PERCEPTIONS AND MANAGEMENT PRACTICES FOLLOWED BY TYPE II DIABETES MELLITUS PATIENTS ATTENDING KENYATTA NATIONAL HOSPITAL IN NAIROBI, KENYA

BY

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DECLARATION

This thesis is my original work and has not been presented for a degree award in any other university.

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SUPERVISOR’S APPROVAL

This thesis has been submitted with my approval as the University supervisor.

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Signature .................................. Date ............................

22/11/2012
DEDICATION
This thesis is dedicated to my parents who taught me that the best kind of knowledge to have is that which is learned for its own sake. It is also dedicated to my siblings – Allan, Dennis and Linda. I have set the academic pace for you, may you follow my footsteps.
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ABBREVIATIONS AND ACRONYMS

ADA  American Diabetes Association
BMI  Body Mass Index
DMI  Kenya Diabetes Management and Information Center
EM  Explanatory Model
GNLD  Golden Neo Life Diamite
HIV/AIDS  Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome
IDDM  Insulin Dependent Diabetes Mellitus
IDF  International Diabetes Federation
KNH  Kenyatta National Hospital
KES  Kenya Shillings
MoH  Ministry of Health
NIDDM  Non-Insulin Dependent Diabetes Mellitus
NIH  National Institute of Health
OPDC  Out-Patient Diabetic Clinic
T1DM  Type 1 Diabetes Mellitus
T2DM  Type 2 Diabetes Mellitus
WHO  World Health Organization
ABSTRACT

Type 2 diabetes mellitus (T2DM) is increasingly an important public health problem the world over. The prevalence rate in Kenya is approximately 10%, with the most at risk group of people between 35 - 64 years. Given its chronic nature, management of the illness by the patient remains central to control of its effects. This study was designed to explore the perceptions and management practices followed by T2DM patients attending Kenyatta National Hospital (KNH) in Nairobi, Kenya.

The study design was cross-sectional and adopted qualitative methods of data collection. Specifically, in-depth interviews, key informant interviews and unstructured observations were used to collect data. In-depth interviews were conducted among thirty two (32) T2DM patients (16 male and 16 female) aged between 35 – 64 years, who were attending the OPDC at KNH and who had been clinically diagnosed with the disease for a period of not less than two years. The patients were recruited at KNH as they attended the OPDC. Consent to participate in the study was sought and they gave their contact information which made it possible to later on be followed to their homes for interviews. Questions about their lived experiences with T2DM in terms of their perceptions of the illness, how they manage it, the role of home caregivers/relatives in diabetes management, and the problems experienced in daily management of their illness were posed. In addition, Key informant interviews with twenty (20) home caregivers/relatives and five (5) health care providers were also conducted. They provided additional information on how the T2DM patients manage their illness at home, the role played by their caregivers and the problems experienced in daily management of their condition. All interviews were audio-taped and the transcripts were analyzed based on emerging themes using a grounded theory approach.
The main findings of this study indicate that T2DM patients had varied perceptions about the etiology, risk factors, symptoms and complications of the disease. The descriptions they gave about the disease contained elements of both the biomedical and folk knowledge system. They utilized both biomedical and non-biomedical management options in their daily living with their diabetic condition. The shift from using one management regimen to another was based on the effectiveness, affordability and the EMs they held about their illness. The findings also reveal that patients’ caregivers, mainly the family members, play significant roles in management of diabetes by providing both tangible and socio-emotional support. In the course of daily management of diabetes, patients do experience numerous problems with financial incapability emerging as the chief of all.

This study contributes to literature on the body of work on T2DM in Kenya. It also has implications for care of patients with T2DM. The study therefore recommends the need for health care providers to improve on patients’ perception of the illness and management practices. This can be done through carrying out diabetes health education programs in a sensitive and culturally competent way. Kleinman’s EMs remains the best avenue in guiding such programs. Similarly, this study contributes rich information on the management of T2DM that can be used by policy makers and programme implementers to make informed decisions that will help abate the mortality and morbidity by giving attention to patients’ perceptions and management practices, considering that diabetes is a chronic illness.
CHAPTER ONE

1.0 BACKGROUND TO THE STUDY

1.1 Introduction

Diabetes mellitus, which consists primarily of Type 2 (85% of all cases) has evolved in association with rapid cultural changes, ageing population, increasing urbanization, dietary changes, decreased physical activity and other unhealthy lifestyles and behaviors (IDF, 2010; WHO, 2008). Currently, it is seen as a growing public health problem the world over. Nearly two thirds of all cases of diabetes reported each year are found in developing countries (Motala, 2002). In Africa, it remains an important cause of morbidity and mortality. Kenya is no exception as the World Health Organization (WHO) estimates the prevalence of diabetes to be around 10% (3.5 million people) (Jalang'o, 2006). The most at risk group of people for Type 2 Diabetes Mellitus (T2DM) in developing countries are between age group of 35 and 64 years (Motala, 2002), although increasingly children and youths are also developing T2DM.

Type 2 Diabetes Mellitus is a major cause of human suffering, placing a considerable burden to human development as well as to the health care systems. However, the high prevalence rate is attributed to the fact that non-communicable diseases of which diabetes is one have taken a back seat in the health care agenda. This is mainly because majority of the health care systems in Africa, including Kenya, are often skewed towards the management of acute illnesses and infectious diseases. Chronic and non-infectious diseases, thus, have a low priority (Motala, 2002).

Given its chronic nature, most diabetes care takes place in everyday life of the patient; the private sphere, rather than the public sphere of the health care system (Kolling et al., 2010). According to the IDF (2010), information constitutes 60%, diet 20%, exercise 15% and medication 5% of the overall
management regimen for T2DM. All these can have promising results in reducing the number of individuals affected and also in preventing those already diagnosed from reaching the severe stages of the condition. However, without proper knowledge about their disease, diabetics often rely on information that is partial, outdated, or incorrect (Murphy, 1995), which in turn affects the way they think and perceive their illness. This further makes them to seek alternative sources to help them manage their illness, yet they are known as contributing much towards high mortality rates from diabetes.

Previous studies in Kenya have reported low levels of knowledge and awareness of diabetes amongst diabetics (Chege, 2010; Dropkin, 2010; Gitonga, 2008; Mwendwa, 2001; Ngalyuka, 2008). Lack of proper knowledge of diabetes by diabetics may lead to their enormous suffering as information on symptoms, complications, risk factors as well as the cause of the disease may lead to the wrong perceptions of their illness thereby translating into poor management practices. In Kenya, this is especially the case whereby upon diagnosis, diabetes patients are not well equipped with knowledge and skills to manage their life with diabetes effectively (DMI, 2010).

There is no question that management of diabetes through knowledge on lifestyle choice is the best way to mitigate the problem (Scott, 1998). It has been noted that harmful management strategies are seen to be contributing much towards mortality from diabetes. However, how T2DM patients manage their condition based on their perceived understanding of the illness is not well understood (Liburd et al., 2004). Indeed, successful management of T2DM by patients requires not only attention to what they say they do, but also to the underlying perceptions they have about their illness, which are mainly based on the Explanatory Models (EMs) of the illness held by the patients. It is also important to note that medical pluralism is pervasive in Sub-Saharan Africa (Rekdal, 1999); thereby remaining a key feature in
chronic disease experiences (Aikins, 2005). Involvement in different medical systems may change what patients know and believe about diabetes (Skelly et al., 2006), and which further may determine management practices that will be followed. The choice and decisions on how the illness will be managed may be made by the individual patient, the family, or kinsmen; who may come up with cumulative ways of successfully managing the illness (Janzen, 1978).

This study was guided by the following assumptions:

i. T2DM patients believe that diabetes has multiple causes, symptoms, and complications.

ii. T2DM patients employ a variety of management practices based on their perceptions of their illness, of which have been noted as contributing greatly towards mortality from diabetes.

iii. Relatives/caregivers of T2DM Patients play a significant role in helping their patients manage their diabetic condition.

iv. T2DM patients experience numerous problems as they manage their diabetic condition.

It aimed at exploring the perceptions and management practices followed by T2DM patients, and also the roles played by relatives in helping their T2DM patients manage their diabetic condition alongside with the problems encountered with the entire management of the illness. The study attempted to provide recommendations on how to improve on patients’ perception of the illness and management practices, through dissemination of appropriate information and in the design and implementation of culturally sensitive health education programs on diabetes management.
1.2 Statement of the problem

Diabetes has been identified as a silent killer, killing as many people each year as HIV/AIDS and it may soon claim more lives than Malaria, HIV/AIDS and tuberculosis combined (Wanja, 2010). In Kenya, it is a major health problem both in urban and rural areas, with an overall prevalence rate of 10%. It is a major threat to public health and development; mostly affecting the age group that is economically active (between 35 and 64 years). It is also a costly disease both to the health agencies in terms of service provision, and to the diabetic individuals and their families in terms of loss of productivity and reduced quality of life. Moreover, utilization of healthcare facilities in Kenya has been undermined by among other things: poor infrastructure, weak health care systems and expensive financial costs. Consequently, most patients opt to manage their conditions by seeking convenient and affordable sectors of health care.

Given the fact that it is a chronic incurable disease, management of this disease by the patient remains central to control of its effects as patients can produce positive outcomes including better monitoring of a condition, fewer symptoms, enhanced physical and psychosocial functioning, and reduced health care use (Clark, 2003).

One of the major problems that impede the management of this disease in Kenya is lack of the acknowledgement of the disease by the patients (Dropkin, 2010). Also important is that patients’ perceptions of their illness are by nature private in that in medical consultations, patients are often reluctant to discuss their perceptions about their illness because they fear conflict with their doctors or risk of being thought of as stupid or misinformed (Weinman & Petrie, 1997). Furthermore, studies aimed at understanding patients’ perception of living with the disease are rare (Liburd et al., 2004).
While health care providers are often principally concerned with disease management, patients may contemplate their disease more broadly within an illness framework (Kleinman et al., 1978).

Liburd et al. (2004) states that how illness is culturally constructed has meanings, and these meanings have implications for successful diabetes management. With an understanding of diabetes that include causes, symptoms, risk factors and complications; diabetics would be more likely to make the difficult choices to eat healthier and get more exercise. However, few studies have documented differences in lay perceptions of the illness (Chege, 2010; Kart et al., 2007).

Moreover, there are no studies in Kenya that have explicitly looked into the perceptions and management practices followed by diabetic patients, yet elsewhere in Ghana, researchers attribute complications and high mortality from diabetes to harmful management practices, including the use of ethno-medicine (Ofei et al. 2002).

Therefore, this study aimed at exploring the perceptions and management practices that were followed by T2DM patients attending Kenyatta National Hospital (KNH) in Nairobi, Kenya. The study sought to answers the following research questions:

i. What perceptions do T2DM patients have of their diabetic condition?
ii. Which practices are followed by T2DM patients as they manage their diabetic condition?
iii. What roles do relatives/caregivers of T2DM patients play in helping them manage their diabetic condition?
iv. Which problems do T2DM patients experience as they manage their diabetic condition?
1.3 Research objectives

1.3.1 Overall Objective
The overall objective of this study was to explore the perceptions and management practices followed by T2DM patients attending Kenyatta National Hospital in Nairobi, Kenya.

1.3.2 Specific objectives
i. To find out the perceptions that T2DM patients have concerning their diabetic condition.
ii. To find out practices followed by T2DM patients in the management of their diabetes.
iii. To establish the roles played by relatives/caregivers in helping T2DM patients manage their diabetic condition.
iv. To identify the problems that T2DM patients experience as they manage their diabetic condition.

1.4 Justification of the study
There is a need for T2DM to be addressed in Kenya in order to reduce the enormous health and financial burdens that accompany the disease. Early exploration of patients’ perceptions of the disease may offer the opportunity of minimizing or avoiding later difficulties such as non-adherence to treatment or recommended behaviour changes (Weinman & Petrie, 1997). Understanding the personal perception of diabetes by the patients is important in health communications that address a person’s unique situation and personal characteristics, all of which have been shown effective for changing health behaviours essential for effective diabetes management by the patient (Krueter, 2000). The practices followed by these patients in managing their conditions can be helpful in improving the existing diabetes management practices. Health educators may also take note that the therapy managing group, and not the sufferer alone, can also be the appropriate focus for public health instruction (Janzen, 1978).

Most studies on diabetes in Kenya have adopted a quantitative approach, with much focus on the knowledge, risk factors and complications of diabetes (Chege, 2010; Gitonga 2008; Mwendwa 2001;
Ngalyuka, 2008). Much has not been done to track how lay people perceive and manage their diabetes condition at home. This study will adopt a qualitative methodological approach with an attempt to bridge these knowledge gaps. It will also be of importance to the scientific community by guiding future researches on diabetes.

1.5 Scope and limitations of the study
This study was carried out at the OPDC at KNH in Nairobi, Kenya. The study was anthropological in approach with an emphasis on the field of Medical Anthropology. The focus of the study was on the lay perceptions of the illness and how it tended to influence the management practices followed by patients with T2DM. The study population was composed of T2DM patients attending the aforementioned clinic. This was so because the potential to have diabetes health education program aimed at improving their well-being and quality of life, and even for the entire nation, can be much successful if their perceptions of the disease and the management practices they followed are incorporated in the design of the program.

The study was generally qualitative in nature thus the small number of participants in Kenya who were involved in this study limit the generalization of the study results.

1.6 Definition of key terms
Diabetics - The term refers to patients who are suffering from diabetes.

Disease - Biomedical, measurable identification of bodily disorder central to the process of biomedical diagnosis.

Explanatory Models - Beliefs and knowledge that individuals use in response to a specific experience of illness.
Folk management practices - Management practices that do not relate with the recommended clinical practices.

Folk sector - a healing entity mostly found in non-industrialized societies where certain individuals specialize in forms of healing that are either sacred or secular, or a mixture of the two.

Illness - It is the subjective response of an individual and those around him to his being unwell.

Management practices - Refers to individual's means to keep the disease and its effect under control by engaging in specific therapeutic behaviours so as to improve health status and quality of life. It is not only restricted to the individual patient, but also refers to what the relatives and care givers of the patients play in helping them cope up with their diabetic condition.

Medical pluralism – Refers to co-existence of various health care systems in the society ranging from the popular sector, the folk sector and the professional sector of health care

Perceptions - Individual knowledge, thoughts and beliefs regarding the causes, symptoms and complications of the illness.

Popular sector- it is the lay, non-professional, non-specialist domain of society where ill health is first recognized and defined, and health-care activities initiated, and with the family forming the main arena of health care.

Professional sector – it is an organized, legally sanctioned healing profession, utilizing modern western biomedicine by physicians and recognized paramedical professionals.

Therapy management group – a set of individuals who take charge of the therapy management with or on the behalf of the sufferer.

Type 2 Diabetes Mellitus - Refers to a state whereby the body does not make enough insulin or the insulin does not work properly due to impaired sensitivity to glucose in the cells of the body, resulting into high blood sugar.
CHAPTER TWO

2.0 LITERATURE REVIEW

This section reviews the literature on the nature of the disease. It is divided into four sections which include:

i. The nature of the disease in terms of its description, risk factors, symptoms and complications, the sources of information on diabetes and the lay perceptions of the illness.

ii. The management of T2DM.

iii. The role of family members/relatives in diabetes management.

iv. Effects of the disease.

v. The theoretical framework and its relevance to the study.

2.1 Nature of the disease

Diabetes Mellitus (DM) is recognized as a group of heterogeneous disorders characterized by hyperglycemia and glucose intolerance, due to insulin deficiency, impaired effectiveness of insulin action or both, all of which is responsible for control of sugar. It is also associated with abnormalities in carbohydrate, fat and protein metabolism.

Various types of DM exist, which are classified on the basis of etiology and clinical presentation of the disorder. They include Type 1 Diabetes Mellitus (T1DM), which defines 10% of the cases; Type 2 Diabetes Mellitus (T2DM), accounting for 85% of all diabetes cases worldwide; and the secondary and gestational types account for about 5% (WHO, 2008). T1DM is an autoimmune disease in which T lymphocytes (white blood cells) attack insulin-producing pancreatic beta cells. T1DM is also referred to as insulin-dependent diabetes mellitus (IDDM) or juvenile-onset diabetes because it tends to occur in children and adolescents and requires the use of synthetic insulin (NIH, 2007). The management for a patient with T1DM is mainly through the use of insulin, plus some dietary and exercise adherence.
Type 2 Diabetes Mellitus is also called Non-insulin Dependent Diabetes Mellitus (NIDDM). It refers to a state where the body does not make enough insulin or insulin does not work properly due to impaired sensitivity to glucose in the cells of the body. The result is consistently high blood sugar, mostly occurring in adults. For T2DM patients, management usually involves special diet, exercise, tablets and sometimes insulin injections.

There are two main risk factors for T2DM: the modifiable and non-modifiable risk factors. The latter risk factors are mostly composed of age and family history of the disease, while the modifiable risk factors comprises of lifestyle factors such as adiposity, physical inactivity, smoking, alcohol consumption and diet.

2.1.1 Symptoms and complications for diabetes
Most people can have diabetes and be completely unaware, simply because the symptoms, when seen on their own, seem harmless (WHO, 2008). However, the earlier the recognition of the symptoms, the greater the chances are that serious complications can be avoided. The most common symptoms of diabetes are: frequent urination, extreme tiredness, constant hunger, sudden weight loss or weight gain, slow or poor healing of wounds, blurred vision, recurrent infections, disproportionate thirst and a dryness of the mouth, sexual dysfunction among men, and numbness of feet and hands among others (IDF, 2010).

The significant complications of diabetes which mainly occur due to inadequate control of the sugar include: stroke, impotence, nephropathy (kidney failure), cardiovascular diseases, retinopathy (loss of vision), and neuropathy (nerve damage which often leads to numbness) (Dropkin, 2010). However,
Kaczmar (1998) has documented that about 85% of all diabetics develop retinopathy, 25-50% develop kidney disease, and 60-70% have mild to severe forms of nerve damage. To him also, diabetics are 2-4 times more likely to develop cardiovascular disease and 2-4 times more likely to suffer a stroke (Kaczmar, 1998).

2.1.2. The sources of information on diabetes
The main source of knowledge of diabetes to diabetics should come from the medical practitioners in the field of diabetes, whereby upon diagnosis, diabetes patients should be equipped with knowledge and skills on how to manage their life with diabetes effectively (DMI Report, 2010). This is a nightmare in Kenya as most medics do not have enough time with patients.

