THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE
DEPARTMENT OF PUBLIC HEALTH

The Patients' Explanatory Models of Diabetes at the University Teaching Hospital in Lusaka

by

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ABSTRACT

Introduction: Despite concordance between the Explanatory Models of patients and those of the health care providers showing a positive impact on patient's outcomes and self-care, little is known about the patients' Explanatory Models of diabetes in Zambia. It is, therefore, important, that this study on understanding the patient's explanatory models of diabetes at the University Teaching Hospital in Lusaka is explored.

Methodology: The study took a qualitative approach in particular case study. The area of study was UTH Clinic Five. Data was collected through in-depth interviews in which 20 adults above the age of 18 were interviewed. The interviews were audiotaped, transcribed verbatim and coded into themes which were informed by Kleinman's explanatory models of disease. Data was then analysed using thematic analysis. Ethical clearance was sought from Excellency in Research Ethics and Science (ERES) with reference number 2014-May-037.

Results: The study found that most diabetes patients associate the cause of diabetes to consumption causes, biological causes such as genetics, psychosocial stress and supernatural causes such as witchcraft. It was also reviewed in this study that the diabetes patients' understanding of the signs of diabetes was similar to the biomedical information although the patients understood the signs of diabetes through body listening other than from biomedical information availed to them. In the study, participants mentioned two categories of treatment which were traditional and conventional treatment. Following good diet was the commonly mentioned way of diabetes prevention. The study revealed that the diabetes patients had challenges with the availability of authentic information on the cause, signs, treatment, and prevention of diabetes. The study also established that there was a need to scale up availing authentic information to the patients which would be very helpful to their self-management and care for the disease.

Conclusion: The study showed that despite some of the similarities between the patients' explanatory models of diabetes and that of the biomedical model, the patients drew their explanatory model mainly from their experience through body listening and observation from the fellow patients' experiences.

DECLARATION

I, Tamishe Mwauseya declare that the work presented in this dissertation entitled, "**The Patients' Explanatory Models of Diabetes at the University Teaching Hospital in Lusaka**" was done by myself and has not been presented to this or any other university for the award of any degree. I have, however, acknowledged all other works referred to in this dissertation.

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DEDICATION

I dedicate this work to my late mum for the support and the firm academic foundation given to me and which has seen me rise to this level. Also to my workmates and colleagues for the moral support and for the encouraging words such as “You can do it Tamishe” which was never missing in their encouragements.

CERTIFICATE OF APPROVAL

This dissertation by Tamishe Mwauseya has been approved as having fulfilled the requirements for the award of Master of Public Health in the School of Medicine by the University of Zambia.

Examiner 1	……..	....…….....
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Examiner 2	……..	....…….....
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May the almighty God bless them all.

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LIST OF ABBREVIATIONS AND ACRONYMS

AIDS……. Acquired Immune Deficiency Virus

HIV……... Human Immunodeficiency Virus

DAZ…….. Diabetes Association of Zambia

EMs……... Explanatory Models

NCDs……. Non-communicable Diseases

USD…….. United States Dollars

UTH…….. University Teaching Hospital

WHO……. World Health Organisation

DEFINITION OF TERMS

Biomedical models of illness – a conceptual model of illness that excludes psychological and social factors and includes only biological factors in an attempt to understand a person's medical illness or disorder.

Conventional treatment - treatment that is widely accepted and used by most healthcare professionals.

Diabetes Mellitus - a Chronic condition associated with abnormally high levels of sugar (glucose) in the blood.

Diabetes authentic information- diabetes information which conforms to facts i.e. biomedical information.

Signs – a phenomenon that can be detected by someone other than the individual affected by the disease.

Sugar Disease - lay man's term for diabetes.

Symptoms - a phenomenon that is experienced by the individual affected by the disease.

Traditional treatment - treatment based on theories, beliefs, and experiences indigenous to different cultures whether explicable or not, used in the maintenance of health as well as disease prevention.

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CHAPTER ONE

INTRODUCTION

1.0 Background

Non-communicable diseases (NCDs) have created a 'double burden' of disease that threatens to overwhelm the health services of many resource-poor countries. Double burden of disease refers to having the burden of infectious diseases and NCDs at the same time. World Health Organisation (WHO) warns that the greater future burden of obesity and diabetes, will affect developing countries, and the projected numbers of new cases of diabetes will run into the hundreds of millions within the next two decades (Prentice *et al*., 2006). This study focused on diabetes because diabetes presents itself during the peak of an income-earning period in an individual's life, those affected are often the breadwinners of their families and loss of primary income in households can lead to despair and poverty. The good health of the workforce is a major factor in economic development; the burden of illness caused by diabetes and the reduction in life expectancy in sub-Saharan Africa is hindering the region's economic growth (Diabetes Leadership Forum. Africa 2010). Therefore, it is important to carry out studies that can help in the management and control of diabetes.

Diabetes is a chronic condition associated with abnormally high levels of sugar (glucose) in the blood. Insulin produced by the pancreas lowers blood glucose. Absence or insufficient production of insulin causes diabetes (Stoppler., 2012). According to Stoppler (2012), there are three main types of diabetes and these include Type 1 diabetes which is an auto-immune disease where the body's immune system attacks the insulin-producing cells of the pancreas. People with Type 1 diabetes cannot produce insulin and require lifelong insulin injections for survival. The disease can occur at any age, although it mostly occurs in children and young adults. Type 1 diabetes is sometimes referred to as juvenile onset diabetes or insulin-dependent diabetes. Type 2 diabetes is associated with hereditary factors and lifestyle risk factors including poor diet, insufficient physical activity, and overweight or obesity. People with Type 2 diabetes may be able to manage their condition through lifestyle changes; however, diabetes medications or insulin injections may also be required to control blood sugar levels. Type 2 diabetes occurs mostly in people aged over 40 years old, though the disease is also becoming increasingly

prevalent in younger age groups (Shaw *et al*., 2011). The third type is gestational diabetes which occurs during pregnancy. The condition usually disappears once the baby is born, though a history of gestational diabetes increases a woman's risk of developing Type 2 diabetes later on in life. The condition may be managed through adopting healthy dietary and exercise habits, although diabetes medication, including insulin, may also be required to manage blood sugar levels.

The global prevalence of diabetes was estimated to be at 6.4% as of 2010 and it was estimated to be 3.8% in Africa in the same year (Shaw *et al*., 2011). According to Diabetes Research Institute Foundation (2016), diabetes afflicts more than 380 million people. It is the leading cause of blindness, kidney failure, amputations, heart failure and stroke. The global annual health expenditure for diabetes in the year 2010 was estimated to be USD 376.0 billion and this is expected to rise up to USD 490 billion in the next 5 years. However, the African region only spends U$1.4 billion for diabetes, or 0.4% of the global total (Zhang *et al*., 2010). The number of people suffering from Diabetes mellitus in Zambia was estimated at 70,000 in 2000. This number is expected to increase to 186, 000 by 2030 (MoH, 2008). About 75% of diabetes cases are diabetes Type2 (Mandal, 2014). The mortality rates due to diabetes occur in low and middle-income countries were about 80% of global deaths occur (WHO report, 2013). In Lusaka alone, the combined prevalence for impaired glucose level or diabetes is 4.4% (Senkwe *et al.*, 2011). The cost of managing diabetes in Zambia was about USD 51.05 per month (Azevedo *et al.*, 2008).

Currently, most of the diabetes control activities in Zambia are done by the Diabetes Association of Zambia (DAZ), whose main activities are to:

- Develop educational activities aimed at giving health workers and persons with diabetes mellitus an understanding of the condition.
- Promote among medical personnel and others the free exchange of knowledge about diabetes mellitus in order to improve standards of treatment of diabetes mellitus in the country.
- Disseminate current and accurate information on diabetes mellitus.
- Educate the public on the importance of early recognition of diabetes mellitus.

- Promote and assist in research related to diabetes mellitus by individuals, hospitals, clinics, universities and other research institutions and organisations.
- Promote activities and services that will enhance the welfare of persons having diabetes mellitus.
- To train health workers in the management of diabetes mellitus.

(Source: Diabetes Association of Zambia, 2014)

Successful management of diabetes requires collaboration between diabetic patients, their health care providers, family and community (Weller *et al.*, 2012). The findings of sociological research into lay health beliefs which focus on discovering the rules and meanings that different social groups use to order their lives and make sense of their experience of health and illness have been of great value to clinicians (Bryant, 2002). Such findings demonstrate the sophistication and complexity of lay's beliefs about health, and point to the need for health professionals not to treat patients' views as merely 'incorrect knowledge' and so improve the patient-professional relationship. Ordinary people develop explanatory theories to account for their material, social and bodily circumstances. Specifically, explanatory models (EM) of illness refer to people's beliefs about the etiology of an illness, its course, the timing of symptoms, the meaning of sickness, its diagnosis, and methods of treatment (Kleinman *et al*., 1978). These they apply to themselves as individuals, but in developing them they draw on all sorts of knowledge and wisdom, some of it derived from their own experience, while some, handed on by word of mouth and other parts of it derived from highly trained practitioners. Thus, lay explanations go beyond common sense, in that explanations beyond the immediately obvious are included. Health care providers and patients often possess different EMs of the etiology, onset, and progression of a given disease (Bryant, 2002).

Concordance between the EMs of patients and their health care providers has been shown to positively impact on patient outcomes. Discordant views may result in misunderstandings, conflict, poor adherence to medical recommendations, or other negative outcomes (Taylor *et al*, 2013). Because where disease only is treated, care will be less satisfactory and less clinically effective than where both disease and illness are treated together (Kleinman *et al.*,2006). Therefore, this study aimed at eliciting the patients' explanatory models of diabetes at the

University Teaching Hospital (UTH) in Lusaka so as to contribute to the baseline information in creating concordance between the EMs of patients and that of the health care providers in Zambia.

Many studies have been conducted using Kleinman's Explanatory Model (1987) to explore patients' beliefs about diabetes and adherence to their prescribed regime (Cohen *et al*., 1994, Weller, 2012, Clark., 2005, Nambi *et al*., 2006). These studies have contributed to the knowledge of lay beliefs of diabetes and the need to have concordance between the EMs of patients and those of the health care providers. However, little is known about whether Zambian patients' explanatory models of diabetes are different from what has been found in previous research as the various researche that has been done on the subject has been done outside Zambia. No studies had applied Kleinman's Explanatory Model regarding diabetes among patients at UTH. Studies that have used the explanatory models, (other than this study) demonstrated that the patients had explanatory models of diabetes that differ from the traditional biomedical model (Cohen *et al*.,1994, Weller., 2012, Clark., 2005, Nambi *et al*., 2006). The use of explanatory models allows clinicians to improve the quality of care. It also helps health researchers understand their subjects, and this could help in the design of appropriate therapies or interventions and can explain why some people reject medication or refuse to comply with a prescribed therapy.

1.1 Statement of the Problem

Diabetes is expected to increase in Zambia from the estimated 70, 000 cases in the year 2000 to 186, 000 cases by the year 2030. However, there are still knowledge gaps regarding diabetes in Zambia. Patient's perceptions of the etiology of an illness, its course, the timing of symptoms, the meaning of the sickness, its diagnosis, and methods of treatment often differ from the professionals' perceptions and this result in poor patients' disease control and treatment outcome (Weller *et al*., 2012). Non-adherence to medication which is as a result of disease perception and lifestyle regimes in diabetes is associated with increased hospitalisations and mortality, yet many patients fail to adhere to treatment recommendations (Broadbent *et al*., 2011). According to Broadbent *et al*., (2011), illness perceptions have been associated with adherence to diet and exercise recommendations, blood glucose monitoring, clinic attendance, and blood glucose levels. For this reason, it is important to study the patient's perceptions of diabetes in a Zambian

context as there has been no study done to understand the patients' perception of the etiology, course, the timing of symptoms and methods of treatment of diabetes.

