process in which a person, sick or well, must maintain himself as a multi-dimensional being in his relationships, not only in his physical, but also in his social environment (Kozier, Erb, Blais & Wilkinson, 1995:245). It is a relative concept and the degree of wholeness is affected by the nature of the patient's relationship with his environment, the duration of his illness, his family, health care professionals and God.

1.4.1.3 Nursing

According to Kotzé (1998:4) nursing is a service to man at all stages of life, ill or well, of which accompaniment is an integral part. Nursing encompasses a dynamic systematic process of management, clinical care and teaching by the nurse and occurs between the person in need of help and the person with the necessary knowledge and skills for support and guidance. The goal is prevention of illness, disability and suffering; the promotion and regaining of wellness; and to facilitate a peaceful and dignified death. Health education is a strategy meant to facilitate self-care in diabetic patients (Kotzé, 1998:4).

1.4.1.4 World

World in this study forms the research focus area and refers to the *personal* world of the diabetic patient as well as his *external* world. It includes his home environment; the nurse and the nursing environment; the world of science and technology; as well as the world of cultural diversity. According to Kotzé (1998:13) the ill person experiences conflict with his environment, his ailing body and with God. Nursing accompaniment enhances the restoration of harmony in a patient's relationship with his world, time, fellow beings and God. As a patient walks through his life world, he is confronted with certain aspects of the external world, including the diseases that he must include in his experience/understanding of his unique life world.

1.4.1.5 Accompaniment

According to Kotzé (1998:14) accompaniment is a deliberate, systematic intervention by the nurse to assist the patient/client to manage his needs and to accept responsibility for his health. In relation to illness, the theory suggests that nursing is a deliberately planned and controlled process that is realised through direct interpersonal involvement between a patient and a nurse. The diabetic patient is helped from a position of dependency to a position of independence and self-care. In accompaniment, which occurs in a planned fashion according to the identified needs of the patient, it is important that the nurse should establish a co-operative relationship between herself and the patient (Kotzé, 1998:11), and also observe ethical issues such as privacy, confidentiality, and the protection of dignity. Both the nurse and the patient have their individual and specific beliefs, norms, knowledge and experience, which should be respected (Kotzé, 1998:11).

1.5 RESEARCH DESIGN AND METHOD

The following research design and method were used in this study:

1.5.1 RESEARCH DESIGN

The design is based on a qualitative, exploratory, descriptive and contextual paradigm (Babbie, Mouton, Payze, Vorster, Boshoff & Prozesky, 2001:79). The study is further based on the phenomenological approach to inquiry, which examines diabetic patients' experiences through descriptions of their lived experiences. The purpose is to describe how Xhosa patients experience living with this disease. The researcher focuses on what is happening in the lives of Xhosa diabetics. This information is then used for the development of the research concepts and themes. This data are categorised to form a complete narrative, based on the experiences of the patients/participants (Brink, 2001:119).

1.5.1.1 Qualitative research

According to Burns and Groove (1999:475) qualitative research refers to a systematic, subjective approach, used to give meaning to life-experiences. It is a process based on specific methods of inquiry that explore social and human problems of understanding how things occur. Qualitative research is aimed at gaining an in-depth understanding of the social world. It involves exploring and describing the nature of a social phenomenon, including culture, and the interrelationship between its components (De Villiers & Van der Wall in Tjale & DeVilliers, 2004:238). The aim of qualitative research is to obtain an in-depth understanding of human beings, their relationships and their experiences. One of the major distinguishing characteristics of qualitative research is the fact that the researcher attempts to understand people in terms of where they live. The selection of a qualitative design for this study is based on the research focus, which explores and describes what it is like for Xhosa patients to live with DM.

1.5.1.2 Explorative study

An exploratory study is used to gain insight in an area for which there is little information available, to formulate a problem or to develop a hypothesis. The aim of exploratory studies is to explore a topic, to gather new data, to determine whether there are new patterns in the data and to gain new insights into the phenomenon (Babbie, et al., 2001:79). This study explores the experiences of Xhosa diabetic patients with regard to their condition.

1.5.1.3 Descriptive study

Descriptive research is aimed at providing a complete and accurate description of a situation, social setting or relationship (Fouché in De Vos, 2002:109). Creswell (1994:145) states that the data that materialise from a qualitative study are applied descriptively when the researcher is interested in the processing, meaning and understanding of facts. The study describes experiences of diabetic patients in real life situations. Understanding their experiences helps the researcher to formulate culturally congruent guidelines for the rendering of optimal nursing care to these patients.

1.5.1.4 Contextual study

In qualitative research, the researcher must understand the events holistically in their context (Babbie, et al., 2001:272). The context of this study is focussed on Xhosa diabetic patients attending an OPD at one of the local state hospitals and the environmental aspects influencing them.

1.5.2 RESEARCH METHOD

The following research methods were used in this study:

1.5.2.1 Population and Sampling method

The research population for this study consists of diabetic patients attending clinics in the OPD at a public hospital in the NMMM. A purposive sampling method was used in order to ensure that specific elements were included in the sample. In purposive sampling the selection of the participants is based entirely on the judgment of the researcher. A sample is composed of elements that contain the most characteristics of the population (Strydom & Venter in De Vos, 2002:207). The researcher, through a gatekeeper, selected the required sample. The registered nurse in charge of the unit acted as the gatekeeper. The minimum requirements for inclusion in the sample were: Xhosa diabetic patients who have been living with the disease for 2 or more years. Participants who best answered the research question were included in the sample. Pilot interviews (Brink, 2001:158) were held with two diabetic patients, using an unstructured interview technique. A pilot study is a small-scale version or a trial run of the major study (Polit & Hungler, 1993:62). It is aimed at obtaining information for improving the study or assessing its feasibility. The population in which the researcher is interested is Xhosa people living with DM. Since it is improbable to use every person belonging to this population, an accessible population of Xhosa diabetics attending OPD at a hospital was chosen. These aspects are discussed further in chapter two of this study.

1.5.2.2 Data collection

Individual interviews were held in the hospital's OPD cubicles. Privacy and comfort were maintained in a quiet environment. The research questions posed to the participants were as follows:

- Tell me how it is for you to live with diabetes? (Khawundixelela ukuba kunjani na ukuphila nesisifo seswekile?)
- Tell me of the role your ancestors and your traditional beliefs have played in your illness? (Ucinga ukuba inkolo yakho nezinyanya zakho zinenxaxheba ni kwimpilo yakho ingakumbi kwisifo seswekile?)

Probing follow-up questions were used to generate clear responses, especially when responses lacked clarity. Participants were encouraged to describe their experiences in their own cultural terms and in their own language, where-after the data were translated by an approved Xhosa language practitioner. All interviews were audio–taped, with prior permission from the participants. Comprehensive field notes were made throughout this period. Gestures and facial expressions were noted (Creswell, 1994:165). The interview took approximately 40 - 60 minutes. Each tape was transcribed verbatim within a few hours after each interview. In instances where permission for tape recording was not granted, extensive field notes and interview notes were taken (Brink, 2001:158). The interviews were continued until data saturation occured (Babbie, et al., 2001:272).

1.5.2.3 Data Analysis

Recorded interviews were transcribed and analysed, using the descriptive analysis technique developed by Tesch (Creswell, 1994:155). Once interviews were completed, the transcripts and observational field notes were subjected to coding (De Vos, et al., 2002:345). Reading and re-reading of the scripts were done in order to identify similar experiences. Opinions, values, beliefs and behaviours were identified as well as similarities, differences, strengths and weaknesses. Finally the themes were grouped into similar categories. Additional themes and concepts that were discovered were put into identified categories. Concepts within the categories were compared to identify variations. Comparison across the categories was done to discover connections between themes. Line-by-line coding was done to identify common patterns, make comparisons and contrast one set of data with another. Larger analytic categories common to groups, common to some people, or unique to some, were grouped together (Creswell, 1994:155). The researcher made use of an independent coder and both reached consensus on identified themes and sub-themes. This process is discussed more comprehensively in chapter two of this study.

1.5.3 LITERATURE CONTROL

According to Creswell (1994:23) a literature control study is used to compare and contrast results of the research with other research findings in order to avoid duplicating of existing work. Once data was collected, analysed and interpreted culturally congruent guidelines were developed in order to help registered nurses to optimise health care of Xhosa diabetic patients in the public health care sector.

1.6 TRUSTWORTHINESS

In qualitative research validity and reliability are described through strategies of trustworthiness. The key principles of good qualitative research are transferability, credibility, dependability, and conformability (Babbie, et al., 2001:276). These principles are discussed in more detail in chapter two.

1.6.1 TRANSFERABILITY

Transferability means that the findings can be transferred to other contexts or with other respondents (Holloway & Wheeler, 2002:255). In qualitative research the researcher cannot conclude that the knowledge gained from one context can be statistically generalised, but rather believes in the uniqueness of each situation, context or experience (Babbie, et al., 2001:277). Transferability is a standard against which applicability of qualitative data is assessed. An extensive, detailed and dense description of a holistic picture of the experiences of participants, and the meaning they attach to their experiences, are provided in this study (Babbie, et al., 2001:277).

1.6.2 CREDIBILITY

Credibility means carrying out the research in such a manner that the findings will be found to be objective. Peer member checks were done to check both data and interpretation, and to assess the overall adequacy of data (Babbie, et al., 2001:277). An independent coder was also used.

1.6.3 DEPENDABILITY

The findings of the study need to be consistent and accurate in order to be found dependable (Holloway & Wheeler, 2002:255). The research must provide evidence that if the study were to be repeated with the same or similar participants, in a similar context, its findings would be similar (Babbie, et al., 2001:278). Triangulation is also used to ensure dependability of the findings.

1.6.4 CONFORMABILITY

The findings of the research should be objective and focus on the inquiry and not the biases of the researcher, for it is the characteristics of the data that are evaluated and not the researcher’s views and opinions. Auditing by the supervisor and co-supervisor took place during the research process (Krefting, 1991:221). Field notes were used to provide further detail about the feelings demonstrated by the participants, either by their tone of voice or body language.

1.7 DISSEMINATION OF RESULTS

The research findings will be made available in a written document accessed via the library of the Nelson Mandela Metropolitan University. An article will be submitted to a scientific journal for publication. An in-service education workshop on the management of DM will also be presented to the registered nurses working in the public health sector in the NMMM.

1.8 ETHICAL CONSIDERATIONS

Mouton (2001:238) states that scientific research is a form of human conduct and therefore it should conform to acceptable ethical norms and values. Great care was exercised to ensure that the rights of the participants were protected. Approval was obtained from the University's Ethics Committee, which assessed whether there are any ethical issues involved, because the study involves direct patient contact (Gillibrand & Flynn, 2001:204). Permission to conduct the study and to access records were obtained from the health care institution. Research objectives were articulated to the participants both verbally and in writing. Methods of data collection were also very clearly explained, as were the data-collection devices and activities.

This research study is guided by the principle of respect for persons as stated by Brink, (2001:39). The participants had the right to decide voluntarily whether or not to participate in the study, without the risk of penalty or prejudicial treatment. The purpose of the study was clearly explained to the participants, who had the right to withdraw from the study at any time. The researcher abided by the principle of beneficence (Brink, 2001:40). No physical or emotional harm was done to the participants, who shared their experiences of living with diabetes. Should there have been any discomfort, the research interview would have been discontinued. The principle of justice (Brink, 2001:40) was observed in the selection of participants. Purposive sample selection was done fairly, from the population of Xhosa diabetic patients attending the clinic at the selected NMMM public hospital.

All participants were given the assurance of privacy during the data collection process. Anonymity of information was preserved and confidentiality maintained (Brink, 2001:41). Information was shared with the immediate research team only. The participant's rights, interests and wishes were considered in the reporting of data (Creswell, 1994:165). Thus the published research report does not identify the participants in anyway. At the end of the study the tapes were deleted in order to maintain confidentiality. Sensitivity on the part of the researcher was observed, as in-depth exploration and probing of personal areas may expose deep-seated fears that were previously repressed by the participants.

1.8.1 NO HARM TO RESPONDENTS

Because the participants can be harmed psychologically during probing of personal matters, the researcher will consciously guard against this (Babbie, et al., 2001:522). The participants were given the choice to withdraw from the study any time if they so wished (Strydom in De Vos, 2002:64). The researcher was sensitive to the delicate issues experienced by the participants. Should it have been necessary, the participants would have been referred for counselling by the researcher.

1.8.2 INFORMED CONSENT

According to Strydom (in De Vos, 2002:65) participants must have a choice to either participate or withdraw from the study at any stage. For the purpose of this study, participants signed an agreement, which was clearly articulated to them.

1.9 CHAPTER DIVISION

Chapter One	Overview of Study
Chapter Two	Research Design and Method
Chapter Three	Data Analysis and Literature Control
Chapter Four	Guidelines, Limitations, Recommendations and Conclusion.

1.10 CONCLUSION

This research study is aimed at exploring and describing the experiences of Xhosa diabetic patients, in order to develop culturally appropriate guidelines for health care programmes in order to facilitate the effective management of diabetic patients in public health care centres. In this chapter the paradigmatic perspective of the research is described, as well as the research design, strategy, methods, ethical principles and trustworthiness criteria.

CHAPTER TWO

RESEARCH DESIGN AND METHOD

2.1 INTRODUCTION

In the previous chapter an orientation to the research study was given, the research problem was identified, and the purpose of the study and study objectives were introduced. The concepts relevant to the study were described and the paradigmatic approach was discussed. In this chapter the research design, method of data collection and analysis are discussed in more detail. Data were collected on the experiences of Xhosa diabetic patients by means of semi-structured interviews. The data include the shared interpretation of both the researcher and the participants and no attempt was made to control the interaction between the two parties (Burns & Grové, 1999:37).

Data in the form of individual responses were collected, categorized, sorted and organized into themes, which were later coded by an independent coder and the researcher (Burns & Grové, 1999:37). The findings of this study are unique and are not intended to be generalized and applied to a larger population. Understanding the experiences of Xhosa diabetic patients related to their living with DM is useful in order to understand the needs and experiences of other patients in similar situations.

2.2 RESEARCH DESIGN

Numerous and ambiguous definitions of the term research design exist. Fouché (in De Vos, 2002:71) identifies terms such as strategies, methods, traditions of inquiry and approaches as related to the term design. All these terms refer to the decisions a researcher makes in planning his/her study. Creswell 1998 (quoted by Fouché in De Vos, 2002:272) identifies five strategies of inquiry, or traditions, that could be used to design qualitative research. These are biography, phenomenology, grounded theory, ethnography and case study.

According to Polit and Hungler (1993:225) a research design refers to a researcher's overall plan for obtaining answers to the research questions. The research design spells out the strategies that the researcher adopts to develop information that is accurate, objective and meaningful. The research design also designates in what setting the study will take place, which may be in naturalistic environments such as in clinics or in people's homes. The research design stipulates the fundamental form that the research takes, which incorporates the data collection plan, the sampling plan and the analysis plan. Furthermore, qualitative researchers almost always create their own design which is best suited to their research, or even design their whole research project around the strategy selected. The qualitative research strategy differs from the quantitative research design in that it does not usually provide the researcher with a step-by-step plan or a fixed recipe to follow (Fouché in De Vos, 2002:72). According to Burns and Grové (1999:228) the research design is a blueprint for the conduct of a study and it directs the researcher in planning and implementing the study in a way that is most likely to achieve the intended goal.

This study is grounded in a phenomenological approach to inquiry, which is aimed at understanding and interpreting the meaning that the participants give to their everyday lives (Fouché in De Vos, 2002:73). This was mainly achieved by following a naturalistic method of study; analyzing the conversations and interactions between the researcher and the participants. Data was systematically collected and meanings, themes and general descriptions of experiences were analysed within a specific context (Fouché in De Vos, 2002:273). The product of this study is a description of the essence of the experiences of Xhosa patients living with DM. This study is based on a qualitative, explorative, descriptive and contextual design.

2.2.1 QUALITATIVE RESEARCH

This study was conducted within the qualitative paradigm, of which the major distinguishing characteristic is the fact that the researcher attempts to understand people in terms of their own definition of their world (Holloway & Wheeler, 2002:3). Qualitative research has its roots in anthropology, sociology and philosophy, as it is meant to study how people make sense of their world and their experiences (Holloway and Wheeler, 2002:8). Burns & Grové (1999:35) state that qualitative research is a systematic, subjective approach, which explores life experiences and the meaning given to these experiences. It enables the researcher to build a complex and holistic picture in a natural setting where human behaviour occurs, reporting specific views of the participants through the analysis of words. The focus of qualitative research is complex and broad and the intent of the research is to give meaning to the whole experience of the participant.

In this study, the characteristics of qualitative research, as described by Creswell (2003:179), were used:

- this study took place in a natural setting, namely the clinics, as opposed to the artificial settings of experiments and surveys. This enabled the researcher to be highly involved in the actual experiences of the participants;
- the methods used for data collection involved active participation by participants and the researcher tried to build rapport and credibility

with the participants. The researcher tried to put herself in the shoes of the people that she studied, in order to understand their actions, decisions, behaviour, practices, and rituals, from their perspective. Babbie, et al., (2001:271) also emphasizes that qualitative research is an attempt to view the world through the eyes (perspective) of the participants;

- a dense description, which is an important characteristic of qualitative research, was used. A dense description is a lengthy description that captures the sense of actions as they occur. Detailed descriptions of events, settings and situations as experienced and understood by participants were put in correct context for the interpretation of results (Babbie, et al., 2001:272);
- a non-judgmental attitude; introspection; acknowledgement of biases, values and interests; openness; and honesty were the researcher's focal points;
- qualitative research largely uses an inductive approach, reasoning from the specific to the general. By utilizing a qualitative approach in this study an attempt was made to understand Xhosa diabetic patients' experiences of living with DM in their everyday lives.

2.2.2 EXPLORATORY STUDY

The aims of an exploratory study are to establish the facts; explore topics which are relatively unknown; formulate a problem; and develop a hypothesis for further study (Babbie, et al., 2001:79).

Babbie, et al., (2001:79) further state that exploratory studies are done for the following reasons:

- to satisfy the researcher's curiosity and desire for better understanding of a topic;
- to test the feasibility of undertaking a more extensive study;
- to develop the methods to be employed in any subsequent study;

- to explicate the central concepts and constructs of a study;
- to determine priorities for future research; and
- to develop new hypothes about an existing phenomenon.

In this study, an explorative design is used to investigate how Xhosa diabetic patients experience their condition. Although limited, a purposive sample is used to enable the researcher to generate new knowledge. Culturally congruent guidelines for registered nurses were then developed, in order to optimise health care of Xhosa diabetic patients in the public health care sector.

2.2.3 DESCRIPTIVE STUDY

Descriptive research is aimed at providing a complete and accurate description of a situation, social setting or a relationship (De Vos, et al., 2002:109). It provides a more detailed understanding of the topic being studied. A descriptive study provides a description of the variables in order to answer the research question. In a descriptive study social aspects are observed, described and explored (Brink, 2001:109).

This research study utilizes semi-structured interviews, where the participants describe their experiences of living with DM. During data analysis similar patterns and common themes were identified. The themes were then interpreted, allowing for a description of the lived experiences of Xhosa diabetic patients.

2.2.4 CONTEXTUAL STUDY

According to Holloway and Wheeler (2002:11) contextual research describes the space and environment of interaction. This includes cultural and historical implications, which are important for understanding the phenomenon being studied. The researcher gives a description of the reality, typical to a specific context in which the phenomenon occurs. The total context of the participants' lives will affect the findings of the study (Holloway & Wheeler, 2002:11). The context involves situating the object of the study or phenomena of study within its immediate setting (Creswell, 1998:68).

In this study a contextual design is used to describe the experiences of Xhosa diabetics. The aim is to describe the experiential world of Xhosa-speaking patients with DM, utilising the NMMM public hospitals complex OPD. The diabetic clinic in the OPD operates daily and patients are seen at monthly intervals and when necessary. The OPD serves the neighbouring black population from the surrounding townships as well as the informal settlements. The effects of urbanisation have resulted in this area having a semi–rural, semi-urban population that is mostly Xhosa speaking. The bulk of the population is unemployed, while others are living on a minimal income. In some homes there is no or little money to buy food, and even less to make use of a health service. Some people live on either a social grant for the elderly, a grant for young children or a disability grant and most people in this area have an income below the level at which payment of taxes for contribution to the economy is possible. The physical environment as well as the socio-cultural context play an important role in the lives and experiences of these people. This is evidenced by the sentiments of the poem by Qaqamba in the first chapter. Respect for patients' culture is important so as to understand the situation being studied.

2.3 RESEARCH METHODS

Research methods are the techniques used by researchers to structure a study and to gather and analyze information relevant to the research question (Burns & Grové, 1999:13). In this study data collection and analysis are implemented in two phases:

2.3.1 PHASE ONE

Exploration and description of the experiences of Xhosa diabetic patients related to their living with DM.

This phase involves identifying the research population and sampling method; data gathering through in-depth, semi-structured, phenomenological interviews; data analysis; and literature control. The stages involved in phase one are described as follows:

2.3.1.1 Target population

The population in a research study is the entire group of persons or objects that are of interest to the researcher (Brink, 2001:132). Population refers to all the individuals who meet the sample criteria for inclusion in the study, while sample refers to the subset of the population that is selected for a study (Burns & Grové, 1999:776). In this study the population consists of all Xhosa diabetics attending the clinics linked to the P.E. Hospital Complex in the NMMM. The units of analysis will be diabetic patients attending a clinic at the OPD of one of the public hospitals a public hospital in the NMMM.

2.3.1.2 Sampling method

A purposive sampling method was used in order to ensure that specific elements were included in the sample. The approach employed a high degree of selectivity, where readily available people for the study were chosen (Brink, 2001:140). The sample consisted of elements, containing the most characteristics of the population. The researcher visited the public hospital on pre-arranged dates and the Xhosa diabetic patients available at that time were included in the sample. This was pre-arranged with the management of the hospital. The researcher relied on her own judgment in selecting participants who would be representative or typical of the chosen population of Xhosa diabetics. The purpose of this study is to understand the world as experienced by this group of people. Continuous sampling was done until data saturation was reached (Kvale, 1996:102).

The minimum criteria for inclusion in the sample are:

- Xhosa diabetic patients;
- who have been living with the disease for two or more years;
- who were willing to participate in semi-structured interviews; and
- who attended the clinics linked to the PE Hospital complex**.**

2.3.1.3 Data collection

The data were collected by means of semi-structured, individual interviews. This is discussed under the following headings:

- phenomenological interviews;
- field notes;
- role of the researcher.

