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EXPERIENCES OF INFORMAL CAREGIVERS OF CHILDREN LIVING WITH EPILEPSY IN TAMALE METROPOLIS: A STUDY AT THE TAMALE TEACHING HOSPITAL

BY

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DECLARATION

I hereby declare that this submission is my work for the award and that, to the best of my knowledge, it does not contain any material that has already been published by another person or that has been approved for the award of any other degree from the University unless the appropriate citation is made in the text.

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ABSTRACT

Families, caregivers, and those with epilepsy all struggle with their lives. Taking care of children with epilepsy is a more difficult task for caregivers due to the nature of the condition and the ages of the children (Gerling's et al., 2016).

The study evaluated the experience of caretakers of little children with epilepsy in Tamale. This research used the Phenomenological qualitative methodology to create a well-structured format or outline for the entire study. Caregivers who visited the psychiatric ward of the Tamale Teaching Hospital (TTH) with children under the age of 18 were purposively selected for the study.

Findings revealed that some caregivers had no knowledge or did not know about the disease. Although the majority of participants relied on traditional medicine, contemporary medicine, and faith healers for the treatment of their children, caregivers had a reasonable understanding of the signs and symptoms of epilepsy. Participants also discussed how the seizure affected the children's development and how the disruption of the school had an impact on their education.

Children with epilepsy and their caregivers experience detrimental effects on their physical, psychological, and social wellbeing (Sodi & Kgopa, 2016). Parents reported that providing care was very challenging and that having a seizure attack was not fun (van Westrhenen, Souhoka, et al., 2021). Despite these, they had accepted their fate and were making every effort to assist the kids. In the future, more resources would have to be invested into research that aims at understanding the coping strategies of caregivers of CLWE and more public health campaigns on epilepsy in the communities for better understanding of epilepsy to reduce the stigma.

KEYWORDS: Epilepsy, Misconception, Challenges, Caregivers, Neurological Condition, sychiatry

LIST OF ABBREVIATIONS

CCLWE	Caregivers of Children Living with Epilepsy
CLWE	Children Living with Epilepsy
CWE	Children with Epilepsy
GHS	Ghana Health Service
LMIC	Low-Middle Income Country
MHD	Municipal Health Directorate
PLWE	Persons Living with Epilepsy
PWE	Persons with Epilepsy
WHO	World Health Organization

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CHAPTER ONE

1.0 BACKGROUND OF THE STUDY

Globally, it is estimated that epilepsy is the most common neurologic condition in the pediatric population affecting 10.5 million children under the age of 15 (Olagunju et al., 2021) and with a prevalence rate of 0.051% (Shaw et al., 2021). Along with migraine, stroke, and Alzheimer's disease, it is the fourth most prevalent neurological disorder in the US (Walker et al., 2015). According to Prévos-Morgant et al. (2014), there are 2.2 million people living with epilepsy in the United States, and 150,000 new cases are reported every year. According to estimates, the disease will affect 1 in every 26 Americans, with a 3.8% prevalence rate. However, children and the elderly are more likely to experience it (Dorris et al., 2017). According to reports, the disease affects 24 out of every 100,000 individuals in Europe, 53 out of every 100,000 people in North America, and 190 out of every 100,000 people in low- and middle-income countries (LMICs) (Lai et al., 2019b). Additionally, it is believed that 500,000 French citizens have epilepsy (Sarlo & Holton, 2021). In the general population of China, the incidence rate is expected to be between 28.835 per 1000 people. Nevertheless, it is estimated that 9 million people in China have epilepsy (Juandó-Prats et al., 2021). However, the prevalence rate is significant in India, where 60 out of every 100,000 persons have the illness (Chen et al., 2018).

Ethiopia has a significant public health problem with epilepsy, impacting 5.2 out of every 1000 people, with 0.5% of individuals thought to have active epilepsy (Chen et al., 2018). For instance, it is estimated that 260,000 people in Mozambique have epilepsy (World Health Organization [WHO], 2015). Rwanda has the highest prevalence of epilepsy in Sub-Saharan Africa, at 49 cases per 1000 people, according to estimates (Sarlo & Holton, 2021). For instance, it is estimated that 1 in 100 people in South Africa has epilepsy. However, even though the prevalence in children is unknown, it is predicted that half of them will experience the condition prior to the age of 15 (Nguyen & Porter, 2020a). According to Akinsulore & Adewuya (2010), the estimated prevalence of epilepsy in Nigeria ranges from 3.537 in every 1000 people.

Estimating the disease in Sub-Saharan Africa is challenging due to a poorly defined population, a lack of patients reporting to the healthcare institutions, and a shortage of trained or competent medical professionals. Despite this, it is known that LMICs have a high prevalence rate of the disease (Thompson R. et al., 2014).

Ghana's exact prevalence of epilepsy is unknown (Ambikile & Outwater, 2012). Nevertheless, it is anticipated that the prevalence rate is 10.2% in every 1000 persons (Ambikile & Outwater, 2012).This is due to the fact that people who live with epilepsy (PLWE) hide their condition out of fear of stigma and do not report it. Parents and family members frequently conceal both the PLWE and their diagnosis from the public (Lagae et al., 2005). Epilepsy prevalence in Ghana is anticipated to be 250,000 (WHO,2015). Epilepsy is one of the top five medical issues in Ghana, and it places a significant financial strain on households (Sodi & Kgopa, 2016).

In a study conducted in china, nearly half of caregivers of CLWE developed psychopathological symptoms including post traumatic stress disorder, depression, anxiety and trouble sleeping which also affected their work and social life (Yang et al 2020).

People with the disorder, their caregivers, family members, everyone connected to them, and society at large are all affected by dread, myth, negative stigma, misunderstanding, and social isolation. The quality of life of persons who have the disease, their families, and those who offer some kind of care and support are all profoundly impacted (Gonçalves et al., 2021).

Family members who do care for children living with epilepsy (CLWE) face severe emotional, physical, psychological, and financial responsibilities because of the disease's characteristics, impairments, chronicity, and stigma. Due to the stigma associated with this disorder, caring for children or relatives who have it is difficult (Ostendorf & Gedela, 2017b). Limitations and emotional turmoil are often among caregivers, which makes living challenging (Etemadifar et al., 2018). Because stigma prevents family members and caregivers from taking part in social activities, it exacerbates mental illness (Yusuf et al., 2013).

The stigma and frustration experienced by caregivers and kids with epilepsy prevent them from participating in social activities. In addition, parents report feeling overburdened by a range of negative social, economic, psychological, and physical effects. The majority of parents experience emotional distress, including feelings of shame and profound disappointment (Juandó-Prats et al., 2021).

Parents and caregivers in particular experience developmental, emotional, social, and physical challenges (Miller et al., 2020). Parents were particularly worried that their child's epilepsy will result in learning challenges such memory and comprehension issues, slowness and laziness in class, and ultimately poor performance, according to Kats et al. (2020). The researchers added that parents were worried about how their child's epilepsy would impede their normal physical development. The majority of parents were also afraid that epilepsy might hinder their child's ability to finish school, find a fulfilling profession, and get married.

Particularly for parents of children with recurrent epilepsy and children with epilepsy who are within the typical developmental age range, parental stress was noticeably high (Chesi et al., 2021). Parents were more affected by the disorder's social effects than by the treatment itself. Parents found it challenging to tell others, school personnel, and the larger social milieu about their children's condition. Additionally, parents lacked sufficient knowledge on how to manage the disease. Parents were unsure whether to disclose the disease to their children because of concern for bullying or exclusion from their friends, or because they felt it was unnecessary given the age of the child and their capacity to comprehend and handle disclosure. Due to cultural challenges, educational limitations, and employment restrictions, parents who had children with epilepsy did not disclose their situation (Turan et al., 2021).

According to Zhichao Yu et al (2022) in china, caregivers go through two types of coping strategies which is emotion focused where caregivers cry, develop positive thinking and seeking emotional support and problem focused coping strategy where caregivers would look for all ways and means to address the problem. While in Ghana, a study showed caregivers coping strategy include positive coping strategies like faith in God, social support, lifestyle changes and negative coping strategies such thinking and worrying and concealing diagnosis (Atiogbe A, Aziato L, & Deegbe,2020)

In conclusion, it can be argued that parents and guardians have always struggled with a variety of care-related issues. Parental coping with the disorder has shown to be particularly challenging due to the stigma and burden it carries.

1.1 PROBLEM STATEMENT

According to Geerlings et al. (2016) caring for patients with epilepsy is difficult and comes with a heavy burden. Therefore, epilepsy caregivers face a significant physical and emotional health burden. Clary et al. (2010) stated that, caregivers have severe physical, psychological, emotional, and coping adjustments due to marital relationships, child-related concerns, employment, financial burden, and disease stigma. Caregiving for a person with epilepsy presented huge challenges because it is a persistent stressor and a significant burden. Due to the physical, psychological, social, and economic costs epilepsy places on people, families, and nations, it requires attention.

Since most people do not visit medical institutions when they or a family member have epilepsy, accurate data on these people, whether they are children or adults, are not readily available, according to Rood et al. (2014).

In Ghana, community members who have children with epilepsy subject parents to anguish and shame. This has an impact on one's physical, social, emotional, and economic quality of life (Penovich et al., 2021). Because of the stigma attached to the ailment, parents are angry that their children have been given a diagnosis. Most of the time, they are astonished, disappointed, downcast, and sorrowful. Parents worry about being stigmatized and rejected if they tell friends and family about their child's illness. They dissociate from friends, family, and socialites, blaming themselves for their current situation of responsibility (Wanigasinghe et al., 2021).

Another study found that children with epilepsy experienced behavioural and emotional issues that were related to learning challenges, poor memory, and comprehension issues (Cooper et al., 2020). Children also struggle with attention issues and cognitive issues, which makes it harder for them to understand what they are being taught (Pasca et al., 2020). In addition to these, parents who have school-age children with epilepsy frequently forbid them from attending because they fear that they will be stigmatized and that they may experience seizure attacks. Parents are so unhappy that their children are unable to live typical lives and achieve their goals in life. As a result of a directive from a traditionalist, herbalist, or priest, the kids are even forbidden from eating a variety of items, such okra and eggs (Ma et al., 2021).

Additionally, parents of CLWE, particularly moms, in Ghana and many other African nations do not receive help from their partners, friends, family, neighbors, or governments (McKeon et al., 2021). Due to the limited resources at their disposal, caregivers are unable to take control of their circumstances, which makes coping challenging. However, in order to deal with the impairment in their current situation, caregivers employed some sort of coping method (Lee et al., 2021).

From the background it can be seen that caregivers go through a lot but much research has not be conducted especially in Africa particularly Ghana but most literature was from Asian and European countries and most focus on epilepsy burden not on the caregivers but the CLWE.

The experiences of parents of children with epilepsy have been disregarded in many countries, including Ghana. This is demonstrated by the little amount of published research on caregivers' experiences with epileptic children, particularly in Ghana and its north, which is why this study was carried out. People would learn from the study about what it was like for CLWE caregivers.

1.3 RESEARCH QUESTIONS

The following are the questions this research seeks to address.

- What is the caregiver’s knowledge, beliefs and understanding of epilepsy?
- What challenges do caregivers of epileptic children face?
- What coping strategies do caregivers of epileptic children employ?

1.4 MAIN OBJECTIVE OF THE STUDY

The main aim of the study is to assess the experiences among caregivers of children with epilepsy the in-Tamale metropolis who attend Teaching Hospital (TTH).

1.5 SPECIFIC OBJECTIVES OF THE STUDY

The specific objectives of the study are:

1. To explore the caregiver's knowledge, beliefs and understanding of epilepsy
2. To identify the challenges among caregivers of epileptic children.
3. To ascertain the coping strategies used by caregivers to overcome these challenges.

1.6 SIGNIFICANCE OF THE STUDY

The study aimed to emphasize experiences and coping mechanisms used by parents of children living with epilepsy and to promote favorable outcomes for these children. The results will be important in guiding and creating future interventions for CLWE caregivers. Results will add to the body of knowledge on the caregiver crisis experienced by parents of children with epilepsy, including the causes of the condition and coping mechanisms used by parents. The outcome will allow decision-makers to incorporate these insights into upcoming epilepsy policy improvements. Any necessary curriculum revisions or repackaging of existing content to reflect the most recent findings from the study will be communicated to nursing education institutions with knowledge of caregiver crises and coping techniques used by parents in this study. It would be expected that following in-service education programs will incorporate outcomes from ongoing education in epilepsy care.

1.7 OPERATIONAL DEFINITION OF TERMS

1.7.1 Epilepsy

Epilepsy is characterized by aberrant brain activity that results in seizures or episodes of strange behavior, sensations, and occasionally unconsciousness. (Gallop et al., 2021).

1.7.2 Neurology

The scientific field of neurology focuses on studying and treating problems of the neurological system. The nervous system is a dynamic and complex structure that coordinates and governs bodily functions. (Joung & Yi, 2017).

1.7.3 Caregivers

A caregiver is someone who is actively involved in meeting the needs of another person, such as a family member or acquaintance who is chronically ill, disabled, or elderly. A caregiver frequently finds themselves in this position without the necessary training, assistance, or remuneration. (Wagner et al., 2009)

1.7.4 Stigmatization

Stigmatization is the process of recognizing and stigmatizing a negative trait in a way that limits a person's social identity to that trait. (Gallop et al., 2021).

1.7.5 Discrimination

The term "discrimination" has undergone substantial changes over time, creating a complex semantic area that is discussed here diachronically. Caregiving is providing all the support that children with epilepsy require.

Children living with epilepsy: children and adolescents who have been diagnosed with epilepsy.

Coping strategies: what caregivers do to curb the situation as well as the resources available to them.

Crisis management: how caregivers deal with the situation.

Crisis: what caregivers generally go through as a result of caring for children living with epilepsy.

Experience: the natural life circumstances that parents go through.

CHAPTER TWO

2.0 LITERATURE REVIEW

A literature review involves identifying studies with keywords that will help them find relevant information. Various sources have been cited, including journals, articles, books, published documents, and Internet use. Sage, Science Direct, Medline, PsycINFO, Wiley Online, Google Scholar, PubMed and other databases were used to access information.

2.1 INTRODUCTION

The challenges of family caregivers regarding children with epilepsy have been described to vary significantly depending on the setting. According to a study by Wheless, (2006), the challenges family caregivers encounter can be classified as either environmental, physical, or other fiscal challenges in the upbringing of children living with epilepsy. The consciousness of the peculiarity of the condition the children pass through predisposed the caregivers to the likely crisis moments they will be meeting. The pain of the challenges is exacerbated when the condition is not anticipated or sporadic (Zhang et al., 2021). Much as caregivers directly bear the brunt of the challenges, the whole family also live and deals with the condition daily. The majority of these are learning how to handle the children living with epilepsy as the direct caregiver might not always be available (Min et al., 2021). Of the different challenges that caregivers face, anxiety has been the common challenge as family caregivers easily get concerned about a child’s safety (Jones et al., 2022). According to Schlag and colleagues (2021), the burden of caring for a family member with a condition that may span over a lifetime has, largely, a negative and pervasive impact. Children with epilepsy have been shown over the years to have poor academic performance, hence are not able to climb higher to greater achievement while also harnessing a withdrawal from society for fear of being ridiculed and stigmatized (El-Amin et al., 2021).

The experience in taking care of children with epilepsy is influenced to a greater extent by the general health of the child, the seizure rates, etc. Paramount is the entire family's health which trickles down to influence the mental state of the parents and how observant they are in giving adequate care to the child with epilepsy. The challenges that parents will have to go through in sustaining the life of a child living with epilepsy may take a great effect on their financial life, physical well-being, and psychological and conjugal stress. Notwithstanding, all of these go a long way to interfere with day-to-day life activities and healthy family functioning (Raspall-Chaure et al., 2014). Epilepsy over the years has been associated with various myths, misinformation, stigma and discrimination, which are all dependent on the society the individual finds him/herself. The downstream impact of these affects the individual living with the disorder, members of the family, close relationships and the entire community. Parents, especially mothers, carry the brunt and impact of the condition (Schlag et al., 2021).

Over time, epilepsy sufferers' parents, caregivers, and friends have endured humiliation because of their connections to these people (Schoonjans et al., 2019). They are stigmatized, devalued, and subjected to discrimination to the point that they are unable to socialize, participate in gatherings, or find fulfilling employment aside from the unmatched stigma that comes along with them (MacEachern et al., 2017).

According to Bouldin et al (2022)'s related interpretative phenomenological analysis of ten Iranian parents' experiences as family caregivers of children with epilepsy, parents occasionally experienced verbal abuse and stigmatization from their community members. According to their assessment, they refused to help with the management of the condition of their wards due to the embarrassment and unfavorable remarks that go along with it. The researchers acknowledged that their methodology was not very rigorous, thus they were unable to remark on how parents cope (Boles et al., 2020). Related research has further demonstrated how parents of children with epilepsy retreat from society, protecting their offspring from prying eyes (Labbé et al., 2002).

Similar studies using mixed methods (qualitative and quantitative) by Murugupillai et al. (2016) revealed that because of the stigma attached to the condition, both parents and children with epilepsy faced difficulties like social exclusion, movement restrictions, harassment, internalized negative epileptic emotions, and dissimulation of the disorder. Much like stigmatization has been accurately stated as a difficult problem It has been done to weigh the difficulty of coping with epilepsy on the various family members, including the father, mother, children, and other close relatives (van Westrhenen, de Lange, et al., 2021a). It's crucial to do this while designing effective coping techniques for families affected by the condition. In understanding the situation in South-East Nigeria, a study that involved 19 participants also indicated the fear of disclosing the status of their kids to others (van Westrhenen et al., 2022). It was remarked that some felt disappointed with the lack of continued care, derogatory remarks made by others, and the assumption that epilepsy is communicable as well as sometimes a curse from the gods. They also emphasized that the societal outlook towards CLWE had a huge effect on both families and sufferers. These remarks were made by women who formed the majority in the study, hence, driving home the actual impact as they tend to be the major caregivers in the home.

According to a related study by Farnalls & Rennick (2003), one in five moms of children with CLWE experience stigma because of their child's epilepsy. Despite the problem's high incidence, there are no societal solutions that can assist moms in effectively controlling their children's epilepsy. The study also showed how chronic stigmatization affects mothers to the point where some experience psychiatric illness. The majority of the study participants were married and educated. This demonstrated that mothers who were uneducated and unmarried would probably experience more discrimination and shame.

The individual with epilepsy and the relatives living with epilepsy both experience the stigma associated with the disorder, which has a negative impact on quality of life, according to Maya Kaye's interrelated quantitative study of 148 consecutive people with epilepsy and 45 family members.

The stress on caregivers causes them to spend a lot of time caring for the patients, which frequently puts them at a high risk of getting sick themselves (Ks et al., 2011). They claimed that they were strained both physically and mentally as a result. Even if the burden of caregiving was underreported, it is important to note that parents experience physical, social, attachment, emotional, and developmental strain when during a comparative study (Packer et al., 2017). Parents of children with recurrent epilepsy and those who have children with epilepsy face extremely high levels of parental strain (Nevin et al., 2022). Despite their findings, it was clearly established that caring for kids with epilepsy was often draining. Wagner et al (2010)'s parenting stress analysis in moms with kids with uncontrollable epilepsy revealed that mothers experienced high levels of stress, social isolation, and health problems. They had little self-reliance and little ability to hold onto their identities. They also discovered that 42% of mothers lack emotional support, are socially isolated, and are overworked. They came to the conclusion that, despite the fact that over one-third of the mothers in this study were effective, caregivers were clearly burned out as a result of their overburdened roles.

In a different study, it was discovered that primary caregivers in Nigeria experienced changes to their domestic routine, family or social connections, jobs, leisure time, and physical health (Seid et al., 2018a).

