CAREGIVERS' EXPERIENCES IN CARING FOR PERSONS WITH EPILEPSY, GULU REGIONAL REFERRAL HOSPITAL, UGANDA

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DECLARATION

I, Otto Mike, declare that this is my own academic work that has never been given to any learning institution for an award of Master of Medical Anthropology.

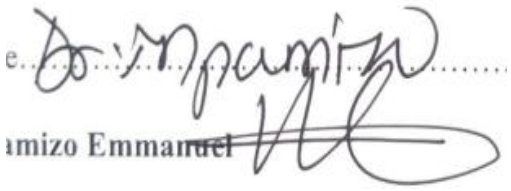
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APPROVAL

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ABBREVIATIONS

AEDs	Anti-epileptic Drugs
LMIC	Low and middle-income countries
NGOs	None-governmental organizations
PWE	Persons with Epilepsy
SSA	Sub-Saharan Africa
WHO	World Health Organization

LIST OF OPERATIONAL DEFINITIONS

Caregiver: a family member or a relative who lives with an epileptic person and offers voluntary care to cover the person dealing with epilepsy's basic needs either directly or indirectly.

Epilepsy: a neurological condition presenting with recurring, spontaneously occurring natural seizure

Persons with epilepsy: People showing signs of epilepsy, such as recurring, spontaneous seizures

ABSTRACT

Introduction: Epilepsy is a chronic neurological condition that places a substantial burden on both affected individuals and their caregivers in Gulu City. Caregivers often face emotional, social, and economic challenges, yet they adopt various coping strategies to sustain the caregiving role.

Objective: This study examined the experiences and coping strategies of caregivers of persons with epilepsy at Gulu Regional Referral Hospital in Northern Uganda.

Methods: A qualitative phenomenological design was employed. Purposive sampling was used to select caregivers attending the hospital's epilepsy clinic. Data were collected through in-depth interviews and Focus Group discussion and analysed thematically.

Results: Caregivers narrated stigma from the community, emotional distress, financial strain, and physical exhaustion as main experiences. Coping strategies included strict adherence to medication schedules, seizure diaries, environmental safety modifications, regular clinical follow-up, reliance on religious faith, participation in spiritual communities, positive reframing, family task-sharing, peer support groups, and community health worker engagement, adjusting work schedules, sharing income responsibilities, and seeking assistance from charitable organizations.

Conclusion: Caregivers of persons with epilepsy employ diverse coping strategies to address the many demands of care. The study recommends that health system and relevant stakeholders strengthen caregiver education, enhancing psychosocial support, promoting economic empowerment, and reducing stigma through community sensitization are essential for improving caregiver well-being and epilepsy care outcomes.

Keywords: Epilepsy, caregivers, coping strategies, experiences, Gulu Regional Referral Hospital, Uganda.

CHAPTER ONE: INTRODUCTION.

1.1 Background to the Study

1.1.1 Global Context

Epilepsy is one of the most common chronic neurological disorders worldwide and remains an important public health concern because of its effects on individuals, families, communities, and health systems. The condition is characterized by recurrent unprovoked seizures resulting from abnormal electrical activity in the brain. Although many people dealing with epilepsy can achieve good seizure control through appropriate diagnosis and treatment with anti-seizure medications, the condition often requires long-term management and continuous support from family members or other caregivers. Consequently, epilepsy should be understood not only as a neurological condition but also as a social and family experience that affects the everyday lives of those who provide care.

Globally, epilepsy affects approximately 50 million people, making it one of the most prevalent neurological disorders. The burden of epilepsy extends beyond recurrent seizures to include physical injuries, cognitive difficulties, psychological distress, educational disruption, reduced employment opportunities, social exclusion, and diminished quality of life. Despite advances in diagnosis and treatment, significant disparities remain in access to quality epilepsy care, particularly in low- and middle-income countries where shortages of trained health professionals, inadequate diagnostic services, inconsistent medicine supply, and social stigma continue to affect disease management.

Increasing attention has therefore been given to the experiences of caregivers, who play an indispensable role in supporting persons dealing with epilepsy. Family caregivers often provide assistance with medication administration, accompany patients to health facilities, monitor seizure episodes, prevent injuries during seizures, provide emotional support, supervise daily activities, and make decisions regarding healthcare. In many settings, caregivers assume these responsibilities without formal training, financial support, or adequate psychosocial assistance. As a result, caregiving frequently becomes a demanding long-term responsibility that influences the caregiver's physical health, emotional well-being, family relationships, social participation, and economic stability (Karakis et al., 2025).

conducted in different parts of the world consistently demonstrates that caregivers of

1.1.2 Symptoms and Signs of Epilepsy

Epilepsy presents with a wide range of signs and symptoms that reflect the type of seizure, the area of the brain involved, and the individual's age and health status. These manifestations differ from one person to another and may vary even within the same individual over time. Seizures may occur with or without warning and can range from brief episodes of altered awareness to prolonged convulsive events. The variability in clinical presentation often influences how epilepsy is recognised, interpreted, and managed by affected individuals, families, and communities.

Common manifestations of epilepsy include sudden loss of consciousness or awareness, staring spells, involuntary jerking of the limbs, muscle stiffness, sudden loss of muscle tone leading to falls, repetitive automatic movements such as lip-smacking or hand rubbing, and episodes of confusion or disorientation. Some individuals experience sensory, emotional, or cognitive changes before the onset of a seizure, commonly referred to as an aura. These warning symptoms may include unusual smells or tastes, visual disturbances, tingling sensations, dizziness, feelings of fear or anxiety, or a sensation of déjà vu. Following a seizure, many individuals experience a postictal period characterised by fatigue, headache, confusion, drowsiness, muscle soreness, temporary weakness, or difficulty recalling recent events. The duration and severity of the postictal phase vary depending on the type and duration of the seizure.

From a medical anthropological perspective, the experience and interpretation of these symptoms extend beyond their clinical manifestations. In many communities, observable signs such as convulsions, loss of consciousness, unusual vocalisations, or involuntary body movements are interpreted through prevailing cultural, religious, and social belief systems. These interpretations shape patterns of help-seeking, caregiving practices, treatment decisions, and social responses to individuals living with epilepsy. Consequently, caregivers often navigate both the biomedical management of seizures and the cultural meanings attached to the condition within their communities. Appreciating the clinical manifestations alongside their social and cultural interpretations provides an important context for understanding caregivers' experiences and the challenges associated with caring for persons living with epilepsy.

1.1.3 Treatment of epilepsy

Sub-Saharan Africa has a shortage of specialists trained in the diagnosis and treatment of neurological disorders, including epilepsy. The region has far fewer neurologists and neurosurgeons than high-income countries, and many countries have only a small number of such specialists serving large populations. According to the World Health Organization (WHO, 2024), this shortage contributes to delayed diagnosis, limited access to specialized neurological care, and a large treatment gap for people living with epilepsy in many African countries including Uganda. The limited availability of neurological specialists places a greater burden on primary health-care workers, families, and caregivers, who often provide most of the day-to-day care with limited specialist support.

Epilepsy is generally regarded as a chronic neurological disorder that often requires long-term management rather than a definitive cure. Although many individuals achieve good seizure control with appropriate antiseizure medication, treatment is frequently prolonged and, in some cases, lifelong. The course of the condition varies depending on the underlying cause, seizure type, and response to treatment. Consequently, sustained access to appropriate medical care and adherence to prescribed medication are essential components of epilepsy management (Chakraborty et al., 2021).

Beyond its clinical manifestations, epilepsy has significant psychological, social, and economic consequences for affected individuals and their families. Recurrent seizures, uncertainty about future episodes, and the social meanings attached to the condition may contribute to psychological distress, reduced participation in social activities, and limitations in education, employment, and community life. The long-term nature of epilepsy also places considerable demands on caregivers, who often assume responsibility for supervising treatment, providing daily support, and meeting the financial costs associated with healthcare, transportation, and ongoing care (Sarkar et al., 2021).

In Uganda, the management of epilepsy is influenced by both health system constraints and sociocultural factors. Access to effective treatment remains limited because of shortages of trained healthcare professionals, inadequate diagnostic services, inconsistent availability of antiseizure medicines, and challenges related to distance and transportation to health facilities. In addition, stigma, religious beliefs, and cultural interpretations of epilepsy-including beliefs that the condition is contagious or caused by supernatural forces-may influence decisions about where and when treatment is sought, adherence to biomedical care,

and the experiences of both persons living with epilepsy and their caregivers. These interconnected structural and cultural factors continue to shape access to treatment and the overall management of epilepsy within many Ugandan communities (Koltai et al., 2021).

1.1.4 Challenges face in caring for persons dealing with epilepsy.

Research persons with epilepsy experience multiple and interconnected challenges. These include persistent anxiety arising from the unpredictable nature of seizures, fear of injury or sudden death, physical exhaustion associated with continuous supervision, financial strain due to treatment costs and reduced income, and emotional stress related to uncertainty about the future (Alyafei et al., 2021). Many caregivers also experience sleep disturbances, social isolation, and psychological distress because caregiving requires constant vigilance and may interfere with employment, education, and participation in community life (Karakis et al., 2025).

Beyond these practical challenges, epilepsy continues to carry substantial social and cultural meanings across many societies. Misconceptions linking epilepsy to supernatural causes, curses, witchcraft, spirit possession, or contagion remain widespread in some communities. Such beliefs often contribute to stigma, discrimination, and social exclusion directed not only at persons living with epilepsy but also at their family members and caregivers (George et al., 2020). Caregivers may therefore experience embarrassment, shame, reduced social interaction, and negative attitudes from community members, which further increase the emotional burden associated with caregiving (Yu et al. (2025).

1.1.5 Coping strategies

Although caregiving is often associated with considerable challenges, international literature also demonstrates that caregivers develop various strategies to adapt to their responsibilities (Shao 2022). These include seeking emotional and practical support from family members, health professionals, friends, and community networks; acquiring knowledge about epilepsy and seizure management; adjusting daily routines to accommodate caregiving responsibilities; participating in caregiver support groups; and drawing strength from religious and spiritual beliefs. (Catalao et al., 2018). These coping strategies help caregivers maintain resilience, continue providing care, and improve their capacity to respond to the long-term demands associated with epilepsy (Kalembo et al., 2018).

From a medical anthropology perspective, caregiving extends beyond providing physical assistance to persons dealing with epilepsy. It represents a socially and culturally situated experience shaped by family relationships, cultural beliefs, community expectations, economic circumstances, health system factors, and historical contexts. Medical anthropology emphasizes that illness is experienced not only through biological symptoms but also through the meanings that individuals and communities attach to disease and caregiving. Understanding caregivers lived experiences therefore requires attention to how they interpret epilepsy, negotiate competing biomedical and cultural explanations, interact with health services, and manage the everyday realities of caring for a family member with a chronic neurological condition.

Recognizing the central role of caregivers is increasingly important for improving epilepsy care globally. While considerable progress has been made in understanding the clinical management of epilepsy, less attention has historically been given to the experiences of family caregivers, particularly in resource-constrained settings. Exploring caregivers lived experiences provides valuable evidence for strengthening family-centred epilepsy care, informing psychosocial interventions, reducing stigma, improving caregiver support services, and promoting policies that address both the medical and social dimensions of epilepsy.

1.1.6 Africa and Uganda Context

In Africa, epilepsy remains one of the most common neurological disorders and is a major public health concern. The burden of the condition is particularly high in many low- and middle-income countries, where access to diagnostic services, specialized neurological care, and continuous supplies of anti-seizure medicines is often limited. As a result, many persons with epilepsy experience delayed diagnosis, interrupted treatment, frequent seizures, preventable complications, and reduced quality of life. These challenges place substantial responsibility on family members, who provide most of the daily care and support for persons living with epilepsy.

The caregiving role in many African societies extends beyond assisting with treatment. Family members often supervise medication, monitor seizure episodes, provide emotional support, accompany patients to health facilities, protect them from injury during seizures, and meet their basic daily needs. Because these responsibilities are usually performed within the family without formal caregiving services, caregivers frequently experience emotional stress, physical exhaustion, financial hardship, and disruptions to their social and economic

activities. The long-term nature of epilepsy means that caregiving often becomes an enduring responsibility affecting the well-being of the entire household.

The experience of caregiving in Africa is further influenced by cultural beliefs and community perceptions about epilepsy. In some communities, epilepsy continues to be associated with witchcraft, ancestral spirits, curses, or other supernatural causes. Such beliefs contribute to stigma, discrimination, and social exclusion of both persons living with epilepsy and their caregivers. Families may delay seeking biomedical treatment, conceal the condition from neighbours, or rely simultaneously on traditional, religious, and biomedical approaches to care. These experiences demonstrate that epilepsy is not merely a neurological disorder but also a social and cultural phenomenon whose meaning varies across communities.

Within this context, caregivers develop different strategies to cope with the demands of long-term care. Many rely on support from extended family members, neighbours, community leaders, health workers, and faith-based organizations. Others draw strength from religious beliefs, prayer, participation in community support networks, and practical adaptations to daily routines. These coping strategies enable caregivers to continue providing care despite the emotional, physical, social, and economic challenges they encounter.

In Uganda, epilepsy remains an important public health challenge, more especially in resource-constrained communities that don't have specialised neurological services. Although the Ministry of Health has integrated epilepsy management into mental health and primary healthcare services, many families continue to face barriers such as long distances to health facilities, shortages of anti-seizure medicines, transport costs, and inadequate public awareness about epilepsy. These barriers often increase the caregiving burden and affect adherence to long-term treatment.

Ugandan studies have shown that caregivers of persons with epilepsy experience psychological distress, stigma, financial strain, physical fatigue, and reduced participation in social and economic activities. Caregivers frequently describe constant worry because seizures occur unpredictably, requiring continuous supervision and limiting their ability to engage in income-generating activities. Families may incur substantial transport costs while seeking treatment, particularly when medicines are unavailable at nearby health facilities. In addition, misconceptions about epilepsy continue to expose both patients and caregivers to discrimination within schools, workplaces, and communities.

Despite these documented challenges, caregivers in Uganda also demonstrate considerable resilience. They draw upon family solidarity, community support, religious faith, and practical experience acquired through years of caring for persons with epilepsy. However, most published Ugandan studies have been conducted outside Northern Uganda, particularly in eastern and southwestern regions. While these studies have contributed significantly to understanding epilepsy and caregiving in Uganda, they do not fully reflect the unique historical, cultural, and social realities of the Acholi sub-region.

The present study was therefore undertaken to explore the lived experiences and coping strategies of caregivers of persons with epilepsy attending Gulu Regional Referral Hospital. By focusing on Northern Uganda, the study seeks to generate context-specific evidence that reflects caregivers' everyday realities within a post-conflict setting and contributes to improving family-centred epilepsy care, psychosocial support, and culturally responsive health services.

1.1.7 Northern Uganda (Acholi Sub-region) and Gulu Regional Referral Hospital

Northern Uganda, particularly the Acholi sub-region, provides a unique social, cultural, and historical context for understanding the experiences of caregivers of persons with epilepsy. For over two decades, the region was affected by armed conflict, population displacement, loss of livelihoods, disruption of social structures, and limited access to health and social services. Although peace has largely been restored, the long-term effects of the conflict continue to influence household livelihoods, family relationships, community support systems, and access to healthcare. These realities shape how families experience chronic illnesses such as epilepsy and how caregivers respond to the demands of providing long-term care.

Within the Acholi community, caring for a sick family member is traditionally regarded as a collective family responsibility rooted in kinship, reciprocity, and cultural obligations. Parents, siblings, spouses, grandparents, and other close relatives are expected to provide physical, emotional, social, and financial support to family members living with chronic illness. Consequently, caregiving for a person dealing with epilepsy is often viewed not only as a personal responsibility but also as a moral and cultural obligation. While this family-centred approach can strengthen social support, it may also place considerable emotional, physical, and economic demands on caregivers, particularly where poverty and limited access to health services exist.

Despite improvements in healthcare delivery, families in Northern Uganda continue to experience challenges in accessing comprehensive epilepsy care. Long distances to referral facilities, transport costs, intermittent availability of anti-seizure medicines, limited specialist neurological services, and shortages of mental health personnel may affect continuity of treatment and increase dependence on family caregivers. In addition, misconceptions about epilepsy remain present in some communities, where seizures may still be associated with supernatural causes, curses, or witchcraft. Such beliefs may contribute to stigma, delayed treatment seeking, social exclusion, and emotional distress for both persons living with epilepsy and their caregivers.

Caregivers in the Acholi sub-region therefore provide care within a complex environment shaped by cultural beliefs, family expectations, economic hardship, and the continuing social consequences of post-conflict recovery. Their caregiving responsibilities frequently extend beyond assisting with medication and responding to seizures. They often accompany patients to health facilities, monitor treatment adherence, provide emotional reassurance, protect patients from injury during seizures, meet household needs, and balance caregiving with farming, employment, and other family responsibilities. These multiple responsibilities influence caregivers' physical health, emotional well-being, social participation, and household livelihoods.

The present study was conducted at Gulu Regional Referral Hospital, the principal public referral hospital serving the Acholi sub-region and neighbouring districts of Northern Uganda. The hospital functions as a regional referral centre and a teaching hospital for Gulu University, providing specialized services for patients with neurological and mental health conditions, including epilepsy. According to the study context described in this thesis, the hospital receives a large number of patients from across Northern Uganda who seek diagnosis, treatment, follow-up care, and psychosocial support for epilepsy and other neurological disorders.

The Mental Health Department of Gulu Regional Referral Hospital provides an important setting for understanding caregivers lived experiences because many caregivers regularly accompany patients during outpatient visits and hospital admissions. Through these interactions, caregivers encounter the realities of long-term epilepsy management, including treatment adherence, medicine availability, transport challenges, financial pressures, and the emotional demands associated with recurrent seizures. The hospital therefore offers an

appropriate environment for exploring how caregivers experience epilepsy within their everyday social and cultural lives.

Although studies conducted elsewhere in Uganda have documented stigma, psychological distress, financial burden, and coping among caregivers of persons with epilepsy, limited qualitative evidence has specifically examined these experiences within the Acholi sub-region. The unique historical experiences of conflict, displacement, changing family structures, and evolving health systems distinguish Northern Uganda from many other parts of the country. Exploring caregivers' lived experiences in this setting provides context-specific evidence that reflects the realities of caregiving within post-conflict communities and contributes to strengthening family-centred epilepsy care, psychosocial support, and culturally responsive health services.

Understanding caregiving within this context is central to medical anthropology because it recognises that epilepsy is experienced not only as a neurological disorder but also as a condition whose meaning and management are shaped by history, culture, social relationships, economic circumstances, and interactions with the healthcare system. Examining caregivers' lived experiences at Gulu Regional Referral Hospital therefore provides a deeper understanding of how families negotiate the everyday challenges of epilepsy while drawing upon cultural values, family support, spirituality, and personal resilience to sustain long-term caregiving.

1.1.8 Knowledge Gap Leading to the Study

Although considerable progress has been made in epilepsy research globally and within Uganda, much of the existing evidence has focused on the epidemiology of epilepsy, clinical management, treatment outcomes, seizure control, prevalence, and the experiences of persons living with epilepsy. Comparatively less attention has been given to the everyday lived experiences of family caregivers, despite their central role in supporting persons with epilepsy throughout the course of the illness.

Available international studies have documented that caregivers frequently experience emotional distress, physical exhaustion, financial hardship, social isolation, and stigma. These studies have also highlighted the importance of family support, health education, spirituality, and community resources in helping caregivers cope with the demands of long-term care. While these findings provide valuable insights into epilepsy caregiving, they

largely reflect experiences from social, cultural, and health system contexts that differ from those of Northern Uganda.

Within Uganda, previous studies have similarly reported that caregivers experience psychological distress, stigma, financial challenges, and caregiving burden. However, most of these studies have been conducted in regions such as Eastern and Southwestern Uganda. Although they contribute significantly to understanding epilepsy caregiving, they provide limited insight into the lived realities of caregivers in the Acholi sub-region, where caregiving occurs within a distinctive post-conflict social and cultural environment.

Northern Uganda has unique historical, cultural, and socio-economic characteristics that may shape caregiving experiences differently from other parts of the country. The legacy of prolonged armed conflict, population displacement, disruption of family support systems, widespread poverty, and continuing challenges in accessing healthcare may influence how caregivers understand epilepsy, respond to caregiving responsibilities, seek support, and develop coping strategies. These contextual realities cannot be fully understood by relying solely on evidence generated from other regions of Uganda.

Furthermore, limited qualitative research has explored caregiving from the perspective of caregivers themselves within the setting of Gulu Regional Referral Hospital. Existing evidence provides insufficient understanding of how caregivers interpret their experiences, negotiate social and cultural beliefs about epilepsy, manage emotional and financial pressures, experience community stigma, and sustain long-term caregiving within their everyday lives. There is also limited evidence describing how caregivers draw upon family relationships, spirituality, community support, and personal resilience to cope with these challenges.

From a medical anthropology perspective, understanding caregiving requires more than documenting the challenges associated with epilepsy. It also requires examining how caregivers construct meaning around illness, how cultural values and social relationships shape caregiving practices, and how broader historical and structural factors influence everyday experiences. Such understanding is essential for developing family-centred responses that focus to the realities about caregivers within their own communities.

This study was therefore undertaken to explore the lived experiences and coping strategies of caregivers of persons with epilepsy attending Gulu Regional Referral Hospital. This research

generates context-specific evidence grounded in caregivers' own narratives and everyday experiences. It adds to more detailed information about caregiving within Northern Uganda and provide evidence that may inform caregiver support programmes, psychosocial interventions, epilepsy service delivery, health policy, and future research aimed at improving the well-being of caregivers and persons dealing with epilepsy.

