UNIVERSITY OF CAPE COAST

PSYCHOLOGICAL DISTRESS AND COPING STRATEGIES OF CAREGIVERS OF CHILDREN WITH CHRONIC CONDITIONS IN THE ASHANTI REGION OF GHANA

AYIMBIRE BENJAMIN ABASS

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BY

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Thesis submitted to the Department of Education and Psychology, Faculty of Educational Foundations of the College of Education Studies, University of Cape Coast, in partial fulfilment of the requirements for the award of Master of Philosophy Degree in Clinical Health Psychology

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DECLARATION

Candidate's Declaration

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

Candidate's Signature ……………………………   Date ……………….

Name: ……………………………………………………………………………

Supervisors' Declaration

We hereby declare that the preparation and presentation of the thesis were supervised in accordance with the guidelines on supervision of thesis laid down by the University of Cape Coast.

Principal Supervisor's Signature …………………   Date…………………

Name…………………………………………………………………………….

Co-Supervisor's Signature …………………......   Date ……………………

Name ………………………………………………………………………

ABSTRACT

Using the family systems theory and the transactional model of stress and coping, the study assessed the coping strategies employed by caregivers of children with chronic conditions (Epilepsy and Sickle Cell Disease) and the psychological distress (Depression, Anxiety and Stress) they experienced in the course of caregiving. The descriptive survey research design was employed and a sample size of 156 caregivers was selected using quota sampling procedure. Questionnaire consisting of adapted DASS 21 was used to collect data on psychological distress whilst data on coping strategies were collected using the Brief Coping Inventory. Descriptive statistics were used in analyzing some research questions while inferential statistics were used to compare differences and relationships among variables using SPSS version 22.0. It was found among other things that more than half of the caregivers of children with SCD have severe to extreme levels of stress whilst only 25.6% of the caregivers of children with epilepsy were found to experience severe to extreme levels of stress. Active and religious coping were found to be the most used coping strategies by both categories of caregivers. There were differences in the levels of psychological distress experienced by caregivers of children with SCD based on their gender but no differences were found in caregivers of children with Epilepsy based on gender. Support systems such as psychotherapy, health education, social and financial support to ease the burden of caregiving on caregivers are recommended.

KEY WORDS

Caregivers

Children

Chronic conditions

Coping strategies

Epilepsy

Psychological distress

Sickle Cell

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DEDICATION

To all caregivers of children with Epilepsy and Sickle cell disease

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LIST OF ACRONYMS/ABBREVIATIONS

BCI	-	Brief Cope Inventory
DASS	-	Depression Anxiety Stress Scale
DSM	–	Diagnostics and Statistical Manual
GHS	–	Ghana Health Service
SCD	–	Sickle Cell Disease
SPSS	–	Statistical Package for Social Sciences
WHO	–	World Health Organisation

CHAPTER ONE

INTRODUCTION

Background to the Study

Children are seen as gifts to parents and families at large but chronic illness in children can be very disruptive to families and may result in undesirable effects on the daily functioning and quality of life of caregivers /family members (Smith, Cheater & Bekker, 2013). The basic function of adults in families is to cater for children and support them through their difficulties and growing process (Horn & Kang, 2012). Even though caring for children is a normal role of parents, when a child has a chronic condition this role becomes more highlighted as living with a child with a chronic ailment can result in tasks above usual parenting responsibilities due to illness-specific demands such as maintaining care regimes, cultural and social constraints and maintaining family relationships (Vermaes, Janseens, Mullaart, Vinck & Gerris, 2008). Caregiver anxiety over poorer life outcomes of their children and increased dependency on family support systems in adulthood leads to heightened psychological effects on caregivers (Perrin, Bloom & Gortmaker, 2007; Juonala et al, 2009).

A study by Bethell, Newacheck, Fine, Strickland, Antonelli, Wilhelm and Wells (2014) indicated that as at 2009, 15.1% of all children in the US were considered to have chronic diseases and one out of every five households in the United States had at least one child with special healthcare needs representing a significant segment of the nation's population (NS-CSHCN

2009/10). Newacheck, Strickland, Shonkoff, Perrin, McPherson, McManus and Arango (1998) postulated that families with income below the federal poverty level are one third more likely to bear children with chronic illness, and families with twelve or fewer years of education have increased prevalence of a child with Chronic disease as well. The prevalence of chronic conditions in children is on the rise (Van Cleave, Gortmaker, & Perrin 2010; Pai & McGrady, 2014) thus showing the picture of a large population size of caregivers experiencing psychological effects in caring for these children with chronic conditions.

According to Tang and Chen (2002) there is an increase in psychological health risks among caregivers of children with chronic conditions which influences their well-being and quality of life. Psychological health risks have been identified as being capable of manipulating the caregivers’ roles in the form of social isolation, personal coping styles, stress, depression and anxiety levels, poor sleeping patterns and other psychological health complications (Fee & Wu, 2011: Greenwood, Mackenzie, Cloud & Wilson, 2009). Caring for children with chronic conditions can also result in occupational imbalance due to family, career, and care giving demands, hence the need for caregivers to employ coping strategies capable of reducing the adverse psychological distress of rendering care (Townson & Wilcock, 2004). Most of the literature on caregivers has purported that providing care to chronically ill individuals plunge caregivers into psychological distress and has ruinous effect on the quality of life for the caregiver (Elliott, Burgio, & DeCoster, 2010). Rendering care services to children with chronic conditions runs down the energy of caregivers and exposes them to psychological and emotional problems and isolation risk, and results in depression, anxiety, mental distress, shame and suicidal thoughts (Abedi, Abbaszadeh, Kazemi, & Pouraboli, 2014). This is why caregivers are sometimes referred to as the “hidden patients” (Sawatzky & Fowler-Kerry, 2003). As the care for children with chronic conditions such as epilepsy and sickle cell expose the caregivers to psychological effects (depression, anxiety and stress), these compel them to make use of certain coping strategies to enable them carry out their caregiver roles with minimal effects (Greenwood, Mackenzie, Cloud & Wilson, 2009). Epilepsy is a chronic condition that usually begins in childhood and is among the most common neurological disorders in children (Hirtz, Thurman, Gwinn-Hardy, Mohamed, Chaudhuri & Zalutsky, 2007). Epilepsy like any other chronic condition in children has an increased risk for psychosocial and emotional challenges to the clients and their caregivers (Mott, Shellhaas, & Joshi, 2013).

Studies indicated that the prevalence of epilepsy in children and adolescents is approximately 0.7% (Boyle et al., 2011; Russ, Larson, & Halfon, 2012). According to the World Health Organisation (WHO), approximately 50 million people worldwide are suffering from epilepsy (WHO, 2012). Epilepsy accounts for 0.5% of the global burden of disease, and 80% of the burden of epilepsy is found in developing countries as epilepsy ranks 19th in its contribution to the total disease burden in both Southern and Eastern sub-Saharan Africa and 14th in Western sub-Saharan Africa—higher than anywhere else in the world (Murray, Vos, Lozano, Naghavi, Flaxman & Michaud, 2012). About 10 million people in Africa are directly affected by epilepsy (WHO, 2016).

According to Hirtz and Nordi (2012) one percent of children are diagnosed of epilepsy though four to ten percent of all children experience a seizure by age 20 years. Epilepsy has high incidence in poor countries especially in Africa and Ghana is no exception (Newton & Garcia, 2012). Despite the prevalence of epilepsy in Ghana and the sub-region, enough studies have not been conducted on the condition and its effects on parents (Ayuurebobi, Adjei & Akpalu, 2015). Epilepsy comes with seizures which are frightening and potentially damaging; creates uncertainty about its possible repercussions and threatens the integrity of family systems (Ott, Siddarth & Gurabani, 2003). In the Ghanaian social context, epilepsy is stereotyped 'sudden craziness' of people and affected family feel shamed by the stigma (Thurman., Beghi, Begley, Berg, Buchhalter, Ding, & Kroner, 2011). When a child has a chronic disease, the labelling affects the family's experience in terms of stress and their coping process. Just a few studies have focused on how parents with an epileptic child adapts to family stress (Wang, Chen, & Chen, 2018).

Sickle Cell Disease (SCD) is classified as a main haemoglobin disorder and has been recognised to have a global impact on both sufferers and caregivers by the World Health Organisation (WHO). According to Weatherall and Clegg (2001) more than 300,000 babies are born worldwide with SCD mostly in middle- and low-income countries, with the majority of these births in Africa. By and large, the prevalence of healthy carriers (sickle cell trait) is between 10% and 40% across equatorial Africa and decreases to between 1% and 2% in Northern Africa but less than 1% in Southern Africa. In African countries such as Ghana and Nigeria, the frequency of carriers is

15% to 30% while the East African countries such as Uganda and Tanzania it indicates wide variations of up to 45% in some areas (WHO, 2006).

Globally, it is estimated that SCD occurs in approximately 300,000 births annually, SCD is most prevalent in malaria endemic parts of the world, primarily Africa, the Middle East and South Asia. Primarily 10% to 40% of the population carries the sickle-cell gene in many African countries, resulting in estimated SCD prevalence of at least 2% (Piel, Hay, Gupta, Weatherall & Williams 2014). Modell and Darlison (2008) indicated in their study that in resource-poor countries, 90 percent of children with SCD do not live to adulthood and this could be a leitmotif to the psychological effects experienced by caregivers of these affected children. This problem is on the rise; by 2050 the number of people with SCD is projected to increase by about 30 percent globally (Piel, Patil, Howes, Nyangiri, Gething, P. W., Dewi, & Hay, 2013).

Biswas (2013), used estimates of the prevalence of sickle cell anaemia to predict that the number of cases in new-borns is likely to rise to about 404 200 in 2050, up from 305 800 in 2010, between 2010 and 2050 about 14.2 million babies will be born with sickle cell disease.

Each phase of a chronic illness in a child can bring about significant challenges and stressors to the caregiver; conversely, there is evidence that chronic conditions may wield greater psychological and physical stress than other conditions that resolve speedily (Marin, Chen, Munch & Miller, 2009). This is in line with more general models of the adverse effects of chronic stress as a consequence of processes of all the allostatic load that include the psychological and emotional wear and tear associated with persistent or recurring demands that characterise chronic stress of caring for children with chronic conditions (Juster, McEwen & Lupien, 2010).

Caregivers of children with chronic diseases adjust in several aspects of life to suit their special care needs. The psychological and physical stress associated with raising such children could be multi-fold as caring for such children can be a physically and mentally involving job (Wang, Chen, & Chen, 2018). While nursing and nurturing these sick children, the needs of the caregivers are seldom thought of (Sawatzky & Fowler-Kerry, 2003). It is very likely that even the parents of these children with chronic conditions need help to cope with the physical, mental and emotional effects they bear while caring for their loved ones (Lazarus & Folkman, 1984). A chronic diseased child's family adjusts in several aspects of life to suit the needs of their child. The physical and psychological effects associated with raising such children could be multi-fold. Caring for such children can be physically and mentally tasking job, depending on the type of condition resulting in compromised quality of life of the caregivers (Thompson, 2000). According to Thompson care that is given to a normal child itself is taxing for the parents many a times and to provide a higher level of life long care to a child suffering from long-term functional limitations may be strenuous for the parents. This according to Thompson may be affecting their depression, anxiety and stress level as becoming the parent of a child who has some disability in itself can be a time of great stress and change in living pattern.

Weiten and Lloyd (2008) found that to reduce the psychological effects and improve the quality of life, parents use conscious efforts which are termed coping strategies. Coping requires a cognitive reappraisal and analysis of the situation to manage it properly, a number of studies have prioritised the degree to which caregivers of children with chronic conditions feel psychologically stressed, how they manage, what factors support them, and what coping strategies they employ (Beckman 1991; Lazarus & Folkman, 1984; Wang, Chen, & Chen, 2018). Becoming the parent of a child who has some form of chronic condition in itself can be a time of great psychological effects and change (Thompson, 2000). Sicknesses that were once deadly are now successfully treated and children stay alive at much higher rates than 20 to 30 years ago as many of the parents cope with their child's condition relatively well and are able to live their lives normally therefore signifying the significant roles good parental coping plays in times of a child's illness (Halfon & Newacheck 2010). However, coping with a child suffering from a chronic condition is a highly individual process. There is enough evidence to suggest that some families may never adjust fully to this event (Koller, Richardson & Katz, 1992; Mokkink, van der Lee, Grootenhuis, Offringa & Heymans, 2008).

Far-reaching evidence proposes that coping responses are not universally effective or ineffective; relatively the level to which a coping strategy leads to good or worse emotional and behavioural adjustment is determined in part on the match between the demands of the stressor and the goals and nature of the coping response of the caregivers (Taylor & Stanton, 2008). From Taylor and Stanton, it can be deduced that the knowledge levels, standard of living, environment and culture are relevant yardsticks in determining the psychological effects and coping strategies employed by caregivers of children with chronic diseases.

Parenting children with chronic conditions can be very stressful. Bethell (2012) for instance, argued that caregivers of children with chronic conditions experiences stress in higher degrees therefore a study on the plight of these parents is deemed necessary. Similarly, Hoare and Kerley (1991) also indicated that parents with children with chronic conditions experience significantly more depression, stress, anxiety and restrictions in parental life than other parents who do not cater for children with chronic diseases. Parenting is a lifelong activity and the roles parents play in the event of their child's sickness cannot be undermined as stress, depression and anxiety threaten the quality of life and psychological wellbeing of parents who lack appropriate coping strategies to handle their child's chronic condition (DeVellis, DeVellis, & Spilsbury, 1988). It appears that the psychological effects associated with being a caregiver of a child with a chronic condition has not been adequately studied in Africa especially Ghana though statistics from existing literature shows this part of the world to be the hub of chronic conditions in children, making it a gap in the study area which this study is intended to resolve.

The effects of childhood chronic condition on the caregivers can be substantial (Thurman, Beghi & Begley, 2011), given that parental emotional well-being can be affected by a child's chronic condition. While Abuosi etal, (2015) investigated the financial burden on caregivers, Yawson etal, (2016) studied the health and social concerns of caregivers of children with chronic diseases in Ghana, other studies (Ae-Ngibise et al., 2013, Nyame & Biritwum, 1997) also dealt with perceptions, stigma, among others. with scanty or no study on the psychological health of caregivers and the coping mechanisms they employ in their caregiving role though high caregiver stress and poor psychological well-being, comprising anxiety and depression negatively affects the behaviour of care recipients (Romero-Moreno, Losada, Mausback, Marquez-Conzalez, Patterson, & Lopez, 2011).

Statement of the problem

Existing literature has shown that a greater number (about 80%) of children suffering from chronic conditions are in Africa (Murray, et al. (2012). The burden associated with caring for children with chronic conditions encompasses the emergence of psychological distress, occupational and social restraints (Smith, Cheater & Bekker, 2013). Caregivers knowledge and awareness, believe systems, education and facilities available determine the types and levels of burden experienced in performing the caregiving roles (Ansong, Akoto, Ocloo & Ohene-Frempong, 2013).

The ways in which a family copes with the psychosocial demands of chronic condition in a child can influence family functioning. However, it appears as if only few studies have examined SCD-related stressors beyond pain or how children and caregivers cope with these stressors (Hildenbrand, Barakat, Alderfer, & Marsac, 2015). Though the prevalence of chronic conditions is in Africa, most of the studies have focused less on Africa and its effects on the caregivers. The findings and conclusions from the developed world may not be generalisable to developing countries due to the cultural, socio-economic and geographical differences that exist between these two factions thus necessitating the need for this study. The prevalence of chronic conditions amongst children in Ghana and its burden on the affected individuals and their families is not entirely different from other parts of

Africa as stigmatisation and myths regarding the causes and management practices of chronic diseases in children are almost the same in Africa (Nyame & Biritwum, 1997; Diop, de Boer, Mandlhate, Prilipko, & Meinardi, 2003).

There are some studies in Ghana on the prevalence, attitudes, challenges and risk factors for epilepsy including the effects of epilepsy on affected individuals in some parts of Northern and Southern Ghana (Ae-Ngibise etal, 2013; Nyame & Biritwum, 1997). However, depression, anxiety, stress and coping strategies of the Ghanaian caregivers appear not to have been examined by any study.

Studies on the psychosocial effects of epilepsy on family’s in London by Thompson and Upton (1992), indicate the burden children with epilepsy poses as a chronic condition that requires prompt attention to avoid injuries and damage to affected children. This burden could lead to psychological breakdown of caregivers of children with chronic diseases which could lead to depression, anxiety and or stress. A systematic review by Ferro and Speechly (2009) indicates that 50% of mothers of children with chronic diseases develop depression during the tenure of care for their sick child and that anxiety disorders ranging from generalised anxiety disorder to phobias of various forms occurs in parents of epileptic children as women are at high risk of developing anxiety disorders.

Despite the plight of parents in seeking appropriate care and treatment for their children with chronic conditions, there appears to be no study conducted in Ghana or West Africa that has investigated the effects a child’s chronic condition poses on the psychological wellbeing of caregivers and the possible strategies employed by the caregivers to enable them cope with the challenges they encounter as a result of caring for the sick child. This study is therefore designed purposely to assess the psychological distress (anxiety, depression and stress levels) of caregivers of children with chronic conditions (specifically sickle cell disease and epilepsy) and also investigate the coping strategies commonly used in caring for these children.

Purpose of the study

Generally, the study sought to assess the coping strategies employed by caregivers of children with chronic conditions and the psychological distress experienced in the course of caregiving in the Ashanti region, Ghana.

Specific Objectives of the study

The study specifically sought to:

Assess the levels of psychological distress (depression, anxiety and stress) experienced by caregivers of children with chronic conditions in Ashanti region, Ghana.

1. Assess the coping strategies used by caregivers of children with chronic conditions
2. Assess the differences in the levels of psychological distress between male and female caregivers of children with chronic conditions
3. Examine the differences in the levels of psychological distress experienced by caregivers of children with epilepsy and sickle cell disease.
4. Examine the relationship that exists between psychological distress and coping strategies used by caregivers of children with chronic conditions.

5. Determine the moderating role of marital status in the relationship between psychological distress and coping strategies in caregivers of children with chronic conditions.

Research question

The following research questions guided the study

1. What is the level of psychological distress experienced by caregivers of children with chronic conditions in Ashanti region, Ghana?
2. What coping strategies are mostly used by caregivers of children with epilepsy and caregivers of children with sickle cell disease in Ashanti region, Ghana?

Hypotheses

The following hypotheses guided the study

1. H_0: There is no significant difference in the levels of psychological distress experienced by male and female caregivers of children with chronic conditions.

   H_1: There is a significant difference in the levels of psychological distress experienced by male and female caregivers of children with chronic conditions.

2. H_0: There are no significant differences in the levels of psychological distress experienced by caregivers of children with epilepsy and sickle cell disease.

   H_1: There are significant differences in the levels of psychological distress experienced by caregiver of children with epilepsy and sickle cell disease.

3. H_0: There are no significant relationships between psychological distress and coping strategies used by caregivers of children with epilepsy and sickle cell disease.

H_1: There are significant relationships between psychological distress and coping strategies used by caregivers of children with epilepsy and sickle cell disease.

4. $H_{0:}$ Marital status does not moderate the relationship between coping strategies and psychological distress in caregivers of children with chronic conditions.

   $H_{1:}$ Marital status moderates the relationship between coping strategies and psychological distress in caregivers of children with chronic conditions.

Significance of the study

This research is deemed significant for identification of the psychological effects (these are; anxiety, depression and stress) on caregivers of children with chronic conditions (epilepsy and sickle cell disease) and the coping strategies they employ in the performance of their care for the child suffering from the chronic condition. The knowledge obtained would be useful in the formulation of recommendations to the Mental Health Authority, Ghana Psychological Council and Ghana Health Service to address the plight of caregivers who have children with epilepsy/sickle cell disease. The study will also serve as a guide to understanding the effects a child's chronic disease poses on the psychological wellbeing of his/her caregivers by health care professionals and other clinicians. Finally, the study will contribute to research on child epilepsy and sickle cell disease and effects of chronic child conditions on parents/caregivers by adding to existing literature.

Delimitations of the study

Though other effects might also be present in the course of rendering care to the children with epilepsy and sickle cell disease the study is delimited to only psychological distress (depression, anxiety and stress) and the coping strategies used by caregivers. Also, only the direct caregivers were selected as they live together with the sick child and are responsible for the care and upbringing of the children suffering from the chronic condition. Additionally, though the prevalence of epilepsy/SCD is said to be nationwide, the study was conducted in only five (Tafo, Manhyia, Pampaso, Ejisu and Effiduase) out of the 30 districts in the Ashanti.

The study did not consider the effects of the chronic condition on the clients though the children with epilepsy and SCD might have psychological and or emotional disturbances due to the condition they are suffering from.

Limitations of the study

This section of the study dealt with what might affect the reliability and validity of the instruments used for the study. One limiting factor was the inability of the researcher to employ varied instruments for data collection as the use of only questionnaire limited the ability of the respondents to express other views about the phenomena.

Again, the study did not consider other places where caregivers go to seek solutions for their children with chronic conditions such as the prayer camps and traditional healing centers due to their improper records keeping and inaccessibility though this could have enriched the data.

Also, the involvement of only caregivers who visited hospitals on the days data was collected made the sampling procedure a convenient technique. Simple random sampling procedure could have given an equal opportunity for all caregivers to participate in the study to give a fairer representation and enhance the reliability of the study.

Definition of terms

Terminologies used in the study are operationally defined as follows:

Caregiver: Anyone who takes care of the needs and welfare of a child with epilepsy and sickle cell disease.

Children: Persons under the age of 18 years diagnosed as suffering from sickle cell disease or epilepsy.

Psychological distress: The anxiety, depression and stress that those caring for children with epilepsy and sickle cell disease experience.

Chronic conditions/diseases: A chronic condition refers to a condition disturbing the daily functions of people for at least three months out of a year. Chronic disease/condition in this study mainly refers to epilepsy and sickle cell disease.

Organisation of the Study

The study is organised into five main chapters. The first chapter dealt with the general introduction of the study, encompassing the background to the study, statement of the problem, purpose of the study, research questions, and significance of the study, delimitation and limitations of the study and organisation of the rest of the study. Chapter two presents the review of related literature. It covers the conceptual review, theoretical frame work of the study and the empirical review. Chapter three presents the methodology underpinning the study, this involves the research design, population, sample and sampling procedure, research instrument, validity and reliability instrument, data collection procedure as well as data analysis. Chapter four focused on the presentation of results and findings of the study. Chapter five which is the final chapter of the study presents the summary of the study, conclusion based on the findings of the study, recommendations and also suggests areas for future research.

Chapter Summary

This chapter dealt with the background of the study, delving into the incidence of SCD and epilepsy in children and its effects on caregivers from Ghana, Africa and the world at large. The statement of the problem which is simply the inadequate attention given to caregivers of children with chronic conditions amidst the psychological distress (depression, anxiety and stress) associated with their roles coupled with the paucity of literature in Ghana of caregiving in this area. The chapter also dealt with the hypothesis and research questions aligning the objectives of the study which provided the route to making the significance of the study realized. Since the study did not cover everything in the area, limitations and delimitations, operational definitions of terms used in the study and the organization of the study were written in this chapter.

CHAPTER TWO

LITERATURE REVIEW

This chapter focuses on the scholarly works or researches that are linked to the problem under investigation. The chapter has three (3) components. They are: Theoretical Review, Empirical Review and Conceptual Review.

Conceptual review

The concept of epilepsy

The word 'epilepsy' is of Greek origin and has the same root as the verb epilambanein, which means to seize, to take hold of, or to attack (Reynolds & Rodin, 2009). Epileptic seizures are usually dramatic events predominantly generalised tonic clonic seizures with loss of consciousness, falls, bilateral rhythmic jerking of the skeletal muscles and minimal or no breathing with cyanosis resulting in a period of profound unresponsiveness that may last minutes or hours and then finally there is a gradual return of consciousness (Camfield & Camfield, 2018). A person is said to be suffering from epilepsy when there are at least two unprovoked seizures 24 hours apart (Fisher, et al. 2014). Throughout history and until the late 19th century and early 20th century, epilepsy was commonly regarded as a mental disorder, albeit Hippocrates and his Greek School first suggested it was a brain disorder in as early as the 5th century B.C. (Reynolds & Trimble, 2009).

In line with the above Engel (1995) also explained the concept of epilepsy as either a genetic or acquired disorder characterised by recurrent paroxysmal seizures that occurs as a result of endogenous or exogenous precipitating factors. In his view, the concept of epilepsy is basically a neurological disorder that manifest primarily with seizure attacks differentially diagnosed from other conditions (such as delirium tremens, alcohol intoxication, systemic infections, malaria and anaemia) that has seizure as one of its signs. The location and extent of cerebral disturbance, as well as the alterations of excitatory and inhibitory mechanisms in the brain determines the type of epileptic seizure a child will experience (Engel, 1995).

In a more elaborative and recent study by Fisher et al (2014) the concept of epilepsy as a disease characterised by a continuing predisposition to produce epileptic seizures. Fisher et al indicated in their findings that epilepsy is a disease involving recurrent unprovoked seizures. A seizure is seen as an event or a consequence of the condition (epilepsy) orchestrated by abnormal excessive or synchronous neuronal activity in the brain. Epilepsy in children could result in epileptic encephalopathy and transient or prolonged effects on learning (Barry & Holmes, 2016). According to Hesdorffer, Benn, Cascino and Hauser (2009) epilepsy comes in several forms irrespective of differences in age with similar but not same manifestations. According to them, what is common is brief loss of consciousness, jerking occurs depending on the aetiology.

From the discussions above, it can be said that a person is said to have epilepsy if he/she experiences not less than two unprovoked (or reflex) seizures occurring greater than 24 hours apart, or a person experiences one unprovoked seizure and with the probability of further seizures akin to the general recurrence risk (at least 60%) (Fisher, et al 2014; Camfield & Camfield, 2018; Engel, 1995).

Epilepsy is considered to be resolved for individuals who have remained seizure-free for 10 years and have not taken any seizure medication for 5 years (Fisher etal 2014).

The concept of Sickle cell disease

Sickle cell disease (SCD) is a major genetic disease usually inherited from parents (Anie, & Green, 2015). The normal round shape of red blood cells become crescent in sickle cell disease. Round red blood cells can move easily through the blood vessels but sickled shaped cells interlock and can result in cyanosis and blood clots leading to pain in affected children (Anie & Green, 2015; Edwards et al, 2005). Sickle cell disease (SCD) is the most common genetic disorder of the blood caused by the production of ominously abnormal haemoglobin molecules in red blood cells (Jacob, 2001). The sickling of red blood cells transpires when deoxygenated haemoglobin molecules distort their normal disk shape, producing rigid, gluey, sickle-shaped cells that blocks small blood vessels and produce vaso-occlusion and the interruption of oxygen to body tissues mostly often around the joints of the body (Edwards et al, 2005; Jacob, 2001). These blood clots can cause severe pain in the chest region, hands, feet and back as blood flow is disrupted. SCD can cause damage to the bones, muscles and some organs and make children with sickle cell disease look pale, feel tired and weak (Anie, 2005). Environmental factors such as harmattan, rains and cold often plays a role in the occurrence of painful attacks. Common environmental triggering factors include cold temperatures, dehydration, excessive amounts of exercise and smoke, plane flights and high altitudes can also trigger an attack in some children (Anie, 2005; Chen, Cole, & Kato, 2004).

In Africa, majority of the children with the most severe form of sickle cell disease die by age 5, commonly from an infection or severe blood loss (Piel, Hay, Gupta, Weatherall & Williams, 2013). In countries such as Ghana and Nigeria the prevalence is estimated to be 20% to 30% while in Uganda it is as high as 45% in some areas (WHO, 2006). Based on the descriptions of the concept of sickle cell disease by WHO (2006), Anie (2005), Chen, Cole and Kato (2004), Anie and Green (2015), Edwards et al (2005) and Jacob (2001) this study refers to the concept of sickle cell disease as a haemoglobin disorder that is characterised by pain in some circumstances such as cold temperature, excessive exercise, extremes of emotions and high altitudes acquired genetically from parents who are carriers of sickle cell traits.

The concept of coping

Coping with nerve-racking situations is one of the major challenges of human life (Dardas & Ahmad, 2015). Coping refers to the behavioural and cognitive efforts that are constantly changing to master, moderate or bear a specific condition appraised as exceeding one's available resources and abilities (Lazarus & Folkman, 1984). Coping strategies are well thought-out as the intermediate processes between stressors and health outcomes hence are the recipes for the psychological wellbeing of caregivers of children with chronic conditions. Having a child is seen as a blessing to most parents though caregiving is considered stressful and task involving, however caregiving of children with chronic conditions poses a greater stress on caregivers and can disrupt a whole family process thus requiring a range of coping strategies

(Gray, 2006). Coping is a cognitive process followed by action that gives us a positive direction as well as a negative direction to handle stressors, but this depends on the choice of coping strategies (Salem & Ahmad, 2016).

