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SCHOOL OF SOCIAL SCIENCES

PERCEPTION OF GENETIC COUNSELLING, ILLNESS BELIEFS AND MENTAL HEALTH OF ADULTS WITH GENETIC DISEASES.

BY

ATTAH ROSELYN

10353913

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DECLARATION

I hereby declare that with the exception of the references used which are duly acknowledge, this thesis is my own work submitted for the award of MPhil Counselling Psychology to the Department of Psychology, University of Ghana.

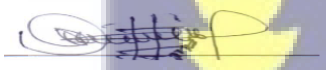
Roselyn Attah

January 13,2022

Signature……. Date:…… ……

(Student)

Prof. Joseph Osafo



January 13, 2022

Signature…… Date: ……..

(Principal Supervisor)

Prof. Charity Akotia

13/01/2022

Signature…… Date: ……

(Co-Supervisor)

DEDICATION

I dedicate this master thesis to family for their support which has brought me this far. I am very grateful.

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ABSTRACT

Many illnesses that affect people are either partly or wholly related to genetics. Diabetes and sickle cell are of no exception. On this premise, this study examined the perception adults with genetic disease have about genetic counselling, their illness beliefs and its impact on their mental health. The study used the concurrent triangulation mixed method approach. A sample of 330 and 12 adults (18years-75years, mean age 44.2) with genetic conditions (i.e. diabetes and sickle cell) were conveniently and purposively selected. The study employed the mixed method approach for its methodology. The data was analyzed using the analytic cross-sectional approach and the thematic approach for the quantitative and qualitative data respectively. The results of the quantitative study revealed that illness perception influenced their level of depression and anxiety but not stress. This further revealed that their genetic illnesses had a toll on their psychological wellbeing. Sickle cell patients reported more mental health problems than type 1 and type 2 diabetes. Gender and level of education did not predict mental health problems. Perception of genetic counselling, impact of genetic condition, causes of genetic condition coping mechanisms, and beliefs about genetic condition were five themes emerged from the qualitative data. Qualitative findings confirmed that illness perception greatly impacted the mental health of adults with genetic conditions. Again, in the qualitative findings, participants with sickle cell reported more mental health problems than those with diabetes. Although, respondents in the qualitative study had fair knowledge about genetic counselling which was not available in Ghana, they perceived genetic counselling and testing to be very essential to them and those at risk of developing a genetic condition. Participant further revealed that genetic education should be done not only at the health service but also all levels of education because knowledge about heritable diseases is low in Ghana. This implies that appropriate psychological interventions, education and

counselling will improve their psychological wellbeing and mental health as well as help those at risk take precautionary measures.

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LIST OF ABBREVIATIONS

BIPQ – Brief Illness Perception Questionnaire
DASS – Depression Anxiety Stress Scale
DM – Diabetes Mellitus
DNA – Deoxyribonucleic Acid
EFA – Exploratory Factor Analysis
GC – Genetic Counselling
GET – Gene-Environment-Time
GP – General Practitioner
GSI – Global Severity Index
GSS – Ghana Statistical Service
Hbc – Hemoglobin C
HBM – Health Belief Model
Hbs – Hemoglobin S
IDF – International Diabetes Federation
KMO – Kaiser-Meyer-Oklin
MANOVA – Multivariate Analysis Of Variance
NHGRI – National Human Genome Research Institute
NIH – National Institute of Health
OMIM – Online Mendelian Inheritance In Man
PCA – Principal Component Analysis
SCD – Sickle Cell Disease
SD – Standard Deviation
SPSS – Statistical Package for Social Sciences
WHO – World Health Organization

CHAPTER ONE

INTRODUCTION

1.0 Background of the Study

Genetic predisposition and environmental factors play an essential role in development and health (Boyce et al., 2021). Several illnesses that affect people are either partly or wholly related to genetics (National Human Genome Research Institute, 2018). According to the National Institute of Health (2018), genetic illnesses are conditions or diseases that are partly or wholly caused by a deviation of the DNA sequence or order from the normal. Furthermore, Bushman (2000) defines a genetic disease as any form of limitation in health that is caused by an alteration in the genetic makeup that results from chromosomal or environmental factors (Khan et al., 2015).

Many genetic conditions are found in all parts of the world. Although new ones are still being discovered, sickle cell disease, diabetes, cancer, kidney disease and other rare genetic conditions are known to be some common genetic conditions in Ghana. This current study focuses on three health conditions that have genetic antecedents. They are; type 1 diabetes, type 2 diabetes and sickle cell. The reason for focusing on these two conditions first is to explore thoughts about genetic counselling and its need with regards to the genetic nature of the condition of these diseases. Also, these two conditions were chosen in order to get a more detailed beliefs about their condition and its related mental health issues they face.

The focus of the study would be on the adult population with these conditions. This will help to obtain experiences of participants and hence necessitates the choice of sickle cell and diabetes over other genetic conditions.

Although these conditions have a genetic basis (Brorsson et al. 2015; Doumatey et al. 2019), it is important to note that, the genotypes are expressed often in conjunction with environmental factors. The Harvard School of Public Health establishes this point in a publication which states that genetic factors make a small contribution to putting an individual at risk of falling victim to a particular medical condition and that "our genes are not our destiny" (Genes Are Not Destiny, 2016).

In a recent study, Boyce et al. (2021) argue that health is the product of crucial protective factors during critical or sensitive developmental phases, which might promote the expression of protective genetic elements. Importantly, as genetic impacts have become gradually disclosed as primarily interacting the frontiers of indication in GET (gene-environment-time domains). They have begun to bridge the gaps between genes and the environment (Boyce et al. 2021)

Usually, people who carry the sickle cell gene do not show symptoms but have the potential of passing off this defective gene to their offspring (Stuart & Nagel, 2004). With improved average life expectancy of 54years worldwide of infants reaching adulthood with sickle cell disease (Lubeck et al.,2019), there appears to be a strong effect on the wellbeing and psychosocial functioning of those affected. Psychological well-being is seen as a crucial part of human health that contributes to overall happiness (Appiah et al., 2020).

Whilst there seems to be little national data on SCD in Ghana, diverse research reports on the epidemiology of SCD in primary healthcare facilities exists. From January 2013 to December 2014, a systematic review of the health files of all SCD patients (aged 13 and older) at the Ghana

Institute of Clinical Genetics, Korle-Bu, revealed that 5,451 SCD patients accessed the facility's health services, with 20,788 clinic visits. Per a study, about 2% of all neonates are detected as having SCD, and at least 25% of the Ghanaian population possesses the sickle cell trait (Edwin et al., 2011).

Sickle cell disease is a recessive gene disorder that presents itself with severe pains known as crisis. This crisis occurs as a result of dehydration, extreme weather conditions, and other infections. These complications that arise as a result of the dormant gene may affect other organs of the body. Due to the obvious formative obstacles and illness issues associated with SCD, patients ultimately require biopsychosocial therapies to live productive and dignified experiences (Crosby et al., 2015). SCD patients are almost always forced to a lifelong treatment protocol that can be pricey, complex, and multifaceted, with a significant risk of poor mental wellness, or their ability to reach their full potential and live a meaningful life (Appiah et al.,2020). Psychological well-being assessment is an important approach for evaluating the result of people with chronic illnesses (Forrester et al., 2015 Ryff & Keyes, 1995).

In a study in Ghana, Appiah et al. (2020) investigated the occurrence of positive mental health in adults with sickle cell. The results showed that 34% were active at suboptimal level though they found high levels of positive mental health. This reveals that there is the need to explore other aspect of psychological wellbeing and not mental health problems alone. This study opted to explore the following areas of psychological wellbeing as a complementary information for future research and interventions. The study will explore these areas of psychological wellbeing; environmental mastery, autonomy, purpose in life and self-acceptance, personal growth and positive relations with others (Ryff,1989).

In the sub-Saharan Region, chronic non-communicable diseases with genetic markers are increasing at an alarming rate (Hall et al., 2011; Mohan et al., 2019). Diabetes, for example, which is largely genetically transmitted is reported to be high in Africa and most people with the condition are undiagnosed (Mohan et al., 2019). The situation is similar in Ghanat, a developing African country. Diabetes is a disorder in which the body's cells do not create enough insulin to keep glucose levels in check (Kumar & Clark, 2002). The World Health Organisation describes diabetes mellitus as a metabolic condition characterized by abnormalities in lipids, carbohydrate protein metabolism and chronic insulin caused hyperglycaemia, insulin, or both deficiencies (World Health Organization, 2021). Chronic diseases are on the rise in Sub-Saharan Africa (SSE). Diabetes and hypertension, on the other hand, are two of the world's fastest-growing chronic disorders (Danquah et al., 2012). Diabetes affects an estimated 4 million Ghanaians, a figure that is expected to rise shortly (National Diabetes Association of Ghana (NDAG), 2012). With diabetes being a hereditary condition, genetic counselling for this condition is worth being examined by looking at the rising prevalence rate (National Diabetes Association of Ghana (NDAG), 2012).

Genetic testing can help patients make critical prevention or early detection decisions in cases such as diabetes. Individuals "from ethnic minority groups are much less likely to receive genetic" counselling according to Hann et al. (2017). To minimize increasing healthcare disparities, it is vital to comprehend different groups' opinion of genetic examination and it being accepted. People who are diagnosed with genetic defects or with a significant familial history in some European nations and the United States can undergo "genetic counselling and testing to check if they have an inherited cancer gene mutation" (Moyer, 2014). Knowing the risk of

hereditary diseases might help healthy people make health-care decisions, such as getting frequent check-ups or having surgery, to lower the risk of further development (Axilbund & Peshkin, 2010).

Public approaches to genetic testing have been generally found to be positive for disease risk (Etchegary, 2014; Haga et al., 2013). In a study in USA, about 97% of participants showed that genetic testing was something they were interested in at least somewhat, with the majority having a positive attitude towards genetic investigation and approving the use of genetic testing to detect diseases (Haga et al., 2013). A Netherland survey also reports that 64 per cent of people thought genetic testing would help people live longer, for that reason, they had positive attitudes towards genetic testing (Henneman et al., 2012). However, the public is also concerned by the use of genetic test results to discriminate against people who are genetically predisposed to illness and that genetic testing may have the effect of labelling people as having "good" or "bad" genes (Henneman et al., 2012).

In the previous study, low awareness and knowledge of genetic tests and services available, language barriers, risk-related stigma, cancer-related fatal views, anticipated negative emotions and uncertainty about the outcome were all identified as potential barriers to accessing the genetic testing of cancer by ethnic groups in Africa, White Irish and South Asia (Allford et al., 2013; Appiah et al,2020, Edwin et al,2011).

The current study aims to investigate factors that might act as barriers or facilitators to the uptake of genetic counselling. The focus will be on awareness, knowledge, illness perceptions, and attitudes towards genetic testing for genetic conditions, and reasoning for and against testing. As has been established, genetic disorders affect the psychological well-being of people who have

been diagnosed or are at risk. McAllister et al. (2007) confirm that having a genetic condition or being at risk of having a genetic condition can affect psychological health, hence, psychological health issues such as sadness, guilt, unease, redemptive alteration may be present with genetic disorders. These psychological health issues are also largely influenced by the perception of illness of those affected.

In a study, illness perception has indeed been recognized as a key factor influencing self-care habits, psychological distress, and other health outcomes among people living with chronic illnesses such as diabetes (Alzubaidi et al., 2015; Kugbey et al., 2015). The link between illness perception and medical outcomes could very well be due to the fact that engaging in self-care activities necessitates effective decision making, which also is influenced by how people with the disease perceive their ailments in terms of whether it is easy to control, comprehensible, treatable, episodic, and catastrophic (Kugbey et al., 2017). However, a study of Ghanaians with chronic illnesses found that their overall assessment of their sickness has an impact on their level of psychological discomfort (Nyarko et al., 2014).

Whilst the relationship between genetic disorders and psychological wellbeing seem linear and simple, the intermediary role of illness perception is crucial. For a case in point, Morgan et al. (2014) highlighted that health-related outcomes such as psychological wellbeing are a corollary of the way, the individual thinks about the condition. Furthermore, the beliefs about a disease consequently influence health behaviours, which in turn affect psychological wellbeing. Edgar (2003) also establishes that illness perception has a direct bearing on psychological wellbeing because it defines a belief that is to an extent a representation of the individual's coping, whether negative or positive.

Genetic counselling plays a vital role in the management of genetic disorders. According to the World Health Organization (2010), genetic counselling is the process by which trained experts disclose information on the genetic features of maladies with somebody who is at an elevated risk of either acquiring an inherited genetic disorder or passing it on to their new-born child. A genetic counsellor provides information on the transmission of diseases and the possibilities of repetition; considers the implications it has on patients, families, and healthcare professionals; and assists patients and families grappling with these disorders.

Although the field of genetic counselling is relatively new, Duric et al. (2003) reveal that genetic counselling helps reduce psychological distress in genetic disorder management. Genetic counselling is now playing an important part in the healthcare coverage of many industrialized countries, thanks to resource and technology improvements, and its promise is now being fulfilled in less developed nations.

In Ghana, little research has been done on the perception of genetic counselling because the field is still emerging in Ghana and there is a lack of genetic counselling services (Appiah et al., 2020). This study seeks to employ the mixed-method research approach to explore the perception of genetic counselling by adults living with genetic conditions. Further to this, it seeks to explore how different their condition would have been, should they have had genetic counselling before the onset of the condition. Lastly, the study will also explore the benefits of genetic counselling services to their younger generations. On a firm note, the scarcity of professional genetic counselling in the country makes this study very important. The outcome of this study will help project the vital role genetic counselling may play in terms of people's perception of

genetically related conditions which will enhance the management of these conditions or diseases. This study will be crucial to the emerging field of genetic counselling in West Africa and help practitioners provide better services to all. It is essential to note that the early detection and management of inherited diseases will go a long way to delay the onset or reduce the severity of genetic diseases in Ghana.

1.1 Statement of Problem

As of now, there are no effective means of preventing the spread of genetic conditions such as sickle cell disease in Ghana and West Africa at large. Sedrak and Kondamudi (2021) point to the fact that "sickle cell disease has no cure and is associated with life-threatening complications." Only prior counselling and testing appear to be the most viable approach to use. The prevalence of genetic conditions such as sickle cell disease in children in Ghana is high because 30% of Ghanaians carry either the HbS or the HbC genes. Survival to adulthood in sickle cell disease was previously rare (Asare et al.,2018).

In Ghana, general population-wide study estimates have suggested somewhere between 3.3 and 6% of the overall population have diabetes, with this percentage increasing with age and being more prevalent, not surprisingly, in urban areas than rural areas (Danquah et al., 2012; IDF Diabetes Atlas Group, 2015). Unfortunately, routine genetic counselling services are non-existent in Ghana (Rusu et al., 2017; Taiwo et al., 2011). Coupled with this concern is the fact that very few people have a good idea of what genetic counselling is as has been confirmed by the few available studies (Allford et al., 2013; Appiah et al,2020, Edwin et al,2011) and also the paucity of studies on genetic counselling in Ghana. The genetic aspect of conditions and its implications

are understudied especially in Ghana where genetic counselling services are few or not in existent (Appiah et al,2020). It is against this backdrop that the current study seeks to examine the perception adults with genetic disease have about genetic counselling, illness beliefs and mental health.

As it has been established earlier, there is the need to explore the perceptions adults with genetic disease have about genetic counselling. Little is known about the beliefs of people concerning genetic counselling in Ghana (Appiah et al., 2020). This study will generate this information from participants and further address the reasons for the patronage of genetic counselling from the information gathered. Genetic conditions can permanently affect one's adult life. Most importantly one's beliefs about genetic conditions can adversely or positively affect wellbeing. Most studies on genetic diseases in Ghana focused on adherence/non-adherence to treatment (Amaltinga, 2017), the financial burden these diseases pose on households in Ghana (Tagoe, 2012). Other research showed the low quality of life of adults living with chronic illnesses in Ghana (Tanor et al., 2019). However, little is known about the beliefs they hold about their genetic conditions and how these conditions affect their well-being psychologically. Few studies have examined the genetic conditions, illness beliefs and psychological wellbeing both in Ghana. Some of these studies revealed that illness perception was a strong predictor of mental health problems (Nuworza,2013). In his study, Appiah et al,(2020) reported that young Ghanaians understood sickle cell and also had good attitude toward genetic counselling. Kubgey et al. (2015) found that illness beliefs have a positive significant association with level of psychological distress among type 2 diabetes patients in Ghana. Another study in Ghana showed that level of religiosity

but not illness perception, predicted mental health problems among diabetic patients in Cape Coast(Amartey,2019)

When people have certain genetic conditions, there is the tendency to focus only on the biological effects of the disease, but very little attention is given to the psychosocial effects of living with a genetic condition or predisposition as Bolton and Gillett (2019) suggested. With healthcare being multi-dimensional by employing the biopsychosocial model, this study will fill in the huge gap on the scathing effects of the selected genetic conditions on the mental health of the participants. Further, there is insufficient research focus on the beliefs people have about their illnesses and how these beliefs affect their psychological wellbeing (Bassi et al., 2016). The gap in this area will be filled by examining the relationship between illness beliefs and psychological wellbeing (via their scaled scores on mental health-related issues) of adults with genetic disease. Finally, much of what is known in studies in Ghana when it comes to health beliefs is that they consider the religious or spiritual antecedents of their illness (Korsah & Domfeh, 2020). However, it is very important to explore knowledge of persons with sickle cell and diabetes about the genetic aspect of condition and their mental health. This is a major gap yet to be filled. This study, through the qualitative method, will obtain a much more detailed health belief of patients with genetic conditions. The choice of a mixed method approach will give a more in-depth illness experience to improve health care for genetic conditions.

1.2 Aims and Objectives

The specific aim of the thesis is to explore the perception adults with genetic disease have about genetic counselling and examine the impact illness beliefs have on their mental health. Specific

objectives of the study include:

1. Explore the perceptions adults with genetic disease have about genetic counselling.
2. Examine the relationship between illness beliefs and psychological wellbeing of adults with a genetic disease
3. Examine the relationship between illness beliefs and mental health-related problems of adults with a genetic disease
4. Investigate which dimension of illness belief would have the greatest variance on mental health-related problems of adults with genetic disease.
5. Examine differences in mental health-related problems of adults with a genetic disease based on differences in gender, and education

1.3 Relevance of the Study

This study will look at the views of Ghanaians about genetic counselling as well as the factors influencing the mental health of patients with various genetic illnesses in Ghana. Recognizing these common mental health disorders would lay the groundwork for including mental health treatment into the care plan (Arango et al., 2018). Along with identifying frequent mental health problems, how individuals with chronic genetic disorders' attitude and knowledge levels are likely to influence such mental health problems would be investigated. This is because both personal and social resources are generally used by patients to cope with health issues (Super et al., 2021).

