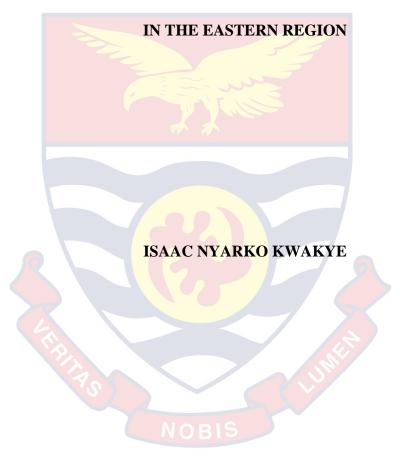
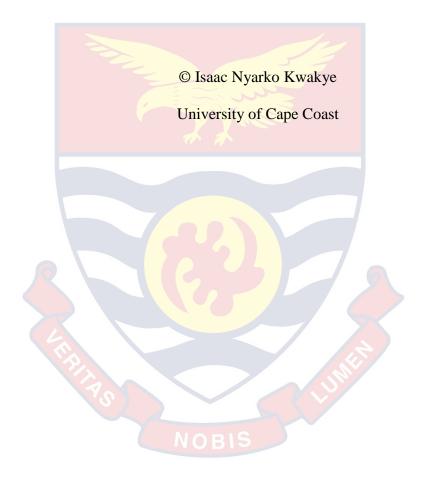
## UNIVERSITY OF CAPE COAST

# LIVED EXPERIENCES OF DIABETICS LIVING IN RURAL AREAS

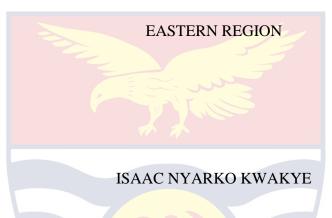


2020



### UNIVERSITY OF CAPE COAST

### LIVED EXPERIENCES OF DIABETICS LIVING IN RURAL AREAS IN THE



Thesis submitted to the Department of Health, Physical Education and Recreation,
Faculty of Science and Technology Education of the College of Education
Studies, University of Cape Coast, in partial fulfilment of the requirements for the award of Doctor of Philosophy degree in Health Promotion (Specialization)

NOBIS

November 2020

## **DECLARATION**

# **Candidate's Declaration**

I hereby declare that this thesis is the result of my own original research and that no part of it has been presented for another degree in this university or elsewhere.

Candidate's Signature	Date
Name: Isaac Nyarko Kwakye	
Supervisors' Declaration	
We hereby declare that the preparation and present supervised in accordance with the guidelines on supervise	
by the University of Cape Coast.	
THE THINK	_
Principal Supervisor's Signature.  Name: Professor Charles Domfeh	Date
Co-Supervisor's Signature	Date
Name: Dr. Thomas Hormenu	

#### **ABSTRACT**

Descriptive Phenomenology was used to explore the lived experiences of diabetic patients living in rural areas of the Eastern Region. Thirty-one diabetes patients were conveniently selected from four hospitals in the Region, and interviewed using semi-structured interview guide. Analysis of the interview data was done in line with Interpretative Phenomenological Analysis (IPA) approach. Themes generated were symptoms identification, initial lifestyle, patient's perception, and knowledge of diabetes; psycho-emotional reactions; accessibility to health care facilities, encounter with health care providers; effects of the disease, challenges of living with the disease; and management strategies. Patients identified the disease through symptoms experienced (frequent urination, sweet urine, weight loss, frequent thirst and hunger, foot sore) and regular check-ups. They acknowledged that the disease was contracted mainly through poor lifestyle. Patients perceived diabetes as dangerous, "disease of the rich", and often described it as "money will finish." Generally, patients had limited knowledge about diabetes. Patients' psychological and emotional needs were not adequately addressed at the hospitals. Patients experienced difficulty accessing health care and they complained of meeting different doctors on clinic days. Diabetes had a debilitating effect on patients and they were financially burdened. Despite these challenges, patients adhered to bio-medical treatment. Based on the experiences shared by patients, a 'stakeholder in diabetes care framework' is suggested to define the role of the various stakeholders in the care of diabetic patients in rural areas in Ghana.

# **KEY WORDS**

Eastern Region

Experiences

Patients

Type 1 Diabetes

Type 2 Diabetes

Rural Area

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# **DEDICATION**

To my dad (late Mannix Amoah Kwakye) and son (Mannix Nyarko Kwakye).



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### LIST OF ABBREVIATIONS

AIHW Australian Institute of Health and Welfare

BDI Buddy Doctor Initiative

BoP Base of the Pyramid

CDCP Centers for Disease Control and Prevention

CHD Coronary Heart Disease

CHPS Community Health Planning and Service

CHV Community Health Volunteers

CSM Common-Sense Model

CVD Cardiovascular Diseases

DM Diabetes Mellitus

DNA Deoxyribonucleic Acid

DPP-4 Dipeptidyl Peptidase 4

DSME Diabetes Self-Management Education

DUK Diabetes UK

ETS Environmental Tobacco Smoke

FBS Fasting Blood Sugar

GDA Ghana Diabetes Association

GDM Gestational Diabetes Mellitus

GHS Ghana Health Service

GHS-DHIMS Ghana Health Service - The District Health Information

Management System 2

GLP-1 Glucagon-like Peptide-1

GSS Ghana Statistical Service

GTT Glucose Tolerance Test

HbA1c Hemoglobin A1c

HBM Health Belief Model

HIV/AIDS Human Immunodeficiency Virus/ Acquired

Immuno-deficiency Syndrome

HPRBA Health Professions Regulatory Bodies Act

IDC International Diabetes Federation

IDDM Insulin Dependent Diabetes Mellitus

IGF Internally Generated Funds

IFAD International Fund for Agricultural Development

IPA Interpretative Phenomenological Analysis

(IV) Intravenous

KRHTS Kintampo Rural Health Training School

MOH Ministry of Health

NCD Non-Communicable Disease

NHIF National Health Insurance Fund

NHIS National Health Insurance Scheme

NHRC Navrongo Health Research Centre

NIDDM Non-Insulin Dependent Diabetes Mellitus

OECD Organisation for Economic Co-operation and Development

OGTT Oral Glucose Tolerance Test

PHC Primary Healthcare

PHCC Primary Health Care Centre

SGLT2 Sodium-Glucose Co-Transporter-2

SPM Shifting Perspective Model

SRMI Self-Regulatory Model of Illness

T1DM Type 1 Diabetes Mellitus

T2DM Type 2 Diabetes Mellitus

THs Teaching Hospitals

UNICEF United Nations International Children's Emergency Fund

VHW Village Health Workers

WHO World Health Organization

ΧV

#### CHAPTER ONE

#### INTRODUCTION

### **Background to the Study**

Diabetes is a chronic illness, very alarming and fastest-growing (Kadirvelu, Sadasivan, & Ng, 2012). It has been a global health problem causing disability, morbidity and death among population groups (Aikins, Owusu-Dabo & Agyemang, 2013). The World Health Organization [WHO] (2002) defines diabetes as a chronic disease caused by acquired or inherited deficiency in insulin production by the pancreas or ineffective use of the insulin produced. This definition shows that diabetes occurs as a result of lack of insulin and the presence of factors that oppose the action of insulin which brings about an increase in blood glucose levels. The disease is therefore characterized by elevated blood glucose levels that result from defects in the body's ability to make and/or use insulin (American Diabetes Association, 2012; International Diabetes Federation [IDF], 2019).

There are three main types of Diabetes Mellitus; Type 1 Diabetes (T1DM), Type 2 Diabetes (T2DM) and Gestational diabetes (IDF, 2019). Type 1 Diabetes occurs as a result of pancreatic beta cell destruction which leads to the body's inability to produce insulin (Hill, Gingras & Gucciardi, 2013) and this occurs mostly in children and adolescents (IDF, 2019). Type 2 diabetes occurs as a result of the body's inability to respond to or use insulin produced, a condition attributable to lifestyle changes (IDF, 2019). Type 2 ddiabetes develops when the pancreas does not produce enough insulin, or when the insulin produced is not

used properly. Type 2 diabetes accounts for the vast majority of people with diabetes around the world (Suresh, 2016). Gestational diabetes results from elevated blood glucose concentration during pregnancy (IDF, 2019). It is the degree of glucose intolerance which is first diagnosed during pregnancy (IDF, 2019).

Population growth is estimated to contribute to one third of all diabetes cases while age-specific prevalence contributes to an increase of 28% (IDF, 2017). Thirty two percent (32%) of diabetes cases are as a result of both population growth and age-specific factors (IDF, 2017). Qualitative studies conducted by Aikins et al. (2013) revealed that the causes of diabetes include heredity, high sugar diets, toxic foods, physiological imbalance and witchcraft or sorcery. However, the primary cause was viewed by the participants to be physiological imbalance and high sugar diets, suggesting that the most efficient means of treating diabetes is by the biomedicine approach.

People suffering from diabetes experience frequent urination, weight loss, slow healing of wounds, and excessive thirst (Nyarko, Kugbey, & Atindanbila, 2014). Other symptoms include "sweet" urine, impotence, and ulcers. Some complications like lack of blood circulation to the heart and limbs, physical and mental health problems might occur if the illness is not well managed (Darkwa, 2011). Stroke, amputation, neuropathy, nephropathy, hypertension and coronary heart diseases are the other complications of diabetes (Nyarko et al., 2014; WHO, 2019). A study by Hall, Thomsen, Henriksen and Lohse (2011) found a significant relationship between diabetes and life expectancy; diabetes reduces the

life expectancy of the individual. It also constitutes a major risk factor for some serious chronic conditions like stroke and coronary heart diseases (Aikins et al., 2013).

Diabetes has implications for social identities and social roles. Thus, loss of limb and sight changes the individual's identity and the roles assigned to them by the society (Aikins et al., 2013; Owiredu, Amidu, Alidu, Sarpong, & Gyasi-Sarpong, 2011). According to Owiredu et al. (2011), men suffer to manage their lost masculine identity when their sexual function is lost through complications and this affects their ego in the society. Some of the challenges experienced by people living with diabetes are psychosocial in nature. Thus, everyday experience of people with chronic illness lies on the psychological-social continuum (Aikins et al., 2013). That is, at one end, the individual deals with the psychological and emotional effects of the illness and, at the other end, lies the structural impact (access and cost) of living with long time illness. The person has to confront the socio-cultural challenges of the illness while the response by the social context determines the strength and weakness of social support received by the person with the illness. Leone, Coast, Narayanan, and Aikins (2012) found a significant link between diabetes experiences and, psychological and emotional distress (depression and anxiety).

Globally, the incidence and prevalence of diabetes has been rising over the years (Wild, Roglic, Green, Sicree, & King 2004). For example, in 2013, about 382 million people globally were affected by diabetes mellitus (Guariguata et al., 2014) and in 2014, 9% of adults aged 18 years and above worldwide had diabetes

mellitus (WHO, 2015). For decades now, estimates for diabetes have been on the rise (IDF, 2017). Diabetes is known to affect between two to five percent of the adult population in industrialized countries (van den Arend, Stolk, Krans, Grobbee, & Schrijvers, 2000). It is estimated that more than 75% of the global population will be living with diabetes by 2025 (Nyarko et al., 2014). Shaw, Sicree and Zimmet (2010) also confirmed that by 2030 the number of people living with diabetes is likely to increase significantly.

In Ghana, the major chronic non-communicable diseases (diabetes, stroke and hypertension) and their risk factors have increased and impacted significantly on the disease burden. The National Diabetes Association of Ghana reported that four million people are living with diabetes in Ghana and in future, this number is likely to increase (Gatimu, Milimo, & Sebastian, 2016). The diabetic population in Ghana is estimated to be between 3.3% and 6% with a steady increase among the adult population in the urban areas (Gatimu et al., 2016; Danquah et al., 2012; Saeed et al., 2013). These numbers indicate that most people are living with diabetes and its associated problems. This situation reflects similar trends in Africa where diabetes is reported to be one of the leading non-communicable diseases (Gatimu et al., 2016; Agyei-Mensah & Aikins, 2010; Danquah et al. 2012).

Ghana is experiencing a difficult task of 'double disease burden' and this suggests that Ghana must, at the same time, deal with the chronic disease and its associated acute communicable diseases (Kratzer, 2012). According to Hall et al. (2011), diabetes is a significant disease burden in Ghana, similar to other African

countries' diabetes profiles. Aikins et al. (2013) indicated that chronic diseases like diabetes and hypertension have been highly rated, and recognized in official health sector documents. However, recognition of both diseases has not been dully translated into practical actions, and this could consequently affect the quality of life of people living with diabetes. Steps have been taken to address and improve diabetes cases and this includes the management of diabetes patients and those with co-morbidities (Guantai et al., 2020).

Diabetes management is complex, and requires lifelong commitment, practical help, and support from family members in order to reduce the stresses of living with such chronic illness. Diabetes is a progressive chronic disease; however, diabetics can live long and enjoy better quality of life if they are to effectively and efficiently manage their condition. There is an urgent need to adopt a systematic management care which includes consistent review of metabolic control and complications, an updated diabetes care plan, and emphasis on access to patient-centred care which is facilitated by a multidisciplinary team of experts in diabetes care (IDF, 2017). In Ghana, people living with diabetes rely heavily on family members for social and limited financial support (Aikins et al., 2013). This is because living with chronic illness affects diabetics' social relationship with others (Aikins et al., 2013). Lack of knowledge by health professionals on chronic diseases (diabetes) also contributes to poor quality of care (Aikins, Anum, Agyemang, Addo & Ogedegbe, 2012).

Most African countries like Ghana rely heavily on pluralistic medical systems which include biomedical services, faith healing, ethnomedical services

and non-African complementary therapies (Aikins, 2005). Healer shopping refers to the "use of a second healer without referral from the first for a single episode of illness" (Aikins, 2005). Thus, it is the situation where a patient goes in for a second healer without referral from the first physician or healer. Most people patronize healer-shopping because of the high cost associated with biomedical treatment and psychosocial burden which affects people's readiness to actively or passively seek treatment for their illness (Aikins, 2005). Most individuals with chronic illnesses such as diabetes get to know of these pluralistic services from many sources including family members, friends, social networks, mass media, social and religious spaces and engagement with the systems themselves (Aikins et al., 2013). Faith healing endangers the life of the diabetes patient. Faith healing involves the use of deliverance, fasting and prayers. For example, fasting which has become a primary source of healing places the diabetic at risk of hypoglycaemia (Aikins et al., 2013).

Lack of team approach to diabetes and insufficient number of health professionals are a major setback to diabetes care (Aikins et al., 2013). Diabetes care in Ghana has suffered some challenges since formal policies on diabetes in Ghana are limited. There are few diabetes specialist hospitals in Ghana found within urban centres which provides services for the urban population, for examples, Korle Bu Teaching Hospital and Komfo Anokye Teaching Hospital. Even though the regional hospitals provide some special care, people from rural areas may often find it difficult accessing their services. Again, these regional hospitals often lack trained specialists to provide services (Mensah, 2008; Aikins,

Unwin, Agyemang, Allotey, Campbell, & Arhinful, 2010; Hall et al., 2011). In order for diabetics to manage their condition successfully, peers, family members and health care professionals must have a positive attitude towards individual diabetics (Burke & Dowling, 2007). Thus, a high degree of support is needed to enable the person achieve and maintain the best control for their illness.

However, there is poor management of diabetes in Ghana due to the fact that people have scanty knowledge about the causes and associated complications of diabetes (Aikins, Awuah, Pera, Mendez, & Ogedegbe, 2014). Again, poor health care and psychosocial support have been found to be barriers to diabetes management in Ghana (Aikins, 2005; Awah, Unwin, &, Phillinore, 2008; Kolling, Winkley, & von Deden, 2010). The management of diabetes could have great impact including excessive use of defense mechanism, isolation, loss of freedom, and co-dependency (Lindsay, Inverarity, & McDowell, 2011) on the individual. However, no studies have examined these impacts qualitatively.

George and Thomas (2010) examined the lived experiences of diabetes among older people in rural areas and found out that living with poorly controlled diabetes led participants to introspection and existential questioning. It is important to base education on and management of diabetes from the patients' insights and experiences. According to George and Thomas (2010), managing diabetes from the client's perspective is as important as solving problems that the patients encounter in self-regulation of their own regimen. Thus, it is important to understand realistically what the patients go through in managing their conditions as this will inform better treatment procedures for diabetic patients. Aikins et al.

(2013) noted that treatment of diabetes in Ghana is very expensive for people with both low and high incomes status. People with low-income struggle to cover cost for everyday management of diabetes, medical cost and prescribed health diets. It must be noted that the cost associated with care significantly influences the person's choice of health care.

The incidence of diabetes is higher among people living in the rural areas than among those in the urban centres; socio-economic life style and racial factors have been identified as risk factors (George & Thomas, 2010). Dabney and Gosschalk (2010) posited that rural individuals are often diagnosed earlier with the illness and they received sub-standard care compared to their counter-parts in the urban areas. This is often attributed to lack of trained specialists and cost associated with diabetes management. People in rural areas especially need quality care due to the fact that resources are limited in their part of the world, and self-care could be difficult because of lack of education, unavailability of glucose monitoring device as well as non-existence of diabetes programme for early detection and prevention (IDF, 2017). However, the experiences of diabetics living in the rural areas have been given little attention. Therefore, it is important for diabetes management to focus on the professional development of health workers thus helping develop guidelines necessary for people in the rural areas.

#### **Statement of the Problem**

Diabetes has become a global public health threat because of its prevalence in both developed and developing countries in the world (Osei-Yeboah et al, 2016). According to IDF report of 2016, 450 million people are living with

diabetes in the world and approximately 5.1 million people die from the disease every year. Globally, it is estimated that 146 million diabetic people were living in rural areas in 2017 and these figures were projected to increase to 279 million by 2045 (IDF, 2017). This global trend has similar implications on Africa. For example, in 2013, almost half of the number of people living with diabetes in Africa died of the condition (IDF, 2013).

In Ghana, diabetes is the cause of prolonged ill health as this has been identified in over four million of the Ghanaian population (Nyarko et al., 2014; Osei-Yeboah et al. 2016). It is alarming to note that the prevalence of diabetes mellitus in some parts of Ghana is even higher than the world average of 2.8%. Aikins and Ofori-Atta (2007) posited that diabetes threatens 50% of Ghanaians. In 2019, approximately 281 adults between the ages of 20-79 years were reported with diabetes in every 1000 individuals in Ghana. One thousand two hundred and nine (1,209) type 1 diabetes cases were found in children and adolescents between 0-19 years (IDF, 2019). In the said year, approximately 5,397 diabetes related deaths were recorded in the Ghanaian adult population, and the national prevalence and age adjusted comparative prevalence of adults' diabetics were 1.8% and 2.5% respectively (IDF, 2019).

Research on diabetes patients' experiences in Ghana is somehow limited, and it is often concentrated in the Brong Ahafo and Ashanti Regions (Aikins, 2005; Aikins et al., 2013; Bossman, Dare, Oduro, Baffour & Nally, 2020). Again, most of these studies concentrated on urban poor Ghanaian communities (Abanilla et al., 2011; Aikins et al., 2012; Awuah, Anarfi, Agyemang, Ogedebge

& Aikins, 2014; Aikins et al., 2014). Yet, people living in rural areas of Ghana find it difficult to access adequate health care due to factors such as financial constraints, inability to drive, poor road network, illiteracy which results in lack of information, mistrust as well as problems with communication.

Also, the population distribution pattern in the Eastern Region shows that 34.6% of the region's population lives in urban settlements while a greater percentage (65.4%) lives in rural communities (Ghana Statistical Service, GSS, 2013). The Eastern Regional Health Service Annual Performance Review revealed that there has been an increase in diabetes cases in the region (Ghana Health Service [GHS], 2017). The performance review showed that diabetes cases have increased from 31,887 in 2014 to 36,857 in 2015. These figures were reduced to 22,001 in 2016. However, there was an increase (23,689) again in 2017 (Ghana Health Service – dhims2, 2018). Rural people experience different illness profile compared to their counter parts in the urban areas (Lewis, 2004), and the beliefs, experiences, and cumulative health outcomes of rural people have received minimum attention in research as an aspect of chronic disease experience (Carruth, 2012).

Some studies concentrated on the lived experience of students with type 1 diabetes (Hill et al., 2013), type 2 diabetes (Aikins et al., 2013, 2014; Handley, Pullon, & Gifford, 2010; Hörnsten, 2004; Owusu, 2016), dietary preference (Doherty, Owusu-Dabo, Kantanka, Brawer, & Plumb, 2014), older adults (George & Thomas, 2010), and among adult Latinos (Cruz, 2014). It is important to gain knowledge and information on the experiences of diabetes patients in other rural

areas. This will help develop quality patient care and interventions in order to reduce the prevalence of diabetes and its associated complications. Again, a number of quantitative studies (Anderson & Christison-Lagay, 2008; DiMatteo, 2004) have been conducted on self-management issues without any major significant changes in the outcome. Therefore, since majority of the people in Eastern region lives in the rural areas, the situation has called for urgent concerns to investigate the lived experiences of diabetes patients, especially the greater percentage who has limited access to health care in the rural areas of the region.

## **Purpose of the Study**

The purpose of this research was to examine the lived experiences of people with diabetes living in rural areas in the Eastern Region of Ghana.

## **Research Questions**

The following research questions guided the conduct of the study:

- 1. What events led to the diagnosis of the disease?
- 2. What are the psycho-emotional experiences of patients after diagnosis?
- 3. What are the experiences of rural diabetics with health care system?
- 4. What are the challenges of living with diabetes in rural areas?
- 5. How do rural diabetics manage the disease?

### **Significance of the Study**

Understanding participants' experiences from their perspectives would help in the development of interventions to assist people with such chronic condition in the rural areas. Knowledge on the experiences of the diabetics living in the rural areas in Ghana will be an important step to develop strategies to

prevent complications and premature deaths. It is envisaged that the study would provide empirical evidence on and comprehensive analysis about people living with diabetes in rural areas of the Eastern Region of Ghana. Understanding their experiences from their perspectives would help identify the best practices for management of diabetes among rural dwellers. Knowing the experience of diabetic patients would help the individual, especially the one suffering from the condition, to voice what really goes on in mind that cannot be said to others but keep suffering in silence. This is because when the disease comes to stay for a long time, it is assumed that the sufferer may successfully manage the condition which may not necessarily be true. The diabetic patient is not a passive recipient of health care but has an active part to play in his/her own management of diabetes.

The use of phenomenology would help capture the meaning and common features of patients' experiences such as the revelation of what patients experienced and how they experienced it. The study would show that the issues relating to experiences of patients from rural areas could best be examined using phenomenology approach. It is envisaged that the method and technique adopted would contribute to the development and improvement in health care policy processes. It also highlights the fact that it can be used to enhance health care. Thus, the outcome of the research would help policy makers outline approaches towards policy development on diabetes in Ghana, and improve patient-centred health care specifically in the rural areas. In this wise, it would help develop a conceptual framework for an understanding of the management of diabetic

patients, especially in the rural settings. Through the interviews with the diabetic patients, they would be able to learn through questions and interactions how to manage and cope with diabetes. Most diabetics do not have the opportunity to ask pressing questions and get to the bottom of issues. After getting to know their experiences and delving deep into them, patients would understand the management of the disease on daily basis.

The diabetic patient needs help and support from both the family and the health care system in order to balance all those different aspects which influence the metabolic controls, such as the quantity and type of food to be taken, insulin to be administered and exercises to be done. Therefore, gaining insight into the experiences of diabetics would pave way for the family and health care systems to be involved in making the diabetic patient achieve the balance. Again, the findings would help develop family-tailored interventions that would help improve the diabetics' adherence to practices and health outcomes in general. Family members would be able to develop supportive relationships with their diabetic relatives in order to help them maintain adherence to dietary regimen. The study would help focus on patients' experiences of and insights into education on diabetes. The findings will help shape patients' perception about the illness, and provide insights into diabetes policy development. By outlining the importance of the experiences of diabetics, an informed dialogue will commence on how to improve diabetes care in Ghana from patients' perspectives. A phenomenological analysis of the various cases could help clarify the need, and engender potential for further studies in this area.

### **Delimitation of the Study**

This study was delimited to diabetes patients living in rural areas of the Eastern region. Only patients who have been diagnosed with the disease for more than six months were included in the study. Again, the study selected participants who have been diagnosed with any type of diabetes (type 1, type 2 or gestational diabetes). Also, the study selected participants who could communicate in a local language (Twi).

## **Limitations of the Study**

The use of Phenomenological limited the extent of generalizing the findings beyond the participants involved in the study. This is because the research aimed to gain an in-depth understanding and detailed description of participants' experiences and this did not allow for generalization covering the general population. Thus, the study aimed at exploring understanding within a relatively small well-defined sample and therefore caution must be exercised about generalizing the findings. Again, taking data from hospitals was a bit challenging as some patients were sometimes in a hurry to see the doctor and therefore had very limited time for the interview, and this could affect the detailed information that must have been derived from the interview. Additionally, patients might have modified aspect of their behaviour in response to the interview because of their awareness of been observed and the hospital premises they find themselves. Finally, interviews were conducted in a local language (Twi) and later translated into English language, and this could distort the meaning of some words and verbatim translation.

## **Definition of Terms**

**Diabetes Mellitus:** Diabetes Mellitus is "a heterogeneous group of disorder of carbohydrate, fat and protein metabolism characterized by chronic hyperglycaemia, degenerative vascular changes and neuropathy.

**Experiences:** This is an event or occurrence which leaves an impression on someone.

**Patient:** This is a person who has been registered to receive medical treatment at a hospital facility.

**Type 1 Diabetes:** is caused by an autoimmune reaction in which the body's immune system attacks the insulin-producing beta cells of the pancreas. As a result, the body produces very little or no insulin.

Type 2 Diabetes: Also known as Non-Insulin Dependent Diabetes Mellitus, occurs as a result of irregular physiological responses to insulin production and uptake, including insulin resistance at the level of the cell membrane.

Rural Area: Rural or village settings are seen as local territorial units dependent on agriculture and mining (Ghana Statistical Service, 2004).

Self-Management: The process through which individuals are actively involved in disease management.

## **Organisation of the Study**

The study was organised into five chapters. Chapter one considered the background to the study, statement of the problem, purpose, research questions, significance of the study, delimitation, limitations and definition of terms. Related literature concerning the study was reviewed under Chapter Two. Topics included

diabetes in Ghana, the rural conditions of Ghana, living with chronic illness, living with diabetes in Ghana, diabetes self-management and social support, and access to health care in the rural areas. Again, the theory (Health Belief Model, Shifting Perspective Model of Chronic Illness, and Leventhal's Self-regulatory Model of Illness Cognitions) underpinning this study was examined and a conceptual review was also presented. Finally, experiences of living with diabetes and factors influencing diabetes experience and personal expectation of diabetes experience were explored in this chapter.

Chapter Three dealt with the methodology. The research design, rationale for its selection, and the philosophical underpinnings of the research design were discussed. The chapter also highlighted the study area, population, sample and sampling techniques, data collection procedure and data collection instrument (interview guide). Furthermore, the chapter reported on how data was analysed and ethical issues considered for conducting the study. Reflexivity issues (bracketing) and my role as the researcher were dully examined in this chapter. Chapter Four described presentation of the results and discussion of the findings. Finally, chapter five reported the summary of the study, conclusions and recommendations from the findings to the health practitioner, care givers and policy makers.

#### CHAPTER TWO

#### LITERATURE REVIEW

The purpose of the study was to explore the lived experiences of diabetics living in the rural areas of Eastern Region of Ghana. The entire literature was organised under the following sub-headings: The Concept of Diabetes (Types, Prevalence); Rural Area; The Rural Conditions of Ghana; Rural and Urban Dynamics; Self-management of Diabetes and Social Support; Access to Health Care in the Rural Areas; Quality of Health Care Delivery; Structure and Composition of Ghana Health Service, Experiences of Living with Diabetes; and Leventhal's Self-Regulatory Model of Illness Cognitions (Leventhal, Nerenz, Steele, Baum, & Singer, 1984).

#### **Diabetes Mellitus**

Walsh and Crumbie (2007) define Diabetes as "a heterogeneous group of disorder of carbohydrate, fat and protein metabolism characterized by chronic hyperglycaemia, degenerative vascular changes and neuropathy" (p 557). According Iregbu and Iregbu (2016), "Diabetes is a chronic disease caused by a genetic or acquired deficiency in the production of insulin by the pancreas or the ineffective use of insulin by the body cells" (p. 5). Diabetes quickens deteriorating changes throughout the human body by widespread vascular changes in the large blood vessels and the microvessels. Kyriakidis, Ahrens and Benner (2016) define diabetes as a condition of the endocrine system that results in hyperglycaemia either from insulin resistance or lack of insulin production. Thus, diabetes is primarily caused by either inadequate secretion of insulin or inability of tissues to

respond to insulin (Seeley, Stephens, & Tate, 2000). It is the inability of the body to produce adequate insulin needed by the body to take up optimal glucose (Nyarko et al., 2014). It is a chronic disease caused by inherited and/or acquired deficiency in production of insulin by the pancreas, or by ineffectiveness of the insulin produced (WHO, 2002).

Diabetes is diagnosed when the patient has the symptoms of diabetes (such as polyuria, unexplained weight loss and excessive craving for water) and a random plasma glucose level ≥11.1 mmol/L. The term random refers to the fact that the blood sample taken at any time of the day regardless of the last meal (Walsh & Crumbie, 2007). A fasting plasma glucose ≥7.0 mmol/L (no food in the previous eight hours) in the presence of the classical symptoms is also diagnostic of diabetes. In the absence of the symptoms, Oral Glucose Tolerance Test (OGTT) is carried out to determine the patient's response to the ingestion of a precisely measured quantity of glucose.

Diabetes Mellitus is characterized by hyperglycemia, lack of protein, excess carbohydrate and slow metabolism of fat secondary to a relative or absolute lack of the insulin hormone. Cook-Huynh et al. (2012); Votey (2010) asserted that elevated blood glucose levels with fasting plasma glucose between 100 and 125 mg/dl or oral glucose tolerance test between 140 and 200 mg/dl characterize pre-diabetes mellitus. This indicates that if a person's glucose levels are greater than these figures then the person is deemed diagnosed of diabetes (Cook-Huynh et al., 2012). Diabetes could also lead to the damage of important body systems like nervous and the cardiovascular, because of insulin deficiencies

and irregularities which result in increased blood glucose concentration (Aikins et al., 2013). Individuals with diabetes experience frequent urination, slow healing of wounds, weight loss, and, when not well managed, consequently resulting in severe complications which include failure of blood circulation to the heart and limbs, severe physical and mental health challenges, and difficulty with adjusting to the experience of living with the disease (Nyarko et al., 2014). Also, the complications could be medical in terms of reduced life-expectancy, amputation, stroke, neuropathy, nephropathy, hypertension, skin lesion, impotence, musculoskeletal problems and coronary heart diseases (Barreto, Passos, Almeida, & Assis, 2007; Langat, 2011). On the other hand, these serious complications can be prevented or delayed if appropriately managed (IDF, 2017).

Diabetes is also a contributing factor for other several deadly non-communicable diseases such as renal and cardiovascular diseases (Brown, 2008) and communicable diseases such as tuberculosis, pneumonia and bacteraemia (Jeon & Murray, 2008; Thomsen et al., 2005). These conditions have negative effects on morbidity and mortality, prompting Hall et al., (2011) to note that diabetes must be given a considerable political attention and financial investment. Diabetes complications and their management could have a significant implication on the life of the sufferer. This includes extreme use of defense mechanisms, co-dependency, loss of freedom and feelings of isolation (Lindsay et al., 2011; Osei-Yeboah et al., 2016). Diabetes is counted among the most common chronic conditions both in developing countries and Europe (Cook-Huynh et al., 2012). Globally, diabetes is known to be the fourth leading cause of

deaths (IDF, 2007). The complications of diabetes are a greater public health problem than any other infectious disease, particularly as many of the patients who develop complications do so before their diabetes is even diagnosed.

### **Types of Diabetes**

There are three main types of diabetes with different aetiologies (IDF, 2017). These are Type 1 Diabetes, Type 2 Diabetes and Gestational Diabetes.

### Type 1 Diabetes

Type 1 Diabetes also known as Insulin Dependent Diabetes Mellitus is caused by the destruction of beta  $(\beta)$  cells in the islets of Langerhans (Walsh & Crumbie, 2007). The destruction is an auto-immune response associated with environmental and genetic factors. The auto-immune process is caused by a combination of environmental factors (chemicals and viruses), immune factors (autoimmune diseases) and genetic susceptibility. The destruction rate of beta cells varies from person to person. Thus, it is said to occur slowly in some individuals while others experience rapid destruction of the beta cells. Children often experience a rapid progressive form which may also be observed in adults. The slow progressive form also called Latent Autoimmune Diabetes in Adults is observed in adults (Boakye, 2015). Adults with the slow progressive form are not overweight and they have insulin sensitivity. A common characteristic of Type 1 Diabetes is the failure of the pancreas to produce insulin; it is mostly a disease of children and adolescents (Aikins et al., 2013).

The symptoms of Type 1 Diabetes include abnormal thirst and dry mouth, frequent urination, lack of energy, fatigue, constant hunger, sudden weight loss,

bedwetting and blurred vision (IDF, 2017). These symptoms provide evidence for the diagnoses of Type 1 Diabetes; however, additional tests may be required to distinguish Type 1 from Type 2. The onset of Type 1 Diabetes can be very rapid and it is usually acute with signs emerging over few days to weeks. According to Hörnsten (2004), 95% of Type 1 Diabetes persons develop the condition before age 25 with increased prevalence among white population and equal cases between males and females. Kratzer (2012) noted that Type 1 Diabetes Mellitus departs from Type 2 Diabetes in that Type 1 Diabetes diagnosis in children is often missed; it is not preventable, and in most cases, it needs a different approach of care. It often develops during periods of childhood and adolescence, and eventually affects the routine lifestyle of the diagnosed child and his/her family members (Kratzer, 2012). Thus, new responsibility of burden is placed on the children and their caregivers with eventual life and death consequences. IDF (2017) reported that it is difficult for people with Type 1 Diabetes to survive without insulin injection. This is because they need insulin injection on daily basis in order to maintain proper glucose levels. This shows that with constant blood glucose monitoring, appropriate daily insulin treatment, and intake of healthy diets and lifestyle, the Type 1 Diabetes patient is likely to avoid the associated complications and enjoy therefore a healthy life.

The treatment for Type 1 Diabetes is often costly, complex and time consuming; however, it is crucial to control the onset and progression of diabetes and its associated complications (Hill et al., 2013) such as neuropathy, blindness, cardiovascular and kidney diseases (Nathan et al., 2006). Ramchandani et al.

(2000) asserted that strictly following the complex treatment regimen and living with the condition can interfere with the patient's economic, social and emotional lifestyle that eventually can reduce the patient's quality of life. The rate of Type 1 Diabetes occurrence is increasing globally, but variations exist in some countries with some regions recording a higher incidence than others (You & Henneberg, 2016). The reason for this variation is unclear; however, Maahs, West, Lawrence and Mayer-Davis (2010) suspected the interaction between genetic and environmental factors to be the underlying reason.

### Type 2 Diabetes

Type 2 Diabetes, also known as Non-Insulin Dependent Diabetes Mellitus, occurs as a result of irregular physiological responses to insulin production and uptake, including insulin resistance at the level of the cell membrane (Aikins et al., 2013). According to Walsh and Crumbie (2007), the basic problem is that either there is increased peripheral resistance to the action of insulin or the islets of Langerhans gradually diminish their insulin output or there is a combination of decreased insulin secretion and increased insulin resistance. Thus, hyperglycaemia is the result of inadequate production of insulin and inability of the body to respond fully to insulin, defined as insulin resistance (IDF, 2017).

The beginning of Type 2 Diabetes is often slow, and patients could live with the condition for a couple of years before diagnoses. Type 2 Diabetes has psychological, social and health implications and it is the most common type of diabetes which accounts for majority (90%) of diabetes cases (WHO, 2016). Osei-Yeboah et al. (2016) also added that Type 2 Diabetes accounts for 85% to 95% of

diabetes cases in low-income countries (IDF, 2017). It is a disease that occurs among older adults; however, children, adolescents and young adults have increasingly reported the disease and this is often due to lack of physical activity, poor eating habits and nutrition, obesity and growth (IDF, 2017). Walsh and Crumbie (2007) asserted that the most common age bracket of onset of type 2 diabetes is 50-70 years during which genetic factors have strong influence. Due to this, certain ethnic groups and families are more susceptible to the disease than others. Additionally, past history of Gestational Diabetes Mellitus (GDM) and the exposure of the unborn child to high blood glucose and smoking have been identified as a significant adjustable risk factor. Furthermore, excessive consumption of sweets and beverages high in sugar content is also an associated risk factor (Imamura et al., 2015; InterAct Consortium, 2013; Malik et al., 2010). Hörnsten (2004) posits that the cause of Type 2 Diabetes is multifactorial with a substantial genetic component but the disease is also associated with environmental and life style changes. Other factors include inadequate intake of fruits, vegetables, whole grains and dietary fibre, and high intake of energy as saturated fat (IDF, 2017).

Type 2 Diabetes is characterized by slow healing of wounds, tiredness, repeated fungal infections, numbness in limbs, frequent urination and increased thirst. Type 2 Diabetes shares a similar symptom with Type 1 Diabetes. The obvious time for the development of Type 2 Diabetes is difficult to notice because of its normal appearance without acute metabolic disturbances as observed in Type 1 Diabetes. This consequently results in prolong pre-detection period, and

because Type 2 diabetes patients could live for years without exhibiting the symptoms; approximately between 30% and 50% of Type 2 Diabetes patients may not be diagnosed (IDF, 2017). Chronic hyperglycaemic complications could develop when type 2 diabetes is unrecognized for a long period of time. The first diagnosis of type 2 diabetes occurs when patients report hyperglycaemic complications like infections, renal failure, change in vision, or foot ulcer. Type 2 Diabetes is the cause of blindness, non-traumatic amputations, end-stage renal disease, heart complications (myocardial infection), stroke; it is the leading cause of death associated with diabetes (Centers for Disease Control and Prevention [CDCP], 2008; IDF, 2015). Poorly controlled high levels of blood glucose damage the blood vessels, the heart, kidneys, and eyes. High levels of blood glucose also cause some disabilities; the condition may lead to premature death (Iregbu & Iregbu, 2016). Infections, liver diseases, nervous system disorders and mental disorders are all associated with Type 2 Diabetes.

The key to the treatment of Type 2 Diabetes is healthy lifestyle which involves increased physical activity, healthy diet, no smoking and general healthy body weight maintenance. Oral medication is often used as a treatment measure when lifestyle modification to control blood glucose levels is inadequate. According to IDF (2017), Metformin has been the most common form of initial treatment globally. Currently, there are other combined alternative therapies for treatment if single anti-diabetic medication fails to work. This includes DPP-4 inhibitors, thiazolidinediones, SGLT2 inhibitors, acarbose, GLP-1 agonists, and sulphonylureas (IDF, 2017). In the event where oral hypoglycaemic medication

fails to control hyperglycaemia to the desirable level, insulin injection is resorted to. A person with Type 2 Diabetes is capable of living long and healthy if there are regular hospital visits, medication and good management of lifestyle. The prevalence of Type 2 Diabetes is high globally and it keeps rising. The rise in prevalence is attributed to economic development, aging population, increasing urbanization which has eventually led to sedentary lifestyles among people and over consumption of unhealthy foods linked with obesity (Basu, Yoffe, Hills, & Lustig, 2013).

# Gestational Diabetes Mellitus

Gestational Diabetes Mellitus (GDM) results from insulin resistance and glucose intolerance during pregnancy (Aikins et al., 2013). Pregnant women can develop gestational diabetes any time during pregnancy, but it mostly occurs during the second and third trimesters. Some women may be diagnosed during the first trimester but in such cases undiagnosed diabetes existed in the person before pregnancy. Guariguata et al. (2014) are of the view that between 75% - 90% of high blood glucose cases during pregnancy are gestational diabetes. GDM occurs when the hormone production by the placenta diminishes the activities of the insulin (insulin resistance) (WHO, 2013). Additional risk factors include overweight (obesity), extreme weight gain during pregnancy, rapid aging, history of stillbirth, family history of diabetes and giving birth to an infant with a congenital abnormality.

It is often difficult to differentiate between observable symptoms of hyperglycaemia in pregnancy and normal pregnancy symptoms. Due to this, it is

suggested that oral glucose tolerance test (OGTT) should be used to screen for gestational diabetes mellitus during 24th and 28th weeks of pregnancy (American Diabetes Association, 2003). However, in cases where the women are of a higher risk, earlier screening is recommended. An OGTT is performed by measuring the plasma glucose concentration while fasting and two hours after ingesting a drink containing 75 grams of glucose (IDF, 2017). It is a transient disorder during pregnancy and resolves at the end of pregnancy. Children born by mothers with GDM are at a greater risk of developing obesity and Type 2 Diabetes in their life time (Anna, van Der Ploeg, Cheung, Huxley, & Bauman, 2008; Bellamy, Casas, Hingorani & Williams, 2009; Fetita, Sobngwi, Serradas, Calvo, & Gautier, 2006). Again, it must be noted that hyperglycaemic pregnant women have a higher risk of developing GDM in their subsequent pregnancies and about 50% of women with history of GDM are likely to develop T2DM between five and ten years after delivery (IDF, 2017).

Women noticed with high glucose during pregnancy are also at higher risk of experiencing pregnancy complications or adverse pregnancy outcomes such as high blood pressure and an 'abnormally large' baby for its gestational age (foetal macrosomia) (IDF, 2017). As a result, normal delivery becomes difficult, risky and eventually endangers the life of the woman and that of the baby. However, these pregnancy outcomes could be decreased if hyperglycaemia is detected earlier in pregnancy and well controlled during pregnancy. Women at their reproductive age who have existing diabetes before pregnancy must be given preconception counselling. Maximum antenatal care and adequate postnatal

management of diabetes is strongly recommended for women with history of high glucose during pregnancy, women formerly undiagnosed with diabetes during pregnancy, and women with diagnosed diabetes. Eating healthy food, moderate exercise, constant monitoring of blood glucose and, in some instances, oral medication or insulin can be effectively used to control hyperglycaemia during pregnancy.

#### **Risk Factors for Diabetes**

Both genetic and environmental factors have been found to contribute to incidence of diabetes in our society. The risk for type 2 diabetes involves interplay between genetic and metabolic factors (Ozougwu, Obimba, Belonwu, & Unakalamba, 2013). Other factors include ethnicity, age, family history of diabetes and lifestyle factors such as unhealthy diet, overweight and obesity, lack of exercises, intake of sweetened beverages, inadequate consumption of dietary fibre, and smoking (Mihaescu, Meigs, Sijbrands, & Janssens, 2011; WHO, 2015). Maternal over weight (obesity), previous pregnancy history of macrosomia, family history, maternal age, neonatal death, unexplained stillbirth, and ethnicity have been identified as risk factors for gestational diabetes mellitus (Dobjanschi & Miulescu, 2015; Shannon, & Wong, 2010). Gestational Diabetes Mellitus highly pre-disposes women to developing type 2 diabetes later in life (Dobjanschi & Miulescu, 2015). Overweight and obesity, together with physical inactivity, are projected for a high percentage of the worldwide diabetes burden (WHO, 2016). Research by Gudjinu and Sarfo (2017) in the Ho municipality of Ghana found out that the risk of diabetes was associated with persons with middle socio-economic

status and physical inactivity. Again, the researchers reported that eating lots of fruits protects individuals against type 2 diabetes. Even though the study helped to identity the risk factors for type 2 diabetes, the selected participants were mainly old diabetes patients and this could possibly affect recall. Again, the participants were from a particular ethnic group and they were mainly type 2 diabetes patients.

Several dietary practices are linked to unhealthy body weight and/or type 2 diabetes risk factors including high intake of saturated fatty acids, high total fat intake and inadequate consumption of dietary fibre (Dabelea et al., 2014; Patterson et al., 2009). In addition, high consumption of raw sugar and sweetened beverages with substantial amounts of free sugars increase the possibility of one becoming overweight or obese, mostly children (Gakidou et al., 2011), and this increases the risk of type 2 diabetes (Beagley, Guariguata, Weil, & Motala, 2014; Patterson et al., 2009; WHO, 2015). Besides, active smoking has been found to increase the risk of type 2 diabetes, with the greatest risk among heavy smokers (Sarwar et al., 2010). All these unhealthy lifestyles or practices significantly contribute to the rising prevalence of diabetes, with type 2 diabetes accounting for well over 90% of diabetes cases in sub-Saharan Africa (Hall et al., 2011).

In addition, poor early childhood nutrition increases the risk of type 2 diabetes later in life. Jiang, Ma, Wang, and Liu (2013) opined that poor nutrition and bad behaviours (drinking, smoking, junk diet), and stress experienced by mothers during pregnancy may increase the child's risk of diabetes later in life. Jiang et al.'s study only reviewed studies that have been documented on type 2 diabetes in adult life that highlighted nutritional, environmental, and physiological

factors of type 2 diabetes. Van Abeelen et al. (2012) also stressed that type 2 diabetes in adulthood is associated with under nutrition during the early development of life. This interface between malnutrition and the high risk of diabetes in later life has been confirmed by Li et al. (2017), De Rooij, Roseboom and Painter (2014), and Zabuga and Vaiserman (2017). Again, poor fetal growth, low birth weight (particularly if followed by rapid postnatal catch-up growth) and high birth weight are factors that appear to increase risk for diabetes (Guariguata, Linnenkamp, Beagley, Whiting & Cho, 2014; WHO, 2015). These are experimental and epidemiological studies that provided evidence for malnutrition and risk of type 2 diabetes.

