DEPRESSION, ANXIETY, AND ASSOCIATED FACTORS AMONG CAREGIVERS OF CHILDREN AND ADOLESCENTS WITH EPILEPSY ATTENDING MUHIMBILI PAEDIATRIC NEUROLOGY CLINIC

Erneus Ernest, MD

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By

Erneus Ernest, MD

A dissertation Submitted in (partial) Fulfilment of the Requirements for the Degree of Master of Medicine (Paediatrics and Child Health) at

Muhimbili University of Health and Allied Sciences

October, 2024

CERTIFICATION

The undersigned certifies that they have read and hereby recommend for acceptance by the Muhimbili University of Health and Allied Sciences a dissertation entitled: "**Depression, anxiety and associated factors among Caregivers of Children and Adolescents with Epilepsy attending Muhimbili Paediatric Neurology Clinic"** in partial fulfilment requirement for the degree of Master of Medicine in Paediatrics and Child Health of the Muhimbili University of Health and Allied Sciences.

_____

Dr. Rodrick Kisenge

(Supervisor)

Date: _____



_____

Dr. Obrey Urio

(Co – Supervisor)

Date: _____

_____

Dr. Zameer Fakih

(Co-Supervisor)

Date: _____

DECLARATION AND COPYRIGHT

I, **Erneus Ernest** declare that this dissertation is my original work and that it has not been presented and will not be presented to any other University for a similar or any other degree award.

Signature: …… Date: …….....

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DEDICATION

To my parents Ernest and Leontina, for your unwavering support, guidance, and wisdom.

To my siblings; Anold, Evensiana, Evance, and Allen for your encouragement.

ABSTRACT

Background: Epilepsy continues to be one of the most prevalent neurological disorders, it affects 50 million people globally. The diagnosis of epilepsy has psychological impacts on the families, particularly the caregivers. The stigma associated with the disease, the economic burden of care, and the unpredictability of seizures contribute to psychological distress in caregivers. Little is known about the prevalence of depression, anxiety, and associated factors among caregivers of children with epilepsy in Tanzania.

Objective: We aimed to determine the prevalence of depression, anxiety, and their associated factors among caregivers of children and adolescents with epilepsy attending the Paediatric neurology clinic at Muhimbili National Hospital (MNH).

Methodology: This was a hospital-based cross-sectional study conducted among caregivers of children and adolescents with epilepsy attending MNH Paediatric neurology clinic between July 2023 to November 2023. Demographic data were collected using a structured questionnaire, and depression as well as anxiety were assessed using Patient Health Questionnaire-9 (PHQ-9) and Generalized Anxiety Disorder 7 (GAD-7) tools respectively. Logistic regression was used to assess factors independently associated with depression and anxiety. A p-value less than 0.05 was considered statistically significant.

Results: A total of 427 participants were enrolled with a mean age of 34.2 ± 6.8 years. Most caregivers were female 397 (93.0%), married 333 (78.0%), and mothers of children 381 (89.2%). Depression was observed in 17.3% of the participants, anxiety was found in another 17.3%, and 9.0% of caregivers were found to have both depression and anxiety. Factors associated with depression were having a child who is: less than 5 years old (adjusted odds ratio (aOR) =8.65; 95% CI: 1.79- 41.82, p=0.007), epilepsy duration more than 5 years (aOR= 3.25; 95% CI: 1.08 – 9.77), history of epilepsy-related injuries (aOR =2.90; 95% CI:1.26 – 6.66, p=0.012) and three or more hospital admissions (aOR=2.70; 95% CI: 1.02 - 7.11, p= 0.044). Caregivers whose children had not started school or were in primary school had lesser odds of depression compared to counterparts in secondary school (aOR=0.01; 95% CI: 0.001 – 0.28, p=0.0004) and (aOR=0.02; 95% CI: 0.002 - 0.36, p= 0.007), respectively. Factors associated

with caregivers' anxiety were having a child with: another comorbidity (aOR=2.01; 95% CI: 1.13 - 3.58, p=0.017), history of epilepsy-related injuries (aOR=2.52; 95% CI: 1.10 – 5.78, p=0.028), 3 or more hospital admissions (aOR= 3.22; 95% CI: 1.27 – 8.12, p= 0.013) and if caregiver was aged between 41 to 50 years (aOR = 3.30; 95% CI: 1.06 – 10.23, p= 0.039). Having a child with a duration of epilepsy of more than 5 years was associated with having concurrent depression and anxiety (aOR = 4.63; 95% CI 1.00 – 26.26, p= 0.049).

Conclusion: Our study revealed that depression and anxiety are common among caregivers of children with epilepsy (CWE). Most of the factors associated with caregivers' depression and anxiety were epilepsy-related.

Recommendations: Integration of mental health services in regular Paediatric neurology clinic offering screening for depression and anxiety and linkage of caregivers for counselling and psychoeducation.

MUHTASARI

Utambulisho: Ugonjwa wa kifafa unaendelea kuwa mojawapo ya magonjwa ya mfumo wa neva yaliyoenea zaidi, ukiathiri watu milioni 50 duniani kote. Utambuzi wa kifafa una athari za kisaikolojia kwa familia, haswa walezi. Unyanyapaa unaohusishwa na ugonjwa huo, mzigo wa kiuchumi wa huduma, na kutotabirika kwa mshtuko huchangia mfadhaiko wa kisaikolojia kwa walezi. Machache yanafahamika kuhusu uwepo wa sonona, wasiwasi uliopitiliza, na visababishi vyake miongoni mwa walezi wa watoto wenye ugonjwa wa kifafa nchini Tanzania.

Malengo: Tulilenga kubaini kiwango cha sonona, wasiwasi uliopitiliza, na visababishi vyake miongoni mwa walezi wa watoto na vijana wenye kifafa wanaohudhuria kliniki ya magonjwa ya mishipa ya fahamu katika Hospitali ya Taifa Muhimbili.

Njia: Utafititi huu ulifanyika katika hosipitali ya taifa Muhimbili kwa kuzingatia njia za kisayansi za utafiti na ulihusisha walezi wa watoto wenye ugonjwa wa kifafa wanaohudhuria kliniki ya magonjwa ya neva ya MNH kati ya Julai 2023 hadi Novemba 2023. Dodoso lilitumika kukusanya taarifa za kidemografia. Kiwango cha sonona na wasiwasi uliopitiliza viliainishwa kwa kutumia madodoso ya “PHQ-9” na “GAD-7”.

Matokeo ya utafiti: Jumla ya walezi 427 wa watoto wenye kifafa walijumuishwa katika utafiti huu na walikua na wastani wa umri wa miaka 34.25 ± 6.82. Walezi wengi walikuwa wanawake 397 (93.0%), walioolewa 333 (78.0%), na mama wa watoto 381 (89.2%). Sonona ilionekana katika asilimia 17.3 ya washiriki, wasiwasi uliopitiliza katika asilimia 17.3 nyingine, na asilimia 9 ya walezi walionekana kuwa sonona na wasiwasi uliopitiliza kwa pamoja. Visababishi vya sonona vilivyogundulika ni pamoja na kuwa mtoto ambaye; ana umri chini ya miaka mitano (aOR =8.65; 95% CI: 1.79- 41.82, p=0.007), mwenye kifafa zaidi ya miaka mitano (aOR= 3.25; 95% CI: 1.08 - 9.77), historia ya majeraha yanayohusiana na kifafa (aOR =2.90; 95% CI:1.26 - 6.66, p=0.012) na kulazwa hospitalini mara tatu au zaidi kutokana na kifafa (aOR=2.70; 95% CI: 1.02 - 7.11, p=0.044). Walezi ambao watoto wao hawajaanza shule au walikuwa shule ya msingi walikuwa na uwezekano mdogo wa kupata sonona ikilinganishwa na wenzao wenye watoto waliokuwa shule ya sekondari (aOR=0.01; 95% CI: 0.001 - 0.28, p=0.0004) na

(aOR=0.02; 95% CI: 0.002 - 0.36, p = 0.007). Visababishi vya wasiwasi uliopitiliza vilivyogundulika ni pamoja na kuwa na mtoto ambaye; ana kifafa pamoja na magonjwa mengine (aOR=2.01; 95% CI: 1.13 - 3.58, p=0.017), historia ya majeraha yanayohusiana na kifafa (aOR=2.52; 95% CI: 1.10 - 5.78, p=0.028), kulazwa hospitalini mara tatu au zaidi kutokana na kifafa (aOR= 3.22; 95% CI: 1.27 - 8.12, p= 0.013) na ikiwa mlezi alikuwa na umri wa miaka 41 hadi 50 (aOR = 3.30; 95% CI: 1.06 - 10.23, p=0.039). Kuwa na mtoto mwenye kifafa zaidi ya miaka mitano kulihusishwa na kuwa na sonona na wasiwasi uliopitiliza kwa pamoja (aOR = 4.63; 95% CI 1.00 - 26.26, p= 0.049).