2.3.1.3.1 *Phenomenological interviews*

In-depth, semi-structured interviews were the primary tools used for data collection in this phenomenological study, since a comprehensive description of how to live with diabetes is the aim of the study. The interviews were scheduled during the off-duty time of the researcher in a private cubicle in the hospital's OPD. The interviews were well suited for exploring and clarifying issues related to the context of the study. Informed consent was obtained from the participants, who subsequently agreed to be tape-recorded. The participants were informed about the aim of the study, the voluntary and confidential nature of their participation, as well as the possible outcome and benefits of the study and a written consent form was signed.

A pre-determined, general opening question was posed to each participant and the participants were allowed to give their own perspectives freely and were encouraged to discuss issues beyond the confines of the question (Struwig & Stead, 2001:98).

The following opening question was used in all the interviews:

> *Tell me how it is for you to live with diabetes? (*Khawundixelele ukuba kunjani ukuphila nesisifo seswekile?)

The following question was asked to explore the cultural aspects of the target group. Participants were encouraged to describe their experiences in their own cultural terms:

> *Tell me of the role your ancestors and your traditional beliefs have played in your illness. (*Ucinga ukuba inkolo yakho ne zinyanya zakho zinenxaxheba kwimpilo yakho ingakumbi kwisifo seswekile?)

The researcher also had to rely on techniques such as observation of non-verbal cues.

A pilot study consisting of two patients who met the inclusion criteria was undertaken. This was done to identify possible problems that were likely to occur in this study and to plan strategies to avoid further problems. Probing follow-up questions were used to generate more responses, especially when responses lacked clarity and this resulted in more issues related to the study being explored.

2.3.1.3.2 *Field notes*

According to Polit and Hungler (1993:436) field notes are made by the researcher about observations that are made in the field. Field notes help to supplement recorded interviews in that the physical setting and impressions made on the researcher by the participants are included in the field notes.

In this study, several types of field notes were made during and shortly after interviews for cross-referencing with recorded interviews (Morse & Field, 1996:91). Relevant information that would not be on audio–tapes was noted and explained. A tape recorder with audiocassettes was used to record the interview sessions with prior permission from the participants. Interviews were transcribed verbatim as soon as possible after each interview and the researcher ensured that no names appeared on the tapes, which were destroyed once the research was completed. Comprehensive field notes were documented throughout this period.

Field notes deepened the insight of the researcher into the life-world of the participants. Gestures and facial expressions were noted (Creswell, 1994:165). Once the participants repeated the same or similar information without giving new information, interviews were stopped because data was saturated (Streubert & Carpenter, 1995:124). The interviews lasted between 40-60 minutes for each participant. A separate journal was kept by the researcher for documenting insights, reactions, questions and impression during the interview sessions (Tutty, Rothery & Grinnel, 1996:80). After the interview, field notes about the interview sessions were written and the researcher’s impressions documented.

- **Observational notes**

During the interviews the researcher gained useful insight into the phenomenon being studied by observing the physical surroundings, verbal responses, and non-verbal behaviours, including facial expression, body language and physical attitude of the participants (Holloway & Wheeler, 2002:104). Observational notes gave an account of what happened; the who, what, when, where and how of human behaviour. Written descriptions of the events were recorded as they were described by the participants (Wilson, 1989:434).

- **Theoretical notes**

Wilson (1989:435) described these notes as purposive attempts to derive meaning from observational notes. These are self–conscious, systematic attempts by the researcher to derive meaning from observational notes (Kvale, 1996:96). The researcher identified common patterns of behaviour that were repeatedly found in different interviews and drew her own interpretations and inferences from observational notes in order to assist with constructing and identifying the themes of the study.

- **Methodological notes**

Methodological notes are instructions used to critique the researcher's methodological approaches (Wilson, 1989:435). In this study the research questions and objectives of the study were relevant to the design and to the methodology chosen.

- **Reflective notes**

These are notes about one's own reflections, experiences and internal environment (Wilson, 1989:435). Creswell (1994:152) describes reflective notes as an opportunity for the researcher to record personal thoughts, for example, suppositions, feelings, problems, ideas, intuition, impressions and biases. In this study, these notes provided additional insight into the experiential world of Xhosa diabetic patients.

2.3.1.3.3 *Role of the researcher*

Creswell (1994:145) describes the primary role of the researcher in qualitative research as that of data collector, as well as the instrument of data analysis. During data collection the researcher stays focussed and listens actively to the descriptions of experiences, as well as what is said 'between the lines' (Kvale, 1996:32). According to Burns and Grové (1999:428) the quality of the data collected depends on the quality of the interviews and observations.

In this study the interviewer established rapport and trust with the participants during data collection. Privacy and comfort were maintained in a quiet, relaxed environment throughout the interview sessions. Informed consent was explained and forms signed by participants, permitting them to withdraw from the study anytime they feel uncomfortable. The participants were aware of the aim of the study, and of the use of a tape recorder to capture information during the interviews. Confidentiality was and will be maintained, even on completion of the study. During the interview the participants were encouraged to talk freely without any interruptions and interviews continued until data saturation occurred, which was after ten interviews.

- **Communication**

According to Anderson (1990:25), communication is an active, ongoing process in which people exchange messages using verbal or non-verbal means to effectively convey the intended meaning to the other person. An open ended statement (*"Tell me how it is for you to live with diabetes?* Khawundixelele ukuba kunjani na ukuphila nesisifo seswekile*?")* gave the participants more control over communication, allowing them to freely verbalise their views and feelings about the phenomenon being studied. Probing questions were used to obtain more information in a friendly, non-threatening and re-assuring way (Kvale, 1996:133). Statements such as *"tell me more"* were used.

Different groups have distinct communication customs, for example, in a black culture eye contact is not as important as in other cultures. The researcher was aware of the participants' culture and how to enhance effective communication with them. It was difficult for the participants to share their experiences, as they could not clearly express their feelings when asked *how it is for them to live with diabetes*. This posed a problem during the interpretation of the tapes, because of a lack of adjectives the information given by the participants seemed to be scanty and not clearly descriptive of their feelings.

The following are some of the major verbal techniques that facilitate communication during a face-to-face encounter.

- **Clarifying**

According to Anderson (1990:57) to clarify is to make clear, to free of confusion and this is essential for effective communication. Clarifying is an attempt to focus on or to understand the basic nature of a statement, for instance, *"Do I understand you correctly when I say you feel …?"* (Kvale, 1996:135).

- **Reflecting**

The use of reflecting involves the repetition of all or parts of messages. Reflection is especially useful in helping the interviewee express feelings and non-verbal behaviour, as it tends to stimulate elaboration on areas that have been vaguely expressed. An example that could be used is, *"You are feeling … because ... ."*

- **Silence**

The researcher used silence, where applicable, to encourage further disclosure by participants (Kvale, 1996:134). Silence gives both the interviewer and participants time to reflect on what has been said, but should not be overused since it can create anxiety (Anderson, 1990:62).

- **Minimal verbal response**

This indicates that the researcher is listening and following what is being said. This could include head nodding or verbal cues such *as "mm-mm", "yes"* and *"I see"*. The interviewer sometimes remained quiet and allowed more time for the participant to talk.

- **Sequencing**

According to Anderson (1990:59) sequencing means placing events in a time sequence. Patients sometimes relate a series of events out of order, making it difficult to understand the sequence of events.

- **Summarizing**

Closure of an interview is achieved by means of summarizing the key points that were identified during the interview in a brief form, which unifies the main themes, content and feelings. This promotes mutual understanding between the interviewer and the participants (Anderson, 1990:59).

The interviews were discontinued once saturation of data occurred. Audio-tapes were numbered, transcribed and taken for independent coding. Participants were given the opportunity to ask questions, to verbalise their perceptions of the interview and were thanked for their willingness to participate in the study.

2.3.1.4 Data analysis

After ten in-depth, unstructured interviews data were deemed saturated, as no new themes emerged. This means the participants started giving similar information without contributing any new information. According to Lincoln and Guba (in Tutty, et al., 1996:82) data are saturated when all resources have been exhausted and all the categories in which the researcher hoped to collect data were covered.

To reduce data the researcher, with the help of an independent coder transcribed and analysed the data into manageable categories, themes and sub-themes. In order to get a general sense of the information the researcher started the analysis process by carefully reading through the transcriptions, using the eight steps developed by Tesch (Creswell, 1994:155) as outlined below:

- the researcher selected one interview and analysed the underlying meaning;
- when the researcher had completed this task for several respondents, a list was made of all topics and similar topics were clustered together;
- the researcher then took the list and returned to the data, where topics were abbreviated as codes and the codes written next to the appropriate segments of the text;
- the researcher found the most descriptive wording for the topics and turned them into categories;
- the researcher made a final decision on the abbreviations for each category;
- the data belonging to each category were assembled in one place and a preliminary analysis performed;
- themes and sub-themes were identified; and
- on completion of data analysis and identification of relevant themes, the researcher and independent coder met to discuss recurring themes and to reach consensus on the themes and categories identified (De Vos, et al., 2002:245).

2.3.1.5 Literature control

A literature control study was done to provide a framework as well as a benchmark for comparing and contrasting the results of the identified themes (Creswell, 1994:3). Holloway and Wheeler (2002:30) describe the reasons for conducting a literature review study as follows:

- to establish what is already known about the subject and to identify gaps;
- to describe how the study contributes to existing knowledge; and
- to avoid duplication.

The purpose of phase one was to understand the experiences of Xhosa diabetic patients from their subjective points of view, by identifying their experiential world and thus giving meaning to their experiences (Willing, 2001:141). The findings of this qualitative research study are not intended to be generally applied to a larger population.

2.3.2 PHASE TWO:

After the data had been analysed and interpreted in phase one, culturally congruent guidelines were developed for registered nurses in order to optimise health care of Xhosa diabetic patients in the public heath care sector. These guidelines were developed based on identified themes and a literature review study.

2.4 TRUSTWORTHINESS

Although reliability and validity are relevant to quantitative research, they are not used in qualitative research to measure quantity. As a result, certain criteria of quality evaluation are used in a qualitative study. In this study trustworthiness was ensured by using Guba's model, which includes: credibility, transferability, dependability and conformability (Krefting, 1991:215).

2.4.1 CREDIBILITY

Reliability plays a minor role in qualitative inquiry, while validity is seen as a strength and is used to determine whether the findings are accurate from the standpoints of the researcher, the participant and the reader (Creswell, 2003:196). Credibility corresponds to the notion of internal validity and was used in this study to consider the true value of the researcher's findings, and to demonstrate that the guidelines are credible and valid for use by registered nurses in the public sector (Holloway & Wheeler, 2002:250).

In this study enough time was spent with each participant to enable the researcher to establish a familiar relationship with each participant (Krefting, 1991:18).

2.4.2 TRANSFERABILITY

Transferability means that the findings can be applied to other contexts or with other respondents, and the knowledge acquired in one context will be relevant in another (Holloway & Wheeler, 2002:255). The findings of this study are transferable to similar culturally congruent studies, because the researcher collected sufficiently detailed descriptions of data (thick descriptions) to allow judgments about transferability to be made. Purposive sampling as opposed to random sampling, was used to maximize the specific information that was required (Babbie, et al., 2001:277).

2.4.3 CONFORMABILITY

In qualitative research conformability has taken the place of the term objectivity. The research is judged by the characteristics of the data and not by the researcher’s biases. Conformability has become the accepted term for qualitative research (Hollloway and Wheeler, 2002:253). Thick description allows the researcher to establish the degree of conformability of the findings. Thick description is done by making extensive use of field notes that should be recorded directly after the interview has taken place. Field notes can be used to give further details about the feelings demonstrated by the participants, either by tone of voice or body language. In this study the supervisor and co-supervisor did auditing and this enhanced the conformability of the research study (Krefting, 1991:221).

This research study was open to objective public auditors, through auditing and scrutinizing by supervisors for honesty and openness (Holloway & Wheeler, 2002:255).

2.4.4 DEPENDABILITY

In qualitative research dependability is used instead of reliability. The findings of the study need to be consistent and accurate in order to be found dependable. The context of the research must also be described in detail in order to help the reader to follow the path of the research process (Holloway & Wheeler, 2002:255). The researcher must provide the reader with the assurance that if the study was to be repeated with the same or similar participants, in a similar context, its findings would be similar (Babbie, et al., 2001:278).

2.5 ETHICAL CONSIDERATIONS

In this study great care was exercised to ensure that the rights of participants were protected. Approval of the research proposal was obtained from the Advanced Degrees Committee of the Nelson Mandela Metropolitan University and permission was also granted to continue with the study (see Annexure G). Permission to conduct the study and to access patients' records was obtained from the Nursing Service Manager of the hospital, the Assistant Director: Training and Development, and the P.E. Hospital Complex Clinical Governance Head (see Annexures B, C and D). Purposive sample selection was fairly done, the aim and objectives of the research study, and the methods of data collection, were articulated verbally and in writing to the participants.

De Villiers and Van der Walt (in Tjale and De Villiers, 2004:255) state that qualitative research is the research of preference in cultural and transcultural studies and suggest that the following ethical considerations which were observed by the researcher during this study:

- ethics are about doing what is good and right;
- ethics and culture are inseparable from each other;
- ethics form the care and caring aspect of research;
- a culture of research ethics needs to be established in all health-care institutions in which research is conducted;
- an ethics committee serves as a constant gatekeeper, binding individual researchers to the research culture; and
- every individual research project poses it's own unique ethical problems.

According to Seaman (quoted in Tjale and De Villiers, 2004:256) the researcher's responsibility is towards the participants, who have the following rights:

- the right not to be harmed;
- the right to self–determination and informed voluntary consent;
- the right to privacy;
- the right to confidentially and anonymity;
- the right to maintain self-respect and dignity; and
- the right to refuse to participate or to withdraw from participation without fear of recrimination.

The researcher used the above aspects to comply with ethical considerations by allowing the participants to sign a consent form, which permits them to withdraw from the study any time they so wish (see Annexure A).

2.5.1 CONFIDENTIALITY AND ANONYMITY

Individuals who agree to participate in a research study have the right to expect that the information collected from or about them will remain private. Confidentiality refers to the researcher's responsibility to protect all data gathered during the study from being divulged or made available to any other person without the permission of the participants. Anonymity refers to the act of keeping the participants nameless in relation to their participation in the research study (Brink, 2001:41). Privacy, anonymity and confidentiality were maintained throughout this study and the published research report does not identify the participants in any way. At the end of the study the tapes were deleted in order to maintain anonymity and confidentiality.

2.5.2 INFORMED CONSENT

Informed consent means that the participants have adequate information regarding how, where and what is to be done in the research. It is the researcher's responsibility to provide the participants with sufficient understandable information, which may be verbal, written, or by means of a taping device (Brink, 2001:42). The participants were informed of their right to withdraw from this study at any time (see Annexure A).

2.5.3 PRINCIPLE OF BENEFICENCE

This principle implies the duty to do and promote good (Pera & Van Tonder, 1996:23). No physical or emotional harm was done to the participants while sharing their experiences (Babbie, et al., 2001:522). The researcher was sensitive to the delicate issues experienced by the participants, who were promised counselling, should the need arise.

2.6 CONCLUSION

In this chapter a more detailed description of a qualitative research design is given. Phase one entails the sampling procedures, data collection, data analysis and literature control, while phase two entails construction of culturally congruent guidelines for registered nurses working in the OPD. The chapter is then concluded with a discussion on ethical considerations.

In the following chapter, a discussion of the research results and identified themes are provided.

CHAPTER THREE

DATA ANALYSIS AND LITERATURE CONTROL

"Bring it on"

A long time ago, but not too long to recall,
My eyes and balance were blurry, and I became likely to fall.
My skin became dry, and I lost some pounds of weight,
Frequenting the loo as I started to dehydrate.
Then a prick from a doctor explained all that,
My glucose was twenty and I'd have to adapt.
He said, " Most diabetics live long so there's no need to worry,
It's just a change in your lifestyle that will fix this story"
"Just change" I expected a pill or a simple remedy,
But never could I guess the extent of this therapy!
A diet, good exercise and injections galore,
Finger pricks and urine sticks, could there be any more?
I struggled at first, unsure of how to cope,
And completed the entire circle of denial, without hope.
Injections were my enemy, and finger pricks the devil.
But diabetes conquered the rebel, when it slammed me onto the ground level.
I was a little naughty, actually "naughty" is quite tame,
But it left me feeling pretty bad and in a lot of pain,
When two drips finally re-hydrated me and I had to make a move,
I headed for the hospital and was put in ICU
"Near-death" was not the case, but a coma was quite real,
But I managed to pull through it, and far better I would feel.
I woke up then and there, splashed cold water on my face,
And told myself I'll never again let some ketones start that race.
Now it's been a couple of years since that day in 2001.

By Mark Koekemoer (Type 1 Diabetes for eight and a half years)

(Diabetes Focus, Spring 2005)

3.1 INTRODUCTION

The goal of this study is to explore and describe the experiences of Xhosa diabetic patients. The data will be used to develop culturally congruent guidelines for registered nurses, in order to optimize the health care of Xhosa diabetic patients in the public health care sector, with emphasis on areas identified during this study.

In chapter two a full description of the research design and method was given, as well as the generic steps for data analysis. How data was organized, prepared for coding and how themes and sub-themes were identified, was also included. This chapter outlines the results of the study and discusses the findings, as derived from in-depth, semi-structured interviews with Xhosa diabetic patients regarding their experiences of diabetes. Interviews continued until data saturation occurred, thus, until no new data emerged.

3.2 DESCRIPTION OF SAMPLE

The sample for this study consisted of ten diabetic patients, eight participants who were included for the main study and the other two who were included in the pilot study. Nine females and one male were purposefully handpicked on the basis of their first hand experience of DM. They were all attending a specialist Out Patient Department (OPD) clinic in one of the Port Elizabeth Complex's hospitals in the NMMM and their ages ranged between 50 and 65 years. Erasmus, et al., (2001:158) also highlighted a prevalence of DM in factory workers from the Transkei, and observed that the highest prevalence of DM was in subjects between the ages of 50 and 59 years. The duration of their condition ranged from two to twenty eight years, while the incidence of complications ranged from none to eye complications, hypertension and impotence. In a study by Ricks (1999:94) on the assessment of specific variables relating to the health status of Xhosa people in Port Elizabeth, it was highlighted that more females than males were suffering from DM. The age groups of the individuals at the time of diagnosis reflected that 87% of the respondents suffering from DM were diagnosed between the ages of 30 - 69 years. According to De Haan (1996:74) an ageing population has certain implications for a society such as:

- a large proportion usually live in poverty and must be provided with financial aid in the form of old-age pension;
- the incidence of disease and disability increase with advancing age and this leads to greater demand for medical services and institutional care; and
- as they are economically inactive, they have to be supported by those who are working.

In this study, the demographic data showed that some participants were married; others were single parents, all had dependents, a few were employed, but the majority were unemployed with the minimum monthly wage being R350. Some of these participants had their disability grant discontinued and had no other financial assistance, while the pensioners were living on old age pensions.

Patients who had attended these specialist diabetic clinics were referred from the primary health care clinics in the NMMM. The minimum criteria for inclusion in the sample were:

- Xhosa diabetic patients who have been diagnosed with the disease and have been living with it for two or more years;
- who were willing to participate in semi-structured interviews; and
- who attended the OPD clinic at the Port Elizabeth complex hospital.

3.3 THE INTERVIEW PROCESS

To establish an appropriate interview technique, two pilot interviews were carried out using an semi-structured format, which was also followed on a one on one basis with the rest of the participants. No inadequacies were detected from the observations made during the pilot study. The interviews were conducted in the hospital's OPD's private consulting rooms and observational notes were made of gestures, and facial expressions were also recorded. The following two open-ended questions were posed to the participants in Xhosa:

- Tell me how it is for you to live with diabetes? (Khawundixelele ukuba kunjani na ukuphila nesi sifo seswekile?).
- Tell me of the role your ancestors and your traditional beliefs have played in your illness? (Ucinga ukuba izinyanya zakho nenkolo yakho zinenxaxheba kwimpilo yakho ingakumbi kwisifo seswekile?).

The researcher's focus was maintained through reflexive probing questions, guiding the participants when additional information was required or vague answers were clarified. The recorded interviews were conducted in Xhosa, and were later translated into English by the researcher and verified by a Xhosa language practitioner. All participants gave their informed consent and were informed of the fact that they could withdraw from the study at any time. Great care was taken to ensure that their rights were protected. This included confidentiality, anonymity, privacy and the maintenance of dignity, as discussed in chapter two. All participants were type 2 diabetics on oral anti-diabetic treatment and/or insulin injections.

Participants were encouraged to respond freely in a narrative form, using their own words while sharing their experiences. The interviews took between 45 to 60 minutes each. The researcher should understand people in their natural setting and try to put himself or herself in the shoes of the people being studied, in order to try to understand their actions, practices and rituals from their perspectives (Babbie, et al., 2001:271).

3.4 DATA MANAGEMENT

Data was collected by means of unstructured interviews, which were tape-recorded. On completion of the interviews the data was translated and transcribed verbatim by the researcher, according to the method described in Creswell (1994:155). Field notes were used to capture and interpret non-verbal impressions during interviews (Mouton, 1996:108). The researcher read and re-read the transcripts in order to become familiar with the data to be coded. Following coding, the final categories and themes were identified.

An independent coder, experienced in the field of qualitative research, was requested to identify themes and sub-themes relating to the collected data. The researcher and independent coder met to compare identified themes, to reach a consensus on identified themes and sub-themes together and confirmed that data was saturated. Meetings also took place between the study supervisors and the researcher and consensus was reached on identified themes.

3.5 IDENTIFIED THEMES AND LITERATURE CONTROL

In this chapter, incorporated into the discussion of the themes, a literature control study is included to re-contextualize the themes and sub-themes identified during data analysis (Morse & Field, 1996:106). The identified themes and sub-themes are presented, discussed and supported by relevant quotations from the participants, who are regarded as reliable storytellers in qualitative research (Holloway & Wheeler, 2002:14). The content of the quotations will help the reader to judge how the results were derived from the data and also give insight into the people's real experiences by illustrating the arguments (Holloway & Wheeler, 2002:247).

The views of the participants were categorised into themes and sub-themes. The results are presented in a table format of four themes and relevant sub-themes (table 3.1). The researcher explains the identified themes, which is supported by verbatim quotations from the participants, where-after it is re-contextualised within the framework of existing literature. The quotations are presented as transcribed by the researcher, without corrections.