1.2 Problem Statement

Epilepsy is a chronic neurological disorder that requires continuous medical care and long-term family support. While considerable attention has been given to the diagnosis, treatment, and clinical management of epilepsy, less attention has been paid to the experiences of family caregivers who provide day-to-day care for persons living with the condition. Caregivers play a central role in supporting treatment adherence, responding to seizures, preventing injuries, providing emotional support, accompanying patients to health facilities, and meeting their daily needs. These responsibilities often extend over many years and may profoundly affect caregivers' emotional well-being, physical health, social relationships, and economic livelihoods.

Existing studies have documented that caregivers of persons with epilepsy frequently experience emotional distress, stigma, financial hardship, physical exhaustion, and disruptions to their normal social and economic activities. However, much of the available evidence has focused on the clinical aspects of epilepsy, treatment outcomes, or the experiences of persons dealing with epilepsy rather than the lived experiences of family caregivers. Furthermore, most previous studies about epilepsy that were carried out in Uganda did not reflect northern Ugandan context. It was particularly in Eastern and Southwestern Uganda, leaving limited qualitative evidence on caregiving experiences within the Acholi sub-region.

The Acholi sub-region has a unique historical and socio-cultural context shaped by prolonged armed conflict, population displacement, poverty, changing family structures, and evolving health services. These contextual factors may influence how caregivers understand epilepsy, experience caregiving responsibilities, access health services, respond to community attitudes, and develop coping strategies. Yet, little is known about how caregivers attending Gulu Regional Referral Hospital experience these realities in their everyday lives or how they make sense of the challenges associated with providing long-term care for persons dealing with epilepsy.

Without such context-specific understanding, interventions designed to improve epilepsy care may overlook the social, cultural, emotional, and economic realities that influence caregiving within families. This may limit the effectiveness of caregiver support programmes, psychosocial interventions, health education, and policies intended to improve the quality of life of both caregivers and persons living with epilepsy.

Therefore, there was a need to explore the lived experiences and coping strategies of caregivers of persons dealing with epilepsy attending Gulu Regional Referral Hospital. Using a qualitative phenomenological approach, this study sought to generate an in-depth understanding of caregivers' experiences within their own social and cultural context and to provide evidence that may inform family-centered epilepsy care, strengthen psychosocial support services, reduce stigma, and contribute to the development of culturally responsive policies and interventions for epilepsy care in Northern Uganda.

1.3 Purpose of the Study

The purpose of this study was to explore the lived experiences and coping strategies of caregivers of persons dealing with epilepsy attending Gulu Regional Referral Hospital in Northern Uganda. Specifically, this research focused on caregivers experienced emotional, physical, social, economic demands of providing long-term care, how they interpreted these experiences within their socio-cultural context, and the strategies they employed to cope with the challenges associated with caregiving. Through a qualitative phenomenological approach, the study aimed to generate context-specific evidence that could contribute to strengthening family-centred epilepsy care, enhancing psychosocial support services, informing culturally responsive healthcare interventions, and guiding future research and policy on caregiver support in Northern Uganda.

1.4 Research questions

1.4.1 Broad research question

The broad research question is: how do Caregivers manage persons dealing with epilepsy in Gulu Regional Referral Hospital?

1.4.2 Specific research questions

i. What are the caregiver’s lived experiences in caring for persons with epilepsy in Gulu Regional Referral Hospital?

ii. What strategies did caregivers employ to cope with negative experiences while caring for a person dealing with epilepsy?

1.5 Study objectives

1.5.1 Broad objective/rationale.

The main objective was to understand the Caregivers' experiences and coping strategies in caring for Persons dealing with epilepsy in Gulu Regional Referral Hospital.

1.5.2 Specific objectives

i. To understand caregiver's experiences in caring for persons dealing with epilepsy in Gulu Regional Referral Hospital.
ii. To investigate coping strategies employed by caregivers in handling negative experiences while caring for a person dealing with epilepsy, in Gulu Regional Referral Hospital.

1.6 Justification of the Study

Caregivers play a fundamental role in the long-term management of epilepsy by providing continuous physical, emotional, social, and practical support to persons dealing with the condition. Despite their central contribution to treatment adherence, seizure management, and overall well-being of persons with epilepsy, caregivers often provide this care with limited recognition and support. While considerable research has focused on the clinical management of epilepsy and the experiences of persons dealing with the condition, comparatively little attention has been given to understanding the lived experiences of family caregivers, particularly within the socio-cultural context of Northern Uganda.

Previous studies conducted in Uganda have documented caregiver burden, stigma, financial hardship, and psychological distress. However, much of this evidence has been generated outside the Acholi sub-region. Consequently, there has been limited qualitative evidence describing how caregivers attending Gulu Regional Referral Hospital experience caregiving within a post-conflict environment characterized by changing family structures, economic constraints, evolving health services, and diverse cultural understandings of epilepsy. This study was therefore undertaken to address this contextual gap by exploring caregivers' experiences from their own perspectives and within their everyday social and cultural realities.

The study is further justified by the need to generate evidence that extends beyond describing caregiving challenges to understanding how caregivers interpret their experiences, negotiate caregiving responsibilities, and develop coping strategies in response to emotional, physical, social, and economic demands. Such understanding is particularly important in qualitative and medical anthropological research because caregiving is shaped not only by the clinical characteristics of epilepsy but also by family relationships, cultural beliefs, community attitudes, spirituality, and broader social conditions.

The findings of this study provide context-specific evidence that may contribute to strengthening family-centered epilepsy care at Gulu Regional Referral Hospital and in similar healthcare settings. They may also inform the design of caregiver support programmes, psychosocial interventions, health education initiatives, and community awareness activities aimed at reducing stigma and improving the well-being of both caregivers and persons dealing with epilepsy. In addition, the findings contribute to the growing body of qualitative evidence on epilepsy caregiving in Uganda and provide a foundation for future research on family caregiving within resource-constrained and post-conflict settings.

From a Medical Anthropology perspective, this study is justified because it examines epilepsy not only as a neurological disorder but also as a lived social experience. By exploring caregivers' narratives within their cultural and historical context, this research adds more useful information on how illness, caregiving, family obligations, social relationships, and cultural meanings interact to shape everyday experiences. This perspective provides valuable insights for researchers, healthcare professionals, policymakers, and programmed planners seeking to develop culturally responsive and socially appropriate interventions for epilepsy care in Northern Uganda.

1.7 Significance of the Study

The findings of this study are expected to contribute to a better understanding of the lived experiences and coping strategies of caregivers of persons dealing with epilepsy within the socio-cultural context of Northern Uganda. By documenting caregivers' perspectives, the study provides context-specific qualitative evidence that may inform the development of family-centred and culturally responsive approaches to epilepsy care.

The study may benefit healthcare professionals, including nurses, psychiatric clinical officers, counsellors, social workers, psychologists, and medical practitioners working at Gulu

Regional Referral Hospital and similar healthcare facilities. An improved understanding of caregivers' experiences may enable healthcare providers to recognise caregivers as integral partners in epilepsy management and strengthen the provision of psychosocial support, caregiver education, counselling services, and family-centred care.

The findings may also be useful to the Ministry of Health, district health authorities, and other policymakers involved in planning and implementing epilepsy and mental health services. The evidence generated may inform policies and programmes aimed at strengthening caregiver support, improving access to psychosocial services, enhancing community awareness, and reducing stigma associated with epilepsy.

The study may further benefit non-governmental organisations (NGOs), community-based organisations (CBOs), faith-based organisations, and development partners implementing programmes in mental health, disability, community health, and psychosocial support. The findings may assist these organisations in designing culturally appropriate caregiver support interventions, community education programmes, stigma reduction initiatives, and family strengthening activities that respond to the needs identified by caregivers.

For caregivers and families of persons dealing with epilepsy, the study provides an opportunity for their experiences, challenges, and coping strategies to be recognised and documented. The findings may contribute to greater awareness of caregivers' needs and encourage the development of interventions that promote emotional well-being, social support, resilience, and improved quality of life for both caregivers and persons dealing with epilepsy.

It also adds more useful information to the field of Medical Anthropology through giving an in-depth focus on caregiving as a socially and culturally situated experience. It demonstrates how cultural beliefs, family relationships, spirituality, community interactions, and broader socio-economic conditions shape the experience of caring for persons dealing with epilepsy. This perspective enriches qualitative scholarship on chronic illness and caregiving within resource-constrained and post-conflict settings.

Finally, the study contributes to the existing body of qualitative knowledge on epilepsy caregiving in Uganda and may serve as a valuable reference for researchers, students, and academics interested in epilepsy, caregiving, chronic illness, mental health, psychosocial support, and medical anthropology. It may also provide a foundation for future qualitative

and mixed-methods studies aimed at improving caregiver support and epilepsy care in Uganda and comparable settings.

1.8 Scope of the Study

The scope of this study was defined in terms of content, geographical area, and time.

1.8.1 Content Scope

The study explored the lived experiences and coping strategies of caregivers of persons dealing with epilepsy. Specifically, it examined caregivers' experiences of providing long-term care, the challenges they encountered in the caregiving process, and the coping strategies they employed to manage those challenges. The study focused on caregivers' own perspectives and narratives regarding the emotional, physical, social, cultural, and economic dimensions of caregiving. Guided by a qualitative phenomenological approach, the study sought to understand the meanings caregivers attached to their experiences rather than to measure the prevalence or magnitude of caregiving challenges.

1.8.2 Geographical Scope

The study was conducted at Gulu Regional Referral Hospital, located in Gulu City in the Acholi sub-region of Northern Uganda. The hospital serves as the main regional referral facility for the districts of Gulu, Amuru, Nwoya, Omoro, Kitgum, Lamwo, Agago, and Pader, among other neighbouring districts. It provides specialised mental health and neurological services, including epilepsy care, making it an appropriate setting for exploring the lived experiences of caregivers of persons dealing with epilepsy. Participants were recruited from caregivers accompanying persons dealing with epilepsy who attended the hospital for treatment and follow-up care.

1.8.3 Peroid of time covered by the study

This research focused on caregivers lived experiences during period in which they were providing care to persons dealing with epilepsy. Data collection was undertaken during the approved study period described in Chapter Three. The study explored caregivers' experiences as they had evolved over time, recognising that caregiving for epilepsy is a continuous process influenced by the duration of caregiving, family circumstances, cultural beliefs, and interactions with the healthcare system.

1.9 Operational Definitions

For the purpose of this study, the following terms were operationally defined:

Caregiver: A caregiver refers to a family member or significant other who assumes the primary responsibility for providing physical, emotional, social, or practical support to a person dealing with epilepsy. In this study, caregivers included parents, siblings, spouses, guardians, or other relatives who were actively involved in the day-to-day care of a person dealing with epilepsy attending Gulu Regional Referral Hospital.

Person dealing with Epilepsy: A person dealing with epilepsy refers to an individual who has been diagnosed with epilepsy and receives ongoing care and treatment for recurrent seizures at Gulu Regional Referral Hospital. The term is used to acknowledge the individual's experience while avoiding language that defines the person solely by the condition.

Epilepsy: Epilepsy refers to a chronic neurological disorder characterised by a persistent predisposition to experience recurrent unprovoked seizures resulting from abnormal electrical activity in the brain. Within this study, epilepsy was understood as a chronic condition requiring long-term medical care and continuous family support.

Lived Experiences: Lived experiences refer to caregivers' personal perceptions, meanings, feelings, interpretations, and everyday realities associated with providing long-term care to persons dealing with epilepsy. These experiences were explored through caregivers' own narratives using a phenomenological approach.

Coping Strategies: Coping strategies refer to the behavioural, emotional, social, cultural, and spiritual approaches employed by caregivers to manage the challenges associated with caring for persons dealing with epilepsy. These strategies included seeking family support, relying on religious faith, adapting daily routines, and other methods described by participants during the interviews.

Phenomenology: Phenomenology refers to a qualitative research approach that seeks to understand and describe how individuals perceive, interpret, and make meaning of their lived experiences. In this study, the approach was used to explore caregivers' experiences of providing care to persons dealing with epilepsy from their own perspectives.

Medical Anthropology: Medical anthropology refers to the study of health, illness, caregiving, and healing within their social, cultural, historical, and political contexts. In this

study, it provided the theoretical lens for understanding how caregivers' experiences were influenced by cultural beliefs, family relationships, community interactions, spirituality, and the broader socio-economic environment.

Stigma: Stigma refers to the negative attitudes, stereotypes, discrimination, and social exclusion experienced by caregivers and persons dealing with epilepsy as a result of societal misconceptions and cultural beliefs about epilepsy.

Family-Centred Care: Family-centred care refers to an approach to healthcare that recognises caregivers and family members as essential partners in planning, delivering, and supporting the care of persons dealing with epilepsy while respecting their knowledge, experiences, and cultural values.

Psychosocial Support: Psychosocial support refers to interventions and services that promote the psychological, emotional, social, and behavioural well-being of caregivers and persons dealing with epilepsy through counselling, health education, emotional support, community engagement, and appropriate referral to relevant services.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter reviews the literature related to the lived experiences and coping strategies about caregivers in caring for persons dealing with epilepsy. The main objective was to examine existing theoretical, conceptual, and empirical evidence relevant to the study and to identify the knowledge gaps that justified the need for the present research. The chapter provides a critical synthesis of literature rather than a simple description of previous studies, thereby establishing the context within which the findings of this study are interpreted.

The literature is organised into five major sections. The first section presents a conceptual review of the key concepts underpinning the study, including epilepsy, family caregiving, lived experiences, and coping strategies. The second section discusses the theoretical perspectives that guided the study, with particular emphasis on the Stress Process Theory and the Medical Anthropology Perspective, which provide a framework for understanding caregiving as both an individual and socio-cultural experience. The third section reviews empirical literature from global, African, Ugandan, and Northern Ugandan contexts, highlighting existing evidence on caregivers' experiences, caregiving challenges, and coping strategies. The fourth section presents the conceptual framework illustrating the relationships among the key concepts investigated in the study. Finally, the chapter identifies the knowledge gap emerging from the reviewed literature and demonstrates how the present study contributes to addressing that gap.

The review is guided by the study objectives, which sought to explore the lived experiences of caregivers of persons dealing with epilepsy, examine the challenges they encounter while providing care, and explore the coping strategies they employ in managing those challenges. In keeping with the qualitative phenomenological design, the literature is reviewed to provide a deeper understanding of caregivers' experiences within their social, cultural, and healthcare contexts rather than to quantify the burden of caregiving.

From a Medical Anthropology perspective, the review recognises that caregiving is shaped by interactions among biological, psychological, social, cultural, economic, and historical factors. Accordingly, the literature considers not only the clinical aspects of epilepsy but also the meanings attached to the illness, family caregiving practices, community beliefs, stigma, spirituality, and the organisation of healthcare services. This broader perspective provides the

foundation for understanding caregivers lived experiences within the context of Northern Uganda and informs the interpretation of the study findings presented in subsequent chapters.

2.2 Conceptual Review

A conceptual review provides an understanding of the key concepts that underpin a study and explains how they are interpreted within the context of the research. In qualitative research, concepts provide the foundation for understanding participants' experiences and the meanings they attach to social phenomena. This study was guided by the concepts of epilepsy, family caregiving, lived experiences, and coping strategies, which are discussed below.

2.2.1 Epilepsy

Epilepsy is a chronic neurological disorder characterised by a persistent predisposition to experience recurrent unprovoked seizures resulting from abnormal electrical activity in the brain. The condition affects individuals of all ages and is associated with a wide range of physical, psychological, social, and economic consequences. Although epilepsy is a neurological condition, its impact extends beyond recurrent seizures to influence education, employment, family relationships, social participation, and quality of life.

From a biomedical perspective, epilepsy requires accurate diagnosis, continuous treatment with anti-seizure medicines, regular clinical follow-up, and adherence to treatment plans. Appropriate management can substantially reduce seizure frequency and improve quality of life. However, in many low- and middle-income countries, including Uganda, access to specialised neurological services, diagnostic investigations, and uninterrupted medication remains a challenge. These barriers increase dependence on family members, who provide continuous support to persons dealing with epilepsy.

From a Medical Anthropology perspective, epilepsy is understood not only as a neurological disorder but also as a condition whose meaning is shaped by cultural beliefs, social relationships, historical experiences, and community values. In many societies, epilepsy is interpreted through both biomedical and traditional belief systems. Some communities attribute seizures to supernatural causes, curses, witchcraft, ancestral spirits, or divine punishment, while others understand epilepsy as a medical condition requiring biomedical treatment. These different interpretations influence treatment-seeking behaviour, family responses, social acceptance, and the caregiving experience. Consequently, understanding

epilepsy requires consideration of both its biological characteristics and the socio-cultural context within which it is experienced.

2.2.2 Family Caregiving

Family caregiving refers to the ongoing physical, emotional, social, and practical support provided by family members or significant others to an individual living with a chronic illness or disability. In the context of epilepsy, caregivers commonly include parents, spouses, siblings, guardians, and other close relatives who assume responsibility for supporting persons dealing with epilepsy in their daily lives.

Caregiving involves a wide range of responsibilities, including monitoring seizure episodes, ensuring medication adherence, accompanying patients to health facilities, preventing injuries during seizures, assisting with activities of daily living, providing emotional support, and making healthcare decisions. These responsibilities often continue for many years and require caregivers to balance caregiving with employment, family obligations, and other social responsibilities.

Within African societies, caregiving is frequently regarded as a family and community responsibility based on cultural values of solidarity, reciprocity, and collective support. In the Acholi community, caring for an ill family member is often viewed as both a moral obligation and a social expectation. While these cultural values strengthen family support systems, they may also increase the burden experienced by caregivers when resources are limited or when long-term care is required.

2.2.3 Literature Review for Objective One: Caregivers' experiences in caring for person dealing with epilepsy

This section reviews literature related to the experiences of caregivers who provide care to persons with epilepsy.

Lived experiences refer to individuals' personal perceptions, feelings, interpretations, meanings, and everyday realities associated with a particular phenomenon. Within phenomenological research, lived experiences are explored from the perspective of those who directly experience the phenomenon rather than through predetermined categories or assumptions.

In this study, lived experiences refer to how caregivers perceived, interpreted, and made meaning of caring for persons dealing with epilepsy within their daily lives. These experiences include emotional responses, physical demands, social interactions, financial realities, cultural beliefs, relationships with healthcare providers, and personal reflections arising from long-term caregiving. Exploring these experiences provides a deeper understanding of caregiving beyond observable behaviours and enables the voices of caregivers to be represented in their own words.

2.2.3.1 Emotional and Psychological Experiences

Caregivers of persons with epilepsy often experience emotional distress because seizures are unpredictable and may occur at any time. Yu et al. (2025) found that caregivers frequently reported anxiety, fear, and constant worry about the safety of the person they cared for. George et al. (2020) also reported high levels of psychological distress among caregivers of people with chronic illnesses.

Zhu et al. (2019) found that caregivers of adults with epilepsy had increased levels of anxiety and depression, which affected their quality of life and caregiving ability. In eastern Uganda, Okiah et al. (2023) reported that caregivers experienced fear, helplessness, sadness, and emotional exhaustion due to repeated seizures and uncertainty about the future of the patient.

These studies show that emotional burden is a common experience among caregivers and may affect both their mental health and the quality of care they provide.

2.2.3.2 Physical Burden

The physical demands of caregiving include staying awake at night, assisting patients during seizures, and providing continuous supervision. Ferro (2021) found that caregivers often experienced fatigue, sleep deprivation, headaches, and physical exhaustion.

Gutierrez-Angel et al. (2018) reported that higher levels of caregiver burden were associated with poorer quality of life. Bapat and Shankar (2021) also found that long-term caregiving negatively affected caregivers' health, especially when they had little opportunity for rest or support from other family members.

2.2.3.3 Social and Cultural Experiences

From a medical anthropology perspective, epilepsy is understood not only as a biomedical condition but also through cultural and social meanings. In many African communities, seizures may be associated with witchcraft, curses, or ancestral spirits, and these beliefs influence how affected persons and their caregivers are treated within society.

Makasi et al. (2023) found that misconceptions about epilepsy contribute to stigma and discrimination against both patients and caregivers. Hansen et al. (2018) described affiliate stigma, where caregivers experience shame or social rejection because of their association with a person dealing with epilepsy. Lai et al. (2019) reported that many caregivers withdrew from social activities because of fear of judgment or embarrassment during public seizures.

Such experiences may lead to social isolation and loss of community support, which are important for coping with caregiving demands.

2.2.3.4 Economic Burden

Caregiving for persons with epilepsy can create financial difficulties for families. Hussain et al. (2020) reported that caregivers often spend money on transport, medication, investigations, and other care-related needs, while at the same time losing income because of reduced working hours.

Pokharel et al. (2020) identified financial burden as a major predictor of caregiver stress. Sarkar et al. (2021) further explained that epilepsy creates both direct costs, such as treatment expenses, and indirect costs, such as loss of productivity and income.

In low-resource settings, shortages of antiepileptic medicines in government hospital or health centres may compel families to buy medicines from individual own clinics, increasing out-of-pocket expenditure and placing additional pressure on household resources.

These findings suggest that physical strain is an important component of the caregiving experience.

2.2.4 Literature Review for Objective Two: Coping Strategies used by Caregivers

This section reviews literature related to the coping strategies used by caregivers to manage the challenges associated with caring for persons with epilepsy.

Coping strategies refer to the cognitive, emotional, behavioural, social, cultural, and spiritual approaches used by individuals to manage stressful or demanding situations. For caregivers of persons dealing with epilepsy, coping strategies are essential because caregiving often involves prolonged emotional, physical, financial, and social demands.

Caregivers employ a variety of coping strategies depending on their personal circumstances, available resources, family support, cultural beliefs, and access to healthcare services. These may include seeking emotional support from family members and friends, relying on religious faith and prayer, participating in community support networks, acquiring knowledge about epilepsy, adapting daily routines, sharing caregiving responsibilities, and maintaining positive attitudes despite ongoing challenges.

From a qualitative perspective, coping is understood as a dynamic process that evolves as caregivers respond to changing circumstances throughout the caregiving journey. Examining coping strategies provides valuable insight into caregivers' resilience, adaptation, and capacity to sustain long-term care despite the multiple challenges associated with epilepsy.