Hitimisho: Utafiti wetu ulionyesha kwamba sonona na wasiwasi uliopitiliza hutokea sana miongoni mwa walezi wa watoto wenye kifafa. Sababu nyingi za sonona na wasiwasi miongoni mwa wazazi zinahusiana na kifafa cha watoto wao.

Mapendekezo: Huduma za afya ya akili ziunganishwe katika kliniki ya magonjwa ya mishipa ya fahamu ya watoto. Hii itasaidia kuchunguza na kubaini walezi wenye sonona na wasiwasi uliopitiliza, na hivyo kuweza kuwaunganisha na wataalamu wa saikolojia kwa ajili ya matibabu.

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LIST OF ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder
aOR	Adjusted Odds Ratio
ASM	Anti Seizures Medications
cOR	Crude Odds Ratio
CWE	Children with Epilepsy
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th edition
GAD 7	Generalized anxiety disorder- 7
ILAE	International League Against Epilepsy
MDD	Major depressive disorder
MNH	Muhimbili National Hospital
MUHAS	Muhimbili University of Health and Allied Sciences
PHQ 9	Patient health questionnaire- 9
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

DEFINITION OF TERMS

Epilepsy: This is a brain disorder associated with a persistent propensity to have epileptic seizures as well as the cognitive, neurological, social, and psychological consequences of the condition.

Epilepsy (clinical definition): The International league against epilepsy (ILAE) defines epilepsy as a brain disease characterized by the following;

1) At least two unprovoked (or reflex) seizures occurring more than 24 hours apart.
2) One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years.
3) Diagnosis of an epilepsy syndrome

Caregiver: An individual above the age of 18 years who has close contact and with a primary responsibility of providing daily care to the child or adolescent for at least 6 months.

Depression (Major depressive disorder): is a mental disorder presenting with at least 2 weeks of a depressed and/or irritable mood that is present for most of the day, nearly every day, and/or loss of interest or pleasure in doing nearly all activities. In this study, depression was defined by a score of 10 and above based on the Patient Health Questionnaire- 9 (PHQ-9).

Generalized Anxiety disorder: is a mental health disorder characterized by excessive anxiety and worry (apprehensive expectation), about several events or activities (such as work or school performance). This anxiety is difficult to control and occurs more days than not for at least six months. In this study, anxiety was defined by a score of 10 and above based on Generalized Anxiety Disorder 7 (GAD-7).

1.0 INTRODUCTION

1.1 Background

Epilepsy continues to be among the most common neurological disorders worldwide, particularly among children and young adults in developing countries, where they are disproportionately more affected (1). It is diagnosed in about 5 million people each year with the incidence being higher in low and middle-income countries (139 per 100,000 person-years) when compared to high-income countries (48.9 per 100,000 person-years) (2). Developing countries also report a higher prevalence of childhood epilepsy that ranges from 3.6-44/1000 compared to developed countries of 3.2-5.5/1000 (1).

The effects of epilepsy not only end with the patient but a significant burden is also shared with the family members and caregivers of patients with epilepsy. Children with epilepsy face problems such as stigma, risks of injury, missing school days, and an increased risk of poor academic performance. As for the caregivers of children with epilepsy, this affects them through spending much time in hospitals when their children have seizures (3). They also face economic constraints posed by taking care of their children, worry about their children getting injuries, and stigma from the community (4). Caregivers might also feel that their child is different when compared to others (5).

The above can result in psychological discomfort, excessive worry, and depression in caregivers of children who have been diagnosed with epilepsy (3). As high as 41% and 52.8% of those who care for patients with epilepsy have depression or anxiety respectively with caregivers of children reporting higher depression severity when compared to caregivers of adults with epilepsy (6). This is a great concern, as psychological distress in caregivers may hurt the children's quality of life and the overall prognosis (7).

1.2 Problem statement

Childhood epilepsy continues to be a widespread issue (8). The burden of epilepsy extends to family members and their caregivers. The social stigma that accompanies the disease, the economic burden of care, fear for the next seizure episode, and the feeling that their child might not live a normal life, all contribute to psychological distress including depression and anxiety among caregivers (3). Therefore, caregivers need to have good mental health to provide quality care to children with epilepsy. Data are scarce on the prevalence of depression and anxiety among caregivers of children and adolescents with epilepsy in East Africa.

Our study aimed to close the gap by determining the prevalence and associated factors for depression and anxiety among caregivers of children and adolescents with epilepsy in Tanzania. Depression and anxiety can impact the caregivers' ability to provide adequate care for the child or adolescent with epilepsy which may lead to poorer health outcomes. This study will contribute to a better understanding of the mental health needs of caregivers of children with epilepsy and inform on the interventions that can be done to ensure psychological well-being in this population.

1.3 Conceptual framework

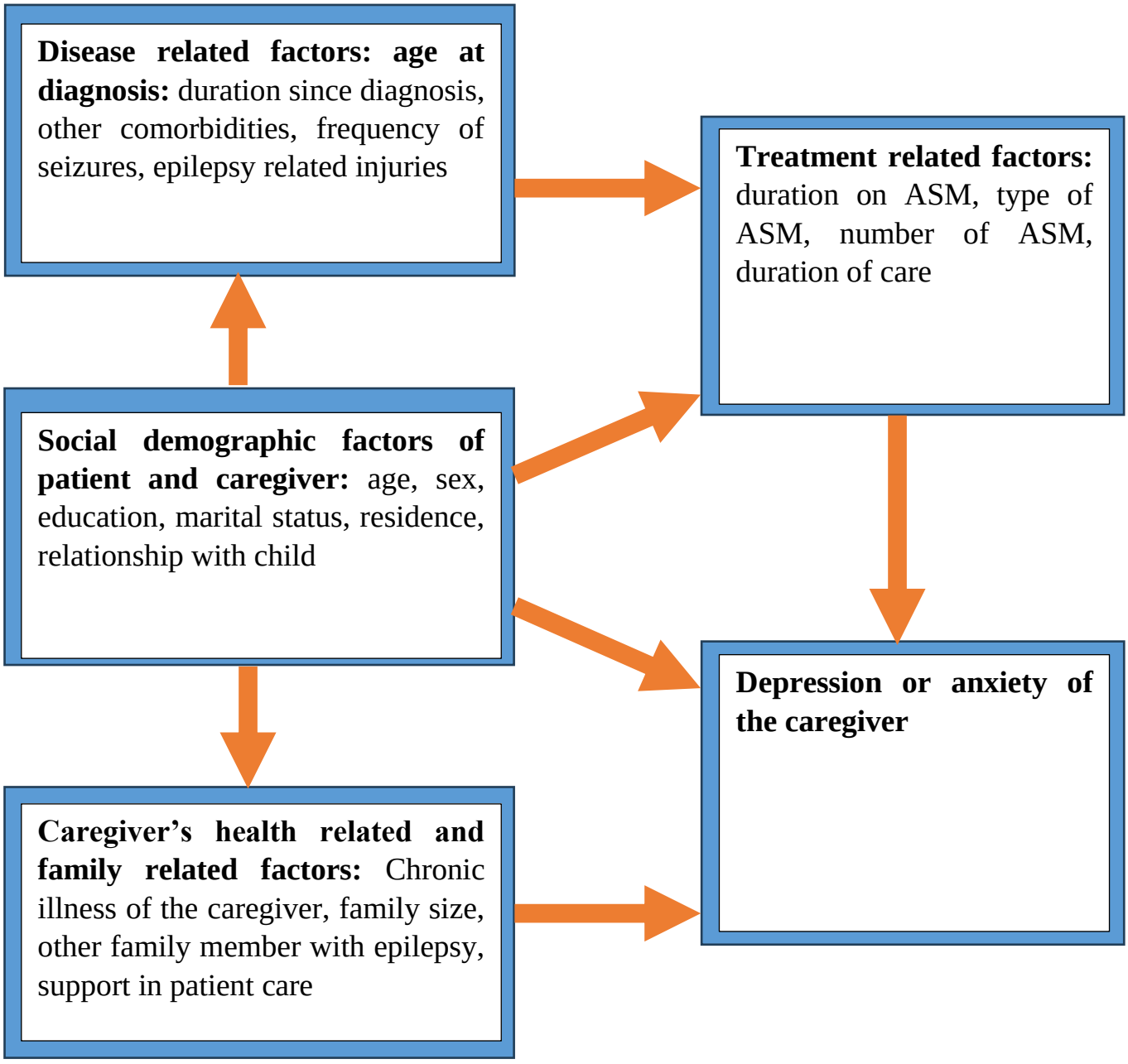


Figure 1: Conceptual framework showing how different factors contribute to depression, and anxiety in caregivers of children with epilepsy. Abbreviation used: ASM – Antiseizure Medication

1.4 Rationale

Despite the literature showing a high prevalence of depression and anxiety among those who care for children and adolescents with epilepsy, its magnitude in Tanzania is not known.