The Concept of Caregiving

Persons at the helm of affairs in the provision of care and other services such as facilitating medications adherence, coordinating with doctors and nurses on behalf of their clients (children with chronic conditions), helping in the observance of self-care needs of children with chronic conditions as well as providing meals or paying bills for others (children with chronic conditions) are referred to as caregivers (Khanna, 2015). Caregivers are persons who take care of other members of the family suffering from a chronic condition which needs the assistance of other people in order to live. People rendering unpaid services to children are usually biological parents or grandparents with no professional certification for rendering care and as such are referred to as informal caregivers (Oliva-Moreno, Trapero-Bertran, Peña-Longobardo, & del Pozo-Rubio, 2017). Caregivers are most often than not suffer from psychological distress when their perceptions on the future outcomes of children with chronic conditions are thought to be poor life and increased dependency on the family (Perrin, Bloom & Gortmaker, 2007).

According to Ridner (2004), caregivers play vital roles in identifying the client's strengths or weaknesses that contribute to distress and also provide support, education, and realistic options for dealing with the discomfort which a chronic condition imposes on the children and as such psychological distress ensues since most parent caregivers assume the roles due to circumstances but not specially trained as givers of care.

The Concept of Psychological distress

Psychological distress is a concept commonly used in psychology, medicine and nursing in reference to a state of discomfort and negative emotions such as irritability, dysphoria resulting from a specific situation or condition (Ridner, 2004). Psychological distress denotes the overall concept of maladaptive psychological functioning in the face of stressful life occurrences (Abeloff, Armitage, Lichter, & Niederhuber, 2000). The stressors and general bio psychosocial implications on caregivers such as loss of time to work and earn, reduction in leisure, social and recreational activities and the psychological facts and distortions makes up the distress in caregiving (Abeloff et al., 2000; Bussing, Gary, Mason, Leon, Sinha, & Garvan, 2003).

Psychological distress as studied in some multiracial women by Chew-Graham, Bashir, Chantler, Burman, and Batsleer, (2002) was conceptually described as the aggregate of emotional (depressive, anxiety) and stress signs and symptoms manifested negatively following an unpleasant situation. Most of the time, women experience psychological distress, this expresses itself in anxiety and depression as they are usually the most burdened caregivers in most families in crisis situations (Chew-Graham et al., 2002). The concept of psychological distress is understood as a multifactorial negative emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that interferes with the ability to cope effectively with a situation, stressor or ailment and its demands and remedies (Mehra, Berkowitz & Sanft, 2018). According to Mehra et al. (2018) the challenges and threats sums up on individuals and plunge them into a state of being where coping is either absent or difficult to apply leading to deterioration in mood and overall performance of affected persons.

Theoretical Framework

The researcher adopted two theories of coping and psychological distress as a lens through which the work was based. Specifically, the theories that were applied in the study are: Transactional model of stress and coping **(**Lazarus & Folk man, 1984) and the Family systems theory (Bowen, 1978).

Transactional model of stress and coping **(**Lazarus & Folk man, 1984)

The Transactional Model of Stress and Coping is an outline which emphasises the assessment to evaluate harm, threat and challenges, which occurs in the process of coping with stressful events (Lazarus, 1966). The transactional theory of stress and coping was first proposed by Lazarus in 1966. Wilborn-lee (2015) indicated that the model values how major life events and daily struggles impact on emotions with the prominence on cognitive appraisal and coping with stress.

Cognitive appraisal comprises of primary appraisal (to estimate the harm or threat the situations may pose) and secondary appraisal (which estimates what can be done and the individual's capability to cope with it) (Lazarus & Folkman, 1984). Coping proceeds from this evaluation of threat and can impact either a change in the person-environment relationship or the quantum of emotional distress faced. Factors such as Personality traits, depressive symptomology and social support influence coping skills and abilities (DeLongis & Holtzman, 2005). Cognitive behaviour therapies and approaches enable people to identify and become conscious of thoughts and feelings that lead to insufficient coping, and learn new ways of problem solving and cope with demands of certain conditions.

Lazarus and Folkman (1984) suggested that stress can be thought of as resulting from an imbalance between demands and resources or as occurring when pressure exceeds one's perceived ability to cope. Stress management was developed with the idea that stress is not a direct response to a stressor but rather one's resources and ability to cope arbitrate the stress response and are susceptible to change, thus allowing stress to be controllable (Wilborn-lee, 2015). Lazarus and Folkman's interpretation of stress focuses on the transaction between people and their external environment (known as the Transactional Model). The model contends that stress may not be a stressor if the person does not perceive the stressor as a threat but rather as positive or even challenging. Also, if the person possesses or can use adequate coping skills, then stress may not actually be a result or develop because of the stressor. The model proposes that people can be taught to manage their stress and cope with their stressors. They may learn to change their perspective of the stressor and provide them with the ability and confidence to improve their lives and handle all of types of stressors. Lazarus and Folkman (1984) proposed a transactional model in which individuals cognitively appraise an event to determine the magnitude to which that event has the potential to deplete their resources.

Core Assumptions and concepts in the transactional model of stress and coping

According to Lazarus and Folkman (1984) the transactional model of stress and coping is an outline for appraising the processes of coping with stressful events. Stressful experiences are interpreted as person-environment transactions. These transactions depend on the waves of the external stressor. This is facilitated by firstly the person's appraisal of the stressor and secondly on the individual and cultural resources at the disposal of a person (Lazarus & Cohen, 1977). Lazarus and Folkman (1984) then indicated that the key constructs of the Transaction Model of Stress and Coping which summarily made up the model encompassed:

Primary appraisal- Involves an estimation of the significance of a threatening event considered as either a stressor or none stressor nor just a challenge to a person. Caregiver decides whether the event is a threat or challenge to them.

Secondary appraisal- Comprises the acts of assessing the controllability of the stressor and the individual's coping resources. People faced with threats or challenges consider coping options and resources available and makes appraisal at conscious level and an effort to make the situation better based on their internal options such as will power, inner strength and external options such as peers, professional health (Lazarus & Folkman, 1984).

Coping efforts- Are the actual strategies that persons challenged by stressors use to mediate primary and secondary appraisals to reduce the effects of stress on them. The coping was divided into two; these are the Problem focused-coping strategies and the Emotion focused coping strategies (Lazarus & Folkman, 1984).

Problem focused-coping strategies are the ones utilised when people who are struck with stressors feel they have control of the situation or challenge and therefore can handle the source of the problem. Coping mechanisms involving defining the problem, generating, evaluating other solutions, learning new skills to manage the stressor or reappraising in attempts to change or reduce the ego negative emotions or stress involvement are classified as problem focused- coping strategies (Lazarus & Folkman, 1984).

Emotional focused-coping strategies are the styles of coping employed when people feel they have little control of a situation in which they cannot manage or deal with the problem from its source. It comprises gaining strategies for regulating psychological distress by avoiding, distancing self from the emotion, acceptance, and seeking emotional support, selective attention in attempts to lessen negative appraisals paired to the stressor, venting anger demands and more.

Strengths of the model are that Lazarus and Folkman (1984) used human subjects in developing the model and cognitive approach to stress with focus on how people cope with psychological stressors or challenges. In conclusion the transactional model of stress and coping helps in integrating individuals and environmental problems and focuses on mental assessment to evaluate the threat posed by the encounter which can end in stress. The model looks at how key life events and daily struggles influence a person's emotions, how they may view the encounter is based on their personal well-being and appraises their ability to cope and deal with any resultant danger. Some individuals are more susceptible to stressful situations than others, especially those with high depressive symptoms, or have certain personality traits such as low optimism or high neuroticism (DeLongis & Holtzman, 2005). Stress can cause biological and psychological defects leading to chronic illness and addictions as well as anxiety and depression (Lazarus & Folkman, 1984). The coping ability of any person is mediated by their features, experiences, beliefs and core values and is well-defined by the relationship between the person and the event, and might not always be the same when experienced at different periods or by different people (Lazarus & Folkman, 1984). Coping strategies involve either varying the person-environment relationship, or handling the psychological distress resulting from the encounter, or both. The cognitive behaviour therapy is best suited to support an individual to identify and become aware of inapt coping strategies which lead to psychological distress, and learn new ways to problem solve and cope with stressful situations (Lazarus & Folkman, 1984).

Justification and application of the transactional model of stress to this study

In the current study, the transactional model of stressor and coping was adopted because its theoretical foundation suggests that specific types of situations result in positive and negative perceptions and also suggest that there are series of cognitive appraisals that individuals make with regard to stressors such as:(1) Is this situation or stimuli capable of depleting my capabilities or resources, (2) Is the stimuli having the potential for personal benefit or not, and (3) how will I best cope with this situation or stimuli (Newness, 2011)? The transactional stress and coping model view the appraisal processes, emotions and coping strategies to be used to assist caregivers to make more favourable appraisals about their reactions and to assess the result in a more helpful way (Lazarus & Folkman, 1984). According to Newness, (2011) a benefit of this stress and coping theory was that it accommodates for individual differences in appraisal and on that grounds the model has been used in previous studies of parenting stress in caregivers of children with chronic conditions (Mullins et al., 2007; Colletti et al., 2008). The psychological distress experienced by caregivers of children with chronic conditions largely depends on their thoughts which motivate their choices of coping strategies in maintaining their wellbeing and enhancing their quality of life by approaching the chronic conditions of their children with a quiet mind (Sedgeman, 2005). Caregivers of children with chronic conditions are said to experience psychological distress based on their cognitive appraisals of the situations they are found in; this plays a major role in their choice of coping strategies.

Simply stated, caregivers of children diagnosed with chronic conditions coupled with its management can result in unhealthy levels of depression, anxiety and stress. According to the transactional model of stress and coping, for one to experience stress (for this study psychological distress) the situation will have to be first cognitively appraised as destructive, stressful and threatening and beyond their coping abilities. In conclusion the model was applied by the use of therapies such as the cognitive behaviour therapy to assist caregivers perceive positively the problems associated with performing caregiving functions on children with chronic conditions to enable them modify their behavior and employ appropriate coping strategies cognizant to their situations to enable them beat down the levels of psychological distress resulting from the caregiving roles they perform.

Family Systems Theory (Bowen, 1978)

Family systems theory was developed by psychiatrist and researcher Murray Bowen (1913–1990). It is a theory backed by a growing body of empirical research stemming from the works of earlier family researchers such as Gregory Bateson and colleagues – Jay Haley, Donald D. Jackson, John Weakland, William Fry,Virginia Satir, Ivan Boszormenyi-Nagy, Paul Watzlawick and others. There was initially a great influence from psychoanalysis (most of the early founders of the field had psychoanalytic backgrounds) and social psychiatry, and later from learning theory and behaviour therapy - and significantly, these clinicians began to amalgamate various theories about the nature and functioning of the family as a unit that was more than a mere aggregation of individuals especially in the event of a member suffering from a chronic disease such as epilepsy (Sholevar, 2008).

The formal development of family therapy dates from the 1940s and early 1950s through the activities of various independent clinicians and groups who began seeing family members together for observation and or therapy sessions in their bids to solve psychological issues and institute appropriate coping strategies to families caring for sick persons (Silverman & Silverman, 1962). Bowen applied his research findings from the National Institute of Mental Health (1954–1959), where entire families lived on the ward with the patient (schizophrenic) making him describe that phenomenon as a triad. The mother and father had to cope by moving into the hospital to join their sick ward indicating how illness of an individual affects the whole family emotionally, psychologically and some of the ways affected families cope in certain situations such as a child suffering from a chronic condition like epilepsy and SCD which are the subjects of this study.

Observation of relationship patterns of these families led to the development of the family theory by Bowen (1978). This triadic relationship is crucial to the Bowen Family Systems Theory. He said ‘it was clear that all families were pretty much alike’ (Bowen, 1978, p. 15) as his trans generational approach had the impression that current family patterns and problems tend to recur over generations and that each family has an emotional system, which seeks ways to reduce psychological effects and maintain family stability since the emotional dysfunction of an individual disturbs all of that person’s relationship systems especially the family system (Bowen, 1978). Bowen muted the idea that the driving forces underlying all human behaviour comes from the push and shove between family members contending for a balance between distance and togetherness (Beckerman, 2000). According to Bowen, family relationships are very complex, and no two families are exactly the same. Even though these differences exist, many theories hypothesize that all families fall into the same model of the emotional system in times of coping for a sick child (Patterson, 1988; Olson, Russell & Sprenkle, 1983; Gottman, Katz & Hooven, 1996). This concept he referred to as the Family Systems Theory.

The Bowen Family Systems Theory model provides a conceptual structure to view the individual as a section of the family. The purpose of Bowen Family Systems Theory is to provide clinical psychologist and other individuals working with children or adolescents (presenting as the children with chronic conditions) a lens to see the roles of family members (caregivers), their coping patterns, and psychological states of the caregivers, and finally, an application of these concepts to specific family's experiencing the psychological effects of having a child with a chronic condition (Haefner, 2014).

Formal efforts to intervene in families to help individuals experiencing various kinds of difficulties have been a part of many cultures, probably throughout history (Heaney & Israel, 2008; Kleinman, Eisenberg & Good, 2006). These efforts to assist have sometimes involved formal procedures or rituals, and mostly included the extended family as well as non- family members of the community (Bowen, 1978; Heaney & Israel, 2008). Following the prominence of specialisation in various societies, these interventions were often conducted by particular members of a community – such as, a priest, chief, physician, and others - usually as an ancillary function (Broderick & Schrader, 1991). Bowen (1978) postulates that perhaps humans evolved to be interdependent on family members to enhance cooperation among families that are necessary for things like shelter and protection especially in growing up. But, in stressful situations, the anxiety that one person feels can spread among family members and the interdependence becomes emotionally taxing rather than comforting. This implies that the burden of caring for a child with epilepsy is a whole family concern and the psychological effects can run through both the parents and significant others (caregivers) depending on the coping strategies they make use of. According to Bowen's theory, even when people may feel they are disconnected from members of their family, the family still has a great impact on their emotions and actions- whether supportive or unsupportive. The arrival of a child with epilepsy brings about a change in the parent's psychological wellbeing and how other members of the family unit (caregivers) act and feel. Though the extent of interdependence can vary between different families, all families have some level of interdependence among the members especially in the care for a sick child since children are believed to be the responsibility of every member of the family. There will always be some persons in the family unit who bears the bulk of the emotions of other members of the family when a member is sick or debilitated, and these persons are most likely to suffer from depression, alcoholism, and physical illness depending on the level of psychological effects and the coping strategies they employ in the process.

Applications of the family systems model

The goal of the model is to assists caregivers towards superior levels of differentiation, where there is less blaming, reduced depression or decreased reactivity and increased responsibility for self in the emotional system. The first stage of the model aims to reduce caregiver's anxiety about the signs and symptoms of psychological distress and how to cope with them. In the latter phases of therapy, caregivers are schooled in differentiating themselves from their family of origin, the postulation being that advances in differentiation will spontaneously flow over into decreased anxiety and greater self-responsibility within the nuclear family system.

Empirical Review

The empirical literature was reviewed in the following areas numbered below detailing the findings, suggestions and conclusions of studies of relevance to this study. The literature was reviewed by looking at the methodologies, findings and the shortcomings studies which delved into coping and psychological distress in caregivers.

1. Levels of psychological distress in caregivers of children with chronic conditions.
2. Differences in the levels of psychological distress based on the gender of caregivers of children with chronic conditions.
3. Differences in caregivers of children with epilepsy and sickle cell disease in terms of psychological distress.
4. Coping strategies of caregivers of children with chronic conditions.
5. The relationship between psychological distress and coping strategies used by caregivers of children with chronic conditions.
6. Marital status as a moderator of the relationship between psychological distress and coping strategies used by caregivers of children with chronic conditions.

Levels of Psychological distress in caregivers of children with chronic conditions

Socially it is one of the responsibilities of parents to provide caregiving roles to their children but caregiving activities become task involving and pose various psychologically distressing effects on the caregivers in event of caring for children suffering from chronic conditions due to illness specific demands (Smith, Cheater & Bekker, 2013; Vermaes et al., 2008). The burden of care is a multi-factorial concept which has emotional, psychological, physical and social implications as well as related distressing feelings such as indignity, embarrassment, anger, feeling of guilt and self-blame on caregivers of children with chronic diseases (Awad & Voruganti, 2008). There is increased health risk in caregivers of children with chronic conditions leading to the development of psychologically distressing behaviour and symptoms such as social isolation, stress, depression, anxiety and poor sleeping patterns et cetera (Fee & Wu, 2011). According to Abedi, Abbaszadeh, Kazemi and Pouraboli (2014), caregiving functions of families of children with chronic conditions renders caregivers vulnerable to psychological and emotional problems such as depression, anxiety, stress, shame and suicidal thoughts. Romao et al. (2009) stated that higher scores for anxiety and depression of caregivers are allied with poor quality of life of caregivers. According to Marin, Chen, Munch and Miller (2009) caregivers of children with chronic conditions suffer higher levels of psychological distress than caregivers of children with conditions in which recovery is speedily due to the emotional and psychological deterioration that correlates with the unflinching need for care and support of children with chronic conditions (Juster, McEwen & Lupien, 2010).

Anxiety among caregivers of children with chronic conditions

There is usually anxiety as the maiden psychological effect experienced by caregivers when the diagnosis of a chronic condition is ascertained as predictions of poorer life outcomes and over dependency of children are predicted by caregivers (Juonala, Magnussen, Berenson, Venn, Burns, Sabin & Sun, 2011).

Toledano-Toledano and Moral de la Rubia (2018), conducted a cross-sectional study at the Federico Gómez Children’s Hospital of Mexico to assess the factors capable of causing anxiety in caregivers of children with chronic conditions. They used a sample of 446 family caregivers of children with chronic diseases hospitalised of which 83% were females and 17% were males, with an average age of 32 years. The study design used was the non-experimental, cross-sectional, and ex post facto, with nonprobability sampling. To assess the caregiver anxiety component of their respondents the Beck Anxiety Inventory scale was used. The data was analysed by running linear regression. Caregiver anxiety level was calculated using the backward-elimination method of SPSS v24. They found that the average levels of anxiety in caregivers of children with chronic conditions in Mexico corresponds to those of the general population and that sex, age, education, and family income, were not predictors of anxiety. The shortfall of their study was that because they used non probabilistic sampling techniques the results do not constitute parametric estimates of the study population (caregivers of children with chronic conditions).

A study conducted in the children’s hospital of Małopolska by Wojtas, Oskędra, Cepuch, and Świderska (2014), to evaluate the severity of negative emotions and ways of dealing with the stress of caregivers of children with epilepsy from a of 213 caregivers (148 females and 65 males) aged between 21 to 66 years. They found that the dominant emotion that accompanied the caregivers of children with epilepsy was anxiety. The researchers used the Hospital Anxiety and Depression Scale Modified (HADS-M) and analysed the data with SPSS by conducting the Mann-Whitney test and t-test. The responses might have been influenced by the hospital environment. Also, a different test instrument such as the DASS-21 could have given a different score since the reliabilities vary.

Burnes, Antle, Williams and Cook (2008) explored the experience of mother’s raising a child with sickle cell disease. They used a qualitative study method in which long interviews with Canadian mothers of African and Caribbean descent was conducted. Through the use of the population health and structural social work perspectives, 10 mothers' experiences were examined and a post interview on 4 mothers after 4 months. The findings revealed that the mothers commonly experienced a high level of anxiety related to fear of their children's death due to the condition, separation anxiety and loss of control over life due to caregiving demands. The small sample size limits the application of the findings of this study to the general population.

Depression among caregivers of children with chronic conditions

According to Karlson, Haynes, Smith, Faith, Elkin, & Megason (2012) half of the caregivers of children with SCD are at high risk of depression as a consequence of providing care.

A systematic review to disparagingly assess the available evidence regarding the prevalence, associated factors, and impact of maternal depressive symptoms on child outcomes in epilepsy was conducted by Ferro and Speechley (2009) in University of Western Ontario, London, Ontario. They used a modified version of the quality index to evaluate the reporting, internal and external validity of some studies around the world that had findings on the impact of child epilepsy on mothers/female caregivers. The conclusions of their meta-analysis were that up to 50% of mothers caring for children with epilepsy are at high risk for clinical depression and that maternal depressive symptoms have negative impacts on the outcomes of the epilepsy in the child including behaviour problems. The findings in their study may not be entirely reliable today since the 15 studies reviewed reflect research conducted over a 24-year period from 1984 to 2008 hence changes in medical and psychological trends and management modalities of chronic conditions might influence the mothers' perception and mood in recent times.

Iseri, Ozten, and Aker (2006) also found that parents who render care to children with epilepsy are usually affected by post-traumatic stress disorder and major depressive disorder when they sampled parents of 80 (77 mothers and 3 fathers) children with epilepsy at the University of Kocaeli Epilepsy Clinic (Turkey) in a cross-sectional study. These findings may not be entirely generalisable since the sample size is quite small and also there was a significant female dominance making the finding skewed.

Van den Tweel, Hatzmann, Ensink, van der Lee, Peters, Fijnvandraat and Grootenhuis (2008) evaluated the quality of life of caregivers of children with sickle cell disease in the Netherlands. They used the TNO-AZL Adult Quality of Life questionnaire (TAAQoL) for caregivers 16 years and older. The participants were 54 female caregivers of children with SCD and 28 control groups (caregivers of healthy children). The socio-economic status of the participants was the same. Data was tested using the independent t-test and mann-Whitney U-test for normal and not normal data. The results showed that caregivers of children with SCD have lower quality of life on the subscales depressive moods, daily activities, vitality, sleeping, happiness and cognitive functioning when the point estimates of the median difference were compared. The results of this study are not fit for generalisation since the sample size was small and the participants were gender biased. In conclusion, this literature reveals that the most common psychological effects experienced by caregivers are stress, depression and anxiety with maternal depression the commonest to female caregivers of children with chronic conditions.

Stress among caregivers of children with chronic conditions

Stress though an inevitable part of life can sometimes be unpleasant and not beneficial thus can best be described as a distress. According to Selye (1956) stress can be caused by any stimuli (people, situations or the environment), when caregiving a child with SCD the stress becomes hefty and distressing.

It was assumed by Hua-Huei and Liang-Po (2011) in their study that, stress levels in caregivers of children with SCD or epilepsy is higher compared to other chronic conditions such as asthma.

Chiou and Hsieh (2008) conducted a study in Taiwan to identify the differences in parenting stress between epilepsy and asthma and also examine the factors associated with parenting stress. The study examined data from 49 parents of children with epilepsy and 54 parents of children with asthma (chronic conditions requiring daily medications and attention). The caregiver's stress was measured using "Abidin's Parenting Stress Index–long form" (Abidin, & Abidin, 1990, p.100). They found that the cross-sample comparisons showed that parents of children with epilepsy had higher levels of parenting stress than the parents of children with asthma. A limitation of the study was the small sample size used, which makes the study results less reliable.

Thompson and Upton (1992) conducted a study in the United Kingdom to explore the psychological and physical well-being of caregivers of persons with epilepsy in the family. Caregivers numbering forty-four were made to respond to questionnaire administered with relation to their mood and physical wellbeing. The results of the analyses of the responses of caregivers showed that the Levels of stress particularly in primary caregivers (the mother in most instances) were high. This finding is only limited to their study since the sample size was small, also the inclusion criteria could make their findings different from this study since the current study is specifically dealing with only caregivers of children and not adults.

Brown et al. (2010) conducted a study to examine the burden of health-care of caregivers of children with sickle cell disease in Nigeria using a sample of 67 caregivers of children with sickle cell disease attending the Paediatric clinic of the University College Hospital of Ibadan. A structured questionnaire of an adaptation of an earlier instrument validated for the study of caregiver burden in sickle cell disease appropriate for the Nigerian culture was administered to the caregivers. They found that over 50% of the caregivers had both financial and psychological stress due to the care they provide to the children with sickle cell disease. The study is limited due to a small sample size used and this could be that because the study was based on a tertiary hospital setting with a higher cost of health-care that resulted in a limited sample size.

Differences in the levels of psychological distress based on the gender of caregivers of children with chronic diseases

Caregiving is said to be a tasking job to every parent but this becomes more tedious and requires extra time, energy, skill, perception and understanding in the case of a child with chronic condition (Smith, Cheater & Bekker, 2013; Fee & Wu, 2011). Living with a child with a chronic ailment can result in tasks above usual parenting responsibilities due to illness-specific demands such as maintaining care regimes, cultural and social constraints and maintaining family relationships (Vermaes, Janseens, Mullaart, Vinck & Gerris, 2008). Parents of children with epilepsy, like parents of children with many other chronic conditions, are embattled with persistent feelings of insecurity about their child's condition (Rani & Thomas, 2019). This insecurity could translate to a decreased capacity to cope leading to increased stress levels, negative mood states, and compromised family functioning (Rani & Thomas, 2019). As poor coping of the parent may have a reflective negative impact on the child's psychosocial adjustment to living with the chronic condition, it is important to identify ways to facilitate positive coping skills in the parents based on their gender as they undertake their caregiver roles in the lives of the child with chronic conditions (Duffy, 2011). There are some proposed reasons why these gender differences in stress, depression and anxiety may exist, including genetic and environmental influences such as gender specific socialisation (Christophersen & VanScoyoc, 2013). The traditional functional roles of parents based on their gender creates a difference in the levels of psychological distress they (caregivers) experience while caring for a child especially when the child is suffering from a chronic condition which calls for stiffer caregiver activity (Wang, Chen & Chen, 2018).

Serr, Mandleco, Olsen and Dyches (2007) of the Brigham Young University, Provo, Utah (USA) conducted a study to determine the relationship between caregiver burden and depression, the differences in caregiver burden and depression according to gender and also examine the differences in caregiver burden of people raising children with different kinds of disabilities/chronic conditions. The study was a descriptive survey. They sampled 132 families comprising both male and female parents from local support groups for families raising a child with a disability/chronic condition. Most families were two parent, Caucasian, middle class, earned more than $50,000, and had an average of 3 children. The mean age of the children with disabilities was 9 nine years, and they were grouped as having autism (20.6%), Down syndrome (25.2%), or other disability (54.2%) respectively.

The method of data collection was by questionnaire where families were mailed a consent letter, instructions, and a questionnaire that each parent was to complete independently. The questionnaire was in two sections measuring depression and another part measuring caregiver burden. The instruments used were the Centre for Epidemiological Studies Depression (CES-D) Scale and the caregiver burden instrument, adapted by Robinson (1983) from the Caregiver Strain Index (CSI) measures major factors influencing caregiver burden.

They conducted independent sample t-test to compare the mothers and father's depression, frequency of burden, hassle of burden, and frequency of no burden. Pearson correlation was calculated and regressions performed with family income, number of children, and mother's/father's depression as independent variables with the following dependent variables; mother's/father's frequency of burden, mother's/father's hassle of burden, and mother's/father's frequency of no burden, analyses of variance (ANOVA) was also performed to determine the differences between mother's /father's depression, frequency of burden, hassle of burden, and frequency of no burden according to the type of family that is raising a child with Down syndrome, autism or any other a disability.

The findings were that mother's and father's frequency of burden and hassle of burden were related to depression in the expected direction and that their stress levels were high. Mothers came out with higher scores for depression, frequency of burden, frequency of no burden, and hassle of burden than fathers. This could be because the mothers in this study, even though most worked either full or part time, were the primary caregivers of the children with chronic conditions. On the other hand, fathers worked full time and may not have spent as much time caring for the children with the disability as did the mothers. This finding is similar to the research findings of Thoits (1991) and Gray (2003) who also discovered that fathers felt their children's condition do not affect them directly because they worked full-time unlike the mothers who provided more of the routine care.

The shortfalls of their study are that the method of administering the questionnaire by mail could make the response questionable since subjects could pass it to friends and significant others to respond on their behalf. The small sample size could also be a reason the inferences suggested those results as a larger sample size may give a different picture or trend in analysing the result. Differences in the age bracket for the male and female parents has the possibility of producing a difference in result of their response since people act and think according to their age and status in society (Noftle & Fleeson, 2010). The gender difference in levels of psychological distress observed may be culturally motivated since the background of the respondents were all from the western world

Wonkam, Mba, Mbanya, Ngogang, Ramesar, and Angwafo (2014) investigated the psychological distress associated with having a child with sickle cell disease. The study was done in Cameroon using 130 Cameroonian urban dwelling parents (comprising male and female, married, single, educated and uneducated) who had children with sickle cell disease. The study aimed at exploring the coping strategies of parents, the financial and psychological distress and the effects of caring for a child with sickle cell disease on family harmony and how these effects are experienced per gender and position in the family. The researcher used a cross-sectional sociological study design, using a quantitative approach; the sampling methods were both purposeful and convenience sampling. He analysed the data using the SPSS (Statistical Package for Social Sciences, Chicago; version 17.0). The skewness of the data informed the use of nonparametric tests. He found that the parents appear to experience major psychological distress due to the condition, also that the high-risk caregivers' groups are mono-parental families, especially single females, unemployed, and caregivers with a low level of formal education but same was not seen for the male gender.