2.2.4.1 Seeking Social Support

Many caregivers rely on family members, friends, neighbours, and health workers for practical and emotional support. Wiebe et al. (2022) found that social support helps reduce stress and improves caregivers' ability to cope with caregiving responsibilities.

Kalembo et al. (2018) also reported that caregivers who shared experiences with others felt less isolated and were better able to manage emotional difficulties.

2.2.4.2 Acquiring Knowledge About Epilepsy

Understanding epilepsy and its management helps caregivers respond more confidently during seizures. Fisher et al. (2017) reported that caregiver education improves seizure management and reduces fear during attacks.

Caregivers who receive information from health workers are more likely to follow medication schedules correctly and recognize situations that require medical attention.

2.2.4.3 Religious and Spiritual Coping

Religious and spiritual practices are commonly used coping strategies in African settings. Malik et al. (2023) found that prayer and participation in religious activities helped caregivers maintain hope and emotional stability during difficult periods.

Broxson and Feliciano (2020) also noted that spiritual coping can provide comfort and help individuals manage stress associated with long-term caregiving

2.2.4.4 Practical Planning and Adaptation

Some caregivers cope by organizing daily activities around medication schedules and seizure patterns. Burneo et al. (2021) found that structured routines improve caregiving outcomes and reduce uncertainty.

Caregivers may also modify the home environment to reduce the risk of injury during seizures and adjust work schedules in order to balance caregiving responsibilities with income-generating activities.

2.2.5 Relationship Between the Key Concepts

The concepts discussed above are closely interconnected. Epilepsy creates long-term caregiving responsibilities that shape caregivers lived experiences. These experiences are influenced by cultural beliefs, family relationships, community attitudes, health system factors, and socio-economic conditions. In response to these experiences, caregivers develop coping strategies that enable them to manage caregiving responsibilities and adapt to the challenges they encounter. Understanding these interrelationships provides the conceptual foundation for exploring caregivers lived experiences and coping strategies within the context of Gulu Regional Referral Hospital and the wider Acholi sub-region of Northern Uganda.

2.3 Theoretical Review

A theoretical review provides the foundation for understanding and interpreting the phenomenon under investigation. It explains the theories that guide the study, demonstrates how they relate to the research problem, and provides a framework for interpreting the study findings. In qualitative research, theory serves as a lens through which participants' experiences are understood rather than as a framework for testing hypotheses. This study was guided by the Stress Process Theory and the Medical Anthropology Perspective. Together,

these theoretical perspectives provided a comprehensive understanding of how caregivers experience and make meaning of caring for persons dealing with epilepsy within their social, cultural, and healthcare contexts.

2.3.1 Stress Process Theory

Stress Process Theory originally developed by Leonard I. Pearlin together with his professional friends to explain how long-term caregiving responsibilities influence the psychological, social, and physical well-being of caregivers. The theory proposes that caregiving is a dynamic process in which continuous demands and responsibilities create stress that may affect caregivers' health and quality of life. At the same time, the theory recognises that personal, family, and community resources can help caregivers cope with these stressors and reduce their negative effects.

According to the theory, caregiving involves several interconnected components. Background and contextual factors, such as age, gender, family relationships, socio-economic status, and cultural expectations, influence the caregiving experience. Primary stressors arise directly from providing care and may include responding to unpredictable seizures, assisting with daily activities, ensuring treatment adherence, accompanying patients to health facilities, and providing continuous supervision. Secondary stressors emerge when caregiving affects other areas of life, such as employment, family relationships, financial stability, and social participation. The theory further explains that caregivers utilise coping resources, including family support, social networks, religious faith, personal resilience, and healthcare services, to manage caregiving demands and adapt to their circumstances.

Stress Process presents a useful ways for exploring challenges experienced by caregivers of persons dealing with epilepsy. The theory helps explain how prolonged caregiving responsibilities contribute to emotional distress, physical fatigue, financial strain, and social isolation while recognising that caregivers develop coping strategies that enable them to continue providing care. It also highlights that caregiving experiences vary according to individual circumstances, family relationships, and the availability of social support.

However, Stress Process Theory primarily focuses on psychological and social responses to caregiving and gives limited attention to the broader cultural meanings attached to illness and caregiving. It does not adequately explain how cultural beliefs, traditional understandings of epilepsy, spirituality, and historical experiences influence caregivers' perceptions and

responses. Consequently, this study complemented Stress Process Theory with the Medical Anthropology Perspective to provide a more comprehensive understanding of caregivers lived experiences.

2.3.2 Medical Anthropology Perspective

Medical Anthropology is an interdisciplinary perspective that examines health, illness, healing, and caregiving within their social, cultural, historical, economic, and political contexts. Rather than viewing illness solely as a biological condition, Medical Anthropology recognises that people's experiences of illness are shaped by cultural beliefs, family relationships, social structures, community values, and interactions with healthcare systems.

Within this perspective, epilepsy is understood not only as a neurological disorder but also as a condition whose meaning varies across different societies and cultures. In many communities, biomedical explanations of epilepsy coexist with traditional, religious, and cultural interpretations. These multiple understandings influence how families interpret seizures, seek treatment, provide care, respond to stigma, and interact with healthcare providers. Medical Anthropology therefore emphasises that caregiving cannot be fully understood without considering the cultural and social environment in which it occurs.

The Medical Anthropology Perspective is particularly relevant to this study because caregivers in Northern Uganda provide care within a context shaped by Acholi cultural values, family obligations, religious beliefs, post-conflict experiences, economic realities, and community perceptions of epilepsy. These factors influence how caregivers understand their responsibilities, cope with caregiving challenges, seek support, and negotiate both biomedical and cultural approaches to epilepsy management.

This perspective also emphasises the importance of understanding caregivers' own narratives and meanings attached to caregiving. By exploring caregivers' lived experiences through their own voices, the study recognises that caregiving is not merely a set of tasks but a social and cultural experience influenced by relationships, values, beliefs, and everyday realities. This understanding is consistent with the phenomenological design adopted in the present study.

2.3.3 Relevance of the Theoretical Perspectives to the Present Study

The two theoretical perspectives complement one another and provide a comprehensive framework for understanding caregivers' lived experiences. Stress Process Theory explains

how caregiving responsibilities generate emotional, physical, social, and economic stress while highlighting the role of coping resources in promoting adaptation and resilience. The Medical Anthropology Perspective extends this understanding by explaining how cultural beliefs, family relationships, spirituality, community attitudes, and historical experiences shape caregiving practices and the meanings caregivers attach to epilepsy.

Together, these theoretical perspectives guided the interpretation of caregivers' narratives throughout the study. They informed the exploration of caregiving challenges, coping strategies, and the influence of social and cultural contexts on caregivers' experiences. The combined use of these perspectives enabled the study to generate a holistic understanding of caregiving that integrates psychological, social, cultural, and anthropological dimensions, thereby providing a strong theoretical foundation for interpreting the findings and drawing conclusions.

2.4 Global Empirical Evidence

Globally, a growing body of empirical research has examined the experiences of caregivers of persons with epilepsy, demonstrating that caregiving extends beyond providing physical assistance to encompass emotional, psychological, social, and economic responsibilities. The literature consistently shows that family caregivers are central to epilepsy management because they supervise medication, monitor seizure episodes, provide emotional support, accompany patients to health facilities, and protect them from injury during seizures. While these responsibilities contribute to improved patient outcomes, they also expose caregivers to considerable caregiving burden and psychosocial challenges.

Studies conducted in different countries have consistently reported that emotional and psychological distress is one of the most common experiences among caregivers of persons with epilepsy. Yu et al. (2025) found that caregivers frequently experienced persistent anxiety, fear, emotional exhaustion, and constant worry arising from the unpredictable nature of seizures. Similarly, George et al. (2020) reported that caregivers experienced high levels of psychological distress associated with continuous caregiving responsibilities. Zhu et al. (2019) further observed that prolonged caregiving increased caregivers' vulnerability to anxiety and depression, negatively affecting their quality of life and caregiving capacity. Collectively, these studies demonstrate that emotional distress is a recurring feature of epilepsy caregiving across different healthcare settings.

Global evidence also indicates that caregiving has significant social and cultural consequences. Several studies have shown that misconceptions and stigma surrounding epilepsy continue to influence caregivers' relationships with family members, neighbours, and the wider community. Caregivers frequently experience social isolation, discrimination, and reduced participation in community activities because epilepsy remains associated with fear, misunderstanding, and negative cultural perceptions in many societies. These findings suggest that caregiving is shaped not only by the clinical characteristics of epilepsy but also by the social environment in which caregiving occurs.

Economic burden has similarly emerged as an important theme in international literature. Hussain et al. (2020) reported that caregivers often incur substantial costs related to transport, medication, and routine healthcare visits while simultaneously experiencing reduced productivity due to the time devoted to caregiving. Continuous caregiving responsibilities frequently limit opportunities for employment and income generation, thereby increasing household financial pressure. These findings suggest that epilepsy affects not only the individual living with the condition but also the economic well-being of the family.

Physical burden is another commonly reported aspect of caregiving. Ferro (2021) found that caregivers of persons dealing with chronic neurological conditions frequently experienced fatigue, sleep disturbances, physical exhaustion, and declining health due to prolonged caregiving responsibilities. Similarly, Bapat and Shankar (2021) reported that continuous caregiving without adequate opportunities for rest or family support negatively affected caregivers' physical well-being. These studies highlight the demanding nature of caregiving and demonstrate that prolonged physical strain may reduce caregivers' capacity to provide sustained care.

Evidence from home-based epilepsy care further demonstrates that family caregivers perform complex responsibilities beyond the health facility. Hussain et al. (2020) reported that caregivers were responsible for administering medication, monitoring seizure patterns, ensuring patient safety, and determining when emergency medical attention was required. However, several studies found that many caregivers received limited formal education or training on seizure management, reducing their confidence in responding to emergencies and increasing emotional stress. These findings emphasise the importance of strengthening caregiver education and follow-up support as integral components of epilepsy care.

Despite these challenges, international studies consistently demonstrate that caregivers develop diverse coping strategies to sustain long-term caregiving. Wiebe et al. (2022) found that support from family members, friends, and healthcare providers reduced emotional stress and strengthened caregivers' ability to continue providing care. Fisher et al. (2017) further reported that caregiver education improved confidence in seizure management and promoted adherence to treatment recommendations. Religious and spiritual coping has also been widely documented, with Malik et al. (2023) and Broxson and Feliciano (2020) reporting that prayer and participation in religious activities provided emotional comfort, hope, and resilience during periods of prolonged caregiving. Burneo et al. (2021) additionally observed that caregivers adapted by organising daily routines around medication schedules, modifying home environments to improve safety, and adjusting work responsibilities to accommodate caregiving demands.

Although the global literature provides substantial evidence regarding caregiver burden and coping strategies, much of the available research has been undertaken in healthcare systems, socio-economic settings, and cultural environments that differ from Northern Uganda. Consequently, the transferability of these findings to the Acholi sub-region should be interpreted cautiously. Furthermore, many international studies have emphasised caregiver burden using quantitative measures, with comparatively fewer studies exploring caregivers' lived experiences through qualitative phenomenological approaches. This underscores the need for context-specific qualitative research that captures caregivers' own narratives and the meanings they attach to caring for persons with epilepsy within their unique social and cultural settings.

2.5 Empirical Evidence from Africa

Empirical evidence from Africa demonstrates that caregivers of persons dealing with epilepsy experience complex emotional, social, cultural, physical, and economic challenges that influence their quality of life and caregiving capacity. Although the nature of caregiving is similar to that reported globally, the African context presents additional challenges arising from limited healthcare resources, shortages of specialist neurological services, poverty, and persistent socio-cultural beliefs surrounding epilepsy. Consequently, caregiving is often undertaken within environments where families receive limited formal support and assume primary responsibility for long-term epilepsy management.

Several studies conducted across sub-Saharan Africa have reported that emotional and psychological distress is a common experience among caregivers of persons dealing with epilepsy. Caregivers frequently describe feelings of fear, anxiety, uncertainty, frustration, and emotional exhaustion associated with the unpredictable occurrence of seizures and concerns about the future of their family members. Continuous caregiving responsibilities, coupled with uncertainty regarding treatment outcomes, often contribute to chronic stress and reduced psychological well-being. These findings indicate that caregiving extends beyond physical assistance and has profound emotional implications for caregivers.

African studies also demonstrate that stigma remains one of the most significant challenges experienced by caregivers. In many communities, epilepsy continues to be associated with witchcraft, curses, ancestral spirits, or other supernatural explanations. Such beliefs contribute to discrimination against both persons living with epilepsy and their caregivers. Families may experience social exclusion, negative community attitudes, and reluctance to disclose the condition because of fear of ridicule or rejection. Consequently, caregivers often become socially isolated, limiting opportunities to access emotional and practical support from the wider community.

Financial hardship has likewise emerged as a recurring finding in African literature. Caregivers commonly incur substantial expenses related to transport, medication, hospital visits, and other healthcare needs while simultaneously experiencing reduced opportunities for employment and income generation. In many households, caregiving responsibilities require one family member to remain at home to supervise the person dealing with epilepsy, thereby reducing household productivity and increasing economic vulnerability. These financial pressures often affect caregivers' ability to meet other family obligations, including education, nutrition, and basic household needs.

Evidence from African countries further indicates that healthcare system challenges significantly influence caregivers' experiences. Limited availability of specialised neurological services, shortages of trained health professionals, interrupted supplies of anti-seizure medicines, and long travel distances to referral hospitals frequently complicate epilepsy management. These barriers increase dependence on family caregivers, who must coordinate treatment, monitor medication adherence, and respond to seizures with limited professional guidance. The interaction between health system constraints and caregiving responsibilities often intensifies emotional stress and caregiving burden.

Despite these challenges, African studies consistently demonstrate remarkable resilience among caregivers. Many caregivers rely on support from spouses, extended family members, neighbours, community groups, faith-based organisations, and healthcare providers to manage caregiving responsibilities. Religious faith and spiritual practices frequently provide hope, emotional comfort, and meaning during prolonged caregiving. In addition, caregivers gradually develop practical skills for recognising seizure triggers, responding appropriately during seizures, organising medication schedules, and adapting daily family routines to accommodate the long-term care needs of persons living with epilepsy. These adaptive strategies strengthen caregivers' ability to sustain caregiving despite persistent challenges.

From a Medical Anthropology perspective, African empirical evidence illustrates that caregiving cannot be understood solely through the biomedical characteristics of epilepsy. Caregivers' experiences are shaped by cultural interpretations of illness, family obligations, community relationships, religious beliefs, socio-economic circumstances, and access to healthcare services. The interaction of these factors influences how caregivers understand epilepsy, make treatment decisions, seek support, and cope with the demands of long-term caregiving.

Although African studies provide valuable insights into caregivers' experiences, many have employed quantitative cross-sectional designs that primarily measure caregiver burden, psychological distress, or quality of life. Comparatively fewer studies have explored caregivers' lived experiences using qualitative phenomenological approaches that privilege caregivers' own narratives and meanings. Furthermore, evidence from post-conflict settings remains limited. These gaps underscore the need for qualitative research that explores caregivers' lived experiences within the unique historical, cultural, and healthcare context of Northern Uganda, thereby providing context-specific evidence to inform family-centered epilepsy care and psychosocial support.

2.6 Empirical Evidence from Uganda

Empirical evidence from Uganda demonstrates that epilepsy remains a significant public health concern with implications that extend beyond the individual dealing with the condition to affect family members who provide day-to-day care. Ugandan studies have consistently shown that caregivers play an essential role in supporting treatment adherence, supervising persons during seizure episodes, accompanying patients to health facilities, and providing emotional and practical support. However, these responsibilities are often undertaken within

a healthcare system characterized by limited specialized neurological services, inconsistent availability of anti-seizure medicines, long travel distances to referral facilities, and persistent socio-cultural misconceptions surrounding epilepsy.

Kaddumukasa et al. (2021) reported that barriers to biomedical epilepsy care in Uganda include limited access to specialized services, shortages of anti-seizure medicines, inadequate knowledge about epilepsy, transport difficulties, and financial constraints. These barriers affect not only persons dealing with epilepsy but also their caregivers, who frequently assume responsibility for navigating the healthcare system while ensuring continuity of treatment. The study further demonstrates that health system limitations may contribute to delayed treatment seeking, interrupted care, and increased caregiving burden.

Similarly, Koltai et al. (2021) found that healthcare providers identified shortages of trained personnel, inadequate diagnostic capacity, stigma, and resource limitations as major challenges affecting epilepsy care in Uganda. These systemic constraints increase reliance on informal family caregiving and require caregivers to undertake responsibilities that might otherwise be supported through formal health and social care services. The findings suggest that strengthening epilepsy care in Uganda requires interventions that recognise caregivers as important partners in treatment and rehabilitation.

Recent qualitative studies conducted within Uganda further highlight the realities of caregiving. Okiah et al. (2023a), working with caregivers attending an epilepsy clinic in Eastern Uganda, reported that caregivers experienced emotional distress, stigma, financial hardship, and disruptions to family life while caring for persons with epilepsy. The study also demonstrated that caregivers relied heavily on family support, religious faith, and information obtained from healthcare workers to sustain long-term caregiving. Likewise, Nanziri et al. (2026), in Southwestern Uganda, found that caregivers frequently experienced emotional strain, social isolation, and economic challenges but gradually developed coping strategies such as seeking social support, adapting household routines, and strengthening spiritual practices. These studies indicate that caregiving is both demanding and adaptive, with caregivers continuously developing ways of responding to changing circumstances.

Other Ugandan evidence has shown that cultural beliefs continue to influence how epilepsy is understood and managed. Misconceptions linking epilepsy to witchcraft, curses, or supernatural forces may delay healthcare seeking, increase stigma, and influence treatment decisions. Such beliefs can also affect caregivers' interactions with the community, contribute

to discrimination, and reduce opportunities for social support. Consequently, caregiving in Uganda occurs within a complex interaction of biomedical, cultural, religious, and socio-economic factors that shape caregivers' everyday experiences.

Despite these important contributions, the available Ugandan literature has several limitations. First, many studies have concentrated on barriers to epilepsy care, healthcare service delivery, or the experiences of persons dealing with epilepsy, with comparatively less attention devoted to caregivers' own lived experiences. Second, the available caregiver studies have largely been conducted in Eastern and Southwestern Uganda. While these studies provide valuable insights, their findings may not fully reflect the realities of caregivers in Northern Uganda, where the social and health system context has been shaped by prolonged armed conflict, population displacement, disrupted family support systems, and continuing socio-economic recovery.

Furthermore, relatively few Ugandan studies have employed a qualitative phenomenological approach to explore how caregivers themselves interpret and make meaning of their caregiving experiences. Understanding caregivers' own perspectives is essential because caregiving is influenced not only by clinical aspects of epilepsy but also by family relationships, cultural beliefs, spirituality, economic circumstances, and community interactions. These gaps justified the present study, which explored the lived experiences and coping strategies of caregivers of persons dealing with epilepsy attending Gulu Regional Referral Hospital in Northern Uganda, thereby contributing context-specific evidence to strengthen family-centred epilepsy care and psychosocial support.

2.6.1 Empirical Evidence from Northern Uganda

Compared with other regions of Uganda, empirical evidence on the lived experiences of caregivers of persons dealing with epilepsy in Northern Uganda remains limited. The available literature indicates that most Ugandan studies on epilepsy caregiving have been conducted in Eastern and Southwestern Uganda, leaving a significant gap in understanding caregiving within the Acholi sub-region. Consequently, little is documented about how caregivers in Northern Uganda experience the day-to-day demands of caring for persons dealing with epilepsy, how they respond to caregiving challenges, and the strategies they employ to sustain long-term care.

The limited evidence that exists suggests that the context of Northern Uganda differs substantially from other parts of the country because of its unique historical, social, and cultural circumstances. The Acholi sub-region experienced prolonged armed conflict, large-scale displacement of communities, disruption of family and community support systems, loss of livelihoods, and long-term socio-economic recovery. These historical experiences have continued to influence household structures, community relationships, access to healthcare, and the ways in which families understand and respond to chronic illnesses such as epilepsy.

The reviewed literature further indicates that caregivers in Northern Uganda provide care within an environment characterised by limited specialised neurological services, long travel distances to referral facilities, inconsistent availability of anti-seizure medicines, and financial constraints. These challenges increase dependence on family caregivers, who assume responsibility for supervising medication, responding to seizure episodes, accompanying patients to health facilities, ensuring patient safety, and balancing caregiving with household and livelihood responsibilities. Despite these realities, there is limited empirical evidence describing how caregivers themselves experience these responsibilities within their everyday social and cultural lives.

The literature also suggests that cultural beliefs continue to shape epilepsy care in Northern Uganda. Families may simultaneously draw upon biomedical services and local cultural or spiritual explanations when interpreting epilepsy and making decisions about treatment. Such beliefs influence treatment-seeking behaviour, community attitudes, family relationships, and caregiving practices. However, there remains limited qualitative evidence exploring how caregivers negotiate these different understandings of epilepsy and how these influence their lived experiences and coping strategies.

Although Gulu Regional Referral Hospital is the principal referral hospital serving Northern Uganda and receives many persons dealing with epilepsy for treatment and follow-up care, previous studies indicates that much is not documented in caregivers who accompany these patients. In particular, there is insufficient evidence describing caregivers' experiences of home-based epilepsy care, their responses to medicine shortages, transport challenges, stigma, financial hardship, and the influence of the Acholi social and cultural environment on caregiving.

From a Medical Anthropology perspective, this limited evidence highlights the importance of understanding caregiving within its local social and cultural context. Caregiving is shaped not only by the clinical characteristics of epilepsy but also by kinship obligations, community relationships, religious beliefs, historical experiences, and everyday socio-economic realities. Exploring caregivers' own narratives is therefore essential for understanding how these interconnected factors influence caregiving practices and coping strategies within Northern Uganda.