This study aimed to establish the prevalence of depression and anxiety in Tanzania and to identify specific factors that contribute to depression and anxiety among caregivers of children with epilepsy. The findings from this study will also help in a better understanding of mental health needs among caregivers of children with epilepsy hence helping in the formulation of strategies to support and improve caregiver mental health.

1.5 Research questions

i. What is the prevalence of depression among caregivers of children and adolescents with epilepsy attending the paediatric neurology clinic at MNH?

ii. What are the factors associated with depression among caregivers of children and adolescents with epilepsy attending the paediatric neurology clinic at MNH?

iii. What is the prevalence of anxiety among caregivers of children and adolescents with epilepsy attending the paediatric neurology clinic at MNH?

iv. What are the factors associated with anxiety among caregivers of children and adolescents with epilepsy attending the paediatric neurology clinic at MNH?

1.6 Objectives

1.6.1 Broad objectives

To determine the prevalence of depression, anxiety, and their associated factors among caregivers of children and adolescents with epilepsy attending the paediatric neurology clinic at MNH.

1.6.2 Specific objectives

i. To determine the prevalence of depression among caregivers of children and adolescents with epilepsy attending the paediatric neurology clinic at MNH.
ii. To determine factors associated with depression among caregivers of children and adolescents with epilepsy attending the paediatric neurology clinic at MNH.
iii. To determine the prevalence of anxiety among caregivers of children and adolescents with epilepsy attending the paediatric neurology clinic at MNH.
iv. To determine factors associated with anxiety among caregivers of children and adolescents with epilepsy attending the paediatric neurology clinic at MNH.

2.0 LITERATURE REVIEW

2.1 Prevalence of depression among caregivers of children and adolescents with epilepsy

Taking care of patients with epilepsy is associated with a significant risk of mental disorders such as depression. It has been shown that caregivers of children with epilepsy are more likely to develop depression when compared to those who care for children with no epilepsy (9,10). A systematic review conducted across different continents reported half of the mothers taking care of children with epilepsy are at risk of depression (7).

Furthermore, studies from high-income countries such as that done in the United States of America (USA) reported depression in 41.0% of the caregivers (6). This does not differ much from studies done in Saudi Arabia, and China (10,11). In low and middle-income countries such as India, the prevalence is 37.5% (12).

Despite the previously mentioned prevalence rates, it should be noted that there is variability in prevalence with some studies reporting a lower prevalence. A study conducted in Nepal showed that 15.1% of the caregivers of children with epilepsy are depressed (13). A Turkish study found that 28.0% of mothers of children with epilepsy experience depression (14). Another study in China found 5.3% of the participants were depressed (15). Of note, one study found no increased risk of depression among mothers of children with epilepsy when compared to mothers of children with no epilepsy (16).

Despite lower-income countries carrying a higher burden of epilepsy (1), there are fewer studies assessing the prevalence of depression among their caregivers when compared to high-income countries. In Nigeria, half of the caregivers were found to have depression (17). However, another study within Nigeria found the prevalence to be lower (18.7%) (18).

The differences in prevalence continues to be observed in other studies in Africa where the prevalence of depression among caregivers of children with epilepsy in Burkina Faso and Ethiopia were found to be 27.0% and 13.7% respectively (3,5).

Studies in Tanzania have also raised concerns about caregiver mental health including depression. In a qualitative study that explored the challenges of caring for children with mental disorders including epilepsy, it was found that caregivers experience emotional challenges such as sadness, inner pain, and psychological distress (19). These results were similar to another qualitative study done in rural Tanzania which revealed that parents of children with conditions that may cause developmental disabilities including epilepsy experience depression as a result of their children's handicap (20). In a cross-sectional study conducted among caregivers of children with mental illness, it was discovered that 22.5% of these individuals experienced mental distress (21).

The existing literature shows that there is a range of prevalence rates for depression among caregivers of children with epilepsy in various geographic locations. There is limited information on the prevalence of depression among caregivers of children with epilepsy in Tanzania, with most published studies restricted to qualitative research and not assessing depression in isolation. Therefore, it is crucial to conduct a local study to determine the extent of this issue given the inconsistency in reported prevalence rates and the limitations of previous research conducted in Tanzania.

2.2 Screening tools for depression

There is a variation of tools used to screen depression across different studies. Patient Health Questionnaire 9 (PHQ-9) is a widely used screening tool for depression created by Spitzer et al (22). It consists of nine items that are based on the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) criteria for major depressive disorder. PHQ-9 is self-administered and elicits symptoms of depression in the previous two weeks. Each item is scored on a scale of from 0 (not at all) to 3 (nearly every day).

Beck Depression Inventory scale is a self-reporting tool created by Beck et al that assesses attitude and symptoms of depression. It contains 21 items with each representing a symptom of depression. Each item has a set of statements reflecting varying degrees of severity (from 0 to 3) with respondent choosing a statement that best reflects their feeling in the past two weeks (23). The Zung Self-Rating Depression Scale is a tool created by William et al used to screen

for depression. It is self-administered and contains 20 items assigned a rating on a scale from 1 (none or some of the time) to 4 (most or all of the time). It has a score ranging from 20 – 30 with higher scores presenting more severe depressive symptoms (24). The variety of tools with different scoring systems may contribute to the observed differences in the prevalence of depression across studies.

2.3 Factors associated with depression among caregivers of children and adolescents with epilepsy

Different factors are associated with depression in caregivers of children and adolescents with epilepsy. In a study conducted in the United Kingdom, there was a positive correlation between increased child emotional-behavioural problems and the depression score of the caregiver (9). This was consistent with studies conducted in Canada and USA (25,26).

Being a mother of a child with epilepsy has also been shown to increase the likelihood of developing depression according to a study conducted in the UK (9). Similar results were seen in other studies (5,7). Likewise, caregiver gender was associated with depression with female caregivers of children with epilepsy more likely to experience depression (3). These findings are in contrast results to a study that did not find an association between the gender of the caregiver and the risk of developing depression (5).

Taking care of children with epilepsy together with other co-morbidities is associated with a higher risk of depression. A study in Canada revealed that mothers whose children had a comorbidity of attention deficit hyperactivity disorder (ADHD) had higher depression scores (7). Another study found mothers of children with epilepsy with comorbidity of intellectual disability to be at higher risk of depression (12). Along with this, poor seizure control of the patient was found to increase the risk of the caregiver developing depression (5). Place of residence has also been shown to have an association with the depression of caregivers with those living in rural areas having a higher risk of depression (15).

In another study, strong social support was found to be protective against depression (3). A study in China showed the absence of a co-caregiver to be associated with a higher risk of depression (27). This is in contrast to a study in Burkina Faso, where it was found that being a married caregiver was associated with depression (5). A study conducted in Ethiopia found that caregivers with longer duration of care were more likely to be depressed (3). This was also observed in a study conducted in Nigeria (17).

According to a qualitative study done in Tanzania that examined difficulties faced by families with chronic illnesses, such as epilepsy, it was discovered that depression was more severe in households where the father had left when the illness was not well-controlled, when the child was older and when the child was female (20). In another qualitative study conducted in a hospital setting, caregivers reported experiencing feelings of sadness as a result of the challenging behaviours exhibited by the children under their care (19). Conversely, a different study found a significant association between place of residence and mental distress among caregivers. Specifically, caregivers residing outside of urban areas were found to be at a higher risk of experiencing mental distress (21).

The literature on depression in caregivers of children with epilepsy reveals a variety of factors associated with this condition, with some studies yielding contrasting results. It is worth noting that in Tanzania, research on depression in caregivers of children with epilepsy often involves other mental illnesses as well, making it difficult to determine which factors are solely associated with depression. Therefore, further research is necessary to identify the specific factors linked to depression in this population in Tanzania.

2.4 Prevalence of anxiety among caregivers of children and adolescents with epilepsy

Caring for children and adolescents with epilepsy is a demanding task that can result in emotional and psychological distress for caregivers, including anxiety. Existing literature has indicated a considerable proportion of caregivers of children with epilepsy are at an elevated risk of developing anxiety, as discussed in further detail below;

According to a study conducted in the United Kingdom, caregivers of children with epilepsy have higher odds of developing anxiety compared to those of children without epilepsy (9). This is further evidenced by a study done in China yielding a similar result that caregivers of children with epilepsy have higher anxiety scores compared to those of healthy children (10).