TABLE 3.1 IDENTIFIED THEMES AND SUB-THEMES RELATED TO THE EXPERIENCES OF XHOSA DIABETIC PATIENTS

MAIN THEMES	SUB-THEMES
Xhosa diabetic patients: 1. Experience being diagnosed with the disease as well as the progress of their disease on an emotional level.	Xhosa diabetic patients: 1.1 Understand the physical symptoms of their disease. 1.2. Are aware of their blood sugar levels and actions to be taken, depending on the results of blood sugar tests. 1.3. Believe that treatment compliance is helpful in the management of their disease 1.4. Believe in the use of both western and traditional medicine. 1.5. Are afraid of physical complications related to the disease. 1.6. Are concerned for their families in the event of their death.
Xhosa diabetic patients: 2. Verbalise different views about the role of registered nurses in the management of their disease.	Xhosa diabetic patients: 2.1. Verbalise fear of being scolded by registered nurses when their "sugar" is high. 2.2. Verbalise that registered nurses are good educators who take care of them although they sometimes default their treatment. 2.3. Believe that privacy during consultations can improve communication between nurses and patients.
Xhosa diabetic patients: 3. Experience financial hardships due to unemployment which impacts on their disease management.	Xhosa diabetic patients: 3.1. Experience poverty, which is a contributory factor to non-compliance in the management of diabetes.
Xhosa diabetic patients: 4. Have opposing beliefs about the role of their ancestors and God related to their disease.	Xhosa diabetic patients: 4.1 Believe that the 'sugar' is a physical disease, not related to ancestral influences. 4.2 Believe that the ancestors will assist in their cure for diabetes. 4.3 Believe that God controls their health.

3.5.1 THEME 1: XHOSA DIABETIC PATIENTS EXPERIENCE BEING DIAGNOSED WITH THE DISEASE AS WELL AS THE PROGRESS OF THEIR DISEASE ON AN EMOTIONAL LEVEL

Diabetes is more than just an inconvenience, the condition impacts strongly upon all aspects of a person's life. The way an individual has experienced life prior to being diagnosed changes and the individual tries to conform to new rules, which may seem confusing to her and those that are close to her. All participants experienced being diagnosed as well as the progress of their disease on an emotional level. The intense feelings such as shock, fear, grief, anger and anxiety, though difficult to express accurately, were manifested in the participant's responses.

At first, being diagnosed with DM is equated to experiences related to the death of a loved one and is often accompanied by negative emotions, anger, frustration, helplessness and loneliness. A diagnosed patient will go through all the stages of grieving. The first goal of assisting patients in coping with DM is for the health care professionals to understand what it is that the patients typically experience in the coping process. This can be achieved by considering the experiences of an individual when being diagnosed with DM.

The way the participants understood their lives differed from one to another, nevertheless, most participants found their perception mostly functional for their daily living as they try to cope and feel comfortable with their existence. Although most people have a natural ability to cope, with some people coping tends to take longer.

Participants in this study expressed different feelings about DM (referred to by participants as 'sugar') and how it affects them. Fear of having a chronic disease like DM was manifested in the patient's responses. When asked how it is for them to live with the disease, the participants reported feelings of anxiety, despair, fear, inadequacy and shock in varying degrees. Some participants were shocked at the knowledge that their symptoms constituted DM. Most of the study participants did not comprehend the physical symptoms of their chronic condition until a nurse or a medical doctor informed them. The following discussions will consider typical ways in which individuals act and feel during the time they are adjusting to being diagnosed.

As DM passes through its several clinical stages, patients experienced feelings of anxiety, not knowing what their symptoms entail. As one participant verbalized:

> *"I was scared … I didn't know it's sugar … I only heard in hospital what was wrong with me … . "*

Lack of control over this chronic illness evokes feelings of helplessness and frustration, as patients feel challenged by the physical symptoms they experience. Some participants expressed feelings of despair, as illustrated by the following participant:

> *"Living with this disease is difficult … it is not nice to have sugar … . "*

Patients are usually diagnosed with DM either as part of the surveillance of high-risk groups such as pregnant mothers attending antenatal clinics or because they present with the typical symptoms at a doctor’s surgery or clinic. The following statement made by a participant illustrates this:

> *“I was working on a farm … I had dizzy spells … my eyes were red … I decided to go to the local clinic … . They checked me and told me I had high blood and sugar.”*

A medical doctor will confirm the diagnosis, using the following criteria (blood glucose concentrations are based on venous plasma samples):

1. In the presence of symptoms of hyperglycemia (polyuria, lethargy, polydipsia, pruritis, loss of weight):
   - random blood glucose ≥11.1 mmol/l
   - fasting blood glucose ≥ 7.8 mmol/l confirms the diagnosis of DM
2. In a symptomatic patients:
   - a single random blood glucose >11.1mmol/l.
   - fasting blood glucose >7.8 mmol/l is inadequate for diagnosis; the abnormal value must be confirmed at least once before DM is diagnosed.
3. If the results are equivocal, the patient requires a glucose tolerance test with ingestion of 75g of oral glucose after an overnight fast. The diagnosis of DM is established if the fasting blood sugar is ≥7.8mmol/l and /2 hours post load blood glucose is ≥ 11.1mmol/l (Ncayiyana, 1997:499). The following participant confirms this as follows:

   > *“The nurse took blood from my arm … those days there was no prick … I waited for two hours for my blood results … .”*

4. The presence of glycosuria (glucose in urine) is a strong indicator of DM. This must be confirmed by blood sugar estimations. The following participants could verbalise how they were diagnosed:

   " … I went to the doctor … he checked my urine … he told me I have sugar… ."

   " … I went to the clinic … the doctor there did some investigations … checked my sugar … he told me I have sugar …."

Rheeder (1997:10) specifies the people who should be screened by medical nursing/personnel for DM. According to the demographic data on patient records, the participants belonged to one or more of the specified criteria as listed below:

Patients with classical symptoms of DM:

- obese patients;
- those with a strong family history;
- patients with previous gestational diabetes;
- delivery of a baby of more than 4kg;
- pregnant women between the 24th and 28th week of gestation;
- the patient with hypertension;
- the patient with dyslipidemia;
- those with recurrent skin or genito-urinary infections; and
- the elderly over 65 years.

The following participant was overwhelmed by the progress of her DM, to such and extent that she could not see any hope in life:

> *"It is not good … I thank God's mercy … I nearly died … I was very, very sick with this sugar … very sick … I felt bad …sometimes I wished God could take me to Him … because you don't feel yourself … you need help … sometimes you don't know what to do … My mouth used to feel dry. It was painful … you don't feel good … you don't feel fresh … you are unhappy … . The other problem that I experienced was feeling hungry all the time … when you are hungry you feel as if you are going to faint there and then … You want food … you must have something … even a sweet … you feel better after that … even a slice of bread … if I don't get food for a long time I feel shaky as if I am going to die … I don't like it … ."*

DM can have a great impact on the patient's mood, both short-term and long-term. The participants felt chronically frustrated, discouraged or enraged with a disease that often does not respond to treatment. It became a difficult emotional struggle to find a way to include DM in their lives, especially when treatment was first initiated and when long-term complications began to occur. In facing a disease that is often difficult and confusing to manage, the participants felt a sense of helplessness and distress, due to diabetes related symptoms. Most participants experienced difficulty living with the disease, as they felt challenged by the physical symptoms they experienced.

The following participant expressed her frustration, as the changes in her mood were inexplicable:

> *"Having this disease has it's ups and downs because sometimes in the mornings you are fresh and then suddenly … without knowing what has happened … at about midday your body becomes tired … you decide to sleep… you don't feel like working … your joints become weak … you don't know exactly what is happening … again at about 5pm you become fresh again … ."*

Another participant expressed her frustration as follows:

> *"It becomes painful … you don't feel good…you don't feel fresh … you are unhappy … your body itches and burns … I don't like it …"*

The following participants shared their different feelings about this disease, which seemed to be uncontrollable:

> *"I can say that this sugar is getting worse because instead of it getting better I get such problems as sore feet, painfull eyes, dizziness … I get this dizziness frequently now that I use this injection … ."*

> *"Like now I have this itchiness … when this itchiness starts I even remove my shoes and scratch hard sometimes with a stone … ."*

The participants also identified stress as an aggravating factor in the progression of their disease. Stress can affect the whole person physically, emotionally, socially and spiritually, as stated below:

> *"There are many things in life when you are a parent … children … and you are not working … the sugar is bound to go up because you are worried … ."*
>
> *"After the death of my son my sugar became 13 … I think it was because of nerves ... ."*

Because diabetes is an incurable, serious disease with life-long implications, patients experience a sense of loss and grief when they are diagnosed with DM. According to Warren (2002:12) some of the concerns are:

- loss of health;
- loss of hope of ever being healthy again;
- restrictions of premature death; and
- expectation of disability.

Warren (2002:12) further states that patients will go through psychological adjustment to the diagnosis over the course of months or even years, which involve: numbness, anxiety, anger, guilt, despair, depression and lastly acceptance. The doctor or nursing personnel who confirms the DM diagnosis is actually delivering bad news to the patient and must understand that the patient will go through the following phases:

- **The Shock phase**

According to Warren (2002:10) this is a temporal phase, which acts as a cushion against the impact of the news and is accompanied by confusion and denial. Patients will seldom understand what they are being told. Msengana (2004:15) in his autobiography could relate to this when he was told that the treatment of his type 2 DM was to change from tablets to insulin therapy. He felt numb and dazed and could not remember much of the conversation between himself and his doctor. He could not listen because he felt as if he was given a death sentence.

➢ Denial

Denial by diabetic patients could be one of the most dangerous stages, as it could lead to non-compliance and resultant complications, such as, hyper/hypoglycaemia (Warren, 2002:10). Some participants neglected their symptoms and seeked medical attention only when complications emerged, as verbalised by the following participants:

> *" … I started treatment in 1992 … I stopped taking it in 1995 … I became sick in 2000 … I went to the clinic … they discovered that my sugar was 18 … ."*

> *"I was very, very sick with this sugar … I also had high blood pressure … I didn't like going to hospital … I then started having nose bleeding and fits … ."*

➢ The anger and fear phase

Denial is often replaced by anger, envy, resentment and blaming which may be directed at another person, the nursing personnel or the world in general. As described by Warren (2002:10) anger is characterised by tears, sleepless nights, fights among family members and friends. Anger needs to be understood and recognized for what it is and the individual should not be judged. Obese type 2 diabetics, who are desperately trying to loose weight, may envy their friends who seem to enjoy their food. It is important to encourage the individual to release the anger, anxiety, grief, despair, and depression by encouraging good communication with the members of family and friends.

A person's illness affects not only the person who is ill but also the family or significant others depending on the seriousness of the illness and the cultural and social customs the family follows (Kozier, et al., 2004:183). During this phase some participants were scared to share their experiences with other people, to such an extent that they kept it to themselves, as the following participants expressed:

> *"I was very much disturbed … very much … I couldn't tell anyone at work for some time … ."*

Another patient expressed the same views:

> *"It was very painful … . To such an extent that I didn't know how to explain this to my children … ."*

If there is no improvement in the patient's condition it may be necessary to involve a psychologist or psychiatrist.

➢ The Acceptance phase

In this stage the individual has come to terms with the reality of the situation. It was clear that eventually some of the participants had reached the acceptance stage and had worked through their feelings, found ways of coping and were at peace with themselves. They had integrated their experiences into their lives and were ready to learn about their condition, as the following participant explains:

> " … *There are things that I must not eat … I crave for those things but I cannot eat them … I cannot force it even when I*

> *feel like it … I am much better now … even the itching is much better … .”*

> *“I think I am eating correctly now … I don’t eat fatty foods … .”*

It is interesting to note that the participants initially indicated that they were concerned about the consequences of DM, but later when the full implications and management of DM were explained to them they accepted their condition; DM became part of their lives and they exercised greater self-care, through close attention to diet, exercise and stress levels. The following participant verbalised how she arrived at a deeper understanding of herself, accepting responsibility for her condition:

> “Living with this disease is difficult … but with me now I can say it is not difficult, because I have followed what the nurses told me to do … but if I had not done that I don’t know how I would be now … I feel much better … it is not like before …even people are now asking, “What was the problem?” I tell them it’s sugar and it’s not worrying me … I am under the good hands of nurses and doctors … I used to worry very much but since I use this treatment I feel much better … .”

Due to the nature of their disease and the fact that they were ignorant about their symptoms, some participants were initially scared of their symptoms*.* One of the symptoms of DM is weight loss, which could be of concern to the patient who is not aware of what is happening to his/her body, as the following participant verbalised*:*

> “Initially I was worried for loosing my weight thinking of these diseases (HIV/AIDS) … but the doctor reassured me

> that I am right like this … when you have sugar you must not be fat it will kill you … I also felt much better because I couldn’t even wash my windows before … I couldn’t even bend to pick up something … my tummy was very big … but now I do everything for myself … it really helped me to loose weight … my weight was 73kg … it came down to 67kg … .”

According to Warren (2002:10) information should be readily available during this stage and should be given systematically to the patient and the significant others especially on the following aspects:

- what diabetes is;
- what risks it brings;
- treatment options and how it works;
- when and how to seek advice; and
- what monitoring routine will be needed.

The demands of diabetes self-care can have a great impact on the psychological state of the patient, both short term and long-term, and this can affect the acceptance phase. Many patients may become chronically frustrated, discouraged, enraged with the disease that does not respond to their best efforts. They may also feel hopeless or despondent about the possibility of avoiding long-term complications. It can be a difficult, emotional struggle to find a way to include diabetes in one’s lifestyle. In addition, chronically elevated blood glucose levels may lead to persistent fatigue, which can exacerbate depressed moods. Similarly, frequent hypoglycaemic episodes can be exhausting, debilitating, discouraging and potentially quite frightening. Facing a disease that is difficult and confusing to manage may lead to helplessness. DM can also affect social functioning, especially when relatives and friends are unsupportive and this can result in strained relations in the family. It is important that health care professionals become acquainted with the above responses, as it is easy to mistake them with a person's inability to cope. These responses are to be seen as normal, and not as resistance to treatment, or an inability to cope.

The study participants had in one way or another illustrated that being diagnosed with DM is a major life stress and has complex psychological effects on patients as they pass through several stages of this condition from the time they were diagnosed. It is important to note that, while these stages provide a useful guide for understanding the different phases, they are not absolute, as individuals vary in the amount of time they need to move though the stages. Some people may not experience all the stages, and not all the people experience the stages in the same order. People who have passed through a particular stage may re-experience it at a later stage (Warren, 2002:12).

3.5.1.1 Sub-theme 1.1: Xhosa diabetic patients understand the physical symptoms of their disease

The aetiology and pathology of DM has been extensively researched. However, whilst a great deal of research effort has been invested in the medical management of people with DM, as evidenced in the bibliography, very little work has been directed at understanding <u>how</u> Xhosa DM patients experience the symptoms of this chronic condition, or if they understand what diabetes really entails. The symptoms experienced by the parti-cipants were many but similar. They were, among others: itchiness of the body, weakness, tiredness, insomnia, blisters on the body and sudden vision changes. Most participants experienced being hungry, and partic-ipants who were suffering from hypertension experienced dizziness. The study population, though initially not understanding what they were suffering from, could state clearly the symptoms of DM, as the following participants verbalized:

> "I had dizzy spells … I used not to want to eat food … I became weak … my whole body … I would feel like that the whole morning and be better in the afternoon … I had itchiness s… I would wake up even at night and scratch myself I would also have headaches … even my neck veins became sore behind the ears…I had problems with my eyes … I had double vision … but I can still read … ."

> "When I started I used to be very, very thirsty, I used to drink a lot of water … I always had a glass of water … I then lost too much weight … I was not seeing properly, I usually got headaches … I felt dizzy … even now at work I get tired … People who know sugar used to tell me that with these symptoms it looked like I had sugar."

> "When I started I had this weakness … I felt shaky … I used to be hungry all the time … I got thirsty I used to drink a lot of water … I lost weight … I had difficulty with my eyes … I couldn't see properly … like now … I used to have dizziness … I needed someone to accompany me … you feel dry inside … you want to drink water … you pass urine frequently … ."

The participants experienced feeling hungry all the time, as was stated by the following participant:

> *"The other problem that I experienced was feeling hungry all the time … If you are hungry you feel as if you are going to faint now … ."*

All participants experienced similar symptoms, which included polyuria (increased urination) and polydipsia (increased thirst). The latter occurs as a result of an excessive loss of fluid associated with osmotic diuresis. The participants also experienced polyphagia (increased appetite) resulting from the catabolic state induced by insulin deficiency, as well as the breakdown of proteins and fats. Other symptoms of DM include tingling or numbness in hands or feet; dry skin; skin lesions or wounds that are slow to heal; and recurrent infections. Participants also experienced weight loss; nausea; vomiting; and abdominal pains (Smeltzer & Bare, 2004:1154). These symptoms were of concern to the participants.

Some participants verbalised that they experienced hypertension symptoms as well:

> *"I have high blood pressure …I think it is caused by thinking too much … sometimes I think too much … I don't get sleep at night … I usually feel as if my eyes are swollen…the whole family has this sugar … I don't know what our future will be."*

According to Huddle (2000:897) hypertension and diabetes are common conditions which frequently coexist and are also risk factors for cardiovascular, cerebral, renal and peripheral atherosclerotic vascular disease. Hypertension also plays a significant role in micro vascular diabetic complications, such as nephropathy and retinopathy. The following participant verbalized her experiences:

> *"I discovered on the same day that I also have high blood pressure … when it is high I feel dizzy … ."*

Huddle (2000:897) estimated that 30-75% of diabetic complications could be attributed to hypertension. Hypertension is twice as frequent in diabetic patients as in non-diabetic individuals. Hypertensive diabetic patients have a greater risk of macro-vascular and micro-vascular disease than those who are normotensive (normal levels of blood pressure). The risk for stroke and coronary artery disease associated with diabetes is double that of non-diabetic individuals. The following participant was concerned about her high blood pressure:

> *"My blood pressure is always high I think it is caused by thinking too much … "*

According to Huddle (2000:897) hypertension also increases the incidence of left-ventricular hypertrophy and congestive heart failure, both of which are more common in people with diabetes. Peripheral vascular disease and amputations are also more common in diabetic patients. Hypertension accelerates the progression of diabetic neuropathy and also increases the risk of development and progression of diabetic retinopathy. The following participants reiterated this:

> *"Even my eyes … they used not to be like this … ."*

> *"I think it was in 2000 … my eye problems started then … ."*

Huddle (2000:897) further explains the difference in the onset of hypertension between type I and type 2 DM and states that in type I DM, blood pressure is usually normal during the first time of diagnosis and remains normal for the first 5 - 10 years of DM. Hypertension will then develop in association with the development of diabetic nephropathy and both the systolic and diastolic pressures will be elevated. Hypertension with type 2 DM is frequently present on diagnosis. It must be remembered that by the time type 2 diabetes is diagnosed, the individual may have been hyperglycaemic for some time. Huddle (2000:897) also states that hypertension is usually associated with obesity, decreased physical activity and advanced age. Advanced diabetic nephropathy affects approximately 10 % of patients with type 2 DM.

3.5.1.2 Sub-theme 1.2: Xhosa diabetic patients are aware of their blood sugar levels and actions to be taken, depending on the results of blood sugar tests

It became evident that patients are aware of their blood sugar levels and actions to be taken, depending on the results of blood sugar tests. At the OPD where this study was done DM patients are assessed once a month and/or when necessary.

Ideally blood sugar levels should be tested four times a day; that is, first thing in the morning when the reading should be below 6 mmol/L, and two hours after breakfast, lunch and supper when the readings should be below 10mmol/L. Ideal targets for blood glucose monitoring are 4-6 mmol/L as a fasting value and less that 10mmol/L two hours after eating (Your personal guide to diabetes, [s.a.]: 7). The following participant could relate to her raised blood sugar levels:

> *"I remember one day my sugar was 31 … I was given 2 drips in casualty … after that I was changed from tablets to*

> *injections … I am injecting myself now … the doctor told me that if my sugar has dropped I will feel shaky and weak … he told me to always have a sweet in my bag ... this sometimes happens to me … I take a sweet or an apple and feel right afterwards, I have an apple even now in my bag … I mean since I injected myself I feel better with my sugar … ."*

The achievement of a stable blood glucose level is the main aim of professional care interventions in DM. Control is perceived as the attainment of blood glucose levels as close to those of the non-diabetic as possible (Gillibrand, et al., 2001:502). Treatment aimed at avoiding hyperglycaemia, as indicated below, has been clearly demonstrated to be of benefit to patients with DM. A participant said:

> "Before this injection my sugar used to be high … it was not controlled. by the tablets that's why the doctor changed me to injection … *."*

The monitoring of DM is based entirely on blood glucose levels and symptoms, and disease control is defined as freedom from the reported symptoms of hyper- and hypoglycaemia. The following participant explained how she was monitoring her condition:

> *"I can feel when my sugar is raised … I get itchiness and also feel weak … I like resting a little … I become better*

> *thereafter … I can feel it when it goes down … the itchiness subsides … I usually take some sweets … I also don't want it to go down too much … when it is down I must always have a sweet in my bag … when it is too much, I must drink water."*

Long-term complications of diabetes are directly related to a persistently high glucose level; therefore, the goal of good control is to keep the blood glucose level within the acceptable range. The following participants had symptoms of hyperglycaemia and they stated their feelings concerning their sugar as follows:

> "I was feeling hungry all the time … if you are hungry you feel as if you are going to faint … you want to eat … you must have something … even a sweet … You feel better after that … even a slice of bread … sometimes I go to a funeral …if I don't get food for a long time I feel shaky as if I am going to die … I ask for even sweet water or I bring along a slice of bread or an apple …."