Overall, the empirical literature demonstrates a clear regional knowledge gap. While studies conducted elsewhere in Uganda provide valuable insights into epilepsy caregiving, they do not adequately capture the experiences of caregivers in the Acholi sub-region. At the time this study was conducted, no known published study had specifically explored the lived experiences and coping strategies of caregivers of persons with epilepsy attending Gulu Regional Referral Hospital. This gap justified the present study, which sought to generate context-specific qualitative evidence to inform family-centred epilepsy care, psychosocial support, and culturally responsive health interventions in Northern Uganda.

2.7 Summary of the Empirical Literature and Knowledge Gap

The empirical literature reviewed demonstrates that caregivers of persons dealing with epilepsy play an indispensable role in supporting treatment adherence, seizure management, emotional well-being, and the overall care of persons dealing with epilepsy. Studies conducted globally, across Africa, and within Uganda consistently report that caregivers experience multiple challenges, including emotional and psychological distress, physical exhaustion, financial hardship, social isolation, stigma, and difficulties in accessing appropriate healthcare services. The literature further indicates that caregivers employ various coping strategies, such as seeking support from family members, relying on religious faith and spirituality, accessing healthcare services, participating in community support networks, and adapting their daily routines to meet caregiving demands.

Although the reviewed studies provide valuable insights into the challenges associated with epilepsy caregiving, important gaps remain. Globally, many studies have primarily measured caregiver burden, psychological distress, and quality of life using quantitative approaches, with comparatively fewer studies exploring caregivers' lived experiences through qualitative phenomenological inquiry. Similarly, African studies have largely focused on describing caregiving challenges within resource-constrained settings, while providing limited

understanding of how caregivers themselves interpret and make meaning of their experiences within specific cultural and social contexts.

Within Uganda, existing studies have contributed significantly to understanding epilepsy care, health system barriers, stigma, and caregiver burden. However, much of the available evidence has been generated from Eastern and Southwestern Uganda. Consequently, limited empirical evidence exists regarding caregivers' lived experiences in Northern Uganda, particularly within the Acholi sub-region. Furthermore, few Ugandan studies have employed a qualitative phenomenological approach to explore caregivers' own perspectives on the emotional, physical, social, cultural, and economic realities associated with long-term caregiving.

The review also demonstrates that Northern Uganda presents a distinctive context for epilepsy caregiving. The region's history of prolonged armed conflict, population displacement, disruption of family and community support systems, widespread poverty, and evolving healthcare services may influence caregiving experiences in ways that differ from other regions of Uganda. Despite these unique contextual factors, the reviewed literature provides limited evidence on how caregivers attending Gulu Regional Referral Hospital experience caregiving, negotiate cultural beliefs surrounding epilepsy, cope with stigma and financial hardship, and adapt to the demands of providing long-term care.

From a Medical Anthropology perspective, the literature further reveals a need to move beyond biomedical explanations of epilepsy by examining caregiving as a socially and culturally situated experience. Existing studies have paid limited attention to how cultural beliefs, kinship obligations, spirituality, community relationships, and historical experiences shape caregivers' perceptions, decisions, and coping strategies. Understanding these dimensions is essential for developing family-centred and culturally responsive approaches to epilepsy care.

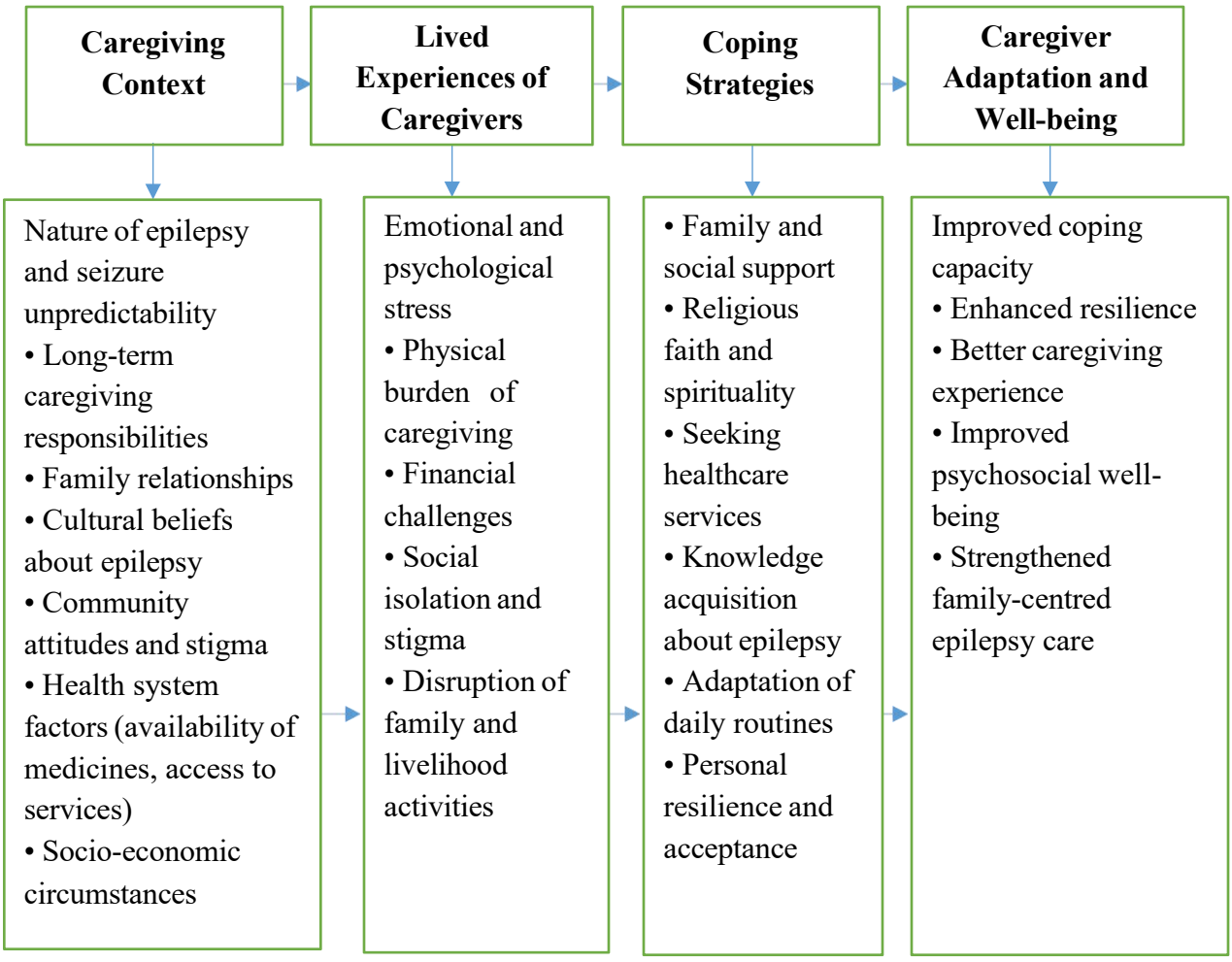
It is against this background that the present study was undertaken. Using a qualitative phenomenological approach, the study explored the lived experiences and coping strategies of caregivers of persons dealing with epilepsy attending Gulu Regional Referral Hospital in Northern Uganda. By giving prominence to caregivers' own narratives and interpretations, the study generated context-specific evidence that contributes to the existing body of knowledge and provides insights that may inform caregiver support programmes, psychosocial

interventions, healthcare practice, policy development, and future research on epilepsy care in Northern Uganda.

2.8 Conceptual Framework

A conceptual framework is a diagrammatic representation of the key concepts under investigation and the relationships among them. In qualitative research, the conceptual framework serves as a guide for understanding the phenomenon being explored rather than testing causal relationships. For this study, the framework was developed from the Stress Process Theory, the Medical Anthropology Perspective, and the empirical literature reviewed. It illustrates how caregiving responsibilities and contextual factors shape caregivers' lived experiences and how caregivers employ coping strategies to respond to the challenges associated with caring for persons dealing with epilepsy.

Figure 2. 1: Conceptual Framework for the Study



Source: Researcher's conceptualisation based on Pearlin's Stress Process Theory, the Medical Anthropology Perspective, and the empirical literature reviewed (2026).

2.8.1 Explanation about Figure 2.1 above

This illustrates relationships among the major concepts that guided this study. The caregiving context comprises the factors that influence caregivers' everyday experiences, including the chronic nature of epilepsy, unpredictable seizure episodes, family responsibilities, cultural beliefs, community attitudes, health system characteristics, and socio-economic conditions. These contextual factors shape the lived experiences of caregivers as they provide long-term care to persons with epilepsy.

The framework further illustrates that caregivers experience a range of emotional, physical, social, and economic challenges while fulfilling caregiving responsibilities. These experiences are not viewed as isolated events but as interconnected realities influenced by caregivers' social and cultural environments.

In response to these challenges, caregivers employ various coping strategies, including seeking support from family members and friends, relying on religious faith and spirituality, obtaining information and assistance from healthcare providers, adapting daily routines, and drawing upon personal resilience. The effectiveness of these coping strategies influences caregivers' adaptation to long-term caregiving and contributes to their overall well-being.

The framework therefore guided data collection, analysis, and interpretation by providing a conceptual understanding of how caregiving responsibilities, contextual influences, lived experiences, and coping strategies are interconnected within the socio-cultural setting of Gulu Regional Referral Hospital and the wider Acholi sub-region of Northern Uganda.

2.9 Knowledge Gap

The literature reviewed demonstrates that considerable research has been conducted globally, across Africa, and within Uganda on epilepsy, caregiver burden, stigma, quality of life, and access to epilepsy care. Existing studies consistently report that caregivers of persons with epilepsy experience emotional distress, physical exhaustion, financial hardship, social isolation, and stigma while providing long-term care. The literature also indicates that caregivers employ various coping strategies, including seeking family support, relying on religious faith, accessing healthcare services, and adapting their daily routines to sustain caregiving responsibilities.

Despite these contributions, important knowledge gaps remain. First, much of the existing literature has employed quantitative approaches that focus on measuring caregiver burden, psychological distress, or quality of life. While these studies provide valuable epidemiological evidence, they offer limited insight into how caregivers themselves perceive, interpret, and make meaning of their caregiving experiences. Consequently, caregivers' own voices and lived realities remain insufficiently documented.

Second, although several studies have been conducted in Uganda, most have focused on epilepsy management, health system challenges, stigma, or the experiences of persons living with epilepsy. Comparatively few studies have explored caregivers' lived experiences using a qualitative phenomenological approach. Furthermore, the available Ugandan caregiver studies have largely been undertaken in Eastern and Southwestern Uganda, leaving Northern Uganda underrepresented in the existing body of knowledge.

Third, the reviewed literature provides limited understanding of how the unique socio-cultural and historical context of the Acholi sub-region influences caregivers' experiences. Northern Uganda has experienced prolonged armed conflict, population displacement, disruption of family and community support systems, and continuing socio-economic recovery. These contextual realities may shape caregiving experiences, coping strategies, treatment-seeking behaviour, and family responses to epilepsy in ways that differ from other regions of Uganda. However, the existing literature provides little empirical evidence on these contextual influences.

In addition, the reviewed studies have paid limited attention to caregiving from a Medical Anthropology perspective. There remains insufficient understanding of how cultural beliefs, kinship obligations, spirituality, community relationships, and broader socio-economic conditions interact to shape caregivers' lived experiences and coping strategies within their everyday lives.

To the best of the researcher's knowledge and based on the literature reviewed, no published qualitative phenomenological study had specifically explored the lived experiences and coping strategies of caregivers of persons with epilepsy attending Gulu Regional Referral Hospital in the Acholi sub-region of Northern Uganda at the time this study was conducted. This study was therefore undertaken to address this gap by generating context-specific qualitative evidence from caregivers' own narratives. The findings contribute to the existing body of knowledge by providing a deeper understanding of caregiving within its social,

cultural, and healthcare context and may inform family-centred epilepsy care, psychosocial support services, health policy, and future research in Northern Uganda.

2.10 Summary of Chapter Two

This chapter examined efficacy of the previous studies to the lived experiences and coping strategies of caregivers of persons dealing with epilepsy. The review began with a conceptual discussion of the key concepts underpinning the study, namely epilepsy, family caregiving, lived experiences, and coping strategies. These concepts provided a foundation for understanding the phenomenon of caregiving within the context of chronic illness and informed the interpretation of caregivers' experiences.

The chapter further examined the theoretical foundations of the study by discussing the Stress Process Theory and the Medical Anthropology Perspective. Together, these perspectives provided complementary lenses for understanding how caregiving responsibilities generate emotional, physical, social, and economic challenges while recognising the influence of cultural beliefs, family relationships, community interactions, spirituality, and healthcare systems on caregivers' lived experiences and coping strategies.

The empirical literature reviewed at the global, African, Ugandan, and Northern Ugandan levels demonstrated that those caring for persons dealing with epilepsy go through diverse challenges, including daily stress, physiological pains, financial hardship, stigma, and social isolation. The review also highlighted that caregivers employ various coping strategies, such as seeking family support, relying on religious faith, accessing healthcare services, and adapting their daily routines to sustain long-term caregiving. However, the review identified important gaps in the existing body of knowledge, particularly the limited use of qualitative phenomenological approaches to explore caregivers' own perspectives and the scarcity of context-specific evidence from Northern Uganda.

The conceptual framework illustrated the relationships among caregiving responsibilities, contextual influences, caregivers lived experiences, coping strategies, and caregiver adaptation. The framework guided the organisation of the study and informed the interpretation of the findings within the broader social, cultural, and healthcare context.

Overall, the literature review established that, even though increasing knowledge about epilepsy caregiving is coming up, challenges still exist about what caregivers go through in caring for persons dealing with epilepsy and coping strategies in social-cultural context of

Acholi sub-region of Northern Uganda. It therefore justified the present study and underscored the need for context-specific qualitative evidence to inform family-centred epilepsy care, psychosocial support, and culturally responsive health interventions.

The next chapter presents the research methodology employed in conducting the study. It describes the research design, study setting, study population, participant selection procedures, data collection methods, data management and analysis, strategies for ensuring trustworthiness, ethical considerations, and the measures undertaken to ensure the rigour of the study.

CHAPTER THREE: RESEARCH METHODOLOGY.

3.1 Introduction

This chapter describes the methodology that was employed to explore the lived experiences and coping strategies of caregivers of persons dealing with epilepsy attending Gulu Regional Referral Hospital in Northern Uganda. It outlines the research methods used to generate trustworthy and context-specific qualitative evidence that addressed the study objectives and research questions.

The chapter presents the research design, study setting, study population, participant selection procedures, inclusion and exclusion criteria, sample size, sampling techniques, data collection methods and instruments, data collection procedures, data management and analysis, strategies for ensuring trustworthiness, ethical considerations, and the limitations encountered during the study. Each methodological component is described to demonstrate the rigour, transparency, and credibility of the research process.

The study adopted a qualitative phenomenological approach because it was considered the most appropriate design for exploring caregivers' lived experiences and the meanings, they attached to caring for persons dealing with epilepsy. Consistent with the Medical Anthropology perspective, the methodology enabled an in-depth exploration of how caregivers understood and interpreted their experiences within their social, cultural, family, and healthcare contexts. This approach provided rich narrative data that informed the findings presented in Chapter Four and the discussion in Chapter Five.

3.2 Research Design

This was a qualitative type of research that utilized a phenomenological method to understand the caregiver's experience and management strategies of persons dealing with epilepsy attending Gulu Regional Referral Hospital in Northern Uganda. A phenomenological approach was considered appropriate because the study sought to understand how caregivers perceived, interpreted, and made meaning of their everyday experiences of providing long-term care to persons dealing with epilepsy. Rather than measuring the frequency or magnitude of caregiving challenges, the study aimed to generate an in-depth understanding of caregivers' personal experiences within their natural social and cultural contexts.

Phenomenology is concerned with understanding how individuals experience a particular phenomenon and how they construct meaning from those experiences. In the present study, the phenomenon of interest was caregiving for persons dealing with epilepsy. The design enabled the researcher to explore caregivers' emotional, physical, social, cultural, and economic experiences, as well as the coping strategies they employed while providing continuous care within their family and community settings.

The study employed in-depth interviews (IDIs) and focus group discussions (FGDs) to collect rich narrative data from caregivers. These methods allowed participants to describe their experiences freely in their own words, providing detailed accounts of how epilepsy affected their daily lives, family relationships, livelihoods, emotional well-being, and interactions with the healthcare system. The use of open-ended discussions enabled the researcher to gain a deeper understanding of caregivers' perspectives within the Acholi socio-cultural context.

Although data were collected during a single period of fieldwork, the study was not cross-sectional in design. Cross-sectional studies are generally quantitative and are used to describe the prevalence or distribution of variables at a specific point in time. In contrast, this study was exploratory and qualitative, focusing on understanding meanings, perceptions, and lived experiences rather than measuring prevalence or testing statistical relationships. The emphasis was therefore placed on generating rich descriptions of caregiving experiences rather than producing numerical estimates.

The phenomenological design was particularly suitable because caregiving for persons dealing with epilepsy is a complex human experience shaped by multiple interacting factors. The design enabled the researcher to explore how caregivers experienced emotional stress, physical burden, stigma, financial hardship, uncertainty, and hope while simultaneously examining how family relationships, cultural beliefs, spirituality, community attitudes, and the post-conflict realities of Northern Uganda influenced these experiences. This holistic understanding was consistent with the Medical Anthropology perspective adopted in the study.

3.2.1 How phenomenology was used in the study

In applying the phenomenological approach, priority was given to caregivers' own voices and interpretations. Participants were encouraged to narrate their everyday experiences, including caring for relatives during seizure episodes, responding to medicine shortages, balancing

caregiving with household and livelihood responsibilities, coping with stigma, seeking family and spiritual support, and adapting their daily routines to meet caregiving demands. These narratives enabled the researcher to understand caregiving as it was experienced and understood by caregivers themselves rather than through predetermined categories or assumptions.

The qualitative phenomenological research design therefore provided the most appropriate methodological framework for achieving the study objectives. It enabled an in-depth exploration of caregivers' lived experiences and coping strategies while recognising the influence of social, cultural, economic, historical, and healthcare factors on caregiving within the Acholi sub-region of Northern Uganda.

3.2.2 Understanding meaning within the Acholi social context

The researcher also paid attention to the social and cultural context of northern Uganda. Caregivers' experiences were understood within Acholi family life, where caring for a sick relative is often seen as a family responsibility. The study explored how community attitudes, kinship obligations, spiritual beliefs, and the history of conflict and displacement influenced caregiving.

For instance, some caregivers connected their strength to prayer and support from church communities, while others feared social isolation because of misconceptions about epilepsy. These experiences were interpreted as part of the caregivers' social world, not simply as individual emotions.

3.2.3 The role of the researcher

During data collection, the researcher remained actively involved in the interview process. The researcher:

- listened carefully to participants' explanations of caregiving;
- encouraged participants to speak freely and in their own words;
- asked probing questions to get clarification and deeper understanding;
- avoided imposing personal opinions or explanations during the interviews;
- observed non-verbal expressions such as silence, crying, hesitation, and emotional reactions;

- paid attention to how caregivers described their relationships, responsibilities, and everyday struggles within their families and communities; and
- recorded field notes immediately after each interview to capture important observations and reflections.

These actions helped the researcher obtain detailed descriptions of caregivers lived experiences and ensured that the findings reflected the participants' own perspectives and meanings.

3.2.4 From lived experiences to themes

After the interviews were transcribed, the researcher read the transcripts several times and identified experiences that appeared repeatedly across participants. These were grouped into themes such as; emotional and psychological stress, financial challenges, social isolation and stigma, physical burden of caregiving, family and social support, religious and spiritual coping and acceptance and adaptation.

These themes were developed from the caregivers' narratives and were used to describe the common patterns in how caregiving was experienced.

3.2.5 What phenomenology helped the study achieve

Using phenomenology enabled the study to move beyond general statements such as "caregivers experience stress." It showed how stress was lived, through sleepless nights, constant vigilance, fear of sudden seizures, loneliness, and uncertainty about the future.

It also showed that caregivers were not only victims of burden; they were active people who developed ways of coping, including sharing responsibilities with relatives, relying on prayer, adjusting daily routines, and seeking support from health workers and neighbours.

Most importantly, phenomenology helped keep the human experience of caregiving. The caregivers' voices remained central throughout the study, allowing the findings to reflect their realities as they are lived in northern Uganda.

In this study, the phenomenon was caregiving for persons dealing with epilepsy. I used in-depth interviews and focus group discussions to allow caregivers to describe their experiences in their own words. I focused on how caregiving affected their emotions, sleep, work, social relationships, and future expectations. After transcribing the interviews, I

analysed the narratives thematically and interpreted the findings within the Acholi social and cultural context. This approach helped me understand caregiving not only as a medical responsibility but also as a lived social experience shaped by family obligations, stigma, spirituality, poverty, and the post-conflict realities of northern Uganda.

3.3 Study Area

The study was conducted at Gulu Regional Referral Hospital (GRRH), located in Gulu City in the Acholi sub-region of Northern Uganda. Gulu City lies approximately 330 kilometres north of Kampala, the capital city of Uganda, and serves as the major commercial, administrative, and healthcare centre for Northern Uganda. Gulu Regional Referral Hospital is one of the regional referral hospitals under the Ministry of Health and serves as the principal referral facility for the Acholi sub-region and neighbouring districts.

The hospital provides specialised healthcare services to a large catchment population, including residents of Gulu, Amuru, Nwoya, Omoro, Kitgum, Lamwo, Agago, and Pader districts, as well as patients referred from surrounding regions. Among its specialised services are mental health and neurological care, including the diagnosis, treatment, follow-up, and counselling of persons dealing with epilepsy. These services attract patients with epilepsy and their caregivers from both urban and rural communities, making the hospital an appropriate setting for exploring caregivers' lived experiences.