However, well-structured educational programs for both health care providers and patients are lacking, and government support frequently is absent (Motala, 2002). This leads into patients having confusing and conflicting information from health professionals, friends and even family members. In Atlanta, several diabetics have mentioned that they primarily talked to their friends and family members for information (Gazmararian et al., 2009). Studies on diabetes among the Latinos (Guatemalans) have reported that they knew more about diabetes if they knew someone with the disease (Weller et al., 1998).

Studies elsewhere have shown that diabetics have proposed different modalities of receiving information on diabetes through pamphlets, prevention magazines, video, expanded clinic hours, support group discussions and follow-up and refresher courses for patients living with diabetes (Gazmararian et al., 2009).
2.1.3 Perceptions of diabetes amongst T2DM patients

Diabetics need to understand that type II Diabetes Mellitus is preventable through lifestyle choices. The number that has even a basic understanding of diabetes in Kenya, and even in other developing countries is startlingly low (Dropkin, 2010). A recent study by Dropkin (2010) in Mombasa has shown that wrong perception of the causes and complications of diabetes exists amongst diabetics. For instance; 9 out of the 25 patients involved in the study perceived inheritance as the primary cause of the disease, 20% of his informants did not know of any complications of the disease, and that some patients associated diabetes with Tuberculosis. However, in the same study, those who mentioned lifestyle habits as a contributing factor towards developing diabetes had all attended nursing school.

In a study by Jezewski and Poss (2002), the informants' perceptions of the cause of T2DM were described using Kleinman's EM, which contained elements of both folk and biomedical perspective. Susto (a fright or scare) from witnessing deaths from motor vehicle accidents or drowning was perceived to be the primary cause of diabetes by all. Also, being overweight, heredity, lack of exercise, and generally not taking care of oneself were also viewed as contributing factors to the development of T2DM.

Kart et al. (2007) have also documented that in their study, majority of the participants' causal factors for diabetes were consistent with the biomedical understanding of Diabetes Mellitus. Two thirds of their participants attributed the cause of the disease to stress, diet and heredity. The others perceived the causes as resulting from poor mental attitude, family concerns and overwork. In a study amongst African-American men with T2DM, majority of the participants identified poor diet, particularly a diet high in refined sugars as the principal reason as to why they developed diabetes (Liburd et al., 2004). Studies in Ghana have also shown that too much sugar, having sexual intercourse with a diabetic patient,
bewitching, curses and punishment from God are believed to be the causal factors for diabetes, and the only cure is by consulting herbalists.

In a study by Chege (2010) amongst diabetics attending a rural hospital in Kenya, perceptions of the risk factors for diabetes seemed to be weak. Most of the respondents in his study perceived childhood starvation and the use of cassava as the main risk factors for developing diabetes. Elsewhere in Atlanta, while most diabetics had a reasonable understanding of the risk factors involved in the progression of diabetes, most of them were unable to articulate a succinct definition of diabetes (Gazmararian et al., 2009).

Studies on diabetics among the British Bangladeshis have also shown that most of them attribute diabetes to be as a result of events or agents outside the body rather than the primary failure of an organ within it (Greenhalgh et al., 1998). All the informants mentioned too much sugar, heredity and germs as the main causes of diabetes. Studies on the perceptions of the seriousness of diabetes amongst patients have produced varied results. For instance, when African-Americans diabetics were asked about the seriousness of diabetes, younger men felt that diabetes was not as serious as HIV/AIDS, as it can be cured (Skelly et al., 2006). However, older men felt that diabetes was a serious disease which could cause death anytime.

Studies on the lay perceptions of the symptoms and complications of diabetes tend to show similarities in patients thoughts (Dropkin, 2010). Weight loss, frequent urination, blurry vision, tired eyes and dry skin were perceived as major symptoms for diabetes (Jezewski & Poss 2002; Liburd et al., 2004;
Dropkin, 2010). Some participants in these studies experienced complications such as kidney failure, cataracts and high blood pressure. They also feared the potential long-term consequences of diabetes.

2.2 Management of T2DM

Literature on management of diabetes amongst T2DM patients in Kenya remains scarce. The most form of diabetes management by diabetic patients is self care management. Self care or medication has been defined as a process by which people function on their own behalf in health promotion and prevention, and in disease detection and treatment at the level of primary health resources in the health care system (Levin, 1981). It includes all the management practices used within the popular and folk sectors such as the use of herbal remedies by traditional healers, special diets, bodily manipulation and injections (Helman, 2007). Management practices comprise the individual’s means to keep the disease and its effects under control (Clark, 2001).

2.2.1 Importance of self management

Self management is the most frequent response to illness. One of the important features of self care is autonomy; a belief that a lay person is able to function effectively on his or her own behalf in health decision making (Levin, 1981). It is not limited to the individual but also includes members of one’s own family or household, clinical expertise, community support, together with conducive policies. Self care constitutes among other things self diagnosis and self treatment. It may imply the use of home-made remedies, herbal medicines, modern pharmaceuticals as well as dietary practices and exercise.

Levin (1981) has identified four rules for self care. First and foremost, according to him, self care ensures health maintenance and disease prevention, self diagnosis, self treatment and patient participation in professional care (use of services). The reason why self care management should be taken seriously is that roughly 80% of all illness episodes are self managed at home. Self care therefore
remains an individual’s first and most common reaction to the experience of not feeling well (Van der Geest, 1988).

Another important reason for self care management is that in third world countries, including Kenya, availability, affordability and accessibility to the health care systems are deemed as obstacles towards proper health care. For instance, distribution of medical services, doctors and other medical personnel in third world poses difficulty in consultation. In the year 2002 in Africa for example, we had only 150 registered diabetes educators, 100 of whom were located in South Africa (Motala, 2002). In Kenya, we have less than 10 endocrinologists, majority of whom are located in Nairobi (Murugi, 2009). Therefore, with all these barriers, most people resort to self care management because it is easily affordable and available.

The third factor underscoring the significance of “self care” is the IDF (2005) policy on self-management as the cornerstone of overall diabetes management, with diabetics being able to achieve optimal outcomes only if they are willing to and capable of managing their condition adequately on a daily basis. The fourth factor is the WHO’s policy on primary health care, whose cornerstone is self-reliance.

2.2.2 Clinical recommendations for management of T2DM
The primary goal in the management of DM is to control elevated blood sugars levels (Kaczmar, 1998).

In a person without diabetes, the blood sugar level is normally regulated by the body to remain within a narrow range of 4.4 and 6.1 mmol/L (82 to 110 mg/dl) (ADA, 2006). For patients with diabetes, it is important for them to maintain their blood sugar between 4 and 7 mmol/L (ADA, 2006). This can be done by the use of a glucometer, a hand held device which quickly delivers a measurement of the
person's blood sugar at the time of testing (Dropkin, 2010). Fundamental to the successful management of T2DM should entail one’s lifestyle changes such as dietary modification, regular exercise and physical activity especially in overweight individuals, as well as cessation of smoking and alcohol intake (IDF, 2005 & Kaczmar, 1998). If these measures fail to curtail the elevated blood sugars, oral hypoglycemic drugs such as Sulphonylureas and Biguanides, and insulin need to be considered (King & Rewers, 1991).

Dietary control is the critical aspect in T2DM management, accounting for 20% of the overall management regimen. Importance should be given to dietary content of carbohydrate, fat and fiber intake. The blood glucose level is closely affected by the intake of carbohydrates. Most young people require 180gm of carbohydrate per day while elderly patients 100gm. If fiber rich foods such as whole meal bread are eaten, then the carbohydrate content of the diet makes up 50% to 55% of the calories (Gitonga, 2008). On the other hand, too much fat is associated with an increased risk of coronary heart diseases and obesity in diabetics. This is the case because fats contain more than twice the energy content by weight than either carbohydrates or proteins (Gitonga, 2008). Dietary fiber is very essential as it helps in delaying the digestion and absorption of complex carbohydrates, thereby minimizing hyperglycaemia.

Exercise and physical activity helps in promoting weight loss and maintaining an ideal body mass index (BMI), when combined with restricted caloric intake (ADA, 1998). An ideal BMI for a normal person should range from 18.5 and 24.9. A BMI of 25 and 29.9 is a sign of overweight while a BMI of above 30 is an indication of obesity. Exercise also helps to increase insulin sensitivity, improves glucose
control thereby reducing cardiovascular risk factors (IDF, 2005). Frequent exercise and physical activity are also known to prevent impotence (ADA, 1998).

Alcohol intake can significantly alter blood glucose levels (Campbell, 1992). When diabetics, especially those over the age of 40 years smoke, and who have high blood pressure and cholesterol, they are usually at a higher risk for cardiovascular problems, stroke, and foot ulcers (Campbell, 1992).

Besides the above strategies, other miscellaneous management practices include foot care, eye care and oral hygiene (Gitonga, 2008). Frequent foot care and hygiene, and the choice of suitable footwear can prevent serious damages, which are likely to occur in diabetics thereby causing serious problems (Faris, 1996). Patients who experience blurred vision problems should seek medical care immediately so as to prevent blindness. Moreover, the most common oral complication of diabetes is gum (periodontal) disease, which if untreated can lead to tooth loss. Early signs of this disease include long-term bad breath or taste, bleeding gums, pus between teeth, or tooth loss (Musey, et al., 1995). The recommended tip for such oral complication involves brushing teeth after every meal and before bedtime, using a soft bristled brush, by lightly brushing the tongue and the surfaces of the teeth. The patient is also advised to visit the dentist after every 3 months for cleaning, polishing and inspection (Campbell, 1992).

2.2.3 Lay management practices utilized

In a developing country characterized by poverty such as Kenya, the management cost for the disease remains a challenge to the diabetics and even their families. In a study by Dropkin (2010:19), most patients stated that: “it is hard to imagine adults changing their diet after eating the same foods for their entire lives”. Affordability of medicines was also described as a major economic burden by practically every patient. In Tanzania, studies amongst diabetics have shown that affordability and availability of
the medicines and insulin in most pharmacies is one of the core barriers towards diabetes management (Kolling et al., 2010). Historically, a high weight has been considered a sign of affluence and success in much of Kenya (Kerns, 2006). When diabetics are advised to lose weight, many of them become concerned about what their friends would think of them (Dropkin, 2010). On the other hand, average price for a hand held glucometer in most pharmacies is 3,608 Kes. and the average cost of a package of 50 testing strips is 1,879 Kes. (Dropkin, 2010), which majority of patients cannot afford. Elsewhere, many patients express difficulty in obtaining food that is both acceptable and palatable; inability to understand information on leaflets, and difficulties in compromising with the dietary changes because of cultural reasons (Greenhalgh et al., 1998).

However, anthropological research suggests that medical pluralism is pervasive across the Sub-Saharan Africa (Rekdal, 1999), and thereby remaining a key feature in chronic illness experience (Aikins, 2005). For many chronic medical problems, patients’ reported improvement may be greater after encounters with marginal or folk practitioners than with modern physicians (Kleinman, 1976). However, the choices about who to consult in the health care system are influenced by whether the patient can afford to pay for the services (Helman, 2007), and the explanatory models (EMs) (Klienman, 1980) that the sick person uses to explain the origin of the ill health and all of which are culturally shaped. On this basis, patients choose what seems to be appropriate source of advice and treatment for their condition. Hence therefore, patients frequently use several different types of management practices, at the same time, or in sequence, on the pragmatic basis that “two or more heads are better than one” (Helman, 2007).
A growing literature suggests that lay perceptions and explanations of chronic illness affect how a patient responds to and manages his/her condition (Kart et al., 2007). Cohen et al. (1993) have noted that a person with diabetes adjusts and adapts to modifications and restrictions of the biomedical management of diabetes within the framework of his or her cultural influences, knowledge and perceptions, regardless of clinical recommendations. This is usually the case because the clinical and lay models surrounding illness and treatment often differs (Tessaro et al., 2005).

Findings from various studies (Lai et al. 2004, Jewewski & Poss 2002) support the view that diabetic patients' perceptions and practices of illness management are interrelated in the EMs developed by Kleinman. For example, to avoid the believed “renal toxicity” of hypoglycemic agents, patients took more efforts in dietary restrictions and physical exercise (Lai et al., 2004). Some drank water and were engaged in physical exercise to sweat so as to eliminate drug toxins. For those who perceived that over-consumption of sugar was the ultimate cause of diabetes, they focused their management on sugar control, thereby overlooking the importance of managing other risk factors. Kart et al. (2007) have stated that in their study, most males were significantly more likely to report engaging in physical activity, whereas females employed prayers or positive thinking in an effort to manage their diabetes.

Other studies have also shown that patients integrate both biomedical and traditional management practices into their EMs of T2DM. In Jezewski & Poss’s (2002) study, all participants mentioned the use of traditional folk remedies as an aspect of management such as the use of young leaf of the prickly pear cactus (Nopal) which was used as food and for its perceived medicinal properties of lowering blood sugar. Insulin and the corresponding injections were also utilized but several participants expressed the fear that using insulin might lead to blindness.
International Diabetes Federation, African region has reported some of the EMs for the causes of diabetes and the immediate strategies that are commonly used to manage or treat the disease in various African countries. In Kenya for instance, diabetes is believed to be as a result of a curse and by eating too much sugar, and it can be cured after a while through prayers and use of GNLD (herbalife) products.

In South Africa, all the aforementioned beliefs exist, including the belief that it is infectious. It is thought that it can be cured by urinating in a hollow pineapple and burying it, eating bitter foods, and through consulting traditional and faith healers (IDF, 2005).

In Tanzania, ethno-medical clinics are highly utilized by diabetics, whereby once a person has been diagnosed, the healer initiates herbal treatment that is claimed to often relieve patients physically by easing the symptoms, and psychologically by imposing hope of cure (Kolling et al., 2010), something biomedicine cannot offer. Dropkin (2010) has also noted that in Mombasa, most diabetic patients utilize herbal and alternative medicine as options for diabetes care, mostly from the Kamirithu Clinic when they don’t get well via conventional care.

2.3 The role of family members/relatives in diabetes management
Living with diabetes or caring for someone with diabetes is very much a family matter in an African context (Kolling et al., 2010). Family members can play a positive role in helping a patient with chronic illness manage his/her condition (Intagliata et al., 1986). They can provide primary support and care needed to counteract the potentially debilitating effects of their relative’s biological vulnerability and stressful environment. Family members can also play a major role in identifying the needs of their ill relative, and are an important source of information about their relative’s history of illness by providing
accurate historical information and longitudinal perspective on the patient’s functioning and symptoms (Intagliata et al., 1986).

Janzen (1978) also notes that a therapy management group mainly consisting of kinsmen comes into being whenever an individual or set of individuals becomes ill. The therapy management group acts by defining the situation and searches for a remedy through lending moral support, making decisions, and arranging details of therapeutic consultation (Janzen, 1978).

2.4 Effects of diabetes

Diabetes Mellitus is a very costly disorder both to health agencies, in terms of provision of additional services, and also to diabetic individuals and their families, in terms of loss of productivity and reduced quality of life (King & Rewers, 1991). As such it affects a country’s economy and social life. It is increasingly affecting the age group of between 35 and 64 years, which is economically active (IDF 2010). Diabetes costs more than money as the burden of the disease on the individuals and their families are not only financial. The pain, anxiety and reduced quality of life also have a devastating effect.

In a study by Tessaro et al. (2005), most participants stated that social stigma was one of the major effects of diabetes to them because of certain related beliefs to diabetes causation, particularly laziness and eating too much of the wrong foods, thus a self-induced disease. Also, other studies have documented that having diabetes can affect one’s employability and job security, sex appeal, and difficulties in obtaining food that is both acceptable and palatable (Liburd et al., 2004; Greenhalgh et al., 1998).
In conclusion therefore, it is thought that many complications of diabetes may be delayed or even prevented if proper information on perceptions and management practices employed by diabetics are incorporated into the health communication and education programs since every diabetics have their own subjective understanding of their illness. Interventions for improved management of diabetes need to be set up, with more emphasis on perceptions and management practices amongst diabetics. This can be a window towards alleviating the mortality burden of the disease as most researchers attribute complications and high mortality from diabetes to harmful self care practices, including the use of ethno-medicine (Ofei et al., 2002).

2.5 Theoretical framework
The phenomenon for this study is the perceptions and management practices employed by type 2 diabetes patients attending KNH in Nairobi, Kenya. Kleinman’s concept of EMs of illness was used as the theoretical orientation. This is discussed in greater detail below and its relevance explained.

2.5.1 The Explanatory Model of illness
Explanatory model (EM) is a concept that was developed in 1980 by Arthur M. Kleinman. The model suggests a way of looking at the process by which illness is patterned, interpreted and treated (Helman, 2007). He defines EM as notions about an episode if sickness and its treatment that are employed by those engaged in the clinical process. Kleinman is also of the view that EMs are stories that people construct to make sense of an illness within the context of their culture. These stories are based on the beliefs and values of the individual, and are manifested in their behavioral responses to their illness (Kleinman, 1980).

According to Kleinman, EMs are held by both patients and practitioners, and they offer explanations of sickness and treatment to guide choices among available therapies and therapists (Helman, 2007). In
particular, the EMs provide explanations for five aspects of illness: (i) the etiology or cause of the condition, (ii) the timing and mode of onset of symptoms, (iii) the patho-physiological processes involved, (iv) the natural history and severity of the illness and (v) the appropriate treatments for the conditions (Helman, 2007). All these are marshaled in response to a particular episode of illness, and are not identical to the general beliefs about illness that are held by a society (Helman, 2007). They incorporate elements of both folk and biomedical perspectives and which tend to change, and are heavily influenced by both personality and cultural factors.

Kleinman’s EMs focus on the individuals’ explanations of the etiology, symptoms, severity, and treatment of the illness. They can only be fully understood by examining the specific context in which they are employed. Such context may include the social and economic organization and the dominant ideology (religion) of the patient’s society. The social and economic context will further influence the types of management practices that patients can afford for their illness, and whether this takes place in the popular, folk or professional sectors of health care.