> *"I feel bad … I take my tablets and also drink water … water drops sugar … 8 glasses per day … water dissolves glucose … the doctors tell us … they tell us to drink a lot of water … water is very good even when your sugar is normal you must drink water everyday … even now … look I have this bottle … it contains 500ml water … it was full in the morning … this is my measurement … 2 glasses … I am going to fill it up again … even if I don't drink 8 glasses exactly … but I do drink water … you see … ."*

> *"To my understanding my sugar is going up because I can see these new problems in my body … even this tiredness I used not to feel it … I used to be fresh … now it seems it's poisoning me … in the beginning I used to inject myself 12 it is now increased … I inject 45 … it seems as if the injection is not controlling my sugar … the doctor increases it … ."*

3.5.1.3 Sub-theme 1.3: Xhosa diabetic patients believe that treatment compliance is helpful in the management of their disease

Most patients verbalised that good treatment compliance is helpful in the management of their condition. Education on treatment compliance is the responsibility of every health care professional that comes into contact with a person with DM and one of the goals in the management of DM is to assist the patients to change their attitudes and behaviours. The choice of pharmacological therapy will be individualised, depending on age, sex, race, type of diabetes, the presence of complications and the severity of hypertension, and will include among others: diuretics, beta-blockers, alpha-blockers, ace inhibitors and calcium channel blockers (Huddle, 2000:900-902). The goal for therapy is to reduce and maintain blood pressure to the target level of below (130/85) with the most cost-effective regimen. In addition to drug compliance, the participants could relate to the education given by their health care professionals, which included advice on a healthy diet, exercise, and drinking a lot of water. One participant said:

> " … Sugar, samp and beans, skins of chicken, there are so many … all the nice things in life … all these things you must not eat because they are dangerous to your health … though I may want to eat these thing I must not because they will make my sugar worse … ."

Good treatment compliance means taking the correct amount of the prescribed medicine at the correct time and in proper dosage, eating a healthy diet and exercising. The following participant believed in compliance:

> "I must take the treatment same time everyday … in the morning I take one tablet for sugar … I take half a tablet at night … there are 2 tablets for high blood pressure … if you take your tablets at 09:00 they should also be taken at 21:00 same day every day … If you take your treatment after or before time it makes you sick … it may be high or low in your blood … you feel dizzy."

As a chronic illness, DM is a disease, which people have to manage for the rest of their lives following diagnosis. All participants acknowledged that changes and adaptations occurred to their lives as a result of DM. The following participant, actually felt that sugar was a blessing to her life:

> "I cook correctly … it also saves my electricity … on the other hand they (family) also eat a healthy diet … ."

Remembering to take medication is the key to compliance because medicines will be effective only when taken correctly as prescribed by a doctor. Treatment non-compliance is very dangerous and costly. A number of participants did not meet treatment demands and this resulted in feelings of helplessness and failure as they felt guilty about letting their health care professional, themselves and their families down. The following participants verbalised that treatment compliance is rewarding in the management of their condition.

> "It was itching here in my private parts. I don't feel it any more … I think these tablets helped me … ."

> "I feel better now that my sugar is better … I think it's the treatment. I think I am also eating correctly, I don't eat red meat … I don't eat chicken skin … I don't want to die … ."

In a study done in the UK by Gillibrand, et al., (2001:505) on DM control, participants felt that they had not been given enough education to facilitate self-care. If they knew more about their illness they could have made more self-management decisions, but they felt that the health care professionals were not giving them enough information. This finding suggested that people with DM needed to be empowered to take control of their illness in order to achieve a good quality of life. Participants in this study, however, commended the registered nurses for giving them good education. It is very important that health care professionals should ensure that all diabetic patients are educated on matters relating to their condition (Working Group of the National Diabetes Advisory Board, 1997:498).

According to the participants, regular exercise should form part of their lifestyle. Ncayiyana, (1997:504) suggest that normal blood glucose concentrations should be maintained before, during and after exercise and the diabetic patient should exercise at the same time, preferably when blood glucose levels are at their peak and in the same amount everyday. Ncayiyana, et al.. further state that regular daily exercise rather than sporadic exercise should be encouraged. Increased blood pressure associated with exercise may aggravate diabetes retinopathy and increase the risk of a haemorrhage into the vitreous or retina of the eye.

Ncayiyana, continue to state that exercise recommendations must be altered as necessary for patients with diabetic complications, such as neuropathy, retinopathy and cardiovascular diseases. Patients with ischaemic heart disease may risk triggering angina or myocardial infarction, which may be silent. Avoiding trauma to the lower extremities is especially important in patients with numbness related to neuropathy. A slow gradual increase in the exercise period is encouraged. Walking is a safe and beneficial form of exercise for many patients as it requires no special equipment and can be performed anywhere, as the following participant verbalises:

> “We are also told to exercise … take walks even if it’s for half an hour … increase to an hour after some days … walking so as to loose weight … I get exercise when going to church … I walk to church … to and fro … I take that as an exercise … It is very difficult to exercise … I am always tired … .”

People with diabetes should discuss an exercise programme with their physician and undergo a careful medical evaluation before beginning an exercise programme. For patients who are older than 30 years and who have two or more risk factors for heart disease an exercise stress test is recommended. Risk factors for heart disease include hypertension, obesity, high cholesterol levels, sedentary lifestyle, smoking, male gender and a family history of heart disease (Smeltzer & Bare, 2004:1161).

Many studies have confirmed that type 2 diabetes is most common among overweight people. There is a strong association between central or visceral obesity and diabetes. It is estimated that 64% of male and 74% of female cases of type 2 DM could have been prevented if the Body Mass Index (BMI) could have been kept below 25 (Mollentze, 2000: 921). The BMI is a key index for assessing body weight in relation to height. BMI can be calculated by dividing a person's weight in kilograms (kg) by their height in meters squared (m²). In the West a person is considered overweight when their BMI is ≥ 25 or obese if ≥ 30. In Asia the recommended corresponding BMI's are 23,25 and 30/m² respectively (Kulkarni, 2002:15). Certain characteristics of obese persons may further increase the risk of type 2 diabetics, such as:

- *obesity during childhood and adolescence;*
- *progressive weight gain from 18 years, especially intra-abdominal fat accumulation; and*
- *lack of physical activity and a diet high in fat and low in carbohydrates and fibre.*

One participant reported this about her weight:

> "I lost weight but I improved after this treatment … even now the doctor suggested that I loose weight because when you have sugar you must not gain weight … ."

Obesity has been referred to as a disease of westernisation and industrialisation. The rise in the prevalence of type 2 DM coincides with the national and international rise in obesity (Liburd & Vinicor, 2003:s74). City life is associated, amongst other things, with a sedentary lifestyle and poor eating habits, which can adversely influence body weight. Overweight DM patients have a greater risk of developing cardiac complications, such as heart failure and hypertension (Working Group of the National Diabetes Advisory Board, 1997:507). An appropriate diet and increased physical activity is the cornerstone in the management of type 2 DM. The following participants shared their experiences as far as their weight problem is concerned:

> "I felt terrible then … now that my weight is better I feel good … I think it's the treatment … even my health … I feel better … itching has stopped … I used to sweat … everything … even shortness of breath is better … I think I am eating correctly … I don't eat red meat anymore … I don't eat chicken skin because I am afraid of this sugar … I want to be well."

> "Losing weight can help me … there is this feeling on my chest … it could be this weight problem … ."

The following is the acceptable table used for the estimation of an ideal body weight:

TABLE 3.2: CLASSIFICATION OF OVERWEIGHT IN ADULTS ACCORDING TO THE BODY MASS INDEX (BMI)

Classification	**BMI**	**Risk of commodities**
Underweight	< 18,5	Low
Normal range	18.5 – 29.9	Average
Overweight	≥ 25	
Pre-obese	25-29.9	Increased
Obese class I	30.0-34.9	Moderate
Obese class II	35.0-39.9	Severe
Obese class III	≥ 40.0	Very severe

In a study done by Erasmus, et al., (2001:158) on Xhosa factory workers in the Transkei, obesity was present in 22.2% of all subjects. Overweight subjects appeared to be at risk of developing impaired glucose tolerance. The researchers also concluded that there is mounting evidence that a rising BMI and obesity constitute important risk factors in the emergence of DM in black females. In the UK a growing obesity problem as well as an aging population resulted in the prevalence of type 2 DM (Drummond, 2003:18). An estimated twelve million overweight Americans aged 45-75 years have impaired glucose tolerance or impaired fasting glucose, which together is known as prediabetes (Satterfield, et al., 2003:s57).

Anthropologists Brown and Krick (cited in Liburd & Vinicor, 2003:S76) argue that cultural and economic factors play critical roles in the aetiology of obesity, and that these same cultural and economic factors limit individual choices and behaviour. Brown and Krick contend that obesity is fuelled by industrial food production systems, which produce high-calorie food products as well as the manipulative use of advertising to create consumer desire for certain food products. The industrial food production system has changed modern culture over the past 25 years. More and more meals are eaten outside the home as the number of establishments selling fast foods have increased. These cultural and economic factors predispose individuals of failure to loose weight and maintain weight loss, consequently increasing the risk of type 2 DM and obesity. Both the middle class and the lower class income segments of American society have found some benefit from the fast food and restaurant industry.

The use of various nutritive and non-nutritive sweeteners is acceptable in the management of DM (Ncayiyana, 1997:504), as one patient stated:

> "I think adding sugar to my tea contributed to the rise in my sugar levels … I had stopped using Canderals … I am using them now … it has gone down … I think it's the Canderals … ."″

3.5.1.4 Sub-theme 1.4: Xhosa diabetic patients believe in the use of both western and traditional medicine

Black patients frequently use herbal medicines or traditional black medicines as an adjunct to western pharmaceuticals and surgery. There is a tendency for people to treat themselves with herbal medicines, and vitamin and mineral preparations as these products are readily available from supermarkets, health food stores and chemists. Participants reported using traditional herbal medicine for the treatment of diabetes, making use of different ingredients such as the following:

- *garlic;*
- *ginger;*
- *groenamarie;*
- *camphor;*
- *"rooipoeie";*
- *aloe leaves;*
- *epsom salts;*

- *plants/herbs; and*
- *guava leaves.*

According to the participants, these ingredients are bought from vendors, herbalists, chemists and supermarkets and then mixed together.

> "I mix grated garlic … I mix with herbs, which I buy from the people who are selling Xhosa medicine … they are green and fresh the bunch is R2 … I boil it for some time … it looks like black tea … I add a cup of aloes … . Some people use aloe leaves from the fields … they are very strong … some people use groenamarie … I also like it … it is bitter … I use it … it makes my sugar go down … ."

Most complementary medicines still lack randomised clinical trails to test their efficacy. As a result, much of the evidence supporting complementary therapies is anecdotal, consisting of success stories told by patients. The referral system is through word of mouth from other patients.

When asked about the source of this traditional medicine, participants stated that they obtained it from other patients at the hospital queues in the OPD while awaiting assessment by nurses. One participant stated that she could not remember who told her about it:

> " … someone said I must treat it … I must drink bitter medicine; sugar is going to be better *…* "

Although Karim, et al., (cited in Van Huyssteen, et al., 2004:28) state that 80% of black patients visit a traditional healer before consulting a western doctor, only one participant consulted a traditional doctor for her sugar, while the other one who sometimes visits spiritual healers for a R20 consultation fee, stated that:

> *"The spiritual healers never said anything as far as the sugar is concerned."*

In a study done in the Northern province by Peltzer, Khoza, Lekhuleni, Madu, Cherion and Cherion (2001:42), the results indicated that all healers were familiar with DM, though not all of them had seen patients suffering from DM. The causes of DM, as perceived by both traditional and faith healers, were diets high in sugar, heredity, supernatural and psychological causes. Most healers indicated that DM is curable. Treatment used by the healers included use of prayer by faith healers, diet and herbs. This view was also echoed by traditional healers in a study done by Van Huyssteen et al., (2004:33) on awareness of DM among African traditional healers, in the Nelson Mandela Metropole. Collaboration between health care workers and traditional healers, as well as education of traditional healers on health issues may broaden their knowledge of DM.

Participants chose not to tell their health practitioners that they are using traditional medicine, either because they are embarrassed, they do not think that the practitioner will understand, or because they are *not aware that the information is relevant. The following participant said:*

> "No … I never told them … unless someone can ask what is helping me … then I can tell her … I will not hide it … ."

The use of complementary medicine in conjunction with orthodox medicine can result in interactions between the forms of treatment because at present very little is known about the possible effects of combining the two forms of treatment. Most of the participants did not mix western and traditional medicine together, as stated below:

> "I don't want to mix tablets with this medicine … don't you think mixing them would be dangerous … all of us who use this medication don't mix it with tablets … I don't want to mix Xhosa medicine with English medicine … I don't know what will happen … I also inject myself … ."

Some participants verbalised that they use both western and traditional medicine for the management of their condition. A multimillion rand trans-Atlantic research venture involving scientist and sangomas has been set up to test the healing powers of indigenous South African plants, which comprise 3000 of the country's 21,000 plant species. The four-year project, funded by a division of the United States of Ameirca. Health Department and costing about R29 million, can eventually lead to the registration of medicines used by traditional healers. For the first time traditional healers and medical doctors will work together to elevate the *understanding of the use and value of traditional medicines. The results of these findings will be shared widely within South Africa and around the world, and the biggest beneficiaries of the research will be South Africa's 200,000 traditional healers, who have been pushing for the scientific world to recognise their profession (Horner, 2005:5).*

Though the participants believe in the use of both types of medicines for the management of their disease, some believe that the traditional medicine is helping them while others believe that the western medicine is good. It is interesting to note that the participants want to use both medicines, but at different times. The following participant said:

> "I have other things that I use for my sugar … though I am not serious about them … I use aloes and mix it with camphor, epsom salts and garlic … I don't drink it everyday … if I drink it today I skip two days and then drink it on the third day … I do believe in these tablets … I don't know if this mixture is helping me … I just heard about it and decided to use it … some people have been using it for a long time … it is not helping them … I do feel light in my body now … I cannot say if it's the mixture or the tablets … I can never stop using tablets … I believe in them … I don't believe much in the mixture but I use it … ."

Bone (2002:7) confirms that herbal treatment for diabetics can prevent long-term complications. He states that, while herbal therapy for type I diabetes can help to control blood sugar, it is largely aimed at preventing long-term organ damage that is often a consequence of this disease. He states that bilberry; ginkgo and grape seed extracts are useful for preventing and treating certain diabetic-related complications involving fine blood vessels, such as diabetic retinopathy, neuropathy and nephropathy. Grape seed extract may help prevent heart disease and evening primrose oil has also been shown to improve diabetes-related nerve damage.

Bone (2002:07) further states that two clinical trials conducted in Thailand provide preliminary evidence that juice derived from the pulp of aloe-vera leaves can reduce blood glucose and triglyceride levels in patients newly diagnosed with DM. These herbal medicines are available at local health-food stores. He advises that herbal treatment should be taken under the professional guidance of a doctor and a suitable qualified clinician, who can help to determine an individualized herbal programme, including doses based on an individual's history and needs.

The participants also stated the frequency of taking traditional medicines as follows:

- a glass once a day;
- a little at night;
- skip two days and take it on the third day; and
- not taking it when not feeling symptoms.

The participants who take traditional medicine believe that the more bitter the medicine is; the better, because the sugar will go down if the blood is not sweet, as stated by the following participant:

> "I believe in Xhosa medicine … your blood should not be sweet every time … that is not correct, you see even the itchiness has subsided … I used to scratch my head and armpits … my urine is even clear now like water but I cannot do without the tablets also … the medicine is also helping me … ."

It is interesting to note that some participants do not use any traditional medicine, but use only western medicine, as the following participants verbalise:

> *"I don't use anything else … you will find that you waste your money using these things … I don't believe in those things … I also never heard of anyone saying she has been cured by traditional medicines … because that is how I would believe in them … a person must bring the medicine and tell me it has helped her … people think they know … in actual fact they don't … I also don't have money to buy that … ."*

Another participant also reiterated her use of western medication rather than traditional medicine:

> *"I don't use anything … I tell you … I only use tablets … I don't want to even start using It … I don't even drink that aloes mixture … the only thing that I drink sometimes is the epsom salts and eno only for bile … those mixtures are very strong … very bitter … what if I become unconscious after drinking it … if I die it must be because I cannot control my sugar … that's all … ."*

Hundreds of herbs and other supplements line the shelves of health stores and pharmacies. Information about supplement efficiency is difficult to obtain and misconceptions are widespread. Herbs may contain many other ingredients, some of which may have medicinal effects or cause allergic reactions and supplements may interact with other supplements or drugs Personal testimonials are not good as reference for a supplement's effectiveness, only scientific studies can prove an herb's efficacy (Supplement Savvy, 2005:32).

3.5.1.5 Sub-theme 1.5: Xhosa diabetic patients are afraid of physical complications related to the disease

The participants verbalised that they are afraid of diabetic complications, such as stroke, amputations, impotence, and blindness, some of which they had experienced first hand. DM is more than just an inconvenience to them, as the condition impacts strongly upon other aspects of their lives, as stated by this depressed, 55 year old male participant:

> *"I feel it is not nice to have sugar … it is limiting a person … I mean as a man you want to be happy with your wife but you cannot … this cannot happen because of this sugar … I used to be a strong person … I mean sexually … but since I have this sugar I became 'swak' (impotent) … sometimes I am normal, but sometimes I am not right … I also hear that a person may not get children because of this sugar … ."*

This participant further states his feelings as follows:

> "I see sugar as something wrong, because you cannot be limited by a disease, which you cannot remove from you … ."

He states that although he has discussed his problem with his wife, who seemed to understand this problem, he wants treatment for this condition.

Smeltzer and Bare (2004:1193) state that sexual dysfunction is a disorder experienced by men who suffer from DM, with the incidence ranging from 5% to 50% in men older than 65 years of age. Male impotence is a known complication of DM, while the effects of autonomic neuropathy on female sexual functioning are not well documented. They further state that although reduced vaginal lubrication has been mentioned as a possible naturopathic effect, no concern was raised by female participants, most of whom belonged to the same age group as the male participants. Impotence occurs with greater frequency in diabetic men than in non-diabetic women of the same age.

According to Smeltzer and Bare (2004:1193) other changes in sexual function in women with diabetes include:

- *decreased libido;*
- *urinary tract infections; and*
- *vaginitis.*

DM is a chronic illness that requires continuous medical care and education to prevent acute complications and to reduce the risk of long-term complications. It is evident that the following participant needs more information and assistance about his problem:

> “The reason I am open with you … I want more knowledge from you … If you can I want to be as fresh as I was before … not ‘swak’ … because I can see that I am not improving … I am getting worse. Even if you can give me tablets.”

According to Robertson (2002:6), in recent years there have been tremendous advances in the understanding of the physiology of sexual functioning, and as a result many effective treatments for erectile dysfunction have been developed. Unfortunately the Essential Drug List prescribed for public hospitals who had erectice dysfunction and clinics does not cater for such treatment; as a result the participant could only receive vitamin tablets. In addition, Robertson's study found that a greater percentage of diabetic patients had a more severe type of erectile condition. According to Robertson (2002:7) the factors that could contribute to erectile dysfunction in diabetics include:

- *endocrine disorders;*
- *vasculopathy;*
- *poor glycaemia control;*
- *smoking;*
- *psychogenic factors;*
- *drugs (statins cause a drop in libido); and*
- *autonomic neuropathy.*

Robertson (2002:7) further encourages medical personnel to obtain a detailed history from their patients before referring patients to an urologist, in order to determine if the problem is psychological or organic. If the onset is sudden, it would more than likely be *psychogenic, while if the onset is gradual, it could be an organic problem. He states that blood tests may reveal a testosterone deficiency and there is not much that can be done to replace testosterone in an effective enough way, until testosterone transdermal patches become available.*

- ***Retinopathy***

Diabetic retinopathy may develop in any person with type 1 or type 2 diabetes. William and Pickup (cited in Obeid, 2003:4) state that retinopathy is known as a micro-vascular complication of DM and refers to disturbances in the retinal blood vessels, which may ultimately lead to visual impairment. Among the most feared diabetic complications are those affecting the eyes. DM is the leading cause of partial vision loss and blindness in the working age population in many countries and diabetic retinopathy can affect both people with type I and type 2 diabetes. The following participants confirmed that they developed eye problems as one of their complications:

> "The reason for me to be afraid of this sugar is that with this sugar you end up being blind … as you see me with these spectacles … I used not to wear spectacles."

> *"I used not to get these problems I'm getting now … these eye problems … now I can say this sugar is getting worse because I get sore feet, painful eyes, dizziness … ."*

When visual impairment is detected during a routine examination the patient is referred to an eye specialist, as stated by this participant:

> *"I was given a letter to go and check my eyes … I have this sore eye on the left side … I cannot see properly … ."*

Arun and Taylor (2002:29) recommend that people with newly diagnosed diabetes should immediately be referred to an eye specialist for a thorough eye examination, and strongly advise those who are already diabetic to have their eyes checked at least once a year. They further state that the advantage of a regular eye examination is to help prevent and delay severe vision loss or blindness and that screening for retinopathy should be part of regular diabetic care, along with blood pressure and feet monitoring. If retinopathy is detected in time, blindness can be prevented with laser treatment or photocoagulation.

The participants' ages ranged between 45-60 years and according to Mackinno (cited in Obeid, 2003:4) diabetic people aged between 45-64 years were found to be 23 times more likely to be blind than their non-diabetic counterparts and over the age of 65 years most diabetics are likely to be blind.

Arun and Taylor (2002:28) state that nearly all people with type 1 and over 60% of those with type 2 diabetes, having had the condition for at least 30 years, have some degree of retinopathy. The longer someone has diabetes, the greater the risk of developing diabetic retinopathy.

- ***Fungal infections***

Diabetics are also highly susceptible to infection, especially by bacteria and fungi. One participant verbalises the following about infection:

> " … I had this problem … what do you call it … sore and septic around the finger nails … I was treated for that also…."

According to a study by Gupta of the Women's Health Sciences Centre in Toronto, (cited in *Bateman and Howse, 2000:66) about one third of diabetics and almost one fifth of elderly patients, eventually contract onychomycosis (infected nails). He also states that when diabetics have infections their blood glucose levels are likely to raise, therefore, care should be taken to prevent infections.*

Gupta further states that in diabetics, onychomycosis can add to existing pedal problems such as ulcers, vascular insufficiency and neuropathy, possibly leading to amputations. Among the factors increasing susceptibility among patients over 60 years are trauma to the nails, peripheral vascular disease, poor eating habits and any immunosuppression as a result of various medical conditions.

According to Gupta infection may cause more complications, if not treated early. Complications may include:

- boils and carbuncles;
- vaginal candidiasis (thrush); and
- pyelonephritis.

➢ ***Leg sores and amputations***

Participants also verbalised fears concerning leg sores and amputations, as stated by the following participants:

> *"I even remove my shoes and scratch my feet hard with a stone. I become afraid and stop scratching when I think of the foot sores that I see on these pictures on the wall.*
>
> The other problem is that some people have their legs amputated … that is why I am afraid of sugar … ."