The mental health department in Gulu Regional Referral Hospital provides comprehensive care that includes clinical assessment, prescription and monitoring of anti-seizure medicines, health education, counselling, and referral to other specialised services when necessary. Family caregivers frequently accompany persons dealing with epilepsy to the clinic, participate in treatment decisions, receive health information from healthcare providers, and provide continuous care at home. Consequently, the hospital offers an appropriate environment for understanding caregivers' experiences throughout the continuum of epilepsy care.

The Acholi sub-region presents a unique socio-cultural and historical context that makes it particularly relevant for this study. The region experienced prolonged armed conflict that resulted in population displacement, disruption of family and community support systems, loss of livelihoods, and long-term socio-economic challenges. Although considerable progress has been made in post-conflict recovery, many households continue to experience

poverty, limited access to healthcare services, and changing family structures. These contextual factors may influence caregiving responsibilities, treatment-seeking behaviour, family support systems, cultural beliefs about epilepsy, and caregivers' coping strategies.

At Gulu Regional Referral Hospital, medics attended to 1.9 million clients annually. Of these, 800 suffered from various mental health and neurological illnesses such as epilepsy (Greater North Agency, 2024).

From a Medical Anthropology perspective, Gulu Regional Referral Hospital provides an important setting for examining caregiving within the interaction of biomedical care and the local socio-cultural environment. Caregivers attending the hospital bring diverse cultural beliefs, family experiences, religious perspectives, and community influences that shape how epilepsy is understood and managed. Exploring caregivers' lived experiences within this setting enabled the study to generate context-specific qualitative evidence that reflects the realities of epilepsy caregiving in Northern Uganda.

Gulu Regional Referral Hospital was purposively selected because it is the largest referral facility providing specialised epilepsy services in the region and receives a high volume of persons dealing with epilepsy and their caregivers. This made it an appropriate site for recruiting information-rich participants capable of providing detailed accounts of their lived experiences and coping strategies, consistent with the objectives of the study.

3.4 Study Population

The study population comprised caregivers of persons dealing with epilepsy who were accessing services at the Mental Health Department of Gulu Regional Referral Hospital in Gulu City, Northern Uganda. The caregivers included parents, spouses, guardians, siblings, other family members, and significant others who had primary responsibility for providing day-to-day care and support to persons dealing with epilepsy. Their caregiving responsibilities included accompanying patients to the hospital, supervising medication, responding to seizure episodes, ensuring safety, providing emotional support, and assisting with other daily care needs.

The study focused exclusively on caregivers because they are central to the long-term management of epilepsy and possess first-hand knowledge of the realities associated with caregiving. Through their continuous interaction with persons dealing with epilepsy, caregivers experience the emotional, physical, social, cultural, and economic demands of

caregiving and are therefore well positioned to provide rich descriptions of these experiences. Their perspectives were essential for achieving the study objective of exploring the lived experiences and coping strategies associated with caring for persons dealing with epilepsy.

Persons dealing with epilepsy, healthcare providers, and community members were left out because primary focus was to understand caregiving from the perspective of those directly responsible for providing continuous care. Restricting the study population to caregivers ensured that the findings reflected their own lived experiences and meanings rather than the perspectives of other groups.

The study population was further consistent with the qualitative phenomenological research design, which seeks to obtain in-depth information by interviewing caregivers of persons dealing with epilepsy. By selecting caregivers with direct caregiving experience, the study generated rich narrative data that enhanced understanding of caregiving within the social, cultural, and healthcare context of the Acholi sub-region of Northern Uganda. The findings therefore reflect caregivers' lived realities rather than attempting to generalise to all caregivers of persons dealing with epilepsy in Uganda.

3.5 Sample Size and Sampling Technique

The study involved 60 caregivers of persons dealing with epilepsy attending the Mental Health Department of Gulu Regional Referral Hospital. The sample comprised caregivers who had direct experience in providing day-to-day care and were therefore rich, detailed information-rich accounts and coping strategies.

In qualitative phenomenological research, the emphasis is placed on obtaining depth, richness, and diversity of experiences rather than achieving statistical representativeness. Consequently, the sample size was determined by the study objectives, the need to obtain detailed narratives from caregivers with direct experience of the phenomenon under investigation, which stopped at the time when no new information was coming from participants' accounts.

This study employed purposive sampling to recruit participants. Purposive sampling was considered appropriate because it enabled the researcher to deliberately select caregivers who possessed first-hand experience of caring for persons dealing with epilepsy and could therefore provide relevant information to address the research questions. Only caregivers who

met the inclusion criteria and were able to describe their caregiving experiences in detail were invited to participate.

With the support of the Mental Health Department, the researcher identified eligible caregivers who accompanied persons dealing with epilepsy to Gulu Regional Referral Hospital for outpatient services or who were caring for admitted patients. Participants' eligibility was verified using hospital medical records and clinical documentation confirming that they were caring for a person diagnosed with epilepsy. Eligible caregivers were approached after they had received the healthcare services for which they had attended the hospital, the purpose of the study was explained, written informed consent was obtained, and those who agreed were recruited into the study.

Recruitment continued throughout the data collection period until the target sample of 60 caregivers was reached and thematic saturation had been attained. The sample included caregivers aged between 20 and 60 years from both inpatient and outpatient settings, thereby ensuring variation in caregiving experiences while maintaining the phenomenological focus on participants who had directly experienced the phenomenon under investigation.

The use of purposive sampling was consistent with the qualitative phenomenological design because it prioritised participants with direct experience of the phenomenon rather than selecting participants through probability-based procedures. This approach enabled the researcher to generate rich narrative data that provided an in-depth understanding of the lived experiences and coping strategies of caregivers of persons dealing with epilepsy within the socio-cultural context of Northern Uganda.

3.6 Inclusion and Exclusion Criteria

Eligibility criteria were developed to ensure that participants possessed direct experience of the phenomenon under investigation and were therefore able to provide rich, relevant, and credible information regarding the lived experiences and coping strategies of caregivers of persons dealing with epilepsy.

3.6.1 Inclusion Criteria

Participants were included in the study if they met all of the following criteria:

- They were primary caregivers of persons diagnosed with epilepsy and were directly involved in providing day-to-day care.

- They had been providing continuous care for a person dealing with epilepsy for at least one year, thereby ensuring they had sufficient caregiving experience to describe their lived experiences and coping strategies.
- They were accompanying or caring for persons with epilepsy receiving services at Gulu Regional Referral Hospital during the period of data collection.
- They were able to provide evidence that the person they were caring for had a confirmed diagnosis of epilepsy through hospital medical records, medical forms, or other clinical documentation.
- They were 18 years of age or older and were willing and able to participate in an in-depth interview or focus group discussion.
- They voluntarily agreed to participate in the study and provided written informed consent before data collection commenced.

The inclusion criteria enabled the researcher to recruit information-rich participants who had direct experience of caring for persons dealing with epilepsy and could meaningfully contribute to achieving the study objectives.

3.6.2 Exclusion Criteria

The following individuals were excluded from participation in the study:

- Individuals who were not the primary caregivers of persons dealing with epilepsy.
- Caregivers who had provided care for less than one year, as they might not have accumulated sufficient experience to describe the phenomenon comprehensively.
- Caregivers who were unable to participate effectively because of severe illness, emotional distress, communication difficulties, or any other condition that could interfere with the interview process at the time of data collection.
- Individuals who were unwilling or unable to provide written informed consent.
- Individuals who could not provide evidence that they were caring for a person with a medically confirmed diagnosis of epilepsy.

The exclusion criteria ensured that only participants with adequate caregiving experience, direct involvement in epilepsy care, and the capacity to provide detailed, credible, and

relevant accounts of their lived experiences were included in the study. This strengthened the trustworthiness and credibility of the findings.

3.7 Data Collection Methods

Prior to the commencement of data collection, the interview guide was pre-tested to assess its clarity, relevance, sequencing of questions, and appropriateness for addressing the study objectives. Feedback obtained during the pre-test informed minor revisions to improve the wording and flow of the interview questions before the actual fieldwork commenced.

Data were collected using In-Depth Interviews (IDIs) and Focus Group Discussions (FGDs). These qualitative methods were selected because they enabled the researcher to obtain rich, detailed, and first-hand accounts of the lived experiences and coping strategies of caregivers of persons dealing with epilepsy. The use of both methods facilitated a comprehensive understanding of caregiving experiences while allowing participants to express their views freely in their own words.

3.7.1 In-Depth Interviews (IDIs)

In-depth interviews were conducted with individual caregivers using a semi-structured interview guide. This method provided participants with the opportunity to describe their personal experiences, feelings, perceptions, and coping strategies in a private and confidential environment. During the interview, caregivers narrated their caregiving experiences without restriction, while probing questions were used to obtain clarification and explore issues in greater depth.

The interviews focused on caregivers' experiences of providing care, the emotional, physical, social, and financial challenges they encountered, the impact of epilepsy on their family and daily lives, and the strategies they employed to cope with these challenges. Interviews were conducted in either Acholi or English, depending on the participant's language preference, to ensure effective communication and facilitate the collection of rich qualitative data.

3.7.2 Focus Group Discussions (FGDs)

Focus Group Discussions complemented the in-depth interviews by providing an opportunity for caregivers to discuss their shared experiences collectively. The discussions encouraged interaction among participants and enabled them to reflect on common caregiving challenges, community perceptions of epilepsy, stigma, family support, healthcare experiences, and

coping strategies. The group setting also allowed participants to build upon one another's experiences, thereby generating additional insights that might not have emerged during individual interviews.

Each Focus Group Discussion was facilitated by the principal researcher with the support of trained research assistants. A discussion guide was used to ensure consistency across the groups while allowing participants sufficient flexibility to introduce issues they considered important to their caregiving experiences.

3.7.3 Data Collection Process

The study was conducted by the Principal Investigator (PI) with the assistance of two trained research assistants. Data collection took place within the Mental Health Department of Gulu Regional Referral Hospital in a quiet, private, and secure room that had been identified in collaboration with the hospital administration. The setting ensured privacy, confidentiality, and minimal interruption during the interviews and discussions.

Participants were interviewed after receiving the healthcare services for which they had attended the hospital. Before each interview or discussion, the researcher explained the purpose of the study, obtained written informed consent, and assured participants of confidentiality, anonymity, and their right to withdraw from the study at any time without affecting the healthcare services they received.

With participants' permission, interviews and focus group discussions were audio-recorded to ensure accurate capture of the information provided. Throughout the interviews, the researcher and research assistants also observed participants' non-verbal expressions, including emotional reactions, pauses, silence, facial expressions, and body language. Field notes were recorded immediately after each interview to capture contextual observations, reflections, and issues that were not adequately represented in the audio recordings.

Data collection continued until thematic saturation was achieved, that is, when additional interviews and discussions no longer generated new information or themes relevant to the study objectives. The combination of in-depth interviews, focus group discussions, audio recordings, observation, and field notes enhanced the depth, credibility, and trustworthiness of the qualitative data collected and provided a comprehensive understanding of the lived experiences and coping strategies of caregivers of persons dealing with epilepsy in Northern Uganda.

3.8 Data Collection Instruments

Data collection instruments are the tools used by a researcher to obtain information from study participants. In this study, data were collected using a semi-structured interview guide, a Focus Group Discussion (FGD) guide, an audio recorder, and field notes. These instruments complemented one another and enabled the researcher to obtain rich, detailed, and trustworthy information on the lived experiences and coping strategies of parents/caretakers of those suffering from this kind of neurological disorders.

Prior to the commencement of the study, the interview guide and the FGD guide were pre-tested among caregivers with characteristics similar to those of the study participants but who were not included in the main study. The pre-test assessed the clarity, relevance, sequence, and comprehensibility of the questions. Feedback from the pre-test informed minor revisions to improve the wording, flow, and appropriateness of the instruments before the actual data collection commenced.

3.8.1 Semi-Structured Interview Guide

A semi-structured interview guide was used to conduct the in-depth interviews. The guide consisted of open-ended questions designed to elicit detailed narratives from caregivers regarding their lived experiences of caring for persons dealing with epilepsy. The questions explored caregiving responsibilities, emotional and psychological experiences, physical challenges, financial burdens, social relationships, stigma, healthcare experiences, coping strategies, and suggestions for improving support for caregivers.

The semi-structured format allowed flexibility during the interviews. Participants were encouraged to explain their experiences in their own words, while the researcher used probing questions to clarify responses and explore emerging issues in greater depth. This flexibility enabled the collection of rich and context-specific qualitative data consistent with the phenomenological design.

3.8.2 Focus Group Discussion Guide

A Focus Group Discussion guide was used to facilitate discussions among groups of caregivers. The guide contained broad thematic questions that encouraged participants to discuss common caregiving experiences, community attitudes towards epilepsy, cultural beliefs, social support, healthcare challenges, and coping strategies.

The guide promoted interaction among participants, allowing them to compare experiences, build upon one another's responses, and generate deeper insights into the shared realities of caregiving within the Acholi socio-cultural context. The researcher facilitated each discussion while ensuring that all participants had an equal opportunity to contribute.

3.8.3 Audio Recorder

With participants' permission, a digital audio recorder was used to record all in-depth interviews and focus group discussions. Audio recording ensured that participants' responses were captured accurately and completely, thereby reducing the likelihood of losing important information during the interviews.

The recordings were later transcribed verbatim to facilitate detailed thematic analysis. All audio files were properly kept to maintain confidentiality of participants' privacy.

3.8.4 Observation and Field Notes

Observation and field notes were used to supplement the information obtained through interviews and focus group discussions. During data collection, the researcher documented participants' non-verbal expressions, emotional reactions, pauses, gestures, and other contextual observations that could not be fully captured through audio recordings alone.

Field notes also included reflections on the interview setting, participants' interactions, and emerging issues that informed subsequent interviews and data analysis. These notes enriched the interpretation of the findings and enhanced the credibility and trustworthiness of the study by providing additional contextual information.

The combined use of the semi-structured interview guide, Focus Group Discussion guide, audio recorder, and field notes enabled the researcher to collect comprehensive, credible, and contextually rich qualitative data that addressed the study objectives and enhanced the trustworthiness of the findings.

3.9 Training and Competence of Research Assistants

To enhance the quality and credibility of data collection, two research assistants were recruited to support the fieldwork. The research assistants possessed prior experience in qualitative data collection and were fluent in both English and Acholi, which facilitated effective communication with participants during interviews and focus group discussions.

Before commencement of data collection, the research assistants received training about objectives, qualitative phenomenological research, procedures, confidentiality, interviewing skills, facilitation of focus group discussions, accurate note-taking, audio recording procedures, and the management of sensitive information. The training also covered the administration of the interview guide, techniques for probing participants' responses, maintaining neutrality during interviews, and ensuring consistency in data collection across all participants.

A pre-test of the data collection instruments was conducted to familiarise the research assistants with the interview process and to identify areas requiring clarification before the actual fieldwork. Feedback obtained during the pre-test was discussed with the research assistants, and minor revisions were made to improve the clarity, sequencing, and appropriateness of the interview guide.

Throughout the data collection process, the principal researcher closely supervised the research assistants to ensure adherence to the study protocol, ethical standards, and qualitative interviewing procedures. Regular debriefing meetings were held to review the progress of data collection, discuss emerging issues, maintain consistency in interviewing techniques, and uphold the quality, credibility, and trustworthiness of the data collected.

3.10 Data Collection Procedure

Data collection commenced after obtaining ethical approval from the Gulu University Research Ethics Committee (GUREC) and administrative permission from the management of Gulu Regional Referral Hospital. Following these approvals, the researcher met with the Head of the Mental Health Department to explain the purpose of the study, discuss the data collection schedule, and coordinate participant recruitment within the hospital.

Before the commencement of fieldwork, the principal researcher trained two research assistants on the study objectives, qualitative phenomenological research methods, ethical principles, participant recruitment procedures, informed consent, confidentiality, interviewing skills, facilitation of Focus Group Discussions, audio recording, note-taking, and the use of the data collection instruments. The interview guide and Focus Group Discussion guide were pre-tested and refined to improve clarity, sequencing, and appropriateness before the actual data collection.

Eligible participants were identified with the assistance of the Mental Health Department staff. Hospital medical records and clinical documentation were used to verify that participants were primary caregivers of persons with a confirmed diagnosis of epilepsy. Caregivers who met the inclusion criteria were approached after receiving the healthcare services for which they had attended the hospital. The purpose of the study was explained, and those who voluntarily agreed to participate provided written informed consent before enrolment into the study.

Data were collected through In-Depth Interviews (IDIs) and Focus Group Discussions (FGDs) using semi-structured interview guides. Interviews and discussions were conducted in either Acholi or English, depending on the participant's preferred language, to facilitate effective communication and ensure that participants expressed themselves comfortably.

All interviews and Focus Group Discussions were conducted in a quiet, private, and secure room within the Mental Health Department to ensure privacy, confidentiality, and minimal interruption. With participants' permission, the interviews and discussions were audio-recorded to ensure accurate capture of the information provided. Throughout the data collection process, the researcher and research assistants also documented field notes, including participants' non-verbal expressions, emotional responses, gestures, pauses, and contextual observations that were considered relevant to understanding their lived experiences.

The principal researcher supervised all stages of data collection to ensure adherence to the study protocol and maintain consistency in interviewing techniques. Regular debriefing sessions were held with the research assistants to review completed interviews, discuss emerging issues, and ensure that data collection remained focused on the study objectives while maintaining high ethical and methodological standards.

Data collection continued until thematic saturation was achieved, that is, when additional interviews and Focus Group Discussions no longer generated new information or themes relevant to the research objectives. At the end of each interview and discussion, participants were thanked for their valuable contribution. Where participants became emotionally distressed while recounting their caregiving experiences, they were offered psychological support through the Mental Health Department and referred to appropriate counselling services when necessary.

Throughout the data collection process, participants' confidentiality and anonymity were strictly maintained. Personal identifiers were replaced with unique codes, and all interview recordings, field notes, and consent forms. These procedures enhanced the credibility, dependability, and ethical integrity of the study.

3.11 Data Management

Effective data management is essential in qualitative research to ensure the integrity, confidentiality, security, and trustworthiness of the information collected. In this study, data management procedures were implemented throughout as planned. For instance, storage, transcription, to disposal of research materials.

Following each in-depth interview and Focus Group Discussion, the principal researcher reviewed the audio recordings and field notes to ensure that all information had been accurately captured and was complete. Interviews conducted in Acholi were translated into English, and all audio recordings were transcribed verbatim as soon as possible after data collection to preserve participants' original meanings and minimise the loss of contextual information.

The researcher compared each transcript with the corresponding audio recording to verify the accuracy of the transcription and translation. Any unclear statements were reviewed repeatedly against the recordings, and where necessary, field notes were used to clarify contextual information, participants' non-verbal expressions, and observations recorded during the interviews.

To protect participants' privacy, name identification instead of using names or other personal identifiers were considered. These codes were used consistently throughout the transcription, coding, analysis, and reporting processes. Any information that could potentially identify participants was removed from the transcripts before analysis.

All electronic data, including audio recordings, transcripts, and NVivo project files, were securely stored on a password-protected computer accessible only to the principal researcher. Backup copies of the electronic files were maintained on an encrypted external storage device to prevent data loss. Hard-copy materials, including signed informed consent forms, interview guides, and field notes, were stored separately in a locked cabinet under the custody of the principal researcher.

Only the principal researcher had access to the complete dataset. The research assistants participated only in data collection and did not have access to the coded transcripts, participant identifiers, or the final dataset used for analysis.

Upon completion of the study and after acceptance of the research report, all research data were retained securely for the period required by the University and applicable ethical guidelines. Thereafter, electronic files were permanently deleted, and hard-copy documents will be securely destroyed to protect participants' confidentiality and prevent unauthorised use of the data.

These data management procedures ensured the confidentiality, security, integrity, and trustworthiness of the qualitative data throughout the research process and complied with the ethical requirements governing research involving human participants.

3.12 Data Analysis

This study employed thematic analysis to analyse data generated through in-depth interviews and focus group discussions. Thematic analysis is a qualitative analytic approach used to identify, organize, interpret, and report recurring patterns of meaning within textual data. The approach was considered appropriate because the study sought to understand caregivers' lived experiences of caring for persons with epilepsy and the meanings they attached to those experiences within their everyday social and cultural environments.

The analysis began immediately after data collection. All audio-recorded interviews and focus group discussions were transcribed verbatim and checked against the recordings to ensure completeness and accuracy. Transcripts were read repeatedly to enable the researcher to become familiar with the data and to gain a comprehensive understanding of participants' narratives. During this stage, reflective notes were made to capture preliminary observations, recurring issues, and emerging ideas related to caregiving experiences.

The researcher then undertook line-by-line coding of each transcript. Segments of text that reflected experiences relevant to the study objectives were assigned descriptive codes representing their underlying meanings. Examples of initial codes included fear of unpredictable seizures, continuous night-time supervision, medicine shortages, transport difficulties, financial hardship, community stigma, family support, prayer, and uncertainty about the future.

Codes expressing similar meanings were subsequently compared and grouped into broader conceptual categories. This iterative process enabled the identification of relationships between different aspects of caregivers' experiences while preserving the context in which participants described them. The categories were then examined across all transcripts to identify patterns that recurred consistently throughout the dataset.

From these categories, broader themes were developed to capture the shared experiences of caregivers. The final themes included emotional and psychological stress, physical burden of caregiving, financial challenges, social isolation and stigma, family and social support, religious and spiritual coping, and acceptance and adaptation. These themes were inductively generated from participants' narratives rather than being predetermined before data collection.

To enhance the credibility of the analysis, the researcher reviewed each theme against the original transcripts to ensure that it accurately represented participants' accounts. Themes that overlapped conceptually were refined, merged, or renamed where necessary, while those that lacked sufficient supporting evidence were discarded. This iterative process ensured coherence between the themes and the data from which they were derived.