This theory has proved effective and useful in understanding the meaning of illness amongst T2DM Mexican-American patients (Jezewski & Poss, 2002). In relation to this study, Kleinman’s explanatory model is organized into a conceptual model as outlined below.
Based on this conceptual model, it is expected that the health seeking behavior of T2DM patients will be influenced by the perceptions that the patients have of the illness in terms of: (i) the etiology of T2DM, (ii) the symptoms and risk factors for T2DM, (iii) the patho-physiological processes involved in diagnosis of T2DM, (iv) the natural history and severity of T2DM by diabetics, (v) and the appropriate treatment adopted for the T2DM condition. However, management practices followed by T2DM patients may either take place in the popular, folk and professional health care sectors of management or through oscillating across all the three sectors, all of which may play a crucial role in determining the healthcare outcomes of the T2DM patient.
2.5.2 Relevance of the theory to the study

The Kleinman’s EMs of illness remains relevant to this study as it helps in understanding the perceptions of illness from the perspective of a group of people experiencing the same illness, who in this case are T2DM patients. Based on the five core aspects of illness, the perceptions and management practices that T2DM do employ will be anchored on them. The theory will also be used to guide development of the interview questions.
CHAPTER THREE

3.0 METHODOLOGY

This section describes the specific ways in which the study was executed. It includes the description of the research site and the study population, sample population, sampling procedures, methods of data collection and analysis, problems and challenges encountered and ethical considerations.

3.1 Study site

The study was carried out amongst T2DM patients attending the OPDC at KNH in Nairobi, Kenya. KNH is the largest public national referral and teaching hospital in Kenya, and in the whole of Eastern and Central Africa. It has 1800 beds, 50 wards and 22 out-patient clinics. “The hospital receives patients of chronic illness from all corners of the country, and even across the Kenya national border” (Anastasia Guantai: Personal communication, 13 September, 2010). The OPDC is located in Room 17, and it receives approximately 3000 diabetic patients annually. It was the main recruitment site for the T2DM patients, whose contact information were sought so as to be reached at their homes for interviews.

3.2 Research design

This study adopted a cross-sectional descriptive research design, utilizing qualitative methods of data collection which guided the exploration of the perceptions and management practices that were followed by T2DM patients attending the OPDC at KNH in Nairobi, Kenya. The study involved collecting ethnographic accounts of personal lived-experiences using in-depth interviews. Key informant interviews were also used to give additional information on the patients’ management practices that they utilized in coping with their diabetic condition.

3.3 Study population

The population included all T2DM patients who were attending the OPDC at KNH in Nairobi, Kenya.
3.4 Sample population
The study targeted adult T2DM patients aged between 35 and 64 years attending the clinic, in whom a clinical diagnosis of diabetes had been made within the previous 24 months and who were willing to participate in the research. Another inclusion criterion was consent. Only those who consented to participate in the study; and those who came from Nairobi and its neighbouring environments so that repeat interviews would be carried out easily, should it become necessary. Exclusion criteria included ill patients who were unable to communicate verbally; patients in whom clinical diagnosis of T2DM has been made in less than 24 months; patients who were not in the age bracket of 35 – 64 years; those who did not give free informed consent; and those who lived far away from Nairobi.

3.5 Sampling procedure
The sample population comprised of adult (between 35 and 64 years) T2DM patients who were recruited from the KNH hospital as they visited the OPDC. This age group was specifically chosen because the most at risk group of people for T2DM in the developing countries are within the age range of 35-64 years (Motala, 2002). They were selected with the help of a clinical officer and the primary care diabetes practitioner at the clinic. Purposive non-probability sampling was utilized to select T2DM patients, who had lived with the disease for more than two years so as to explore their lived experiences in managing their condition. Purposive non-probability sampling was used to select 32 informants for the in-depth interviews. It was also used to select 3 health care providers from the OPDC and 2 representatives from the DMI, who were the key informants for the study. Also included in the key informant interviews were the relatives/caregivers of these patients, found at home at the time when interviews were conducted.
Thus in total 32 in-depth interviews with diabetic patients, 20 key informant interviews with the relatives, 3 key informant interviews with health care providers at KNH OPDC and 2 key informant interviews with representatives at DMI were conducted.

3.6. Methods of Data collection
In-depth interviews, key informant interviews and structured observation were used to collect primary and qualitative data. Secondary data sources were also utilized.

3.6.1. In-depth interviews
Thirty two individual in-depth interviews were conducted amongst adult T2DM patients who had lived with the disease for more than 2 years. The study subjects comprised of 16 adult male and 16 adult female who were purposively sampled. It was the main data collection instrument for this study. This method was utilized as it provides rich and detailed exploration of individual’s own accounts of their lived-experiences, thereby helps in achieving a holistic understanding of the interviewee’s situation. The interviews were conducted in a naturalistic setting (patient’s homes) when the patients were in a relaxed mood other than in the clinic. The interviews were conducted with the help of an interview guide containing open-ended questions which provided room for thorough probing to elicit detailed information. It was used to elicit the patients’ perceptions about the nature of the illness and the management practices that they had been following. This was so because it is believed that the patients’ perceptions in terms of the beliefs and the EMs that they hold about the disease tends to influence which management practices will be employed.

3.6.2. Key informant interviews
Key informants are people knowledgeable on the topic under investigation (Nkwi et al. 2001; Fetterman 1989; Bernard 1994). Three health personnel from the OPDC at KNH, consisting of the diabetes educator, clinical officer and a nurse; and two representatives from the DMI center were interviewed.
Relatives/ the caregivers of the patients were also interviewed. An interview guide was used in order to obtain standardized data.

3.6.3. Structured observation

Structured observation was used so as to give additional information to the study. It involved observation of the patients' behavior in their natural settings/ homes, the kind of food they consumed, visible complications from the patients, management regimen used, and the roles of the caregivers, among others.

3.6.4. Secondary data sources

Documentary materials such as health education pamphlets, newspaper clippings and journals were also explored. Relevant literature on perceptions and management practices amongst diabetes patients were also reviewed to provide additional information for the study.

3.7 Data processing and analysis

All tape-recorded qualitative data obtained from in-depth interviews and key informants were transcribed verbatim and then translated into English. The data collected was coded along general emerging themes from the study. Thematic data analysis was used to analyze the study results in line with grounded theory procedures and techniques. The results were then organized for presentation along emerging themes. Quantitative data on socio-economic and demographic characteristics of the patients collected after the individual in-depth interviews were coded and analyzed using descriptive statistics.
3.8 Problems and challenges encountered

Generally, the research was successfully completed. However, a few problems and challenges were experienced which, in various ways, affected the study. First, during the first two days while recruiting the study subjects at the KNH OPCD, I was unable to get any sample since the patients could not identify with me. Following the clinical officer’s advice, I had to put on a doctor’s coat for identity purposes, which finally made the process easy. However, the patients mistakenly called me “doctor” to the extent that almost all of them wanted to be visited in their homes irrespective of the sampling criterion used. Even after explaining to them clearly about the purpose of the study with the help of the clinical officer, most of them felt that it was a KNH sponsored study. This left some of the patients emotional and unhappy. As the researcher, I was forced to take their contact information and contacted them after a few days explaining to them further about the purpose of the study.

In addition, wearing a doctor’s coat at the clinic while recruiting the study subjects somehow affected the quality of information given to me. For instance, some informants (three male T2DM patients) were not free when being interviewed. They were mistakenly referring to me “doctor” even after visiting them to their homes, and explaining to them that I was just a student. In-depth Interviews with these patients took a shorter period (lasting about fifteen minutes) as they were just mentioning responses and did not want to be prompted. One of them stated that “doctor, I am answering you based on what you and your colleagues at the clinic usually teach and advise us”. This meant going back to the KNH OPDC to recruit other male research subjects for the study and book appointments with them for home visits.

Secondly, to penetrate some areas in the rural areas was a bit difficult especially for those patients who were located far away from the main road. Indeed, the situation was such bad that even when there were
no rains; it was still not easy to get vehicles or even motorbikes plying to some of the routes. This forced me to sometimes trek several kilometers on foot, which undoubtedly slowed down the data collection process.

Thirdly, despite the good reception accorded to us from our informants, thanks to the efforts of the research assistant who was conversant with the Agikuyu language, as some of the patients were unable to speak fluently in either Swahili or English. The research assistant remained resourceful in conducting some of the interviews, transcribing and translating them into English.

Fourthly, because of the cultural beliefs held by a few patients, I was unable to conduct some of the interviews despite having arrived in their homes. For instance, I visited a male Muslim T2DM patient; who explained to me that based on their religion, a married man is not allowed to speak face to face with a woman. Being the principle investigator, I was unable to interview him. This somehow slowed down the data collection process.

Lastly, since the study was based on interviewing equal number of male and female patients, the researcher had difficulty in booking appointments for interviews with the male patients. Most of them said they were busy throughout the week, and if they happened to be available in their homes, mostly it had to be on weekends and in the evening. As the principal investigator, I was forced to hang around mostly at their market place waiting for them. However, if it happened to be too late and the patient had not showed up, I had to go back and reschedule the interview for another day. This translated into loss of resources by the researcher in terms of time and money.
3.9 Ethical considerations

Before the interviews were conducted, a statement of consent was read to all the study subjects, who were asked for their informed consent to participate. Explanations were given to all the informants concerning confidentiality. The study ensured privacy and confidentiality by using fictitious names instead of real names to refer to informants. Confidentiality and privacy were maintained throughout data collection, analysis and dissemination stages. Due to the nature of the study, informants were briefed on the study topic and expectations in the consent form, which they were expected to sign so as to show their willingness to participate in the study.

Ethical approval from the KNH/University of Nairobi Ethics and Research Committee was obtained to conduct the study. Approval from the Ministry of Education, National Council for Science and Technology was also sought and a research permit was issued to conduct the study.
CHAPTER FOUR

4.0 STUDY FINDINGS

This chapter presents the study findings. It is divided into 5 sections which include: profile of the patients; perceptions of diabetes; lay management of diabetes; the role played by care givers in diabetes management; and the problems faced by patients in daily management of diabetes.

4.1 Profile of the T2DM patients

4.1.1 Gender

The study is based on an equal number of male and female T2DM patients interviewed over a period of three months. A total of thirty two (32 – 16 male, 16 female) patients were interviewed.

4.1.2 Lived duration with the illness and marital status

The mean lived duration with the illness for the 32 T2DM patients interviewed was 10 years, ranging between 2 to 30 years. Marital status of the T2DM patients indicated that 87.5% were married while 9.4% and 3.1% were widowed and divorced respectively (Table 4.1).

4.1.3 Religious affiliation and education

Majority of the T2DM patients interviewed were Protestants accounting for 68.8% of the study subjects. Another 21.9% identified themselves as catholic and 9.4% as Muslim (Table 4.1). More than half (56.3%) of those interviewed had completed primary education while 21.9% had completed secondary education. About 12.5% had never gone to school while 6.3% had completed tertiary level of education and 3.1% had gone through the adult education (Table 4.1).
Table 4.1: Profile of the T2DM patients (n=32)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency (n)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>16</td>
<td>50</td>
</tr>
<tr>
<td>Female</td>
<td>16</td>
<td>50</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
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<td></td>
</tr>
<tr>
<td>Married</td>
<td>28</td>
<td>87.5</td>
</tr>
<tr>
<td>Widowed</td>
<td>3</td>
<td>9.4</td>
</tr>
<tr>
<td>Divorced</td>
<td>1</td>
<td>3.1</td>
</tr>
<tr>
<td><strong>Religious affiliation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protestant</td>
<td>22</td>
<td>68.8</td>
</tr>
<tr>
<td>Catholic</td>
<td>7</td>
<td>21.9</td>
</tr>
<tr>
<td>Muslim</td>
<td>3</td>
<td>9.3</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>4</td>
<td>12.5</td>
</tr>
<tr>
<td>Primary</td>
<td>18</td>
<td>56.3</td>
</tr>
<tr>
<td>Secondary</td>
<td>7</td>
<td>21.9</td>
</tr>
<tr>
<td>Tertiary</td>
<td>2</td>
<td>6.3</td>
</tr>
<tr>
<td>Adult education</td>
<td>1</td>
<td>3.1</td>
</tr>
<tr>
<td><strong>Main source of livelihood</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private business</td>
<td>18</td>
<td>56.3</td>
</tr>
<tr>
<td>Farmer</td>
<td>7</td>
<td>21.8</td>
</tr>
<tr>
<td>Private sector</td>
<td>3</td>
<td>9.4</td>
</tr>
<tr>
<td>Government employee</td>
<td>2</td>
<td>6.3</td>
</tr>
<tr>
<td>Casual laborer</td>
<td>1</td>
<td>3.1</td>
</tr>
<tr>
<td>Remittance</td>
<td>1</td>
<td>3.1</td>
</tr>
<tr>
<td><strong>Ethnic affiliation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kikuyu</td>
<td>22</td>
<td>68.8</td>
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<tr>
<td>Maasai</td>
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<td>6.3</td>
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<tr>
<td>Congolese</td>
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<td>3.1</td>
</tr>
<tr>
<td>Kamba</td>
<td>1</td>
<td>3.1</td>
</tr>
<tr>
<td>Nubian</td>
<td>1</td>
<td>3.1</td>
</tr>
<tr>
<td>Luo</td>
<td>1</td>
<td>3.1</td>
</tr>
<tr>
<td>Rwandese</td>
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<td>3.1</td>
</tr>
<tr>
<td>Somali</td>
<td>1</td>
<td>3.1</td>
</tr>
<tr>
<td>Taita</td>
<td>2</td>
<td>6.3</td>
</tr>
</tbody>
</table>
4.1.4 Main source of livelihood and ethnic affiliation

The most commonly reported main source of livelihood was engagement in private business, accounting for 56.3%. This was followed by 21.8% who identified themselves as farmers; 9.4% who were employed in the private sector and 6.3% who were government employees. The remaining two patients reported being casual laborer (3.1%) and relying on remittance (3.1%) (Table 4.1).

When the T2DM patients were asked about their ethnicity, 68.8% reported being Agikuyu, followed by 6.3% each, who were Maasai and Taita. The remaining patients belonged to: Kamba, Luo, Congolese, Rwandese, Nubian, Somali, each representing 3.1% as shown in Table 4.1.

4.1.5 Monthly family income and expenditure on medication

The mean family monthly income as reported by thirty two (32) T2DM patients in this study was 16,379.00 Kenya Shillings (approximately 200 USD) while the monthly expenditure on diabetes management was Kenya Shillings 7,524.00 (approximately 92 USD), which is about 46% of the average monthly family income.

4.1.6 Household composition

Of the 32 T2DM patients interviewed, 21 were household heads (16 males, 5 females). For the remaining 11 T2DM patients, ten of them reported that their husbands were the household heads and one patient reported his elder son. For the purpose of this study, the household composition was defined as the number of people who had been living in the T2DM patient’s house for at least 3 months. This was important in eliciting who the caregivers were. The average household composition for the T2DM patients’ interviewed was 5, comprising on average 2 males and 3 females. The average number of children below the age of 18 residing within the household was one.

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1 At the time of the interview, 1 USD was equivalent to 82 Kenya shillings.
4.1.7 Current locations of residence

The T2DM patients who participated in this study were residing both in rural and urban areas. The actual locations of residence where interviews were conducted were: Kangemi (2F); Kabiria (2F); Thika (2F); Juja (2F); Ruiru (1F); Kijabe (1F, 1M); Eastleigh (2M, 1F); Njabini (2M, 1F); Limuru (1M, 2F); Kangari (1F); Muguga (1M); Kimathi Estate (1M); Tigon (1M); Gatundu (2M); Kibera (1M); Pangani estate (1M); Kayole (1M); Githurai (1M) and Ngong (1M, 1F). These locations and approximate distance are depicted in Figure 4.1.

Figure 4.1: Approximate distance and location of the patients from Kenyatta National Hospital
4.2 Perceptions of diabetes

The T2DM patients were asked questions to explore their perceptions about diabetes causation and risk factors associated with it, symptoms and complications experienced, and on prevention.

4.2.1 Lay Perceptions about diabetes causation

The mean lived duration with the illness for the 32 patients who participated in this study was 10 years. However, most of them (66%) could not explain what caused their diabetic condition. Prior to probing, majority of them used the phrase: “But I think” or “I was told”, where they then reported multiple causal factors for diabetes. The most commonly perceived causal factor reported thereafter was stress, accounting for 47% of the responses which was caused variously such as disharmony and conflicts within the family, death of a family member and financial problems. This is illustrated in the following excerpt:

I don’t know the exact cause of my diabetes. But I strongly think it was caused by stress. I remember when my condition developed; I had a lot of problems especially financial problems which, I think brought stress and led to the disease. ...when I went home there was a person whom we were quarrelling over land and this escalated the problem. When I sought treatment I was diagnosed with diabetes. (Mr. Pau\(^2\), 53 years, Eastleigh)

However, stress as a causal factor for diabetes was mainly reported by the female patients (11 out of 15), who associated the onset of their illness with frequent quarrels with their husbands, daughters-in-law and mothers-in-law. Some attributed the stress resulting from being widowed or divorced, and having been left alone to cater for the family needs as a main cause of their diabetes. For instance, a T2DM patient who had been divorced asserted: “I think mine was stress. I was stressed by the fact that my husband divorced me and left me with 5 children, all of who are boys. You know how difficult it is to

\(^2\) The names of all T2DM patients who participated in this study have been changed. Fictitious names have been used to protect their identity.
bring up boys alone. I went through a lot of problems and I think this is what resulted in my diabetes”

(Mrs. Flo, 43 years, Ruiru).

Heredity was also reported by about 25 % of the T2DM patients, although quite a number of them were not sure about it and could not explain how inheritance causes diabetes. Some explained how the other family members had died of diabetes or were currently living with diabetes, though to them, this was still not clear. For example, a patient stated that “… in the past our grandfathers and grandmothers did not suffer from diabetes. So, I don’t believe the inheritance theory so much. This disease has just started affecting us recently” (Mr. Nga, 45 years, Gatundu). For others, even though diabetes was running within their families, they felt that it was a normal disease and only God knew about how it develops.

This is exemplified using the following excerpt:

I really don't know what causes it. But I have heard that if one member of your family is diabetic then they normally pass it on to the children. My mother died of diabetes and maybe that’s why I have it. ...I think it's just a disease like any other. It’s not a question or issue of inheritance. I think God is the only one who really knows how it develops. (Mrs. Wa, 61 years, Kangemi)

The same patient, who had no formal schooling, asserted that she always prayed that her children do not inherit it from her.