Since this study is one of the few in the domain of genetic disorders and mental health outcomes, the findings will provide physicians with knowledge on how to meet the mental health

requirements of patients with chronic genetic conditions in Ghana.

The study's findings will aid policymakers in making decisions by suggesting ways to improve diabetes patient care. This study will add to the present understanding in the domain of sickness perception and diabetic effects because related research is scarce, if not non-existent (mental health problems). Additionally, this study will be relevant to the West African Genetic Medicine Center whose focus is to improve access to genetic health care in Ghana and Africa. In the long run, this research will assist to change the existing predominantly biological management of genetic precursor illnesses by including more allied health specialists into the care plan.

CHAPTER TWO

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.0 Introduction

This chapter consists of two sections. The first section is a survey of the theoretical and empirical literature that illustrates the theories that serve as a basis for the study. The second part is an evaluation of previous research on the key variables in this study. Furthermore, the chapter presents the hypotheses of the study, and operational definitions of several essential terms and ideas.

2.1 Theoretical Frameworks

The two theories that guide this research are the Health belief model and the Leventhal's self-regulation theory.

2.1.1 The Health Belief Model (Hayden, 2009)

The health belief model was postulated by Hayden (2009) and this theory has been used largely as predictor of health behaviours. It was originally created in the 1950s and was most recently updated in the 1980s. Boskey (2019) posits that the theory is hinged on the premise that an individual's desire or intent to alter their health behaviours is majorly influenced by the kind of perceptions they have concerning their health.

The HBM is predicated on psychological and behavioural school of thought, with two segments of health-related behaviour: one, the means of avoiding disease or, put another way, the belief that a particular health action will reduce the risk of developing illnesses; and two, the belief that a specific clinical intervention will thwart or promote healing. Finally, an individual's views

on the benefits and drawbacks of physical exercise are influential in determining their behaviour. HBM is a well-known framework for figuring out why patients participate in disease prevention efforts or don't (Glanz et al., 2008). The HBM contains six elements that "predict if and why people might take action to prevent, identify, or manage sickness conditions," according to the researchers (Glanz et al., 2015, p. 76). Perceived susceptibility, severity, perks, impediments, cues to action, and self-efficacy are the factors to consider.

It has been revealed that a person's beliefs of their genetic problems and self-care behaviours influence the types of maintenance and self-care activities they employ (Tan et al., 2018). Some of the factors that influence the belief model of people are as follows; One is that the sufferer of the condition should feel a level of threat by their improper healthcare practices (perceived susceptibility and severity), also, they must have the believe that a change in the current ill-conceived self-care practice would lead to a significant positive outcome at a cost that is bearable and beneficial to them (perceived benefit), and believe they are competent (self-efficacy) to overcome perceived barriers to action for the behaviour (self-care practice) to succeed, according to the model. This indicates that patients who have a high perceived vulnerability to the illness, are much more inclined to participate in self-care strategies (Ayele et al., 2012).

HBM was used as a theoretical foundation to look into why people take precautionary measures. What is the purpose of screening, and how can diseases be managed? This framework has principally been implemented mostly on prevention and treatment of diseases and behaviour to avoid illness and genetic disorder chain (Glanz et al., 2008; Karimy et al., 2016), with a vital and precise model to predict behavior and HBM made available in health measures (Jeihooni et al., 2015).

2.1.2 Self-Regulatory Model of Illness Perception (Levanthall et al., 1980, 1997)

Illness perception is a subjective perspective that focuses on one's experience and situation as a consequence of an illness, and it can help chronic patients maintain their health practices. It is influenced by cognitive and emotional variables such as the illness's expected timeframe, the illness's life implications, how the illness is controlled or treated, the diagnosis and source of the illness, and feelings of dread or fear linked with the illness. Individual disease perception is linked to psychosocial and clinical outcomes in patients and serves as a driving factor and starting point for illness coping and action plans (Chilcot, 2011).

Patients' perceptions and expectations regarding an illness or somatic symptom are referred to as illness perception. The depiction of illness is fundamental to Leventhal's Self-Regulation Theory (Leventhal, 1970; Leventhal et al., 1980). Six characteristics or components of illness representations have been identified through research: The first one is Identity, which is concerned with a threat's title or label (e.g., sore throat, lump in the breast, weight loss). The next is Timeline, which is concerned with the threat's expected temporal course (e.g., acute, chronic, cyclical). Also, there is the symptoms' perceived consequences. In this scenario, the individual's anticipated outcome in the event of a danger (that is to say, whether the illness is minor or major). The fourth point to consider is the illness's cause. This fourth aspect examines if the person perceives the ailment is caused by inherited, extrinsic, or internal factors. Fifth, keep the sickness under control or cure it. This phase, according to Lau and Hartmann (1983), is about determining whether or not something can be done to combat the threat. Finally, disease coherence refers to how well a person's views regarding the condition are aligned.

The field of cancer is a good example of how people perceives illness. A young woman notices a strange bulge in her breast. The word "cancer" comes to mind for a lot of women (identity). The word "cancer" conjures up images of pain and potentially life-threatening repercussions, as well as long-term treatment (cure) and likely speculative causes. A strong emotional response of anxiety and terror is triggered at the same time. This is why cancer is sometimes referred to as a "hot cognition," in which disease representations and affective reactions are merged (Benedict et al., 2020). Two sorts of memories shape illness perceptions. The first category includes conceptual or referential memories or information derived from the individual's abstractions of sickness experiences. In contrast, schematic memories, the second form of memory, represent the recall of previous sickness events as well as their emotional correlates (i.e., experiences of what the health threat felt like). In this study, the researcher believes that illness perception as explained by this theory would influence the mental wellbeing of participants.

2.1.3 Criticisms of the Health Belief Model

Abbatangelo-Gray et al. (2007) suggested that the health belief model is reductive since it ignores social factors, emotions and some contextual factors like culture. They went on to say that HBM arose from a desire to prevent disease and is based on ideas concerning only unidentified illnesses. It is also a "rational exchange" model, which claims that people carefully identify and analyze the advantages and cost of dissimilar behaviours. Kendall (2010) claims that this disregards behavioral economics research that demonstrates how frequently people fall short of performing the mental labor necessary to recognize and evaluate every potential decision consequence.

In its place, people frequently make decisions based on mental shortcuts and mental rules of thumb (Kendall, 2010). Individual variations like sensation-seeking or primary personality type are not taken into account. Individual differences in attention to health messages, as well as their processing and motivating value, could have an impact (McCrae & Terracciano, 2005). Another limitation that is seen in the HBM is that it appears to favour a more descriptive approach than the provision of an explanation for people's health beliefs. It further makes no recommendation for the alteration of health-related behaviours. This current research will bridge that gap through the qualitative studies which will explore areas of health belief not covered by this theory. Previous study on preventive care measures indicated that perceived vulnerability, benefits, as well as restrictions which were often associated with desired health behaviour. Perceived severity was not often connected to desired health behaviour (Green et al., 2020). Specific factors are advantageous depending on the desired clinical outcomes, but for the model to be most effective, it should be paired with other models that compensate for the situational context and provide modification approaches.

2.2 Review of Related Literature

2.2.1 Overview and Socio-Demographic status of Genetic Counselling

According to the OMIM Gene Map, there are over 6,000 known genetic disorders and constantly new ones are being described in the medical literature. Fridovich and Fridovich-keil (2020) revealed that in developed nations, genetic diseases account for thirty per cent of postnatal infant death. Additionally, thirty per cent of paediatric and ten per cent of adult hospitalization are mostly as a result of genetic causes (Fridovich & Fridovich-keil, 2020). Human genetic disorders come in many different forms, and they can be classified as coming from chromosomal, single-

gene Mendelian, single-gene non-Mendelian sources or multifactorial (Fridovich & Fridovich-keil, 2020). This study will be based on genetic conditions, which are caused by multiple (multifactorial) genes acting together with environmental factors. Examples of such are heart disease, and diabetes etc. Most treatment of genetic diseases revolves around managing the symptoms of the disorders to improve patients' life. Diabetes causes most limb amputations as a result of damage to the nerves due to reduced blood flow. It also causes blindness and the nerves in the retina gradually get damaged. Kidney diseases, heart attacks and stroke are also some consequences of diabetes (WHO, 2015). Roughly 463 million individuals (20-79 years) have diabetes. Before the year 2045, this figure is projected climb to 700 million, accounting for 79% of persons with diabetes in poor and middle-income nations (IDF, 2019). This literature review demonstrates the combination of variables and their impact on genetic counselling.

With regards to gender differences, in Zambia, Muzata (2020) conducted a study which had an objective to determine whether knowledge about genetic counselling would differ by gender and also whether attitudes towards genetic counselling would be influenced by gender. To obtain data from respondents, the study used a survey design. The study used stratified and simple random selection to recruit 157 respondents from four higher institutions. In terms of knowledge and attitudes toward genetic testing and counselling, no significant gender disparities were detected among students, according to the study. Siani and Ben-Zvi (2015) discovered that gender had minimal impact on views regarding genetic counselling, indicating a mixed pattern of influence.

Gerard et al. (2019) sampled 1389 college students from 230 in the sciences at 23 universities across the United States to determine their awareness, perspectives, understanding,

and enthusiasm towards genetic counselling. Their research indicated no significant differences in pre-survey enthusiasm for genetic counselling with regards to gender, but substantial disparities in post-survey interest in genetic counselling, with females expressing higher levels of interest in general.

Considering the religious nature of most Ghanaians, it is useful to investigate the role religion plays in attitudes towards genetic counselling. Siani and Ben-Zvi (2015) examined the attitudes of Israeli undergraduate students regarding genetic issues, and how these are influenced by their discipline of study, their affiliation to religion, and their gender. A total of 490 students were sampled for the study. The most influential factor among the variables was students' religious devotion. More secular than religious students ($p=0.0001$) trust genetic tests, especially those religious students who do not study the life sciences (LS). Life sciences students display more critical thinking of genetic testing than other students are ($p=0.0128$).

Furthermore, Gemmell et al. (2017) surveyed 111 Christians and had them complete an anonymous survey regarding their understanding of genetic counselling and attitudes on it, as well as their views on its aim, scope, and practice, and their desire to use genetic counselling services. Despite the fact that several of the participants had never heard of genetic counselling, they all had positive perceptions and feelings about it. Average ratings, for example, demonstrated trust in genetic counsellors' knowledge and understanding that genetic counselling corresponds with their beliefs.

2.2.2 Knowledge about Genetic Counselling

Knowledge plays a vital role in people's perception about their illness as well as their attitude towards genetic conditions and genetic counselling. Veritable examples to confirm this

assertion are discussed in this study under this theme. Rolf et al. (2013) in their study to assess the attitudes and knowledge of genetic counselling in the U.S revealed that genetic counselling on Hemophilia was mostly done by nurses and Physicians which mostly created some inconsistencies in the information provided to patients. Further, Sheppard et al. (2016) examined how awareness affected Genetic Counselling and Testing (GCT) for Hereditary Breast and Ovarian Cancers (HBOC).

A telephone survey involving 50 Black at-risk breast/ovarian cancer survivors was conducted. The use of GCT was assessed across a continuum (awareness, referral, and use). HBOC expertise was the main predictive factor. Again, higher knowledge and higher self-efficacy were significantly associated with genetic counselling engagement.

Sutton et al. (2020) assessed demand by offering elective genetic counselling to 5110 persons before to sequencing and 2310 people who obtained neutral results. Many participants seemed to have no knowledge of genetic counselling being provided and were unfamiliar with the discipline, according to the researchers. Respondents stated that they did not require counselling prior to sequencing. Counselling was likewise judged unneeded after seeing the neutral results after sequencing. The respondents did not consider that consulting with a genetic counsellor would be worthwhile.

The function of education in genetic counselling has been extensively researched around the world. Bener et al. (2019) investigated knowledge and attitudes concerning premarital screening and genetic counselling in Qatar. The study found that the public's understanding of the genetic counselling program was limited, and sentiments concerning genetic counselling were not

very positive. The researchers opined that educational campaigns at schools and universities are critical for reinforcing program understanding and increasing motivation to comply with it.

Jacobs et al. (2021) studied patients' familiarity with, understanding of, and attitudes of genetic counselling (GC) services in Ethiopia. A student's t-test was used to compare the results of 102 patients to those of North American populations. Thirty percent of respondents said they were familiar with GC, largely from the media or healthcare practitioners. Patients had reasonably good opinions regarding genetic counselling, saying that they would rely on the information supplied by a "genetic counselor and that GC is consistent with their values. When compared to results from North American populations, knowledge of GC exhibited comparable patterns overall.

Van et al. (2016) obtained some genetic family history information from patients in South Africa. Overall, 22 (36.1%) of GPs directed patients to appropriate facilities for evaluation and testing, whereas 32 (52.5%) were aware of genetic testing services. The majority (38/61, or 62.3 per cent) were unaware of the genetic counselling services offered but believed that patients should be counselled before testing. Only approximately half of the participants were aware of the possibility of paternal inheritance or the low rate of hereditary mutations and their penetrance.

Moving to Africa, studies revealed that some Ghanaian university students in Accra have little knowledge about genetic because the services are rare (Appiah et al., 2020). Thirty-two (32) young individuals from a private institution in Ghana were sampled using an exploratory descriptive qualitative design. There were four focus group discussions and twelve in-depth interviews. The study's findings suggested that young adults had an understanding of sickle cell disease (SCD) and, as a result, had favorable attitudes regarding genetic counselling in SCD. They were, however, unaware of any genetic counselling services available in the country.

2.2.3 Illness Belief and Psychological Wellbeing

A study by Sin (2016) among persons living with cardiovascular disease suggested that high psychological well-being played an active role in their treatment and positive outcomes. The researcher found that enhanced psychological wellbeing had the potential to affect persons with cardiovascular disease in three possible ways. This could be through (a) a direct effect on the patient's neurobiological processes; (b) indirect effects through the adoption of healthy behaviors; and (c) the promotion of psychosocial resources needed to buffer the toxic effects of stress on the person.

Sin's (2016) view on the positive role of psychological wellbeing on patients with cardiovascular disease was supported by subsequent studies that explored several variables that explain such relationships (Kubzansky et al., 2018). Kubzansky et al. (2018) reported a complex series of direct and indirect correlations between positive psychological wellbeing and better cardiovascular health through health behaviours, biological function, and psychosocial factors. It was also reported by these researchers that psychological well-being among patients with cardiovascular disease had the likelihood of reducing their levels of stress and anxiety based on social and environmental factors. Again, the effects of psychological wellbeing had the strength to reduce deteriorative processes in persons such as smoking and inflammation. It also had the strength to increase restorative processes such as optimal sleep.

Boccardi and Boccardi (2019) also reported that intervention to reduce depression, anxiety and stress among adults living with genetic disorders through enhanced psychological wellbeing

promotes healthy ageing. The researchers found that stress, anxiety and depression modulate the ageing process especially among adults with genetic disorders. They even found that long term effects of these mental health issues (that is, depression, anxiety and stress) have a role to play in the subsequent development of metabolic disorders and dementia. Recommendations from this study show the need to put in active measures to promote the psychological wellbeing of persons living with genetic disorders to slow down the ageing process.

In a study conducted in Ghana, Nuworza (2013) discovered that the level of religiosity of diabetic patients had no significant relationship with mental health concerns. However, their generalized symptoms of illness (GSI) and particular symptoms, such as degrees of obsessive-compulsive disorder, somatization, anxiety, depression and psychoticism, were significantly and strongly connected with their illness perception. Further research utilizing multiple regression analysis found that the number of general mental health issues was strongly determined by the impression of sickness.

Genetic conditions can permanently affect one's adult life. Most importantly one's beliefs about genetic conditions can adversely or positively affect wellbeing. Most studies on genetic diseases in Ghana focused on adherence/non-adherence to treatment (Amaltinga, 2017), the financial burden these diseases pose on households in Ghana (Tagoe, 2012). Other research showed the low quality of life of adults living with chronic illnesses in Ghana (Tanor et al., 2019). However, little is known about the beliefs they hold about their genetic conditions and how they affect their well-being psychologically.

Tang and Gao (2020) looked into Chinese patients with type 2 diabetes' disease perceptions and associated predictors. The study employed a descriptive, exploratory and correlational design.

Between September 2016 and February 2017, the Revised Illness Perception Questionnaire, Chinese Version, was used to gather data. Patients identified less than five of the fourteen frequent symptoms of type 2 diabetes on average, according to the study. Moreover, dietary behaviours had the greatest mean score of the six causative components, whereas psychological factors had the lowest. The majority of patients had no idea what type 2 diabetes was. They saw it as a chronic and stable condition with no negative affective response that they could manage on their own or with treatment.

2.2.4 Genetic Conditions (Sickle Cell and Diabetes) and Mental health

Diabetes and sickle cell are among the fastest growing conditions that has genetic basis. With the many symptoms and complications and lifelong duration the two conditions, Adults living with these genetic conditions are faced with mental health related issues. Some literatures reviewed on genetic conditions and mental health are discussed below.

Jonassaint et al. (2021) in his study which aimed to determine the disparity in the incidence of mental health disorders between those sickle cell disease black Americans and those and those without any condition /non heritable medical conditions. Sampling from a non-institution led, community of black United States adults, the finding revealed that 38.8% of the sickle cell group reported having at least one mental health ailment, 17.6% indicated that they had a mood disorder, 2-4% said they had an eating disorder, 24.7% said they had an anxiety problem and 11.8% with a childhood disorder which were similar to Black adults with other medical/non heritable conditions. However, Black adult without any medical conditions had lower occurrence of mental health disorders. The study revealed that many unaccounted factors across medical conditions links to mental health disorders.

Using the Becks Depression Inventory fast screen, depression symptoms were identified in a cross-sectional investigation. Jenerette et al. (2005), with Sickle cell disease patients in a sample of 232 African Americans, revealed that there were greater levels of depression (26%) and depressed symptoms (32%) among adults with sickle cell than the entire American population (9.5%). This study highlighted the importance of including mental health screening and care in adults with genetic conditions. However, it is important to explore their perception about their illness as well. This is that which this current study seeks to achieve.

Appiah et al. (2020) explored the proportion of Ghanaian people with sickle cell disease who report good mental health and functioning. A sample of 62 persons receiving care at the Ghana Institute of Clinical Genetics filled out the mental health continuum-short form (MHC SF) to be used in a quantitative cross-sectional research design.