On a contrary view his findings could have been different if the sample size was doubled since in Cameroon population carrier frequencies of sickle cell disease ranges from 8 % to 34 % with a birth incidence of 1.6 %. Also, the participants might not have been fairly represented since only urban dwelling caregivers were selected using convenient sampling technigue without rural dwelling caregivers of sickle cell disease children. The setting was also a factor which possibly influenced his findings as all participants were from the

Yaoundé Central Hospital, Cameroon amidst other hospitals hence the conclusions.

Khanna, Prabhakaran, Patel, Ganjiwale and Nimbalkar (2015) conducted a cross sectional study on the social, psychological and financial burden on caregivers of children with chronic illness in India. The participants were recruited from ambulatory and hospital areas in paediatrics department following informed consent. The respondents were caregivers of children 18 years or below in age with chronic illness. A total of 204 (89 females and 115 males) participated. Socio-demographic details were collected using a semi structured questionnaire, adapted from Family Burden Interview Schedule (FBIS). The psychological well-being of caregivers was assessed using Patient Health Questionnaire (PHQ-9) and Generalized Anxiety Disorder (GAD-7). Descriptive analysis and ANOVA was done for comparing mean scores of responses to analyze financial, psychological and social burden across different diagnosis. The findings of the study were that most caregivers reported moderate depressive symptoms and mild to moderate anxiety symptoms, 25% caregivers reported no depressive symptoms as no anxiety symptoms were reported by 33%, while 37% reported mild and 38% moderate to severe depressive symptoms, 50% reported mild and 17% moderate to severe anxiety symptoms. No relationship was seen between genders of the caregivers and depressive or anxiety symptoms.

These findings could have been different if the subjects were given semi-structured questionnaire in the comfort of their homes since hospital anxiety and depression is a possibility in producing bias in the responses of the caregivers (Zigmond & Snaith, 1983). Additionally, the test administered could be the reason for those results as different test might give similar or different figures and directions with regards to their psychological and emotional states and wellbeing not forgetting the fact that the cultural determinants of the roles of male gender in caregiving is likely to give different results since the Ghanaian culture is different from the Indians.

Adegoke and Kuteyi (2012) in their study of the psychological and social burden of sickle cell disease on the family conducted in the University Teaching Hospital in Ado- Ekiti, Nigeria said Sickle Cell Disease (SCD) is the most common genetic disorder amongst black people that poses a significant psychological and social burden on the sufferers, the caregivers and their significant others altogether. The objectives of the study were to assess the psychological and social burden and coping strategies of the caregivers of children suffering from sickle cell disease in Nigeria. A descriptive cross-sectional study was carried out over a period of 9 months on 225 caregivers comprising mothers, fathers and grandparents of the children with SCD, they analysed the data with SPSS 17.0.

The findings were that 73.3% of these caregivers lost income due to the time they spent on the care of the children whilst 42.2% also described the burden of caregiving to restrict them socially hence they neglected their families and important social functions. They concluded that caregivers are faced with enormous financial, interpersonal and psychological distress. The results showed no differences in the responses based on gender; this may be due to the smaller number of males involved (there were only 8 fathers from a sample of 225 caregivers). Using subjects from just one hospital for a study of national interest makes generalisation questionable since clients who patronise the service of the hospital were similar in standard of living and coping hence the pattern of their responses. If Adegoke and Kuteyi (2012) had used inferential statistics in the analysis of the data gathered over the period, the basic differences in the responses could have been interpreted differently.

Yusuf, Nuhu and Olisah (2013) conducted a survey on emotional distress among caregivers of patients with epilepsy in Katsina State, Northern Nigeria. The participants of the study were from the department of Psychiatry, Ahmadu Bello University Teaching Hospital, Shika-Zaria, Nigeria and the Federal Neuropsychiatry Hospital, Barnawa, Kaduna, Nigeria. They sampled 166 caregivers of children with epilepsy, most from areas far from a mental health clinic/hospital. The respondents were interviewed using the: i. Socio-demographic data collection sheet ii. Hospital Anxiety Depression Scale (HADS). The study aimed at identifying the magnitude and factors associated with emotional distress among care givers of children with epilepsy in a poorly resourced environment. The study also provided awareness into the problems facing the "hidden patients." Using descriptive statistics, they calculated for all continuous variables. Chi square test and student t- test were used to test for relationships. The study revealed that emotional distress (anxiety, depression, feeling of loneliness, isolation, fearfulness and being easily bothered) resulting from providing care for a sick relative was found to be very high among 109 (65.7%) of the caregivers and were significantly associated with the males, providing care for male patients, siblings, and residing in a rural area. The study was hospital based and access to hospital care is not easy in low resourced areas since majority of the subjects were from rural Nigeria. As such the findings of this study may not necessarily reflect the situation in the wider community.

According to a study by Macedo, da Silva, Paiva and Ramos (2015) on the burden and quality of life of mothers of children and adolescents with chronic illnesses, most mothers have higher levels of depression due to the condition of the child contrary to the findings of previous researches in the area such as that of Levin and Banks (1991) who said fathers of children with epilepsy reported more psychological distress than the normative group. No differences for mothers and fathers and that greater psychological distress is associated with caregiver unemployment, seizure type (not well-controlled), and greater number of child medications. The caregiver's stress was unrelated to parent's sex, age, education, family income, frequency of seizures, and child's age at diagnosis in the findings of their study.

Similarly, a study in Basel – Switzerland by Javalkar, et al. (2017) on the predictors of Caregiver Burden among Mothers of Children with chronic conditions indicated that mothers experience stress in immeasurable levels and that caregiving burden affects their psychological wellbeing and mood rendering most of them either overburdened to work for money or unable to take up full time jobs leaving them financially handicapped but same was not said about the male caregivers in the study. A sample of 160 respondents was taken from a population of 781 caregivers. The study was a quantitative one using a cross sectional survey design. Respondents were made to fill the Zarit Burden Scale questionnaire. The data was analysed using inferential statistics. The result of the study is short chained since the participants were only 160 out of 781 (Krejcie & Morgan, 1970). Also, the test instrument when changed might give a different result. Finally, the study was gender biased since only 10 males participated in the survey.

Differences in psychological distress of caregivers of children with epilepsy and sickle cell disease

Caregiving for children with chronic conditions is very tiring and psychologically tasking as distressing feelings such as shame, embarrassment, anger, feeling of guilt and self-blame (psychological distress) ensues compared to controlled groups (Westphal-Guitti, 2007). According to some researchers (Nuhu, et al., 2010; Akinbiyi, 2001) the burdensomeness of caregiving to children with chronic conditions depends on the educational level, financial strength, place of residence (urban/rural) of the caregiver, the age of the child with chronic condition and the severity of the child’s condition. Caregivers have been described as the “hidden patients” and it was suggested that caregiver’s symptoms such as mood swings, fatigue, headaches, joint and muscle pains, marital and family conflicts, and financial problems may be a mirror image of caregiver stress in looking after a sick child (Medalie, 1994). According to Anderson and Barton (1990) most caregivers of children with epilepsy have high levels of anxieties and worries about what will happen to the child in future when the caregiver’s will not be available to cater for the patient in the event of changes in financial state, old age or death.

Cousino and Hazen (2013) of the Case Western Reserve University – USA investigated parenting stress among caregivers of children with chronic illnesses. Their aim was to critically review, analyse, and synthesize the literature on psychological distress among caregivers of children with asthma, cancer, cystic fibrosis, diabetes, epilepsy, and sickle cell disease. They collected data from the databases of Psych Info, MEDLINE, and Cumulative Index to Nursing and Allied Health Literature. The search was limited to articles published in peer-reviewed journals from January 1980 to June 2012 limited to current medical practice. They conducted the meta-analysis on 13 studies and qualitative analysis of 96 studies. They concluded that caregivers of children with chronic conditions experience greater general parenting stress than caregivers of healthy children.

The following were conclusions from some of the studies Cousino and Hazen used, who's findings were specifically on psychological distress on caregivers of children with epilepsy or sickle cell disease;

Cushner-Weinstein et al. (2008) indicated that greater psychological stress correlated with greater child depressive symptoms. Caregivers of children with epilepsy and learning disabilities reported higher psychological distress than parents of children with epilepsy only.

Camfield, Breau and Camfield (2001) also indicated that psychological distress (depression, anxiety and stress) was great for caregivers reporting high waves of epilepsy on the child. Cousino and Hazen (2013) concluded in their meta-analysis that the psychological distress associated with caring for children with sickle cell disease was high compared to the levels experienced by caregivers of children with epilepsy. The differences in the levels of psychological distress and predictors reported in the literature in their study probably is accounted for by the broad differences in study populations, the multifaceted nature of epilepsy, and the variance in research methodologies used by the various researchers.

Modi, (2009) with the purpose of comparing parenting stress and activity patterns in parents of children with new-onset epilepsy (NOE, n= 30) and parents of children without epilepsy (controls, n= 29). Participants completed parenting stress measures and Daily Phone diaries, a cued-recall procedure to track parents through their activities over a 24-h period. He found that no significant differences were found in parenting stress among caregivers of children with different chronic conditions.

Karakis, Cole, Montouris, San Luciano, Meador and Piperidou (2014) conducted a cross-sectional study between September 2009 and June 2011 at Massachusetts General Hospital to identify the levels of psychological distress and its relation to caregiver quality of life. They used 48 patient-caregivers of people with epilepsy. Participating caregivers were made to complete the Zarit caregiver burden inventory, their health-related QOL was assessed by administering the second version of the SF-36 generic questionnaire (SF36v2) (Ware Jr & Gandek 1998) 22-item inventory adapted from the original 29-item inventory (Zarit, Reever & Bach-Peterson, 1980). The results were analysed using descriptive statistics, Univariate associations between the Zarit burden score as the outcome of interest and the various caregiver related predictors were explored by using *t*-test or one-way ANOVA and Pearson correlation or nonparametric equivalents. The mean age of the caregivers was 46. Most of them were Caucasian women, married, employed, of higher education, and cohabitated with the patients they cared for. The average Zarit burden score was 20, that is, on the border of mild-to moderate range. There was a statistically significant moderate inverse correlation between caregiver psychological distress and caregiver quality of life physical component summary score. In the selected cohort they concluded that epilepsy is associated with modest degree of psychological distress to the caregiver. The small sample size of caregiver participants may have under powered the study for the finding of additional associations. The study population was mostly in families of higher socio-economic and educational status, it may have significantly limited generalisability of their findings to the community and to other countries where different socioeconomic barriers exist. In conclusion, the findings of existing literature from studies suggest that the psychological distress associated with caregiving to a child with SCD is higher compared to epilepsy.

Coping strategies of caregivers of children with chronic conditions

The burden of caring for children with chronic conditions is a key challenge for caregivers in countries with fragile health systems especially the low- and middle-income countries (Bygbjerg, 2012). When caregiving activities are threatening the psychological wellbeing and puts pressure on the resources of caregivers, it makes them experience stress (Hua-Huei & Liang-Po, 2008). The cognitive and behavioural response to these situations to reduce the psychological distress is termed coping. Coping strategies therefore comprises the efforts made by caregivers to lessen the burden, manage their emotions and social relationships in times of caregiving burden (Stephenson, King, & DeLongis, 2016).

Caring for children suffering from chronic conditions limits caregiver’s participation in income generation undertakings resulting in financial privation (Engelgau, Karan, & Mahal, 2012; Steinhardt et al., 2008). Poverty in developing countries is closely allied with illness: poverty leads to ill health and ill health perpetuates poverty and influences the choice of coping strategies the caregivers of children with chronic conditions will use since the health care systems available to the caregivers depends on their geographical location, perceptions and financial status (Barnett et al., 2012). Caregivers' emotions are intensely related to caregiver resources and it is possible to influence emotions in order to maintain resources or counteract negative feelings and thus influences the choice of coping caregivers will use (Graungaard, Andersen & Skov, 2011).

Similarly, Wong and Heriot (2008), found in their study that vicarious hope was related to less caregiver emotional impact caused by the child having chronic condition, and that vicarious despair was the robust forecaster of caregivers' anxiety. Graungaard, Andersen and Skov (2011) indicated that caregiver's experiences severely decreasing resources by non-empathic social relations or lack of social support as also reported by Green (2007), therefore most caregivers use social support as a coping strategy. According to the findings of Thompson and Upton (1992) low levels of support (a type of coping strategy) is associated with high depression level. Existing literature reveals that better caregiver coping skills are allied with low psychologically distressing symptoms, regardless of the severity of child's condition (Churchill, Villareale, Monaghan, Sharp & Kieckhefer, 2010)

Avoidant Focused Coping Strategies

Ganjiwale, Ganjiwale, Sharma and Mishra (2016) conducted a cross sectional survey to assess the quality of life (QOL) and coping mechanisms used by caregivers of children with physical disabilities in a special school in India. In all a total of 116 caregivers of children with mental or physical incapacity of either congenital or caused by injury (epilepsy, autism, cerebral palsy, mental retardation et cetera) were sampled for the study. The participants were made to answer a questionnaire on coping using the brief cope inventory (Carver, 1997) while the World Health Organisation Quality of life scale was used to assess the quality of life of the caregivers. The findings of the study were that all coping mechanisms are relevant to caregivers of children with developmental disabilities. Though all the coping strategies were used by caregivers, the predominantly used coping strategy by the caregivers was active emotional coping (venting, positive reframing, humour, acceptance, and emotional support scales). Per their responses, the caregivers have accepted the condition and were trying to look for something good in it. They try to make fun of the situation which can provide an outlet for stress for some time but which is more of an escape tendency and this does not help them realistically in managing with the situation in the long run. The shortcomings in the study were that the sample size was small and may have affected the strength of the results. The children with disabilities were all attending the same special school (not representative of all socioeconomic classes). A large sample would have validated the findings of the study better and improve the capacity to generalise the findings. The findings of the study could be different if the study area, the socio-economic status, levels of education and the conditions of the children are varied.

A study by Hildenbrand, Barakat, Alderfer and Marsac, (2015) aimed at describing the coping and coping assistance among children with SCD and their parents. Participants were recruited from a large paediatric hospital in the north-eastern region of the United States. Using a triangulated mixed method design they sampled fifteen children with SCD between the ages of 6- 14 years and fifteen families of these children. Enrolled children and parents independently participated in semi-structured interviews to explore SCD-related stressors, coping, and coping assistance, subsequently children completed the How I Coped under Pressure Scale (HICUPS) (Ayers, Sandier, West & Roosa 1996) and parents completed the Parent Socialization of Coping Questionnaire (PSCQ) (Miller, Kliewer, Hepworth & Sandler, 1994) to assess child coping and parent coping assistance, respectively. In the findings of the study, case-by-case analysis suggested that qualitative and quantitative data concerning family coping and parent coping assistance were generally consistent at the subscale/theme level as the approach coping assistance strategies were utilised by parents both qualitatively and quantitatively, such as emotional expression, direct problem solving, cognitive decision making encouraging cognitive restructuring, , acceptance, practical disease management strategies, and religious or spiritual coping, as well as educating others about SCD, providing emotion and problem focused support, modelling self-advocacy, and coordinating with the school and medical team. The next adequately used coping strategy was the avoidance strategies such as distraction, cognitive avoidance, and behavioural avoidance strategies endorsed in both qualitative and quantitative data though none of the parents used the avoidance coping strategy neglect. The small sample size barred more sophisticated analyses and limited the scope of the quantitative section of this study. Precisely, they were unable to look at the differences in coping strategies based on factors that may be important in understanding current or future distress and for generalization of the findings. Given that coping with

SCD is a lifelong process, longitudinal investigations are needed to understand differences in coping over time and to inform interventions delivered at various stages of development hence limiting the age of children with SCD to 6 -14 years limits the outcomes of the findings.

Ali and Razeq (2017) studied the coping behaviours, support systems and psychological health outcomes in caregivers of children with epilepsy, the lived experiences of caregivers of children with sickle cell disease in Al – Salt, Jordan. In a qualitative approach, 11 caregivers (consisted of eight mothers and three fathers) of children with SCD under the age of 18 years were interviewed with a semi structured interview schedule to generate a narrative discussion on a timeline, from the time of the first diagnosis of the disease in the children to the everyday management of SCD by caregivers. The interviewer narrowed the questions towards more specific questions encouraging the parents to express feelings and coping strategies related to their experiences. The conclusion of the finding was that caregivers of children with SCD face complex caregiving demands and altered family dynamics leading to principal need of the family for social support. Also, religious and spiritual means of coping are the commonly used. The finding in this study is consistent with other (Hildenbrand, Barakat, Alderfer & Marsac, 2015) findings, the smaller sample size places limitation on the usefulness of this study to other population since the results cannot be generalised. The use of only descriptive statistics does not show minor but relevant diverse opinions of the participants of the study.

Emotion and Problem Focused Coping Strategies

In the United States, Carlson and Miller (2017) conducted a survey on 152 caregivers of children with epilepsy. The participants were predominantly women from diverse backgrounds, the mothers completed questionnaires assessing the effects of their child's disability on the family via a web-based interface. They found that mothers of children with epilepsy most often use emotion-focused and social support seeking behaviours as ways of coping with the psychological distress accompanying the care of their children. Their findings are not entirely different from most of the findings in existing literature, the result could have been different if they included fathers and other caregivers in the study and conducted a face to face interview/questionnaire instead of via the web.

Gona et al. (2016) conducted a study to explore differences in the coping strategies used by caregivers of children with chronic conditions in rural and urban settings in Kenya. They used purposive – convenient sampling procedure, 103 caregivers of children with chronic diseases were interviewed and focus group discussions (FGDs) was utilised in the data collection as they used a qualitative design and applied a phenomenological methodology. The interviews and the FGDs were recorded, transcribed, and translated into English from Swahili, Content analysis as described by Taylor-Powell and Renner (2003) was used to analyse the data. The findings of the study were that caregivers coping strategies were mostly emotion and problem focused coping: They had dietary regulations, respite care (keeping client in school relieves part of the burden), belief in supernatural healing, prayers and spiritual healing of men of God can help cure chronic conditions (irrespective of place of dwelling; thus caregivers from rural or urban Kenya had similar coping strategies). The shortcomings of the study are that the sample size is smaller hence generalization is not possible. The condition is only one (autism), hence the results are skewed and could have been different if the coverage included other chronic conditions in children such as epilepsy, sickle cell and intellectual disability.

Relationship between psychological distress and coping strategies used by caregivers of children with chronic conditions

Caregiving of children with chronic conditions entails coping with a number of stressors, such as administering medication, helping the child manage their pain, frequent hospital visits, and helping the child cope with negative feelings about having a chronic condition (Moskowitz, 2010). The ability of a caregiver to employ effective coping strategies is vital to healthy caregiver psychosocial functioning (Welkom, 2009). The findings of some studies on correlational analysis of psychological distress and coping strategies showed that emotional, social support and social needs mediated the relationship between psychological distress and social support (Chronister et al., 2010).

Bachanas et al. (2001) examined coping styles in caregivers of children with a chronic condition and found that the increased use of emotion-focused coping strategies as opposed to problem-focused coping strategies was significantly correlated with psychological and social functioning.

Rodenburg, Meijer, Dekovi and Aldenkamp (2007a) conducted a quantitative study on 91 parents of children with epilepsy to investigate the stress, stressors and parental coping in parents caring of children with epilepsy in the Netherlands. Questionnaires were used for collecting data in that the Parental problem-focused coping and emotion-focused coping behaviours were measured with the Utrecht Coping Checklist (UCL) (Bijstra, Jackson, & Bosma, 1994) whiles the Parenting stress was measured with the Parental Burden of Caregiving Scale, a subscale of the Parental Stress Index (PSI) (Abidin, & Abidin, 1990). The finding of the study was that coping behaviours were related to parenting stress. The finding that emotion focused coping is related to parental stress in caregivers of children with epilepsy does not give details as to which specific coping strategy correlates to stress and the strength of the relationship of the individual cope items.

Kiral, Yetim, Ozge and Aydin (2017) examined the relationships between cognitive emotion regulation strategies, social support and depression among Turkish dementia care-givers by sampling 141 caregivers, they explored whether different coping strategies and social support were correlated to levels of depression, as well as whether social support influences this relationship. The findings of their study were that there is a relationship between social support, and symptoms of depression and cognitive emotion regulation strategies and social support can play substantial roles in lessening care-giver depression. The results of this study cannot be overemphasized since the caregivers were caring for adults with chronic conditions and not children with SCD and epilepsy.

Gheibizadeh, Gholami, Bassaknejad and Cheraghian (2017) investigated the coping strategies of parents of children with chronic illnesses (including Nephrotic syndrome, diabetes, congenital heart disease, metabolic disease, cerebral palsy, epilepsy, cystic fibrosis of the pancreas) who were hospitalized in educational hospitals of Ahvaz -Iran. They conducted a cross – sectional study on a sample of 252 parents (150 mothers and 102 fathers) of 150 children with chronic diseases using convenience sampling technique. Data collection tools were the self-administered demographic and clinical checklist and standard questionnaire of Coping Inventory for Stressful Situation (CISS). The principal coping strategies of parents who had a child with chronic disease were problem-focused (52.3%), and emotion-focused (54%) strategies, respectively. The results of their data analyses showed that coping strategies and psychological distress were inversely related; good coping leads to reduced psychological distress and vice versa. Gheibizadeh et al. (2017) also indicated that the use of emotion focused coping strategies helps in the reduction of symptoms of depression and anxiety in caregivers of children suffering from chronic conditions. The findings of this study could vary with a changed population with different culture, belief system, financial and educational levels of caregivers.

In a different vein, Liu, Lee, Greenwood and Ross (2011) surveyed the relationship between problem solving, psychological distress, and social support for informal caregivers of stroke victims. They conducted a correlational study on 103 family caregivers. They found that the caregiver’s confidence in problem-solving predicted the caregiver’s perceived social support and well-being (Liu et al., 2011).

To determine whether there is a significant connection between caregiver stressors: stressor involving the demands of caregiving, caregiver’s appraisal of ability to cope, knowledge and utilisation support resources, and caregiver psychological and physical health, Wilborn-lee (2015) conducted a quantitative study on a sample of 309 caregivers of chronically ill clients in the USA. Using Pearson correlations, the data analysed indicated that there is a correlation between coping and quality of life of the caregivers.

Sutan, Al-Saidi, Latiff and Ibrahim (2017) assessed the correlation between coping strategies and the health-related psychological distress levels of parents with children suffering from acute lymphoblastic leukemia (chronic condition). With a cross – sectional design, they administered structured questionnaire of the World Health Organization Quality of Life Questionnaire (WHOQOL- BREF) and the Malay version (or English) of the Brief COPE scale to a sample of 299 parents of children with acute lymphoblastic leukemia in Malaysia. They analysed the data using Pearson's correlation for normal distribution variables and Spearman's Rho test for non-normally distributed variables to examine the strength and direction of the correlation between parents' health related quality of life and coping strategies. The findings of their study revealed that problem-focused coping significantly positively related to overall health related quality of life and with all of its domains.

This assertion is in consonance with the findings of Compas et al. (2015), Greening and Stoppelbein (2007) who found the use of problem-focused coping to be correlated with lower levels of anxiety and depression in parents of children with chronic conditions. Then again, significant moderate negative correlation was found between emotion-focused coping strategies and overall WHOQOL BREF scores and all its domains with the exception of physical health domain where only small correlations were found indicating that the greater use of, denial, self-distraction, behavioural disengagement, venting, substance abuse and self-blame strategies correlated to high psychological distress levels just like the reports of previous studies by Zarina, Radhiyah, Hamidah, Zakaria and Jamal (2012), Trask et al (2003) who found that emotion- focused coping strategies are accompanied with higher levels of psychological distress. The findings of the study might be this way because the participants were predominantly women. Since they conducted the study in two centres in Kuala Lumpur only, the findings may not reflect the general population of all parents of children with chronic conditions in Malaysia or the world at large. Last but important is the fact that these findings were not on caregivers of children with SCD or epilepsy only hence suggestive of different responses when conducted amongst caregivers of children with SCD or epilepsy is a possibility.

Marital status as a moderator of the relationship between psychological distress and coping strategies in caregivers of children with chronic conditions

It has been researched and accepted that caregiving activities to children with chronic conditions are cumbersome and dents the psychological states of caregivers; this becomes more frustrating and intense in the case of a single caregiver to a child with a chronic condition (Woessmann, 2015; Brown et al., 2007).

Over the past several years, the percentage of children in two-parent families has declined from 85 to 69%; as a result, in the region of 3 out of 10 children lives in single-parent homes (Shudy et al., 2006) making caregiver psychological distress levels unbearable compared to married caregivers. According to Collazo, Ryan and Bauman (2010) over one-fourth of children under the age of 18 in the United States live in a single-parent family, this proportion is almost triple the rate reported in 1970 (Amato, 2008). Single parenthood may transpire as a consequence of loss (divorce, death, separation, or abandonment by one parent) or by choice (choosing to become or remain pregnant without a partner or adoption). Notwithstanding the cause, single-caregiver homes have been associated with financial drain and caregiver psychological distress (Brown etal. 2007; Mullins et al., 2010). As the average income of a single-parent caregiver is significantly lower than that of married-couple families (Shudy et al., 2006; Collazo, Ryan & Bauman, 2010). Marriage is not only a good avenue for affection as it also lessens the burden of caring for children on one person especially in times of caring for a child embattled with a chronic condition (Kantor, 2016).

To examine the influence of marital status on the experience of psychological distress by caregivers of children with chronic conditions Mullins, et al. (2010) conducted a quantitative study and assessed 383 mothers (308 married and 75 single parents) of children with chronic health conditions in the U.S. They analysed the results using inferential statistics such as chi squares and t-test and lastly post hoc analysis. The findings of their study were that there is a direct relationship between marital status and parenting stress. Precisely, single mothers reported significantly greater levels of parenting stress than married mothers. The results also indicated the presence of a significant relationship between marital status and income such that single-parent status was connected with lower income. In conclusion, the results revealed that marital status was the significant predictor of level of caregiver psychological distress but income levels mediated this relationship. The shortcomings of the study are that only mothers were participants indicating gender bias hence the results cannot be generalised. Also, some single mothers have significant others who support in the care of children with chronic conditions as some single mothers are also earners of high incomes thus some of the conclusions of this study could be flawed.

An integrative review to identify scientific evidence about families of children with sickle cell disease in Brazil by Gesteira, Bousso, Misko, Ichikawa, and Oliveira, (2016) reviewed sixteen articles from the databases of MEDLINE, LILACS, CINAHL, and PubMed, and looked for articles published between January 2005 and January 2015 and concluded that the family remains the key provider of care for children with sickle cell disease, and that families encounters challenges in achieving complete care and fighting for their children’s quality of life. Mothers were also regarded as the main caregivers in families and that social support especially spousal support and income moderated the impact of psychological stress and determined the coping strategies used by caregivers of children with sickle cell disease. The findings of the review did not specifically test the impact or moderating role of only marital status but also social support thus enough reliance on marital status as the main moderator of the relationship between coping strategies and psychological distress is contestable.

In the bid to assess the relation between single parenting and socioeconomic factors, including low income and parental emotional distress among caregivers of chronically ill children, Wiener, Pao, Battles, Zadeh, Patenaude, Madan-Swain and Lone-Parent Study Group (2013) conducted a longitudinal study assessing the findings from two articles with a combined sample of 425 participants (single or lone caregivers of children under the age of 18 with chronic conditions). They found from the reviews that juggling the effective management of a child's chronic health condition with the necessities of everyday parenting and living appears to be more task-involving and distressing for caregivers who are doing so on their own or without the supposed support of a partner or spouse and that forty-five percent of those who were demographically single had incomes under $24,000 (considered as poor and suffering financially).

In both studies Wiener et al. (2013) found that psychological distress is highest in the subgroup of caregivers who perceive themselves as lone parents when it comes to caring for their children with chronic conditions. This group of parents had high scores in the clinical range for depression, anxiety, and stress. This supported the findings of other researchers that marital status and income levels moderates the relationship between psychological distress and coping strategies amongst caregivers of children with chronic conditions (Woessmann, 2015; Kantor, 2016). The shortfalls as noted in the review is that the cut off used for a family of four living under the poverty level was $24,000 though they did not find out how many family members were living in the home at the time the study was conducted hence they might have under- or over-reported the number of caregiver participants living in poverty. Longitudinal research is necessary to determine the impact of single parenting and low income on parental and child health conditions over time instead of the cross-sectional research they did.