Being overweight prior to being diagnosed with the disease was also reported by some (16%) of T2DM patients as the causal factor for their diabetic condition. For instance, they stated that "sometimes back, I was overweight, like 80Kgs, then I started losing weight drastically all over a sudden within two months” (Mr. Jack, 52 years, Gatundu). A similar number of patients related the cause of their illness to chemicals found in foods grown by fertilizers and poor dietary habits of mainly taking tea with sugar, eating a lot of food rich in fats, eating food containing too much salt, and consuming a lot of starch.
Others (10%) asserted that their diabetic condition could have been as a result of other diseases such as malaria, typhoid and goitre. This can be illustrated using the following words:

_I really don’t know what causes diabetes. ...I think it was as a result of goiter. I had goiter and it did not protrude outwards as it normally does. It was swollen internally. The doctors said it might have released some infections into the bloodstream. So I think this might have caused my condition. The blood had impurities._ (Mrs. Grac, 60 years, Limuru)

Moreover, shock (6%) resulting from gunshots and death of a spouse was also perceived as the primary cause of diabetes. Below is a description of how shock caused a patient to have diabetes:

_I think I was just shocked because of the fighting in Somalia. The sound from the gunshots really shocked me in 1993. I really desire to live in a peaceful place. It forced me to run away from home and went to settle in Liboi, the border of Kenya and Somalia. I started feeling weak and very sick and unable even to walk. A good Samaritan just took me to Daadab camp where we met with other people from Somalia who had also become diabetic because of the shock resulting from the same gunshots._ (Mr. Ham, 38 years, Eastleigh)

For this patient, he believed that most Somali diabetics, who he always met at the health care facility (KNH) and who they stay with in the same residential area, their condition was a result of sounds from gunshots that shocked most of them during the 1993 civil war in Somalia.

Diabetes was also perceived to be caused by forces within the social and supernatural world such as witchcraft practices (3%) and as a punishment from God (3%). A diabetic patient explained how witchcraft led to progression of her diabetes as stated in the excerpt below:

_In 1986 -1987 I just started having bodily complications. I’m not sure it was diabetes because where I was married there was so much witchcraft. I even carried a pregnancy for one year and two months. The pregnancy really complicated my health. It was like someone had bewitched me. It was not until God delivered me that I was able to give birth. ...my mother-in-law had harbored a lot of hatred towards me. ...she made everybody to turn against me. ...I think this was the main cause of my diabetes._ (Mrs. Flo, 43 years, Ruiru)
Only one diabetic patient, who had gone up to a secondary level of schooling, reported the inability of the body to produce insulin or insulin not functioning normally as a causal factor for her diabetes. She stated:

... From what we have been taught at KNH, we were told that the body is not able to produce insulin or if you have insulin, it may not be functional. That’s why we have to inject ourselves with insulin so that when we eat, the food is digested completely and absorbed into the bloodstream. (Mrs. Suu, 57 years, Kabiria)

4.2.2 Perceived risk factors

Majority of the T2DM patients (56%) interviewed did not know “which people are at a greater risk of acquiring diabetes”. On further probing, multiple responses concerning the risk factors for diabetes were reported. Almost half (53%) of them cited that “anyone can get the disease”, simply because “you are not sure what causes the disease”. Some felt that “a long time ago it only affected old people but currently almost anyone can be affected”. They even reported seeing all sorts of people seeking medication at the KNH outpatient diabetic clinic.

The way I have seen at KNH, I think everyone is at risk of acquiring diabetes. I have seen small children and even slim people suffering from diabetes at the clinic. I don’t think it affects specific people. You get small children and even young people who are not married all have diabetes. So I don’t think it discriminates against a certain groups in terms of gender or age. (Mrs. Ter, 55 years, Njambini)

Some informants (28%) also cited poor dietary habits as one of the risk factor for diabetes. “I think the way the most people are eating can cause the disease. For instance I have a boy who likes eating sugary foods. He likes eating cakes, Sodas and other sugary foods, chips and chicken, the foods that I was prohibited from” (Mrs. Ros, 53 years, Thika). Other risk factors cited were overweight and obesity which accounted for 25% of responses, which most of them reported being overweight prior to diagnosis. “I think the obese and overweight are also mostly at risk. I was also overweight before I was diagnosed with it” (Mr. Fran, 61 years, Ngong).
Gender of an individual was also reported by a few patients (19%) as a risk factor for diabetes. They felt that women were more at risk of acquiring diabetes compared with men simply because “most women led stressful lives than men” because of bearing so many problems in life. This is exemplified in the following excerpt:

_I think women are most at risk because they are the backbone of the home and society. Whenever there is a problem in the family it always affects the women. A woman is like a classroom. She has to bear all the problems both from their children and their husbands. This puts them at risk since they have to think about all these problems._ (Mrs. Meg, 64 years, Kangari)

In addition, a patient also reported that women are more at risk because of complications brought about during childbirth such as prolonged labor pains and bleeding.

For men, the informants reported that they are more likely to get diabetes because “when stressed, they don’t share their problems with others unlike women who are able to share their problems” (Mrs. Grac, 60 years, Limuru). Engaging in risky behaviours such as smoking cigarettes and excess use of alcohol accompanied with consumption of too much roasted red meat also denoted why men are more at risk. “I think men are more at risk of acquiring diabetes. They have very poor lifestyle habits. They eat roasted red meat, smoke and take a lot of alcohol. I have seen many of them who are diabetic in this village.” (Mrs. Son, 50 years, Ngong). Even though excess consumption of alcohol was reported as a risk factor for diabetes, some of them could not understand how it leads to diabetes. “I have really wondered why it affects some men and not others. My father is an alcoholic and a chain smoker yet he doesn’t suffer from diabetes. How does it work?” (Mrs. Jan, 50 years, Limuru).

Heredity was also reported as a risk factor for diabetes by a few patients (16%), as some of them had seen their relatives suffer from the same disease. Even though most of them could not explain how heredity works, they felt that diabetes is a “new” disease which “some people are just born with it”.

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4.2.3 Symptoms and complications experienced

The most frequently reported symptoms were frequent urination (69% - 38%M and 31%F\textsuperscript{3}), frequent thirst (63% - 28%M and 35%F), general body weakness (34% - 22%M and 12%F), blurred vision (31% - 19%M and 12%F) and constant headaches (28% - 9%M and 19%F). Other symptoms cited included: frequent fatigue (6%M and 16%F), weight loss (9%M and 13%F) and dizziness (13%M and 9%F), each accounting for 22% of the responses. Numbness of the feet (19% - 6%M and 13%F), constant hunger (16% - 6%M and 10%F), sweating profusely (16% - 13%M and 3%F), trembling (13% - 10%M and 3%F), and frequent stomachaches (6% - 6%F) were also reported. These findings revealed that majority of them had a good understanding of the signs and symptoms of diabetes, which were almost close to the biomedical symptoms of the disease. These symptoms as reported by both male and female patients are represented in Figure 4.2.

\textsuperscript{3} The letters M and F denotes the responses reported by male and female T2DM patients respectively.
When asked about complications that they had ever experienced, slightly more than half of the informants (53%) reported high blood pressure as a complication of diabetes. About 41% reported having poor vision, while 31% who were male diabetic patients reported erectile dysfunction. Other complications cited were frequent seizures (25%), kidney failure (25%), amputation (16%), poor healing of wounds (6%) and recurrent infections (3%). In addition, poor memory, stroke and muscle pain accounted for 13% each of the responses. However, from the researcher’s observation, some of them reported complications that they had observed from other diabetic patients other than themselves. This was evident where some mentioned amputation which was not physically justifiable.
4.2.4 Perceptions regarding prevention of diabetes

The T2DM patients were asked whether diabetes could be prevented. Of the thirty-two (32) patients interviewed, fifteen (47%) said ‘Yes’ while seventeen (53%) said ‘No’. For those who reported that diabetes can be prevented, four of them (27%) felt that through monitoring one’s dietary intake by avoiding certain foodstuffs as advised at the hospital (KNH), those not affected can protect themselves from getting diabetes. Some (20%) noted that God is the only one who can prevent diabetes from attacking people. The same number of patients reported that people should try not to be angry and also avoid stress. Others (13%) were of the view that diabetes can be prevented “only if the people are educated when still young” on how to detect symptoms and take appropriate action. A similar number also noted that for those not yet affected by diabetes; “the only prevention available is to try and slim”. However, one of them reported that if one is financially capable, s/he can protect her/himself from getting diabetes.

In contrast, for those who reported that diabetes cannot be prevented, a majority of them (88%) noted that “it is hard to prevent it since you don’t know how you acquire it”. The remaining 12% did not know how it can be prevented as presented in Table 4.2.
Table 4.2: Perceptions regarding prevention of diabetes (n=32)

<table>
<thead>
<tr>
<th>Response</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you think diabetes can be prevented?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, it can be prevented</td>
<td>15</td>
<td>47</td>
</tr>
<tr>
<td>No, it cannot be prevented</td>
<td>17</td>
<td>53</td>
</tr>
<tr>
<td>If yes, how can it be prevented?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Monitoring one’s dietary intake</td>
<td>4</td>
<td>27</td>
</tr>
<tr>
<td>• God can prevent one from acquiring diabetes</td>
<td>3</td>
<td>20</td>
</tr>
<tr>
<td>• Avoid stress and being angry</td>
<td>3</td>
<td>20</td>
</tr>
<tr>
<td>• Educating people when still young</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>• Try and be slim</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>• If one is financially capable</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>If no, why can it not be prevented?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• It is hard to prevent since you don’t know how you acquire it</td>
<td>15</td>
<td>88</td>
</tr>
<tr>
<td>• Don’t know how it can be prevented</td>
<td>2</td>
<td>12</td>
</tr>
</tbody>
</table>

4.2.5 Information on diabetes before diagnosis

This study found out that majority (59%) of the T2DM patients had not heard of diabetes before they were initially diagnosed with the disease. For the few (41%) who had heard about it prior to diagnosis, they received information pertaining to diabetes from their relatives and friends (77%), the radio (15%) and through reading newspapers (8%). The most common kind of information received by these patients was that: "if a diabetic patient develops wounds, they don’t heal easily"; "one looses weight, feels thirsty more often and frequently goes for short calls"; "men who are suffering from diabetes do not function sexually"; "diabetic patients do not use sugar and too much of starch"; and that "diabetes has
no cure”. They all agreed that what they had heard was a true reflection of their daily experiences with their diabetic condition.

4.3 Lay management of diabetes

4.3.1 Biomedical management options

4.3.1.1 Adherence to treatment

Once diabetes was clinically diagnosed, the T2DM patients were given prescriptions to help manage their high sugar levels, and a follow-up medical appointment was also recommended. Majority of them (n=29) reported that they managed their diabetic condition by regularly going for the clinical appointments at KNH OPDC, where the doctors kept on monitoring their condition, having other complications for the disease checked and prescribed medication. They were also reminded and taught on how to manage their diabetic condition while at home. This was usually done through the diabetes health education sessions that were offered at the clinic every Wednesday morning from 0800 hrs to 1100 hrs, which all of them reported they had attended. They also acknowledged the importance of the diabetes education sessions with regard to how they were conducted and the advice about diabetes management that they received. “I like all that they do during the clinical appointments. But what I like most is the learning sessions. We are normally put in one class, where we are then taught about diabetes and even hold discussions amongst ourselves. We are also advised on how to manage diabetes while at home” (Mrs. Net, 58 years, Juja).

However, since the cost of drugs and insulin at KNH was quite cheaper than in other health care facilities or pharmaceutical shops, it also motivated most of them to adhere to clinical follow-ups. “...The cost of the drugs is fairer at KNH when compared to others chemists. For example, insulin
costs 350.00 Kes at KNH but when you go to a chemist outside KNH, the same insulin goes for 1,400.00 Kes. This is what makes me not miss the appointments” (Mr. Geo, 52 years, Njambini).

To some of them, adherence to clinical appointments at the out-patient diabetic clinic (OPDC) of KNH was driven by the fact that “it is the only health care facility that detects diabetes”. This was mainly the views of diabetic patients who had prior been misdiagnosed and received treatments for other illnesses from other health care facilities.

I really like the services at KNH. I had stayed for a very long time moving from one hospital to another where they could not identify what I was suffering from. I had even gone to a laboratory in Thika and they did a number of tests yet they did not identify my diabetes. I would take drugs without any improvement. They would say I was suffering from Malaria and Typhoid which was not the case. At St. Mary’s [in Lang’ata - Nairobi], they even tested me for a funny female disease which was absent. They never identified the disease. I like KNH so much because it is where they identified the disease. I just have to go back when the doctor recommends. (Mr. Pat, 58 years, Kayole)

Even though regular clinical follow-up visits was at the heart of most patients in helping them continue manage their diabetic condition, they complained of the long waiting hours at the KNH out-patient diabetic clinic for them to be served. “I always attend all my clinical appointment but sometimes they keep us waiting for long at the hospital. You feel hungry and you cannot leave because you want to see the doctor. Most patients don’t like the way we are kept there for a very long time” (Mrs. Mar, 64 years, Kijabe).

After receiving the correct diagnosis and during clinical follow ups, they were given prescriptions of medicines they required. Almost all of them were prescribed for insulin injections and oral tablets, which were identified to me by the nurse as Glucomet/Metformin and Glibenclamide. They considered diabetes as a disease which requires mainly oral drugs and insulin for its management. When asked about which management practice they preferred, of the thirty two patients, thirty reported the use of
drugs and insulin. "The drugs and insulin injections have really helped me this condition [diabetes]. If I miss taking the drugs, my condition deteriorates" (Mrs. Fat, 56 years, Eastleigh).

However, in line with this management practice, there were some differences regarding the information given by the patients themselves and their home caregivers. For instance, while some patients reported that they attended all the clinical appointments, their caregivers stated that:

He sometimes misses his clinical appointments. Sometimes it is because of lack of funds but at other times he just refuses to attend them. He feels he has attended the clinics for a long time. (Mrs. Ham, 47 years, caregiver [wife], to Mr. Ham)

... He used to attend all clinical appointments until a certain time that he stopped. He said his blood sugar level was okay. (Mrs. Free, 52 years, caregiver [wife], to Mr. Free)

4.3.1.2 Dietary restrictions

Most patients (n=27) reported that even though oral drugs and insulin were vital in their daily management of diabetes, monitoring one's dietary intake was also helpful for their diabetic condition.

"Drugs cannot just work alone, you must eat something before taking the drugs, and whatever you eat must go hand in hand with what we have been recommended to take" (Mrs. Pris, 56 years, Thika). They were following the doctor’s advice which included; avoiding sugar and sugary foods, cutting down on carbohydrates intake, avoiding foods with too much salt and fats, consuming brown foodstuffs and ensuring that vegetables were part of every meal. Typical to such responses was a 55 year, female patient who said that "following what we are usually told at KNH, I take tea without sugar; I take brown bread and a lot of vegetables. I cook using very little oil. I take a little ugali and rice" (Mrs. Ao, 55 years, Kangemi). Another patient stated:

... I also check my diet. In the morning I take beans mashed with pumpkin leaves. I take tea without sugar. Mid morning I take porridge or a little food. For lunch I take little rice with a lot of traditional vegetables. In the evening I take a little ugali with vegetables. (Mrs. Nje, 64 years, Juja)
In line with this management regimen, a few patients, who mainly resided in the rural areas, reported that they had to adapt towards managing their diabetic condition by growing a lot of vegetables and rearing of goats whose produce are diabetic friendly, even though it is an expensive venture. This is exemplified using the following excerpt:

“My condition has forced me to grow vegetables since I am meant to eat a lot of them. I was informed by the doctor that all my meals must be accompanied by vegetables. I also have three goats. ... We are always told that the goat milk is the best. And in this area, I have never seen people rearing them, thus it is rare to get such milk. Though they are expensive to feed, I struggle as long as I get a cup of milk for my day. (Mrs. Meg, 64 years, Kangari)

4.3.1.3 Exercise

Thirteen (13) patients reported that exercise was important when it came to diabetes management. This was cited mainly after probing on whether there were other management practices they utilized based on their illness. It was labeled as at least not staying idle or not having other people do certain work for them. They reported having exercised mainly through the daily activities that they were engaged in, sometimes to the extent of sweating as advised by their health care givers. “I normally work. We have been advised to work until we sweat. I perform all my domestic chores alone” (Mrs. Wa, 61 years, Kangemi).

Daily treks to places of work and riding bicycles were also forms of exercises undertaken by the informants. “For exercises I normally take a walk. I walk every day to town [Nairobi] where I work and sometimes go back home on foot. In some instances, I may exercise by riding a bicycle especially when I am carrying my merchandise” (Mr. Ju, 45 years, Pangani).

Some of them were willing to exercise, but due to the nature of the complications that they were experiencing such as amputation, poor vision and frequent seizures; they were unable to exercise much.
I would really like to exercise but I'm unable for now. Even right now, I cannot see clearly. I have had this vision problem since 2008. Again as you can see, they cut my left leg so am always on clutches. Therefore I can only try to exercise when going to the toilet or walking up to our gate. (Mr. Free, 52 years, Githurai)

However, differences in information emerged out of this management practice, in that while some patients reported that they had been exercising, their care givers reacted differently by citing that some of them were not carrying out any form of exercise. For instance, a patient stated that: "... I exercise by digging and walking a lot. This has also helped me a lot" (Mr. Sam, 48 years, Muguga). Yet in an interview with her care giver, she reported that "he only uses the drugs and monitors his diet. Though diabetic patients are usually advised to do exercises, I have never seen him exercise. He just stays here the whole day" (Mrs. Sam, 41 years, caregiver [wife], to Mr. Sam).

4.3.2 Non-biomedical management options

4.3.2.1 Religion and Prayers

Almost half of the patients (n=15) reported that they used prayers as a form of management for their diabetes. This was a practice mainly reported by the female patients (n=11), who noted that through prayers, they found refugee in God hoping one day they would be cured of their diabetes. Those who strongly subscribed to prayers were mainly the ones who associated the etiology of diabetes with witchcraft, stress and punishment from God. "The issue of witchcraft contributed to this disease. ...But through prayers the Lord has protected me. I have continuously rebuked their witchcraft. ...With God, I believe diabetes is not a big issue. I know through having constant prayers, one day God will cure me through his great healing powers" (Mrs. Flo, 43 years, Ruiru). She further reported how she prayed for other patients who got cured using the following words:

I prayed for my brother. He also had diabetes like me and he got cured completely. I have also prayed for many others and they have been cured of various diseases including diabetes.
She also noted that “… When I get the drugs from the hospital I always pray for the drugs so that God can heal me through the drugs. Even for the patients, who seek my assistance in prayers, I always tell them to come with the drugs and I pray for them and the drugs” (Mrs. Flo, 43 years, Ruiru).