➢ ***Atherosclerosis***

According to Smeltzer and Bare (2004:1152), as one gets older, blood vessels are damaged, narrow progressively (atherosclerosis) and can lead to a heart attack or stroke. With DM this narrowing of arteries happens faster and blood clots form more easily. Smoking also causes damage to the blood vessels and therefore diabetic smokers are even more at risk. The following participant verbalised her fears with regard to uncontrolled DM, which may ultimately result in her having a stroke with no one to assist her.

> *"I am afraid of this sugar … I hear if it is not controlled I can get a stroke … I am afraid of a stroke … who will look after me … I stay with my sister's children … when they are old … are they going to have time for me? I don't want a stroke … who is going to push me on a wheelchair … it would be difficult …I respect this sugar …"*

Other diabetic complications not mentioned by the participants include**:**

- nephropathy;
- neuropathy;
- hypoglycaemia;
- hyperglycaemia;
- ketoacidosis; and
- lower limb amputations.

3.5.1.6 Sub-theme 1.6: Xhosa diabetic patients are concerned for their families in the event of their death

When participants were asked how they felt when told that they had DM most reported that they feared death and were concerned for their families in the event of their death. One participant said:

> "I was afraid … during those days sugar was dangerous … if you have sugar it quickly goes up and you suddenly die … I thought of my children … I am still young what will happen to them … but now I have seen years passing by … there is nothing happening."

When compared with the general population, mortality and morbidity is increased in individuals with diabetes, due to associated chronic micro vascular; retinopathy; neuropathy; nephropathy; macro vascular, and arteriosclerosis complications (Motala, 2000:894). This participant expresses her fears:

> "I don't like this sugar … I am afraid of it taking me without me having finished talking to God … I am afraid of it because it kills … I stay alone … I may need help because sometimes I may be weak … I may even wet myself with urine … with everything … I hear that sick people do those things … but God has helped me so far … ."

In a study done by Kalk, Pick and Sayed, (1998:1259) it is stated that in South Africa a large proportion of deaths is attributable to diabetic complications, especially in the Asian population and in coloured and black women. In each group there were significantly more deaths among women than men. Whatever the actual causes of death among South African diabetic populations, the data suggest an association between diabetes and premature deaths, especially in the poorest segments of the community, that is, among blacks and a significant proportions of the coloured and Indian communities.

As explained above, each individual experiences being diagnosed and living with DM differently. DM does not only affect the inflicted individual, but all their significant others because all individuals function as a system. The family of an individual diagnosed with DM experience the same psychological phases experienced by the patient. It is for this reason that the inclusion of the family system is paramount when working with individuals diagnosed with DM. The following participants expressed concern for their families:

> "I was afraid to tell them … here I am … still young … I have sugar … I am going to die young … all those things came to my mind because during these days we used to hear that sugar is going to kill you … ."

> *"… People used to say that sugar is a killer … my two aunts died of sugar … I was afraid that I was going to die, I was thinking of my children … what is going to happen to them… someone said I must treat it … I must also use bitter medicine … I am going to be fine … ."*

One participant expressed feelings of despair at having DM and its effects:

> "I am afraid of this sugar … I want to be well ... I don't want to die … my grandchildren are still young … I want to see them grow … I don't want to die now … when I die I must be old enough … ."

Another participant expressed feelings of anxiety when she realised that having DM could result in her children being orphaned.

> "As you know you don't accept any illness … my children are very close to me … they do not have a father … they also know that their grandmother died because of high blood pressure … their mother was going to die … It was so hard, to such an extent that I didn't know how to tell them … I was afraid of getting sick with sugar … I was forced to tell them … it was not easy… I was afraid the sugar would kill me, and my children would be left without a mother … ."

The following participant expressed her feelings about death and who would burry her, should she die, since she has no money, and even her disability grant has been discontinued:

> *"I do think of my future … as a person I always think who will bury me when I die … what will I take, from whom … it was better when I had the grant, I organised a burial club for me … with sugar people die … now when I am alone I think of this … who will bury me … I think of my end because when you have sugar you must know that anytime your life may come to an end but when you have the burial club the other members will bury you … they know you … ."*

3.5.2 THEME 2: XHOSA DIABETIC PATIENTS VERBALISE DIFFERENT VIEWS ABOUT THE ROLE OF REGISTERED NURSES IN THE MANAGEMENT OF THEIR DISEASE

The participants expressed different views about the role of registered nurses in the management of their disease. One participant expressed her views about the different types of nurses she meets at the hospitals. It was interesting to hear from her that she thinks there are nurses who are called to the profession, and those who only studied to be nurses She expressed what happens when a DM patient meets the latter type of nurse*:*

> *"You get different types of people … there are nurses in the hospitals who are called to be nurses … there are nurses who just studied to be nurses … if you are unfortunate that day and get a nurse who has just studied to be a nurse, your sugar is bound to go up because firstly she has no way of speaking to you and secondly she does not treat you as a human being … but when you get a nurse who took nursing as a calling … she is able to handle any problems you come here with … ."*

A day at the hospital's OPD is usually a long one. The participants related waking up as early as 05:00 so as to be at the front of the queues. A day starts with the collection of the OPD cards, followed by the nurse's consultation queue and, lastly, the long queue at the dispensary. Most participants felt that nurses started their consultations late, as they always start their days with their meetings. Participants said that sometimes they had to wait for a long time before being seen by the nurses in the consulting rooms. The following participants raised their concerns:

> *" … I request that we must be attended to immediately … we must not stay here until we get hungry … because sometimes I arrive early but my name is called late … I see people called in front of me … that hurts because I know I woke up very early … why do they call someone who has just arrived … that worries me … ."*
>
> *" … If only they can be quick … like today they started late … we have been here very early in the morning … they excused themselves … they told us they had a meeting … but we are used to staying for a long time without knowing what is really happening … but maybe they are solving their problems … they are working too much … I mustn't blame them … but my problem is that I must go back to work from here … ."*

The following participant stated that the nurses are not consistent in picking up their cards for consultation. Some nurses attend to their relatives first, as quoted below:

> "Like for instance if today I was number five according to the queue in front … but when I arrive here … for example if a nurse's mother is sick or a relative or a friend the nurse takes the card that side (to the consultation room) or the relative brings the card to her … I will then end up being number ten … because the nurses have their own people … ."

One participant who reported that she requested to be attended to early, so that by 10:00 she would be able to go and sign a consent form for her sick child in hospital, stated that the nurse shouted her:

> *"She shouted at me in front of other patients … so I also thought … " No she cannot shout at me" … firstly she is not supposed to speak to me in that manner in front of other people … I was requesting her specifically … I never accepted that … I will never forget that experience … I reported this to other nurses … they pleaded with me not to take the matter forward because she will end up being punished because that is not how she should speak to the patients … ."*

Other participants had opposing views about nurses. One participant felt that the patients and nurses must understand each other because everyone has his or her own attitude. Another one felt that this OPD is better than another one she attended, because the nurses and doctors here are not rude.

> *" … We also have our problems … sometimes a person can be cheeky and the nurse also having her own attitude … but we must understand each other … if one person rises the other one must calm down … ."*

> *" … It is still better here nurses are not rude … even when we are told the first time about this sugar they were not rude … even the doctors have respect … ."*

3.5.2.1 Sub-theme 2.1: Xhosa diabetic patients verbalise their fear of being scolded by registered nurses when their “sugar” is high

Participants verbalised that sometimes when they cannot manage their sugar they are being scolded by the registered nurses, as verbalised by this participant:

> *" … There is nothing else I can tell you, except that you will be scolded when your sugar is high … like today they talked about dieting … I know they are right but there is no dieting when you have nothing … you eat what is in front of you … ."*

DM represents a considerable burden to people with the condition. Funnel and Siminerio (2004:22) recorded that people with DM sometimes feel overwhelmed by the responsibility of adequately managing their condition. Before asking patients why they have not complied or are hyperglycaemic, the health professional should rather find out what hindered them from doing so. They suggest that the professionals should not insist on a certain diet that the patient cannot afford, rather they should encourage them to alter what is available, because it may happen that the patient may not have anything to eat. The suggested foods, fruit and vegetables can be too expensive for a patient to purchase, but assisting patients in growing their own may not be impossible.

Funnel and Siminerio further state that health care professionals must be aware that individual behaviour is greatly influenced by the surrounding social environment, cultural issues, political issues, literacy and economic issues, which are important in DM prevention and control. A participant had this humble request:

> *" … I wish to be treated like a human being … a person must not shout at patients … because we have stresses … we have high*

> *blood pressure and everything else … this will make the sugar go up even if it was right … we wish to be treated well … .”*

Nurses should take into account that patients are becoming more aware of the rights of all citizens, as stated in the constitution (Constitution of the Republic of South Africa, Act no. 108 of 1996). Although the nurse has her own personal feelings, she must never forget to always act professionally. The Department of Public Service and Administration has introduced the Batho Pele Principles, which provide a framework for the delivery of services to patients with dignity, and also involve patients in decision making in all matters relating to their health (Department of Public Service and Administration, 1997:13).

Pera and Van Tonder (1996:57) state that the nurse-patient relationship forms the basis of nursing. It is a dynamic relationship in which the humanity of both the patient and the nurse plays a role and is determined by the needs of the patient and the nurse’s response to those needs. Nursing requires that a nurse assume a variety of roles, as an advocate; adviser; confidante; decision maker; custodian; teachers; and co-ordinator. Pera and Van Tonder (1996:58) believe that not all patients respond in the same way to a state of illness or injury, and the nurse’s role is to understand the psychological reaction to illness experienced by the specific patient. The nursing profession is a person-centred profession and nurses spend the most of their time with individual patients in their daily practice. This can influence the quality of care patients receive.

3.5.2.2 Sub-theme 2.2: Xhosa diabetic patients verbalise that registered nurses are good educators who take care of them although they sometimes default their treatment

It is hugely rewarding to hear what some of the participants had to say about nursing staff. One participant verbalised that nurses are good educators:

> *" … Nurses are very important people because they advise us … I wish they don't get tired … some of us do not follow their advice … all the time they advise us …*
> *… they take care of our health … ."*

Education about the disease starts when the patient is diagnosed with DM and continues in subsequent visits to the clinic. New situations can be discussed when these arise or are about to occur, which can include complications. The aim of education is to inform and empower patients to completely and confidently manage their condition independently, so as to reduce their frustrations related to diabetic care and to improve their quality of life as diabetics. The following participant said:

> *" … Since I came here I have seen nothing wrong with the nurses … the nurses are treating us well … if there is something I don't understand … the nurses sit down and explain it to me … ."*

Effective diabetic management depends on the adherence of the patient to the prescribed treatment regimen, but sometimes they default, as stated by the following participants:

> *" … With me … if my sugar is raised I know it is because I did not use my tablets correctly … normally I hate taking tablets, that is in my nature … I used to come here and tell them that my tablets are finished, meanwhile those packets are lying there at home … but now I take my treatment … ."*

> *" … I cannot say I feel good about cheating on my diet … sometimes you do feel like taking something though you are not allowed to … but what a person must remember is that those things destroy your health … it is up to you to destroy your health …*

> *It goes up whenever I eat anything that I am not supposed to eat … fat meat affects it … I sometimes eat It … red meat is not right … you don't get sleep when your blood pressure and sugar are raised … ."*

According to Hoey (2004:25) in diabetes care the principal objective is to improve the patient's health and ensure the total well being of the patient through patient education. Effective DM management not only reduces complications, but is also associated with an improved quality of life. The initial diabetic educators are members of the multi- disciplinary diabetes nursing team, comprising medical and nursing staff, a dietician and a psychologist, particularly during the early stages of care. Re-assurance, praise and encouragement are necessary to boost patients' self esteem during this period.

According to Hoey (2004:26) diabetes education should help patients to:

- ➢ acquire knowledge about the symptoms of the disease and the management there of;
- ➢ develop behaviour-changing skills;
- ➢ develop the assertiveness and communication skills necessary to collaborate effectively with their health-care team; and
- ➢ assess whether their recommended self-care plan is realistic, relevant and sustainable.

Van de Wiel and Wijnberg-William (2004:19) state that health care workers who are committed to providing quality diabetic care must be prepared to spend time mediating intense emotional interactions with DM patients. To achieve this, health care workers requires improved communication skills and adequate psychological knowledge. The following participants had this to say about nurses:

> *" … They teach us about this sugar … what causes it … failure of the pancreas … in order to control sugar you must eat this and*

> *that. Don't eat red meat ... eat chicken or fish … it is only us who do not accept the truth … ."*
>
> *" … I was told what this injection is … Sister told me how to inject myself … in the morning I give myself 40 … late I give 20 … The nurses say when it is down I must always have a sweet in my bag … I must take a sweet … if it is raised I must drink water … ."*
>
> *" … They also tell us that we must be careful not to walk barefoot because we will get a cut and have a sore that will not heal … this may result in a person getting amputated."*
>
> *"I must eat a cup of porridge … rice must be half a cup or a cup … the bulk of what I eat must be the vegetables … half a potato even with fruit … if you eat banana you must take one … banana is sweet … you must alternate fruit because they are also sweet … ."*
>
> *" … Oily food … I must not eat … but sometimes I crave for it … after eating it I will feel guilty … I won't sleep that night … I will regret what I did … I was told not to eat this… even meat with fat I am not supposed to eat it … when I eat it I always feel sick ... I crave for it … ."*

3.5.2.3 Sub-theme 2.3: Xhosa diabetic patients believe that privacy during consultations can improve communication between nurses and patients

The participants verbalised that they would communicate more freely with the nurses if there was privacy during consultations. The following participant expressed her/his wishes:

> *"I want more knowledge about my problem … being 'swak' … I could not tell this other sister my problem because there were people nearby … I didn't want other people to hear my problem … you see … as a man … that is why I tell you this side … ."*

Nurses enter into relationships with patients when providing nursing interventions. Certain environmental factors can hinder good communication between the nurse and the patient, such as noise, language barriers, cultural differences and a lack of privacy. The following participant said:

> "My wish is … as I am here today … the two of us … I wish it could be the same when I come to tell the nurses my problems … I wish it could be like this … myself and the nurse only … ."

It is important for patients to be able to express themselves freely without any hindrance from the health care providers or the environment. Patient autonomy care is best served when they are able to express their feelings and concerns to a health care worker in privacy. The health care professionals should be able to support patients in the translation of their concerns into high quality of life and effective self-care needs. The lack of privacy in consulting rooms seems to constitute the crux of the problems experienced by patients.

An attempt should be made to eliminate any interfering factors in order to encourage high quality and effective communication between the nurse and the patient. Privacy is the health-care professional's obligation, in order to ensure patients' right to confidentiality. The nurse should always strive to be accountable for her conduct and to remember that a patient has certain expectations regarding nursing. It is in the interest of both nurse and patient to have good relations.

In accordance with the patient's right to dignity, information concerning a patient's health, including information concerning treatment, may only be disclosed with informed consent from the patient. Everyone has the right to complain about the health care services that they receive, to have such complaints investigated and to receive a full report on such investigations.

3.5.3 THEME 3: XHOSA DIABETIC PATIENTS EXPERIENCE FINAN-CIAL HARDSHIPS DUE TO UNEMPLOYMENT WHICH IMPACTS ON THEIR DISEASE MANAGEMENT

Unemployment is evident in the NMMM, with estimates ranging from 40% in rural areas, rising to 50-60% in the urban areas (Proposed Aluminium Pechiney within the Coega IDZ, 2002:4-8). The bulk of the participants are unemployed; some live on minimal income wages; others receive old-age pensions and child support grants; while others have their disability grants discontinued, resulting in financial hardships. Under these circumstances, participants feel that they cannot properly manage their sugar, as advised by the health care workers.

This participant was in a daily stressful situation, unemployed, hoping that one day she would receive financial assistance:

> "There are many things as a parent … the fact that I am not working … things like those … having a lot in your mind … you always think if you were working things would be better … ."

The following participants expressed that unemployment effects the education of their children, because they cannot always provide for their children's education and this affects their sugar:

> "At school they need something from your child … you don't have money … you think and think … the sugar goes up because of thinking too much … ."

> "All these things are worrying because when the children want something … you cannot give it to them … ."

To illustrate how the participants experience unemployment, extracts will be used from a report by a group of researchers led by Julian May on Poverty and Inequality in South Africa (1998), for the Office of the Executive Deputy President and the Inter-Ministerial Committee for Poverty and Inequality.

May, (1998:13) state that unemployment rate tend to be highest among Africans, in rural areas, among women and the youth, and also among those with no previous work experience. Using the 1995 *broad definition of unemployment cited by May, (1998:13), in 1995 93% of the unemployed poor were Africans; 56% females; 70% were below the age of 35; 58% from rural areas; 50% had completed primary education or less; and 72% had no previous work experience. Of the unemployed poor who have work experience 78% are in elementary occupations, such as domestic workers, farm workers and construction workers. The following participant, a domestic worker, earning R300 a month, states that sometimes she asks relatives for assistance:*

> *"Sometimes I don't have money … I work three days a week … I usually go to my cousin for assistance … sometimes what I get is not the correct diet for me … I eat so that there is something in my stomach … I get R300 a month … ."*

The following participant, a grandmother who is also working in an elementary occupation, is trying to survive with the bare minimum she earns by polishing cars at a bodywork shop:

> "I am the only person who supports my family … I have children and grandchildren … I don't earn much … I am polishing cars at a bodywork shop … I don't have grant."

May, (1998:13) further states that poor people face the double problem of both unemployment and the low quality of jobs they occupy, as private, community and domestic services comprise the largest employment sector in South Africa, particularly for African *women. One unemployed participant, whose daughter is also unemployed, expressed how she was struggling to make ends meet:*

> " … Even my children are not working I have three children … this other one couldn't finish standard nine … she cannot get work … in some places they want standard ten certificate … my other child is with my sister and the other one with my brother … they took them because I am struggling … I hope that one day I will get my grant back …"

The bulk of the participants state that their disability grants were discontinued because, according to their doctor's certificates they were fit to seek employment, or it was taken away when it was discovered that there are people who have misused the grant money. This aggravated their condition, as the following participants verbalised:

> "I was given a grant, but it was taken away … now I sell so as to make things better at home for my children … my grant was taken away in March this year after having it for twelve months … for me to survive now I must sell goods … my husband and my children are not working."

" … Now that I don't get this grant I cannot manage my sugar well… you know … the sugar doesn't get controlled if you have nerves … you must not get worried … the sugar goes up because of that …"

> *"I was getting grant for sugar in 2003 until October 2004 … it was stopped because the doctor said I am fit for work … I think that made my problems worse … there is no one to support me at home … it was better then, when I had grant … I used to buy things I was told to eat … its difficult now… ."*

Some participants verbalised that they live on child support grants, which they use to buy and sell goods, so that they can obtain more money:

> "I use the money I get for the grant of my child to buy things and sell them so that I get some money for bus fare to come to hospital and to buy some things for my house because I must eat … ."

> *'… I don't have money … even my grant was taken away during the time when everybody else's was taken … I get R360 now for my children … ."*

Some participants live on old age pensions because they have reached 60 or 65 years and this has resulted in some loss of income. De Haan (1996:80) states that this position is particularly serious among unskilled and semi-skilled workers, the domestic and farm workers, who did not qualify for pension benefits and who have been unable to accumulate any significant savings. But even those who may have accumulated some pension often find that their pensions *are inadequate and that their savings and insurance policies have been eroded by inflation.*

3.5.3.1 Sub-theme 3.1: Xhosa diabetic patients experience poverty, which is a contributory factor to non-compliance in the management of diabetes

There is a strong link between poverty and unemployment, as discussed above. All participants experience poverty, which in varying degrees is a contributory factor to non-compliance in the management of their disease. According to the Concise Oxford Dictionary of Current English (1995:1071), poverty can be defined as a state of being poor and living below the poverty line. The poverty line can be defined as the minimum income level to secure the necessities of life. The following participants described their plight as follows:

> *"I cannot cope financially … and with this sugar you must eat healthy food … I stay far from here … I pay the person who brought me here R10 because it was still dark and the area where I live is rough … I must come early for this queue."*

> "I must pay R15 here for taking out card [folder] … I tell them I don't have money … they give me the card but say that my account is adding up … ."

> *" … What made me not to come to clinic some days was not having money … I stay very far, it is very difficult for me to come some days … it is even worse in Winter … during Summer it is better because I can leave my house at 5am and walk here … it is not dark in Summer … I walk with other people on the way … ."*

May, (1989:3) define poverty as "the inability of individual households or communities to command sufficient resources to satisfy a socially acceptable minimum standard of living". She stated that poor people are alienated from the rest of the community, that they experience food insecurities; crowded homes; usage of unsafe and inefficient means of energy; lack of jobs that pay adequately; fragmentation of the family; and the occurrence of diseases like tuberculosis and such.

Poverty results in exclusion from the labour market and from opportunities to earn an income. The following participant shared her experience of unsuccessful job-hunting for a domestic employment:

> *"I mean now even working in the kitchen is difficult … she took me for testing … I was wondering why I was being checked by this doctor because I never said I was sick … I didn't get the job because the doctor said I have sugar and high blood pressure."*

Poverty affects the lives of people in different ways. According to Clark (2002:203) poverty affects:

- the health status of a person, as it contributes to poor health;
- a person's ability to procure housing and food;
- the education status of a person, as the poor tend to be less educated; and
- the knowledge of a person, as the poor have less knowledge of self- care and health promotion.

May, (1998:5) further states that poverty is distributed unevenly among the nine provinces, with the Eastern Cape having a 71% poverty rate and Gauteng having the lowest rate of 17%. Poverty is not confined to any race group, but is concentrated among blacks (61%), coloureds (38%), Indians (5%) and whites (1%). She further reports that three children in five live in poor households and many children are exposed to public and domestic violence, malnutrition and inconsistent parenting and schooling. Women are likely to be poorer than men, with poverty among female-headed households ranging at 60%, as compared with 31% for male-headed households. Her report further postulates that there is a very strong correlation between the level of education and the standard of living. The poverty rate among people with no education is 69%, compared with 54% among people with primary education, 24% among those with secondary education and 3% among those with tertiary education.