2.2 KNOWLEDGE, BELIEFS AND UNDERSTANDING OF EPILEPSY

Research conducted by Yang et al, (2021) in India established that there is non-existence of knowledge, attitudes, and beliefs concerning victims and their family caregivers regarding the management of epilepsy. Lower middle-income countries at the sight of numerous literature accept and carry along that epilepsy is a development by mystical controls (Arzimanoglou et al., 2014). It is therefore evident from collected literature that not only is the public limited to the nonexistence of knowledge, bad attitude, and wrong perception about epilepsy, but family caregivers who are in contact with clinicians do also have wrong perceptions.

The caregiver's conviction dictates its response to a disease and its methods of handling it. Learning the beliefs and attitudes of caregivers is an important early step toward improving patient care. Earlier studies in underdeveloped countries have demonstrated a strong belief that epilepsy is the course of supernatural powers and spirits (Saengow et al., 2018). Successful treatment of epilepsy in rural areas is mainly influenced by prevailing attitudes and beliefs. The main reasons for poor treatment compliance include a lack of understanding of drug treatment principles, other factors such as cost and self-management, quacks treatment, and fear of drug side effects (Samanta et al., 2022). Epilepsy is one of the world's most common non-communicable classes of brain diseases, or chronic seizures (Turky et al., 2008). It has been shown that the severity of negative perceptions is exacerbated by the prevalence of CLWE's myth that involves the view of epilepsy as a cause of hysteria, being untreatable, infectious, and inherited or a form of mental retardation (Rodenburg et al., 2011). Most work has repeatedly found that epilepsy patients and relatives in their families do not have a thorough knowledge of basic details regarding the condition ranging from how the diagnosis was made, seizure precipitants, forms of seizures, the intent and possible adverse effects of medications, health worries about the dangers and possible seizure outcomes (Penovich P. E. et al., 2017). Although several studies have shown that patients and the attitude of caregivers and their families toward epilepsy have become less aggressive over time, stigma concerns remain pervasive (Samia et al., 2021). In the last two decades, several investigations linked to the psychological consequences of epilepsy have shown the impact of this disease on the health-related quality of life of patients and caregivers. Family caregivers with a strong understanding, experience and disposition towards this disease have been reported to have improved quality of life in their health (Karanja et al., 2021).

Most research has found that epilepsy patients and family members frequently lack a thorough understanding of fundamental information about the condition, including how the diagnosis was made, seizure triggers, types of seizures, the purpose and potential side effects of medications, and health concerns regarding the risks and potential seizure outcomes. Stigmatization worries persist despite several studies showing that patients, caregivers, and families' attitudes regarding epilepsy have softened over time (Allen, 2007).

Numerous studies into the psychological effects of epilepsy over the past 20 years have revealed how this condition affects patients' and caregiver's ability to lead healthy lives. It has been reported that family caregivers who have a solid grasp of, experience with, and inclination towards this condition have higher quality of life in terms of health. Therefore, to deal with the misinformation about epilepsy successfully and enhance family caregivers' quality of life in terms of safety, a thorough analysis of understanding, facts, and attitudes is essential. Due to the paucity of general caregiver study, family caregiver studies were required as the topic gained future research attention (Johnson, 2003).

There are various perspectives on epilepsy that relate to spiritual causes, medical issues, and myths (Gutierrez-Angel et al., 2018). The native religion of Africa links epilepsy to witchcraft, demonic possession, demonic attack, evil spirit, or God's condition. According to Wiley Online Library (2017), epilepsy has long been thought of as a bizarre and enigmatic illness with a variety of fantastical causes. Epilepsy is thought to be caused by hidden beings who live in the mountains and woods, and it is frequently advised as a treatment to avoid bothering the hidden.

According to a research by Ohaeri et al. (2009) that examined caregivers' knowledge and beliefs regarding seizures, caregivers believed that seizures were caused by fever, brain disorders, demons, or evil spirits. At the Bustamante Hospital, an exploratory cross-sectional study was carried out. The study comprised 71 parents or caregivers of hospitalized children from Jamaica. This investigation was carried out in a city rather than a rural area where epilepsy knowledge might be less and true beliefs about the condition more easily ascertainable. The quantitative nature of the study's methodology prevented a thorough examination of the parents' study-related experiences. Various qualitative study methods allow for the elicitation of data in a natural situation and the extraction of meaning (Ohaeri et al., 2009).

Al-Khateeb & Al-Khateeb (2014) hypothesized that the communities, including those of families with epileptic children, had misconceptions about epilepsy in another study they did among Saudi families. They also became aware that some individuals thought epilepsy was a mental disorder, a hereditary sickness, and even communicable. Additionally, they revealed that 44.7% of families linked Jinn to their epilepsy (i.e., spirits or demons).

In a similar survey conducted by Dewar et al. in Urban Suriname in 2021, it was found that 22% of the participants believed that meningitis, strokes, and neurotrauma were the main causes of epilepsy. However, "fiofio" was one of the causes that was also highlighted (i.e., spiritual revenge due to an ancestral curse). According to a similar study on the attitudes and beliefs about epilepsy in Mali, even though parents of affected children had more knowledge about seizures, false ideas persisted and were much more prevalent in households without epilepsy (Vigevano et al., 2018). According to the data, 52% of parents of children with epilepsy knew the condition was physical, while 29% thought it had purely supernatural or spiritual roots. The remaining individuals thought it was contagious. They went on to say that despite recent developments in clinical treatment and earlier campaigns to increase public awareness, there are still many misconceptions about epilepsy.

The researchers came to the conclusion that parents misunderstood and held incorrect views about whether or not they had an epileptic child (Bowins, 2010).

It was revealed that epilepsy is traditionally thought of as a curse by the ancestral spirits or as the result of being possessed by bad spirits, which motivated researchers to examine into the present psychological beliefs and understanding regarding epilepsy. The researchers also discovered that epilepsy was believed to be both highly contagious and the result of "poisoning" and witchcraft. Even though this survey was done among elite university students, some of the common misconceptions about epilepsy persisted, with 13.3% of participants believing it to be contagious.

In Ghana, this survey was carried out among university students (Bruno et al., 2020). According to a report by Berg et al., (2019), many people believed epilepsy was contagious, some thought it was caused by ghosts known as "irans," and still others thought it was a blood disorder and the retribution for sins done by parents, families, or communities. This study looked at the cultural attitudes of epileptics and other physically challenged people in Guinea-Bissau.

In a similar study conducted in Northern Ghana by Thompson et al., (2019) on the beliefs surrounding epilepsy, the researchers expressed the opinion that epilepsy occurs when a family is cursed, when a baby is bathed late, when women are unfaithful or commit adultery, when all firstborns are not delivered at home, and when a woman is pregnant, but no ritual is performed for her. Additionally, they learned that the native's thought epilepsy was contagious and that pregnant women who took their baths late would be visited by malevolent spirits. In a similar vein, Jafarpour et al., cross-sectional's study of 167 people in a rural community in Northern Tanzania on their beliefs about epilepsy and attitudes toward those who have it found that 46.7% believed it was caused by supernatural causes, while 51.5% believed it was brought on by brain disorders or was inherited.

According to a related survey, just a small percentage of the participants understood that epilepsy is a brain illness. Most people believed that witchcraft and genetics were to blame for epilepsy's occurrence, and they also believed that a demon could possess someone with epilepsy. They claimed that bodily contact, making fun of someone who has epilepsy, sharing utensils, and saliva all increase the risk of contracting epilepsy. They came to the conclusion that epilepsy is still a condition with a poor understanding in underdeveloped nations due to erroneous local views and cultural beliefs. In a qualitative study of 41 epileptics and the people who cared for them, epilepsy was frequently attributed to witchcraft, curses, God's illness, and demonic force (Nguyen & Porter, 2020b). It was discovered that patients' and caregivers' beliefs were similar. Participants thought that a chameleon breathing into someone's nostrils could cause seizures. Family transgressions, disregard for customs or rules passed down through the generations, and other notions were also held. The researchers came to the conclusion that epilepsy was characterized by inadequate understanding and strong cultural and religious beliefs. However, it was mentioned that the study was carried out in a medical context. This might prevent patients and caregivers from freely expressing themselves, as opposed to if it took place in their native environment. In Ghana, mothers' knowledge, beliefs, and practices regarding febrile convulsions and home management were examined. It was hypothesized that mothers believed seizures were typically brought on by witchcraft and evil spirits that fly like birds in the night. This may therefore limit the information they would have provided on their perception of epilepsy. Epilepsy-related myths, misconceptions, and misunderstandings continue to be a significant barrier in our cultures and communities. Epilepsy was traditionally thought to be brought on by witchcraft, ancestral spirits, demons, and bad spirits. Additionally, it was thought to be largely communicable. The majority of parents similarly associated spiritual connotations with the ailment, leading them to look for other remedies.

2.3 CHALLENGES EXPERIENCED BY THE CAREGIVERS

2.3.1 CHALLENGES WITH HEALTH CARE

Severe childhood disease and disability pose many difficulties that families will address while caring for their children (Asadi-Pooya et al., 2021). According to Bailey & Im-Bolter, (2018), family caregivers in many situations forget and forgo the need to check their medical status regularly. These affect their physical state of health (Mushi et al., 2011). Caregiving-related feelings of distress and fatigue often adversely impact the physical well-being of caregivers. Caring for patients living with epilepsy is more difficult than just caring for a mentally ill patient. People with epilepsy usually require extra care and are less likely to show appreciation for the help they get and are more likely to be distressed. All of these factors were linked to negative outcomes for caregivers (Friedman et al., 2014).

2.3.2 SOCIAL HEALTH

The amount of money involved in handling chronic neurological illnesses such as epilepsy is very high and is acknowledged by developed countries (Geerlings et al., 2015). The combination of chronic neurological illness management and other issues brings a lot of financial burden on the family caregivers (Cereghino et al., 1998). It is extremely concerning how difficulties affect the social connections of family caregivers. Due to the focus on providing care, this in some ways results in the rejection of close friends and family members (Carbone et al., 2013). The CLWE tracks health issues and lack of focus in class that may have an impact on future employment prospects. The individuals have a history of co-occurring diseases and frequently reside in families with poor annual incomes (Pastrana et al., 2011). Additionally, CLWEs are more likely to be fat, to be inactive, and to have major life-altering events. Additionally, children with this illness have a greater mortality rate and a higher risk of suicide (Boubour et al., 2020; Bruno et al., 2018). It has been demonstrated that those who have only experienced one seizure face prejudice in the job market (Kluger et al., 2021). Low socioeconomic status has been proven to increase the likelihood of having epilepsy and frequently results in further hospital admissions for epilepsy (Bruno et al., 2018). Inadequate social and emotional support, lack of progress in the areas of education or socialization with family and friends, and poor mental health are all significant predictors of CLWE (Chew et al., 2017b). People with epilepsy frequently find themselves fired, transferred to a remote workplace, or isolated after a seizure at work, making them fearful of the future. More severe work-related seizures (partial seizures of frontal lobe origin, tonic-clonic seizures), on the other hand, are distressing to see and disrupt others on the job. Numerous studies have shown that patients with epilepsy have significant rates of underemployment or unemployment. Since telling the truth could jeopardize their prospects of landing a job, PLWE might be tempted to lie to potential employers (Chew et al., 2017b).

Due to the time needed to care for them and their current health, caregivers who have epileptic children may have trouble finding and keeping a job. 60 PLWE participated in a study by Mugumbate & Nyanguru (2013) to evaluate the issues facing PLWE in Harare, Zimbabwe. They discovered that PLWE's issues with getting a suitable income and obtaining and maintaining employment were economic in nature. The authors also discovered that, when compared to the problems of other lives, the economic hardship for PLWE was the second highest.

The researchers went on to say that employed PLWE only made half as much money as employed control subjects, which amounted to indirect costs to PLWE. Epilepsy posed disadvantages for anyone who lived with it in the workplace. Even if PLWE is applied, the authors continued to contend that assumptions about them are frequently gloomy and do not promote successful engagement in the job. The authors also stated that it is not surprising that there is a significant rate of unemployment and underemployment among PLWE. Since they are frequently perceived as withdrawn, ugly, mentally ill, and undesirable employees. People may decline jobs at PLWE as a result of these stigmatizing viewpoints. According to UK research on workers, the majority of businesses turned down PLWE's application for employment. Such employers often cited issues with other staff members' health, social anxiety among coworkers, and PLWE's decreased capacity for production as justification for their actions (Bapat & Shankar, 2021). McLellan (1987) conducted a different investigation in Britain and discovered that PLWE faced challenges in the job market, including as inequitable care. The author also mentioned that between 50,000 and 100,000 people in Britain were thought to have mild to severe difficulties finding and maintaining a career in 1986 as a result of epilepsy. People with epilepsy are now less likely to be employed (Joung & Yi, 2017). They are more likely to be unemployed or underemployed (Nevin et al., 2022).

In 2001, Bishop & Allen published a study on PLWE employment issues in the United States and Puerto Rico. They reported that the unemployment and underemployment of people with epilepsy remained a serious issue and thought the concern related to PLWE's jobs was well known. The unemployment rate among PLWE has frequently been higher than that of the general population (Carbone et al., 2013).

Conway (2016) looked into how epilepsy and its treatment affected the employment status of 90 PLWEs. According to the analysts, 59.5 percent of respondents said their economic and financial situation was very decent, decent, or acceptable, while 40.5% said it was poor or very poor. Additionally, according to the research, 24% of people worked part-time, 39% worked full-time, and 11% were unemployed. However, 63% of those who are unemployed or part-time workers believe that epilepsy is a major contributor to this. The fact that 40.5% of participants said their financial and economic situation was extremely poor may help to explain this.

2.3.3 PSYCHOLOGICAL CHALLENGES

When taking care of a child who has epilepsy, family caregivers are undoubtedly vulnerable to harming themselves (Gonçalves et al., 2021). Stress and mental health disorders are brought on by caregivers' inability to ask for assistance, according to Labbé et al., (2002). According to MacEachern et al., (2017), the rising prevalence of epilepsy has an impact on public welfare through pressure, general psychological discomfort, and depressive symptomatology linked to caregivers' psychological morbidity. Min et al., (2021) conducted a thorough investigation of Chinese epilepsy caretakers. In order to better understand and meet the requirements of caregivers of patients with epilepsy, a study was conducted. Interviews were conducted with up to 27 participants in four different groups, each of which had 6-7 caregivers. The study's conclusions showed that care is just as difficult and demanding as it is in other high-income countries (Soleman et al., 2018). The emotional toll taken by family members was also the most stressful theme that emerged from the four focus groups when the findings were categorized. Seventy percent of subjects reported experiencing psychological distress, and 58% reported having a low mood. In-depth explanations of the behavioral and psychological challenges caregivers encountered while giving care have been presented by caregivers. which included hostility, annoyance, violence, obstinacy, loneliness, sleeplessness, and altered perception (Boubour et al,2020 & Pastrana et al., 2011). Additionally, giving care all year round, around-the-clock, was extremely taxing on caregivers and a significant strain. The researcher noted that although this study had significant findings, they could not be applied generally due to the small number of participants compared to Hong Kong's whole population (Chew et al., 2017b). Similar to the study, the paper was translated from Chinese into English before being produced, which suggests that some crucial information may have been lost in the translation process and contributed to the results' incompleteness.

In order to determine whether differences in patients' day-to-day behavior skills and psychological discomfort (more specifically, depression, anxiety, and hostility) indicate an improvement in the precise caregiver burden phases over a year, Lai et al., (2019) conducted a retrospective study with a sample size of 44 caregivers. The research showed that epilepsy progressed, leading to substantial cognitive dysfunction that reduced everyday function and heightened psychological anguish (Geerlings et al., 2016). It has been demonstrated that the pattern of variation in the patient's and the caregiver's characteristics can predict differences in the various stages of the caregiver burden research. According to earlier research, there has been a satisfying correlation between depressive and anxious symptoms in both patients and caregivers (Yusuf et al., 2013). The researcher discovered several flaws in this investigation, including the tiny sample size that rendered the findings difficult to generalize. In addition, while the majority of the caregivers were women, the majority of the patients were men. This demonstrates biases towards women. A review of the literature on the psychosocial consequences of epilepsy on caregivers was undertaken by Dorris et al. in 2017 and included seventeen (17) studies. Numerous studies have documented negative psychological and emotional outcomes of caring for epileptic individuals. Nearly all of the studies cited by the current researcher had tiny sample sizes that didn't correspond to the quantitative sample size and may have affected generalization. Findings have shown that epilepsy caregivers experience high levels of stress and sadness (Rood et al., 2014). The detrimental emotional and psychological impacts of caring for epileptic patients have been documented in numerous other researches. Examples include low mental health, social estrangement, rage, melancholy, and guilt (Raspall-Chaure et al., 2014). Nearly all of the studies cited by the current researcher had tiny sample sizes that didn't correspond to the quantitative sample size and may have affected generalization. It is advised that scholars make an effort to compile all the publications, nevertheless.

2.3.4 STIGMA AND DISCRIMINATION CHALLENGES

Epilepsy can cause cognitive decline, depression, or low self-esteem as a biological mechanism. Additionally, this could result in prejudice and a lowering of educational prospects for children who have epilepsy (Etemadifar et al., 2018). As a result of their weak social bonds, Chinese parents of epileptic children are less likely to find spouses than parents of healthy children (Chen et al., 2018)

Stigma is defined as a quality that has the power to denigrate a person and whose existence impairs social identity (Gallop et al., 2021). According to the author, persons who have unfavorable characteristics like ethnicity, class, religion, gender, or health issues like epilepsy are stigmatized. It identified three distinct categories of stigma: (a) racial and religious stigma; (b) flaws in human character; and (c) what are known as body abominations. He asserted that those who are stigmatized are seen by others as less than fully human, regardless of how any one of the three categories apply.

Boer, (2010) described how PLWE's experiences with stigma have been shaped by the varied historical and cultural foundations of epilepsy. Shame and prejudice connected to PLWE are deeply ingrained in the history of neurological health and the general understanding of epilepsy. It also results from a lack of understanding of neurological disorders (Nuhu et al., 2010). Throughout history, epilepsy has gone by various names. In the past and even now, CLWE has a reputation for being chosen or possessed by spirits or other deities. Many individuals tend to give epilepsy a mystical explanation because they don't know what causes it (Soleman et al., 2018). The work of Scambler (2004) centered on the experiences of epilepsy patients. The researcher used Goffman's theory to discuss the ideas of stigma. Scambler (2004) defined stigma as the internalized sense of being undervalued. Additionally, it connotes the anticipation of stigma or other unfavorable responses to the declaration of epilepsy, which also suggest sentiments of distinction and humiliation. Unlike actual perceptions, which are the center of stigma, felt stigma is based on presumptive social reactions to epilepsy and is just as crippling as the stigma itself.

The enforced stigma, on the other hand, pertains to acts of hostility against CLWE because of their alleged intolerance or inadequacy. This may include overt discrimination in the workplace or educational system, carelessness, hostility, or harassment, as well as what the participants believed to be reasonable and legal discrimination, such as driving restrictions or the use of heavy machinery (El-Amin et al., 2021).

The perceptions and actions of individuals in society show indications of the stigma and discrimination experienced by PLWE (Ma et al., 2021). According to the author, stigma and discrimination may have a number of explanations, such as cultural roots, which make it challenging to spread and eradicate. Due to stigma, CLWE are frequently discouraged, shamed, and denied participation in social or public activities (Hesdorffer et al., 2020). The author went on to say that stigma and discrimination might manifest at the level of the individual, the community, or the entire society. Stigma against PLWE has the ability to victimize and have an impact on them. These actions are commonplace and widespread around the victim (Murugupillai et al., 2016). Additionally, stigma diminishes PLWE personalities and leads to labeling, stereotyping, and separation of attitudes and behaviors from those of the general population (Ks et al., 2011).