A study conducted in the USA among those who care for children with epilepsy found that at least 52.8% of the caregivers experience anxiety (6). This reported high incidence is consistent with that of other studies conducted in high-income countries where the prevalence of anxiety was found to be 60.0% and 54.8% in Italy and Saudi Arabia respectively (11,28). In two studies conducted in China, it was found that 56.2% and 41.9% of caregivers experience anxiety (27,29), the difference might be explained by the difference in study population and assessment tools used. Moreover, a study conducted in India discovered that almost half of the mothers of children with neurodevelopmental disorders including epilepsy experience anxiety (12).

Of note, is the inconsistency in literature where other studies report a lower prevalence of anxiety compared to the aforementioned. For example, a study done in Turkey did not find a difference in the risk of developing anxiety among caregivers of children with epilepsy when compared to those of healthy children (16). A study in China found the prevalence of anxiety among caregivers of children with epilepsy to be 21.6% (10). In Nepal, the prevalence of anxiety among caregivers of patients with epilepsy was 6.6%, this is significantly lower compared to the studies discussed above (13).

Despite, low-income countries reporting a higher prevalence of epilepsy. Few studies explore anxiety among caregivers of children with epilepsy. These studies also show variability in the prevalence across different countries. A study conducted in Nigeria found almost half of the

caregivers of children with epilepsy to have psychological distress including anxiety (30). This is further seen in Burkina Faso in which 56.0% of the caregivers had anxiety (5).

It should be noted that some studies conducted in other African countries have reported lower prevalence rates of depression among caregivers of children with epilepsy. A study conducted in Ethiopia found the prevalence of anxiety among caregivers of children with epilepsy to be 10.4% (3). A different study conducted in Nigeria found a prevalence of 38.6% (18).

Studies in Tanzania have also shown that anxiety is a problem among caregivers of children with epilepsy. In a qualitative study among caregivers of children with mental disorders including epilepsy, it was found that caregivers experience excessive worry, particularly about the future of their children (19). Another qualitative study done in rural Tanzania reported similar findings where caregivers of children with permanent childhood developmental disabilities were found to experience anxiety (20).

2.5 Tools used in screening for anxiety

There is a wide range of tools used to screen for anxiety with Generalized anxiety disorder- 7 (GAD 7) being one of the commonly utilized tools. It was created by Spitzer et al and comprises of seven questions to assess for symptoms of anxiety in the preceding two weeks. Each item is scored on a scale of 0 to 3 based on the frequency of symptoms (0: Not at all, 3: Nearly every day) (31). The State-Trait Anxiety Inventory for Children, created by Spielberger et al, serves as another screening tool for anxiety, consisting of 21 items that prompt children to evaluate their feelings of anxiety at a specific moment using a 3-point scale (1: Hardly ever, 2: Sometimes, 3: Often) (32). Additionally, the Zung Self-Rating Anxiety Scale was formulated by William et al. It assesses the severity of anxiety using 20 items on a four-point scale ranging from “a little of the time” to “most or all of the time”(33). The variation in screening tools may account for the disparities in prevalence of anxiety across studies.

2.6 Factors associated with anxiety among caregivers of children and adolescents with epilepsy

Caregiver anxiety in children and adolescents with epilepsy has been linked to a variety of factors. It has been shown that those taking care of younger patients of epilepsy have higher anxiety scores when compared to caregivers of older patients according to a survey in the USA (6). Higher seizure frequency has also been found to have a positive correlation with the anxiety of the caregiver (29).

A study carried out in China demonstrated that caregiver anxiety was significantly associated with monthly income, with lower income being positively correlated with higher levels of caregiver anxiety (29). In another study that was done in Nigeria, it was found that a long caregiving period is associated with caregiver anxiety. This study also showed that older caregivers were more likely to experience anxiety (17).

Conversely, studies conducted in the UK, Ethiopia, and Burkina Faso have revealed that mothers who have children with epilepsy are more likely to develop anxiety (3,5,9). The Ethiopian study also found that being a parent of a child with epilepsy was associated with a higher likelihood of anxiety (3). In Burkina Faso, female caregivers and those caring for male patients were found to have higher levels of caregiver anxiety (5).

On the other hand, another study found that parents with more knowledge of epilepsy had lesser odds of experiencing anxiety (29). In India, a study revealed that mothers of children with epilepsy who had comorbid attention deficit hyperactivity disorder were at a higher risk of experiencing anxiety (12).

In a qualitative study, that involved caregivers of children with enduring disabilities like epilepsy in Tanzania, it found that anxiety was linked to marital status. Specifically, female caregivers who had undergone marital separation were more prone to experience anxiety. Furthermore, the study identified that the uncertainty surrounding disease management was a contributing factor to anxiety (20). In a separate study that evaluated the psychosocial challenges faced by caregivers of patients with mental illnesses including epilepsy, anxiety was found to be linked to the patient's disruptive behaviour (34). Conversely, a cross-sectional investigation

of caregivers of children with mental illness found that mental distress in caregivers was linked to their place of residence, with those living outside urban areas having a greater likelihood of experiencing mental distress (21).

The available literature reveals a range of factors associated with anxiety among caregivers of children with epilepsy, but these may not apply to Tanzania due to socio-economic and cultural differences. Furthermore, studies conducted in Tanzania often do not assess anxiety as an individual entity, but rather in combination with other mental illnesses, raising questions about the influence of the identified factors on anxiety specifically.

3.0 METHODOLOGY

3.1 Study design

This was a hospital-based cross-sectional study.

3.2 Study area

This study was conducted at the Paediatric neurology clinic of Muhimbili National Hospital (MNH). It is part of the Paediatric and child health department at MNH. MNH is situated in Ilala district, Dar es Salaam region.

This is a national referral hospital, university teaching hospital, and research centre that treats patients from all of Tanzania's regions.

The paediatric neurology clinic is located within the paediatric department. The clinic is conducted on Monday and Wednesday. Approximately fifty children with neurological conditions are attended to on a single day. The clinic has two paediatric neurologists, who collaborate with paediatricians, residents, and medical officers from the paediatric neurology ward in delivering patient services. The clinic's facilities support the caregivers by providing ample places for them to wait while their children receive care.

3.3 Study population

Caregivers of children and adolescents with epilepsy attending the Paediatric neurology clinic at MNH were recruited. To be eligible, they must have been caring for the children for at least six months before the study's commencement.

3.4. Inclusion criteria and Exclusion criteria

3.4.1 Inclusion criteria

All caregivers of children and adolescents with epilepsy who had been providing care for at least six months before the study’s commencement.

3.4.2 Exclusion criteria

- Caregivers who did not know how to read, write, and speak Swahili were excluded from the study because the screening tools for depression and anxiety were self-administered.
- Those who refused to consent.

3.5 Study duration

Data was collected for five months, from July 2023 to November 2023.

3.6 Sample size estimation

Was calculated by using the Kish Leisle formula, which is a formula used to calculate sample size in cross-sectional studies

$N = \frac{Z^2 P(100-P)}{e^2}$ Where;

N=sample size

Z=Standard normal deviation=1.96

P=Estimated prevalence of depression in caregivers. This was 50.5% based on a study done in Southwestern Nigeria (17). (Note: The prevalence of depression was used in the estimation of sample size over that of anxiety because it gives a larger sample size than that of anxiety).

e=Margin error taken at 5%

$N=\frac{1.96^2 \times 50.5(100-50.5)}{5^2} = 384$

Adjusting for non-response 10%, the minimum sample size was 427 participants.

3.7 Sampling technique

Participants were recruited by convenience sampling.

3.8 Variables

3.8.1 Dependent variables

- Depression among caregivers.
- Anxiety among caregivers.

3.8.2 Independent variables

- **Caregiver-related factors** include sex, age, level of education, residence, marital status, occupation, relationship of the caregiver with the child, support in child care, family income per month, family size, and caregiver epilepsy status, duration of care, and comorbidities of caregiver.
- **Patient-related factors** such as age, sex, level of education, presence of other comorbidities such as cerebral palsy
- **Disease and treatment-related factors:** type of epilepsy, duration of illness, duration since diagnosis of epilepsy, duration that the child has been on Anti Seizures Medications (ASM), number of ASM the child is on, types of ASM the child is on, number of seizure episodes in the past one month, history of injury due to epilepsy, number of admissions due to epilepsy, any other family member with epilepsy.