Olley, Brieger, and Olley, (1997) who indicated in their study that family support systems are key determinants in the quantum of psychological distress experienced in caring for children with sickle cell disease;

monogamously married mothers reported less caregiving stress than non-married mothers or those in polygamous marriages. Highly religious caregivers suffer less psychological distress of caregiving than non-religious colleagues. Caregivers of older children and mothers of more than one child with sickle cell disease reported greater caregiving stress.

Conceptual framework

The connection of concepts, expectations, beliefs and theories that support and inform the research is the conceptual framework of the study. This explains the study graphically, the main variables to be researched, the key factors, concepts or variable and the relationships between or among the variables.

Based on the review of the empirical and theoretical literature, the following conceptual framework was used (see Figure 1).

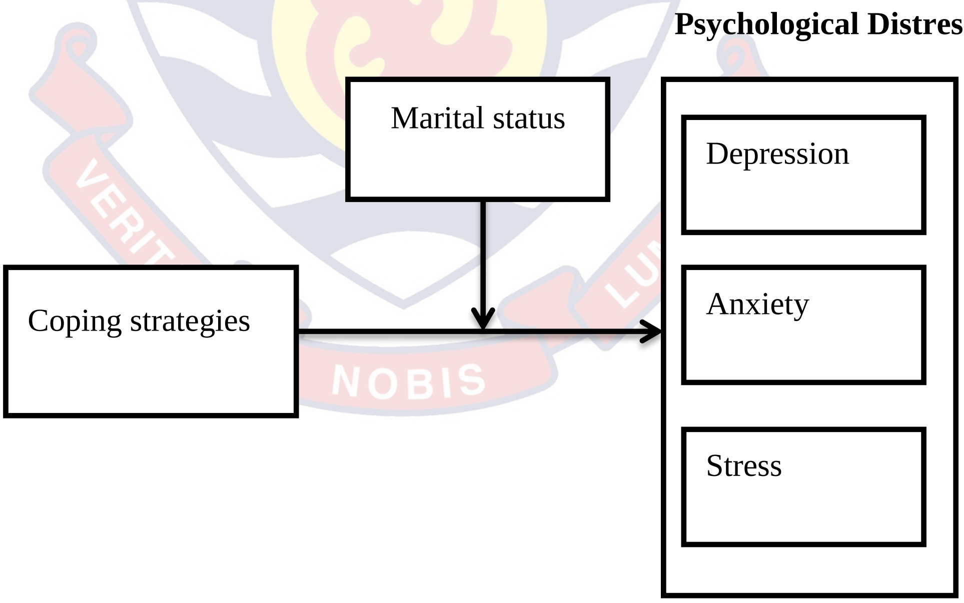


Figure 1: Relationship between psychological distress and coping strategies

The Figure 1 depicts the concept that chronic conditions in children could affect the psychological wellbeing of caregivers in the forms of depression, anxiety and stress (psychological distress) and compel caregivers to employ the use of coping strategies which will either reduce or perpetuate the psychological distress experienced as a result of providing care for the children with chronic conditions. Coping and psychological distress affects each other as better coping strategies when used are expected to reduce the depression, anxiety and stress levels.

Summary of Literature

An extensive review of the existing literature threw more light on the relevance of caregiving and the associated problems resulting from the roles of caregivers due to the attention and services children with chronic conditions needs. Some important aspects of caregiving are not considered in the existing literature such as: None of the studies tackled sickle cell and epilepsy together or solely with regards to caregiver's psychological distress and or their coping strategies. Most of the studies were gender biased as majority of them had fewer or no male caregiver's as samples of their studies.

The sample sizes were also found to be smaller though literature indicates that epilepsy and SCD is high among children. The methodologies of the studies were mostly cross-sectional with none using the DASS – 21 and the Brief Cope Inventory simultaneously. Most of the studies did not analyse the relationship between coping strategies and psychological distress and those that did lacked analyses on the moderating factors of the relationships. Though some studies examined the psychological distress in caregivers, none of them specifically compared the anxiety, depression and stress suffered by caregivers of children with epilepsy and SCD. A few studies were found to be conducted in Africa although epilepsy and SCD is found to be higher in this part of the world. No study was found in Ghana to have researched on the psychological distress and the coping strategies of caregivers of children with epilepsy and SCD concomitantly. The gaps found in the existing literature were addressed in this study by employing a different methodology (descriptive survey), using a large sample size from a Ghanaian population and also examined the moderating role of marital status in the relationship between coping strategies and psychological distress.

CHAPTER THREE

RESEARCH METHODS

This chapter gives the details of the research design, population, sample and sampling procedure, data collection and data analysis processes used in this work. The methodology is the overall research approach that outlines the ways in which research is embarked on and, among other things, ascertains the methods used in it. These methods, described in the methodology, define the means or modes of data collection or, occasionally, how a specific result is to be calculated (Howell, 2013).

Research Design

A research design is the overall plan for obtaining answers to the research questions or for testing the hypothesis hence it determines the structural framework within which the study is implemented (Creswell & Poth, 2017). The study employs a quantitative approach which allows for objective analysis and conclusions. Consequently, the researcher used a descriptive survey in conducting this work (Bernard, 2013). The research design is the benchmark for conducting the study that maximises control over factors that could interfere with the validity of the findings (Blaike, 2009; Blaikie & Priest, 2019). The research design helped the researcher in planning and implementing the study in a way that was more appropriate in achieving the goals of the study.

With the use of descriptive survey, the researcher will be able to provide an accurate account of the characteristics of a particular individual, situation or group for the purpose of discovering new meaning, describing what exists, determining the frequency with which something occurs and categorising information (Patten, & Newhart, 2017). Again, descriptive survey design has good statistical significance because it is highly representative; thus, it is often easier to find statistically significant results and yields higher validity and reliability than other research designs (Creswell, 2014). The purpose of descriptive survey in this study was to explore and describe phenomenon in the real-life situation of caregivers of children suffering from chronic conditions. The descriptive survey generates new knowledge about concepts or topics about which limited or no research has been conducted (Dulock, 1993). Through descriptive surveys, concepts such as epilepsy, sickle cell disease, psychological distress and coping strategies in this study are described and relationships identified that provides a basis for further quantitative research and theory testing. In this study the caregivers of children with chronic conditions were requested to respond to questionnaire on the psychological effects they experienced and the coping strategies they employed in caring for the children with chronic conditions. Descriptive surveys result in rich data that is collected in large aggregates with the use of questionnaire, meriting its usage in this study (Creswell, 2014)

Study Area

The study was conducted in five (5) districts in the Ashanti region of Ghana comprising five hospitals that render treatment services to children (from the urban or rural areas) with chronic conditions within the health facility. Caregivers of children with chronic conditions in Tafo Government Hospital, Maternal and Child Health Hospital, Manhyia Government Hospital, Effiduase Government Hospital and Ejisu Government Hospital in the Ashanti region of Ghana were the research participants of this study as the records available showed higher number of cases in these hospitals in the region.

Population

The population of the study comprised both male and female caregivers of either rural or urban dwelling, literate or illiterate who care for children with chronic conditions under the age of 18 years. A total of 204 caregivers were estimated, of which 94 were caregivers of children with SCD whilst 110 were caregivers of children with epilepsy from the five hospitals used in the study (Ghana Health Service, District Health Information Management Systems report). The accessible population was only caregivers who visited Tafo (epilepsy 48, SCD 16), Maternal and Child Health (epilepsy 11, SCD 32), Manhyia (epilepsy 17, SCD 18),, Effiduase (epilepsy 14, SCD 15), or Ejisu (epilepsy 20, SCD 13) Government hospitals during the month in which the data was collected and were willing to participate in the survey. The accessible population possessed the same characteristics as the target population as they were randomly selected at designated areas hence are a reflection of the target population.

Sampling procedure

Sampling is the selection of a subset (a statistical sample) of individuals from within a statistical population to estimate characteristics of the whole population (Lance & Hattori, 2016). In this study, a convenience sampling procedure was used for selecting the hospitals whilst the quota sampling procedure was used for selecting the participants (caregivers). Convenience is a type of non-probability sampling which involves the sample being drawn from that part of the population which is close to hand. That is, a population is selected because it is readily available and convenient (Emerson, 2015). This technique was employed to ensure accessibility to the population since the complete data on the sample was not accessible to the researcher to facilitate random sampling. The convenience sampling was used to collect data from parents who were available at the facilities and willing to participate in the survey (Etikan, Musa, & Alkassim, 2016).

With the population of 204 caregivers of children with chronic conditions in the five selected hospitals known from the records of Ghana Health Service, the Krejcie and Morgan (1970) sample determination formula was used to determine the appropriate sample size for the study, given as follows:

$$s = \frac{x^2NP(1-P)}{d^2(N-1)+x^2P(1-P)}$$

$$s\ (for\ caregivers) = \frac{3.8416(204)(0.5)(1-0.5)}{0.05^2(204-1)+3.8416(0.5)(1-0.5)} = 134$$

S = required sample size

x^2 = the table value of chi-square for 1 degree of freedom at the desired confidence level (3.8416)

N = the population size

P = the population proportion (assumed to be .50 since this would provide the maximum sample size)

d = the degree of accuracy expressed as a proportion (.05)

To cater for incidence of non-return rate of some of the questionnaire, Cohen, Manion and Morrison (2004) suggest that the sample can be increased up to half of the required number. Therefore, the sample size was increased by twenty percent to give opportunity to more caregivers to participate and also cater for incidence of non- return of questionnaire. Finally, 160 caregivers comprising 54% caregivers of children with epilepsy and 46% caregivers of children SCD were selected for the study (Tafo (epilepsy 36, SCD 13), Maternal and Child Health (epilepsy 8, SCD 25), Manhyia (epilepsy 13, SCD 14),, Effiduase (epilepsy 10, SCD 12), or Ejisu (epilepsy 15, SCD 10)) instead of the 134 respondents determined by the sample determination formula of Krejcie and Morgan (1970).

Inclusion Criteria

All caregivers of children with SCD or epilepsy under the age of 18 years who live in the same house and seek care and treatment from a health facility in any of the selected hospitals. The child should have had at least five (5) episodes of seizure attacks within six months (Diagnostic and Statistical Manual – 5 (2013)), the child with sickle cell disease should have experienced not less than three (3) sickle cell crisis in the last six months.

Exclusion Criteria

Caregivers of children with SCD or epilepsy above 18 years of age were excluded from the study. Additionally, a caregiver of a child with epilepsy who has not experienced a seizure in over six months were excluded from the study, the DSM - 5 criteria indicates a no seizure attack in over six months is an inactive epilepsy. Caregivers of children with SCD who have not experienced the sickle cell crisis up to two times in the last six months were excluded.

Data Collection Instruments

Questionnaire was the main instrument for data collection in the study. Two different standardised scales were adapted into the questionnaire to elicit responses on coping strategies and psychological distress (depression, anxiety and stress) of caregivers of children with sickle cell disease or epilepsy. The Depression Anxiety Stress Scale (DASS-21) was used to collect information on psychological distress while the Brief Coping Inventory (BCI) was used to collect information on coping strategies.

The Depression, Anxiety and Stress scale (DASS-21) (Psychological Distress Measure)

DASS is one of the commonly-used scales for detection of mental health problems in adults. The scale was developed by researchers at the University of New South Wales (Australia) in 1995 (Le, Tran, Holton, Nguyen, Wolfe & Fisher, 2017). The reliability and validity of the DASS-21 have been established among clinical as well as non-clinical adult samples (Clara, Cox & Enns, 2001). The same three-factor structure (depression, anxiety and stress) has been seen when the measure is used among diverse cultural and ethnic groups (Clara et al 2001). The DASS-21 is a 21 item self-report scale designed to measure depression, anxiety and stress (operationally defined as psychological distress) and is scored on a four point Likert scale (in which **0** = Did not apply to me at all, **1=** Applied to me to some degree, or some of the time, **2=** Applied to me to a considerable degree and **3=** Applied to me very much or most of the time) and has been found to demonstrate a high internal consistency with Cronbach's Alpha ranging from .761 to .906 (Le et al., 2017), thus showing a high reliability. Also, the DASS-21 convergent validity is confirmed with moderate correlation coefficients (.47 to .66) hence showing high validity (Le et al., 2017). The DASS 21 comprised 7 items each for depression, anxiety and stress and makes room for the measure of the severity of these symptoms by multiplying the total score of each group of seven items by two since the DASS-21 is a short version of the DASS-42 (Lovibond & Lovibond, 1995)(see appendix B for the score range).

The Brief Coping Inventory (BCI) (Coping strategy measure)

The Brief COPE inventory is a 28-item scale; it is an abbreviated version of the COPE inventory developed by Carver (1997), which assesses a wide range of coping strategies such as spiritual, emotional, social coping and even substance use. The Brief COPE inventory scale has 14 dimensions with 2 items per scale which are: Self-distraction, Active coping, Denial, Substance use, use of emotional support, use of instrumental support, Behavioural disengagement, Venting, Positive reframing, Planning, Humor, Acceptance, Religion and Self-blame. The scales of the Brief COPE are divided into two/three broad coping styles by summing items into the following categories: Problem/Emotion-focused (positive) coping strategies (Planning, Positive reframing, Active coping, Religion, Acceptance, Instrumental support, Emotional support, and Humor) and the Avoidance-focused (negative) coping strategies (Denial, Venting, Behavioral disengagement, Self-distraction, Self-blame and Substance abuse). The scores are based on the sum of the scores of each sub-scale. These dimensions are assessed on a four-point Likert scale (in which **0** = Did not apply to me at all, **1=** Applied to me to some degree, or some of the time, **2=** Applied to me to a considerable degree and **3=** Applied to me very much or most of the time). Both the maladaptive and adaptive scales of the Brief COPE inventory have high Internal Consistency with Cronbach's Alpha of .81 and .88 respectively. This high internal consistency depicts a high reliability of the instrument (Sutan, Al-Saidi, Latiff & Ibrahim, 2017).

In summary, the questionnaire that was used for the data collection consisted of three sections. Section A was made up of 5 items that elicited demographic information such as age of respondent, age range of the child, gender of respondent, condition of the child, income range of respondent and marital status of the caregiver. Section B consisted of 21 items that assessed depression, anxiety and stress (psychological distress) (DASS-21) while Section C consisted of 28 items which assessed the coping strategies of the caregivers of children with chronic conditions (Brief COPE Inventory). The data collection instrument was made up of 54 items all together.

Pilot-testing of Instrument

To ensure the clarity and appropriateness of the questionnaire to address the research objectives, a pilot-test was conducted to pre-test the questionnaire using 32 purposively sampled caregivers (SCD (15) and epilepsy (17)) in Suntresso government hospital and Kumawu government hospital to give the researcher fore-knowledge on the populations that was surveyed and to enable the researcher amend the questionnaires to eliminate avoidable errors. The respondents comprised both married and unmarried, literate and illiterate, male and female caregivers within the age range of 22 – 55 years. Certain words from the DASS-21 such as 'touchy, wind down, blue and agitated' were rephrased to offended, calm down, sad, restless to make understanding easier for the participants but the arrangement and compositions of the scales remained same.

Validity and Reliability of the instrument

The questionnaire was given out to experts at the Department of Education and Psychology in the University of Cape Coast to assess and certify the face and content validity of the instrument and its application to the Ghanaian population (Padilla & Benítez, 2014; Zamanzadeh, 2015). To test the reliability of the Brief Cope and DASS 21, Cronbach's Alpha was used using the pilot study data. The Cronbach's Alpha coefficient for the DASS-21 scale in the pilot test was found to be 0.88 signifying high reliability of the instrument comparative to the original DASS-21 that has internal consistency with Cronbach's Alpha ranging from .761 to .906 (Le et al, 2017; Tavakol & Dennick, 2011). The Brief Cope inventory had high internal consistency with Cronbach's Alpha of .82 similar to the original scales chronbach's Alpha of .81 respectively (Sutan, Al-Saidi, Latiff, & Ibrahim, 2017).

Data Collection Procedure

In this study the researcher used standardised questionnaire to collect the data. An introductory letter was taken from the Department of Education and Psychology to the various hospitals to seek permission to conduct the research (see appendix B) after ethical clearance was obtained from the Institutional Review Board of the School of Graduate Studies of University of Cape Coast (see appendix A). Contacts were made with some hospital administrators and nurse in-charges in order to get the needed assistance necessary to conduct the survey. The researcher introduced briefly the topic and the purpose of the research and the importance of the study to the participants. The participants were assured of anonymity, confidentiality and their voluntary participation was elicited. They were also assured that they could withdraw at any time. The questionnaires were administered after the consent of participants was informed to caregivers who met the inclusion criteria and were willing to participate in the survey. The acquired data was kept confidential as all information was treated with adequate confidentiality and used only for this research purpose. There was no identification information on the questionnaire to ensure anonymity.

The questionnaire was self – administered. The data collection exercise was done on Mondays to Fridays 8:00am to 2:00 pm for a period of four weeks. Questionnaires were administered to caregivers who have children with sickle cell disease or epilepsy who visited the hospitals to seek treatment or for review after authorisation from the heads of the facilities are sought with a letter of introduction from the Department of Education and Psychology of the University of Cape Coast clearly stating the purpose of the study. Questionnaires were administered to respondents who could read and write to respond to whilst those who could neither read nor write, the researcher read the questions and responses to them in a language they understood (mostly Twi) and their choices of answers were ticked accordingly. In all 154 respondents returned their questionnaire representing a return rate of 96.3%.

Data Processing and Analysis

In order to achieve the objectives of the study, a number of analytical tools were employed. Descriptive statistics such as means, frequencies, percentages and standard deviations were used to describe the demographic profile and illustrate the diversity of the participants. Percentages and frequency bars and charts are also used to identify the coping strategies employed by caregivers of children with chronic conditions. Research questions one and two are analysed using descriptive statistics such as means, standard deviations, frequencies and percentages.

Inferential statistics were used to investigate differences and relationships between variables and groups. To this end, the multivariate analysis of variance (MANOVA) and the Independent samples t-test was used to analyse hypotheses 1 and 2 to test for differences in psychological distress and coping strategies between independent groups. The MANOVA and Independent t-test was used because the researcher sought to determine the differences between groups and they are appropriate statistical test tools for analysing difference between independent groups (Bakker & Wicherts, 2014). Hypothesis 3 was analysed with the multiple regression analysis test. This was to test the relationships between psychological distress and coping strategies (Lee, 2003; Hall, 2015) and the fourth hypothesis was tested by conducting a moderation analysis using PROCESS by Hayes (2012).

Chapter Summary

The research design used in the study was descriptive survey. The study area was (selected hospitals in 5 districts) in the Ashanti region of Ghana. The population comprised of caregivers of children with epilepsy or SCD, sampling procedure and sample size of 160 respondents. Pilot study was done in Suntresso and Kumawu hospitals to test the reliability of the instruments and its application to the population under study. Ethical considerations, data collection, processing and analysis are addressed in this chapter.

CHAPTER FOUR

RESULTS AND DISCUSSION

Introduction

This chapter presents the analysis and interpretation of the results from the study. The purpose of the study was to assess the coping strategies employed by caregivers and the psychological distress experienced by caregivers of children with epilepsy or sickle cell disease in the Ashanti region of Ghana. The analysis and interpretation of data were carried out based on the results of the research questions and hypothesis set for the study. The analysis was based on the 97.5% return data obtained from 160 caregivers of sickle cell and epileptic patients. The data was analysed using descriptive statistics (frequencies, percentages, means and standard deviations) and inferential statistics (Independent Samples t-test, Pearson Product-Moment Correlation and Moderation Analysis). The first part of this chapter describes the demographic characteristics of the respondents. In the second part, the research findings are presented based on the research questions and hypothesis formulated for the study.

Socio-Demographic Characteristics of the Respondents

This study was conducted in the Tafo, Manhyia, Ejisu, Effiduase and the Maternal and Child Health Hospitals in the Ashanti region of Ghana. The total number of caregivers who responded and returned the questionnaire were 156. The demographic data included the age of the respondent, age of child, gender of respondent, marital status of respondent, income range of respondent and the condition of the child cared for. These are presented using means, percentages and frequencies.

Distribution of respondents by Age

The ages of the caregivers and the children with chronic conditions was examined. Item one and two in Section A of the questionnaire elicited information about the ages of the respondents and children respectively. The result of the analysis of their responses is presented on Table 1.

Table 1- *Distribution of the Respondents by Age*

Age	N	Minimum	Maximum	Mean	Std. Dev.
Caregivers	156	20	55	41.10	7.693

Source: Field Survey (2019)

Table 1 show that the mean age of the caregivers of the children with chronic conditions was 41 years. Therefore, it implies that majority of the caregivers aged around 41 years with few being around 20 and 55 years of age.

Distribution of Respondents by Gender

The researcher considered the gender of the caregivers as relevant for descriptive and analytical purposes hence item 3 in section A of the questionnaire elicited information about the gender of respondents. The result of the analysis of responses is presented in Table 2.

Table 2- *Distribution of the Respondents by Gender*

Variable	Frequency	Percent (%)
Male	60	38.5
Female	96	61.5
Total	156	100.0

Source: Field Survey (2019)

Table 2 shows that 96 (61.5%) of the caregivers are females whilst 60 (38.5) are males. From the table, it is evident that female caregivers are in the majority.

Distribution of Respondents by Marital Status

The marital status of the respondents was examined to give insight on the support systems available to the caregivers. Item 4 of section A of the questionnaire solicited for information on the marital status of the respondents. The result of the analysis of their responses is presented on Table 3.

Table 3- *Marital Status of the Respondents*

Variable	Frequency	Percent
Unmarried	68	43.6
Married	88	56.4
Total	156	100.0

Source: Field Survey (2019)

Table 3 show that 88 (56.4%) of the respondents are married whilst 68 (43.6%) are unmarried. From the table, it is evident that the majority of the respondents are married caregivers.

Distribution of Respondents Based on Monthly Income Levels

The study also considered the income levels of the respondents as a form of support system hence item 5 of section A of the questionnaire elicited information on the income ranges of the respondents. The result of the analysis of their responses is presented in Table 4.

Table 4- *Distribution of Monthly Income Level of Respondents*

Amount (GH₵)	Frequency	Percent (%)
≤ 499	43	27.6
500 – 999	57	36.5
1000 – 1499	31	19.9
1500 – 1999	18	11.5
≥2000	7	4.5
Total	156	100.0

Source: Field Survey (2019)

Table 4 shows that 57 (36.5%) caregivers earn between GH₵ 500 - GH₵ 999 while 7 (4.5%) caregivers earn GH₵ 2000 or more. From the table it can be seen that the majority of the caregivers earn between GH₵ 500 - GH₵ 999.

Distribution of Respondents by Condition of Child

The study considered the caregivers based on the conditions of the children they cater for. Table 5 presents the results of the analysis of responses of the respondents according to the conditions of their children.

Table 5- *Distribution of Respondents by Condition of Child*

Variable	Frequency	Percent (%)
Sickle Cell	74	47.4
Epilepsy	82	52.6
Total	156	100.0

Source: Field Survey (2019)

Table 5 shows that 82(52.6%) of the caregivers were taking care of children with epilepsy whiles 74(47.4%) were taking care of children with sickle cell disease. From the table, it can be concluded that the majority of the caregivers were responsible for the care of children with epilepsy.

Main Analysis

Research Question One: *What are the levels of psychological distress among caregivers of children with epilepsy and sickle cell disease?*

The study sought to examine the level of psychological distress among caregivers of children with epilepsy and of sickle cell disease in terms of stress, anxiety and depression. The levels were established based on the score's respondents attained in the Depression, Anxiety and Stress questionnaire multiplied by two and compared to the reference scale (see Appendix B). The analysis of the results of the respondents is presented in Table 6.

Table 6- *Levels of Psychological Distress among Caregivers of Children with Epilepsy and SCD*

Variable	EPILEPSY		SCD	
	Freq.	Percent	Freq.	Percent
Level of Stress				
Normal	23	28.0	12	16.2
Mild	20	24.4	6	8.1
Moderate	18	22.0	17	23.0
Severe	14	17.1	33	44.6
Extreme	7	8.5	6	8.1
Total	82	100	74	100
Level of Anxiety				
Normal	6	7.3	7	9.5
Mild	1	1.2	5	6.8
Moderate	23	28.0	20	27.0
Severe	11	13.4	7	9.5
Extreme	41	50.1	35	47.2
Total	82	100	74	100
Level of Depression				
Normal	2	2.4	0	0
Mild	8	9.8	1	1.4
Moderate	33	40.2	9	12.2
Severe	18	22.0	19	25.6
Extreme	21	25.6	45	60.8
Total	82	100	74	100

Source: Field Survey (2019)

Table 6 shows that 52.4% of caregivers of children with epilepsy have normal to mild stress levels whilst 24.3% of caregivers of children with SCD have normal to mild stress levels. Majority (52.7) of the caregivers of children with SCD were found to have severe to extreme levels of stress whilst only 25.6% of the caregivers of children with epilepsy were found to experience severe to extreme levels of stress. Again, only 8.5% of the caregivers of children with epilepsy had normal to mild level of anxiety as 16.3% of caregivers of children with SCD had normal to mild levels of anxiety. Over half (63.4%) of the caregivers of children with epilepsy had severe to extreme levels of anxiety whilst 56.8% of the caregivers of children with SCD had severe to extreme levels of anxiety. In terms of depression, the majority (86.5%) of the caregivers of children with SCD had severe to extreme levels as only 1.4% had mild to normal levels of depression whilst only 47.6% of caregivers of children with epilepsy had severe to extreme levels of depression with 12.2% of them having normal to mild levels of depression.

Research Question Two: *What coping strategies are mostly used by caregivers of children with chronic conditions?*

The study examined the coping strategies used by caregivers of children with chronic conditions. The analysis was based on means and standard deviations. The results of analysis of their responses are presented in Table 7.

Table 7- *Coping Strategies Employed by Caregivers of children with Epilepsy and SCD*

Coping Strategy	Epilepsy		SCD	
	Mean	SD	Mean	SD
Problem Focused Strategies	18.04	4.48	21.50	2.30
Active coping	4.37	1.51	5.28	1.21
Planning	3.76	1.52	5.41	1.02
Instrumental support	4.11	1.48	3.82	1.18
Self-destruction	4.15	2.73	5.19	1.16
Humour	1.66	1.82	1.80	1.54
Emotion Focused Strategies	17.78	4.46	20.76	3.19
Acceptance	4.15	1.42	4.62	1.21
Religion	4.16	1.81	5.32	1.42
Emotional support	3.60	1.51	3.58	1.36
Positive reframing	3.24	1.54	4.22	1.26
Venting	3.02	1.31	3.64	1.30
Avoidance Focused Strategies	9.76	4.64	10.47	4.12
Denial	2.63	1.60	3.01	1.60
Behavioural disengagement	2.76	1.64	2.68	1.68
Self – blame	2.24	1.68	2.76	1.67
Substance use	1.73	1.97	1.41	1.57

Source: Field Survey (2019)

Table 7 shows that Active coping is the most used coping strategy by caregivers of children with epilepsy with the highest mean score of 4.37 and standard deviation of 1.51, followed by Religion which has a mean score of 4.16 and standard deviation of 1.81. On the other hand, planning is the most used coping strategy by caregivers of children with SCD with a mean score of 5.41 and standard deviation of 1.02, followed by religion which has a mean score of 5.32 and standard deviation of 1.42. Substance use is the least used coping strategy with mean score of 1.73 and standard deviation of 1.97 and a mean score of 1.41and standard deviation of 1.57 for caregivers of children with epilepsy and SCD.

Again, the table shows that problem focused coping strategies are the most used group of coping strategies by the respondents with mean score of 18.04 and standard deviation of 4.48 for caregivers of children with epilepsy and a mean score of 21.50 and standard deviation of 2.30 for caregivers of children with SCD, followed emotion focused coping strategies, whilst the least used coping strategies by caregivers of children with chronic conditions are the avoidant focused coping strategies.

Research Hypothesis One: *There are significant differences in the levels of psychological distress (anxiety, depression and stress) experienced by male and female caregivers of children with chronic conditions*.

The purpose of this hypothesis was to test whether there is a difference in the psychological distress (anxiety, depression and stress) experienced by caregivers based on their gender or not.

Based on the nature of the variables, differences could best be tested using the Multivariate Analysis of Variance test after assumptions were satisfied. A normality test was conducted. Figure 2 shows the normality test for the variables.