Others reported that with prayers, they believed that one day they will be healed since God had previously rescued them from very difficult situations. This is illustrated using the following words:

> My condition was caused by my daughter-in-law. She was very rude and whenever she was around she was all chaos. One day I narrated the whole story to my neighbor and she told me that we should pray. We prayed in the maize farm. She said that if the lady was not meant to be my daughter-in-law, then God would just move her out of my life. The prayers worked. The lady just came back and demanded for her child and her properties. She went away. Since then, I believe there is no disease that is greater than my God. I believe God can cure all diseases. When I believed in God, all my problems were solved. (Mrs. Ter, 55 years, Njambini)

While some patients reported that they sometimes had gaps in their medication, opting to reflect and wait upon the Lord based on what they had seen other diabetic patients do, others decided to miss clinical appointments and wait upon the Lord to heal them.

> I know many diabetic patients in Congo, who just live by the grace of God. Most of them never use drugs but instead, they rely on prayers. ...That is what I sometimes do. I can take the drugs but when I start reflecting upon God’s healing powers, I may even miss to take the drugs for a week while just praying and fasting. (Mrs. Fur, 55 years, Kabiria)

Moreover, some (n=4) male patients also reported that the use of prayers was vital in helping them manage their diabetes as exemplified in the following statement:

> ... I always pray very much for my condition. You know prayers help reduce anxieties in life and foster positive thinking. I always pray to God to provide me with everything that I require in my life while living with this condition. (Mr. Neph, 63 years, Kimathi)

During a follow-up visit, a patient reported that he had received healing for his diabetes. This was after going for an outreach ministry on repentance and holiness where I religious leader prayed for him, and announced in the congregation that he had been cured. He was informed thereafter to do away with any medication meant for diabetes, which he actually subscribed to.
Towards the end of last year (2011), I went for the outreach ministry on repentance and holiness
movement which was held in Kisumu. ... This was just but the long awaited day for me. I was
prayed for by Reverend Awour, a time when I received healing for my diabetes. ... Since then, I
have never taken any medication. I even threw away the drugs I was having. I am even feeling
much better as compared to the last time when you visited me. I believe God heals, and his
timing is always the best. (Mr.Geo, 52 years, Njambini)

For this patient, who is also a pastor for a local church in his location, he further reported that following
the preaching by the Reverend, “diabetes is not only about leading poor lifestyles or having a family
history with the disease. It is currently one of the emerging diseases that cannot be cured by humankind
but only by God Himself, and only for those who believe in Him”.

4.3.2.2 Use of herbal remedies

Patients (n=9) reported, though after probing, that they had also used herbal remedies in the
management of diabetes. This was mainly after the conventional medicines, which were expensive,
failed to cure their diabetes. They were following advice given to them by their friends, religious
leaders, relatives and even doctors; which they resorted to. Some had also seen and heard on the
television and radio other patients testifying how they had been cured of diabetes after using herbal
remedies, which prompted them to try out. Even though getting the herbal medicines for diabetes was
resource consuming in terms of time and money, diabetics expressed having had no choice but to search
for them. This is reinforced using following excerpts:

But you know it is good to speak the truth. You know there is this traditional doctor in Loliondo. He
was even shown on Television and newspapers. He was even widely broadcasted in the
radios. Even very rich people in this country went there. I also went there and took the drug. But
the medicine was very little, about quarter a cup. I paid 100.00 Kes for the medicine and 4,000
Kes for the bus fare from Kiserian to Loliondo. (Mrs. Son, 50 years, Ngong)

At one point I used herbal medicines. This was after I had taken a lot of drugs that we are
usually given from KNH. The herbal medicine was going for about 10,000Kes for one month. I
used to go very far to get it [from Murang’a]. There is a Catholic Priest who treats many
diseases including diabetes. I used to go for the medicine on a weekly basis. I would come with
the medicine and take it for a whole week. When you go there you would take six glasses at the
premises and then three glasses per day. I used the medicine for about five months and stayed for almost three years feeling just okay. (Mr. Free, 52 years, Githurai)

Some had used the herbal remedies together with the conventional drugs, following the herbalists' instructions. “I used to take the herbal medicines as well as the drugs from the hospital. The herbalist told me to use the two remedies together. ... I used them for about six months” (Mr. Jack, 52 years, Gatundu). Though, when certain signs appeared, they had to go back to the hospital. “After six months (while using both herbal and conventional drugs), I started losing weight. I stopped taking the herbal medicines and went back to the hospital (Mr. Free, 52 years, Githurai).

However, for those who had used the herbal medicine, none of them reported to have been cured. Even though, some testified that the herbal remedies had relieved them for some time; they reported that later on the disease came back with various complications that were too expensive to treat. “The medicine really helped me. I even forgot that I was sick. When I would go to the hospital the doctors would even query whether I had diabetes. But when it came back, it was more disastrous. I could not see clearly. Everything appeared misty. Even as we speak now, my left kidney is not functioning. I was told to go for dialysis at KNH mid next month, which will cost me about 60,000 Kes” (Mr. Dav, 50 years, Tigoni).

Others reported that they had been advised by the health care providers from the KNH OPDC to use a certain herbal remedy in curing wounds and sores that had developed on their bodies as a result of diabetes, which are sometimes difficult to heal.

Some wounds would just develop from nowhere and they keep on developing, which are difficult to treat. But we have been trained at KNH on how to take care of such wounds. They taught us that you can use Aloe Vera on the wounds and eyes. When the wounds develop, you should wash and press them with Aloe Vera. I have been using Aloe Vera to treat the wounds and they disappear. (Mr. Bosc, 58 years, Limuru)
The same patient, who was residing in an urban area, actually showed the researcher where he used to get the fresh Aloe Vera (Aloe *nyeriensis*) from. He had planted them in four plastic containers, placed along his corridor.

However, in a follow up visit, a patient reported that she was tired of daily insulin injections which she feared might cause boils on her body in future. She opted to use the Golden Neo Life Diamite (GNLD) products for management of her diabetes. This was following several visits to her home by the GNLD salesperson, and after attending one of the seminars organized by GNLD members where most people who were once diagnosed with diabetes testified how they had been cured only by using “Carotenoid complex” [a GNLD product that cures diabetes].

> ... I stopped using insulin last November. With diabetes, sometimes you can become tired of daily injections of insulin. I was a victim of this. Some of the GNLD salesmen who used to visit me at my home invited me in one of their seminars. When I went for the seminar, I saw wonders. People were giving testimonies on how they had previously struggled with their diabetes, but only got well only after using a GNLD product called Carotenoid complex for almost three months. (Mrs. Fat, 56 years, Eastleigh)

For the few days she had used the product, she reported that she had felt much better than before, to the extent that she was even able to work tirelessly.

### 4.3.2.3 Use of home remedies

The use of home remedies such as drinking a lot of water and taking herbal teas was also reported by a few patients and a caregiver respectively, as a management regimen for diabetes. This was after receiving advice from a doctor, a traditional healer or relatives who was also suffering from diabetes. Some opted to rely on such practices, without complying with the clinically prescribed medication, which afterwards did not cure their diabetes. This is supported using the following illustrations:

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4. The scientific name for this species was identified to me by a botanist at the National Museums of Kenya. In Kenya, it is commonly referred to as Aloe Vera.
At one time there was a traditional healer who came to this village saying that he cures diabetes. He was at our market place for three days telling people that if you take water in the morning at 5:00 am before eating anything you can be cured. I tried this for sometimes by taking about 5 litres of water daily without taking the drugs. When I checked my blood sugar level, it was okay. However, this did not work for long because later on, my blood sugar level shot up once again. (Mr. Nga, 45 years, Gatundu)

I also take a lot of water. ... The doctor advised me to take a lot of water. He said that my diabetes condition might have sometimes been caused by dehydration. (Mrs. Ros, 53 years, Thika)

In another instance, a caregiver reported that:

She once used herbal teas but later on stopped after running short of them. Our son who stays in USA used to send them to her. But I don't think it helped her simply because there were no improvements at all. (Mr. Pris, 59 years, caregiver [husband], to Mrs. Pris, Thika)

A healthcare provider corroborated this information by noting that “while in the field screening for diabetes somewhere in Eastern Province, I got two patients who believed that taking raw French beans juice lowers the glycemic index, which was their management remedy” (Diabetes educator, DMI).

Nevertheless, in a follow up visit, a patient who previously had never used an alternative remedy in management of diabetes reported that she had stopped using the drugs and insulin in favour of daily uptake of a concoction of garlic, lemon and honey in the morning. Being a business woman, sometimes she was unable to travel in the morning due to dizziness that could last for almost three hours after taking an insulin injection. After sharing this experience with her aunt, she was advised to be taking the concoction and do away with insulin and the drugs, which she complied to. This is exemplified in the following excerpt:

... I am a business woman and at the same time a widow. I have so many responsibilities with me such that if I fail to go to work, everything goes wrong. When I used insulin as had been advised by the doctor, I felt dizzy, and could sit down for almost three hours until I felt better. ... This meant that sometimes, I could not go for my merchandise. I shared this with my aunt who advised me to be taking a concoction of garlic, lemon and honey in the morning instead of insulin. Since then, I have felt better and I don't think I can go back to insulin anymore. (Mrs. Ao, 55 years, Kangemi)
4.3.2.4 Other folk management remedies utilized

The use of folk management remedies such as raw chicken liver and a "diabetes healing bangle" were also reported during follow up visits. This emerged from patients who in the first interview reported to have never used alternative treatments in management of their diabetic condition. The shift towards the use of such management remedies was based on information received from other people concerning their effectiveness. For instance, a patient reported that she had previously used a "diabetes healing bangle" bought from a witch doctor, whom she had met while on her normal business trip to Tanzania. This was after being informed of its effectiveness such that if worn on the wrist all the times, it has magnetic powers that work on the human body by bringing the blood sugars back to normal. These were her words:

*You know it is good to say the truth. I was a business woman and I used to go to Tanzania for merchandise. I happened to have met a man in Dodoma, where most patients were going to get bangles to help them cure their diabetes. ... He explained to me that once you have the bangle, you are not supposed to remove it from your wrist unless when bathing. You must also sleep with it. When I asked him how it works, he said that the bangle has some magnetic power of returning the high sugar levels back to normal once it is in touch with the human body. If you remove it, the sugar simply shoots up.* (Mrs. Son, 50 years, Ngong)

In another follow up interview, a patient reported that he was told by a Catholic priest that "if you eat 100 raw chicken liver, ten per day, then your blood sugar level will be fine. It worked for somebody who had diabetes like you" (Mr. Woll, 61 years, Kijabe). The patient asserted that he was shocked at first, but since the person who was giving him such advice was a religious leader; he felt that he could not be lying. Thereafter, he attempted to use this remedy as had been advised. By the day I was conducting this follow up interview, he was on his fourth day of taking the raw chicken liver.

5 Following the patient’s description, it is a black bangle worn on the wrist and has a magnetic effect on human body that helps in controlling the sugar levels.
4.4 The role of care givers in diabetes management

Out of the 20 care givers interviewed, 14 were women (10 spouses, 2 daughters and 2 daughters’ in-law) while 6 were men (4 spouses and 2 sons). Majority of them were from the nuclear family, providing care to the patients in terms of ensuring timely uptake of prescribed medication and even sometimes giving them the insulin injections. “I also help in injecting him with insulin” (Mrs. Free, 52 years, caregiver [wife], to Mr. Free). This care was labeled necessary by some caregivers whose T2DM patients had already developed visual problems, thereby not being able to inject themselves properly.

Sometimes the patients would forget to take the drugs as required due to memory loss, thus in need of home care givers to remind them. “I normally ensure that he takes the drugs as prescribed by the doctor. Sometimes he forgets to take the drugs. This disease [diabetes] has really affected his memory. Every now and then, I always remind him to take drugs” (Mrs. Geo, 47 years, caregiver [wife], to Mr. Geo).

Due to the nature of the illness, some patients were unable to seek treatment on their own. They had to be accompanied by their care givers to the health care facility (KNH). In some instances, their caregivers were forced to hold their hands while directing them where to go. This is exemplified in the following statement:

... After sometimes, his condition deteriorated and he could not even see clearly. ...I had to lead him by holding his hand when accompanying him to hospital. (Mrs. Free, 52 years, caregiver [wife], to Mr. Free)

For those patients who experienced frequent seizures, some of them reported being in need of someone who could ensure that they went to and from the hospital safely. “My condition is quite critical. I collapse every now and then. There was a day I collapsed when coming from the hospital yet I was
alone. From then hence forth, I don't go to the hospital alone. I always have to be accompanied by my wife” (Mr. Ju, 45 years, Pangani).

However, for most of the caregivers, they were able to tell whether the patient was in a critical condition and in need of help through observing some of the physical changes that occurred to the diabetic patient. Such changes included: sweating, trembling, eyes looking tired and reddish, shedding of tears and a feeling of restlessness. Some reported to have taken the necessary action such as giving food immediately for a patient who sweated profusely. For patients who happened to go unconscious every now and then, their caregivers had to give them a sugary substance so as to help them regain their consciousness. Some were very cautious of the care they gave to a patient in such a critical condition.

This is illustrated using the following excerpt:

... I was informed that when he is unconscious, I should give him honey. They had talked of sugar but later on they told me that it can choke him. They told me to ensure that I get honey. ... After giving him the honey, he regains consciousness after about 10 minutes. (Mr. Nic, 22 years, caregiver [son], to Mr. Neph)

Caregivers also had the obligation of ensuring that the patients received a balanced diet as advised by the health care providers. Some were forced to prepare a separate meal for the patient in addition to a normal family meal. They reported that in most instances, it always had to comprise of little unrefined starch such as ugali or rice and a lot of indigenous vegetables, all prepared with little salt and cooking oil. Others had even learnt to monitor the kind of food that when prepared for the patient; it caused short-term complications after consumption.

... I monitor his diet so much. There are some foods that when he eats them, he wakes up very weak and collapses. For instance when I cook rice, I normally make it separately and prepare a stew of beans, potatoes and cabbages. When I prepare it this way he is normally okay. But if I mix everything together, the food is not usually good as he collapses in the morning. (Mrs. Dav, 41 years, caregiver [wife], to Mr. Dav)
It is important to note that even though this role was mainly taken up by the female caregivers in the household, the male caregivers were also forced to help in cooking for the diabetic patients. This happened quite often in households which only comprised of the spouse, with the female partner suffering from diabetes. The caregivers stated that such care was necessary as the patients had been advised to keep off from direct heat and for some; they were very weak to the extent that they could not do anything.

The selection and appropriate decision making on therapeutic treatment was also one of the core responsibility of the caregivers. They had to make decisions on where the patient would seek treatment, which in most instances was the hospital treatment. However, when the conventional treatment failed to cure the illness, some of them had to introduce the patient to alternative treatments based on their final decision. Such decisions were based on perceived inefficacy of the earlier treatment sought. This prompted some patients to try either conventional or alternative treatments, or sometimes complimented the two hand in hand, hoping to be cured. Though, even after resorting to alternative treatments, none of the patients as reported by themselves and even by their caregivers got cured.

*He used to feel weak. I did not think it was something serious. But when he was unable to see, I felt it was now serious. I took him to the hospital at KNH. He was given drugs which even after taking them for almost six months, I did not see any improvement. It came to a point when I decided again to look for a herbalist, who gave him some herbal medicine to take. He seemed quite okay after taking it [for three years]. However, after sometime his condition deteriorated as he could not see completely. (Mrs. Free, 52 years, caregiver [wife], to Mr. Free)*

Some reported being the ones who persuaded the diabetic patient to seek medical care in the initial stages of the illness based on the symptoms recognized by their caregivers, a time when they were diagnosed with diabetes. It mainly happened when they were taking a family member to the hospital, while in the company of the diabetic patient, who were then requested to have their blood sugar checked. This is exemplified in the following excerpt:
I'm the one who told him to go to the hospital. He used to eat normally yet he kept on losing weight. He would even wet the bed, and this happened for almost four months or so. Initially, I told him to go to the hospital but he refused. We struggled until one day when we took our daughter to hospital, I begged him to have his blood sugar level checked and that is when he was diagnosed with diabetes. (Mrs. Ju, 41 years, caregiver [wife], to Mr. Ju)

Others offered moral support to their patients, especially for those who were in deep thoughts regarding illness. "I always encourage him to accept that he has diabetes, and should only remember it when taking the drugs. Sometimes he is normally in deep thoughts and says that his condition is like HIV / AIDS. ... I always try just to support him morally" (Mrs. Pa, 53 years, caregiver [wife], to Mr. Pa).

They also encouraged patients against having gaps in their prescribed medication, in favor of other remedies. "He had even said that after the operation [for a visual problem], he will stop using insulin and go herbal but I encouraged him to honor the doctor's advice and should continue using the insulin" (Ms. Nya, 32 years, caregiver [daughter], to Mr. Fran).

4.5 Problems faced by patients in daily management of diabetes

4.5.1 Financial constraints

Financial burden was often the first and most commonly reported problem experienced by the T2DM patients and even by their caregivers. They noted that the financial constraints ranged from money spent on seeking medication, buying drugs and insulin, and affording an appropriate diet which majority of them could not afford. Based on their little mean monthly income of 16,379.00 Kes and average monthly expenditure of 7,524.00 Kes on diabetes management, coping with their diabetic condition remained problematic. Some patients were even unable to afford going for all clinical follow-up visits.

Mr. Jack, a 52 year old patient; who resides in Gatundu reported that “... Sometimes I don't go for all my clinical appointments because of lack of funds. Like last month, I missed the appointment. You know, at KNH it is all about money. Before you can be attended to, you must pay. Sometimes you are not even
able to raise the bus fare. I also missed some appointments in 2006 due to lack of money”. Others also reported that the cost of treatment was very high and that if one did not have enough money; they would reduce the drugs so as tally with how much they had and sometimes one could not be attended to by the doctor.