1.2 Study Justification and Significance

Although similar studies as this one have been done in other parts of the world, little is known about patients' explanatory models of diabetes in the Zambian context. This study elicited the explanatory models of diabetes among outpatients at the UTH in Lusaka. Specifically, patients' beliefs regarding the meaning, causes, symptoms, prevention and treatment of diabetes were elicited. Asking patients about their beliefs may provide medical practitioners with an opportunity to address poor adherence to self-care which often results to poor glycemic control Otekeiwebia *et al*. (2015). This study was necessary as it contributes to the knowledge that may aid the development of culturally appropriate treatment plans, behavioural and educational interventions targeted at developing diabetes policies.

1.3 Research Questions and Objectives

1.3.0 Research Question

Based on the literature review, statement of the problem and the guide from Kleinman's (1978) explanatory model, this study was designed to answer the question:

What are the patients' perspectives of diabetes?

1.3.1 General Objective

To understand the patients' explanatory models of diabetes at the University Teaching Hospital in Lusaka.

1.3.2 Specific Objectives

In this study, Kleinman's (1980) concept of explanatory models was applied in order to achieve the following objectives:

1. To find out lay's causal theories of diabetes.
2. To explore lay's signs and symptoms of diabetes.
3. To understand the patients' perspectives on treatment and prevention of diabetes.
4. To find out the patients' experience of living with diabetes.

CHAPTER 2

LITERATURE REVIEW

2.0 Introduction

This section discusses the explanatory model and different studies that are similar to this study and in which the explanatory model has been used..

2.1 Explanatory Model

An explanatory model reveals how people make sense of their illness and their experiences of it. Explanatory models are often used to explain how people view their illness in terms of how it happens, what causes it, how it affects them, and what will make them feel better. Explanatory models are used in both clinical and community research as a way of obtaining individual explanations of a particular phenomenon (Kleinman *et al.,* 1978).

Explanatory models are elicited through a series of specific open-ended questions. The first model was devised by Kleinman *et al*., (1978), and contains eight questions described below. Kleinman *et al*., (1978) came up with these questions in an attempt to distinguish between disease and illness, and to bridge the gap between clinical knowledge and constructions of clinical reality.

Explanatory models could be used alone in qualitative research or with other techniques such as life histories, key-informant interviews, participant observations, focus groups and pile sorting. In medical and research settings, explanatory models provide clinicians and health researchers with an idea of how patients experience and interpret their conditions. This method helps clinicians to improve the quality of care. It also helps health researchers to understand their subjects, and this could help in designing of appropriate therapies or interventions, or explain why some people reject medication or refuse to comply with a prescribed therapy (Weller, 2012).

Explanatory models can be administered either as a qualitative interview or through a structured questionnaire. Kleinman's model contains eight questions which are as follows:

•What do you think has caused your problems?

•Why do you think it started when it did?

•What do you think your sickness does to you?

•How severe is your sickness? Will it have a long or short course?

•What kind of treatment do you think you should receive?

•What are the most important results you hope to receive from this treatment?

•What are the chief problems your sickness has caused for you?

•What do you fear most about your sickness?

Explanatory models have advantages in that they are able to "integrate clinical, epidemiological and social science frameworks" by improving the depth of scientific understanding of disease and illness. The major advantage of this method is that it allows researchers and clinicians to draw illness experiences from their participants in a structured way. Results of these interviews can be used to complement or reinforce quantitative data, providing researchers with lived illness experiences that would otherwise be overshadowed by numbers and statistics. Textual data derived from explanatory model interviews can either stand on their own in research or be used as a way to form hypotheses for further studies. They can also be paired with other qualitative techniques and complement quantitative findings to flesh out hypotheses. Explanatory models are flexible and applicable in many scenarios, such as studying violence in Iceland, HIV-related stigma among South Asians in Canada, or understanding hypertension and sick roles among Americans.

However, explanatory models can be limiting in several ways. Researchers have shown that the demographic background of an interviewer, such as ethnicity, may influence a respondent's answers. When working in international or non-English-speaking settings, researchers often have to deal with the translation of the questions and answers, and this could be a tedious and difficult process. Also, there is need for more research on comparing illness explanatory frameworks so as to understand or reconcile how illness is perceived and experienced among different groups, an important factor when trying to understand treatment-seeking behaviour. Some critics also argue that the use of the approach in clinical settings assumes the primacy of the biomedical perspective and that effort to reconcile the doctor-patient models of an illness result in the alignment of the patient's views with that of the doctor. Also, the usefulness of explanatory

models is limited if the interviewer is just focused on the diagnosis or introducing treatment or solution (Blue., 2012).

2.2 Lay Health Beliefs

The concepts of lay-health beliefs were reviewed from some of the literature available on the subject. Lay-health beliefs (LHB) refer to beliefs held by individuals about health illness and diseases. LHBs are not simply diluted versions of medical knowledge; rather they are shaped by people's wider milieux such as their structural location, cultural context, personal biography and social identity.

2.3 Biomedical Perspectives of Diabetes Causality

The professional or biomedical model reports that high prevalence of excessive body weight, high blood pressure, and hyperlipidemia are risk factors for diabetes mellitus (Izadi *et al*, 2013). According to Baliunas, 2009, several factors increase the risk of diabetes, some of these factors include being overweight, lack of physical activity, and family history of diabetes. There is a growing consensus that alcohol consumption is an influencing factor. The biological mechanism of its influence is uncertain but there are several factors that may explain the relationship which includes, increases in insulin sensitivity after moderate alcohol consumption, changes in levels of alcohol metabolites, increases in HDL (high-density lipoprotein) cholesterol concentrations, or via the anti-inflammatory effect of alcohol. Being overweight has come out common between the two studies done by Izadi *et al*., 2013 and Baliunas *et al*., 2009.

2.4 Lay Perspectives of Diabetes Causality

Walter, 2000 wrote that persons with a family history of a common chronic disease develop a personal sense of vulnerability that is informed by the salience of their family history and interpreted within their personal models of disease causation and inheritance. Features that give meaning to familial risk may be perceived differently by patients and professionals (Walter *et al.*, 2000). The findings from a Cameroonian study by Kiawi *et al*., 2006 showed that most participants had heard of diabetes but had limited knowledge of its risk factors or how it is acquired. Among those who claimed knowledge of diabetes, the most common beliefs about cause were that it is acquired through genetic inheritance; through birth from mother to child; or

most commonly, through lifestyles that involve high consumption of sugar and sugar-related products. Some believed that diabetes could be transmitted sexually (Kiawi *et al*., 2006). This causality knowledge was different from the biomedical knowledge except on lifestyle risk factor to diabetes. The biomedical perspective also puts emphasis on a healthy diet to avoid diabetes. The lay perspectives must not be viewed as mere misconceptions, but must be considered as striking a balance between lay people and professional knowledge for successful health promotion practice.

In another study done in Bangladeshi by Middleton, 2012) participants believed sugar and a Western diet were the cause of their diabetes. Often they cited physical or psychological stress as causes. Some of them believed they acquired it during a visit to Bangladeshi. A lot of similarities are seen in the knowledge of diabetes causality among lay people in different studies discussed above.

2.5 Biomedical Perspectives of Prevention and Treatment of Diabetes

Preventing Type 2 diabetes involves avoiding the risk factors such as being overweight or lack of physical activity. There is growing consensus that excessive alcohol consumption is an influencing factor that must be avoided (Izadi *et al*., 2013).

According to the biomedical perspectives, the major goal in treating Type 2 diabetes is to control blood sugar (glucose) levels within the normal range, with minimal excursions to low or high level. When weight reduction, a diabetic diet, and exercise fails to be effective in controlling the blood sugar, oral medications are prescribed to a patient with Type 2 diabetes in order to control the elevated blood sugars of Type 2 diabetes. If oral medication becomes ineffective, treatment with insulin is initiated. The examples for possible treatments for Type 2 diabetes include Metformin (Glucophage, Glumetza, others). Generally, metformin is the first medication prescribed for Type 2 diabetes. Other medicines include Sulfonylureas, Meglitinides, Thiazolidinediones, DPP-4 inhibitors, GLP-1 receptor agonists and SGLT2 inhibitors. Insulin was used as a last resort but today because of its benefit, it is prescribed as soon as Type2 of the disease is discovered in a patient (Mayo clinic staff., 2016).

2.6 Lay Perspectives of Prevention and Treatment of Diabetes

In a similar study which was done in urban Cameroon, a qualitative approach was used employing in-depth interviews. In this study, participants were purposively selected from four sites to achieve a mix of sexes, age groups, educational levels, and socioeconomic positions. Health personnel were excluded because their views were likely to be informed by their training and practice. The study was done in four communities with participants being of above 15 years and lived in the community for more than 6 months. Approximately, 15 interviews were anticipated per site, though recruitment ceased when no additional themes emerged from interviews. Findings were that most participants believed that since diabetes is caused by excessive sugar consumption, the logical way to prevent it was to reduce sugar intake. Some believed that high blood sugar (diabetes) could be neutralised by drinking very bitter herbal liquids. Informants stated that some community members used this as a reason for drinking beer which has a bitter taste to help control or reduce the chance of developing diabetes. Some participants thought that people with diabetes should consume honey in the place of sugar as it did not raise blood sugar (Kiawi *et al*., 2006). A study carried out in Bangladesh by Middleton, (2012), found similar results. Eating bitter gourd was believed to achieve better control of diabetes in Bangladesh (Middleton *et al.*, 2012).

A study done in Pakistan by Zuhaid *et al*., 2012, concluded that the level of education is a significant predictor of optimum knowledge and perceptions of risk factors, symptoms, complications and prevention of diabetes. In this study, a recommendation was made that creating awareness among masses through health education will help in controlling diabetes by promoting screening, early diagnosis, and initiation of effective treatment resulting in preventing diabetes-associated complications and disabilities. The taking in of bitter substances has come out significantly between these two communities. This study will provide the answer as to whether Zambians also believe in taking bitter substances as a way of treating diabetes and this will add to the understanding of the direction that the diabetes treatment messages should take considering the information that the Zambian patients have.

2.7 Difference between Patients and Biomedical Models

The majority of the studies have shown that the explanatory models of the patients and the biomedical explanatory models differ (Weller *et al*., 2012; Zuhaid *et al*., 2012, Middleton *et al*., 2012; Kiawi *et al*., 2006). Education levels and class differences may play an important role in patients' understanding and the gap in patient's provider understanding (Weller *et al*., 2012). These studies were done in different study sites and by different people and have different perspectives on the patients' and the professionals' explanatory models. However, a study done in Zambia in which explanatory model was used found no difference between patients and professionals explanatory models. This study was focusing on mental illness, hence the need to explore the patients' explanatory models of diabetes in Zambia.

2.8 Importance of Understanding the Patients Explanatory Models of Diabetes

A number of writers and researchers, including Kleinman *et al*., (1980) have highlighted the importance of understanding the patients' explanatory models of disease. Bokhour *et al*.,2012), found out that encouraging patients to discuss their EMs can enhance clinician understanding of patients' lived experience of hypertension and subsequent self-management behaviours. They also found that some patients expressed EMs which were inconsistent with biomedical knowledge leading to poor self-management. In these instances, providers should acknowledge these differences and tailor their intervention to accommodate those beliefs. Similar to Bokhour *et al*., (2012), Kandula., (2013) stated that understanding patient's explanatory models gives a critical insight into what is most important to the patient, what the patient believes about health and illness and what they think will help them better. Kandula also added that the patients cannot be counseled to change their diet as a control measure for their disease or to take medication unless they understand their illness and how it should be treated. Once that is understood, discussions can be made with the patient in the language that both the patient and professional understand. If the goal is to improve health care quality and outcomes, clinical care must be guided by the meeting of the doctor's expertise and what matters most for the patient.