Epilepsy patients experience discrimination, seclusion, and cruel treatment; they are also stigmatized in society as angry and violent (Chew et al., 2017b). In addition, the author claimed that since CLWE are aggressive and violent, they endanger society and are not as capable as other individuals. In the past, CLWE has only been used in jails, mental hospitals, or leprosy colonies (Ks et al., 2011). As a result of their estrangement from society, the professor claims that it is a symbolic representation of the fact that CLWE are not regarded as normal individuals. They internalize their social perceptions as a result of this stigma. The stigma and discrimination connected to social meanings is typically what causes CLWE's social burdens (Arzimanoglou et al., 2014).

The occupational stigma of epilepsy may appear to have a significant effect on both CLWE and those linked with epilepsy, according to (Boles et al., 2020). Parents and coworkers believed that people with a connection to or affiliation with CLWE are also likely to experience comparable levels of rejection. This is in addition to the significant disadvantages that CLWE faces at school and at the workplace. The authors found that people who are not themselves a part of a stigmatized community would also have the chance to be exposed to the same forms of social rejection and discrimination experienced by others in the group, for instance by proximity or by having any kind of affiliation with members of the group (Pasca et al., 2020). According to statistics, psychiatric nurses are frequently stigmatized by their peers as being less professional, less logical, more reserved, and more reliant on other specialties than other nurses, probably as a result of their interactions with patients who have mental illnesses (Friedman et al., 2014). This is attributed to what is known as stigma by affiliation, also known as courtesy stigma (Shaw et al., 2021); In stigma through association, the mental images of perceivers of the stigmatized individuals and those who are closely connected to them have been associated through associative pathways (Dorris et al., 2017).

As noted in the study conducted by Dorris et al., (2017), PLWEs experienced social alienation and were subjected to discrimination because they were seen as vulnerable and risky. According to a staggering 83% of teachers in the Northwest Nigeria study, violence against students who have epilepsy is common (Olagunju et al., 2021). According to the authors, 60% of teachers agreed that students who have epilepsy should be taught separately from students who do not. The child with epilepsy was not allowed to attend the child's school, according to the same number of teachers.

2.4 ECONOMIC CHALLENGE

Most caregivers have difficulty when providing care for children with epilepsy is money issues. Due to medical expenses and their inability to secure or maintain employment, caregivers of children with epilepsy frequently face financial difficulties. (Vadivelan et al., 2020; Dogbe et al., 2019) As a result, caregivers find it challenging to find meaningful employment despite having to spend more money on their children's health care (WHO, 2011). Zuurmond,(2018) & Geiger, (2010) further noted that the majority of families with epilepsy children are low-income and have precarious financial circumstances. For instance, a study carried out in Accra revealed that parents of children with epilepsy are frequently burdened financially when attempting to meet their children's demands. The majority of caregivers were reportedly unable to afford medication and rehabilitation services since the NHIS did not cover these costs, according to a new Accra report (Dogbe et. al., 2019). Additionally, a study conducted in Malahapye, Botswana, found that caring for children with Epilepsy requires a lot of time, which prevents caregivers from working paid jobs. This has an impact on their ability to provide for the children's needs, particularly the purchase of diapers and nutritional supplements (Diseko, 2017). Parents in Zambia have also stated that they were unable to pay for the child's medical care due to financial constraints, including the expense of transportation to health centers (Singogo et. al., 2015). This could have the effect of making the child's disability worse.

These caregivers' top priority has been to solicit financial assistance (Diseko, 2017). The majority of caregivers have made connections between financial needs and the child's home, education, transportation, purchase of necessary assistive gadgets, and medical care (Nuri et. al., 2019). Caretakers of children with Epilepsy in Zambia have recognized a need for government financial assistance (Chiluba & Moyo, 2017). Similar to this, caregivers of children with Epilepsy in India pushed for an increase in disability funds because the amount provided for their care was insufficient (Vadivelan et. al., 2020).

Families that provide care for sick relatives have been referred to as "forgotten patients," and it has been argued that symptoms including mood swings, exhaustion, migraines, joint and muscle pains, marital and family strife, and financial difficulties may be signs of caregiver stress.

According to studies, those who care for people who have epilepsy have significant levels of stress, anxiety that the condition may result in harm or death, and worry about what will happen to the patients in the future when the caregiver is no longer able to provide for them. It has also been demonstrated that relatives of patients with epilepsy experience a greater burden of care than control groups, and that depression, patients' functioning outside of seizure management, and low income are all indicators of caregiver load. This high burden was linked to factors such as living in rural areas, having a large family, the severity of the patient's illness, and the caregiver's lack of education. We researched caregiver of epileptic children in our facility to determine their level of burden in caring for their patients because there is a dearth of literature on the load faced by caregivers looking after patients with epilepsy, particularly in the northern part of Ghana.

2.5 CAREGIVERS' CRISIS AND COPING STRATEGIES

The experience of caring for a kid with epilepsy is complex and depends on a variety of factors, including the child's health status, seizure frequency, and other factors. Parents of children with epilepsy worry about the quality of care, preserving the health of the child, and safeguarding their own and the family's overall wellness. Parents may experience changes in their lives, including financial strain, physical, psychological, and marital strain, to name a few, all of which interfere with managing daily activities and a functioning family (Rood et al., 2014).

Epilepsy has been characterized as a debilitating condition with a lot of misunderstandings, false information, stigma, and discrimination attached that affects the person with the condition, family members, close friends, and the community at large over time by many researchers. Mothers, in particular, are the ones who directly suffer the effects of the condition (Etemadifar et al., 2018).

To precisely determine the mothers' perspectives, the researchers could have used mothers from both lower and higher levels of formal health care. Additionally, it would have provided an accurate picture of the situation on the ground (Soleman et al., 2018). Nabi, Nasrabadi, and Navab (2017) conducted a related interpretative phenomenological study with 10 Iranian parents to better understand the lived experiences of parents of children with epilepsy, and they found that parents experienced verbal abuse and stigmatization from members of their community.

Benson et al. (2015) proposed that both parents and children with epilepsy experienced social exclusion, activity restriction, bullying, internalized negative feelings about epilepsy, concealment of the condition, and parental stigma-coaching in a study related to this one that used mixed methods (qualitative and cross-sectional survey). They came to the conclusion that these experiences continue to be a significant challenge for families who are dealing with childhood epilepsy and have a big impact on how the families even talk about the condition. It was noted that the gender bias in this study was due to the researchers' preference for using one parent over the other. They did not say whether the study included more fathers or mothers. However, using both genders would have made the study's conclusions more pertinent. Additionally, it would have presented the full picture of the phenomenon under investigation.

The majority of participants in a related phenomenological study Olagunju et al., (2021) conducted among 19 participants in South-Eastern Nigeria to elicit the lived experiences of people who had experienced the burden of social exclusion while they lived and cared for patients with epilepsy expressed fear of having family and friends avoid them out of prejudice.

Due to the lack of support, disparaging remarks, and widespread misconception that epilepsy is contagious, many people felt dissatisfied. They added that the social perception of PLWE has a significant impact on both family members and those who suffer from it. In addition, 12 of the 19 participants in the study were mothers, thus the results may not have been a real depiction of what was actually taking place. This is due to the lack of accurately represented additional family members, or better yet, fathers.

As a result, the researchers came to the conclusion that mothers faced significant stigma and prejudice due to their child's condition as well as their link with epilepsy. The participants in this study had higher levels of education and were more likely to be married. This demonstrated that unmarried, uneducated mothers would certainly face greater stigma and discrimination, which the researchers may have also investigated. The researchers discovered that both the person with epilepsy and cohabiting relatives have a perception of stigma which was associated with worse quality of life in the person with epilepsy in an interrelated quantitative study conducted by Labbé et al., (2002) on 148 consecutive persons with epilepsy and 45 cohabiting relatives. Only 9 of the 45 cohabiting relatives were found to be fathers, whereas 36 were moms. This demonstrated that due of the extreme gender gap, the findings might not be representative of the problem.

According to a study done by Chesi et al., in (2021), caregivers spent a lot of time with patients, which contributed to a high illness burden. They came to the conclusion that the burden has an impact on caregivers' physical health as well as their psychological wellbeing even more. The caregiver load was said to be understudied by the researchers, which has been the case. Parents and other caregivers, in particular, face physical, social, dependency, emotional, and developmental costs, according to a study of a similar nature by Pasca et al., (2020).

Furthermore, this researcher did not investigate how caregivers dealt with these pressures. However, Sister Callista Roy's adaption model served as the study's foundation.

In a subsequent study by Cooper et al., (2020), it was concluded that parenting children with recurrent epilepsy and parents of children with epilepsy resulted in significantly higher levels of parental stress. They therefore came to the conclusion that the stress levels of parents of children with epilepsy are higher. The stress associated with raising children who have epilepsy was further increased by this study. Conway, (2016) found that moms of children with intractable epilepsy experienced considerably high levels of stress, were socially isolated, had role limits, and suffered from poor health. They concluded by stating that despite having an emotional connection to their children, two thirds of the moms had high levels of stress. The parental responsibilities of 42% of moms limited their freedom and capacity to preserve their own identities. They also discovered that 42% of women felt overworked, socially separated from friends and family, lacking in emotional support, and receiving inadequate caregiving help. They came to the conclusion that while the majority of mothers in the research were doing okay, about a third were not. There was clear caregiver burnout, and caregivers were overworked. Despite the fact that the researchers suggested that some interventions would involve talking to parents indirectly, addressing isolation, and similar things, they made no mention of the fact that these interventions were actually carried out.

Researchers Nuhu et al. (2010) found that changes in household routine, family or social relationships, work, leisure, and physical health occurred for 231 primary caregivers in Nigeria. They claimed that family were also in trouble. The study was cross-sectional, although it was only carried out at one location there. Despite this, the researchers stated that it was done to ensure that the stress placed on caregivers by looking after family members who have epilepsy and no other diseases was minimized.

According to the aforementioned academic studies on the stigmatization and discrimination of parents or caregivers, parents were equally subject to stigma and discrimination from members of their communities or the wider public. The dread and discomfort that stigmatization and prejudice cause parents and caregivers to experience badly impacts them in every part of their life. Therefore, it was crucial that parents receive all the necessary support and not be stigmatized, undervalued, or discriminated against because doing so would only make their already difficult condition worse and would not help them cope (Radhakrishnan et al., 2018).

2.5.1 CARING PATIENTLY AND ENDURING SUFFERING

Patients with epilepsy are subject to a wide range of particular psycho-social effects, some of which may even be more harmful than the medical problems they face (Piazzini et al. 2016). This makes it crucial to take into account the varied coping mechanisms used by CLWE as they cope with this neurological illness throughout their lives. Having patience and enduring the suffering are the two coping mechanisms that Piazzini et al., (2007) divided the coping mechanisms into. Patience according to Piazzini et al. (2007), is the propensity to examine and reassemble the problem's essential components in order to determine the most effective course of action. Patience is essentially a proactive method of addressing the issue and trying to address its impacts. Suffering and endurance are characterized by an outright rejection of problems, a denial of their existence, or a downplaying of their importance. However, they are passive attitude that seeks to avoid acknowledging the truth of the illness and its implications. It is highly likely that caregivers of CLWE who use denial will refuse to think about the situation and so completely erase it from consciousness.

CHAPTER THREE

METHODOLOGY

3.0 INTRODUCTION

The methodology is concerned with how the researcher goes about learning information about the outside world that could aid in achieving the study's goals and research questions (Turan et al., 2021). An explanation of the study's methodology was provided in this chapter. There were descriptions of the research paradigm, design, setting, target population, sampling size, and sampling technique. Tools for gathering data, testing the interview guide beforehand, procedures, data management, analysis, methodological rigor, and ethical issues were all covered.

3.1 RESEARCH SETTING

The Tamale Metropolis in Ghana's Northern Region served as the study's site. The Metropolis has an estimated overall land area of 646,90180 square kilometers (GSS-2010). With 233,252 residents, or 9.4% of the region's total, it has borders with Sagnarigu Municipal to the west and north, Mion District to the east, East Gonja to the south, and Central Gonja to the south-west. Males make up 49.7% of the population, while females make up 50.3%.

Within the Northern Region, the Tamale municipality has the highest population density of 480.77/Km2 according to the 2010 population and housing census (Al-Hassan, Yahaya & Konlaa., 2010). (Fuseini, Yaro & Yiran, 2017). The Metropolis contains sixteen (16) other smaller healthcare facilities in addition to five (5) larger hospitals such the Tamale Teaching Hospital, Tamale West, Tamale Central, Seventh Day Adventists (SDA) Hospital, and the Kabsad Hospital.

Basic through tertiary educational facilities, including both private and public schools, are present throughout the city. There are roughly nineteen (19) secondary cycle institutions there, both public and private. among others, Tamale Technical University and the University for Development Studies.

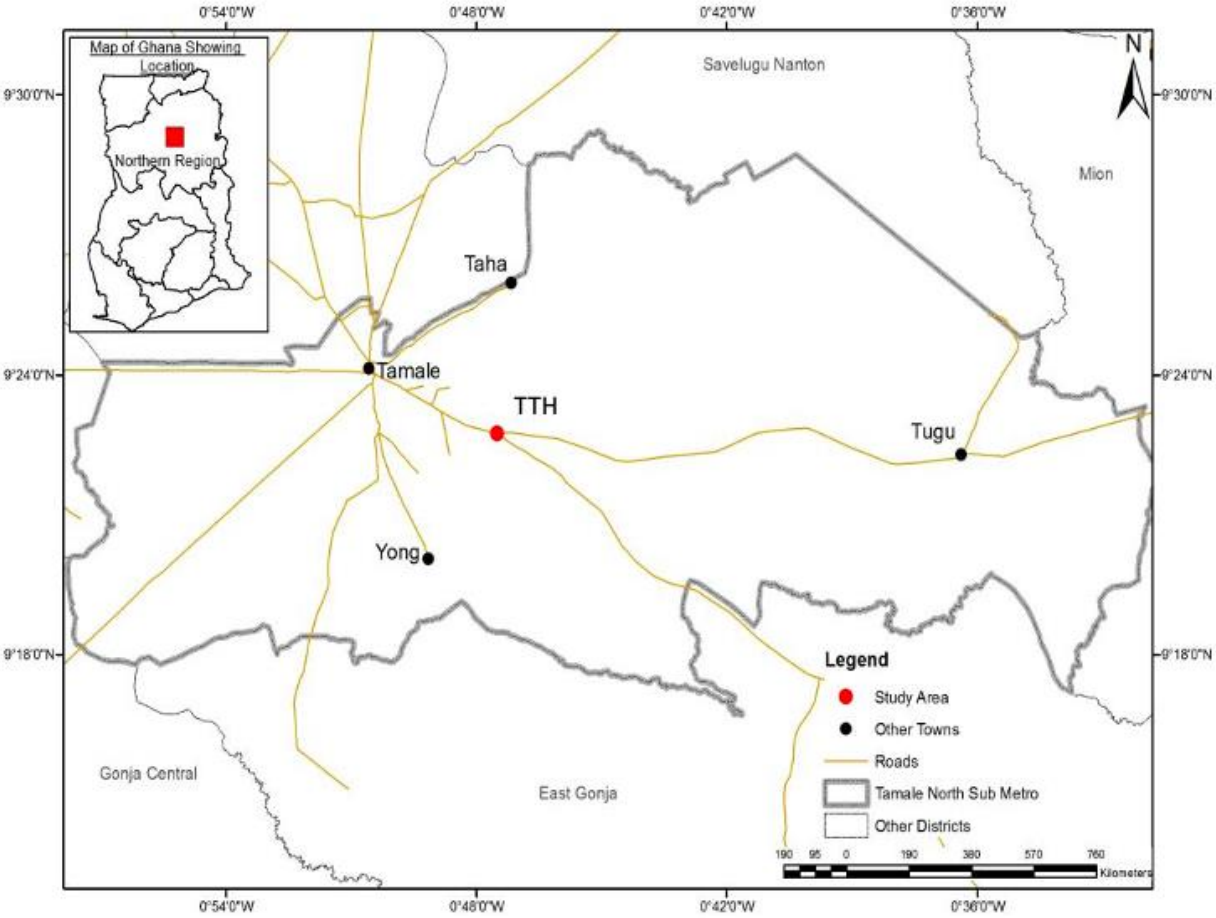

Image Source: Ghana Statistical Service,2010

Figure 3. 1 Map of Tamale Metropolis

The Metropolis only experiences one rainy season per year, which has a negative impact on the region's ability to produce food efficiently. Seasonal differences in daily temperature can be found in the Metropolis. Compared to the dry season, which is marked by dry Harmattan winds from November to February and bright sunshine from March to May, the rainy season brings residents high humidity, light sunshine, and frequent thunderstorms (Ghana Statistical Service, 2018). The lack of adequate water bodies in the metropolis has a negative impact on the regular flow of water into homes there. Several seasonal streams that have water throughout the season but dry up during the season are the only natural water systems (Ghana Statistical Service, 2018). The majority of the population in the city are Dagombas, but it also has a variety of other ethnic groups, such as Dagaabas, Mamprusis, Frafra, Gonjas, Sissala, Akans, Ewes, and most of Ghana's tribes, as well as foreigners from other nations. Annual festivals, naming rituals, and marriage ceremonies are just a few of the deeply ingrained cultural practices present there. Damba, Begum (fire festival), and the two Muslim Eid festivals are a few of the holidays that are observed annually (Eid Fitr and Eid Adha). Muslims are the majority religion in the city, followed by Christians, Spiritualists, and Traditionalists (Hilson et al., 2013). The majority of the population works in service and sales, crafts, and associated trades. There are employed professionals in the forestry, fishing, and agriculture industries.

The city has places for recreation, including athletic grounds and stadiums. Additionally, traditional or circle music is occasionally played in public spaces for amusement on weekends and holidays. The municipality contains all necessary facilities, including transportation, media for communication, and other social amenities.

3.2 RESEARCH DESIGN

This study utilized a phenomenological approach which is qualitative research that focuses on the commonality of a lived experience within a particular group. The fundamental goal of the approach was to arrive at a description of the nature of the particular phenomena. This approach has roots in philosophy, psychology, and education. It helped to attract the purest, untainted data and uses bracketing to document the personal experience with the subject to help remove the researcher from the process (Maxwell, 2013). This design was used to explore, understand and describe the experiences of caregivers of children living with epilepsy. The design helped to identify and assess all on-the-ground experiences, and challenges of caregivers with epileptic children in a patriotic manner, where the outcomes reflect actual sayings and inputs of participants in dealing with epilepsy among their wards. This method also helped to reveal changes in the thinking and perception of family caregivers of children with epilepsy.

3.3 POPULATION

The population for this study included all informal caregivers of children with epilepsy within the Tamale Municipal.

3.3.1 INCLUSION CRITERIA

Participants for the study were selected based on the criteria that, the person is;

a. A caregiver of a child with epilepsy ≤18 years of age

b. A caregiver who resides with and provides care for a child with epilepsy

c. A caregiver with a child clinically diagnosed with epilepsy by a medical professional

d. Caregivers who freely consent to participate and are ready to share /her caregiving experience

3.3.2 EXCLUSION CRITERIA

The following caregivers were excluded from the study: Caregivers who do not live in Tamale Metropolis and who do not stay with children living with epilepsy.

3.4 SAMPLE SIZE

Fifteen (15) people made up the study's sample size. By the fifteenth interviewee, the data was saturated since subsequent interviewees provided consistent answers; as a result, no fresh insights were produced. The most crucial guiding factor for assessing the suitability of data is the definition of saturation (Morse, Field, et al., 1995; Morse 2015).