The results showed a high level of positive mental health and functioning with no significant difference between gender. It further revealed that 34% of the participants were functioning on the suboptimal level therefore were at risk of psychopathology. This study emphasises the need for increased mental health care for adults with sickle cell to avoid future psychopathologies. This study did not investigate if there is any form of support or counselling provided to adults with sickle cell and how it promoted positive mental health.

A study in Turkey to explore the level and relationship "that exist among coping strategies, anxiety, socio-demographic and medical characteristics" among 250 type 1 and 2 diabetic patients Tuncay et al.(2008), found that 79% of the study participants experienced anxiety It further revealed that sociodemographic characteristics influenced anxiety in patients with diabetes. The

sample adopted coping strategies such as religion, planning, positive reframing, emotional support, self-distraction and acceptance to help them manage their condition.

The results of additional prevalence studies on diabetes patients' mental health outcomes and the factors that influence them were also examined.

A 12-month prevalence rate of anxiety, mood and alcohol use disorders was estimated by Lin and Korff (2008) among population samples of diabetes individuals. After adjusting for age and gender, he evaluated whether relationships that exists between certain mental problems and diabetes were consistent across national boundaries. The results showed that when age and sex were maintained constant, those with diabetes had a higher risk of developing mood and anxiety disorders than people without diabetes.

Liu et al. (2010) in their study among patients of type-2 diabetes in China, discovered that majority of the patients with "type 2 diabetes experienced at least one form of complication or the other." The study also found that "the patients had both macro vascular and micro vascular difficulties." Age, duration of illness and the city of patients had a significant influence on their level of chronic complications. Furthermore, it was discovered that the patients' glycemic control was influenced by the number of diabetes-related problems.

In relation to sex and body mass index (BMI), Roupa et al. (2009) investigated the occurrence of anxiety and depression symptoms in individuals with Type 2 Diabetes Mellitus. The study used the self-completed questionnaire (HADS) for anxiety and depression level evaluation, therefore the impacts of the respondents' demographic and clinical aspects on their level of anxiety

and depression were explored. According to the findings, women had three times as many cases of anxiety symptoms than males did.

Again, with regards to symptoms of depression, women had a percentage twice of that of men. In addition, When the association between sex, body mass index (BMI) and age and symptoms of depression and anxiety was explored, it was discovered that high BMI favors the incidence of mild to severe symptomatology, with the risk rising with each additional BMI unit.

Roupa et al.'s study sheds light on the fact that "patients' gender can influence their mental health outcomes." Indeed, application of this finding can be useful in the development of gender-related mental health interventions.

Similar study by Sulaiman et al. (2010) testified that there is a clear connection between diabetic problems and mental health. Thus, depressed diabetic patients reported poor self-care, adherence issues, and acute physical symptoms. Results of this research showed when left untreated, it results in noteworthy patient complications. Nevertheless, the study did not allow for causal references because it only used correlation.

Naranjo et al. (2011) in their study through time, major depressive disorder and its associated variables were evaluated among patients with type-2 diabetes. According to the study, patients' experiences of negative affect and a history of depression significantly predicted the development of future depression. Also, in this study, mediational, there are correlations and whether Diabetes Mellitus (DM) patients' elevated levels of anxiety, depression and stress symptoms correlate with those of a group of controls.

Just as other studies among diabetic patients, Bener, et al (2011) explored whether Diabetes Mellitus (DM) patients' elevated levels of anxiety, depression and stress symptoms correlate with those of a group of controls. Findings emanating from their study showed that most of the investigated healthy controls (30.9%) and diabetic cases (33.6%) cases belonged to the 40-49 age range, and substantially more Diabetes Mellitus subjects than healthy controls, reported severe anxiety, severe depression and severe stress. Additionally, the research found some predictive relationships among the study variables such that obesity, duration of diabetes and systolic blood pressure. These were found to be significant predictors for high depression ratings among diabetics. Again, obesity, systolic blood pressure and smoking were the key predictors for high anxiety ratings among diabetic subjects, and finally, diastolic blood pressure, physical activity and systolic blood pressure predicted high scores for stress.

The outcome of the study also showed that in comparison to men, women with diabetes scored higher on stress, anxiety and depression. However, no significant connection was seen between the complications of diabetes and stress scores, anxiety and depression.

Identifying related factors was the goal of a study comparing the prevalence of psychological discomfort and mental illnesses among diabetes and non-diabetic sufferers. Jimenez-Garca et al. (2011) utilized a case-control research and found that diabetics had a greater prevalence of mental illnesses (18.6%) than the control group (16.4%). Additionally, psychological anguish was experienced by 26.9% of diabetics and 18.9% of non-diabetics while younger age, female sex, worse self-rated health, hospital visit in the last 4 weeks, comorbidity and emergency room attendance within the last year were among diabetic variables suffering a mental disorder and psychological distress."

A hospital-clinic based prevalence study was conducted by Shakya et al. (2012) to ascertain the prevalence of psychiatric illnesses in diabetic patients who were undergoing therapy. According to research, of the 200 diabetic patients in the clinic, 136 (68%) had a GHQ-12 score of 2 or higher, i.e. psychiatric cases". Again, it was realized that, 105 (52.5%) had moderate (13-24), 15 (7.5%) had severe (25-36), 9 (4.5%) had no symptomatology and 71 (35.5%) had mild (1-12).

The most highly rated item on the GHQ-12 was "felt that you couldn't solve your issues" (39.0%), followed by "feeling always under strain" (37.5%). In their outcome-based conclusion, the researchers suggested that "psychiatric problem is common among patients with diabetes." From a critical analysis, their study relied extensively on general health indicators in assessing the mental health of patients with diabetes.

Similar to the above study, Guruprasad et al. (2012) explored "the association of socio-medical factors, demographic and depression in type 2 diabetes patients using epidemiological and cross-sectional study designs." The researchers admit that psychiatric and physical examinations were performed on diabetic patients who gave their consent while attending to Medical OPD.

Further, by use of Beck Depression Inventory, depression symptoms were screened for. Findings from their study indicated that Females and those who are overweight, and diabetic were found to have depression-like symptoms, as were one-fourth of the tested diabetes patients. Once more, people with extensive histories of diabetes and taking multiple antidiabetic drugs were much more likely to experience depression.

The study also revealed that ischemic heart disease was a concomitant medical condition that affected 25.9% of diabetic patients. The main focus on mental health was depression and this gives room for other mental health problems to be explored.

Diabetes patients "have considerable levels of anxiety and depression that warrants them for clinical diagnosis," according to Jadoon, et al. (2012) in their prevalence study. It was found that the diabetes patients' characteristics such as sex, age, marital status, employment status, exercise, income, level of glycemic control had a considerable impact on the heights of sadness and anxiety. These results add more understanding to "the diabetes- mental health link." It is however noteworthy to admit that the researchers failed to consider the processes by which patients come to interpret their illness. This is based on the fact that, illness perception has been reported to actually affect psychological distress levels and mental health problems.

The risk factors for depression in people with type 2 diabetes were explored by Rahimian-Boogar and Mohajeri-Tehrani in 2012. By means of cross-sectional study of a descriptive kind. Between 2010 and 2011, 254 type 2 diabetic patients were chosen through convenience sampling from Tehran University of Medical Sciences' diabetes outpatient clinics and the Iranian Diabetes Society. Once more, significant differences between the diabetic patients with and without depression were observed in decreased social support, increased pain and functional disability, longer duration of diabetes, decreased performance for diabetes self-care, complications from diabetes, requiring insulin therapy, BMI > 25 kg/m2, HbA1c > 9% and major life events.

Nevertheless, the researchers observed "no significant difference in sex, age and socio-economic status between the two groups. One thing to note is that, the sampled group was not representative considering how varied diabetes mellitus in the study population is.

A study by Kugbey et al. (2015) examined the relationship between illness Perception, type 2 diabetes and Psychological Distress among patients with type 2 diabetes in Accra, Ghana. The study further explored whether this association is influenced by demographic features such as age, level of education and sex. Moreover, "a sample of 139 persons living with type 2 diabetes were employed from Accra in Ghana, precisely the Teaching Hospital (Korle-Bu). Demographic questionnaire, the Brief Illness Perception Questionnaire and the Brief Symptom Inventory were administered to the participants." Pearson product moment correlation and Hierarchical Multiple regression analyses helped us to come to know that "illness perception has a significant positive connection with the amount of psychological trauma among patients with type 2 diabetes.

This shows that the demographic factors of sex, educational attainment and age have no appreciable impact on the relationship between illness perception and psychological distress in people with type 2 diabetes. According to the study, patients' negative thought patterns about their condition should be changed as a focus of psychological interventions.

Similar quantitative research in the Cape Coast Metropolis in the central region of Ghana was conducted to find the relationship between mental health and religiosity, and mental health and illness perception of patients with diabetes. With a descriptive survey design, "a sample of 103 diabetic patients were selected." The study used the Santa Clara Strength of Religious Faith Questionnaire by (Plante & Boccaccini, 1997), Brief Symptom Inventory Derogatis (1993) and Brief illness Perception Questionnaire (Broadbent, Petrie, Main, & Weinman, 2006), Results showed that the level of religiosity but not illness perception, predicted mental health problems. Again, findings revealed that female diabetic patients had a better mental health than male (AMARTEY, 2019).

A more recent study by de Alba et al, (2020) which aimed at studying mental health comorbidity prevalence in patients with type 2 diabetes and its associated type 2 diabetes outcomes in Spain EpiChron Cohort. Using an observational study where age, sex, and comorbidities were controlled, logistical regression models was used to analyse the prospect of 4-year mortatlity,1year all-cause hospitality, and type 2 diabetes hospitalization. Out of 63,365 adults in the cohort who had type 2 diabetes, 19% of them had concurrent mental health comorbidity. It also reported that there were more women in the group with at least one mental health than the group with no mental health comorbidities. Findings revealed a higher mortality risk in type 2 diabetes patients with comorbid mental health problems. Also, comorbid mental health problems increased hospitalization for patients with type 2 diabetes.

In conclusion, there have been several studies on diabetes and sickle cell and the mental health problems patients with such genetic conditions face. This study seeks to explore both conditions as genetic conditions and adult's perception about the genetic illness which contributes to mental health issues. Secondly, this current study seeks to gain a deeper understanding of adults with genetic conditions' perception about genetic counselling.

2.3 Statement of Hypotheses

1. There would be a significant negative correlation between illness beliefs and mental health-related problems of adults with a genetic disease
2. There would be a significant positive correlation between illness beliefs and the psychological wellbeing of adults with a genetic disease
3. Female adults with a genetic disease would have higher mental health-related problems compared to males.

4. There would be education level differences in mental health-related problems.
5. Illness Belief, Stress, Anxiety and Depression will predict psychological wellbeing.
6. Illness beliefs will predict mental health-related problems of adults with genetic disease.

   a.Emotional representations dimension of illness beliefs would have the highest variance on mental health-related problems of adults with genetic disease.

   b. Cognitive illness representations (Illness concern) dimension of illness beliefs will have the highest variance on depression

   c. Cognitive illness representations (Illness concern) dimension of illness beliefs would have the highest variance on anxiety.

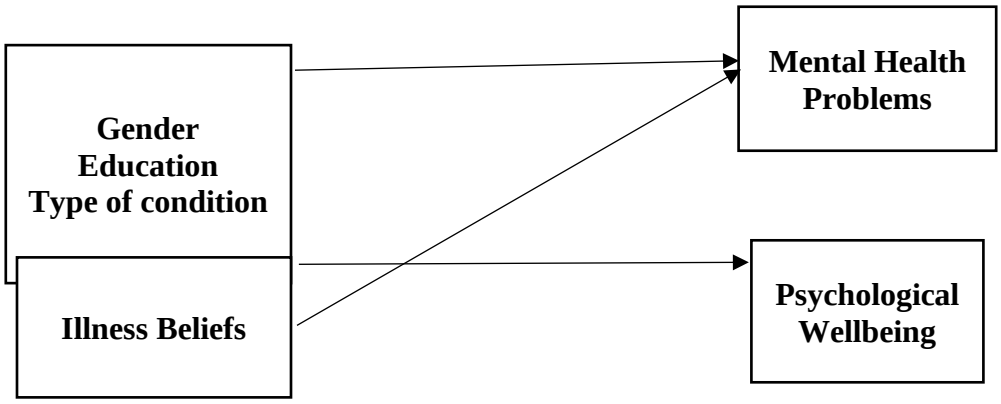
7. The mental health problems of participants will differ based on the type of genetic condition.

2.4 Research Questions

1. What does genetic counselling mean to adults with a genetic disease?
2. How do people with genetic conditions feel about undergoing genetic counselling?

2.5 Conceptual Model

Figure 1: Hypothesized Model



The hypothesized model predicts that socio-demographic factors such as age, gender, education, and type of genetic condition will influence mental health problems. The model also believes that illness beliefs will predict mental health problems and psychological wellbeing.

2.6 Operational definition of terms

Genetic counselling: Genetic counselling refers to the process in which a trained professional provides information to a person on the risk of acquiring an inherited genetic disorder and its health implications.

Mental Health Outcomes: These include the patients' reported experience of Stress, depression and anxiety which occurred as a result of the genetic condition they are living with.

Illness beliefs: This refers to the understanding given to their genetic conditions such as diabetes mellitus and sickle cell as being nonthreatening or threatening. Illness perceptions and illness beliefs are use interchangeable to mean the same definitions provided here.

Illness Perception Components: They are duration, perceptions of Consequences, Treatment Control, Personal Control, Concern, Emotional Response and Perceived Causes Symptoms and Coherence,

Psychological wellbeing: This study focuses on the following aspect of psychological wellbeing; the establishment of quality ties to others; self-acceptance; the ability to manage complex environments to suit personal needs and values; a sense of autonomy in thought and action; continued growth and development as a person; a sense of purpose in life and the pursuit of meaningful goals. It is introduced in this study in order not to overlook such areas of the life of persons living with sickle cell and diabetes.

CHAPTER THREE

METHODS

3.0 Introduction

The protocols observed during data collection, the equipment utilized, how the scoring was done, and the results from hypotheses testing are summarized in this chapter. It also includes a summary of the research concept, survey type, questionnaires and screening procedures, participation and omission conditions, and ethical guidelines for gathering data from participants. The method section has the information for quantitative (Study I) and qualitative (Study II). The research design describes how the study will be carried out. It is concerned with the structure of the research challenge as well as the exploration strategy (Creswell et al., 2003).

A concurrent triangulation mixed-method approach was used in the research. It is made up of the qualitative methodology, which strives to comprehend a complicated reality and the meaning of acts in a given context, and the quantitative technique, which seeks to gather accurate and reliable measurements that allow statistical analysis. This mixed-method approach involves gathering both qualitative and quantitative data at the same period. In addition, a mixed-method approach can be used to handle potentially complicated psychological concerns in a variety of socio-cultural settings (Braun & Clark 2013). The aim of the concurrent mixed method approach is to properly define relationships between illness beliefs and mental health using both qualitative and qualitative study (Creswell,2013). Study I(quantitative) was a quantitative study that used survey method to collect information from participants on their perceptions of sickness, and their mental health. On the other hand study II(qualitative study) used semi-structured interviews to gain in-depth information on the illness beliefs and mental health as well as explore respondents perception of genetic counselling. This mixed method design was chosen to help each study

validate the other with its results (Creswell,2013). In study II (qualitative), participants were interviewed one on one to learn about their experiences, which the quantitative study was unable to capture. Because of its usefulness in addressing possibly inexplicable psychological disorders in a variety of socio-cultural contexts, a mixed-method approach was adopted (Creswell, 2013).

3.1 Study I (Quantitative Phase)

3.1.1 Research Design

For quantitative data collection, a survey was employed to study the illness beliefs and mental health of adults with genetic diseases (diabetes and sickle cell). This strategy entailed handing out questionnaires or online questionnaires (whichever is preferred to participants). This survey technique was chosen because it encourages the collecting of vast amounts of data in a short amount of time. The survey questionnaire screened for illness beliefs, mental health related problems and psychological wellbeing using the appropriate instruments.

3.1.2 Research Setting

The research took place in selected hospitals in the metropolis of Accra within the Greater Accra region. The data was obtained at three hospitals: The Ghana Institute of Clinical Genetics, Achimota hospital, and the Greater Accra Regional Hospital. According to a regional-level analytical survey conducted by the Ghana Statistical Service, the region has a total population of 4,943,075 people, with 2,430,858 men and 2,512,217 women (GSS, 2019). These areas were chosen within the Greater Accra Region because it is a national and international capital with a cosmopolitan environment that attracts people from diverse racial and socio-demographic

backgrounds. The focal areas were regarded as very good settings, along with their large adult demographics, to explore their beliefs about genetic conditions they are diagnosed of and how it shapes their mental health.

Inclusion Criteria

Adults 18 years of age and older who are diagnosed of diabetes and sickle cell, not critically ill and are willing to participate in the research were eligible for the study. Additionally, participants (diagnosed with type 2 diabetes) gave a verbal confirmation that they have a family history of the condition (suggesting that their condition was inherited) to have them participate in the study.

Exclusion Criteria

Patients who were under 18years of age, critically ill and those who confirmed that the condition was not as a result of inherited genes (diabetes) were excluded from the study.

3.1.3 Population

The study was centered on the population of Adults aged 18years and above who have been diagnosed with genetic condition specifically diabetes (type 1 and 2) and sickle cell. Research shows that genetic diseases that mostly occur with the mutation of multiple genes interacting with some environmental factors begin at early and late adulthood. (WHO, 2012) which justifies the reason for the age group selected. The population of adults diagnosed with genetic diseases at the Achimota hospital, and Ridge hospital were studied. These study sites were suitable for the study because they care for patients with different socioeconomic levels, coming from all part of the Accra and even beyond the Capital of Ghana. These sites were helpful in terms of gaining a more representative sample of the population being studied.

3.1.4 Sample/Sampling Techniques

The nested concurrent sampling design was used. This is one of the sampling methods for mixed method studies which allows for a small group of people selected from one stage of the study (i.e. study I) to participate in the other part study II (Onwuegbuezie & Collins,2007). This sampling design helped corroborate findings in both study as the purpose of mixed method study seeks to achieve. The study used a sample size of 330 for the quantitative study out of 400 people approached. According to Field (2009), to be able to obtain a medium effect size and a high statistical power as well as conduct multiple regression, there is the need for a bigger sample size. This contributed to the sample size selected for the quantitative study (study I). The number of persons who willingly opted to participate in the qualitative (study II) were 20(out of the 330) who also participated in the survey for study I

3.1.5 Quantitative Sample (Study I)

To collect data for the quantitative aspect of the study, convenience sampling technique was used. This was accomplished through the researcher's decision to take a sample of the population that was close at hand or readily available for the study. Additionally, the study sites recorded fewer number of patients on each clinic day therefore convenient sampling was helpful in getting the target sample of the population being studied. The sample size parameters were determined using the Tabachnick and Fidell's (2007) method: N>50 + 8k (where k = number of Independent variables, N=sample size). In this current study, the independent variables are illness beliefs, stress, anxiety, depression and psychological wellbeing. This means that the sample size

for this study should not be less than 90 since N> 50+8(5)= 90. Therefore, the sample size 330 was used. A total of about 400 patients were approached but had only 340 questionnaires answered.