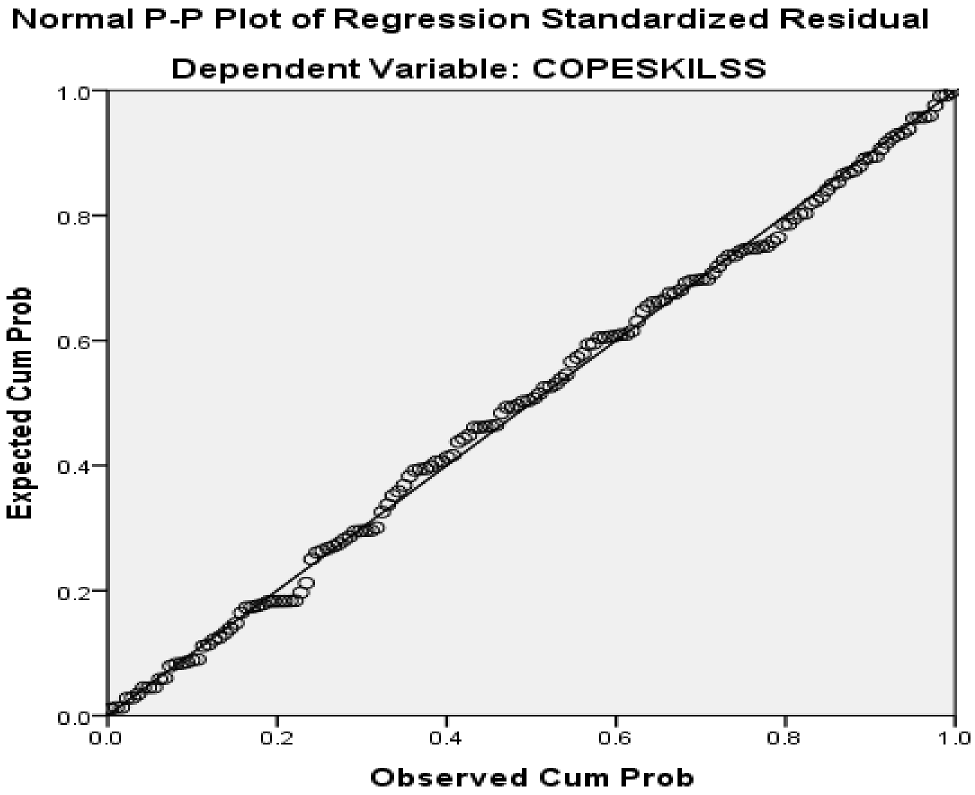


Figure 2: Normality Test for the Variables

Table 8 presents the group statistics results of the differences in psychological distress based on the gender of caregivers of children with epilepsy.

Table 8- Group Statistics results for Gender on Psychological distress (Anxiety, Depression and Stress) for caregivers of children with epilepsy

Variable	Gender	Mean	SD
Stress	Male	20.42	7.48
	Female	19.88	8.12
Anxiety	Male	19.33	8.91
	Female	19.31	8.14
Depression	Male	21.09	6.88
	Female	21.55	8.61

Source: Field data (2019) n=156

Table 8 shows that the mean and standard deviation scores for male caregivers of children with epilepsy was M= 20.42, SD = 7.48 whilst the mean and standard deviation scores for the female caregivers was M=19.88, SD= 8.12 in the experience of stress, in terms of anxiety, the mean and standard deviation scores for male caregivers was M=19.33, SD = 8.91 whilst the mean and standard deviation scores for the female caregivers was M= 19.31, SD=8.14. Finally, the male caregivers had a mean score of 21.09 and SD=6.88 whilst the female caregivers had a mean of 21.55 and SD=8.61 in terms of depression. From the table it can be said that there are no significant differences in the experience of psychological distress among caregivers of children with epilepsy based on their gender since the means values are almost the same.

The results of the Multivariate analysis of variance on the differences in psychological distress based on gender are presented in Table 9.

Table 9- *MANOVA results for Gender on Psychological distress for caregivers of children with Epilepsy*

	Variable	df	Mean Square	F	Sig
Gender	Anxiety	80	5.894	.095	.758
	Depression	80	.015	.000	.989
	Stress	80	4.175	.068	.798

Source: Field data (2019) df = (1, 78) *Significant at p≤ 0.05 (2-tailed)

Table 9 shows that there are no statistically significant differences in the levels of psychological distress (anxiety and stress) experienced by caregivers of children with epilepsy based on their gender. With the observed covariance matrices of the dependent variables equal across groups, the Wilk's Lambda =.994, F (3,78) = 161, p = .922 leading to a fail to reject the null hypothesis. The results of the multivariate analysis of variance showed that Anxiety (F (1, 78) = .095, *p*= .758, Depression (F (1,78) = .000, p= .989 and Stress (F (1,78) = .068, p= .798.

Table 10 presents the group statistics results of the differences in psychological distress based on the gender of caregivers of children with SCD.

Table 10- *Group Statistics results for Gender on Psychological distress (Anxiety, Depression and Stress) for caregivers of children with SCD*

Variable	Gender	Mean	SD
Stress	Male	20.89	5.56
	Female	26.55	8.48
Anxiety	Male	13.56	7.20
	Female	23.15	9.82
Depression	Male	26.74	7.00
	Female	31.19	6.81

Source: Field data (2019) N=156

Table 10 shows that the mean and standard deviation scores for male caregivers of children with SCD was M= 20.89, SD = 5.56 whilst the mean and standard deviation scores for the female caregivers was M=26.55, SD= 8.48 in the experience of stress, in terms of anxiety, the mean and standard deviation scores for male caregivers was M=13.56, SD = 7.20 whilst the mean and standard deviation scores for the female caregivers was M= 23.15, SD=9.82 and finally, the male caregivers had a mean score of 26.74 and SD=7.00 whiles the female caregivers had a mean of 31.19 and SD=6.81 in terms of depression. From the table it can be said that, there are significant differences in the experience of psychological distress among caregivers of children with SCD based on their gender since the means values are not close.

The results of the Multivariate analysis of variance on the differences in psychological distress based on gender are presented in Table 11.

Table 11- *MANOVA results for Gender on Psychological distress for caregivers of children with SCD*

	Variable	df	Mean Square	F	Sig	Effect size
Gender	Anxiety	72	550.203	9.633	.003	.118
	Depression	72	1578.241	19.644	.000	.214
	Stress	72	339.700	7.180	.009	.091

Source: Field data (2019) df = (1, 70) *Significant at p≤ 0.05(2-tailed)

Table 11 shows that there are statistically significant differences in the levels of psychological distress in caregivers of children with SCD based on their gender. With the observed covariance matrices of the dependent variables equal across groups, the Wilk's Lambda =.776, F (3,70) =6.716, p < .001 leading to a rejection of the null hypothesis. The results of the multivariate analysis of variance showed that Anxiety (F (1, 70) = 9.633, *p* =.003), Depression ((F (1, 70) = 19.644, *p*< .001), Stress ((F (1, 70) = 7.180, *p* =.009) levels are different in caregivers of children with SCD based on their gender. The effect sizes of the differences in their experience of psychological distress was calculated and the results showed that the standardised differences in the levels experienced were all smaller (Anxiety = .118, Depression = .214 and Stress = .091) (Cohen, 1988).

Research Hypothesis Two: *There are significant differences in the levels of psychological distress (anxiety, depression and stress) experienced by caregivers of children with epilepsy and caregivers of children with sickle cell disease.*

The purpose of this hypothesis is to test for the differences in anxiety, depression and stress (together as psychological distress) between caregivers of children with epilepsy and sickle cell disease. Based on the nature of the variables, the differences were analyzed using the multivariate analysis of variance test after assumptions were satisfied. The results of the analysis are presented in Table 12.

Table 12- *Group Statistics results for type of Condition on Psychological distress (Anxiety, Depression and Stress)*

Variable	Condition	Mean (M)	SD	N
Anxiety	Sickle cell	19.86	10.043	74
	Epilepsy	19.32	8.405	82
Depression	Sickle cell	29.57	7.164	74
	Epilepsy	21.37	7.912	82
Stress	Sickle cell	24.49	7.992	74
	Epilepsy	20.10	7.818	82

Source: Field data (2019) N=156

Table 12 shows that caregivers of children with sickle cell disease (M= 19.65, SD = 10.04) were not different from caregivers of children with epilepsy (M=19.32, SD= 8.40) in the feeling of anxiety but caregivers of children with sickle cell disease (M= 29.57, SD = 7.16) were different from caregivers of children with epilepsy (M=21.37, SD= 7.91) in the experience of depression. Again, caregivers of children with SCD (M= 24.89, SD = 7.99) were different from caregivers of children with epilepsy (M=20.10, SD= 7.82) in the experience of stress resulting from the caregiving roles they perform.

Table 13 is a presentation of the results of the analysis of the data using multivariate analysis of variance on the type of condition of children caregivers take care of on psychological distress.

Table 13- *MANOVA results for type of Condition on Psychological distress (Anxiety, Depression and Stress)*

	Variable	Df	Mean Square	F	Sig.	Effect size
Condition	Anxiety	154	4.276	.050	.823	.000
	Depression	154	2616.557	45.700	.000	.229
	Stress	154	749.268	12.002	.001	.072

Source: Field data (2019) n = 156 df = (1, 154) Significant at 0.05

Table 13 shows that there are statistically significant differences in the levels of psychological distress in caregivers of children with chronic conditions, based on the condition of the child one caters for. With the observed covariance matrices of the dependent variables equal across groups; Wilk's Lambda =.713, F (3,152) =20.442, p<.001. Results of the multivariate analysis of variance shows that there is a significant difference in the level of depression experienced by caregivers based on the type of condition of the children they care for (F (1, 154) = 45.700, *p*< .001). Also, there were statistically significant differences in stress levels based on the type of condition (F (1, 154) = 12.002, p=.001). However, there were no significant differences in anxiety levels between the caregivers based on the type of condition of their child (F (1,154) =.050, p=.823). Since there were significant differences in depression and stress levels based on condition, the effect sizes were calculated and were 0.23 for depression (signified a small effect in terms of differences in depression levels experienced by caregivers of children with epilepsy and sickle cell disease) and 0.07 for stress (signified a very small effect size in terms of differences in stress levels in caregivers of children with SCD and caregivers of children with epilepsy) (Cohen, 1988).

Research Hypothesis Three: *There are significant relationships between psychological distress and coping strategies used by caregivers of children with epilepsy and sickle cell disease.*

The hypothesis sought to determine if there would be linear correlations between psychological distress (anxiety, depression and stress) and coping strategies used among caregivers of children with epilepsy and sickle cell disease. To achieve this, multiple regression analysis was done. The results of the multiple regression analysis are presented in Table 14,15,16 and 17.

Table 14- *Relation between Positive coping strategies and psychological distress in caregivers of children with Epilepsy*

	Variable	P. Coping	Stress	Anxiety	Depression
Correlation	P. Coping	1.00			
	Stress	.467**	1.00		
	Anxiety	.330**	.590**	1.00	
	Depression	.566**	.675**	.581**	1.00

Source: Field data (2019) **p<0.01
n=82
R^2 = .336 (Adjusted R^2 = .310)

Table 14 shows that there is a significantly positive but weak correlation between the use of the positive coping strategies (problem and emotion focused coping strategies) and stress with r = .467, p < .01, anxiety is also significantly positively correlated with the use of positive coping strategies with r = .330, p < .01, but depression had a moderately positive correlation with the use of positive coping strategies with r = .556, p < .01.

Based on the correlation coefficients, it implies that the use of positive coping strategies by caregivers of children with epilepsy goes to minimise the levels of psychological distress in caregivers of children with epilepsy. It can therefore be deduced that the use of positive coping strategies does not entirely eliminate the presence of psychological distress in caregivers of children with epilepsy.

Table 15- *Relation between Positive coping strategies and psychological distress in caregivers of children with SCD*

	Variable	P. Coping	Stress	Anxiety	Depression
Correlation	P. Coping	1.000			
	Stress	.310**	1.000		
	Anxiety	.191	.737**	1.000	
	Depression	.331**	.601**	.483**	1.000

Source: Field data (2019) **p<0.01
R^2 = .134 (Adjusted R^2 = .097)

Table 15 shows that there is a significantly positive but weak correlation between the use of the positive coping strategies (problem and emotion focused coping strategies) and stress with r =.310, p = .004, depression is also significantly positively correlated with the use of positive coping strategies with r = .331, p = 002. Based on the correlation coefficients it implies that the use of positive coping strategies by caregivers of children with epilepsy goes with psychological distress in caregivers of children with SCD but in minimal levels, it can therefore be deduced that the use of positive coping skills does not entirely eliminate the presence of psychological distress in caregivers of children with SCD. However, anxiety did not predict coping (r =.191, p = .052), implying that caregivers of children with SCD experiences anxiety irrespective of the positive coping strategies they use.

Table 16- *Relation between Negative coping strategies and psychological distress in caregivers of children with Epilepsy*

	Variable	N. Coping	Stress	Anxiety	Depression
Correlation	N. Coping	1.000			
	Stress	.423**	1.000		
	Anxiety	.512**	.590**	1.000	
	Depression	.346**	.675**	.581**	1.000

Source: Field data (2019) *p<0.01
$R^2 = .285$ (Adjusted $R^2 = .257$)

Table 16 shows that there is a significantly positive but weak correlation between the use of the negative coping strategies (Avoidance focused coping strategies) and stress with r = .423, p < .01 anxiety has a significant moderately positive correlation with the use of negative coping strategies with r =.512, p < .01 depression also had a weak positive correlation with the use of negative coping strategies with r = .346, p < .01.

This implies that the use of negative coping strategies by caregivers of children with epilepsy increases the levels of psychological distress (stress, anxiety and depression) in caregivers of children with epilepsy.

Table 17- *Relation between Negative coping strategies and psychological distress in caregivers of children with SCD*

	Variable	N. Coping	Stress	Anxiety	Depression
Correlation	N. Coping	1.000			
	Stress	.490**	1.000		
	Anxiety	.568**	.737**	1.000	
	Depression	.543**	.601**	.483 **	1.000

Source: Field data (2019) **p<0.01
n=74
$R^2 = .417$ (Adjusted $R^2 = .392$)

Table 17 shows that there is a significantly positive but weak correlation between the use of negative coping strategies (Avoidance focused coping strategies) and stress with a correlation coefficient of .490, anxiety has a significant moderately positive correlation with the use of negative coping strategies with a coefficient of .568, depression also had a moderately positive correlation with the use of negative coping strategies with a coefficient of .543.

This implies that the use of negative coping strategies by caregivers of children with SCD increases the levels of psychological distress (stress, anxiety and depression) in caregivers of children with SCD.

Research Hypothesis Four: *Marital status moderates the relationship between coping strategies and psychological distress in caregivers of children with chronic conditions.*

A moderation analysis was conducted to explore the role marital status plays in the relationship between coping strategies and psychological distress. The predictor was coping strategies, the moderator was marital status, and the criterion was psychological distress. The criterion, however, was multidimensional in nature such that the composite of it could not be used. The psychological distress comprised of three dimensions: stress, anxiety and depression. The moderation was done using 5,000 bootstrap samples.

Stress as Outcome variable

Table 18- *Moderating Role of Marital Status in the Relationship between Positive Coping strategies and Stress in caregivers of children with Epilepsy*

	Coeff	BootSE	t-value	BootLLCI	BootULCI
Constant	-13.852	13.223	-1.048	-40.177	12.473
Positive Coping (PCS)	.986	.354	2.735	.264	1.673
Marital status (MS)	10.437	1.705	1.355	-4.902	25.775
PCS*MS	-.306	.208	-1.470	-.721	.109

Model summary: R^2=.241; F (3, 78) =8.258, p<.001
PCS*MS: R^2 *change*=.021; F (1, 78) = 2.161, p=.146
Criterion: Stress

The results from Table 18 indicate that marital status was not a significant moderator in the relationship between positive coping strategies and stress levels in caregivers of children with epilepsy, b= -.306, t= -1.470, CI (-.721, .109).

Stress as Outcome variable

Table 19- *Moderating Role of Marital Status in the Relationship between Positive Coping strategies and Stress in caregivers of children with SCD*

	Coeff	BootSE	t-value	BootLLCI	BootULCI
Constant	28.393	18.703	1.518	-8.909	65.694
Positive Coping (PCS)	.270	-8.082	.620	-.598	1.138
Marital status (MS)	-12.653	11.550	-1.096	-35.688	10.383
PCS*MS	.063	.271	.231	-.478	.603

Model summary: R^2=.487; F (3, 70) =22.133, p<.001
PCS*MS: R^2 *change*=.000; F (1, 70) = .053, p=.818
Criterion: Stress

The results shown in Table 19 indicate that marital status was not a significant moderator in the relationship between positive coping strategies and stress levels in caregivers of children with SCD, b= -.063, t=.231, CI (-.478, .603). Positive coping did not significantly predict stress among caregivers of children with SCD.

Anxiety as Outcome variable

Table 20- *Moderating Role of Marital Status in the Relationship between Positive Coping Strategies and Anxiety in caregivers of children with Epilepsy*

	Coeff	BootSE	t-value	BootLLCI	BootULCI
Constant	13.699	15.155	.904	-16.474	43.871
Positive Coping (PCS)	.287	.407	.707	-.521	1.094
Marital status (MS)	-4.050	8.831	-.469	-21.630	13.531
PCS*MS	.032	.239	.134	-.443	.507

Model summary: R^2=.137; F (3, 78) =4.137, p<.001
PCS*MS: R^2 *change*=.000; F (1, 78) =.0180, p=.894
Criterion: Anxiety

The results from Table 20 indicate that marital status was not a significant moderator in the relationship between Positive coping strategies and anxiety in caregivers of children with epilepsy, b=.032, t=.134, CI (-.443, .507).

Anxiety as Outcome variable

Table 21- *Moderating Role of Marital Status in the Relationship between Positive Coping Strategies and Anxiety in caregivers of children with SCD*

	Coeff	BootSE	t-value	BootLLCI	BootULCI
Constant	1.750	20.862	.084	-39.860	43.359
Positive Coping (PCS)	.955	.485	1.968	-.013	1.923
Marital status (MS)	6.215	12.884	.482	-19.480	31.911
PCS*MS	-.498	.302	-1.646	-1.100	.105

Model summary: R^2=.772; F (3, 70) =34.369, p<.001
PCS*MS: R^2 *change*=.016; F (1, 70) =.2.710, p=.104
Criterion: Anxiety

The results as shown in Table 21 indicates that marital status was not a significant moderator in the relationship between Positive coping strategies and anxiety in caregivers of children with SCD, b=-.498, t=-1.646, CI (-1.100, .105).

Depression as Outcome variable

Table 22- *Moderating Role of Marital Status in the Relationship between Positive Coping Strategies and Depression in caregivers of children with Epilepsy*

	Coeff	BootSE	t-value	BootLLCI	BootULCI
Constant	-14.426	12.530	-1.151	-37.372	10.521
Positive Coping (PCS)	.990	.335	2.952	.323	1.658
Marital status (MS)	9.125	7.301	1.250	-5.411	23.660
PCS*MS	-.251	.197	-1.271	-.643	.142

Model summary: R^2=.578; F (3, 78) =13.072, p<.001
PCS*MS: R^2 *change*=.014; F (1, 78) =1.614, p=.208
Criterion: Depression

The results from Table 22 indicate that marital status was not a significant moderator in the relationship between positive coping strategies and depression in caregivers of children with epilepsy b= -.251, t= -1.271, CI (-.643, .142).

Depression as Outcome variable

Table 23- *Moderating Role of Marital Status in the Relationship between Positive Coping Strategies and Depression in caregivers of children with SCD*

	Coeff	BootSE	t-value	BootLLCI	BootULCI
Constant	75.399	17.993	4.190	39.512	111.285
Positive Coping (PCS)	-.833	.419	-1.991	-1.668	.002
Marital status (MS)	-40.481	11.112	-3.643	-62.642	-18.319
PCS*MS	.797	.261	3.058	.277	1.317
Conditional effects of the focal predictor at values of the moderator(s):					
Unmarried	-.036	.189	-.191	-.413	.341
Married	.761	.179	4.242	.403	1.119

Model summary: R^2=.639; F (3, 70) =16.135, p<.001
PCS*MS: R^2 *change*=.079; F (1,70) =9.352, p=.003
Criterion: Depression

Results as shown in Table 23 indicates that marital status was a significant moderator in the relationship between positive coping strategies and depression in caregivers of children with SCD b= .797, t= 3.058, CI (.277, 1.317). Further analysis revealed that the effect of Positive coping strategies on depression is high for married caregivers, b=.761, t=4.242, CI (.403, 1.119) than the unmarried ones. Figure 3 gives a graphical view of the result.

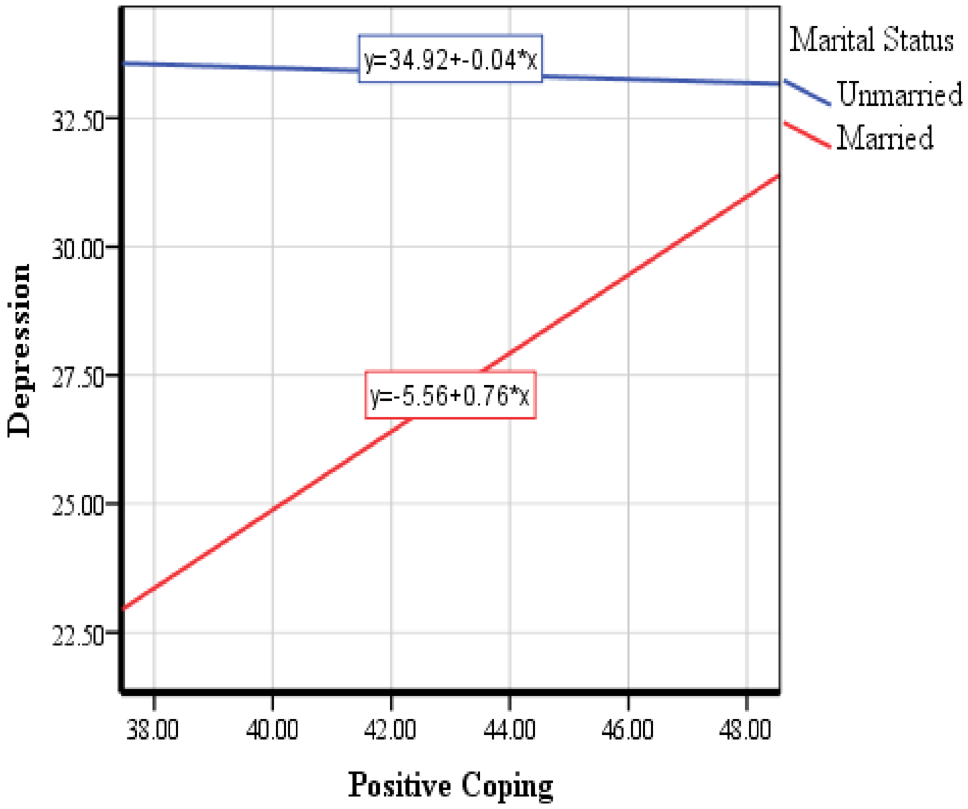


Figure 3: Moderating role of marital status on caregivers of children with SCD

Stress as Outcome variable

Table 24- *Moderating Role of Marital Status in the Relationship between Avoidant Coping Strategies and Stress on caregivers of children with epilepsy*

	Coeff	BootSE	t-value	BootLLCI	BootULCI
Constant	15.296	6.226	2.457	2.902	27.690
Avoidant Coping (NCS)	.628	.553	1.135	-.473	1.729
Marital status (MS)	-1.313	3.790	-.346	-8.858	6.232
NCS*MS	.050	.347	.146	-.640	.741

Model summary: R^2=.182; F (3, 78) =5.768, p<.001
NCS*MS: R^2 *change*=.000; F (1, 78) =.021, p=.885
Criterion: Stress

The results from Table 24 indicates that marital status was not a significant moderator between Avoidant coping strategies and stress in caregivers of children with epilepsy, b=.050, t=.146, CI (-.640, .741).

Stress as Outcome variable

Table 25- *Moderating Role of Marital Status in the Relationship between Avoidant Coping Strategies and Stress on caregivers of children with SCD*

	Coeff	BootSE	t-value	BootLLCI	BootULCI
Constant	37.048	9.069	3.534	13.960	50.136
Avoidant Coping (NCS)	.572	.709	.807	-.842	1.986
Marital status (MS)	-6.991	5.061	-1.381	-17.085	3.104
NCS*MS	-.195	.438	-.446	-1.069	.678

Model summary: R^2=.447, F (3, 70) =18.843, p<.001
NCS*MS: R^2 *change*=.001; F (1, 70) =.199, p=.657
Criterion: Stress

From Table 25, the results indicate that marital status was not a significant moderator between Avoidant coping strategies and stress in caregivers of children with SCD, b=-.195, t=-.446, CI (-1.069, .678).

Anxiety as Outcome variable

Table 26- *Moderating Role of Marital Status in the Relationship between Avoidant Coping Strategies and Anxiety on caregivers of children with epilepsy*

	Coeff	BootSE	t-value	BootLLCI	BootULCI
Constant	16.694	6.246	2.673	4.259	29.128
Avoidant Coping (NCS)	.708	.555	1.277	-.396	1.813
Marital status (MS)	-3.901	3.802	-1.026	-11.470	3.669
NCS*MS	.127	.348	.364	-.567	.820

Model summary: R^2=.287; F (3, 78) =10.474, p<.001
NCS*MS: R^2 *change*=.001; F (1, 78) =.132, p=.717
Criterion: Anxiety

The results from Table 26 show that marital status was not a significant moderator between Avoidant coping strategies and anxiety in caregivers of children with epilepsy, b=.127, t=.364, CI (-.567, .820)

Anxiety as Outcome variable

Table 27- *Moderating Role of Marital Status in the Relationship between Avoidant Coping Strategies and Anxiety on caregivers of children with SCD*

	Coeff	BootSE	t-value	BootLLCI	BootULCI
Constant	22.797	9.684	2.354	3.484	42.111
Avoidant Coping (NCS)	1.482	.757	1.957	-.028	2.992
Marital status (MS)	-5.510	3.914	-1.020	-16.289	5.268
NCS*MS	-.696	.468	-1.487	-1.628	.237

Model summary: R^2=.601; F (3, 70) =35.086, p<.001
NCS*MS: R^2 *change*=.013; F (1, 70) =2.211, p=.141
Criterion: Anxiety

The results from Table 27 show that marital status was not a significant moderator between Avoidant coping strategies and anxiety in caregivers of children with SCD, b=-.696, t=-1.487, CI (-1.628, .237).

Depression as Outcome variable

Table 28- *Moderating Role of Marital Status in the Relationship between Avoidant Coping Strategies and depression on caregivers of children with epilepsy*

	Coeff	BootSE	t-value	BootLLCI	BootULCI
Constant	20.055	6.512	3.080	7.091	33.020
Avoidant Coping (NCS)	.213	.578	.369	-.938	1.365
Marital status (MS)	-2.853	3.964	-.720	-10.744	5.039
NCS*MS	.246	.363	.679	-.476	.970

Model summary: R^2=.126; F (3, 78) =3.739, p<.05
NCS*MS: R^2 *change*=.005; F (1, 78) =.461, p=.499
Criterion: Depression

The results from Table 28 indicate that marital status was not a significant moderator between Avoidant coping strategies and depression in caregivers of children with epilepsy, b=.246, t=.679, CI (-.476, .970).

Depression as Outcome variable

Table 29- *Moderating Role of Marital Status in the Relationship between Avoidant Coping Strategies and depression on caregivers of children with SCD*

	Coeff	BootSE	t-value	BootLLCI	BootULCI
Constant	38.353	8.757	4.380	20.888	55.819
Avoidant Coping (NCS)	-.171	.684	-.250	-1.537	1.194
Marital status (MS)	-9.722	4.887	-1.989	-19.469	.025
NCS*MS	.533	.423	1.259	-.311	1.376

Model summary: R^2=.358; F (3, 70) =13.013, p<.001
NCS*MS: R^2 *change*=.014; F (1, 70) =1.586, p=.212
Criterion: Depression

The results from Table 29 indicate that marital status was not a significant moderator between Avoidant coping strategies and depression in caregivers of children with SCD, b=.533, t=-1.259, CI (-.311, 1.376).