Stanhope and Lancaster (1992:370) state that low socio-economic groups are less likely to be able to afford a nutritious diet and are likely to live and work in hazardous environments. Poverty can affect the health of these people and this can unintentionally result in non- compliance, which can again aggravate the disease. Participants indicate the following:

> *"I eat what I have in front of me because I cannot inject myself on an empty stomach … I must eat … then I do not go according to the diet … I don't have any money … ."*

> *" … Even my eyes … they used not to be like this … I don't eat what I was told to eat, I cannot even afford that brown bread I was told to eat … you eat what you get … I think this is killing me…"*

3.5.4 THEME 4: XHOSA DIABETIC PATIENTS HAVE OPPOSING BELIEFS ABOUT THE ROLE OF THEIR ANCESTORS AND GOD RELATED TO THEIR DISEASE

Some of the participants verbalised that they maintain a dualistic approach to illness, that is, they adhere to Christian practices and also carry out traditional rites. Some participants will slaughter a goat and make African beer, both in happiness and in sorrow, when communicating with God and their ancestors, as quoted below:

> *"Sometimes I think of thanking God … I slaughter a goat or something and have African beer … I call people and relatives and tell them that I now want to thank God for keeping me healthy …"*

Some African Christians do hold beliefs and perform rituals related to the ancestor cult of Xhosa tradition (Pauw, 1975:140). The following participants believe that when they pray to God, they also involve their ancestors:

> *"I take these tablets and pray to God that they must go to the relevant place in my body and cure it … I also ask my ancestors to help me … ."*

> *" … I pray to God … I also involved my ancestors … ."*

According to De Villiers and Herselman (in Tjale and de Villiers, 2004:16), cultural values and beliefs play an important role in health care among Xhosa people. The ancestral spirits (izinyanya) have an important influence on the people's lives. If a misfortune, suffering or disease occur, it is interpreted as the anger of the ancestors. Rituals such as sacrifice ensure that anger is kept at bay. According to Pauw (1975:248) many Xhosa Christians turn to cultural techniques when confronted with misfortune outside the scope of medical practitioners, although they still believe in the power of prayer. In order to render holistic nursing care, nurses should have an understanding of the patient's culture and religious convictions and must respect the patient's view of health (Pera and Van Tonder, 1996:231).

The ancestors are believed to be the protectors of the people. Schmidt and Power (cited in Pera and Van Tonder, 1996:233) state that a characteristic of many black cultures is never to say that someone is dead, but rather to say that the person has gone away, he has left them or that he is no longer with them. The following participant, who is also an elder in his church, quoted a verse from the Bible supporting the view that the ancestors, although they have passed on, still remain in spirit.

> *"In the Bible … I don't know the chapter and verse … but in the book of Hebrews the verse says, "He (ancestor) may be dead but is still speaking " Sometimes, as preachers, people ask us why do Christians worship ancestors … but I do believe in ancestors because I take it from the Bible."*

3.5.4.1 Sub-theme 4.1: Xhosa diabetic patients believe that the "sugar" is a physical disease, not related to ancestral influences

Some black people believe that illness and adversity are caused by sorcery; witchcraft and the vengeance of the ancestors, while others believe that there are natural causes for illness. Some of the study participants believe that sugar is a disease unrelated to the influence of ancestors. They believe that it is a genetic disease, that is incurable once it is in the blood, like any other disease.

One 55-year-old participant had his own version of what diabetes is:

> *" … I can only say that sugar is just a disease … I discovered that it is a disease that I cannot trace where it comes from … some say it's caused by the food we eat, spices … a lot of things … . When I was young the only problem the older*

> *people suffered from was lower backache … I never heard about this sugar … there are people now who tell me they had it since 1960 … but I think it is like any other disease… there are people that get it easily … . Some people say you get it from your parents who suffered from it … I always ask, "Where does it come from?" … I am just like a cow with a net on its mouth … the cow stands in front of the food but cannot eat … ."*

The following participants also expressed their beliefs:

> *"… Once sugar is already in your blood it cannot be cured … because the sugar is in your blood … why I say so there are many sangomas who are also attending treatment here for sugar … because it is in your blood it cannot be cured … you must only treat it … but you feel better now and again when you do your rituals … ."*

> *" … I don't associate sugar with anything … I don't think it is caused by not doing any ritual … I can just say sugar is just a disease … ."*

> *" … I don't think there is any relationship between the sugar and the ancestors … it is just like any disease affecting anybody ... Like high blood pressure … my mother died of cancer … it is a disease … my father died of sugar … he had a stroke twice."*

> *" … There is no role that my ancestors have played in my sugar … I do believe in them though … rituals are made in my family … but I don't think they can help me with my sugar … they can help with other conditions like fertility … sugar is just like any condition … you cannot slaughter a goat for suffering from sugar … ."*

The following participant verbalised that she does believe in Xhosa culture. She did all the rituals, slaughtered a goat and visited a traditional healer because she was told that her sugar would be cured. Although she performed all these rituals her sugar became worse, to such an extent that she is now injecting herself. She now believes that sugar is just like any other disease, and not related to ancestors.

> *" … I went to this traditional healer … I was told even my sugar will be cured … I even slaughtered a goat … I cannot say that this sugar is related to Xhosa culture because when I did all these rituals I never thought that I would be injecting myself by now … I wanted this sugar to be cured … I don't say there is no Xhosa culture but I have done the rituals but the sugar is going up … in your body there are different diseases that occur without any influence of the ancestors … ."*

The following participant also stated that all the rituals known by her uncle were done when she fell ill with diabetes, and the uncle then suggested that she seeks western medication:

> *" … When I started being sick … I was not aware then that I had sugar … my uncle took me to the kraal and talked to my ancestors … he said every known ritual was done for me … my ancestors must show me what to do … he then suggested that if nothing else, I must seek medical attention … ."*

3.5.4.2 Sub-theme 4.2: Xhosa diabetic patients believe that the ancestors will assist in their cure for diabetes

Faith in the ancestral spirits is prevalent among blacks and ancestral rites are performed during times of illness and adversity. When the source of illness is unexplainable, traditional methods of solving the problem are used. The traditional medicines are used among the sick and the healthy.

It is believed that the plants and other substances contain power and strength, which can be used for good purposes and also to do harm. According to Allias (1995:232) the good purposes for which medicine can be used are:

- fertility;
- healing;
- success in risky situations;
- protection of fields, homesteads, crops and property;
- protection against police raids, harzadous jobs and bad-tempered employers;
- to improve personality of a man or a woman; and
- to increase dignity, prestige wisdom, independence and courage.

The following participant consulted her ancestors when she was diagnosed with diabetes. She believed that she felt better afterwards:

> *"Earlier on … when my sugar was so high that I was about to die my parents took me to the river, the forest and to the sea … asking for my health from the ancestors … I felt better after that … I went to all those places with a sangoma … he was a spokesman for me … you must also speak for yourself to your ancestors … ."*

Hopa (1996:10) discusses three broad categories of traditional healers in African culture, namely, diviners (amagqira), herbalists or pharmacists (amaxhwele) and spiritual or faith healers (abathandazeli). She states that the training of these three categories differs significantly. The training of the diviner begins with the "calling" or a state of apprehension (ukuthwasa), which takes the form of a dream involving the appearance of an ancestor who informs the individual that the ancestors wish to use him or her for healing of the people. The training of the herbalist is similar to the training of a western doctor in that the individual embarks on it by choice and is trained by a qualified herbalist to recognize certain herbs. The spiritual healer is "called " in the same manner as the diviner; the difference is the actual training and the rituals involved.

Some black people believe that the ancestors are with God in heaven and in some instances the ancestors are viewed as angels or are associated with the Holy Spirit who acts as mediator between man and God. It is at the graves of ancestors that the sacrifices are made and where the ancestors are consulted (Pera and Van Tonder, 1996:233).

Others believe that there are natural causes for illness or that God causes illness. In a 1994 study by Zaldivar and Smolowits (cited in Bopape, 2000:3) some black patients were reported to believe that they had DM because of God's will, so there was no need for them to adhere to treatment, while others reported using herbs to treat their DM. The challenge facing the health care professional is to understand the cultural and socio-economic factors affecting their patients, in order to improve compliance to treatment.

The following participant stated her belief in ancestors:

> *" … Ancestors can help me though I haven't considered asking them for help … there are people who are lucky who can tell you that while a person was asleep he was told by an ancestor what to do … this hasn't happened to me yet … . But I believe the ancestors can help me … I grew up with this belief … I do specific rituals for them … ."*

According to Pera and Van Tonder (1996: 231) some black people believe that illness and adversity are caused by sorcery, witchcraft and the anger of the ancestors. This participant believes that when she was very sick with sugar she asked for help from her ancestors and she believes that they have saved her life:

> "I do call on them (ancestors) … I call on my ancestors to help me find a solution in this sugar … I do believe that they can help me … when you pray you must not leave them behind because when you are in darkness they are always there to protect you … there is something that I did for my ancestors … I was thanking them that they have saved me in this sugar when I was very sick … I asked for help because there is no one else who has sugar in my family … I felt much better thereafter … I feel fresh now."

Pauw (1975:205) states that the early missionaries, believing in the values and beliefs of Christianity, considered the Xhosa ancestor cult to be incompatible with the gospel they preached and assumed that Xhosa Christians should renounce their faith in the ancestors and the rituals it involved. In spite of that, an ancestor cult still persists among Xhosa Christians.

3.5.4.3 Sub-theme 4.3: Xhosa diabetic patients believe that God controls their health

Some of the diabetic patients were Christians who showed strong religious beliefs in God, whom they believed controls their health and gives them strength in whatever they do. Their faith in God makes them feel better; feel that help and strength are provided. Faith provides them with comfort, trust and courage both for fighting and acceptance of their situation.

According to Lubbe (cited in Tjale and De Villiers, 2004:90), Christians believe in one God, who created people and watches over them. They believe that God is kind and loving, is everywhere and is responsible for their well-being. The greatest majority of people in Southern Africa belong to one or other of the large number of Christian denominations. A fascinating aspect of Christianity in Southern Africa has been the emergence of the African Indigenous Churches which are the fastest growing body of Christians in the country.

Since the participants believed in Christian teachings, they believed that Jesus is the healer. One participant said:

> *" … I never contacted my ancestors for sugar … I just talk to God; he gives me strength as a person who believes … In the Bible we are told that there are many illnesses that Jesus healed … the patient who was sick for 38 years … the woman who had a bleeding problem and others … I believe that God can cure even my disease … I ask God … ."*

De Villiers and Van der Wal (cited in Ricks, 1999:157) state that religion, like world view, provides a frame of reference for understanding the world, health and disease. They further state that religion is not just a belief, but a way of life for many people which may affect their attitude to life. An individual aims to maintain or restore equilibrium with the spiritual world by means of rituals like prayer and offerings to God.

Prayer is of great importance to Xhosa Christians, because they believe in the power of prayer, which implies that the difficult and unexpected may be accomplished through prayer and their troubles may come to an end through their faith in prayer (Pauw 1975:80). Christians believe in praying for themselves or to be prayed for by other Christians or a pastor (Lubbe in Tjale and De Villiers, 2004:90). This participant surrenders herself to God:

> *" … I believe in God … Yes, there are ancestors but I believe in God … even with my health I always ask God to help me … I surrender myself to God … ."*

Christians normally do not have any particular dietary requirements. However, during Lent, when the suffering of Jesus is commemorated, many Christians fast for a greater or lesser extent. Lent stretches over 40 days from Ash Wednesday to Good Friday. Fasting can affect the health of a Christian diabetic patient as a result health-care professionals should be able to discuss the advantages and disadvantages of this with the patient (Lubbe in Tjale & De Villiers, 2004:91).

After an extensive literature search the researcher could not get any more information to substantiate or to rebuke this sub-theme. A short story from the Good News Bible, however, confirms that Jesus is the healer. Mark, chapter 8 verses 22-26 states that some people brought a blind man to Jesus and begged him to touch him. He took the blind man by the hand and led him outside the village. When he had spit on the man’s eyes and put his hands on him, Jesus asked the man if he could see. The man looked up and said that he could see people; they look like trees walking around. His eyes were open. The healing aspect of Jesus’s own ministry and his command to his followers to preach, teach, heal and baptize is encouraging the Christians and giving them hope in their daily living. An essential element in the Christian response to sickness is the life, death and resurrection of Jesus.

3.6 CONCLUSION

The aim of this chapter is to sensitise health care professionals to the psychological experiences of Xhosa diabetic patients and to take them on a journey similar to that which an individual diagnosed with diabetes would travel. The health care professionals will learn to appreciate and understand what Xhosa diabetic patients at different stages of disease progression experience. Gaining this understanding will be of assistance in dealing more effectively with diabetics.

The message entailed in the poem at the beginning of this chapter empowers diabetic patients to take diabetes seriously, but also to remember that it is not the end of the road. Controlled adequately and sensibly, a diabetic can live a healthy, normal life because the best hope for diabetes lies in close control of blood glucose levels.

CHAPTER FOUR

GUIDELINES, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION

4.1 INTRODUCTION

In the previous chapter, data was collected by means of phenomenological interviews. Themes and sub-themes related to the stories as told by Xhosa diabetic patients were identified. The identified themes serve as a baseline in the development of guidelines to assist registered nurses working in the public sector in the management of diabetic patients. In addition, recommendations will be brought to the attention of registered nurses working in the OPDs of public hospitals for the optimal management of diabetic patients. In this chapter, a summary of findings, limitations, recommendations for nursing research and nursing education, as well as the conclusion to the study are included.

The objectives of the study were two fold:

- firstly, it aimed to explore and describe the experiences of Xhosa diabetic patients related to living with DM; and
- secondly, it aimed to construct culturally congruent guidelines for registered nurses in order to optimise health care of Xhosa diabetic patients in the public health care sector.

On completion of this study the researcher had reached the above objectives. In attaining the above objectives, two questions were posed to the participants:

> *Tell me how it is for you to live with diabetes*? (Khawundixelele ukuba kunjanina ukuphila nesisifo seswekile?).
>
> *Tell me the role that your ancestors and your traditional beliefs have played in your illness?* (Ucinga ukuba izinyanya zakho nenkolo yakho inanxaxheba ni kwimpilo yakho ingakumbi kwisifo seswekile?).

According to the responses from the participants on their diabetic experiences the first objective was reached. Data was generated by the semi-structured in-depth interviews. The transcribed, coded and organized data was discussed under identified themes in chapter 3.

4.2 SUMMARY OF RESEARCH FINDINGS

The following findings were compiled from semi-structured, in-depth individual interviews, as well as from a literature control study. Xhosa diabetic patients shared different experiences, both negative and positive, and this resulted in the identification of specific themes and sub-themes. The participants described how they experienced having to deal with DM at home with their families as well as in the hospital's OPD with the health care professionals. Information obtained from the interviews and from literature reviews led to the following:

1. Xhosa diabetic patients experienced being diagnosed with DM as well as the progress of their disease on an emotional level. The participants experienced both positive and negative emotional feelings, such as:
   - shock, accompanied by confusion and denial at the knowledge that they have the disease;
   - anger, fear and depression at the knowledge of the limitations that they must face/accept and how they should involve their family members into their lives;
   - a sense of loss and loneliness because DM is incurable and can result in a number of complications such as visual impairment, hypertension and impotence;
   - anxiety, frustration, helplessness and despair when they cannot manage their disease; and
   - eventual acceptance of their condition, at which point they were ready to learn about it and to share their feelings with the rest of the world.

2. As a result of being diagnosed with DM, the participants had various experiences and concerns related to the symptoms as well as the management of their disease.
   - They understand the physical symptoms of DM, including the interpretation of their high blood sugar levels.
   - They believe in treatment compliance when using both western and/or traditional medicines for the management of their disease, though they admit that sometimes they don’t comply with the treatment.

  - They are concerned for their families in the event of their death due to diabetic-related complications.

3. Participants expressed their different experiences during consultations with the registered nurses.
   - Participants see the registered nurses as good educators, though they sometimes scold their patients when they are hyperglycaemic. Participants experienced the physical environment in the OPD as not conducive to optimal holistic care, since there is no privacy during consultations.

4. Participants had opposing religious beliefs, such as that God controls health; the ancestors can help with the curing of DM; and that DM is a physical disease not related to the influence of the ancestors.

5. Participants experienced financial hardships, which were contributory factors to non-compliance in the management of their disease.

From the above findings it became evident that the registered nurses working in OPD should be knowledgeable of DM and all factors related to it as stated in the identified themes and sub-themes. They should provide a therapeutic environment during accompaniment, have good counselling skills, and also be culturally sensitive to their patients during accompaniment in order to provide quality care to them. The guidelines to address the needs of Xhosa diabetic patients does not focus on each theme individually, as listed in table 3.1, but discussions are integrated into three guidelines, which are based on the research findings as well as on relevant literature.

4.3 GUIDELINES FOR REGISTERED NURSES TO OPTIMISE HEALTH CARE DELIVERY TO XHOSA DIABETIC PATIENTS IN THE PUBLIC HEALTH CARE SECTOR

Clinical practice guidelines can be regarded as a practical educational resource tool for health care professionals. Guidelines are not to be used in a regulatory fashion, in the sense it that may limit the clinical judgment of the health care practitioner, but to provide a set of principles to aid in the management of diseases in the clinical setting. Practice guidelines have a number of strengths, which if properly applied can:

- describe appropriate care based on the best available scientific evidence and broad consensus from aspects in the field;
- reduce inappropriate variation in practice;
- provide a more rational basis for referral;
- provide a focus for continuing medical education;
- promote the efficient use of health care resources;
- act as a focus for quality control, including audit;
- highlight the shortcomings of existing literature, and suggest appropriate future research (Todd, et al.,1998: 5).

The recommended guidelines are based on the findings of the study as well as appropriate literature and are designed to assist registered nurses working in the out patient departments of public hospitals. By telling their stories during the interviews, Xhosa diabetic patients contributed to the construction of these guidelines:

Table 4.1 GUIDELINES TO OPTIMISE HEALTH CARE OF XHOSA DIABETIC PATIENTS

MAJOR GUIDELINES	SUB-GUIDELINES
1. Provide educational information to both the registered nurse and the diabetic patient.	1.1. Empower registered nurses working in the OPD in the management of DM. 1.2. Empower diabetic patients on management of their condi-tions. 1.3. Provide relevant educational information to diabetic pa-tients.
2. Encourage registered nurses to render culturally congruent health care, observing the beliefs, norms and health practices of patients.	
3. Create and maintain a therapeutic environment necessary for delivering holistic patient care during accompaniment.	

GUIDELINE 1

This guideline consists of three sub-guidelines and will be discussed accordingly.

4.3.1 PROVIDE EDUCATIONAL INFORMATION TO BOTH THE REGISTERED NURSE AND THE DIABETIC PATIENT

RATIONALE

The initial educators that the diabetic patient is exposed to during his/her initial diagnosis are the nursing staff in the clinics and the medical practitioners, who should be in a position to understand the feelings of their patients and not add more stress to the already stressed patient. If the patient's concerns and fears are dealt with sympathetically by a knowledgeable nurse, he/ she is more likely to be in a calm frame of mind and ready to receive any education provided to him/her by the healthcare practitioner.

Because of his/her focus on the health of people, the registered nurse working in the OPD is accountable for health-promotive and illness-preventive care of patients. Health promotion may be achieved through health education directed at the patient and his/her family. Education sessions involve education and counselling; teaching patients about symptoms related to thier disease; how to manage the disease including diet, compliance to treatment, foot care, exercise, measures to prevent hyperglycaemia and thus, preventing the dreaded diabetic complications. During each contact session the needs of each patient are explored, understood and responded to appropriately. The patients should constantly be updated on their progress. The nurse should listen to patient's problems and acknowledge their anxieties, frustrations and feelings of helplessness.

A knowledgeable patient going through the stages of DM diagnosis will be in a position to reach the acceptance stage and make informed choices about their disease, especially since the western and *traditional methods of DM management seem to clash in African culture. It is, therefore very important that the registered nurse's communication skills and knowledge of diabetes are developed in order to improve communication between herself and the patient, in order to improve the quality of care of her patients*.

Poverty is experienced by the participants as an external force over which they and the nurses have no control, and which hinders their compliance, they can therefore benefit from patient education given by registered nurses in order to manage their lives.

OPERATIONAL IMPLICATIONS

The following action steps will assist in the implementation of guideline one**.**

SUB-GUIDELINE 1.1

4.3.1.1 Measures to empower registered nurses working in an OPD in the management of DM

- Registered nurses working in an OPD should be given the opportunity to attend congresses related to diabetic management, so as to be constantly updated on diabetic care measures.
- Nurses attending such congresses should be given the opportunity to give feedback to the rest of the staff in order to empower the entire staff complement of the OPD clinic.
- Registered nurses should attend multi-disciplinary Diabetic Association meetings, comprising of dietitians, pharmacists

and physicians in order to update themselves on DM management.

- Registered nurses should attend the Port Elizabeth Steering Committee meetings where local representatives from all organizations dealing with DM converge to share information.
- The in-service educational programs must be available and accessible to all staff members to keep them updated.
- In- service education programmes should be scheduled monthly to refresh the staff on diabetic issues. Other members of the multi-disciplinary team, such as the psychologist and the dietitian should be included in the in-service programs.
- Since the nurses working in the OPD may deal with patient's psychological reactions during diagnosis, they should be trained in counselling and communication skills, such as good listening and empathy.
- Relatives of diabetic patients should be involved in the educational programmes designed for their family member, because they will provide the support necessary for self-care.
- A documentary for Xhosa radio or even television can be produced, which discusses the causes and symptoms of DM, its associated complications, management, simple prevention strategies and the social and economic impact of the condition.
- Seminars, lectures, and role-plays can be used to promote lifestyle modifications and to transmit important information.
- Regular staff meetings should be instituted, preferably in the afternoons, which can be used as information sharing sessions Meetings should always have an agenda as a

measure of time control and should be restricted to 30-45 minutes.

- The national guidelines for the management of DM should be available for each registered nurse attending to a diabetic patient. Provision should be made to train the nurses working in the unit on the use of these national guidelines.
- Due to staff rotation some staff members working in OPD may be unfamiliar with the national guidelines. Training for new staff on these national guidelines should be provided so as to orientate them and to improve the quality of diabetic care.
- A library should be established in the unit with books, posters and articles, which will encourage the taking of responsibility for self-development. Availability of this resource will also help during the accompaniment of student nurses. As a control measure, one staff member per week may be responsible for books that are taken out.
- Health programmes should be developed involving the traditional healers, because collaboration between registered nurses and traditional healers may be the answer to providing effective health education to the patients.
- *Short courses, workshops and peer presentations on the following diabetic topics should be provided:*

    anatomy and physiology;

    pathophysiology and epidemiology;

    types/classification /causes;

    clinical manifestations;

    prevention and screening;

diagnostic criteria;

risk factors ;

diabetic management;

nutritional management;

treatment modalities;

exercise/precautions and recommendations;

pharmacological therapy;

side effects of drugs;

disease-related complications;

hypoglycaemia;

hyperglycaemia;

foot care;

treatment-related complications;

emotional needs of the patient and their family; and

interpersonal skills/communication.