3.5 SAMPLING METHOD

The purposive sampling technique, also referred to as judgmental, selective, or subjective sampling, was employed for this study and snowballing technique where information from the next participant is gotten from the previous one. In order to enable the researcher to reply to the study questions, purposive and snowball sampling was adopted. It aims to concentrate on specific population traits that are of interest. Using this method, the researcher was able to concentrate on her judgment and pick the epilepsy-affected child's caregivers who satisfied the inclusion criteria for this study. Again, this kind of sampling strategy proved to be the most effective because the purpose was to find significant informants and because the objective was to obtain the breadth and depth of the information, they have to offer rather than merely representativeness.

3.6 DATA COLLECTION INSTRUMENTS

Qualitative research uses structured, semi-structured, and unstructured formats of interviews (Rosenberg, 2017). For this study, an in-depth face-to-face interview using a semi-structured interview guide was used as a data collection tool. The guide to the interview was broken down into two main parts. Section A consists of demographic data for the participants and section B consists of the key questions using open-ended questions (Min et al., 2021). Section A was used to establish a cordial relationship with caregivers such as their age, residence, occupation, etc., and section B was used to collect details on the experiences of caregivers a with focus on their knowledge and understanding of epilepsy, challenges and coping strategies. The audiotape was used for recording interviews. A clinical psychologist was on standby to counsel. A third person was present to watch the gestures of participants during the interview to record some strong nodding of indifference or seeming inhibitions that may be demonstrated at any question.

3.7 DATA COLLECTION PROCEDURE

Each participant underwent a face-to-face, in-depth interview using a semi-structured interview guide. The opportunity to express their feelings, thoughts, and opinions in their own words was provided to the participants as a result. The open-ended questions in the interview guide were created based on the research questions, the study's goal, and the literature review. The researcher and the participant were able to communicate easily during the interview.

About forty (40) minutes were allocated for the interview. The participants gave their permission to use a tape recorder to capture the conversations. In-depth reporting was given after careful observation of non-verbal communication in the field. The interviewer was trained to probe further into the participants' responses using gestures of silence, neutrality, phase assertion, words of echo, directedness, and details.

The guide was read to individuals who could not read and interpreted out verbatim to ensure that he/she understood the aim of the study. Participants were issued a consent form requesting for them to append their signatures and those who couldn’t read appended their thumbprint before they could finally be considered in the study.

Lastly, there was a psychological advisor for caregivers who felt emotion-driven or caregivers who were going through extremely stressful situations owing to the conditionality of their wards but for free. To minimize the risk of infection amid Covid-19, safety measures for interviews were carried out. Consent was first sought from the participants and briefed on the purpose of the research study before the interviews were done. Confidentiality and anonymity were ensured throughout the data collection procedures by the researcher. The practice of social distancing was implemented throughout the study period. Handwashing facilities (portable veronica bucket) with a running pipe and soap were provided by the researcher for the participants and the researcher to wash their hands before interviews were held. Surgical facemasks were distributed to the participants by the researcher. Participants were encouraged to wear facemasks during the interviews. The interviews were conducted in a place of convenience for the research participants which was sometimes in the facility and various places like their workplaces and the home of the participant.

3.8 DATA ANALYSIS

A translator who was knowledgeable in the many languages used transcribed the survey data verbatim and then translated it into English. In order to organize and integrate narrative data in accordance with emergent themes and notions, latent content analysis was performed. The field notes and data were both subjected to the thematic content analysis suggested by Braun & Clarke (2006). The process of creating and organizing descriptive data in accordance with developing themes and concepts is known as content analysis. It entails identifying, classifying, and categorizing the main patterns that were discovered in the data. In order to be able to recognize the codes in the data, the researcher reviewed the transcripts numerous times and identified the primary themes based on the study's objectives. Using the key themes discovered, persistent words, phrases, and concepts were found in each response to each question, and they were used to code each response.

3.9 DATA MANAGEMENT

The goal of data management is to preserve data for usage as needed in the future (Bell, 2010). The research will advance as a result of this. The researcher manually controlled the data that came from the investigation. In the order that participants were recruited for the study, each one was given a code. On the laptop, the recorded interview was translated from Dagbani (the local dialect), Twi, and English to English in order to determine the participant's true meaning. To assure translation while keeping confidentiality, the researcher discussed the transcription with a speaker of Dagbani and Twi (the local dialect) and English. To verify accuracy and check translations, this was done. The translator was informed by the researcher of the requirement for confidentiality. False names were also used in place of the numbers. At the conclusion of each interview, a summary of the major points was used to confirm the participants' meanings for each participant. The interviews' printed transcripts were kept safe in a locked cabinet. The demographic information sheets, which contained personally sensitive information, were divided into Section B. Every interview was painstakingly typed using a variety of colored fonts and saved with a unique file name. To avoid data loss, the interviews were also recorded, saved, and kept on an external disk.

3.10 METHODOLOGICAL RIGOR

Trustworthiness or methodological rigor in qualitative research had to do with the accuracy and dependability of the study design. Shenton (2004) cites Lincoln and Guba in his book as saying that credibility, transferability, reliability, and confirmability can all help with this.

3.10.1 CREDIBILITY

One of the most crucial elements in determining reliability or rigor is credibility. By adopting a sound research methodology, becoming familiar with the research environment of participants before collecting the first data, purposefully selecting participants, using triangulation, and employing strategies to help ensure participant honesty, the researcher ensured credibility in the phenomenon under investigation. These include the use of iterative questioning, negative case analysis, frequent debriefing sessions, and peer review of the research (Maher et al., 2018).

The researcher developed and asked insightful questions while gathering data by using a strategy that had been well investigated. To find out if participants were telling deliberate lies, the researcher used iterative questioning. The researcher accomplished this by investigating and revisiting issues that participants had previously addressed. As the supervisors brought their experiences and acuities to bear, there were numerous debriefing meetings between the researcher and the supervisors to provide the researcher a wider perspective on the phenomenon. In the process of the study, this also exposed the researcher's shortcomings. The study was subjected to peer review, and once the researcher presented the results, colleagues were free to comment and raise concerns. The researcher was able to clarify and improve the research design as a result. One of the crucial elements that improved the study's trustworthiness was member checking. This was done by giving participants the opportunity to read the transcripts of the activities they took part in and determine whether their words corresponded to what they meant to say in the audio recordings. A thorough overview of the phenomenon under investigation was given, guaranteeing a thick description of it. The researcher accurately described the situation that was the subject of the investigation and the surroundings. In order to determine how closely the project's findings matched those of earlier studies, the researcher also looked at earlier research findings.

3.10.2 TRANSFERABILITY

The question of transferability focuses on how broadly the study's conclusions can be used in different contexts. The level of reader confidence in applying the research findings and conclusions offered, though, depends on the reader. By giving readers enough context about the settings, the researcher assured transferability and allowed them to apply the findings on their own. The researcher gave readers a detailed, detailed description of the phenomenon under study so they could better grasp it and compare the occurrences mentioned in the research account with those they had observed emerging in other circumstances. Additionally, the researcher made sure that readers could understand the study's findings in the context of that context (Maher et al., 2018).

3.10.3 DEPENDABILITY

This was addressed by detailing the process used for the investigation so that future researchers might duplicate the work and potentially obtain the same outcomes. This would therefore enable readers to evaluate how closely the researcher complied with best practices for doing research and gain a greater comprehension of the method employed and its efficacy. By describing the research strategy and how it was carried out, the specifics of how the data was acquired, and the philosophical assumptions made about the inquiry, the researcher further ensured dependability (Maher et al., 2018).

3.10.4 CONFIRMABILITY

Objectivity has to do with confirmability. The degree to which the researcher acknowledges their own biases is crucial to confirmability. The researcher made sure that the results accurately reflected the opinions and encounters of the participants rather than their own traits and preferences. In order to lessen researcher bias, the researcher additionally emphasized triangulation. The report acknowledged the beliefs that guided the researcher's choices and techniques. Again, a thorough explanation of the methodology was ensured to enable readers to assess the acceptability of the data and constructs that come from the study. Another strategy was to create an audit trail, which would enable the reader to follow each step of the investigation as it was made using the disclosed decisions and methods. The researcher's supervisors had access to the interview recordings, transcribed data, and field notes that served as an audit trail for an unbiased evaluation and validation of document information (Maher et al., 2018).

3.11 ETHICAL CONSIDERATION

The Kwame Nkrumah University of Science and Technology (KNUST) ethical review committee's (CHRPE/AP/073/22) approval was requested. Tamale Teaching Hospital's written permission was received in order to perform this investigation (TTH). In conducting this investigation, the study adhered to the rules set forth by various regulatory committees. All participants were asked for their written, informed permission (This included the recording and transcription of the interview process). Participants received guarantees of privacy and anonymity. During the interview and discussion process, the participants' privacy was guaranteed, and the information gathered was kept private. Nobody was coerced or forced to participate in the study. In other words, interviewers were given information about the research and the potential indirect advantages before being given the choice of whether or not to engage in the interview. Respondents were urged to participate freely and without any constraints. It was made clear to participants that there would be no incentives and that they might leave the study at any moment. They were also told that taking part in the study would have no or minimum negative effects on their physical and emotional health. Participants were made aware that the data would only be utilized for academic research and that it would never be used again without obtaining additional ethical approval. Additionally, they were informed that the study's findings would only be utilized to improve healthcare. Participants were asked for their approval because the interview process would be recorded verbally. They were also informed that typed information and consent forms would be securely stored for around 5 years, while audio recordings would be stored in a database and password-protected. The thumbprints of some participants and the addition of their signatures serve as confirmation that they are in favor of moving on. Participants also received instruction on Covid-19 prevention methods.

3.11.1 INFORMED CONSENT PROCESS

The study obtained participants' informed permission in accordance with the necessary protocol and ethical standards. The study and its purpose was explained to clients for understanding and that it was mainly for academic purpose and they could drop out at any point and there was risk for emotional breakdown but there was a psychologist to help them before they signs or thumbprint the consent form.

3.11.2 RIGHT TO FREEDOM

Even after agreeing to participate in the study and signing the consent form, participants were informed of their freedom to withdraw without repercussions. They were informed that declining to participate in the study would not have any impact on the level of care they received at the various community psychiatric units.

3.11.3 ANONYMITY, POSSIBLE RISK AND DISCOMFORT

Each participant received a code during recruitment, which was then used on all notes and transcripts, ensuring anonymity. Additionally, identities stated in the interview as well as later verbatim quotes from the participants were replaced with codes. Participants were given the assurance that their identities would not be connected to the data they provided without their consent. Participants who felt comfortable answering the questions and those who did not were directed to a psychologist who had been hired in case of any unforeseen circumstances.

3.11.4 CONFIDENTIALITY

Participants were informed that all data, consent forms, audio recordings, transcripts, and other documentation would be safely stored for a maximum of five years following the study. They were told that before using the data for any other reason in the future, ethical approval would be obtained. The data would be utilized for the purposes for which it was obtained, and only the researcher and her supervisor will have access to it, the participants were also told.

During the publishing of any portion of the study, the participants were given the assurance of anonymity. In addition to encouraging individuals to create self-help groups, the researcher plans to debrief participants on the findings.

3.12 LIMITATIONS OF THE STUDY

There is no intended bias in purposive sampling, despite the fact that it is commonly referred to as a judgmental sample. Purposive sampling, could occasionally be subjected to selection bias and inaccuracy because it doesn't always involve random sample and another limitation was lack of enough financial resources of the researcher but did not prevent the study from being carried out.

CHAPTER FOUR

4.0 PRESENTATION OF RESULTS

4.1 INTRODUCTION

This chapter presents the results of the data developed from participants' experiences with Children Living with Epilepsy. The themes that emerged are knowledge, beliefs, understanding, Healthcare burdens, Social burdens, the burden of care, and economic burdens. The subthemes are epilepsy as a medical condition, epilepsy as a curable disease, epilepsy as a spiritual disease, epilepsy as a contagious disease, period of diagnosis, caregivers' attitude after child diagnosis, HealthCare Challenges, stigma, interruption in education, uncertainty about child's future, inadequate support from others, increased financial burden, interrupted income, caring patiently, enduring sufferings. The main themes were described along with the subthemes. A background description of participants was also included in this chapter.

4.2 DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

Fifteen (15) participants were interviewed in this study, out of which nine (60%) were females and six (40%) were males. Their ages ranged from 25 to 70 with an average age of 45 years. The ages of participants' children/adolescents ranged from 3 to 18 years with an average age of 12. Four (26.6%) of the children were between 2 to 5 years old, three (20%) were between 5 to 10 years, another four (26.6%) were between 11 to 15 years old and the remaining four (26.6%) were 16 to

18 years old. Ironically, five (33.3%) of these children were firstborn, and five (33.3) were second born whiles the rest were third, fourth, and sixth born respectively.

Table 4. 1 SOCIO-DEMOGRAPHIC DETAILS OF CAREGIVER

VARIABLES	FREQUENCY	PERCENTAGE
SEX		
Male	6	40%
Female	9	60%
AGES		
20-30	3	20%
31-40	6	40%
41-50	5	33.3
OVER 50+	1	6.6%
EDUCATION		
Tertiary	8	53%
SHS	4	26%
JHS	2	13%
Not Schooled	1	7%
RELIGION		
Christianity	5	33%
Islam	9	60%

others	1	7%
OCCUPATION		
Government employed	4	27%
Self-Employed (Private)	11	73%
MARITAL STATUS		
Single	1	7%
Married	11	73%
Divorced	2	13%
Widowed	1	7%
AGE OF CHILD WITH EPILEPSY		
2-5	4	27%
5-10	3	20%
11-15	4	27%
16-18	4	27%

The ages of caregivers range from 25 to 70 years. Three of the participants representing 20% were between the ages of 20 and 30 years. Six (40%) fell between the ages of 31-40 years. Eight (8) people representing 53 per cent reported that they had completed tertiary while four per cent completed senior high school (SHS) while two completed junior high school.

The data collected saw five (5) representing 33 per cent of people reporting that they are Christians. Islam had a representation of nine (9) representing 60 per cent of the participants, Eleven of the participants are self-employed while the remaining four (4) representing 27 percent works for the government of Ghana.

4.3 THE CAREGIVER'S EXPERIENCES

Caregivers' descriptions of their experiences were organized into categories and subcategories based on the study's aims and research questions. As a result of the insights provided by participants, the experiences of caregivers of children living with epilepsy have been grouped as shown in the summary below (table 4.2)

Table 4. 2 SUMMARY OF FINDINGS

OBJECTIVES	THEMES	SUB-CATEGORIES
	1. Knowledge	▪ Period of Diagnosis ▪ Epilepsy as a medical condition ▪ Epilepsy is a Curable Disease

OBJECTIVES	THEMES	SUB-CATEGORIES
Caregiver's Knowledge, Beliefs and Understanding of Epilepsy	2. Beliefs	▪ Epilepsy as a spiritual disease ▪ Epilepsy as a contagious disease
Challenges Among Caregivers of Epileptic Children	1. Healthcare Burdens	• Difficulty Accessing Health care
	2. Societal issues	▪ Stigma ▪ Interruption in education ▪ Uncertainty about child's future
	3. The burden of care	• Inadequate support from others
	4. Economic Burdens	▪ Increased Financial burden ▪ Interrupted income
Coping Strategies Used by Caregivers to Overcome These Challenges.	1. Patience on what happened	• Caring patiently" • Enduring sufferings

4.3.1 CAREGIVER'S KNOWLEDGE AND BELIEFS ABOUT EPILEPSY

It was evident from the study that epilepsy was perceived differently by the caregivers. From the findings, caregivers got to know about the condition after several ill health of their patients. Knowledge, belief and understanding of this condition got expressed in different sub-themes: On knowledge and understanding, the subthemes are epilepsy as a medical condition, epilepsy as a curable disease, period of diagnosis and caregivers' attitude after diagnosis. While (a)epilepsy as a spiritual disease and (b) epilepsy as a contagious disease emerged as a subtheme for belief. They are;

Theme 1. Knowledge and understanding of epilepsy

This theme describes the preconceived knowledge of the participant. Some participants gave vivid descriptions and explained what they knew about epilepsy.

Understanding about epilepsy

On the understanding of epilepsy, the caregiver's narration clearly indicated that, they had a deeper understanding through the incidences leading to diagnosis, the diagnostic processes and aftermath issues of diagnosis. This was captured under the following sub-theme: (a) Period of Diagnosis

Period of diagnosis

All the respondents could recall the ages at which their wards were diagnosed with the condition. They could also recall their initial reactions and their lack to little understanding of the condition. A good number of them were not aware of the condition from the beginning since they had not witnessed such a condition with their wards before. However, things have improved according to them. Caregivers have embraced the situation and have learned to accept and understand the condition better. Parents underlined that the children were healthy before the sickness started, except for a handful who had delayed developmental milestones (Strzelczyk et al. 2019). This according to most of them has helped them to give better care to their ailing child. Respondents P6 had this to say:

> *"He was getting sick with high fever months after he was born. I normally bathe him with cold water to get the fever down. In the next moment, he will be playing and the fever comes again during the evenings…. He Snores a lot when he is sleeping. I took him to the hospital and complain about the signs I have seen. He is normally afraid and sometimes shouts so loud. Initially, I was worried. I could recall getting confused about what to do but I think right now, medical care underway, things are improving, and I'm getting to understand the condition. I have read extensively about it and I know how to help him better even as a health professional handle him." … (P6).*

Another caregiver made mentioned that, for some time, she thought the daughter was suffering a spiritual attack until it got confirmed. She had this to say:

> *…, I thought my child was suffering from some spiritual attack until it was confirmed that, he is suffering from Epilepsy. I was worried but if not for a doctor who made me understand the*

> *condition. Aside from the doctors and the nurse here, I think my child now enjoys good care at home….(P4)*

However, one of the participants said, the child's condition started years ago, and this is what he said:

> *"She was eleven years when one evening she fell on the ground. We didn't know what was happening to her. We took her to a clinic nearby where she was given some anti-malaria medications. She was not sick; nothing was wrong with her. So, three days later the seizure occurred again and even occurred in school. And this continued subsequently for three times" we tried seeking help. … I thought, the gods were after her. I consulted pastors and mallams. Her condition did not improve. It became even worse. Right now, she is better though the conditions occur occasionally, I do understand that one day my daughter would be fine Inshallah … (P7).*

Another caretaker also confirmed that the child was attacked multiple times and was taken to the hospital. At the hospital, no test was done and so the doctor prescribed rest and some painkillers. This caretaker also confirmed that she now has a better clue as to what the condition is and how she could help serve the child's special needs.