Discussion of Results

Psychological distress levels in caregivers of children with chronic conditions

The study was aimed at determining the levels of stress, anxiety and depression (psychological distress) experienced by caregivers in the cause of providing care for children embattled with epilepsy or sickle cell disease. It was realised from the study that 39.1% of caregivers of children with epilepsy experiences stress in moderate to severe levels whilst 67.6% of caregivers of children with SCD experiences stress in moderate to severe levels. This finding is best understood by the application of the transactional model of stress and coping which says that cognitive appraisals of demands of situations or conditions is the cause of stress in people (Lazarus & Folkman, 1984). This implies that most caregivers' experience stress due to the roles they perform to meet the demands of the children's chronic conditions. According to Juster, McEwen and Lupien (2010) high levels of stress in caregivers is attributable to the emotional and psychological deterioration that correlates with the unflinching need for care and support of children with chronic conditions.

This finding is not in isolation as Marin, Chen, Munch and Miller, (2009) also found that caregivers of children with chronic conditions suffer moderate to severe levels of stress than caregivers of children with conditions in which recovery is speedily. Hua-Huei and Liang-Po (2011) stated in their study that, stress levels in caregivers of children with SCD or epilepsy is higher compared to other chronic conditions such as asthma. In studying the levels of stress among caregivers, Chiou, and Hsieh, (2008) found results similar to the findings of this current study when they concluded in the findings of their study that stress levels in caregivers of epilepsy was high compared to other conditions in children. According to Brown et al (2010) stress is severe or moderate in caregivers of children with SCD depending on the financial strength of the caregivers.

The level of anxiety was found to be extreme in caregivers of epilepsy and SCD according to the results of the analysis of this study. Specifically, while 41.4% of the caregivers of children with epilepsy had moderate to severe levels of anxiety, 50.0% had extreme levels of anxiety. On the other hand, 36.5% of caregivers of children with SCD had moderate to severe levels of anxiety whilst 47.2% experienced anxiety in extreme levels. The diagnosis of epilepsy and SCD alone is enough to cause anxiety in caregivers coupled with the anticipated burden of care demanded, notwithstanding the scare an epileptic seizure or sickle cell attack brings to the caregivers are enough justifications to why majority of caregivers of children with chronic conditions experience extreme levels of anxiety in caregivers (Burnes, Antle, Williams & Cook, 2008).

According to Juonala et al. (2011) anxiety is usually the maiden psychological symptom experienced by caregivers when the diagnosis of a chronic condition is established as predictions of poorer life outcomes and over dependency of children are predicted by caregivers. Wojtas, Oskędra, Cepuch, and Świderska (2014) found in their study of severity of negative emotions that, the dominant negative emotion that accompanied caregivers of children with epilepsy was anxiety. According to the findings in an exploratory study by Burnes, Antle, Williams and Cook (2008) mothers commonly experienced severe levels of anxiety related to fear of their children's death due to the condition, separation anxiety and loss of control over life due to caregiving demands. These findings support the findings of this current study that a severe level of anxiety is experienced by caregivers of children with epilepsy and sickle cell disease.

Depression levels of caregivers of children with chronic conditions were also shown to be moderate to severe (62.2%) in caregivers of children with epilepsy whilst extreme (60.8%) in caregivers of children with SCD per the results of the analyses of the data of this study. This implies that the incidence of depression amongst caregivers is very common but caregivers of children with SCD harbours the majority of victims comparatively. The transactional model of stress and coping indicates that when caregivers fail in their coping strategies in certain situations, stress ensues leading to personality disintegration in the forms of depression. It could be said that the frequent and long stay in hospital on admission by caregivers of children with SCD is attributable to the incidence of depression since in and out of hospital mars the schedules of caregivers irrespective of their coping strategies.

This finding is similar to literature on caregiver's depression as Karlson et al. (2012) indicated that up to half of the caregivers of children with SCD are at high risk of depression as a consequence of providing care whiles Ferro and Speechley (2009) also concluded in their meta-analysis that up to 50% of mothers caring for children with epilepsy are at high risk for clinical depression. According to Iseri, Ozten, and Aker (2006) parents who render care to children with epilepsy are usually affected by major depressive disorder. The finding that caregivers of children with chronic conditions are mostly affected by severe levels of depression is not in isolation since it's not peculiar to only this current study. The presence of severe depression amongst caregivers could be attributed to the role demands, insecurity over the prognosis, inadequate financial and or emotional or social support.

Coping strategies mostly used by caregivers of children with chronic conditions

It was realised from the results of the analyses that caregivers of children with chronic conditions used multiple coping strategies in providing care for their sick children as well as managing the psychological distress associated with the roles of caregiving (Stephenson, King, & DeLongis, 2016). The above-mentioned coping strategies can be grouped into Problem focused coping strategies, Emotion focused coping strategies and Avoidant coping strategies according to Carver, Scheier and Weintraub (1989).

According to Table 7, the means and standard deviations showed that problem focused coping strategies are the most used group of coping strategies by caregivers of children with epilepsy and SCD. Caregivers of children with epilepsy mostly used Active coping whilst caregivers of children with SCD were found to mostly use planning. The next group of coping strategies used by caregivers of children with chronic conditions after the problem focused coping strategies are the emotion focused coping strategies. Religion was found to be the most used emotion focused coping strategy by caregivers of children with epilepsy and SCD this is possibly attributable to their believe in supernatural power for help.

The use of problem focused coping by caregivers in this study could best be explained by the transactional model of stress and coping which says that the choice of coping strategy used in all situations is dependent on the cognitive appraisals of the affected individuals, caregivers' cognitive appraisals influences their choice of coping strategies (Folkman, Schaefer & Lazarus, 1979). Also, the choice of problem focused coping strategy as the primary approach to caregiving in this study could be said to depend on the health care systems available, geographical location, perceptions and financial status of the caregivers of this study (Barnett et al., 2012). The use of active coping as the most used coping strategy by caregivers of children with epilepsy is supported by Ganjiwale, Ganjiwale, Sharma and Mishra (2016) who also found that though all the coping strategies had some caregivers using them, the coping strategy predominantly used by the caregivers was active coping.

Hildenbrand, Barakat, Alderfer and Marsac (2015), Ali and Razeq (2017), caregivers of children with sickle cell disease face complex caregiving demands and altered family dynamics hence they use planning, active coping, religious coping and social support principally. Gona et al (2016) also indicated that coping strategies used by caregivers of children with chronic conditions in rural and urban settings in Kenya were mostly problem and emotion focused coping strategies.

From Table 7 of the analyses of results the next class of coping strategies mostly used after the aforementioned are; Instrumental support, followed by Positive reframing, Emotional support and then Venting. These coping strategies are grouped into a class of coping strategies commonly referred to as emotion focused coping strategies by Carver, Scheier and Weintraub (1989). From Table 7, Emotion focused coping strategies (seeking of emotional social support, positive reinterpretation, acceptance, denial, turning to religion) are also adequately used by caregivers of children with chronic conditions. This finding is similar to the findings of Ganjiwale, Ganjiwale, Sharma and Mishra (2016) who reported that all coping strategies are relevant to caregivers of children with developmental disabilities but emotion focused coping strategies are used by many in the course of caregiving.

According to Ali and Razeq (2017), caregivers of children with chronic conditions uses social support and religious or spiritual means of coping to reduce the emotions associated with providing care and support to these children. Carlson and Miller (2017) found results similar to the current study that mothers of children with epilepsy often use emotion-focused coping strategies (religious and social support seeking behaviours) to cope with the psychological distress accompanying the care of their children.

The least used coping strategies according to the analysis of results are Substance use. The results also showed that the least and seldom used class of coping strategies are the avoidant coping strategies. According to Carver, Scheier and Weintraub (1989) caregivers do not always use avoidant coping strategies as they neither realistically relieve the negative emotions nor solves the challenges associated with taking care of children with chronic conditions in the long run. Hildenbrand, Barakat, Alderfer and Marsac (2015) also stated that avoidance coping strategies are used by caregivers but in lesser frequencies compared to the other coping strategies available and this was found to be consistent with the results of the analysis of this current study.

It can thus be safe to say that problem focused coping strategies are the most used coping strategies used by caregivers of children with chronic conditions, followed by emotion focused coping strategies and finally avoidant coping strategies are the less frequently used according to the findings in this study and that is consistent with some literature on the choices of coping strategies used by caregivers of children with chronic conditions.

Differences in the psychological distress experienced by caregivers based on their gender

The study revealed that there were significant differences in the anxiety, depression and stress levels experienced by the male and female caregivers of children with SCD but there were no differences in the anxiety and stress levels in the caregivers of children with epilepsy based on their gender as shown in the results of the manova in Table 8 of the analysis of results. Inference from the Bowen (1978) family systems theory can be used to explain the reasons for the differences in the psychological distress levels in male and female caregivers in that the impact of a child's chronic condition lies much on the primary caregivers. Usually, the females in most families act as the primary caregivers in situations of children with chronic conditions. Lazarus and Folkman's theory (1984) of stress and coping also throws light on the gender differences in appraisals of threat and challenges as well as the biological differences in gender in response to unfavourable situations.

According to Christophersen and VanScoyoc (2013) genetic and environmental factors such as gender specific socialisation is fundamental for the differences in anxiety levels in caregivers of children with chronic conditions. Likewise, Wang, Chen and Chen (2018) also established in their study that the traditional functional roles of parents based on their gender creates a difference in the levels of psychological distress they (caregivers) experience while caring for a child especially when the child is suffering from a chronic condition which calls for stiffer caregiver activity. Similar findings were arrived at by Noftle and Fleeson (2010) and they indicated that differences in the age and social or cultural status bracket for the male and female caregivers has the possibility of producing a difference in the results of their responses since people act and think according to their age and status in society.

In terms of anxiety and stress, the results indicated that there were no statistically significant differences between the male and female caregivers of children with epilepsy in this study. Adegoke and Kuteyi (2012) indicated that over 70% of caregivers of children with chronic conditions in Nigeria experiences enormous levels of stress due to the financial, social and psychological demands involved in caregiving. The results in their analysis showed no differences in the experience of stress based on the gender of caregivers. Hence both male and female caregivers of children with epilepsy are victims of caregiver stress in no statistically significant different levels.

Levin and Banks (1991) also found that parents of children with chronic conditions reported more stress than normative group. No significant differences in stress and anxiety levels were found between mothers and fathers and that greater stress was rather associated with caregiver unemployment, seizure type (not well-controlled), and greater number of child medications but not based on the gender of the caregivers.

Differences in caregivers of children with epilepsy and sickle cell disease in terms of psychological distress (anxiety, depression and stress)

It was shown from the results of the manova test in table 13 that there was no statistically significant difference between the caregivers of children with SCD and epilepsy in the experience of anxiety based on the condition of the child they care for. This study finding supports the conclusions of Modi (2009) who also found that no significant differences in stress was found in caregivers of children with epilepsy and caregivers of children with other chronic conditions.

According to Anderson and Barton (1990) most caregivers of children with chronic conditions have high levels of anxieties and worries about what will happen to the child in future when the caregiver’s will not be available to cater for the patient in the event of changes in financial status, old age or death. This insecurity over the future coupled with the perceptions of caregivers on the diagnosis and prognosis of their children are common anxiety provoking thoughts amongst caregivers of children with chronic conditions hence the similarity in anxiety.

Levine, Reinhard, Feinberg, Albert and Hart (2003) stated that the performance of care giving roles or rendering of care to clients with chronic conditions is anxiety provoking to the inexperienced professional caregivers, this is heightened among untrained persons caring for people with chronic illnesses living at home, in consequence the influx of anxiety among caregivers of children with epilepsy and SCD at near same levels is justified in this study.

The study showed that there was a statistically significant difference between the caregivers in the experience of depression based on the condition of the child they care for. The results imply that caregivers of children with sickle cell disease were more depressed than caregivers of children with epilepsy.

Results in Table 12 showed that there was a statistically significant difference between the caregivers in the experience of stress based on the condition of the child they care for. The result suggests that caregivers of children with sickle cell disease were more stressed than caregivers of children with epilepsy.

The differences in psychological distress as experienced by caregivers in this study is best explained by the Bowen family systems theory (1978) which elaborates on the need for families to adjust to accommodate the unfavourable situations members of the family unit may encounter. In the case of a child with epilepsy or sickle cell disease family systems may break if the coping strategies are frail leading to high levels of psychological distress. The differences in experience of psychological distress between the two categories of caregivers is attributable to the differences in care needs or cost of care and the caregiver's perceptions and knowledge (Davis-Ali, Chesler & Chesney,1993; Reinhard, Huhtula & Given, 2008). The transactional model of stress and coping is also a way to understanding the differences in the experience of psychological distress in the caregivers as it draws attention to the balance between the individual's choice of coping strategy and the experience of distress motivated by the nature of the threats, challenges, cognitive appraisals and that when a situation exceeds our ability to cope stress sets in (Lazarus & Folkman, 1984). The demands of children with sickle cell disease and epilepsy in terms of medication, hospitalisation and general needs are different hence the difference in psychological distress experienced by their caregivers.

According to Nuhu et al. (2010) and Akinbiyi (2001) the stress of giving care to children with chronic conditions depends on the educational level, financial strength, place of residence (urban/rural) of the caregiver, the age of the child with a chronic condition and the severity of the child's condition, thus the differences in stress levels between caregivers of epilepsy and SCD might have been as a result of the above reasons. The findings in a cross-sectional study conducted by Karakis et al. (2014) was that unlike other chronic conditions among children epilepsy is associated with modest degree of psychological distress to the caregiver.

Cousino and Hazen (2013) had findings similar to the results in this current study when they concluded in their meta-analysis of studies on caregivers of children with chronic conditions that the psychological distress associated with caring for children with sickle cell disease was on the high compared to the levels experienced by caregivers of children with epilepsy. Beach et al. (2005) elaborated that care recipient's behaviour such as restlessness, screaming, crying and threatening are associated with increased clinical symptoms of depression in caregivers. Epileptic seizures are short lived unlike sickle cell crisis which is associated with pains leading to restlessness and screaming among affected children and invariably causing higher levels of depression to their caregivers.

To this end, the findings in the current study backed by findings of existing literature from other studies suggest that the psychological distress associated with giving care to a child with SCD is higher compared to epilepsy.

Relationship between psychological distress and coping strategies used by caregivers of children with chronic conditions

It was realised from the results of the correlation analysis in table 14 of the study that psychological distress (anxiety, depression and stress) significantly and positively correlates with the positive coping strategies. Specifically, stress and anxiety weakly correlate with positive coping strategies as depression is moderately correlated with the positive coping skills in caregivers of children with epilepsy. Similarly, psychological distress is significantly weakly correlated with positive coping strategies in caregivers of children with SCD though the results in table 15 indicated that anxiety did not predict coping, implying that caregivers of children with SCD experiences anxiety irrespective of the positive coping strategies they use.

The results in tables 14 and 15 imply that there is relationship between positive coping strategies and psychological distress, and deductively imply that the use of positive coping strategies reduces the levels of distress caregivers' experience but does not completely eliminate the presence of the psychological distress. On the other hand, it was found in Tables 16 and 17 that psychological distress is significantly weakly correlated with the negative coping strategies in caregivers of children with epilepsy and SCD and implies that psychological distress levels increases with the use of negative coping strategies in caregivers.

According to the transactional model of stress and coping of Lazarus and Folkman (1984) caregivers are always in a trade between psychological distress and their coping strategies in order to ameliorate the impact of the children's chronic conditions on them hence the relationship and that good coping strategies leads to less psychological distress and vice versa. Welkom (2009) opined that the ability of a caregiver to employ effective coping strategies is vital for healthy caregiver psychosocial functioning, caregivers' aims to provide care with minimal psychological distress compelling them to create a good relationship between their coping skills and the expected psychological distress in caregiving. Chronister et al. (2010) found in their correlational analysis of psychological distress and coping strategies that, emotional, social support and social needs mediated the relationship between psychological distress and social support. Bachanas et al. (2001) examined the coping strategies in caregivers of children with chronic conditions and found that the increased use of emotion-focused coping strategies and problem-focused coping strategies (positive coping strategies) was significantly correlated with psychological and social functioning of the caregivers.

Goldbeck (2006) also conceptualised that coping helps the family adapt to the demands of chronic conditions in children and as such good coping strategies relieves the burden of care by reducing the psychological distress associated with caregiving of children with chronic conditions when he found a strong correlation of coping strategies and psychological distress in his study. Similarly, Gheibizadeh, Gholami, Bassaknejad and Cheraghian (2017) investigated the coping strategies of parents of children with chronic illnesses (epilepsy, diabetes nephrotic syndrome etcetera) and the results of their data analysis showed that coping strategies and psychological distress were inversely related; good coping skills leads to reduced psychological distress and vice versa.

According to Rodenburg, Meijer, Dekovi and Aldenkamp (2007a) coping behaviours were related to parenting stress in their study of parents of children with epilepsy; to investigate the stress, stressors and parental coping in parents caring for children with epilepsy in The Netherlands. This finding is similar to the findings of the current study though he did not include caregivers of children with SCD in his study. To determine whether there is a significant connection between caregivers' stressors and coping abilities, Wilborn-lee (2015) found in the correlational results of his data analysis that, there is a correlation between coping and stress of caregivers.

Some studies support the finding in this current study that depression is strongly correlated with coping strategies. For example, Kiral, Yetim, Ozge and Aydin (2017) examined the relationships between cognitive emotion regulation strategies, social support and depression among caregivers and also found out that cognitive emotion regulation strategies and social support (coping) plays substantial roles in lessening caregiver depression levels. Compas et al. (2015), Greening and Stoppelbein (2007) also said the use of problem-focused coping is correlated with lower levels of anxiety and depression in parents of children with chronic conditions when they found strong relationships in the correlational results in the analysis of their study. Similar findings were also reported by Sutan, Al-Saidi, Latiff and Ibrahim (2017) when they assessed the correlation between coping strategies and the health-related psychological distress levels of parents with children suffering from acute lymphoblastic leukaemia in Malaysia.

Marital status as a moderator of the relationship between coping strategies and psychological distress in caregivers of children with chronic conditions

The results of the study revealed that marital status has a significant role in the relationship between positive coping strategies and psychological distress experienced by caregivers of children suffering from chronic conditions. Because psychological distress (criterion variable) was multidimensional in scope it was treated as anxiety, depression and stress

Specifically, marital status moderated the relationship between positive coping strategies and depression in caregivers of children with SCD. Further analysis revealed that the effect of positive coping strategies on depression was high for married caregivers of children with SCD than the married ones as shown in Table 23 and Figure 3 of the analysis and results.

On the contrary, marital status was not seen as a significant moderator between coping strategies and psychological distress among caregivers of children with epilepsy and SCD except for depression in caregivers of children with SCD in this study as shown in the analysis and results. Woessmann (2015) confirms the finding of this study, as he stated in his findings that, caregiving becomes more frustrating and intense in the case of a single caregiver to a child with a chronic condition. Brown et al. (2007) also found marital status as a moderator of the relationship between coping strategies and psychological distress when they found single mothers caring for children with chronic conditions were more psychologically distressed than their married colleagues caring for children with the same conditions in their study. Shudy et al. (2006) opined that about 3 out of 10 children live in single-parent homes making caregivers psychological distress levels unbearable compared to married caregivers and that these caregiving demands are heightened in the case of a child battling with a chronic condition. This adds substance to the findings in this current study that marital status moderates the relationship between positive coping strategies and depression among caregivers of children with SCD.

Collazo, Ryan and Bauman (2010) indicated that over one-fourth of children under the age of 18 in the United States live in a single-parent family and that the psychological distress levels in their caregivers are higher when they care for a child with a chronic condition alongside their domestic duties. Amato (2008) also found that notwithstanding the cause, single-caregiver homes have been associated with financial drain and caregiver psychological distress in higher levels than married parent homes.

Mullins et al. (2010) found in their study that, there is a direct relationship between marital status and parenting stress, single mothers reported significantly greater levels of depression than married mothers and the high levels of psychological distress among unmarried caregivers are partly as a result of financial constraints as the average income of a single-parent caregiver is significantly lower than that of the married-parent families. In the meta-analysis of Gesteira et al. (2016), mothers were found as the main caregivers in families and that spousal support moderated the impact of psychological stress and determined the coping strategies used by caregivers of children with sickle cell disease.

Wiener et al (2013) also specified that psychological distress is highest in the subgroup of caregivers who perceive themselves as lone parents when it comes to caring for their children with chronic conditions. Unmarried caregivers had high scores in the clinical range for depression, anxiety and stress and this was similar to the findings of this current study and others such as Shudy et al. (2006), Kantor (2016) and Brown et al. (2007) all found that marital status moderates the relationship between coping strategies and depression levels among caregivers of children with chronic conditions just as it was found in this current study.

It is noteworthy the findings of this study that, marital status is not a significant moderator of the relationship between psychological distress and coping strategies in caregivers of children with epilepsy and SCD all save depression in caregivers of children with SCD. This is not in isolation as Gesteira, Bousso, Misko, Ichikawa and Oliveira (2016) indicated in the conclusions of their study that income and social support moderates the relationship between psychological distress and coping strategies and not merely marital status. It is thus prudent to say marital status was not a moderator of the relationship between psychological distress and coping strategies in this study attributable largely to social support (external family system). Olley, Brieger, & Olley (1997) also indicated in their study that family support systems are key moderators in the quantum of psychological distress experienced in caring for children with sickle cell disease.

Chapter Summary

The chapter entailed the presentation of results of the analysis of the study and discussions of the findings. The results showed that depression, anxiety and stress are experienced by all caregivers of children with chronic conditions but in different levels. There are significant differences in the experience of psychological distress among caregivers based on their gender and the condition of the child they care for due to the cultural, social, biological and illness specific demands on caregivers. Problem focused coping (active coping and planning) and the emotion focused coping strategies (religion) were the category of coping strategies highly used whilst the least used was avoidant coping strategies. This was because most caregivers probably chose coping strategies capable of solving their problems.

The results also showed that there is a strong relationship between Coping strategies and psychological distress and finally marital status was found to moderate the relationship between positive coping strategies and depression in caregivers of children with SCD and this could be due to the support couples give to each other in crisis situations.

CHAPTER FIVE

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Introduction

The summary, conclusions and recommendations and suggestions for further research are presented in this chapter of the study. The study was conducted to determine the psychological distress and coping strategies of caregivers of children with chronic conditions (epilepsy and sickle cell disease) in the Ashanti Region of Ghana.

The research design used was a descriptive survey design. A sample of 156 respondents was used. The sampling procedures used in the selection of participants were the convenient and quota sampling techniques. Adapted questionnaires of the Depression, Anxiety and Stress Scale (DASS-21) and the Brief Cope Inventory (BCI) were the main instruments used in collecting data for this research work. A total of 55 items of closed – ended type questions containing variables for depression, anxiety and coping strategies was presented to the respondents. The instruments had a Chronbach's alpha coefficient of .88 for the DASS- 21 and .82 for the BCI. Two research questions and four hypotheses guided the study.

Summary of the Findings

The summary of the findings of the study are;

1. The study revealed that more than half of the caregivers of children with SCD were found to have severe to extreme levels of stress. Also, more than one third the caregivers of children with epilepsy had severe

to extreme levels of anxiety whilst a little above half of the caregivers of children with SCD had severe to extreme levels of anxiety. Finally, almost all the caregivers of children with SCD had severe to extreme levels whilst 47.6% of caregivers of children with epilepsy had severe to extreme levels of depression.

2. The results again showed that active coping is the most used problem focused coping strategy as religion is the most used motion focused coping strategy by caregivers whilst substance use is the least used coping strategy. The problem focused and emotion focused coping strategies are the category of coping strategies mostly used by caregivers whiles the avoidant coping strategies are the least used.
3. Additionally, the study results showed that there are no significant differences in the levels of psychological distress experienced by caregivers of children with epilepsy based on their gender but there are significant differences in the levels of psychological distress experienced by caregivers of children with SCD based on their gender.
4. The results of the analysis indicated that significant differences exist in the levels of psychological distress experienced by caregivers of children with epilepsy and caregivers of children with sickle cell disease. Specifically, in terms of their stress and depression levels experienced.
5. The study found significant relationships between psychological distress (depression, anxiety and stress) and coping strategies used by caregivers of children with epilepsy and sickle cell disease. There is a moderately positive relationship between psychological distress and

negative coping strategies whiles the relationship between psychological distress and positive coping strategies are weakly positive.

6. Finally, the study showed that marital status does not moderate the relationship between coping strategies and psychological distress in caregivers of children with chronic conditions but moderates only the relationship between positive coping strategies and depression in caregivers of children with SCD.

Conclusions

This study examined the presence of psychological distress in caregivers of children with epilepsy and SCD in the Ashanti Region of Ghana. Caregivers are burdened with psychological distress (depression, anxiety and stress) in varying degrees and this could be as a result of the caregiver's choice of coping strategies used, marital status and the type of condition of the child they catered for. With judicious use of coping strategies and support from married partners, psychological distress levels in caregivers might be minimal.

All the coping strategies are relevant to caregivers of children with chronic conditions in dealing with the psychological distress associated with caregiving. In the search for support and the bid to mitigate the psychological distress associated with caregiving, most caregivers of children with chronic conditions in the Ashanti Region use religion and active coping. The use of religious coping could be a way of relieving the experience of psychological distress by believing in the presence of supernatural power for help and healing. The use of active coping could be because caregivers feel the best could be achieved by dealing directly with the demands of the conditions of their children.

Though the levels of psychological distress are not gender biased in caregivers of children with epilepsy, Female caregivers of children with SCD experiences higher levels of psychological distress than their male counterparts. Mostly, female caregivers are the sole bearers of caregiving responsibilities to children with SCD and this could be attributing to their psychological distress levels. The active involvement of the male members of the families of children with SCD will reduce the psychological distress levels burdening the female caregivers.

The type of chronic condition of a child a caregiver caters for is a key determinant to the level of psychological distress he or she experiences. In this study, caregivers of children with SCD experiences higher levels of depression and stress than caregivers of children with epilepsy possibly due to the frequency of hospitalisation and illness specific caregiving demands accompanying SCD crisis.

There is a relationship between psychological distress and all categories of coping strategies. In the bid to manage the level of psychological distress in caregiving, caregivers employ more of the positive coping strategies than the avoidant coping strategies since the positive coping strategies probably guarantees lower levels of psychological distress comparatively. However, no category of coping strategies entirely eliminates the presence of psychological distress in caregivers but minimises their levels.

Marital status of a caregiver does not influence the relationship between psychological distress and coping strategies in caregivers of children with epilepsy but plays a significant role on the depression levels of caregivers of children with SCD. The presence of a spouse is deemed crucial in determining the depression level of a caregiver as the burden of caregiving is shared, loneliness and boredom that leads to psychological breakdown declines when caregivers are in a marriage.

Recommendations

Based on the findings and conclusions drawn from the study the following are recommended;

1. Clinical Health Psychologist are entreated to render psychosocial services in the application of therapies capable of alleviating the symptoms of psychological distress in caregivers of children with chronic conditions.
2. Health education by the staff of the SCD Clinics and Epileptic Clinics on the causes and management of epilepsy and SCD to the public is recommended since psychological distress is found in both categories of caregivers but in varying degrees.
3. Since it was found that coping strategies of caregivers influences the levels of psychological distress they experience, Clinical Health Psychologists or psychotherapists are recommended to all caregivers of children with chronic conditions to empower them in their choices of coping strategies.
4. It is recommended that the media and religious bodies advocate for the active involvement of males and families to give support to caregivers since the findings indicated that the presence of a spouse or support

system helps control the psychological distress levels associated with chronic conditions of children on their caregivers.

5. As appropriate coping strategies and support systems are capable of minimising the burden of psychological distress on caregivers, health care providers such as the Ghana Health Service and the Christian Health Association of Ghana and the Ghana Psychological Association are recommended to inculcate interventional programs into their health care delivery systems for caregivers.

Suggestions for further research

The research suggests that;

Research should be conducted on the coping strategies and psychological distress among children with parents suffering from chronic conditions. This will unearth the effects of caregiving on the young informal caregivers.

Research on caregivers of children with asthma and sickle cell disease can be compared in terms of distress levels, burden of care and coping strategies since they are both physical conditions with periodic crisis/attacks. A study on the coping strategies and psychological distress of children with epilepsy and sickle cell disease is a good aspect to delve into. This will give us the direct and indirect consequences of these two conditions on affected children.

Research on the educational and social functioning of children with chronic conditions ought to be studied to help psychologist and parents in the areas to concentrate to make the lives of these children productive.

REFERENCES

Abedi, H., Abbaszadeh, A., Kazemi, M., & Pouraboli, B. (2014). Silent screams: experiences of caregiver suffering by parents of children with thalassemia: a qualitative study. *Journal of Qualitative Research in Health Sciences*, *3*(3), 281-291.

Abeloff, M. D., Armitage, J. O., Lichter, A. S., & Niederhuber J. E. (2000). *Clinical oncology*. New York: Churchill Livingstone *2*, 556 – 570

Abidin, R. R., & Abidin, R. R. (1990). *Parenting Stress Index (PSI)* (p. 100). Charlottesville, VA: Pediatric Psychology Press.