3.1.6 Quantitative Measure

Standard scales were obtained to form a survey for the study. Selected questionnaires were obtained from studies who have looked at similar areas to this research and the scales were assessed for appropriateness. This section explains the scales used for quantitative study. This study assessed for the following demographic information: age, sex, marital status, religion, education, condition diagnosed and duration of diagnosis in the section A. The section B of the quantitative measure explored the perception of participants illness with the Brief illness perception questionnaire. To examine the state of their mental health, the Depression, Anxiety and stress scale was used. Lastly, the Ryff's psychological wellbeing scale was employed to assess some areas of their wellbeing as explained below.

3.1.7 Quantitative instruments

Brief Illness Perception Questionnaire (Broadbent et al, 2006)

Brief IPQ assesses the emotional and cognitive representation of illness including one's perceptions of illness consequences, duration, personal control, treatment control, symptoms, coherence, concern, emotional response, and causes. The scale uses a single item approach to assess a person's perception of their illness. It is a nine items scale, of which each item is rate on a 11 point-Likert Scale from 0(not threatening) to 10(highly threatening). With the exception of item 9, an open-ended question that measures the causal factor. Evidence shows the Brief IPQ to be a valid and reliable measure of illness perceptions in a variety of illness groups with a Cronbach's alpha is r=.70 (Broadbent et al, 2006). For this current study, the scale had a

Cronbach's alpha of 78. Examples of items on this scale include 'How much does your illness affect your life'(consequence), 'How much control do feel you have over your illness'(Personal control). According to Broadbent et al. (2006) items 3,4 and 7 are scored in the reverse and added to items 1,2,5,6 and 8 to obtain a total illness perception score. The higher the score the more threatening interpretation of illness

Depression Anxiety Stress Scale (DASS) (Lovibond & Lovibond,1995).

Mental Health of adults with Genetic disease was measured using the Depression Anxiety Stress Scale (DASS).The Depression, Anxiety and Stress Scale - 21 Items (DASS-21) is a set of three self-report scales planned to measure the emotional states of depression(items 3,5,10,13,16,17 and 21), anxiety(items 2,4,7,9,15,19 and 20) and stress(items 1,6,8,11,12,14,18). The depression scale assesses hopelessness, devaluation of life, lack of interest, anhedonia etc. The anxiety scale assesses automatic arousal, skeletal muscle effects and subjective experience of anxious affect. The stress scale measures difficulty relaxing, nervous arousal, being easily upset and impatient. Participants were asked to respond to a 4-point Likert scale on the extent to which they have experienced each state over the past week. Examples of items are 'I couldn't seem to experience any positive feeling at all' (item for Depression), 'I found it difficult to relax' (item for stress). Responses range from 0,1,2,3 which mean never, sometimes often and almost always respectively. The lowest possible score for this scale is 8 and the highest possible score is 35 since scores on DASS 21 are doubled. The subscales had Cronbach 's alpha of .80 for stress,.74 for anxiety and .76 for Depression.

Ryff's Psychological Wellbeing Scale (Ryff, 1989)

Psychological Wellbeing would be measured using the 18-item version of Ryff's Psychological Wellbeing Scale (Ryff, 1989). This scale assesses autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self-acceptance. Items 1, 2, 3, 8, 9, 11, 12, 13, 17 and 18 are scored in the reverse. Higher scores for each category reflect a higher control over that area of life whiles lower scores shows participant's struggles in that aspect of wellbeing. Higher scores reflect higher psychological wellbeing. Examples of items on the scale include, "I like most part of my personality'', ''in many ways I feel disappointed about my achievements in life''. Participants were asked to choose on a 7-point Likert scale with responses ranging from strongly agree to strongly disagree. Highest possible score on the scale is 90 indicating high levels of psychological wellbeing while lowest possible score is 18 indicating low levels of psychological wellbeing. The Cronbach's alpha for this scale in this current study is .77.

3.1.8 Procedures for Data Collection

Before conducting the main study, the data collection procedures included conducting a pilot study to evaluate the questionnaire and interview guide. The study began with obtaining ethical clearance from the University of Ghana's Ethics Committee for Humanities (ECH) (refer to appendix 4). The approval from ECH was taken to the Ghana Health Service for permission to conduct the study in the various hospitals. Additionally, a separate research approval and permission was sought from Achimota hospital, Ridge hospital and the Institute of Clinical genetics which enabled the research to be conducted at their sickle cell day clinic at Korle-bu.

Participants were given a detailed consent form that explained the study. Participants were also made aware that they could choose whether or not to participate in the study. To ensure confidentiality, the questionnaire was designed in such a way that no participant was implicated. Participants were given the option to answer the questionnaire either on goggle form or hard copy. However, all the participants opted to answer the questions using paper and pen. The questionnaire took about 10-15 minutes to answer for those who answered on their own. Some participants who needed assistance in terms of reading or clarifications took 20 to 30 minutes to complete the questionnaires. Data collection was completed after four weeks for once a week at each study site.

3.1.9 Data Analysis

Participants were given 340 questionnaires, however only 330(97% of the sample) responses were eligible for analysis. To obtain total scores for each scale, the scores from the various scales were added. All analyses in this study were carried out using the IBM Statistical Package for Social Science (SPSS) version 22.0. Descriptive statistics on demographic characteristics were computed. The data were checked for normality using skewness indices ranging from -2 to +2 and kurtosis indices ranging from -3 to +3, as defined by (Das & Imon, 2016). It was intended that scale items that violated the normalcy assumptions were excluded from the analysis, however, this was not necessary. To investigate the construct dimensionality of the study variables, exploratory factor analyses (EFA) were performed on each variable. EFAs were done on each scale independently because the bulk of the study variables had a multidimensional factor structure. The principal component analysis (PCA) method was utilized to extract the factors. The Kaiser—Meyer–Olkin (KMO; Kaiser, 1974) sampling adequacy assessment and Barlett's Test of Sphericity were used to analyze data factorability (Bartlett, 1954). The number of components to keep was determined using Cattell's scree test and Kaiser's criterion (>.40; Field,

2009) was used to calculate the minimum factor loading for item retention. Cronbach's alpha was utilized after the EFAs to calculate internal consistency reliability for each subscale. To determine internal consistency for each of the multidimensional scales used in this study, Stratified Alpha Reliabilities (Moussa, 2016) were calculated. Cronbach's alpha coefficients and stratified coefficients are shown in Table 2 in the results section.

Seven hypotheses were tested in the study using a set of statistical tests depending on how each was stated. The next section in this chapter presents the hypotheses and the statistical results for each hypothesis. Hypotheses 1 and 2 were tested using bivariate correlation, 3, 4 and 7 were tested using One-way Multivariate Analysis of Variance (MANOVA). Hypothesis 5 and 6 were tested using standard multiple regression analysis. Assumptions of linearity, normality, multicollinearity, and singularity were checked before analysis and there was no significant violation.

3.1.10 The Pilot Study

The pilot study was carried out after receiving ethical approval. Basis for the pilot test was to determine the scales' psychometric qualities as well as the interview guide's capacity to elicit the appropriate replies. Table 1 below provides the result of pilot testing for the quantitative questionnaires

Table 1: Internal Consistency (Cronbach's Alpha) for Scales Used

Scale	α	No. of Items
Illness Belief	.83	11
Stress	.81	7
Anxiety	.79	7
Depression	.89	7
Psychological wellbeing	.84	18

It is informative to mention that the pilot test involved a total of ten patients. Participants were invited to complete the questionnaires and provide comments on any issues they encountered while doing so. From the results, no changes in the structure or content of the scales were necessary.

3.2 Study II: Qualitative Phase

3.2.1 Research design

The qualitative portion of the study used a phenomenological approach, which focuses on subjective beliefs about participants' genetic conditions diagnosed and their knowledge and perception of genetic counselling. This strategy was chosen to provide an explanation for the difficulties raised in the quantitative research. To collect data, the researcher conducted semi-structured, in-depth person interviews. The purpose of the interviews was to gain a deeper understanding of some response's participant gave in the study one as well as explore their perception of genetic counselling. The study's ontological and epistemological setting was the fundamental reason for favoring individual interviews over other methods of obtaining qualitative data, such as focus group discussion. Individual interviews, rather than other observational data

collection methods, are the only way to gain richer and better information from this event.

3.2.2 Research setting

This study used patients with diabetes and sickle cell attending the Greater Accra regional Hospital (Ridge Hospital), Achimota Hospital and the Ghana Institute of Clinical genetics, Korle-Bu. The Ridge and Achimota hospital were the main site for collecting data from patients with diabetes since there was no specific clinic for sickle cell patients in the above hospitals so very few patients with sickle cell were recorded in these two sites. The Ghana Institute of Clinical Genetics was the main unit for most participants with sickle cell. The unit cares for about 20- 30 sickle cell patient every day of the week. These study sites were chosen because they care for people from all part of the country and also serve as a major health care facility in the Capital city Accra. This site caters for sickle cell patients who are 16years and above. Hence the site was chosen to be able to reach the adult population who had sickle cell disease.

3.2.3 Population and Sampling

The study was centered on the population of Adults aged 18years and above with genetic condition specifically sickle cell who seeks medical care at the Ghana Institute of Clinical genetics, Korle-Bu.

Purposive sampling was utilized for the qualitative study because the researcher needed subjects with specified demographics. Purposive sampling is when a researcher selects a responder based on the characteristics they possess (Etikan et al., 2016). Selection of participants for qualitative data was based the respondent's ability to speak fluently preferably in English. Additionally, participants with type two diabetes were selected upon verbally confirming that their

condition was inherited. Twenty participants confirmed they will participate in qualitative study, However, only 15 out of the 20 were available to participate. According to Mason (2010), the saturation point in qualitative research is when participants stops coming out with fresh information. Saturation was attained after 12 participants have been interviewed. The qualitative sample consist of 5 males and 7 females. It also had 4 respondents with sickle cell,2 with diabetes type 1 and 6 with diabetes type 2. Participants' ages ranged from 20 years to 61 years.

3.2.4 Qualitative measure and instrument.

This study gathered information on demographic characteristics of participants such as age, sex, marital status, religion, education, condition diagnosed and duration of diagnosis in the first part of the interview guide.

A semi-structured interview guide was used to collect qualitative data. The interview guide was developed based on the objectives of the topic being researched. The semi-structured interview guide consisted of open-ended questions with sub-questions to help probe further when needed. Examples of questions used in the interview guide are; "Tell me what comes to mind when you hear genetic counselling", What do you think will be the benefits of genetic counselling". Other handy items used included a pen, a book (for taking field notes), and a recorder for data collection. Many researchers employ note-taking to supplement audio-recorded interactions (Sutton & Austin, 2015). The importance of field notes in this study was to critically examine and take notes on behaviour, nonverbal clues, and ambient variables that would not have been noted by audio-recording.

3.2.5 Data collection Procedure for Study II

Participants were briefed about the study and its purpose and consent was read out and clarified to them. Participants were allowed the time to give their consent and signature to the form. Confidentially was highly assured by avoiding any form of identification on the questionnaires and assuring them that their responses are only for academic purposes. As much as possible the research ensured participants are not harmed in any way. The participants were informed of their right to withdraw from the study at any point. As a result of the corona virus infection, researcher and assistants strictly observe all the COVID -19 protocols in the process of collecting data to ensure the safety of participants. Interviews were recorded at a quiet but open place within the hospitals to avoid distractions from other activities ongoing. An interview took about 45 minutes to an hour to be completed. Qualitative data collection began and ended within the same period as quantitative data was collected.

3.2.6 Qualitative Data Analysis for (study II)

Qualitative data was analysed using Braun and Clarke (2006)'s thematic analysis. This is the type of analysis that finds themes in data by analysing meanings of words and sentences. Data recorded were transcribed into text, read and understood, codes generated, and sort into themes (Braun and Clarke.,2006). Coding was deductive as some pre-existing themes in the thesis topic as well as the research questions were highly considered. Two research assistants who had good knowledge in transcribing and coding aided with the study II analysis. The researcher also went through all the qualitative data, coded and analysed them. Again, three of the transcribed data were recoded by another person to check for any differences in themes generated by the researcher.

3.2.7 Pilot Study for Qualitative Phase.

Four interviews were conducted, recorded, transcribed, coded and lastly themes generated. This pilot study helped the researcher to check if there is need for any corrections to be done. The pilot study also helped the researcher to check if the semi structured interview guide was eliciting exactly what it seeks to measure. Results of the pilot study revealed that the semi structured interview guide measured exactly what the research seeks to measure. However, the order of the questions was change to make it coherent.

3.2.8Trustworthiness of Qualitative study results.

To ensure trust and validity in this study. The following standards were adhered to. Credibility was ensured by recruiting participants who willingly opted to participate in the research. The interviews were audio recorded with the consent of the participants. The audios were transcribed and information were validated by participant again to ensure a true representation of their ideas, experiences and opinions. The data was coded and developed into themes relevant to the research questions for study II. Again, three of the transcribed data were re coded by a third person to check for any differences in codes generated by the researcher. To enable replication of this study, details of the research design are clearly reported which will address the issue if reliability. This procedure for trustworthiness was ensured using standards proposed by Shenton (2004).

CHAPTER FOUR

RESULTS

4.0 Introduction

This chapter presents the quantitative (study I) and qualitative (study II) findings. The quantitative findings are addressed first, then the qualitative findings. For Study I, it offers an initial analysis of data and descriptive statistics. Because the methodologies used in the two investigations were so diverse, separate analyses were required. The findings are shown below.

4.1 Results of Quantitative Study (Study I)

4.1.1 Descriptive Statistics, Normality and Reliability of Variables

Table 4. 1: Demographic Characteristics of participants for quantitative study.(N=327)

Variable	Category	Frequency	Percent	M±SD
Age	Young Adult(below 35)	126	38.7	44.9(18.3)
	MiddleAgedAdult(36-59)	109	33.4	
	Older Adult(60 -75)	91	27.9	
Gender	Male	121	37.0	
	Female	206	63.0	
Education	Primary	64	19.6	
	Secondary	124	38.0	
	Tertiary	134	42.3	
Religion	Christianity	292	89.3	
	Islam	31	9.5	

	Traditional	4	1.2
Marriage	Single	144	44.0
	Married	128	39.1
	Divorced	20	6.1
	Widowed	34	10.4
Genetic	Diabetes Type 1	41	12.5
Condition	Diabetes type2	129	39.4
	Sickle Cell	157	48.0

As shown in Table 4.1 in terms of gender distribution, females constituted 63% of the sample whiles males constituted 37%. In terms of education, the majority of them fall in the category of tertiary (42.3%), closely followed by secondary (38.0%) and then primary and below (19.6).

Table 4.2: Summary of Means, SD, Reliability, Skewness and Kurtosis of Variables

Variables	Mean	Std. Deviation	α	Skewness	Kurtosis
Illness Belief	37.6055	11.75458	.78	-.338	-.394
Stress	5.0390	4.21342	.80	.943	.405
Anxiety	4.1054	3.63981	.74	1.084	.637
Depression	4.1536	3.86506	.76	1.212	1.188
Psychological Wellbeing	98.8914	12.17199	.77	-.606	.258

Table 4. 3: Descriptive Statistics and Bivariate Correlations between the Study Variables (N = 330)

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Age[a]	-														
2. Gender	.15**	-													
3. Education	-.34**	-.17**	-												
4. Genetic[b] Condition	-.62**	-.12*	.294**	-											
5. Illness Belief	-.06	.03	-.15**	.01	-										
6. Stress	-.10	.01	-.03	.11	.39**	-									
7. Anxiety	-.29**	.02	.01	.21**	.35**	.68**	-								
8. Depression	-.22**	.04	-.03	.22**	.40**	.61**	.64**	-							
9. Autonomy	.17**	.10	-.09	-.07	-.09	-.14*	-.15*	-.10	-						
10. Mastery	.21**	-.01	-.02	-.15**	-.29**	-.24**	-.29**	-.39**	.21**	-					
11. Personal Growth	-.01	-.01	-.01	.03	-.08	-.19**	-.24**	-.25**	.29**	.19**	-				
12. Positive relations	.29**	.09	-.17**	-.24**	-.17**	-.20**	-.29**	-.23**	.24**	.17**	.23**				
13. Purpose in life	-.02	-.02	.04	.03	-.03	-.18**	-.12*	-.10	.03	.034	.15*	.08	-		

14. Self-Acceptance	.15**	.05	.01	-.01	-.25**	-.25**	-.22**	-.32**	.24**	.39**	.18**	.27**	.13*	-
15. Psychological Wellbeing	.24**	.05	-.08	-.11	-.24**	-.35**	-.36**	-.38**	.55**	.56**	.55**	.61**	.42**	.66**	-

Correlation is significant at the 0.01 level (2-tailed).**

Correlation is significant at the 0.05 level (2-tailed).*

[a]Male=0, Female=1.

[b]Genetic condition= Diabetes type 1=1,Diabetes type 2=2,Sickle cell=3

Education=primary=1,secondary=2,Tertiary=3.

Table 4. 4: Correlation among Illness Belief subscale and Mental Health problems

Variables	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.
1. Consequences											
2. Timeline	.242**										
3. Identity	.423**	.130*									
4. Concern	.335**	.132*	.212**								
5. Emotions	.492**	.285**	.409**	.405**							
6. Treatment	-.086	-.026	-.112*	-.250**	-.046						
7. Coherence	.137**	-.102	.046	-.074	.073	.247**					
8. Personal	-.184**	-.020	-.039	-.078	.007	.377**	.036				
9. Stress	.191**	.078	.302**	.171**	.413**	.049	.117	.070			
10. Anxiety	.174**	.150*	.231**	.149*	.420**	.009	-.062	.144**	.679**		
11. Depression	.286**	.117	.240**	.170**	.485**	-.002	.005	.111	.611**	.643**	

Correlation is significant at the 0.01 level (2-tailed).**

Correlation is significant at the 0.05 level (2-tailed).*

4.1.2 Hypotheses Testing

Seven hypotheses were tested in the study using a set of statistical tests depending on how each was stated. This section presents the hypotheses and the statistical results for each hypothesis. Hypotheses 1 and 2 were tested using bivariate correlation, 3, 4 and 7 were tested using One-way Multivariate Analysis of Variance (MANOVA). Hypothesis 5 and 6 were tested using standard multiple regression analysis. Assumptions of linearity, normality, multicollinearity, and singularity were checked before analysis and there was no significant violation.