3.9 Data collection method

A standardized questionnaire pretested in 10% of the sample size was used in data collection. It collected information such as social demographic data, and questions aiming at finding the factors associated with depression and anxiety. Information on depression was collected using Public Health Questionnaire 9 (PHQ-9) while information on anxiety was captured using Generalized Anxiety Disorder Tool -7 (GAD-7).

Study participants were enrolled at the paediatric neurology clinic after being attended, a signed informed consent was obtained from the caregivers before their study participation. The principal researcher and one research assistant (medical officer) were involved in data collection. The research assistant was oriented to the tools used to gather data in this study and was also involved in the pilot of the study. Phone numbers of study participants were obtained to facilitate communication especially for those who were found to have depression and anxiety for referral to the appropriate unit for further evaluation and management.

3.10 Data collection tools

3.10.1 Public Health Questionnaire 9

The Public Health Questionnaire 9 was created by Spitzer et al. It is a globally used and accepted tool in the assessment of depression across populations. Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) criteria for diagnosing Major Depressive Disorder (MDD) form the foundation of PHQ-9.

The Swahili version of the PHQ-9 was used in the assessment of depression. It has been validated for use in Tanzania with sensitivity and specificity determined to be 78% and 87%, respectively. It was also found to have reasonable reliability Cronbach alpha – 0.8 (35). A cut-off point of 10 and above has been used to screen depression (36).

PHQ-9 elicits symptoms of depression for the previous two weeks. It is a nine-item questionnaire with scores ranging from 0 (“not at all”) to 3 (“nearly every day”). Depression in this tool is graded based on the severity of the scores as; minimal (1-4), mild (5-9), moderate (10-14), moderately severe (15-19), and severe depression (20-27). A cut-off of ten and above was defined as depression in this study.

3.10.2 Generalized Anxiety Disorder 7 tool

Information on anxiety was obtained using the General Anxiety Disorder (GAD-7) tool. The tool was created by Spitzer et al. It is widely used to screen for anxiety in different populations. It has been validated for use in East African settings with the Swahili version having a strong internal consistency of ($\alpha = 0.82$). At a cut-off of 10 and above GAD-7 was found to have a sensitivity of 89% and specificity of 73% in screening for generalized anxiety disorder (37).
GAD-7 is a tool with seven items that elicit anxiety symptoms that have occurred in the last two weeks. Each item is scored as follows based on its frequency of occurrence; 0 (Not at all), 1 (several days), 2 (more than half the days), and 3 (Nearly every day). The level of anxiety is graded depending on the overall score as Minimal (0-4), mild (5-9), moderate (10-14), and severe anxiety (15-21). A cut-off of ten and above was defined as anxiety in this study.

3.11 Data analysis

The collected data was processed and analysed using SPSS version 23.0. Simple frequency analysis, mean standard deviation, and percentages were used to analyse demographic data. Continuous data were summarized as mean and standard deviation. Chi-square test was used to determine the initial association between categorical variables and depression, anxiety, or concurrent depression and anxiety. Logistic regression analysis was used to assess the independent associations between depression, anxiety, and various factors. Univariate analysis was conducted for variables deemed to have an association with depression or anxiety based on prior literature. Variables with a p-value < 0.2 on univariate analysis were included in the multivariate model to adjust for confounders. Statistical significance was established by a p-value of < 0.05.

3.12 Ethical consideration

Approval was sought from the Muhimbili University of Allied and Health Science Ethical Committee of Research and Publication. Permission to conduct the study at Muhimbili National Hospital was obtained from the Directorate of Research, Training, and Consultancy at Muhimbili National Hospital (MNH). All identifiers that could reveal a patient's identity were not used on the questionnaire to maintain confidentiality. Caregivers found to have depression and anxiety were linked to appropriate care for further assessment and treatment.

4.0 RESULTS

4.1 Study enrolment

A total of 436 participants were screened, out of which 5 did not consent and 4 did not meet the minimum duration of care of six months. The remaining 427 participants were enrolled in the study. The participants' enrolment process is illustrated in Figure 2.

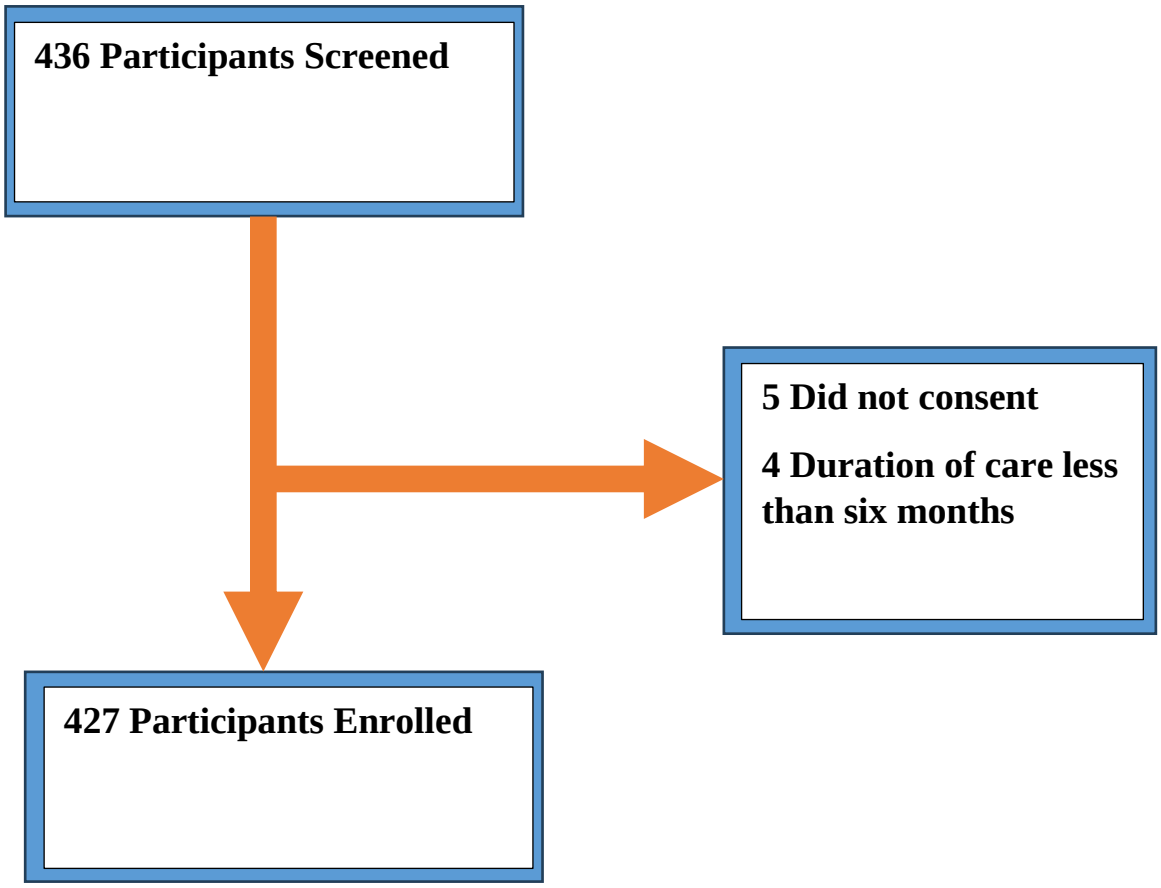


Figure 2: Flow diagram of the study participants

4.1 Social demographic characteristics of caregivers of children and adolescents with epilepsy

The social demographic characteristics of the caregivers are summarized in Table 1. A total of 427 caregivers participated in the study. The mean age of caregivers was 34.2 ± 6.8 years and the majority 397 (93.0%) were female. Three-quarters 333 (78.0%) were married and 371 (86.9%) resided in Dar es Salaam. Almost half 186 (43.5%) had secondary education and most 381 (89.2%) were mothers of children with epilepsy being attended at the clinic. Half 215 (50.4%) of the caregivers were self-employed and three-quarters 322 (75.4%) reported their spouse as a source of support in taking care of the child. More than two third 290 (67.9%) were living in families constituting of 4-6 members. The duration of care in half 215 (50.4%) of the caregivers was ≤ 5 years and the majority 388 (90.9%) reported having no chronic illness. Finally, 25 (5.9%) reported another family member with epilepsy apart from the index child.