> *… he was taken to a health facility where he was given painkillers and the doctor advised him to get enough sleep.*

> *Months later, we went back to the regional hospital with the same complaints and this time, the child had a seizure right at the hospital, confirming the condition. I became scared and didn't know what to do since my first child was also discharged a few days before this case. I became frustrated. Am calm now because I do know the support to give this child …. (P9)*

Epilepsy as a medical condition

Two of the participants clearly understood the condition of epilepsy to be a medical condition. They narrated their experience about their knowledge of a condition that can be cured medically. A study in south Africa showed about 43.7% of caregivers had medical knowledge about epilepsy (Musekwa, O.P et al., 2023). Participant 3, a nurse had this to say:

> *Recurrent seizures are a neurological disease known as epilepsy. A seizure is commonly defined as a transient disruption in the electrical activity of the brain that results in an abrupt change in behavior.*

When asked what she knows about epilepsy, participant 6, said:

> *… I heard it is a long-term illness caused by a malfunction in some part of the brain. One would need surgery to be well.*

Epilepsy is a Curable Disease

Another belief among caretakers was that the illness might be cured. Most caregivers sought advice from spiritual leaders and conventional healers as a kind of sickness treatment. A research in South Africa highlights unsatisfactory knowledge and practices towards epilepsy and emphasizes the need for increased education and awareness among caregivers and family members (Musekwa, O. P et al., 2023). When asked about receiving treatment from a traditional healer, a caregiver stated:

> *Yes, since the onset of this illness, we have sought treatment from numerous traditional herbalists, but all of our efforts have been in vain. To find healing, we go to a multitude of individuals and locations. We were in Navrongo, Wa, and Bolga. Without receiving a remedy from them, we simply squandered our money on them (P10).*

For a caregiver, the spiritual church was an option for regaining wholeness:

> *My mother took us to a preacher when we were in the hamlet, who informed us that epilepsy was a spiritual illness that could be cured. We were content and eager to find a solution. ... The priest revealed to us the person who, in my opinion, was responsible for the child's illness. After that, he instructed us to place coins on the child's bed each night, sleep on them, wake up, and distribute the monies*

> *to others, which I did. The child's seizures stopped occurring, but they returned a few months later. (P9)*

Theme 2: Beliefs about epilepsy

Because epilepsy is frequently viewed as a shameful illness in the eyes of the general population, people with epilepsy are stigmatized and discriminated against in Africa in terms of education, work, and marriage. Epilepsy is also commonly thought of as an ancestor spirit curse or as a result of being possessed by demonic spirits. It is also frequently believed to be extremely contagious and is attributed to "poisoning" and witchcraft.

Epilepsy as a spiritual disease

Some caregivers believed that epilepsy was a spiritual ailment brought on by family, neighbors, and the community as retribution for sins and is supported by Işler, Turan, and Gözüm (2014), who discovered that parents turned to prayer, holding their sobbing kids in their arms, and expressing affection as supplementary or alternative coping techniques to deal with their worries. For instance, a caregiver who had conflict with the extended family described epilepsy as follows:

> *I believe that my grandfather gave the boy this terrible illness in order to prevent him from growing up to be the outstanding member of my*

> *family that he was destined to be. Everyone claims that my boy received this illness spiritually from my extended family. My grandfather, a traditional herbalist (healer), once requested that I bring him to be treated, but I declined. His plea did not surprise me. I understood he was in charge. If I had taken the boy with me to see him, he would have made things worse by causing additional seizures. (P5)*

Another participant recounted how some residents of the neighborhood spiritually infected her child with the illness:

> *I believe that my daughter has a spiritual illness that some members of this society have given her in order to keep her from achieving success in life. They may be envious of my family's positive reputation. Do I appear to be someone who has epilepsy, look at me? Do my family members resemble an epileptic family when you look at them? No! I'm not. They chose to give her this dreadful illness, which has no cure till the day of your death, because they recognized how beautiful our future was (P6)*

A participant explained the atonement of sins as follows:

> *In all honesty, I believe she is being used to atone for any transgressions our royal family may have committed. Dad worked as a chief. I also believe that she is atoning for my grandmother's crimes, who, according to what my mother told me, refused to thank the gods when they granted her a child at her request. I believe the youngster should not have been the target of the gods' wrath. (P1)*

A caretaker also believed that the condition was caused by a spiritual force, which is why, despite the use of pharmaceuticals, it had not been cured for so long: this caregiver described her experience in this way;

> *I believe it to be a spiritual illness. If so, I fail to comprehend why the condition has not yet been treated despite early consultations with spiritual leaders and traditional healers, as well as the years spent using pharmaceuticals. I have no doubt that this illness is caused by a spiritual force, and that only God can provide relief (P2).*

Another participant stated that the problem affected their mother, who had the following to say about it.

> *My mother was affected by it because, as you may know, they always place an emphasis on spirituality. Someone would approach her and suggest taking her to a spiritual herbalist, and when that didn't work, she would return. It was concerning since the woman was getting thinner*

> *and, to some extent, thinking about the illness caused her to have high blood pressure. I had to decide to take her and bring her here so that my mother could also rest. (P3).*

Epilepsy as a Contagious Disease

Some caregivers disclosed that the public believed epilepsy to be contagious and that one may contract it by interacting with a patient. People still believe epilepsy is incurable and contagious (WHO,2023). They held the view that a diseased person's fart or contact with it can spread the disease to a healthy person. For instance, a caregiver described how a patient was helped in the following ways:

> *No one in his vicinity ever wants to assist him while he is under attack. They do not want to go close since they believe it to be contagious. They claim that if they get in contact with his saliva while he is having a seizure and contract the illness (P10).*

Interesting enough, some family members believed that epilepsy was contagious:

> *Hmm, my sisters, with whom we reside, also think the illness is contagious. They wouldn't want to be around the kid. They wouldn't provide her with the assistance she needs to live a life of quality. (P5).*

A participant indicated that community members viewed epilepsy to be infectious:

> *When I ask him to offer the clients sachet water when I'm busy, they refuse to do so and demand that I do it instead. Some people occasionally won't let him play or touch their kids. Some individuals merely do not want him to approach them. Because of the widespread belief that epilepsy is contagious, all of these things are occurring (P1).*

Another participant said,

> *They believe that when the person gets close to her and the person flatulates on you then you also contract the sickness. As a result, they don't want to go closer to her. (P3).*

4.3.2 CHALLENGES CAREGIVERS GO THROUGH

The study also explored the caregiving challenges faced by informal caregivers of children with Epilepsy. Three main categories of challenges emerged from the synthesis of the data gathered. These included social challenges, strenuous daily care, and economic challenges. The sub-categories constituting these challenges and their supporting verbatim quotes are presented next.

Theme 1: Healthcare challenge

Health care challenges talk about the daily challenges caregivers of children living with epilepsy encounter as they go about seeking to care for their children.

Difficulty Accessing Healthcare

Most of the caregivers interviewed shared tears as they narrated their experience with health care as far as their child's condition is condition. Almost all the women had a thing to say about the condition of the hospital, the attitudes of health workers and health care finances (WHO,2023). A participant who has been trolling within the hospital's environment for years had this to say about the child's conations about health care:

> *(With tears all over) I don't know what wrong I have done to deserve this treatment from the doctors and the nurses. They do not seem to care about my child's condition little bit. It is difficult to get the attention of a nurse or a doctor to talk about the child's condition. No one wants to help. I have been here for months and the condition doesn't seem to improve…(P2)*

A participant who was angry with the health system said she wish the doctors and the nurses would give the same attention they give other conditions to the epileptic condition as they have little respect for the case.

> *My sister, let me tell you. It is as if the doctors do not respect children with epilepsy. You need to see what we go through here. The nurses talk to us anyhow as if we called for what the child is suffering. A nurse told me to take my child home for treatment if I think they are not doing enough to help. That saddens me a lot to look at the love I have for my child.*

> *I think that more can be done to help us as caregivers to make things easy for the child…(P5)*

The narration was however different for a midwife, who works in the hospital and has her child undergoing treatment at the same centre. According to her, care was okay and, management has provided the resources needed to expedite the management of cases of this nature. She was again fast to say that, her child has seen a massive improvement since he was brought to the facility for care. She had this to say:

> *I heard the other women complain about the care they receive at the hospital… things are different. I don't have any challenges accessing the nurses and the doctors. We have enjoyed good services ever since we reported here. The only challenge I have is the cost of the medications since health insurance doesn't cover most of their medication. Aside from that, I have no major challenge.*

While accessing health care at hospitals, some caregivers felt that they were not being provided with adequate information regarding the condition and care needs of their children. This left most caregivers wondering exactly what was wrong with their child and whether she/he will get better. A participant poured out her heart this way:

> *The first day that we came to the hospital, they (doctors) told us the child was sick but they didn't tell us exactly what*

> *was wrong. They didn't say what happened, they only said we should come to this place. They asked me questions some time ago about the child's condition which they wrote down but I have not been given any information regarding his condition since then… (P9).*

Some caregivers who could read had to resort to the internet to learn about their children's condition themselves because they had less information from the health care providers.

> *At first, I didn't know what was wrong with him, because the doctors will not give me more information about this condition. So I was following people to get local treatment for him. I roamed a lot to the extent somebody will tell you to buy a dog, buy a white fowl, a red fowl, and get this… 'hmm'… sister. Now I'm beginning to understand because I just browse and read about it…(P14)*
>
> *Sometimes you just go and the doctor will not have time for you, they will not sit you down to tell you the problem, I don't know whether it is because I go there in suit…You just go and they will just write without communicating and they will just tell you that since you are educated, go and read. Is that how it's done? I have been inquisitive about this condition, so I do a lot of reading about it myself… (P15)*

Theme 2. Social issues

Social challenges describe the relationships and difficulties encountered by caregivers as they interact with others in their society and other formal institutions. Some of the challenges narrated by caregivers centred around stigma and education.

Mockery and stigmatization

Because of the cruel comments from others, having a child with epilepsy was associated with shame, humiliation, and stigma, according to caregivers and their families. Some parents complained that their children were described by neighbours and friends as being crazy, and numerous comments on whether the child was human or not. Hartley et al., (2021) revealed rejection from the woman's neighborhood and family was common for both mother and child.Friends and others persuaded parents to kill or abandon their children since they were considered spirits rather than humans, as illustrated in the following illustrations:

> *My daughter complains about her mates in school making fun of her with her condition. Some parents don't want their children to play with her or eat with her. There is a certain boy in my daughter's school who use to tease her about her condition and sometimes sing to tease her about the condition. "Now some of her friends cannot come closer to her. I think that going forward, there should be some form of massive education to encourage these kids to socialize with the affected children… This is the time we need the support and the assurance of the general populace the most…*

Also, P4 had this to say;

> *"The condition of my son has affected my relationship with family and other people. People I don't expect even talk/gossip about my son's condition. Family members mock us and say a lot of things about us. Now, my son can no longer play with the children in my*

> *neighborhood because they have heard about his condition and are avoiding him. Most people feel that the condition is contagious. I doubt if it is true... we need to let people know of this the most. It is very important to their psychosocial well-being.".*

Likewise, P12 has even moved to the outskirt of the town to avoid stigmatization. She also got avoided by her church members. The people that are socially responsible for the welfare of their members like the church have also abandoned her to her faith

> *"Because of my daughter's condition, I cannot go into public places and my daughter cannot also mingle with others even at school because we are all afraid that she might get a seizure. My family members do not get closer to us; we have been fighting the condition alone. Church members also, I have not gotten any support from them. We have decided to stay outskirt of the town so that we will not face any stigmatization. I have no friend because of my child's conditions"*

Two of the participants also revealed their feeling about their ward's condition as indicated below:

> *"My son can't mingle and play with other kids. But the condition has not affected my relationship with family, friends and my church members. They all come around to encourage and pray for us" (P13)*

Again,

> *"To be honest with you my son's condition has not affected the relationship with friends, family and the community in which we leave. They are all free with us and he can go out and play with other children". (P11).*

Interruption in Education

The study's findings revealed that the education and future prospects of the children posed a significant obstacle. Participants admitted that they faced certain difficulties with regard to their kids' education. People with epilepsy experience reduced access to educational opportunities (WHO,2023)

Some participants said that when school officials discovered the children had the disease, others refused to let them enroll, some indicated they couldn't have such children in their schools, and others expelled the kids. Many participants brought out the children's poor recall and their inability to grasp as a result of the disease. A participant said that the school administration had told the child to stay at home until the issue was resolved since they were unable to handle the child's circumstances. He described:

> *"Since the attack also occurs at schools, the authorities have informed us that they are unable to handle the problem at hand. We were instructed to get her medical care by them.*

> *She can continue with her studies once she feels better. I said that she should stay at home because I lack the funds to continue her treatment. Because of the condition of the infant, this has made me feel even more guilty and rejected. (P9)*

Several times, according to another parent, the child's admission was denied due to the ailment. She said:

> *"I couldn't afford his tuition, so I changed his school, but no matter where I sent him, they wouldn't take him because of the disease. They just don't accept him, especially when I suggest that the child might be suffering from a condition like that. I visited four distinct schools. A nurse made the choice to assist us. To find a school where she could enroll him, she traveled to various locations. This has gotten really awful. I wish my son's experience hadn't occurred. (P4)*

She said, clapping her fists,

> *"They just don't accept him. I walked around schools, and one let him in without knowing about his condition. He suffered the attack one day after school had ended, three weeks after they had taken the boy in. The school's*

> *proprietor contacted me and informed me that he was unable to accept the youngster because of his condition. He claimed he was incapable of caring for or handling such a youngster. I asked the owner, but he said no and returned all of my money, including the admittance costs. (P6)*

According to one of the participants, the disease has caused the child's academic performance to decline.

> *The manner she used to learn has changed, he observed. She currently has a very poor capacity for learning. She has also been psychologically impacted by the disease. She can't grasp anything because of the assault. Her academic performance has been extremely poor—very, very, very poor. Her memory has also gotten worse. That is what slightly irritates me. (P8)*

Participants' perspectives on the kids' education ranged widely. Most interviewees said that the sickness had impaired the children's memory, causing them to be unable to understand anything at school. Some participants had their children boycotted at school. However, several of the kids were absent from class due to illness. The future for the kids was dubious because the instruction was moderated. One of the participants narrated how embarrassed she felt when the child told her about the impact of his condition on his educational ambitions, as the majority of them had their children in school. The participants had these to say:

> *" I was one day embarrassed when my child returned from school to tell me that because of his condition, his teachers did not allow him to stand for the position of a school prefect in his school. Sometimes I feel like taking him out of that school but I have no other option" …(P12).*

A man had this to say:

> *"He was in one school but sometimes the seizure will occur and I will be called. So I change his school to a private one where they can take good care of him. He is not allowed to mingle with other people during break time because we are all afraid that the seizure will occur again. The teachers in the new school are very supportive, unlike the other school where he was mishandled." (P7)*

Again, (P13) spent much time taking care of the sick child. she posited that:

> *"I spend most of my time taking care of him to the extent of stopping my business to go and sell in the school where my son attends. He is in school and once I am around, I can handle the situation where the need arises".*

One of the respondents had support from teachers of the school and this is what he said:

> *"I have made effort to put her in school. I have made her teachers aware of her condition and they are supporting her" (P2).*

The conditions however compelled parents to stop their wards from school. The case of Participant five, who is a trader and mother confirm this assertion, as she indicated that:

> *"The condition made her stop her education in class three (3) since the seizure had been occurring in the school. It has also affected my education since I am taking care of her. I couldn't continue my education after SHS"*

UNCERTAINTY ABOUT CHILD'S FUTURE

Participants were unable to predict the future for their wards due to the situation they are currently dealing with. Nearly everyone is baffled by what the kids might grow up to be. Some participants expressed their doubt that their kids will ever be able to learn a trade. Some participants said they had no idea what to say, while others claimed that the child's education was muddled. One of the participants said she didn't think the kid would amount to much in the future. In the Tamale Teaching Hospital a few weeks ago, she told this me.

> *The child won't grow up to become anything, and I don't see him having any future. I don't even imagine him being able to master a trade or do anything significant. His future hence does not appear promising. Unless God steps in... (P12)*

Another participant said

Since she has a condition, she has had to stop going to school, but she is learning hairdressing, and she is doing well. (P4)

Another participant said that because the child was not in school, he was unable to forecast his future. He described:

> *"Her education is now hazy; therefore I can't currently anticipate her future." Since education is the secret to success, I feel quite uneasy. I, therefore, don't feel at ease. Even though there are times when I wish it had never occurred, life continues.*

One parent said she had given the child's future considerable thought and was unsure of whether the child was capable of working. She said the following.

> *"As for his future, I give it a lot of thought... I give it a lot of thought because I don't even believe he can pick up a trade. I'm curious to see how he will work if he can even learn a trade. Well, I really can't predict what his future will be like. (P2)*

One participant admitted that he spent a lot of time thinking about how the child's life might be in the future because it bothered him. His words were:

> *"I worry about his health when I consider it. I continue to consider his future. I don't know what would happen to him after I'm no longer here to show him the affection he is experiencing right now. This has upset me a lot because it was not what I expected. His situation has made me consider more things, particularly his future and how he was going to fare. You see, I consider his future as well as other things. To avoid discussing the emotional impact, demanded a lot of my time and attention. (P5)*

All of the participants expressed concern for the future and hoped that the illness would end so that the kids could have something to aspire to in the future. They all claimed to have given the children's future a lot of thought. Some participants expressed the expectation of supernatural intervention. A participant expressed concern about the condition and how the youngster might fare in the future. There were implications for the children's seizure frequency.

Theme 3: The burden of Care

Physical care burden describes the challenges with providing daily physical routine care for children as well as the difficulties caregivers encounter in getting support from others to render care to their children.

Inadequate support

Some caregivers stated that they were responsible for the child's care at home on their own, with little or no help from family members or outsiders. Some of the participants in this study reported anxiety about not receiving appropriate physical care, as well as financial and psychological assistance from their families and community. Caregivers were concerned that if they were not present, their children would be abandoned and neglected.

> *It is not easy to get someone to provide care for him especially when I am not feeling so well, I must still manage and care for him because, the way he is, who will have time to take care of him? …(P10). After his father accompanied us to the hospital in February, he doesn't come here or even support us with money. This shows that if I were not around, the child would have gone through a lot of suffering… (P12).*
>
> *I don't have anyone to support me, like money for his food, drugs, and even coming here (physio unit). His father like this is not taking care of him. When I was pregnant, my father called and informed him about the pregnancy, he told my father that the pregnancy is not for him. So from that day up to now, his father has never asked me to talk to the child (P11)*

Some female parents narrated that their partners were not supportive at home. This burdened them with a load to the extent that they never wished to give birth again. A caregiver shared tears while narrating her ordeal of caring for the child:

> *With this one my husband is not helping me take care of him, do you think it will cross my mind to give birth again?*

Some caregivers also felt that they were not being understood and supported by their employers and co-workers. This made it difficult for them to manage formal work and childcare.

> *In my line of work, for example, I have a problem because I was in one facility and, as a midwife, you're meant to stay and do deliveries and other things. Because of this child, I am unable to stay at the facility and conduct deliveries as a midwife. So, I was transferred from that location to another, which is now my current working facility, which is one village 'be' away from my family, but I had to go to work and come home because of this youngster. Those in the office are aware of my predicament, but I'm at a loss for words (P11)*

Theme 4: Economic Burdens

This talks about the economic hardship of the caregiver. It talks about how the caregivers survive with the means he or she makes.

Increased Financial Burden

Some of the caregivers reported higher expenditure owing to the purchase of drugs, assistive devices, transportation costs, laboratory tests, and food purchases. According to them, this put financial strain on the company. Out of pockets and productivity losses creates substantial financial burdens on households (WHO,2023)

> *There are days I don’t have money for transport to come here, or money to even buy foodstuff. Where is the money? It’s not easy. I*

> *am forced to borrow from friends as my husband is not supportive (P5)*

> *I have spent money to get a cure for my daughter but to no avail. I have tried traditional remedies too. It was recently that I had a message from a neighbour whose son is also suffering from epilepsy that I should send her to the hospital. But even there I struggled to buy the medicine when they give me the prescription. At school, the teachers have been supportive. Since they know about her situation, they call her to the office so that she doesn't play too much to get any seizure" (P10).*

Interrupted income.

Caregivers' financial status was made worse when they were unable to engage in income-generating activities, which was compounded by increased expenditure. Participants in this survey stated that they were unable to continue working due to their child's needs. Some quotes from participants exemplified this.