Furthermore, there are strong genetic factors that contribute to the development of diabetes. In the works of Kumar et al. (2015), it was reported that genetic factors influence the development of diabetes in an individual. According to Yu (2012), the development of familial linkage studies, candidate gene analysis and genome-wide association studies have helped to identify monogenic diabetes causative genes and many susceptible genes that often lead to the development of type 1 and type 2 diabetes. Yu (2012) only reported reviewed studies on the genetics of type 1, and type 2 diabetes, and other monogenetic diabetes of childhood and neonates. Research shows that individuals are 75% more likely to develop diabetes if both parents are diabetic (Diabetes United Kingdom (UK), 2010). Again, ethnic background has been found to be strongly linked to the development of type 2 diabetes, and the prevalence is three times more common in people of Black African and Black Caribbean origin and six times more

common in people of South Asia (including Bangladeshi, Indian, Pakistani and Sri-Lankan) (Diabetes UK, 2010).

Stress is a common factor in physical illness, and it is increasingly becoming a risk factor in the onset and progression of a disease. It is established in literature that stress has a role to play in the incidence of diabetes, especially type 2 diabetes as a predictor of the onset of the disease and a prognostic factor in individuals with already existing diabetes condition (Hackett & Steptoe, 2017). Kelly and Ismail (2015) conducted a comprehensive review of literature to identify the link among diabetes psychosocial factors such as stress and depression. The review found out that people who are exposed to stressful working environment, depression, and traumatic experience are highly at risk of developing type 2 diabetes. Persaud and Williams (2017) identified stressful working conditions as an important precursor and causative agent of diabetes.

Most of the above studies were review of previous research that provided evidence for the link between diabetes and genetics, malnutrition or famine, environmental and stress. All these studies concentrated on type 2 diabetes.

#### **Effects of Diabetes on Patients**

The impact of diabetes ranges from medical, to psychological and social. Diabetes, specifically type 2 diabetes, is strongly associated with severe health effects, caused principally by micro and macrovascular changes (Pagano et al., 2013). These changes give rise to a number of co-morbidities such as cardiovascular diseases, renal diseases, peripheral neuropathies, and visual deterioration (Bays 2012; Khalil, Roussel, Mohammedi, Danchin, & Marre, 2012)

while recent evidence suggests a link between diabetes and cancer (Johnson et al., 2012). Diabetes also contributes significantly to early and excess mortality from co-morbidities (Australian Institute of Health & Welfare [AIHW], 2008). People who are in a hyperglycemic state may show signs of deep breathing, rapid heart rate, and, if the symptoms remain untreated, may go into coma (DePaepe, Garrison-Kane, & Doelling, 2002). Individuals in low hypoglycaemia may complain of headaches, nausea and vomiting, restlessness, fatigue, excessive hunger, sudden changes in behaviour, and, under serious circumstances, may experience convulsions or coma (DePaepe et al., 2002). A person who experiences ketoacidosis will exhibit a higher breathing rate, acidification of the urine, and high levels of potassium in the blood. If ketoacidosis goes untreated for a prolonged period of time, it can lead to circulatory collapse, and cause coma or even death (Touchette, 2000). When blood sugars stray out of the ideal range, a variety of acute and long-term complications may ensue. In the short-term, fluctuations may cause feelings of anxiety, aggression, or antisocial behaviours. In the long-term, if these fluctuations are left unresolved, they can lead to more serious complications such as kidney failure, blindness, stroke, and, possibly, death (Bryden et al., 2001).

The disease condition imposes physical limitations on the diabetic person and causes social, physical, psychological and cultural disruptions in the life of the affected person (Aikins, 2013). The individual's socialization is often limited because of the changes in lifestyle such as maintaining balance of blood glucose, constantly watching body weight and changing eating patterns. Additionally,

Iregbu and Iregbu (2016) reported that patients are also burdened with the financial strain associated with managing diabetes. According to Kralik, Price & Telford (2010) living with a chronic illness is an experience of living a restricted and socially isolated life, and becoming a burden to others. Kralik et al. selected participants who had multi-morbid medical diagnosis Some people with diabetes lose their sense of identity often due to blindness, loss of limb and sexual function, as well as modification in social relationships (Aikins, 2013; Chinenye, Ofoegbu, Onyemelukwe, Uloko, & Ogbera, 2013). Stuckey et al. (2014) reported that diabetes patients expressed worry, fear and anxiety about the complications associated with the disease and often experienced discrimination at their work place. The study (Stuckey et al. (2014) selected a very large sample size, however, the qualitative data analysed were the participants response to the openended questions in the survey questionnaire. This did not allow for further interrogation of the participants responses

Historically, adults with diabetes have two-or three-times higher rate of cardiovascular diseases (CVD) than adults without diabetes (Sarwar et al., 2010). The risk of a cardiovascular disease increases continuously with rising fasting plasma glucose levels, even before reaching levels sufficient for a diabetes diagnosis (Singh et al., 2013; Danaei, Lawes, Vander, Murray, & Ezzati, 2006). Diabetes appears to dramatically increase the risk of amputation of lower extremities because of infected, non-healing foot ulcers (Moxey et al., 2011). Rates of amputation in populations with diagnosed diabetes are typically 10 to 20 times higher than those of non-diabetic populations, and over the past decade

have ranged from 1.5 to 3.5 per 1000 persons per year in populations with diagnosed diabetes (Moxey et al., 2011).

Studies have shown how diabetes has impacted on patients physically (Barreto et al., 2007; Habte, Kebede, Fenta & Boon, 2016; Langat, 2011). Using Kleinman's model, Habte et al. (2016) examined the perceptions about type 2 diabetics in Ethiopia and how patients managed the disease. Thirty-nine patients were purposively selected from Addi Ababa and Butajira (Ethiopia), and the findings revealed that patients reported physical health problems such as heart, liver or kidney complications, loss of or diminished eye sight, amputation, paralysis of the body which led to loss of speech. This, in the long term, left some patients bed-ridden. Habte et al. study only recruited type 2 diabetes patients from urban centres in Ethiopia. It again excluded patients who might be using traditional care option and were not strictly adhering to diabetes medication. Patients interviewed in a study by Langat (2011) and Hjelm and Mufunda (2010) reported similar physical effects on diabetics. This physical debility decreased patients' ability to work, thereby becoming unproductive at the workplace (Tuncell et al., 2000). Zimmermann, Bunn, Namadingo, Gray and Lwanda (2018) conducted a review of researches to synthesize studies on experiences of type 2 diabetes patients in sub-Saharan Africa. Eleven databases were searched for related studies using NVivo (10) to produce the analytical synthesis of the studies selected. It was revealed that six of the studies had reported on how diabetes complications affected patients' ability to work. This review by Zimmermann et al. (2018) only selected studies published on type 2 diabetes. Again, only peer

reviewed articles were selected while the non-peer reviewed articles were excluded. Ruston, Smith and Fernando (2013) also supported this by examining diabetics' perception and, experiences at the workplace. Using the constant comparative analysis approach, it was found out that diabetes impeded patients' ability to work. Ruston et al. (2013) recruited both type 1 and type 2 diabetes patients. However, the selection of the type 1 diabetes patients could be biased because it only selected patients who accessed online support for diabetes. Patients' income was affected due to their inability to work (Aikins, 2003; Zimmermann et al., 2018).

Complications of diabetes sometimes affect the sexual strength and functioning of patients, especially male patients (Aikin, 2003; Osei-Yeboah et al., 2016; Owiredu et al., 2011; Owusu, 2016). Diabetes mellitus also poses a threat to the individual's social life. Social interactions may be further limited by the unwillingness of the adolescent to test blood glucose in a public setting for fear of blood-borne disease, and the possibility of contracting an illness (Cheung, Wong, & Mclean, 2006). The restrictive nature of the diabetes regimen might also interfere with the teenager's participation in a variety of social activities, including sports, driving, and dining out with friends (Carroll & Marrero, 2006). In the study by Aikins (2003) on living with diabetes in rural and urban Ghana using a critical social psychological examination of illness action and scope for intervention, it was discovered that participants experienced minor and major body discomforts such as dizziness, body weakness, persistent wounds, headaches, sexual dysfunction, visual impairment and physical disability. The use

of different interviewers for the urban and rural interviews may introduce some biases to the interpretation. Similar studies evaluated the quality of life of diabetes patients in Ho (Ghana). Osei-Yeboah et al. (2016) found that patients suffered deteriorating quality of life and sexual dysfunction which was associated with the male patients. This is in consonance with the findings of Tabong, Bawontuo, Dumah, Kyilleh and Yempabe (2018) which identified loss of libido and inability to satisfy spouses as negative impact experienced by male diabetics. Diminished sexual strength brings about spousal conflict and loss of masculine identify in the community (Aikins et al., 2013; Owiredu et al., 2011; Tabong et al., 2018). According to Aikins (2003) and Aikins et al. (2013), diabetes disrupts the social roles of sufferers and causes patients to restructure their social and physical identities. Thus, individuals are unable to engage in social activities because of the limitations and restrictions placed on them by the disease. To Kralik et al. (2010), living with a chronic illness comes with social and physical consequences, and disruption of general lifestyle. Some of the studies were quantitative in nature which used self-reported semi-structured questionnaire to collect data. This did not allow for follow up questions about patients' quality of life

Psychologically, diabetes patients experience comorbid depression which may lead to poorer outcomes and increased risks of complications by lowering adherence to glucose monitoring, exercise, diet, and medication regimens (Ciechanowski, Katon, & Russo, 2000). In a study by Hood et al. (2006) on 145 youths with diabetes, the researchers found out that the individuals who scored higher on the Children's Depression Inventory reported checking their blood

glucose levels less frequently, had higher HbA1c levels, and a higher level of diabetes-related stress. Hood et al. (2006) simply aimed at children and adolescents with type 1 diabetes. Another proposed mechanism for the hyperglycemia that is seen in depressed diabetic individuals is that cortisol abnormalities that are associated with depression may have hyperglycemic effects, as might the insulin resistance that accompanies depression (Lustman & Clouse, 2005).

Though the above studies sought to shed light on the impact of diabetes on patients, these studies have methodological difference in terms of research approach and analytical processes. Again, some of the studies concentrated on impact of work performance, and countries outside Ghana. Even studies conducted in Ghana focused on other regions, excluding the Eastern Region.

**Challenges of living with Diabetes** 

Living with diabetes requires a total change in an individual's life. These changes which patients often describe as demanding include dietary modification, lifestyle adjustment, medication adherence, regular blood testing, frequent hospital visits and regular exercise. Researches have highlighted the many challenges experienced by patients in their attempt to align themselves with the lifestyle adjustments of diabetes. One of such challenges had to do with financial burden associated with the purchase of drugs, dietary requirement, transportation and general management requirements (BeLue et al. 2013; Khandan, Abazari, Tirgari, & Cheraghi, 2018). BeLue et al. (2013) using PEN3 model as a cultural framework in a study examined the experiences of patients on self-management.

It was found out that financial burden was one of the main barriers that impeded management of diabetes. This financial challenge was in relation to accessing health care and adhering to recommended diet. Again, Khandan et al. (2018) interviewed 11 Iranian mothers of children with type 1 diabetes with the aim of exploring mothers' experiences with the transfer of care. Three themes were generated by the researchers: that is, facing care management challenges, care in the shadow of concern, and hard life in the incidence of diabetes. It was also evident in the mothers' accounts that caring for their diabetic children imposed heavy financial burden on the families. This was due to the cost associated with lifelong insulin treatment, control of blood sugar and management requirement. This caused families to reduce other expenses in order to cover medical bills. In some instances, the associated cost prevented patients from adhering to medications and lifestyle adjustment. Mothers selected by Khandan et al.'s study were not from the rural areas. Again, different analytical approach (Colizzi's phenomenological method) was used to analyse the qualitative data.

Through a systematic analysis of illness practices by Ghanaians with diabetes, Aikins (2005) provided counter evidence to the already existing literature on healer shopping. She reported that even though patients perceived biomedical management as the appropriate self-care practices, the psychosocial impact of the disease and high cost of biomedical care caused medical inaction and drove care seeking behaviours. Thus, patients' medical inaction included active engagement with faith healing and partial disengagement with biomedical care. Cure-seeking behaviours, on the other hand, constituted healer shopping

including faith healing, ethonomedicine, and biomedicine. Patients in Aikins' (2005) study opined that their medical inaction was caused by extreme complications of diabetes, financial difficulties and lack of social and family support. That is to say, patients' disengagement with biomedical care was due to high financial cost of biomedicine and recommended foods, as this was common with low income and financially deprived patients. The use of door-to-door technique by Aikins (2005) to recruit participants from the study areas helped to gain their unique experiences. However, the study was silent on where the interviews were conducted. Additionally, the use of multiple or different interviewers may impact the interpretation of the data collected.

These findings corroborate the results of Metta et al. (2015) and Yasmin et al. (2020). Participants in Metta et al.'s study raised concerns about patients' ability to meet medication bills, and indicated that they (patients) sometimes sell properties or borrow money from friends or source medicine from pharmacies to mitigate financial burden. In some instances, patients resort to skipping of dosages, reducing recommended dosage or sharing medicines with other patients to help meet the financial demands. The concept "village" was not well defined by Metta et al. (2015). Additionally, the study adopted the grounded theory principle with the help of Nvivo in analysing the data. The use of village leaders in recruiting participants from semi-urban village might introduce some selection biases. Yasmin et al.'s (2020) findings also emphasized the financial demands that caused patients to delay visits to hospital, or skip medication. These factors underlie patients' non-adherence behaviours. The study (Yasmin et al., 2020)

recruited patients from a tertiary hospital and they do not represent those from rural areas. Only type 2 diabetes patients were used for the study, and proximity to the hospital as a criterion limited the selection of potential participants for the study. Another challenge that patients encounter and which affects their non-adherence behaviours is the large quantity of drugs they take every day (Adeniyi, Yogeswaran, Wright, & Longo-Mbenza, 2015). Adeniyi et al. (2015) purposively selected diabetes patients from South Africa to examine the factors affecting diabetes control. The study revealed patients complaining of being tired with taking many pills every day for the rest of their lives, and in addition, not having money for blood sugar control. Cohen, Christensen & Feldmen (2012), and Miller and DiMatteo (2013) also support the assertion that non-adherence among patients is caused by side effects of medication, difficulty with managing complex treatment regimen, literacy and lack of social support.

Storage of drugs, particularly insulin, has been a major challenge for patients and this is exceptional for diabetics with low socio-economic status and those from the rural areas (Gill, 2000). Insulin for daily injection must be kept at recommended room temperature to remain potent and stable for 28 days (Gary, 2009). However, insulin stored outside the refrigerators must be kept cool within 12°c and 30°c. Insulin will maintain its stability and potency until its expiry if kept between 2°c and 8°c in a refrigerator (Kedogo, 2015). Patients who did not have access to refrigerators used proxy arrangement with relatives, friends, butchers, bars, and shop keeps. Lack of refrigeration is prevalent in rural areas and inadequate power supply in these areas is an obstacle to storage of insulin. In

some parts of rural Africa, the appropriate practice of insulin storage is practically impossible for the poor economic class (Kedogo, 2015). According to Kedogo (2015), non-refrigeration methods of insulin storage include the use of shady corners of huts or rooms, boxes outside the house, porous clay pots with water and sand inside, and holes created in the ground. It is hoped that evaporation of water through the porous clay pot lowers the temperature inside the pot.

Mcferran (2008) reported that one of the challenges confronting diabetes patients in Kenya was the unavailability of or few refrigerators which makes home storage of insulin very difficult. Mcferran further observed that some diabetics lived in poor housing conditions because of social economic challenges, cultural practices and political challenges, and this aggravated their problems with insulin storage. The poor who were unable to afford refrigeration resorted to the use of pots with sand and water contraptions to preserve the insulin (Kedogo, 2015). Kedogo studied the impact of insulin storage and administration technique on glycated heamoglogin among adult diabetics in Kenya. It was revealed that home storage was mostly used by patients; however, only 30.1% used refrigerators while the majority (69.9%) used cotton wool soaked in spirit. The overall storage method by patients was ineffective as was evident in the responses given by 95.9% of the patients. Kedogo (2015) study employed the crosssectional design and the interviewer questionnaire was used. The interviewer questionnaire has potential to bias the responses provided by the participants. In a cross-sectional survey, Kpekura (2017) sampled 201 diabetics from the Upper West Region of Ghana to assess their knowledge of and attitude towards selfmanagement practices. Even though patients demonstrated adequate knowledge about and attitude towards diabetes, they had some issues with self-management. Patients raised concerns about the costly nature and scarcity of insulin, its storage and administration. This study (Kpekura, 2017) also employed the cross-sectional study design which often restricts participants responses.

One other challenge confronting patients is the modification of their lives to strictly adhere to dietary and mediation instructions. Mensah, Affram, Richter and Banful (2017) used descriptive phenomenological approach to describe women's experience of acquiring, and living with GDM. The study recruited 10 pregnant women diagnosed with diabetes; the patients reported that they had difficulties with modifying their lifestyle to meet the demands of diabetes. Mensah et al., selected participants from urban centre, and different analytical approach was used. According to Walker (2008), these challenges were in connection with the large quantity of drugs the patients had to take for the rest of their lives, and to Carolan, Holman and Ferrari (2015), patients who are unable to conform to the medication and dietary requirements of diabetes go back to their old lifestyle and this eventually compromises treatment. Similarly, Murrock, Taylor and Marino (2013) investigated the self-management challenges faced by African-American women living with diabetes. Specifically, the researchers were concerned with dietary challenges, and the results highlighted the frequent difficulties the women faced in changing dietary habits.

In another study, Mathew, Gucciardi, De Melo and Barata (2012) tried to understand the differences in diabetes self-management between male and

females with type 2 diabetes. The interest of the researchers was to understand the needs, challenges and barriers male and female diabetics experienced in managing the disease. Thirty five participants were sampled and the researchers used both individual interviews and focused group discussion to solicit participants' views. It was found out that the participants struggled with dietary modification. Foods that women perceived as prohibitory were restricted whereas the men moderated the intake of foods considered unhealthy. Thus, the patients struggled with food restrictions, moderation, and integration of dietary recommendations. Selection of participants from an already existing diabetes group may limit the representativeness of the population. Also, the use of different interviewers may introduce some biases to the study. Participants in Tabong et al.'s study (2018) attributed this difficult to financial burden that comes along with diabetes, and poor socio-economic status of patients from rural areas (Metta et al., 2015). To participants in Bhattacharya's study (2012), dietary modification, strict adherence to medication and physical exercises are practically impossible and culturally irrelevant, and elusive (Vanstone, Rewegan, Brundisini, Dejean, & Giacomini, 2015).

The above studies have some limitations such as methodological issues, and unclear definition of concepts. Some studies had sample selection biases and the data collection procedure such as interviewer questionnaire could equally impact the data. Again, some of the qualitative studies used different or multiple interviewers in collecting data and this also had the potential to influence the interpretation of interview questions and the entire data.

### Psychological and Emotional Reactions of Living with Diabetes

Diabetes as a physical illness with its complications has an impact on mental health (Kucuk, 2015). An internet-based survey study conducted by Browne, Ventura, Mosely and Speight (2013) revealed that 63% of respondents reported severe diabetes-related distress due to patients having to adjust to the illness, while more than 25% reported impaired general emotional well-being. The psychological outcomes associated with living with diabetes include depression, anxiety, cognition and disturbed eating disorders (Browne et al., 2013). Also, several studies have found depression, anxiety, sexual dysfunction, suicidal ideation and cognitive deficits as some of the common psychological complications associated with type 2 diabetes (Lin, von Korff, & WHO, 2008; Peyrot et al., 2005). In a related study to examine the prevalence of anxiety and depression in a population aged over sixty years with type 2 diabetes, Masmoudi et al. (2013) found out that prevalence of anxiety and depression among patients was 40.3% and 22.6% respectively. Individuals experiencing hyperglycemia are prone to feelings of irritability, restlessness, and agitation (Warren, Deary & Frier, 2003). Similarly, individuals in a hypoglycemic state show evidence of impaired judgment, emotional instability, moodiness, irritability, belligerence, and fatigue (Gould, 2002).

According to Demir, Akinci and Yesil (2007) individuals diagnosed with diabetes often have a negative perception about their lives. These negative perceptions result in a lot of mental health problems. One key psychological experience that comes along with type 2 diabetes is depression (Walker, 2007).

Individuals often express varied psychological and emotional imbalances after they have been diagnosed. Studies have revealed that patients upon diagnosis get shocked, terrified or frightened, frustrated, sad and are prone to weeping (Almino, Queiroz, & Jorge, 2009; Carolan-Olah, Cassar, Quiazon & Lynch, 2013; Li, Drury & Taylor, 2013; Manderson & Kokanovic, 2009; Messias & Skotzko, 2000; Park & Wenzel, 2013; Tabong et al., 2018; Zimmermann et al., 2018). In the findings of Zimmermann et al. (2018), some patients expressed disbelief and even questioned their behaviours. Yasmin, et al. (2020) used a mixed method of sequential explanatory design to understand patients' experiences of living with type 2 diabetes and how effectively they managed the disease. Again, the study aimed at exploring patients' perception of mobile health intervention in diabetes management. This qualitative study was a follow-up study of a randomised control trial conducted in Bangladesh. Eighteen patients were purposefully selected for the study and the results showed that diabetes caused patients to experience emotional distresses like depression, tension, irritation, anger, and frustration. However, it was observed that patients involved in this study were type 2 diabetes and they did not come from the rural areas since the controlled trial was conducted at the Bangladesh Institute of Health Science Hospital.

Similarly, in a qualitative study to explore the emotions, thoughts, and experiences of diabetes patients, Yilmaz, Gun and Yaman (2019) reported that patients experienced psychological problems related to diabetes. Patients shared their experiences that psychologically (mentally), they felt bad, quick-tempered, wept and never wanted to be alone at home. However, they later regretted these

initial actions. In a further study, Hjelm, Bard and Apelqvist (2018) examined the beliefs about health, illness and health care among African migrant women with GDM living in Sweden. Thus, the women were born in Africa and migrated to live in Sweden. This prospective qualitative study sampled nine women, aged between 23-40 years, on three different occasions (during pregnancy, three months after delivery, and 14 months after delivery). Patients were being managed at a diabetes specialist clinic in Sweden. The researchers found out that the women were constantly worried about relapse, and their baby's health. They were also worried about their inability to live ordinary life and the changes that came with diabetes management. A limitation of Hjelm et al. (2018) is that the selection of women from different African countries with different language and religious beliefs could compromise their health seeking behaviours which will eventually affect their responses. Again, the study did not highlight the unique experiences of women from each individual country.

Mothers with GDM in Ghana have also reported that diabetes has affected their psychological well-being (Mensah et al., 2017). Furthermore, Kalra, Jena and Yeravdekar (2018) revealed that patients experience emotional distress upon diagnosis. These psychological distresses if not addressed, lead to suicidal ideations and attempts as reported by Chung et al. (2014), Tabong et al. (2018), and Necho, Mekonnen, Haile, Birkie and Belete (2019). Necho et al. in a cross-sectional study investigated suicidal plans and attempts, and their determinants among diabetes patients in Bahirdar, Ethiopia. It was found out that the prevalence of suicidal plans and attempts among patients was as high as 10.7%

and 7.6% respectively. The suicidal attempts were mostly associated with female patients and those with comorbidity and associated depression. Again, it was associated with patients with poor social support and glycemic control. This also confirms the findings of Chung et al. (2014) which recorded 15.3% increase in suicidal thoughts and behaviours among diabetes patients in China.

The presence of these psychological problems can interfere with self-care practices and management of type 2 diabetes which will result in poor health outcomes among patients. Evidence suggests that when persons living with diabetes also experience depression, it affects their adherence to medication and self-care practices in turn resulting in severe physical symptoms (Sulaiman, Hamdan, Tamim, Mahmood & Young, 2010) that create the criteria for major depression (Anderson, Freedland, Clouse & Lustman, 2001; De Groot, Anderson, Freedland, Clouse & Lustman, 2001).

Even though these research outcomes have highlighted the prevalence of suicide tendencies among diabetes population, some studies were quantitatively examined and their main concern was the suicidal behaviours associated with people suffering from diabetes mellitus. The factors that necessitated patients' thoughts needed to be qualitatively examined in order to gain much insight from patients' experiences. Some studies were also conducted in hospitals in the cities which might not be representative of patients from the rural areas.

### **Self-Management of Diabetes**

Iregbu and Iregbu (2016) defined self-management as a process through which individuals are actively involved in disease management. Thus, the individual should be able to manage the symptoms, lifestyle modifications, social and physical consequences of having to live with chronic illness (McCorkle et al., 2011). Richard and Shea (2011) were of the view that successful management of illness is the responsibility of the patient in collaboration with the community, health professionals and family. That is to say, these people pull their efforts together to manage patients' lifestyle adjustments, symptoms, treatments, and the cultural, spiritual and psychosocial effects of the illness. People with diabetes have high levels of blood glucose and often at risk of stroke, cardiovascular diseases, kidney failure, and foot ulcers (leading amputation), premature death, nerve damage and blindness, when not properly controlled or managed (WHO, 2016; Zaccardi et al., 2015).

Lifestyle adjustments are key to diabetes management for maintaining normal glycaemia and decreasing the threat of long-term complications (Mendenhall & Norris, 2015; Tewahido & Berhane, 2017; Zimmermann et al., 2018). Self-management includes effective physical exercise, weight management, eating healthy diet, and adhering to treatment medication and regimen (Aikins, 2003, 2005; Awah & Phillimore, 2008; Awah et al., 2008; Bagnasco et al., 2014; Murphy, Chuma, Mathews, Steyn & Levitt, 2015; Nielsen, Bahendeka, Bygbjerg, Meyrowitsch, & Whyte, 2016). According to Weaver, Lemonde, Payman and Goodman (2014), the primary responsibility for diabetes

treatment lies with the patient because of its complicated nature of management, and the need to change everyday lifestyle and make choices. Psychological acceptance is also a key step in the management process. Several studies have reported on patients' acceptance of the disease as a first step to management (Carolan et al., 2015; Ruston et al., 2013). Accepting the occurrence of the disease enables patients to psych up themselves and take the responsibility of living with the disease (Kalra, et al., 2018; Yilmaz et al., 2019; Zimmermann et al., 2018).

There is no cure for diabetes; however, the individual affected with diabetes must effectively manage the condition by adhering to medication and adjusting lifestyle in order to control glycaemic levels, decrease the risk of complications and eventually improve quality of life (WHO, 2016). Adhering to medication is inadequate for the management of diabetes because of the complicated nature of its management, modification of daily and personal decisions, and the chronic nature of the disease (Funnell & Anderson, 2004). Iregbu and Iregbu (2016) noted that choices and decisions made by diabetes patients concerning their daily management of the disease occur mostly inbetween hospital visits. For patients to manage diabetes successfully, they must engage in constant monitoring of blood glucose, practice healthy eating habits, exercise regularly, adopt effective coping and problem-solving skills, adhere to prescribed prescriptions and reduce risky behaviours (Shrivastava, Shrivastava & Ramasamy, 2013).

Research conducted in the area of self-management of diabetes found out that effective self-management reduces the financial burden associated with

health, improves glycaemic control and quality of life, and averts complications (Chodosh et al., 2005; Minet, Lønvig, Henriksen & Wagner, 2010). Schulman-Green et al. (2012) also conducted a study to outline self-management processes in order to develop interventions and improve the health outcomes of people living with chronic illnesses. The researchers adopted a qualitative metasynthesis to analyse 101 studies and identified three main themes for self-management that is, activating resources focusing on illness needs and living with chronic disease. The result shows that self-management could be facilitated by health professionals through the recognition that patients place premium on a particular self-management process depending on the situation. Thus, to the patients, selfmanagement processes vary over-time. Likewise, healthcare providers must harmonize self-management activities and continuously communicate with patients to establish efficient and effective plans for self-management. The metasynthesis captured a wide range of studies involving different chronic diseases such as diabetes, cardiovascular, cancer and other diseases. Again, several qualitative methodological studies were included.

Similarly, Iregbu and Iregbu (2016) described three key categories of selfmanagement to include: learning to acquire new roles and utilize available resources to help the person deal with the everyday health; psychological and social effects of the long-term illness; the individual taking good care of his/her health needs; and finally, identifying and tolerating the barriers imposed by the illness and learning to adjust to the different ways of living. Engaging in selfmanagement could be challenging, as poorly managed diabetes could result in increased rate of morbidity and mortality (IDF, 2013). In 2011, Nam, Chesla, Stotts, Kroon and Janson (2011) conducted a systematic review of many studies to identify the barriers that impede self-management of diabetes. The researchers identified barriers to include negative attitudes of patients, ignorance, differing beliefs (cultural and illness beliefs) about treatment, social support, co-morbidity and financial constraints. Respectively some of the above factors could either prevent or facilitate self-management of diabetes. This study by Nam et al. Did not provide adequate summaries of the selected studies.

Poor glycaemic control has been found to be a poor self-management practice by diabetes patients. A study by Yusuff, Obe and Joseph (2008) revealed that less than half (50%) of the cohort patients observed adequate glycaemic control and majority of the participants were non-adherent to anti-diabetes drugs. The result shows that diabetes self-management was generally low among the group studied. Similar results have been reported in Africa (Abdulrehman, Woith, Jenkins, Kossman, & Hunter, 2016; Adisa, Alutundu & Fakeye, 2009; BeLue et al., 2013; Ogbera & Adeyemi-Doro, 2011). Abdulrehman et al. (2016) conducted an ethnographic study on self-management practices among diabetes patients living in some coastal areas of Kenya. Thirty participants were selected for the study and the results showed that self-management of diabetes was inadequately and insufficiently practiced. A limitation of Abdulrehman et al.'s study was that patient were sometimes selected based on the researcher's knowledge about them. Again, patients self-reporting of their diabetes status without further prove was inappropriate. The status of the interviewer in the community could influence

participants responses to the interview questions Additionally, Camara et al. (2015) in a cross-sectional study evaluated the prevalence and predictors of poor glycaemic control among diabetes patients in Africa and their findings corroborated the above results which concluded that the control of blood glucose among patients studied was poor. Adisa et al. (2009) further stated in their study that 81.8% of patients had never monitored their blood glucose and this indicated that non-adherence practices were high among the diabetes patients. This study only selected type 2 diabetes patients.

Other reasons that have accounted for the poor self-management practices include poverty or financial constraints (Abdulrehman et al., 2016; BeLue et al., 2013; Yusuff et al., 2008), high cost of biomedical care (Abdulrehman et al., 2016; Adisa et al., 2009), family dynamics and cultural beliefs, otherwise known as psychosocial factors (Abdulrehman et al., 2016; BeLue et al., 2013; Ogbera & Adeyemi-Doro, 2011). Yusuff et al. (2008) reported that patients' non-adherence to anti-diabetes drugs was due to financial constraints, side effects of drugs, and perceived inefficacy of the drug; this eventually led to the patients relying on local herbs as an alternative means of self-medication. Again, financial challenges were reported in the study by BeLue et al. (2013) and Abdulrehman et al.'s (2016) findings as having prevented diabetes patients from accessing medical care and influenced self-management practices (adhering to diabetes drugs and diet). In the findings of Adisa et al. (2009), high cost of medication was a major factor in poor self-management practices. The objective of the study was to identify possible factors for non-adherence to medication by patients and to develop interventions

to improve adherence and management practices.

As part of the self-management practices, it's been recorded that patients also resort to the use of non-biomedical drugs to compliment the biomedical treatment (Aikins, 2005; Broder et al., 2014; Zimmermann et al., 2018). According to Aikins (2005), patients resorted to using biomedicine, ethnomedicine and faith healing in their management of diabetes. Patients were unlikely to use biomedicine or had to abandon it because it failed to explain the spiritual causes of chronic diseases. Furthermore, Habte et al. (2016) and Zimmermann et al. (2018) posited that patients used traditional medicine and religious healing as alternatives or compliments to biomedicine because of the uncertainty patients expressed about diabetes. Sometimes these healer shopping behaviours are influenced by cultural factors, since cultural practices are a major threat to achieving biomedical self-care (Aikins, 2005; BeLue et al., 2013). Broder et al. (2014) also confirmed that the choice of traditional medicine is influenced by cultural factors and the belief that traditional medicine works better than biomedicine.

Although the above studies review shed light on self-management practices of diabetes patients, some limitations were identified among the studies. It was evident that some of the studies used metasynthesis which sampled published studies that selected wide range of chronic conditions, and different qualitative methods. Again, some of the studies had limitations with the strategy used in selecting the sample. The adopted strategies could bias the selection process which will eventually affect the outcome of the study.

### **Social Support for Diabetes Patients**

Social support is referred to as "those aspects of social relationships that provide a sense of self-worth and offer resource in tackling life's troubles" (Keyvanara, Hosseini, & Emami, 2012). Kadirvelu et al. (2012) also defined social support as "an exchange of resources between at least two persons aimed at increasing the well-being of the receiver." It is a powerful force that mediates physical and mental health problems (Berkman, Glass, Brissette & Seeman, 2000). Social support is hypothesized to work directly or indirectly to benefit the patient irrespective of the existing stress levels, and to provide resources or materials to change the negative impact of high levels of stress. Social support comes from families, relatives, friends, peers, neighbours, fellow patients, colleagues, pen-friends, and social networks on the internet (Kadirvelu et al., 2012). Social support operates at different levels, including emotional support, informational support and instrumental support (Keyvanara et al., 2012). Patients who receive emotional support get the reassurance that they are still being cared for and they have the opportunity to redirect their negative feelings and worries. Informational support, on the other hand, provides individuals with information about the disease such as adherence to medication, exercise, and lifestyle modification. The essence of instrumental support is to help patients with the management of diabetes on daily basis. This involves providing physical care, financial assistance, diet, medication, exercise, managing appointments, and glucose monitoring.

The complexity and chronic nature of diabetes make its management

complex and challenging for patients. Patients' attempts to properly control diabetes and adhere to treatment usually occur in the social setting and this can significantly change social and family dynamics (Rintala, Jaatinen, Paavilainen, & Astedt-Kurki, 2013). Social support has been identified as key management strategy required for diabetes health behaviour change (Ahmed & Yeasmeen, 2016). As part of the social support, family members provide enormous support for their diabetes patients (Alam, Speed & Beaver, 2012; Mayberry & Osborn, 2012; Shen, Edwards, Courtney, McDowell & Wei, 2013; Speight & Singh, 2013). The kind of support provided by families includes providing diabetes-related information (Ahmed & Yeasmeen, 2016), reducing stress (DiMatteo, 2004), supplying foods, financial support (Hjelm & Mufunda, 2010; Murphy et al., 2015), emotional and appraisal support, encouragement, and reminders of adherence to self-care behaviours (Mwangome, Geubbels, Klatser, & Dieleman, 2016; Nielsen et al., 2016; Shrivastava et al., 2013; Zimmermann et al., 2018).

Psychosocial factors such as family dynamics and cultural beliefs have been found to influence self-management practices. Research has found out that family members can either facilitate or hinder self-management practices, especially in providing financial support and planning meals (Iregbu & Iregbu, 2016). In Africa, for example, family meals are often prepared by mothers and sisters. In situations where a family member lacks knowledge about diabetes management, self-management practices could be compromised. In the work of Ahmed and Yeasmeen (2016), it was emphasized that patients were able to adhere to treatment when there was high family cohesion. They further posited that

families provided safe foods, economic and emotional support, ensured strict patients' adherence to treatment, and reduced stress and depression experienced by the patients. Thus, to Ahmed and Yeasmeen, family members could provide an environment in which diabetics could survive and live longer with ultimate satisfaction.

Miller and DiMatteo (2013) were also of the view that family support provided patients with practical help and mechanisms that reduced stress of living with such a chronic disease. DiMatteo (2004) further stresses that family and friends' support encourage the diabetic's self-esteem, optimism, and patient's adherence to advice which contributes to the reduction of stress and depression. Health care providers could also provide informational, affirmational and emotional support (Stewart, 2000). Gleeson-Kreig (2008) and Tang, Brown, Funnell and Anderson (2008) postulated that social support from health care providers is essential for newly diagnosed diabetes patient learning self-management skills.

In a related study to explore whether patients with good social support have lower levels of well-being and coping than patients with poor social support, Ramkisson, Pillay and Sibanda (2017) found out an indirect association between social support and coping, meaning, and as patients' social support increases, their emotional distress decreases. This shows that social support plays a critical role in patients' management of diabetes and adherence. The researchers concluded that families must be educated on the disease, its complications, and importance of adherence to medication. Additionally, health care providers must recognise the

significance of psychosocial factors in the management of diabetes. Similarly, Sharoni et al. (2015) found out that higher social support was associated with higher levels of fasting blood sugar, glycated haemoglobin, decrease body mass index and duration of diabetes. There was a negative correlation between a decrease in self-care activity and an increase in social support. Furthermore, patients who received adequate support showed improvement in self-management, medication, dietary, exercise adherence, clinical outcome, and decrease in depression (Ingram et al., 2007). These are quantitative studies which used questionnaire which did not allow for detailed description by participants. Again, the ages of participants in Sharoni et al.'s study could affect their recall bias as aging is associated with some health complications

According to Keyvanara et al. (2012), vulnerable diabetes patients can better be controlled when social support is central in the management process. Schiøtz, Bøgelund, Almdal, Jensen and Willaing (2012) have also reported that health promotion behaviours and well-being of diabetes patients are significantly associated with social support. Higher self-care of diabetes patients is associated with better social support (Karimy, Koohestani, & Araban, 2018). In order to improve continuity of care, Mwangome et al. (2016) conducted a study to identify how diabetes and HIV patients and their caregivers experienced, perceived and practiced health care. A total of nineteen diabetes and HIV patients, and 13 of their caregivers were interviewed. Data was analysed using Nvivo 10 and it was established that female caregivers supported patients through direct assistance in their daily activities and this included reminding them of medication, monitoring

well-being and cooking. This study selected patients with different chronic conditions (HIV and diabetes) and their care givers. The researchers (Mwangome et al., 2016) used multiple interviewers and this could compromise the data collected.

Social networks offer patients with considerable information on diagnosis, management, complications and expectations (Winocour, 2002). Furthermore, social networks provide emotional support in the form of cognitive support such as information, advice, knowledge, and material support in the form of goods. Social support provides patients with coping strategies that enable them to plan daily routines, deal with stressful situations, adhere to treatment and reduce poor health outcomes caused by stress (Winocour, 2002). However, research has shown that lack of inadequate social support is associated with higher risk factor for morbidity and mortality (Kadirvelu et al., 2012). Non-supportive parents, family conflict and lack of family responsibility for diabetics are linked to poor adherence to treatment (Nicklett & Liang, 2010; Rintala et al., 2013). Therefore, it is important that social support from families, friends, communities, health providers, colleague patients, and social networks be given a vital role in the management of diabetes and its complications.

It can be seen that some studies aimed to quantify social support and that means self-report questionnaires were used to collect data from the various participants. This did not allow participants to freely articular their views on the social support as this current study sets out to do. In some studies, the selected participants were older patients with type 2 diabetes. Older patients may

sometimes find it difficult to recall some information about themselves and their condition. Other studies also recruited patients who had different chronic conditions.

#### **Definition of Rural Areas**

According to Carruth (2012), the concept rurality is complex and often interwoven with geography, history and demographics. This complexity is attributable to factors such as settlement, size, population sparseness or density, remoteness from urban areas, employment groups, land use, economic activity, socio-economic status, and access to general services like health care facilities. As reported by Carruth, the controversy over the concept "rural" is whether it is a community of social representation in terms of interest or culture (way of life), or it is a geographical concept which is located on the map with recognizable borders.

According to the WHO (2009), the term 'rural area' is associated with distance from cities, population densities, socio-economic patterns and infrastructure. Serneels and Lievens (2008) associate rural areas with communities with limited access to infrastructure and good schools. The Organization for Economic Co-operation and Development (OECD, 2004) recognises rural areas from three main levels viz: Local level which describes a community with a population density less than 150 people per square kilometer; rural regions are areas with more than 50% of the people living in rural areas; considerably rural regions are areas where 15% – 50% of the population live in rural areas. It may include remote rural areas, small or remote islands, and areas

occupied by ethnic minorities. In Ghana, rural or village settings are seen as local territorial units dependent on agriculture and mining (GSS, 2004). Whereas rural and village communities have been characterised by their homogenous similarities in tradition, culture and custom, urban communities in Ghana are heterogeneous with a mixture of traditional characteristics on the one hand and modern traits on the other.

#### The Rural conditions of Ghana

Ghana is gradually becoming a nation where economic growth benefits and poverty reduction are unevenly distributed among economic divides, gender and the entire country. This is likely to weaken progress and undermine social connections (UNICEF, 2014). About half of the world's population lives in rural areas. Available data from the United Nations showed that in 2009, 3.41 billion lived in rural areas whereas 3.42 billion lived in urban centres. This is similar to the Ghanaian demographics pattern which puts rural population at 49.1% (GSS, 2013). A large percentage of the population of African countries resides in rural areas, and Ghana is not an exception. Typical characteristics of these rural areas include poor nutrition and health, poor sanitation and housing, abject poverty, lack of access to educational facilities, limited health service, depletion of natural resources, limited job opportunities, low productivity and lack of portable drinking water (Adjei, 2008; Bernard, 2018). The occupations in rural areas are dominated by agriculture, forestry and fishing (GSS, 2013). Ghana is basically characterized as a rural economy with most of the people experiencing low standard of living; the national per-capita income of Ghana is relatively low and the country has a poor infrastructure (Adjei, 2008). The majority of Ghana's population living in rural areas is denied of the limited resources mostly centred in the towns and cities. Due to this, migration from rural areas to urban centres is gradually increasing because of the favourable socio-economic advances in the urban areas, a socio-economic phenomenon that continues to widen the rural-urban dichotomy (International Fund for Agricultural Development [IFAD], 2001).

Generally, rural areas in Ghana have limited access to health care services, poor sanitation and unsafe drinking water. Comparing rural and urban areas, 44% of the rural inhabitants have access to adequate sanitation as compared to 62% of urban residents (Adjei, 2008). With regards to drinking water, 88% of urban dwellers had access to safe drinking water as compared to 52% of the rural dwellers. Access to health services is a challenge for the rural dwellers. Adjei (2008) reported that 92% of urban dwellers had access to health services as compared to 45% of rural dwellers. The biological and physical environments, as well as institutional arrangements in rural areas do not generate conditions that are healthy for the inhabitants. Malnutrition is high among the rural population because of their over dependency on agriculture for food supply (MeadCain, 1999). Quisumbing (2003) and Stryker, Salinger and Plunkett (2003) also reported that rural populations are saddled with physical and health deterioration, social inferiority and poverty. The records on poverty in African explain the need to re-direct development to rural areas in order to improve the quality of life of the rural dwellers, and build their capacity. Thus, in order to promote rural

development, policy makers and economic planners are to allocate resources for the development of the rural areas.

Accessing good health services in the rural areas is a huge challenge. Unfortunately, the poor are denied of good health services due to the high cost of drugs. Another major underlying factor that hinders people from the rural areas in getting good health care is lack of or inadequate health facilities. Rural dwellers travel the whole day on poor, long, dusty roads before they can access inadequate health services which are even beyond their financial reach. This condition has contributed significantly to high mortality rate in rural communities.

# **Rural and Urban Dynamics**

In Ghana, rural and urban areas are classified according to population, infrastructure and economy. Mostly, people living in rural areas often believe that they are isolated from the cities and towns and that their life experiences cannot be affected by the experiences in the cities. They often see their traditional heads as the final authority, and sometimes regard government officials from the cities or their own people living in the cities as strangers. Most often rural dwellers perceive that they have become victims of circumstances of limited opportunity to better education or jobs in the cities. Rural areas in Ghana vary according to size, tradition, occupation, and location of natural resources; they are dominated by agriculture. A few studies have classified rural settings as evolving from the result of declining infrastructure in urban areas. The tendency to migrate to urban areas in search of education, good jobs or flee from tribal or domestic conflicts is very high resulting in high manifestations of rural-urban migration.

The aforementioned features are not only limited to rural areas in Ghana but other rural settings in many low-income countries. For example, in India, there has been an institutionalisation of a concept of social distancing between rural dwellers and government officials (Wood, 1980). Botswana also presents a leadership structure in rural areas where traditional authorities are considered the highest form of governance (Walt, 1998). Rural-urban migration is also common in many developed countries as well. For example, Canada with 99.8% of its land classified as rural has just about 24% of the population living in rural areas (WHO, 2009). The Scottish Executive Annual Rural Report (2004) indicates that about 20% of the entire population of Scotland live in rural areas with severe climatic conditions and poor transportation network. Challenges associated with rural areas clearly pose a threat to the provision of quality healthcare. For instance, high cases of rural-urban migration of health workers in Mozambique affected access to quality health care for people living in rural areas (Cliff & Noormohammed, 1988). In Northern parts of Ghana, domestic and ethnic conflicts in the early 2000's resulted in shortages of medical supplies to rural health facilities, and insecurity among health workers especially in rural areas (Anekunabe, 2009).

# **Structure and Composition of the Ghana Health Sector**

Health services in Ghana are typical of a combination of many models viz: pluralistic health care which is mainly delivered at several levels by private and public providers; and National Health Insurance Scheme (NHIS) to improve community access to health services without financial constraints. The Ministry

of Health is the lead stakeholder in health care delivery. The Ministry of Health (MOH) is one of the Ministries of the central government set up by an Act of parliament and is responsible for health policy formulation for the country. The structure of the health system in Ghana follows a top-down approach with the Ministry of Health being at the national level. The core mandate of the MOH is policy and institutional development, strategic planning, co-ordination of all agencies and partners in health development, capital investment, management of health training institutions, and governance. It also serves as the overarching body for resource mobilisation and allocation for the entire health sector (Ministry of Health [MOH], 2003).