Table 1: Social demographic characteristics of caregivers of children and adolescents with epilepsies (N= 427)

VARIABLE	SUBTYPE	FREQUENCY (N)	PERCENT %
Age (years)	18-30	153	35.8
	31-40	226	52.9
	41-50	34	8.0
	>50	14	3.3
Mean	34.2 (± 6.8) years		
Sex	Male	30	7.0
	Female	397	93.0
Residence	Dar es Salaam	371	86.9
	Other regions	56	13.1
Marital status	Married	333	78.0
	Separated	87	20.4
	Widow/widower	7	1.6
Education level	No formal education	12	2.8
	Primary education	157	36.8
	Secondary education	186	43.5
	College/University	72	16.9
Employment status	Employed	77	18.0
	Self-employed	215	50.4
	Unemployed	135	31.6
Relationship with child	Mother	381	89.2
	Father	23	5.4
	Others	23	5.4
Source of support in childcare	No support	71	16.6
	From my spouse	322	75.4
	From other people	34	8.0
Duration of care	5 years or less	215	50.4
	More than 5 years	212	49.6
Family size	3 and less	111	26.0
	4-6	290	67.9
	7 and above	26	6.1
Chronic illness of a caregiver	No chronic illness	388	90.9
	Chronic illness	39	9.1
Other family member with epilepsy	No	402	94.1
	Yes	25	5.9

4.2 Social demographic and epilepsy-related factors of children and adolescents with epilepsy

The social demographic characteristics of the caregivers are summarized in Table 2. A total of 427 children were recruited in the study. Nearly half 211 (49.4%) of the children were under five years of age with a mean age of 6.5 ± 3.6 years and more than half 235 (55.0%) were male. The majority 224 (52.5%) were in primary school and the duration since onset of epilepsy was less than 5 years in two third 269 (63.0%) of the participants.

Most 320 (74.9%) were on one anti-seizure medication; about half 209 (48.9%) had additional comorbidities, 42 (9.8%) reported epilepsy-related injuries and 286 (67%) had not experienced a seizure in the previous one month. About one-third 130 (30.4%) had one previous hospital admission.

Table 2: Social demographic and epilepsy-related factors of children and adolescents with epilepsy (N = 427)

VARIABLE	SUBTYPE	FREQUENCY	PERCENT %
Age (years)	5 and less	211	49.4
	6-10	146	34.2
	11 years and above	70	16.4
	Mean	6.5 ± 3.6 years	
Sex	Male	235	55.0
	Female	192	45.0
Education level	Not started school	198	46.4
	Primary education	224	52.5
	Secondary education	5	1.1
Duration of illness	5 years and less	269	63.0
	More than 5 years	158	37.0
Number of ASM	Not on medication	2	0.5
	One drug	320	74.9
	Two or more drugs	105	24.6
Comorbidity status of the child	No comorbidity	218	51.1
	Comorbidity	209	48.9
Frequency of seizures in the past one month	No episode	286	67.0
	1	90	21.1
	2	16	3.7
	3	8	1.9
	4 or more	27	6.3
Epilepsy related injuries	No injury	385	90.2
	Injury	42	9.8
Number of hospital admissions	No admission	172	40.3
	1 admission	130	30.4
	2 admissions	79	18.5
	3 or more admissions	46	10.8

4.3 Prevalence of depression among caregivers of children and adolescents with epilepsy, N = 427

The proportion of caregivers of children and adolescents with epilepsy who were found to have depression was 17.3% as shown in Figure 3.

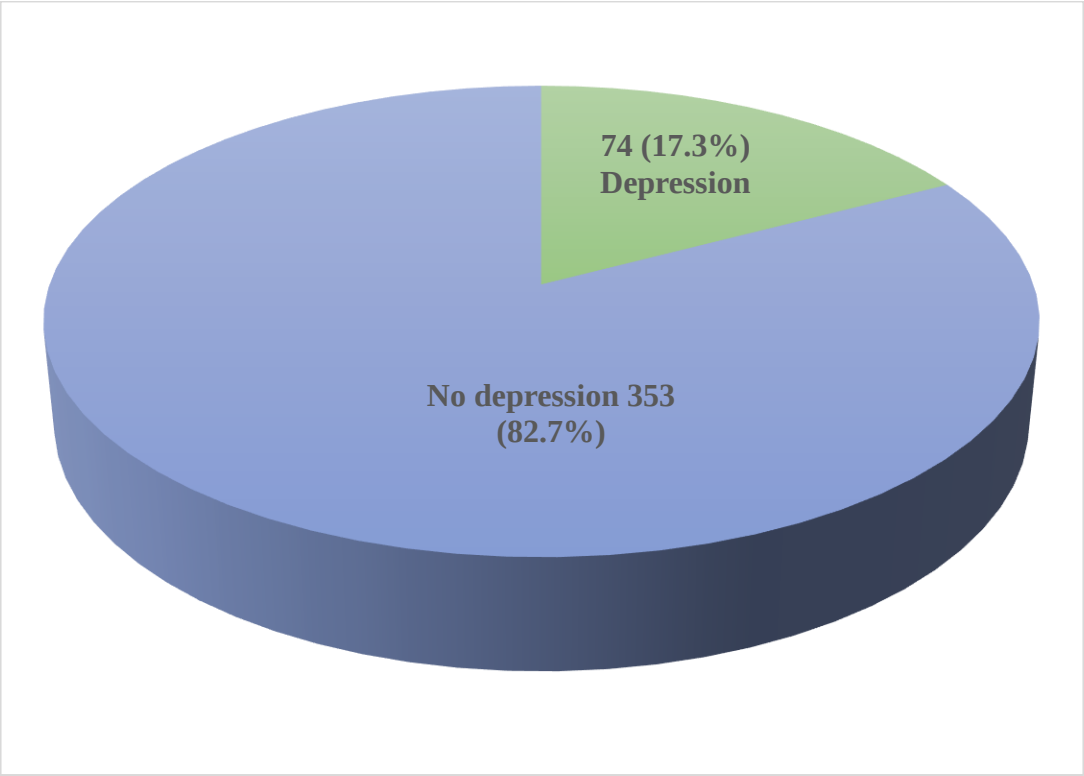


Figure 3: Proportion of caregivers of children and adolescents with epilepsy found to have depression

4.4 Prevalence of anxiety among caregivers of children and adolescents with epilepsy, N = 427

17.3% of caregivers of children and adolescents with epilepsy were found to have anxiety. This is illustrated in Figure 4.

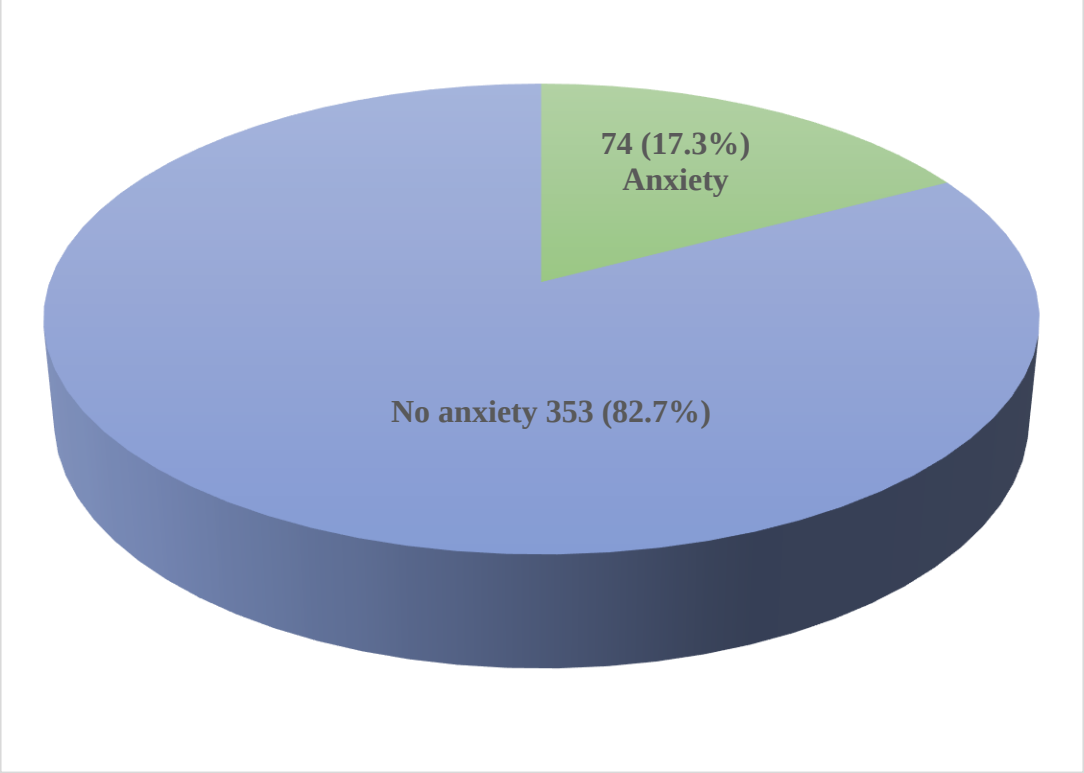


Figure 4: Proportion of caregivers of children and adolescents with epilepsy found to have anxiety

4.5 Proportion of caregivers of children and adolescents with epilepsy with both depression and anxiety

Overall, 9.0% of the caregivers of children and adolescents with epilepsy had concurrent depression and anxiety, this is shown in Figure 5.