> *I can't do anything right now because of her health; there's nothing I can do. I used to be a trader, but due to her health, I have to stay at home and look after her (P7).*

> *I won't be able to work again until he is well. I used to work in a boutique before I had my child, but now that he's like this, I've had to stop because of him (P15).*

Another caregiver said,

so, I had to stop working when I brought her from the village since it was giving my mother stress so I had to take over. I have to let her come here with the medication and prayers so I let her come and I had to stop working then we will be going for prayers and day breaks we were just there together. (P4)

One participant had to say this about her husband's work situation,

It was the father the condition that affected his work because they remove him. it was private work. The dad spent a lot of time at the hospital with us and so he was unable to frequent his work site his causing his dismissal (P11)

4.3.3 COPING STRATEGIES USED BY CAREGIVERS

Caring for children with epilepsy has not been easy. The condition has come to stay. Caregivers must learn to live by the new norm and advance towards getting help for the kid and themselves. Coping mechanisms got documented under the following sub-themes. In Ghana, a study showed caregivers coping strategy include positive coping strategies like faith in God, social support, lifestyle changes and negative coping strategies such thinking and worrying and concealing diagnosis (Atiogbe A, Aziato L, & Deegbe,2020).

Theme 1: Patience on what happened:

The subthemes of "caring patiently" and "enduring sorrows" were included in this topic. Nearly all of the participants in this study made an effort to maintain patience during each stage of their children's illness and treatment; they also made an effort to put up with the stress that came with the circumstance.

Caring patiently:

The caregivers patiently nursed their sick children at all stages and endured many hardships during their children's illness.

> *The sickness has come to stay. Whether we like it or not, this is something that one must learn to accommodate and be patient with…(P2)*

> *It was difficult because it took me a while to get my child to the hospital due to my precarious financial condition. I have honestly accepted the circumstance and am prepared to do everything in my power to ensure the child's wellbeing(P1)*

One participant said

> *…that thing, when it happens, I will feel sad especially when she falls into the fire. When that happens, she sustains a series of injuries. It took her half a year before the wound was able to heal. And so we have to be patient and go with her everywhere, hmm… (P3)*

Some of the participants however lamented that, though they would have welcomed any assistance from family members, they had to forge on since help was not forthcoming. To this caregiver, caring for the child is something they would have to do at all costs. To them, the child is theirs and they owe the child the responsibility of care, whether help comes or not. One of the respondents put it his way;

> *You see, in this world, when you need people to come in to assist you in your difficult times, you won't get them. You got to have patience and do things your way. I don't mind if friends and relatives come in to help but the truth is that I got to endure and carry the cross my way*

Enduring sufferings: In this study, all the parents made direct or indirect reference to the challenges they encountered and the weights they bore throughout this time. A participant's response to this was as follows:

> *I barricaded myself inside for at least six months because I didn't want my child to have any other illnesses on top of the ones he already has, and if I went to even a little party, I would make sure the child wasn't left alone. I was constantly by his side to make sure everything was okay. (P3)*

Another participant describes the struggles she faced with her child and how they affected her.

> *Last year, I faced a challenging circumstance because we didn't have a fundamental understanding of what was going on with my child's situation, which was upsetting him. When I arrived at work, I was unsure of what to*

> *do with him. He struggled when I wanted to take him to school. It was a trying moment. I was unsure about what to do. I don't want to go through those times again. (P5)*

HOPES FOR FUTURE

All participants reported having a great hope that shortly their wards were going to be well and recovered from the situation they find themselves in. They believe that someday, the people who are not willing to come through for them would be touched to come to help them. They believe that God would someday help them.

This is what P6 said:

> *We are now hopeful that things will get better since we have seen improvement with the current treatment from the hospital. I think medications are working now and the child has fewer seizures than before…..(P6)*

Another caregiver was hopeful that, someday, they would receive what they have long hoped for. She seems to have high hope in God and that, God does things perfectly in his own time.

My sister,…one thing is sure for us all. God does things perfectly well in his own time. Who are we to question the acts of God? Am just hopeful and praying but yes, I know my redeemer would come through for us. I don't and won't depend on any mortal being for anything. I put all my trust and hope in my redeemer the highest God….(P2)

CHAPTER FIVE

5.0 DISCUSSION OF FINDINGS

The findings from the current study are compared with pertinent literature in this chapter to support or challenge other studies that have been long published on the topic under investigation. The results have been examined about the three objectives, namely, caregivers' challenges and coping mechanisms, as well as their knowledge, beliefs, and understanding.

5.1 KNOWLEDGE, UNDERSTANDING AND BELIEF ABOUT EPILEPSY

According to the study, there is a knowledge vacuum about the causes of epilepsy. It was not mentioned that these kids had any known medical issues, even though brain infections in kids can lead to epilepsy. However, studies by Strzelczyk et al. (2019) on parents' and caregivers' comprehension of epilepsy and convulsive seizures in Jamaica and Iran, respectively, found that parents and caregivers had high and appropriate levels of knowledge about the causes of the condition as well as positive attitudes.

Although the children's parents claimed that the children's fever and a string of convulsions were the illness's earliest signs, the parents were unable to tell whether or not the children would eventually develop epilepsy despite the children's fever and convulsions. These results support a previous study conducted in Turkey, where some kids had convulsions due to fever. The study also showed that children were more likely to acquire epilepsy when they had a fever and frequent convulsions (Muchada et al., 2021).

They did not consider taking the kids to the hospital for treatment as a result. If parents had even the slightest comprehension of the ailment, they would have surely sought early medical assistance. The findings were consistent with those of research done in Thailand, where caregivers had similar knowledge gaps while thinking they needed to be aware of the illness (Bapat & Shankar, 2021).

As a result, parents took their children to a clinic for therapy, and an electroencephalogram (EEG) and CT scans later confirmed the diagnosis. According to Chew et al., (2017a), some caregivers were unable to perform EEG tests because of a lack of resources (e.g., financing and equipment). Given that few parents could afford to pay for the study due to financial constraints, this conclusion was made reasonably.

A study by Yang et al., (2020) found that approximately one-third of epilepsy patients still experience seizures despite excellent treatment. The drug could not be functioning as planned since parents can't routinely get prescriptions. The fact that the children's condition wasn't improving despite taking medication either meant they required evaluation or that the drug wasn't working. The new finding thus confirms studies by eight eminent epilepsy researchers who found that between 30 and 40% of people with refractory epilepsy experience seizures that do not respond to antiepileptic drugs and other treatments (Modi et al., 2017a). It was also discovered that the medicine didn't improve the situation; rather, it made it worse.

Nearly all of the parents in the current study thought that the sickness had a spiritual component. This research supports a study from Zimbabwe by Hartley et al. (2021), which found that the original African medical system thought epilepsy was brought on by witchcraft and spirit possession, a demon attack, or an evil spirit.

Many spiritual causes were attributed to the sickness, even though some caretakers thought the ailment was spiritual in nature. For instance, some parents thought that the illness was demonic because of the information that spiritualists had provided them about it. There are many misconceptions concerning the genesis of epilepsy, for example, among Ethiopians and Nigerians, claims Kroner et al. (2018). Many people, including the parents who took part in this study, had the concept that it was brought on by demons, witchcraft, ancestral spirits, or evil eyes. However, very few of the parents were able to determine if the ailment was spiritual or physical, and very few of them were aware of its origin. They thus admitted that they were perplexed by the children's position. Their parents were readily deceived by pastors and spiritualists because of the way they perceived their circumstances. Epilepsy is traditionally viewed in Ghana as a curse from the ancestor spirit or as the result of being possessed by bad spirits because of the spiritual connotations associated with the ailment, according to a study by Lai et al. (2019a). The parents' claims were supported by the theories of witchcraft and "poisoning." Because they have high regard for pastors and traditionalists as well as for them as Africans and Ghanaians, parents trust all these people say. Because they thought that if their children were burned, it would be the end and they would never be able to recover, some parents were always on the lookout for their kids. They took this to be real because a spiritualist had claimed it to be so. As a result, parents were concerned and circumspect. According to traditional healers in Zambia, burns are regarded as a portent of the victim's future. This finding is supported by a related study by Jakobsen et al., (2020), titled "Epilepsy Management in Africa: Main Challenges and Solutions."

The study's findings showed that parents looked for spiritual assistance. Because they believed in divine intervention, parents who asked other pastors and their pastors to pray for their children did so. Parents did not mock the prayers when they accompanied their children to several pastors. Some claimed to have visited Ghanaian pastors in search of the children's healing. This is in line with the findings of Işler, Turan, and Gözüm (2014), who discovered that parents turned to prayer, holding their sobbing kids in their arms, and expressing affection as supplementary or alternative coping techniques to deal with their worries. The majority of the parents' strategies were effective in helping them accomplish that goal. Even while parents did end up praying in this study, there were no good outcomes like there were in the one previously mentioned. In the current study, parents did not report that their children felt better after they were consoled or shown affection. At the prayer camps, additional parents asked for assistance. Along with the items they had to purchase, parents also had to pay a set amount of money. Parents invested a considerable sum of money in helping their kids recuperate. On account of their ailing children, some parents also asked mallams and fetish priests for help.

The children displayed warning indications before the attack, and many of them shouted when the seizure first started, according to another study found. According to other parents, the kids started yelling as soon as the seizure attack started. Additionally, it was found that the repeated attacks the patients in this study had been subjected to prevent them from being able to care for themselves. Due to the compromise and performance of their everyday tasks for them, some of the children even required assistance peeing. After suffering seizures, some of the kids always had marks on their bodies, while others reportedly fell asleep or lost consciousness. A few of the kids were drooling in addition to frothing at the mouth, peeing, and having faeces all over their bodies. This is comparable to what Saengow et al. discovered (2018). They found that the kids had lacerations of the skin and soft tissues in addition to mild head injuries, dental injuries, tooth loss, and injuries to the tongue and soft tissues of the mouth. Parents claim that the seizures their children suffered in this recent study affected their lives. Each disaster usually left the kids exhausted and uninterested in anything else. The lives of children with epilepsy were shown to be significantly impacted by post-seizure symptoms, such as weakness, sleepiness, fatigue, exhaustion, peeing, and defecating, according to a research by Fong et al., (2016).

The attacks hurt the children's memory, which may have made it more difficult for them to take care of themselves. Generalized epilepsy is likely to make it more difficult for children to comprehend and complete memory tests, according to Ramsey et al., (2018). This outcome supports the study's findings about the impact of epilepsy on memory. Parents in this study also reported that the sickness had delayed their children's memory, making it difficult for them to understand classroom material. According to a study by (Benson et al., 2016) in Nigeria, children with epilepsy experienced emotional and behavioral issues, which supported the claims that the children behaved erratically and that some of them were verbally and physically hostile. Parents reportedly began to worry and seek explanations as a result of these unfavourable seizure events. It was typical for parents to be ignorant of the illness' causes, symptoms, and warning signals. Parents postponed taking their kids to the doctor as a result. The children's parents claimed that after getting their children counselling, the children's medications were still not controlling their seizures. Because they couldn't always afford to pay for the prescriptions, parents may have supplemented natural treatments or sought help from a pastor or fetish priest.

The interviews made clear that parents experienced great hardship, particularly since the majority of them were unable to work and some even had no job. Despite their claims that they relied only on their income, few of the parents were found to be employed. Some parents relied on irregular menial occupations. To pay for prescriptions, for instance, parents had to grovel to friends and relatives. A handful of them occasionally needed loans to pay for the fundamental lab work and prescription medications for their kids. Due to financial constraints, some parents only sometimes take their children to the hospital for an examination. According to Cramer, Wang, Chang, Power, Copher, Cherepanor, and Puka et al. (2017), children with uncontrolled epilepsy had a larger economic burden and used considerably more healthcare resources. These findings are supported by these data.

The results of the investigation also revealed that some parents owed money to others because they had to pay for specific prescriptions. They also admitted that it was challenging for them to support those they were caring for. Childhood epilepsy has a considerable financial impact and incurs high costs, according to Ostendorf & Gedela (2017a). The financial toll of the illness makes it depleting from an economic perspective. Several folks stopped buying their drugs because they couldn't afford them. Sending their children to prayer camps, where they had to pay a set entrance fee, costs parents a lot of money (Stuart et al., 2021). Additionally, they were required to purchase cement sacks at regular intervals from various prayer camps. Some parents argue that money allocated for their kids may go toward building a home. Every step is taken to care for the kids, according to the report, involved spending money. This data was part of a cohort study on pediatric epilepsy costs that was carried out in Nigeria. According to the study, families devote a significant portion of their household income to caring for epileptic children (Jensen, Liljenquist, et al., 2017).

The children's health had not improved despite the parents' considerable financial investment in their care. Parents who believed that providing care was a waste of money because they saw no improvement in their children's health backed a study that found the societal cost of providing care for children with epilepsy was high overall, widening the treatment gap (Jensen, Liljenquist, et al., 2017). It was discovered that if someone had a room full of cash, they would spend it all if their child exhibited the same behaviour. Additionally, it was found that some of the parents struggled to focus at work, turned down jobs that required the very minimum, and as a result, were unable to earn the money they so desperately needed.

5.2 CHALLENGES CAREGIVERS GO THROUGH

Epilepsy is typically treated at neurological and mental health centres. For instance, in the majority of Nigeria, patients were treated in both psychiatric hospitals and mental health facilities. Because caregivers were ostracized for visiting certain sites, caregiving became difficult (Puka et al., 2017). But in the US, patient management falls under the purview of the neurological departments. There are no barriers between patients and caregivers receiving care ((Ramsey et al., 2018); (Modi et al., 2017b)).

Parents have dealt with changes in expectations, roles, and welfare in general, as well as social, physical, and psychological issues. After hearing about the children's condition, friends, classmates, and neighbours tended to steer clear of them. However, because of the ailment, the mother occasionally faced prejudice from her neighbour. This finding is consistent with a study by Hartley et al., (2021) that revealed rejection from the woman's neighbourhood and family was common for both mother and child.

This study's findings also indicated that parents faced several challenges as a result of providing care. The interviews showed that many parents did not have regular jobs and were therefore unable to meet the needs of their children. As a result, it was quite difficult for them to purchase pricey medication. Parents were consequently unable to regularly purchase the kids' food and medications. Caregiving became incredibly difficult since the limited funds they had were spent and no new funds were coming in. This is consistent with a related study that was conducted in Enugu, Southeast Nigeria, which discovered that raising an epileptic child was extremely expensive and necessitated catastrophic medical expenses (van Westrhenen, Souhoka, et al., 2021).

Children were left alone at home without a place to go by their parents since they were unable to predict when an assault would take place. Some of the kids would run around when left alone, which worried some of the neighbours, while others would get lost outside and become unable to find their way back inside. The few parents who worked frequently took time off to care for the children. Now and then, their workplace would phone to let them know that the kids had had an attack, and most of the time they had to rush the kids to the hospital. Similar to this, Jakobsen et al., (2020) study found that caregivers encountered challenges with the kids and employment as a result of the disease's financial hardship. They found it extremely challenging to care for those who had epilepsy; it was a constant source of stress and a tremendous burden.

It was noted once more that the children were still having seizures so frequently despite taking their recommended medications. It severely concerned all the parents, and they wondered if the children's condition would ever improve. Because of this, a study by Goodall et al., (2018). that discovered that roughly one-third of epilepsy patients continue to experience seizures while getting appropriate medication therapy is supported. Parents worried about whether the illness would ever fully leave their children's life or if the attacks would go on until the child died. According to a study, the risk factors for epilepsy that worry caretakers the most are sudden unexpected death in those who have persistent tonic-clonic and sleep seizures (Fong et al., 2016).

Parents in this study hoped that the disease would leave their children. The fate of their children if they were unable to raise them, worried parents, just as much. This indicates that parents may have been anxious about their children's safety while they were away. This is consistent with a study by Jakobsen et al., (2020) that indicated high burdens for more than half of caregivers, with their main concern being what will happen to their loved ones when they might not be able to care for them in the future. It was obvious that taking care of the children's needs and raising them was a big job, made all the more difficult by how quickly the children were growing. This is because some of the children at the time already had a fiercely hostile attitude toward their parents. As a result, parents feared what would occur when their children grew up and they were no longer able to control them. This result corroborated a study by Karim, Ali, and Deuri, (2014) that found epilepsy care to be exceedingly challenging and burdensome. Again, this made giving care challenging and very challenging. Although this was the case, parents nevertheless made sure to buy the medications whenever they had the cash, regardless of whether they required a loan.

As a result of their children's ailments, parents endure severe hardship because they are unable to work. The only income used to maintain the children was that of the few people who did work. Parents find it quite challenging to get medications because of their restricted financial means. Being a caregiver is demanding since parents have to manage all of their kids' everyday activities in addition to everything else. The cost of providing care puts a strain on parents' income. According to parents, providing care is challenging.

According to a study by Hansen et al., (2018), stigmatization continues to be a major barrier for families living with juvenile epilepsy. Many of the children's parents allege that neighbours have verbally abused them as well. The kids' abuse and restriction from interacting with other children alarmed the parents. This was analogous to a study by Puka et al.,(2017), which discovered that stigma continued to be a major barrier in the lives of families living with pediatric epilepsy. Since parents could not leave their children alone at home, they had no trouble going out, mingling with others, or otherwise socializing. Instead, they merely lacked the time. This opposed the findings of van Westrhenen, Souhoka, et al., (2021) study on parenting stress in mothers of children with intractable epilepsy, which revealed that the caregivers' parental obligations significantly limited their freedom and capacity to maintain their own identities.

The results of the most recent poll showed that parents' experiences with their physical health differed. Some children with the condition had headaches, sleeplessness, and stomach ulcers, while others had restlessness and high blood pressure. This might be a result of parents being preoccupied with their kids' health and seizure activity all the time. It's possible that spending time with the kids is to blame. Even some parents have endured verbal and physical abuse at the hands of their children. It was thought that the physical state of the parents had been greatly affected by caring for them. The findings of a study by Puka et al., (2017), which tries to corroborate the experiences of the parents in the current study, indicate that the physical wellness of parents declines as a result of the burden of care.

Psychological crises were shown to be one of the issues parents dealt with. Even though parents were continually terrified and apprehensive, it was revealed that their psychological experiences varied. The children's sickness made them reflect frequently and worry constantly. Some parents claimed that providing care was not always an easy task. Others agreed, saying it was terrible, especially when the kids were being attacked. It was unpleasant for some parents to have to watch while their kids occasionally suffered an attack. While other parents claimed it was just uncomfortable, some parents characterized caring for their children as agony and anguish. Some parents wished for it not to go on forever. This was probably because there was a chance that the children would experience an attack, which would be extremely traumatic even without the increased caring responsibilities. A study by Seid et al., (2018b) that demonstrated caregivers frequently experienced psychosocial disorders like anxiety, stress, and depression was corroborated by the findings of this study, which also showed that parenting was particularly stressful and tiring. These were significantly influenced by the child's conduct and the demand for caregiving. Only a small number of the children were attacked at any point in the day, but many of them, according to the parents, were attacked right when the sun rose.

Some parents reported a desire for their children to have passed away as a result of their feelings of embarrassment over their children's health issues, which negatively impacted their sense of general well-being. Parents felt that having such children was inappropriate. It's possible that the parent's sense of helplessness and annoyance about the condition of their children led to this. Significant effects were also seen on the lives and well-being of those who provided care for children with severe epilepsy. They felt guilty, angry, anxious, and helpless, according to a study by (Saleh et al., 2022). The parents' narration revealed self-pity and an unsettling level of anxiety about their situation.

Parents stressed how dreadful and uncomfortable it was to have a child with this type of condition. Parents generally felt bad because of the conditions of their kids and the challenges they had to deal with as parents. This backed up the conclusion from a study by Modi et al., (2017a) that epileptic seizures had a considerable detrimental impact on people with epilepsy and their families. The parents did not express joy, but they did state that the children were very important to them and that their illness made them very unhappy. Parents acknowledged that nobody thought it was easy. The children's health and caregiving had a huge impact on their lives, given all the challenges that came with it.