Health services delivery in Ghana is mainly by government (public), private, traditional and non-governmental agencies, civil society, and community groups. It also involves collaboration and partnership with other ministries, departments, and organizations whose policies and services have a major impact on health outcomes. The provision of health care in Ghana dates to the precolonial era when a disease was considered a wrath from the gods. It evolved through the post-colonial era during which the focus on health was on health care financing (Brenya & Adu-Gyamfi, 2014). The first president of Ghana instituted free health care financed by the state. In 1971 a token user fee towards healthcare was introduced. Finally, the economic crises in the 1980s and 1990s had serious effects on the financing of healthcare in Ghana (The World Bank, 2013), leading to the "cash and carry" (paying upfront for treatment and medications received from a health facility) system of health financing until the introduction of

National Health Insurance Scheme (NHIS) in 2004.

Health administration in Ghana is organized at the national, regional and district levels while service delivery follows the WHO Primary Health Care system (Ghana report for WHO, 2003), in hierarchical order for effective decentralisation. This form of health system is very beneficial as it tries to make basic health care accessible to the people in rural communities since about 46.8% of Ghana's population live in rural areas (United Nations, 2015). The Ghana Health Service (GHS) and Teaching Hospitals (THs), which were established by an Act of Parliament (Republic of Ghana, Act 525, 1996), are the largest bodies responsible for public health service delivery. The GHS is mandated to implement a comprehensive and accessible health service with emphasis on primary healthcare. The GHS is a semi-autonomous body and is administratively organised at three levels: national, regional and district. The teaching hospitals provide tertiary and specialised health services. The THs are also semiautonomous bodies contributing to policy formulation, training and research, and providing tertiary and specialised health services. The Health Professional Regulatory Bodies Act (HPRBA) 857 of 2013 was established in 2013 by Parliament (Republic of Ghana, Act 525, 1996) to set out the regulatory framework in which individual health regulatory bodies can operate in Ghana (HPRBA, 2013). Health facilities in Ghana are graded at different levels depending upon the complexity of services they deliver and the administrative zones they serve. The THs are the tertiary institutions followed by the regional hospitals, district hospitals, health centres and the Community Health Planning

and Service centres (CHPS).

# **Primary Health Care**

The World Health Organization (WHO) and the United Nations Children's Fund (UNICEF) (2018:2) point out that the foundation of primary healthcare is based on commitment to social justice, equity and participation. The Constitution of the World Health Organization (2006) reflects the need for all humankind to enjoy the highest standard of health as a basic right without distinction of race, religion, political beliefs, or socio-economic status. Article 1, which relates to the overall objective of the organization, provides that the WHO aims at attaining the highest possible level of health by all human beings. In addition, Article 25 of the United Nations Universal Declaration on Human Rights points out the right of everyone to have access to reasonable health and well-being, including basic amenities such as food, shelter, clothing, and medical care. According to the WHO and UNICEF (2018), all governments are entrusted with the responsibility of ensuring availability of and accessibility to quality essential health services including implementation of policies that promote and protect the health and well-being of citizens.

In 1979, policy strategies on primary healthcare (PHC) were introduced in Ghana which relied on four basic principles: political will to implement health projects; increased collaboration among sectors of the economy; involvement of communities in planning and implementing health projects; and, using other more appropriate means in cases where essential technology was not available. The implementation of the PHC concept resulted in the expansion of health centres

and building of new ones in many rural communities. However, the creation of the PHC was immediately followed by a worldwide economic crisis in the 1980s as a result of rising interest rates in Europe and the US (Witter, Kusi, & Aikins, 2007). Oil prices rose and the world experienced a fall in the prices of export products such as cocoa, coffee, tea and minerals. The economic downturn affected most economies in Africa resulting in a fall of per capita income. As a result of economic hardships in many African countries, several health economists argued about the reality of implementing a healthcare package that was comprehensive and suggested more focused and specific health projects instead (Walsh & Warren, 1979).

Primary healthcare serves as a tool for achieving universal health coverage, and its relevance in public administration needs to be made clear to ensure quality healthcare delivery (Novignon & Nonvignon, 2017). Shaw (2017) reflects that well-functioning primary healthcare systems rely on effective application of public administration principles. This entails sound administrative and financial planning, good health management information systems and proper regulatory and accountability frameworks (Shaw, 2017). Budrevičiūtė, Kalėdienė and Petrauskienė (2018) posit that as primary health care organizations seek to position themselves better in terms of providing service to the public, understanding the concept of public administration becomes critical. Budrevičiūtė et al. (2018) add that this helps in improving the value of the services provided to the people - thus attaining universal health coverage.

Primary health care in Ghana is structured to serve both rural and urban

populations according to priority. Areas which do not have access to permanent health care centres have been prioritised with programmes such as the Community Health Planning Service (CHPS), which focuses on "transforming clinic-based primary health care and reproductive health services to communitybased health services". This has encouraged the nation to embark on the training of health workers for the rural commutants. However, most CHPS do not have permanent but mobile workers who move from one area to another to educate the communities on preventive practices as well as administer curative services (Ghana CHPS, 2009). As stated earlier, the following health centres have been established to train health professionals viz: the Kintampo Rural Health Training School (KRHTS), situated in the middle of the rainforest region of Brong Ahafo, Navrongo Health Research Centre (NHRC) situated farther in the north-east of the country, and others of their kind in other regions train community health workers, nurses and health administrators for deployment to rural areas (Ghana CHPS, 2009).

### **Secondary and Tertiary Care**

The sub-divisions of the secondary and tertiary health cares are based on the services they render. Mostly, secondary and tertiary health care are classified as purely curative depending on the status of the facility. Most of these private institutions are basically established with the aim of making profit thereby charging high fees for services rendered to non-insured people on a 'cash-and-carry' basis. Therefore, patients who visit these private hospitals do so at their own cost. Teaching hospitals like Korle Bu, Komfo Anokye, Cape Coast and

others take referral cases and also serve as first point of contact for patients. The military and police hospitals of Ghana serve as tertiary health care institution, serving both as first points of contact and as referral centres but do not serve as teaching hospitals. In Ghana now, two of the income generating avenues are the secondary and tertiary health cares.

#### Access to Health

In simplest terms, access to health refers to geographic availability whereas from a broader perspective, it is defined on four dimensions which include availability, accessibility, affordability, and acceptability (O'Donnell, 2007). Peters et al. (2008) defined access to health as "the timely use of service according to need". Access could also be defined as gaining opportunity to use health facilities. To some other researchers (Oliver & Mossialos, 2004) there is no universal definition of access, and also there is no difference between access and use because these terms mean the same. Access to health care could be of great benefit; however, many people from developing countries do not have access to proper adequate health care (O'Donnell, 2007). O'Donnell further asserted that there is effective intervention for some conditions; however, many people suffer and eventually die due to their inability to access health care. It is important to note that those who are likely to receive less effective health care in developing countries are the disadvantaged and the vulnerable. This calls for effective measures to deal with the level of distribution of health facilities in developing countries.

It is estimated that the rural population makes up half (50%) of the total

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global human population (Sulemana & Dinye, 2014) and according to the United Nations (2009) report, 3.41 billion people live in rural areas compared to 3.42 billion in urban areas. The Ghana Statistical Service also confirms that 49.1% of the Ghanaian population lives in rural areas. Good health contributes to the achievement of national and international goals like the Millennium Development Goals. Therefore, in order to improve access to healthcare services in Ghana, facilities and services must be provided that will ensure that each person regardless of his geographical location benefits from the health care services. People in rural areas are confronted with high cost of health care due to limited access to health services. According to the Ministry of Health (2007), the high cost of health care consequently results from the cost associated with accessing health services and loss of productive days. It is important to improve access to good quality health care in order to achieve the Millennium Development Goal and a decent health status among the rural populace. However, this has been a challenge for many governments in developing countries (Sulemana & Dinye, 2014).

Some barriers to effective health care delivery in developing countries have been identified as inappropriate distribution of, inadequate resources (financial, material and human) (O'Donnell, 2007; Filmer, Hammer, & Pritchett, 2000), lack of social support (Rutherford, Mulholland, & Hill, 2010), insufficient quality (Filmer, Hammer, & Pritchett, 2000) and possible negative cultural practices (Jacobs, Ir, Bigdeli, Annear, & Damme, 2012). Other factors that have been identified as constrains for rural dwellers to access health care include long

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distances to health care facilities, inefficient and ineffective transport systems, insufficient health facilities, high cost of health services, and few health personnel (Lu, Samuels, Kletke, & Whitler, 2010) these factors have contributed to the difference in mortality rates between rural and urban populations (Sulemana & Dinye, 2014). Sulemana and Dinye revealed that the situation is more serious for those living along water bodies where river transportation becomes a challenge and a barrier to accessing quality health care in the district capitals. Dealing with these deficiencies will help solve the problem of access.

Peters et al. (2008) conducted a study to document access to health care service disparities between low- and middle-income countries. The main focus was to examine the quality, financial accessibility, geographic accessibility, availability and acceptability of health care services. It was evident that the poor in these countries were at a disadvantage on all the access dimensions identified. In order to improve access to the poor and disadvantaged people, Peter et al. (2008) noted that different multi-dimensional approaches must be adopted to involve both government and non-governmental organisations, and adopt appropriate strategies to organize and finance health services. There should be a conscious effort to reach the disadvantaged people to engage them and their communities in planning and improving health care access. Peoples' health worsens when health care is needed but inaccessible, or when health care is delayed (Peters et al., 2008). The problem with access to health often occurs in developing countries (World Bank, 2000).

### Access to Health Care among Rural Dwellers in Ghana

Access to health facilities is important as it improves the living standards of the entire populace. Therefore, despite a person's socio-economic status and geographical location, it is important that access to health care becomes imperative. The situation has not been anything better among Ghanaians, especially those living in the rural areas. The rural communities are often disadvantaged since most of the health facilities and hospitals are concentrated in the urban areas. The Government of Ghana has not relented on its effort to increase the quality of health care for the rural populace. However, this objective of reaching the rural people with close-to-client service has not materialized (Ministry of Health, 1998). One of the strategies which were adopted to enhance access to health among the rural people has been the Village Health Workers (VHW) system which was established in the 1980s, but this has not necessarily been achieved. The VHW initiative was faced with some barriers that prevented its success (Nyonator, Awoonor-Williams, Phillips, Jones, & Miller, 2005), and these challenges included training, resources, organization, supervision and monitoring which eventually led to the collapse of the entire initiative (Sulemana & Dinye, 2014).

Despite the Government's effort to achieve Health for All, many Ghanaians (70%) still travel from long distances (8km) to the nearest health facility to access health care (MOH, 1998) and this has eventually increased the mortality rate (Sulemana & Dinye, 2014). According to Nyonator et al. (2005), the Ministry of Health has targeted access to health care delivery as its main focus

and has therefore introduced some other policies and strategies to achieve main goal. Some of these policies include Community-based Health Planning and Services (CHPS) which was introduced in 1999, National Health Insurance Scheme (NHIS) introduced in 2004, and Health Sector ICT Policy and Strategy introduced in 2004. With all efforts, Ghana has not been able to achieve the Millennium Development Goals which are health related (Goals 4 and 5) (Escribano-Ferrer et al., 2016). A modest achievement has been made in the area of non-communicable diseases; however, MOH (2014) noted that sufficient information on the actual size of burden of non-communicable disease (NCD) was difficult to access.

According to van den Boom, Nsowah-Nuamah and Overbosch (2002), Ghana with a population of 23.5 million had only 1,439 health care facilities and this remained a problem. Research conducted by van den Boom et al. (2002) noted that healthcare facilities or centres were not proportionally distributed across the country, thus preventing most of the rural dwellers from accessing proper health care. Most Ghanaians do not live close to a healthcare facility where medical consultants could be reached; however, half of the populace lives about 5km to hospital facilities (van den Boom et al., 2002). Even though others live 5km away from health care centres, they cannot access health care because of transportation problems. About 25% of the people studied by van den Boom et al. (2002) lived more than 15km from where health care could be accessed.

Sulemana and Dinye (2014) also examined access to health care among rural dwellers and the result showed that 70% of the participants had at least once

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in their lifetime accessed hospitals, clinics and health centres located in the district capitals. The findings of the study also revealed that accessing these health facilities was not encouraging to participants due to ineffective transportation systems and long distances. This situation has increased the mortality rate among rural dwellers, and the cost of health care associated with transportation challenges. Tricycles and boats were often the expensive and dangerous means by which individuals visited hospital in case of emergencies when the person's condition was severe and threatening. Finally, Sulemana and Dinye concluded that access to health services in the rural areas was limited due to few health workers, inadequate health facilities, and equipment, poor transportation system, high illiteracy rate, low-income levels, and poor communication services. Similar transportation challenges have been reported by Carolan et al. (2015), Kagee, Le Roux and Dick (2007), and Metta et al. (2015). In Sulemana and Dinye's study, the role of key community stakeholders in the sampling process was not clearly detailed. This could compromise the representativeness of the sample selected for the study.

In order for patients to accommodate the problem with accessing health care and improve health outcomes, issues bordering on inequalities must be addressed. Africa Health Workforce Observatory emphasized that there was unfair distribution of health facilities and human resources both within and among regions (WHO, 2012). This was also confirmed by National Health Insurance Authority [NHIA] (2012) and the Ghana Statistical Service (2011) that rural dwellers and the poor were less likely to access health facilities (like National

Health Insurance Scheme [NHIS] cards) than the rich households and people in the urban centres. Findings from Drislane, Akpalu and Wegdam (2014) indicated that it was difficult for rural areas to receive medical training because of lack of health personnel and health care facilities. Thus, there is an urgent need for health personnel (physicians) in the rural areas; however, their working conditions are not attractive enough to lure and retain the physicians in the rural areas.

### The National Health Insurance Scheme

Challenges associated with financing public health care in Ghana presented two main issues; first, the 'out-of-pocket payment' created inequality in health care among the rich and the poor; secondly, it failed to encourage service utilisation for early case detection of certain diseases. These issues have also been raised in the literature as weaknesses of 'out-of-pocket payments' for health financing (International Finance Corporation, 2006). As a result, the New Patriotic Party (NPP) government introduced a new system of health financing which resulted in the passage of the National Health Insurance Act 2003 (Government of Ghana, 2003, Act 650). This law established the National Health Insurance Authority (NHIA) to manage the scheme. The National Health Insurance is operated on three levels – the district health insurance scheme, the private commercial health insurance scheme, and the private mutual insurance schemes. The Authority was to administer about 145 district mutual insurance schemes throughout the country (NHIA, 2010).

The introduction of the NHIS was the government's campaign promise and was aimed at providing healthcare to the people in lieu of payment. The main sources of financing health insurance are through government tax revenues constituted as the National Health Insurance Fund (NHIF), 2.3% tax contributions from the formal sector and premiums from the informal sector. The overall financing of the health sector is through four main sources – central government support through tax revenues which constitute 35%; donor assistance through sector budget support, donor earmark, grants and donations which make up 8%; the NHIF which makes up 46%, and 11% from the Internally Generated Funds (IGF) which represent receipts from households for services received (MOH, 2009).

### **Quality of Health Care Delivery**

The main focus of health care is the promotion of health and well-being of people, its major aim being ensuring the provision of adequate, efficient and equitable access to preventive and curative health care as suggested by the Alma-Ata Declaration (Guanais et al., 2018). The Alma-Ata Declaration states that primary health care is the key to the achievement of the goal of Health for All. Patient-centred health care is a person-oriented approach which intends to meet the needs, preferences and expectations of individuals. Donabedian (1988) conceptualized health care as a system, but also noted that the relationship between quality and system was difficult for people to understand (Best & Neuhauser, 2004). According to him, the success of a system is dependent on the individual's ethical perception. Therefore, Donabedian (1988) proposed that love is the ultimate secret to quality. Thus, health care professionals need to love the patient, love the profession and have love for God. That means that with love,

health care providers are capable of working backward to monitor and improve the system.

Researches from advanced countries have reported that patient-centred health care improves quality of care processes, user's self-management, satisfaction, and reduces the general cost of health care due to emergencies and hospitalization (Guanais et al., 2018; Nielsen et al., 2014; Rathert, Wyrwich & Boren, 2013). Patient-centred health care that provides patients with diabetesrelated information increases patients' feelings of autonomy and self-confidence, and reduces cost and complications (Samancioglu, Donmez, Surucu & Cevik, 2017). Respondents in Tabong et al. (2018) study expressed satisfaction at the care given to them by the health care professionals. They reported a positive experience with the health system, and opined that the health care providers treated them well. In a study by Dube, van den Broucke, Dhoore, Kalweit and Housiaux (2015) to review the current state of policies and implementation of Diabetes Self-Management Education (DSME) in South Africa, it was recognised that doctors, nurses and dieticians usually provided diabetes self-management education. The content of the education programme included physical activity, self-monitoring of blood glucose, healthy eating, taking medication, reducing risks, solving problem and living with diabetes. Similar findings about health providers' care have been confirmed by Bayındır Çevik, Özcan and Satman (2015). The study by Dube et al. (2015) only included policies and guideline documents relating to type 2 diabetes. Furthermore, combining self-report questionnaire and interviewer questionnaire was likely to influence the responses

given by the participants.

Health care systems are to provide better health outcomes and more social values due to changes in public expectations, health needs, and innovative goals (Kruk et al., 2018). Kruk et al. further outlined that there is the need for a highquality health system that greatly emphasizes health care in a given situation or context, and continuously delivers care to maintain and improve health. Again, the health care system must be trusted and valued by the end-users, and it should be in a position to change the needs and expectations of clients. Kruk et al. (2018) held the view that quality should be the basic component (deoxyribonucleic acid [DNA]) of every health care system and that it should not only be limited to the educated or a goal to be achieved in the future. They suggested that if a health care system cannot improve and upgrade health into good quality service, the human right to health is meaningless and worthless. A high-quality health care system must be informed by efficiency, resilience, and equitability. Donabedian (1988) in another study suggested that the pillars of quality include efficiency, efficacy, equity, legitimacy, acceptability and cost (Best & Neuhauser, 2004). He further stressed that health quality must address issues such as access, measurement and evaluation of quality health care, accuracy of and completeness with keeping medical records, patient satisfaction, observer bias and cultural preferences with regards to health care. Inadequate health care is often provided for the vulnerable like adolescents, illiterates and people with stigmatized conditions in many countries. In some instances, attention to health emergencies is slow and this reduces the patient's chances of survival.

Studies have cited some negative experiences of patients with regards to time spent (usually within five minutes) (Adeniyi et al., 2015; Yasmin et al., 2020), communication (Murphy et al., 2015; Yasmin et al., 2020), attention and respect (disrespect and abuse) (Booysen & Schlemmer, 2015; Kruk et al., 2018; Murphy et al., 2015; Yasmin et al., 2020; Zimmermann et al., 2018). O'Brien, van Rooyen and Ricks (2015) conducted a qualitative, descriptive, exploratory and contextual study at Nelson Mandela Bay in South Africa, to explore selfmanagement experiences of diabetes patients. As part of patients' view on how professional nurses assisted them to achieve self-management, they reported that the nurses were at times insensitive to the manner and time in which diabetes information was presented. Thus, education of patients was done at the convenience of the nurses but not when the patient was ready. In other instances, health care professionals failed to establish relatedness with their patients and this affected time spent, communication skills, ability to explain information, counselling, emotional support and reassurance, and this usually occurred at the time of diagnosis (Murphy et al., 2015). Some service providers exhibited rude and impatient behaviour, and eventual separation from patients.

The disappointment of and misbehaviour from health care providers have also been reported by patients in Booysen & Schlemmer (2015), Yasmin et al. (2020) and Zimmermann et al. (2018). Studies have reported on the time spent and delays that occurred at the health facilities which could also compromise quality of health care (Carolan et al., 2015; Hjelm & Mufunda, 2010; Mwangome et al., 2016). Carolan et al. (2015) explored the concerns and experiences of

patients was the time they had to wait in order to meet the doctor for consultation due to long queues. These delays and waiting time as reported by Mwangome et al. (2016) might have caused the collapsing of some patients because they could only eat after they had tested for fasting blood sugar and met the doctor.

Consistently meeting a particular health provider is key factor in the quality of care as this helps with establishment of rapport and relatedness with patients thereby improving doctor-patient relationship. For example, in Sweden, diabetes patients were taken care of at the primary health care centres with a physician specialized in family medicine, and a diabetes nurse (Pikkemaat, Boström, & Strandberg, 2019). According to Pikkemaat et al., diabetes patients who did not have any complications visited the facilities twice every year to meet the physician and nurse on scheduled basis. Any additional visits by the patients could occur only when there were complications due to changes in medication. Patients were only referred to another specialist outside the facility only when their complications could not be managed at the primary health care centre. The researchers only selected participants (type 2 diabetics) who have been diagnosed with diabetes in the last 12 months or one year.

According to Guanais et al. (2018) and Doubova et al. (2016), patients' perception of quality health care is associated with patient-centred health care attributes like availability of health care providers who have appropriate information about a patient's medical history, spend enough quality time with patients, solve most of health problems, easy to reach and communicate with, and

coordinate the overall health care.

# **Leventhal's Self-Regulatory Model of Illness Cognitions**

A number of theories have been advanced to explain how the chronicallyill patients make sense of their conditions. Notable among them is Leventhal's Self-Regulatory Model of Illness Cognitions or Common-Sense Model (SRMI or CSM) (Leventhal et al., 1984). The Self-Regulatory Model helps to identify factors that influence how patients process information regarding their diseases and how these pieces of information are combined into a 'lay' view of illness, which in turn directs coping behaviours and outcomes (Hagger & Orbell, 2003). Thus, the model helps to understand how patients cognitively interpret their illness and how this cognitive interpretation influences their coping behaviours and the management of the illness. Hager and Orbell (2003) further noted that the model enables patients to create a mental interpretation of the illness based on concrete and abstract information available to them, thus helping them to make sense of the illness, and manage it. This initial interpretation forms the first step in the process of seeking help and adopting the right strategy in managing the illness.

According to Leventhal et al. (1984) interpreting a health condition depends on three basic sources of information which include: pool of information already assimilated by the individual; external social environment; and, current experiences. The model explains further that humans reflect on their lives to form subjective perceptions and interpretations of their experiences (representation) (Gray & Rutter, 2007). The model has five dimensions which guide the patient's

cognitive interpretation of the illness, and provides a framework for them to adopt a means of coping with the illness. These dimensions according to Gray and Rutter (2007), include identity (the label patients give to the disease and its symptoms), causes (ideas about how the illness was acquired), consequences (emotional, physical, social, psychological and financial effects of the illness), timelines (duration of the illness), and cure/controllability (patient's idea about what they or their physician can do to promote good health).

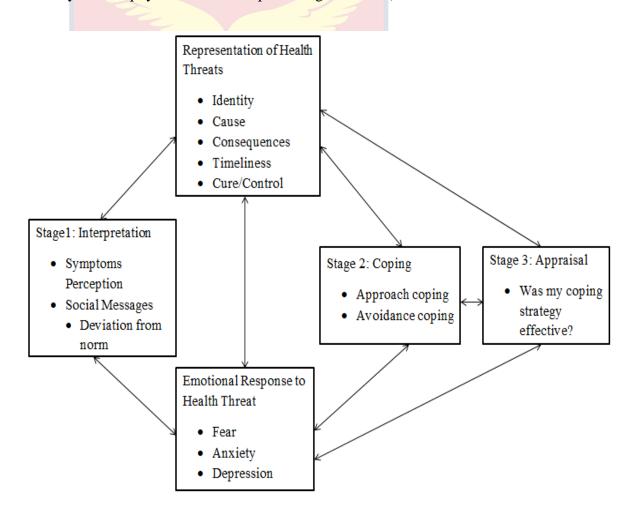


Figure 1: Leventhal's Self-Regulatory Model of Illness Cognition Source: Ogden, 2007

Leventhal's model of illness behaviour is a model that studies relationship between someone's cognitive representations of his or her illness on the

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successive coping behaviour (Leventhal et al, 1980). This model is founded on problem solving and proposes that we deal with illness and their symptoms. Problem solving according to the traditional models occur in three stages namely interpretation, coping and appraisal. Interpretation is making meaning of a problem. Coping is dealing with the problem in other to reclaim a state of balance. Appraisal is assessing how successful coping has been, either effective or ineffective (Ogden, 2007). These three stages are said to continue until the coping strategies are considered to be successful and a state of balance has been achieved. This process is regarded as self-regulatory in that the three elements of the model relate in a continuing and dynamic fashion in other to maintain the balance. In other words, they regulate the self. In relation to health and illness, if healthiness is a normal state, then an onset of illness would be interpreted as a problem and one would be motivated to re-establish a state of health (Ogden, 2007).

Relating the Leventhal's Self-regulatory model of illness cognition to this study, if diabetes patients view diabetes as problem, they would try to make sense of the problem (interpretation) and find ways to deal with the problem in other to regain their previous state of health (coping). Diabetes patients are confronted with the disease either through symptom perception or social messages. Symptom perception has to do with how the individual interpret the symptoms that he/she experiences. Example, in the case of the diabetes patients, the individual may be experiencing frequent urination, weight loss, slow healing of wound or excessive thirst. These symptoms influence how the person often interprets the problem of

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illness. It must be noted that cognition, mood and individual differences affects the individual's perception of illness symptoms. Other people within the social context may also provide the individual with information about the illness. These include health professionals, media, results from regular health checks, seeking advice from friends, family members, working colleagues (often called "lay referral systems" [Ogden, 2000]). Example, frequent urination in the presence of friends or loss of weight may end up with friends advising the person to seek advice from others who had similar experiences, or seek help from other sources (lay perception) or equally be advised to seek for professional advice from a medical officer. Likewise, an individual experiencing slow healing of wound could equally be advised by the social context to either seek advised from friends or health professionals. Such social messages greatly affect how the individual interpret the problem of illness.

Information received by the individual through these means (symptom perception and social messages) indicate that there is the presence of illness and there is a deviation and change in the individual's health status. The individual recognizing the change in health status is motivated to take an action to return to the normal problem free state. This will mean that the individual will assign meaning to the problem communicated. These meanings are assigned by accessing the individual's illness beliefs which are created by the five dimensions proposed by Leventhal et al. (1984). Thus, illness belief is developed by the contribution of symptom perception and social messages. The individual accessing the problem along these cognitive representations will help give

meanings to the problem and eventually enables the individual adopt appropriate and effective coping strategies to deal with the problem. Additionally, identifying the existence of illness affects the individual's emotional state. Perceiving the presence of illness or receiving social messages that slow wound healing or weight loss or frequent urination may be related to diabetes may cause the individual to experience fear, anxiety or depression. Therefore, coping strategies adopted must be suitable to address the person's illness belief and emotional state.

In the model, two coping approaches were identified (approach coping and avoidance coping). Approach coping involves taking actions to combat the disease or illness such as regular visits to the clinic, adhering to medication, discussing your emotions with friends, taking enough rest and eating healthy foods or change in lifestyle (in the case of diabetes patients). Avoidance coping on the other hand include deliberate attempt by the individual not to recognize the existence of illness. Example includes wishful thinking or denial. If the diabetes patient in the rural area cognitively represented the illness to be caused by some biomedical factors (example, genetic factors) or poor eating habit and considers the illness along the five dimensions, he/she may cope by visiting the clinic regularly and adhere to treatment regimen. On the other hand, if the patient interprets the illness to be caused by some spiritual factors and believe that it could be cured spiritually, the person resort to prayer camps, fasting and traditional healers as a means of coping with the illness. Again, depending on the identity of the illness, cause, illness duration, consequences of illness and whether it could be cured, the patient may adopt other coping strategies like healer

shopping where the person move from one healer to the other in an attempt to cure the illness.

Lastly, the patient evaluates the coping strategy adopted to determine if it was successful in managing the diabetes. If it was unsuccessful, the person adopts another strategy; however, if it was appraised to be effective, the same coping strategy will be continued. Thus, the patients self-regulate by consistently appraising the on-going process to determine whether the coping strategy is effective or not until the patient mange the condition to achieve the state of stability in health. This shows that the self-regulatory model does not follow a linear pathway but rather it is dynamic in nature and an ongoing process.

Several studies have documented how patients' beliefs about their chronic illness influence their coping and self-management skills (Bopape & Peltzer, 2002; Aikins et al., 2014; Hjelm et al., 2018; Hjelm & Mufunda, 2010; Hjelm & Nambozi, 2008). Hjelm and Mufunda (2010) explored Zimbabwean diabetes patients' belief about health and illness, and how their beliefs affect health seeking behaviour and self-care practices. The study consecutively sampled 21 persons from a diabetes clinic who were aged between 19 and 65 years. The qualitative data gathered were analyzed using content analysis. Participants perceived the cause of diabetes mellitus to be due to overweight, hereditary, wrong diet and supernatural factors (witchcraft and punishment from God). In the event of self-care, patients combined consulting health care professionals with the usage of herbs and religious activities (prayers, fasting, and use of holy water). The researchers concluded that patients' health seeking behaviour and self-care

were influenced by their belief about health and illness which relate to biomedical and supernatural factors.

Similarly, Hjelm et al. (2018) qualitatively explored African migrant women (with gestational diabetes mellitus) beliefs about health and illness, health care, and how these beliefs develop over time, during and after pregnancy. Again, the researchers were interested in how these beliefs influenced pregnant women living in Sweden self-care and health seeking behaviour. Semi-structured interview guide was used to interview nine pregnant women during pregnancy, three months after pregnancy and 14 months after pregnancy. The result showed that patients' belief about health and illness were stable over time and the beliefs were associated with social and individual factors. Patients' belief and health seeking behaviours were greatly influenced by the information provided by health care professionals about the seriousness of GDM. It was obvious that the social messages received from the health professionals contributed to the meanings given to the illness and subsequently influenced coping strategies. Therefore, competent health professionals must be made to provide information to patients on timely manner. All these findings corroborate the results of Hjelm and Nambozi (2008) and Aikins et al. (2014). Hjelm and Nambozi (2008) found that men and women belief about health and illness shows that they were less knowledgeable about diabetes. Aikins et al. (2014) interviewed 20 Type 2 diabetes patients from poor communities in Accra in order to examine the explanatory models of diabetes and its complications. Patients related diabetes with lifestyle, family history, supernatural factors, psychological stress and diet.

Biomedical and cultural models of diabetes and illness influenced the association made by the patients. However, it was observed that biomedical model was the major source of information for patients in choosing self-care practices.

From the evidence given above on the Self-Regulatory Model, it is hoped that it will serve as a backbone for this research to help identify the beliefs patients form about their illness and how these beliefs system influence their coping strategies in the rural areas. This will help design appropriate strategies to deal effectively with their experiences.

### Summary

The chapter has examined literature on the concept of diabetes, health systems in Ghana and access to health care in rural areas. It also examined literature related to the various research questions and the conceptual framework. The chapter has examined the definitions provided in literature for diabetes and rurality and has gone further to conceptualize the terms. In general, there is evidence to support the experiences of diabetes patients. However, there is little empirical evidence on the experiences of diabetes patients in rural areas. This makes it difficult to develop evidence-based policies for health promotion interventions in rural areas. The available empirical evidence on patients' experiences is mainly found in advance countries and some African countries. Even studies that have been conducted in Ghana concentrated on other regions either than the Easter Region. Again, some of studies concentrated on a particular type of diabetes (type 1, type 2 and gestational) patients. The literature review also identified some methodological gaps in terms of research approach and

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analytical process. This makes it difficult to apply the findings to the rural diabetics in the Eastern Region. In light of this, the current study seeks to address these gaps identified in the literature.

The theory underpinning the study was self-regulatory model of illness cognition (SRMI). The shifting perspective model and health belief model have proven to be inadequate. The SRMI was the theory applied in the study and it was adopted to situate it in the context of the experiences of people living with diabetes in rural areas of the Eastern Region. This helped to explain and understand patients' experiences. Several studies have also used the SRMI to explain how patients' beliefs about their illness influenced the psychological well-being and coping skills.

The next chapter sets out the methodology and the research designs used to search for answers. It continues to establish the philosophical underpinning and provides justification for the use of one particular methodology. It also presents the methods and data collection tools used in the study, and identifies the selection criteria and the research process.

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#### CHAPTER THREE

#### **RESEARCH METHOD**

The purpose of the study was to explore the lived experiences of people with diabetes living in the rural areas in the Eastern Region of Ghana. This chapter presents a description of the research design, research setting, population, sample procedure, instruments, data collection procedure, data processing and analysis. It further considers trustworthiness and ethical issues. It also explains the philosophy underpinning the research design, and addresses the reasons and rationale for choosing Phenomenology as an appropriate design for the study.

### **Research Design**

The design appropriate for this study was a descriptive research design from which the study adopted the Descriptive Phenomenological approach. Phenomenology is interested in the subjective meaning people give to events in their lives rather than just representing or recording objective events (Flowers, Smith, Sheeran & Beail, 1998). It is concerned with how participants make meaning of their personal and social worlds, and then the researcher attempts to interpret and understand the situation (Smith & Osborn, 2008). Phenomenology was more suitable for this research since the aim was to understand from the perspective of participants, their experiences, feelings and how they coped with the conditions in which they found themselves with the disease. Phenomenology is not interested in generalizing findings but rather seeks an in-depth description from individual cases and experiences. With this design, there is suspension of all pre-existing knowledge, predetermined research hypothesis and personal

experiences when entering into the research process and doing analysis (Flowers et al, 1998; Langdridge, 2007). The researcher then tries to produce a phenomenological analysis; that is, an interpretation of the participants' experiences (Willig, 2008). The design was selected to add in-depth understanding to what was already known about people living with diabetes in rural areas.

### Rationale for choosing phenomenology

There was an attempt to unravel the meaning behind participants' experiences. This was done through the process of interpretive engagement with the texts and transcripts. According to Creswell (2007), phenomenology is described as the object of human experience. Thus, the individual's description of phenomenon includes what was experienced and how it was experienced. Phenomenology is concerned with how people found within a particular context, and at a particular time experienced their world instead of general abstract statements about the world (Willig, 2008). The research is situated in the hermeneutical tradition, and it distinguishes between the natural and the social world. It discards the opinion that there is an objective 'truth' waiting to be discovered, and agrees to the position that most facts exist only because certain functions or meanings are attributed to them. According to Guzzini (2000), social facts depend on an inter-subjective shared set of meanings and it is these that the constructivists hold on to.

This research design is based on the interpretivism research paradigm. The aim of research in interpretivism is to understand and interpret daily happenings,

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experiences and social structures as well as the values people attach to these happenings (Collis & Hussey, 2009; Kawulich, 2012; Rubin & Babbie, 2010). Livesey (2011) describes interpretivism as a method that sees the social world as something that can only be formed and replicated on everyday basis by people. Something that may be true for now might not certainly be true tomorrow, or in another society. Individuals often attach subjective meanings to their social actions and the interest of the interpretive researcher is to study these social actions meaningfully. Thus, to the interpretivist, social life is "out there" which is independent of human awareness or consciousness (Neuman, 2000). There is no reality waiting to be discovered; rather, reality is what people perceive, process and define to be in a particular situation (Neuman, 2000). Interpretivists view humans as subjective beings who attribute meanings to every situation which is unique to them. Thus, the world is unique to everybody based on how the individual experiences it. Interpretivists believe that experiences vary from person to person and as a result, people's experiences must be studied from the person's perspective. The point of the researcher is to discover what actions mean to those who experience them. Social life and experiences cannot simply be deduced from abstract and logical theories that may have little or no significant relation with people's experiences and feelings (Neuman, 2000).

Interpretivism researchers are not separated from the phenomenon or situation under study. Edge and Richards (1998) argue that interpretive researchers "see themselves as participants in the situation they investigate". Holliday (2007) believes that the participation of the interpretivist in the research

allows them to have a detailed description of the phenomenon being studied. This approach enabled the researcher examine the nuances and 'taken-for-granted' assumptions that are often not considered.

Burell and Morgan (1982) categorized paradigms of research into four main dimensions: Radical humanist, Radical structuralist, Interpretive and Functionalist. The four research paradigms provide the end-product of a research in relation to epistemologies and ontologies of research as shown in Figure 2 below (Saunders, Lewis, & Thornhill, 2009). Radical humanist paradigm uses subjectivist ontological view and radical change dimension. This paradigm is more concerned with changing the status quo within roles and functions. Radical structuralist paradigm uses objectivist ontological view and radical change dimension to make fundamental change based on facts without any attempt to understand meanings of phenomena in the perspectives of the participants. Interpretive paradigm uses subjectivist ontological view and regulation dimension; this is concerned with understanding what is going on and explaining it from the perspective of the respondents. The functionalist paradigm uses objectivism ontological view and regulation dimension, and it is concerned with amendments within existing structures based on facts.

Drawing from the four dimensions described above, my study predicts two out of four research paradigms as the end product of the research; the first paradigm is the interpretive paradigm. This paradigm asks the basic question as what the experiences of diabetics from rural areas are, and why the management of people with diabetes from rural areas remains a problem, and further provides

explanations to the existing problem from the respondents' view point. The second paradigm is the radical humanist which is located in the subjectivist dimension. It asks the question of how human behaviour affects health care facilities in their efforts to address the problem in question. The synthesis of the two-dimensional paradigms provides an appropriate tool to inform the roles and functions of key stakeholders involved in the management and care of diabetic patients living in rural communities in the Eastern Region of Ghana.

# Radical Change RADICAL HUMANIST RADICAL STRUCTURALIST Objectivism INTERPRETIVE FUNCTIONALIST

# Regulation

Figure 2: Four Paradigms for the Analysis of Social Theory Source: Burell and Morgan (1982) cited in Saunders et al. (2009)

## **Study Area**

The information on the study area was culled from Ghana Statistical Service Report (2013). The Eastern Region is the sixth largest and the third most populous region with about 11.1% of the population of the country. The population is made up of 49.2% males and 50.8% females. The region shares common boundaries with Ashanti and Brong Ahafo regions at the north, Greater Accra and Central regions at the South, Volta region at the East, and Ashanti

region at the west. The region's population is very young, with 41.7% below 15 years, and 5.8% above 64 years. The labour force in the region is between the ages of 15-64 years which constitutes 74.2% of the population. The major economic activity in the region is agriculture, the major source of employment, especially in the rural areas. Majority of the employed population (58.4%) are engaged in agriculture (including hunting, forestry and fishing), 13.5% in wholesale and retail trade, and 9.1% in manufacturing. The population of Eastern Region experienced a tremendous increase from 1,635,421 (in 2000) to 2,633,154 (in 2010) (GSS, 2013). It is expected that the population will see an annual growth rate of 2.1% which will push the population to 4.5 million by 2040.

Forty percent (40%) of the region's population resides in four of the districts (Kwahu North, West Akim, Kwaebibirem and New Juaben). There is a vast difference in rural-urban distribution, and this suggests that access to certain social amenities and employment opportunities is not equitable in the region. Christianity is the dominant religion in the region (84.5%) followed by Islam (6.7%) with 1.4% being adherents of traditional religion. Sixty-nine percent (69%) of the population in the region is employed, 4.1% are not employed and the remaining 27.3% economically inactive. Though the rate of unemployment is higher in the less urbanized districts, unemployment is more characteristic of the urban population.

#### **Population**

The population was made up of diabetic patients who lived in the rural areas, and visited the diabetes clinic for regular clinical schedules at the

Koforidua Regional Hospital, Akwaktia St. Dominic's Hospital, Oda Government Hospital and Nkawkaw Holy Family Hospital, all in the Eastern Region. The Hospitals had a specialist unit for diabetes and hypertension patients. The units ran services for hypertension patients on Mondays, Tuesdays and Fridays while diabetes clinic was held on Wednesdays and Thursdays, and often attended by over 90 patients on daily basis. So, it was expected that about 180 patients attended the diabetes clinic every week. Attendance was often by appointment basis and depending on patients' adherence level and how well sugar/glucose was controlled, patients were given between two weeks to four months appointment. Almost half of the clients were from the rural areas. Most of the clients were elderly patients (60 years on average), and were mostly females. In terms of their occupation, majority of them were farmers and traders. Information gathered from the clinics indicated that most cases reported were Type 2 diabetes with only few adolescents reporting with Type 1 diabetes. The Koforidua Regional Hospital diabetes clinic, for example, had two physician specialists, a cardiologist, one laboratory scientist, a dietician and four nurses who provided services for the clients. The senior physician specialist was the head of department for the diabetes and hypertension clinic and worked once a week on diabetes patients.

The clinic had a pharmacy, a laboratory and a dietetic unit. The pharmacy issued medication that would last two months, and patients reported for replenishing when their medication stock was about finishing, in addition to checking blood sugar level. This helped to reduce the number of patients to be served in a day, long queues and time waiting for the physician. On the day of

appointment, patients were expected to arrive early enough for fasting blood sugar (FBS) to be taken by the laboratory scientist for analysis after which they were seen by the doctor, and those who needed to see the dietitian were referred as such. Quarterly, the clinics ran general laboratory tests including BUE creatinine, liver functioning test, glycated hemoglobin and lipid profiles for all patients. The clinics often organized out-reach programmes within the municipality. The one or two days allocated for diabetes patients were not enough since the clinics had few staff coupled with heavy workloads on a typical clinic day.

The four hospitals were chosen because they recorded high number of diabetes cases in the year under review. For example, the Koforidua Regional Hospital Diabetes clinic is the biggest clinic in the region, and it recorded the highest number of diabetes cases (2,960) in 2017 (Ghs-dhims2, 2018). It used to be the only clinic within the municipality until St. Joseph and S.D.A. hospitals stating operating diabetes clinics. Again, it served as the main referral centre for other hospitals within the region and beyond. Due to this, there was contact with other patients coming from other districts and rural areas, thereby enabling the researcher to obtain detailed descriptions of patients' experiences in rural areas.

# Inclusion criteria

To be selected for the study, participants had to meet the following criteria, that is, be a diabetic patient diagnosed not less than six months at the time of research. This allowed in-depth information to be obtained on how participants had coped and managed their lives for a long period of time. Those who had lived with the condition for a long period of time would have richer and deeper

experience to share, which was the objective of this research. Again, participants should be living in rural areas. Since the focus of this study was to explore the lived experiences of diabetes patients living in rural areas, it was imperative that only rural dwellers be selected for the study. In addition, they had to come from a rural area located in the Eastern Region. Some patients from outside the region patronized diabetes clinics at the hospitals in the Eastern Region. Therefore, in selecting participants, the study focused on only participants who came from rural areas in the Eastern Region. A person diagnosed with any type of diabetes (Type 1, Type 2 and Gestational Diabetes) was accepted into the study. Thus, the study was not limited to a particular type of diabetes. Furthermore, participants should be able to articulate their views and communicate well in a local language (Twi). Finally, patients selected were those who were willing to participate in the study.

# **Exclusion criteria**

Patients who were diagnosed for less than six months were excluded from the study. Again, the study excluded diabetes patients who have been diagnosed with some other conditions. Patients who were not from the rural areas in the Eastern Region were also excluded.

# Sampling Procedure Noble

Qualitative study requires small sample sizes that have been selectively or purposefully determined (Schatzman & Strauss, 1973; Patton, 2002; Starks & Trinidad, 2007). The research aimed at selecting individuals who had sufficient and adequate experience, and knowledge concerning the phenomenon under investigation (diabetes in rural areas). Therefore, the kind of participants needed

for the study was those who would be able to provide in-depth information about living with diabetes in rural areas. Phenomenology studies are conducted using small sample size (Smith & Osborn, 2008; 2015). Thus, phenomenology studies sacrifice breath for depth. To them (Smith & Osborn, 2008), published studies in phenomenology had one, four, nine, fifteen or more samples. According to Starks and Trinidad (2008), typical sample sizes for phenomenological studies range from 1 to 10 persons. For students' project, five or six people have been recommended as a reasonable sample size (Smith & Osborn, 2008). This allows for in-depth engagement and involvement with each case, and also allows a detailed examination of differences and similarities, divergences and convergences. Phenomenology researchers are interested in selecting a sample that is fairly homogeneous with similar characteristics.

In other to select patients for the study, the hospital administration was contacted about the purpose of the study and nursing officers in charge of the diabetes clinics gave participants a brief introduction to the study and its objectives, and asked for verbal consent from those who met the inclusion criteria and were willing to participate in the research. In order to confirm that participants were from the rural areas, they were followed up to their locations during the member checking. Using the convenience sampling procedure, the study selected 31 participants: Oda Government hospital (7), St. Dominics hospital (8), Koforidua Regional hospital (9) and Nkawkaw Holy Family hospital (7). The convenience sampling was used because patients happened to be situated at the hospital at the time of the data collection, they were readily available, and

willing to participate. However, window of opportunity was provided for data collection to continue till the point of saturation. Thus, participants were continuously selected until nothing new emerged about the concept under discussion. The sample was homogeneous because they were a group of individuals with characteristics significant for the purpose of the study.

#### **Data Collection Instrument**

Semi-structured interview was used to investigate participants' perceptions, thoughts, feelings, and experiences about their chronic condition. Semi-structured interview enabled the engagement of participants in a dialogue whereby initial questions were modified in the light of the participants' responses, and the investigator was able to probe interesting and important areas which arose therefrom (Smith & Osborn, 2008).

The interview guide was in three parts and consisted of 18 open-ended questions about participants' experiences. The initial part of the guide sought to find out events that led to the discovery of the participants' diabetes status. The questions solicited for the initial lifestyle of the person up to the point of diagnosis, and their reactions upon diagnosis. The second part of the guide focused on the typical experiences of the participants living in the rural areas with such illness. The questions also included some challenges encountered by people with the disease. Again, it focused on how the condition had affected their daily lives, the kind of social support received, and how they accessed health care from the rural areas. The final part of the interview guide concentrated on participants' knowledge of diabetes, coping strategies and the management skills adopted in

managing their condition in these areas. The semi-structured interview guide was adapted from a standard structured interview guide developed by Carruth (2012). Carruth designed the interview guide to investigate the health experiences of people living with Type 2 diabetes in the rural environment of Southern Queensland, Australia. The original interview guide had 31 questions divided into three parts. The first part was the initial open-ended questions which had 11 questions that focused on the individual's life style before diagnosis. The second part (mid-interview questions) had 15 probing questions which were used to prompt people's description of their experiences related to their initial diagnoses, meanings assigned, feelings, attitudes towards glucose control and strategies for self-care management. Part three, which is the ending questions, was made up of five questions that concentrated on participants' knowledge on diabetes. The interview guide was adapted because some of the questions were modified to suit the prevailing issues in literature and to make it sensitive to the research setting (Eastern Region). It was again modified to be in line with the current objective of the research.