The cost of treatment is very high. You have to pay for the doctor’s consultation fee, laboratory fee and the drugs. For the blood pressure you pay 800.00 Kes, for the doctor’s consultation fee, it is 500.00 Kes and between 1,000.00 – 2,000.00 Kes for the drugs. You must pay cash before they attend to you. Sometimes when I go to the hospital and the doctor prescribes for me the drugs, if you don’t have enough money, they just reduce the drugs to tally with the amount of money that you have. (Mrs. Ma, 64 years, Kijabe)

In addition, most of the health care providers interviewed also reiterated that diabetic patients were heavily burdened financially. “There is the cost of managing the new expensive condition [diabetes]. They have to be monitored. Their sugar levels have to be tested. There are tests that need to be done at intervals in the laboratories. Some are done every three months, others are done annually. This is quite expensive. Most patients we see are on many different tablets. So if you look at the prescription of just one patient and this is someone who does not have any complication, the cost runs beyond the reach of the average Kenyan” (Clinical Officer, OPDC – KNH). Some patients have to share drugs and insulin with their neighbors when they run out of money just to keep them going.

The drugs are not that cheap. … Some may run out of drugs because they don’t have money. I have seen patients share insulin. Just because I have run out of insulin and my neighbor is using it, I go with my syringe and borrow a few units to keep me going till I get my mine. (Diabetes educator, DMI)

Financial constraint in terms of affordability of the daily dietary requirements of the patients was also a problem, to the extent that some of them opted to eat any food that was available. “You know, we are usually told at KNH to use cooking oil like Elianto, and eat mostly the brown foods accompanied with a lot of indigenous vegetables. I can’t afford purchasing such foods every time. Vegetables [indigenous] are very expensive, and you know you can’t eat alone when other family members are watching.
Sometimes you just have to eat what the rest of the family is eating” (Mrs. Grac, 60 years, Limuru).

Preparing a meal for a diabetic patient separately from the normal family meal was costly also in terms of fuel consumption. Some had to prepare a normal family meal regardless of following the dietary requirements of their diabetic condition.

Sometimes you may not have enough money to cater for your own diet. ...You see, I have four children staying with me here and I can’t afford preparing my meals separate. I normally cook using charcoal or stove. Nowadays the cost of paraffin is high, and I can’t light the jiko [cooking stove] thrice in a day. I have just to make one meal for the whole family irrespective of my diabetic condition. (Mrs. Ao, 55 years, Kangemi)

However, patients who were mainly the breadwinners in their households, and who accounted for 66% of all the informants (16 male and 5 female patients) also faced financial constraints. Their roles as breadwinners were compromised by the illness, resulting into difficulties in fulfilling their obligations to the rest of the household members, thus undermining their social roles. This was very problematic to households that had several members, more specifically children. For instance, some patients reported that their children had to stop schooling because of financial incapability that had set in as a result of their illness. To cope up with the problem, some were forced to sell their property to keep up with the demanding expenditures; while others had to forgo some diabetes management regimens based on their financial capabilities. This is exemplified in the following two excerpts extracted from interviews with patients who were breadwinners.

For diabetics, you cannot fail to talk about financial problems. Personally, I have great financial problems. For instance I have a son who was in Form two, who has stopped schooling due to lack of money. I had some cattle and I have sold all of them to cater for my condition. My condition [diabetes] has really consumed most of my income. Sometimes I even fail to go for clinical appointments due to lack of money. ... I normally pay 400.00 Kes to Nairobi in the morning. Then when you get to the hospital you have to pay. You also have to buy the necessary food so that the condition does not deteriorate. Sometimes you opt to follow the dietary requirements instead of going to the clinic. (Mr. Sim, 64 years, residing in Njambini with 6 household members)

You have to choose what to fulfill first depending on the available funds. ... I am the breadwinner with 4 children who are young and schooling. Their school fee is required and I
also have to cater for their daily needs. Even my youngest daughter is diabetic; sometimes we are forced to share the drugs. I use so many drugs which cost me a lot of money. Sometimes I use about 2,500.00 Kes in two weeks. Like now I have to buy insulin for both my daughter and I. (Mr. Ju, 45 years, residing in Pangani with 8 household members)

For the patient in the first excerpt, he also reported to have spent a lot of money in catering for other minor ailments and complications which he encountered more often. “Lack of money is a big problem. You also have other bodily complications. You get minor ailments every now and then. This makes you spend a lot” (Mr. Sim, 64 years, Njambini).

Moreover, a few patients reported that the illness had really drained them financially in terms of frequent travel in search for alternative medication to cure their diabetes; and the cost of the alternative remedies. Some were even unable to go to Loliondo in Tanzania to be cured of diabetes because of the high cost of bus fare, which was going for about 4,000.00 Kes from Nairobi.

4.5.2 Disruption of economic and daily activities

Disruption of patients’ economic and daily activities as a result of diabetes was also reported. Some patients had to go for early retirement from their jobs because of the complications of the disease that they were experiencing, which could not allow them to continue with their work. This was a common problem to patients whose main sources of livelihood were engagement in business activities. Some of the complications which were viewed as impediments to normal involvement in daily activities included: poor vision, amputation, frequent seizures and memory loss. This led to closure of businesses as reported by a few patients.

“Sometimes back, I used to do my own businesses. I would supply milk to nearby schools and later on go out to sell my merchandise. I used to be a hawker. But with time, my eyes got affected. I could not visualize properly. My right leg was also cut as you can see. I became weak. ... For now, I just stay at home. (Mr. Free, 52 years, Githurai)
Others reported that their clients and even workers took advantage of their diabetic condition, specifically pertaining to poor memory and frequent seizures, where they kept on looting their merchandise and not returning excessive balances. This led to low returns, thus prompting some of them to engage in other activities that were low paying, though less controlled. This is exemplified using the following excerpt:

Before I was diagnosed with diabetes I was a businessman. I had butcheries and shops at Adams [Nairobi]. The disease started affecting me so much. I felt very weak and could collapse more often. Most of my customers and even workers took much advantage of my condition. They would loot my goods and money. My returns drastically went down. I decided to come back home and do small jobs even though the returns are little. I keep chicken, cattle and do a little farming; activities that are not so much controlled. (Mr. Sam, 48 years, Muguga)

Inability to continue performing daily household chores and other small activities was also reported by some female patients. The illness had weakened them to the extent that they could not even clean their houses, prepare meals for their family members and even go to the shamba.

In terms of working, I cannot wash clothes or even clean my house. It is difficult for me to do jobs that require too much bending and waking up. I like digging but for now, I cannot go to the shamba and dig very well. This disease is very problematic. (Mrs. Meg, 64 years, Kangari)

4.5.3 Availability of insulin and other drugs

For most of the patients, they reported that drugs and insulin were not easily available, given that “... At KNH, they give out a very long prescription but when you go to their pharmacy the drugs are not there” (Mrs. Net, 58 years, Juja). Sometimes, patients could stay for long without taking the oral drugs and insulin injections due to their scarcity.

The main problem is that sometimes the drugs are not available at KNH. You can even walk to other chemists the whole day and you miss to get the drugs. So you are forced to go for a number of days without medication until you find them. ...This is a very big problem. (Mr. Geo, 52 years, Njambini)

Some insisted that even in most government hospitals and other pharmacies they visited, the drugs were still not available. This was corroborated by one health care provider who reported that “Most of them
Diabetic patients) will even have gaps in their medication. They may even go for a week or so without the drugs. They may run out stock at our facility (KNH), which at other facilities, they may also not be there” (Clinical officer/diabetes educator, KNH). From the researcher’s observation while at the OPDC of KNH recruiting these patients, some of them left the clinic without drugs simply because they were not available at the hospital’s pharmacy.

To cope up with this problem, some patients were forced to make phone calls to the personnel at the clinic inquiring whether the drugs were available, a time when they would go for them. For others, they have to share their drugs with their neighbours. “Like when I was at KNH the last time I met with you, I was given some drugs, which I had to share with my neighbour, who is suffering from diabetes like I. She could not find where to buy the drugs, yet she had stayed for almost 2 weeks without it”. (Mr. Geo, 52 years, Njambini)

4.5.4 Access to health care

A few patients reported to have experienced difficulties of getting to the health facility on time, given that on the appointment day, they were meant to report latest by nine o’clock in the morning. Due to the traffic jams, they took several hours on the road which delayed them to their appointments at the facility. They also reported that by them not getting to the clinic on time, the health care providers at the clinic would even re-schedule that day’s appointment for another day. A care giver who always accompanies her wife to the clinic exemplified this using the following excerpt:

Whenever there are traffic jams along Thika Road, she sometimes arrives at KNH at around 0900 hrs – 0930 hrs. The clerical officers at the hospital would send her away. ... They cannot retrieve the files for patients who come after 0900 hrs. The rule at KNH is that patients with appointments should be at the clinic between 0800 hrs and 0900 hrs. She is normally sent away and given another appointment which may be after 6 months or up to 1 year. ... This is not fair at all. (Mr. Pris, 59 years, caregiver [husband], to Mrs. Pris)
In addition, due to accessibility pitfalls, some patients ended up missing their appointments. This happened mostly when there were heavy rains on the appointment day. This was commonly reported by patients who came from rural areas, where the roads were impassable when raining; who had to travel long distances to get to the main road so as to board matatu’s going to the clinic.

The roads are also not so good in this area, yet you have to go to the hospital even if it is raining. Like last week, I was meant to go for my appointment which I missed because it was raining heavily. Sometimes if it rains so much, it may force you to miss the appointment. ... You have to walk up to the tarmac road which is almost 3 KMs from here. I fear motorbikes because they can easily slide when it is raining and even put you into more problems. (Mrs. Jan, 50 years, Limuru)

This was corroborated by a health care provider who reported that: “Some of the healthcare services are far away. Most of the patients in the rural and marginalized areas are not able to access health care especially during the rainy seasons. They have to grapple with such issues” (A nurse, OPDC – KNH).

However, for most rural homes that I visited, this was actually true since I was sometimes forced to trek instead of boarding a bicycle or a motorbike when it rained because the roads were messy. Sometimes you would wait for a taxi, although it took too long for it to be full so as to take you where you were heading to.

4.5.5 Erectile dysfunction

Erectile dysfunction was a common problem reported by majority of the male patients (14 out of 16). Most of them felt that it is a serious problem that can even lead to marital breakdown. This can be depicted using the following statement: “The major problem is sexual dysfunction whereby I’m unable to fulfill my conjugal obligation. This makes my wife think so much to the extent that we quarrel. I think it can even lead to marital break-up. ... She even goes out with other men. This makes me to think a lot” (Mr. Pa, 53 years, Eastleigh.) The patient was very much depressed while explaining this problem. He
further reported that his wife thought that he was having extra-marital affairs. He added that he had not
seen his wife three days prior to the day when this interview was conducted.

In another interview with a patient who had lived with diabetes for seven years, he also reported that he
had been experiencing an erection problem from the time he was diagnosed with diabetes. This led into
disruption of his marital life to the extent that they once separated with his wife. These were his words:

... As a man, I am unable to hold an erection. I cannot fulfill her sexual desires, though I have
taken it positively. ... I have seen the difference in my life from the time when I was okay and
after I was diagnosed with diabetes. [While in tears] Even there was a time [three years back]
when she [the wife] went back to her parents because of this problem. She stayed there for six
months. I struggled by all means to get her back. That incidence always keeps me stressed when
I think about it. (Mr. Dav, 50 years, Tigoni)

One health care provider, who is a diabetes educator and counselor, supported this by citing that erectile
dysfunction is a very big problem for men, for which some of them try to avoid it by “hanging out” with
their friends so much and thereby getting home late. In return, while with their friends who are
drunkards, they may find themselves drinking. This may result to poor sugar control.

4.5.6 Emotional and psychological impacts

Emotional trauma was a challenge experienced by the patients. It involved thinking too much about their
illness and how to deal with it. Some felt that their illness was not curable; it is related to HIV/AIDS
which is also incurable. “You know it’s a disease without cure. Sometimes you may even think it is
related to HIV / AIDS because it also has no cure. This makes you think a lot” (Mr. Jack, 52 years,
Gatundu). Others were psychologically disturbed following what they had seen at the facility (KNH).

It is really tough to live with this condition. Sometimes you go to KNH and find so many diabetic
patients in the waiting room. On the other side of the same room, you see many patients with
Tuberculosis waiting to see the doctor. For them they are lucky because TB is curable and the
drugs are free. (Mrs. Ter, 55 years, Njambini)
Another form of trauma reported was the fear of long-term complications of the disease. "I have heard from people that it can lead to amputation of feet. ... I really fear this disease" (Mrs. Fur, 55 years, Kabiria). Frequent anger was also experienced by patients, where some of them could wake up when feeling very angry. On such days, "one may not even go to work" (Mr. Pa, 53 years, Eastleigh). Some of their caregivers had to suffer from emotional trauma resulting from frequent anger and tempers experienced by their patients. A caregiver whose mother had suffered from T2DM for 8 years said that:

Initially, I had a problem with my mother because when angry; she would even throw us out of the house. At times I had to stay outside the house at night with my child and my brothers until she could let us in. She would get angry and beat us with a metallic object. (Ms. Lee, 24 years, caregiver [daughter], to Mrs. Ao)

Other emotional problems reported included a feeling of loneliness; fear of daily injections of insulin and fear of having some of their children inherit the "new disease".

4.5.7 Lack of adequate and correct information

There was a lot of confusion by patients about their dietary requirements, especially for those who had already developed complications of the disease such as kidney failure. Almost all of them were very eager to receive more information about their nutritional requirements. For instance, a patient who was having a problem with her kidneys reported that:

I try to check my diet but it is very confusing because my kidneys are also affected. I don't take a lot of sugary foods as advised by the doctor. I eat a little ugali and rice. To take care of the kidneys, I have to boil the vegetables, pour out the soup, and then fry them. I was also advised [by the doctor] to take sweet potatoes because of the kidneys, but it has a lot of sugar which when I take them, I feel very weak. He also said that as a diabetic patient, it is good to take about half a litre of milk per day. He doesn't tell us which milk in particular. ... When I visited the nutritionist, she said that because of my poor kidneys, I should try to avoid milk and vegetables. I am confused on what to eat and what to avoid. (Mrs. Pris, 56 years, Thika)

In another interview, a patient reported that he had received confusing and contradicting information concerning his dietary requirements from the doctor and a nutritionist, which left him in a dilemma.

The advice we are given on diet usually conflict. For instance, I recently asked the doctor whether taking milk is okay. He said it was fine. Later on, I asked the nutritionist the same
question who answered that milk, is not good. ... I was confused whether I should really take milk or not. In addition, the diabetic dietary manual that we are usually given concerning the diet does not exactly show the kind of foods we should eat. It is very shallow. For example, they tell us that we should take porridge but they don't tell us what kind of porridge we should take. Is it sorghum, millet or maize flour porridge? The doctors and dieticians keep on confusing us. They don't explain issues clearly. (Mr. Sim, 64 years, Njambini)

This was corroborated by most health care providers interviewed with one of them reporting that: “The medical system that we operate in is one where our health care professionals do not update themselves with current information. They operate with inaccurate and inadequate information that almost 20 years out-dated from the time they came out of school. Meaning, we as health care personnel do not use the same language when advising the patients. I may tell a patient today to do this, and tomorrow he is told different stories from different health care personnel. This makes the patients suffer because they don’t get up to date information on management” (Doctor, KNH-OPDC).
CHAPTER FIVE

5.0 DISCUSSION, CONCLUSION AND RECOMMENDATIONS

The study sought to explore the perceptions and management practices followed by T2DM patients attending the OPDC of KNH in Nairobi, Kenya. In this chapter, the major issues emanating from the findings presented in Chapter Four are discussed. Based on the findings, conclusions and recommendations have also been made.

5.1 Discussion

5.1.1 Lay perceptions of diabetes

Basic questions regarding the causes, symptoms, complications and risk factors for diabetes were asked to explore the patients’ perceptions about the disease. The descriptions which most of them gave applied more to the risk factors of the disease rather than the primary cause of diabetes. These included: stress, poor dietary habits, heredity, overweight and shock. However, a few of them gave folk causal explanations of the disease by reporting factors such as witchcraft practices and as a result of punishment from God.

Consistent with these findings, participants in studies by Kart et al. (2007) and Dropkin (2010) interwove aspects of both biomedical and folk beliefs into their EMs of diabetes. In their study amongst T2DM patients in Kathmandu, Nepal, Kart et al. (2007) reported that majority of the lay explanation of diabetes causation were attributed to biomedical causal factors such as stress, diet and heredity. A few of them perceived its causes as resulting from folk beliefs including poor mental attitude and overwork. In his recent study on “exploring diabetes awareness and care in Mombasa, Kenya”, Dropkin (2010) also reported that participants had diverse understandings of the causes of diabetes. They mentioned inheritance, stress, weight, poor diet and that only God can know.
Although most of the informants reported biomedical causal factors for diabetes, they also alluded to a folk belief model in which life stressors such as being widowed, financial problems and frequent quarrels were seen as a trigger to this disease. Another research study found that Mexican Americans with diabetes identified specific emotional experiences such as death of a loved one, an accident, or other tragic events in their life as contributing to their diagnosis of diabetes (Jezewski and Poss, 2002).

More importantly, the study revealed that some of the perceived causal factors for diabetes were gender-driven. Specifically, majority of the patients who reported stress and witchcraft were women as opposed to male patients whose responses revolved around the biomedical causes.

In studying people’s perceptions of illness, their educational background is very important. Sometimes people with different levels of education hold different beliefs and perceptions with regard to illness and management choices. However, this study discovered that even though the literacy of the patients who participated in this study was generally lower, majority of the patients who gave the folk causal explanations of the disease were all illiterate with a few having basic (primary) level of education.

Researchers have found that people’s illness explanations for chronic disease are highly context-specific, firmly situated within their specific life-histories and social and environmental contexts, and synergistically produced within the context of ongoing experiences in pursuing treatment (Hunt and Arar, 2001). Indeed, patients’ explanations of the etiology of the illness, in the current study, were compilations of their own cultural beliefs, what they had observed as part of their life experiences, and the lessons learnt from the health care personnel. For instance, for those who reported stress as a causal
factor, they explained it in relation to social and economic circumstances which they had previously experienced.

The recognition of symptoms is often the start of action to counter an illness. Lay people learn to recognize illnesses on the basis of observable symptoms. The interpretation of symptoms varies from one person to another even if dealing with the same illness. The findings show that a majority of the patients had experienced symptoms which were generally consistent with the biomedical symptoms of the disease. These symptoms included frequent urination, frequent thirst, general body weakness, blurry vision, frequent fatigue, weight loss, dizziness, constant hunger among others. It is important to note that some of the symptoms reported were gender-based. For instance, while most male patients reported sweating (13%) as a symptom of diabetes ever experienced, only female patients reported stomachache (6%) as a symptom of diabetes. Almost contrary to this are findings documented by Weller et al. (1999).