SUB-GUIDELINE 1.2

4.3.1.2 Measures to empower diabetic patients on the management of DM

The most important way of assisting patients in coping with DM is by giving them information about their disease in order to improve their self-care. The following guidelines have been suggested by Shillitoe (cited in Gilbert and Lahav, 1998:13) and can be used by registered nurses:

Maintain open communication by helping patients talk about their fears.

- *Help patient and family members to understand the psychological reactions and stages that they are likely to go through.*
- *Help patients and family to cope with these reactions and let them know they are normal.*
- *Help the family and patient to plan for activities and responsibilities, which can be continued despite the disease.*
- *Help to mobilise necessary support for the family.*
- *Help the family to maintain a positive attitude and limit criticism.*
- *Help the family to maintain cohesion while encouraging the patient to function as independently as possible.*
- *Know when to refer to mental health professionals for assistance.*
- *It is the health professional's role to provide patients and their families with sufficient information and insight on the*

management of DM to allow them to make informed decisions on disease management.

- A team approach to the control of DM with a doctor, suitably trained professional nurse, dietitian, psychologist and chiropodist is ideal but not always practicable.
- A health professional must take the history the patient into consideration and must be well informed and willing to spend the time necessary to educate his/her patients
- Team members must be trained to provide supportive guidance to patients. If more than one person is providing advice to patients with DM, they should give consistent messages, which should not be conflicting (Brown & Dennil, 2004:143).

Points to reflect upon when discussing patient empowerment:

- Walk the path with the patient, side by side. Do not expect them to follow blindly or take the lead before they know the road they must follow.
- Allow for different stages they may be at.
- Allow for different beliefs without prejudice.
- Negotiate rather than tell.
- Understand that sometimes diabetes is frightening and this may hinder progress and acceptance.
- Treat diabetes as a condition rather than a disease. When we make people with a condition "sick" we hinder progress and reduce their functional ability. Diabetes only becomes a disease when poorly managed or complications develop due to poor control. This should always be regarded as temporary and the diabetic should be encouraged to get out of the "ill phase" as quickly as possible. This occurs only with good control of the condition.

- Self-care is vital and the person with diabetes is the most important member of the team, not the doctor or any other member of the health care team (Brown & Dennil, 2004:182).
- *Negative attitudes about the value of the treatment may be revealed in the course of discussion and some attempt should be made to correct these. The nurse should be sufficiently well informed to be able to converse intelligently with patients and family members about treatment they are receiving.*
- *A referral can also be made to a dietician or psychologist if the last two are available.*
- Patient education is directed at achieving the following:
  - minimal symptoms;
  - normoglycaemia;
  - blood pressure control;
  - minimal complications; and
  - reduced risks of cardio vascular disorders on subsequent visits to the health clinic. Later on, future self-care can be discussed (Hoey, 2004:26).

SUB-GUIDELINE 1.3

4.3.1.3 Provide relevant educational information to diabetic patients

The following information could be included in the educational sessions with patients and nurses.

- ***Physical exercise***

The patient can try some of the following:

- walking up the stairs instead of taking the lift;

- walking about while they are waiting for something;
- playing actively with their children or grandchildren;
- starting a small vegetable garden;
- starting an exercise routine by exercising for 30 minutes three to four times per week and increasing this gradually to 45 minutes three to four times per week, if this is possible;
- choosing a form of exercise that you enjoy;
- starting gradually but exercise regularly;
- wearing comfortable and suitable clothing/footwear during exercise sessions; and
- always having a small snack before and after exercising, as hypoglycaemia can develop up to 24 hours after an exercise session.

➢ ***Diet***

- There is no such thing as a ' diabetic diet'. Following a healthy eating plan is important to help keep your blood glucose and cholesterol levels within the acceptable ('normal') range. All people with diabetes, irrespective of whether they have type 1 or type 2 diabetes, need to eat a healthy balanced diet to prevent the complications of a consistently high blood glucose (sugar) level.
- If a patient has type 2 diabetes, losing weight with an energy-restricted healthy eating plan may be an important part of their treatment. If possible, a dietician should be consulted for personalized meal planning.
- At least three regular meals a day should be eaten.
- Ideally, these should be three equally sized, evenly spaced meals, eaten at more or less the same time every day. If you are overweight, you must lose weight by following an energy-restricted eating plan.
- Most people who have diabetes do not need snacks between meals. However, there are certain groups for whom snacks are

essential (including children, adults who have high energy requirements and people using certain types of insulin).

- Meals should never be skipped.
- Fibre in the form of fruits and vegetables, whole wheat bread, oats, beans and other legumes should be eaten. Legumes are a particularly good source of fibre, because they are digested more slowly and will help to control blood sugar. They will also help to prevent feelings of hunger.
- Starchy foods should be the basis of your meals
- The total amount of fat in the diet should be reduced. Low-fat foods and grilling baking or steaming should be chosen rather than frying. All visible fat should be removed from meat prior to cooking and low-fat dairy products such as low-fat or skimmed milk and low-fat cheeses should be used.
- Vegetable oils (for example sunflower, corn or olive oil) should be used when cooking and soft (vegetable-based) tub spread/ margarines.
- Small portions of proteins (foods such as meat, fish, chicken and cheese) and bigger portions of vegetables and starchy foods should be eaten.
- Three to four servings of fresh fruit a day, eaten at meal or snack times, are recommended. Fruit juices should be avoided, as they are a very concentrated source of fruit.
- 1.5 litres of fluid must be drunk per day.
- ‘No sugar added’ does *not* mean sugar-free.
- As little salt as possible should be used, especially in cases of high blood pressure. Herbs, salt-free spices and other flavoring agents should rather be used to make food tasty.
- Nutritive sweeteners, for example fructose, and sugar alcohols, such as sorbitol, have the same or even a greater energy value than sugar and should be used in moderation. Non-nutritive sweeteners, e.g. Canderel and Natreen, are better choices.

- Alcohol can be used in limited amounts (for examples on glass of dry white wine per day) by people with well-controlled diabetes. Alcoholic drinks should be taken with a meal or snack and not on an empty stomach.
- Diabetic foods are not necessary, as they are often higher in fat than non-diabetic foods, and a lot more expensive. 'Diet' and 'sugar-free' alternatives are better.
- Home-prepared meals should be eaten wherever possible. When eating out, choose foods such as clear soup, plain salad, grilled fish, plain baked potato and vegetables. Cut down on convenience foods such as pies, chips, and fast foods, as they often have a high hidden fat content (Novo Nordisk [s.a.]: 14).

- ***Foot care:***
  - People with type 2 diabetes need an annual foot examination to check for features such as absent foot pulses and insensitivity to 10g nylon monofilament that render a foot "at risk" of ulceration.
  - If risk features are found, the person needs to be referred to a podiatrist, if available, to receive extra foot education, assessment of the degree of risk and regular review (Gadsby, 2005:11).
  - Feet should always be kept clean.
  - Feet should be dried well, especially between the toes
  - Regular check under the side of your feet should be done.
  - If the underside of your feet can't be seen, a mirror should be used or someone else should to check for the patient.
  - Corns should never be cut or sharp objects used on your feet, assistance should be obtained from a clinic or doctor.
  - Long boots should be avoided.
  - Tight socks should be avoided.
  - High-heeled shoes with no support should be avoided.
  - Well fitting flat shoes should be worn.
  - Extreme heat should be avoided.
  - Feet should never be put near open heat.

- A diabetic should never walk barefoot.

The scope of health education that can be covered by the registered nurse during accompaniment is broad. The above discussion highlights only the topics that were commonly mentioned by the participants during the interviews.

GUIDELINE 2

4.3.2 REGISTERED NURSES SHOULD BE ENCOURAGED TO RENDER CULTURALLY CONGRUENT HEALTH CARE, OBSERVING THE BELIEFS, NORMS AND HEALTH PRACTISES OF PATIENTS

RATIONALE

A registered nurse working in an OPD clinic encounters many different cultural and ethnic groups, social classes, ages, sexes and religious backgrounds on a daily basis in her practice. Leininger (cited in Zoucha and Husted, 2000:327) defines cultural care as the subjectively and objectively learned and transmitted values, beliefs and patterned life ways that assist, support, and enable an individual to maintain health and well-being. It is therefore, of paramount importance that the registered nurse is acquainted with the different cultures she comes across.

OPERATIONAL IMPLICATIONS

- When rendering culturally congruent care a nurse should ascertain a patient’s attitudes and beliefs regarding health and illness. An understanding of the patient’s health beliefs and practices can be obtained from data collected during the nursing assessment.
- Allowing the patient to describe the difficulties that he/she encounters on a personal and daily basis provides insight on basic values and attitudes regarding the impact of illness on activities in daily living. States of health and illness are strongly influenced and primarily determined by the cultural background of the individual.
- The nurse should understand that culture and social interaction influence how a patient perceives, experiences, and copes with health and illness. Each culture has ideas about health and these are transmitted from parents to children.
- The assessment of a patient’s family structure will enable the nurse to use the next of kin as a support system in health- care.
- The nurse should be able to provide nursing care across cultural boundaries and should be able to take into account the context in which the diabetic patient lives and the situation in which his/her health problems arise.
- Consideration should be given to the social environment associated with the socialization of the patient into a group in society, which affects how a patient perceives health and illness.
- Assessment of the dietary practice, the cooking and eating times of the patient must be done. One of the most

important factors in promoting, maintaining and restoring a patient's health is the nurse's ability to encourage the intake of the right types and quantities of food since diabetes is one of the disorders for which diet is a major component of the treatment regime.

- When helping patients improve their nutrition practices, the nurse should remember that it is essential to understand and appreciate the culture and dietary practices of the patient.
- It is important to ask the patient about possible food restrictions, taboos or intolerance so that acceptable alternatives can be found without compromising nutrient intake. Knowing the patient's religious practices related to food enables the nurse to suggest improvements or modifications that will not conflict with dietary laws.
- The nurse should be able to assist the patients with the management of their diet during Xhosa cultural festivities as well as during religious festivities like Christmas and Easter celebrations, since people tend to have large meals and traditional high-calorie and high-fat foods during these times. The national guidelines for the management of DM mention the importance of the inclusion of cultural aspects in lifestyle management of the diabetic patient (Department of Health, 2004:5).
- Culture determines which foods are served, the number of and frequency of meals and who should be given the biggest portions. These culturally based dietary practices are especially significant in the care of patients with DM. A nurse should be culturally sensitive about the health traditions of diabetic patients and should posses some basic knowledge of how people live and cope with this illness.

- As some black patients believe in ancestral spirits, the nurse must always try and accommodate inherent religious differences between herself and the patient.
- During accompaniment the nurse should apply her knowledge competently in a culturally appropriate manner, attending to the total context of the patient's situation.
- A nurse should ascertain information about the use of alternate methods of treatment as most black patients make use of both western and traditional methods of treatment. Knowledge of what the patient believes in is helpful in planning for nursing interventions.
- Nurses must consider the physiological impact of culture on patients' responses to medications since the use of herbal supplements can affect the effectiveness of the treatment and compliance with the treatment regime (Smeltzer & Bare, 2004:119).
- The nurse should ascertain information about the family support systems of the patient. The family is the most important social system. How the family or the patient reacts to a disease may influence compliance with the treatment regime. The family can be the principal source of support during illness.
- Some black patients believe in the culture of traditional lifestyle, which looks for causes of illness and solutions outside the individual. Witches and sorcerers are supernatural beings who are believed to manipulate their powers to harm people in various ways. Nurses should take these beliefs into consideration as this will help in the interpretation of the cultural data.
- According to Tjale and De Villiers (2002:162) health-care professionals should understand their patients' religious

affiliation as well as the practices that influence health-care delivery and be able to use it in the planning for culture-congruent care.

- Should the patient require prayer or other religious rituals to be performed during the consultation sessions the nurse, if unable to adhere the request herself, should be able to refer the patient to a relevant person.
- During health education sessions with the patient, the nurse communicates with the patient using a language of verbal and non-verbal communication style. While some patients show respect by maintaining eye contact, most Xhosa patients do so through avoidance of eye contact. The nurses should be able to detect this expression of respect.
- One patient may perceive the nurse sitting close to her as an expression of warmth and care, while another may perceive the nurse’s act as a threatening invasion of personal space (Smeltzer & Bare, 2004:116). The nurse should always consider cultural preferences regarding space and distance during consultations with her patients.
- People from black cultures pay little attention to time as far as hours and minutes are concerned. This can be a barrier to effective communication between the nurse and the patient, if either the nurse or the patient does not adhere to scheduled appointment times.
- The meaning people associate with touching is culturally determined to a great degree. A black man may find it uncomfortable to be touched by a female nurse on the head, citing different reasons. Assessment of the head during a physical examination may require alternative approaches
- The socio-cultural environment is particularly influential in shaping patients’ attitudes about health and health-related

behaviours and this can also influence the patient's exposure to health-related information. A patient of lower educational levels must be accommodated by choosing the content and teaching strategies appropriately.

- Even though a nurse may feel strongly about her values and beliefs, it is important not to lose sight of the fact that values differ from one culture to another and that a patient's values may often be entirely contradictory to her/his own. Ethical conduct requires that nurses respect each patient, irrespective of his/her cultural values and beliefs (Pera & van Tonder, 1996:1950).

Thompson and Wilson (1996:27) state that, in order to render culturally congruent care to the patient the nurse should:

- recognize that cultural diversity does exist;
- recognize the uniqueness of and demonstrate respect for individuals and families of cultures other than her own;
- respect the unfamiliar cultural beliefs that he/she encounters;
- identify and explore his/her own cultural beliefs;
- recognize that some cultural groups have definitions of health and illness that may differ from his/her own;
- recognize that some cultural groups maintain health and healing practices that may be different from his/her own;
- be willing to modify health care delivery to be more congruent with the client's cultural background;
- recognize the diversity and uniqueness of individuals within a recognized cultural group; and
- recognize and appreciate that each and every person's cultural values are ingrained and therefore very difficult to change.

GUIDELINE 3

4.3.3 CREATE AND MAINTAIN A THERAPEUTIC ENVIRONMENT NE-CESSARY FOR DELIVERING HOLISTIC PATIENT CARE DURING ACCOMPAIMENT

RATIONALE

Patients have a right to a safe environment that will ensure their physical and mental well being. The researcher endorses the viewpoint of Kotzé (1998:10) that a sense of security is a prerequisite for successful nursing accompaniment. Accompaniment is a deliberate intervention by a nurse, aiming at enabling the diabetic patient to reach self-care in a safe environment. The patient will not be prepared to engage him/herself in any therapy unless he/she experiences a sense of security and believes that he/she is in the safe and capable hands of the nurse, in a safe environment. In order for a relationship of co-operation to develop, certain factors need to be considered by a registered nurse attending a patient in the OPD clinic. These factors, if not met, can affect the patient’s comfort level and the effectiveness of patient care in the creation of a therapeutic environment.

OPERATIONAL IMPLICATIONS

- The environment has a direct influence on the creation of holistic care, the quantity of information gathered and the quality of patient care. Whenever possible privacy should be maintained at all times in a private room with controlled lighting and temperature.
- If a private room is unavailable the screens can be used to divide a big consulting room in order to control the environment, to minimise distractions and to increase the comfort level of the patient (Estes, 2006:20). Privacy, as requested by one participant, is essential when private matters are discussed in order to create a therapeutic environment for the patient.

- During the physical examination, health professionals should show respect for the patients' body by examining the patient in a closed room, offering the patient a gown to wear when requesting him/her to get undressed and only exposing that part of the body, which needs to be examined. Health professionals should be caring and gentle during physical examinations
- Feedback should be given to patients regarding the findings.
- Permission should be obtained from patients before proceeding with examinations.
- Health professionals must show respect by being friendly and polite to patients.
- The nursing personnel in the OPD should strive towards establishing a therapeutic environment, which is flexible and conducive to both the individual patient and his/her close relatives.
- Nursing personnel must be knowledgeable, compassionate and understanding in order to give the necessary support to their patients and their family members.
- Nurses should have an inclusive and friendly approach when dealing with diabetic patient's concerns, making the patients feel welcome and included in the decision-making process related to their health.
- The necessity for the establishment and maintaining of a therapeutic environment to counteract the insecurity of the diabetic patient is of paramount importance in the management of DM. Kotzé (1998:6) states that the subjective experience, or life-world of the patient is the environment the patient knows well, where he/she is safe, secure and feels wanted.
- Confidentiality is essential in developing trust between nurse and patient. The patient's willingness to communicate private and personal information is predicated on the assumption that the

information will be used with discretion and for the benefit of the patient.

- The nurse's verbal assurance of confidentially eases the patient's concerns and fosters trust in the relationship. If the patient has brought family members or friends the nurse should inquire whether they should remain in the consulting room during consultation with the patient. Privacy and confidentiality will help in the creation of a therapeutic environment (Estes, 2006:20).
- The nurse should encourage the development of trust and respect. The diabetic patient needs to feel accepted by the nurse and other health care members as part of the establishment of a trust.
- The establishment of trust depends on the nurse's capability to secure and create privacy and confidentiality, as well as protection of the dignity of the patient.
- The quality time the nurse gives to the patients, listening to their concerns, and assisting them in expressing their feelings and fears, will develop into a feeling of trust on the part of the patient and will assist in the building of a therapeutic environment as the patient will be able to open up more freely to the nurse (Estes, 2006:21).
- Observing the patient's rights is important in the creation of a therapeutic environment. Brown and Dennil (2004:185) name the following patient rights, which must be observed by both the nurse and the patient in the creation and maintenance of a therapeutic environment. They state that health care workers should acknowledge that every patient has a right to:
  - a healthy and safe environment that will ensure their physical and mental well being;
  - participation in decisions regarding their own health;
  - access to health care services that include:
    - receiving timely emergency care;
    - treatment and rehabilitation;
    - provision for special needs; and

  - counselling without discrimination.
- *develop the assertiveness and communication skills necessary to collaborate effectively with their health-care team;*
- a positive disposition displayed by healthcare professionals;
- access to health information, knowledge of their medical aid and the facilities offered by them;
- choice of a health care provider in line with prescribed service delivery guidelines;
- information regarding their health being given with confidentiality and privacy and that such information will only be shared with others if informed consent is given unless it is required by order of a court;
- refuse treatment as long as it does not affect the health of other people; and
- complain about health care, have these complaints investigated and receive a response to their complaint.

Brown and Dennil (2004:186) also state that the patient has a responsibility to:

- take good care of their own health;
- care for and respect the environment they live in;
- utilise health care services wisely and not abuse them;
- know their local healthcare services and make use of them;
- provide health care givers with accurate information for treatment to be effective;
- advise the health care team of their wishes; and
- comply with prescribed treatments.

4.4 LIMITATIONS OF THE STUDY

- As with most qualitative studies, the limited sample size and the fact that the study was only conducted with patients from a single hospital, means that generalizations are not possible.
- The study does not include the experiences of other Xhosa diabetic patients in other public and/or private hospitals,
- Because only one hospital was used, the nurses may identify some experiences cited by participants and this might impair anonymity and confidentiality.
- Only one male agreed to take part in the study.

4.5 RECOMMENDATIONS

Recommendations, based on the findings from the research, are discussed under the following headings:

4.5.1 NURSING RESEARCH

The following recommendations are proposed for nursing research:

- ➢ The study should be used to compare these Xhosa individual experiences with those of other diabetic patients from other cultures.
- ➢ Research should be done to determine the effectiveness of the above guidelines once they are implemented. A similar study can be conducted comparing Xhosa diabetic patients attending clinics in the private sector with those attending clinics in the public sector

- The experiences of registered nurses working with DM patients in hospital's OPD could also be explored.
- An investigation can be made regarding the effectiveness of traditional medicine used by Xhosa diabetic patients.
- A study to assess the relevance and effectiveness of education given to poor, unemployed and diabetes patients can be done.
- A study on the role of ancestors in the lives of black people.
- A replication of the same study could be done.
- The effect of lifestyle modifications and interventions in the prevention of DM in the Xhosa community can be investigated.

4.5.2 NURSING EDUCATION

The following are recommended:

- In-service courses and workshops on the management of DM need to be developed.
- Curriculum revision must be done to include cultural aspects of diabetic patients.
- Opportunities for feedback and communication between staff members must be provided.
- Batho Pele principles and ethical principles should be emphasized in the training of student nurses.
- Workshops on relevant diabetic courses should be done regarding management of DM.

4.5.3 NURSING PRACTICE

The following recommendqtions for nursing practice are proposed:

- Registered nurses in the OPD must be oriented on clinical diabetic guidelines.
- Regular staff development programmes that are aimed at the improvement of diabetic care should be encouraged.
- Registered nurses must be educated on cultural aspects of diabetic management.
- Patients should be made aware of their rights with regard to health care.
- All nurses working in the OPD’s should be given an opportunity to update themselves on the management of DM.
- Staff members who attended courses should give feedback to their colleagues.
- Monitoring and evaluation of nursing care given to assess its affecttiveness must be done.

4.6 CONCLUSION

Through this study the researcher gave a broad overview of the experiences of Xhosa diabetic patients in their natural setting. The participants expressed their feelings from the time they were diagnosed with DM until they reached the acceptance stage. Guidelines were constructed for registered nurses to help them to optimise the health care of Xhosa diabetic patients in the public health care setting.

The study discusses the cultural parameters for registered nurses in giving holistic care to the patients in OPD. The importance of culture in a person's life is highlighted, since culture defines health, illness and the search for relief from disease or distress. Since patients bring their own world-views, expectations, norms and taboos to the clinical areas, culturally congruent patient care will improve patient satisfaction. Various issues related to the environment were also discussed, which encourage open communication and transparency during the disclosure of information by the patient. A nurse should understand that time must be allowed for both the nurse and the patient to learn how to communicate with one another, to test each other's trust-worthiness, and to learn about each other. It takes time to build trust and to effect cultural change.

The study also highlighted the need for health workers to be sensitive to the health-related religious and traditional beliefs of patients, in order to provide efficient culturally congruent care. Diabetic patients try to achieve a sense of integrity in accepting responsibility for their health so as to understand the disease in a positive manner and to make effective adjustments in their lives and social relations. A nurse attending to a patient who uses traditional medicine must provide information on the purpose and consequences of western medicine without condescending to the patient's medical preferences.