#### **Trustworthiness**

According to Czech, Wrisberg, Fisher, Thompson and Hayes (2004) and Dale (1996), the reader should be able to follow the process used by the researcher to draw conclusions from the analysis irrespective of the fact that she or he agrees with the researcher. Eight procedures were described by Creswell (1998) that ensure an increase in the validity or trustworthiness of qualitative research. These include: (a) prolonged engagement and persistent observation; (b)

triangulation (or crystallation); (c) peer review and debriefing; (d) negative case analysis; (e) clarification of researcher bias; (f) member checking; (g) rich, thick description; and (h) external audit. According to Glesne (2011) all the procedures do not necessarily have to be used in every single study; however, in order to ensure the trustworthiness of this study, the peer review and debriefing, member checking, and external audit were used.

Using the peer review and debriefing, a person (peer debriefer) was identified to review and ask questions about the qualitative study to ensure that the accounts resonated with the participants other than the researcher. This strategy-involved an interpretation beyond the researcher, and invested in another person, adds validity to an account. Again, in order to ensure trustworthiness of the study, 'Member checking' was done. According to Patton (2002), 'member checking' allows participants to review the transcript as accurate recordings of their experience. In this study, participants were contacted to review the transcript materials. This ensured that the transcripts had captured what transpired during the interview. Again, each participant was engaged in a discussion on the final themes generated. This allowed for clarifications and verifications in areas that were not clear during the interviews, and it also helped to add to the depth of data collected (Nicholls, Holt & Polman, 2005).

Finally, an external auditor who was not familiar with the project reviewed the entire research. The aim was to enable the external auditor to provide an objective assessment of research process and its conclusion. Thus, the auditor assessed the accuracy of transcription, how the research questions related to the data gathered, the level of data analysis and its interpretation. This enriches the entire validity of qualitative research.

#### **Data Collection Procedure**

Data collection took place between the months of March and July 2019. Interviews were conducted at the hospital premises (in private rooms in each facility), and they were audio taped and later transcribed. This allowed the researcher to take down notes and listen attentively to the participants.

Interviews lasted between 45 minutes and an hour. Interviews were conducted in the local language (Twi) and later transcribed into English for easy analysis. The face-to-face interview helped the interviewer to establish rapport, trust and intimacy with each participant. Smith (1995) noted that trust and rapport are key elements in qualitative research interviews. A semi-structured interview guide is appropriate for phenomenological study because it allows the researcher the flexibility to ask follow-up or probing questions. It allowed for probes into areas that needed clarification or elaboration from participants. Before each interview, the researcher introduced himself to participant and described the format of the interview. Participants were informed that they would be asked questions about some situations they experienced in the rural area.

There was brief chat with participants about general issues in the rural areas. This prepared participants for the main interview, and also enabled the establishment of a common grounds. The interview started with general questions, for example: "How did you come to live in this area?" This enabled participants to talk freely; where responses were insufficient, the interviewer probed further.

After the interviewer had established rapport with participants, initial questions were asked to elicit participants' experiences in the rural area. The questions were then narrowed to events that led to how participants realized they had contacted the disease: "Kindly describe how you found out you had diabetes." This question was to enable participants talk about the initial events that took them to hospital to be told about the illness. The question was also to elicit from participants where they got information about their disease. A follow-up question was to find out participants' thoughts and feelings when they got to know about their diabetes status. The interest was to identify participants' mental and emotional state and reactions upon knowing they had got the disease.

The participants were again asked to describe any advice, information or help they received when they were first diagnosed. In order to be diagnosed with diabetes, there must have been particular life styles participants led. Therefore, there was a question that elicited how participants lived their lives before diagnoses and how their lives had changed after diagnosis. They were asked to describe a typical experience of living with diabetes in the rural area. Questions included: "Who do you contact about diabetes if something goes wrong?" "Which aspect of the illness frustrates your life?" "How has your family reacted to your condition?" "What kind of support have you received from your family?" Another question was: "How far is the nearest hospital and how often do you visit the hospital?" They were also asked if they visited other places apart from the hospital and some challenges they encountered. Diabetes requires a life-long treatment and change in life style patterns; so, participants were asked how they

coped with the condition, taking into consideration the situation in which they found themselves. Finally, participants were asked if they had any other information to share that had not been asked. There was an attempt to really understand participants' stories rather than just following an ordered set of questions.

## **Data Processing and Analysis**

The interview data collected were transcribed to text format. Interview texts were then crossed checked with footnotes taken during the interview to ensure that the texts reflected what participants described. Having done this, the analysis was done in accordance with principles and guidelines of interpretative phenomenological analysis outlined by Smith, Jarman and Osborn (1999). In doing interpretative phenomenological analysis, it is important to withhold all previous knowledge, experiences and ideas about the phenomena (experiences) under investigation (Langdridge, 2007; Smith & Osborn, 2003). The analysis followed the following stages:

Stage One: Reading and Rereading of Texts: In this study, the texts produced from the interviews were read several times, and notes that reflected the initial thoughts and observations of the participants were taken down. This enabled familiarization with the texts in order to an understanding of participants' experiences. Again, the transcripts were read several times in order to ensure that the true meaning of the text had been captured and understood. The initial notes and comments were often recorded at the left margin of the transcript (See Appendix G).

Stage Two: Identification and Labelling of Themes: During the second stage of analysis, themes were formed from the texts using the notes that had already been made. This was done separately for each interview transcript. These themes reflected psychological and theoretical terms, and were recorded on the right-hand margin of the transcript. All the themes identified at the second stage were listed on a separate paper. Stage Three: Introducing Structure (Deriving Meaning): At this point, themes were grouped into clusters to introduce a structure into the analysis and themes that shared a common link; ideas were grouped into one cluster. Each original transcript was constantly referred to in an attempt to restructure the themes. Themes were reordered in a coherent manner and a label given to each cluster of themes.

Stage Four: Production of Summary Table: Finally, there was a production of summary table of themes with titles, relevant quotations and line numbers from the original texts. Analysis was done for subsequent transcript using the same principles and stages stated above (See Appendix H for individual summary table). Stage Five: Integrating Cases: Themes from each participant's transcript were captured in order to identify common themes and new ones. The themes identified from the various transcripts were finally integrated for a final list of Master Themes and their constituent themes. These themes were given superordinate themes which reflected the essence of participants' experiences in the rural area.

Stage Six: Discussion with an Expert (Supervisor): The final master theme was discussed with the supervisor to ensure that all the experiences of the

participants had been captured by all the superordinate themes. The integrated master themes with constituent themes are shown in Appendix I.

Reflexivity and the role of the researcher (Bracketing)

It is important to acknowledge the researcher's role in the documentation of the research since the research process unavoidably shapes the object of inquiry. Reflexivity requires an awareness of the researcher's contribution to the construction of meanings throughout the research process, and an acknowledgement of the impossibility of remaining 'outside of' one's subject matter while conducting research (Willig, 2008). Reflexivity means acknowledging personal 'biases' (Willig, 2008). Personal reflexivity encapsulates reflecting upon the ways in which our own experiences, interests, values, beliefs, political commitments, social identities and wider aims in life have shaped the research study. Reflexivity is important in qualitative research because it helps to ensure that the entire research process is scrutinized and examined thoroughly and the researcher constantly review his own role in the research.

The research was borne out of the interest to highlight the needs and challenges of people living in rural areas. This interest emanates from the fact that the researcher was born and brought up in rural area, and had experienced the challenges of living in rural area. Again, there is a history of a relative who died of diabetes and that adds to the situation that heightened the interest to study into the diabetes phenomenon. However, these experiences did not influence the interpretation of participants' perspectives about the disease. Since the researcher lived in the rural area and stayed in the region for quite some time, it did not

influence his opinions and thought during the interview session and analysis. The purpose of the study was strongly upheld throughout the study by cutting any connection with the topic or the participants. In view of this, none of the participants selected were related to the researcher. There was a consistent self-reflection to ensure that the study considers the perspectives of the participants. Again, the self-reflection helped to examine the researcher's beliefs, values and assumptions about the phenomenon. A conscious effort was made to ensure that the analysis of transcripts, development of themes, and discussions resonate with participants' world view.

#### **Ethical information**

Before data collection, ethical clearance was obtained from the University of Cape Coast Ethical Review Board (UCCIRB/CES/2019/04). This was to ensure and safe guard every ethical consideration of the participants. Approval was also obtained from the various local hospitals from where the participants were selected. Informed consent was also obtained from each eligible participant after they had been provided with detailed information about the study. Each respondent was informed of his/her right to withdraw from the study at any time without suffering any negative consequences. Names of the respondents were not included in the study report. In order to conceal the identity of the participants, pseudonyms were used to represent the names of participants throughout the study. All information gathered from study participants was treated confidentially and anonymously. No physical risk was involved in this study since interviews were carried out at the hospitals premise. However, it was explained to

participants that some minimal emotional risk might be involved. This is because participants were asked for detailed accounts of their experiences that might be unpleasant. In order to deal with these emotions, participants were counselled before and after the interviews. During the interview, they were constantly reminded that their participation was voluntary and they had the freedom to quit at any point in time if they were not comfortable with the line of questioning.

# **Summary**

The chapter established the research strategy and guidelines that were used which supported the qualitative means of answering the research questions. Rationale for using phenomenological approach was justified, and the philosophical position for the use of phenomenology was underpinned by the social construction or interpretive approach with more subjective and rational thought. Sampling procedures, data collection instrument (semi-structured interview guide), data collection procedure and analysis of interview data were done in accordance with IPA guidelines. All ethical procedures involved in the study were dully addressed.

The next chapter presents the results of the analysis of the interview data and discusses them in relation to the literature.

#### **CHAPTER FOUR**

#### **RESULTS AND DISCUSSION**

The purpose of the study was to explore the lived experiences diabetics living in rural areas in the Eastern Region of Ghana. Descriptive Phenomenology was adopted since the study was interested in the experiences of patients. Patients were conveniently selected and interviewed using the semi-structured interview guide, and interviews were recorded. The audio-recorded interviews were transcribed into text format for easy analysis. The transcription and analysis were done in line with IPA guidelines suggested by Smith et al. (1999). Peer review and debriefing, member checking, external audit and reflexivity (bracketing) were used to validate and ensure trustworthiness of the analysis. Both ideographic and nomothetic approaches were used in the presentation of the findings. This is because some themes were not common to the participants but they were, however, rich enough to be represented. The extracts used were those that were frequently expressed by the participants, and also represented the common themes. Pseudonyms were used to conceal the identity of the participants. The discussions of the themes were done in line with the research questions.

#### **Background Characteristics of Patients**

Table 1 shows the background characteristics of respondents. Twenty six of these participants were type 2 diabetics, and the remaining five had been diagnosed with Type 1 diabetes. The participants were made up of 25 females and six males suggesting that more females attended diabetes clinics than men. The ages of participants ranged between 33 and 89 years; with a 33-year-old being the

youngest interviewed and an 89-year-old being the oldest. In terms of marital status of participants, 13 of them were married, eight widowed and five single. Additionally, three were divorced and two were separated. Participants were mostly farmers and traders (28). Only two were seamstresses and one a food vendor. Majority of them were farmers since they were from the rural areas where agrarian activity is dominant.

Most of the patients were born in the rural areas, and they had lived and spent all their lives there. Thus, some had stayed at their current abodes from birth to over 60 years. There were few who settled there because of marriage, or relocated to the rural area after retirement. Again, others had to move and stay with their relatives in the rural area after they had been diagnosed diabetic. This shows that on the average, participants had stayed in the rural area for more than 15 years. This means that participants living in these areas would be able to articulate the dynamics and challenges that came with living with diabetes. They would be able to give a detailed description of their experiences of having to commute from the rural areas to access health care in towns and cities. Additionally, from the perspectives of participants who had stayed in the rural area for over 10 years with diabetes, readers will be able to understand the health implications of staying in the rural area, challenges associated with diabetes, support systems, and management strategies available.

The years during which participants had the diabetes varied greatly. The shortest period during which a patient was diagnosed for diabetes was one year, while the longest period a patient had lived with diabetes was 25 years. In terms

of medication, five patients reported that they had been on insulin injection, 23 had been taking drugs only, and the remaining three participants used both insulin and drugs. This shows that majority of the diabetics were being treated with drugs any time they visited the clinic for their regular appointment. The appointment schedules of patients to clinic ranged between two weeks and four months, with majority on a two-month schedule. The appointment schedule was often dependent on the patient's condition, and availability of drugs.

Ten of the patients representing 32% (n = 10) indicated that diabetes was a family illness. They had a history of diabetes in their families. Patients were asked to indicate their first point of call in case anything happened to them concerning the illness, and considering where they stayed: 71% (n = 22) of them indicated that they called either their children (family members) or church elders since they were close to them. Most patients called on family members when they realized they were in crisis. Others still doubted the symptoms and therefore ignored the sickness until it got worse when there was little to be done about it. On the other hand, 29% (n = 9) opined that they went to hospital because they had been advised by the doctors to report back to hospital for treatment as early as possible whenever they experienced the symptoms. Therefore, they believed going to see the doctor or reporting first at the hospital was the best option. The study proposed five research questions and answers have been provided to all of them.

**Table 1: Background Characteristics of Participants** 

Characteristics	Frequency	Percentage (%)
<b>Types of Diabetes</b>		
Type 1	5	16.1
Types 2	26	83.9
Gender		
Males	6	19.4
Females	25	80.6
Age Range	33-89	
Marital Status		
married	13	41.9
Widowed	8	25.8
Single	5	16.1
Divorced	3	9.7
Separated	2	6.5
Occupation		
Farmers/Traders	28	90.3
Seamstress	2	6.5
Food vendor	1	3.2
Years of Diabetes	1 – 25 years	
Appointment Schedule	2 months	
Medication		
Insulin Injection	5	16.1
		74.2
Drugs Insulin Injection & Drugs	3	9.7
Family History		
Yes	10	32.3
No	21	67.7
First Point of Call		
Family/Church members	22	71.0
Hospital	9	29.0

Source: Field Data, 2020

## Research Question 1: What Events Led to the Diagnosis of the Disease?

The research question focused on the events that led to the diagnosis of the disease by patients. Thus, it aimed at exploring the events that enabled patients to recognise that they had diabetes. In view of this, patients were asked how they got to know that they had had diabetes. These included the bodily changes that indicated the presence of a disease, initial lifestyle. Questions were also asked about patients' perception and knowledge about the disease. This research question generated the following themes: symptoms identification, initial lifestyle, and perception about the disease (see table 2). It was therefore important to appreciate patients' understanding of the disease; how they recognised the presence of the disease (symptoms identification), the negative lifestyle that might have contributed to the incidence of diabetes, how they perceived the disease and their general knowledge about diabetes. The themes are summarized in Table 2.

## **Symptoms Identification**

Patients recognised the presence of the disease through the symptoms and bodily changes they experienced. Symptoms are subjective means or ways of indicating the presence of an illness, usually from the perspective of patients. In the course of this study, one of the symptoms noted by the participants was frequent urination (polyuria). Frequent urination was cited by majority of the patients interviewed as the symptom that got them worried and so they had to seek for further clarification or confirmation from hospital. Some patients complained they could urinate throughout the night, and in actual fact, the urination was in excess.

Table 2: Events led to the Diagnosis of the Disease and Patient's Perception about Diabetes

	Number of
Themes	Participants
Symptoms Identification	
Frequent urination and sweet urine	13
Frequent thirst and hunger	7
Weight reduction	2
Regular check-up/Blood pressure	5
Blisters, foot sore (wound)	4
Initial Lifestyle	
Drinks alcohol	9
Poor eating habit (Loves sweets and meats)	22
Patient's Perception	
Positive view of the disease	7
Spiritual cause	3
Disease of the rich	9
Dangerous disease (Kills easily)	5
Limited Knowledge	7

Source: Field Data, 2020

This often interrupted their sleep since they had to wake up most of the time since urination occurred at short intervals. This was the account given by Participant 9:

I was urinating too frequently; about 10 times a day. I didn't understand why I was urinating too frequently. So, I decided to come to this hospital.

To Participant 9, she could not understand why she was urinating that excessively so she eventually decided to go to hospital for confirmation.

Participant 2 also disclosed to the interviewer that her frequent urination made her discuss the issue with the husband who advised her to go to hospital.

I was urinating frequently. So, I informed my husband, and he asked me to come to hospital and check.

It was interesting to note that some diabetics tasted their urine for initial confirmation that the urine was sweet. This is because patients came to know that sweet urine could signal the presence of diabetes. This information was received either on the radio as in the case of Participant 1, or given to them by the nurse at the hospital. This is what Participant 1 had to say:

...what I hear on radio is that when you get diabetes, your urine tastes sweet; even when you urinate, you see that ants will gather around the urine on the ground. Anytime I urinate, I will see ants around there. So, when I was urinating, I decided to taste the urine, and it was sweet; that made me come here.

According to Participant 1, she saw ants gather around the urine anytime she finished urinating on the ground. This was regular and that kept her wondering what the problem could be and that made her taste her urine for confirmation of its sweetness.

Participant 30 also added that seeing ants at where she urinated made her complain to her sister who advised her to taste her urine. She tasted, and it was sweet. According to Participant 30:

...during that period, I used to urinate a lot and sometimes I found ants at the place where I urinated, so my sister advised me to taste my urine and it tasted sweet...

To some diabetics, excessive urination resulted in weight reduction (Participant 24), frequent thirst (Participant 11) and hunger (Participant 7). Participant 24 gave the following account:

I urinated frequently when I went to sleep in the night; again, I realized I was losing weight.

The frequent and excessive urination caused patients to thirst for water (polydipsia) at brief intervals. Expectedly, the more frequently they drank water, the more frequent the urination. This was the case of Participant 11:

I have been urinating frequently... and I frequently become thirsty. When I'm thirsty, I drink plenty of water and once I drink water, I have to urinate. So, I came to hospital and check what is happening.

Another account given by a patient was that she experienced frequent hunger but unfortunately, she could not eat. This eventually led to a reduction in weight. This was because in uncontrolled diabetes where blood glucose level remains abnormally high (hyperglycemia), glucose from the blood cannot enter the cells due to either low production of insulin by the pancreas, or insulin resistance (Seeley et al., 2000). Participant 7's condition prompted her children to bring her to hospital for a thorough examination and diagnosis. Below is the experience of Participant 7:

First, I was urinating frequently... At some point I felt hungry, but I could not eat. Whatever food I requested for was given me but I would lose appetite there and then. But in a short while I would feel hungry again. The urination was excessive, and I lost weight too. So, my children decided to bring me to this hospital...

Aside the above symptoms that caused patients to recognise the presence of the disease, some of the diabetics observed that they got to know they were diabetic after they had fallen sick and visited hospital. Thus, their diagnosis of

diabetes came at a point they had to visit hospital for treatment of some other illness. They never experienced any of the signs that indicated the likelihood of being diabetic, indicating the asymptomatic nature of diabetes. Participant 10 had this experience to share:

I fell into coma and I was rushed here. That was when the doctor told me it was a symptom of diabetes. For me, it didn't give me any information. I didn't see any signs or symptoms.

Another patient shared a similar experience:

Before the onset of the diabetes, I was experiencing pains in my heart; later I collapsed and I was admitted here. It was on admission that the doctor told me I had diabetes. (Participant 13)

From the accounts of Participant 10 and Participant 13, it was at the hospital and on admission that they were informed of being diabetic. They were in the hospital for a different reason other than the presence of diabetes but they ended up being diagnosed of diabetes.

Some of the patients made it known that they had diabetes through blood pressure (BP); they were known BP patients at the clinic which had put them on medication. So it was through their regular check-ups that it was confirmed they had had diabetes. This was the narration of Participant 16:

I had BP; sometimes when I went to check, it would be around 180/140mmHg or 160/100mmHg. So, another time I went, I was told I had diabetes the level of which was around 5.6mmol/L. Since then, I have been battling with it and recently my sugar level recorded 24mmol/L, the highest.

The constant rise in Participant 16's blood pressure resulted in the diagnosis of diabetes. Unfortunately, he had been battling with the high levels of glucose in his system since he was diagnosed. Similarly, Participant 23 shared the view that it was during one of her regular visits to hospital for BP medication that she was told to go for laboratory text. The text revealed that she had high levels of glucose in her blood. She was confirmed to be diabetic in addition to the BP so she was given medication for diabetes as well.

I had BP so they asked me to go to the lab and check and when I came, they told me there was sugar in my blood. So, they gave me medicine for diabetes...

A sign that was evident among some patients was blisters and foot sore. According to Participant 25, he saw blisters around the leg close to the ankle; it was painful and itchy. This is his observation:

What happened was that before this leg was amputated, it felt itchy and numb. I thought it was foot rot; so, I scratched it. One day I saw blisters around the foot area and I thought it was foot rot. So, I used orange sticks to scratch it and I realized there was fluid coming from it. That part of the body was quite swollen and hard. I didn't understand so decided to bring it to hospital.

From Participant 25's narration, he could spend time scratching the blisters due to its itchy nature. This eventually developed into a sore which spread to other parts of the lower foot. This was the experience he had which made him decide to go to hospital for treatment. Some diabetics became aware of the disease as a result of the wounds on the body, especially on the leg. These patients got wounds by hurting themselves mostly on their farms or through falls. These

wounds took much time to heal; others wounds could not heal at all even though they were being managed. Patients were then advised to run some tests for confirmation; most tests were positive. Participant 28 shared her experience:

When I went to farm, I hit my leg against a tree and I got wounded. It got swollen, and I brought it to hospital. I applied treatment to the wound, but my leg was still swollen. So, I brought it back to hospital, and I was told I had had diabetes.

Considering the experience shared by Participant 28 on the signs and symptoms of diabetes, she never had the blisters on the foot though she was wounded on the farm. The wound never got healed after she had been on medication for some time. The wound rather worsened, and the leg got swollen.

Participant 26 shared her experience of having a swollen leg which eventually turned into sore which never got healed. It was during one of her regular visits to hospital for treatment of the wound that she got to know she was diabetic.

One leg got swollen, and it became sore. It could not even heal.

(Participant 26)

From the accounts given by the patients above, it could be inferred that some of them had confirmation of their diabetes from hospital after clinical investigations had proved positive. In most of the hospitals, as soon as a patient reported of signs and symptoms of the disease, even though medication started as soon as possible, it would be concluded that a patient was diabetic after the various tests had been conducted, especially the random blood sugar test to

measure the glucose level. One case of interest is where the patient visited a herbalist for treatment after she realized that she had been urinating excessively in the night. This is the experience of Participant 27:

When it first started, I went to a herbalist but the illness persisted...

Yes, when I first went to hospital, I was told it was diabetes.

It could be seen from Participant 27's experience that she might have had little knowledge about the signs and symptoms of diabetes from either the mass media or friends and relatives. She might have been informed that the best way to manage or cure the disease was through herbal treatment, and that explained her first point of call at the herbalist. Upon realizing that she was not getting better with treatment from the herbalist, she came back to hospital for biomedical treatment.

It was found that patients were first diagnosed of diabetes after they had presented symptoms such as frequent urination and sweet urine, frequent thirst and hunger, weight loss and foot sore (wound). Some also confirmed being diabetic after they visited hospital for regular check-ups or being treated for other conditions. The evidence of frequent urination, sweet urine, frequent thirst and hunger have been reported by IDF (2017); Habte et al. (2016); Metta et al. (2015); Metta et al. (2015); Mwangome et al. (2016); Walker (2008); and Zimmermann et al. (2018). A study conducted in Southeastern Tanzania by Metta et al. (2015) on the use and continuity of medication by diabetics, identified frequent urination, fever, and fatigue as symptoms reported by patients. This corroborates the subsequent findings of Metta et al. (2015) in which participants associated

symptoms of diabetes with those for malaria and other diseases. Again, Walker (2008), Nyarko et al. (2014) and Darkwa (2011) highlighted that patients reported for medical attention after the onset of symptoms such as excessive thirst, fatigue and urination. Mwangome et al. (2016) and Zimmermann et al. (2018) also found that patients sometimes tasted their urine to determine the presence of high sugar levels after they had recognised that their urine attracted ants. The tasting of the urine for sweetness was influenced by social factors (family, friends, and media) as reported by Zimmermann et al. (2018), and in some cases, lack of funds for blood tests (Mwangome et al., 2016). This is because patients turned to family members and friends for advice and as the first points of call when symptoms of diabetes were recognised (Matta et al., 2015). Additionally, the practice of communalism among rural dwellers promotes sharing of an individual's problems by the entire community. Expectedly, health facilities were not close enough for easy accessibility, and the individual may lack adequate knowledge about symptoms of diabetes and that could explain the reason patients sometimes contacted family and friends for information about the symptoms experienced.

Patients in the current study reported at hospital for confirmation and medical attention, and this was consistent with the findings of Walker (2008) because the symptoms experienced were recognised by the patients themselves. This contradicts the findings of Zimmermann et al. (2018) and Habte et al. (2016) which stated that health care professionals mostly recognised the symptoms first before the patients. Other studies (Hjelm & Mufunda, 2010) also reported that participants could not recognize the symptoms of diabetes when taken ill;

however, they considered it as a different disease. Furthermore, the studies cited above failed to outline the fact that patients also reported weight loss, blisters or foot sore (wounds) and regular hospital visits as part of the symptoms that led to the diagnosis of the disease; however, these were evident in the current study.

In line with Leventhal's theory (1984), patients recognised the disease through the symptoms perception they experienced. Some patients had the information about the disease through social messages from family members and friends who advised them to taste their urine when they realized they were urinating frequently and also check for ants at where they discharged urine. These symptoms were confirmed by doctors when patients visited hospital for check-up. Patients integrated these representations with existing schema often influenced by social and cultural factors (Brownlee, Leventhal, & Leventhal, 2000; Leventhal, Brissette & Leventhal, 2003), and these schemata eventually enabled patients to make sense of the symptoms that guided their choice of action. Mora, Robitaille, Leventhal, Swigar and Leventhal (2002) affirmed that when people experience bodily changes that are strange, new and with unexpected duration, they turned to health professionals for diagnosis and treatment. Doctors were seen as experts who were able to trace the symptoms to an identifiable illness, and recommend appropriate action (Leventhal et al., 2003). It was then that patients interpreted and ascribed meanings to the symptoms experienced. Through the education given by the health professionals, patients identified the symptoms for diabetes as often caused by lifestyle changes, mainly through inappropriate dietary practices or lack of physical activities. Patients understood that it was a life-time disease

(time lines) which could not be cured (control) and could cause financial burden, social dislocation and strain (consequences). Knowledge of the signs and symptoms would help reduce the onset of acute and chronic complications of the disease (Contreras et al., 2017) as this would enable health professionals to intensify health education about the disease among rural dwellers. This would eventually increase health literacy among rural dwellers, patient's skills, and better the quality of life of the individual and community.

#### **Initial Lifestyle**

Negative lifestyle has often been associated with diabetes (IDF, 2017). Some of these lifestyles like poor eating habit (high consumption of sweets and beverages, consumption of high-fat dietary products) increase the risk of diabetes (Malik et al., 2010). Other unhealthy behaviours like drinking, smoking and irregular physical exercise significantly contribute to the rise in diabetes (Hall et al., 2011).

Patients might have engaged in some lifestyle before the diagnosis and as part of the experiences, some factors that complicated or contributed to the incidence were identified. Some patients made it known that they had poor lifestyle, particularly poor eating habits. They were not particular with their diet, and the time of eating. Some could eat late in the night and went to bed immediately after eating. This sedentary lifestyle did not enable the body system to break down the food particles to be used effectively. This is the account of Participant 7:

Those times I could eat at any time. Anytime I am hungry I can eat even when it is late in the night.

Participant 25 also added that:

Before, I didn't have a wife. We divorced, so I was eating at a chop bar. When I returned from the farm, I washed down and went straight to the chop bar. Sometimes when I got there, there would be a long queue so before I got some food it would be late but I would eat at that time then I went straight to sleep.

Other patients also noted that they loved eating sweets and taking in lots of meat. Participant 14 shared her experiences:

I used to eat very late. I enjoyed eating sugary foods. I used a lot of sugar in my diet.

Participant 10 also loved taking sweets and sugary foods. In the case of Participant 16, this was what he said about his initial lifestyle.

I loved taking meat... something like cake and biscuits I used to eat them well but now no... I used to drink alcohol as well.

Another initial lifestyle that was identified was the craving for alcohol. Some patients admitted drinking alcohol heavily before the diagnosis of the disease. In the words of Participant 6 this is what he had to share:

I used to drink a lot... Akpeteshie; beer, I love sweets, like fan milk, meat pie... My favourite meat was pork. I used to enjoy it a lot.

Considering his experience, his general lifestyle was poor. Similarly, Participant 28 explained her initial lifestyle as follows:

I was drinking alcohol. I was selling it, so I drank some for appetite. Sometimes I could drink heavily, I would drink to stupor. It was that which the nurses told me was a contributing factor of my diabetic condition.

For Participant 17, her craving for alcohol was so intense that she ended up being an alcoholic. She added that she used to eat to be overly satisfied. Alcoholics have poor nutrition, which eventually triggers the incidence of diabetes. This is because the moderate amount of alcohol a person takes may cause a rise in sugar levels. Excessive alcohol can actually decrease blood sugar level, sometimes causing it to drop to dangerous levels that may affect will power for making poor choices (Polsky & Akturk, 2017). All these experiences narrated by the patients seem to have contributed to their illness.

The above findings corroborate other studies that found out that unhealthy lifestyle such as consumptions of high sugar diet and beverages are risk factors for diabetes (Imamura et al., 2015; InterAct Consortium, 2013; Malik et al., 2010). Again, Tabong et al., (2018) found out that diabetes patients in Brong Ahafo Region of Ghana engaged in behaviours such as unhealthy eating, lack of exercise and sedentary lifestyle that were high diabetes-related risk factors. It was noted that patients engaged themselves in these lifestyles despite their prior knowledge about the effects. Since participants in the current study engaged in some unhealthy lifestyle before diagnosis, it is suggested that health promotion must be targeted at the community levels, especially those in rural areas, to provide adequate health information. Community sensitisation and health education must consistently highlight possible lifestyle activities that make people

vulnerable and predisposed to the disease.

# **Patient's Perception of Diabetes**

Again, the interest was to identify the perception of patients about diabetes. It was discovered that few patients had a long-held negative belief and perception about diabetes, and this influenced their attitude towards the disease. Some were of the view that it was "disease of the rich". The reason for this perception was that it was only the rich who could afford every kind of food and enjoy living a luxurious lifestyle, so eventually they ended up getting diabetes. Furthermore, patients believed that management of diabetes was financially demanding and it was the rich who could afford all the drugs and other management strategies. To the patients, it was surprising for a poor person to get the disease. It was this perception that sometimes influenced the psychological reactions and emotional outbursts of patients. Participant 8 expressed her negative perception as:

I wonder, after eating too much plantain, how come I had this disease. I thought it was disease meant for the rich so how come I had it. My family is not rich.

Few believed that diabetes had a spiritual cause, so the patient had no control over the disease. Thus, some believed they got diabetes through the work of evil spirits or even through a curse by the gods they served. It was thought the disease had no biological connection, and this evoked a lot of fear among some patients, and heightened the dreadful nature of the disease. Participant 22 had this to say:

I also heard that it can be bought for you spiritually, so I thought that was what happened to me. In fact, I was really scared.

To some rural dwellers, anything that happened was attributed to the smaller gods they served or to evil spirits. Some went to a man of God (pastor) who told them that it was somebody who put the disease in her food.

I went to a man of God and he told me it was somebody who put it in my food for me to eat (the case of Participant 8)

Others were of the view that diabetes was a dangerous disease which could kill very easily.

It is not a good illness, it is dangerous (says Participant 22)

Patients' perception about the disease points to the fact that they got the information from friends and other people who did not have much knowledge about the disease. This is because when asked where they got the information from, the chorus response was that "they heard that..." As to where they heard it from, they could not give specific answers. Thankfully, some of these perceptions were corrected when patients were given some information at the hospital concerning the disease. The doctors and nurses were able to educate patients on the cause of diabetes; that it was not a spiritual disease, neither was it a dangerous disease that killed easily. All that patients needed to do was to concentrate on taking the medication and managing the condition effectively.

From the interviews, it was realised that patients had limited knowledge about the disease. Some narrated that they never knew or heard about the disease until the very day they were diagnosed. This means they did not know anything about its causes and management. It was the doctors and nurses who gave patients information about the disease. Others explained diabetes as *sugar disease* and that was all they knew about diabetes.

I don't know; all that I know is that they call it sugar disease because of the sweetness of the urine. (Participant 7)

It was the best explanation and definition patients could give to the disease. Apart from frequent urination which participants stated early as the symptom they identified; they did not know anything else about diabetes. From the transcripts and interactions with patients, it was found that their knowledge concerning diabetes, its causes, signs and symptoms, and management was woefully inadequate. Apart from the information patients were given about the disease from the hospital, none of the patients spent time to search for additional information on diabetes. The use of the expression "sugar disease" was also reported by Aikins (2003). This was the simplest definition given by doctors, nurses and sometimes family members, friends and the media that patients often relied upon. Some patients could give information about the symptoms because of their personal experiences and discussions they had about the disease with relatives or friends in the rural areas. When asked about the management of the disease, patients were able to give brief information about what the doctors told them. This was what Participant 1 said:

The nurse at that time advised that I should not be moving from one place to the other in search of cure. Because if you suffer from diabetes, you may think somebody has done juju against you so she said I shouldn't be frightened over this and be using different kinds

of drugs. I should make sure the drugs given to me at the hospital, I take them accordingly and also eat well. I should take some in the morning and one in the evening. If my sugar level is down or high then they know what to do. I should not eat in the night. This is what was given me till date.

It was evident from the results that some patients had positive perception about the disease and this was also confirmed by the findings of Metta et al. (2015). On the contrary, studies in Ghana (Aikins, 2003, 2005; Tabong et al., 2018) and other African countries (Hjelm & Mufunda, 2010; Hjelm & Nambozi, 2008; Metta et al., 2015; Zimmermann et al., 2018) have confirmed these negative perceptions of diabetics expressed by patients in the current study. One of the objectives of Aikins' (2003) study was to examine how diabetics made sense of the disease, health and illness in general. The research sampled diabetes patients from rural and urban areas, the rural people stating that diabetes was "nto yare" (disease bought spiritually), meaning the disease was caused by a spiritualist who was contracted to do so. This made patients seeks for spiritual intervention to cure or manage the disease (Aikins, 2005; Metta et al., 2015; Tabong, 2018). Metta et al. (2015) also explored the meaning participants ascribed to diabetes symptoms and care-seeking practices. It was reported that the respondents perceived the symptoms to be caused by witchcraft and when the patients reported to the traditional healers, they also confirmed to the patients that they had been bewitched. Despite the negative perception held by some of the patients that the disease was caused spiritually, majority of the patients in the current study did not engage in healer shopping as found by Aikins (2005). Aikins found out that patients healer shopped by moving from one healer to another in search for cure. Interestingly, these healer shopping behaviours worked for some time but later patients' conditions worsened. These patients often returned to the hospital when the condition worsened after realizing that their health was deteriorating. Almost all the patients in this study did not engage in healer shopping probably due to the education or information given to them at the time of diagnosis as well as when they went for their regular check-ups.

Again, the evidence that some patients associated the disease with affluence is consistent with the findings of Aikins (2003) in which participants used the expression "esikafoo yare" (disease of the affluence), and in the works of Tabong et al. (2018), participants referred to it as a condition of the aged and the rich. In the same study (Aikins, 2003), participants explained that it was only the rich who were prone to diabetes since fatty foods and sweets were mostly patronized by them. Additionally, the rural participants associated the disease with affluence due to the financial burden involved with its management because of the need to buy expensive biomedical drugs and to eat healthy foods (Doherty et al., 2014; Hjelm & Mufunda, 2010). This suggests that patients of the current study believed that for a person to be diagnosed with diabetes and for a patient to live a healthy life without any complications, the person should be rich enough to afford luxurious lifestyle and access good health care, respectively (Aikins, 2003). This assertion by the rural participants may not hold true since diabetes is known to afflict people from different socio-economic backgrounds, old and young, literate or illiterate, rich or poor and rural or urban. This is because patients in this

study had spent the greater part of their lives in rural areas and they were not necessarily rich, yet, they were diagnosed with the disease. This was evident in the background characteristics of the patients because they had stayed in the rural area for the greater part of their lives. Factors like prenatal exposure to famine or childhood malnutrition (van Abeelen et al., 2012; Jiang, Ma, Wang & Liu, 2013; Li et al., 2017; De Rooij et al., 2014; Zabuga & Vaiserman, 2017), stress (Hackett & Steptoe, 2017; Kelly & Ismail, 2015; Persaud & Williams, 2017), and genetics (Kumar et al., 2015; Park, 2011; Yu, 2012) could predispose people to diabetes later in life, but not necessarily on their economic status.

Patients in the study considered diabetes as one of the most dangerous diseases in the world and this was their fears. This is because both hypoglycemia (low glucose levels) and hyperglycemia (high glucose levels) exhibit more or less similar serious signs and symptoms. This means it is imperative for the monitoring of glucose levels all the time to avoid any serious attack. Furthermore, refusal to take medication on time or taking different meals or anything apart from the prescribed diet was another issue that made patients believe that diabetes was a dangerous disease. Patients narrated that it was really a hell to live with diabetes since they were to manage it for the rest of life. Health promotion and education should be carried to the door steps of these vulnerable rural dwellers. Patients must not always come for diabetes clinics in towns before they receive information on diabetes; rather, community health workers must regularly educate members of the community through durbars, and public address systems in the communities to broadcast information on health.

In terms of patients' limited knowledge on diabetes, similar studies have identified the lack of in-depth knowledge about the management of diabetes among patients in Africa (Adeniyi et al., 2015; Booysen & Schlemmer, 2015; Hjelm & Mufunda, 2010; Metta et al., 2015). This limited knowledge is a result of inadequate information provided by health care professionals, and the hurried nature in which they attended to patients. It was noted that information on diabetes was given only at the hospital. This means that information on health should not be limited only to the hospital. Public health officers and community health workers should pay regular visits to rural areas and organise health sensitization programmes for diabetics on how to monitor their health condition, and to conscientise them on management strategies. This would go a long way to reduce complications.

It could be found from this research question that events that led to the discovery of the disease was through the symptoms experienced which included frequent urination/sweet urine, frequent thirst, weight loss, regular hospital visits (BP) and blisters/foot sore(wound). Patients noted that initial lifestyles such as drinking alcohol, and eating sweets and fatty foods contributed to the development of the disease. Few patients had negative perception about diabetes as they perceived it as disease of the affluence, or spiritually induced and dangerous. This shows that most patients did not have in-depth knowledge about diabetes. One thing that was evident in the findings was the fact that family and friends provided patients with some information about symptoms of diabetes

before patients visited hospital for confirmation. This social influence affected patients' symptoms interpretation, perception and knowledge about the disease.

# Research Question 2: What are the Psycho-emotional Experiences of Patients after Diagnosis?

It was important to explore the psychological state of patients after diagnosis since diabetes is often associated with psychological and emotional disturbances (De Groot et al., 2001). The psychological and emotional reactions of patients helped to recommend appropriate means of dealing with patients if none existed. In view of this, patients were asked about the thoughts that came to mind and how they felt when told about the disease. There were further probes as to why patients experienced those thoughts and feelings. This enabled patients to talk about their psychological and emotional experiences and how they managed them. The main themes that emerged from the phenomenological deduction were psychological shock and emotional outburst. This is shown in Table 3.

Table 3: The Psycho-emotional Experiences of Patients after Diagnosis

4	Number of
Themes	<b>Participants</b>
Psychological Shock	
Shocked (Surprised)	9
Frightened (Fear and Terrified)	4
Frustration (Lost hope) NOBIS	3
Worry (Excessive thinking)	12
Self-blame (Self-questioning and Disbelief)	2
Suicidal thoughts	1
Emotional Outburst	
Wept (Sad and Pain)	23
Hyperactive	4
Emotional exhaustion (Confronted with reality)	4

Source: Field Data, 2020

# **Psychological Shock**

After hearing the news of testing positive for diabetes, most of the patients experienced a sudden intense feeling of fear, as they were taken by surprise because of the danger the disease poses to one's health and well-being, and the stress involved in its management and treatment. Patients got frightened upon hearing the results of the diagnosis.

I was frightened because I have never seen anybody with that illness in my family. Even my mother who was very old did not have that illness. (Participant 22)

Diabetes could be dangerous and can lead to death if the treatment process is not started on time, and intensive care and monitoring not delivered to the patient (IDF, 2017). As a result of the severity of the disease, patients had no choice but exhibit fear for the state of their health and well-being. Participant 11 had this to say:

I was afraid because it is a scary disease. People often say diabetes kills so I was afraid.

The fear expressed is due to the scary nature of the disease and sometimes the financial burden it imposes on the patient which may eventually lead to her death; its cure was a lifetime struggle. Participant 5 was frightened because she thought the disease affected only the elderly so she was surprised at how a young lady like her could be afflicted by such a disease. This is how Participant 6 narrated his fears:

It was diabetes that killed my father. So, when I was told that I had it, I was terrified ... How it killed my father: I saw everything. My father got blind and had stroke in addition. He was bed ridden for seven years before he died. I knew how it affected my father. I was the one supporting and carrying him around.

Others were shocked and terrified due to their perception of diabetes as a disease that affected the rich. *I was shocked, frightened and I cried*, says Participant 21.

Getting to know that diabetes was a chronic disease made patients anxious, especially with the thoughts of taking medicine to manage the sickness for the rest of their lives. These thoughts and their effects haunted patients, resulting in emotional and psychological instability (excessive thinking). Some patients could not believe the results of tests conducted on them. It was a moment of disbelief for Participant 29.

I didn't believe the first time they told me.

For her, it was difficult accepting the results of the laboratory tests. Worry was one of the psychological shocks experienced by the patients. When the news was broken to patients about testing positive for diabetes, the threats of the disease to health of the patients caused anxiety about actual or potential problems related to the disease. Because of the dangers attributed to the disease, most of the patients became anxious and began to worry about their future with the disease and the stress involved in managing it. This is because the treatment process is time consuming which was going to affect patients' daily activities and thus

having a negative impact on their lives. This was the perspective of Participant 12:

I was really sad, and it worried me. My grandmother had diabetes before she died and she was 95 years. My mother was also diagnosed of this same disease and she has been coming for check-up here, but hers is better now. So, I was very worried.

However, Participant 4 was not bothered about the outcome of the laboratory tests being positive or negative. This was because he knew it was a congenital disease, so it was not a surprise to him.

I thought it was a family disease so I was not bothered at all.

It was a frustrating experience for some of the patients when they realised that they were not in control of the outcome and the challenges associated with diabetes. Patients were frustrated by their inability to take control over their lives and achieve something meaningful, in addition to difficulties in dealing with the challenges that the disease presented. This could be deduced from the experiences of Participant 3:

What frustrates me most is the urination. I can urinate all day and it is that which disturbs me. I urinate at short intervals. Additionally, I experience discomfort in my stomach and this also worries me.

This led to loss of hope on her part. *I don't have any hope from anywhere*, says Participant 3.

Some patients attributed the occurrence of the stressful condition to themselves, taking responsibility for their actions that led to the disease, and also

questioned their own actions and motives as to why they were in that particular situation. This was how Participant 11 blamed herself:

When the doctor said it, I realized I hadn't taken good care of myself. Because as a seamstress, I don't sleep and I drink a lot of coffee so when the doctor told me, I blamed myself.

She believed her sedentary lifestyle of sitting for long hours and not getting enough sleep contributed to her illness. Like Participant 28 who was a drunkard and always drank to stupor, Participant 11 admitted she would not blame anybody for her disease but rather herself. The two patients wished to have made other choices that could have changed the results of the tests. Other patients also questioned themselves, had flashbacks to their previous lifestyles and wondered how they contracted the disease. Participant 21 had this to say:

I was asking myself about where it came from, how I got it and in which way did I get it. In fact, when he (doctor) told me, I didn't know how it came about. So, when I came back again, I asked the doctor how come I got this disease.

The most threatening psycho-emotional reaction a patient revealed was the suicidal ideation. Suicidal tendency was the available option when he realized that life was not going to be the same as it used to be.

My thinking is that now my leg has been amputated, I cannot do anything again. So, I had a suicidal thought that if I got any poison I would drink and die ... But as I'm sitting here right now what work can I do? I cannot do any work, unless somebody visits and gives me some money to buy some food. (Participant 25)

Participant 25 was emotionally exhausted after being confronted with the reality that his leg had been amputated. To him, there was no need to live since he would no longer be in position to do what he used to do. Thus, he needed to completely adapt to a new lifestyle due to the amputation. It was really a disturbing moment for him upon hearing that his leg would be amputated because of the foot sore. He narrated that he became hyperactive after the surgery. In fact, he refused to eat. Participant 25 was further questioned if he ever tried the suicide to which the patient responded in the negative. He noted that coming to the hospital to see other patients gave him hope. Again, when patients met at the clinic, they encouraged each other and that gave him the hope to carry on with the treatment and realized that his amputation was not a death sentence.

Seeing other patients in that condition gave me hope. Although some patients died three days after the amputation, others have also survived and lived with the condition for many years and they are still doing well. So, sharing experience with such people was helpful for me at that time.