2.9 Theoretical Framework

The definition of the term explanatory model of illness underscores the non-universal nature of the manner in which illness is defined and experienced, bringing to bear the thesis that illness is a

socially constructed experience and not solely the result of purely biological factors Lechuga (2015). Studies on this topic began with the seminal work of medical anthropologist Arthur Kleinman. The term "explanatory model of illness" attempts to capture the idea that factors outside of the individual, such as culture, influence the way illness is conceptualised and experienced. Studies have shown that healthcare providers and patients often possess different EMs of the etiology, onset, and progression of a given disease (Bryant.,2002). Kleinman (1978) argues that patients and healthcare providers have distinct sets of explanatory models and that the discrepancies between these lay people and professional models can lead to conflict and affect treatment outcomes. In order to harmonise the EMs of the healthcare providers and those of patients, studying and understanding the patients' EMs of their illnesses is very vital (Weller *et al*., 2012).

This study employed kleinman's explanatory model of 1978 to understand lay causal theories of diabetes, explore lay signs and symptoms of diabetes, understand the patients' perspectives on treatment and prevention of diabetes and to find out the patients' experience of living with diabetes. This model is very useful in this study as it attempts to answer cause, time and mode of onset, nature of the pathology, severity and course of sickness and treatment.

Despite the limitations of this model, it was used in this study as a guide because most studies which have used it have produced similar results which suggest that this model is consistent. Thorough consultations regarding the translations of the questions into local languages were made to minimise the limitation of the model. Additional questions to the ones given in this model were used to achieve all the objectives of this study. This model helped in understanding the local health beliefs related to diabetes. This knowledge contributes to the information which may be helpful in the formulation of diabetes health promotion strategies that are informed by both lay and professional perspectives of disease and illness.

CHAPTER THREE
METHODOLOGY

3.0 Study Site and Population

The study was done at the University Teaching Hospitals' Clinic 5 in Lusaka. This hospital was purposefully selected because it serves many people from all over Zambia as it is a referral hospital. Purposive sampling is a form of non-probability sampling in which decisions concerning the individuals to be included in the sample are taken by the researcher, based upon a variety of criteria which may include specialist knowledge of the research issue, or capacity and willingness to participate in the research (Boyce, 2006). This process made it possible for patients with different ages, educational background, and social economic status to be captured. The study population comprised of patients with confirmed diabetes and of ages 18 and above. This age group was chosen because the majority of the patients who visit Clinic 5 are above the age of 18 (UTH, Clinic 5 Record Book). The age group was also chosen because the patients who are above 18 are able to make consent for participating in the study on their own. The participants must have lived in Zambia for more than 10 years. It is assumed that an individual would have internalised the Zambian beliefs within that period if they had been out of the country.

3.1 Study Design

The study took a qualitative approach, and specifically a case study. A case study is an in-depth investigation of a single person, group event or community McLeod (2008). Case study method was chosen to be used in this study because case studies are responsible for the intensive study of a unit and they are a thorough and deep investigation and exploration of an event. . In-depth interviewing technique was used. In-depth interviewing is a qualitative research technique that involves conducting intensive individual interviews with a small number of respondents to explore their perspectives on a particular idea, program, or situation. In-depth interviews are useful when you want detailed information about a person's thoughts and behaviours or if you want to explore new issues in depth (Boyce, 2006). The primary advantage of in-depth interviews is that they provide much more detailed information than what is available through

other data collection methods, such as surveys. They may also provide a more relaxed atmosphere in which to collect information. According to Boyce, 2006 people may feel more comfortable having a conversation with you about their problem as opposed to filling out a survey.

3.2 Sampling and Sample Size

This study employed quota sampling technique in that participants were drawn according to different age groups and sex. In quota sampling, a population is first segmented into mutually exclusive sub-groups, just as in stratified sampling. Then judgment is used to select the subjects or units from each segment based on a specified proportion (Boyce, 2006).

Participants were purposively selected in order to capture individuals of different demographics that is age, sex, and education background. However, convenient sampling was also employed in that only those individuals who were able to give concert to be interviewed were interviewed. Data saturation was reached at interview 16, but the interviews continued up to 20 interviews for verification of the data saturation. According to Boyce, 2006, data saturation is the point at which no new information is being obtained and signifies when sampling should cease in qualitative research studies. Among the total number of 20 in-depth interviews conducted were 14 females and 6 males. The number of females interviewed was more than that of males because recruiting males was difficult as there was a small number of males with diabetes who were visiting the clinic during the study period. The number of participants who were less than 35 years of age was also small compared to that of those above the age of 35. This was also due to the small number of individuals who are less than 35 years with confirmed diabetes who visited the clinic during the study period. Fifteen of the interviews done were done at the hospital premises particularly, in the office of the registration clerks at Clinic 5. The other 6 interviews were done in the homes of the participants who were initially recruited at the hospital. The participants who had the interviews at home had a choice to do the interview at their own appropriate time and in their own homes.

The details of other demographic information for participants of this study have been summarised in Table 1.

Table 1: The Distribution of the Interviews Done in this Study

	Total Number of Participants
Sex	
Female	*14*
Male	*6*
Age	
Below 35	*3*
36-60	*10*
Above 60	*7*
Education	
No Education	*3*
Primary	*9*
Secondary	*4*
Tertiary	*4*
Occupation	
Un-Employed	*4*
Farmer	*1*
Civil Servant	*3*
Trader	*5*
Manual Worker	*2*
Retired	*5*

3.3 Data Collection

Data was collected by means of in-depth interviews over a period of one month. Each interview was guided by open-ended questions adopted from the Kleinmans' explanatory model (1978).

Follow-up questions were also used depending on the answers given by the participants in order to answer the research questions and meet the objectives of the study. Each interview took an average of 45-60 minutes and was recorded using a digital recorder. Patients were then asked a series of open-ended questions. The following are some of the questions;

1. Do you believe you have diabetes?

2. When did you first discover this illness?

3. What are the signs which you saw which pointed to you having diabetes?

4. Did you have prior information about diabetes before you were diagnosed with it?

5. What does this illness do to you? How does it affect your body?

6. What do you fear most about this illness?

7. Do you think this is a serious illness?

8. What do you think has caused this illness?

9. What are the major problems this illness has caused you?

10. What treatment is available for this illness?

11. What kind of treatment do you think you should receive? What are the most important results you expect from the treatment?

12. What do you think are the ways to prevent your illness?

Probes were used when needed to increase the richness and depth of responses, and give clues to the interviewee about the level of response that is desired (Tailor et al., 2013).

3.4 Data Management and Analysis

Manual data management and thematic analysis were employed in this study. Martyn (2010) states, thematic analyses are a historically conventional practice in qualitative research which involves searching through data to identify any recurrent pattern of ideas. According to Martyn, themes are a cluster of linked data categories conveying similar meanings and usually emerge

from the inductive analytic process which characterises the qualitative paradigm. The data management and analysis was done in seven stages in order to enhance the exploratory power of the thematic analysis.

In the first stage, the recorded interviews done in other languages other than English were translated into English and transcribed verbatim. The ones done in English were transcribed directly into texts and the texts were formatted so that the margin could be used for identifying individual bits of data. This was done by assigning line numbers as identifiers for cross-referencing. The second stage involved the initial reading of the text, re-reading of the text and the annotation of the thoughts which was made in the margin within the text script. During the re-reading, the information was assigned to the themes guided by Kleinman's model (1978) and De-graft et al.'s study in 2014. In the same process, open coding which identified new information by de-contextualising bits of data embedded within the primary material was done. The items of interest were then sorted into proto-themes in the third stage and in the fourth stage the proto-themes were examined and initial definitions were attempted. The fifth stage was the re-examination of the text carefully for relevant incidents of data for each proto-theme. The final form of each theme was constructed in stage six and finally, in stage seven, the themes were finalised and illustrated with quotations from the original text.

3.5 Ethical Considerations

3.5.1 Informed Consent

The study was explained to the participants and written informed consent was sought from the study participants before they took part in the study. In order to observe respect for autonomy, the participants were asked to choose the place where they were comfortable to hold the interview. Participants were free to withdraw from the interview at any point in the process in cases where they felt they were unable to continue with the interview. If unable to answer certain questions, they were free not to answer. It was clearly explained to them that whether they agreed or refused to take part in the study their treatment at the hospital was not in any way going to be affected.

None of the participants withdrew from the interview or declined to answer any question.

3.5.2 Confidentiality

In order to ensure participants' confidentiality, no names or personal identifiers were included in the recording and on written notes which were made to back up the recording. Identification of an informant was only done through numerical codes. The interviews were done in seclusion (only between the interviewer and the participants) to ensure confidentiality.

3.5.3 Risks

Since having a chronic disease such as diabetes affects the emotional and physical well-being of patients, many patients experience stress, anxiety, and depression during the course of their disease. In-depth discussion of their disease may, therefore, raise negative emotions in them. To address the possible risk in this study such as emotional breakdown (crying) during the interview and not finishing the interview, caution was taken by alerting and involving counselors from UTH Counseling Centre and the UTH Chapel for spiritual support, who were informed in advance about the study.

3.5.4 Benefits

All patients had an equal chance of being included in the study by interviewing any patient who arrived during the study period provided the patient had given consent. The participants were informed that they would not receive any direct physical, social and financial benefits from the study. The anticipated benefit is the emotional and spiritual support from UTH counseling Centre and UTH chapel. The other benefit is also that treatment and care may be improved after the patients' perspectives are taken into consideration. The participants were given the much needed biomedical diabetes information form or a leaflet at the end of the interview as a benefit. Usually when one is in a distressful condition, receiving emotional and spiritual support uplifts the emotions and give them hope. The information that the patients contributed to the study is of benefit to many other patients and of help to health professionals to contain diabetes effectively.

3.5.5 Ethical Clearance

Ethical clearance was sought from Excellency in Research Ethics and Science (ERES) with reference number 2014-May-037. Permission was also obtained from the Ministry of Health,

Lusaka District and UTH authorities, UTH management and the head of the department of UTH Clinic 5.

3.5.6 Results Dissemination

The results from this study will be disseminated as publication in peer-reviewed journal as a journal article online, full report to the University of Zambia, a summary report to Diabetes Council of Zambia, and as a summary report to the Ministry of Health. The participants will be given the information based on their request with respect to how well they will understand the findings of the study.

3.5.8 Disposal Plan

After all the collected data was analysed and thesis development completed, a time frame of three months passed after which all the tape recorded and the written data collected forms for the interviews were disposed of.

CHAPTER FOUR

RESULTS

4.0 Introduction

The results have been presented through five themes. These themes have been drawn from the specific objectives of the study which have also been informed by Kleinman's explanatory model and are as follows; diabetes causal theories; symptoms of diabetes; treatment and prevention and general experience of living with diabetes. The comparisons between the biomedical model and lay perspectives on causality and signs have been presented in tabular form.

4.1 Characteristics of the Participants

Participants with different characteristics were interviewed. Among them were both sexes and different age groups ranging from 33 to 72 years of age. With respect to occupation, more participants were in informal employment while others were retirees and the least were those in formal employment. Most participants in this study had a form of education although the majority had only gone up to the primary level of education. It was noted that the participants who were above the age of 60 years of age had more to say about the disease regardless of their educational background.

Participants perceived causes can be categorised into four; consumption causes; biological causes; psychological stress and; supernatural causes. Some participants mentioned more than one cause, while some could only mention one. It was evident that the causes mentioned were more of what the participants experienced than what they heard or learned from other sources of information. Despite the perceived causes, the majority of the participants indicated having no legitimate information about diabetes. The participants also indicated having no information on the causes of diabetes prior to being diagnosed with diabetes and even after the diagnosis they still did not get legitimate information on the causes of diabetes.

4.1.1 Consumption Causes

Consumption causes were identified as causes which are due to what humans consume intentionally through the mouth or as food. Consumption causes were dominantly mentioned among the participants and were mentioned by all the participants directly or indirectly. The consumption which emerged includes unhealthy diets and unhealthy eating habits. The difference between the males and females regarding consumption was noticed.

Unhealthy diets as mentioned by the participants meant consumption of food and drinks that are not good for health. Sweet food and drinks were sighted as unhealthy consumption according to the patients and were cited as some of the causes of diabetes.