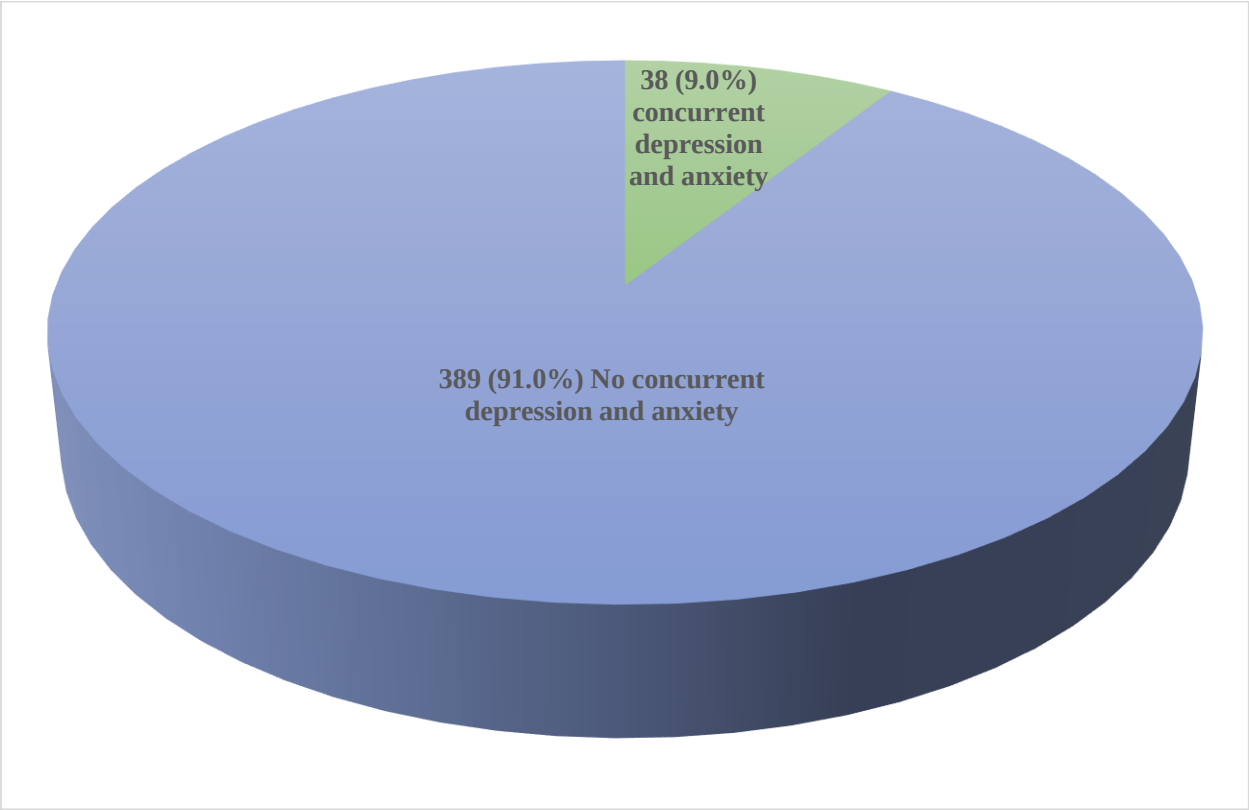


Figure 5: Proportion of caregivers of children and adolescents with epilepsy with concurrent depression and anxiety

4.6 Distribution of factors associated with depression among caregivers of children and adolescents with epilepsy

Factors significantly associated with depression of caregivers included caregivers whose children had; epilepsy-related injury ($p<0.001$) and a higher number of hospital admissions ($p=0.005$). Depression was also associated with caregivers with no formal education ($p=0.008$) and those who did not have support in child care ($p=0.001$). Other factors were not significantly associated with the caregiver's depression. Table 3 summarizes factors associated or not with depression in caregivers of children with epilepsy (CWE).

Table 3 Distribution of factors associated with caregivers' depression. P-value calculated using chi-square.

VARIABLE	NO DEPRESSION n (%)	DEPRESSION n (%)	P-value
Sex of child			
Male	200 (85.1)	35 (14.9)	0.141
Female	153 (79.7)	39 (20.7)	
Child's age			
5 years or less	177 (83.9)	34 (16.1)	
6 to 10 years	113 (77.4)	33 (22.6)	0.059
Above 10 years	63 (90.0)	7 (10.0)	
Child's education			0.251
Not started school	168 (84.8)	30 (15.2)	
Primary education	182 (81.3)	42 (18.8)	
Secondary education	3 (60.0)	2 (40.0)	
Number of ASM			0.585
Not on medication	2 (100.0)	0 (0.0)	
One drug	267 (83.4)	53 (16.6)	
Two or more drugs	84 (80.0)	21 (20.0)	
Duration since epilepsy onset			
5 years or less	228 (84.8)	41 (15.2)	0.137
More than 5 years	125 (79.1)	33 (20.9)	
Seizure frequency (past one month)			
No episode	244 (85.3)	42 (14.7)	
One episode	71 (78.9)	19 (21.1)	
Two episodes	12 (75.0)	4 (25.0)	
Three episodes	5 (62.5)	3 (37.5)	0.225
Four or more episodes	21 (77.8)	6 (22.2)	
Another comorbidity in child			
No comorbidity	183 (83.9)	35 (16.1)	0.477
Has another comorbidity	170 (81.3)	39 (18.7)	
Epilepsy related injuries			
No injury	329 (85.5)	56 (14.5)	
History of injury	24 (57.1)	18 (42.9)	**<0.001**
Number of admissions			
No admission	154 (89.5)	18 (10.5)	
One admission	107 (82.3)	23 (17.7)	**0.005**
Two admissions	59 (74.7)	20 (25.3)	
Three or more admissions	33 (71.7)	13 (28.3)	
Sex of caregiver			
Male	27 (90.0)	3 (10.0)	0.271
Female	326 (82.1)	71 (17.9)	

Caregiver age (years)			
18-30	128 (83.7)	25 (16.3)	0.960
31 – 40	185 (81.9)	41 (18.1)	
41 – 50	28 (82.4)	6 (17.6)	
> 50	12 (85.7)	2 (14.3)	
Marital status			
Married	282 (84.7)	51 (15.3)	
Separated	66 (75.9)	21 (24.1)	0.112
Widow/widower	5 (71.4)	2 (28.6)	
Education of caregiver			
No formal education	6 (50.0)	6 (50.0)	
Primary education	137 (87.3)	20 (12.7)	**0.008**
Secondary education	153 (82.3)	33 (17.7)	
College or university	57 (79.2)	15 (20.8)	
Caregiver employment status			
Employed	62 (80.5)	15 (19.5)	
Self-employed	180 (83.7)	35 (16.3)	0.805
Unemployed	111 (82.2)	24 (17.8)	
Relationship with the child			
Mother	311 (81.6)	70 (18.4)	
Father	21 (91.3)	2 (8.7)	0.261
Others	21 (91.3)	2 (8.7)	
Source of support in childcare			
No support	48 (67.6)	23 (32.4)	
From spouse	275 (85.4)	47 (14.6)	**0.001**
From others	30 (88.2)	4 (11.8)	
Family size			
3 or fewer members	96 (86.5)	15 (13.5)	
4 - 6 members	234 (80.7)	56 (19.3)	0.282
7 or more members	23 (88.5)	3 (11.5)	
Chronic illness of a caregiver			
No chronic illness	322 (83.0)	66 (17.0)	0.582
Has a chronic illness	31 (79.5)	8 (20.5)	
Other family member with epilepsy			
No	332 (82.6)	70 (17.4)	0.856
Yes	21 (84.0)	4 (16.0)	
Duration of care			
5 years or less	180 (83.7)	35 (16.3)	0.563
More than 5 years	173 (81.6)	39 (18.4)	

4.7 Distribution of factors associated with caregiver's anxiety

Table 4 summarizes the distribution of factors associated with caregiver's anxiety. Factors associated with anxiety were caregivers whose children had; more than 5 years since the onset of epilepsy (p =0.017), an increase in seizure frequency in the past month (p= 0.029), if the child had other comorbidities (p=0.025), epilepsy related injuries (p < 0.001) and higher number of hospital admissions (p=0.001). Being a widow or separated (p= 0.027), family size of four to six members (p= 0.026) and caregivers whose duration of care was more than 5 years (p= 0.042) were other factors associated with caregivers' anxiety. Other assessed factors did not show an association with anxiety.