Abuosi, A. A., Adzei, F. A., Anarfi, J., Badasu, D. M., Atobrah, D., & Yawson, A. (2015). Investigating parents/caregivers financial burden of care for children with non-communicable diseases in Ghana. *BMC Pediatrics*, *15*(185), 1-9

Adegoke, S. A., & Kuteyi, E. A. (2012). Psychosocial burden of sickle cell disease on the family, Nigeria. *African Journal of Primary Health Care & Family Medicine*, *4*(1), 1-6.

Ae-Ngibise,K. A., Akpalu, B., Ngugi, A.,Akpalu, A.,Agbokey, F., Adjei, P., Punguyire, D., Bottomley, C., Newton, C., & Owusu-Agyei, S. (2015). Prevalence and risk factors for Active Convulsive Epilepsy in Kintampo. *Pan African Medical Journal*, *21*, 21-29.

Akinbiyi, A. (2001). The psychosocial burden of caring for some Nigerians with dementia. *National Postgraduate Medical College of Nigeria Part II Dissertation in Psychiatry*.

Ali, R. M. A., & Razeq, N. M. A. (2017). The Lived Experience of Parents of Children with Sickle Cell Disease: A Qualitative Study. *Open Journal of Nursing, 7*(11), 1348-1364.

Amato, P. R. (2008). Recent changes in family structure: implications for children, adults, and society. *National Healthy Marriage Resource Center*, 1-10.

American Academy of Pediatrics (2002). Hematology/Oncology Committee on Genetics: Health supervision for children with sickle cell disease. *Pediatrics, 109*(3), 526 – 535.

Anderson E, & Barton R. (1990). Epilepsy: a family burden? *Clinical Psychology Forum*. 25(1), 3-5.

Anie, K. A. (2005). Psychological complications in sickle cell disease. *British Journal of Haematology*, *129*(6), 723-729.

Anie, K. A., & Green, J. (2015). Psychological therapies for sickle cell disease and pain. *Cochrane Database of Systematic Reviews*, (5).

Ansong, D., Akoto, A. O., Ocloo, D., & Ohene-Frempong, K. (2013). Sickle cell disease: management options and challenges in developing countries. *Mediterranean Journal of Hematology and Infectious Diseases*, *5*(1),

Awad G., & Voruganti L., (2008). The burden of schizophrenia on caregivers: a review. *Pharmacoeconomics*. 26(2): 149-162.

Ayers, T. S., Sandier, I. N., West, S. G., & Roosa, M. W. (1996). A dispositional and situational assessment of children's coping: Testing alternative models of coping. *Journal of Personality*, *64*(4), 923-958.

Ayuurebobi, K., Akpalu, B., Ngugi, A., Akpalu, A., Agbokey, F., Adjei, P., Punguyire, D., Bottomley, C., Newton, C. & Owusu-Agyei, S. (2015). Prevalence and risk factors for active convulsive epilepsy in Kintampo, Ghana. *Pan African Medical Journal*, *21*(1), 21 –31.

Bachanas, P.J., Kullgren, K.A., Schwartz, K.S., McDaniel, J.S., Smith, J., & Nesheim, S. (2001). Psychosocial adjustment in caregivers of school-aged children infected with HIV: Stress, coping, and family factors. *Journal of Pediatric Psychology*, *26*, 331-342.

Bakker, M., & Wicherts, J. M. (2014). Outlier removal, sum scores, and the inflation of the type I error rate in independent samples t tests: The power of alternatives and recommendations. *Psychological Methods*, *19*(3), 409.

Barnett, K., Mercer, S. W., Norbury, M., Watt, G., Wyke, S., & Guthrie, B. (2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *The Lancet*, *380*(9836), 37-43.

Barry, J. M., & Holmes, G. L. (2016). Why are children with epileptic encephalopathies encephalopathic? *Journal of Child Neurology*, *31*(13), 1495-1504

Beach, S. R., Schulz, R., Williamson, G. M., Miller, L. S., Weiner, M. F., & Lance, C. E. (2005). Risk factors for potentially harmful informal caregiver behavior. *Journal of the American Geriatrics Society*, *53*(2), 255-261.

Beckerman, N. L. (2000). Couples of mixed HIV status: Bowenian contributions to an assessment framework. *Family Therapy: The Journal of the California Graduate School of Family Psychology, 27*(1) 101 -114.

Beckman, P. J. (1991). Comparison of mothers' and fathers' perceptions of the effect of young children with and without disabilities. *American Journal on Mental Retardation, 95*(5), 585–595.

Bethell, C. D., Newacheck, P. W., Fine, A., Strickland, B. B., Antonelli, R. C., Wilhelm, C. L., ... & Wells, N. (2014). Optimizing health and health care systems for children with special health care needs using the life course perspective. *Maternal and Child Health Journal, 18*(2), 467-477.

Bethell, L. (2012). *Stress and its covariates in carers of children newly diagnosed with epilepsy* (Doctoral dissertation, University of Liverpool), *1*, 8 - 18.

Bijstra, J. O., Jackson, S., & Bosma, H. A. (1994). De Utrechtse Coping Lijst voor Adolescenten. *Kind en Adolescent, 15*(2), 98-109.

Biswas, T. (2013). Global burden of sickle cell anaemia is set to rise by a third by 2050.

Blaike, N., (2009). *Designing social research* (2nd edition). Polity press; Cambridge UK

Blaikie, N., & Priest, J. (2019). *Designing social research: The logic of anticipation*. John Wiley & Sons.

Bowen, M. (1974). Alcoholism as viewed through family systems theory and family psychotherapy. *Annals of the New York Academy of Sciences*, *233*(1), 115-122.

Bowen, M. (1978). On the differentiation of self. *Family Therapy in Clinical Practice*, 467-528.

Boyle, C. A., Boulet, S., Schieve, L. A., Cohen, R. A., Blumberg, S. J., Yeargin-Allsopp, M.,... & Kogan, M. D. (2011). Trends in the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics*, *127*(6), 1034-1042.

Broderick, C. B., & Schrader, S. S. (1991). The history of professional marriage and family therapy. *Handbook of Family Therapy*, *2*, 3-40.

Brown, B. J., Okereke, J. O., Lagunju, I. A., Orimadegun, A. E., Ohaeri, J. U., & Akinyinka, O. O. (2010). Burden of health-care of carers of children with sickle cell disease in Nigeria. *Health & Social Care in the Community*, *18*(3), 289-295.

Brown, G. W., & Harris, T. (2012). *Social origins of depression: A study of psychiatric disorder in women*. London: Routledge.

Brown, R. T., Wiener, L., Kupst, M. J., Brennan, T., Behrman, R., Compas, B. E., ... & Kazak, A. E. (2007). Single parents of children with chronic illness: An understudied phenomenon. *Journal of Pediatric Psychology*, *33*(4), 408-421.

Burnes, D. P., Antle, B. J., Williams, C. C., & Cook, L. (2008). Mothers raising children with sickle cell disease at the intersection of race, gender, and illness stigma. *Health & Social Work*, *33*(3), 211-220.

Bussing, R., Gary, F.A., Mason, D.M., Leon, C.E., Sinha, K.M. & Garvan, C.W. (2003) Child temperament, ADHD, and caregiver strain: exploring relationships in an epidemiological sample. *Journal of the American Academy of Child & Adolescent Psychiatry* 42, 184– 192.

Bygbjerg, I. C. (2012). Double burden of noncommunicable and infectious diseases in developing countries. *Science*, *337*(6101), 1499-1501.

Camfield P., Camfield C., (2018). Regression in children with epilepsy. *Published by Elsevier Ltd.*

Camfield, C., Breau, L., & Camfield, P. (2001). Impact of pediatric epilepsy on the family: a new scale for clinical and research use. *Epilepsia*, *42*(1), 104-112.

Carlson, J. M., & Miller, P. A. (2017). Family burden, child disability, and the adjustment of mothers caring for children with epilepsy: Role of social support and coping. *Epilepsy & Behavior*, *68*, 168-173

Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. International Journal of Behavioral Medicine, 4, 92-100.

Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: a theoretically based approach. *Journal of personality and social psychology*, *56*(2), 267.

Chen, E., Cole, S. W., & Kato, P. M. (2004). A review of empirically supported psychosocial interventions for pain and adherence outcomes in sickle cell disease. *Journal of Pediatric Psychology*, *29*(3), 197-209.

Chew-Graham, C., Bashir, C., Chantler, K., Burman, E., & Batsleer, J. (2002). South Asian women, psychological distress and self-harm: lessons for primary care trusts. *Health & Social Care in the Community*, *10*(5), 339-347.

Chiou, H. H., & Hsieh, L. P. (2008). Parenting stress in parents of children with epilepsy and asthma. *Journal of child neurology*, *23*(3), 301-306.

Christophersen, E. R., & VanScoyoc, S. (2013). *Treatments that work with children: Empirically supported strategies for managing childhood problems*. *American Psychological Association 2*, 83-107.

Chronister, J., Chan, F., Sasson-Gelmam, F. J., & Chiu, C-Y. (2010). The association of stress-coping variables to quality of life among caregivers of individual with 130 traumatic brain injury, 27, 49-62.

Chukhraev, N., Vladimirov, A., Zukow, W., Chukhraiyeva, O., & Levkovskaya, V. (2017). Combined physiotherapy of anxiety and depression disorders in dorsopathy patients. *Journal of Physical Education and Sport*, *17*(1), 414.

Churchill, S. S., Villareale, N. L., Monaghan, T. A., Sharp, V. L., & Kieckhefer, G. M. (2010). Parents of children with special health care needs who have better coping skills have fewer depressive symptoms. *Maternal and Child Health Journal*, *14*(1), 47.

Clara, I. P, Cox, B.J, Enns, M. W., (2001). Confirmatory factor analysis of the Depression-Anxiety-Stress Scales in depressed and anxious patients. *Journal of Psychopathology and Behavioral Assessment*, 23, 61–67.

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences*. London: Routledge.

Cohen, L., Manion, L., & Morrison, K. (2004). *A guide to teaching practice*. London: Sage Publication.

Collazo, S. G., Ryan, C. L., & Bauman, K. J. (2010). US Census Bureau: Housing and Household Economic Statistics Division. In *Proceedings, Annual Meeting of the Population Association of America. Dallas, TX*.

Colletti, C. J., Wolfe-Christensen, C., Carpentier, M. Y., Page, M. C., McNall-Knapp, R. Y., Meyer, W. H.,... & Mullins, L. L. (2008). The relationship of parental overprotection, perceived vulnerability, and parenting stress to behavioral, emotional, and social adjustment in children with cancer. *Pediatric Blood & Cancer*, *51*(2), 269-274.

Compas, B.E., Bemis, H., Gerhardt, C.A., Dunn, M.J., Rodriguez, E.M., Desjardins, L., Vannatta, K., et al. (2015) Mothers and Fathers Coping with Their Children's Cancer: Individual and Interpersonal Processes. Health Psychology: *Official Journal of the Division of Health Psychology, American Psychological Association*, 34, 783-793.

Cousino, M. K., & Hazen, R. A. (2013). Parenting stress among caregivers of children with chronic illness: a systematic review. *Journal of Pediatric Psychology*, *38*(8), 809-828.

Creswell, J. W. (2014). *A concise introduction to mixed methods research*. London: Sage publications.

Creswell, J. W., & Poth, C. N. (2017). *Qualitative inquiry and research design: Choosing among five approaches*. London: Sage publications.

Cushner-Weinstein, S., Dassoulas, K., Salpekar, J. A., Henderson, S. E., Pearl, P. L., Gaillard, W. D., & Weinstein, S. L. (2008). Parenting stress and childhood epilepsy: the impact of depression, learning, and seizure-related factors. *Epilepsy & Behavior*, *13*(1), 109-114.

Dardas, L. A., & Ahmad, M. M. (2015). Coping strategies as mediators and moderators between stress and quality of life among parents of children with autistic disorder. *Stress and Health*, *31*(1), 5-12.

Davis-Ali, S. H., Chesler, M. A., & Chesney, B. K. (1993). Recognizing cancer as a family disease: worries and support reported by patients and spouses. *Social Work in Health Care, 19*(2), 45-65.

DeLongis, A., & Holtzman, S. (2005). Coping in context: The role of stress, social support, and personality in coping. *Journal of Personality*, *73*(6), 1633-1656.

DeVellis, B. M., DeVellis, R. F., & Spilsbury, J. C. (1988). Parental actions when children are sick: The role of belief in divine influence. *Basic and Applied Social Psychology*, *9*(3), 185-196.

Diop, A. G., de Boer, H. M., Mandlhate, C., Prilipko, L., & Meinardi, H. (2003). The global campaign against epilepsy in Africa. *Acta Tropica*, *87*(1), 149-159.

Donkor, M. D. (2016). *Experiences Of Persons Living With Epilepsy In Accra, Ghana*, Doctoral dissertation, University of Ghana, Accra, Ghana.

Duffy L.V., (2011). Parental coping and childhood epilepsy: the need for future research. *Journal of Neuroscience Nursing*. 43(1), 29-35.

Dulock, H. L. (1993). Research design: Descriptive research. *Journal of Pediatric Oncology Nursing*, *10*(4), 154-157.

Elliott, A. F., Burgio, L. D., & DeCoster, J. (2010). Enhancing caregiver health: findings from the resources for enhancing Alzheimer's caregiver health II intervention. *Journal of the American Geriatrics Society*, *58*(1), 30-37.

Emerson, R. W. (2015). Convenience sampling, random sampling, and snowball sampling: How does sampling affect the validity of research?. *Journal of Visual Impairment & Blindness*, *109*(2), 164-168.

Engel, J. (1995). Concepts of epilepsy. *Epilepsia*, *36*, 23-29.

Engel, J. (2013). *Seizures and epilepsy*. Oxford University Press, 83, 347 – 366.

Engelgau, M. M., Karan, A., & Mahal, A. (2012). The economic impact of non-communicable diseases on households in India. *Globalization and Health*, *8*(1), 9.

Etikan, I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics*, *5*(1), 1-4.

Fayers, P. M., & Machin, D. (2013). *Quality of life: the assessment, analysis and interpretation of patient-reported outcomes*. New York: John Wiley & Sons.

Fee, H. R., & Wu, H. S. (2011). Negative and Positive Care giving Experiences: A closer look at the intersection of gender and relationships. *Centre for Family and Demographic Research*, *7*,1-32.

Ferro, M. A., & Speechley, K. N. (2009). Depressive symptoms among mothers of children with epilepsy: a review of prevalence, associated factors, and impact on children. *Epilepsia*, *50*(11), 2344-2354.

Fisher, R. S., Acevedo, C., Arzimanoglou, A., Bogacz, A., Cross, J. H., Elger, C. E., ... & Hesdorffer, D. C. (2014). ILAE official report: a practical clinical definition of epilepsy. *Epilepsia*, *55*(4), 475-482.

Folkman, S., Schaefer, C., & Lazarus, R. S. (1979). Cognitive processes as mediators of stress and coping. *Human Stress and Cognition*, 265-298.

Ganjiwale D, Ganjiwale J, Sharma B, & Mishra B., (2016). Quality of life and coping strategies of caregivers of children with physical and mental disabilities. *Journal of Family Medicine and Primary Care*. *5*(2): 343–348.

Gesteira, E., Bousso, R., Misko, M., Ichikawa, C., & Oliveira, P. (2016). Families of children with sickle cell disease: an integrative review. *Online Brazilian Journal of Nursing, 15*(2), 276-290.

Gheibizadeh, M., Gholami, Z., Bassaknejad, S., & Cheraghian, B. (2017). Coping strategies of parents with chronic ill children hospitalized in educational hospitals, Ahvaz-Iran. *International Journal of Pediatrics*, *5*(10), 5813-5825.

Goldbeck, L. (2006). The impact of newly diagnosed chronic paediatric conditions on parental quality of life. *Quality of Life Research, 15,* 1121–1131.

Gona, J. K., Newton, C. R., Rimba, K. K., Mapenzi, R., Kihara, M., Vijver, F. V., & Abubakar, A. (2016). Challenges and coping strategies of parents of children with autism on the Kenyan coast. *Rural and Remote Health*, *16*(2), 3517.

Gottman, J. M., Katz, L. F., & Hooven, C. (1996). Parental meta-emotion philosophy and the emotional life of families: Theoretical models and preliminary data. *Journal of Family Psychology*, *10*(3), 243.

Graungaard, A. H., Andersen, J. S., & Skov, L. (2011). When resources get sparse: A longitudinal, qualitative study of emotions, coping and resource-creation when parenting a young child with severe disabilities. *Health*, *15*(2), 115-136.

Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science & Medicine*, *56*(3), 631-642.

Gray, D., (2006). Coping over time. The parents of children with autism. *Journal of intellectual disability research, 50,970-976*

Green S, E., (2007) 'We're Tired, Not Sad': Benefits and Burdens of Mothering a Child with a Disability. *Social Science and Medicine 64*(1), 150–163

Greening, L. & Stoppelbein, L. (2007). Brief Report: Pediatric Cancer, Parental Coping Style, and Risk for Depressive, Posttraumatic Stress, and Anxiety Symptoms. *Journal of Paediatric Psychology*, *32*, 1272-1277.

Greenwood, N., Mackenzie, A., Cloud, G. C., & Wilson, N. (2009). Informal primary carers of stroke survivors living at home–challenges, satisfactions and coping: a systematic review of qualitative studies. *Disability and Rehabilitation*, *31*(5), 337-351.

Haefner, J. (2014). An application of Bowen family systems theory. *Issues in Mental Health Nursing*, *35*(11), 835-841.

Halfon, N., & Newacheck, P. W. (2010). Evolving notions of childhood chronic illness. *Journal of the American Medical Association*, *303*(7), 665-666.

Hall, G. (2015). Pearson's correlation coefficient. *Other words*, *1*(9).

Heaney, C. A., & Israel, B. A. (2008). Social networks and social support. *Health behavior and health education: Theory, Research, and Practice*, *4*, 189-210.

Hesdorffer, D. C., Benn, E. K., Cascino, G. D., & Hauser, W. A. (2009). Is a first acute symptomatic seizure epilepsy? Mortality and risk for recurrent seizure. *Epilepsia*, *50*(5), 1102-1108

Hildenbrand, A. K., Barakat, L. P., Alderfer, M. A., & Marsac, M. L. (2015). Coping and coping assistance among children with sickle cell disease and their parents. *Journal of Pediatric Hematology/Oncology*, 37(1), 25 – 34.

Hirtz, D., Thurman, D. J., Gwinn-Hardy, K., Mohamed, M., Chaudhuri, A. R., & Zalutsky, R. (2007). How common are the "common" neurologic disorders? *Neurology*, *68*(5), 326 -337.

Home, P., & Kerirey, S. (1991). Psychosocial adjustment of children with chronic epilepsy and their families. *Developmental Medicine & Child Neurology*, *33*(3), 201-215.

Horn, E. M., & Kang, J. (2012). Supporting Young Children With Multiple Disabilities: What Do We Know and What Do We Still Need To Learn?. *Topics in Early Childhood Special Education*, *31*(4), 241-248.

Howell, K. E. (2013). *Introduction to the Philosophy of Methodology*. London: Sage Publications

Hua-Huei, C., & Liang-Po, H. (2008). Parenting Stress in Parents of Children With Epilepsy and Asthma. *Journal of Child Neurology*, *23*, 301-306.

Iseri, P. K., Ozten, E., & Aker, A. T. (2006). Posttraumatic stress disorder and major depressive disorder is common in parents of children with epilepsy. *Epilepsy & Behavior, 8*(1), 250-255.

Jacob, E. (2001). Pain management in sickle cell disease. *Pain Management Nursing*, *2*(4), 121-131.

Javalkar, K., Rak, E., Phillips, A., Haberman, C., Ferris, M., & Van Tilburg, M. (2017). Predictors of caregiver burden among mothers of children with chronic conditions. *Children, 4*(5), 39 - 50

Juonala, M., Magnussen, C. G., Berenson, G. S., Venn, A., Burns, T. L., Sabin, M. A., ... & Sun, C. (2011). Childhood adiposity, adult adiposity, and cardiovascular risk factors. *New England Journal of Medicine*, *365*(20), 1876-1885.

Juster, R. P., McEwen, B. S., & Lupien, S. J. (2010). Allostatic load biomarkers of chronic stress and impact on health and cognition. *Neuroscience & Biobehavioral Reviews*, *35*(1), 2-16.

Kantor, H. S. (2016). *"We earn less than we eat": Food, farming, and the caring family in Bihar, India*. Cornell University

Karakis, I., Cole, A. J., Montouris, G. D., San Luciano, M., Meador, K. J., & Piperidou, C. (2014). Caregiver burden in epilepsy: determinants and impact. *Epilepsy Research and Treatment, 2014*, 808421.

Karlson, C. W, Haynes, S. L, Smith, M, Faith, M. A, Elkin, D, & Megason G. (2012). Examination of risk and resiliency in a pediatric sickle cell disease population using the psychosocial assessment tool 2.0. *Journal of Pediatric Psychology 37*(9), 1031-40.

Kiral, K., Yetim, Ü., Özge, A., & Aydin, A. (2017). The relationships between coping strategies, social support and depression: an investigation among Turkish care-givers of patients with dementia. *Ageing & Society*, *37*(1), 167-187.

Kleinman, A., Eisenberg, L., & Good, B. (2006). Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. *Focus*, *88*(1), 251-149.

Koller, H., Richardson, S. A., & Katz, M. (1992). Families of children with mental retardation: Comprehensive view from an epidemiologic perspective. *American Journal on Mental Retardation*, 97(3), 315–332.

Krejcie, R. V., & Morgan, D. W. (1970). Determining sample size for research activities. *Educational and psychological measurement*, *30*(3), 607-610.

Lance, P. M., & Hattori, A. (2016). Sampling and Evaluation. *researchgate. net*

Lazarus, R. S. (1966). *Psychological stress and the coping process*. The Salmon Tower Building, New York: Springer Publishing Company.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. The Salmon Tower Building, New York: Springer Publishing Company.

Lazarus, R. S. & Cohen, J. B. (1977). “Environmental Stress”. In Altman, I. & J. F. Wohlwill (eds.), *Human Behaviour and Environment.* (Vol 2) New York: Plenum, 89-127.

Le, M. T. H., Tran, T. D., Holton, S., Nguyen, H. T., Wolfe, R., & Fisher, J. (2017). Reliability, convergent validity and factor structure of the DASS-21 in a sample of Vietnamese adolescents. *PloS one*, *12* (7), e0180557.

Lee, J.K. (2003). Job stress, coping and health perceptions of Hong Kong primary care nurses. *International Journal of Nursing Practice*, 9(2), 86-91.

Levin, R., & Banks, S. (1991). Stress in parents of children with epilepsy. *Canadian Journal of Rehabilitation, 4,* 229-238.

Levine, C., Reinhard, S., Feinberg, L. F., Albert, S., & Hart, A. (2003). Family caregivers on the job: Moving beyond ADLs and IADLs. *Generations*, *27*(4), 17-23.

Liu, M. H., Lee, D. T., Greenwood, N., & Ross, F. M. (2011). Informal stroke caregivers’ self-appraised problem-solving abilities as a predictor of well-being and perceived social support. *Journal of Clinical Nursing, 21*, 232-242.

Lovibond, P. F., & Lovibond, S. H. (1995). The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour Research and Therapy*, *33*(3), 335-343.

Macedo, E. C., da Silva, L. R., Paiva, M. S., & Ramos, M. N. (2015). Burden and quality of life of mothers of children and adolescents with chronic illnesses: an integrative review. *Revista Latino-Americana de Enfermagem*, 23(4), 769-77.

Marin, T. J., Chen, E., Munch, J. A., & Miller, G. E. (2009). Double-exposure to acute stress and chronic family stress is associated with immune changes in children with asthma. *Psychosomatic Medicine*, *71*(4), 378.

Medalie, J. H. (1994). The caregiver as hidden patient: theory and research on health care triads. *Journal of Health Social Behaviour*, *35*(1), 1-12.

Mehra, K., Berkowitz, A., & Sanft, T. (2018). Psychosocial Consequences and Lifestyle Interventions. *In The Breast/Elsevier*. 1039-1048.

Miller, P. A., Kliewer, W., Hepworth, J. T., & Sandler, I. N. (1994). Maternal socialization of children's postdivorce coping: Development of a measurement model. *Journal of Applied Developmental Psychology*, *15*(3), 457-487.

Modell, B., & Darlison, M. (2008). Global epidemiology of haemoglobin disorders and derived service indicators. *Bulletin of the World Health Organization*, *86*, 480-487.

Modi, A. C. (2009). The impact of a new pediatric epilepsy diagnosis on parents: Parenting stress and activity patterns. *Epilepsy & Behavior*, *14*(1), 237-242.

Mokkink, L. B., Van Der Lee, J. H., Grootenhuis, M. A., Offringa, M., & Heymans, H. S. (2008). Defining chronic diseases and health conditions in childhood (0–18 years of age): national consensus in the Netherlands. *European Journal of Pediatrics*, *167*(12), 1441-1447.

Moskowitz, J. T. (2010). Coping interventions and the regulation of positive affect. *Handbook of Stress, Health and Coping*, 407-427.

Mott, J., Shellhaas, R. A., & Joshi, S. M. (2013). Knowledge of epilepsy and preferred sources of information among elementary school teachers. *Journal of Child Neurology*, *28*(6), 740-744.

Mphuthi, D. D. (2010). *Coping behaviours of haemodialysed patients families in a private clinic in Gauteng*. Doctoral dissertation, North-West University Vanderbijlpark, South Africa.

Mullins, L. L., Wolfe-Christensen, C., Chaney, J. M., Elkin, T. D., Wiener, L., Hullmann, S. E., ... & Junghans, A. (2010). The relationship between single-parent status and parenting capacities in mothers of youth with chronic health conditions: The mediating role of income. *Journal of Paediatric Psychology*, *36*(3), 249-257.

Mullins, L. L., Wolfe-Christensen, C., Hoff Pai, A. L., Carpentier, M. Y., Gillaspy, S., Cheek, J., & Page, M. (2007). The relationship of parental overprotection, perceived child vulnerability, and parenting stress to uncertainty in youth with chronic illness. *Journal of Paediatric Psychology*, *32*(8), 973-982.

Murray, C. J., Vos, T., Lozano, R., Naghavi, M., Flaxman, A. D., Michaud, C., ... & Aboyans, V., (2012). Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010. *The Lancet*, *380*(9859), 2197-2223.

Newacheck, P. W., Strickland, B., Shonkoff, J. P., Perrin, J. M., McPherson, M., McManus, M., ... & Arango, P. (1998). An epidemiologic profile of children with special health care needs. *Pediatrics*, *102*(1), 117-123.

Newness, K. A., (2011); Stress and Coping Style: An Extension to the Transactional Cognitive-Appraisal Model. *FIU Electronic Theses and Dissertations. 346.*

Newton, C. R., & Garcia, H. H. (2012). Epilepsy in poor regions of the world. *The Lancet*, *380*(9848), 1193-1201.

Noftle, E. E., & Fleeson, W. (2010). Age differences in big five behavior averages and variabilities across the adult life span: moving beyond retrospective, global summary accounts of personality. *Psychology and Aging*, *25*(1), 95-107.

Nuhu, F., Jika Y. A., Akinbiyi, A., Fawole, J., Babalola, O., Titilope, S. Z. & Olaniyi, A., (2010): The burden experienced by family caregivers of patients with epilepsy attending the Government Psychiatric Hospital, Kaduna, Nigeria. *The Pan African Medical Journal*, *5*(1), 8-18

Nyame P. K. & Biritwum R. B., (1997). Epilepsy: knowledge, attitude and practice in literate urban population, Accra, *Ghana.West African Journal of Medicine*, *16*(3), 139-145.

Olley, L. B., Brieger, W. R., & Olley, B. O. (1997). Perceived stress factors and coping mechanisms among mothers of children with sickle cell disease in western Nigeria. *Health Education Research*, *12*(2), 161-170.

Olson, D. H., Russell, C. S., & Sprenkle, D. H. (1983). Circumplex model of marital and family systems: Vl. Theoretical update. *Family Process*, *22*(1), 69-83.

Ott, D., Siddarth, P., Gurbani, S., Koh, S., Tournay, A., Shields, W. D., & Caplan, R. (2003). Behavioral disorders in pediatric epilepsy: unmet psychiatric need. *Epilepsia*, *44*(4), 591-597.

Padilla, J. L., & Benítez, I. (2014). Validity evidence based on response processes. *Psicothema*, *26*(1), 136-144.