> *This same thing of adding sugar to whatever food we are eating is what causes sugar disease. Even the same drinks that we buy have too much sugar in them* (Male, 35 years old, primary).

> *You know in my village sugar is a big deal. That is why most people from my village move to town. It is the taste of sugar we follow in town. We say, what is town for if you can't eat sugar? That same saying makes us eat sugar a lot and we end up with sugar disease. We really like sugar and that is why most people of my tribe develop sugar disease in most cases* (Female, 30 years old, primary).

The difference in the food preference by people of different sex can be seen here as having an impact on the perception that the participants have on the causes of diabetes. However, in most cases, men view sweet food like biscuits and many sweet drinks as being for women and not for men. For example, a 50-year-old male participant said,

> *I would have said what caused my disease is taking too much sugar, but no. I don't like sweet food or even drinks. You know us men don't like sweet food it is for women.* (Male, 50 years old, tertiary).

Another cause related to the consumption mentioned is beer drinking. Some participants mentioned beer drinking and all of them were men. The men who participated in this study associated drinking beer to their diabetes. For example, one 60-year-old man said;

> *That day I came from drinking and I just fainted. But when I gained conscious I knew something had gone wrong. I then decided to go to the clinic to have a check up and they found that my sugar levels were very high. I had no idea that I had diabetes until that day when I fainted* (Male, 68 years old, tertiary).

More women were interviewed in this study than men, however, none of the women associated beer drinking to sugar diseases. Another drink that was mentioned by men is a coca-cola. A 39 year old male participant who works as a trader used to drink a lot of coca-cola and he said that the acid in the coca-cola could have caused his diabetes.

> *I think it is coca-cola. You know I don't drink beer so I replaced it with coca-cola and am sure it is the one which caused my sugar disease. You know coca-cola has some acid so that same acid brings complications in the stomach and increases the sugar levels* (Male, 39 years old, primary).

Another cause related to unhealthy diets which emerged from some participants was taking in of too much oil. The taking in of too much oil meant eating the food which has a lot of oil such as meat or the addition of too much oil to the food.

> *When eating meat one needs to roast the meat properly so that you reduce on the fat in the meat. And for vegetables, you need to add very little oil because it is the oil which causes diabetes.* (Female, 56 years old, primary).

Unhealthy eating habits meant eating practices that are not good for health. One of the two unhealthy eating habits which according to the participants causes diabetes is taking in too much food than what the body requires. A 40-year-old female participant said;

> *The way we eat nowadays can cause sugar disease. We eat too much more than what is necessary. The way people are fed in the workshops, for example, too much food is given and you eat at every break time* (Female, 40 years old, tertiary).

Another unhealthy habit related to eating mentioned was physical inactivity. The participants who mentioned this practice brought out the idea that, for a proper digestion of the food eaten, one needs to be active after eating.

Laziness also causes sugar disease, because most of the time we like sleeping or sitting just lazing around instead of being active to allow smooth movement of food in the body (Female, 30 years, Primary).

4.1.2 Biological Cause

Biological causes were associated with the changes in the body or the natural body makeup. These causes included family history, age, and medical conditions which came out as obesity and goitre.

The participants who mentioned family history did not directly link it to their diabetes but just brought out the idea that family history also affects one's diabetes status.

I don't know why I even have diabetes when no one in my family has it. Because I hear it follows in families (Male, 33 years old, no education).

The knowledge of family history as a cause of diabetes indicated that the participants also had information from elsewhere for example, experiencing what had happened to others in addition to self-experience. One of the female participants who mentioned family history said she had feared diabetes because her elder sister had diabetes which made her develop a heart failure and instead died of a heart failure. She said, *"I fear this disease because my elder sister had it and she ended up developing a heart disease and died."*

On age as a cause of diabetes, most participants indicated that they learn from others that age is associated with diabetes. However, one of them cited that age caused his diabetes and he was very confident that it was expected to have diabetes at his age. A 71-year-old male participant narrated that,

Most people who have diabetes are of my age. So at my age I mean am 71 it is expected to have such diseases. At the moment it doesn't even worry me because I am not the only one who has diabetes at this age (Male,71 years old, tertiary).

There were also medical conditions that were cited by female participants as associated with diabetes. Two of the medical conditions which was cited were goitre and obesity. Regarding obesity, one female participant, a 27-year-old lady with a secondary level of education said that she used to be very fat when she was 18 and she thought that is what could have caused her

diabetes. She narrated; *"You know being too fat causes diabetes, me I used to be fat when I was 18. I was weighing 90 kg at that age."*

A 40-year-old female civil servant with a tertiary level of education explained that she heard that having a goitre causes diabetes because the goitre sucks out iodine from the blood. For her, the diabetes was caused by the goitre *"I was told that because I had a goitre my levels of iodine in the blood were always low because the goitre sucks iodine from the blood."* She explained.

4.1.3 Psychosocial Causes

Psychological stresses were cited as one of the causes. These include stress due to getting angry and depressed. Some participants explained that getting too stressed from time to time is dangerous and causes diabetes. The participants who attributed to psychosocial stress had a general narrative that those life stressors such us financial hardships and loss of loved ones had a part to play in the onset of diabetes. One female participant, a 46 years old married woman explained the issue of psychological stress as follows,

> *Especially for us women, our husbands upset us a lot. Mostly when they are cheating, that anger we get is so bad that it can cause diabetes. Every time a woman is upset, she cannot eat properly. All she can have is tea from time to time. So the sugar in the tea goes in the body and accumulates. This causes sugar disease* (Female, 46 years old, primary).

4.1.4 Supernatural Causes

The supernatural causes include causes which are beyond human understanding. Two supernatural causes emerged from the participants. The first one was the will of God and the second one was witchcraft. The participants who attributed the cause of their diabetes to the will of God said only God knows why they have diabetes and that it is God himself who placed the illness on them. The participants emphasised that God put the disease on them and that only God knows why they are sick.

> *I don't know why I have this same disease because even in my family I am the only one who has sugar disease. I guess it is the will of God himself. God himself who made me*

> *knows why this disease is on me and he knows when I will get well* (Female, 44 years old, primary).

In relation to the will of God, a male participant who is a manual worker said it was wise to involve God in his life as God is the one who permits diseases on his people, he narrated

> *I am not afraid of this disease because I know that it is the will of God. He is the one who can allow a disease on me if he wants too. Who am I? After all!* (Male, 41 years old, primary).

Witchcraft was indirectly mentioned by some of the participants as a cause of diabetes. The participants mostly associated their disease to witchcraft at the beginning of their illness. Most of the participants who mentioned witchcraft indicated that the first signs of the illness made them associate their diabetes to witchcraft. However, at the time of the interview, most of the participants had ruled out witchcraft as a source of their illness.

Three of the participants who had a suspicion of witchcraft at the beginning of their illness had a problem with legs at the beginning and because of that, they thought they were bewitched. One of the female participants stated,

> *I never used to sleep at night because I used to have a lot of pain in my legs used to pain. Sometimes I used to feel like someone was pounding on my legs or as if I had applied some chili on them. So I thought maybe a witch had set a trap for me and I stepped on the black magic medicine because mostly, witches set up traps to make people suffer from pain and even killed people that way* (Female, 56 years old, primary).

When probed about the association of the problems with the legs, participants indicated that in some Zambian communities having problems with or pain in the legs were associated with witchcraft. According to the participants, people who practice black magic pour some black medicine on the road for their targeted individual to step on and when that person steps on the medicine they develop problems with their legs and consequently this leads to other illnesses leading to death. For this reason, when a person's illness is accompanied by problems with the legs, some people think of witchcraft as being at play in their illness.

Nevertheless, some participants indicated that all illness may be engineered by witchcraft although they did not state that their diabetes was due to witchcraft. One of them narrated the issue of witchcraft as follows;

> *These days witchcraft is in all diseases. The witches are taking advantage of these same diseases which have no cure. They bewitch people and when a person goes to the hospital they say it is sugar disease or HIV or AIDS or even heart disease when in actual sense it is witchcraft. Have you not heard that the witches are using these diseases especially HIV or AIDS?* (Male, 50 years old, tertiary).

Pain in the legs made most of the participants attribute their illness to witchcraft. They said the problems with legs usually originate from witchcraft. One of the participants explained how she had several meetings with the pastor for prayers as she believed her illness was of the supernatural origin and so needed supernatural intervention. She stated,

> *My toes were feeling so numb, and my legs were getting hot and painful. I believed that it was the work of the devil. I thought I was bewitched. So I decided to go for prayers. The pastor used to pray for me and to apply some anointing oil on my legs. But there was no change, I decided to go to the hospital where I was found with diabetes. You know it is scarring when you have problems with the legs because you start suspecting that you have been bewitched.* (Female, 65 years old, primary).

4.2.0 Treatment

Treatment of diabetes was explored through the question, what treatment is available for your illness? The responses that came out can be divided into two categories, conventional and folk treatment.

The biomedical treatment meant the treatment which is given in hospitals and clinics. It is actual drugs or any medical advice given by medical practitioners. It is, therefore, sub-divided into two categories: medication and lifestyle advice. All the participants mentioned biomedical treatment as one of the available and reliable treatments available. Most participants argued that the biomedical treatment works better than the traditional treatment. One participant said he

heard that the herbal medicines work but he believed that the biomedical treatment is what works well for him.

> *I hear some herbs work, but I believe the best medicine is just the biomedical one. You know these herbalists most of the time they just talk but their medicines have not been tested to check how efficient they are* (Male 33 years old).

Regarding medication, all the participants said medication was the best treatment for them. The participants talked about medication in two ways that is tablets and injections. Most of the participants confirmed being on tablets while others were on injections. All the participants had the knowledge of both tablets and injections. However, one participant cautioned,

> *What I know is that there are injections and tablets, but you really have to take care of yourself because if you are not careful you may make things worse for yourself and you may start taking injections, and when you start taking injections that meant your sugar level has really advanced* (Male, 41 years old, primary).

Some of the participants wondered why some people with diabetes are on insulin injections while some are on tablets. They thought it was the doctor's preference to put the patient on tablets or insulin.

> *I am on injections. I told the doctor to put me on tablets but he insisted that I should be on these same injections. I think these injections are the ones which make me weak. I don't know why he insists that I should be on injections* (Female, 41 years old, primary).

However, one participant explained why some patients are on tablets while others are on injections.

> *There is no reasonable treatment for this illness. The only thing that is there is just taking medication in form of injections or tablets. If your sugar level is high they normally give injections and you have to start injecting yourself. If it is low they give tablets. But for me they only thing I take are tablets.* (Female, 68 years old, primary).

On lifestyle advice given to the patients by the medical practitioners, the participants said the common advice given to the patients is mostly on diet. The participants said following good diet

was very vital in the treatment of diabetes. Most of them emphasised that if the dietary advice is not achieved; the diabetic condition worsens and leads to death.

> *You have to really follow medical advice on good diet. Some people live very long with it if they are following very good diet strictly. Not where by one day you take good diet the other day you don't. Those who are not strict with their diet the way I am, don't even stay well; they are in and out of the hospital and some even die. There are no problems with sugar disease if you follow a good diet. Some people even come to me for advice on how to control sugar disease* (Male, 50 years old, primary).

As indicated above, folk treatment was also cited as one way to manage diabetes. Although most participants were not sure of how effective folk treatment was.

> *I have heard that these traditional healers give some treatment for diabetes. We even see the posters and fliers in town about traditional medicine but I don't like associating myself with the traditional healers they are demonic* (Female, 58 years old, primary).

The information that came out on traditional treatment of diabetes varied from participant to participant. The traditional treatment which came out varied from herbs to animal organs. Some participants mentioned the use of the animal organ which is taking the pancreas of the chicken.

> *They used to say that you have to take the pancreas of a chicken and drink it with water, it kills sugar in the body. I have drunk all that. But it doesn't work it is a lie. So the only thing that one has to do is to follow a good diet and take the medication* (Female, 69 years old, tertiary).