The sociological and psychological perspectives on DM were explored in this study. Fear of having a chronic illness like DM was manifest in the participants' responses Coping mechanisms and how these patients will ultimately make sense of their world were explored.

Although poverty was experienced as an external force over which the patient and the nurse have no control, and which hinders the patient's compliance, the patient can still benefit from patient education rendered by registered nurses, which is aimed at assisting him/her in managing his/her life.

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ANNEXURE A

PARTICIPANT CONSENT FORM

EXPERIENCES OF XHOSA DIABETIC PATIENTS IN THE NELSON MANDELA METROPOLITAN – A NURSING PERSPECTIVE

CONSENT FORM

Researcher: Mrs. Z.P. Ngamlana
Department of Nursing Science
Nelson Mandela Metropolitan University
Port Elizabeth
6000
Tel: 0722257676

Declaration by Participant:

I, the undersigned……………………………………………………..(name)
(I.D. No:…………………….) the participant

A. HEREBY CONFIRM AS FOLLOWS: 1.I was invited to participate in the abovementioned research project which is being undertaken by Mrs. Z.P. Ngamlana of the Department of Nursing Science in the Faculty of Health Science at the Nelson Mandela Metropolitan University	Initial
2.The following aspects have been explained to me 2.1 Aim: To explore and describe the experience of Xhosa diabetic patients. The information will be used to construct guidelines for registered nurses related to culturally - appropriate management of patients with diabetes in the public health care sector	Initial
2.2. Possible risks: I will not be exposed to any form of risk or harm.	Initial
2.3 Procedures: I understand that the information and	Initial

findings of the study will be available to me if so required.	
2.4 Possible benefits: As a result of my participation in this study, registered nurses may be enabled to render culturally - holistic care to diabetic patients	Initial
2.5 Confidentiality: My identity will not be revealed in any discussion, description or scientific publications by the investigator.	Initial
2.6 Voluntary participation: My participation is voluntary. My decision whether or not to participate will in no way affect my present or future medical care employment/ lifestyle	Initial
3.No pressure was exerted on me to consent to participation and I understand that I may withdraw at any stage without penalisation	Initial
4.Participation in this study will not result in any additional cost to myself	Initial
5.I was given opportunity to ask questions.	Initial
6.The information above was explained to me by Z.P. Ngamlana	Initial
B. I HEREBY CONSENT VOLUNTARILY TO PARTICIPATE IN THE ABOVEMENTIONED PROJECT.	
Signed / confirmed at …………………… on ……………………….2005 (Place) (Date) ………………………………… ……………………………… Signature of participant Signature of witness	

ANNEXURE B

APPLICATION TO CONDUCT RESEARCH: NURSING SERVICE MANAGER

39 De La Rey Street
Linton Grange
Port Elizabeth
6025

Mrs. E.V. Thomas
Nursing Service Manager
Dora Nginza
Private Bag X 11951
Algoa Park
Port Elizabeth
6001

Dear Madam

Application To Conduct Research Amongst Diabetic Patients Attending The Out Patient Department Of Dora Nginza Hospital

I am currently registered as a postgraduate student at the Nelson Mandela Metropolitan University in a Magister Curationis degree programme. The title of my research project is “Stories of Xhosa Diabetic Patients in the Nelson Mandela Metropole - a Nursing Perspective”. This study will assist with the design of a culturally-congruent educational framework to ensure optimal diabetic management. My supervisors for this research study are Professor RM van Rooyen and Mrs E Ricks.

I hereby request your permission to do individual interviews (each lasting about 40-60 minutes) on selected diabetic patients attending the Out Patient Department (OPD) of Dora Nginza Hospital The patients will experience no risk or discomfort whilst sharing their stories. Participation will be entirely on a voluntary basis and informed consent will be obtained from the participants. All ethical principles will be adhered to. The participants will be free to withdraw at any time should they so wish. Participants will also be informed about the purpose of the research. Your institution will be provided with a copy of the results of the research study.

Should you have any queries, please contact my supervisor Professor RM van Rooyen during office hours at [041] 504 2122

Thank you for considering my request.

Yours sincerely

Ms Zodumo Ngamlana

Magister Curationis Student: Nelson Mandela Metropolitan University

ANNEXURE C

APPLICATION TO CONDUCT RESEARCH: ASSISTANT DIRECTOR: TRAINING & DEVELOPMENT

39 De La Rey Street
Linton Grange
Port Elizabeth
6025

Mrs. N.G. Mtshake
Assistant Director: Training & Development
P.E. Hospital Complex
Port Elizabeth
6001

Dear Madam

Application To Conduct Research Amongst Diabetic Patients Attending The Out Patient Department Of Dora Nginza Hospital

I am currently registered as a postgraduate student at the Nelson Mandela Metropolitan University in a Magister Curationis degree programme. The title of my research project is “Stories of Xhosa Diabetic Patients in the Nelson Mandela Metropole - a Nursing Perspective”. This study will assist with the design of a culturally-congruent educational framework to ensure optimal diabetic management. My supervisors for this research study are Professor RM van Rooyen and Mrs E Ricks.

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Should you have any queries, please contact my supervisor Professor RM van Rooyen during office hours at [041] 504 2122

Thank you for considering my request.

Yours sincerely

Ms Zodumo Ngamlana

Magister Curationis Student: Nelson Mandela Metropolitan University

ANNEXURE D

APPLICATION TO CONDUCT RESEARCH; PE HOSPITAL COMPLEX
CLINICAL GOVERNANCE HEAD

39 De La Rey Street
Linton Grange
Port Elizabeth
6025

Dr F Rank
P.E. Hospital Complex Clinical Governance Head
Walton Building
Parsons Hill
Port Elizabeth
6001

Dear Madam

Application To Conduct Research Amongst Diabetic Patients Attending The Out Patient Department Of Dora Nginza Hospital

I am currently registered as a postgraduate student at the Nelson Mandela Metropolitan University in a Magister Curationis degree programme. The title of my research project is “Stories of Xhosa Diabetic Patients in the Nelson Mandela Metropole - a Nursing Perspective”. This study will assist with the design of a culturally-congruent educational framework to ensure optimal diabetic management. My supervisors for this research study are Professor RM van Rooyen and Mrs E Ricks.

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Should you have any queries, please contact my supervisor Professor RM van Rooyen during office hours at [041] 504 2122

Thank you for considering my request.

Yours sincerely

Ms Zodumo Ngamlana

Magister Curationis Student: Nelson Mandela Metropolitan University

ANNEXURE E

APPLICATION TO CONDUCT RESEARCH: CHIEF DIRECTOR: QUALITY HEALTH CARE ASSURANCE SYSTEM

39 De La Rey Street
Linton Grange
Port Elizabeth
6025

Dr B.N. Mjamba - Matshoba
Chief Director: Quality Health Care Assurance System
Department of Health
Private Bag X0038
Bhisho
5605

Dear Sir or Madam

Application To Conduct Research Amongst Diabetic Patients Attending The Out Patient Department Of Dora Nginza Hospital

I am currently registered as a postgraduate student at the Nelson Mandela Metropolitan University in a Magister Curationis degree programme. The title of my research project is "Stories of Xhosa Diabetic Patients in the Nelson Mandela Metropole - a Nursing Perspective". This study will assist with the design of a culturally-congruent educational framework to ensure optimal diabetic management. My supervisors for this research study are Professor RM van Rooyen and Mrs E Ricks.

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Should you have any queries, please contact my supervisor Professor RM van Rooyen during office hours at [041] 504 2122

Thank you for considering my request.

Yours sincerely

Ms Zodumo Ngamlana

Magister Curationis Student: Nelson Mandela Metropolitan University

ANNEXURE F

INTERVIEW NO 5

INTERVIEW NO. 5

R = Researcher
P = Participants

R: Tell me how it is for you to live with diabetes?

P: I started having sugar in 2001… I couldn't go to work… I felt so tired… I was always thirsty… I was always hungry… I went to hospital.. I was tested there… My sugar was still controlled…they told me… It was November then, I think 2001… and then January or February 2002 I went to the doctor… I had a problem of always passing urine… he checked me and found that I had sugar… he gave me a letter to bring here…my sugar was 12 then… I started taking treatment … but I started with low doses… one tablet once a day… now I take them twice a day… 2 in the morning and 2 at night… it's going higher and higher.

R: You say you always felt tired?

P: I was always tired. I didn't feel like working… without even having worked hard… I felt tired… I had itchiness, sometimes I felt hungry. I was hungry all the time. I was thirsty… I felt dry… what used to help me is to rest a little… when I woke up I felt fresh… I used to do that, even if it's just half hour sleep, I would feel better afterwards.

R: Do you still experience these problems?

P: I still do… as if they are even worse now than before… I eat in the morning but I feel hungry soon afterward… I ate my porridge and had tea before I came here… I drank my tablets but I am hungry right now.

R: You say your tablets were in low doses?

P: I was taking them one once a day… the doctor increased the doses… now I can say that my sugar is not controlled… last month I saw a doctor here… she sat down with me…she told me to use canderal tablets instead of sugar in my tea… but there is a sister who said canderals cause cancer… I stopped using them… instead I used a little bit of sugar in my tea… this other doctor here told me to stop using sugar altogether… I stopped it… I am now using canderals, because she told me so… and really my sugar has gone down now that I am using canderals, I am not using sugar anymore.

R: Are you only using tablets for your sugar?

P: Yes

R: You said you have itchiness, lets talk about it.

P: It was here in my private parts, I don't feel it anymore. I think these tablets are helping me.

R: Tell me how did you feel during that time?

P:I felt bad… It was always itchy… you feel unhappy, you must scratch yourself… you see, I first thought it was my roll on… but underneath I didn't use roll on, what could be the cause? I took these tablets… I don't feel anything now… nothing at all. Last month the doctor increased my tablets to two tablets… I get sugar and high blood treatment. She changed my tablets and tried other tablets. I can say they are helping me because my sugar today has gone down… last month it was 23, but today it is 8.3… I don't know if it is the new treatment or not… she even stopped one tablet and added a new one plus disprin… I am also having arthritis… she told me she is going to stop this treatment for arthritis because she said in the long- run it will affect my stomach… she told me that and cancelled the Ibrufen altogether and another tablet for arthritis… she gave me disprin instead.

R: You said your sugar was not controlled?

P: I think due to the fact that I was adding sugar in my tea, my sugar used to be high… sometimes 16… but last time it was the first time for it to be 23…it is going up… I don't know why because I do the cooking myself at home… I am strict with my diet. When cooking… we are told not to use oil… it doesn't mean you are not going to use it totally, but not too much… I don't fry… I use water for my vegetables… I think its because I add sugar… In the morning I eat porridge and add sugar… I also drink tea… I like my tea very much. Even before I go to sleep I have my last cup of tea (laughing). I think adding sugar contributed to the rise in my sugar levels. I had stopped using canderals… now it has gone down I think it's the canderals that are helping me.

R: You also said you have high blood pressure.

P: I also have high blood pressure… I get treatment for it… I was diagnosed at the same time with this sugar.

R: How do you feel now that there is this change on how you must prepare your food?

P: I feel fine… I don't have any problems about that… if someone wants to add spices in the food they are free to do so… I must take care of my health… as you can see me… I am healthy… no worries… I used to cook different types of food for myself and for my family… they wanted gravy… now I just have their gravy separately… I tell them that my sugar goes up… the doctor is not happy… I must cook correctly… It also saves my electricity, and they also eat a healthy diet…I don't add spices or gravy.

R: What else can you tell me about your sugar?

P: We are told to exercise … take walks… and sweat even if it's for half an hour.

R: Are these things manageable?

P: It's very difficult… I'm always tired… I cannot manage these exercises. I get exercise when going to church… I walk to church… it is far away at Veeplaas… I take that as an exercise… to and fro… even the diet… it is difficult to comply with… sometimes you do want to taste something which you are not supposed to eat… You don't eat it all the time… like now my neighbours are going to have a birthday party… they have invited me… they are going to give me a piece of cake… I am going to eat it… but it is not right… I know that I mustn't eat it… I personally don't buy cake… not at all… my sugar goes up.

R: How do you feel when your sugar is high?

P: I feel bad… but I take my tablets and sleep and drink water… water drops sugar… 8 glasses per day… water dissolves glucose… the doctors tell us… They tell us to drink a lot of water… water is very good… even if your sugar is normal… you must drink water everyday… even now… look I have this bottle… it's a 500ml bottle… it was full in the morning when I came here…it's empty now… this is my measurement… this bottle is 2 glasses… I am going to fill it up again and drink another 2 glasses to make 4 glasses… I will refill it again… even if I don't drink 8 glasses per day… but I do drink water… you see?

R: You told me you don't have a permanent job how do you manage to buy and maintain your diet?

P: I don't manage… even my grant was taken away in December 2004… It was for a year only… I don't manage now… the canderals are so expensive… There is nothing I can do but to take these tablets… I am in the process of reviving my grant… I don't know if I will get it… I don't manage financially now.

R: Is there anything else you want to tell me about how you feel about your sugar?

P: They also tell us that we must be careful not to walk barefoot… because you will get a cut and have a sore that will not heal… you can only walk barefoot in your house… this may result in you getting amputated. I never had any sores… I put on my shoes.

R: Do you have any other experiences that you can tell me as far as your sugar is concerned?

P: No… I can't remember anything else.

R: Is there any treatment that you use for your sugar?

P: I don't use anything…nothing… I tell you… I use my tablets only… there is another person who was advertising her treatment in the queue outside. It is in a bottle…Starmeta or something; I don't know its name. I use nothing I don't want it… I don't want to start drinking Starmeta… what if I get sick because I drink this strong medicine… I don't even drink that aloes bottle… the only thing that I drink sometimes is epsom salts… people say you must rid your body of the effects of these tablets that we drink… they can make a person not feel right…sick… I drink epsom salts and eno only… for bile… I don't drink anything else. I only take the tablets that I am given by the doctor… those medicines are too strong… I don't believe in that stuff…no… how are they going to make me feel? They are very strong those medicines… the lady in the queue made us taste it. It's very bitter… just a taste with the bottle lid… bitter… bitter… I will never drink that… what if I become unconscious because of that strong medicine? Myself? A person suffering from sugar? Unconscious? No if I die it must be because I cannot control my sugar… that's all… finish.

R: Are you afraid of death?

P: No… I am not afraid of death… I am ready any minute.

R: Are you afraid of your sugar?

P: I am afraid of it. I hear if it is not controlled, I will get a stroke… who will look after me… I don’t have children… I stay with my sister’s children… they are old… are they going to have time for me? No… so I am afraid of a stroke... I am afraid of this sugar… that is why when the doctor suggested canderals, I used them… you understand? My sugar dropped…I don’t want stroke… who is going to push me on a wheel chair? Yoo! I respect sugar… It would be difficult… I don’t even eat sweets.

R: My next question is, tell me the role your ancestors and your beliefs have played in your illness?

P: You mean as far as sugar is concerned?

R: Yes.

P: There is no role that my ancestors have played in my sugar. I do believe in ancestors though… rituals are done in my family… but I don’t think ancestors can help me with my sugar. They can help in other conditions like infertility…. Rituals can be done for people who do not get children… you see? Some people do get babies after that… what I don’t believe is the ancestors having something to do with my sugar…Sugar is just like any condition… you cannot slaughter a goat for suffering from sugar… no…no… it’s a waste of money… you will be only offering meat for free to the people.

R: So you don’t think there is a role that your ancestors have played in your sugar?

P: No… not with sugar… not with high blood pressure… it can in the case of infertility… and other illnesses… then rituals can be done for such conditions… sugar? … …no… control your sugar that's all.

R: So you think you must only control your sugar.

P: Yes. (emphatic) you must control your sugar… that's all… not to say that your ancestors will help you… no I don't agree.

R: Okay my last question… How would you like us as nurses treat you?

P: There is no other way. You teach us about this sugar… you tell us what causes it…failure of the pancreas or something… I don't know exactly… my standard 6 hygiene… the pancreas has failed in order to control your sugar… you must eat this and that… there is no other way… control your sugar… don't eat red meat… eat chicken or fish… you understand? What else is the nurse supposed to tell us? There is this patient whose sugar was 2 here in OPD… he was given glucose… another patient had also raised sugar… he was given a drip… you see all those things… those people cannot control their sugar… You tell us everything… I am satisfied with you… even when you ask us… why is your sugar up? What have you taken? You are speaking the truth…there is something I have eaten… that is the truth... It is only us who don't accept the truth… a person says I will eat what I want… I crave for it… sweets everything… I don't care what the nurses say …meanwhile the nurses are busy teaching us… the sugar is bound to go up… I will then be admitted… drips and so on, because of not listening.

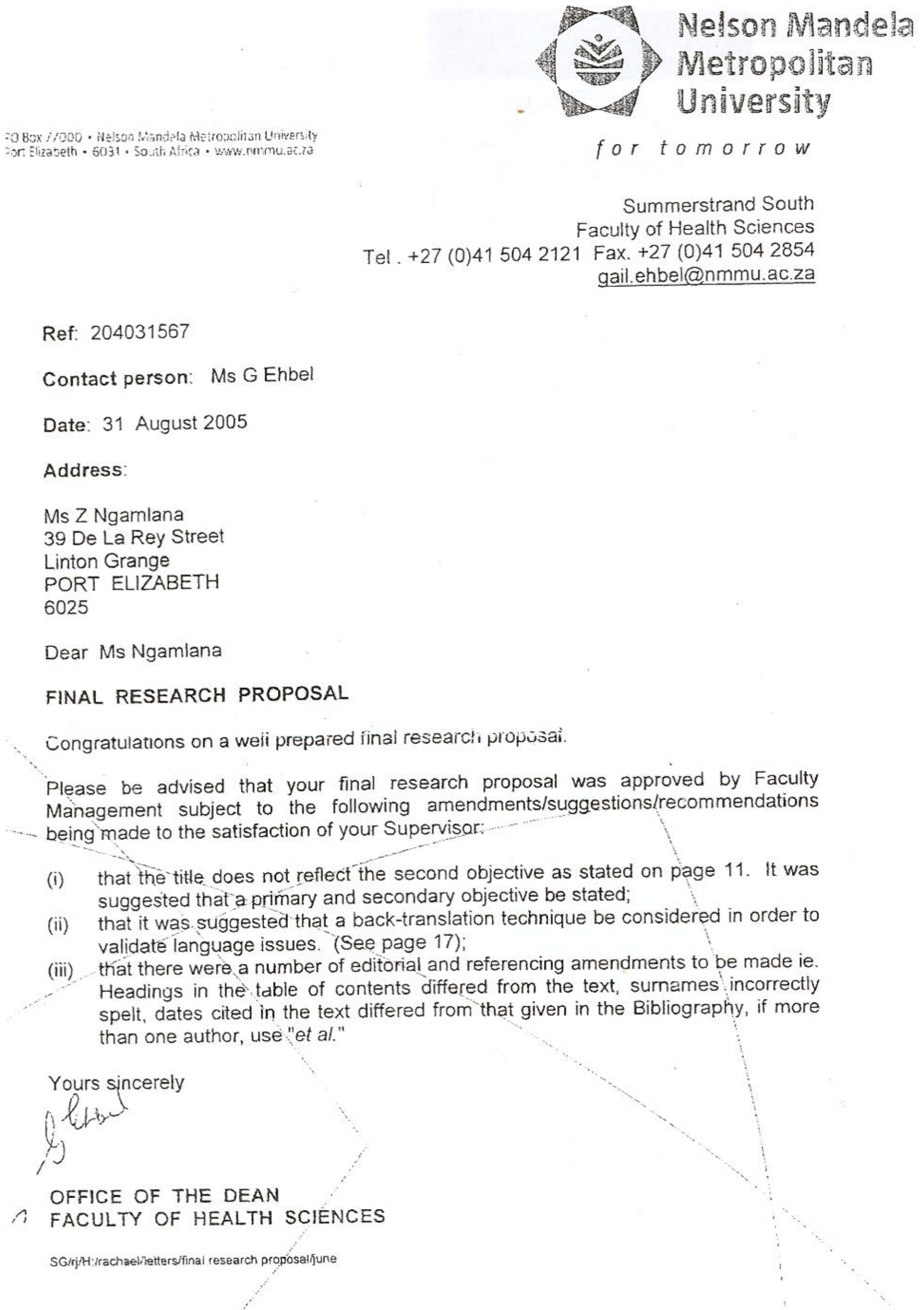
Silence.

R: Thank you very much.

P: Thank you.

ANNEXURE G

PERMISSION TO DO RESEARCH – FINAL RESEARCH PROPOSAL (ADC)



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Ref: 204031567

Contact person: Ms G Ehbel

Date: 31 August 2005

Address:

Ms Z Ngamlana
39 De La Rey Street
Linton Grange
PORT ELIZABETH
6025

Dear Ms Ngamlana

FINAL RESEARCH PROPOSAL

Congratulations on a well prepared final research proposal.

Please be advised that your final research proposal was approved by Faculty Management subject to the following amendments/suggestions/recommendations being made to the satisfaction of your Supervisor:

(i) that the title does not reflect the second objective as stated on page 11. It was suggested that a primary and secondary objective be stated;
(ii) that it was suggested that a back-translation technique be considered in order to validate language issues. (See page 17);
(iii) that there were a number of editorial and referencing amendments to be made ie. Headings in the table of contents differed from the text, surnames incorrectly spelt, dates cited in the text differed from that given in the Bibliography, if more than one author, use "*et al.*"

Yours sincerely

OFFICE OF THE DEAN
FACULTY OF HEALTH SCIENCES

SG/rj/H:/rachael/letters/final research proposal/june

ANNEXURE H

LETTER TO INDEPENDENT CODER

39 De La Rey Street
Linton Grange
Port Elizabeth
6025

Dr. Carlson
Nelson Mandela metropolitan University
Summerstrand South Campus
Port Elizabeth
6001

Dr. Carlson

Thank you for being my independent coder for my research project. Kindly receive my 10 scripts of interviews. Data will be analysed according to Tesch's method as described by Creswell (2003:192). The steps identified by Tesch as the most useful method of providing an analysis of the data are:

- get a sense of the whole by reading all transcriptions carefully;
- pick one document to analyze the underlying meaning;
- after completing this task for several documents, make a list of topics, clustering those that are similar;
- assign codes to the topics. Return to the data and assign codes to the appropriate segments;
- assign categories to the topics, grouping them and indicating interrelationships;
- decide on the abbreviation for each category;
- perform a preliminary analysis buy assembling the data for each category together;
- if necessary, recode existing data.

Thank you for your help.

Yours faithfully,

Ms Zodumo Ngamlana