From the excerpts of Participant 25, there is the need to build social networks for patients to encourage each other and to share ideas relating to the disease. Sharing experiences together as diabetes patients will help reduce some of the psychological and emotional distress associated with the disease. Thoughts of harming oneself can be intense and overwhelming and it is common for depressed people to kill or harm themselves. Therefore, patients must be made aware that these are thoughts and that they need not keep to themselves and act on it later. Rather they should make these thoughts known to doctors who can then

recommend treatment. Family members and friends should be made aware of patients' suicidal thoughts so they can call for help at the right time.

#### **Emotional Outburst**

It was really a sad moment for some of the patients. Some were sad because of the fact that they had BP and additionally, they had been diagnosed of diabetes. The thought of taking medication and managing these two diseases was a major challenge for them. This is how Participant 3 described her sadness:

I was sad. It pains me I have BP and I am taking medicine which I think and pray it works and now I have to battle with another disease.

# Participant 7 also had this to say:

I was sad that a poor person like me living on the farms could be struck by the disease. I don't take tea, I go to my farm, return and enjoy some ampesi. I know it is a disease associated with the rich so how come a poor person like me could have this disease. In fact, I have been thinking about it since I was told.

Participant 7 was very unhappy about the thought that diabetes cannot be cured completely, and that she just needed to manage it with medications from hospital. The fact that the illness is lifetime saddened her most of the time.

The sadness led to uncontrollable weeping. It was a heart-breaking experience as some patients could not control their emotions. They wept uncontrollably for the pain of coming to deal with a disease for the rest of their lives. At that point, the only option left for them to express their emotions of pain and sadness was to weep. Some wept at home when left alone, and this was the

case of Participant 2. It was a painful confrontation and she was extremely sad.

This is how Participant 2 expressed her emotion of sadness:

I really wept to the extent that the doctor had to calm me down... I always cried, especially when my husband went to work and I was left alone, I could cry to the extent my eyes reddened and I felt dizzy.

Even during the interviews, patients' narration of their experiences and ordeal with the disease were so emotional that some of them could not control themselves. They broke down in tears at some point, and this led to the suspension of the interview for some time and ensured that patients were emotionally stabilized before continuing. It was very well understood that discussing and sharing such an experience could be difficult and traumatizing moments for some of the patients.

The findings revealed that patients experienced psychological shock and emotional outburst upon diagnosis. The psychological shock included surprised (shock), fear, frustration, excessive worry, self-blame and suicidal ideations. The emotional outburst experienced involved sadness, weeping, and emotional exhaustion. The findings corroborate the work of O'Brien et al. (2015) which posited that being diagnosed with diabetes often comes with a shock that turns a patient's life upside down. It is psychologically and emotionally overwhelming (Walker, 2008), as the diabetic struggles to accommodate the disease. Other studies have reported that upon receiving the news about the diagnosis, patients were shocked, surprised and confused (Zimmermann et al., 2018; Khandan et al., 2018). Almino et al. (2009), Carolan-Olah et al. (2013), Messias and Skotzko

(2000), Stuckey et al. (2014), and Yilmaz et al. (2019) highlighted that patients were frightened, terrified and anxious. Other patients also worried excessively (Hjelm et al., 2018; Manderson & Kokanovic, 2009; Tabong et al., 2018); and disbelieved or blamed themselves (Carolan et al., 2015; Tabong et al., 2018; Zimmermann et al., 2018). Similarly, George and Thomas (2010) used existential phenomenology to examine the lived experiences and perceptions of rural old people on management of diabetes. The findings showed that living with poorly controlled diabetes led participants to introspection and existential questioning.

In a qualitative study conducted by Yasmin et al. (2020) to explore patients' perception of mobile health intervention (m-health) in relation to diabetes management, patients reported that living with diabetes caused them to experience physical and emotional stress such as irritation (anger), frustration, tension, and depression. These psychological reactions were due to the fact that patients considered the geographical location in which they found themselves in relation to accessibility to health care from towns or cities, and the economic burden the illness imposed on them. Furthermore, these reactions stemmed from the perception and beliefs patients had about the disease, and the idea that it was life-long condition which could not be cured (Zimmermann et al., 2018). Zimmermann et al. again noted that some of the reactions were because patients perceived the disease as a threat to their lives. This perception created fear and anxiety in patients (Almino et al., 2009; Messias & Skotzko, 2000). In the works of Manderson and Kokanovik (2009), respondents worried all the time with diabetes diagnosis because they felt the disease would interrupt their daily

activities. Some of these reactions were a rejection of the idea that patients never expected that reporting the symptoms at the hospital would lead to such "unfair" diagnosis (Carolan et al., 2015).

According to the findings of Carolan et al. (2015) and Kalra, et al. (2018), participants indicated that they were distressed. Patients disbelieved when the unexpected diagnosis was given. These psychological distresses in extreme cases caused depression (Manderson & Kokanovik, 2009) and negative psychological consequences (Owusu, 2016) which led to suicidal ideations among patients. This was experienced by one participant whose leg was amputated and had to adopt an alternative lifestyle to manage the situation. Thought of helplessness and hopelessness increased patient's risk of suicidal behaviours. Chung et al. (2014) and Necho et al. (2019) also found that diabetes was associated with a high prevalence and marked increased in suicidal thoughts and attempts. Although some studies (Asibey, 2016; Kalra et al., 2018; Nash, 2014; Owusu, 2016) had reported on depression experienced by patients after diagnosis, none highlighted the extreme cases of suicidal plans and attempts as reported by a patient in this study. Unfortunately, on the part of patients in the current study, health care providers did not provide adequate psychological and psychosocial support (Tabong, et al., 2018) to enable patients cope with the distresses. It was important for health care professionals to have concentrated on the physical, social and emotional needs of patients (Pilger & Abreu, 2007) rather than devoting all the time to the technical aspects involved with the treatment (Almino et al., 2009). Thus, the doctors could have referred the patients to the psychologist or

counsellor to provide patients with counselling and psychotherapy.

Some patients experienced emotional outburst (sadness and wept) and this was similar to the findings of Almino et al. (2009). In examining the experiences of diabetic adolescents and their mothers, Almino et al. (2009) discovered that adolescents expressed emotions of sadness and frustration when they were diagnosed of the disease. This is consistent with the findings of Mensah et al. (2017) which stated that pregnant women with gestational diabetes experienced mixed feelings of sadness, anxiety, fear and surprise. Similarly, Carolan et al. (2015) found out that participants were emotionally exhausted when confronted with the reality because diabetes was emotionally, physically and socially challenging for them. Almino et al. (2009) further asserted that acknowledging the psychological aspects of the disease at the beginning and controlling it was important since the disease could endanger development.

This finding highlighted the need to integrate and establish counselling or psychotherapy unit at the various diabetes clinics to help address these psychological and emotional reactions. As part of the essential elements of evidence-based care, proper health education and counselling are needed especially in the management of chronic diseases (Kruk et al., 2018). Patients must be coached or counselled on the effective ways to deal with their thoughts when they experience emotions of helplessness and hopelessness. This would complement the care given by the diabetes clinics. Again, it would help build the psychological well-being of patients and heal their psychological wound. For example, the patient who had the leg amputated and experienced suicidal ideation

(depression) would require constant counselling and emotional support. This should not end only at the hospital; follow-up checks at home would have been very helpful. Psychological and emotional responses accompanied patients' interpretation of the somatic cues or symptoms perception (Singh, 2011). These psycho-emotional responses were evident in Leventhal's common-sense model as patients experienced fear and anxiety when they recognised the symptoms perception, social messages and interpretation of the disease. This research question highlighted the psycho-emotional reactions that patients experienced after diagnosis. The experiences included shock (surprised), fear, frustration, excessive thinking, sadness, emotional exhaustion, suicidal ideation, and self-blame.

# Research Question 3: What are the Experiences of Rural Diabetics with Health Care System?

This research question sought to understand patients' experiences with the health care system, especially patients' access to health care, drugs, and their encounter with doctors and nurses at the hospital. The interest lay in how patients were treated by doctors and nurses at the hospital, and again, whether patients were satisfied with the health care system. It is believed effective communication and attitude from health professionals will significantly influence patients' commitment towards treatment adherence. Therefore, patients were asked to give a narration of what they went through at the diabetes clinic. They were asked to describe the advice and help they received from the doctors and nurses when they were diagnosed, and if the advice was helpful. Finally, patients were required to

share their experiences on how easy or difficult they accessed health care. The generated themes from this research question are shown in Table 4.

Table 4: The Experiences of Rural Diabetics with Health Care System

Themes	Number of Participants
Accessibility to Health Care Facilities	
Transportation challenge (Long distance and poor road)	9
Long queue (Time consuming)	7
Meeting different doctors	6
Waking up early	5
Difficulty meeting appointments	4
Encounter with Health Care Providers	
Positive attitude of health workers	27
Inadequate consultation time (lack of patience, inability	
to ask questions)	4

Source: Interview Data, 2020

# **Accessibility to Health Care Facilities**

Accessibility is considered as the existence of transport between people and service. In this instance, access had to do with the movement of patients from their homes to hospital and back. Some of such challenges had to do with transportation. Patients had problem with commuting to hospital because it was difficult getting a vehicle and, in some cases, the vehicle did not get full on time for the driver to start the journey. Poor road network contributed to transportation problem because some patients lived in areas with bad roads thus making it difficult for them to report at hospital in time. In this case, patients resorted to the services of motor bike riders (okada) to assist them get to the main road on time in order to get a vehicle early enough.

I pick a motor bike to the road side, before I pick a car ... (said Participant 9).

Participant 12 also shared her experience as follows:

Coming from my village to the main road is far, so when I wake up at dawn, I am afraid. But if I delay too much, I will not get to the main road early; I may find it difficult getting a car. So, I must come early.

Again, the distances between patients' villages and the hospital are far. Some picked as many as four vehicles before they got to hospital. Participant 28 had this to say: *I really suffer to get here*...

Long distances, coupled with transportation difficulties prompted patients to wake up early. Some indicated that they woke up very early at dawn in order to get to the road side on time to get a vehicle.

Today for instance, I woke at 4am to prepare the children for school and by the time I finished it would be 5am. I left home at 5:30am and got to the roadside by 6am. Not long after, I had a car. (Participant 12)

From the narration given by patients, it could be seen that accessing health care was a challenge since patients had to go through transportation difficulties because of poor road networks. The rural communities are also far from the cities and this sometimes compromises patients' willingness to attend clinics. These challenges are characteristics of rural areas, and often prevent patients from accessing certain amenities in the urban centres. Due to this, many patients depended on motor bikes as their means of transportation. Those who did not

have their own motor bikes had to depend on public transports which also delayed patients' appointment schedules. The transport services in rural areas are not reliable, safe and trusted, and sometimes cannot deliver to the expectations of the people. Again, the poor nature of the roads makes it hazardous for commuters. This makes the ability to reach basic and crucial services in urban centres more difficult. All these tend to impact negatively on patients' accessibility of health care (diabetes clinics) in the cities. Despite all these, patients defied all odds to get to the hospital on time. So, by 6am, they would be at the hospital. Patients were of the view that if they did not go through this transportation ordeal to get to the hospital on time, they would face another challenge with long queues at the hospital.

Patients noted that they met long queues at the hospital because many of them reported on particular clinic days. Diabetes clinics were scheduled for particular days in most hospitals visited. On a particular scheduled day, patients with their numerous complaints visited the clinic for medications which would serve them till the next visit. On such visits, patients would be frustrated by tedious travelling and hectic consultation. This was so because those coming from far places would have to set off as early as 4am to get to hospital on time. The situation was worse when the consultation day was not a market day during which vehicles would be available for travelling. Despite the stress from travelling, they had to join long queues and wait for hours before their blood samples were taken for blood sugar tests, and wait for the results before going to see the doctor. This test had to be done before the patient could eat; by the time patients met the

doctor, they were already frustrated. This delayed their eating time since they had to go through a series of laboratory tests before they could take their medicine and eat. So, if they did not come in early, they would not be attended to on time which meant they would leave the hospital late. This is the narration of Participant 12:

We suffer, especially when going to do the lab we will be in a queue and will be pushing and jostling so by the time you leave the hospital, you are already tired. So, you see, we really suffer. Again, collecting drugs from the main pharmacy is a problem for us. They should bring our medicines to the clinic so that immediately we finish seeing the doctor, we take the medicine. But we will suffer and wait for a long time at the clinic and when we are done, we have to go through that same challenge at the pharmacy. You see, so by the time we are done from the hospital, it will be about 6pm or 7pm.

To Participant 12, there were long queues at every department of the hospital and to her; there must be decentralization of services. Diabetic patients must be treated, and all their drugs given at the diabetes clinic. That is, patients are not to go for their drugs at the main hospital pharmacy as this consumes a lot of time. Participant 31 concluded that the entire process of coming for regular check-up was time-consuming.

Another challenge indicated by the patients was meeting different doctors on clinic days. This shows that patients were not familiar with their care-givers and had no personal relationship with them. A patient indicated that she wished she was attended to by one particular doctor, but this was always not the case

since it was a matter of chance to meet this doctor. Additionally, she did not have the choice to determine which particular doctor she wanted to meet:

There are some of the doctors who are very nice, so anytime I come I want to go to them but it's not feasible. So, you can't go to them and they wouldn't mind you if you request to go to them. Whoever they take you to, you accept him like that. (Participant 11)

This was a source of worry for Participant 11. Patients did not know the doctors personally, neither did they have personal contacts to call any time or book an appointment. This may not enhance a doctor-patient relationship which could lead to improvement in patients' health.

#### **Encounter with Health Care Providers**

Another theme that emerged from the interview transcripts was the encounter patients had with health care professionals. This specifically explored the attitude of the health professionals towards patients when they (the latter) visited the hospital for their regular check-ups. Some diabetics were happy with how the doctors and nurses treated patients, their interactions with patients, time spent with them, care given by these professionals, their patience with patients and their ability to explain issues concerning diabetes. Most of the patients interviewed indicated that the attitude of the health care professionals was positive in relation to explaining issues concerning medication, diet, management of the disease and general lifestyle which included exercising and reducing strenuous work. Patients were educated on when to eat, the type of food to eat and avoidance of certain foods that could complicate the disease or increase sugar levels. The doctors and nurses also advised patients on medications. Some

patients indicated that the doctors had patience to explain issues about the disease. Generally, most of the patients shared the view that they were satisfied with the health care providers' attitude. Participant 7 shared her opinion as follows:

When we come, they have the patience to attend to us. They are able to explain to us how to take our medicine and eat well because sometimes our sugar levels will be high... We shouldn't be eating one type of food all the time; we have to balance our diet.

From Participant 7's account, it could be deduced that the doctors and nurses explained issues about diabetes and the misconceptions people had about the disease. However, few patients indicated that the attitude of the health professionals was negative. This was how Participant 12 explained the attitude of the health workers:

No, no; they don't have patience for me to ask questions just as you have asked me, no. They are in a hurry to finish with me and attend to somebody else so they don't have the time to questions. The moment I enter the consulting room, they just check my lab results and prescribe the medicines I am to take, then I leave. They just ask about my condition and where I feel pains; that is all. They will not ask me anything else.

From the narration given by Participant 12, it seems the doctors did not have patience with patients. Patients were rushed through simply because the doctors had to attend to many clients on a particular clinic day and within time. Again, she shared her frustration of not given opportunity to ask questions.

Two main themes emerged from this research question: accessibility to health care facilities and encounter with health care providers. Accessibility to

health care facilities had sub themes like transportation difficulties (poor road network), time consuming (long queues), and meeting different doctors on clinic days. The problem with transportation in the current study corroborates the same difficulties and challenges cited in Metta et al. (2015), Sulemana and Dinye (2014), Lu et al. (2010), Kagee et al. (2007), and van den Boom et al. (2002) which identified the challenges experienced by rural dwellers to include waking up at dawn, long distances, poor transportation, long waiting for and on vehicles, using motor bikes and in the worst instances, abandoning the journey altogether. Carolan et al. (2015) highlighted lack of transportation as one of the logistical challenges that limited patients' access to health care. This was in line with other studies conducted among patients in Africa, especially those in the rural areas, who reported that commuting between their villages and health care centres was extremely difficult (Adeniyi et al., 2015; Kagee et al., 2007; Matta et al., 2015). Financial burden coupled with transportation challenges made it difficult sometimes for patients to keep to regular clinical appointments (Mwangome et al., 2016; Zimmermann et al., 2018). This meant that diabetes had a significant health and economic challenges for patients and families (Ruston et al., 2013).

Patients complained of long queues and delays at the hospital. They recounted the ordeal and frustrations they had to endure at the hospital; according to Mwangome et al. (2016), patients could be at risk of collapsing for lack of food in the system. Some patients in Carolan et al.'s study (2015) also complained of the long waiting appointments they experienced when they visited the hospital. Patients opined that they had to wait in long queues for two to three hours before

they met the doctor. Similar sentiments were shared by respondents in Hjelm and Mufunda's study (2010) that they delayed in seeing the doctors or collecting drugs from the pharmacy. Zimmermann et al. (2018) conducted a scoping review of studies on Type 2 diabetics' experiences in Africa and found out that sampled participants described how they experienced long delays at the hospital.

Another related challenge of accessibility to health care that literature failed to mention was the situation where patients met different doctors any time they went for their appointment. Patients in the current study reported that they met different doctors any time they visited the clinic for their regular schedule. This is in sharp contrast with the report by Pikkemaat et al. (2019) that in Sweden diabetes patients are treated by a General Physician who is a specialist in family medicine and diabetes specialist nurse at the Primary Health Care Centre (PHCC). Pikkemaat et al. noted that patients visited the PHCC twice every year to meet the general physician and the nurse. Patients are only referred to other specialists only when there are complications that cannot be managed at the PHCC. This was not the case for patients in this study who were from the rural areas. Perhaps to the doctors, it is a normal practice and just a continuation of care. Going through the patient's folder enabled the doctors to understand the patient's condition and continue with the care. However, to the patients, it is a new world of experience and it raises an issue about consistency of care. Patients believed that meeting different doctors actually does not enhance patient-doctor communication. Again, the hospital could have done better by explaining to patients why doctors are constantly being changed, but these explanations are often not given and this might eventually create doubts about the quality of care provided. It is idle for health care professionals to provide patients with information on what is to be done at every stage of the care process. According to Donabedian (1988), the contribution of health care must include but not limited to addressing issues concerning patient's satisfaction and preferences in health. Donabedian emphasized that improving quality of care is not only limited to systems thinking, rather love is the secret to quality. Thus, the health care provider must love the patients, love the profession and love God. With love, the health care provider can work backwards to monitor and improve the system.

In view of the patients' encounter with health care providers, Almino et al. (2009) posited that a good and healthy relationship between physician and patient is said to enhance the control of diabetes. According to Guanais et al. (2018), health care provider's communication and time spent with patients is associated with better trust in health care systems. In their narration, patients commended the doctors for their patience and professionalism. Patients were given information on dieting and medication. Dube et al. (2015) and Bayindir et al. (2015) indicated that the information provided by health professionals on diabetes centred on the meaning of the disease, its complications (effects), and management strategies (often physical activities and healthy diet). However, in the current study, the information provided to patients centred more on management strategies. Patients' satisfaction with attitudes of doctors and nurses was also echoed by respondents in the study of Tabong et al. (2018) that they were treated very well when they visited the hospital for treatment, and were satisfied with the total care

(Booysen & Schlemmer, 2015). Should health care professionals continue to educate and provide patients with information on their disease, it would increase patients' confidence and autonomy (Samancioglu et al., 2017).

Although most patients admitted anytime they visited the hospital they were educated on how to manage diabetes, a few felt the doctors and nurses did not do enough to provide comprehensive education and care. Carefully examining the transcripts of the participants and the information given about the health professionals, it came to light that the health care professionals did not really have adequate time to attend to patients. So, in essence, what the participants said the doctors and nurses had time for them did not reflect in the transcripts. Patients were given general information when they went for consultation and the time doctors and nurses spent with them was inadequate. Likewise, some patients in Yasmin et al. (2020) complained strongly about the lack of attention and inadequate consultation time provided by physicians. They never had the opportunity to ask questions or be well examined as doctors were always in a rush during consultations and this was evident in the experiences of Participant 12. This revelation is in line with the findings of Zimmermann et al. (2018) who described how participants felt they were not given the necessary support by the health care professionals. Again, Murphy et al. (2015) pointed out that health care providers failed to establish rapport with their patients because they did not have enough time for patients; their communication skills were poor and they failed to provide counselling at the time of diagnosis. In this situation, patients became anxious and frustrated about the quality of care.

Participants studied by Adeniyi et al. (2015) expressed disappointment at the hurried attitude of doctors during consultations. Respondents remarked that though doctors counselled them, the counselling was not practical because patients felt they were not rich enough to afford the management strategies (healthy eating) suggested by the doctors. This was consistent with Booysen and Schlemmer's (2015) study which found out that few participants reported that nurses were sometimes harsh, and embarrassed patients in the presence of others. Nurses were insensitive to the manner and time in which information about the disease was given (O'Brien et al., 2015). This could be explained by the large number of patients attending clinic on the same day, compelling doctors and nurses to attend to a large number of patients. Aside that, clinics were normally scheduled for a particular day in the week, at times just once or twice in a week and this really stressed up the doctors and nurses since clients from far and near all visited the hospital on that scheduled day or days. According to O'Brien et al. (2015), the large attendance on a clinic day made it impossible for the health care professionals (doctors and nurses) to attend to all clients. This probably explains why clinical counselling was ineffective in the study area. Competent care and positive experiences which are attributes of good quality care can significantly impact the patients' health, their confidence and trust in the health system (Kruk et al., 2018). This could eventually affect the patients' decisions regarding where and when to seek health care.

Considering the challenges diabetic patients go through in accessing health, it is important that health centres, clinics, and Community Health Planning

and Services (CHPS) compounds in these rural communities are upgraded and well-resourced to cater for the needs of diabetes patients. Instead of patients going to towns for clinics, they can be directed to the CHPS compounds. This would reduce the stress patients go through on clinic days. It is suggested these clinic days at the hospitals could be decentralized to the community levels, precisely CHPS compounds, where specialist doctors and nurses would visit to take care of patients. This again will reduce the build-ups and congestions that occur on clinic days at the hospitals in towns and cities. This would eventually reduce the pressure on health care professionals and increase the time patients spend with doctors when they go for their regular check-ups. The proposition of bringing health professionals to the community level would reduce or completely eliminate most of the challenges experienced by patients. Even though majority of the patients reported they were satisfied with the attitudes of doctors and nurses, and information given to them, few patients had their reservation about the professional conduct of the health care providers. These mixed reactions about the attitudes of doctors and nurses need to be addressed by future research. Health facilities must step up their effort to respond appropriately to the needs of patients.

Patients' experiences with the health care system included problem with accessing health care facilities (transportation difficulties, poor road networks, long distances, and long queues, time consuming, meeting different doctors), positive attitudes of health care professionals and inadequate consultation time.

# Research Question 4: What are the Challenges of living with Diabetes in Rural Areas?

This research question explored how diabetes had changed the lives of patients, and how it had affected the lives of others around them, and the entire community. Diabetes patients often experienced many challenges that impeded their socio-economic lifestyles. This is because diabetes comes with conditions that restrict the life of a patient. Patients were asked how diabetes had affected their lives, the challenges of living with the disease in the rural community, and the problem with accessing health care. Again, patients were asked if the challenges and frustrations of the disease forced them to seek help from non-medical sources. Two main themes with sub-themes were generated and they include: Effects of the disease (physical and social restrictions), and Challenges of living with the disease and these are presented in Table 5.

## **Effects of the Disease**

#### Physical Effects

Suffering from diabetes comes with some physical effects (Habte et al., 2016; Langat, 2011). Patients narrated they experienced weaknesses in the body (debilitation) making it difficult for them to work. That is to say, the strength and energy they once enjoyed had reduced drastically because of the illness. They were of the view that they could not do what they used to do, neither could they engage in any rigorous activity. Their ability to go to the farm had gone down drastically, meaning they hardly went to farm and even when they did, they were unable to work. The negative effect of the disease affected patients' walking as well.

Table 5: Challenges of living with Diabetes in Rural Area

Themes	Number of Participants
Effects of the Disease	
Physical Effects	
Debilitation (Inability to work)	15
Emaciation	5
Retinopathy (Blurred vision/Low vision)	5
Amputation	1
Sexual weakness	3
Insomnia	2
Social Restrictions Poor social relations	15
Challenges of living with the Disease	
Financial burden (Purchase of drugs)	12
Taking too many drugs	2
Poor storage of drugs	7
Difficulty following dietary/medication instructions	10

Source: Field Data, 2020

Some complained they could not walk long distances without resting. This is the case of Participant 6:

A lot of changes have come into my life. Before, I was strong but now I'm weak.

One of the participants indicated that the disease had restricted his movement; he could not move freely as he used to do. This was because diabetes led to the amputation of one of his legs. As a result, he had become totally dependent on others, and this dependency on family and grandchildren frustrated him considerably. This is how Participant 25 puts it:

...but my inability to move freely and do things on my own is what worries me.

Some of the patients showed traces of emaciation due to the illness. This is how Participant 19 narrated her story:

I was fat but I have reduced in weight because of the illness.... I stopped eating a lot of foods, and later I realized I was growing lean. I was fat but because I stopped eating those foods, I grew lean.

According to her, she was good-looking but since the incidence of the disease; she had to stop taking certain foods and to adapt completely to a new lifestyle which, she believed, had had negative effects on her physical appearance. Again, patients were of the view that diabetes had affected their family's diet. This is because the family had to eat what the patient ate, and on time.

Yes, it has changed their eating habits. My soup must be different from theirs because I don't take salt. I don't take beef, even chicken must be smoked. So, they have seen a difference in their diets because of the changes in my diet. That is what they often say. (The case of Participant 6)

According to Participant 27, the disease had destroyed her life.

It has destroyed my life. I was beautiful but the disease has destroyed me... I have changed. How I looked before has changed ... I had an eye problem. As I sit here, I can't see well.

Participant 28 also had this to say:

Yes, it has destroyed my life. With my eyes, I worked and did everything but since I suffered from diabetes, I'm going blind. And it is true; there is nothing I'm able to do so I just don't know what to do again. Whatever I do, my eyes keep deteriorating. I cannot see. I have to use my hands as a guide when I'm walking.

These patients had blurred vision (retinopathy), one of the major effects of diabetes. They could not move freely and so needed assistance from others. According to Participant 27, going to hospital was a problem for her. Even when she managed to go, she was often assisted by the nurses, and sometimes she was made to sit at one place while the nurses assisted her with everything. Some of the male patients interviewed indicated that diabetes had made them sexually weak.

Sexually I am weak. I am not strong in bed like before ... It happened about six years ago. It is due to some of the medicine I am taking. My sexual strength has reduced considerably. (Says Participant 6)

The male patients attributed this to the side effects of drugs that had been prescribed for them. They suspected it was the medicine that had weakened their sexual energies, making them uninterested in sex and their inability to satisfy their spouses. To them, their libidinal energy was gradually being destroyed by the medicine. Participant 31 voiced his experience:

One thing is that when you frequently take the hospital medicine, it weakens you sexually... I tell you honestly. I was weakened sexually. When I complained to the doctors, they prescribed another medicine for me. Yes, I became very weak sexually. But when I started taking the local medicine, it came back to normal.

Sexual weakness was the reason Participant 31 resorted to taking herbal medicine given to him by a prophetess. He stated that the herbal medicine rather boosted his libido, so anytime he was given medicine from the hospital, he dumped it somewhere and used the herbal medicine. In other breath, he noted that he was taking both the hospital medicine and the herbal preparation to treat the diabetes. Insomnia was experienced by some patients; as they were unable to sleep at night or they slept at short intervals. The insomnia was as a result of the frequent urination coupled with thirst and hunger. This was Participant 4's experience:

I cannot sleep well. I sleep at short intervals. I can wake up three times before day break.

Participant 4 experienced a secondary insomnia, which means he had trouble sleeping due to the diabetes condition. His inability to get enough sleep could compromise his health. Thus, this could lead to higher risk of health problems like anxiety, depression and high blood pressure.

#### Social Restrictions

Social restrictions characterised the social effects of the disease because it affected some patients' social relationships with friends. For the restricted dietary requirements, some patients were unable to go out with friends for fear that friends might influence them to eat or drink what they were not supposed to eat or drink. They always had to ensure that they ate from home. Participant 6 opined that he could no longer move with friends or even meet for a drink. This is because when friends met, he could not drink alcohol or eat a lot of meat as he

used to. Because of these changes in his lifestyle, anytime he was invited by friends for an outing, he was unable to go. Participant 25 also had this to share:

For example, if they are playing football I can't go and watch, perhaps, there could be a pot hole which will make me fall. The doctor also advised that that I should be careful with my other leg ... so I can't go out to enjoy social life.

This shows that the disease had placed a social restriction on them making it difficult to enjoy social life with friends.

The study identified physical and social effects on patients to include debilitation, emaciation, retinopathy, amputation, sexual weakness, troubled sleeping (insomnia) and social restrictions. Studies have cited some physical health challenges associated with diabetes to include debilitation, blurred vision (retinopathy), amputation, and heart or liver complications (Barreto et al., 2007; Habte et al., 2016; Langat, 2011). Most of the study patients could not go back to their normal work since they became weaker and weaker day after day. Since patients were from rural farming communities, they relied on their physical strength for farming activities and other occupations. Other studies highlighted how diabetes affected patients' ability to work, and loss of productivity (Habte et al., 2016; Ruston et al., 2013; Tuncell et al., 2000; Zimmermann et al., 2018). Ruston et al. (2013) investigated patients' experiences of managing diabetes at the workplace the findings of which established that the disease made patients unproductive at work and often led to absenteeism. This usually occurred due to the complications that come with the disease (Tuncell et al., 2000). This was the

case of patients in this study who noted they were unable to work as effectively as they used to. Some reported that diabetes prevented them from going to their farms, while others had to stay off from their menial work. This affected patients' income (Aikins, 2003; Zimmermann et al., 2018). Aikins (2003) also noted that diabetes impacted on patients' ability to work and carry out social roles. Patients were also at risk whenever they had a cut on any part of the body. Since the bacteria travel from one part of the body to the other, the best option was amputation of the affected limb to prevent the disease from spreading to the other parts of the body.

Some patients were emaciated by the disease; their weight had reduced drastically as a result of changes in diet and of the medication. Others experienced retinopathy (blurred vision) where there was a reduction in visual acuity which eventually affected their movement. The effects significantly disrupted their daily activities. These findings have been confirmed by Aikins et al. (2013), Hjelm and Mufunda (2010), Habte et al. (2016), and Zimmermann et al. (2018) who cited poor eyesight (reduced vision) and loss of a limb as complications of diabetes. Some male diabetics in the current study revealed that the disease had affected their sexual strength, and this is consistent with the findings of Owusu (2016), and Osei-Yeboah et al. (2016). The male patients reported they experienced suppression of libidinal energy due to the medication coupled with the psychological distress, and this made them lose interest in sexual activities completely. Similarly, Owiredu et al. (2011) conducted a study to determine the sexual functioning of 300 diabetic men who visited Tema General Hospital

diabetic clinic. They found out that majority of the men experienced low sexual activity, premature ejaculation and, in extreme cases, impotence. Tabong et al. (2018) also reported cases of loss of libido in both men and women interviewed. This often brought about spousal conflict (Tabong et al., 2018) and loss of masculine identities (Owiredu et al., 2011). Contrary to the findings of Tabong et al. and Owiredu et al., the male diabetics in the current study who experienced sexual weakness did not report any spousal conflict or loss of masculine identity. They were rather encouraged and supported by their spouses especially, with dietary control and treatment regimen.

Patients opined that the disease has restricted their social life and limited their social movement with friends within the community. This corroborates the assertion by Kralik et al. (2010) that the incidence of a chronic disease (diabetes) leads to restricted and socially isolated life, and the patient eventually becomes a burden on others. Again, the blurred vision, debilitation (loss of strength), amputation and emaciation (loss of weight) affected patients' ability to attend social functions. This affected patients' social roles and identities as posited by Aikins et al. (2013) and Habte et al. (2016); however, these complications did not affect patients' relationship with their families as stated by Carolan et al. (2015).

Debilitation, emaciation, blurred vision (retinopathy), sexual weakness, destruction of life, sleeplessness (insomnia) and social limitations were the physical and social effects experienced by patients in this study. Therefore, community health workers must be empowered and provided with enough information and resources to carry out their mandates effectively in these rural

areas. It is hoped that constantly providing rural dwellers with information about diabetes would reduce the resulting effects and complications.

### **Challenges of living with the Disease**

Patients faced some challenges with diabetes, considering the rural setting.

These challenges identified from the interview transcriptions have been grouped into four themes: financial burden, too many drugs, poor storage of drugs, and difficulty with dietary and medication instructions.

### Financial Burden (Purchase of Drugs)

First, it was discovered that diabetes placed financial burden on patients. They were of the view that treatment required huge financial expenditure to keep them healthy. Thus, to stay long, healthy and strong would mean patients had to spend a lot of money on drugs, diet and transportation. That was the reason some patients referred to it as "disease of the affluence", the reason being that it was the rich who could afford good meals and other things to make life comfortable. Participant 27 described diabetes as "money will finish."

As for this disease, it is called money will finish. Whatever you do, it will not be cured. The doctor told me the disease could not be cured but I will take the medicine to manage it.

Participant 27 believed that no amount of money could cure the disease so she must keep spending money on drugs to manage her illness till death.

Another area of concern that financially stressed patients was the purchase of drugs. Patients explained that they were made to buy drugs at the hospital any time they went for check-up. Ideally, it is a policy under the National Health

Insurance Scheme (NHIS) that diabetes drugs are not to be sold but that was not the case at the various hospitals some patients have been visiting. In other instances, where drugs were not available at the hospital, a prescription was given to patients to buy drugs from outside. This puts a lot of financial strain on them. This is how Participant 12 narrated her experience:

I buy my medicines. They always prescribe for us to buy, and this is another major problem for me. Buying the medicine is difficult. The last time I came, I didn't get money to buy the medicines. I just took what I had on me. I couldn't buy them... My major challenge is the drugs they ask us to buy. I don't have money. If you don't get the medicine too, you will die.

Sometimes patients could not buy the drugs due to the cost. To a large extent, the financial burden prevented few of them from meeting their appointments. In other words, they were unable to go for their regular visits. Some were of the view that despite the financial strain, they had to do everything possible to raise money for their transportation fare. They knew the effect of skipping an appointment, so they did not want to experience any complications with the disease.

## Taking Too Many Drugs

Another challenge with medication had to do with patients taking too many drugs for the rest of one's life. It was a challenge for patients to wake up early in the morning to take medicine, and also ensure that they took the medicine on time. Some of these medicines were to be taken at least once to three times daily; those on insulin injections were also supposed to inject themselves a

number of times in a day in order to stabilize, manage and control their sugar levels. This was really difficult for them. This was not their usual lifestyle so adapting to this style of living for the rest of their lives was difficult to compromise. In all these, patients accepted to continue taking the drugs for they knew and had been educated that it was the only means to stay alive and healthy. One of the patients narrated that a wrong medication was once administered to him. This greatly affected him since he could not hold his urine. He was then advised by a relative nurse to return the drugs. Apparently, when the drug was shown to the doctor, he explained that it was the fault of the nurses who could not read his handwriting, and that explained why the wrong medicine was administered. So, he was advised by the doctor to immediately report any changes he encountered with the drug.

#### Poor Storage of Drugs

Additionally, it was discovered that drugs were poorly stored by the patients. Drugs must be stored at certain room temperature in order to preserve its potency, but that was not the case for some patients. Most patients did not have appropriate resources like a refrigerator to store the medicine (insulin). In the case of Participant 25, he stored the insulin in a son's refrigerator. This was how Participant 25 stored his insulin:

I put it in the fridge. One of my sons operates a beer bar and he has a fridge that is where I store my insulin... Yes. I wrap it in a polythene bag so when I need some, I go for it... It is far, so I call them on phone to bring it to me.

There could be many implications to this storage arrangement; as to whether it was properly kept in the fridge should be a matter of concern to the patient. When he needed it, he had to call for it to be brought to him at home or he had to send somebody for the insulin. The process of transporting the insulin to the patient could be a problem when it is not well handled. In some cases, the patient had to move a few minutes earlier to the storage point, but the unexpected could happen should any of the symptoms set in before the patient reached the drug. This is because walking from the patient's house to the storage point could drain his strength thereby triggering the incidence of hyperglycemia or hypoglycemia. Other patients said they kept the drugs in an unused fridge. Some also kept insulin in the polythene pack given to them at the hospital and just put it somewhere in their rooms. Considering the heat in the unused refrigerator, and polythene pack, the effectiveness or efficacy of the drug could be compromised. This is how patients stored their insulin and drugs for the period the drugs were issued until patients' next appointment was due for them to go for fresh supplies.

### Difficulty with Dietary and Medication Instructions

Diabetic diet simply means eating the healthiest foods in moderation and sticking to regular meal times. Key foods are fruits, vegetables and whole grains. It has been recognised that most patients had problem following dietary and medication instructions. The problem with following these instructions occurred because it was related to previously acquired habits. Having a well-lived lifestyle meant patients had everything at their disposal, ate whatever they wanted, drank as much as they wanted and even socialized as much as they wanted, but

unexpectedly, the incidence of diabetes became part of them and they had no option than to adopt a different lifestyle. This is one of the most difficult challenges faced by people diagnosed with diabetes. Looking back at their lives or shifting away from something that had been part of their lives was really difficult but eventually, they had to abide by it since they had no option. Patients found it difficult changing their entire lifestyle to meet the demands of the disease. Most of these patients were used to taking particular foods.

I follow the instructions but sometimes it is difficult. They tell us not to eat at night but because of my kind of work, I even forget to eat. So, I find it difficult following the advice. I can be busy to the extent that I forget to eat and by the time I realize it is already late. When this happens, I eat anyhow. (Participant 11)

Patients were advised to be on a particular diet regimen in order to help reduce the risks involved with the management of diabetes. This involved the intake of high fibre and complex carbohydrates and low-fat diets. Diabetic patients were advised to eat small quantities of food no matter the level of hunger. Patients were advised on meal times in a day, and to avoid eating fats, white bread, and fruit-flavoured yogurt. Changing eating habits really became difficult as most of these diets were not easy to prepare, neither could patients get them to buy easily. Shifting from a normal diet to diabetic diet was really difficult for these patients but as time went on, they slowly adjusted to it. This was the account given by Participant 19.

But once a while, I crave for some of these new sweet drinks, but my children will not buy them for me. So, if I get money somewhere, I will buy them. Sometimes I could take three bottles of the sweet drinks.

Difficulty in following regulations on medication was also one of the major problems faced by the patients. The moment one was diagnosed of diabetes, taking of drugs became part of the person for the rest of their lifetime. Some of these drugs were administered in oral form, others in the form of intravenous (IV) while others through injection. Some drugs were to be taken before or after meals, morning and night. With oral medication, patients were to take drugs 30 minutes before meals. This posed a challenge because the moment patients took the medicine, their level of hunger rose and waiting for 30 minutes before eating was an ordeal to cope with. Others even experienced spasms and sweated profusely until some food was eaten. Patients therefore ended up not abiding by the rules. Others also found it burdensome carrying their drugs around away from home. With administration of insulin injection, some patients felt uncomfortable with self-injection; the illiterates did not know how to administer the drug while others felt shy to inject themselves in public. Financial aspects could also be considered since some patients found it difficult getting money to buy the quantity of drugs prescribed, thus ending up buying the quantity that the money available could buy. Patients on injection of insulin and mixtard and on oral medication were advised on medication but most of them preferred taking the drugs during periods of crises.

The challenges identified by patients were financial burden (purchase of drugs), taking too many drugs, poor storage of drugs, difficulty with dietary and medication instructions. Living with diabetes in rural areas was challenging for

patients by placing physical, emotional, social and psychological burdens on them (Carolan et al., 2015). Diabetes is known as a lifetime disease which requires careful and accurate management till the end of time. One of the challenges patients were faced with was the difficulty taking medicines each and every day for the rest of one's life. Similar to the experiences of patients in Adeniyi et al. (2015), participants in the current study reported taking so many drugs and its associated drudgery as the reasons for patients' non-adherence behaviour. This complex treatment of diabetes which affects adherence behaviour has also been confirmed by Cohen et al., (2012), and Miller and DiMatteo (2013). This really became frustrating for patients since they needed to carry drugs and insulin on them when stepping out of home to carry out their daily activities.

Patients from the rural areas were also not exempted from the financial responsibilities of managing diabetes, and according to BeLue et al. (2013) and Khandan et al. (2018) patients from rural areas experienced the greatest impact of the financial burden. Purchase of drugs by patients may stem from the fact that not all drugs are covered by the central medicine list or NHIS. Holders of NHIS had their drugs covered by the insurance policy; however, not all diabetes drugs are covered on the NHIS drug list. This means depending on the doctor's discretion, a particular drug could be beneficial to the patient but when it is not covered by the NHIS or central medicine list, the patient will be made to pay at the pharmacy or even buy it outside. Another reason for the purchase of drugs is the situation where there is shortage of drugs at the hospital pharmacy. Patients are then given prescriptions to buy the drugs from outside. On the purchase and

shortage of drugs, Nartey (2017) a Joy News correspondent in Ghana, filed a documentary which revealed that diabetes drugs were being diverted and sold by those in charge of some hospital pharmacies. He noted that the International Diabetes Federation (IDF) in collaboration with Ghana Diabetes Association (GDA) developed Life for a Child Programme where children living with diabetes were to be supplied with insulin, glucometers and test strips for free. However, there was under-supply of vials of insulin because the drugs meant for children were sold to adult diabetics who were unintended beneficiaries. This resulted in the deaths of most children who were the direct beneficiaries. This means that hospital management and the medical fraternity must ensure effective monitoring and improve the medical supply chain system to prevent diversions and shortages. NHIS needs to review its drugs supply list to include other drugs in order to reduce the cost associated with the purchase of drugs.

To Matta et al. (2015) and Yasmin et al. (2020), the cost associated with purchase of drugs, and management of the disease forced patients to either skip or reduce recommended dosage. A study by Aikins (2005) on healer shopping in Africa identified high cost of biomedical drugs and recommended foods as factors that reduced patients' commitment to medication. Additionally, mothers of diabetic children interviewed in a study conducted by Khandan et al. (2018) mentioned that the cost of life-long treatment and management requirements was burdensome for families. Most patients complained they could not work and therefore had to rely on families for support. Contrary to the findings of Adeniyi et al. (2015), Matta et al. (2015), and Aikins (2005), taking many drugs with its

financial burden (cost of drugs) did not affect the adherence behaviour and medication commitment of patients in the current study. Even though some patients admitted that sometimes they bought less of the prescribed drugs because of financial stress, they were committed in taking the medicine, and even expressed worries that their inability to buy all the medicines could be harmful to them. The differences in the current findings and studies reported above may have occurred because patients in the current study had the perception that diabetes was a dangerous disease that could easily kill them so they needed to follow the advice of the doctors and nurses regarding its management. Again, patients trusted the doctors and nurses, and perceived them as knowing the best treatment for them so they strictly abided whatever the doctors told them. That was why patients reported that even if they did not have money, they did their best to mobilise money to meet appointment schedules. Another related challenge that literature failed to identify was the poor storage of insulin and drugs by patients.

Poor storage has been one of the major concerns of diabetes patients, especially those from the rural areas. This was the case of patients in this current study as they reported that they often kept their insulin and drugs in a relative's refrigerator or unused refrigerator, respectively. Similar to Kedogo (2015) findings, most of the patients studied did not have refrigerators but rather depended on relatives, friends, bars, shops, and butchers, and this is what the researcher termed as 'proxy arrangement'. Literature on diabetic patients' experiences in Ghana had been silent on the challenges with regards to storage of drugs, especially insulin. Most of the published literature in Ghana focused on

storage of vaccines and drugs in general (MOH, 2016; 2014) but not on how diabetic patients stored drugs. Although Kpekura (2017) identified the costly nature of insulin medication, storage and administration as one of the barriers to effective management among diabetes patients in Upper West Region of Ghana, the study failed to outline the reasons for poor storage and other alternative measures adopted by patients to store their insulin. According to Kedogo (2015), the lack of storage equipment and poor climatic conditions are likely to compromise the quality of insulin storage requirement. Diabetes complications and associated mortality among rural dwellers are likely to reduce if patients are educated effectively on appropriate insulin storage and administration. Poverty has prevented a large number of patients to store their insulin by refrigeration (Mcferran, 2008). Kedogo (2015) added that socio-economic challenges associated with living in rural areas caused a person to live in pathetic housing conditions that makes it practically impossible to store insulin. Additionally, lack of power supply and refrigeration facilities in rural areas accounts for the challenges with insulin storage. Gill (2000) confirmed that rural areas lack more refrigeration facilities for insulin storage than urban centres. It will be prudent if future research focuses on the experience of diabetic patients with regards to storage of drugs and insulin.

Patients had problems with dietary modification, medication requirements, and demanding drastic changes in lifestyles. This confirms the findings of Mensah et al. (2017). Expectedly, the diagnosis of diabetes would mean a change in diabetics' dietary habits in terms of kinds of foods and quantity of meals to be

taken and meal times as aspects of the management of the disease. Additionally, diabetics should be on medication for the rest of their lives, something they found very demanding (Walker, 2008). No wonder patients indicated that they sometimes gave in to what they craved for but were deprived of, and this confirms what participants in Carolan et al. (2015) stated. Tabong et al. (2018) also reported that patients had problem with dietary requirements and lifestyle modifications. Some of these challenges could emanate from the financial burden associated with the disease. Thus, patients sometimes did not have the financial means to afford the kinds of food they had to eat. Studies had reported that patients complained about the challenges they had with dietary changes and medication requirements (Mathew et al., 2012; Murrock, Taylor & Marino, 2013; Walker, 2008), and Vanstone et al. (2015) added that sustained dietary requirements had been elusive for most patients. Murrock et al. (2013) studied African-American diabetic women's challenges with management of diet and found out that participants expressed concern about changing dietary habits. Matta et al. (2015) noted that the poor dietary practices among rural diabetics could be due to low economic status of patients because they did not have the means to eat foods rich in nutrients. Also, rural individuals lacked adequate knowledge about the disease and healthy life practices. As a result, patients engaged in some of these poor eating lifestyles that pre-disposed them to the disease. Diabetics interviewed by Matthew et al. (2012) reported their struggles with the management of diabetes. In other instances, cultural factors might influence patients' dietary adaptations compelling them to ignore biomedical

treatment just as participants in Bhattacharya (2012) described dietary modification, medications and physical exercise as culturally irrelevant and impractical.