The final stage involved interpreting the findings in relation to the study objectives and the broader social, cultural, and health system context of northern Uganda. Consistent with a medical anthropological perspective, interpretation extended beyond describing individual experiences to examine how caregiving was shaped by family relationships, community expectations, cultural understandings of epilepsy, religious beliefs, economic realities, and the post-conflict context of the Acholi sub-region. Direct quotations from participants were incorporated into the findings chapter to illustrate each theme and to ensure that caregivers' voices remained central throughout the analysis.

NVivo version 17 was used to facilitate the management and organization of qualitative data. The software supported the storage, coding, retrieval, and comparison of interview transcripts and focus group discussions, thereby improving the systematic organization of the dataset. However, the interpretation of the data remained the responsibility of the researcher and was informed by repeated engagement with participants' narratives, reflexive interpretation, and careful consideration of the social and cultural meanings embedded within caregivers' experiences.

3.13 Ethical Considerations

Ethical approval for this study was obtained from the Gulu University Research Ethics Committee (GUREC) before commencement of data collection. Administrative permission to conduct the study was subsequently obtained from the management of Gulu Regional Referral Hospital.

Participation in the study was entirely voluntary. Eligible caregivers received a clear explanation of the study objectives, procedures, potential benefits, possible risks, and their rights as research participants before recruitment. Individuals who agreed to participate provided written informed consent before the interviews or focus group discussions commenced. Participants were informed that they could decline to answer any question or withdraw from the study at any stage without any consequences for their access to healthcare or any other services.

Confidentiality and privacy were maintained throughout the study. Participants' names were not recorded on interview transcripts or study documents. Instead, unique identification codes were assigned to protect their identities. Audio recordings, transcripts, field notes, and consent forms were securely stored in password-protected electronic files and locked storage accessible only to the researcher. Information obtained during the study was used solely for research purposes.

Given the sensitive nature of discussing caregiving experiences, particular attention was paid to participants' emotional well-being. Interviews and focus group discussions were conducted in a private setting that ensured confidentiality and minimized interruptions. Participants who became emotionally distressed during data collection were given adequate time to recover, offered psychological support through counselling, and, where appropriate, referred to available mental health or psychosocial support services within Gulu Regional Referral Hospital.

The researcher remained mindful of the ethical principles of respect for persons, beneficence, non-maleficence, and justice throughout the research process. Respect for participants' cultural values, personal beliefs, and lived experiences was maintained during data collection, analysis, and reporting. Particular care was taken to present participants' narratives accurately and respectfully without compromising their anonymity.

The findings of the study will be shared with Gulu Regional Referral Hospital and other relevant stakeholders to contribute to improving caregiver support and epilepsy care services. Dissemination of the findings will preserve participants' confidentiality by ensuring that no individual caregiver can be identified from the reported data.

3.14 Methodological Limitations

As with many qualitative studies, this research has several methodological limitations. The phenomenological design sought to generate an in-depth understanding of caregivers' lived experiences rather than produce statistically generalizable findings. Consequently, the findings reflect the experiences of caregivers who participated in this study and should be interpreted within the context of Gulu Regional Referral Hospital and the Acholi sub-region.

The study relied on participants' personal accounts of caregiving. To minimize these limitations, the researcher encouraged participants to speak freely, used probing questions to clarify responses, and compared information across interviews and focus group discussions to identify consistent patterns.

Because discussions centred on emotionally sensitive experiences, some participants became emotional during interviews. The researcher addressed this by conducting interviews respectfully, allowing participants sufficient time to respond, and providing appropriate psychosocial support or referral when necessary.

Despite these limitations, the use of purposive sampling, prolonged engagement with the data, thematic analysis, reflexive interpretation, and the inclusion of participants' direct quotations.

CHAPTER FOUR: DISCUSSION OF FINDINGS

4.1 Introduction

This chapter presents the findings of the study on caregivers' experiences of caring for persons living with epilepsy at Gulu Regional Referral Hospital. The findings are derived from data generated through in-depth interviews and focus group discussions conducted with caregivers who had direct experience of providing care to family members dealing with epilepsy. The chapter presents participants' accounts of caregiving as they described and interpreted them within their everyday social, cultural, and family contexts.

The findings are presented thematically based on Caregivers' narratives. The themes emerged inductively from the data through an interactive process of coding, categorisation, and interpretation, allowing caregivers lived experiences and meanings to guide the analysis. Participants' verbatim quotations are presented throughout the chapter to illustrate the themes and to ensure that their voices remain central to the presentation of the findings.

The chapter begins by describing the characteristics of the study participants to provide context for understanding the findings. It then presents the major themes and sub-themes that emerged from the analysis, including emotional and psychological stress, physical burden of caregiving, social isolation and stigma, financial challenges, family and social support, religious and spiritual coping, acceptance and adaptation, and gaps in support systems for caregivers. The chapter concludes with a summary of the key findings in relation to the study objectives.

A total of 60 caregivers of persons living with epilepsy participated in this study. The characteristics of the participants are presented to provide contextual information about the individuals whose lived experiences informed the findings. In phenomenological research, describing participants' characteristics helps situate the findings within the social and cultural contexts in which caregiving occurs rather than to make statistical comparisons or generalisations.

The study included both female and male caregivers. Female caregivers constituted the majority of participants (43), while 17 participants were male. This distribution reflects the prominent role that women often assume in providing day-to-day care for family members living with chronic illnesses within many households in northern Uganda. Nevertheless, the

inclusion of male caregivers enriched the study by providing diverse perspectives on caregiving experiences.

Participants were immediate family members of persons living with epilepsy, including parents, brothers, and sisters. Parents formed the largest group of caregivers, followed by brothers and sisters. This pattern highlights the central role of the family in providing long-term care, emotional support, and supervision for persons living with epilepsy.

Most participants were not formally employed, while only a few reported formal employments. This finding provides important context for understanding the economic circumstances within which caregiving was undertaken, particularly the challenges of balancing household responsibilities, income generation, and continuous care for a family member living with epilepsy.

The participants represented different marital circumstances, including married, unmarried, and cohabiting individuals. These varied family situations provided diverse experiences of caregiving responsibilities and social support within households.

With regard to educational attainment, participants had completed different levels of formal education, ranging from primary to tertiary education. This diversity contributed to varied experiences in understanding epilepsy, accessing health information, communicating with healthcare providers, and navigating available treatment services.

Participants also differed in the duration of caregiving. Some had cared for a family member living with epilepsy for less than five years, while others had provided care for more than a decade. These differences enabled the study to capture a broad range of caregiving experiences, including the challenges encountered during the early stages of caregiving and the adaptations developed through prolonged caregiving.

The characteristics presented in Table 4.1 provide contextual information that supports the interpretation of the findings presented in the subsequent sections of this chapter. They should be understood as descriptive of the study participants and not as measures for statistical inference.

Table 4. 1: Socio-demographic Characteristics of Study Participants (N = 60)

Characteristic	Category	Frequency (n)	Percentage (%)
Sex	Female	43	71.7
	Male	17	28.3
	Total	**60**	**100.0**
Relationship to person dealing with epilepsy	Parents	34	56.7
	Brother	16	26.7
	Sister	10	16.6
	Total	**60**	**100.0**
Employment status	Employed	2	3.3
	Not employed	58	96.7
	Total	**60**	**100.0**
Marital status	Married	28	46.7
	Not married	19	31.7
	Cohabiting	13	21.6
	Total	**60**	**100.0**
Education level	Primary	46	76.7
	Secondary	10	16.7
	Tertiary	4	6.6
	Total	**60**	**100.0**
Duration of caregiving	Less than 5 years	21	35.0
	5–10 years	27	45.0
	More than 10 years	12	20.0
	Total	**60**	**100.0**

Source: Field data, 2026

4.1.1 Description of Study Participants

Table 4.1 presents the socio-demographic characteristics of the 60 caregivers who participated in the study. The information provides contextual background for understanding the participants whose lived experiences form the basis of the findings presented in this chapter. In keeping with the qualitative and phenomenological design of the study, these characteristics are presented descriptively and are not used to make statistical comparisons or generalisations. Rather, they help situate participants' accounts within their family, social, educational, economic, and caregiving contexts.

The participants comprised 43 females (71.7%) and 17 males (28.3%). The participation of both women and men provides accounts from caregivers occupying different positions within family life. The predominance of female participants provides an important context for interpreting the findings, particularly because caregiving responsibilities are often organised within household and family relationships. However, the findings do not assume that

caregiving is inherently a female responsibility. Instead, participants' narratives provide insight into how caregiving responsibilities were experienced and negotiated within their particular families.

In terms of relationship to the person dealing with epilepsy, 34 participants (56.7%) were parents, 16 (26.7%) were brothers, and 10 (16.6%) were sisters. This indicates that caregiving was largely situated within close family relationships. The involvement of parents and siblings is important for understanding epilepsy as a condition experienced not only by an individual but also within a network of kinship and household relationships. Participants' accounts consequently reflected responsibilities such as supervision, protection, emotional support, assistance with daily activities, and accompanying relatives in seeking healthcare.

Regarding employment status, 58 participants (96.7%) were not employed, while 2 (3.3%) were employed. This characteristic provides an important social and economic context for understanding participants' accounts of caregiving and financial challenges. For some caregivers, time spent supervising or assisting a person dealing with epilepsy may compete with opportunities for productive activities and income generation. However, the study does not interpret employment status as a cause of particular caregiving experiences. Rather, it provides context for understanding how caregiving was situated within participants' everyday economic circumstances.

With regard to marital status, 28 participants (46.7%) were married, 19 (31.7%) were not married, and 13 (21.6%) were cohabiting. These different household circumstances indicate that caregiving occurred within varied family and relationship arrangements. Such arrangements are relevant to understanding how caregiving responsibilities were shared, negotiated, or sometimes carried by individual family members. The qualitative findings therefore consider caregiving as a relational experience embedded within family life rather than as an isolated responsibility of an individual caregiver.

In relation to education, 46 participants (76.7%) had primary-level education, 10 (16.7%) had secondary education, and 4 (6.6%) had tertiary education. These characteristics provide context for understanding participants' interactions with health information and health services. Nevertheless, the study does not assume that educational attainment determines how caregivers understand epilepsy. Participants' narratives demonstrate that knowledge about epilepsy was also shaped by everyday caregiving experiences, interactions with health workers, family relationships, community beliefs, and other sources of information.

The participants also differed in the length of time they had provided care. Twenty-one participants (35.0%) had cared for a person dealing with epilepsy for less than five years, 27 (45.0%) had provided care for between five and ten years, and 12 (20.0%) had provided care for more than ten years. This variation enabled the study to capture experiences from caregivers at different stages of their caregiving journeys. Those with longer caregiving experience had lived with the condition and its demands over an extended period, while those with shorter caregiving histories provided accounts of more recent experiences of adjusting to the caregiving role.

From a Medical Anthropology perspective, these characteristics are important because caregiving does not occur in isolation from the social world. The experience of caring for a person dealing with epilepsy is shaped by kinship, household responsibilities, economic circumstances, community relationships, education, religious beliefs, and interactions with the health system. The participants' characteristics therefore provide a social context within which their experiences of fear, physical burden, stigma, financial challenges, family support, spirituality, and adaptation can be understood.

Overall, Table 4.1 provides a descriptive profile of the caregivers whose narratives informed the study. The table is not intended to establish statistical relationships between participant characteristics and caregiving experiences. Instead, it provides the context necessary for interpreting the themes that emerged from participants' accounts. The subsequent sections therefore focus on the meanings participants attached to their lived experiences of caring for persons with epilepsy.

4.2 Summary of Qualitative Findings

The analysis of caregivers' narratives generated five major themes:

Table 4. 2: Summary of Qualitative Findings

Main Themes	Sub-themes
1. Emotional and Psychological Stress	Fear and anxiety related to unpredictable seizures
2. Physical Burden of Caregiving.	Constant Monitoring and Supervision of Persons with Epilepsy
3. Social Isolation and Stigma	Social withdrawal and reduced community participation Emotional effects of stigma on caregivers
4.Financial Challenges	Loss of income and reduced economic activities
5: Family and Social Support	Support from family members in daily caregiving
6: Religious and Spiritual Coping	Reliance on Prayer and Faith for Strength Balancing Spiritual Beliefs with Biomedical Treatment
7: Acceptance and Adaptation	Adjusting family roles and daily life. Developing Resilience and Emotional Strength
8.Gaps in Support Systems for Caregivers	Limited caregiver education; inadequate psychosocial support; need for caregiver involvement

The findings are presented using participants' own words to provide a fuller understanding of the lived realities of caregiving. Longer quotations have been included to show caregivers' emotions, relationships, daily responsibilities, and coping strategies within their social and cultural context.

4.3 Major Qualitative findings with related participants quote.

4.3.1 Theme 1: Emotional and Psychological Stress

Many caregivers described living with constant fear because seizures could occur at any time. They said that the uncertainty of not knowing when the next seizure would happen affected their sleep and peace of mind.

> *"I am always worried because the seizure can start suddenly, even when we are eating or sleeping. At night I do not sleep deeply because I keep listening for any movement. Sometimes I wake up many times to check whether he is breathing well."* (IDI, Female caregiver, 42 years)

"When I leave home, my mind is not settled. I keep thinking that he may fall into the fire or get injured while I am away. Even when I am in the garden, I rush back home from time to time to check on him." (IDI, Male caregiver, 50 years)

*"The fear is not only during the seizure. After the seizure, you remain worried about when the next one will come. That fear stays with you every day." (*FGD participant, Female caregiver*)*

*"Sometimes I feel helpless because I cannot stop the seizure when it starts. I just hold him and wait for it to pass, and during that time I feel very anxious." (*IDI, Female caregiver, 39 years*)*

These experiences show that caregivers lived with continuous uncertainty, and the emotional burden extended beyond the seizure episode itself.

4.3.2 Theme 2: Physical Burden of Caregiving

Caregivers reported that providing care was physically demanding, especially during severe seizures and at night.

*"It is very difficult to care for a person dealing with epilepsy. I cannot sleep well at night, and in the morning, I wake up feeling weak and tired even before starting any work." (*IDI, Female caregiver, 44 years)

"When the seizure comes, I have to hold him so that he does not injure himself. After the seizure, I help him bathe and change clothes. By the end of the day, my whole body is painful." (IDI, Male caregiver, 36 years)

"I am the one who stays with the patient most of the time. If he becomes restless at night, I also remain awake. This has affected my strength and I get headaches frequently." (IDI, Female caregiver, 40 years)

*"There are days when I fail to do any productive work because I spend all my energy caring for the patient." (*FGD participant, Female caregiver*)*

These quotations show that caregiving involved constant physical effort and lack of adequate rest.

4.3.3 Theme 3: Social Isolation and Stigma

Some caregivers said that community members avoided them or spoke negatively about epilepsy, which made them feel isolated.

> *"Some neighbours do not allow their children to play near our home because they fear epilepsy. After experiencing this several times, I stopped attending some community gatherings." (IDI, Female caregiver, 38 years)*

> *"People talk about us as if epilepsy is a curse in the family. Those words are painful, and sometimes I prefer to remain at home rather than hear what people are saying*." (IDI, Female caregiver, 46 years)

> *"You can be in a meeting and people start whispering about your patient. Even if they are not speaking directly to you, you feel uncomfortable and isolated."* (FGD participant, Male caregiver)

> *"Because of the condition, some friends stopped visiting us. I felt as if we were being left alone with the problem."* (IDI, Male caregiver, 41 years)

These accounts show that stigma affected both the patient and the caregiver and contributed to withdrawal from social life.

4.3.4 Theme 4: Financial Challenges

Caregivers described the economic burden of transport, medicines, and loss of working time.

> "*When the seizures become frequent, I cannot go to the garden or do casual work. The whole day may be spent watching the patient, and sometimes I borrow money for transport to the hospital*." (IDI, Male caregiver, 35 years)

> *"We have sold some household items to meet transport and treatment costs. I worry about school fees for the children because much of the money is spent on caring for the patient."* (IDI, Female caregiver, 41 years)

> *"The problem is that epilepsy is not treated once. You keep returning to the hospital, and each visit requires money for transport, food, and sometimes medicines."* (FGD participant, Female caregiver)

> *"When medicines are not available at the hospital, buying them from private pharmacies becomes very difficult for us."* (IDI, Female caregiver, 50 years)

These narratives show that caregiving created ongoing financial pressure and affected household stability.

4.3.5 Theme 5: Family and Social Support

Despite the challenges, many caregivers said that support from relatives and friends helped them continue caring for the patient.

> *"I request some family members to take care of him when I am out. If I did not get that help, it would be very hard for me to manage everything alone."* (IDI, Female caregiver, 40 years)

> *"My sister sometimes stays with the patient when I go to the market. That support gives me time to rest and attend to other family responsibilities."* (IDI, Female caregiver, 35 years)

> *"When the patient becomes sick, relatives contribute some money for transport to the hospital. Their support encourages me not to give up."* (IDI, Male caregiver, 52 years)

> *"Sharing the responsibility with other family members reduces the burden because one person cannot manage all the care alone."* (FGD participant, Male caregiver)

These quotations show that caregiving was often sustained through family cooperation and social networks.

4.3.6 Theme 6: Religious and Spiritual Coping

Many caregivers said that prayer and faith gave them strength and comfort.

> *"When the seizures become severe, I pray because it is the only thing that gives me strength. Prayer helps me calm down and continue caring for him even when I feel exhausted."* (IDI, Female caregiver, 55 years)

> *"I ask church members to pray with us. When people pray together, I feel that I am not carrying the burden alone."* (IDI, Male caregiver, 48 years)

> *"Faith does not remove all the problems, but it helps us accept the situation and continue caring for our relatives."* (FGD participant, Female caregiver)

> *"Whenever I feel overwhelmed, I pray first before making any decision. It gives me hope that things may improve."* (IDI, Female caregiver, 43 years)

These practical experiences show that spiritual support was an important source of emotional comfort and hope.

4.3.7 Theme 7: Acceptance and Adaptation

Some caregivers explained that, over time, they learned how to organize their daily lives around the patient's condition.

> *"I balance my productive time after giving medicines because seizures do not usually come immediately after medication. That is the time I use to do household work and gardening."* (IDI, Female caregiver, 37 years)
>
> *"At first I was confused and fearful, but with time I learned the signs that come before a seizure and how to respond quickly*." (IDI, Male caregiver, 46 years)
>
> *"We have changed our daily routine. Someone must always remain near the patient, and we plan our activities around that responsibility."* (IDI, Female caregiver, 40 years)
>
> *"I have come to accept that this condition may take a long time. Instead of becoming angry, I now focus on how to help the patient live safely."* (FGD participant, Male caregiver)

These quotations show that caregivers gradually developed practical ways of living with the condition and maintaining care.

4.4 Summary of Findings

The findings demonstrate that caregiving for persons with epilepsy is not only a medical responsibility but also a social, cultural, emotional, and economic experience. Caregivers continuously negotiate between biomedical explanations and local understandings of epilepsy while managing significant caregiving challenges. The findings highlight the need for epilepsy interventions that recognise caregivers as important partners in treatment, support, and rehabilitation.

CHAPTER FIVE: DISCUSSION OF FINDINGS

5.1 Introduction

This chapter presents a discussion of the findings based on the study objectives. The discussion focuses on caregivers' experiences in caring for persons dealing with epilepsy and the coping strategies they use. The findings are compared with existing literature to show similarities and differences, and to explain their meaning in relation to the study context.

5.2 Caregivers' Experiences in Caring for Persons dealing with Epilepsy

5.2.1 Theme 1: Emotional and Psychological Stress Among Caregivers

The study found that caregivers experienced emotional and psychological stress while caring for persons with epilepsy. This stress was mainly linked to the unpredictable nature of seizures, fear of sudden attacks, and the responsibility of providing continuous care. Many caregivers reported feeling worried, overwhelmed, and mentally exhausted, especially when seizures occurred without warning.

This finding is consistent with George et al. (2020), who reported that caregivers of persons with epilepsy often experience high levels of psychological distress, including anxiety and emotional strain. Similarly, Zhu et al. (2019) found that caregivers are at risk of developing depression and stress due to the demands of caregiving and the uncertainty associated with seizures.

The findings also agree with Karakis et al. (2025), who noted that caregiving in epilepsy places a significant emotional burden on individuals due to constant monitoring and fear of medical emergencies. This suggests that emotional stress is not unique to this study setting.

In addition, the emotional stress reported in this study may be influenced by limited access to health information and support services, which increases caregivers' uncertainty in managing seizures. This is supported by Kaddumukasa et al. (2021), who found that limited knowledge and access to care in Uganda contribute to the challenges faced by caregivers.

*"I feel a lot of pain when I see my patient falling badly. I feel powerless, weak, and lonely without love from others." (*FGD participant, Female caregiver*)*

Overall, the findings show that emotional and psychological stress is a key part of the caregiving experience. The constant need to monitor patients and respond to seizures creates

pressure that affects caregivers' mental well-being. This highlights the need for emotional and psychological support for caregivers in order to improve both caregiver well-being and quality of care provided to persons with epilepsy.

5.2.2 Theme 2: Financial Challenges Faced by Caregivers

The study found that caregivers experienced financial challenges while caring for persons with epilepsy. These challenges included costs related to medication, transport to health facilities, and meeting daily household needs. Some caregivers reported difficulty balancing caregiving responsibilities with income-generating activities, which further increased financial pressure.

This finding is consistent with Hussain et al. (2020), who reported that caregiving in epilepsy is associated with significant economic burden due to the cost of treatment and loss of productivity. Similarly, Pokharel et al. (2020) found that caregivers often experience financial strain as a result of continuous care demands and medical expenses.

The findings also agree with Sarkar et al. (2021), who noted that epilepsy places both direct and indirect financial burdens on families, especially in low-resource settings. This suggests that financial challenges are a common experience among caregivers and may affect their ability to provide consistent care.