Hypothesis One (1): There would be a significant positive correlation between illness beliefs and mental health problems (Depression, Stress and Anxiety) among adults with genetic diseases.

The Pearson product-moment correlation coefficient was used to establish the association between illness beliefs mental health problems as measured by the DAS among individuals with genetic diseases. Preliminary investigations were carried out to check that the assumptions of normality, linearity, and homoscedasticity were not violated. For illness belief and stress, there was a substantial, positive association between the two measures, with poor illness beliefs linked with high levels of stress (r = .39, n = 263, p.01). For illness belief and anxiety, there was a significant, positive association between both measures, with poor illness beliefs linked with high levels of stress (r = .35, n = 263, p.01). For illness belief and depression, there was a substantial, positive association between both measures, with poor illness beliefs linked with high levels of depression (r = .40, n = 263, *p*=.01).

As a result, at the .01 level of significance, hypothesis one, which claimed that there will be a significant positive relationship between illness beliefs and mental health problems, was supported. Refer to table 4.3 above for this hypothesis.

Hypothesis Two (2): There would be a significant negative correlation between illness beliefs and psychological wellbeing among adults with a genetic disease.

The Pearson product-moment correlation coefficient was used to evaluate the association between illness beliefs and psychological wellbeing as measured by the Ryffs psychological wellbeing scale among individuals with genetic diseases. Preliminary investigations were carried out to check that the assumptions of normality, linearity, and homoscedasticity were not violated. The analysis revealed a significant, negative association between illness beliefs and psychological wellbeing with an increase in negative illness beliefs leading to lower psychological wellbeing (r = -.24, n = 240, *p*=.01). See table 4.3 above.

Hypothesis Three (3): Female adults with a genetic disease would have higher mental health-related problems compared to males.

Table 4. 5: Summary of MANOVA results for gender differences in mental health measures

Variable	Gender					
	Male	Female				
	Mean ± SD	Mean ± SD	*df*	*F*	*p*	η^2
Stress	5.09± 4.10	4.95±4.39	1,260	.061	.806	.000
Anxiety	4.0± 3.56	4.05±3.82		.013	.908	.000

Depression	3.88± 4.06	4.11±3.76	.213	.645	.001

To investigate gender differences in mental health problems, a one-way between-groups multivariate analysis of variance was done. These variables are conceptually related and as suggested by Pallant (2011), were eligible for MANOVA. Three dependent variables were used: Measures of Stress, Anxiety and Depression which make up the DAS 21. The independent variable was gender. Tests to determine the normality, homogeneity of variance, multicollinearity, the presence of outliers and other assumptions were performed with no serious violations observed. Difference between men and women were not statistically significant on the combined dependent variables**,** F(1, 261) = .22, p >.05; Wilks' Lambda = .997; partial eta squared = .003. Therefore, the hypothesis that there would be gender differences in mental health problems was not supported by the data.

Hypothesis Four (4): Educational level differences will influence mental health-related problems

Table 4. 6: Summary of MANOVA results for educational level differences in mental health measures

Variable	Educational Level						
	Primary Mean ±SD	Secondary Mean±SD	Tertiary Mean±SD	*df*	*F*	*p*	η^2
Stress	5.63(4.78)	4.72(4.32)	4.97(3.96)	2, 259	.802	.449	.006
Anxiety	4.02(3.80)	3.91(3.82)	4.16(3.63)		.113	.893	.001
Depression	4.16(3.81)	4.17 (3.79)	3.81(3.98)		.269	.765	.002

NOTE. SD = Standard deviation; p<0.05

To investigate educational differences in mental health problems, a one-way between-groups multivariate analysis of variance was done. These variables are conceptually related and as suggested by Pallant (2011), were eligible for MANOVA. Three dependent variables were used: Measures of Stress, Anxiety and Depression which make up the DAS 21. The independent variable was educational level. Tests to determine the normality, homogeneity of variance, multicollinearity, the presence of outliers and other assumptions were performed with no serious violations observed. Difference between levels of education were NOT statistically significant on the combined dependent variables,f(2, 260) = .834, p >.05; Wilks' Lambda = .981; partial eta squared = .010. Therefore, the hypothesis that there would be educational level differences on mental health problems was not supported by the data.

Hypothesis Five (5): Illness Belief, Stress, Anxiety and Depression will predict psychological wellbeing

Table 4. 7: Summary of Hierarchical regression

	B	Std. Error	Beta	T	Sig.
Constant	107.527	2.419		44.457	.000
Illness Belief	-.068	.068	-.065	-.993	.322
Stress	-.309	.247	-.107	-1.250	.212
Anxiety	-.458	.293	-.137	-1.563	.119
Depression	-.638	.260	-.203	-2.450	.015

The capacity of four measures (illness belief, stress, anxiety and depression) to predict psychological wellbeing was done using a standard multiple regression. Preliminary analyses were

carried out to confirm that normality, linearity, multicollinearity and homoscedasticity assumptions are not violated.

Table 4. 8 : Summary of standard regression (DV=Stress

Model	B	Std. Error	*β*	T	P
(Constant)	1.036	.893		1.160	.247
Consequences	-.090	.091	-.068	-.985	.326
Timeline	-.028	.062	-.027	-.455	.650
Identity	.263	.090	.184	2.910	.004
Concern	.048	.090	.034	.537	.592
Emotions	.423	.082	.362	5.169	.000
Treatment	.086	.103	.053	.840	.402
Coherence	.124	.094	.077	1.318	.189
Personal	.059	.087	.041	.672	.502

After entry of the 4 variables, the total variance explained by the model as a whole was 16%, F (4, 239) = 12.89, $p < .001$.

In the model, only depression (*beta* = -.20, $p < .05$) was the variable that significantly predicted psychological wellbeing. The other variables illness belief (beta=-.065, p>.05), anxiety (*beta* = –.137, $p>.05$) and stress (*beta* = -.107, $p >.05$) were not statistically significant.

Hypothesis Six *(6)*:
Illness beliefs will predict mental health-related problems of adults with genetic disease.

a. **Emotion dimension of illness beliefs would have the highest variance on stress.**

Table 4. 8: Summary of standard regression (DV= Stress)

To test this hypothesis, a standard multiple regression was used. Preliminary investigations were

performed to ensure that the normality assumption, linearity, multicollinearity, and homoscedasticity were not violated. According to the results provided in the table above, the model explained 19% of the variance in Stress and that overall disease belief measures are a predictor of Stress, F (8, 269) = 8.67, P=.000. Only Identity (beta =.1, p =.004) and Emotions (beta =.362, p=.000) were significant predictors of the mental health problem of Stress. However, Emotions (beta=.36, p=.00) was a significant predictor of stress and had the largest variance of 36 percent among all factors. As a result, the hypothesis that the emotional component of disease beliefs will have the highest variance on Stress was supported.

b. Cognitive illness representations (Illness concern) dimension of illness beliefs will have the highest variance on depression

Table 4. 9: Summary of standard regression (DV= depression)

A standard multiple regression was carried out to test this hypothesis. Necessary assumptions essential for this analysis were checked and the outcome showed no major violations. The results as shown in the table above indicated that, the model explained 24% of the variance in Depression

Model	B	Std. Error	β	t	P
(Constant)	1.012	.780		1.298	.196
Consequences	.127	.080	.106	1.598	.111
Timeline	-.038	.054	-.039	-.694	.488
Identity	.040	.079	.031	.509	.611
Concern	-.063	.079	-.048	-.799	.425
Emotions	.486	.071	.453	6.797	.000
Treatment	-.028	.090	-.019	-.308	.759
Coherence	-.076	.082	-.051	-.922	.357
Personal	.174	.076	.132	2.285	.023

and that the overall illness belief measures are a predictor of Depression, f (8, 270) = 11.81, P= .000. Of these variables, only Personal Control, (beta = .132, p = .023) and Emotions, (beta= .453, p=.000) were significant predictors of the mental health problem of Stress. The variable of interest, Illness Concern (beta= -.048, p=.43) was not a significant predictor of Depression. Therefore, the hypothesis was not supported.

c. Cognitive illness representations (Illness concern) dimension of illness beliefs would have the highest variance on anxiety.

Table 4. 10: Summary of standard regression (DV=Anxiety)

A standard multiple regression was carried out to test this hypothesis. The results as shown in the table above indicated that, the model explained 19% of the variance in Anxiety and that the overall

Model	B	Std. Error	β	t	p
(Constant)	1.293	.760		1.701	.090
Consequences	-.021	.078	-.019	-.272	.786
Timeline	.023	.053	.025	.432	.666
Identity	.107	.077	.086	1.390	.166
Concern	-.032	.077	-.026	-.422	.673
Emotions	.407	.070	.403	5.849	.000
Treatment	-.001	.088	-.001	-.013	.990
Coherence	-.135	.080	-.097	-1.688	.093
Personal	.178	.074	.144	2.395	.017

illness belief measures are a predictor of Stress, f (8, 268) = 9.05, P= .000. Of these variables, only Personal Control, (beta = .144, p = .017) and Emotions, (beta= .403, p=.000) were significant predictors of the mental health problem of Anxiety The variable of interest, Illness Concern (beta= -.048, p=.43) was not a significant predictor of stress. Therefore, the hypothesis was not supported.

Hypothesis Seven (7): The mental health problems of participants will differ based on the type of genetic condition.

Table 4. 11: Summary of MANOVA results for differences in genetic condition and mental health measures

Variables	Diabetes type1 (N=36) Mean ± SD	Diabetes type 2 (N=113) Mean ± SD	Sickle Cell (N=112) Mean ± SD	*F*	*P*	*η2*
Stress	5.0 ± 4.25	4.49 ±4.17	5.00 ±4.30	1.701	.185	.013
Anxiety	3.78 ± 3.12	2.99 ±3.13	5.17 ±4.09	10.43	.000	.075
Depression	3.75 ±2.90	3.13 ±2.90	5.02 ±4.6	7.16	.001	.053

Table 4.11 illustrates the mean differences in scores on mental health measures acquired by people with type 1 diabetes, type 2 diabetes, and sickle cell disease. Preliminary assumptions were tested, and no serious violations were discovered. On the overall dependent variables, there was a statistically significant difference among the groups, F (2, 261) = 4.57, p = .000; Wilks' Lambda =.90. Bonferroni's correction, p <. 017. When the dependent variables' findings were considered in isolation, practically all of them were statistically significant. The only variable that failed to approach statistical significance, at a Bonferroni adjusted alpha threshold of .017, was on the Stress subscale, F(1, 261) = 1.70, p =.19, partial eta squared =.013. Overall, the data show that participants with type 2 diabetes had the least mental health difficulties, followed by those with type 1 diabetes, then Sickle cell patients, who scored the highest mean on anxiety and depression, indicating that they had more mental health problems. As a result, the findings partially confirmed the hypothesis that there would be differences in mental health problems amongst groups.

Table 4. 12: Summary of Post Hoc Tests (least significant difference) for differences in genetic condition and mental health.

Dependent variable	(I)Gene Condition	(J) Gene Condition	Mean Difference (I-J)	Sig
Anxiety	1 Diabetes Type 1	2 Diabetes type 2		
		3 Sickle cell	-1.3919[a]	.044
	2 Diabetes Type 2	1 Diabetes type 1		
		3 sickle cell	-2.1785[b]	.000
	3 Sickle cell	1 Diabetes type 1		
		2Diabetes type 2	2.1785[b]	.000
Depression	1 Diabetes Type 1	2 Diabetes type 2		
		3 Sickle cell		
	2 Diabetes Type 2	1 Diabetes type 1		
		3 sickle cell	-1.8940[c]	.000
	3 Sickle cell	1 Diabetes type 1		
		2 Diabetes type 2	1.8940[c]	.000

Notes * Significant at the .05 level of significance

As shown in Table 4.12, a Post hoc analysis was conducted using Least Significant Difference to identify where the differences among the three groups occurred. As indicated with superscript 'a', there was a significant difference between diabetes type 1 and sickle cell in anxiety, (p=.044). Superscript 'b' and 'b' represents a significant difference between sickle cell and diabetes type 2 also in anxiety(p=.000). The superscript 'c' is used to indicate a significant difference in diabetes type 2 and sickle cell in depression(p=.000).This means that Anxiety differs based on Diabetes type 1 and sickle cell. Anxiety also differs based on sickle cell and diabetes type 2. Depression differs based on Diabetes type 2 and sickle cell.

Descriptive statistics was used to analyze item 9 on the Brief illness perception scale.On the perceived causes of the genetic conditions' diabetes and sickle cell, 189 reported that their conditions were biological. Lifestyle and Diet was another perceived cause that had 147 responses and finally 31 believed it was a result of Spiritual causes.

4.1.3 Summary of Quantitative findings (Study I)

- There was a significant negative correlation between illness beliefs and mental health-related problems of adults with a genetic disease
- There was a significant positive correlation between illness beliefs and the psychological wellbeing of adults with a genetic disease
- Gender differences and educational level differences did not influence mental health problems
- Depression was the only variable that significantly predicted psychological wellbeing.
- Illness beliefs 's dimension 'Emotions' was a significant predictor of stress
- Illness beliefs 's dimensions 'personal control 'and 'emotions' were significant predictors of Stress and Anxiety.
- There were differences in mental health problems with regards to the types of genetic conditions. Participants with type 2 diabetes recorded the least mental health difficulties followed by type 1 diabetes and the highest level of difficulties was recorded by sickle cell participants

4.2 Qualitative Study Results (Study II)

Table 4. 13: Demographic characteristics of participants

Characteristics	Total number (N).	M±SD
Sex	**12**	
Male	5	
Female	7	
Age range(20-63yrs)	**12**	**44.42, (12.39)**
Marital status	**12**	
Single	4	
Married	7	
Widowed	1	
Religion	**12**	
Christian	11	
Muslim	1	
Level of education	**12**	
Primary	1	
Secondary	2	
Tertiary	8	
Diploma	1	

Genetic condition diagnosed	**12**
Diabetes type 1	2
Diabetes type 2	6
Sickle cell	4

Table 4. 14: Summary of themes and subthemes in Qualitative finding.

Themes	Sub-themes
Perception of genetic counselling	Knowledge about genetic counselling
	Importance of genetic counselling
	Introduction and Intensification of genetic counselling
	Suggested service that Genetic counselling should offer
Causes of the genetic condition	Hereditary
	Lifestyle
	culture.
Impact of the genetic condition	Loss of physical strength,
	Changes in social relations
	Emotional impacts.
	Financial burden
	Education and work
	Relationship and marriage
Coping mechanisms	Family support
	Education on self-care
	Prayer

Five major themes emerged from the qualitative data, which include *perceptions of genetic counselling, causes of genetic condition (diabetes and sickle cell), the impact of genetic condition, coping mechanisms and beliefs and reactions about illness*. Verbatim quotations are provided to illustrate each theme and subtheme extracted from the data.

4.2.1 Perception of genetic counselling

This theme centers on how participant perceives genetic counselling. Participants' narratives indicated that four major factors (sub-themes) describe their perception of genetic counselling. These are: participants' *knowledge about genetic counselling, their perceived importance of genetic counselling, urgent need and intensification of genetic counselling and services they suggest genetic counselling should offer*. The above sub-themes are explained below.

4.2.2 Knowledge about genetic counselling

Most of the participants know what genetic counselling means. That is, the majority of the participants (n=9) indicated that they have heard about genetic counselling. The participants could tell that genetic counselling was related to hereditary. They also used the words: educate, advice, counsel, to explain what they think the field genetic counselling does. Some participants explained that: *"What comes to mind is counselling people about, um, yeah, their genotypes."* (Participant 8, female, sickle cell). *"it is educating someone on genetics"* (Participant 7, female, sickle cell) However, knowledge of genetic counselling varied such that those who have at least tertiary education appeared to be more knowledgeable than those who did not have tertiary education. Two participants who appeared to be more knowledgeable about genetic counselling explain the phenomenon as follows: The first explained genetic counselling in relation to the

genetic conditions he is diagnosed with. *"Genetic counselling has to do with hereditary if you know the case that we have, you know like AS, SS and all that. I think I've heard something like that so for instance if you're going to marry for instance yeah what type and which blood group or type and all those stuff"* (Participant 1, male, diabetes type 2). However, the second participant was able to relate the field to other genetic conditions aside the one she is diagnosed with.

> Genetic counselling, what comes, what comes to my mind that is erh your genes. Er herrh your genes, how your how you were formed, er herrh. Whether the genes from the er the mother or the father. So if there is any problem, either it comes from the paternal or maternal er herrh. That's how I understand it" They tell all types of sickness. Because if you are, err an asthmatic for instance, they will tell you what to do, the weather, you know how you go about our things. Then the Sickler too, if my child is a sickler or myself they will teach us the do's and don'ts er herrh that will help us, there are so many there. I can say cancer and other things, they will tell you this and that and that, how you will go about how you will take your drugs, your diet and everything, they will tell you so that you know how to manage, er herrh , monitor everything. (Participant 12, female, diabetes type 2)

On the other hand, another participant, whose highest educational level is high school said that "*No, I've never heard of it before"* (Participant 6, male, diabetes type 2) after he was asked about genetic counselling. It should be noted that the participants' source of knowledge about genetic

counselling varied as well such that whereas some learnt about it from school, one participant acquired her knowledge *from friends* (Participant 4, female, diabetes type 2).

4.2.3 Importance of genetic counselling

Another sub-theme that emerged under this theme is the importance of genetic counselling. Although some participants were not fully knowledgeable about genetic counselling, all of them (n=12) acknowledged that genetic counselling is beneficial. Among the benefits, all the participants indicated that genetic counselling serves as a precautionary measure in making decisions about their health. The following extracts illustrate some participants' reflections on how genetic counselling would have helped them if they had gotten it earlier: One participant had this to say *"Okay in the first place I know my mum is diabetic, my dad died out of it but because I didn't have that counselling, I wasn't taking care of myself properly. Because if I knew of it very well, I think I will take care of myself properly that I won't be"* (Participant 4, Female, diabetes type 2). She believes that prior knowledge about her conditions through genetic counselling would have helped her put healthy measures in place earlier in life.