Epilepsy impacts may have an effect on both a child's and the child's parents' lives, according to a study by Hussain et al., (2020) that served as an example in the current study. Parents in this study accepted their fate and dealt with things as they were. This was because they would always have to care for the children. After all, they have nowhere else to go and were responsible for bringing them into the world. This indicated that the parents had accepted the fact that their child had an impairment like epilepsy. They also realized they weren't the only parents of children like these. Parents who received some form of encouragement and assistance from friends and relatives felt relieved that at least one person cared and offered assistance. This was consistent with a study by Jakobsen et al., (2020) which discovered that parents' primary coping strategies consisted of accepting the situation and having an active emotional perspective on the child's condition. They underlined the need of having informal help from friends and family to manage daily life once more. They had also come to terms with it as a part of life and had learnt to live with it because there was nothing, they could do about it.

Parents desired both material and emotional support, but they had various expectations towards adjusting expectations. Parents sounded irate over the lack of financial support. For instance, they wished the government would help in some way to provide them with some comfort. In particular, they felt that the government shouldn't let them suffer in silence and shouldn't let parents bear the burden of childcare on their own and some also wished for a special school for epileptic kids. Similar findings were made by Ali et al., (2014) who discovered that many caregivers' frustrations in a tertiary mental health facility in Southeast Nigeria were a result of a lack of support. When caring for such children, it was essential to have both physical resources and emotional and psychological support. According to a study by Dorris et al., (2017) caregivers did not receive support from their spouses, friends, family members, or the government. This conclusion was consistent with those studies.

Parents occasionally couldn't afford to see their children in the hospital in the current study. While some parents wanted assistance with child care so they could go to work, others wished they could locate a doctor or anyone who could treat the illness. This, however, shows that parents lacked the help they needed to take care of their children. This assertion thus backs up a study by Chew et al., (2017a) that discovered the majority of caregivers, especially women, did not receive assistance from family, friends, or the government, which put a lot of stress on them.

Parents' roles have changed as a result of the children and the duty of caring for them. This study demonstrated that parents have to put everything else on hold to care for their children. Particularly, a lot of people had to quit their jobs to take care of their kids, interrupting their employment because they had to rush the kids to the hospital for treatment or evaluation or because they were experiencing one form of attack or another. Parents kept an eye on and checked up on their kids to make sure they took their daily medications and took care of their daily needs because almost all of the kids couldn't. Some parents had to quit their jobs to travel and stay with the children at the prayer camps, while other parents sent their children from church to church. Caregivers generally reported feeling a strong sense of obligation to the children with epilepsy that went beyond parental duty as a result of the diagnosis, which confirmed the findings of the parents in the current study.

The parent's physical and mental health was impacted by the state of the kids. The parents were unable to work because of their kids. Resources are necessary for families with epileptic children so that they can satisfy their needs and determine if the resources at their disposal were adequate or not. Having access to community psychiatric units and being able to attend government hospital facilities conveniently was enough for the parents in this study. This evidence, therefore, lends credence to the study by Fong et al., (2016) that discovered epilepsy patients in the Southern Caribbean had access to government clinics and hospitals. However, it was found that even though parents had access to health care, they did not have enough money to give their kids the care they needed. Parents typically lacked sufficient resources, such as money, except for the small percentage of parents who worked but relied mostly on their income and infrequent financial aid from family members. To ascertain the degree of strain experienced by caretakers of patients with epilepsy, (Modi et al., 2017a) conducted a study along a similar line. The findings showed that caregivers struggled to cope because they lacked the tools, they needed to take charge of their condition.

Particularly for the children, the cost of medication was always factored into their budget. This was in line with a study that revealed that Nigerian families and caregivers of children with epilepsy have a huge financial burden due to significant unforeseen expenses (Puka et al., 2017). However, many parents did not have nurses visiting them in their homes to help them in any way. This could be a result of insufficient preparation and transportation for medical staff to undertake home visits effectively. Visits to parents and children at home were also an essential kind of support at this time. It provided both parents and kids with emotional and psychological support. The nonprofit Compassion assisted some parents with the cost of their children's drugs.

According to the parents' testimonies, friends and family members offered these individuals support, encouragement, and consolation. Only a few parents' families expressed worry and concern for the children. This implied that they were in good relationships with their family, friends, and some locals.

Instead of avoiding them, some people got along well with them. The few children that were enrolled in school, according to the parent submissions for this study, had supportive and helpful teachers, particularly during attacks. The findings of a study evaluating the efficacy of a thorough epilepsy education program for school teachers in Chandigarh City, India, were corroborated by these findings. According to the study, teachers were essential in providing first aid to students who were suffering from g from seizures (Modi et al., 2017b).

However, the study discovered that some of the parents received no financial assistance from any family members, except the sympathy and encouragement they received from friends and family. This is supported by a Malaysian study conducted by Ramsey et al., (2018) which discovered that the majority of caregivers needed financial aid to pay for the expenses related to their children's diseases. In addition to not offering financial assistance to the parents, it was also noted that other family members showed no concern at all. This finding is in line with a study conducted in India, which discovered that informal help from friends and family was essential for surviving day-to-day life (van Westrhenen, de Lange, et al., 2021b).

Some participants, according to participant descriptions, had relatives and friends who cared about them, supported them, and expressed sympathy. Some people had healthy relationships with their family, friends, and locals. They don't avoid them; they get along just fine with them. Additional information was discovered through participant contributions, such as the fact that some child teachers offered help and support, particularly during attacks. A participant asserted that the child receives good treatment from her teachers because they look out for her while some family members appeared to be completely unconcerned.

Education is just one of the many things that epilepsy as a condition has a big impact on. Examined about schooling were disruption, unpredictability, and seizure effects. The few children who attended school were unable to complete their lessons due to a series of attacks. Due to seizure attacks, they frequently had to be taken out of class, which is consistent with research showing that children with epilepsy were more likely to skip school and that low attendance could have an impact on academic achievement (Jensen, Brunklaus, et al., 2017). When administrators at the school found out about some of the kids' circumstances, they either refused to enroll or expelled them.

Since many of the children could hardly understand anything, were easily distracted, and didn't love studying, their parents often refused to allow them to attend school. These findings are in line with a study by Fong et al., (2016), which discovered that parents were extremely concerned that epilepsy could result in learning difficulties, such as problems with memorization, comprehension, slowness, and laziness, which hurt academic performance. In research conducted in Nigeria by Modi et al., (2017a), where the majority of the children exhibited behavioural problems and learning difficulties, this was also made obvious. Parents were unsure and unable to foresee what the future might hold for the kids. In a study that supported this one, parents' top worries were how epilepsy may affect their child's ability to seek higher education, get a successful career, marry and have children. In that survey, parents also mentioned that the stigma associated with epilepsy affected how they felt about their child's future (Loiselle et al., 2016). However, in our current study, the later component of their study that identified stigma as the basis for their opinion did not reflect the reason for parents' anxiety and concern about their children's future. The majority of parents believed they were unable to anticipate what lay ahead for their children's future since they had given their children's futures considerable attention. Along with the emotional impact, they underlined that it needed a lot of their attention. The effects of epilepsy on a child's and the child's parent's lives were revealed in another study, which made these clear (Tschamper & Jakobsen, 2019). Some parents could not just predict the future, while others didn't think their kids had much of a future—much less the capacity to learn a trade—at all. In a study by Puka et al., (2017), it was also suggested that parents were more worried about their children's safety, academic progress, and prospects for the future in terms of employment and marriage (2016a). Only in studies where caregivers felt a significant burden and were anxious about what the patients' futures might hold did parents claim to be unable to predict the future (Benson et al., 2016). However, a few parents were upbeat and believed their children would have a bright future.

Numerous children were forced to stop going to school because of their frequent seizure attacks, which have several detrimental implications. Children with epilepsy commonly leave school, according to a study by (Nunley et al., 2019). Parents said that almost all of the children suffered from memory loss as a result of frequent attacks. Some of them just couldn't go to school since they found it impossible to learn there. It was shown that since the onset of the illness, the children's standards have drastically decreased. These findings, therefore, added to those of Hartley et al., (2021), who found that children with generalized epilepsy had more challenges with memory tasks and understanding sarcasm.

As a result of the frequent assaults their children had been experiencing, which interfered with their ability to learn, parents forbade their kids from going to school. Parents were worried that their kids might be bullied by their classmates and attacked at school. The children's repeated attacks affected their memory, short-circuited their attention span, and made it more difficult for them to comprehend classroom material. In addition, parents had no way of knowing what lay ahead or what the future held for their kids. Parents frequently experienced fear of the unknown.

COPING STRATEGIES FOR CAREGIVERS

The current study made many discoveries about the challenges that caregivers of children with epilepsy encountered in their care for their patients. Despite having these challenges as mentioned early, caregivers were swift with coping strategies. The finding in this research is similar to that of Jensen, Brunklaus, et al.,(2017) were caregivers of CLWE developed some sort of resistance to the angering psychosocial effects of the issues they have at hand. Additionally, throughout time, some parents adapted more swiftly than others. For instance, some parents were still baffled three or four years later as to why their child was ill. Many parents acknowledged that they tried to be sympathetic to their child's situation. The participants in this study believed in patience. They considered theological doctrines that exhort perseverance in the face of adversity and the notion that God wills what occurs. In this study, parents who had more ardent religious beliefs were calmer and more at ease. Most of the parents improved their mental and patient abilities by going to mosques and taking part in spiritual activities. Additionally, prior studies have shown that going to church and praying may aid in achieving serenity. According to Whaley and Wong, (2014), some families believe that every challenge presents an opportunity to demonstrate greater grace and faith. The parents who participated in this study were all caregivers of patients.

Parents who care for themselves are essential, and nurses should consider this since they will be better equipped to care for their children. Studies have shown that parents' health has a big impact on how well their sick child recovers physically and mentally.

In this study, the caregivers of these children make efforts to change their situation by engaging in particular activities. Nurses can better understand the needs of these kids and their parents and better understand how to treat the illness if they have a solid understanding of the adaptation process. As a result, parents get more assistance and education. They adapt more quickly and can therefore deliver more precise care. Detailed knowledge of compatibility methods can also be used to enhance the lives of other children and help parents provide their children with the care they require.

After going through many stages of stress and worry throughout diagnosis and treatment, the families and sick children in the current study concluded that they should accept and get used to the disease, limitations, and regular medical appointments.

CHAPTER SIX

6.0 SUMMARY, CONCLUSION, AND RECOMMENDATION

6.1 INTRODUCTION

The study's summary, conclusion, and recommendations are presented in this chapter. This chapter also emphasizes the effects on clinical practice, research and policy, and education.

6.2 SUMMARY

In this study, family caregivers of children with epilepsy in the Tamale Metropolis were asked about their experiences.

Findings revealed that some caregivers did not know about the disease. However, caregivers took the kids to the hospital so they could get treated. Most parents believed that epilepsy was a spiritual rather than a medical ailment. As a result, they looked for any available remedies to stop the issue. The research again revealed conflicting emotions among those who care for epilepsy patients. Although the majority of participants relied on traditional medicine, contemporary medicine, and faith healers for the treatment of their children, caregivers had a reasonable understanding of the signs and symptoms of epilepsy.

The majority of participants reported feeling melancholy, frightened, and afraid of social stigma because of the disease their kids had. This was a challenge to them. The majority of the participants in the study frequently sobbed about the state of their kids. Parents were on edge because they had no way of knowing when their kids may be attacked or what would happen to them. Screaming and running around were two of the children's warning signs.

They acknowledged that providing care was mentally and physically challenging. The condition of the children altered their typical duties. To sustain the children's everyday activities, for example, they had to physically do everything. In addition to the fact that mothers in particular practically ceased working to devote their time to the children, they claimed that caring for the children financially depleted them. However, this made it extremely difficult for the parents, especially because they also had other children and obligations to take care of. The children were still having seizures, so even though the drugs were expensive, they had no effect. These caused parents to become dissatisfied, anxious, and preoccupied with their children's well-being. The children were unable to attend school since their memory was impaired by the seizure bouts. Parents were unsure of what the children's future may hold.

Some of the participants lost their jobs, leaving them jobless. Additionally, the poor health of the children had a severe impact on the caregiver’s financial situation and the educational standing of the kids. Due to the condition of their children or relative, the caregivers, their children, and their kin suffered stigma.

To put it simply, epilepsy hurts the physical, psychological, and social well-being of caregivers and children who have the condition. Parents reported that providing care was very challenging and that having a seizure attack was not fun. Despite these, they had accepted their fate and were making every effort to assist the kids.

Despite having these challenges as mentioned early, caregivers were swift with coping strategies. Caregivers of CLWE developed resistance to the angering psychosocial effects of the issues they have at hand. Additionally, throughout time, some parents adapted more swiftly than others. The participants in this study believed in patience. They considered theological doctrines that exhort perseverance in the face of adversity and the notion that God wills what occurs. In this study, parents who had more ardent religious beliefs were calmer and more at ease. Most of the parents improved their mental and patient abilities by going to mosques and taking part in spiritual activities. Some families believe that every challenge presents an opportunity to demonstrate greater grace and faith.

They adapt more quickly and can therefore deliver more precise care. Detailed knowledge of compatibility methods can also be used to enhance the lives of other children and help parents provide their children with the care they require.

6.3 PUBLIC HEALTH IMPLICATIONS

The findings of this study directly affect health practice. To deliver high-quality healthcare that enhances the quality of life for children with epilepsy, health workers can benefit from having a thorough understanding of the lived experiences of those who care for these children. The emotions health workers experience when providing medical care to patients are influenced by their knowledge and understanding of the different aspects that affect the quality of life of children with epilepsy. Thus, for epilepsy education, to improve healthcare delivery, and improve the quality of life for kids with epilepsy, nurses are necessary to investigate the thoughts, beliefs, experiences, and expertise of caregivers.

Additionally, knowing the caregivers' worries aid in developing educational interventions including treatment recommendations, counselling, symptom management, and information to enhance the quality of life. Despite this, the job of mental health workers is equally important in managing epilepsy, particularly when coupled with psychological support.

There should be a hospital for general impairments and other mental diseases, including epilepsy, to improve the care of kids with epilepsy. To provide comprehensive treatment for the physical, social, and psychological health of both caregivers and their children with epilepsy, children with epilepsy need to be treated by professionals. Along with providing financial assistance for their medicines and food, there is a need to support children with epilepsy physically, socially, and psychologically. This is in addition to educating friends and family members of those children about how to manage their condition. Social workers must assist caregivers who are receiving insufficient or no support so they can contribute to the cost of their care and daily costs. To prevent stigmatizing or alienating children with epilepsy and their caregivers, society should be informed about epilepsy.

Faith healers and traditional healers must be integrated into modern healthcare delivery, particularly for the treatment of epilepsy. In order to do this, nurses must identify the spiritual and herbal requirements of caregivers, assist the process, and inform faith healers and conventional healers of the necessity of referring children with epilepsy to hospitals. When providing spiritual care, health workers must also recognize the cultural peculiarities of each patient. Clinicians and social professionals can advocate for support for caregivers of children with epilepsy in their treatment and education by contacting the Ministries of Health and Education on their behalf. In this context, the ministry of education ought to release a model aimed at improving the academic performance of kids with epilepsy. To make healthcare accessible and affordable for all epilepsy patients and to lessen the financial burden on caregivers, the Ministry of Health should work with the National Health Insurance Scheme to include the treatment of epilepsy under health insurance.

6.4 EDUCATION IMPLICATIONS

The development of nurses continues to be crucial to the development of society. As a result of their contact with patients, nurses play a crucial role in educating both patients and caregivers.

Nurses care for patients from the time they are admitted until they are discharged and do home visits, thus they should have access to information about the experiences of those who care for children with epilepsy. The treatment of epilepsy is already provided through a specialist program. To make mental healthcare available and affordable for everyone, more mental health nurses must be trained. Additionally, there is a need to train additional clinical psychologists to assist in providing caregivers with information about epilepsy and the effects of associated treatments on both caregivers and children with epilepsy.

The creation of instructional resources for those who look after children who have epilepsy is also necessary. They will be forced to deal with the disease's effects on their bodily, social, and psychological health as a result. Programs intended to raise awareness of epilepsy will help improve early detection and treatment while preventing stigmatization of children with epilepsy and their caregivers in society. The knowledge gathered from caregivers' experiences will help nurses better understand the potential needs and worries of caregivers of kids with epilepsy, and it will also help instructors instruct students to look into the needs of kids with epilepsy and their caregivers.

6.5 POLICY REPERCUSSIONS

The study's findings focused on the experiences of caregivers with children who have epilepsy. Based on the findings of this study, a national policy must be made to improve epilepsy management to help caregivers and children with epilepsy live better lives. More nurses need to be trained with the requisite skills needed to care for children with epilepsy and their caregivers and high-quality healthcare and to educate family members of caregivers so they won't face social stigma. A supportive organization comprising of nurses and Doctors using the mass media must be established to spread knowledge and understanding of epilepsy. The government must be made to make and implement health policies that seek to give people with epilepsy a fair share of good and affordable healthcare. To enhance the healthcare-seeking behaviours of people with epilepsy, the Ministry of Health should also put in place strategies and policies that seek to encourage the use of traditional medicine and faith healing in our contemporary treatment.

6.6 FUTURE RESEARCH DIRECTION

In the future, it is recommended that researchers focus on the following:

1. How Single parents of epileptic children seek medical attention without the support of family.
2. The effect of psychosocial support on caregivers
3. Integration of spiritual healers, herbal medicine and conventional medicine.

6.7 RECOMMENDATION

1. The ministry of health and Ghana Health services should launch a thorough public health education campaign on epilepsy and the risk factors related to it. This will aid society in kicking the practice of stigmatizing the friends and family of epilepsy sufferers.
2. To boost their confidence, caregivers of people with epilepsy should be encouraged by the Ministry of Health and other well-meaning social organizations to join already-existing peer support groups. To be able to access solutions that will lessen their concerns and enhance their general quality of life, these groups should be encouraged to establish in places where there aren't any already.

3. Health education efforts should be maintained, strengthened, and expanded to lessen the stigma associated with epilepsy. This can be accomplished by having nurses and doctors from the health facilities give a rigorous instructional talk every morning at the Out-Patient Department.
4. The Ministry of Health and the Ministry of Education should develop a new educational model that will improve the educational standing of children with epilepsy.
5. In the future, more resources would have to be invested in understanding the coping strategies of these caregivers and also the quality of life of epilepsy sufferers.

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APPENDICES

Appendix 1. Interview Guide

SECTION A: Background Information Form

1. Age (years): 18 - 29 [ ]; 30 – 49 [ ]; 50 – 69 [ ]; 70 and above [ ]
2. Sex…………………………………………………………………………..
3. Place of residence………………………………………. ……………………
4. Nationality……………………………………………………………………..
5. Marital Status…………………………………………………………………..
6. Several children………………………………………………………………
7. Occupation……………………………………………………………………..
8. Level of education……………………………………………………………..
9. Languages are spoken…………………………………………………………
10. Religion………………………………………………………………………..
11. How long has your child been suffering from epilepsy?.....................................
12. Age and class of the child……………………………………………………..

SECTION B: INTERVIEW GUIDE

Main question:
Please can you share with me your story of when you found out that your child was suffering from epilepsy?
Sub- questions (probe as needed):

1. Please tell me how you felt when you discovered that your child was suffering from epilepsy

Probe:
- what happened next?
- what did the doctors or nurses tell you?

2. Can you please share with me what could have been the cause of your child's illness?

3. Please can you share with me how you have been managing your life after giving birth to your child?

Probe:

-What do you worry about the most?