The challenges experienced by patients included financial burden (purchase of drugs), intake of too many drugs, poor storage of drugs, and difficulty with following medication instructions. Finally, patients experienced challenges with dietary medication which had to do with inability to eat on time, difficulty following dietary instructions, and changing lifestyle.

### Research Question 5: How do Rural Diabetics Manage the Disease?

This research question focused on how diabetic patients from rural areas managed to handle the incidence of the disease, and what had facilitated the management process. This helped to highlight the management experiences of patients from their perspective. Thus, patients were made to describe the processes they went through in managing and coping with diabetes. Questions asked included how they managed and coped with the disease, and if they felt they were managing their health properly considering the rural conditions they found themselves in, coupled with the challenges. Furthermore, they were asked about the kind of support they received from the family and community. There were probes to determine if support network existed for patients and the kind of support they received. This can be seen in table 6.

**Table 6: Managing and Coping with the Disease** 

	Number of
Themes	<b>Participants</b>
Management Strategies	
Psychological Acceptance	8
Social/Spiritual (Family support, Encouragement,	
Prayers)	8
Compliance with medication (Biomedical treatment)	7
Dietary and lifestyle changes	8

Source: Field Data, 2020

### **Management Strategies**

Patients adopted various management strategies to cope with the disease.

These strategies were sub-categorised into psychological acceptance, social/spiritual support, medication adherence, and lifestyle changes.

### Psychological Acceptance

Despite the challenges faced by diabetic patients, they accepted their condition; there was an element of psychological acceptance by the patients. They were ready to go to every extent to manage the disease. Patients accepted the fact that they were sick and therefore had to accept treatment in order to be healthy and live a good life. This was the management strategy by Participant 1:

What I can say is that no matter what, we are in an evil world. We have already suffered from the illness. So, we must take good care of ourselves. How we eat. We shouldn't do unnecessary things but concentrate on the drugs we are taking. We pray you help us get the strength to move and take care of our children. We shouldn't think too much about the illness. If you think about it, it is a worry and it makes your BP rise.

From Participant 1's account, she no longer thought about the situation because she was used to it. Accepting the condition enabled patients take control

of its management by adhering to the prescribed medication and treatment all the time.

### Social/Spiritual Support

One strategy that helped with the management of the disease was the support patients received from the family or the society. It was evident from the interview transcripts that most patients received support from the family. Social support seemed to be limited; those who received support were often assisted financially by some family members. Others depended on their grandchildren and children to perform certain chores for them. The support or assistance given to patients was from children, husbands, wives, and siblings. They gave patients financial support for transportation and purchase of drugs. This was the view shared by Participant 1:

Every support has been from my children... If I need to buy any medicine, I call them to send me money. My children have been helpful.

In some cases, family members saw to the preparation of meals at the right time. Again, few patients mentioned that their children reminded and monitored them to take their medicines, and not to engage in unhealthy behaviours that could complicate the condition. Families and friends served as a source of encouragement for the patients. They encouraged them on the treatment regimen.

Despite the strict compliance with medication, diet and lifestyle changes to manage diabetes, some patients still adopted spiritual means to manage the diabetes. They resorted to prayers and fasting as a means of curing diabetes. Patients expressed their hope and faith in God, trusting and believing in Him for

healing mercies and also to help them survive. Thus, God is the Supreme Being (supernatural force) who can conquer every ailment. Participant 31 had this to say:

I first pray to my God... God is first in everything. The blessing makes one prosperous. God has been good because what I have gone through in life has been through His help... With my medication, I could fast... Yes, I fast. Sometimes at 2pm or 2:30pm I feel as if I have eaten.

According to Participant 31, the fasting sustained his hunger for long periods of time. He narrated that any time he took the medicine, he easily went hungry. On the part of Participant 12, she often prayed to God that He should hold her, irrespective of the situation because God was her shield.

### Compliance with Medication

Most patients complied with the medication regimen prescribed at the hospital. They preferred using the biomedical treatment (drugs) from the hospital. Patients ensured that they took their medicine according to prescription. They spurned people's advice on alternative medicines. This is the case of Participant 3:

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Oh yes, as for my medicine, I am always particular about it. Even when I was coming, I took some in my bag. When I finish eating, I will take it. I will not stop taking it. I will always take it. If I am with my children and my medicine is getting finished, I worry them until they take me to hospital for the drugs. They always asked whether I carried my medicines along anytime I went to visit them.

Participant 3 was extremely careful about the disease, knowing the complications that come with refusal to adhere to advice on treatment. So, she ensured that she always followed her medications to avoid any unforeseen lapses in her life. Patients believed that different herbal medicines not prescribed by the doctor could be dangerous to their health. However, that was not the case of Participant 31 who believed that herbal medicine was more helpful to him than biomedical treatment.

Yes, because when I take the hospital medicine and I don't eat by 12pm, I feel very weak but when I take the herbal medicine, I feel comfortable. Those times when I was not diagnosed of diabetes, I could fast. When I take the woman's medicine, I don't feel anything but it is not the same when I take the hospital medicine. (Narration by Participant 31)

To him, the hospital medication resulted in sexual weakness and made him go hungry and this limited his ability to fast to follow his Christian faith. So, he preferred taking the herbal medicine given by a prophetess.

### Dietary and Lifestyle Changes

Lifestyle change was also a fundamental management strategy adopted by patients in the management of the disease. This included dietary modifications, exercise and a careful lifestyle. Through good diet, exercise and good self-care, patients could improve their quality of life and reduce the risk of developing complications. It can also help to reduce hospital admissions. Patients ensured that they stuck to the dietary advice given by the health professionals. They did

not eat foods they were not supposed to eat, ate on time, and took the right quantity of food. This is what Participant 3 said:

For what I have been asked not to eat, no matter what I won't eat it.

She ensured that she did not eat from the street but prepared her meals at home. Participant 6 also added that he was careful with what he ate, and, especially, observing meal times. Two patients engaged in some form of exercises like walking, to keep fit. Participant 17 noted that she walked bare footed on gravels every morning. Finally, as part of the lifestyle modification, a few patients were of the view that they were extremely careful with their lives because they did not want to hurt themselves and battle with any diabetes wound. This was a remark by patients who were farmers and those who worked with metals.

The themes that emerged from this result included psychological acceptance, social/spiritual support, medication adherence, and dietary and lifestyle changes. These were the strategies adopted by patients in the current study to manage and cope with diabetes. Though patients found their condition unbelievable, heart breaking, painful, and worrisome, they accepted that they were diabetic and, that the disease would be with them till death. They accepted the responsibility of adhering to recommended diet and biomedicines in order to control the disease for the rest of their lives. This is in line with the findings from Zimmermann et al. (2018) which suggested that patients acknowledged the fact that diabetes cannot be cured completely and so made a conscious effort to psychologically accept their condition in order to manage the disease. Additionally, participants in Carolan et al. (2015), Kalra, et al. (2018), Ruston et

al. (2013) and Yilmaz et al. (2019) studies highlighted that the first thing patients did to manage the disease was to accept the incidence of the disease. Considering the psychological burden that comes with the disease, acceptance is an important step to initiate appropriate behaviour towards management of the disease.

Family support had been found to improve diabetes management and control (Alam et al., 2012; Shen et al., 2013; Speight & Singh, 2013). Patients reported that they received adequate support from their various family members and friends. This was often the case in the rural areas where people enjoyed a lot of communal relationships so it was not surprising diabetics received encouragement and support from family members and friends (Zimmermann et al., 2018). Family members and friends provided financial support (Hjelm & Mufunda, 2010; Matta et al., 2015; Murphy et al., 2015) and encouragement (Carolan et al., 2015); sometimes family members served as reminders for patients on their medication (BeLue et al., 2016; Kagee et al., 2007; Mwangome et al., 2016; Nielsen et al., 2016). Support was usually provided by spouses and children. Few patients mentioned that families sometimes commented on behaviours that could complicate the disease.

Even though patients emphasized the importance of family support, the support received was inadequate. This is because support should go beyond financial, encouragement and reminders. It should also include assisting patients to monitor their blood glucose, practice healthy eating, exercise regularly, reduce stress and risky behaviours, and adhere to prescribed medication as suggested by Ahmed and Yeasmeen (2016), DiMatteo (2004) and Shrivastava et al. (2013).

Families could also serve as reminders for the diabetic relatives to meet regular appointment, and according to Iregbu and Iregbu (2016), families must be engaged in planning patients' meals. This was because within the African culture, meals are mostly prepared by mothers or sisters and in this situation if they lack knowledge about diabetes and the patient's dietary requirements, the management practices could be compromised. As part of the support system, Yasmin et al. (2020) noted that patients can be enrolled into a reminding system to follow up with the treatment recommendation through the mobile health project (m-health). As a matter of policy, the Ministry of Health and Ghana Health Service could probably adopt the m-health project in which diabetic patients are reminded to follow recommended treatment (physical exercise, diet, medication, lifestyle changes, and hospital visits) through interactive voice call. This could help reach patients irrespective of their geographical location, and reduce cost associated with transportation and consultation. This service has been recommended by WHO (2011) as the most widely and frequently used initiative to reach patients. However, the m-health service could be more efficient and possible in our rural context when care is decentralized to the community levels, and CHPS compounds are equipped with modern technological resources to follow up with patients within their catchment area.

Some patients also complemented the management of diabetes with prayers. They exercised their faith in supreme God who was believed to be in control of everything (Yilmaz et al., 2019). Patients attended prayer meetings in the hope that the disease would be cured. Thus, God was considered as the

supreme healer (Nielsen et al., 2014). Not that patients avoided biomedical drugs and depended on prayers, but they continued to take their medication and ate healthy foods. Evidence exists to support this view from patients (Broder et al., 2014; Zimmermann et al., 2018). Thus, they combined biomedical treatment with This suggests that for effective management of diabetes, traditional/spiritual healers should be registered and integrated into the management system to avoid extreme complications of diabetes. This recognition would enable traditional/spiritual healers recommend or refer patients to the hospital for biomedical treatment at the benign stage of the disease before it degenerates to the malignant stage at which patients may lose their lives. As part of health promotion exercise, community and public health nurses should visit the traditional healers and prayer camps (pastors) to educate them on diabetes and the need to report cases early to the hospital to avert serious consequences. This would prevent the pastors and traditional healers from subjecting patients to unnecessary fasting and taking of concoctions that could worsen patients' health. There is the need for holistic approach to the management of diabetes, whereby patients would understand that they can adhere to their biomedical treatment regimen while they still exercise their faith or spiritual beliefs.

Compliance with medication was a key management strategy used by patients. Despite the perception and knowledge patients had about diabetes, they took their medication seriously. Most of these patients were also doing very well with the help of the health professionals, as well as dear ones. Some patients took their drugs with little or no supervision which really kept them going and

healthier. Patients did well by visiting hospital at the appointed time and promptly reported any new development. This was because they had been educated by the doctors and nurses that biomedicine was the only means for controlling diabetes. Patients also accepted that combining other herbal medicines with the biomedical drugs caused complications. So, patients tried their best to follow the recommended treatment regimen. Most studies reporting experiences of diabetic patients also stressed that patient used biomedical drugs in the treatment of their disease (Aikins, 2003, 2005; Awah & Phillimore, 2008; Awah et al., 2008; Hjelm & Mufunda, 2010; Matta et al., 2015; Zimmermann et al., 2018). Even though some of these studies suggested that patients used both biomedical and nonbiomedical drugs (Aikins, 2005; BeLue et al., 2013; Habte et al., 2016; Zimmermann et al., 2018), that was not the case for patients in this study. It was only one male patient who admitted that he combined both herbal and biomedical drugs. His reason was that he believed more in the herbal medicine than the biomedical drugs to cure his diabetes. This same reason was espoused by Aikins (2003; 2005), Broder et al. (2014), and Habte et al. (2016) when patients studied reported that herbal medicine resulted in better outcomes.

Dietary requirements and lifestyle changes are major contributing factors to diabetes management (Mendenhall & Norris, 2015; Murphy et al., 2015; Nielsen et al., 2016; Tewahido & Berhane, 2017; Zimmermann et al., 2018). Patients stated that they changed their lifestyles in order to manage the disease. Additionally, they modified their diet to conform to the recommendation by the doctors. According to Yasmin et al. (2020), patients stated that as part of the

management strategies, they followed the dietary recommendations by the physician. Patients in this study reported that this had helped with their management of the disease. The lifestyle changes concentrated on diet but not on physical activities (exercise). Contrary to other studies (Adeniyi et al., 2015: Hjelm & Mufunda, 2010; Murphy et al., 2015), many of the patients did not engage themselves in exercises as one of the management strategies. The lack of exercise by patients in the management of diabetes was also reported in the studies of Booysen and Schlemmer (2015), and Tawahido and Berhane (2017). Lack of exercise by patients in rural areas could be traced to the fact that they did not recognise the importance of exercise or their attention, interest and priorities lay with going to their farms. Studies had reported reasons why diabetics did not exercise to include lack of information (Nielsen et al., 2016), lack of knowledge, lack of interest, busy schedules (Tewahido & Berhane, 2017), pain when exercising, unsuitable and unsafe environment (Zimmermann et al., 2018), and lack of access.

Exercise is considered to be the most significant lifestyle change needed to manage diabetes, but most difficult to be implemented by patients (O'Brien et al., 2015). Murphy et al. (2015) asserted that lack of discipline explains why patients find it difficult to exercise. Tabong et al. (2018) noted that simply providing diabetics with information without creating an appropriate avenue or platform for the adoption of healthy lifestyle may render the care process ineffective. Therefore, community health workers ought to visit patients to provide them with care and support, as well as other health information that would be needed by

patients or community members. Health workers must ensure that patients follow their medication as they are supposed to and adhere to other treatment regimen. This form of social network created by health professionals would enable diabetics to share their experiences and ready to commit to the treatment regimen including physical activity.

In Leventhal's model, the interpretation and meaning given to the symptom's perception influenced the coping and management strategies adopted. In this study, patients identified the symptoms as diabetes with poor lifestyle as the aetiology. This meant that the disease could only be managed by biomedical treatment and healthy lifestyles. That was the reason most patients adopted hospital visits and biomedicine as management and coping strategies. By adopting this approach, patients were hopeful that the disease would be controlled successfully. This reduced the initial anxiety and fear they experienced. The coping strategies adopted had to effectively address the psychological and emotional distress that accompanied the symptoms perception and its interpretation. That was why patients needed to be counselled often. However, psychosocial supports such as counselling services were not adequately rendered to patients as suggested by the Leventhal model to deal with patients' emotions. It is important that health professionals acknowledge the various levels patients' illness representation operate and how these representations guide patients' preferred choices for long-term treatment behaviours. Finally, patients appraised or evaluated the management strategies adopted to see how they had effectively controlled the disease. When patients recognised that the management approaches

were effective, they continued with them, and this raised their hopes that they were on the right path of managing the disease. That was why majority of the rural diabetics alluded to the fact that they had been on biomedical treatment since diagnosis.

Diabetic patients living in rural areas managed diabetes through psychological acceptance, and social/spiritual support where patients enjoyed some support (finance, encouragement, reminders) from family members and prayers. Patients exercised their spiritual faith as a complement to other treatments. Furthermore, patients complied with recommended biomedical requirement, and changed their lifestyle to that effect. The lifestyle changes included dietary modification, careful and risk-free life. From the synthesis of the discussion, the findings have confirmed the two paradigms in Chapter Three (page 93) which was predicted to be the outcomes of the study. Thus, the interpretive paradigm has helped to explain what goes on in patients' lives from their perspectives and the radical humanist has helped to recognise the need to change human roles and functions to help manage diabetic patients in rural areas. This brings to the realization that the maintenance of diabetic patients in rural areas is dependent on certain key stakeholders who have been modeled in Figure 3 below.

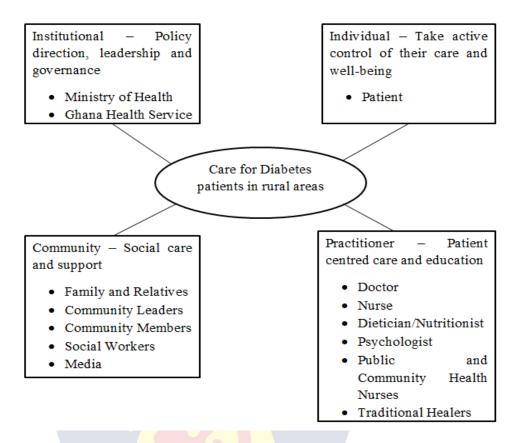


Figure 3: Model of Stakeholders in Diabetes Care in Rural Areas Source: Constructed by Researcher from Field Data, 2020

The roles of the various stakeholders have been outlined in Table 7 which is the framework developed to guide the care for diabetic patients in rural areas. However, in order to validate this framework, further studies are needed to engage stakeholders and to compare the roles to existing standards, possibly used by MOH, GHS or WHO to ensure conformity and to develop national guideline. In the event where there are no standards, stakeholders' consultation could help establish some.

Table 7: Framework Outlining the Roles of Stakeholders in Diabetes Care in Rural Areas

Stakeholders	Roles
Institutional	
Ministry of Health Ghana Health Service Individual	Policy direction, leadership and governance.  Develop guidelines on diabetes care.  Develop institutional structures and regulations to support diabetes care.
Patient	Accept the situation.  Follow treatment recommended (dietary and modification adherence, regular exercise, change in lifestyle, monitoring of blood glucose).  Go for regular check-ups, meet appointment.  Report any complications.  Read and watch diabetes-related videos to serve as a reminder.  Stock healthy foods at home, and have backyard garden.
Practitioner	garden
Doctor	Must not rush through the consultation processes.  Care must be patient-centred.  Educate patients on diabetes (signs, symptoms, causes, and management strategies) and drugs.  Establish good rapport, and healthy relationship with patients.  Thoroughly assess patients during physical examination for signs of diabetes.  Discharge teaching should be well done.  Allow patients to give feedback and come up with questions bothering them.
Nurse	Correct monitoring of patients' vital signs. Ensure correct in drug administration.
Dietician/Nutritionist	Educate patients on diet.

Table 7 cont.

Stakeholders	Roles
Psychologist	Conduct pre-test and post-test counselling for patients.
	Conduct psychological assessment on each
	patient after diagnosis.
	Provide psychological care and support to
	patients exhibiting psychological distress.
Public & Community Health	Continuous health education at the community
Nurse	level.
	Educate family members and community on the
	need to support patients.
	Regular fellow-ups on patients in the
	communities (home visitations or phone calls).
	Collaborate with traditional healers/pastors to
	identify individuals who first report their
	condition at the prayer and herbal camps.
Traditional Healers	Need to be well informed and educated on
	diabetes
	Desist from frightening patients with the
	disease.
	Refer possible diabetes cases to the hospital.
	Must scientifically test their medicine to know
Community	its efficacy, standard, specification, and dosage.
Community	
Family and Relatives	Provide patients with financial assistance,
	groceries, encouragement, and diabetes-related
	information.
	Help them with daily activities.
	Serve as reminders for appointments,
	medications, diet, and healthy living.
	Provide practical help and mechanism that
	reduce the stress of living with diabetes.
	D 11 4 2 C 2 1 14
Community Leaders	Provide opportunity for community health workers to educate community members
	workers to educate community members through durbars.
	Continuous education and sensitisation of
	community members on diabetes, and the need
	to support patients.
	Set a day aside to engage community members
	in health promotional activities like health walk.
	Development of regulations for sale of healthy
	foods.

Table 7 cont.

Stakeholders	Roles
Community Members	Development of community support groups
	made up of people with similar conditions to
	provide communal support and to also remind
	members of healthy habit.
Social Workers	Advocacy.
	Assess patient's home environment and
	availability of management.
	Direct patients to appropriate contacts for help
	and link them to NGOs for assistance.
Media	Publication of educative materials and content
	on diabetes.
	Provide platform for social networking of
	people with diabetes to share experiences, and
	make contact with others.

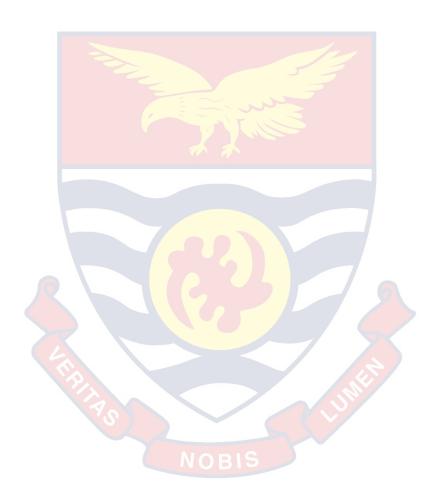
Source: Constructed by the Researcher

### **Summary**

The chapter provided qualitative analysis and results of each research question. It had identified the unique experiences of diabetes patients in rural areas of the Eastern Region. Research question one identified four main themes (symptoms identification, initial lifestyle, and patient's perception). Research question two generated one theme (psycho-emotional reactions) with two sub themes (psychological shock and emotional outburst). Two themes were identified from research question three and this included accessibility to health care facilities, and encounter with health providers. Analysis of research question four produced two main themes which included effects of the disease, and challenges of living with diabetes. Research question five identified one main theme: management strategies and this involved psychological acceptance, social/spiritual support, compliance with medication, and dietary and lifestyle changes. The results originated from the qualitative data helped with the

development of a model which will guide the care of diabetes patients in rural areas, and the roles of the stakeholders involved in the care process have clearly been outlined.

The next chapter discusses the summary of the research, conclusion drawn from the findings and recommendations.



#### **CHAPTER FIVE**

#### SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

This study explored the lived experiences of diabetes patients living in rural areas in the Eastern Region of Ghana. This section gives a summary of the entire research conducted, main findings, conclusions drawn, and recommendations based on the findings and conclusions. It is hoped that the recommendations and suggestions will help inform policy formation and enable other stakeholders such as the Government of Ghana, MOH, and GHS to modify certain policies and actions to facilitate the care given to diabetic patients in rural areas.

### **Summary**

Phenomenology approach was used to investigate the lived experiences of diabetes patients in rural areas of the Eastern Region of Ghana. Five research questions guided the study. These questions sought issues such as disease diagnosis, emotional and health care system experiences, as well as challenges and management of rural diabetes. Literature was reviewed on the concept of diabetes mellitus, self-management of diabetes and social support, definition of rural area, the rural conditions of Ghana, and rural-urban dynamics, Additionally, the literature focused on access to health care in the rural areas, structure and composition of Ghana health service, experiences of living with diabetes and the theoretical review. The Leventhal's Self-Regulatory Model of Illness Cognitions was adopted to serve as the conceptual framework. Thirty one diabetes patients were conveniently selected from the diabetes clinics of the hospitals. A semi-

structured interview guide was used to interview patients at the hospital premises. The interview guide enabled follow-up questions to be asked in order to seek for more clarifications where necessary. Interviews were audio-recorded and later transcribed into a text format with the help of transcribing peddle. The audio-recordings helped the researcher to listen carefully to patients and take down notes during the interview. All ethical protocols concerning the thesis were dully addressed. The analysis followed the IPA guidelines proposed by Smith et al. (1999). Main themes and sub-themes were generated from the various research questions and discussed in relation to literature. The key findings identified have been summarised to answer various sub-research questions.

#### **Key Findings**

Due to the gaps identified in the literature, this research set to identify empirical data to support policy changes that would aim at addressing the unique experiences and challenges encountered by diabetes patients from rural areas. These research questions have been critically and adequately discussed, and they have shown that diabetes patients from rural areas have been greatly affected by ineffective health care system, and yet little empirical study into the issue has been carried out in Ghana, especially in the Eastern Region.

Four main themes generated were: symptoms identification, negative lifestyle, patients' perception of diabetes, and patients' knowledge of diabetes. The symptoms that patients identified included: frequent urination, sweet urine, frequent hunger and thirst, weight reduction, and blisters/foot sore (wound). The findings showed that the negative lifestyle that exposed patients to diabetes was

excessive alcohol consumption and poor eating habits (love sweets and meat). With regards to patients' perception of diabetes, the findings revealed that some patients perceived diabetes as disease of the rich, and few believed that it was spiritually induced. Some patients held the perception that diabetes was a dangerous disease that could easily kill patients. In terms of patients' knowledge on diabetes, it was evident that they had limited knowledge on diabetes as a disease and apart from the information given to them at the hospital; they did not make any conscious effort to search for additional information on the disease. These findings revealed that patients recognised illness through the symptom perception and social messages they received from family members, friends, health checks and health professionals. Patients therefore interpreted these symptoms perception and social messages along these dimensions: identity, cause, consequences, timelines, and cure/control. The outcome of patients' interpretation of symptoms subsequently influenced their coping and management strategies, and the effective appraisal of the strategies adopted. Social factors such as family members and friends influenced patients' interpretation of the symptoms identified.

One main theme (psycho-emotional reactions) with two sub-themes (psychological shock and emotional outburst) was generated. Psychological shock experienced by patients after being diagnosed with diabetes included: Shock (surprised), Fear (frightened and terrified), Frustration (lost hope), Worry (excessive thinking), Self-blame (self-questioning and disbelief), and Suicidal ideations. The accompanied emotional outbursts were: Sadness (pain and

weeping), and Emotional exhaustion (confronted with). Patients' psychological and emotional needs were not adequately addressed. Thus, psychosocial support like counselling and psychotherapy were not readily available at the diabetes clinics. These services were also not available at the various rural communities where patients lived, thereby making it difficult or impossible for their psychological and emotional needs to be addressed. There seemed to be lapses in the general health care system; especially those in rural communities experience the greatest negative impact. In line with Leventhal's framework, patients' interpretation of the symptoms often results in some emotional experiences, and this was confirmed as patients experienced the identified mentioned psychoemotional reactions upon diagnosis.

It was also evident that accessing health care by patients in rural areas was very difficult. Two main themes were identified in relation to experiences of rural diabetics with the health care systems: accessibility to health care facilities and attitude of health care providers. Accessibility to health care facilities generated the following sub-themes: Patients experienced transportation challenges. They had to travel long distances on poor roads in order to access health. Again, it was difficult getting a vehicle to take patients to the cities or towns with health facilities. Therefore, patients had to resort to motor bikes or walking several miles on journey to access diabetes care. These challenges sometimes caused patients to abandon hospital visits and treatments and resort to traditional care leading to complications. The transportation services in rural areas were not reliable, trust worthy and safe for patients. It was time consuming accessing health care any

time patients arrived at the clinic. They often met long queues at the clinics and this prolonged the time they spent at the clinics. Patients complained about the fact that they met different doctors any time they went for their regular checkups at the clinics.

As regards the theme 'encounter with health care providers,' some patients generally expressed satisfaction about the attitudes of the doctors and nurses. They opined that the doctors and nurses advised patients on adhering strictly to the medication and dietary requirements, and general life habits. Even though some patients were satisfied with the doctors and nurses, others had their reservations. Some patients complained about the hurried attitude of doctors during consultations. They also talked about the impatience of doctors and nurses which made it difficult for patients to ask questions. Evidence from the empirical data showed that doctors and nurses did not have enough time for patients during consultations because of the large numbers of patients on a clinic day.

It was found that diabetes affected patients physically and socially. Physically, patients experienced debilitation (inability to work), blurred vision (retinopathy), leg amputation, sexual weakness, and sleeplessness (insomnia). Socially, diabetes restricted patients' social relationships with friends, thus, preventing them from moving freely and eating desired foods. This created poor social relations between some patients and their friends.

Patients were financially burdened by the disease; this came about as a result of the purchase of drugs and the cost associated with transportation and dietary requirements. Patients also complained of the large quantity of drugs they

had to take. Another challenge that patients experienced was the storage of drugs. It was noted that rural patients did not have appropriate facilities for storing their drugs, especially insulin. Patients had challenges following strict dietary and medication instructions recommended by the doctors.

Four themes were generated on how rural diabetics manage the disease. The findings indicated psychological acceptance, social/spiritual support, adherence to medication, and dietary and lifestyle changes. As part of the management strategies, patients accepted they were sick and needed to manage the disease. Patients received support (financially) from family members, especially, their children. Patients supported treatment with prayers. They adhered to medications and dietary regimen recommended by the doctors. Finally, patients changed their lifestyles to meet the demands of the disease. As noted earlier, the challenges experienced did not stop patients form following the suggested treatment requirement. As in the framework, patients' interpretation of the symptoms of the disease and confirmation from health professionals made patients conclude that the disease was biologically caused and that it could have serious consequences if not well managed. This made patients adopt biomedical treatment (hospital visits) as the appropriate means of managing the disease. Patients often appraised the coping and management strategies, and concluded that they (strategies) had been effective.

#### Conclusions

Based on the findings, the following conclusions have been drawn.

Diabetes patients recognised the disease through both the symptoms experienced

(frequent urination, sweet urine, weight reduction, frequent thirst and hunger, foot sore) and hospital diagnosis. Again, negative lifestyle contributed to the development of the disease. Patients perceived diabetes as 'disease of the rich' and their knowledge about the disease was generally limited. Social factors influenced patients' identification of symptoms. This could influence their interpretation of disease, perception and knowledge about the diabetes. Again, social messages from especially family members and friends could heighten patients' emotions and eventually compromises their health seeking behaviours as it sometimes leads to delay in reporting at the hospital and delay the chances of early intervention.

Patients' psychological and emotional needs were not adequately addressed. This could lead to extreme forms of psychological distress (anxiety and depression), and patients may report more suicidal ideations or attempts.

Access to health care facilities was challenging and patients met different doctors whenever they visited the clinic. Transportation difficulties and poor road network often impeded patients' access to health care in the urban areas. The difficulty of accessing health care could lead to non-attendance or skipping hospital visits. Meeting different doctors on each visit without adequate explanation would cause mistrust in the care process and affects patients' general satisfaction with the general health care system. This eventually, increases patients' use of traditional medicines and prayer camps.

Diabetes imposed physical and social restrictions on patients, and they were also financially burdened by the disease. Additionally, storage of drugs

(insulin) was a challenge for them. These challenges could worsen patients' condition and increase diabetes related complications (amputation, retinopathy, nephropathy), and in extreme cases, death.

Patients managed diabetes through psychological acceptance, social support, prayers, lifestyle changes and medication adherence. This implies that acceptance of the disease at the early stages is an important step to initiate appropriate behaviours towards management. However, patients' preparedness to manage the disease was outweighed by the challenges experienced.

#### Recommendations

Based on the conclusions, the following recommendations were made for policy, education and health interventions.

- 1. There must be early screening for non-communicable diseases within the community coupled with health promotion to help early detection of the disease. Since social factors influenced patients' identification of symptoms, health promotion and education about diabetes must be a top most priority at the community level in the rural areas. Community sensitization and health education must consistently highlight possible lifestyle activities that make people vulnerable and predisposes them to the disease. This will help correct some of the misconception patients have about diabetes and improve their knowledge as well.
- 2. There must be an integrated care model for diabetes patients in rural areas that encompasses a psychosocial therapy built around the primary health care concept with establishment of counselling units in all primary health

care facilities. The units will be able to counsel patients on effective ways of dealing with their thoughts when they experience feelings of helplessness and hopelessness. This would complement the care given by the diabetes clinics. Again, it would help build patients' psychological well-being and heal their psychological wounds. As part of the measures to improve patients' psychological well-being, there must be follow-up visits on patients, especially those who express severe psychological and emotional distresses in order to avert any extreme depressions.

3. In order to improve access to health care by patients from the rural areas, it is important that the MOH and GHS review policies regarding health centres, clinics, and community health planning and services (CHPS) compounds in these rural communities so that these centres can be upgraded and well-resourced to meet the demands of diabetes patients. Instead of patients going to towns for clinics, they can be directed to these centres to reduce the stress they go through on clinic days. Once these centres are well-equipped, clinic days at the hospitals could be decentralized to community levels, precisely to CHPS compounds where specialist doctors and nurses would visit to take care of patients. This calls for increase in recruitment and training of doctors and nurses to take up such roles to support the already burdened health system. This policy will reduce the build-ups and congestions that occur on clinic days at the hospitals in towns and cities. The pressure on health care professionals would be reduced and the time doctors spend with patients during consultation would increase. Additionally, there must be a team of doctors assigned to provide care for patients to have a continuous relationship and trust with health care providers. Patients would also have the belief that if a number of the team of doctors is absent, the others will continue to attend to the patient in providing proper care. This will reduce the complaints made by patients about meeting different doctors on clinic days.

4. Diabetes had a debilitating effect on patients so the community health workers must constantly educate patients to enable them adjust well with the physical and social changes that come with the disease. Education on diabetes should not be limited only to the hospital. GHS could design a programme to train community health volunteers (CHV) who will visit the homes of patients on regular basis to provide them with care and support as well as other health information that would be needed by patients or community members. Public health officers and community health workers should pay regular visits to rural areas and organise health sensitization programmes for diabetics on how to monitor their health condition, and to conscientise them on management strategies. This up-todate information about diabetes would go a long way to reduce effects and complications. Also, the MOH and GHS could adopt the interactive voice call project (mobile health project) through which diabetes patients will be regularly reminded of the recommended treatment. This could help reach

- patients irrespective of their geographical location, and reduce cost associated with transportation and consultation.
- 5. For effective management of diabetes, social network support system must be established and facilitated by community health workers in the rural areas to enable patients share their experiences to motivate each other, erase negative perceptions, and increase patients' psychological acceptance and emotional stability. This form of social network created by the health professionals will also influence patients' readiness to commit to the treatment regimen. There is the need for holistic approach to the treatment of diabetes, by which patients would be made to understand that they could adhere to the biomedical treatment regardless of their spiritual beliefs and faith.

# **Suggestions for Future Research**

Future researchers must consider engaging more patients from other parts of the country to examine their unique experiences as well. Additionally, it will be prudent if future research selects more sample size to enable broad generalization of the findings. Future research must consider using other approaches apart from phenomenology to examine the variables under study. It is hoped that further studies will consider conducting interviews at the homes of patients or patients' place of choice to enable them have enough time to engage in the interviews. Finally, other studies must consider selecting health care professionals to examine their perspectives as well.

#### REFERENCES

- Abanilla, P. K. A., Huang, K. Y., Shinners, D., Levy, A., Ayernor, K., Aikins, A.
  D. G., & Ogedegbe, O. (2011). Cardiovascular disease prevention in Ghana: Feasibility of a faith-based organizational approach. *Bulletin of the World Health Organization*, 89, 648-656.
- Abdulrehman, M. S., Woith, W., Jenkins, S., Kossman, S., & Hunter, G. L. (2016). Exploring cultural influences of self-management of diabetes in coastal Kenya: An ethnography. *Global Qualitative Nursing Research*, 3, 1-13. doi: 10.1177/2333393616641825.
- Adeniyi, O. V., Yogeswaran, P., Wright, G., & Longo-Mbenza, B. (2015).

  Diabetic patients' perspectives on the challenges of glycaemic control.

  African Journal of Primary Health Care & Family Medicine, 7(1), 1-8.
- Adisa, R., Alutundu, M. B., & Fakeye, T. O. (2009). Factors contributing to nonadherence to oral hypoglycemic medications among ambulatory type 2 diabetes patients in Southwestern Nigeria. *Pharmacy Practice*, 7(3), 163-169.
- Adjei, P. O. (2008). The impact of poverty on the health of rural communities in Ghana: A case study of the Amansie West District, Ashanti Region.

  \*Unpublished PhD thesis\*, Kwame Nkrumah University of Science and Technology, Kumasi
- Agyei-Mensah, S., & Aikins, A. D. G. (2010). Epidemiological transition and the double burden of disease in Accra, Ghana. *Journal of Urban Health*, 87(5), 879-897.

- Ahmed, Z., & Yeasmeen, F. (2016). Active family participation in diabetes self-care: A commentary. *Diabetes Management*, 6(5), 104-107.
- Aikins, A. D. G. (2013). The socio-cultural and socio-economic context of Africa's chronic disease burden. *Chronic Non-Communicable Diseases in Ghana: Multidisciplinary Perspectives*, 124-136.
- Aikins, A. D. G. (2005). Healer shopping in Africa: New evidence from rural-urban qualitative study of Ghanaian diabetes experiences. *BMJ*, *331*, 1-7. doi:10.1136/bmj.331.7519.737.
- Aikins, A. D. G. (2003). Living with diabetes in rural and urban Ghana: A critical social psychological examination of illness action and scope for intervention. *Journal of Health Psychology*, 8, 557. doi: 10.1177/13591053030085007.
- Aikins, A. D. G., Anum, A., Agyemang, C., Addo, J., & Ogedegbe, O. (2012).

  Lay representations of chronic diseases in Ghana: Implications for primary prevention. *Ghana Medical Journal*, 46(2), 59-68.
- Aikins, A. D. G., Awuah, R. B., Pera, T. A., Mendez, M., & Ogedegbe, G. (2014).

  Explanatory models of diabetes in urban poor communities in Accra,

  Ghana. *Ethnicity* & *Health*, 20(4), 391-408. doi:

  10.1080/13557858.2014.921896.
- Aikins, A. D. G., & Ofori-Atta, A. L. (2007). Homelessness and mental health in Ghana: Everyday experiences of Accra's migrant squatters. *Journal of Health Psychology*, 12(5), 761-778.

- Aikins, A. D. G., Owusu-Dabo, E., & Agyemang, C. (2013). Diabetes in Ghana:

  A review of research on prevalence, experiences and healthcare. *Chronic Noncommunicable Diseases in Ghana: Multidisciplinary Perspectives*, 1, 41-55.
- Aikins, A. D. G., Unwin, N., Agyemang, C., Allotey, P., Campbell, C., & Arhinful, D. (2010). Tackling Africa's chronic disease burden: From the local to the global. *Globalization and Health*, 6(1), 1-7.
- Alam, R., Speed, S., & Beaver, K. (2012). A scoping review on the experiences and preferences in accessing diabetes-related healthcare information and services by British Bangladeshis. *Health & Social Care in the Community*, 20(2), 155-171.
- Almino, M. A. F. B., Queiroz, M. V. O., & Jorge, M. S. B. (2009). Diabetes mellitus in adolescence: Experiences of adolescents and their mothers. *Revista da Escola de Enfermagem da USP*, 43, 760-767.
- American Diabetes Association. (2012). Medical management of Type 2 diabetes (7<sup>th</sup> ed.). *Burant CF, Young LA, Eds. Alexandria*, VA: American Diabetes Association.
- American Diabetes Association. (2003). Gestational diabetes mellitus. *Diabetes*Care, 26(1), s88-s90.
- Anderson, D., & Christison-Lagay, J. (2008). Diabetes self-management in a community health center: Improving health behaviors and clinical outcomes for underserved patients. *Clinical Diabetes*, 26(1), 22-27.

- Anderson, R. J., Freedland, K. E., Clouse, R. E., & Lustman, P. J. (2001). The prevalence of comorbid depression in adults with diabetes: A meta-analysis. *Diabetes Care*, 24(6), 1069-1078.
- Anekunabe, M. (2009). Conflicts in the northern regions: Challenges, solutions and way forward. Accra, Institute of Journalism
- Anna, V., Van Der Ploeg, H. P., Cheung, N. W., Huxley, R. R., & Bauman, A. E. (2008). Sociodemographic correlates of the increasing trend in prevalence of gestational diabetes mellitus in a large population of women between 1995 and 2005. *Diabetes Care*, 31(12), 2288-2293.
- Asibey, E. W. (2016). Association between psychosocial factors and glycemic level of diabetic patients. Unpublished Doctoral dissertation, University of Cape Coast, Cape Coast.
- Australian Institute of Health and Welfare. (2008). Diabetes: Australian facts

  2008. Diabetes series no. 8. Cat. no. CVD 40. Canberra: AIHW.
- Awah, P. K., & Phillimore, P. (2008). Diabetes, medicine and modernity in Cameroon. *Africa*, 78(4), 475-495.
- Awah, P. K., Unwin, N., & Phillimore, P. (2008). Cure or control: Complying with biomedical regime of diabetes in Cameroon. *BMC Health Services Research*, 8(1), 1-11.
- Awuah, R. B., Anarfi, J. K., Agyemang, C., Ogedegbe, G., & Aikins, A. D. G. (2014). Prevalence, awareness, treatment and control of hypertension in urban poor communities in Accra, Ghana. *Journal of Hypertension*, *32*(6), 1203-1210.

- Bagnasco, A., Di Giacomo, P., Da Rin Della Mora, R., Catania, G., Turci, C., Rocco, G., & Sasso, L. (2014). Factors influencing self-management in patients with type 2 diabetes: A quantitative systematic review protocol.

  \*\*Journal of Advanced Nursing, 70(1), 187-200.
- Barreto, S. M., Passos, V. M. A., Almeida, S. K. F., & Assis, T. D. (2007). The burden of diabetes mortality is increasing among Brazilian adults. *Rev Panam Salud Publica*, 22(4), 239-245.
- Basu, S., Yoffe, P., Hills, N., & Lustig, R. H. (2013). The relationship of sugar to population-level diabetes prevalence: An econometric analysis of repeated cross-sectional data. *PloS One*, 8(2), e57873. doi: <a href="http://dx.doi.org/10.1371/journal.pone.0057873">http://dx.doi.org/10.1371/journal.pone.0057873</a>.
- Bayındır Çevik, A., Özcan, Ş., & Satman, I. (2015). Reducing the modifiable risks of cardiovascular disease in Turkish patients with type 2 diabetes:

  The effectiveness of training. *Clinical Nursing Research*, 24(3), 299-317.
- Bays, H. E. (2012). Adiposopathy, diabetes mellitus, and primary prevention of atherosclerotic coronary artery disease: Treating "sick fat" through improving fat function with anti-diabetes therapies. *The American Journal of Cardiology*, 110(9), 4B-12B.
- Beagley, J., Guariguata, L., Weil, C., & Motala, A. A. (2014). Global estimates of undiagnosed diabetes in adults. *Diabetes Research and Clinical Practice*, 103(2), 150-160.

- Bellamy, L., Casas, J. P., Hingorani, A. D., & Williams, D. (2009). Type 2 diabetes mellitus after gestational diabetes: A systematic review and meta-analysis. *The Lancet*, *373*(9677), 1773-1779.
- BeLue, R., Diaw, M., Ndao, F., Okoror, T., Degboe, A., & Abiero, B. (2013). A cultural lens to understanding daily experiences with type 2 diabetes self-management among clinic patients in M'bour, Senegal. *International Quarterly of Community Health Education*, 33(4), 329-347.
- Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. E. (2000). From social integration to health: Durkheim in the new millennium. *Social Science & Medicine*, *51*(6), 843-857.
- Bernard, J. (2018). Rural quality of life–poverty, satisfaction and opportunity deprivation in different types of rural territories. *European Countryside*, 10(2), 191-209.
- Best, M., & Neuhauser, D. (2004). Avedis Donabedian: Father of quality assurance and poet. *BMJ Quality & Safety*, *13*(6), 472-473.
- Bhattacharya, G. (2012). Self-management of type 2 diabetes among African Americans in the Arkansas Delta: A strengths perspective in social-cultural context. *Journal of Health Care for the Poor and Underserved*, 23(1), 161-178.
- Boakye, M. D. S. (2015). *Knowledge on Diabetes among Adults in the Kwahu*South District. Unpublished Doctoral dissertation, Kwame Nkrumah

  University of Science and Technology, Kumasi.

- Booysen, B. L., & Schlemmer, A. C. (2015). Reasons for diabetes patients attending Bishop Lavis Community Health Centre being non-adherent to diabetes care. *South African Family Practice*, *57*(3), 166-171.
- Bopape, M. W., & Peltzer, K. (2002). Health beliefs and stress among non-insulin dependent diabetes out-patients in a rural teaching hospital in South Africa. *Health SA Gesondheid*, 7(4), 38-46.
- Bossman, I., Dare, S., Oduro, B. A., Baffour, P. K., & Nally, J. E. (2020).

  Patients' knowledge of diabetes complications and self-management practices in Ghana. *Research Square*, 3(1), 1-17. doi: http://doi.org/10.21203/rs.3.rs-44873/v1.
- Brenya, E., & Adu-Gyamfi, S. (2014). Interest groups, issue definition and the politics of healthcare in Ghana. *Public Policy and Administration Research*, 4(6), 88-96.
- Broder, H. L., Tormeti, D., Kurtz, A. L., Baah-Odoom, D., Hill, R. M., Hirsch, S. M., & Sischo, L. (2014). Type II diabetes and oral health: Perceptions among adults with diabetes and oral/health care providers in Ghana. *Community Dent Health*, 31(3), 158-62.
- Brown, W. V. (2008). Microvascular complications of diabetes mellitus: Renal protection accompanies cardiovascular protection. *The American Journal of Cardiology*, 102(12), 10L-13L.
- Browne, J. L., Ventura, A., Mosely, K. & Speight, J. (2013). 'I call it the blame and shame disease': A qualitative study about perceptions of social stigma

- surrounding type 2 diabetes. *BMG Open*, *3*(11), e003384. https://doi.org/10.1136/bmjopen-2013-003384.
- Brownlee, S., Leventhal, H., & Leventhal, E. A. (2000). Regulation, self-regulation, and construction of the self in the maintenance of physical health. In: Boekartz, M., Pintrick, P. R., Zeidner, M., editors. *Handbook of Self-Regulation*. San Diego, CA: Academic Press. pp. 369–393.
- Bryden, K. S., Peveler, R. C., Stein, A., Neil, A., Mayou, R. A., & Dunger, D. B. (2001). Clinical and psychological course of diabetes from adolescence to young adulthood. *Diabetes Care*, 24 (9), 1536 1540.
- Budrevičiūtė, A., Kalėdienė, R., & Petrauskienė, J. (2018). Priorities in effective management of primary health care institutions in Lithuania: Perspectives of managers of public and private primary health care institutions. *PloS One*, *13*(12), e0209816. doi: <a href="https://doi.org/10.1371/journal.pone.0209816">https://doi.org/10.1371/journal.pone.0209816</a>.
- Burell, G. & Morgan, G. (1982). Sociological paradigms and organisational analysis. London: Heinemann.
- Burke, H., & Dowling, M. (2007). Living with diabetes: Adolescents' perspectives. *Journal of Diabetes Nursing*, 11(3), 90-95.
- Camara, A., Balde, N. M., Enoru, S., Bangoura, J. S., Sobngwi, E., & Bonnet, F. (2015). Prevalence of anxiety and depression among diabetic African patients in Guinea: Association with HbA1c levels. *Diabetes & metabolism*, 41(1), 62-68.