The herbal medicine which was mentioned was not clearly known by the participants. According to the participants, the people who give the traditional medicine hardly disclose the type of leaves or roots used and mostly the medicine is in powder form. One herbal medicine which was clearly mentioned by the participants is the *Moringa* leaves and ginger roots. A 43-year-old female participant said the *Moringa* leaves have been very common these days but she had no proof of its positive effect. "*These days the moringa leaves are getting common as a cure for diabetes but I haven't proved how good they are in curing diabetes."* She narrated.

Although the traditional medicine was mentioned, the participants said it does not work. All the participants who had tried taking the traditional medicine said it did not help them. Their expectation was healing but it did work. For example, one participant stated;

> *I have tried every bitter root I was told to drink but it did not work. Even in town people advertise these herbal medicines but it doesn't work. It doesn't heal. So the best is just the hospital. You get the tablets or the injections* (Male, 68 years old, tertiary).

4.3.0 Signs of Diabetes

One of the objectives was to learn the perceived signs and symptoms of diabetes. The signs of diabetes mentioned by the participants in order of the commonly mentioned included body weakness, thirsty which was being mentioned together with frequent urination in most cases, drowsiness, excessive appetite, weight loss, painin the legs, and constipation. Body weakness was the most common symptom mentioned. It was cited in two ways, that is the general weakness of the body and the weakness related to sexual activities. The general body weakness was mentioned by all the participants. The participants argued that the general body weakness included failure to be fully functional in physical work. This weakness was reported to be responsible for some of the participant's retrenchment and financial hardships due to less or non-productiveness.

> *I was feeling very weak, I couldn't even function well at work and I lost my job because my boss wanted someone very strong as my job involved manual work* (Male, 33 years old, no education).

On the other hand, the weakness related to sex was also brought out. Sexual weakness was said to be responsible for bringing other illness such as sexually transmitted infections in homes where the partners cannot stand the other partner's sexual weakness. The participants said some partners may not understand the sexual weakness of the other and might opt to go outside the marriage to satisfy their sexual desire. One 68 years old male said his manhood was weak and that he could not function in bed. He emotionally narrated

> *This disease has finished me. It has really reduced me. I no longer feel like a man because I am very weak and I can't function in bed. It is very depressing sometimes I feel*

like I don't exist because am ashamed of even talking about the disease to other people because they will definitely know that I am weak and can't function in bed (Male, 68 years old, tertiary).

Some women also indicated that they had lost their sexual feelings due to diabetes and that they rarely get to have sexual encounters with their partners. One of the women raised a concern and said she feels maybe her husband has found another sexual partner since she can no longer participate fully in sexual activities. She feared that this problem could be a source of other diseases like HIV and AIDS and other sexually transmitted infections because infidelity could come into their marriage.

I and my husband now just stay like sister and brother because I no longer have feelings. I no longer have strength to participate in the sexual encounter I used to have. I only hope he understands me. But my fear is that he might find someone else just to satisfy himself. You know such issues bring about HIV and AIDS that is my greatest worry (Female, 50 years old, secondary).

On the issue of thirsty for water as a symptom of diabetes, most participants argued that there was a tendency to take water frequently more than normal. It was the second commonly mentioned symptom by the participants. Almost all the participants who mentioned thirsty, coupled it with frequent urination. The participants viewed frequent urination as a big problem and an inconvenience because they could not move freely as they always ask for the toilet. Some of them said it caused them embarrassment as they could sometimes pass urine on themselves.

I just got surprised that I was drinking too much water from time to time and was going to the toilet from time to time to the point where I once urinated on myself and I was very embarrassed. It is very hard with such a condition to move out of home grounds. So I was always bound to the home vicinity for fear of asking for the toilet from time to time or worse still just urinating on myself (Female, 56 years old, primary).

Drowsiness was another sign and symptom which was mentioned by the participants. Drowsiness was described as getting drowsy at all times or more than what can be termed as normal drowsiness. The participants, who cited it as a sign of diabetes, cited it as a bad sign of diabetes.

> *I am a driver and you know driving requires concentration, but I used to feel very drowsy. Little did I know that it was because of diabetes. It was hard because I could not do my work very well. I used to fear that one day I may find myself in a head-on collision with another car* (Male, 39 years old, primary).

Drowsiness had also an economic impact on the participants because it made them less productive. The participants explained that a lot of time was wasted in sleeping and being slow at work due to drowsiness. The amount of work done over the time taken reduces and this, in turn, reduces the amount of income and individual produces over time.

> *I was ever late for work because I was sleeping too much. And when I went for work I was always very drowsy and tired. Most of the time I would sneak out of work to go and have a sleep just to rest. I was even threatened with dismissal from my job because I had become less active and less productive* (Female, 40 years old, tertiary).

Another sign and symptom mentioned was excessive hunger. Participants complained that it drained them of resources because they had to buy food all the time. The excess appetite was said to be difficult to handle because apart from buying different types of food, it had to be specific type of food.

> *I used to feel hungry within a short time after eating. So I needed food every time. I had to keep asking my children for money to buy food and specific food for that matter all the time* (Male, 71 years old, secondary).

Weight loss was another symptom which was cited by the participants. One of the participants mentioned having mistaken her illness for HIV and AIDS as she said she had no idea that diabetes could come with weight loss until she was diagnosed with it. One female participant explained this issue as follows:

> *I lost a lot of weight. I was not looking like this you would have been shocked had you seen me then. I was very skinny and I used to feel very light as if I can be blown off by the wind* (Female, 30 years, primary).

Some participants talked about complications with the legs as a sign of diabetes. These complications ranged from the pain in the legs, feeling hot in the legs, swelling legs and

numbness of the toes. The way the participants described the pain differed from one participant to another depending on how each one felt. Some of the participants had the combination of pain and swelling in the legs while for some the legs were paining but not swelling. One of them said the pain was a hot and pounding pain.

> *I never used to sleep especially at night, I used to feel pain in the legs as if someone is pounding my legs and sometimes as if I have applies chili on them but I just prayed to God to heal me.* (Female, 43 years, primary).

Lastly, numbness was also mentioned as a sign and symptom. One participant, a 30-year-old female said there is numbness in the legs when a person has diabetes. But in her case, she said only her toes were feeling numb. She narrated;

> *My toes started feeling numb. Even now they still fell numb. That is why I don't wear closed shoes anymore because I need air to be passing through my toes. So, feeling numb is also a sign for diabetes* (Female, 30 years, primary).

4.4 Treatment and Prevention

4.4.1 Treatment

Treatment of diabetes was explored with the question, what treatment is available for your illness? The responses that came out can be divided into two categories, conventional and traditional treatment.

The conventional treatment meant the treatment which is given in hospitals and clinics. It is the actual drugs or any medical advice from medical practitioners. It was, therefore, divided into two categories which were medication and lifestyle advice. All the participants mentioned conventional treatment as the most available and reliable treatment there is. The participants had a common narrative that the conventional treatment is what works better than the traditional treatment. One participant said

> *They used to say that you have to take the pancreas of a chicken and drink, it kills sugar in the body. I have drunk all that. But it didn't work it is a lie. So the only thing that one*

has to do is to follow a good diet and take the medication (Female, 45 years old, secondary).

Regarding medication, all the participants subscribed to medication as the best treatment for them. The participants talked about medication in two ways that is, tablets and injections. Sixteen participants confirmed being on tablets while the remaining participants were on injections. All the participants had the knowledge of both tablets and injections. For example, one participant said

You really have to care for yourself because if you are not careful you may make things worse for yourself and you might start taking injections. And when you start taking injections then your sugar has really advanced. (Male, 56 years old, tertiary).

Some of the participants exhibited a lack of knowledge as to why some people with diabetes are on insulin injections while some are on tablets. They thought it was the doctor's preference to put some on tablets and some on insulin. A male participant who was on injections said

I am on injections. I told this doctor to put me on tablets but he insisted that I should be on the same injections. I think the injections were the ones that made me weak. I didn't know why he insisted that I should be on injections. (Male, 68 years old, tertiary).

Some, however, had the knowledge of why they are on a particular type of treatment. One of the participants narrated;

There is no reasonable treatment for this illness. The only thing that is there is just drinking the medicine. They just give the medicine to drink. But if you are not lucky and your sugar disease gets worse, they give injections. You have to start injecting yourself. But me they only thing I take are tablets (Female, 45 years old, tertiary).

Lifestyle advice was said to be the advice given to the patients by the medical practitioners. The participants said the common advice given to the patients is mostly mainly on the diet. The participants said following a good diet was very vital in the treatment of diabetes. Most of them emphasised that if the medical advice given regarding what to eat and what not to eat is not followed, the diabetic condition worsens and leads to death. A participant narrated

You have to really follow medical advice on good diet. Some people live very long with it if they are following a very good diet strictly. Not one day you take good diet the other day you don't. Those who are not strict with their diet the way I am, don't even stay well the way I do. They are in and out of the hospital and some even die. If you are following good diet there are no problems with sugar disease. Some people even come to me for advice on how to control sugar disease. (Male, 47years, primary).

Traditional treatment was said to be all the medications and practices about diabetes which are not of biomedical origin. The participants had some knowledge of the traditional treatment but five participants of the nine who had knowledge of traditional treatment did not link it to themselves. They explained what they had heard from the community regarding traditional treatment of diabetes but declined having used it. For example, one participant said

I have heard that these traditional healers give some treatment for diabetes. We even see the posters and fliers in town about traditional medicine but I don't like associating myself with the traditional healers they are demonic. (Female, 65years, tertiary).

The information that came out on traditional treatment of diabetes varied from participant to participant. The traditional treatment which came out varied from herbs to animal organs. The herbal medicine which was mentioned was not clearly known by the participants. According to the participants, the people who gave the traditional medicine hardly disclose the type of leaves or roots used as they mostly made the medicine in powder form. The herbal medicine which was clearly mentioned by the participants is the moringa leaves and ginger roots. Two participants mentioned the use of the animal organ which is taking the pancreas of the chicken. Although the traditional medicine was mentioned, some of the participants said it does not work. All the four participants who had tried taking the traditional medicine said it did not help them. Their expectation was healing but it did not come. The participants said they still had hope that the traditional medicine could still work.

For example, one participant stated;

I have tried every bitter root I was told to drink but it did not work. Even in town, people advertise these herbal medicines but it doesn't work. It doesn't heal. So the best is just to go to the hospital. You get the tablets or the injections. (Male, 55 years old, tertiary).

The participants revealed that they were not free to discuss the issues of folk or traditional medicine with some people for fear of stigmatisation. The participants also said people viewed folk medicine as retrogressive and as such they could not open up about their beliefs in folk medicine.

> *"It is very difficult to accept that we mix this English medicine* (biomedical) *and our own* (folk or traditional) *because people take our own medicine as old fashioned and demonic or satanic. Even if most people still believe in this same traditional medicines they can't open up about it for fear of embarrassment"* (Female, 69 years old).

The participants also exhibited a strong belief that prayers to God can treat diabetes. The participants believed that God is capable of doing anything that man cannot do including the healing of diabetes. A 33-year-old male participant said

> *I know that if God so wishes, I can be cured of this disease* (diabetes). *That is why I keep praying because I know that by his power and help one day I will be well*. (Female 35years, no education).

4.4.2 Prevention

Three subthemes emerged on prevention of diabetes. These include; healthy diets, avoiding alcohol and emotions.

On prevention measures related to healthy diets, 16 participants said good diet was a prevention measure. Good diet was described as taking food with less sugar, carbohydrates, and oils. The participants also said eating natural food like vegetables and fruits also contributed to a good diet. Some participants mentioned avoiding being obese as a measure of prevention. Obesity is related to a healthy diet as it comes as a result of unhealthy eating habits.

> *We have been too careless with the way we eat in this country that is why we are having these diseases. We eat whatever we want. But to avoid these diseases we need to choose what to eat. Number one, we have to avoid too much sugar in our food and we have to eat natural foods. The problem is that people eat a lot of chicken and chips. So they are ending up getting fat and getting these diseases* (Male, 33 years old, no education).