Pai, Ahna L. H, & Meghan McGrady (2014). "Systematic review and meta-analysis of psychological interventions to promote treatment adherence in children, adolescents, and young adults with chronic illness." *Journal of Paediatric Psychology 39*(8), 918-931

Patten, M. L., & Newhart, M. (2017). *Understanding research methods: An Qverview of the Essentials*. London: Routledge.

Patterson, J. M. (1988). Families experiencing stress: I. The Family Adjustment and Adaptation Response Model: II. Applying the FAAR Model to health-related issues for intervention and research. *Family Systems Medicine*, *6*(2), 202–237.

Perrin J. M, Bloom S. R, & Gortmaker S. L., (2007). The increase of childhood chronic conditions in the United States. *Journal of American Medical Association*, 297, 2755–2759.

Piel, F. B., Hay, S. I., Gupta, S., Weatherall, D. J., & Williams, T. N. (2013). Global burden of sickle cell anaemia in children under five, 2010–2050: modelling based on demographics, excess mortality, and interventions. *PLoS Medicine*, *10*(7), 1001484.

Piel, F. B., Patil, A. P., Howes, R. E., Nyangiri, O. A., Gething, P. W., Dewi, M., ... & Hay, S. I. (2013). Global epidemiology of sickle haemoglobin in neonates: a contemporary geostatistical model-based map and population estimates. *The Lancet*, *381*(9861), 142-151.

Piel, F. B., Tatem, A. J., Huang, Z., Gupta, S., Williams, T. N., & Weatherall, D. J. (2014). Global migration and the changing distribution of sickle haemoglobin: a quantitative study of temporal trends between 1960 and 2000. *The Lancet Global Health*, *2*(2), 80-89.

Rani, A., & Thomas, P. T. (2019). Stress and perceived stigma among parents of children with epilepsy. *Neurological Sciences*, 1-8.

Reinhard, S., Huhtula, N., & Given, B. (2008). Supporting family caregivers in: R. Hughes (Ed.) Patient safety and quality: an evidence-based handbook for nurses. *Agency for Healthcare Research and Quality, Rockville (MD)*, 1–64

Reynolds, E. H., & Trimble, M. R. (2009). Epilepsy, psychiatry, and neurology. *Epilepsia*, *50*, 50-55.

Ridner, S. H. (2004). Psychological distress: concept analysis. *Journal of Advanced Nursing*, *45*(5), 536-545.

Robb, S. J., & Connor, J. R. (2002). Nitric oxide protects astrocytes from oxidative stress. *Annals of the New York Academy of Sciences*, *962*(1), 93-102.

Rodenburg, R., Meijer, A. M., Dekovi, M., & Aldenkamp, A. P. (2007a). Parents of children with enduring epilepsy: predictors of parenting stress and parenting. *Epilepsy & Behaviour*, 11, 197–207.

Romao A, P., Gorayeb R., Romao G, S., & Poli-Neto, O. B., (2009). High levels of anxiety and depression have a negative defect on quality of life. *International Journal of Clinical Practice*, *63*(5), 707 – 711,

Romero-Moreno, R., Losada, A., Mausback, B. T., Marquez-Conzalez, M., Patterson, T. L., & Lopez, J. (2011). Analysis of the moderating effect of self-efficacy domains in different points of the dementia caregiving process. *Aging and Mental Health*, *15,* 221-231.

Russ, S. A., Larson, K., & Halfon, N. (2012). A national profile of childhood epilepsy and seizure disorder. *Pediatrics*, *129*(2), 256-264.

Sahler, O. J. Z., & Carr, J. E. (2009). Coping strategies. In *Developmental-Behavioral Pediatrics*. *WB Saunders*, 491-496.

Salem, A., & Ahmad, M. (2016). Maturity of the concept of coping in health research. *International Journal of Applied Sciences and Innovation*, *2*, 95-100.

Sawatzky JE, & Fowler-Kerry S. (2003). Impact of caregiving: listening to the voice of informal caregivers. *Journal of Psychiatry Mental Health Nursing*. 2003; *10* (3), 277–86.

Sedgeman, J. A. (2005). Comments to. *Medical Science Monitor*, *11*(12), 47-52.

Selye, H. (1956). *The stress of life*. New York: McGraw Hill.

Serr, J., Mandleco, B. L., & Roper, S. O. (2007). Linkages between depression and caregiver burden in parents raising children with disabilities. In *18th International Nursing Research Congress Focusing on Evidence-Based Practice*.

Sholevar, G. P. (Ed.). (2008). *Textbook of family and couples therapy: clinical applications*. American Psychiatric Publication.

Shudy, M., De Almeida, M. L., Ly, S., Landon, C., Groft, S., Jenkins, T. L., & Nicholson, C. E. (2006). Impact of pediatric critical illness and injury on families: a systematic literature review. *Pediatrics*, *118*(3), 203-218.

Silverman, M., & Silverman, M. (1962). Psychiatry inside the family circle. *Saturday Evening Post*, *235*(28), 47-51.

Smith, J., Cheater, F., & Bekker, H. (2013). Parents' experiences of living with a child with a long-term condition: a rapid structured review of the literature. *Health expectations: An International Journal of Public Participation in Health Care and Health Policy*, *18*(4), 452-74.

Stein, R. E., & Silver, E. J. (1999). Operationalizing a conceptually based noncategorical definition: a first look at US children with chronic conditions. *Archives of Pediatrics & Adolescent Medicine*, *153*(1), 68-74.

Steinhardt, L. C., Waters, H., Rao, K. D., Naeem, A. J., Hansen, P., & Peters, D. H. (2008). The effect of wealth status on care seeking and health expenditures in Afghanistan. *Health Policy and Planning*, *24*(1), 1-17.

Stephenson, E., King, D. B., & DeLongis, A. (2016). Coping process. In *Stress: Concepts, cognition, emotion, and behavior*. Massachusetts, United States: Academic Press. 359-364

Sutan, R., Al-Saidi, N. A., Latiff, Z. A., & Ibrahim, H. M. (2017). Coping strategies among parents of children with acute lymphoblastic leukemia. *Health*, *9*(7), 987-999.

Tang, Y. Y., & Chen, S. P. (2002). Health promotion behaviors in Chinese family caregivers of patients with stroke. *Health Promotion International*, *17*(4), 329-339.

Tavakol, M., & Dennick, R. (2011). Making sense of Cronbach's alpha. *International Journal of Medical Education*, *2*, 53–55.

Taylor, S. E., & Stanton, A. L. (2007). Coping resources, coping processes, and mental health. *Annually. Revised Clinical Psychology*, *3*, 377-401.

Taylor-Powell, E., & Renner, M. (2003). Program development and evaluation. Analyzing qualitative data. *University of Wisconsin Cooperative Extension. Madison, Wisconsin. Retrieved May*, *1*(2011), 658-12.

Thoits, P. A. (1991). Gender differences in coping with emotional distress. In *The social context of coping*. Springer, Boston, MA. 107-138

Thompson, C. E. (2000). *Raising a handicapped child: A helpful guide for parents of the physically disabled*. Oxford, United Kingdom: Oxford University Press.

Thompson, P. J., & Upton, D. (1992). The impact of chronic epilepsy on the family. *Seizure*, *1*(1), 43-48.

Thurman, D. J., Beghi, E., Begley, C. E., Berg, A. T., Buchhalter, J. R., Ding, D., ... & Kroner, B. (2011). Standards for epidemiologic studies and surveillance of epilepsy. *Epilepsia*, *52*, 2-26.

Toledano-Toledano, F., & de la Rubia, J. M. (2018). Factors associated with anxiety in family caregivers of children with chronic diseases. *BioPsychoSocial Medicine*, *12*(1), 20.

Townsend, E. & Wilcock, A. (2004): Occupational justice and client centred practice: A dialogue in progress. *Canadian Journal of Occupational Therapy*, 2004; 71(2), 75-85.

Trask, P.C., Paterson, A.G., Trask, C.L., Bares, C.B., Birt, J. & Maan, C. (2003) Parent and Adolescent Adjustment to Pediatric Cancer: Associations with Coping, Social Support, and Family Function. *Journal of Pediatric Oncology Nursing*, 20, 36-47.

Van Cleave, J., Gortmaker, S. L., & Perrin, J. M. (2010). Dynamics of obesity and chronic health conditions among children and youth. *Journal of the American Medical Association*, *303*(7), 623-63.

Van den Tweel, X. W., Hatzmann, J., Ensink, E., van der Lee, J. H., Peters, M., Fijnvandraat, K., & Grootenhuis, M. (2008). Quality of life of female caregivers of children with sickle cell disease: a survey. *Haematologica*, *93*(4), 588-593.

Vermaes, I. P. R., Janssens, J. M. A. M., Mullaart, R. A., Vinck, A., & Gerris, J. R. M. (2008). Parents' personality and parenting stress in families of children with spina bifida. *Child: Care, Health and Development*, *34*(5), 665-674.

Wang, K. W. K., Chen, I. H., & Chen, M. (2018). Uncertainty of parents with children undergoing herniorrhaphy. *Clinical Nursing Research*, *27*(3), 343-363.

Ware Jr, J. E., & Gandek, B. (1998). Overview of the SF-36 health survey and the international quality of life assessment (IQOLA) project. *Journal of Clinical Epidemiology*, *51*(11), 903-912.

Weatherall, D. J., & Clegg, J. B. (2001). Inherited haemoglobin disorders: an increasing global health problem. *Bulletin of the World Health Organization*, *79*, 704-712.

Weiten, W. & Lloyd, M.A. (2008) *Psychology Applied to Modern Life (9th ed.)*. Mason. Ohio: Wadsworth Cengage Learning.

Welkom, J. S. (2009). An examination of the influence of stress and coping on psychosocial functioning in caregivers of children with sickle cell disease. *Thesis, Georgia State University*, 1-31.

Westphal-Guitti, A. C., Alonso, N. B., Migliorini, R. C. V. P., da Silva, T. I., Azevedo, A. M., Caboclo, L. O. S. F., ... & Yacubian, E. M. T. (2007). Quality of life and burden in caregivers of patients with epilepsy. *Journal of Neuroscience Nursing*, *39*(6), 354-360.

Wiener, L., Pao, M., Battles, H., Zadeh, S., Patenaude, A. F., Madan-Swain, A., ... & Lone-Parent Study Group. (2013). Socio-environmental factors associated with lone parenting chronically ill children. *Children's Health Care*, *42*(3), 264-280.

Wilborn-Lee, B. (2015). *The effects of stress and burden on caregivers of individuals with a chronic illness*. Doctoral dissertation, Walden University, Minneapolis, Minnesota.

Woessmann, L. (2015). An international look at the single-parent family; family structure matters more for US students. *Education Next*, *15*(2), 42-50.

Wojtas, K., Oskędra, I., Cepuch, G., & Świderska, E. (2014). The level of negative emotions, coping with stress and social support for parents of children with epilepsy. *Folia Medica Cracoviensia*, *35*(1),79-86.

Wong, M. G, & Heriot, S. A, (2008). Parents of Children with Cystic Fibrosis: How They Hope, Cope and Despair. *Child Care, Health and Development 34*(3), 344–354.

Wonkam, A., Mba, C. Z., Mbanya, D., Ngogang, J., Ramesar, R., & Angwafo, F. F. (2014). Psychosocial burden of sickle cell disease on parents with an affected child in Cameroon. *Journal of Genetic Counseling, 23*(2), 192-201.

World Health Organization (2006). Sickle-Cell Anaemia Report by the Secretariat. *Fifty ninth world Health Assembly*

World Health Organization. Department of Measurement and Health Information, Global Burden of Disease update, 2004. Geneva: WHO. 2008. 4

World Health Organization. Epilepsy Fact Sheet. (2016).

Yawson, A. E., Abuosi, A. A., Badasu, D. M., Atobra, D., Adzei, F. A., & Anarfi, J. K., (2016). Non-communicable diseases among children in Ghana: health and social concerns of parent/caregivers. *African Health Sciences, 16*(2), 378-88.

Yusuf, A. J, Nuhu, F. T., & Olisah, V. O., (2013). Emotional distress among caregivers of patients with epilepsy in Katsina State, Northern Nigeria. *African Journal of Psychiatry, 16*, 41–44.

Zamanzadeh, V., Ghahramanian, A., Rassouli, M., Abbaszadeh, A., Alavi-Majd, H., & Nikanfar, A. R. (2015). Design and implementation content validity study: development of an instrument for measuring patient-centered communication. *Journal of Caring Sciences, 4*(2), 165.

Zarina, A., Radhiyah, R., Hamidah, A., Zakaria, S.Z.S. and Jamal, R. (2012) Parenting stress in Childhood Leukaemia. *Medicine & Health*, 7, 73-83

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist*, *20*(6), 649-655.

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, *67*(6), 361-370.

APPENDIX A

QUESTIONNAIRE FOR CAREGIVERS

UNIVERSITY OF CAPE COAST

DEPARTMENT OF EDUCATIONAL FOUNDATIONS AND PSYCHOLOGY

Dear Caregiver,

This research questionnaire seeks to solicit information on the psychological effects and the coping strategies adopted by caregivers of children with sickle cell disease or epilepsy in Ashanti region.

The questionnaire you provide will only be used for academic purposes. If you have any questions for clarification do not hesitate to call me on; Mr. Abass 0244225606 / 0207620333. Thank you.

SECTION A

Please read each statement and tick [√] or fill in the answer

Personal data

1. Age of respondent is ……………………………….
2. Age of the child……………………………….
3. Gender of respondent is Male [ ] Female [ ]
4. Marital status Single [ ] Married [ ]
5. The condition of your child is? Sickle cell disease [ ]

Epilepsy [ ]

SECTION B

Please circle the appropriate response. **The rating scale is as follows:**

0. *Did not apply to me at all*

1. *Applied to me to a considerable degree.*

2. *Applied to me very much or most of the time*

3. *Applied to me to a considerable degree*

1. I found it hard to relax and rest	0	1	2	3
2. I sometimes experience dryness of the mouth	0	1	2	3
3. I couldn't seem to experience any positive feeling/joy at all	0	1	2	3
4. I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5. I found it difficult to work up the initiative to do things	0	1	2	3
6. I tended to over-react to situations	0	1	2	3
7. I experienced trembling/shaking (e.g. in the hands)	0	1	2	3
8. I felt that I was using a lot of nervous energy	0	1	2	3
9. I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10. I felt that I had nothing to look forward to	0	1	2	3
11. I found myself getting agitated/restless	0	1	2	3
12. I found it difficult to relax	0	1	2	3
13. I felt down-hearted (unhappy) and having no hope	0	1	2	3
14. I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15. I felt I was close to panic	0	1	2	3
16. I was unable to become enthusiastic about anything	0	1	2	3
17. I felt I wasn't worth much as a person	0	1	2	3
18. I felt that I was rather touchy/sensitive/reactive	0	1	2	3
19. I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)	0	1	2	3
20. I felt scared without any good reason	0	1	2	3
21. I felt that life was meaningless	0	1	2	3

SECTION C

Please circle the appropriate response.

1. I've been turning to work or other activities to take my mind off things.	0	1	2	3
2. I've been concentrating my efforts on doing something about the situation I'm in.	0	1	2	3
3. I've been saying to myself "this isn't real."	0	1	2	3
4. I've been using alcohol or other drugs to make myself feel better.	0	1	2	3
5. I've been getting emotional support from others.	0	1	2	3
6. I've been giving up trying to deal with it.	0	1	2	3
7. I've been taking action to try to make the situation better.	0	1	2	3
8. I've been refusing to believe that it has happened.	0	1	2	3
9. I've been saying things to let my unpleasant feelings escape.	0	1	2	3
10. I’ve been getting help and advice from other people.	0	1	2	3
11. I've been using alcohol or other drugs to help me get through it.	0	1	2	3
12. I've been trying to see it in a different light, to make it seem more positive.	0	1	2	3
13. I’ve been criticizing myself.	0	1	2	3
14. I've been trying to come up with a strategy about what to do.	0	1	2	3
15. I've been getting comfort and understanding from someone.	0	1	2	3
16. I've been giving up the attempt to cope.	0	1	2	3
17. I've been looking for something good in what is happening.	0	1	2	3
18. I've been making jokes about it.	0	1	2	3

19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	0	1	2	3
20. I've been accepting the reality of the fact that it has happened.	0	1	2	3
21. I've been expressing my negative feelings.	0	1	2	3
22. I've been trying to find comfort in my religion or spiritual beliefs.	0	1	2	3
23. I’ve been trying to get advice or help from other people about what to do.	0	1	2	3
24. I've been learning to live with it.	0	1	2	3
25. I've been thinking hard about what steps to take.	0	1	2	3
26. I’ve been blaming myself for things that happened.	0	1	2	3
27. I've been praying or meditating	0	1	2	3
28. I've been making fun of the situation.	0	1	2	3

APPENDIX B

Interpretation of DASS – 21 scores

The DASS-21 scores are multiplied by two so that you can compare the DASS-21 score with the normal DASS.

Meaning	**Depression**	**Anxiety**	**Stress**
Normal	0 -9	0 – 7	0 - 14
Mild	10 - 13	8 – 9	15 - 18
Moderate	14 - 20	10 - 14	19 - 25
Severe	21 - 27	15 - 19	26 - 33
Extremely severe	28+	20+	34+

APPENDIX C

INFORMED CONSENT FORM

I, the undersigned confirm that, I have read and understood the information about the project, as provided by the researcher. I have been given the opportunity to ask questions about the research and my participation. I voluntarily agree to participate in the research. I understand that I can withdraw at anytime without giving any reasons and that I will not be penalized for withdrawing nor will I be questioned on y I have withdrawn. The procedures regarding confidentiality have been clearly explained, that is, the use of names, pseudonyms, anonymization of data to me. The use of the data in research, publications, sharing and archiving has been explained to me. I understand that other researchers will have access to this data only if they agree to preserve the confidentiality of the data and if they agree to the terms I have specified in this form.

I understand that what I have said or written as part of this study will be used in reports, publications and other research outputs so that anything I have contributed to this project can be recognized.

I, along with the researcher, agree to sign and date this informed consent form.

Participant:

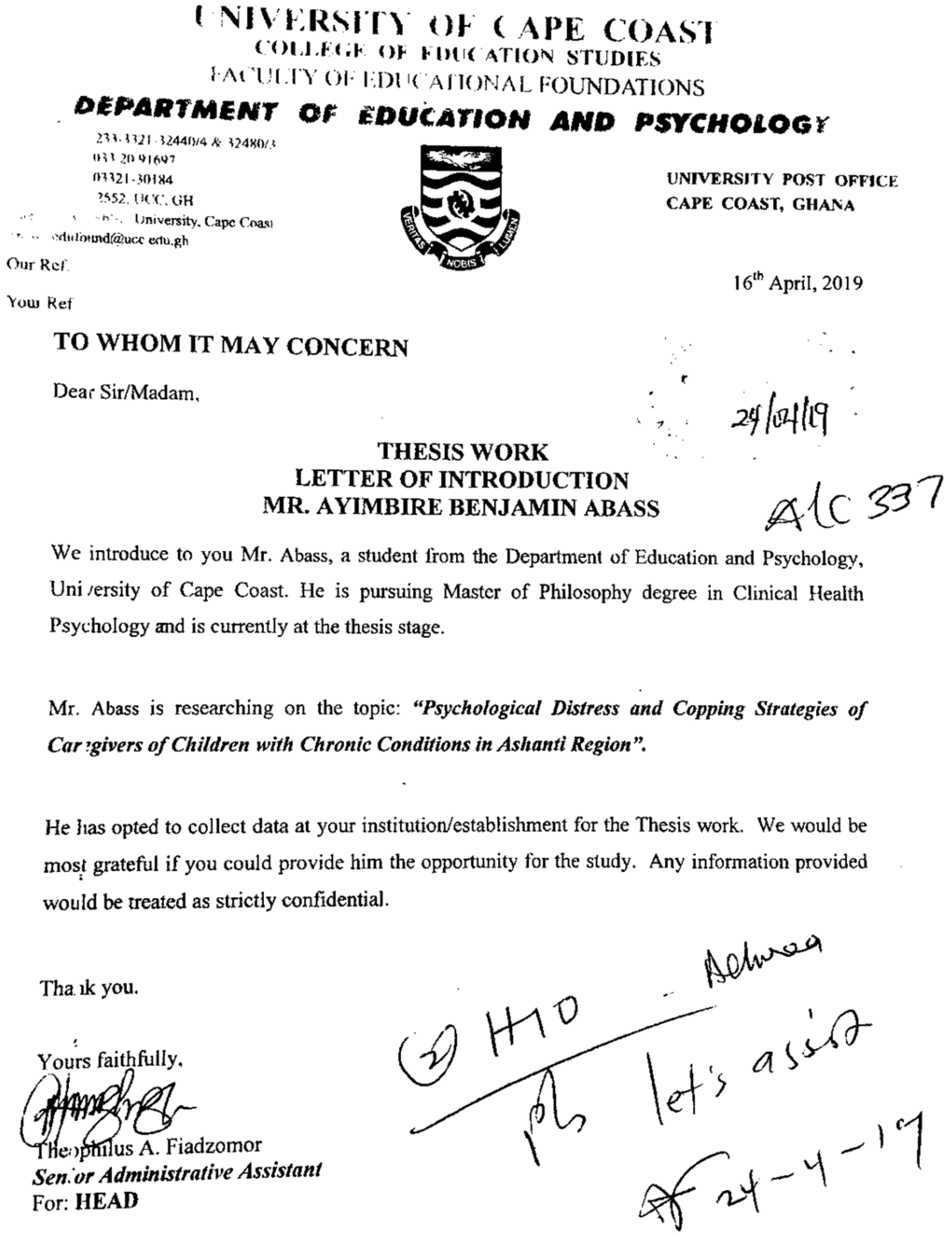
Name of participant	Signature	Date
______________________	________________	__________

Researcher:

Name of participant	Signature	Date
______________________	_________________	__________

APPENDIX D

Introductory Letter



UNIVERSITY OF CAPE COAST
COLLEGE OF EDUCATION STUDIES
FACULTY OF EDUCATIONAL FOUNDATIONS
DEPARTMENT OF EDUCATION AND PSYCHOLOGY

233-3321-32440/4 & 32480/3
033 20 91697
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2552, UCC, GH
University, Cape Coast
edufound@ucc edu.gh

UNIVERSITY POST OFFICE
CAPE COAST, GHANA

Our Ref.

Your Ref

16th April, 2019

TO WHOM IT MAY CONCERN

Dear Sir/Madam,

24/04/19

THESIS WORK
LETTER OF INTRODUCTION
MR. AYIMBIRE BENJAMIN ABASS

A/C 337

We introduce to you Mr. Abass, a student from the Department of Education and Psychology, University of Cape Coast. He is pursuing Master of Philosophy degree in Clinical Health Psychology and is currently at the thesis stage.

Mr. Abass is researching on the topic: ***"Psychological Distress and Copping Strategies of Caregivers of Children with Chronic Conditions in Ashanti Region".***

He has opted to collect data at your institution/establishment for the Thesis work. We would be most grateful if you could provide him the opportunity for the study. Any information provided would be treated as strictly confidential.

Thank you.

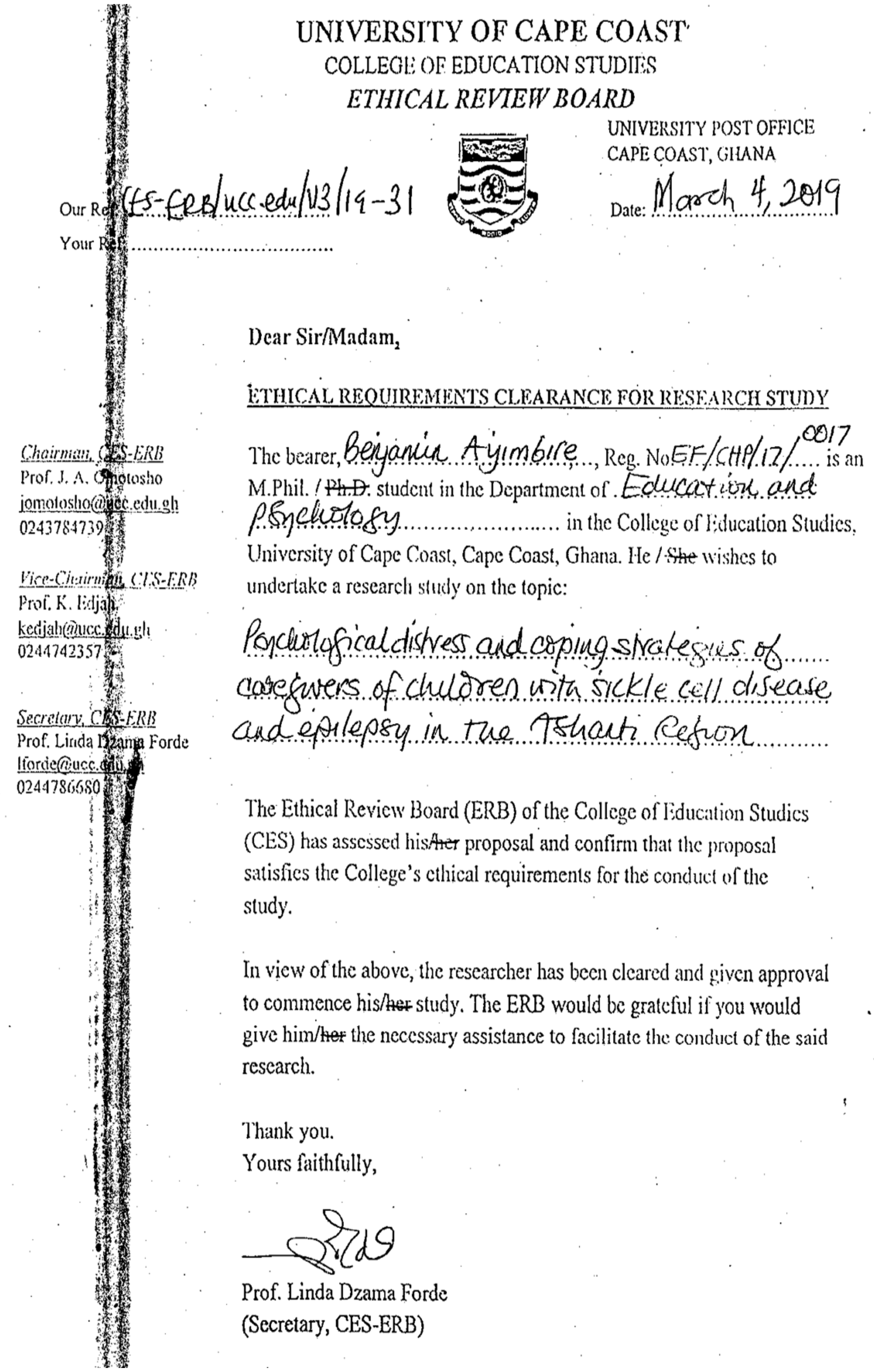
② HOD - Adwoa
pls let's assist
24-4-19

Yours faithfully,

Theophilus A. Fiadzomor
Senior Administrative Assistant
For: **HEAD**

APPENDIX E

Ethical Clearance



UNIVERSITY OF CAPE COAST
COLLEGE OF EDUCATION STUDIES
ETHICAL REVIEW BOARD

UNIVERSITY POST OFFICE
CAPE COAST, GHANA

Our Ref: CES-ERB/ucc.edu/V3/19-31
Your Ref: ....

Date: March 4, 2019

Chairman, CES-ERB
Prof. J. A. Omotosho
jomotosho@ucc.edu.gh
0243784739

Vice-Chairman, CES-ERB
Prof. K. Edjah
kedjah@ucc.edu.gh
0244742357

Secretary, CES-ERB
Prof. Linda Dzama Forde
lforde@ucc.edu.gh
0244786680

Dear Sir/Madam,

ETHICAL REQUIREMENTS CLEARANCE FOR RESEARCH STUDY

The bearer, Benjamin Ayimbire, Reg. No EF/CHP/17/0017 is an M.Phil. / ~~Ph.D.~~ student in the Department of Education and Psychology in the College of Education Studies, University of Cape Coast, Cape Coast, Ghana. He / ~~She~~ wishes to undertake a research study on the topic:

Psychological distress and coping strategies of caregivers of children with sickle cell disease and epilepsy in the Ashanti Region

The Ethical Review Board (ERB) of the College of Education Studies (CES) has assessed his/~~her~~ proposal and confirm that the proposal satisfies the College's ethical requirements for the conduct of the study.

In view of the above, the researcher has been cleared and given approval to commence his/~~her~~ study. The ERB would be grateful if you would give him/~~her~~ the necessary assistance to facilitate the conduct of the said research.

Thank you.
Yours faithfully,

Prof. Linda Dzama Forde
(Secretary, CES-ERB)