4. Can you please share with me those who are involved in taking care of your child?

Probe:

- How do you/they manage/cope (with) it?
- stress, financial demand, time…

5. Please tell me how caring for your child has affected your relationship with other people.

Probe

- Other children
- Family members (1. How do they relate to you?
  2. Describe the help/support they give you?)
- Community and/or church members
- Friends

6. Can you please share with me the skills you have acquired in taking care of the child?

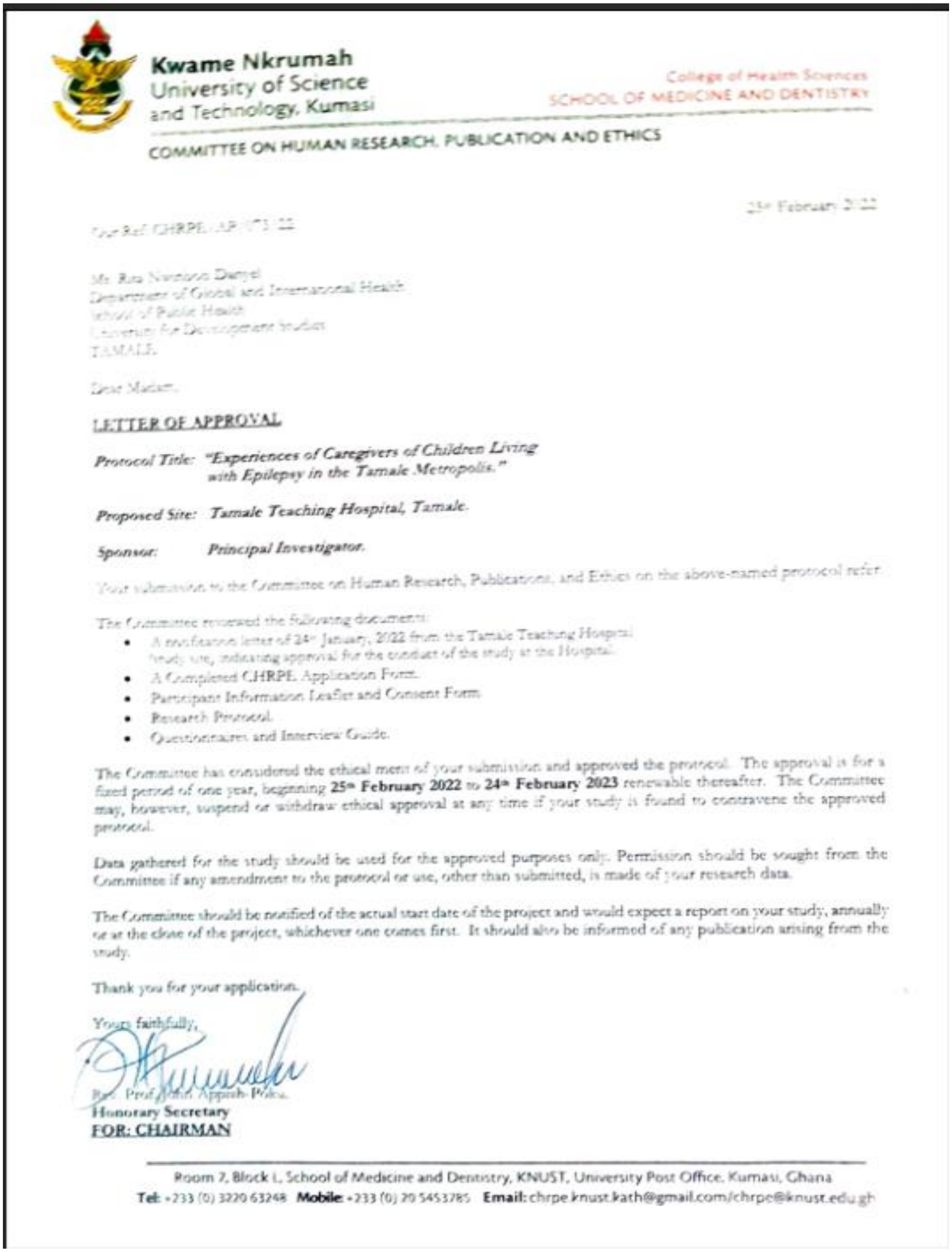
Probe

- What are the warning signs?
- If so, what do you do at the time of a seizure?
- Treatment

7. Is there any hope for your child's future?

8. Is there anything else you want to share with me?

Appendix 2: Ethical Clearance



Kwame Nkrumah
University of Science
and Technology, Kumasi

College of Health Sciences
SCHOOL OF MEDICINE AND DENTISTRY

COMMITTEE ON HUMAN RESEARCH, PUBLICATION AND ETHICS

25th February 2022

Our Ref: CHRPE/AP/[illegible]/22

Ms. Rita [illegible] Danyel
Department of Global and International Health
School of Public Health
University for Development Studies
TAMALE.

Dear Madam,

LETTER OF APPROVAL

Protocol Title: ***"Experiences of Caregivers of Children Living with Epilepsy in the Tamale Metropolis."***

Proposed Site: ***Tamale Teaching Hospital, Tamale.***

Sponsor: ***Principal Investigator.***

Your submission to the Committee on Human Research, Publications, and Ethics on the above-named protocol refer.

The Committee reviewed the following documents:

- A notification letter of 24th January, 2022 from the Tamale Teaching Hospital study site, indicating approval for the conduct of the study at the Hospital.
- A Completed CHRPE Application Form.
- Participant Information Leaflet and Consent Form.
- Research Protocol.
- Questionnaires and Interview Guide.

The Committee has considered the ethical merit of your submission and approved the protocol. The approval is for a fixed period of one year, beginning **25th February 2022** to **24th February 2023** renewable thereafter. The Committee may, however, suspend or withdraw ethical approval at any time if your study is found to contravene the approved protocol.

Data gathered for the study should be used for the approved purposes only. Permission should be sought from the Committee if any amendment to the protocol or use, other than submitted, is made of your research data.

The Committee should be notified of the actual start date of the project and would expect a report on your study, annually or at the close of the project, whichever one comes first. It should also be informed of any publication arising from the study.

Thank you for your application.

Yours faithfully,

Rev. Prof. John Appiah-Poku
Honorary Secretary
FOR: CHAIRMAN

Room 7, Block L, School of Medicine and Dentistry, KNUST, University Post Office, Kumasi, Ghana
Tel: +233 (0) 3220 63248 **Mobile:** +233 (0) 20 5453785 **Email:** chrpe.knust.kath@gmail.com/chrpe@knust.edu.gh

Appendix 3: Authorization Letter to Collect Data

Department of Research & Development
Tamale Teaching Hospital

TTH/R&D/SP/008
24/01/2022

TO WHOM IT MAY CONCERN

CERTIFICATE OF AUTHORIZATION TO CONDUCT RESEARCH IN TAMALE TEACHING HOSPITAL

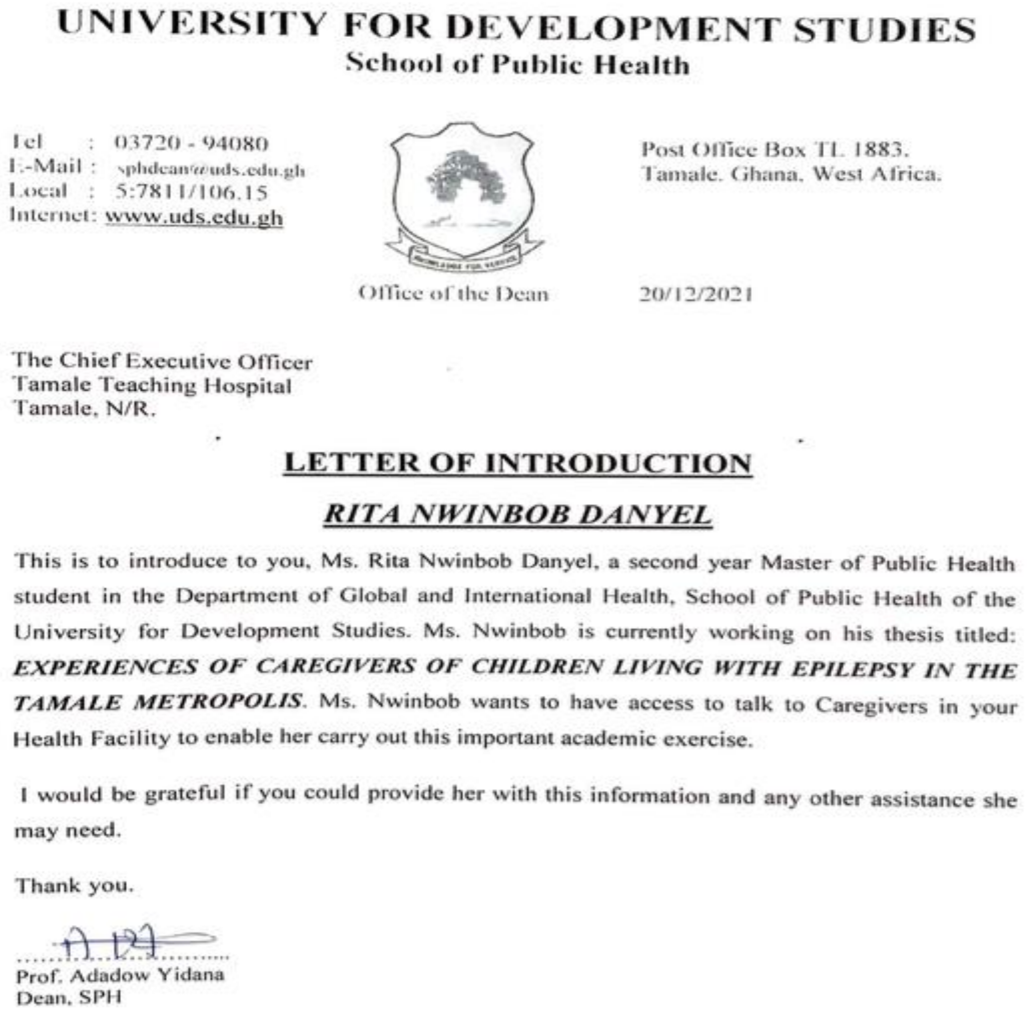
I hereby introduce to you **Ms. Rita Mwinbob Danyel,** a second year Master of Public Health student at the Department of Global and International Health, School of Public of Public, University for Development, UDS. The Student has been duly authorized to conduct a study titled **"Experiences of Caregivers of Children Living with Epilepsy in the Tamale Metropolis".**

Kindly accord the student the necessary assistance to enable him completes the study. If in doubt, kindly contact the Research Unit on the second floor of the administration block or on Telephone 0209281020. In addition, report any misconduct of the Student to the Research Unit for necessary action.

Please note that this approval is given for a period of six months, beginning from 24th of January, 2022 to 23rd of June, 2022.
Thank You.

ALHASSAN MOHAMMED SHAMUDEEN.
(Deputy Director and Head, Research & Development)

Appendix 4: Letter of Introduction from University



UNIVERSITY FOR DEVELOPMENT STUDIES
School of Public Health

Tel : 03720 - 94080
E-Mail : sphdean@uds.edu.gh
Local : 5:7811/106.15
Internet: www.uds.edu.gh

Post Office Box TL 1883,
Tamale, Ghana, West Africa.

Office of the Dean

20/12/2021

The Chief Executive Officer
Tamale Teaching Hospital
Tamale, N/R.

LETTER OF INTRODUCTION

RITA NWINBOB DANYEL

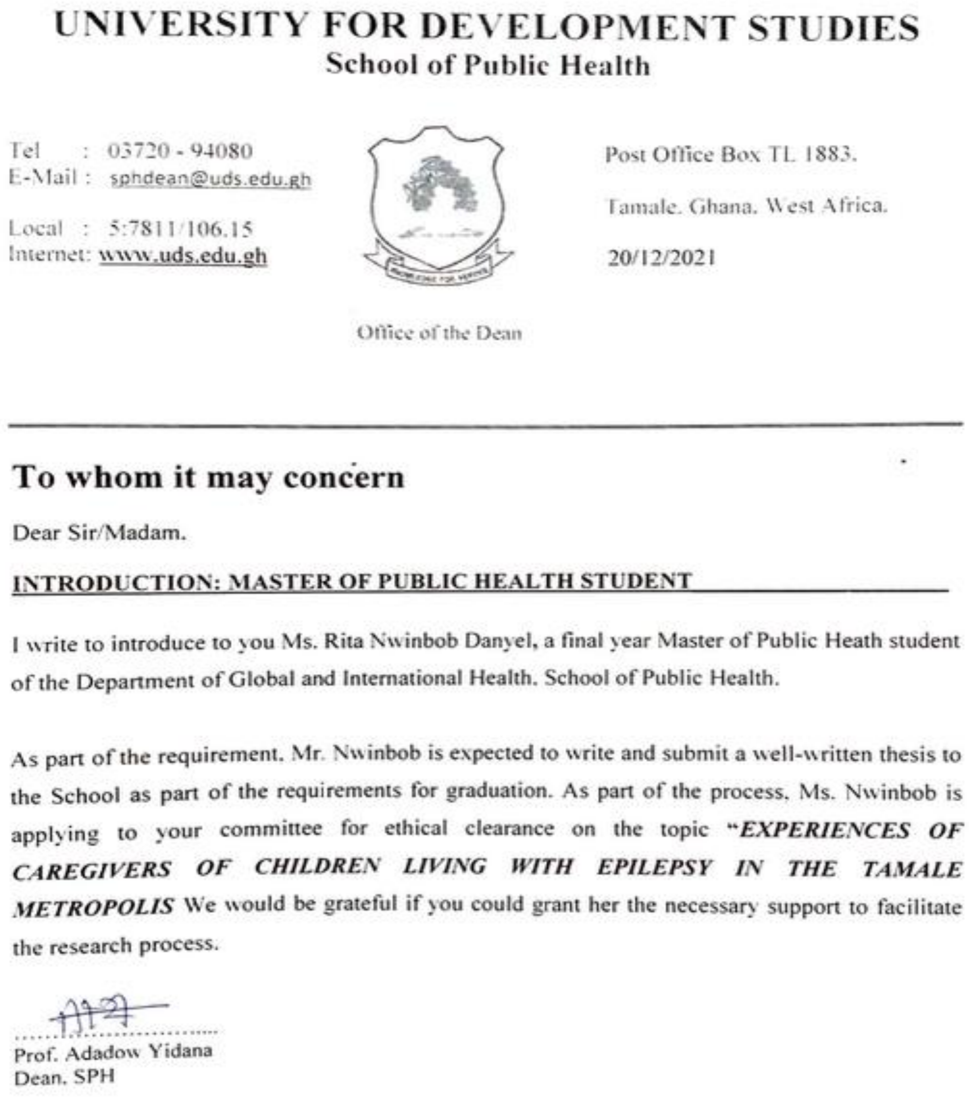
This is to introduce to you, Ms. Rita Nwinbob Danyel, a second year Master of Public Health student in the Department of Global and International Health, School of Public Health of the University for Development Studies. Ms. Nwinbob is currently working on his thesis titled: ***EXPERIENCES OF CAREGIVERS OF CHILDREN LIVING WITH EPILEPSY IN THE TAMALE METROPOLIS***. Ms. Nwinbob wants to have access to talk to Caregivers in your Health Facility to enable her carry out this important academic exercise.

I would be grateful if you could provide her with this information and any other assistance she may need.

Thank you.

....
Prof. Adadow Yidana
Dean, SPH

Appendix 5: Dean's Introduction Letter



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Post Office Box TL 1883.

Tamale. Ghana. West Africa.

20/12/2021

To whom it may concern

Dear Sir/Madam.

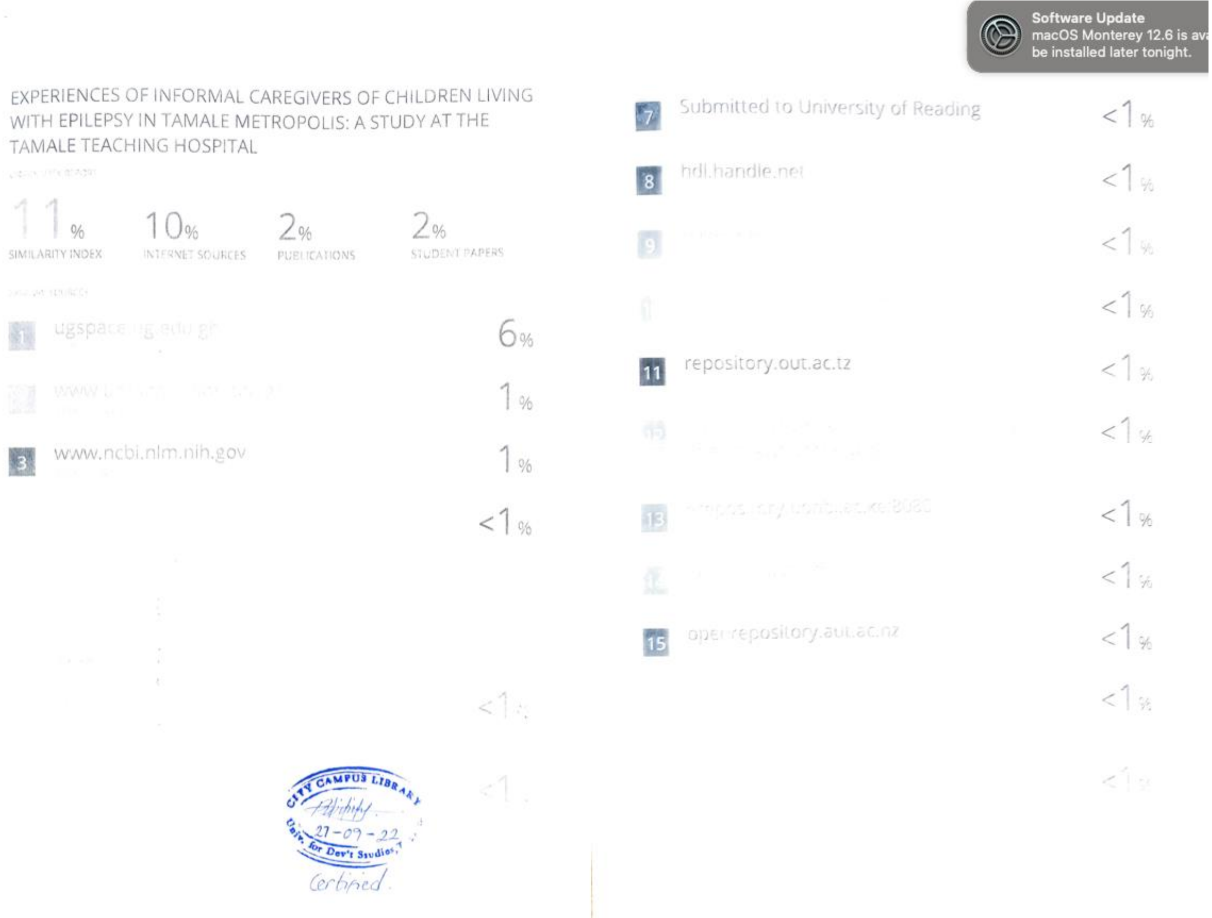
INTRODUCTION: MASTER OF PUBLIC HEALTH STUDENT

I write to introduce to you Ms. Rita Nwinbob Danyel, a final year Master of Public Heath student of the Department of Global and International Health. School of Public Health.

As part of the requirement. Mr. Nwinbob is expected to write and submit a well-written thesis to the School as part of the requirements for graduation. As part of the process. Ms. Nwinbob is applying to your committee for ethical clearance on the topic "***EXPERIENCES OF CAREGIVERS OF CHILDREN LIVING WITH EPILEPSY IN THE TAMALE METROPOLIS*** We would be grateful if you could grant her the necessary support to facilitate the research process.

Prof. Adadow Yidana
Dean. SPH

Appendix 6: Turnitin Plagiarism Report



Software Update
macOS Monterey 12.6 is ava
be installed later tonight.

EXPERIENCES OF INFORMAL CAREGIVERS OF CHILDREN LIVING WITH EPILEPSY IN TAMALE METROPOLIS: A STUDY AT THE TAMALE TEACHING HOSPITAL

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