Avoiding drinking alcohol was mentioned by the male participants only. The participants said alcohol brings a lot of complications in the human body. A 33-year-old male participant explained;

> *Alcohol is very bad even if we like it. It brings a lot of complications in the body because it reduces the immune system. That is why these days we are having a lot of diseases. It is because we are taking too much beer. Sometimes this same alcohol burns our liver and we become too weak to fight diseases and we end up with diseases like this one.*

The participants said avoiding emotions such as anger is one of the prevention measures for diabetes. The participants said one needs to stay calm in order to avoid diabetes.

> *I used to get easily angered. I even used to beat my children a lot when they anger me. And once angry the anger used to take time before I calm down. My BP used to get high and also my sugar when am angered. So anger is not good it can cause someone to have diabetes.* (Female, 46 years old, primary).

Other participants said diabetes was difficult to control. Among them, some of them stated that it is simply not preventable. Even after being probed, they still insisted that they didn't know. For example, regarding the difficulty in prevention, one of the participants said

> *With sugar disease, prevention is very difficult because it is not like these diseases where prevention is by washing hands like in the case of cholera or HIV and AIDS where they say you simply have to abstain or use protection. Sugar disease just comes. So really I don't know how to prevent it. I just can't be prevented* (Female, 69 years old, tertiary).

4.5.0 Experience of Living with Diabetes

The experiences of living with diabetes differed with the difference in the period each participant had lived with the disease. The experiences ranged from physical challenges, financial challenges, and social challenges.

4.5.1 Physical Challenges

The physical challenges were malfunctioning of body parts or pain in the body. The physical challenges ranged from body weakness, bad eyesight, and frequent urination. The major challenge under this subject was the weakness of the body. The participants who had lived with diabetes for more than two years said they had learned to deal with this body weakness and had devised ways of coping up with it. Meanwhile, those who had lived with it for less time complained of it bitterly and said it was hard to cope with the condition. Body weakness was said to be the reason for the financial hardships in some families where the affected is a bread winner.

> *My life is very hard now. I don't work as much as I used to in my farm. Even the crop yield from the time I got sick has been very low because I am weak and can't manage to work well now* (Female, 46 years old, primary).

Body weakness was also said to be a factor in marriages as it affected the sexual behaviour of partners. One female participant said she was unable to participate fully in sexual activity because her body was weak and as such she suspected that her husband could be having an affair outside their marriage which could bring in other diseases like HIV and AIDS and other sexually transmitted infections.

> *I have no feelings for my partner anymore; and even if I get involved with him I don't fully participate. I am weak with this disease* (Female, 43 years, primary).

Regarding body weakness with respect to sexuality, similar complaints were brought out by the males and the females. They complained that their partners could not enjoy conjugal relations with them anymore because they were weak. Some males added that this condition was very humiliating to them.

> *Sugar disease is a major challenge, especially in the house. I am not able to perform and I hope this issue will not bring much more complicated issues in my home especially that my wife is a young woman* (Male, 50 years old, tertiary).

Another physical challenge mentioned was bad eyesight. The problems which bad eyesight had brought as mentioned by three participants who mentioned bad eyesight are a failure to read and

write properly. The participants feared that it may lead to blindness which will be a major challenge as they would have to depend on others; for example a participant said his bad eyesight due to diabetes has caused him to be failing to read well and write. Copying with bad eyesight had brought challenges as he had to call someone to read for him and direct him when signing. For some, they said they had no major challenges with diabetes as they had not reached an advanced stage with it. They said they only had challenges with it before they started the treatment.

> *At the moment, it does not give me any problem but may be in future because I hear it reduces strength for men* (Male, 39 years old, primary).

Frequent urination was mentioned as a challenge which was due to the malfunctioning of the bladder. It was said to be a great challenge because it restricted the affected from moving freely in public places because of frequent urination and maybe passing the urine on themselves if the toilet is not near them. Participants said that long distance travel was a challenge, especially that most local transport systems have no toilets inside. Frequent urination was said to affect the long distance business people and in turn, affect their finances.

> *My sister, this disease really affected me. I used to go to Chipata to buy maize and groundnuts for resale so that distance from Lusaka to Chipata became hell for me. Because I kept asking the driver to stop the bus so that I go out to urinate until people in that bus got mad at me and started saying all sought of things. I was ashamed and from that time I stopped going there. I will only start when I get better* (Female, 58 years old, primary).

4.5.2 Financial Challenges

The financial challenges were uniform in all the participants with exception of two participants. The challenges were said to be that of purchase of food and drugs.

The purchase of food was an aspect which brought about financial challenges according to the participants. The participants said the specific diet required for diabetes is expensive in most cases. For example, the participants said buying brown bread which is better for their illness is more expensive than white bread. They also said they are forced to buy two different types of

food in their homes because they could not ask everyone in their homes to be eating the food recommended for them as it is said to be less tasty. This fact, therefore, brought an extra financial burden on the participants.

> *I am now forced to buy two bags of maize meal because my family does not like roller meal which is recommended for me. So I buy them breakfast meal and I buy myself roller meal. This is becoming expensive* (Male, 33 years old, no education).

The participants also had challenges buying the medication. They said most of the time when they go to the hospital they do not find the drugs and they are forced to buy the drugs with their money which is very expensive for them. Retrenchment and general less productivity were also another factor brought by diabetes which had a major financial impact on households. Most of the participants complained of failing to work well due to diabetes. For example, one of the participants who was a manual worker said he had been retrenched due to his body weakness which resulted from diabetes. He said he could no longer pay his children's school fees and life was very difficult for him and his family. Two participants subscribed to retrenchment due to diabetes. Another participant who is a trader said her business had gone down due to her sickness and this brought about financial challenges in her home.

> *I am unable to do my trading business because I am not as strong as I used to be. This illness has really affected me negatively and now I have financial problems at home. You know with these rented houses we stay in, it's difficult to even explain to the landlord about the situation am faced with because I would be thrown out of the house if it is known that my working is not stable at the moment* (Female, 58 years old, primary).

4.6 Comparisons of the Results between Males and Females

The difference in the responses between the male and the female participants' were noted in the causal theories were only males mentioned the drinking of beer as a cause of diabetes. The following table summarises the results with respect to sex. , Only females mentioned obesity goitre loss of weight and pain in the legs as causes and signs of diabetes while the rest of the signs were similar between the two sexes. All the treatment theories were similar between the two sexes while prevention had a difference with the females adding the reduction of temper as a prevention method.

Table 2: Summary of Participant's Theories with Respect to Sex

Theory	Females	Males
Causes	Sugar Anger God Age Witchcraft Family history Goitre Obesity	Sugar Anger God Age Witchcraft Family history Beer drinking
Signs and symptoms	Body weakness Thirsty/Frequent urination Excessive appetite Dizziness Drowsiness Pain in legs Weight loss	Body weakness Thirsty/Frequent urination Excessive appetite Dizziness Drowsiness
Treatment	Injections Faith in God Tablets Traditional medicine	Injections Faith in God Tablets Traditional medicine
Prevention	Good diet Reduce obesity Reduce temper Do not know	Good diet Avoiding beer drinking Do not know

4.4.3 Social Challenges

The social challenges as a result of diabetes were cited as lack of enjoyment at social and spiritual gatherings because of consumption restrictions. The other social challenge mentioned is that of visiting the toilet frequently for urination as it caused them embarrassment. One of the participants narrated

Going to church had become very hard for me. I always spend the whole time getting up to go the toilet for urination. Now I feel embarrassed and stay back home. I am even worried that the church members would forget me and would not help me if am faced with a problem or even when I die they would not come for my funeral. All this was because of this same sugar disease (Female, 56 years old, primary).

CHAPTER 5

DISCUSSION OF THE FINDINGS

5.0 Introduction

The study aimed at understanding the patients' explanatory models of diabetes at the University Teaching Hospital. Therefore, this chapter generally provides an overview and discussion of results in comparison and contrast with other studies similar to this study on the four research specific objectives. The chapter also gave the significance and limitations of the study. This discussion is based on the following subthemes; Diabetes Causal Theories, Signs and Symptoms, Treatment and Prevention and Experience of Leaving with Diabetes.

5.1 Summary of Results

It was evident from this study that the patients' explanatory models of diabetes in the study area were mainly influenced by the patients' experience. The patients also drew their explanatory models of diabetes from the biomedical information and from other patients' experiences. The study also found that the patients had no information on diabetes prior to being diagnosed with the disease. It was also evident that there was very little information on diabetes in circulation among the patients and other lay people. In terms of causes and risk factors of diabetes, the patients formulated their models by assuming that particular practices could have been responsible for their disease. The challenge was the consolidation of their assumption. The theories on the signs were entire in.

5.1 Diabetes Causal Theories

The causal theories of diabetes have been presented as dietary, biological and supernatural causes. Another causal theory was related to psychosocial stress.

This study revealed that most of the causal theories were related to dietary practices. It was evident that the dietary causal theories were shaped by the biomedical theories drawn from the dietary advice by medical practitioners. The majority of the participants showed little knowledge

on the causes of diabetes as most of them advanced that they were not sure of what caused their disease but had little speculations. On biological causes which included family history and body parts defects, the participants indicated that their source of information on this cause was external rather than through experience. In this study, the patients' theories on psychosocial stress were drawn from experience and observation. These findings were in line with other similar studies which revealed that participants related the causes of diabetes to dietary practices, family history and psychosocial stress (Aikins *et al*., 2014 and Weller *et al*., 2012). These studies also revealed that some of the causes mentioned by the participants were in line with the biomedical models. However, this study went further to note the difference between the male and female participants' dietary causal theories which came out. Only male participants attributed their diabetes to beer drinking. This difference can be attributed to public conceptions of health and illness which vary according to the immediate material and social circumstances in which people find themselves in and that illness is seen as a consequence of the interaction of social factors particularly class, gender and ethnicity (Brown *et al*., 2006). WHO Global status report on alcohol and health, 2014 states that men drink more frequently and in large quantities than women and that the total burden of disease attributed to alcohol is 7.4% in men compared to 2.3% in women. This report shows that men were more exposed to alcohol than females. Therefore, the mention of beer drinking as a causal factor of diabetes in this study can be attributed to this fact. Regardless of these findings, Otekeiwebia *et al*., (2015) reported that there was no correlation between the components of the illness explanatory models and gender. This difference could be because of the difference in the geographical location of the study areas and different community setups and behaviours.

According to this study, although the participants mentioned witchcraft as one of the supernatural causes, they considered it as a mere act of superstition which they had prior to being diagnosed with diabetes. The study shows that the participants believed in the will of God as the final authority for their illness. These findings were in concordance with similar studies done in Africa by Aikins *et al*., (2014) which revealed similar findings in which participants attributed their cause of diabetes to supernatural causes such as witchcraft and the will of God. The findings of this study regarding the supernatural causes can be attributed to the recently increased beliefs in the supernatural power of God and teachings of Christianity in Zambia. This study established that the mention of witchcraft was as a result of accurate knowledge of diabetes.

This study reviews that there is a similarity between the biomedical and the patient's theories of diabetes causality although the causes mentioned by the participants were not comprehensive. These findings are not in isolation with the findings of the studies by Clark, (2005) and Otekeiwebia *et al*., (2015) which showed that the causal theories of the patients were similar to the biomedical theories although the patients had no authentic sources of information.

The following table summarises the comparison between biomedical and lay causal theories.

Table 3: Comparison of Biomedical and Lay Causal Theories of Diabetes

Biomedical Theory	***Lay Theory***
Physical inactivity	
Family history	*Family history*
Age	*Age*
Psychosocial stress	*Psychosocial stress*
Unhealthy diets	*Unhealthy diets*
Obesity	*Obesity*
-	*Supernatural causes*
Ethnic background	
High blood pressure	
Gestational diabetes	
Impaired glucose syndrome	
Insulin resistance	
Exposure to certain	
Drugs and viruses	

Overall, the implication of these findings indicated that there were limited deliberate measures to inform people about the causes of diabetes. Despite information being the most powerful tool for self-management of disease, the diabetes patients at the University Teaching Hospital did not benefit from the information, education and communication materials. The patients' explanatory

models of the cause of diabetes are not grounded and the patients await authentic (biomedical information) information on which to ground their explanatory models.