In their study on “Latinos beliefs about diabetes”, with respondents who were predominantly female, they reported symptoms such as excessive thirst, frequent urination, dizziness, headaches, loss of vision among others were reported. Stomachache as a symptom of diabetes was never reported.

The informants considered their illness as serious as it had impacted negatively in most areas of their lives including their interpersonal relationships with spouse, family and their means of livelihood. For instance, given that a majority of them depended on business and farming for their livelihood, anything that prevents them from performing their daily duties was considered serious. The seriousness of diabetes was also denoted through the various complications that they had experienced. This included among others high blood pressure, poor vision, kidney failure, sexual dysfunction, stroke, frequent seizures and amputation of lower limbs. Even though some of them reported complications that they had
seen in their friends or relatives, most of them concurred with the known biomedical complications of the disease.

In their study, Skelly et al. (2006) have reported that most of the respondents were aware of the complications of diabetes which included amputation, blindness, seizures and coma. However, many of the participants had observed these changes in relatives and friends. Naemiratch and Manderson (2007) in their study on “lay explanations of T2DM in Bangkok”, patients reported complications such as renal failure, amputations from infected wounds, blindness and impotence.

Understanding the causes, symptoms, complications and risk factors for diabetes can be overwhelming and perplexing for patients (Gazmararian et al., 2009). While patients in this study had a reasonable understanding of the symptoms and complications of diabetes, most of them (53%) were unable to articulate the risk factors of the disease. They felt that “anyone can get the disease simply because you are not sure of what causes the disease”. After being prompted, they gave multiple risk factors for the disease which contained elements of both modifiable (poor diet, stress, smoking and alcohol intake, obesity and overweight) and non-modifiable (heredity, age, sex of an individual) risk factors for the disease.

It is not clear as to whether they had knowledge of these risk factors or they were just guessing. Apparently, some of the risk factors reported were linked directly to what they thought were the causes of diabetes. The study also noted that physical inactivity as a risk factor for T2DM was not reported. However, while men were perceived as at risk of diabetes because of their poor social habits (smoking cigarettes, the excess use of alcohol and roasted red meat), Chege (2010) reported that abdominal
obesity presented a double risk of developing diabetes among women. In his study, Chege (2010) also noted that childhood starvation and use of cassava for sustenance during childhood starvation, diabetes in close relatives and abdominal obesity were cited as the main risk factors for diabetes.

In a nutshell, the study demonstrates that T2DM patients integrate factors from the biomedical model and folk belief systems in their understanding of diabetes. This implies that Kleinman’s EM remains important when studying a disease holistically, as it enables a researcher to explain both biological and cultural aspects of the disease.

5.1.2 Management of diabetes

Diabetes is a chronic illness that requires daily management to control blood glucose levels, including a dietary regimen, regular exercise, routine monitoring of blood sugar levels, regular physician office visits, and for some, daily hypoglycemic agents; behaviours that must be maintained throughout the patient’s life (Rood, 1996; Tessaro et al., 2005). Kleinman (1980) has suggested that in looking at any complex society, one can identify three overlapping and interconnected sectors of health care: the popular sector, the folk sector and the professional sector. Each sector has its own ways of explaining and treating ill health, defining who the patient is and who the healer is; and specifying how the healer and the patient should interact in their therapeutic encounters. According to him, for people with chronic illness, the popular sector is conceived as the most significant arena of care because they spend much more time taking care of themselves within this sector than in the professional sector or in the folk sector (Kleinman, 1980). This is consistent with the study findings whereby patients sought health care assistance pertaining to management of their diabetes from the professional and folk sectors of health care, and engaged into various management practices within the popular sector.
Kleinman (1980) further notes that for people who become ill, self-treatment which falls under the popular sector is usually a first line of action. If they are not helped by self-treatment, they make choices about whom to consult in the other sectors of healthcare. This study found out that patients managed their diabetes in the professional sector before opting for other sectors. In this sector, management is based on knowledge and advice given by the health care professionals pertaining to exercise, diet and use of oral drugs and insulin. If the outcomes are not satisfactory, they move either to folk sector or popular sector, or may combine both of them.

Generally, the findings show that patients utilize both biomedical and non-biomedical (folk) management practices in dealing with their diabetic condition. They make shifts from one management remedy to another based on the EMs they hold about the illness, advice and information received about its effectiveness from friends, family members, and mass media among others. A growing body of work in Ghana and other African countries suggest that chronic illness beliefs are rooted in complex socio-cultural knowledge systems drawn from sources such as the family and friends, through regional and international travels, pluralistic health professionals, mass media and unique experiences of self in health and disease (Aikins et al., 2010). These sources of knowledge inform multiple themes of diabetes and its management. Other studies (Dropkin, 2010 and Kolling et al., 2010) have also shown that patients use both ethno-medicine and biomedicine in management of diabetes. In their study in Tanzania, Kolling et al. (2010) reported that biomedical health care systems and ethno-medical health clinics exists side by side, offering different EMs concerning the causes of diabetes and means of effective treatment. Thus patients confirmed that they had interrupted their biomedical treatment in order to follow an ethno-medical treatment which was more affordable and offering a cure for their illness. In
Mombasa, Dropkin (2010) also noted that though patients reported that conventional medicine was good for their diabetes management, alternative medicine was also used as a supplement after failing to get well via conventional care.

A broad argument made is that due to complexity of the behavioral management regimens and the chronic nature of the disease, the chronically ill do not comply with biomedical treatment because it offers no practical answers to the underlying social or supernatural nature of chronic illness, thus making compliance difficult (Aikins, 2005; Hunt & Arar, 2001). This is also in line with the EMs that patients held about the disease, which tends to influence the management regimen used. For instance, for patients who reported that diabetes is as a result of stress, witchcraft or punishment from God, most of them used prayers and herbal medicines in addition to the biomedical treatment to manage their illness. This basically implies that the use of conventional treatment or folk treatment by patients is driven by the EMs they hold about the cause of their illness, and the effectiveness of the regimen used.

Since correct clinical diagnosis reinforces behaviour of regular clinical follow-up visits and management through biomedicine and recommended lifestyle changes (Von Korff et al., 1997), most patients in this study also preferred and utilized the biomedical diabetes management practices. This included adherence to treatment (regular clinical follow-up visits, the use of oral drugs and insulin injections), dietary management and exercise. However, the use of drugs and insulin was the first and the most significant aspect of diabetes management utilized by these patients. This might have been the case because all the patients who participated in this study had attended diabetes health education sessions at the KNH OPDC and were recruited at this facility. In their study among diabetes patients in British Bangladesh, Greenhalgh et al. (1998) found out that majority of the informants utilized biomedical
treatment in management of diabetes. They felt that the doctor’s instructions should always be obeyed as the doctor was viewed as a busy, authoritative and knowledgeable person who rarely makes mistakes and has full understanding of the conditions he or she treats.

Lifestyle behavioural changes such as dietary restrictions and exercise were also part of the biomedical diabetes management practices followed by the diabetic patients. The most important of this was dietary management, since “drugs cannot work alone”. This meant that one had to follow the dietary instructions given by the clinicians and the nutritionist, which basically involved taking tea without sugar, consuming little unrefined starches and a lot of indigenous vegetables. In their study amongst diabetic patients in Atlanta, Gazmararian et al. (2009) reported that, “developing diabetes translates to behavioral changes”. The most significant lifestyle modifications made by the diabetic patients included preparing separate meals for themselves, reducing food portions and eating a lot of vegetables (Gazmararian et al., 2009).

Exercise as a biomedical management practice seemed to be of little significance as it was hardly reported. It was only after probing that a few patients recalled the specific advice they had received from the doctor, such as working until one sweats, taking a walk and generally not staying idle. Probably, this means that patients place little value in carrying out exercises or are not aware of its importance in diabetes management. Studies have shown that exercise contributes to 15 % of the overall diabetes management regimen for T2DM, and has promising results promoting weight loss, increases insulin sensitivity and is known to prevent impotence (ADA, 1998; IDF, 2005; IDF 2010). Findings from various studies (Greenhalgh et al., 1998; Skelly et al., 2006) support the idea that exercise to diabetic patients seems to have little importance in diabetes management.
According to Greenhalgh *et al.* (1998), exercise in the context of health and fitness seemed to have little meaning for the Bangladeshi informants, as they recalled the doctor’s advice on the importance of exercise. In addition, the association between sweating and exercise was not made by any informant but ritual Muslim prayers were often cited as worthy and healthy giving form of exercise. It is also important to note that while a few patients in this study reported complications being experienced such as amputation and loss of vision as impediment to exercising, some informants in Greenhalgh *et al.* (1998) study gave physical and material constraints for not exercising. In particular, many of the women rarely left their houses because of fear of physical attack. Though some of them lived in high rise flats with no lift, they also commented on the absence of parks, dirty pavements, and street crime.

However, while exercise as a management practice helps in promoting weight loss for patients with diabetes, the subjective meaning of losing weight among informants in this study was never reported. Awah *et al.* (2007) reporting on an anthropological study of diabetes in Cameroon observes that people with diabetes often struggle to engage with biomedical management. Diet and weight management, which involves weight loss, was one site of resistance. According to them, In Cameroon as well as in many African societies, rapid weight loss is often attributed to HIV/AIDS status (Awah *et al.*, 2007).

Since medical pluralism is key feature in chronic disease experiences (Aikins, 2005), and healers offer a cure which biomedicine cannot (Kolling *et al.*, 2010); the lay end up “sampling” various folk remedies. Studies have shown that if persons are not satisfied with information and help they are receiving from their health care providers, they will seek alternative sources to help them manage their disease (Tessaro *et al.*, 2005). In this study, due to patients’ financial incapability and information received from
relatives, friends, religious leaders and the local media about the effectiveness of folk remedies, some of them relied on them in managing their illness. Some of the folk remedies used included: the use of prayers and religion, herbal medicines, water, "diabetes healing bangles", herbal teas and concoctions, and raw chicken liver, some of which have also been cited in other studies (Awah et al., 2009; Dropkin, 2010; Greenhalgh et al., 1998; Kolling et al., 2010; Skelly et al., 2006). In contrast to the aforementioned studies, the use of raw chicken liver and bangles emerged out as new folk management remedies also utilized by the patients.

However, while patients in this study used prayers to enhance the efficacy of the drugs, reduce anxiety and help cure diabetes, Skelly et al. (2006) have reported that African-Americans with diabetes believed that in curing, God act through both changed behavior of the individual and the work of a doctor. This study also found out that in using prayers, some of the patients sought intervention from spiritual and religious leaders for management of their illness. In contrast, a study by Aikins (2003) demonstrated that even though respondents had assessed traditional religious and faith healing practices, they preferred to "pray privately" for successful treatment rather than seeking religious intervention.

Indeed, for patients who used folk remedies in diabetes management, most of them reported having found no cure for their illness but instead it worsened the condition. Some of them experienced complications as a result of using folk remedies, which were more expensive to treat. Though, during a follow-up visit, a patient reported that he had been cured after being prayed for by a religious leader. In a study amongst diabetic patients in Ghana, Aikins (2005) reported that all patients who accessed ethnomedical care reported negative experiences revolving around bad reactions to herbal medications. Thus,
complications and high mortality from diabetes can be attributed to harmful management practices, including the use of ethno-medicine (Ofei et al., 2002).

5.1.3 The role of caregivers in diabetes management

A chronic illness such as diabetes often results in an increased need for socio-emotional and tangible support, all of which are extremely important in the lives of patients with diabetes mellitus as they manage their illness (Ford et al., 1998; Westaway et al., 2005). A study among Black South Africans with diabetes showed that lack of socio-emotional and tangible support for patients with diabetes was related to poor functioning, higher hospital admission rates, poor diabetic control, increased complications and mortality (Westaway et al., 2005). However, Kleinman (1980) states that the family is the main domain of health care in popular sector, with women commonly providing the health care support. In this study, the immediate family members, and mainly the women, were the care givers for the diabetic patients. They provided tangible support which included: ensuring timely uptake of prescribed medication by the patients, ensuring that patients upheld a balanced diet, accompanying patients to the health care facility, and providing first aid for patients who encountered frequent seizures. On the other hand, the socio-emotional support provided by the caregivers of diabetic patients in this study included making decisions on the appropriate therapeutic treatment and offering moral support.

By contacting patients at specified intervals, care providers can obtain information on medical and functional status, identify potential complications early, make necessary modifications and reinforce patient efforts (Von Korff et al., 1997). Such ideas were part of the care givers’ roles in this study, whereby they had learned to interpret the symptoms experienced by the patients and would act accordingly. Similarly, in their study amongst diabetes patients in Tanzania, Kolling et al. (2010)
reported that the family members in the household, particularly members of the nuclear family, provided care to the person afflicted by diabetes in terms of acquiring medicine, accompanying the person to health care services, knowledge sharing, and ensuring the diabetic upheld a healthy diet. Weller et al. (1999) in their study on “Latinos beliefs about diabetes” also noted that family support was a key variable in assuring compliance with dietary and other aspects of diabetes day-to-day-management. Such support is associated with adherence to diabetes treatment regimens which reinforces positive health outcomes (Ford et al., 1998). This means that there is a growing recognition of the importance of care givers within the family as part of diabetes management.

It is worth noting that the concept of therapy management groups was not so strong among the patients who participated in this study as opposed to what happens in Kongo to patients with chronic illnesses. Janzen (1987) noted that whenever an individual becomes ill, the therapy management group coalesces with various maternal and paternal kinsmen, and occasionally their friends and associates, rally for the purpose of sifting information, lending moral support, making decisions, and arranging details of therapeutic consultation. Citing an example with a mother who was struck by life-threatening disease (cardiac failure) in Kongo, the question of who took charge and made crucial decisions in the care process was vested in the group, with the matrilineage and the father taking over the therapy management process (Janzen, 1978). Contrary, findings in this study clearly demonstrate that the immediate family members, and mainly within the nuclear family, were the therapy managers for their diabetic patient. On the other hand, given that this study was based on interviewing T2DM patients within the age bracket of 35 -64 years, and who were not severely debilitated, it might provide insights as to why the therapy management group was not strong.
Therefore, this mutual involvement and care performed by the care givers within the family; supports the existing anthropological knowledge of the function of kinship system in which the kinship groupings are the most important social units for most people across Sub-Saharan Africa (Kolling et al., 2010). Based on the current study, diabetes thus remains a family disease whose daily management responsibility rests with patients and their families (Solowiejczyk, 2004).

5.1.4 Problems faced by patients in daily management of diabetes

Findings in this study show that patients with T2DM face a myriad of problems. This include: financial constraints, disruption of economic and daily activities, availability of drugs and insulin, access to health care, emotional and psychological problems, erectile dysfunction and lack of adequate and correct information. Given that most patients preferred to manage their illness following the clinicians’ recommendations, most of them were unable to fully carry out the recommended management behaviors due to their limited economic power.

Literature review shows that education and income are major socio-economic determinants of health (Brown et al., 2004). Often lower education begets lower income. This might help to explain why financial constraint was reported by almost all patients, given that their literacy level and family monthly income were generally lower. Nwankwo et al. (2010) have also documented that a poor economic base and low education can result in poor outcomes of diabetes. In their study among diabetes patients attending government health facilities in South East, Nigeria, they found out that majority of the patients had only secondary education which was responsible for low income. The lower income of the patients was very significant in their inability to procure diabetes supplies, medication and doctor’s visits (Nwankwo et al., 2010).
Studies have shown that throughout the African region, the cost of diabetes management, mainly the drug costs for diabetes are beyond the reach of many (Beran et al., 2005; Levitt, 2008), which is also reflected in this study. Owing to the fact that there is lack of free national health care services in most Sub-Saharan African countries, it means that the burden of diabetes care remains with the patient (Levitt, 2008). Given that patients spent almost half (46%) of their family monthly income on management of the illness, it was very much burdensome for them, especially for those who had other financial obligations to fulfill within their households.

A study done in Mombasa (Kenya) showed that the cost of medication was a major burden for virtually all diabetic patients paying out of pockets, spending almost Kshs. 6,000.00 each month (Dropkin, 2010). Elrayah-Eliadarous (2007) has also pointed out that in Sudan, the cost for outpatient visits, medication and other supplies places heavy burden on the patient. Specifically, the direct cost of diabetes care required 65% of the health expenditure of the whole family, with insulin constituting to about one third of the total diabetes care expenditure.

However, this study discovered that due to the heavy financial burden faced by patients, most of who were parents, some of their children had to stop schooling since the cost of diabetes management was beyond their means. For others, they had to sell their properties such as cattle to keep up with the demanding expenditures. This demonstrates that not only does diabetes affect the individual patient, but also their entire households.

Literature review shows that in Africa, the essential drugs for diabetes are not always available (Beran et al., 2005), a problem reported by patients in this study. They would walk into various health care
facilities and pharmacies, sometimes failing to get the drugs; thereby making them have gaps in their medication. Such a challenge hampers improved health outcomes for diabetes. A study in Ghana has shown that high rates of disability and premature deaths are linked to poor quality services especially lack of medicines and medical equipment (Aikins et al., 2010). In Tanzania, most diabetic patients did not take the medicine (oral tablets and insulin) regularly because of its unavailability at the hospital pharmacies (Kolling et al., 2010). The findings in this study demonstrate that with shortage of drug supplies, some patients share drugs and insulin with their neighbors to keep them going, until they are available.

Disruption of patients’ daily activities, more so the economic ones, as a result of diabetes related complications seems to have impacted directly towards the financial burden that they were experiencing. Given that T2DM affects the age group of between 35-64 years that is economically active (IDF, 2010) mainly through disruption of economic activities; this translates to loss of productivity to the patients. A study in Ghana showed that diabetes led to loss of earnings amongst the diabetic patients, who were unable thereafter to comply with the biomedical treatment as drug and dietary management was compromised by a lack of financial resources (Aikins, 2003).