Another participant believed that prior knowledge about one's genetic status is essential for preventing so genetic related health complications which has no cure. *"Yes. Prevention is better than cure. If curing is that easy, I'd have cured mine after these ten years that I've carried this disease. It is better to find out your health conditions early before it becomes too late."* (Participant 11, female, diabetes type 2)

In addition, some participants (n=5) reported that genetic counselling aids in choosing a life partner. In many cases, would-be couples are required to undergo medical screening including genetic tests to know if they are compatible or otherwise. Individuals who get access to genetic

counselling are, therefore, able to select compatible partners thereby, minimizing the risk of a person with hereditary diseases. One participant explained that genetic counselling prevents future family crises. He said: *"Yeah it's a good thing to get people to know especially young men who want marry in church you know.... they do a white wedding and shortly after that there's a problem or they give birth, young life and then the crises in the situation"* (Participant 1, Male, diabetes type 2).

4.2.4 Introduction and Intensification of genetic counselling

Furthermore, the participants reported that genetic counselling needs to be introduced and intensified in Ghana to curb the negative consequences of a developing a genetic condition (diabetes and sickle cell). Although Genetic counselling services are yet to be fully established in Ghana, most participant voiced out that it is a very essential health care service that will be embarrassed. One participant questioned that the introduction of genetic counselling services has been long overdue. He had this question for the field: *"But my question, uhm, it will be based on the facts that, um, it's, it's like genetic counselling is now being a major focus, but why, why now? So like why, why have they waited for long, till now?* (Participant 10, male, Sickle cell).

The data showed that genetic counselling awareness needs to be created in all spheres of life. Some participants indicated that genetic counselling campaigns should not be left to only health professionals. They reported that it should be taught in the church and also be made part of schools' syllabus to let the young generation know what it is about. One participant had this to:

"Yes, it shouldn't be one-sided too. It should be all round. It should be in education system. It should be err the health system. They should put it in places whereby, we are all, all we could, we all have, so that we all have the knowledge. When we have it aa, we can pass it on… to the next generation" (Participant 3, Female, diabetes type 1).

Another participant reported that passing genetic counselling to the next generation is the way forward. He had this to say: *"So we mentioned leaders, we could also say teachers also where from the tender age they could be taught so they have it at their back of their mind; ooooh we have hospital schools, polyclinics and we have the other social centers. You see if the people are aware they'll start asking questions and will definitely get answers to them yeah "*(Participant 1, Male, diabetes type 2). To him, as early as possible, genetic counselling education should be given to people wherever they find themselves.

4.2.5 Suggested services that Genetic counselling should provide

Lastly, on the subtheme suggested services that genetic counselling should offer; three areas of needs emerged. These were education to reduce the myths and stigma others have about genetic conditions, interventions for patients to have a better life, and a cure for the pain. Participants also suggested that the field should help those with genetic conditions have a better life by educating the public on stigmatizing people with genetic conditions. Two participants recalled a story of stigma that cause them to emotional trauma:

> Back in secondary school, they didn't understand why all the time I was sick. I had crisis. And someone even came to ask me, that time I think I was 18. And then the person came to ask one of my friends. Uh, why, why am I still alive? Because she knows that we don't live up to 18 years. So, I'm still 18 and, she doesn't understand why I'm still alive. laugh. So, when my friend came to tell me, I laugh about it initially, but later on, I was like, wow. So, someone is some somewhere thinking I should, I have to die. (Participant 8, female Sickle cell)

To her, people expected her life to end at a younger age which is one of the myth about sickle cell patients. This can pose some mental health problems to them. Another participant also

recounted a similar incident cause her cousin who had sickle cell's death. He explained that he had to avoid an activity he enjoys as a result of stigma and being tagged as someone whose life is short. This was what he said:

> Cause of the way they sometimes are not around the way they talk about you. I remember in a church. Okay. I remember, something happened. I'm a sound engineer. Okay. I did for that for fun. So it got to a time because of what was going on, I just, I decided not to do it again I wanted to stay at home. Okay. And I remember one of my friends came and told me that this elder said something about you and I wanted to ask, is it true? And he said what? They say you may die tomorrow because you are the type of people who may die anytime. (Okyena wo be wu,wo ye ko fie ko wu fuo no bi) and I've been hearing lot of these. These are the things my cousin went through, and my cousin died early so I will be avoiding those kind of things. (Participant 9, male, sickle cell).

Participants further stated that things are not the same as it used to be since people with genetic conditions are able to live longer when they follow healthy lifestyle and take medications. Therefore, the genetic counselling field should help carry the message across that *" this is not a death sentence. Yes*. "(Participant 8, female, sickle cell). Another participant explained that one can equally live a long and fulfilled life if he or she practices healthy lifestyles and take their medications. He said: *"…If patients would follow the medical directions; eat what is supposed to be eaten, ignore what is not good to be eaten, do what is required, take all prescribed drugs, a diabetic patient can live long enough."* (P11, Female, Diabetes type 2)

Most participant who were diagnosed with diabetes suggested that the genetic counselling field should focus on educating people on familiar illnesses, this will help prevent or reduce the future happenings. On had this to say:

> Now a days I can say diabetics has been more than malaria. It's rampant, so if the genetic counsellors, they will just have or they will err bring people together or educate them. So if he educate you, you know that oh in case you, you don't know but later when you know that your family you have this condition, then you already have the education, so you know how you will take your steps." (participant 12, female, diabetes type 2)

One of the participants appealed to the genetic counselling field to collaborate with other health professionals to find a relief for the pain they experience during crisis. She said:*"I think they should, they should help find a cure. Ehr, something that will suppress the pain. Yeah. So that even, even when it's rains all week, there will be no crisis. There'll be no joint pain. So something, something that will really suppress the pain because it's not easy".*(Participant 8,female,sickle cell)

4.2.6 Causes of illness (diabetes and sickle cell)

It should be noted that all the participants have been diagnosed with diabetes or sickle cell such that six participants were diagnosed with type 2 diabetes whiles two were diagnosed with type 1 diabetes. Four participants were diagnosed with sickle cell. This theme, therefore, captures the main causes of participants' disease as well as the other contributory factors involved in their disease. Subthemes that emerged are *hereditary, lifestyle, culture and lack of knowledge.*

Hereditary

Most of the participants (n=12) reported that their condition was due to hereditary. They indicated that someone in their family had already been diagnosed with the disease and therefore, theirs was transferred to them as a result of their blood relations with the person. The disease was contracted through a close relative notably, their mother, father or sister. Although some participants knew their close relatives had the disease, they did not believe they are susceptible to the disease, hence they failed to take any precautionary measures. Some participants shared their ordeal in the following extracts: *"It would have, because though I knew my mother was (diabetic), I never knew I could get it so easily and all my life I thought it was when you eat real sugar"* (Participant 2, Female, Type 1 diabetes). Another participant said: *"Okay in the first place I know my mum is diabetic, my dad died out of it but because I didn't have that counselling, I wasn't taking care of myself properly. Because if I knew of it very well, I think I will take care of myself properly that I won't be"* (Participant 4, Female, Type 2 diabetes)

Some participants were oblivious to the presence of the disease in their families. This prevented them from taking precautionary measures earlier. One participant had this to say: *"Since from the onset I knew that it was in the family, it would have helped me a lot. Seriously, it would have even saved me from going through these nine years of hardship. It would have prevented me from going through it but all the same it's a lesson"* (Participant 3, Female, Type 1 diabetes).

All participants who have been diagnosed with sickle cell explained that the condition was inherited. However, they indicated that their parents had no prior knowledge about their genotype before they were born and diagnosed. One of the participants explained in the following extract:

*"It all about knowledge. If my mother and my father were educated early enough, I think this won't happen." (*Participant 9, male, sickle cell)

Lifestyle

Another subtheme that emerged under this theme is lifestyle. From the data, it was evident that the lifestyle of participants contributed massively to the causes of diabetes but not sickle cell. These lifestyle choices include their eating habits. It was evident that all of the participants practiced poor eating habits and sedentary lifestyle. One participant observed that "*along the line working and schooling, I was eating late too. So late eating too was part and sedentary life, like sit in your car, go to work, sit in the office, come down"* (Participant 1, Male, Type 2 diabetes). To him, late-night eating which mostly results from daily busy schedules was reported by the participants as one of the main contributory factors to their disease.

The choice of food was also a contributory factor. It was evident that some foods increase a person's chances of contracting diabetes. Foods that are rich in carbohydrates, as well as foods that are high in cholesterol, were reported by the participants as a contributory factor. Some participants shared their experiences in the following quotes:

"Hmmm it's true, our eating (sighs)… It's true because it's all over here. Everything we have here is full of carbohydrate. So that one too is another aspect (Participant 4,female,diabetes type 2).

Few participants (n=2) reported that lack of exercise was another contributory factor to the disease diabetes. One participant shared his experience in the following extract: *"So late eating too was part and sedentary life like sit in your car, go to work, sit in the office, come down without doing*

any exercise" (Participant 1, Male, Type 2 diabetes). They observed that not exercising made them more susceptible to the disease.

Culture

Some participants also observed that culture is a contributory factor to the causes of diabetes and sickle cell. The geographical location of a particular people and their way of life determine the kind of food they consume. The participants reported that culture dictates the kind of food they should consume and since these foods are high in carbohydrates, they ended up contracting the disease. For instance, one participant had this to say:

> Our culture, I would say our culture, our way of eating. I think the carbohydrate part of the meal is always too much but from the word go you have been brought up with that, so you have the taste for it. It's not easy switching from your day one upbringing of way of eating to a healthy style. So cultural, I think our way of eating. (Participant 2, Female, Type 1 diabetes).

With regards to culture as a cause of sickle cell disease, one participant indicated that arranged/betrothed marriages can cause a person to acquire the sickle cell disease. He said this:

> Yes! arranged marriages and stuff like that. Yeah. That is what I'll say can lead to that because some of them, the counselling may not be allowed and then, you know, yeah. An arranged marriage, they just betrothed someone and they just say, this is your husband, this is your wife and they just go ahead and marry the person. Nothing is done. No background check and anything. I think those, those may be some form of cultural causes, but it's all genetics.(Participant 10, Male, sickle cell)

4.2.7 Impact of Genetic Condition

This theme discusses how diabetes and sickle cell has affected the participants individually. Some of the subthemes that emerged are *loss of physical strength, changes in social relations, emotional impacts, financial burden, education and work and lastly relationship and marriage.*

Loss of physical strength

Most of the participants (n=10) reported that their physical strength has reduced following the disease. The reduction in sugar intake implies that the energy the body needs reduces as well. Individuals who have diabetes then start to reduce in size. Therefore, since their physical strength reduces, they stop engaging in activities that require a lot of energy: *"Yes.it has affected my physical strength. Because there are some things you have to call somebody to come and lift for you.* (Participant 9, male, sickle cell). Some participant describes the changes in his body due to diabetes and sickle cell in the following extracts:

> Truly because formerly, I was big. Now because of this I have slimmed somehow. So, it cannot make me work like I used to do. Yes because, what I supposed to do, in terms of strength, I cannot do anymore. Somehow because, that's what I'm saying some work, I'm supposed to involve myself in it but because my strength has come down, I can't do"(Participant 5,male,Diabetes type 2).

To some participants, the loss of physical strength meant that they had to quit their jobs. In instances where they are the breadwinner, it brings about hardship to the whole family. One participant indicated that: *"I've stopped working because of the diabetes and at first, I had a lot of strength but for now it has reduced a little"* (Participant 6,male,diabetes type 2).

Changes in social relations

Most participants (n=10) reported that the genetic diseases have altered their social relations in so many ways. The participants reported that being diabetic or sickle cell has restricted their social relations as well as their lifestyle choices, notably where to eat, what to eat and the kind of people to hang out with. To some participants, being diabetic implies that they cannot hang out with their friends anymore because most of the places they hang out are not conducive for people with their conditions. The following extract explains further how social relations are altered because of diabetes:

> It has restricted me from certain things, certain aspects. Some things that I used to do to have fun now I can't do it again. I have realized it's not a healthy way of living. Emotionally sometimes you know that oh we are going here to do this, you go there you are restricted, you have to lie to your friends that oh I am diet meanwhile you know it's because of your condition. (Participant 2, Female, diabetes type 1).

Participants with sickle cell also reported that they avoided most social affairs because they would not want to get into crisis. They further indicated that they choose to be reserved to avoid some negative comments and labels friends described them with. For instance, one participant had this to say:

> When I was in secondary school, I was so antisocial. I wouldn't want to mingle with anybody. I wouldn't want to do stuff because I, every time I tried there was crisis. when I was in, um, JHS and even secondary school. They used to call me a "sickler". Okay. I didn't have a problem with it, but I didn't like hearing it. Mm it's irritated me. Mm. So I'll tell them I am not a sickler. Then they say you are, you are always falling sick. A person who is always falling sick is called a sickler. I say that I am not. even up till now. it irritates me when I hear that word Sickler. (Participant 8,female,sickle cell)

Another participant had to stop church activities which made him happy because they mostly spoke ill of him. *"So, it got to a time because of what was going on, I just, I decided not to do it again I wanted and to stay at home.* (Participant 9, male, sickle cell). This is detrimental to his mental health.

Relationship and Marriage

The genetic diseases sometimes make some participants lose friends and other relatives. To some, they lose friends after disclosing their condition. Others also reported that some friends stay with them but eventually leave them due to advice and judgements from those around them. One participant indicated that: "I *don't even have a life because nobody wants to associate themselves with someone who is always sick: they try to shun away from you… so you don't have normal life"* (Participant 3, female, Type 1 diabetes).

Additionally, people with genetic conditions specifically sickle cell reported very challenging relationship life as a result of their condition. They reported to have lost their partners upon disclosing they had sickle cell and even when their partner's genotype could match with theirs, their family was against the relationship. One participant explained her ordeal:

> Is there anything positive about this when it comes to relationship? I don't think so. Well mm-hmm. At first, I didn't like telling someone who shows interest in me that this was the situation. So, and immediately I tell them they, they run off so that was really difficult. But then I came to understand that someone who wants to be with you will be with you. Yeah. No matter what." (Participant 8, female,sickle cell)

Emotional Impacts

Emotionally, some of the participants reported that the disease caused them sadness as well as anger. These feelings were, however, much evident in the initial stages of diagnoses. Occasionally, these emotions resurface. One participant explained the emotion she goes through in the following extract: *"A little bit sad but I knew that was not the end of the world. And was at the same hospital I was taking my mother for her routine checkup. So, I wasn't happy of this. I never want it at that age"* (Participant 2, female, diabetes type 1).

Participant who were diagnosed with sickle cell reported severe emotional and psychological distress which could lead to mental health related problems. Some reported they were scared of dying at the early stages of life. Others reported that they felt left out whenever the family engaged in some activities. One participant reported that she had frequent panic attacks as a result of fear whenever she was in crisis. She said: *I always get panic because it brings this sort of fear, fear of dying''.*(Participant 8,female, sickle cell).

Sickle cell participants recorded more emotional and psychological problems compared to participants with diabetes. This occurs as a result of frequent crisis and other complications that comes with the genetic condition. One participant said: *''hmm,I do cry, sometimes I don't talk to anyone, I just come into my room and just cry and sleep''*.(Participant 7,female, sickle cell).

Another participant explains that he experiences some discomforts whenever he is in public places due to his physical features which was caused by the genetic condition. He said:" …*Sometimes when I walking on the street the way people see you, it makes you think like, maybe if you die by this time like you will even be free (Se by this time wo wu a wo be ye free), sometimes it bothers me a lot*." (Participant 9, male, sickle cell)

It should be noted that the disease did not affect only the participants but rather, their entire families were affected by the disease. Most of the participants (n=5) indicated that the disease (diabetes) brought changes in the family diet. Diabetics are restricted from eating some kinds of foods hence, most families tend to change the diet of the whole family to suit the diabetic. In some households, different meals are prepared for the diabetic and the other family members. This was what one of the participants shared:

> For four years, I've never tasted sugar and so anytime anybody or even as I'm around they know sugar is not something they should take. In any form both natural or… at times they try to hide with honey but they know that it's they realize it's not making things better. It has really shaped how we should eat and how and when (Participant 1, male, diabetes type 2).

Some participants reported that the disease have made other family members more cautious about their lifestyles and health. For those whose diagnoses resulted from hereditary, other family members have already taken precautionary measures. One participant had this to say: "***…****So I always advise him. Yeah, because now my son for instance, he eats more of vegetables, because that helps him*" (Participant, 4, female, diabetes type 2). They ensure the people around them are well informed about their genetic conditions so they can take precautions. One participant said: "*so I've made everyone, those who didn't even know their genotype now they do. Okay. So they have an understanding...".* (Participant 8, female, sickle cell)

Education and work

Lastly, on the sub-theme education and work, participants with diabetes reported that they had no impact on their work as a result of the condition. However, participants with sickle cell reported that their conditions affected their education. They indicated that they had crisis often throughout

their education. One said ; *"it did really affect me because I wanted to go to school and get to the highest level. But I couldn't. And so it just really affected me".*(Participant 9,Male, sickle cell)

They also reported that frequent sick leaves affected their work life which made it difficult to work for people. Here are some abstract to explain their concerns:

> I remember when I was during my national service, it was like every two weeks, I was always taking sick leaves. Like I'm not well. So just, after my national service, I just told myself. You know what? I don't want to work for anybody because people do not really understand what is going on. They might feel, you are just being lazy. You just don't want to work, but you, yourself, you know, what is going on with you. (Participant 8, female, sickle cell)

4.2.8 Coping mechanisms

This theme discusses ways in which participants cope with the effect of having diabetes. Two major subthemes emerged namely, *family support, education and Prayer.*

Family support

Some participants (n=10) reported that their families are the major source of coping strategies employed in curbing the effects of the disease. The family provides social support as well as financial support to participant. She said and I quote: *"The emotional, the financial, every support. They tried to take my mind off it. It was good. Because they know so they were with me. And it has even made my children more conscious of themselves*"(Participant 2,female,Diabetes type 1).Thus, members of the family sometimes give out money for medication. The following quote summarizes the role of the family in coping with diabetics and sickle cell.

> My mom has been the one doing everything like <affirmative>. Yeah. Since I was born and oh, working. So she, she really helped, like, she's been really helpful. Oh, okay.

Because she always makes sure you take your drugs, you do what you have to do so that you wouldn't get into crisis because when you get into crisis, the whole family also gets into crisis. Yes. Yes. So she really, she she's really doing a good job. I know sometimes I'm stubborn and all that, I had people around me who were always telling me what to do and what not to do. Oh, . So I had my grandpa, . Always waking me up to take my folic acid and other, um, drugs I had take, I had my mom always ensuring I wear my socks and my pajamas and all those things when it was cold. So I, I understood it's early, so anytime it's cold, I know I have to wear my socks. I have to wear my cardigan. I have to do things not to get any crisis. (Participant 8,female ,sickle cell)

Education on self-care practices

Some participants observed that education on self-care is another way of coping with these genetic diseases. Participants indicated that education from doctors and other health professionals play a major role. One of them indicated that: *"whenever you go to the clinic, they teach you, they give you a gist about what you are facing and how to manage, they, its like helps*." (Participant 7, female, sickle cell).Education tends to remind the individual of some of the foods they should stay away from activities they should avoid and thus, serves as a precautionary measure. Some participants had these to say:*I think they should, the education should be more. Because my first time, yeah, the education should be increased. If I had known, I wouldn't have been in this situation now* (Participant 2, female, diabetes type 1).