In this study, financial stress may also be linked to limited access to affordable health services and lack of social support systems. As a result, caregivers may struggle to meet both caregiving and household needs.

> *"Transport to the hospital is sixty thousand shillings. When I don't have money, I miss medicines." No one cares about this because of my patient; I always struggle to make sure I collect the medicines from the hospital here.*
>
> *"Caring for persons with epilepsy has brought poverty into my house because I spent all my time caring for her. Nothing productive is being done''."* (IDI, Female caregiver, 40 years)

Overall, the findings show that financial challenges are a key concern among caregivers and may affect the quality of care provided to persons with epilepsy. This highlights the need for financial and social support interventions to assist caregivers.

5.2.3 Theme 3: Social Isolation and Stigma

The study found that caregivers experienced social isolation and stigma from the community while caring for persons with epilepsy. Some caregivers reported being avoided by others, while others felt uncomfortable participating in social activities due to negative attitudes towards epilepsy.

This finding is in line with Makasi et al. (2023), who found that misconceptions about epilepsy contribute to stigma and discrimination against both patients and caregivers. Similarly, Hansen et al. (2018) reported that stigma increases caregiver burden and affects their social relationships.

The findings also agree with Lai et al. (2019), who noted that caregivers often withdraw from social interactions due to fear of judgment or misunderstanding from the community. This suggests that stigma remains a major barrier affecting caregivers' social well-being.

In addition, the social isolation observed in this study may be influenced by cultural beliefs and lack of awareness about epilepsy. Negative community attitudes may discourage caregivers from seeking support or sharing their experiences.

> *"No going out for long because I have to be with the patient and monitor his condition".*
>
> *"Some people also fear eating food or drinking water from my place, thinking they can get epilepsy because my child is epileptic.".."* (IDI, Female caregiver, 52 years)

Overall, the findings show that stigma and social isolation significantly affect caregivers' quality of life. Addressing community misconceptions about epilepsy may help improve social support for caregivers.

5.2.4 Theme 4: Physical Burden and Caregiving Demands

The study found that caregivers experienced physical burden due to the demands of caring for persons with epilepsy. Caregivers reported fatigue, lack of rest, and physical exhaustion, especially when patients required constant supervision or assistance during seizures.

This finding is consistent with Karakis et al. (2025), who reported that caregiving responsibilities can lead to physical strain due to continuous monitoring and support.

Similarly, Bapat and Shankar (2021) found that caregivers often experience fatigue as a result of long-term caregiving duties.

The findings also agree with Gutierrez-Angel et al. (2018), who noted that caregiver burden includes both physical and emotional strain, which affects overall well-being. This suggests that caregiving in epilepsy is physically demanding and may impact caregivers' health.

In this study, the physical burden may also be linked to the lack of support from other family members and limited access to health services. As a result, caregivers may take on multiple responsibilities without adequate rest.

> *"It is very difficult to care for a person dealing with epilepsy… I can't sleep well at night… I feel tired with a headache early in the morning, even if I have not done anything."* (IDI, Male caregiver, 48 years)

Overall, the findings show that physical burden is a significant part of caregiving and may affect caregivers' ability to provide effective care. This highlights the need for shared caregiving responsibilities and support systems.

5.3 Coping Strategies used by Caregivers

5.3.1 Theme 5: Use of Social and Family Support

The study found that caregivers relied on family members and social networks to cope with caregiving challenges. Support from relatives and friends helped caregivers manage stress and share responsibilities.

This finding is consistent with Kalembo et al. (2018), who found that caregivers use social support systems to reduce stress and improve coping. Similarly, Catalao et al. (2018) reported that community support plays an important role in helping caregivers manage epilepsy care. This suggests that social support is an important coping strategy that helps caregivers deal with the demands of caregiving.

> *''I request some family members to take care of him when I am out'' This gives me a bit of freedom to do outside activities for short hours."* (IDI, Female caregiver, 31 years)

5.3.2 Theme 6: Religious and Personal Coping

The study found that caregivers used religious beliefs and prayer as a way of coping with caregiving challenges. Many caregivers expressed faith as a source of strength and comfort.
This finding agrees with Broxson and Feliciano (2020), who noted that spiritual coping helps individuals manage stress in difficult situations. It suggests that religious coping plays an important role in helping caregivers deal with emotional challenges.

> *"I have learned to depend on my faith. Whenever I become worried about the patient, I pray and I feel emotionally relieved."* (FDG, Male Caregiver, 55)

5.3.3 Theme 7: Acceptance and Adaptation

The study found that some caregivers coped by accepting the condition and adjusting their daily routines. They learned how to manage seizures and organized their activities around caregiving responsibilities.
This finding is supported by Yu et al. (2022), who reported that caregivers develop adaptive strategies over time to manage caregiving demands. This suggests that acceptance helps caregivers reduce stress and improve their ability to cope.

> *''I balance my productive time after giving medicines. Seizures do not come immediately after taking medicines'* (FDG, Caregiver, 47)

5.4 Unique finding from the Study

A unique finding that emerged from this study was the constant fear among caregivers about what would happen to the person dealing with epilepsy if the caregiver became sick, died, or was no longer able to provide care. Caregivers repeatedly expressed anxiety about the future of the patient and uncertainty about whether other family members would continue providing support.

One caregiver explained that:

> "My biggest worry is not only the seizures. I keep asking myself who will remain with him if I die first or become too weak to care for him."

Another caregiver stated that:

> "Sometimes I look at my age and I become worried. I do not know whether my children or relatives will accept the responsibility of caring for this patient when I am gone."

While previous studies reviewed in the literature reported emotional stress, stigma, physical burden, and financial difficulties among caregivers of persons with epilepsy, they did not clearly highlight this fear of the patient's future abandonment and the caregiver's concern about continuity of care after their own death or incapacity.

This finding is important because it shows that caregiving was not experienced only as a present burden; it was also experienced as a long-term social responsibility that extended into caregivers' thoughts about aging, death, inheritance of responsibility, and the stability of family support systems. In the Acholi context, where care is often expected to be provided through family networks, caregivers worried about whether those networks would remain strong enough to protect the patient in the future.

Another important finding was that caregivers organized their daily work around the patient's medication schedule and periods when seizures were less likely to occur. Some caregivers reported that they planned farming, market activities, and other household responsibilities immediately after giving medication, when they believed the patient was relatively stable. This practical reorganization of time and labour was not clearly discussed in the studies reviewed and shows how epilepsy shaped the everyday economic life of caregivers.

Together, these findings show that caregiving in northern Uganda involved not only emotional and financial challenges but also long-term worries about the future of the patient and continuous adjustment of family labour and daily routines to the realities of epilepsy care.

In summary, A unique finding from my study was the caregivers' persistent fear about who would care for the person dealing with epilepsy if the caregiver became sick, died, or was no longer able to provide care. This concern about the future and continuity of care was not clearly highlighted in the studies I reviewed, which mainly focused on emotional stress, stigma, physical burden, and financial challenges. I also found that caregivers reorganized their farming, market, and household activities around medication schedules and periods when seizures were less likely to occur, showing how epilepsy shaped the everyday economic life of families.

CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

The study focused on caregivers' experiences in caring for persons with epilepsy at Gulu Regional Referral Hospital. It also looked at how caregivers manage the challenges they face in their daily lives in caring for persons with epilepsy.

The findings showed that caregivers go through several difficulties. These include emotional stress due to fear of sudden seizures, physical strain from providing care, social problems such as stigma, and financial challenges related to treatment and reduced working time.

Despite these challenges, caregivers use different ways to cope. These include getting support from family members and health workers, learning more about epilepsy, prayer and faith, and adjusting their daily routines to fit caregiving responsibilities.

6.2. Implications of the Study.

The findings of this study have implications for policy, research, training, and public health practice. The study showed that caregiving for a person dealing with epilepsy affects many areas of a caregiver's life, including emotional well-being, physical health, household income, social relationships, and future expectations. The findings also show that caregivers are an important part of epilepsy care and should be considered in planning health services and support programs.

6.2.1 Policy Implications

The study suggests the need for policies that recognize caregivers as part of the epilepsy care system. Caregivers provide continuous support at home, yet many of them receive little emotional, practical, or financial assistance. Health authorities should strengthen caregiver support within mental health and epilepsy services by ensuring regular availability of anti-epileptic medicines, improving follow-up services, and providing counselling and health education for caregivers during clinic visits.

The findings also show that transport costs and medicine shortages increase the burden on families. Policies that support community-based epilepsy services and strengthen referral systems may reduce the need for repeated long-distance travel to health facilities. In addition,

caregiver support groups should be encouraged because they can provide opportunities for sharing experiences, receiving information, and reducing isolation.

6.2.2 Research Implications

This study provides evidence from caregivers attending Gulu Regional Referral Hospital in northern Uganda. Further research is needed in community settings and other districts to compare caregiving experiences across different social and cultural environments. Future studies should examine effects of caregiving in the lives of caregivers' psychological well-being, family relationships as well as economic situation.

This study also identified caregivers' concerns about who would care for the patient if the caregiver became sick, grew old, or died. This issue of continuity of care was not widely discussed in the literature reviewed and deserves further investigation. Additional research is needed to identify interventions that can reduce caregiver burden and improve support for families affected by epilepsy.

6.2.3 Training Implications

Many caregivers reported that they had limited information on seizure management and home-based care. Health workers should therefore receive additional training on caregiver education, communication, and psychosocial support. Training programs for nurses, clinical officers, and mental health workers should include practical skills on how to teach families to respond safely during seizures, administer medicines correctly, reduce the risk of injury, and support caregivers who are experiencing emotional distress.

Community health workers should also be trained to provide follow-up support and health education at household level. Such training may improve caregivers' confidence and help families manage epilepsy more safely at home.

6.2.4 Public Health Implications

The findings show that epilepsy remains an important public health concern that affects patients, caregivers, and communities. Misconceptions about epilepsy continue to contribute to stigma and social exclusion. Public health programs should strengthen community awareness activities to improve understanding of epilepsy, reduce fear and discrimination, and encourage early treatment seeking.

The study also highlights the need to integrate mental health and psychosocial support into epilepsy services. Caregivers who experience persistent stress, anxiety, or emotional

exhaustion should be identified and linked to appropriate support services. Addressing caregiver well-being may improve the quality of care provided to persons with epilepsy and contribute to better treatment outcomes, family functioning, and community participation.

6.3 Recommendations

The recommendations are based on the study findings and the study objectives, which focused on caregivers' experiences and the ways they manage challenges.

6.1.1 Recommendations related to caregivers' experiences

6.1.1.1 Emotional and psychological support

Caregivers reported stress, fear, emotional pain, and constant worry due to the unpredictable nature of seizures. Gulu Regional Referral Hospital should strengthen counselling and psychosocial support services for caregivers attending the epilepsy clinic. Caregivers should also receive guidance on how to respond during seizures and how to manage stress associated with long-term caregiving.

6.1.1.2 Improving health service support

Caregivers reported challenges related to medicine shortages and long distances to the hospital. Health authorities should work toward improving the availability of antiepileptic medicines and strengthening follow-up services for patients and caregivers in the community.

6.1.1.3 Reducing stigma and social isolation

Some caregivers experienced stigma, discrimination, and reduced participation in community activities. Community leaders, health workers, and local authorities should conduct regular community education on epilepsy to correct misconceptions and encourage acceptance and support for affected families.

6.1.1.4 Addressing physical burden

Caregivers reported fatigue, sleep disturbances, and physical exhaustion, especially when seizures occurred at night. Families should be encouraged to share caregiving responsibilities where possible so that caregivers can have time to rest and attend to other household and personal responsibilities.

6.1.1.5 Financial and practical support

Caregivers experienced financial difficulties related to transport, medication, and reduced time for income-generating activities. Government and local support programs should

consider providing assistance for transport and access to essential medicines for persons with epilepsy, especially for families with limited financial resources.

6.1.2 Recommendations related to caregivers' coping strategies

6.1.2.1 Caregiver education on epilepsy management

Hospitals should provide simple and practical information on epilepsy, including seizure management, medication adherence, safety measures at home, and when to seek medical care. This can help caregivers feel more confident and better prepared to manage the condition.

6.1.2.2 Strengthening family and social support

Caregivers reported that support from relatives and neighbours helped them manage caregiving responsibilities. Families should be encouraged to maintain open communication and provide practical support to the main caregiver during periods of increased caregiving demand.

6.1.2.3 Supporting positive coping practices

Many caregivers used prayer, faith, acceptance of the condition, and adjustment of daily routines to cope with challenges. Health workers should recognize these coping practices and guide caregivers on safe and helpful ways of managing emotional stress while continuing with medical care.

6.1.3 Recommendation for further research

Further studies should be conducted in other districts of northern Uganda to compare caregivers' experiences and coping strategies in different settings. Future research should also examine the long-term effects of caregiving on caregivers' mental health and the availability of support systems for families caring for persons with epilepsy.

The study shows that caregiving for persons with epilepsy is demanding and affects many areas of a caregiver's life. However, with proper support, information, and understanding from the health system, government and community, caregivers can manage better and continue to provide care.

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APPENDICES

APPENDIX I: INTERVIEW GUIDE FOR IN-DEPTH INTERVIEW

1. What is your gender
2. Are you currently employed?
3. What is your relationship with the patient?
4. What is your marital status?
5. What is your education level?
6. How many years have you been caring for this patient?
7. How do you care for persons living with epilepsy at home?
8. Have you had any negative experiences as you deliver care?
9. Have you ever experienced a positive in caring for epilepsy patients?
10. Have you got some social experience in caring for epilepsy patients?
11. What are some of the financial/ economic experiences you have in caring for the epilepsy patient?
12. Have you ever tried traditional medicine in giving care to epilepsy patients?

APPENDIX 2: INTERVIEW GUIDE FOR FOCUS GROUP DISCUSSION

1. How do you relate to community members since most of your time is spent caring for epilepsy patients?
2. How do you feel physically in caring for these epilepsy patients?
3. How do you balance your time between productive work and caring for the patient?
4. What do you think about the future of these patients?
5. What do you think should be done to help people who are caring for epilepsy patients like you?

APPENDIX 3: COMMUNITY ENGAGEMENT PLAN

		This will require us to;
Goal	The goal is the caregiver's experience in caring for persons with epilepsy.	Conduct a study among caregivers of a person dealing with epilepsy seeking their experiences.
Objectives	To understand caregivers' experience in caring for persons with epilepsy. To investigate coping strategies employed by caregivers in handling negative experiences. To determine how society shapes the meaning of recovery in central Uganda.	Visit the Mental Health Department, Gulu Regional Referral Hospital, and ask questions to get the caregiver's experience in caring for a person dealing with epilepsy. Ask questions to understand how caregivers of persons dealing with epilepsy cope with negative experiences in caring for persons with epilepsy.
Key Community stakeholders	Caregivers.	Seek their experiences and coping strategies.
Research Team responsible	PI: Otto Mike Two research assistants.	Seek consent from persons caring for people dealing with epilepsy to participate during study. Train research assistants on how the research is going to be conducted Carry out the research.
Approach	It will be phenomenological approach.	Interviews and Focus Group discussions will be used for data collection.
Communication Strategy for the engagement	Physical (one one-on-one & approach)	Stay in constant communication with the participants to understand both their verbal and nonverbal cues.
An Evaluation Plan	Researchers will discuss and analyze notes daily. Refer to the key stakeholders for clarity	Be in constant touch with a great rapport with the participants.
	whenever necessary	
Risks and Conflict Mitigation Plan	Understand the study envi before the study. Understand and be abreast with the knowledge of the guidelines, norms, dos, and don'ts of the study area and participants	It is to ask and acquire knowledge in the area. Understand what to ask when, how, and what not to. Know where to go and not while in the hospital settings. Seek and use conflict management whenever required.
Feedback and Dissemination of Study Findings	Help the caregivers understand the importance and applicability of the study. Hence, the shared information will help inform caregivers of persons with epilepsy.	Findings will be shared with the interested stakeholders in the community by email or on the phone. Feedback will always be expected at any time from the stakeholders during the study period, for this will further influence the study.

APPENDIX 4: COVID-19 MITIGATION PLAN

VERSION 2.0

Measures for the Prevention and control of the risk of spread of COVID-19 and other infectious diseases during the implementation of research

Study Title: **Caregivers' experiences in caring for persons with epilepsy, Gulu regional referral hospital, Uganda.**

Research team

Name	Title	Qualifications	Role on the research team	Affiliation
Dr. Loum S.L. Constantine (PhD)	Lecturer	NUTRITIONIST/MEDICAL ANTHROPOLOGIST, PhD	Research supervisor	Gulu University
Dr. Mpamizo Emmanuel (MMED)	Lecturer	MbChB, MMED Psychiatry.	Research supervisor	Gulu university
Mr. Otto Mike	Student	MMA	Principal investigator	Gulu university

Introduction:

The novel Coronavirus and other diseases are spread by close contact especially body fluids of the person suffering the disease.

Novel Coronavirus and other infectious disease signs of infection include respiratory symptoms, fever, cough, shortness of breath, and breathing difficulties. In more severe cases, infection can cause pneumonia, severe acute respiratory syndrome, kidney failure, and even death

Implementation of the prevention and control measures

In the implementation of the research activities, the investigators are committed to ensuring the safety of their research team, research participants, and communities where the study will be conducted. The study team undertakes to comply with the Standard Operating Procedures

issued by the Ministry of Health, and presidential directives to mitigate against the risk of infection of COVID-19, rapidly detect and effectively respond to any COVID-19 case that may occur in the process of carrying out the study, screening, face covering, physical distancing, and good hand hygiene.

Procedures to be followed during the implementation of the research.

Before data collection and Training

1. **Health guidance:** There will be training sessions dedicated to COVID-19 and other infectious disease sensitization and awareness, to equip the research team with knowledge of signs and symptoms of the infectious diseases, and preventive measures such as hand hygiene before placing and removing the mask, as well as storage of the mask, and social distancing. The research team will circulate notices, posters, and charts on common signs and symptoms of COVID-19 as provided by the Ministry of Health, and develop and/or use an existing plan for the appropriate referral pathway for identified and/or suspected cases.
2. **Personal Screening:** All researchers, research assistants, research participants, and any other individuals engaged in research activities will screen their temperature daily for fever. Screening for temperature will be carried out during planning meetings, trainings, and community outreach. Any individual found with COVID-19 and other infectious disease signs will be isolated for treatment and proper management until recovery is realized and proof of its is given indicating total recovery.
3. **Covering of the mouth:** Everybody that participated in the study covered all their mouths with locally made clothes to prevent spread of COVID -19 and other infectious disease that could easily be spread through coughing and so on. They were provided by the Principal Investigator.
4. **Working space:** All research participants including the Principal Investigator observed social operating procedure in order to control spread of any infectious disease including COVID-19.

APPENDIX 5: INFORMED CONSENT FORM FOR IN-DEPTH INTERVIEW-

ENGLISH

VERSION 2.0

For caregivers of persons with Epilepsy.

Title of the study: Caregivers' experiences in caring for persons with epilepsy, Gulu Regional Referral Hospital.

Investigators:

Otto Mike 14/U/0273/MMA

Institution: Gulu University

Introduction:

The investigator is a student in Gulu University doing Medical Anthropology at Master Degree level researching caregivers' experiences in caring for persons with epilepsy, Gulu regional referral hospital.

"The study is disclosed to you in this informed consent, after which any questions you may have will be answered. Having decided to participate in the study, you will be asked to sign a consent.

Source of funding:

The student used his own money for this study.

Purpose:

The study seeks to understand caregiver's experiences in caring for persons with epilepsy, Gulu regional referral hospital.

The steps:

All research participants answered the questions as guided by the investigator or interviewer.

People who will take part in this research?

Caregivers to persons who have been diagnosed with epilepsy in Gulu Regional Referral Hospital. The interview will last for about 30 minutes. The researcher will collect patients daily until the sample is reached.

Risks/discomforts:

Apart from the global COVID-19 pandemic and other infectious diseases, there is no foreseeable risk of harm or discomfort that will arise from your participation in this study. The research will therefore ensure covid-19 and other infectious diseases spread prevention by sensitization of the research team on the relevant measures to practice to avoid the spread of the diseases, daily screening of the research assistance before going to the field, use of facemask and sanitizers during the data collection, observing social distancing to avoid overcrowding and practicing good hygiene by ensuring they wash their hands frequently. The only risk or discomfort will be the inconvenience in terms of time spent during the interview.

Benefits:

The findings of the study help to improve service delivery for the participants, which in turn makes participants feel valued and may gain access to treatments that are not yet readily available to the general public.

The findings can serve as reference points for future study and filling in gaps, and generating new perspectives within the discipline.

Confidentiality:

Your identity will not be revealed to anyone, as we shall only use codes to identify participants. Information obtained will only be accessible to the research team. Soft copies of the data will be protected by a password, and hard copy files will be kept under lock and key. Confidential information will only be accessed by the investigator.

Alternatives:

You do not have to participate in this study if you are not interested. There is no penalty in case of no participation.

Cost:

Participants are going to be given refreshments in the course of the study and transport refund/reimbursement of at least five thousand shillings (5,000=) per participant, minimum amount.

Questions:

If you have any questions related to the study or your rights as a research participant, you can contact the investigator named Otto Mike at the telephone number 0777323242.

Statement of voluntariness:

Participation in the research study is voluntary, and you may join on your own free will. You have a right to withdraw from the study at any time without penalty.

If you have any issues about your rights and participation in the study, please contact the

Chairperson, Gulu University Research Ethics Committee, Dr. Julaina A. Obika Tel: No.,

0772964491; email: j.obika@gu.ac.ug; or the Uganda National Council for Science and Technology, on plot 6 Kimera Road, Ntinda, Kampala on Tel 0414705500.

Statement of consent:

The research team has described to me what is going to be done, the risks, the benefits involved and my rights as a participant in this study. I understand that my decision to participate in this study will not affect me in any way. In the use of this information, my identity will be concealed. I am aware that I may withdraw at any time. I understand that by signing this form, I do not waive any of my legal rights but merely indicate that I have been informed about the research study in which I am voluntarily agreeing to participate.