People with diabetes have the responsibility to manage their condition on a day to day basis by communicating with their health care provider periodically throughout the year and seeking advice where necessary (Nwankwo et al., 2010). Since health care facilities in Africa are not easily accessible in all areas (Levitt, 2008), this greatly undermines optimum diabetes management. In the present study, even though patients valued the clinical follow-up visits at KNH OPDC, they reported having difficulties of continuously engaging with the health care providers due to accessibility pitfalls. This was
very much problematic during rainy season when most roads remained impassable, together with the heavy traffic jams in Nairobi, where KNH is located. In Mombasa, it has been noted that if it happens to be raining, many patients will choose not to visit the clinic as a result of the impassable roads (Dropkin, 2010). Therefore, poor road network to the facility (KNH) may negatively influence patients’ behaviours regarding management choices and even compliance to treatment. According to the informants, this is beyond their control and the government should come in for assistance. Some of them opined that the services offered at KNH OPDC be duplicated to other local health care facilities.

From an anthropological perspective, having sexual problems as an African man makes one feel like he is less a man as many people believe that to be a man, one has to function sexually. Studies have shown that living with diabetes can have major obstacles to social relationships which can contribute to divorce, sexual problems and infertility (Cohen et al., 1993). In the current study, erectile dysfunction as a result of diabetes was a major problem for the male patients; which did not only impact negatively on their sexual lives, but also in their marital relationships, which they felt that it can be a key towards marital break-up. In many cultures and many traditional norms and values defining men and masculinity, the notions of masculinity are closely associated with male honor, which is equivalent to virility, sexuality and sexual performance (Connell, 1995; Silberschmidt, 2001). Men who have lost their libido may experience loss of self-esteem and may live in fear of divorce by their spouses, thus impacting negatively on the family relations.

In a study by Liburd et al. (2004) among African American men with Type 2 diabetes, they documented that having diabetes as a man affected their sexual appeal and social relationships. In their study, changes in the ability to perform sexually were stressful to the male diabetic patients. It was also seen as
a source of torment for these men, who tended to have few outlets for expressing and reconciling their emotions. Findings in this study demonstrate that for patients who experience this problem, they tend to deal with it by "hanging out" with their friends. In the process, they may engage into the poor social habits (cigarette smoking and alcohol intake), thus ending up with poor sugar control. This calls for sex-appropriate educational and clinical interventions that health care providers, patients and families can use collaboratively to better manage diabetes in men (Jack, 2004).

According to Von Korff et al. (1997), diabetic patients are more likely to define problems in terms of emotional distress or fears about unpredictable health consequences of illness. In a study by Hendricks and Hendricks (1998), patients reported fear of long-term complications, which included amputation, cardiovascular disease, nephropathy, neuropathy, retinopathy and stroke. Retinopathy emerged as the most feared complication (Hendricks and Hendricks, 1998). Findings from this study show that majority of the patients did not only fear the long-term complications of the disease such as amputation, but also having their children inherit the disease. They also reported having distracted thoughts pertaining to their daily experiences with the illness such as frequent anger, daily injections and the high cost of managing this "new disease". In their study of diabetes in an Appalachian Population, Tessaro et al. (2005) documented that diabetes was considered a burdensome disease, and which was feared most because of its severe complications especially amputation and blindness.

The findings of this study highlight that T2DM patients lack adequate and correct information from the health care providers particularly concerning their dietary requirements. This creates confusion among patients on what to consume and not to, and in what quantities. This was really hard for patients who were having problems with their kidneys. Research suggests that chronic disease knowledge is poor
among health workers. Studies on diabetes highlight poor knowledge among doctors, nurses, and conflicting knowledge among dieticians (Aikins et al., 2010). In Ghana, poor health worker knowledge has been implicated into poor communications, the development of complications and in healer shopping. It is important to understand that the platform upon which management of diabetes is based lies on adequate and correct information, which constitutes to 60% of the overall management regimen for T2DM (IDF, 2010). The contradicting information received by T2DM in this study basically indicates that health care providers do not use the same ‘language’ when advising the patients, yet Motala (2002) clearly states that information on diabetes should come from them. The health care providers should be aware that family and friendship networks, and the print and electronic media are the most commonly reported sources of information on diabetes by T2DM patients. They should be aware that herbalists are keen at advertising their products and their information may change patients’ perceptions of the illness and engagement with different management options. Elsewhere in Ghana, it has been reported that mass media is the key site for disseminating information on chronic diseases (Aikins et al., 2010). According to Aikins et al., (2010), there is also a growing trend of influential herbalists providing incorrect chronic disease information on radio and television as part of their advertising strategy. This may also pose a challenge to T2DM patients on what information is true and not true. They may rely on information that is partial, outdated, or incorrect (Murphy, 1995), which in turn affects proper management of their diabetic condition.

In a nutshell, the framework in Figure 5.1 summarizes the findings of this study. It clearly shows that T2DM patients who participated in this study had varied perceptions regarding the etiology, symptoms, complications and risk factors about diabetes. This influenced the choice of management options to be followed, whether biomedical or non-biomedical management options. The framework also depicts that
in daily management of diabetes by the individual patients, caregivers play various roles in helping them manage their illness. Nevertheless, T2DM patients experience numerous problems some of which are impediments to management and others are implicated to the disease.
Figure 5.1: A conceptual diagram showing how patients perceive and manage their diabetic condition.

T2DM PATIENTS’ PERCEPTIONS OF DIABETES

ETIOLOGY
- Stress
- Poor dietary habits
- Heredity
- Overweight
- Witchcraft
- Shock
- God’s Punishment
- Inactivity of insulin

SYMPTOMS
- Frequent urination
- Frequent thirst
- General body weakness
- Blurred vision
- Frequent fatigue
- Weight loss
- Dizziness
- Constant hunger

COMPLICATIONS
- High blood pressure
- Poor vision
- Kidney failure
- Sexual dysfunction
- Stroke
- Amputation
- Frequent seizures

RISK FACTORS
Modifiable
- Stress
- Poor diet
- Smoking & alcohol intake
- Obesity & overweight

Non-modifiable
- Heredity
- Gender

MANAGEMENT PRACTICES FOLLOWED BY T2DM PATIENTS

Biomedical options
- Adherence to treatment
- Dietary restrictions
- Exercise

Non-biomedical options
- Prayer, religion, herbal medicine, water, herbal teas, raw chicken liver, bangles, GNLD products.

THE ROLE OF CAREGIVERS IN DIABETES MANAGEMENT
Tangible support
- Monitoring dietary intake of patients
- Monitoring daily intake of medication
- Accompanying the patients to hospital

Socio-emotional support
- Moral support
- Decision makers on appropriate therapy.

PROBLEMS EXPERIENCED IN DAILY MANAGEMENT OF DIABETES

- Financial constraints
- Disruption of economic and daily activities
- Access to health care
- Availability of drugs and insulin
- Erectile dysfunction in men
- Emotional and psychological trauma
- Lack of correct and adequate information.
5.2 Conclusion

From this study, it can be argued that diabetic patients have different views and perceptions regarding diabetes. The way they perceive and interpret the cause, symptoms, complications and risk factors of their ill health tends to influence how they manage their condition, whether to use biomedical or folk management regimens. The findings generally demonstrate that patients perceive diabetes as more than a biomedical disease. Therefore, the biomedical framework alone will not enable health care providers to effectively manage this chronic disease. But through the inclusion of folk belief model, they can understand the realities about their worldviews, and the impact of such realities on diabetes management. Given that diabetes is a condition whose management requires ongoing modifications of patient behaviors, exploring diabetics’ perceptions and management practices that they follow in their daily lives with this condition can be helpful to explain patient’s non-compliance with the treatment recommendations (Hunt & Arar, 2001).

A chronic illness particularly diabetes calls for the need of home care givers, who in this study contributes significantly in helping patients manage their diabetic condition. This simply means that diabetes remains “a family disease” whose daily management responsibility rests with patients and their families (Solowiejczyk, 2004). Such a disease presents complex challenges to patients in their daily management of the condition, and therefore has the potential to cripple the population if not addressed immediately. While communicable disease like HIV/AIDS has been the major challenge in Kenya going almost for the last thirty years with now ready access to anti-retroviral drugs, I believe that diabetes, a non-communicable disease, is going to be the major challenge of the next thirty or so years; presenting the greatest management challenge not only for the individual patient, but also to the health care in this century.
The results of this study contribute to the body of literature on T2DM, particularly with regard to patients' worldviews about the illness and how they manage it in their day-to-day living.

5.3 Recommendations

Based on the findings of this study, the following recommendations are made:

1. Further studies involving a community-based sample with persons not already in clinical care would be necessary to determine whether these findings can be generalized to a wider population.

2. At a policy level, there is need for the government to subsidize on the cost of drugs and insulin meant for patients with diabetes, and which should be made available in other health care facilities and pharmacies across the country. In addition, the health care system should recognize the needs of these patients by duplicating the services offered at KNH OPDC to other subsidiary hospitals so as to ease them from covering long distance in order to seek health care.

3. While this study focused on the perceptions and management practices that diabetics utilize in respect to their illness, the results have important implications for care of patients with T2DM. Health care providers should be aware that most patients use folk remedies to manage diabetes. Health care providers can be able to elicit information about the use of these remedies from their patients in a sensitive, culturally competent way. Kleinman’s explanatory model remains the best avenue for eliciting such information.

4. Given that patients' home caregivers also play significant roles in diabetes management, health care providers would want not only to educate the patients, but also their family with regard to beliefs about diabetes and management practices that are not in concordance with the biomedical model of the disease. They should incorporate into their practice a discussion on the use of
alternative treatment, which is responsible for increase in morbidity and high mortality from the disease.

5. For adult T2DM patients, couple counseling should be made an integral part of diabetes management, emphasizing the relationship between diabetes and men’s sexuality.
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APPENDIX 1: CONSENT AND CONSENT INFORMATION

Hello informant,
My name is Millicent L. Liani, a post-graduate student from the University of Nairobi. As part fulfillment for my Master’s degree in Anthropology, I am supposed to carry out a research in the field of Anthropology.

Research
My area of interest is Type II diabetes mellitus, and the title of my study is “Perceptions and management practices followed by type 2 diabetes mellitus patients attending Kenyatta National Hospital in Nairobi, Kenya”. I am carrying out a study on patients like you who are attending the Outpatient diabetes clinic at KNH. The study aims at exploring how you perceive and manage your diabetic condition, the roles played by your care-givers at home in helping you manage your diabetic condition, and the problems you have ever encountered with the entire management of your illness.

Methodology
I have a set of questions to ask you. These will be asked to patient aged 35-64 years. I intend to interview 32 adult (35-64 years) T2DM patients in whom clinical diagnosis of diabetes has been made within the previous 24 months and above, and who will be willing to participate in the study. The KNH will act as my recruitment site for the study subjects and that interviews will be conducted in your homes or places convenient to you.

Confidentiality
All the information you give will be treated with strict confidence. Information that may identify you or your name as an informant shall not be disclosed to anyone as fictitious names will be used in place of your name.
Benefits

There will be no immediate direct benefits to you. However, after completion of the study, the results will be used to make recommendations aimed at improving diabetes education and management.

Risks

The study will not pose any physical harm to you as it will be purely based on interviewing and no samples will be drawn from you. I will be working closely with your health care providers who will ensure constant counseling to ensure maximum comfort if anything arises.

Participation

Your participation in the research is voluntary. You may withdraw anytime during the interview should you desire to do so, and that you will continue to have medical care even if you withdraw from the study. You are free to ask any questions regarding the study which are unclear to you. Please also feel free to contact the chairman of KNH/Ethical Research Committee if you have any questions regarding the study. The telephone number is 020-726300-9, and the email address is KNHplan@ken.Healthnet.org. You may also contact my supervisor: Professor Isaac K. Nyamongo on +254 722 706 839.

DECLARATION BY THE RESEARCHER

I, MILLICENT LIANI, NATIONAL ID NO., 24052488 OF TEL. NO.: +254 723 258 104; have clearly explained the purpose and benefits of the study to the informant. I have also explained that participation is voluntary and the research will not jeopardize the patient’s treatment in any way.

SIGNATURE ............................... DATE .................................
DECLARATION BY THE PATIENT

I, .............................................ID/PP NO., .................................. do hereby voluntarily agree to take part in this research study on “Perceptions and management practices followed by type 2 diabetes mellitus patients attending Kenyatta National Hospital in Nairobi, Kenya”. The nature and the purpose of the study have been explained to me. I have clearly understood the benefits involved and that my participation is voluntary. I also understand that there are no harmful physical risks involved as the study is purely based on interviewing, and that my failure to participate will not jeopardize my treatment. I have also been adequately briefed on objectives and methodology of the research and I hereby agree to participate in the interview.

SIGNATURE OF PATIENT ....................... DATE .........................

SIGNATURE OF WITNESS ....................... DATE .........................
APPENDIX II: IN-DEPTH INTERVIEW GUIDE

1. Could you describe to me your experience of living with your diabetes?
   - When did you develop/realize that you had diabetes?
   - How did you know that you had diabetes?
   - What happened to you? (Probe for: what happened to them, their activities – economic, social i.e. social stigma & not attending functions, their diets?).
   - What do you think causes this problem (diabetes)? (Probe for all possible causes from both the naturalistic and personalistic causes). Can you think of anything else that may cause diabetes? How do you think the aforementioned causal factors lead to diabetes?
   - What are the symptoms that you have ever experienced with your diabetes? Why do you think this illness started when it does?
   - What does this illness do to you (complications)? Why do some people get this illness and others not?
   - Who are the people most at risk for developing a diabetic problem like yours? (Males, females, children, adults).
   - How serious is your diabetes?
     i. Do you think it can be treated? If yes, how can it be treated? If no, why can it not be treated?
     ii. Do you think diabetes can be prevented? If yes, how can it be prevented? If no, why can it not be prevented?

2. Had you heard about diabetes before you developed your condition?
   - How did you hear about diabetes?
   - What did you hear about diabetes?
   - How does what you heard fit with your lived-experience with diabetes?

3. Do you always attend all your clinical appointments/ follow-up visits? Yes, No.
   - If yes, what do you like about the services/ care offered at the clinic? Is there anything that you don’t like about in terms of the services/ care offered at the clinic?
   - If no, what are some of the reasons for not attending? (Probe for: busy with economic activities - availability, forget the appointment dates, affordability of the clinical services, accessibility to the clinic e.t.c.).

4. Do you seek health care elsewhere besides the medical office?
If yes, when, where, and to who do you seek treatment/medication from? How do you decide to get treatment/medication from the other sources mentioned? How would you compare this medication to the one offered at the clinic? Is this the main reason that makes you seek care elsewhere besides the clinic, or is there something else? Do you feel that you have experienced any benefits from seeking care from these other sources? Which benefits are they?

5. How convenient is the method of payment at the clinic, and at the other health care providers? (Payments made on the spot, payments can be made later, payment not necessary to be in monetary form).

6. Do you manage your diabetes at home? If yes, how do you manage it? (Probe for: Avoid sugary foods, exercise, eat regularly, herbal remedies, take drugs, inject insulin et c.). Of these management practices, which one do you mostly prefer, and why? How much does it cost you to manage your diabetes by this preferred management practice?

7. Are there different management practices for diabetes for different symptoms/complication? If yes, what are they and for which symptoms/complications?

8. Have you ever recommended these management practices to someone else who is diabetic like you?
   - If yes, what did you say/recommend?
   - If didn’t recommend; suppose a neighbor or relative who is diabetic asked you on how they can manage their diabetes, what would you tell them?

9. Who takes care of you when you are in a critical condition with your diabetes?
   - How are you related with this person?
   - How did you/the family decide that this person (use name or relationship, whatever the informant said) should be the one?
   - What does the care-giver do for you when you are in a critical condition with your diabetes?

10. Are there any problems that you have encountered while managing your condition? (Probe for: financial, educational, individual, systems barriers).
SOCIO-ECONOMIC AND DEMOGRAPHIC DATA

1. Gender of the patient.
   1) Male  2) Female.

2. Patient’s current age? ------- (years).

3. What is the marital status of the patient?
   1) Unmarried/single  2) Married  3) Widowed  4) Divorced/separated

4. What is the patient’s religious affiliation?
   1) Catholic  2) Protestant  3) Muslim  4) Other (Specify)

5. What is the patient’s ethnic affiliation? ................................

6. What is the patient’s current residence?
   1) Urban  2) Rural

7. What is the patient’s completed level of formal education?
   1) None  2) Primary  3) Secondary  4) Tertiary  5) Adult Education

8. What is the patient’s main source of livelihood?
   1) Government Employed
   2) Private sector
   3) Private Business
   4) Remittance
   5) Unemployed
   6) Others (specify)

9. What is the patient’s family income per month in Kes?
1) 0 -10,000  2) 11,000 - 20,000  3) 21,000 - 30,000  4) 31,000 - 40,000
5) 41,000 & above.


11. Who is the head of your household?

12. How many people have been living in your household in the last three months?
   Number of members:

13. How many males currently live in your household?
   Number of males:

14. How many females currently live in your household?
   Number of females:

15. How many children (under 18 years) currently live in your household?
   Number of children:

Thank You!
APPENDIX III: KEY INFORMANT INTERVIEW GUIDE:
A: FOR THE HEALTH STAFFS AND REPRESENTATIVE AT DMI

1. How many diabetic patients do you receive/handle? (Per day, per week, per month).


3. From your own experience, what are the main sources of information on diabetes that T2DM have access to? (Friends, family members, pamphlets, magazines, video, support groups).

4. What do you think are some of the problems that the T2DM patients experience in their lives as they manage their diabetic condition? (financial, economic, social, psychological).

5. What are your views towards how the T2DM patients manage their diabetes in their daily lives? Do they oscillate within the professional, folk and popular sectors of health care? How?

6. From your own experience, what do you think can be done to help T2DM patients improve on their diabetes management?

Thank you for your cooperation.
B. FOR THE RELATIVES/CARE-GIVERS OF THE PATIENT

1. How are you related to the patient?
2. When did the patient develop his/her diabetic condition?
3. Where does this patient seek health care following his/her diabetic condition?
4. Does the patient always attend all the clinical appointments? If no, what could be the reason(s) for not attending?
5. Does the patient seek health care elsewhere besides the medical office? If yes, where in particular?
6. How does this patient manage his/her diabetic condition while at home? (Diet, exercise, oral medicines, use of herbal remedies, use of folk remedies e.t.c.).
7. How do you assist this patient in terms management of his/her diabetic condition?
8. How do you tell that this patient is in a critical condition with his/her diabetes that needs help? When in such a condition, what do you usually do?
9. Who makes decisions on the kind of management practices that the patient should receive? Which decisions are usually made?
10. Are there any problems that this patient encounters in his/her daily management of the diabetic condition? (Financial, individual, social, psychological, e.t.c.).

Thank you for your cooperation.