5.2 Signs and Symptoms

The participants advanced a number of signs of diabetes and these signs showed a similarity with the biomedical theory of diabetes signs. The study established that the participants derived the signs which included among them body weakness, thirsty, frequent urination, drowsiness, excessive appetite and weight loss from their experience through body-listening rather than knowledge from other sources. Body-listening or body monitoring involves 'knowing the body's unique responses and accurately predicting and interpreting these responses. These findings were not new, as a similar study which was conducted in West Africa reported that, "Subjective experience through the process of 'body-listening' shaped knowledge of diabetes symptoms and complications among the participants of the study" (Eikins *et al*., 2014). Furthermore, our study revealed that the participants took any ill feeling they had prior to being diagnosed with diabetes as a sign or symptom of diabetes. The participants indicated lack of knowledge on the signs and symptoms of diabetes prior to being diagnosed with the disease. This led to most of them delaying in seeking medical treatment as they kept debating on what their illness could be. This is similar to a study done by Terasso *et al*., (2005) who reviewed that most participants with diabetes never recognised the symptoms before diagnosis and were diagnosed when under care for another health problem.

Although the signs mentioned by the participants were similar to the biomedical signs, the study shows that the signs by the patients are not comprehensive. A similar study by Otekeiwebia *et al*. (2015) revealed similar results in which most of the signs mentioned by the participants (Thirsty, excessive hunger, frequent urination, body weakness, weight loss) were similar to the biomedical models but were not comprehensive. The summary of comparisons between biomedical and lay theories of diabetes signs has been tabulated below.

Table 4: Comparison between Biomedical and Lay Theories of Diabetes Signs

Biomedical Signs	***Lay Signs***
Thirsty	*Thirsty*
Excessive hunger	*Excessive hunger*
Frequent urination	*Frequent urination*
Body weakness	*Body weakness*
Weight loss	*Weight loss*
Drowsiness	*Drowsiness*
Body pain	*Pain in the legs*
-	*Constipation*
Organ damage	
Dizziness	*Dizziness*
Numbness	*Numbness*
Tingling in hands and feet	-

Our study findings indicate that inability to recognise symptoms of diabetes was a major barrier to early detection and diagnosis of diabetes. The study also shows similar indications as in the causal theories where there are limited deliberate measures to inform people on various aspects of diabetes.

5.3 Treatment and Prevention

Our study established that the participants use both traditional and conventional medicine. The participants identified conventional treatment as the authentic measure of treating diabetes. The study further revealed that although the patients in the study area believed in the presence of traditional or folk medicine for diabetes, they have no knowledge of how it works in treating their disease but had beliefs in the treatment efficacy of the folk medicine. These findings are not in isolation with the findings of other similar studies. For example, a study done in the Caribbean established that a variety of non-prescribed medicines predominantly folk medicines were used as a means of self-care in treating diabetes (Moss, M.C., and McDowell, J.R.,2005). Our study also established that the participants had strong beliefs in God healing their disease.

The participants advanced that without God, even the conventional medicine they take cannot work in treating diabetes. According to the participants, God was the basis of all treatment remedies. Similarly, the previously mentioned study reported that a strong religious influence formed a basis of diabetes treatment and offered some symptom relief and therefore, treatment satisfaction through spiritual revelations about remedies. The study established that the patients are not free to share the information on their beliefs in folk medicine as most of them admitted not being free to discuss the issue of traditional and folk medicine for fear of stigmatisation and stereotyping. The participants advanced an increase in the promotion of conventional medicine in preference for folk medicine which has led to the perception of folk medicine as retrogressive. They also mentioned that there is an increase in the Christian teaching which has also made folk medicine seem demonic.

With regard to the prevention of diabetes, the study revealed that there was a knowledge gap among the patients on how to prevent diabetes. The study also established that the participants were lacking a legitimate source of information on how to prevent diabetes regardless of them mentioning some of the preventive measures which are similar to the biomedical models of diabetes prevention. The participants drew their knowledge of diabetes prevention from their logic based on their causal theories. Similar to this study, a study done in Bangladesh by Middleton *et al*., (2012) found that most participants believed that since diabetes is caused by excessive sugar consumption, the logical way to prevent it was to reduce sugar intake. These findings imply that since there is a knowledge gap in the patients on how to prevent diabetes, there is room for some biomedical counter theories to be developed. This may pose a challenge to the prevention of new cases of diabetes as information from the patients also filters to the communities.

5.4 Experience of Living with Diabetes

This study showed that experience of living with diabetes differs with the difference in the period that each participant had lived with the disease. The participants who had lived with the disease for longer periods had more experience and knowledge on various aspects of diabetes. The participants expressed knowledge that the longer they stay with the disease, the more likely they were to develop diabetes complications such as loss of eyesight. However, the participants showed confidence in good personal disease management to prevent major diabetes

complications such as organ failure. Otekeiwebia *et al*. (2015) also report that patients with longer duration of illness viewed diabetes as a disease with serious consequences and were found to be more likely to have understood the course of their illness.

The participants' advice that reduced sexual desire and manly weakness caused by diabetes may cause the increase in the spread of other sexually transmitted diseases like HIV/AIDS as the unaffected (without diabetes) partner may opt to seek sexual satisfaction from alternative partners resulting in multiple-partner relationships. The study also established that reduced working ability due to diabetes effects brought less income in homes and this translated into many other challenges such as poor diet and school drop-out children. If the breadwinner is affected, the entire family gets affected negatively. The research also revealed that purchasing recommended diet and drugs for diabetes was a challenge for some participants and caused financial stress on families. It may also cause financial stress on the government as they will have to be spending money which could have been directed to other developmental programmess on diabetes treatment.

Overall, the study established that explanatory models of diabetes were similar among participants of different social demographic background except for the causal theory difference which was noted between the males and the females. This was similar to the study by Otekeiwebia *et al.* (2015) who reported that there was no significant correlation between components of the illness explanatory model and educational status, age or gender. However, some studies found that educational background and other demographic factors had an impact on the knowledge of diabetes among the patients (Weller *et al*., 2012, de-Graft *et al.*, 2015). These different findings among the studies could be due to the different geographical positions of the study areas and also due to different community factors among the study areas.

5.6 Limitations and Strengths of the Study

This study had limitations and strengths. The first limitation was that the study was focused on one institution - UTH, generalising findings of this study on other places that are far from UTH may not be possible. However, valuable information was generated concerning patients' explanatory models of diabetes in Zambia and in particular, UTH. Other limitations included;

the effect of age and sex between the interviewer and the participant. It was noted that the participants above the age of sixty were not opening up freely to the interviewer. According to the Zambian culture, certain topics are viewed as culturally inappropriate or as taboos to be discussed between people of a different age or sex. Owing to the same reason, some men were not comfortable to discuss some information with the female interviewer and as such, the details of certain information could have been left out. However, the interviewer was of Zambian origin and was preview to the culture and norms in the study and was able to use the language which presented the interviewees of the opposite sex with minimum comfort during the interview. Conducting a similar study with interviewee specific interviewers, targeting a particular sex or individuals of particular age groups would reveal some of the information which this study may have left out. Also, the number of males interviewed was less than that of females. Similarly, the number of patients below the age of 35 was less than that of those above that age of 35. This could have affected the conclusion on the explanatory models of diabetes among people of different sex and age groups. This study had a specific period in which data collection was done and in a specific institution. Broadening study area, study period and also applying other method which would ensure that patients with different demographics are captured in equal numbers would add to the information generated by this study. A study with a broader study area and study period is recommended.

This study only employed one form of data collection and was a purely qualitative study. A follow-up quantitative study with mixed data collection methods is also recommended to consolidate the findings of this study even further. In qualitative research approach, data analysis is by far the most time-consuming stage of the research process. The time lapse between data collection to the actual reporting of final data could have had an impact on the final study outcome, but the rigorous quality of mechanisation in data capturing and a close collaboration of the researcher with experienced research co-supervisor and supervisor guaranteed the reliability and validity of data analysis and the study findings.

5.5 Significance of the Study

The heterogeneity that exists across all cultural groups requires us not to overgeneralise results of the studies done on populations of one culture on others. It was, therefore, necessary to do this study in Zambia in order to apply the findings on Zambian settings. The findings of this study

complement other studies which have been done in the area of diabetes. This study also contributes to the development of concordance between the EMs of patients and their health providers which have been shown to have a positive impact on patient outcomes. Studies that have used the explanatory models demonstrated that the patients had explanatory models of diabetes that differ from the traditional biomedical model (Cohen *et al*., 1994; Weller., 2012; Clark., 2005; Nambi *et al.*, 2006). Therefore, this study contributes to the basic understanding of diabetes and health beliefs linked to the disease among urban residents in Zambia. Specifically, the findings contribute to highlighting the importance of understanding lay diabetes beliefs and demonstrate the importance of anthropological perspectives and in-depth qualitative research to complement the findings of quantitative epidemiologic research in informing the development and delivery of programmes to prevent and treat chronic diseases like diabetes, especially in Zambia, where outcomes are highly dependent on cultural variables.

Moreover, this study contributes to informing the development of meaningful health policy which requires accepting the validity of various forms of knowledge and developing frameworks that will see experts and lay individuals working together to develop and achieve public health and health promotion goals for diabetes. The findings also contribute to the information that DAZ has in order to understand why some patients do not adhere to lifestyle regimes or medication for diabetes. The study will also help inform the incorporation of the patients' explanatory models of diabetes into the control strategies in order to have further positive patient's outcome.

CHAPTER SIX

CONCLUSION

6.0 Conclusion

The findings of this study suggest that there are areas of similarities between the patients' explanatory models of diabetes and the biomedical models. The study also reveals that the areas of divergence of the patients' knowledge of diabetes may pose challenges to the patients' diabetes self-care, management and adherence to medication.

The study also showed that there is a knowledge gap among the patients regarding the cause or risk factors of diabetes, signs, and treatment. This study also established that there were limited deliberate measures to avail biomedical information on diabetes to the patients. It was revealed in this study that most of the diabetes patients seek medical attention late due to misinterpretation of the signs by the patients. This misinterpretation of the signs was found to be as a result of the patients' limited knowledge of the signs of diabetes. These findings emphasise that the areas of the patients' explanatory models of diabetes' divergence from the biomedical models can present a challenge to developing secondary interventions for diabetes. Therefore, medical interventions will require technical input from anthropological and psychological models of illness experience, in order to enhance understanding of the competing sociological and subjective theories that may undermine healthy self-care and diabetes management.

6.1 Recommendations

Information Dissemination

There is need for the responsible organisations to scale up the efforts to educate people on diabetes with a major concentration on risk factors and prevention of the risk factors. Failure to scale up the information dissemination meant that the information gap will translate into patients' explanatory models that will pose a challenge to the implementation of diabetes prevention and control strategies.

Integration

There was need for the health promoters to integrate the patients' views in policy making for diabetes. The study also recommends that the views of that lay people must be addressed when designing the Information, Education and Communication materials (IEC).

Capacity Building

There was need for government to build capacity for health workers so that they could know how to handle the patients' individual explanatory models in giving prescriptions.

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APPENDIX 1

Information Form

Title of study: The Patients' Explanatory models of Diabetes at the University Teaching Hospital in Lusaka.

Introduction: My name is Tamishe Mwauseya and I am working with [names of research Assistant and Counsellor]. To start with, I would like to extend greetings to you. I am a student at the University of Zambia in the Department of Public Health. I am carrying out this study as part of the requirement for the award of a Master of Public health. I am going to read to you a consent form that explains the research study you are being asked to join. Please, feel free to ask me any questions before you agree to join. You may also ask questions at any time after joining the study.