Prayer

Some participants also indicated that find hope in praying to God for healing and protection. They are able to cope with faith in God and prayer. One participant said that she

believes she can get healed as she continues to have faith in God. She said…." But God he works in a mysterious way so when we spiritually ask God to heal, intervene, he is our healer." (Participant 12, female, diabetes type 2)." Another participant says she is now able to do things she could not do because God helps her to do that:

> …You have to pray about it. So, you tell God, you don't want to fall into any kind of crisis because you are trying to live. Okay. Yes. So now I do most things I, I didn't used to do when I was in secondary school, in the, or in the university. Now I do it. I go for walks. I, I, I even climb the mountain. I, I do stuff. Okay. And now I mingle, like, whatever people are doing normal. (Participant 8, female, sickle cell)

CHAPTER FIVE

DISCUSSION

5.0 Introduction

The chapter discusses the findings of this current investigation. The quantitative and qualitative findings are addressed separately for clarity and convenience, with the quantitative (Study I) findings coming first, followed by the qualitative (study II) findings. The findings are also explored in relation to the study's objectives. Finally, the findings are integrated to get a better understanding as well as fulfil the mixed method objective.

5.1 Quantitative Findings (Study I)

One objective of the study was to examine whether some socio-demographic factors (gender, type of genetic condition and education) impacts the mental health of people with genetic conditions. On gender differences, it was observed that men and women did not differ on mental health problems as measured in terms of stress, anxiety and depression. The findings from other studies differ from the current study. For example, Al-Marzouki et al. (2021) found out that men were more depressed than females. Interestingly, a previous study by Onyeaka et al. (2019) found that women were more depressed than men. Another study revealed that women with Type 2 diabetes reported more mental health problems especially depression that men. (de Alba et a., 2020). A possible factor that can explain the finding that gender played no role in mental health of adults with genetic conditions will be changes in the family system as well as gender roles in which both men and women share roles and responsibilities in caring for the family. Also, the study found that like gender, level of education played no role in the mental health problems of people with genetic conditions. The researcher assumed that higher educational levels meant more

understanding of the specific condition. However, this was not seen the analysis of the data available. One reason that can account to the fact that level of education did not play a role in the mental health of participants will be the fact that education on these conditions are not limited to the classroom only. Education on most illnesses happens at the various clinics, through the media as well as community educational talks, which helps people become aware of these illnesses thereby reducing fear after diagnosis. This was confirmed by some participants of the qualitative study. They reported that the talks given to them by some health professionals (dieticians, doctors, nurses) have been informative in terms of understanding and managing their conditions.

Further, the study's objective was to find out if the type of genetic disease plays a role in mental health problems. As per the analysis, it was found that having diabetes or sickle cell influenced mental health problems but only in terms of anxiety and depression. This finding is in consonance with that of a study by Myrvik et al. (2012), who concluded that patients with genetic conditions such as sickle cell disease (SCD) are faced with a myriad of mental health challenges. Similar to this was a finding by Yarhere and Enameguolo (2020) who found out that people with sickle cell and diabetes experience a wide range of mental health problems with their study zeroing in on the fact that patients with sickle cell have higher scores for depression than those with diabetes. Similar findings have been revealed by this current study. The mental health problem, 'stress', was not influenced by the type of genetic disease.

Another objective of the study was to examine the relationship between illness beliefs and mental health of people with a genetic condition. The analysis revealed a substantial, negative association between illness beliefs and mental health problems with an increase in negative illness beliefs leading to lower mental health. Further analysis of the subscales showed that the *Identity*,

Personal control, Consequence, Concern and *Emotion* components of illness belief lead to an increase in stress, depression and anxiety. The self-regulation model of illness(1980) explains how one's experience and position as a result of an illness might help chronic patients maintain their health habits. It is regulated by cognitive and emotional factors such as the illness's predicted duration, the illness's life implications, how the sickness is controlled or treated, the illness's diagnosis and source, and feelings of dread or terror associated with the illness. Individual disease perception is associated with psychological and clinical outcomes in patients, and it serves as a motivator and starting point for sickness coping and action plans (Chilcot et al., 2011).

In this study, adults with genetic conditions mostly identified their conditions through the many severe symptoms they experienced which led to developing depression, anxiety and stress. Additionally, this study revealed that adults with genetic conditions felt they have no personal control over their illness which affected their wellbeing. Lastly the use of emotions to represent the illness resulted in these adults developing anxiety, stress and depression. Findings in a research by Fortune et al (2002) revealed that illness perception predicted most variance in health outcomes compared to demographic variables. Illness perception considerably predicted diabetes related distress (Paddison et al., 2010) and, anxiety and depression among Parkinson's disease patients (Evans & Norman, 2009). This finding is also in line with a study in Ghana, which discovered that general mental health problems had a strong significant connection with illness perception. (Nuworza, 2013)

Illness beliefs were also correlated with psychological wellbeing in this study. Considering the composite scores of psychological wellbeing, total illness beliefs led to a decrease in psychological wellbeing. A cursory look at the specific effects on the subscales of psychological

wellbeing showed that it led to a decrease in mastery, positive relations, and self-acceptance. This is supported by previous findings of Morgan et al. (2014) who realised in their study that Illness perceptions were linked to measures of psychological well-being. In both sadness and anxiety, regression analysis revealed that disease perceptions accounted for a considerable fraction of the variance.

Findings in this regard are explained by the health belief model which posits that an individual's desire or intent to alter their health behaviours is majorly influenced by the kind of perceptions they have concerning their health (Boskey, 2019). Concerning the individual perceptions, it was realized from this present study that participants' perceived seriousness of the disease affected their experience of mental health problems and psychological wellbeing. Similarly adults who perceived their genetic disease as threatening reported mental health problems and poor psychological wellbeing. Glanz et al. (2015) point to the fact that perceived seriousness of disease and perceived threat are components of illness beliefs which affects the mental health of persons. In this study, differences in gender and education did not relate with mental health problems experienced by adults. However, adults who believed that they have no personal control over their illness suffered poor psychological wellbeing. According to Haydon (2009), such perception of having no personal control impeded the likelihood of taking health action on the side of adults with genetic disease.

Further in relation to the health belief model by Haydon (2009), onea's perceived benefits and perceived barriers to health affected their likelihood of taking health action. In this study, it was discovered that adults with genetic disorders who entertained negative illness perception reported poor mental health symptoms such as depression, stress and anxiety. In this wise, Tan et

al. (2018) who assessed the authenticity of the health belief model in health and healthcare explained that, for healthy outcomes, persons with specific illness should believe that a change in the current ill-conceived self-care practice would lead to a significant positive outcome at a cost that is bearable and beneficial to them (perceived benefit) while believing also that they are competent (self-efficacy) to overcome perceived barriers to action for the behavior (self-care practice). In this study therefore, it was realized on this premise that those who entertained negative illness perception had less perceived benefits of taking health actions but more perceived barriers such as no personal control to effect a positive change in health outcomes. This definitely explains their high measures in mental health problems pertaining to stress, anxiety and depression.

5.2 Qualitative Findings (Study II)

The qualitative component of the study goes further to understand the phenomenological experiences of the participants which most likely influenced the findings in the quantitative study. Findings from study 2 have shown that people with genetic diseases face various challenges in their lives as a result of the condition.

The study found that the perception of genetic counselling was influenced by the participants' knowledge about genetic counselling, their perceived importance of genetic counselling, as well as the intensification of genetic counselling. The study found that the participants had a fair idea of genetic counselling, with the educated participants appearing to have more knowledge about genetic counselling. This knowledge, however, played no role in the mental health problems of participants as the quantitative study rightly showed. Interestingly, the study also found that some participants believed they had the phenotypical expressions of their genetic diseases because they did not have genetic counselling and this affected their mental health upon

diagnosis and after. This finding could clarify what was seen in the quantitative study which showed that as illness beliefs got more negative, it led to more mental health problems and subsequently reduced psychological wellbeing. The findings of this current study are consistent with other studies that revealed that genetic counselling is an essential health care which will be embraced in Ghana, even though, there is fair knowledge about it. (Appiah et al., 2020). Additionally, this study findings on whether genetic counselling will be pursued was congruent with another study that revealed that patients had reasonably good opinions about genetic counselling and would rely on the information provided to them by genetic counsellors. (Jacobs et al.,2020). Lastly, Ilesanmi (2013) in his study concluded that there is the need for the introduction of genetic education starting from basic education as well as at the national level to help create awareness of genetic condition which results in severe complications for sufferers.

Further, this study found that, participants had their own opinions on the causes of their conditions. Similarly, the consequences of their illness seemed to play a role in their mental health and psychological wellbeing in general. Participants made comments that alluded to the feelings of isolation as a result of their clinical status. This undoubtedly influences the psychosocial health of people with a genetic disease. The responses fluctuated around the subthemes of hereditary, lifestyle and cultural influences. In line with the quantitative data, responses on causes of illness ranged from biological, lifestyle and spiritual causes.

The theme of the impact of genetic disease, which is the qualitative version of the illness consequence as seen in the illness belief scale was very relevant in this study. The loss of strength, impact on social relations and the emotional consequences the disease brought undoubtedly affected their mental health. This is congruent with the findings of the quantitative study where the correlation analysis showed that the ‘consequence’ component of illness beliefs led to an

increase in all mental health problems as assessed by this study. The psychosocial impact of a genetic disorder varies depending on the type of the ailment and the person's relationship to the individual involved. Every family is unique, so predicting how people would react to a genetic diagnosis is challenging. However, it is beneficial to plan ahead of time for some of the likely reactions so that you can react swiftly and with as little suffering as possible.

A genetic diagnosis may also elicit unfavourable reactions. Genetics may be a perplexing issue, and sufferers are frequently upset until they gain a better understanding of the problem. Individuals who have been recognized may believe they are at fault or "broken," or they may view their diagnosis as leading to something they cannot fight. Concerns regarding financial and workplace discrimination can arise as a result of a genetic diagnosis. The response to a diagnosis differs from person to person and is influenced by a variety of characteristics such as gender, education, and religious and cultural views (Genetic Alliance & The New England Public Health Genetics Education Collaborative, 2010).

According to the results of this research, participants received emotional support in the form of encouragement or words of hope from significant others, instrumental support in the form of assistance with chores, and informational support, which is assistance provided by people through the provision of information (education) about the ailment. This suggests that patients may be able to adjust well to changes in their lives, endure minimal discomfort, and then have a higher quality of life than persons who do not have a network of support. According to LaRocca et al. (2015), people who are satisfied with the form of support they obtain are more likely to enhance their wellbeing.

According to this current research, people with genetic diseases utilize more emotional coping mechanisms to deal with their affliction. Carver (2011) defines emotionally focused coping

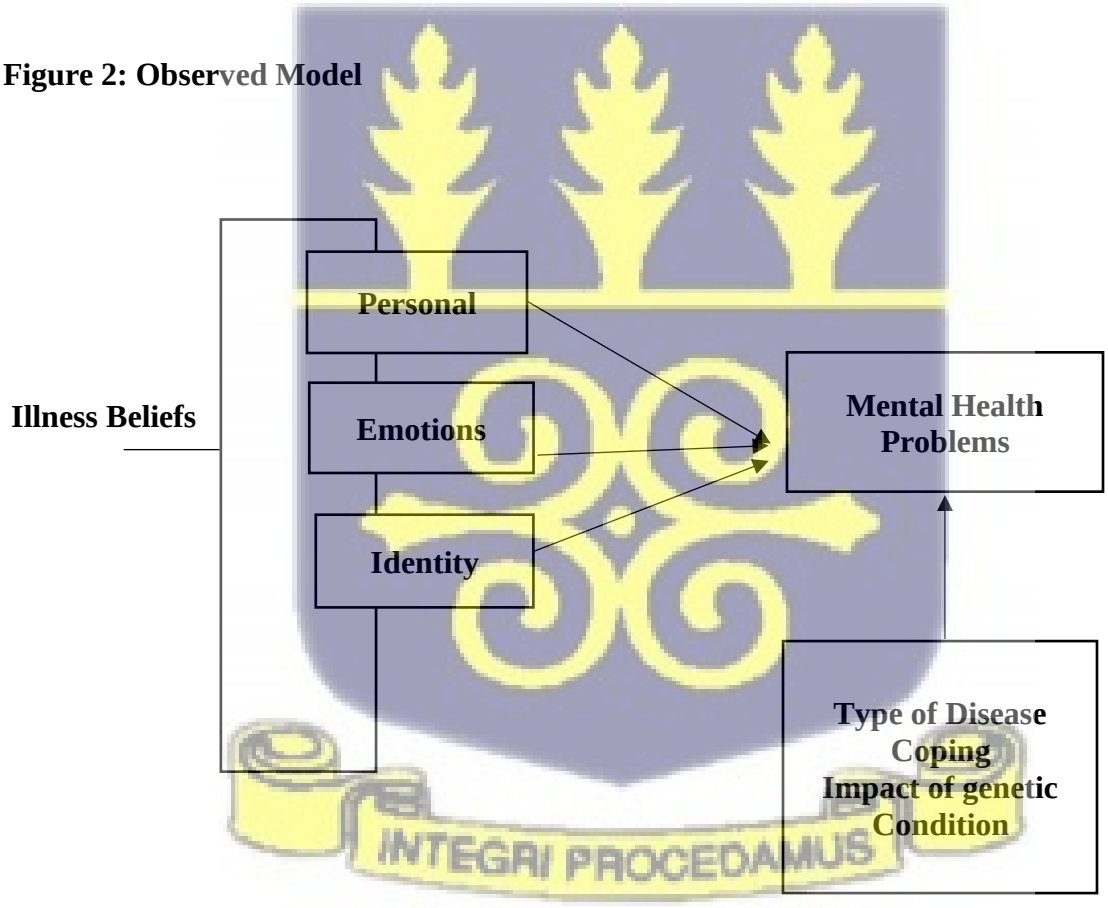
as a strategy for limiting or avoiding the affective component of a stressor. This form of coping usually utilizes prayer, meditation and cognitive reframing. As can be seen from the qualitative analysis, prayer was major coping strategy used by many of the participants in this study. Emotion-focused coping primarily regulates negative emotional reactions to stress, such as worry, fear, sadness, and rage. As can be seen from the responses of the participants in this study, the above-mentioned emotions play a big role in their mental health status. When a stressor is unchangeable, the emotional method of coping may be beneficial. Folkman and Lazarus (1988) also showed that emotional focus coping is acceptable for stressors that appear daunting, such as a chronic illness condition.

5.3 General discussion (study I and study II)

Integrating the findings of the two studies, study I revealed that negative illness beliefs have adverse effects on mental health and result in a deficiency in psychological wellbeing. This finding was supported by an examination of qualitative data in which participants described their mental health status in terms of their overall well-being, and it was discovered that negative illness beliefs do not bode well for mental health and psychological well-being. This finding is in congruent with another study by Nuworza (2013) which found that perception of illness was a strong predictor of general mental health problems. Similar findings came up in other studies where adults with inheritable diseases had high occurrence of mental health issues (Jonassaint et al.,2020), patients illness perception affects the quality of life (Mohammed et al.,2016) and also patients with genetic condition (type 2 diabetes) recorded concurrent mental health problems (de Alba et al., 2020) which led to risk of hospitalization and mortality. In contrast, Amartey (2019) found that, illness perception did not predict mental health problems in adults with the genetic

condition diabetes however religion predicted mental health problems. Furthermore, in study I, the variable *Emotion* was a strong predictor of mental health problems, which is consistent in study II because individuals mostly expressed emotional difficulties. They described the difficulties they have as a result of their disease and how this impacts their emotions. They expressed feelings of despair, uncertainty, and concern, as well as psychological distress. This finding is in contrast with other studies where coherence (Kugbey.2013) predicted mental health problem in diabetic patients. However, results of this current study concur with Al-Kayyis & Perwitasari (2018) where emotions of patients impacted their quality of life and mental health.

Figure 2: Observed Model



The figure 2 model indicated above represents the graphical findings of the study. Only Personal treatment, emotions and Identity subscales of the illness belief model were predictors of mental health problems.

In study I, findings revealed that adults with sickle cell had poor mental health as a result of the representations they give to their conditions. Adults with type 1 diabetes followed and lastly, those with type 2 diabetes. Study II revealed a deeper explanation and confirmation to the above. All participants with Sickle cell disease(n=4) expressed emotions such as fear, extreme worry, frustration and anger to represent their genetic conditions. They further reported that it causes them to feel unworthy, sad, thought of death, anger etc which leads to low psychological wellbeing. Type of genetic disease also influenced mental health problems in both quantitative and qualitative findings. Participants with sickle cell according to this study showed more mental health problems followed by type 1 diabetics and lastly type 2 diabetics. Some literature have shown similar results where sickle cell patients recorded higher levels of the mental health problem depression (Jenerette et al., 2005; Yarhere and Enameguolo, 2020) One reason that could account for higher mental health problem is stigmatization as a result of the impact of the genetic condition in the life of sickle cell patients as identified in the qualitative part of this study. Most of participants with sickle cell reported that societal views about the sickle cell are worrying. For instance, there were perceptions that they will die early and therefore they were left out of some social functions. Again, adults with sickle cell are unlikely to get the same kind of support and care they received during childhood which can contribute to mental health problems. Lastly the seasonal crisis and complications sickle cell patients experience can lead to more mental health problems.

In both study I and II of this current study, demographic characteristics of patients had no role to play in the mental health of patients with genetic conditions. This outcome is in line with Kubgey, (2013) whose study revealed that demographic variables are less significant in predicting mental health problems of adults with genetic conditions similar to Appiah et al. (2020) where no significant difference in demographic characteristics were found in diabetic patients and positive mental health. On the contrary, demographic features of patients with genetic conditions were found to be crucial in their mental health outcomes in some studies (Jadoon et al.,2012; Liu et al., 2010; Roupa et al., 2009).