- Carolan-Olah, M. C., Cassar, A., Quiazon, R. & Lynch, S. (2013). Diabetes care and service access among elderly Vietnamese with type 2 diabetes. *BMC Health Services Research*, *13*(1), 1-9. doi: 10.1186/1472-6963-13-447.
- Carolan, M., Holman, J., & Ferrari, M. (2015). Experiences of diabetes self-management: A focus group study among Australians with type 2 diabetes. *Journal of Clinical Nursing*, 24(7-8), 1011-1023. doi: https://doi.org/10.1111/jocn.12724
- Carroll, A. & Marrero, D. G. (2006). The role of significant others in adolescent diabetes: A qualitative study. *The Diabetes Educator*, 32(2), 243-252. doi: 10.1177/0145721706286893.
- Carruth, A. (2012). A qualitative investigation into the different health experiences of people living with type II diabetes, in the rural environments. Unpublished Doctoral Dissertation, Queensland University of Technology, Australia.
- Cheung, N., Wong, V. & Mclean, M. (2006). The hyperglycemia: Intensive insulin infusion in infarction (hi-5) study: A randomized controlled trial of insulin infusion therapy for myocardial infarction. *Diabetes Care*, 29(4), 765–770.
- Chinenye, S., Ofoegbu, E. N., Onyemelukwe, G. C., Uloko, A. E., & Ogbera, A.
  O. (2013). Clinical Practice Guidelines for Diabetes Management in Nigeria. Nigeria, Diabetes Association of Nigeria (DAN).

- Chodosh, J., Morton, S. C., Mojica, W., Maglione, M., Suttorp, M. J., Hilton, L., ... & Shekelle, P. (2005). Meta-analysis: Chronic disease self-management programs for older adults. *Annals of Internal Medicine*, *143*(6), 427-438.
- Chung, J. H., Moon, K., Kim, D. H., Min, J. W., Kim, T. H., & Hwang, H. J. (2014). Suicidal ideation and suicide attempts among diabetes mellitus: The Korea National Health and Nutrition Examination Survey (KNHANES IV, V) from 2007 to 2012. *Journal of Psychosomatic Research*, 77(6), 457-461.
- Ciechanowski, P. S., Katon, W. J., & Russo, J. E. (2000). Depression and diabetes: Impact of depressive symptoms on adherence, function, and costs. *Archives of Internal Medicine*, *160*(21), 3278–3285.
- Cliff, J. & Noormohammed, A. R. (1988) South Africa's destabilisation of Mozambique, *Social Science and Medicine*, 27(7), 717–722.
- Cohen, J., Christensen, K. & Feldmen, L (2012). Disease management and medication compliance. *Population Health Management*, 15(1), 20–28. doi: <a href="https://doi.org/10.1089/pop.2011.0020">https://doi.org/10.1089/pop.2011.0020</a>.
- Collis, J., & Hussey, R. (2009). A practical guide for undergraduate and postgraduate students, (4<sup>th</sup> ed.). New York, USA, Palgrave Macmillan.
- Cook-Huynh, M., Ansong, D., Steckelberg, R. C., Boakye, I., Seligman, K., Appiah, L., & Amuasi, J. H. (2012). Prevalence of hypertension and diabetes mellitus in adults from a rural community in Ghana. *Ethnicity and Disease*, 22, <a href="http://hdl.handle.net/123456789/7784">http://hdl.handle.net/123456789/7784</a> on 17<sup>th</sup> May, 2020

- Contreras, J. A., Goñi, J., Risacher, S. L., Amico, E., Yoder, K., Dzemidzic, M., & Saykin, A. J. (2017). Cognitive complaints in older adults at risk for Alzheimer's disease are associated with altered resting-state networks. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, 6(12), 40-49.
- Creswell, J. W. (2007). Five qualitative approaches to inquiry. In J. W. Creswell (Eds.), *Qualitative inquiry and research design: Choosing among five approaches* (pp. 53-84). London, Thousands Oaks: Sage Publications.
- Creswell, J. W. (1998). Qualitative inquiry and research design: Choosing among five traditions. London, Thousands Oaks: Sage Publications.
- Cruz, I. I. (2014). The lived experience of insulin-dependent diabetes among adult

  Latinos in a primary care clinic in San Antonio. Unpublished dissertations, University of Iowa, Nigeria.
- Czech, D. R., Wrisberg, C. A., Fisher, L. A., Thompson, C. L., & Hayes, G. (2004). The experience of Christian prayer in sport: An existential phenomenological investigation. *Journal of Psychology and Christianity*, 23(1), 3-11.
- Dabelea, D., Mayer-Davis, E. J., Saydah, S., Imperatore, G., Linder, B., Divers, J., ... & Liese, A. D. (2014). Prevalence of type 1 and type 2 diabetes among children and adolescents from 2001 to 2009. *JAMA*, 311(17), 1778-1786.
- Dabney, B., & Gosschalk, A. (2010). Diabetes in rural America. *Rural Healthy People*, 2, 57-72.

- Dale, G. A. (1996). Existential phenomenology: Emphasizing the experience of the athlete in sport psychology research. *The Sport Psychologist*, 10(4), 307-321.
- Danaei, G., Lawes, C. M., Vander, H. S., Murray, C. J., & Ezzati, M. (2006).

  Global and regional mortality from ischaemic heart disease and stroke attributable to higher-than-optimum blood glucose concentration:

  Comparative risk assessment. *Lancet*, 368 (9548), 1651–1659.
- Danquah, I., Bedu-Addo, G., Terpe, K. J., Micah, F., Amoako, Y. A., Awuku, Y. A., & Mockenhaupt, F. P. (2012). Diabetes mellitus type 2 in urban Ghana: Characteristics and associated factors. *BMC Public Health*, *12*(1), 1-8.
- Darkwa, S. (2011). Prevalence of diabetes mellitus and resources available for its management in the Cape Coast Metropolis. *ISABB Journal of Health and Environmental Sciences*, *I*(1), 1-7.
- De Groot, M., Anderson, R., Freedland, K. E., Clouse, R. E., & Lustman, P. J. (2001). Association of depression and diabetes complications: A meta-analysis. *Psychosomatic Medicine*, *63*(4), 619-630.
- De Rooij, S. R., Roseboom, T. J., & Painter, R. C. (2014). Famines in the last 100 years: implications for diabetes. *Current Diabetes Reports*, 14(10), 536.
- Demir, T., Akinci, B. & Yesil, S. (2007). Diagnosis and treatment of diabetic foot ulcers (in Turkish). *Journal of DEU Faculty of Medicine*, 21(1), 63-70.
- DePaepe, P., Garrison-Kane, L. & Doelling, J. (2002). Supporting students with health needs in schools: An overview of selected health conditions.

- Focus on Exceptional Children, 35(1), 1-24.
- Diabetes United Kingdom. (2010). Diabetes in the UK 2010: Key statistics on diabetes. London: Diabetes UK.
- DiMatteo, M. R. (2004). Social support and patient adherence to medical treatment: A meta-analysis. *Health Psychology*, 23(2), 207-218.
- Dobjanschi, C. & Miulescu, R. D. (2015). Risk factors for gestational diabetes An update. *Romanian Journal of Diabetes Nutrition and Metabolic Diseases*, 22(2), 201-207. doi: 10.1515/rjdnmd-2015-0025.
- Doherty, M. L., Owusu-Dabo, E., Kantanka, O. S., Brawer, R. O., & Plumb, J. D. (2014). Type 2 diabetes in a rapidly urbanizing region of Ghana, West Africa: A qualitative study of dietary preferences, knowledge and practices. *BMC Public Health*, *14*(1), 1-8.
- Donabedian, A. (1988). The assessment of technology and quality: A comparative study of certainties and ambiguities. *International Journal of Technology Assessment in Health Care*, 4(4), 487-496.
- Doubova, S. V., Guanais, F. C., Pérez-Cuevas, R., Canning, D., Macinko, J., & Reich, M. R. (2016). Attributes of patient-centered primary care associated with the public perception of good healthcare quality in Brazil, Colombia, Mexico and El Salvador. *Health Policy and Planning*, *31*(7), 834-843.
- Drislane, F. W., Akpalu, A., & Wegdam, H. H. (2014). Establishment of a general medicine residency training program in rural West Africa. *The Yale Journal of Biology and Medicine*, 87(3), 327.

- Dube, L., Van den Broucke, S., Dhoore, W., Kalweit, K., & Housiaux, M. (2015).

  An audit of diabetes self-management education programs in South

  Africa. *Journal of Public Health Research*, 4(3), 176-184.
- Edge, J., & Richards, K. (1998). May I see your warrant, please? Justifying outcomes in qualitative research. *Applied Linguistics*, 19(3), 334-356.
- Escribano-Ferrer, B., Cluzeau, F., Cutler, D., Akufo, C., & Chalkidou, K. (2016).

  Quality of health care in Ghana: Mapping of interventions and the way forward. *Ghana Medical Journal*, 50(4), 238-247.
- Fetita, L. S., Sobngwi, E., Serradas, P., Calvo, F., & Gautier, J. F. (2006).

  Consequences of fetal exposure to maternal diabetes in offspring. *The Journal of Clinical Endocrinology & Metabolism*, 91(10), 3718-3724.
- Filmer, D., Hammer, J. S., & Pritchett, L. H. (2000). Weak links in the chain: A diagnosis of health policy in poor countries. *The World Bank Research Observer*, 15(2), 199-224.
- Flowers, P., Smith, J. A., Sheeran, P., & Beail, N. (1998). 'Coming Out' and sexual debut: Understanding the social context of HIV risk-related behaviour. *Journal of Community & Applied Social Psychology*, 8(6), 409-421.
- Funnell, M. M., & Anderson, R. M. (2004). Empowerment and self-management of diabetes. *Clinical Diabetes*, 22(3), 123-127.
- Gakidou, E., Mallinger, L., Abbott-Klafter, J., Guerrero, R., Villalpando, S., Ridaura, R. L., ... & Murray, C. J. (2011). Management of diabetes and associated cardiovascular risk factors in seven countries: A comparison of

- data from national health examination surveys. *Bulletin of the World Health Organization*, 89, 172-183. doi: doi:10.2471/BLT.10.080820.
- Gary, G. (2009). *How to safely store your insulin*. Retrieved from <a href="http://type1diabetes.about.com/od/insulinandmedications/qt/insulin\_storage.htm">http://type1diabetes.about.com/od/insulinandmedications/qt/insulin\_storage.htm</a> on 21st July, 2019.
- Gatimu, S. M., Milimo, B. W., & San Sebastian, M. (2016). Prevalence and determinants of diabetes among older adults in Ghana. *BMC Public Health*, 16(1), 1174.
- George, S. R., & Thomas, S. P. (2010). Lived experience of diabetes among older, rural people. *Journal of Advanced Nursing*, 66(5), 1092-1100. doi: 10.1111/j.1365-2648.2010.05278.x.
- Ghana CHPS. (2009). Community-based health planning and services (CHPS).

  Community health volunteer's training manual. The Population Council,

  Inc. and Ministry of Health/Ghana Health Service.
- Ghana Health Service. (2018). The district health information management system 2 (Ghs-dhims2). Ghana Health Service.
- Ghana Health Service. (2017). Eastern Regional Health Service Annual Performance Review: 2016 Annual Report. Ghana Health Service.
- Ghana Statistical Service. (2013). 2010 Population & housing census: National analytical report. Ghana Statistics Service.
- Ghana Statistical Service. (2011). Presentation on the 2010 population and housing survey, Accra.
- Ghana Statistical Service. (2004). Ghana demographic and health survey, 2003.

- Ghana Statistical Service.
- Gill, G. V. (2000). Stability of insulin in tropical countries. *Tropical Medicine & International Health*, 5(9), 666-667.
- Gleeson-Kreig, J. (2008). Social support and physical activity in Type 2 Diabetes:

  A social-ecologic approach. *The Diabetes Educator*, 34(6), 1037-1044.
- Glesne, C. (2011). Chapter 6: But is it ethical? Considering what is right.

  \*Becoming Qualitative Researchers: An Introduction, 4, 162-183.
- Gould, S. J. (2002). *The structure of evolutionary theory*. USA, Harvard University Press.
- Government of Ghana. (2003). National health insurance act, 2003 (Act 650).
- Gray, S. E., & Rutter, D. R. (2007). Illness representations in young people with chronic fatigue syndrome. *Psychology and Health*, 22(2), 159-174.
- Guanais, F., Doubova, S. V., Leslie, H. H., Perez-Cuevas, R., García-Elorrio, E., & Kruk, M. E. (2018). Patient-Centered primary care and self-rated health in 6 Latin American and Caribbean countries: Analysis of a public opinion cross-sectional survey. *PLoS medicine*, 15(10), e1002673.
- Guantai, A. N., Godman, B., Oluka, M., Niba, L. L., Pillay, Y., Basu, D., ... & Mwita, J. C. (2020). Review of ongoing activities and challenges to improve the care of patients with Type 2 Diabetes across Africa and the implications for the future. *Frontiers in Pharmacology*, 11(108), 1-21. doi: 10.3389/fphar.2020.00108.
- Guariguata, L., Linnenkamp, U., Beagley, J., Whiting, D. R., & Cho, N. H. (2014). Global estimates of the prevalence of hyperglycaemia in

- pregnancy. Diabetes Research and Clinical Practice, 103(2), 176-185.
- Guariguata, L., Whiting, D. R., Hambleton, I., Beagley, J., Linnenkamp, U., & Shaw, J. E. (2014). Global estimates of diabetes prevalence for 2013 and projections for 2035. *Diabetes Research and Clinical Practice*, 103(2), 137-149.
- Gudjinu, H. Y. & Sarfo, B (2017). Risk factors for type 2 diabetes mellitus among out-patients in Ho, the Volta regional capital of Ghana: A case control study. *BMC Research Notes*, 10(1), 1-10. doi 10.1186/s13104-017-2648z.
- Guzzini, S. (2000). A reconstruction of constructivism in international relations.

  European Journal of International Relations, 6(2), 147-182.
- Habte, B. M., Kebede, T., Fenta, T. G., & Boon, H. (2016). Explanatory models of adult patients with type 2 diabetes mellitus from urban centers of central Ethiopia. *BioMedical Central Research*, 9(1), 1-11. doi 10.1186/s13104-016- 2248-3.
- Hackett, R. A., & Steptoe, A. (2017). Type 2 diabetes mellitus and psychological stress a modifiable risk factor. *Nature Reviews Endocrinology*, *13*(9), 547-560.
- Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and Health*, 18(2), 141-184.
- Hall, V., Thomsen, R. W., Henriksen, O., & Lohse, N. (2011). Diabetes in Sub Saharan Africa 1999-2011: Epidemiology and public health implications.
  - A systematic review. BMC Public Health, 11(1), 1-12.
- Handley, J., Pullon, S., & Gifford, H. (2010). Living with type 2 diabetes:

- 'Putting the person in the pilots' seat'. *Australian Journal of Advanced Nursing*, *The*, 27(3), 12-19.
- Health Professions Regulatory Bodies Act (HPRBA), (2013), Act 857.
- Hill, S., Gingras, J., & Gucciardi, E., (2013). The lived experience of Canadian university students with type 1 diabetes mellitus. *Canadian Journal of Diabetes*, 37(4), 237-242.
- Hjelm, K., Bard, K., & Apelqvist, J. (2018). A qualitative study of developing beliefs about health, illness and healthcare in migrant African women with gestational diabetes living in Sweden. *BMC Women's Health*, 18(1), 1-14.
- Hjelm, K. & Mufunda, E. (2010). Zimbabwean diabetics' beliefs about health and illness: An interview study. *BMC International Health and Human Rights*, 10 (1), 1-10. http://dx.doi.org/10.1186/1472-698X-10-7.
- Hjelm, K., & Nambozi, G. (2008). Beliefs about health and illness: A comparison between Ugandan men and women living with diabetes mellitus.

  International Nursing Review, 55(4), 434-441.
- Holliday, A. (2007). *Doing and Writing Qualitative Research*. London, Sage Publications Limited.
- Hood, K. K., Huestis, S., Maher, A., Butler, D., Volkening, L., & Laffel, L. M.
  (2006). Depressive symptoms in children and adolescents with type 1 diabetes: Association with diabetes-specific characteristics. *Diabetes Care*, 29(6), 1389–1391.
- Hörnsten, Å. (2004). Experiences of diabetes care-patients' and nurses'

- perspectives. Unpublished Doctoral dissertation, Omvårdnad, Umeå Universitet. Sweden.
- Imamura, F., O'Connor, L., Ye, Z., Mursu, J., Hayashino, Y., Bhupathiraju, S. N., & Forouhi, N. G. (2015). Consumption of sugar sweetened beverages, artificially sweetened beverages, and fruit juice and incidence of type 2 diabetes: Systematic review, meta-analysis, and estimation of population attributable fraction. *Bmj*, *351*, h3576, 1-12. doi: doi: https://doi.org/10.1136/bmj.h3576
- Ingram, M., Torres, E., Redondo, F., Bradford, G., Wang, C., & O'Toole, M. L. (2007). The impact of promotoras on social support and glycemic control among members of a farmworker community on the US-Mexico border. *The Diabetes Educator*, 33(S6), 172S-178S.
- InterAct Consortium. (2013). Consumption of sweet beverages and type 2 diabetes incidence in European adults: Results from EPIC-InterAct.

  Diabetologia, 56(7), 1520-1530.
- International Diabetes Federation. (2019). *IDF Diabetes Atlas*, (9<sup>th</sup> ed.). Brussels, Belgium: International Diabetes Federation.
- International Diabetes Federation. (2017). *IDF Diabetes Atlas* (8<sup>th</sup> ed.). Retrieved from http://fmdiabetes.org/wp-content/uploads/2018/03/IDF-2017.pdf on 9th August, 2019.
- International Diabetes Federation. (2016). Diabetes voice global: Perspectives on Diabetes. *Diabetes Voice*, 62(4), 1-25.
- International diabetes federation. (2015). Atlas Diabetes. IDF Diabetes Atlas, (7th

- ed.). Brussels, Belgium: International Diabetes Federation.
- International Diabetes Federation. (2013). *IDF Diabetes Atlas*, (6<sup>th</sup> ed.). Brussels, Belgium: International Diabetes Federation.
- International Diabetes Federation. (2007). *IDF Diabetes Atlas* (3<sup>rd</sup> ed.) IDF.

  Brussels, Belgium: International Diabetes Federation.
- International Finance Corporation. (2006). The business of health in Africa:

  Partnering with the private sector to improve people's lives. Washington,

  DC: World Bank.
- International Fund for Agricultural Development, IFAD. (2001). Rural poverty report 2001: The challenge of ending rural poverty. New York, USA:

  Oxford University Press Inc.
- Iregbu, S. C., & Iregbu, F. U. (2016). A review of self-management of diabetes in Africa. *African Journal of Diabetes Medicine*, 24(2), 5-8.
- Jacobs, B., Ir, P., Bigdeli, M., Annear, P. L., & Van Damme, W. (2012).

  Addressing access barriers to health services: An analytical framework for selecting appropriate interventions in low-income Asian countries. *Health Policy and Planning*, 27(4), 288-300.
- Jeon, C. Y. & Murray, M. B. (2008). Diabetes mellitus increases the risk of active tuberculosis: A systematic review of 13 observational studies. *PLoS Med*, 5(7), 1091-1101.
- Jiang, X., Ma, H., Wang, Y., & Liu, Y. (2013). Early life factors and type 2 diabetes mellitus. *Journal of Diabetes Research*, 485082, 1-11. doi: 10.1155/2013/485082.

- Johnson, J. A., Carstensen, B., Witte, D., Bowker, S. L., Lipscombe, L. & Renehan, A. G. (2012). Diabetes and cancer: Evaluating the temporal relationship between type 2 diabetes and cancer incidence. *Diabetologia*, 55(6), 1607-1618. doi:10.1007/s00125-012-2525-1.
- Kadirvelu, A., Sadasivan, S., & Ng, S. H. (2012). Social support in type II diabetes care: A case of too little, too late. *Diabetes, Metabolic Syndrome* and *Obesity: Targets and Therapy*, 2012(5), 407-417.
- Kalra, S., Jena, B. N., & Yeravdekar, R. (2018). Emotional and psychological needs of people with diabetes. *Indian Journal of Endocrinology and Metabolism*, 22(5), 696.
- Kagee, A., Le Roux, M., & Dick, J. (2007). Treatment adherence among primary care patients in a historically disadvantaged community in South Africa: A qualitative study. *Journal of Health Psychology*, *12*(3), 444-460.
- Karimy, M., Koohestani, H. R., & Araban, M. (2018). The association between attitude, self-efficacy, and social support and adherence to diabetes self-care behaviour. *Diabetology & Metabolic Syndrome*, 10(1), 1-6.
- Kawulich, B. (2012). Collecting data through observation. *Doing Social*Research: A Global Context, 150-160.
- Keyvanara, M., Hosseini, S. M., & Emami, P. (2012). Social support and diabetes control: A study among patients admitted to specialized clinic of Dr. Gharazi Hospital in Isfahan. *Medical Archives*, 66(1), 24-27.
- Kedogo, E. K. (2015). Impact of insulin storage and administration technique on

- glycated heamoglobin among adult diabetic patients at Kenyatta National Hospital. Unpublished Doctoral dissertation, University of Nairobi, Kenya.
- Kelly, S. J., & Ismail, M. (2015). Stress and type 2 diabetes: A review of how stress contributes to the development of type 2 diabetes. *Annual Review of Public Health*, *36*, 441-462.
- Khalil, C. A., Roussel, R., Mohammedi, K., Danchin, N., & Marre, M. (2012).
  Cause-specific mortality in diabetes: Recent changes in trend mortality.
  European Journal of Preventive Cardiology, 19(3), 374-381.
  doi.org/10.1177/1741826711409324.
- Khandan, M., Abazari, F., Tirgari, B., & Cheraghi, M. A. (2018). Lived experiences of mothers with diabetic children from the transfer of caring role. *International Journal of Community Based Nursing and Midwifery*, 6(1), 76-88.
- Kolling, M., Winkley, K., & von Deden, M. (2010). "For someone who's rich, it's not a problem". Insights from Tanzania on diabetes health-seeking and medical pluralism among Dar es Salaam's urban poor. *Globalization and Health*, 6(1), 1-9.
- Kpekura, S. (2017). Knowledge and attitudes of diabetes patients on selfmanagement practices in government hospitals in the Upper West Region. Unpublished Dissertation, University of Cape Coast, Cape Coast.
- Kralik, D. K, Price, K., & Telford, K. (2010). The meaning of self-care for people with chronic illness. *Journal of Nursing and Healthcare of Chronic*

- Illness 2(3), 197–204. doi: 10.1111/j.1752-9824.2010.01056.x.
- Kratzer, J. (2012). Structural barriers to coping with type 1 diabetes mellitus in Ghana: experiences of diabetic youth and their families. *Ghana Medical Journal*, 46(2), 39-45.
- Kruk, M. E., Gage, A. D., Arsenault, C., Jordan, K., Leslie, H. H., Roder-DeWan, S., ... & English, M. (2018). High-quality health systems in the Sustainable Development Goals era: Time for a revolution. *The Lancet Global Health*, 6(11), e1196-e1252.
- Kucuk, L. (2015). Psychological Aspects of Diabetes. Okmeydanı Medical Journal 31, 52-56.
- Kumar, M. K., Kanapuram, R., Narayana, N., Kambham, N. C., Mallempati, M.K., Achanti, M. M., ... & Mishra, A. (2015). Genetic risk factors in Diabetes. *Journal of Medicine*, 1(1), 20-30.
- Kyriakidis, P., Ahrens, T., & Benner, P. (2016). Adult health I and II, NovEx, novice to expert learning. Saddleback, NJ: Pearson Publishers.
- Langat, M. K. (2011). Prevention of diabetes mellitus complications among adults. Unpublished Thesis, Turku University of Applied Sciences, Turku, Finland.
- Langdridge, D. (2007). *Phenomenological psychology: theory, research, and method*. England, Pearson Education Limited, Prentice Hall.
- Leone, T., Coast, E., Narayanan, S., & Aikins, A. D. G. (2012). Diabetes and depression comorbidity and socio-economic status in low- and middle-

- income countries (LMICs): A mapping of the evidence. *Globalization and Health*, 8(1), 1-10.
- Leventhal, H., Brissette, I., & Leventhal, E. A. (2003). The common-sense model of self-regulation of health and illness. In: Cameron, L. D., Leventhal, H. (eds). *The self-regulation of health and illness behaviour*. New York: Routledge, pp. 42–65.
- Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common-sense representation of illness danger. *Contributions to Medical Psychology*, 2, 7-30.
- Leventhal, H., Nerenz, D., Steele, D. J., Baum, A., & Singer, J. (1984). Handbook of psychology and health. Social Psychological Aspects of Health. Erlbaum, Hillsdale, NJ, 219-252.
- Lewis, T. (2004). Using the NO TEARS tool for medication review. *BMJ*, 329(7463), 434.
- Li, J., Drury, V., & Taylor, B. (2013). 'Diabetes is nothing': The experience of older Singaporean women living and coping with type 2 diabetes.

  Contemporary Nurse, 45(2), 188-196.
- Li, J., Liu, S., Li, S., Feng, R., Na, L., Chu, X., ... & Deng, H. (2017). Prenatal exposure to famine and the development of hyperglycemia and type 2 diabetes in adulthood across consecutive generations: A population-based cohort study of families in Suihua, China. *The American Journal of Clinical Nutrition*, 105(1), 221-227.

- Lin, E. H., Von Korff, M., & WHO WMH survey consortium (2008). Mental disorders among persons with diabetes results from the World Mental Health Surveys. *Journal of Psychosomatic Research*, 65(6), 571-580.
- Lindsay, G., Inverarity, K., & McDowell, J. R. (2011). Quality of life in people with type 2 diabetes in relation to deprivation, gender, and age in a new community-based model of care. *Nursing Research and Practice*, 2011(613589), 1-8. doi:10.1155/2011/613589.
- Livesey, C. (2011). *The mass media* (1<sup>st</sup> ed.). [ebook] United Kingdom: Sociology Central, p.1. Retrieved from http://www.sociology.org.uk/media\_defined.pdf on 21<sup>st</sup> May 2018.
- Lu, N., Samuels, M. E., Kletke, P. R., & Whitler, E. T. (2010). Rural-urban differences in health insurance coverage and patterns among workingage adults in Kentucky. *The Journal of Rural Health*, 26(2), 129-138.
- Lustman, P. & Clouse, R. E. (2005). Depression in diabetic patients: The relationship between mood and glycemic control. *Journal of Diabetes* and its Complications, 19(2), 113-122. doi: 10.1016/j.jdiacomp.2004.01.002
- Maahs, D. M., West, N. A., Lawrence, J. M., & Mayer-Davis, E. J. (2010). Epidemiology of type 1 diabetes. *Endocrinology and Metabolism Clinics*, 39(3), 481-497. doi:10.1016/j.ecl.2010.05.011.
- Malik, V. S., Popkin, B. M., Bray, G. A., Després, J. P., Willett, W. C., & Hu, F.
  B. (2010). Sugar-sweetened beverages and risk of metabolic syndrome and type 2 diabetes: A meta-analysis. *Diabetes Care*, 33(11), 2477-2483.

- Manderson, L., & Kokanovic, R. (2009). "Worried all the time": Distress and the circumstances of everyday life among immigrant Australians with type 2 Diabetes. *Chronic Illness*, 5(1), 21-32.
- Masmoudi, J., Damak, R., Zouari, H., Ouali, U., Mechri, A., Zouari, N., & Jaoua, A. (2013). Prevalence and impact of anxiety and depression on type 2 diabetes in Tunisian patients over sixty years old. *Depression Research* and *Treatment*, 2013(341782), 1-6. https://doi.org/10.1155/2013/341782
- Mathew, R., Gucciardi, E., De Melo, M., & Barata, P. (2012). Self-management experiences among men and women with type 2 diabetes mellitus: A qualitative analysis. *BMC Family Practice*, *13*(1), 1-12.
- Mayberry, L. S., & Osborn, C. Y. (2012). Family support, medication adherence, and glycemic control among adults with type 2 diabetes. *Diabetes Care*, 35(6), 1239-1245.
- McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L. S., Lorig, K., & Wagner, E. H. (2011). Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA: A Cancer Journal for Clinicians*, 61(1), 50-62.
- Mcferran, L. (2008). Obstacles to diabetes care in Kenya. *Medical Journal of Therapeutics Africa*, 2(2), 127-129.
- MeadCain, G. M. (1999): *Rural Development and Population*. New York: Oxford University Press, pp. 3-24.
- Mendenhall, E., & Norris, S. A. (2015). Diabetes care among urban women in Soweto, South Africa: A qualitative study. *BMC Public Health*, 15(1), 1-7.

- Mensah, G. A. (2008). Epidemiology of stroke and high blood pressure in Africa. *Heart*, 94(6), 697-705.
- Mensah, G. P., Affram, C. K., Richter, S. & Banful, R. (2017). Experiences of mothers with gestational diabetes in Ghana. *Journal of Research in Nursing and Midwifery (JRNM)*, 6(2), 025-032. doi: http://dx.doi.org/10.14303/JRNM.2016.011.
- Messias, E., & Skotzko, C. E. (2000). Psychiatric assessment in transplantation.

  \*Revista De Saude Publica, 34(4), 415-420.
- Metta, E., Bailey, A., Kessy, F., Geubbels, E., Hutter, I., & Haisma, H. (2015). "In a situation of rescuing life": Meanings given to diabetes symptoms and care-seeking practices among adults in Southeastern Tanzania: A qualitative inquiry. *BMC Public Health*, *15*(1), 1-11.
- Metta, E., Haisma, H., Kessy, F., Geubbels, E., Hutter, I., & Bailey, A. (2015). "It is the medicines that keep us alive": Lived experiences of diabetes medication use and continuity among adults in Southeastern Tanzania.

  \*\*BMC Health Services Research, 15(1), 1-8.\*\*
- Mihaescu, R., Meigs, J., Sijbrands, E., & Janssens, A. C. (2011). Genetic risk profiling for prediction of type 2 diabetes. *PLoS Currents*, *3*(1), 1-15.
- Miller, T. A., & DiMatteo, M. R. (2013). Importance of family/social support and impact on adherence to diabetic therapy. *Diabetes, Metabolic Syndrome* and Obesity: Targets and Therapy, 3(6), 421-426.
- Minet, L. K. R., Lønvig, E. M., Henriksen, J. E., & Wagner, L. (2011). The experience of living with diabetes following a self-management program

- based on motivational interviewing. *Qualitative Health Research*, 21(8), 1115-1126.
- Ministry of Health, Ghana. (2016). RTS'S Malaria vaccine technical brief.

  Accra: MOH.
- Ministry of Health, Ghana. (2014). *Health sector medium term development plan* 2014 -2017. Accra: Ministry of Health.
- Ministry of Health, Ghana. (2009). Census of health workers in the public sector.

  Accra: Ministry of Health.
- Ministry of Health, Ghana. (2007). *The Ghana health sector annual programme* of work. Accra: Ministry of Health.
- Ministry of Health, Ghana (2003). Global expenditure report (1999–2002).

  Accra: MOH-PPME.
- Ministry of Health, Ghana. (1998). A profile of health inequities in Ghana.

  Ministry of Health. Accra, Ghana.
- Mora, P. A., Robitaille, C., Leventhal, H., Swigar, M., & Leventhal, E. A. (2002).

  Trait negative affect relates to prior-week symptoms, but not to reports of illness episodes, illness symptoms, and care seeking among older persons.

  Psychosomatic Medicine, 64(3), 436-449.
- Moxey, P. W., Gogalniceanu, P., Hinchliffe, R. J., Loftus, I. M., Jones, K. J., Thompson, M. M., & Holt, P. J. (2011). Lower extremity amputations A review of global variability in incidence. *Diabetic Medicine*, 28(10), 1144-1153.

- Murphy, K., Chuma, T., Mathews, C., Steyn, K., & Levitt, N. (2015). A qualitative study of the experiences of care and motivation for effective self-management among diabetic and hypertensive patients attending public sector primary health care services in South Africa. *BMC Health Services Research*, *15*(1), 1-9.
- Murrock, C. J., Taylor, E., & Marino, D. (2013). Dietary challenges of managing type 2 diabetes in African-American women. *Women & Health*, 53(2), 173-184.
- Mwangome, M. N., Geubbels, E., Klatser, P., & Dieleman, M. (2016). "I don't have options but to persevere." Experiences and practices of care for HIV and diabetes in rural Tanzania: A qualitative study of patients and family caregivers. *International Journal for Equity in Health*, 15(1), 1-13.
- Nam, S., Chesla, C., Stotts, N. A., Kroon, L., & Janson, S. L. (2011). Barriers to diabetes management: Patient and provider factors. *Diabetes Research* and Clinical Practice, 93(1), 1-9.
- Nash, J. (2014). Understanding the psychological impact of diabetes and the role of clinical psychology. *Journal of Diabetes Nursing*, 18(4), 137-142.
- Nathan, D. M., Buse, J. B., Davidson, M. B., Heine, R. J., Holman, R. R., Sherwin, R., & Zinman, B. (2006). Management of hyperglycemia in type 2 diabetes: A consensus algorithm for the initiation and adjustment of therapy: A consensus statement from the American Diabetes Association and the European Association for the Study of Diabetes. *Diabetes Care*, 29(8), 1963-1972.

- National Health Insurance Authority (NHIA). (2012). 2012 annual report. Accra.
- Nartey, Q. (2017). Diabetic diversions Hotline documentary on JoyNews (23-10-17). Retrieved from <a href="https://www.youtube.com/watch?v=E5tKXuMJRI8&t=98s">https://www.youtube.com/watch?v=E5tKXuMJRI8&t=98s</a> on 20th June, 2019.
- Necho, M., Mekonnen, S., Haile, K., Birkie, M., & Belete, A. (2019). Suicidal plan, attempt, and associated factors among patients with diabetes in Felegehiwot referral hospital, Bahirdar, Ethiopia: Cross-sectional study. *BMC Psychiatry*, 19(1), 1-8.
- Neuman, L. W. (2000). Social Research Methods: Qualitative and Quantitative Approaches (4<sup>th</sup> ed.) Boston, MA: Allyn and Bacon.
- Nicholls, A. R., Holt, N. L., & Polman, R. C. (2005). A phenomenological analysis of coping effectiveness in golf. *The Sport Psychologist*, 19(2), 111-130.
- Nicklett, E. J., & Liang, J. (2010). Diabetes-related support, regimen adherence, and health decline among older adults. *Journals of Gerontology Series B:*Psychological Sciences and Social Sciences, 65(3), 390-399.
- Nielsen, J., Bahendeka, S. K., Bygbjerg, I. C., Meyrowitsch, D. W., & Whyte, S.
  R. (2016). Diabetes treatment as "homework" consequences for household knowledge and health practices in rural Uganda. *Health Education & Behaviour*, 43(1), 100S-111S.

- Nielsen, M., Buelt, L., Patel, K., Nichols, L. M., & Fund, M. M. (2014). The patient-centered medical home's impact on cost and quality. *Annual Review of Evidence*, 2015, 1-40.
- Novignon, J., & Nonvignon, J. (2017). Improving primary health care facility performance in Ghana: Efficiency analysis and fiscal space implications. BMC Health Services Research, 17(1), 1-8.
- Nyarko, K., Kugbey, N., & Atindanbila, S. (2014). Illness perception, religiosity and mental health of diabetic patients in Ghana. American *Journal of Applied Psychology*, 3(1), 12-20. doi: 10.11648/j.ajap.20140301.13.
- Nyonator, F. K., Awoonor-Williams, J. K., Phillips, J. F., Jones, T. C., & Miller, R. A. (2005). The Ghana community-based health planning and services initiative for scaling up service delivery innovation. *Health Policy and Planning*, 20(1), 25-34.
- O'Brien, C. A., Van Rooyen, D., & Ricks, E. (2015). Self-management experiences of persons living with diabetes mellitus type 2. *Africa Journal of Nursing and Midwifery*, 17(2), 103-117.
- O'Donnell, O. (2007). Access to health care in developing countries: breaking down demand side barriers. *Cadernos De Saude Publica*, 23(12), 2820-2834.
- Ogbera, A., & Adeyemi-Doro, A. (2011). Emotional distress is associated with poor self-care in type 2 diabetes mellitus. *Journal of Diabetes*, *3*(4), 348-352.
- Ogden, J. (2007). Essential readings in health psychology. McGraw-Hill

- Education (UK).
- Ogden, J. (2000). The correlates of long-term weight loss: A group comparison study of obesity. *International Journal of Obesity*, 24(8), 1018-1025.
- Oliver, A., & Mossialos, E. (2004). Equity of access to health care: Outlining the foundations for action. *Journal of Epidemiology & Community Health*, 58(8), 655-658.
- Organization for Economic Co-operation and Development [OECD]. (2004). The OECD principles of corporate governance. *Contaduría y Administración*, (216).
- Osei-Yeboah, J., Owiredu, W K. B. A., Norgbe, G. K., Lokpo, S. Y., Allotey, E. A., Doe, E. A. & Attah, F. A. (2016). Quality of life of people living with type 2 diabetes in Ho, Ghana: A cross-sectional study. *American Journal of Biomedical Science*, 8(4), 297-310; doi: 10.5099/aj160400297.
- Owiredu, W. K. B. A., Amidu, N., Alidu, H., Sarpong, C. & Gyasi-Sarpong, C. K. (2011). Determinants of sexual dysfunction among clinically diagnosed diabetic patients. *Reproductive Biology and Endocrinology*, *9*(1), 1-11. doi: 10.1186/1477-7827-9-70.
- Owusu, Y. (2016). Psychosocial experiences of patients with type -2 diabetes mellitus: A study at the Korle-Bu Teaching Hospital. Unplished Dissertation, University of Ghana, Legon, Accra.
- Ozougwu, J. C., Obimba, K. C., Belonwu, C. D., & Unakalamba, C. B. (2013).

  The pathogenesis and pathophysiology of type 1 and type 2 diabetes mellitus. *Journal of Physiology and Pathophysiology*, 4(4), 46-57.

- Pagano, E., Gray, A., Rosato, R., Gruden, G., Perin, P. C., Merletti, F., & Bruno,
  G. (2013). Prediction of mortality and macrovascular complications in
  type 2 diabetes: Validation of the UKPDS Outcomes Model in the Casale
  Monferrato Survey, Italy. *Diabetologia*, 56(8), 1726-1734.
- Park, H., & Wenzel, J. A. (2013). Experience of social role strain in Korean women with type 2 diabetes. *Journal of Advanced Nursing*, 69(6), 1400–1409. doi: 10.1111/jan.12001.
- Park, K. S. (2011). The search for genetic risk factors of type 2 diabetes mellitus. *Diabetes & Metabolism Journal*, 35(1), 12-22.
- Patterson, C. C., Dahlquist, G. G., Gyürüs, E., Green, A., Soltész, G., & EURODIAB Study Group. (2009). Incidence trends for childhood type 1 diabetes in Europe during 1989–2003 and predicted new cases 2005–20: A multicentre prospective registration study. *The Lancet*, *373*(9680), 2027-2033.
- Patton, M. Q. (2002). Two decades of developments in qualitative inquiry: A personal, experiential perspective. *Qualitative Social Work*, 1(3), 261-283.
- Persaud, H., & Williams, S. (2017). Long working hours and occupational stress-related illness and injury: Mini Review. *Journal Health Science Education*, 1(3), 1-4.
- Peters, D. H., Garg, A., Bloom, G., Walker, D. G., Brieger, W. R., & Hafizur Rahman, M. (2008). Poverty and access to health care in developing countries. *Annals of the New York Academy of Sciences*, 1136(1), 161-171.

- Peyrot, M., Rubin, R. R., Lauritzen, T., Snoek, F. J., Matthews, D. R., & Skovlund, S. E. (2005). Psychosocial problems and barriers to improved diabetes management: Results of the Cross-National Diabetes Attitudes, Wishes and Needs (DAWN) Study. *Diabetic Medicine*, 22(10), 1379-1385.
- Pikkemaat, M., Boström, K. B., & Strandberg, E. L. (2019). "I have got diabetes!" Interviews of patients newly diagnosed with type 2 diabetes.

  \*\*BMC Endocrine Disorders, 19(1), 1-12.\*\*
- Pilger, C., & Abreu, I. S. (2007). Diabetes mellitus in childhood: Repercussions in the daily life of the child and his/her family. *Cogitare Enfermagem*, 12(4), 494-501.
- Polsky, S., & Akturk, H. K. (2017). Alcohol consumption, diabetes risk, and cardiovascular disease within diabetes. *Current Diabetes Reports*, 17(12), 1-12.
- Quisumbing, A. R. (2003). Food aid and child nutrition in rural Ethiopia. World Development, 31(7), 1309-1324.
- Ramchandani, N., Cantey-Kiser, J. M., Alter, C. A., Brink, S. J., Yeager, S. D., Tamborlane, W. V., & Chipkin, S. R. (2000). Self-reported factors that affect glycemic control in college students with type 1 diabetes. *The Diabetes Educator*, 26(4), 656-666. doi:10.1177/014572170002600413.
- Ramkisson, S., Pillay, B. J., & Sibanda, W. (2017). Social support and coping in adults with type 2 diabetes. *African Journal of Primary Health Care and Family Medicine*, 9(1), 1-8.

- Rathert, C., Wyrwich, M. D., & Boren, S. A. (2013). Patient-centered care and outcomes: A systematic review of the literature. *Medical Care Research and Review*, 70(4), 351-379.
- Republic of Ghana Act 525. (1996). Ghana Health Service and Teaching Hospitals Act.
- Richard, A. A., & Shea, K. (2011). Delineation of self-care and associated concepts. *Journal of Nursing Scholarship*, 43(3), 255-264.
- Rintala, T. M., Jaatinen, P., Paavilainen, E., & Åstedt-Kurki, P. (2013).

  Interrelation between adult persons with diabetes and their family: A systematic review of the literature. *Journal of Family Nursing*, 19(1), 3-28.
- Rubin, A. & Babbie, E. (2010). Essential research methods for social work. New York: Brooks/Cole Cengage Learning.
- Ruston, A., Smith, A. & Fernando, B. (2013). Diabetes in the workplace diabetic's perceptions and experiences of managing their disease at work:

  A qualitative study. *BMC Public Health*, 13(1), 1-10.

  <a href="http://www.biomedcentral.com/1471-2458/13/386">http://www.biomedcentral.com/1471-2458/13/386</a>.
- Rutherford, M. E., Mulholland, K., & Hill, P. C. (2010). How access to health care relates to under-five mortality in Sub-Saharan Africa: Systematic review. *Tropical Medicine and International Health*, *15*(5), 508-519.
- Saeed, B. I., Abdulf, A. R., Blay, S. N., & Zhao, X. (2013). The effect of socioeconomic predictors of chronic diseases in Ghana: Results of a nationwide survey. *Global Journal of Health Science*, 5(5), 115-123.

- Samancioglu, S., Ozturk Donmez, R., Arda Surucu, H., & Bayindir Cevik, A. (2017). Experiences of clinic nurses regarding diabetes education in Turkey'health system. *Health System and Policy Research*, 4(3), 59-64. doi: 10.21767/2254-9137.100078.
- Sarwar, N., Gao, P., Seshasai, S. R., Gobin, R., Kaptoge, S., Di Angelantonio, E., & Stehouwer, C. D. (2010). Emerging risk factors collaboration diabetes mellitus, fasting blood glucose concentration, and risk of vascular disease: A collaborative meta-analysis of 102 prospective studies. *Lancet*, 375(9733), 2215-2222. doi.org/10.1016/S0140-6736(10)60484-9.
- Saunders, M., Lewis, P., & Thornhill, A. (2009). Research methods for business students. USA, Pearson education.
- Schatzman, L., & Strauss, A. L. (1973). Field research: Strategies for a natural sociology. London, Prentice Hall.
- Schiøtz, M. L., Bøgelund, M., Almdal, T., Jensen, B. B., & Willaing, I. (2012).

  Social support and self-management behaviour among patients with Type

  2 diabetes. *Diabetic Medicine*, 29(5), 654-661.
- Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., ... & Whittemore, R. (2012). Processes of self-management in chronic illness. *Journal of Nursing Scholarship*, 44(2), 136-144.
- Scottish Executive Annual Rural Report (2004). Scottish index of multiple deprivation 2006 technical report. Office of the Chief Statistician, Scottish Executive, 10.

- Seeley, R. R., Stephens, T. D., & Tate, P. (2000). *Anatomy and Physiology* (5<sup>th</sup> ed.). UK, McGraw-Hill.
- Serneels, P., & Lievens, T. (2008). Institutions for health care delivery: A formal exploration of what matters to health workers-evidence from Rwanda.