Purpose of the Study. To understand the patient's perspectives of diabetes mellitus (sugar disease)

Procedure: You are being asked to participate in this study because its people like you who can inform this study on the patient's views of diabetes. If you agree to participate in this study, you will be asked questions on diabetes. This exercise will take about 20 to 30 minutes. We will request that the discussion be recorded because we want to be able to refer back to the interview for accurate information. If you agree, we will proceed with the recording but you can stop us at any point during the interview. Only the people on our research team will have access to the recording. At the end of our study, we will return here and share with you what we have found.

Risks / Discomforts: There are no physical risks involved in this study. However, you may feel uncomfortable answering some of the questions, especially in the presence of other people. You may decline to answer any questions that you do not want to answer or questions that make you feel uncomfortable. Your responses or participation in this study will not affect you in any way or even your access to health care at the University Teaching Hospital or anywhere else.

Benefits: There are no financial benefits in participating in this study. However, you have a benefit of talking to the counselor concerning your disease after the interview at your own choice. The information you will contribute to this study will be very helpful to the successful treatment and control of diabetes not only to you but many other diabetes patients as well.

Alternatives to participation: You can either choose to be in the study or choose not to be in the study. If you choose to be in the study you do not have to stay in the study until it ends. You can decide to leave the study at any time and this will not affect you or any other privileges that you enjoy now. If you choose not to be in the study, you will still get the same health care

services at University Teaching Hospital or anywhere else and you will not be affected in any way.

Confidentiality: You are invited to take part in this study. If you agree to be in the study we will ask you some questions about diabetes and your experience of it. In order to make sure things are secret, your name will not be used in any recordings or notes taken. You will be assigned a study number so that it will not be possible to identify you individually. No one will know you by name in the study. Only people who are conducting this study will be able to get this information. Once we are finished with the study, all the audio recordings and other study information collected will be destroyed.

Voluntariness: Your taking part in this study is completely voluntary. You are free to withdraw at any time, for any reason. In the event that you decide to withdraw from the study, the information you have already provided will be kept in a confidential manner and will not be shared with anyone else to personally harm or affect you. This will not in any way affect you or you taking part in future or any other privileges.

Reimbursement: There is no financial reimbursement for participating in this study. However, transport refund and refreshments will be provided.

Contact: If you want to talk to anyone about this study because you think you have not been fairly treated, or you have any other questions about the study, you should call the Principal Investigator of the study, Tamishe Mwauseaya on +260979189133 or call the University of Zambia, Department of Public Health on Tel. +260-211-256181, or Fax +260-211-256181. The Study Principal Investigator or the Research Assistants will answer your questions.

If you agree to join the study, you will be given a signed copy of this consent form and a written summary of the study. Do you agree to join the interview?

Yes □___/ No□__ [Tick]

APPENDIX 2

Information Form (Nyanja)
Title: The Patients' Explanatory Models of Diabetes at the University Teaching Hospital in Lusaka.

Chiyambi: Dzina langa ndi Tamishe Mwauseya ndiponso ndili ndi (names of Research Assistant and Counsellor). Poyamba ndikupasani moni. Ine ndine mwana wasukulu pa University of Zambia. Nichita mapunzilo yoyangana pali shuga. Pochita aya mapunziro, ndiyenekera kufufuzako zinthu zina ndizotere pali matenda ya shuga kuchokera ku antu odwala matendaya. Ndizamiwerengerako mawu yomwe yakamba pali mafufuzo ya shuga yomwe ndikufunsani kuti mutengemo mbali. Chonde, unkale omasuka kundifunsa mafunso musanavomere kutengako mbali muli uku kufufuza. Ndiponso mungafunsenso mafunso nagakale muta lola kale kutengako mbali muli uku kufufuza.

Choringa cha punziro: Kuziwa mangaizo ya antu odwala matenda ya shuga pa zamatenda awo.

Ndondomeko: Ndinu opempempedwa kutengako mbali muli aya mapunziro chifukwa ndi antu onga inu amene tingapunzirileko zamaganizo a antu adwala shuga pa nkani ya shuga.Mukalola kutengako mbali mu mapunziroya, ndizakufunsaniko mafunso pa nkani ya shuga. Aya mafinso yazatenga maniniti yali 30 kufika napali 45 chabe. Tipempa ngati mungatilole kujambula mafunsowa kuti titenge mawu yazoona. Mukandilola ndizapityiliza kujambula koma mungandiletse pantawi iliyonse ngati mukumudwa nadzo. Omwe azakala ndi mpata owona mayanko anu ndiomwe tikuchita nawo mapuzilowa chabe. Koma pambuyo yamapuzilowa tizabweranso kuti tkuziwiseni zomwe tapezamo mumapunzilowa.

Ziopyezo: Kulibe chiopyezo chilichonse chingachitike patupi yanu mukatengako mbali mumapunzirowa. Koma mungapezeke kuti simukunvela kumasuka poyanka mafunso ene maka pa antu. Ngati zikatero, mulindiufulu wosayanka mafunsowo. Kuyanka mafunso kwanu olo kutengako mbali mumapunziro aya sikuzasokoneza landiro ya tandizo lanu pano pachipatala cha University Teaching Hospital ngakale kuchipatala kwina.

Zopedzamo: Kutenga mbali mumpuzirowa sikuzapasa malandiro yandalama ayi. Koma kutenga mbali mumapunzirowa kuzakupatsani mwayi wokamba ndi a kansela pazamatenda anu mukufuna kwainu noka. Ndiponso mawu yomwe muzapasa mumapunzirowa yazagwira nchito yaikulu kwambiri muzinchito zoteteza matenda yashugakwainu ndiponso kuodwala ena.

Sankulo potenga mbali mumapunziro: Muli ndiufulu osanka kutengako mbali mupapunzirowa olo yayi. Mukasanka kutenga mbali mungasankenso kusapitiliza ngakale titayamba kale mafunso. Mungatsanke kuchoka mupunziroli pantawi ina iliyonse ndiponso ichi sichizasokoneza tandizo yomwe mulandila pano pachipatala. Musanka kusatengako mbali mumapunzirowa, tandizo omwe mumatenga pano pachipatala si izasokonezekabe. Izakala chimodzimodzi chabe.

Kusunga mawu: Muka sanka kutenag mbali mumapunzirowa ndizakufunsani mafunso pa matenda yanu yashuga. Koma potsimikiza kuti mawu yomwe muzayanka yankale yobisika, sindizaika dzina pachipela chomwe ndizalembapo mayanko yanu ndizaikapo chame nambala. Ndizakupatsani nambala kuti mawu mayanko yanu siyazaziwika kuti yachoka kwaimwe. Kulibe munthu wina wamene azaziwa zamayanko anu koma amene ndikuchita nawo punziroyi. Pambuyo pamapuzirowa zomwe talembapo ndiponso marekodi yamawu tizayaononga.

Kuzipeleka: Kutenga mbali mumapunzirowa ndikodzipeleka inu noka chabe kosakakamidzidwa ayi. Mukasanka Kuchoka mumapunziro awa, mawo yomwe muzandipatsa yazasungidwa bwino muchisinsi. Ndiponso kuchoka mupuziro iyi sikuzasokoneza mwayi wanu wotengako mbali mumapunziro yena musogoro olo mwayi wanu wolandila tandizo.

Kutengana mbali mumapunzorowa sikuzakupatsani malipiro yandalama ayi koma muzapasidwa ndalama yokwerera ndiponso chakumwa.

Ngati mulindimafunso olo zina zokamba pamapunziro awa, mungatume foni Kuli a Tamishe Mwauseya pa 0979180133 olo ku University of Zambia, Department of Public Health pa +260-211-256181. Eni mapunzirowa olo otandizira azakuyankani.

Mukavomera kulowa mumapunziro awa muzapatsidwa chipepala chosaina . Kodi mwavomera kulowa mumapunzirowa?

Ndavomere_____ Sindinavomere_____ [Tick]

APPENDIX 3

Consent Form

I have read and have understood the information written in the information form and oral explanation has also been made to me. I voluntarily agree to participate in this study which is aimed at understanding the patient's views of sugar disease.

Name of participant ……...

Signature/Thumbprint of participant
or legally Authorized representative or ……..... Date…….

Signature of the person obtaining consent …….. ……Date
……

Signature of Witness to Consent Process ……. Date …….
(Must not be a member of study team)

IF THEY DECIDE NOT TO PARTICIPATE, THANK THEM STILL.

APPENDIX 4

Consent Form (Nyanja)

Ndawerega ndikutsimikiza mawu yomwe yali papepala la imformation form ndiponso nda nvesesa zomwe andifotokozela pamawuwa. Ndavomera kulowa mozipeleka mupapunzirowa yomwe yayangana pa maganizo ya antu odwala matenda ya shuga pa matenda awo.

Dzina_____

Signature/ thumbprint_____ Date_____

Signature of person obtaining consent_____ Date_____

Signature of witness to consent_____ Date_____
(Must not be a member of a study team)

IF THEY DECIDE NOT TO PARTICIPATE, THANK THEM STILL.

APPENDIX 5

In-depth Interview Guide

Greetings, my name is Tamishe Mwauseya and I am with [names of research Assistant and Counsellor]. Since you have agreed to participate in this study, I will ask you some questions concerning your experience of diabetes. Please feel free to talk to us. In case you are not able to answer some of the questions, I am going to ask you, you are free to say you are not able to. If you feel like withdrawing from the interview even after the interview has started you are also free to do so. In case you do not understand the question, you can stop me and ask for clarification at any time. Thank you for your time.

1. Do you believe that you have diabetes?

2. When did you first notice this illness?

3. What does this illness do to you? How does it affect your body?

4. What do you fear most about this illness?

5. Do you think this is a serious illness?

6. What do you think caused this illness?

7. What are the major problems this illness has caused you? Personally, in your home and at work?

8. What treatment is available for this illness?

9. What kind of treatment do you think you should receive? What are the most important results you expect from the treatment?

10. What do you think are the ways to prevent your illness?

Thank you very much for the information and you have given us and thank you for your patience.

APPENDIX 6

In- Depth interview Guide (Nyanja)

Choyamba ndikupasani moni. Dzina langa ndi Tamishe Mwauseya ndiponso ndili ndi (names of research assistant and councilor). Pomwe mwalola kutengako mbali muli uku kufufuza, ndizamifunsako mafunso pali zowe muziwa ndiponso zomwe munaziona pali matenda ya shuga. Ndipempa kuti munkale omasuka kukamba naine. Ngati muzalepera kuyanka mafunso yena yamene ndizakufunsani, muli naufulu okamba telo. Ndiponso ngati mwaona kuti simungapitilize kuyanka mafunso mulindiufulu wakundilesa kufunsa ngakale kuti tayamba kale mafunso. Mukankala kuti simunanvese ntantauzo yafunso mungandifunse kuti ndifotokoze bwino za funso yameneyo pantawi iliyonse. Dzikomo kwambiri pantawi yanu.

Tsopano ndiyamba mafunso,

1. Kodi ndinu okulupirira kuti muli na matenda ya shuga?

2. Nintawi iti yamene munawona aya matenda poyambilira?

3. Aya matenda yamachita chani kuli imwe? Yachita chani mutupi yanu?

4. Kodi nichani chamene muyopako maningi pali aya matenda ya shuga?

5. kodi aya matenda ya shuga nimatenda yolimba?

6. Mukuganizila kwanu, nichani chamene chinaleta aya matenda mutupi mwanu?

7. Nimavuto bwanji yamene matenda ya shuga yanaleta mumankalidwe yanu, panyumba olo mukusebenza kwanu?

8. Nimakwala bwanji yamene yaliko ya matenda ya shuga?

9. Mukuona kwanu nimunkwala bwanji olo tandizo bwanji yamene mufunikira kulandira? Ndiponso nichani chamene mungafune kuona pambuyo pamankwala olo tandizo Yamane iyi?

10. Kodi aya matenda ya shuga, yangatetezedwe munjira bwaji?

Dzikomo kwambiri pamawu yomwe mwatipasa ndiponso dzikomo pantawi yanu.

APPENDIX 7

Approval Letter