On the perceived causes of the genetic condition's diabetes and sickle cell, similar responses such as hereditary, and lifestyle were given by participants in both qualitative and quantitative studies. Participants in the qualitative study did not consider spiritual causes as some quantitative respondents did. However, there was culture as a perceived contributor to the genetic conditions in the qualitative study. Three major responses of the perceived causes in study I (quantitative study) showed that majority of the participants related their illness to Hereditary (189 cases), followed by lifestyle (143 cases) and spiritual causes (31 cases). Few participants did not answer this part of the questionnaire for reasons unknown or they could not tell what caused their condition. Hereditary was the main response from all participants in study II. However, culture, lifestyle and lack of knowledge were also highlighted as factors that contributed to their genetic condition. Similar results were found in a related study in Ghana (De-Graft, 2003).

Additional findings from the qualitative study were that, coping styles and the impact of the condition influenced the mental health of adults with a genetic condition (diabetes and sickle cell).

5.4 Implications and Recommendations

The study's major findings confirm that people with genetic conditions are more likely to have poor mental health. The difficulties faced by people with genetic disorders, as well as negative illness beliefs that patients identified as a barrier to their psychological well-being, are crucial to these findings. Due to these difficulties, professionals' clinical management skills must be enhanced to include the ability to screen for mental health deficits in patients with genetic conditions, or, better yet, an eclectic health care approach in which other professionals, such as psychologists and counselors, are involved in the care as well as management of these patients.

Furthermore, the findings of this study make recommendations to the Ministry of Health and the Ghana Health Service on how to adopt and effectively implement the biopsychosocial approach to chronic illness management by employing qualified clinical psychologists, health psychologist and counselling psychologists in various health care institutions to assist in the psychological care and management of patients with genetic diseases. Also, future studies can explore other mental health problems such as suicide, of adults with chronic genetic diseases. Additionally, future studies should use a sampling technique that will be representative of the population being studied.

Finally, counselling of people with genetic diseases will be very essential in helping them to manage their conditions right from the beginning before things get out of hand.

The outcome of this study implies that there is the need for more awareness or education on genetic conditions as well as counselling which help alleviate the mental health problems patients face.

Again, compulsory testing and accessible counselling will help reduce the growing burden of diabetes and sickle cell on health facilities in Ghana and Africa.

5.5 Strength and Limitations of the Study

This study outcome is essential to the development of psychological interventions tailored towards addressing mental health problems within the population of adults with genetic conditions. It can also serve as a baseline for other research areas on genetic counselling which are very few in Africa especially Ghana. This will help improve the quality of healthcare accessible to persons with genetic conditions. Finally, it will help inform health care providers on the need to boost education on genetic diseases.

Various limitations should be considered when interpreting and applying the study's findings. The study site had few people visiting for their clinical appointment which will be as a result of another wave of the COVID infection. The outbreak of the delta variant could be a possible extraneous variable which can contribute to some of the mental health challenges participants faced at the time of conducting the study(Joensen et al., 2020). Further to this, only few participants agreed to take part in the qualitative interviews. They were mostly people who could express themselves in English. The fact that others who could have responded in a local language were not included in the study should be considered when interpreting the findings. Last but not the least, the use of the Brief illness perception scale is case to consider when interpreting this study. Although the scale is short and suitable for studies where fatigue may occur, if questionnaire is too long. It is not adequate to completely obtain the scales construct-domains as each subscale is represented by a single item only.

5.6 Conclusion

Genetically acquired diseases: diabetes and sickle cell comes with depression, stress and anxiety as the study has shown. This study examined illness perception of adults with genetic conditions (diabetes and sickle cell) and their mental health quantitatively. It went further to explore it qualitatively, and sought to explore their perception about genetic counselling as well. Findings revealed that more severe illness perceptions lead to mental health problems such as depression and anxiety. It was also revealed that adults with genetic conditions perceiving their illness as more threatening lead to a low psychological wellbeing. In both studies, the illness perception components such as personal, identity and emotional response predicted mental health problems such as depression and anxiety. The type of genetic condition predicted more of mental health problem with sickle cells participants reporting more mental health problems, followed by type 1 diabetes and type 2 diabetes in both qualitative and quantitative findings. Demographic characteristics such as sex, and level of education showed no significant differences in the mental health problems faced by adults with genetic conditions.

Interestingly, genetic counselling, which is not very common in Ghana was perceived by adults with genetic condition as an essential part of health care that needs to be intensified. They further showed interest in pursuing and recommending the services of a genetic counsellor when made available in the Ghana. To patients with diabetes and sickle cell, there is the urgent for genetic education and awareness creation to help prevent or delay the onset of genetic conditions in general.

In conclusion, this study outcomes will be importance for future studies regarding genetic conditions and genetic counselling as well. The study will help in the development of interventions

geared towards dealing with the emotional responses to genetic illness which was the major contributory factor to mental health related problems of patients with diabetes and sickle cell as seen in the outcome of this study. Lastly, this study will add up to the limited research on illness perceptions and mental health issues that arise as a result of genetic conditions as well as genetic counselling related studies.

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Appendix 1: Questionnaire

UNIVERSITY OF GHANA-LEGON

Dear Participant,

My name is Roselyn Attah, a graduate student of the University of Ghana, pursuing a course leading to the award of an MPhil in Counselling Psychology. As a partial fulfillment, I am conducting a research to explore your beliefs about the condition you are diagnosed with and how these beliefs shape your mental health. Your contribution through honest completion of this survey is very much appreciated. Please note that **you do not have to provide your name or contact on any part of this document**.

Confidentiality is assured and information provided will be used strictly for academic purposes. There is no right or wrong answer!

Kindly sign (**Again your name is not required**) if you have agreed to take part in this study…….

Feel free to contact me if you have questions, suggestions or concerns; 0554337648/rattah@st.ug.edu.gh

Section A.

Sex: Male[ ] Female [ ]

Age: [ ]

Marital Status : Single [ ] Married [ ] Separated /Divorced [ ] Widowed [ ]

Religion: Christian [ ] Muslim [ ] Other[ ]

Education: None [ ] Primary [ ] Secondary [ ] Tertiary [ ] Master [ ]

Condition Diagnosed: Diabetes type 1[ ] Diabetes type 2 [ ] ,Sickle cell type (example :**SS,SC**,etc) [ ] ,

Duration of diagnoses…… _

INSTRUCTIONS: Please read the following sentences and tick against each sentence the number (0,1,2,3,4,5,6,7,8,9 or 10) that corresponds to your views.

Note that each question has its own meanings to the ratings written below.

		0	1	2	3	4	5	6	7	8	9	10
1	"How much does your illness affect your life? **(0-not affected at all – 10-severely affect my life)"**											
2	"How long do you think your illness will continue? **(0-very short time - 10-forever)"**											
3	"How much control do you feel you have over your illness?" **"(0-absolutely no control – 10 extreme amount of control)"**											
4	"How much do you think your treatment can help your illness? **(0-not at all- 10- extremely helpful)"**											
5	"How much do you experience symptoms from your illness?											

	(0-no symptoms at all- 10-many severe symptoms)"											
6	"How concerned are you about your illness? (**0-not at all concerned- 10 –extremely concerned)"**											
7	"How well do you feel you understand your illness? **(0-don't understand at all, 10 –understand very clearly)"**											
8	"How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?) **(0-not at all affected emotionally, 10-extremely affected emotionally**)"											

9. "Please list in rank-order the three most important factors that you believe caused your illness."
The most important causes for me:
1. _____

2. _____

3. _____

INSTRUCTIONS: "Please read through carefully and tick a number 0, 1, 2, or 3, which indicate how much the statement applied to you over the past week**. (0 means Never, 1 means Sometimes, 2 means Often, 3 means Almost Always**)"

	0	1	2	3
"I found it hard to wind down"				
"I was aware of dryness of my mouth"				
"I couldn't seem to experience any positive feeling at all"				
"I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)"				
"I found it difficult to work up the initiative to do things"				
"I tended to over-react to situations"				
"I experienced trembling (eg, in the hands)"				
"I felt that I was using a lot of nervous energy"				
"I was worried about situations in which I might panic and make a fool of myself"				
"I felt that I had nothing to look forward to"				
"I found myself getting agitated"				
"I found it difficult to relax"				
"I felt down-hearted and blue"				
"I was intolerant of anything that kept me from getting on with what I was doing"				
"I felt I was close to panic"				
"I was unable to become excited/interested about anything"				
"I felt I wasn't worth much as a person"				
"I felt that I was rather quick to take offense"				
"I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)"				
"I felt scared without any good reason"				

"I felt that life was meaningless"				

Instructions: "Mark one response below each statement to indicate how much you agree or disagree"

	Strongly agree 1	**Somewhat agree 2**	**A little agree 3**	**Neither agree nor disagree 4**	**A little disagree 5**	**Somewhat disagree 6**	**Strongly disagree 7**
"I like most part of my personality"							
"When I look at the story of my life, I am pleased with how things have turned out so far."							
"Some people wonder aimlessly through life, but I am not one of them"							
"The demands of everyday life often get me down"							
"In many ways I feel disappointed about my achievements in life."							
"Maintaining close relationships has been difficult and frustrating for me"							
"I live for one day at a time and don't really think about the future"							

"In general, I feel I am in charge of the situation in which I live"							
"I am good at managing the responsibilities of daily life"							
"At times, I feel as if I've done all there is to do in life"							
"For me, life has been a continuous process of learning, change and growth"							
"I think it is important to have new experiences that challenge how I think about myself and the world"							
"People would describe me as a giving person, willing to share my time with others"							
"I gave up trying to make big improvements or changes in my life long time ago"							
"I tend to be influenced by people with strong opinions"							
" I have not experienced many warm and trusting relationships with others"							
"I have confidence in my own opinions, even if they are different from the way most other people think"							
"I judge myself by what I think is important, not by the values of what others think is important"							

Thank you for participating.

Appendix 2: Semi-structured interview

UNIVERSITY OF GHANA - LEGON
(All rights reserved)

Dear Participant,

Thank you for agreeing to be interviewed. This research is to explore your knowledge and thoughts about genetic counselling services. Your participation is vital to generate research outcomes that has great significance to informing professionals to provide a more appropriate health services needed to improve the diagnosing and treatment of genetic diseases. Part One of this interview seeks information about your background or biographical information. Part Two seeks your thought and knowledge about genetic counselling, your beliefs about the illness you are diagnosed with and how it shapes your mental health. "Kindly note that your answers will neither be considered right nor wrong as such you are free to answer the questions in any way you want to. You can also choose not to answer the questions you are uncomfortable with." "If at any point during the interview, you do not want to continue, please feel free to let me know. If during or after the interview you feel anxious or scared, please let me know." "You are at liberty to ask me any questions that you have in mind at any point in the interview." Please note that this interview will remain anonymous. Please permit me to record an audio for easy reference.

Part One: Demographic Information.

(1) Sex:
(2) Age:
(3) Marital Status:
(4) Religion:
(5) Level of Education:
(6) Medical Condition Diagnosed
(7) Number of years of Diagnosis/treatment.

Part two: Semi structured interview

Perception/Awareness of genetic counselling

1.Tell me what comes to mind when you hear genetic counselling?

   a. Where did you first hear the term?
   b. Tell me whether you had such a service before? when was that? where?
   c. Or a friend /family member had such service before
   d. Tell me if a friend in that profession mentioned it.
   e. Tell me if a healthcare provider mentioned it.

2. Tell me what you think are the services you can gain from genetic counselling
   a. Who should provide such services?
   b. For what purpose do you think the service should serve?

Diagnosis, beliefs and reactions about illness.

3. What was your reaction when you were first diagnosed of the illness?
   a. Who communicated it to you?
   b. How was it communicated to you?
   c. Tell me how you felt when this was communicated to you.
   d. Tell me what came to mind that moment?

4. What were the reactions of your family or friends when you told them?
   a. How was their reaction?
   b. What was their concern?
   c. How did that affect you?

Importance of genetic counselling if available

5. Tell me how different you think your condition would have been if you had genetic counselling services before the condition was diagnosed
6. What do you think will be some of the benefits of providing genetic counselling to people who are at risk of developing genetic conditions?
7. Will you recommend the services of a genetic counsellor to friends, relatives and children?
   a. Why would you recommend it?

Other causes of illness

8. Apart from genetic causes, what other causes do you believe underlie your disease
    a. Lifestyle? Tell me more
    b. Ageing? Tell me more
    c. Spiritual? Tell me more
    d. Cultural? Tell me more
    e. Are there any other causes?

Impact of the condition on one's life

9. How has this condition affected your life?
    a. Relationship life? Tell me more
    b. Social? Tell me more
    c. Work life? Tell me more
    d. Family life? Tell me more
    e. Psychologically? Tell me more
    f. Emotionally? Tell me more
    g. Physically? Tell me more
    h. Overall mental health.
10. What suggestions would you like to give regarding genetic counselling?
    a. Is it needed? Tell me more
    b. When is the right time/age to get such service? Tell me more
    c. Any advice to the field of genetic counselling.? Tell me more

Debriefing

1.Tell me how you have felt during this interview?

2. Are there any questions you want to ask me for clarification?

3. Tell me if there are other questions you wished I had asked

4. Tell me if this study could be useful to those in similar situation.

Thank you.

Appendix 3: Consent form

UNIVERSITY OF GHANA

Consent Form

Title of Study:	Perception of genetic counselling, illness beliefs and mental health of adults with genetic conditions.
Student Investigator:	Roselyn Attah
Certified Protocol Number	ECH 142/20-21

General Information about Research

The purpose of this research is to understand your beliefs about the genetic conditions you are diagnosed with and how those beliefs influence your mental health. I would also want to find out, what you think genetic counselling is and whether you would like the services of a genetic counselor if introduced as part of the treatment or diagnoses of genetic diseases in the form of an interview.

The study will be in two parts. The first part, which is the survey, will last for 20minutes whereas the follow up interview sessions will last for 30-40minutes

The study will first be in a paper and pen format where you will be required to tick an answer that applies to each question. You will then be given the opportunity to participate willingly in an interview later, where you provide a more detailed information.

Benefits/Risks of the study

There is no direct benefit of this study to participants. However, your participation and contributing of your knowledge to a scientific research, which will inform future interventions to provide an improved healthcare services for genetic diseases, will be much appreciated.

You will not be exposed to any risk as a result of your participating in this research. However, should you experience any discomfort, sadness or any other emotional trauma, you will be referred to the appropriate unit for therapy.

Confidentiality

Please be assured that all the information you will provide here will be purposely for the study and nothing else. The study has been planned or designed in a way that there will be no form of identification. However, you will be required to sign this document to acknowledge your consent.

Please note that all other information provided in the interview will be used purposely for academic work therefore will not be shared with anyone apart from my academic supervisors. The results of the study maybe published in an academic journal and again your identity will be protected. All recordings will be saved in a password-protected manner where only the research can access.

Compensation

Please note that there is no compensation for your participation, however your participation will be very much appreciated.

Withdrawal from Study

Please note that participation in this research is voluntary and you are free to withdraw from the study at any point in time without any consequences. I will monitor your behavior such that certain issues such as discomfort, extreme sadness etc. may mean you cannot continue with the study. Again, leaving the study halfway will not go against you in any way.

Contact for Additional Information

If you have any questions or clarifications about this study, kindly contact the principal investigator through the following contacts

Ms. Roselyn Attah, Department of Psychology, University of Ghana, Legon. P. O Box LG 84,Legon.Email: rattah@st.ug.edu.gh/rossattah@yahoo.com, mobile number:0554337648

- If you have any questions about your rights as a research participant in this study you may contact the Administrator of the Ethics Committee for Humanities, ISSER, University of Ghana at ech@ug.edu.gh or 00233- 303-933-866.

PARTICIPANT AGREEMENT

"I have read or have had someone read all of the above, asked questions, received answers regarding participation in this study, and am willing to give consent for me, my child/ward to participate in this study. I will not have waived any of my rights by signing this consent form. Upon signing this consent form, I will receive a copy for my personal records."

_____

Name of Participant

_____

Signature or mark of Participant Date

"If participant cannot read and or understand 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."

_____

Name of witness:

Signature of witness / Mark Date

"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."

Name and signature of Person who Obtained Consent

Please provide your contact if you would like to participate in an interview session.
Number……..

Appendix 4:Ethical Approval from Ethics Committee for Humanities

UNIVERSITY OF GHANA

ETHICS COMMITTEE FOR THE HUMANITIES (ECH)

P. O. Box LG 74, Legon, Accra, Ghana

My Ref. No…ECH 142/ 20-21…

May 12, 2021

Roselyn Attah
Department of Psychology
University of Ghana
Legon

ETHICAL CLEARANCE
(ECH 142/ 20-21)

The protocol title below has been reviewed and approved by the ECH Committee.

TITLE OF PROTOCOL: **PERCEPTION OF GENETIC COUNSELLING, ILLNESS BELIEFS AND MENTAL HEALTH OF ADULTS WITH GENETIC**

DISEASES PRINCIPAL INVESTIGATOR**: ROSELYN ATTAH**

"Please note that the final review report must be submitted to the Committee at the completion of the study. Your research records may be audited at any time during or after the implementation. Any modification of this research project must be submitted to ECH for review and approval prior to implementation."

"Please report all serious adverse events related to this study to ECH within seven (7) days verbally and in writing within fourteen (14) days."

This certificate is valid till May 11, 2022. You are to submit annual reports for continuing review.

Please accept my congratulations.

Yours Sincerely,

Professor C. Charles Mate-Kole
ECH Chair

Cc: Prof. Joseph Osafo, Department of Psychology, UG
Prof. Charity Akotia, Department of Psychology, UG

Tel: +233-303933866 Email: ech@ug.edu.gh

Appendix 5: Demographic characteristics of qualitative participants

Participants	Sex	Age	Marital Status	Religion	Level of Education	Genetic condition diagnosed	Number of years diagnosed
P 1	Male	61	Married	Christian	Tertiary	Diabetes type 2	15years
P2	Female	41	Married	Christian	Tertiary	Diabetes type 1	8years
P3	Female	41	single	Christian	Tertiary	Type 1 diabetes	9years
P4	female	48	married	Muslim	tertiary	Diabetes types 2	3years
P5	male	47	married	Christian	Senior high school	Diabetes type 2	1 year
P6	male	43	married	Christian	primary	Diabetes type 2	3years
P7	female	20	single	Christian	secondary	Sickle cell (SS)	20 years
P8	Femal	30	single	Christia	tertiary	Sickle	30years

	e			n		cell (SS)	
P9	Male	43	single	Christian	Diploma	Sickle cell (SS)	43years
P10	Male	35	Married	Christian	Tertiary	Sickle cell (SS)	35years
P11	Female	61	widowed	Christian	Tertiary	Diabetes type 2	10years
P12	female	63	married	Christian	Tertiary	Diabetes type 2	8years