  Working paper. JEL code: I18, J44.
- Shannon, A., & Wong, C. K. (2010). Risk factors associated with gestational diabetes mellitus. *International Journal Bioautomation*, 2010, 14(1), 15-26.
- Sharoni, S. A., Shdaifat, E. A., Abd Majid, H. M., Shohor, N. A., Ahmad, F., & Zakaria, Z. (2015). Social support and self-care activities among the elderly patients with diabetes in Kelantan. *Malaysian Family Physician:*The Official Journal of the Academy of Family Physicians of Malaysia, 10(1), 34-43.
- Shaw, T. (2017). Healthcare workers' perceptions of organizational culture and the impact on the delivery of compassionate quality care. *Journal of Research in Nursing*, 22(1-2), 57-59.
- Shaw, J. E., Sicree, R. A., & Zimmet, P. Z. (2010). Global estimates of the prevalence of diabetes for 2010 and 2030. *Diabetes Research and Clinical Practice*, 87(1), 4-14.
- Shen, H., Edwards, H., Courtney, M., McDowell, J., & Wei, J. (2013). Barriers and facilitators to diabetes self-management: Perspectives of older community dwellers and health professionals in China. *International Journal of Nursing Practice*, 19(6), 627-635.

- Shrivastava, S. R., Shrivastava, P. S., & Ramasamy, J. (2013). Role of self-care in management of diabetes mellitus. *Journal of Diabetes and Metabolic Disorders*, 12(1), 1-5.
- Singh, G. M., Danaei, G., Farzadfar, F., Stevens, G. A., Woodward, M., Wormser, D., ... & Di Angelantonio, E. (2013). The age-specific quantitative effects of metabolic risk factors on cardiovascular diseases and diabetes:

  A pooled analysis. *PloS One*, 8(7), 1-10.
- Singh, R. (2011). Psychological model of illness. UK, Cambridge Scholars.
- Publishing. Smith, J. A. (1995). Semi structured interviewing and qualitative analysis. In: Smith, Jonathan A. and Harre, R. and Van Langenhove, L. (eds.) *Rethinking methods in psychology*. London, Sage Publications, pp. 9-26. ISBN 9780803977334.
- Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. Qualitative Health Psychology: Theories and Methods. London, Sage, 218-240.
- Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British Journal of Pain*, 9(1), 41-42.
- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenologival analysis. In J. A. Smith (Ed) *Qualitative Psychology*. A *Pratical Guide to Methods* (2nd ed.). London: Sage.
- Speight, J., & Singh, H. (2013). The journey of the person with diabetes. Diabetes Education. London, Wiley-Blackwell, 12-27.

- Smith, J., & Osborn, M. (2003). Interpretative phenomenological analysis.

  Qualitative psychology: A practical guide to methods. London: Sage.
- Starks, H., & Trinidad, B. S. (2007). Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research*, 17(10), 1372-1380.
- Stewart, M. J. (2000). Chronic conditions and caregiving in Canada: Social support. Toronto: University of Toronto Press.
- Stryker, D., Salinger, L., & Plunkett, D. (2003). Ensuring the benefits of globalization reach the poor. Associates for International Resources and Development.
- Stuckey, H. L., Mullan-Jensen, C. B., Reach, G., Burns, K. K., Piana, N., Vallis, M., & Peyrot, M. (2014). Personal accounts of the negative and adaptive psychosocial experiences of people with diabetes in the second Diabetes Attitudes, Wishes and Needs (DAWN2) study. *Diabetes Care* 37(9), 2466–2474. doi: 10.2337/dc13-2536.
- Sulaiman, N., Hamdan, A., Tamim, H., Mahmood, D. A., & Young, D. (2010).

  The prevalence and correlates of depression and anxiety in a sample of diabetic patients in Sharjah, United Arab Emirates. *BMC Family Practice*, 11(1), 1-7.
- Sulemana, A., & Dinye, R. D. (2014). Access to healthcare in rural communities in Ghana: A study of some selected communities in the Pru District. European Journal of Research in Social Sciences, 2(4), 122-132.
- Tabong, P. T., Bawontuo, V., Dumah, D. N., Kyilleh, J. M., & Yempabe, T.

- (2018). Premorbid risk perception, lifestyle, adherence and coping strategies of people with diabetes mellitus: A phenomenological study in the Brong Ahafo Region of Ghana. *PLoS One*, *13*(6), 1-19. <a href="https://doi.org/10.1371/journal.pone.0198915.">https://doi.org/10.1371/journal.pone.0198915.</a>
- Tang, T. S., Brown, M. B., Funnell, M. M., & Anderson, R. M. (2008). Social support, quality of life, and self-care behaviors among African Americans with type 2 diabetes. *The Diabetes Educator*, 34(2), 266-276.
- Tewahido, D., & Berhane, Y. (2017). Self-care practices among diabetes patients in Addis Ababa: A qualitative study. *PloS One*, *12*(1), 1-10.
- Thomsen, R. W., Hundborg, H. H., Lervang, H. H., Johnsen, S. P., Schønheyder, H. C., & Sørensen, H. T. (2005). Diabetes mellitus as a risk and prognostic factor for community-acquired bacteremia due to enterobacteria: A 10-year, population-based study among adults. *Clinical Infectious Diseases*, 40(4), 628-631.
- Touchette, N. (2000). Kids and type 2. Diabetes Forecast, 53(11), 79-84.
- Tuncell, K., Bradley, C. J., Nerenz, D., Williams, L. K., Pladevall, M., & LaFata, J. E. (2000). The impact of diabetes on employment and Work Productivity. *Diabetes Care* 28(11), 2662–2667. doi: 10.2337/diacare.28.11.2662
- UNICEF. (2018). WHO, WB & UN. Levels and trends in child mortality Report

  2019 estimates developed by the UN inter-agency Group for Child

  Mortality Estimation. New York: UNICEF

- UNICEF. (2014). Inequality in Ghana: A Fundamental National Challenge.

  UNICEF Briefing Paper.
- United Nations. (2015). World population prospects: The 2015 revision. *United Nations Econ Social Affairs*, 33(2), 1-66.
- United Nations. (2009). *Monitoring global population trends*. Retrieved from <a href="http://www.un.org/en/development/desa/population/publications/urbanization/urban-rural.shtml">http://www.un.org/en/development/desa/population/publications/urbanization/urban-rural.shtml</a> on 18th September, 2019.
- van Abeelen, A. F., Veenendaal, M. V., Painter, R. C., de Rooij, S. R., Dijkgraaf, M. G., Bossuyt, P. M., ... & Roseboom, T. J. (2012). Survival effects of prenatal famine exposure. *The American Journal of Clinical Nutrition*, 95(1), 179-183.
- van den Arend, I. J. M., Stolk, R. P., Krans, H. M. J., Grobbee, D. E., & Schrijvers, A. J. P. (2000). Management of type 2 diabetes: A challenge for patient and physician. *Patient Education and Counseling*, 40(2), 187-194.
- van den Boom, G. J. M., Nsowah-Nuamah, N. N. N., & Overbosch, G. B. (2002).

  Curative health care utilization in Ghana. A multinomial analysis of equitable access opportunities. Working paper; No. 02-02. Stichting onderzoek wereldvoedselvoorziening (SOW).
- Vanstone, M., Rewegan, A., Brundisini, F., Dejean, D., & Giacomini, M. (2015).

  Patient perspectives on quality of life with uncontrolled type 1 diabetes mellitus: A systematic review and qualitative meta-synthesis. *Ontario Health Technology Assessment Series*, 15(17), 1-29.

- Votey, S. (2010). *Diabetes mellitus, type 2 A review*. Retrieved 16th March, 2018, from: http://emedicine.medscape.comlarticle1766143–overview.
- Walker, K. T. (2008). A bittersweet existence: The lived experiences of four young women with diabetes mellitus. Unpublished dissertation, Queens University, Ontario, Canada.
- Walsh, M., & Crumbie, A. (2007). Watson's clinical nursing and related sciences e-book. Elsevier Health Sciences.
- Walsh, J., & Warren, K. (1979). Selective primary health care: An interim strategy for disease control in developing countries. *Social Science & Medicine: Medical Economics*, 14(2), 145-163.
- Walt, G. (1998). *Health Policy: an introduction to process and power*. London: Zed Books.
- Warren, R. E., Deary, I. J., & Frier, B. M. (2003). The symptoms of hyperglycaemia in people with insulin-treated diabetes: Classification using principal components analysis. *Diabetes/Metabolism Research and Reviews*, 19(5), 408-414.
- Weaver, R. R., Lemonde, M., Payman, N., & Goodman, W. M. (2014). Health capabilities and diabetes self-management: The impact of economic, social, and cultural resources. *Social Science & Medicine*, 102, 58-68.
- Wild, S., Roglic, G., Green, A., Sicree, R., & King, H. (2004). Global prevalence of diabetes: Estimates for the year 2000 and projections for 2030. *Diabetes Care*, 27(5), 1047-1053.

- Willig, C. (2008). Qualitative research design. Introducing qualitative research in psychology: Adventures in theory and method. New York: Open University Press.
- Winocour, P. H. (2002). Effective diabetes care: A need for realistic targets. *BMJ*, 324(7353), 1577-1580.
- Witter, S., Kusi, A., & Aikins, M. (2007). Working practices and incomes of health workers: Evidence from an evaluation of a delivery fee exemption scheme in Ghana. *Human Resources for Health*, 5(1), 1-10.
- Wood, H. (1980). *Third class ticket London*. London: Penguin Books.
- World Bank Group. (2013). Global financial development report 2014: Financial inclusion (Vol. 2). World Bank Publications.
- World Bank. (2000). World Development Report 2000/2001: Attacking Poverty, Washington, DC.
- World Health Organization. (2019). *Classification of diabetes mellitus*. Geneva: World Health Organization.
- World Health Organization. (2016). *Global report on diabetes*. World Health Organization.
- World Health Organization (2015). *Diabetes: WHO fact sheet* NO. 312 updated in January, 2015. World Health Organization
- World Health Organization. (2015). Health in 2015: from MDGs, millennium development goals to SDGs, sustainable development goals. Geneva: World Health Organization.

- World Health Organization. (2013). *Diagnostic criteria and classification of hyperglycaemia first detected in pregnancy* (No. WHO/NMH/MND/13.2). Geneva, World Health Organization.
- World Health Organization. (2012). Human Resources for Health Observatories:

  Contributing to evidence-based policy decisions. Geneva, Switzerland:

  World Health Organization.
- World Health Organization. (2011). New horizons for health through mobile technologies (Global Observatory for eHealth Series, Volume 3). Geneva, Switzerland: World Health Organization, 1-102.
- World Health Organization. (2009). World health statistics 2009. World Health Organization.
- World Health Organization. (2006). World health report: Working together for health: Working together for health. Geneva: World Health Organization.
- World Health Organization. (2002). *Innovative care for chronic conditions:*building blocks for actions: Global report (No. WHO/MNC/CCH/02.01).
  Geneva, World Health Organization.
- Yasmin, F., Ali, L., Banu, B., Rasul, F. B., Sauerborn, R., & Souares, A. (2020).

  Understanding patients' experience living with diabetes type 2 and effective disease management: A qualitative study following a mobile health intervention in Bangladesh. *BMC Health Services Research*, 20(1), 1-13.

- Yilmaz, M., Gun, M., & Yaman, Z. (2019). Emotions, Thoughts and Experiences of Diabetes Patients: A qualitative study. *International Journal of Caring Sciences*, 12(3), 1806.
- You, W. P., & Henneberg, M. (2016). Type 1 diabetes prevalence increasing globally and regionally: The role of natural selection and life expectancy at birth. *BMJ Open Diabetes Research and Care*, 4(1), e000161. doi:10.1136/bmjdrc-2015-000161
- Yu, J. (2012). Genetics in diabetes mellitus-contribution to the classification and management. *Annals of Pediatric Endocrinology & Metabolism*, 17(4), 211-218.
- Yusuff, K. B., Obe, O., & Joseph, B. Y. (2008). Adherence to anti-diabetic drug therapy and self-management practices among type-2 diabetics in Nigeria. *Pharmacy World & Science*, 30(6), 876-883.
- Zabuga, O. G., & Vaiserman, A. M. (2017). Malnutrition in early life and risk of type 2 diabetes: Theoretical framework and epidemiological evidence.

  Moscow University Biological Sciences Bulletin, 72(2), 37-46.
- Zaccardi, F., O'Donovan, G., Webb, D. R., Yates, T., Kurl, S., Khunti, K., & Laukkanen, J. A. (2015). Cardiorespiratory fitness and risk of type 2 diabetes mellitus: A 23-year cohort study and a meta-analysis of prospective studies. *Atherosclerosis*, 243(1), 131-137.
- Zimmermann, M., Bunn, C., Namadingo, H., Gray, C. M. & Lwanda, J. (2018). Experiences of type 2 diabetes in sub-Saharan Africa: A scoping review.

Global Health Research and Policy,

3(1),

1-13.

https://doi.org/10.1186/s41256-018-0082-y.



# **APPENDICES**



#### APPENDIX A

#### **Ethical Clearance (University of Cape Coast)**

# UNIVERSITY OF CAPE COAST

### INSTITUTIONAL REVIEW BOARD SECRETARIAT

TEL: 0558093143 / 0508878309/ 0244207814 E-MAIL: irb@ucc.edu.gh OUR REF: UCC/IRB/A/2016/331 YOUR REF:

YOUR REF: OMB NO: 0990-0279

IORG #: IORG0009096

C/O Directorate of Research, Innovation and Consultancy



Mr. Isaac Nyarko Kwakye

Department of Health, Physical Education and Recreation University of Cape Coast

Dear Mr. Kwakye,

#### ETHICAL CLEARANCE - ID: (UCCIRB/CES/2019/04)

The University of Cape Coast Institutional Review Board (UCCIRB) has granted **Provisional Approval** for the implementation of your research protocol titled **Experiences of Diabetes patients Living in Rural Areas of the Eastern Region of Ghana.** This approval requires that you submit periodic review of the protocol to the Board and a final full review to the UCCIRB on completion of the research. The UCCIRB may observe or cause to be observed procedures and records of the research during and after implementation.

Please note that any modification of the project must be submitted to the UCCIRB for review and approval before its implementation.

You are also required to report all serious adverse events related to this study to the UCCIRB within seven days verbally and fourteen days in writing.

Always quote the protocol identification number in all future correspondence with us in relation to this protocol.

Yours faithfully

Prof P. K. Buah-Bassuah

**UCCIRB** Chairperson

CHAIRMAN
INSTITUTIONAL REVIEW BOARD
UNIVERSITY OF CAPE COAST
Date: 12 17 4 17

#### APPENDIX B

#### **Approval Letters from the Hospitals**



### NATIONAL CATHOLIC HEALTH SERVICE

(CATHOLIC DIOCESE OF KOFORIDUA)

Tel:

+233243559076 +233246647025

Bankers: GCB, Kade Branch

Stdominicsakwatia@kofdiocese.org

St. Dominic Hospital

P.O. Box 59

Akwatia, Eastern Region

Ghana, West Africa

Our Ref : SDHIGEH1035

Your Ref :

4<sup>th</sup> March, 2019

MR: ISAAC NYARKO KWAKYE WEST END UNIVERSITY COLLEGE P. O. BOX AN 15402 ACCRA-KASOA

Dear Mr. Kwakye,

#### RE; PERMISSION TO USE THE HOSPITAL FOR ACADEMIC RESEARCH

I write to acknowledge receipt of your letter dated 27th February, 2019 on the subject supra.

Your request for permission to collect data from the Diabetic Clinic to undertake your PhD thesis on the topic "Experiences of Diabetes Patients Living in Rural Areas of the Eastern Region of Ghana" is approved.

You are entreated to strictly adhere to the stipulations of your ethical clearance

I count on your usual cooperation.

Thank you.

REV. FR. EBENEZER KENNETH ABBAN

(BOSPITAL ADMINISTRATION)

Ce: Medical Director, St. Dominic Hospital, Alewalia Head of Nursing Services, S., Dominic Hospital, Akwatic, HoD- Laboratory, St. Dominic Hospital, Akwatia OPD In-Charge, St. Dominic Hospital, Akwania

West End University College Box AN 15402 Accra – Kasoa

27th February, 2019

The Medical Superintendent Oda Government Hospital Akim Oda

Dear Sir/Madam,



# PERMISSION TO USE THE HOSPITAL FOR ACADEMIC RESEARCH

I humbly request your permission to collect data from the Diabetes Clinic to undertake my PhD Thesis on the topic: Experiences of Diabetes Patients Living in Rural Areas of the Eastern Region of Ghana. This is to enable me fulfill partial requirement for my PhD studies at the Department of Health, Physical Education and Recreation, University of Cape Coast.

Kindly find attached other documents for your perusal and approval.

Hoping to hear from you soon.

Thank you.

Yours faithfully,

Isaac Nyarko Kwakye PhD Candidate ED/HTP/16/0005

254

West find University College Box AN [5402] Accra - Kasoa

4th April, 2019.

The Medical Superintendent Koforidus Regional Hospital Koforidus

Dear Sir-Madam.



#### PERMISSION TO USE THE HOSPITAL FOR AN ACADEMIC RESEARCH

I humbly request your permission to collect data from the Diabetes Clinic to undertake my PhD Thesis on the topic: Experiences of Diabetes Patients Living in Rural Areas of the Eastern Region of Ghana. This is to enable me fulfil! partial requirement for my PhD studies at the Department of Health, Physical Education and Recreation, University of Cape Coast.

Kindly final attached other documents for your perusal and approval,

Hoping to hear from you soon.

Thank you.

Yours faithfully,

Isaac Nyarko Kwakye PhD Candidate ED/HTP/16/0005

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#### APPENDIX C

#### **Introductory Letter (University of Cape Coast)**

#### UNIVERSITY OF CAPE COAST

COLLEGE OF EDUCATION STUDIES
FACULTY OF SCIENCE AND TECHNOLOGY EDUCATION
DEPARTMENT OF HEALTH, PHYSICAL EDUCATION & RECREATION

TELEPHONE: +233 - (0)206610931 / (0)543021384 / (0)268392819

TELEX: 2552, UCC, GH.

Our Ref: ED/HTP/16/0005/5



EMAIL: hper@ucc.edu.gh

Cables & Telegrams: UNIVERSITY, CAPE COAST

29th January, 2019

TO WHOM IT MAY CONCERN

#### INTRODUCTORY LETTER: MR. ISAAC NYARKO KWAKYE (ED/HTP/16/0005)

The above named person is a student of the Department of Health, Physical Education and Recreation of the University of Cape Coast. He is pursuing a Doctor of Philosophy degree in Health Promotion. In partial fulfilment of the requirements for the programme, he is conducting a research for his thesis titled "Experiences of Diabetes Patients Living in Rural Areas of the Eastern Region of Ghana".

We would be very grateful if he is granted the opportunity to conduct his research and also provide him with the information needed from your outfit. The data will be used for academic purposes only and be assured that the information collected will be treated with utmost confidentiality.

We count on your usual co-operation.

Thank you.

Yours faithfully,

Dr. Daniel Apaak (Head of Department)

Tel.: +233 (0)208587866 Email: daniel.apaak@ucc.edu.gh

TEPT. OF HEALTH, PHYSICAL EDUCATION
SE RECREATION COLLEGE OF EDUCATION
STUDIES
WHIVERSITY OF CAPECORST
THE COAST - GRANA

#### APPENDIX D

#### **Recommendation Letter from Supervisor (University of Cape Coast)**

#### UNIVERSITY OF CAPE COAST

CAPE COAST, GHANA
Department of Health, Physical Education & Recreation

TELEPHONE: +233 - (0)244213465Cables & Telegrams:

Our Ref: ED/HTP/16/0005



UNIVERSITY, CAPE COAST

January, 10, 2019

#### TO WHOM IT MAY CONCERN

#### **COVER LETTER: MR. ISAAC NYARKO KWAKYE**

It is my pleasure to recommend Mr Isaac Nyarko Kwakye for ethical clearance from your office. He is a Ph.d Health Promotion student of the above department and conducting a study into the topic; Experiences of Diabetes Patients Living in Rural Areas of the Eastern Region of Ghana. The study has been envisaged to explore the lived experiences and coping strategies adopted by this cohort of people living in the rural areas with diabetes. I think Mr Isaac Nyarko Kwakye has the capacity to conduct this research and need your swift assistance. As one of his supervisors, I think we have observed all the necessary ethical considerations for the study.

For any further information, please do not hesitate to contact me.

Your faithfully,

Dr.Thomas Hormenu thormenu@ucc.edu.gh

#### APPENDIX E

#### **Information and Informed Consent Form for Patients**



# UNIVERSITY OF CAPE COAST, INSTITUTIONAL REVIEW BOARD (UCC-IRB)

#### C. INFORMED CONSENT FORM

Title: Experiences of Diabetes Patients Living in Rural Areas of the Eastern Region of Ghana

Principal Investigator: Isaac Nyarko Kwakye

Address: Department of Health, Physical Education and Recreation (HPER),
University of Cape Coast, Cape Coast.

#### **General Information about Research**

The objective of this research is to explore the livid experiences of diabetes clients living in rural areas in Eastern Region, Ghana. The purpose is to describe the meanings that rural people with diabetes make out of the experiences of diabetes and its management. Upon acceptance to take part in the study, you will be interviewed at the hospital premises (diabetes clinic) for approximately 45 minutes to an hour. Interviews will be centred on your experiences, expectations, feelings and challenges of living with diabetes in the rural areas.

#### **Procedures**

To find answers to some of these questions, we invite you to take part in this research project. If you accept, you will be required to participate in an interview with myself.

You are being invited to take part in this interview because I feel that your experience as a diabetes client living in the rural area can contribute much to this discussion.

The initial part of the interview question will find out about events that led to the discovery of the participants sickling status. The questions will solicit for the initial lifestyle of the person till the point of diagnosis. The second part of the question will focus on the typical experiences of the participants with such illness living in the rural areas. Again, it focuses on how the illness condition has affected their daily lives, the kind of social support patients receive, and how they accessed health care from the rural areas. Additionally, questions will be asked on some challenges confronting clients with the condition at the rural area. The final part of the interview guide will concentrate on the coping strategies and the management skills adopted by the participants in managing their condition in these areas.

If you do not wish to answer any of the questions posed during the interview, you may say so and the interviewer will move on to the next question. The interview will take place in Koforidua Regional Hospital, specifically the diabetes clinic, and no one else but the interviewer will be present. The information recorded is considered confidential, and no one else except (Dr Thomas Hormenu) will have access to the information documented during your interview. The expected duration of the interview is about 45 minutes to an hour.

#### Possible Risks and Discomforts

No physical risk will be involved in this study, however, it will be explained to the participants that some minimal emotional risk might be involved. This is because participants will be asked for detailed accounts of their experiences that might be unpleasant. In order to deal with these emotions, participants will be counselled before and after the interviews.

#### **Possible Benefits**

Your participation in the study will help in the development of interventions to assist people with such chronic conditions in the rural areas. Thus, it will help to identify best practices for the management of diabetes among rural dwellers. Your involvement in the study gives you the opportunity to voice what really goes on in your mind that cannot be said to others but keep suffering in silence.

#### Confidentiality

The audio-recordings of the interview will be kept for 10 years after which it will be destroyed and the transcribed data (which will not include your name or any identity characteristics) will be kept confidentially in a password protected computer. Any personal details (e.g., your name, email address) will only be available to the principal investigator and people who are directly involved in the research team. We will use quotes from your interview in the reporting for this study, but will not include your name or other personally identifiable characteristics. This study complies with University of Cape Coast ethical guidelines for confidentiality.

#### Compensation

Being part of the study gives you the opportunity to be attended to earlier at the diabetes clinic. This is to give you the opportunity to have enough time for the interview session.

#### Voluntary Participation and Right to Leave the Research

Participation in the research is voluntary and you are at liberty to withdraw at any time without your legal rights as a client being affected.

#### **Contacts for Additional Information**

If you have questions about your rights as a participant in the research, or if you feel you have been placed at risk you may contact Dr. Thomas Hormenu, Department of Health, Physical Education and Recreation, University of Cape Coast (+233 244213465, thormenu@ucc.edu.gh)

#### Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of University of Cape Coast (UCCIRB). If you have any questions about your rights as a research participant you can contact the Administrator at the IRB Office between the hours of 8:00 am and 4:30 p.m. through the phones lines 0558093143/0508878309/0244207814 or email address: <a href="mailto:irb@ucc.edu.gh">irb@ucc.edu.gh</a>.

#### **VOLUNTEER AGREEMENT**

The above document describing the benefits, risks and procedures for the research title (*Experiences of Diabetes Patients Living in Rural Areas of the Eastern Region of Ghana*) has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

Date

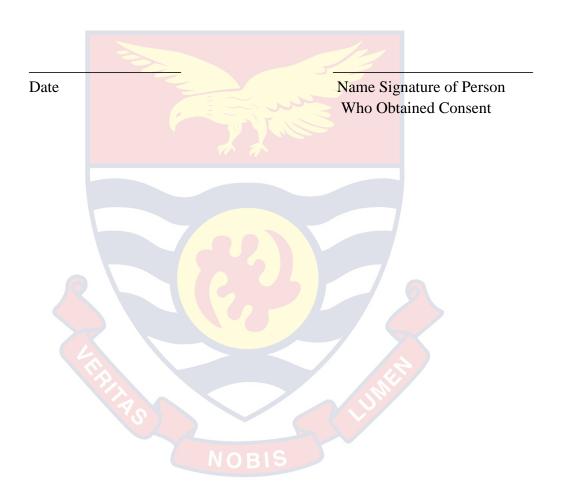
Name and signature or mark of volunteer

#### If volunteers cannot read the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

Date	Name and signature of witness

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.



#### APPENDIX F

# Semi-Structured Interview Guide for Patients INTERVIEW GUIDE

# **Experiences of Diabetes Patients Living in Rural Areas of the Eastern Region of Ghana**

**Preamble:** Before the interview starts, the researcher will introduce himself, go through the information and consent forms with the participant and obtain written informed consent, and familiarise the participant with the recording equipment.

#### Introduction

Thank you for agreeing to take part in this interview. I would like to record the conversation we are going to have today so that I can refer back to it at a later date. This will enable me to listen to you better. Is that well with you?

Before we start, there are a few things I would like to mention. What we are going to discuss today is solely research so to ensure anonymity and to protect your privacy, your name will not be used in any part of this study. Therefore, we will give a study number. Is that ok?

If at any point you would like to stop participating then please tell me and we will stop the interview. I am contacting a number of diabetes clients to find out about their experience of living with the condition in the rural areas. Anything you can tell me about your experiences including good and bad points would be useful for programmes, policy intervention and donor support.

Do you have any questions before we start? Are you happy to continue?

#### Section A: Events that led to the discovery of the diabetes status

- 1. How long have you been living in the rural area? Kindly tell me how you came to live there?
- 2. Can you describe the events that led up to you finding out you had diabetes? Can you describe your life at that time before diagnosis?

- 3. What were your feelings when you found out you had diabetes?
- 4. What thoughts came to mind when you were told of your illness? Probe, why those thoughts?
- 5. Describe the advice/information or help you received when you were first diagnosed. Were the advices helpful? Probe, how was the advice helpful?

#### Section B: Participants experience in the rural areas

- 6. In what ways has your life changed? Prompts: I'm interested in how the diabetes has affected your life.
- 7. Who else was affected by your illness? When were they affected and how were they involved?
- 8. What aspects about your diabetes frustrate you? Tell me the source of these problems.
- 9. Whom do you contact about your diabetes if something goes wrong? Why?
- 10. What are some of the challenges you have with the disease living in the rural area? Probe: challenges interacting with the community members, challenges with medication.
- 11. How easy was it to access the hospital and how many times have you attended that clinic?
- 12. Tell me about some of the experiences when you visit the hospital?
- 13. Is there anyone else you see in connection with your diabetes?
- 14. How far do you live from the nearest hospital/health centre/ clinic? Thus, this poses any challenge for you?

#### Section C: How participants cope with the diabetes at the rural areas

- 15. How are you coping or managing your diabetes? Probe: Do you feel that you are coping/managing your health properly?
- 16. Do you receive some form of support from your family or the community? Yes / No. Probe: I'm interested; kindly tell me the kind of support provided by the family or community.

- 17. Do you have any idea about diabetes? What are the causes, signs and symptoms of diabetes and how can it be managed? When you get diabetes, what is the ideal thing you do?
- 18. Is there anything else you would like to say about your experience of diabetes, living in the rural area with this disease, or about seeking health?

#### General Prompts and Techniques to be used throughout the interview:

- Examples of Prompts:
  - o Could you tell me a bit more about that?
  - o That's really interesting, please go on
  - o How did you feel?
  - o I'm not sure I understand what you mean, could you explain that for me

#### APPENDIX G

#### Sample of Notes written during the Initial Reading of the Text

INTERVIEW 3 Interviewer: Where do you stay? Respondent: I stay at Gyadamu. Interviewer: How long have you stayed there? Respondent: That is where I have stayed all my life. I was born Interviewer: How did you got to know you have diabetes? Respondent: I had BP so I have been coming to the hospital for medicine. About four years ago, I realized that I was urinating frequently. We went for a funeral somewhere and stayed for three days and the rate at which I was urinating was too much. So when we returned, I came to the hospital and I was told I had diabetes. Interviewer: How did you feel when you were told you had Respondent: I was sad. It pained me that I have BP and I am taking medicine which I'm praying it stops and now additional one has come. Interviewer: Hmmmm. What came to mind? Respondent: What came to mind was that I will take my medicines and if my time of death comes then I go. I don't have any hope from anywhere. Interviewer: You never thought it was spiritual or somebody working against you? Respondent: Before I thought it was somebody who had bewitched me. But when you come to the hospital, they explain things to you, they will tell you that if you have BP, you can also get diabetes along the line. The two walk together. So when they told me I understood that perhaps that's why the diabetes 30 Interviewer: So now you are calmed down? Respondent: Himmmmin

1

#### INTERVIEW 3

Interviewer: The first time you came to the hospital and you were told you had diabetes, what advice were you given? Respondent: One senior nurse will sit you down on your first visit and tell you what you should be doing and what you shouldn't do. The kind of food that will be good for, how you can take your medicine effectively every tie. Take one in the 38 morning and one in the evening. If you sugar level is down then they know what to do. This is what was given us till date. Interviewer: Has the advice helped you? Respondent: It has really helped me, I followed everything I was told. I am particular with the food I eat. Even when I visit my children, they complain about how careful I am with my eating. For what I have been asked not to eat, no matter what I won't eat it. I sometimes experience discomfort a in my heart so some of the foods. I don't take them. The food I love to eat is plantain. I take banku but with little cassava dough inside. They prepare plenty for me. Fufu, they use small cassava with plenty for my fufu. I don't buy food from outside. I don't take rice. It was recently I came here that the nurses advised that we can eat 51 rice with palm nut soup. So beaus is what I often eat, 52 Interviewer: How many years have you had diabetes? Respondent: Four years now. Lose of strength Interviewer: Within the four years, has it affected you? Has it affected your strength, the food you eat and any other thing? It has made me loose strength to work. Interviewer: Hmmmm. Respondent: Hnuninm, Even now I go to farm once a week. I am not strong like before. Before, I had the strength to work to look after my children. It was after the death of my last born that I had this illness. So I can no longer work hard. My waist and legs are weak so I don't have enough strength now. Interviewer: Hmm. What is it about diabetes that often frustrates trustration with frequent utimbor Respondent: What frustrates me most is the urination. I can urinate all day. I can really urinate and it is that which disturbs 2

## APPENDIX H

# **Sample of Summary Table for Individual Patients**

# Participant 1

Themes	Line numbers	
Signs of Diabetes		
Frequent urination	10-18	
Sweet urine	15-18	
	12	
Psychological and Emotional Reactions		
Not Frightened	29, 57-58	
(4, 64,		
<b>Attitudes of Health Care Providers</b>		
Advice on eating and medication	41-42, 58-60, 67, 135- 137, 177-178	
1005		
Patient's Perception of Diabetes		
Not spiritual cause	55-56-225-226	
The state of the s	W.	
Effects of the illness	[III]	
Debilitation (Weakness in strength)	85, 89-90	
Weight reduction/Emaciation	73	
Challenges of the Illness		
Long distance	192-194	
Difficulty in changing lifestyle	111-115	
Life time medication	118-119	
Long queue	192-194	

Management Strategies	
Acceptance	36-38, 111-115, 237
Family support	123
No local medicine	53-55, 227-228
Prayers	46-48
Dietary modification	201-210
Compliance with medication	227
Change in lifestyle	229, 240-241

# Participant 6

Themes	Line numbers	
Signs of Diabetes		
Frequent urination	12-14	
Sweet urine	14-17	
Initial Lifestyle	(3)	
Drinks alcohol	32	
Loves sweets and meats (Poor lifestyles)	34-35	
NOBIS		
Psychological and Emotional		
Reactions		
Terrified	46-47	
Frightened	51-54	
Thoughts of taking medicine	57-58	
Wept	65	

Excessive thinking	81-82, 84-85	
Attitudes of Health Care Providers		
Advice on eating	42-43, 70, 214-219	
Exercise	70-71	
Advice on thinking	94-95	
Advice on treatment	130-134	
Satisfactory	328-330, 338-340	
Patient's Perception of Diabetes		
Not spiritual illness	369	
Knowledge of Diabetes		
Adequate knowledge of diabetes	427-430, 432-433, 436- 439, 442-443	
Effects of the illness	7	
Stroke	76-81	
Lack of sleep (insomnia)	90-91	
Debilitation (Weakness in strength)	103-104	
Sexual weakness	106-107, 111-112	
Foot sore	114-119, 138-141	
Effect on the family's diet	164-165, 167-171	
Poor social relations	204-207, 212-214	
BP	445-450	
Challenges of the Illness		
Discouragement from friends	125-127	

Financial burden		
Eats desired foods (Difficulty following	154-155, 157-161, 178-	
dietary instructions)	180, 260-261, 264-266,	
	268-270	
Wrong medication	226-229, 242-245, 247-	
	254	
Disorganised long queue	308-315	
Waking up early	319-320	
Inability to eat on time	320-323	
Management Strategies		
Acceptance	182, 300, 362-366	
Family support (monitoring)	272-275, 286-289, 396-	
	399, 411-416	
No local medication	370-372	
Careful life	387-390, 402-408, 458-	
	462	
Dietary modification	392-395	

# Participant 25

Themes	Line numbers
Signs of Diabetes NOBIS	
Painful and itchy leg	17-19
Blisters around the foot	19-20
Foot sore	58-59
Confirmed from the hospital	35-36
Initial Lifestyle	

Poor eating habits	173-178, 486-491		
Psychological and Emotional Reactions			
Disturbed	80		
Wept	82, 333, 339-340, 512- 515		
Confronted with reality	82-85, 102-103		
Sad	91		
Hyperactive	110-116		
Refusal to be amputated	124-130		
Suicidal thoughts	138-141		
Emotional exhaustion	378-379		
Attitudes of Health Care Providers			
Advice on eating	270-273		
Advice not to think	181-184		
Satisfactory	398-401		
T. J.	W.		
Knowledge of Diabetes	(Ull)		
Poor knowledge of diabetes	495-496		
NOBIS			
Effects of the illness			
Leg amputation	48-50		
Inability to work	210-211		
Inability to move freely	254-255		
Social restrictions	301-303		

Challenges of the Illness		
Distance	318	
Poor storage of drugs		
Financial burden	325-326	
Transportation challenge	320-322	
Wakes up early	343	
Delays in eating (delays at the hospital)	354	
Long queue	382-384	
Management Strategies		
Family support	424-425, 433-438	
No local medication	409-410	
Dietary changes	444-447	
Compliance with medication	440-444	
Self-care	303-307, 359-361	

NOBIS

# APPENDIX I Integrated Master Themes for Patients

What life events led to the discovery of the disease?  1. Symptoms Identification  • Frequent urination and sweet urine • Frequent thirst and hunger • Weight reduction • Regular check-up/Blood pressure • Blisters, foot sore (wound)  2. Initial Lifestyle • Drinks alcohol • Poor eating habit (Loves sweets and meats)  2. Spiritual cause • Spiritual cause • Disease of the rich • Dangerous disease (Kills easily) • Limited Knowledge  What are the psychological and emotional experiences of patients after diagnosis?  1. Psychological shock • Shocked (Surprised) • Frightened (Fear and Terrified) • Frustration (Lost hope) • Suicidal thoughts  1. Emotional Outburst • Wept (Sad and Pain) • Hyperactive • Emotional exhaustion (Confronted)	Themo	es		Number of Participants
disease?  1. Symptoms Identification  • Frequent urination and sweet urine • Frequent thirst and hunger  • Weight reduction • Regular check-up/Blood pressure • Blisters, foot sore (wound)  2. Initial Lifestyle • Drinks alcohol • Poor eating habit (Loves sweets and meats)  22  3. Patient's Perception • Positive view of the disease • Spiritual cause • Disease of the rich • Dangerous disease (Kills easily) • Limited Knowledge  7  What are the psychological and emotional experiences of patients after diagnosis? 1. Psychological shock • Shocked (Surprised) • Frightened (Fear and Terrified) • Frustration (Lost hope) • Worry (Excessive thinking) 12 • Self-blame (Self-questioning and Disbelief) • Suicidal thoughts  1 Wept (Sad and Pain) • Hyperactive • Emotional exhaustion (Confronted)				I di dicipulità
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Frequent thirst and hunger  Weight reduction  Regular check-up/Blood pressure  Blisters, foot sore (wound)  2. Initial Lifestyle  Drinks alcohol  Poor eating habit (Loves sweets and meats)  Positive view of the disease  Spiritual cause  Disease of the rich  Dangerous disease (Kills easily)  Limited Knowledge  What are the psychological and emotional experiences of patients after diagnosis?  Psychological shock  Shocked (Surprised)  Frightened (Fear and Terrified)  Frustration (Lost hope)  Worry (Excessive thinking)  Self-blame (Self-questioning and Disbelief)  Suicidal thoughts  Hyperactive  Wept (Sad and Pain)  Hyperactive  Emotional exhaustion (Confronted)	1.	Sy	mptoms Identification	
Weight reduction     Regular check-up/Blood pressure     Blisters, foot sore (wound)  2. Initial Lifestyle     Drinks alcohol     Poor eating habit (Loves sweets and meats)  22  3. Patient's Perception     Positive view of the disease     Spiritual cause     Disease of the rich     Dangerous disease (Kills easily)     Limited Knowledge  7  What are the psychological and emotional experiences of patients after diagnosis?  1. Psychological shock     Shocked (Surprised)     Frightened (Fear and Terrified)     Frustration (Lost hope)     Self-blame (Self-questioning and Disbelief)     Suicidal thoughts  1  2. Emotional Outburst     Wept (Sad and Pain)     Hyperactive     Emotional exhaustion (Confronted)		•	Frequent urination and sweet urine	13
<ul> <li>Regular check-up/Blood pressure</li> <li>Blisters, foot sore (wound)</li> <li>2. Initial Lifestyle <ul> <li>Drinks alcohol</li> <li>Poor eating habit (Loves sweets and meats)</li> <li>Positive view of the disease</li> <li>Spiritual cause</li> <li>Disease of the rich</li> <li>Dangerous disease (Kills easily)</li> <li>Limited Knowledge</li> </ul> </li> <li>What are the psychological and emotional experiences of patients after diagnosis? <ul> <li>Psychological shock</li> <li>Shocked (Surprised)</li> <li>Frightened (Fear and Terrified)</li> <li>Frustration (Lost hope)</li> <li>Self-blame (Self-questioning and Disbelief)</li> <li>Suicidal thoughts</li> <li>Wept (Sad and Pain)</li> <li>Hyperactive</li> <li>Emotional exhaustion (Confronted</li> </ul> </li> </ul>		•	Frequent thirst and hunger	7
Blisters, foot sore (wound)  Initial Lifestyle Drinks alcohol Poor eating habit (Loves sweets and meats)  Positive view of the disease Spiritual cause Disease of the rich Dangerous disease (Kills easily) Limited Knowledge  What are the psychological and emotional experiences of patients after diagnosis? Psychological shock Shocked (Surprised) Frightened (Fear and Terrified) Frustration (Lost hope) Self-blame (Self-questioning and Disbelief) Suicidal thoughts Wept (Sad and Pain) Hyperactive Emotional exhaustion (Confronted)		•	Weight reduction	2
2. Initial Lifestyle  • Drinks alcohol  • Poor eating habit (Loves sweets and meats)  22  3. Patient's Perception  • Positive view of the disease  • Spiritual cause  • Disease of the rich  • Dangerous disease (Kills easily)  • Limited Knowledge  7  What are the psychological and emotional experiences of patients after diagnosis?  1. Psychological shock  • Shocked (Surprised)  • Frightened (Fear and Terrified)  • Frustration (Lost hope)  • Worry (Excessive thinking)  • Self-blame (Self-questioning and Disbelief)  • Suicidal thoughts  1  2. Emotional Outburst  • Wept (Sad and Pain)  • Hyperactive  • Emotional exhaustion (Confronted		•	Regular check-up/Blood pressure	5
2. Initial Lifestyle  • Drinks alcohol  • Poor eating habit (Loves sweets and meats)  22  3. Patient's Perception  • Positive view of the disease  • Spiritual cause  • Disease of the rich  • Dangerous disease (Kills easily)  • Limited Knowledge  7  What are the psychological and emotional experiences of patients after diagnosis?  1. Psychological shock  • Shocked (Surprised)  • Frightened (Fear and Terrified)  • Frustration (Lost hope)  • Worry (Excessive thinking)  • Self-blame (Self-questioning and Disbelief)  • Suicidal thoughts  1  2. Emotional Outburst  • Wept (Sad and Pain)  • Hyperactive  • Emotional exhaustion (Confronted		•	Blisters, foot sore (wound)	4
Drinks alcohol     Poor eating habit (Loves sweets and meats)      Positive view of the disease      Positive view of the disea				
Drinks alcohol     Poor eating habit (Loves sweets and meats)      Positive view of the disease      Spiritual cause     Positive view of the disease      Disease of the rich     Positive view of the disease      Disease of the rich     Positive view of the disease      Positive view of the	2.	In	itial Lifestyle	
Poor eating habit (Loves sweets and meats)  3. Patient's Perception Positive view of the disease Spiritual cause Spiritual cause Disease of the rich Dangerous disease (Kills easily) Limited Knowledge  What are the psychological and emotional experiences of patients after diagnosis? Psychological shock Shocked (Surprised) Frightened (Fear and Terrified) Frustration (Lost hope) Self-blame (Self-questioning and Disbelief) Suicidal thoughts  Wept (Sad and Pain) Hyperactive Emotional exhaustion (Confronted)		•		9
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<ul> <li>Dangerous disease (Kills easily)</li> <li>Limited Knowledge</li> <li>What are the psychological and emotional experiences of patients after diagnosis?</li> <li>Psychological shock</li> <li>Shocked (Surprised)</li> <li>Frightened (Fear and Terrified)</li> <li>Frustration (Lost hope)</li> <li>Worry (Excessive thinking)</li> <li>Self-blame (Self-questioning and Disbelief)</li> <li>Suicidal thoughts</li> <li>Wept (Sad and Pain)</li> <li>Hyperactive</li> <li>Emotional exhaustion (Confronted)</li> </ul>		•	Spiritual cause	3
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What are the psychological and emotional experiences of patients after diagnosis?  1. Psychological shock  • Shocked (Surprised)  • Frightened (Fear and Terrified)  • Frustration (Lost hope)  • Worry (Excessive thinking)  • Self-blame (Self-questioning and Disbelief)  • Suicidal thoughts  1  2. Emotional Outburst  • Wept (Sad and Pain)  • Hyperactive  • Emotional exhaustion (Confronted)		•	Dangerous disease (Kills easily)	5
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<ul> <li>Frustration (Lost hope)</li> <li>Worry (Excessive thinking)</li> <li>Self-blame (Self-questioning and Disbelief)</li> <li>Suicidal thoughts</li> <li>Emotional Outburst</li> <li>Wept (Sad and Pain)</li> <li>Hyperactive</li> <li>Emotional exhaustion (Confronted)</li> </ul>		•		
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Self-blame (Self-questioning and Disbelief)     Suicidal thoughts     Suicidal thoughts      Wept (Sad and Pain)     Hyperactive     Emotional exhaustion (Confronted)		•		_
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Emotional exhaustion (Confronted		•		_
· · · · · · · · · · · · · · · · · · ·		•	• •	
with reality) 4			with reality)	4

What are the experiences of rural diabetics	
with health care system?	
1. Accessibility to Health Care	
Facilities	
<ul> <li>Transportation challenge (Long distance and poor road)</li> </ul>	9
Long queue (Time consuming)	7
Meeting different doctors	6
Waking up early	5
Difficulty meeting appointments	4
2. Encounter with Health Care Providers	
Positive attitude of health workers	27
Inadequate consultation time (lack)	
of patience, inability to ask	
questions)	4
What are the challenges of living with diabetes in rural area?	
1. Effects of the Disease	
a. Physical Effects	
Debilitation (Inability to work)	15
• Emaciation	5
Retinopathy (Blurred vision/Low vision)	5
Amputation	2 1
Sexual weakness	3
• Insomnia	2
b. Social Restrictions	
Poor social relations	15
2. Challenges of living with the Disease	
<ul> <li>Financial burden (Purchase of drugs)</li> </ul>	12
Taking too many drugs	2
<ul> <li>Poor storage of drugs</li> </ul>	7
Difficulty following dietary/medication instructions	10

	How do rural diabetics manage the disease?		
1.	M	anagement Strategies	
	•	Psychological Acceptance	8
	•	Social/Spiritual (Family support,	
		Encouragement, Prayers)	8
	•	Compliance with medication	
		(Biomedical treatment)	7
	•	Dietary and lifestyle changes	8