Name of participant ……..…….....

Signature/thumbprint……Date…….....

Name of the witness …….…….....

Signature/thumbprint…….……..… Date…….....

Name of the interviewer …….....

Signature/thumbprint……Date…….....

APPENDIX 6: INFORMED CONSENT FORM FOR IN-DEPTH INTERVIEW-ACHOLI/LUO LANGUAGE.

VERSION 2.0

For caregivers of persons with Epilepsy.

Kwed eni kilwongo ni: Ngec pa jo ma gi gwoko jo ma gi tye ki two yamo onyo two cimo onyo two olili kun gi tye ka nongo kony me yot kom I ot yat pa miri madit I Gulu Citi, Uganda.

Lakwed man aye:

1. Otto Mike 14/U/0273/MMA.

Gang pwonye: Gulu University

Nyute:

An abedo latin kwan me Gulu University ma tye ka kwan me bedo dakta.

kwed man kiyaro boti I karatac man me nongo yeyo, me gamo lapeny mo keken. Ka dong ityeko moko tami me bedo I kwed man ki bi penyi me keto cingi I karac me yeyo man.

Jo ma ocullu pi kwed man:

kwed man lakwed aye oreyo cente me timo ne.

Tyen lokke:

Kwed/kwan man obineno kwayi yoo ma pat-pat ma kitye ka gwoko ki lutwo Cimo onyo olili ki paco ony gec ma lugwok lutwo tye ka nongo ne ikare me gwoko lutwo magi.

Gin aluba:

Tic pa in i kwed man obibedo gamo lapeny.

Nga ma bibedo I kwed man?

In giyeri pi bedo iyub me kwan man, pien in lanyodo/lagwok dano ma tye ki two cimo onyo olili matye iot yat pa Miri madit iGulu City. Lapeny obitero kinne dakika 30. Obibedo kit meno wang ma lakwed man onongo ni dong oromo.

Gin marac maromo time:

Ma pat ki two Covid-19 ki two mukene matwero kobo ikin dano, dok ma oromo wilobo kacel ki nya pa two Ebola ikin kare ni, pe tye gin mo ma aneno ni rac ma twero kelo peko onyo gin mo peke maromo kelo awano ni aa ki bedo pa in ikwed man. I kwed man ki bi tiyo ki yoo

mogo me gengo nya pa two magi I kin dano. Ki bi pimo jo mawoto ikin piny weng, lutic magi bibdo ki lawum dog ki uum, lalony cing ikare me kwed eni, ki bedo ma kin dano lac kun no cing kilwoko I pol kare. Gin marac aye obibedo balo cawa ni keke ikare me miyo lapeny boti.

Ber pa kwed man:

Adugi pa kwed man bimedo rwom me tic iot -yat tutwale jo ma gi tye ka gwoko jo ma twoyo two Olili onyo two cimo onyo two yamo ma weko gin bene tamo ni pi gi tek dok ki woro gi bene ma biweko gi bibedo ki kero me nongo kony maber iot yat pigwoko two-man ma ngece pud peya tye bot lwak mapoli.

Adugi pa kwed ma bene konyo me miyo ngec bot lwak mapol pi anyim bot jo ma kibikwano lok kom two olili onyo two cimo onyo two yamo ma gin bibedo ki tam me medo ngec ma odong ma nongo pire dok bene kelo neno manyen ikwan me lok kom two olili onyo two cimo onyo two yamo. Kwed man bene bimedo ngec manyen bot jo ma bibedo ikwed man pien gin bidedo ka leyo tam mapata ki luwot gi kit me gwoko lutwo olili ki kit me bedo ki tek cwiny ikare me gwoko lutwo kace dong Odoko tek. I kwed man, ikine obinywako tam kweddi iyoo me mung.

lok ma kwoko komi pe kibitito bot ngat mo keken kit ma dul pa lukwed obi tiyo ki nyuta me ngeno jo ma gitye I kwed man. Dul pa lukwed keken aye bibedo ki kare me neno ngec mo keken ma kicoko. Ki bi tiyo ki yoo mediro me gwoko lok mo keken ma tye I nyonyo pa munu ki bene gin acoya I karatac ki bi gwokko ne kakama kipwungu wiye woko liting. Lakwed madit keken aye tye ki kare me neno mung mo keken.

I kwed man, lakwed bi mino gin acama onyo pi amata ma bidedo maber me konyo ki ikare me kwed man dok ikine obinywako tam kweddi iyoo me mung.

lok ma kwoko komi pe kibitito bot ngat mo keken kit ma dul pa lukwed obi tiyo ki nyuta me ngeno jo ma gitye I kwed man. Dul pa lukwed keken aye bibedo ki kare me neno ngec mo keken ma kicoko. Ki bi tiyo ki yoo mediro me gwoko lok mo keken ma tye I nyonyo pa munu ki bene gin acoya I karatac ki bi gwokko ne kakama kipwungu wiye woko liting. Lakwed madit keken aye tye ki kare me neno mung mo keken.

Yoo mukene

Pe iromo bedo ikwed man kace cwinyi peke iye. Pe ibirwenyo gin mo keken kace pe ibedo ikwed man.

Gin acula

Jo ma bi bedo ikwed man gin weng obinongo gin acama onyo pi amata ma biyengo gi pi kereman me kwed ni dok bene cente alip abic (5,000=) ki bi miyo bot ngat acel, acel ma bibedo ikwed man me konyo gi me giwot me dok paco gi ma bibedo manok onyo matidi loyo.

Lapeny

Kace itye ki lapeny ma lupe ki kwed eni, onyo twero me bedo I kwed man, iromo kuppe ki lakwed Otto Mike. Inumba cim 0777323242.

Lok me dyere

Bedo ikwed eni tye dyere, iromo bedo iye imitti ni giri. I tye ki twero bene me weko ne I cawa mo keken, pwod mo peke iye.

Kace itye ki lok ma kwako twero ni me bedo I kwed man, iromo kuppe ki wonkom pa jo ma loyo lok kom kwed me Gulu university, lapwony dakita Julaina A. Obika Tel: No., 0772964491; email: j.obika@gu.ac.ug; or the Uganda

National Council for Science and Technology, on plot 6 Kimera Road, Ntinda, Kampala on Tel

0414705500

Lok me yeyo

Dul pa lukwed gutito bota ngo ma obitime, gin mo marac kace gwok tye, ber ne, ki twero ma mega calo ngat ma ki bipenyo I kwed man. Aniang ni moko tama me bedo I kwed eni pe bi yella iyo mo keken. I tic ki ngec ma aa ki ikwed, an bene pe ki nyutta woko. Atye ki ngec ni aromo aa cawa mo keken. Aniang ni keto cinga I karatac man, pe amiyo twero na mo keken ento lanyut ni kinianga pi kwed man ci aye gira pira kena.

Nying ngat ma tye I kwed man……

Cinge……Nino dwe…….

Nying caden…….....

Cinge……Nino dwe…….

Nying lamii lapeny…….

Cinge ……. Nino dwe……....

APPENDIX 7: INFORMED CONSENT FORM FOR FOCUS GROUP DISCUSSION

ENGLISH

VERSION 2.0

For caregivers of persons with Epilepsy.

Title of the study: Caregiver's experiences in caring for persons with epilepsy, Gulu Regional Referral Hospital.

Investigators:

Otto Mike 14/U/0273/MMA

Institution: Gulu University

Introduction:

The investigator is a student in Gulu University doing Medical Anthropology at Master Degree level researching caregivers' experiences in caring for persons with epilepsy, Gulu regional referral hospital.

"The study is disclosed to you in this informed consent, after which any questions you may have will be answered. Having decided to participate in the study, you will be asked to sign a consent.

Source of funding:

The student used his own money for this study.

Purpose:

The study seeks to understand caregivers' experiences in caring for persons with epilepsy, Gulu regional referral hospital.

Procedures:

Your participation in this study will answer the questions as guided by the investigator or interviewer.

Who will participate in the study?

You have been chosen to participate in this study because you are a caregiver to persons who have been diagnosed with epilepsy in Gulu Regional Referral Hospital. The discussion will last for about 30 minutes or more. The researcher will collect patients daily until the sample is reached.

Risks/discomforts:

Apart from the global COVID-19 pandemic and other infectious diseases, there is no foreseeable risk of harm or discomfort that will arise from your participation in this study. The research will therefore ensure covid-19 and other infectious diseases spread prevention by sensitization of the research team on the relevant measures to practice to avoid the spread of the diseases, daily screening of the research assistance before going to the field, use of facemask and sanitizers during the data collection, observing social distancing to avoid overcrowding and practicing good hygiene by ensuring they wash their hands frequently. The only risk or discomfort will be the inconvenience in terms of time spent during the interview.

Benefits:

The findings of the study help to improve service delivery for the participants, which in turn makes participants feel valued and may gain access to treatments that are not yet readily available to the general public.

The findings can serve as reference points for future study and filling in gaps, and generating new perspectives within the discipline.

Confidentiality:

Your identity will not be revealed to anyone, as we shall only use codes to identify participants.

Information obtained will only be accessible to the research team. Soft copies of the data will be protected by a password, and hard copy files will be kept under lock and key. Confidential information will only be accessed by the investigator.

Alternatives:

You do not have to participate in this study if you are not interested. There is no penalty in case of no participation.

Cost: Participants are going to be given refreshments in the course of the study and transport refund/reimbursement of at least five thousand shillings (5,000=) per participant, minimum amount.

Questions:

If you have any questions related to the study or your rights as a research participant, you can contact the investigator named Otto Mike at the telephone number 0777323242.

Statement of voluntariness:

Participation in the research study is voluntary, and you may join on your own free will. You have the right to withdraw from the study at any time without penalty.

If you have any issues about your rights and participation in the study, please contact the

Chairperson, Gulu University Research Ethics Committee, Dr. Julaina A. Obika, Tel: No.,

0772964491; email: j.obika@gu.ac.ug; or the Uganda National Council for Science and Technology, on plot 6 Kimera Road, Ntinda, Kampala, on Tel 0414705500.

Statement of consent:

The research team has described to me what is going to be done, the risks, the benefits involved, and my rights as a participant in this study. I understand that my decision to participate in this study will not affect me in any way. In the use of this information, my identity will be concealed.

I am aware that I may withdraw at any time. I understand that by signing this form, I do not waive any of my legal rights but merely indicate that I have been informed about the research study in which I am voluntarily agreeing to participate.

Name of the participant …….....

Signature/thumbprint……Date…….....

Name of the witness …….....

Signature/thumbprint……Date…….....

Name of the interviewer …….....

Signature/thumbprint…….……Dat…….....

APPENDIX 8: INFORMED CONSENT FORM FOR FOCUS GROUP DISCUSSION

ACHOLI/LUO LANGUAGE.

VERSION 2.0

For caregivers of persons with Epilepsy.

Kwed eni kilwongo ni: Ngec pa jo ma gi gwoko jo ma gi tye ki two yamo onyo two cimo onyo two olili kun gi tye ka nongo kony me yot kom I ot yat pa miri madit I Gulu Citi, Uganda.

Lakwed man aye:

2. Otto Mike 14/U/0273/MMA.

Gang pwonye: Gulu University

Nyute:

An abedo latin kwan me Gulu University ma tye ka kwan me bedo dakta.

kwed man kiyaro boti I karatac man me nongo yeyo, me gamo lapeny mo keken. Ka dong ityeko moko tami me bedo I kwed man ki bi penyi me keto cingi I karac me yeyo man.

Jo ma ocullu pi kwed man:

kwed man lakwed aye oreyo cente me timo ne.

Tyen lokke:

Kwed/kwan man obineno kwayi yoo ma pat-pat ma kitye ka gwoko ki lutwo Cimo onyo olili ki paco ony gec ma lugwok lutwo tye ka nongo ne ikare me gwoko lutwo magi.

Gin aluba:

Tic pa in i kwed man obibedo gamo lapeny.

Nga ma bibedo I kwed man?

In giyeri pi bedo iyub me kwan man, pien in lanyodo/lagwok dano ma tye ki two cimo onyo olili matye iot yat pa Miri madit iGulu City. Lapeny obitero kinne dakika 30. Obibedo kit meno wang ma lakwed man onongo ni dong oromo.

Gin marac maromo time:

Ma pat ki two Covid-19 ki two mukene matwero kobo ikin dano, dok ma oromo wilobo kacel ki nya pa two Ebola ikin kare ni, pe tye gin mo ma aneno ni rac ma twero kelo peko onyo gin

mo peke maromo kelo awano ni aa ki bedo pa in ikwed man. I kwed man ki bi tiyo ki yoo mogo me gengo nya pa two magi I kin dano. Ki bi pimo jo mawoto ikin piny weng, lutic magi bibdo ki lawum dog ki uum, lalony cing ikare me kwed eni, ki bedo ma kin dano lac kun no cing kilwoko I pol kare. Gin marac aye obibedo balo cawa ni keke ikare me miyo lapeny boti.

Ber pa kwed man:

Adugi pa kwed man bimedo rwom me tic iot -yat tutwale jo ma gi tye ka gwoko jo ma twoyo two Olili onyo two cimo onyo two yamo ma weko gin bene tamo ni pi gi tek dok ki woro gi bene ma biweko gi bibedo ki kero me nongo kony maber iot yat pigwoko two man ma ngece pud peya tye bot lwak mapoli.

Adugi pa kwed ma bene konyo me miyo ngec bot lwak mapol pi anyim bot jo ma kibikwano lok kom two olili onyo two cimo onyo two yamo ma gin bibedo ki tam me medo ngec ma odong ma nongo pire dok bene kelo neno manyen ikwan me lok kom two olili onyo two cimo onyo two yamo. Kwed man bene bimedo ngec manyen bot jo ma bibedo ikwed man pien gin bidedo ka leyo tam mapata ki luwot gi kit me gwoko lutwo olili ki kit me bedo ki tek cwiny ikare me gwoko lutwo kace dong odoko tek.I kwed man, ikine obinywako tam kweddi iyoo me mung.

lok ma kwoko komi pe kibitito bot ngat mo keken kit ma dul pa lukwed obi tiyo ki nyuta me ngeno jo ma gitye I kwed man. Dul pa lukwed keken aye bibedo ki kare me neno ngec mo keken ma kicoko. Ki bi tiyo ki yoo mediro me gwoko lok mo keken ma tye I nyonyo pa munu ki bene gin acoya I karatac ki bi gwokko ne kakama kipwungu wiye woko liting. Lakwed madit keken aye tye ki kare me neno mung mo keken.

Yoo mukene

Pe iromo bedo ikwed man kace cwinyi peke iye. Pe ibirwenyo gin mo keken kace pe ibedo ikwed man.

Gin acula

Jo ma bi bedo ikwed man gin weng obinongo gin acama onyo pi amata ma biyengo gi pi kereman me kwed ni dok bene cente alip abic (5,000=) ki bi miyo bot ngat acel, acel ma bibedo ikwed man me konyo gi me giwot me dok paco gi ma bibedo manok onyo matidi loyo.

Lapeny

Kace itye ki lapeny ma lupe ki kwed eni, onyo twero me bedo I kwed man, iromo kuppe ki lakwed Otto Mike. Inumba cim 0777323242.

Lok me dyere

Bedo ikwed eni tye dyere, iromo bedo iye imitti ni giri. I tye ki twero bene me weko ne I cawa mo keken, pwod mo peke iye.

Kace itye ki lok ma kwako twero ni me bedo I kwed man, iromo kuppe ki wonkom pa jo ma loyo lok kom kwed me Gulu university, lapwony dakita Julaina A. Obika Tel: No., 0772964491; email: j.obika@gu.ac.ug; or the Uganda

National Council for Science and Technology, on plot 6 Kimera Road, Ntinda, Kampala on Tel

0414705500

Lok me yeyo

Dul pa lukwed gutito bota ngo ma obitime, gin mo marac kace gwok tye, ber ne, ki twero ma mega calo ngat ma ki bipenyo I kwed man. Aniang ni moko tama me bedo I kwed eni pe bi yella iyo mo keken. I tic ki ngec ma aa ki ikwed, an bene pe ki nyutta woko. Atye ki ngec ni aromo aa cawa mo keken. Aniang ni keto cinga I karatac man, pe amiyo twero na mo keken ento lanyut ni kinianga pi kwed man ci aye gira pira kena.

Nying ngat ma tye I kwed man …….……

Cinge……Nino dwe……..….

Nying caden…….....

Cinge……Nino dwe…….

Nying lamii lapeny……..…….

Cinge ……. Nino dwe…….....

APPENDIX 9: GUREC APPROVAL LETTER

GULU UNIVERSITY
P.O. Box 166, Gulu (U)
Website: www.gu.ac.ug
Email: gurec@gu.ac.ug
Tel: +256 471 432 096
Fax: +256 471 432 913
Mob: +256 772 964 491
+256 776 812 147
RESEARCH ETHICS COMMITTEE

08/11/2024

To: Mike Otto

Gulu Univsersity
0777323242

Type: Initial Review

Re: GUREC-2024-842: CAREGIVERS' EXPERIENCES IN CARING FOR PERSONS WITH EPILEPSY, GULU REGIONAL REFERRAL HOSPITAL.

I am pleased to inform you that at the **112th** convened meeting on **18/04/2024**, the Gulu University REC meeting voted to approve the above referenced application.
Approval of the research is for the period of **08/11/2024** to **08/11/2025.**

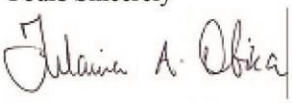
As Principal Investigator of the research, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the protocol or the consent form must be submitted to the REC for re-review and approval **prior** to the activation of the changes.
3. Reports of unanticipated problems involving risks to participants or any new information which could change the risk benefit: ratio must be submitted to the REC.
4. Only approved consent forms are to be used in the enrollment of participants. All consent forms signed by participants and/or witnesses should be retained on file. The REC may conduct audits of all study records, and consent documentation may be part of such audits.
5. Continuing review application must be submitted to the REC **eight weeks** prior to the expiration date of **08/11/2025** in order to continue the study beyond the approved period. Failure to submit a continuing review application in a timely fashion may result in suspension or termination of the study.
6. The REC application number assigned to the research should be cited in any correspondence with the REC of record.
7. You are required to register the research protocol with the Uganda National Council for Science and Technology (UNCST) for final clearance to undertake the study in Uganda.

The following is the list of all documents approved in this application by Gulu University REC:

No.	Document Title	Language	Version Number	Version Date
1	Interview Guides for Focus Group Discussion	English language	2.0	2024-09-21
2	Interview Guides for In-depth Interview	English language	2.0	2024-09-21
3	Protocol	English	2.0	2024-09-21
4	Informed Consent forms	English and Luo language	2.0	2024-09-21
5	Community Engagement plan	English language	2.0	2024-09-21

Yours Sincerely



Julaina A. Obika (PhD)
For: Gulu University REC

APPENDIX 10: ADMINISTRATIVE CLEARANCE

Hospital Director office:
+256774408228
Telephone Hospital Director
+256774408225
E-mail:
gulurrhospital@gmail.com
mukpet@gmail.com

THE REPUBLIC OF UGANDA

MINISTRY OF HEALTH
GULU REGIONAL REFERRAL HOSPITAL
P. O. Box 160,
Gulu, Uganda.

14/5/2025

In any correspondence on this matter quote:

OTTO MIKE 14/U/0273/MMAs

RE: Administrative clearance for a research titled: **GUREC-2024-842: CAREGIVERS' EXPERIENCES IN CARING FOR PERSONS WITH EPILEPSY, GULU REGIONAL REFERRAL HOSPITAL, UGANDA**

This is to inform you that the Gulu Regional Referral Hospital Research and Ethics Interim Committee (GRRHREC) has cleared you to collect data for the above referenced research study.

Note that this clearance expires. It is therefore valid until 6th, April, 2026. Renewal of this clearance is conditional upon your compliance with the following requirements:

Significant changes to the current protocol and all anticipated problems that may involve risks to study subjects or patients information or that may affect integrity of the research must be promptly reported to (GRRHREC).

You will be required to share the study findings with the GRRHREC and corresponding department.

Yours Faithfully;

GULU REGIONAL REFERRAL HOSPITAL For: DIRECTOR 14 MAY 2025 P.O. BOX 160 GULU

PP

Dr. Baifa Arwinyo

(CONSULTANT OBSTETRICIAN and GYNAECOLOIST)

CHAIRPERON GRRHREC

APPENDIX 11: PLAGIARISM REPORT

GULU UNIVERSITY

P.O. Box 166
Gulu, Uganda

Tel: +256-471-32924
Fax: +256 471343095
Emails: ul@gu.ac.ug
URL: www.gu.ac.ug

OFFICE OF THE UNIVERSITY LIBRARIAN

PLAGIARISM CHECK

Declaration for Originality Form

This form must be completed and signed for all scholarly work produced.

Name: OTTO MIKE (MR.)

Personal File No. (staff) Reg. (student). REG. NO. 14/U/0273/MMA

Faculty/Institute: FACULTY OF MEDICINE, GULU UNIVERSITY

Department: PUBLIC HEALTH

Title and bibliographic description of the work

CAREGIVERS' EXPERIENCES IN CARING FOR PERSONS WITH EPILEPSY, GULU REGIONAL REFERRAL HOSPITAL, UGANDA.

Declaration.

1. I understand what plagiarism is and I am aware of the University policy on this regard,
2. I declare that this … **Dissertation** … (Proposal, thesis, essay, assignment, paper, report etc.) is my original work and has not been submitted elsewhere for examination, award of a degree or publication. Where other people's work or my work has been used, this has been properly acknowledged and referenced in accordance with Gulu University requirements,
3. I have not sought or used the services of any professional agency to produce this work,
4. I have not allowed, and shall not allow anyone to copy my work with the intention of passing it off as his/her own,
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