Table 4: Distribution of factors associated with caregiver's anxiety; P-value calculated using chi-square.

VARIABLE	NO ANXIETY n (%)	ANXIETY n (%)	P-value
Sex of child			
Male	198 (84.3)	37 (15.7)	
Female	155 (80.7)	37 (19.3)	0.338
Child's age			
5 years or less	182 (86.3)	29 (13.7)	
6 to 10 years	113 (77.4)	33 (22.6)	0.094
Above 10 years	58 (82.9)	12 (17.1)	
Child's education			
Not started school	166 (83.8)	32 (16.2)	
Primary education	183 (81.7)	41 (18.3)	0.835
Secondary education	4 (80.0)	1 (20.0)	
Number of ASM			
Not on medication	1 (50.0)	1 (50.0)	
One drug	264 (82.5)	56 (17.5)	0.451
Two or more drugs	88 (83.8)	17 (16.2)	
Duration since epilepsy onset			
5 years or less	231 (85.9)	38 (14.1)	
More than 5 years	122 (77.2)	36 (22.8)	**0.017**
Seizure frequency (past one month)			
No episode	245 (85.7)	41 (14.3)	
One episode	72 (80.0)	18 (20.0)	
Two episodes	11 (68.8)	5 (31.3)	**0.029**
Three episodes	4 (50.0)	4 (50.0)	
Four or more Episodes	21 (77.8)	6 (22.2)	

Another comorbidity in child			
No comorbidity	189 (86.7)	29 (13.3)	
Has another comorbidity	164 (78.5)	45 (21.5)	**0.025**
Epilepsy related injuries			
No injury	328 (85.2)	57 (14.8)	
History of injury	25 (59.5)	17 (40.5)	< **0.001**
Number of admissions			
No admission	152 (88.4)	20 (11.6)	
One admission	107 (82.3)	23 (17.7)	
Two admissions	65 (82.3)	14 (17.7)	**0.001**
Three or more admissions	29 (63.0)	17 (37.0)	
Sex of caregiver			
Male	26 (86.7)	4 (13.3)	0.549
Female	327 (82.4)	70 (17.6)	
Caregiver age (years)			
18-30	131 (85.6)	22 (14.4)	
31 – 40	185 (81.9)	41 (18.1)	0.375
41 – 50	25 (73.5)	9 (26.5)	
> 50	12 (85.7)	2 (14.3)	
Marital status			
Married	283 (85.0)	50 (15.0)	
Separated	66 (75.9)	21 (24.1)	**0.027**
Widow/widower	4 (57.1)	3 (42.9)	
Education of caregiver			
No formal education	9 (75.0)	3 (25.0)	
Primary education	131 (83.4)	26 (16.6)	
Secondary education	151 (81.2)	35 (18.8)	0.696
College or university	62 (86.1)	10 (13.9)	
Caregiver employment status			
Employed	63 (81.8)	14 (18.2)	
Self-employed	179 (83.3)	36 (16.7)	
Unemployed	111 (82.2)	24 (17.8)	0.947
Relationship with the child			
Mother	312 (81.9)	69 (18.1)	
Father	19 (82.6)	4 (17.4)	
Others	22 (95.7)	1 (4.3)	0.238
Source of support in childcare			
No support	54 (76.1)	17 (23.9)	
From spouse	271 (84.2)	51 (15.8)	
From others	28 (82.4)	6 (17.6)	0.263

Family size			**0.026**
3 or less members	99 (89.2)	12 (10.8)	
4 - 6 members	230 (79.3)	60 (20.7)	
7 or more members	24 (92.3	2 (7.7)	
Chronic illness of a caregiver			
No chronic illness	324 (83.5)	64 (16.5)	
Has a chronic illness	29 (74.4)	10 (25.6)	0.150
Other family member with epilepsy			
No	335 (83.3)	67 (16.7)	
Yes	18 (72.0)	7 (28.0)	0.146
Duration of care			
5 years or less	185 (86.0)	30 (14.0)	
More than 5 years	168 (79.2)	44 (20.8)	**0.042**

4.8 Distribution of factors associated with caregivers having concurrent depression and anxiety

Concurrent depression and anxiety in caregivers of CWE were associated with being a widow or widower ($p= 0.004$) and having no support in child care ($p= 0.009$). Other associated factors were caregivers whose children had; more than 5 years since the onset of epilepsy ($p= 0.015$), epilepsy related injuries ($p < 0.001$), and three or more hospital admissions ($p< 0.001$). Other factors were not associated with concurrent depression and anxiety in caregivers. Table 5 summarizes the distribution of factors associated with concurrent depression and anxiety among caregivers of CWE.

Table 5: Distribution of factors associated with concurrent depression and anxiety in caregivers of CWE. P-value calculated using chi-square.

VARIABLE	NO CONCURRENT DEPRESSION AND ANXIETY n (%)	HAVE CONCURRENT DEPRESSION AND ANXIETY n (%)	P-value
Sex of child			
0.181	0.181	0.181	0.181
Female	171 (89.1)	21 (10.9)	
Child's age			
5 years or less	197 (93.4)	14 (6.6)	
6 to 10 years	127 (87.0)	19 (13.0)	0.098
Above 10 years	65 (92.9)	5 (7.1)	
Child's education			
Not started school	185 (93.4)	13 (6.6)	
Primary education	200 (89.3)	24 (10.7)	0.223
Secondary education	4 (80.0)	1 (20.0)	
Number of ASM			
Not on medication	2 (100.0)	0 (0.0)	
One drug	290 (90.6)	30 (9.4)	0.780
Two or more drugs	97 (92.4)	8 (7.6)	
Duration since epilepsy onset			
5 years or less	252 (93.7)	17 (6.3)	**0.015**
More than 5 years	137 (86.7)	21 (13.3)	
Seizure frequency (past one month)			
No episode	268 (93.7)	18 (6.3)	
One episode	79 (87.8)	11 (12.2)	
Two episodes	13 (81.3)	3 (18.8)	0.055
Three episodes	6 (75.0)	2 (25.0)	
Four or more episodes	23 (85.2)	4 (14.8)	
Another comorbidity in child			
No comorbidity	203 (93.1)	15 (6.9)	0.135
Has another comorbidity	186 (89.0)	23 (11.0)	
Epilepsy related injuries			
No injury	358 (93.0)	27 (7.0)	
History of injury	31 (73.8)	11 (26.2)	**< 0.001**

Number of admissions			
No admission	165 (95.9)	7 (4.1)	
One admission	117 (90.0)	13 (10.0)	**<0.001**
Two admissions	72 (91.1)	7 (8.9)	
Three or more admissions	35 (76.1)	11 (23.9)	
Sex of caregiver			
Male	29 (96.7)	1 (3.3%)	
Female	360 (90.7)	37 (9.3)	0.267
Caregiver age (years)			
18-30	138 (90.2)	15 (9.8)	
31 – 40	208 (92.0)	18 (8.0)	
41 – 50	30 (88.2)	4 (11.8)	0.851
> 50	13 (92.9)	1 (7.1)	
Marital status			
Married	311 (93.4)	22 (6.6)	**0.004**
Separated	73 (83.9)	14 (16.1)	
Widow/widower	5 (71.4)	2 (28.6)	
Education of caregiver			
No formal education	9 (75.0)	3 (25.0)	
Primary education	147 (93.6)	10 (6.4)	
Secondary education	169 (90.9)	17 (9.1)	0.137
College or university	64 (88.9)	8 (11.1)	
Caregiver employment status			0.932
Employed	70 (90.9)	7 (9.1)	
Self-employed	195 (90.7)	20 (9.3)	
Unemployed	124 (91.9)	11 (8.1)	
Relationship with the child			
Mother	345 (90.6)	36 (9.4)	
Father	22 (95.7)	1 (4.3)	0.518
Other	22 (95.7)	1 (4.3)	
Source of support in childcare			
No support	58 (81.7)	13 (18.3)	**0.009**
From spouse	300 (93.2)	22 (6.8)	
From others	31 (91.2)	3 (8.8)	

Family size			
3 or fewer members	104 (93.7)	7 (6.3)	0.288
4 - 6 members	260 (89.7)	30 (10.3)	
7 or more members	25 (96.2)	1 (3.8)	
Chronic illness of a caregiver			0.136
No chronic illness	356 (91.8)	32 (8.2)	
Has a chronic illness	33 (84.6)	6 (15.4)	
Other family member with epilepsy			0.575
No	367 (91.3%)	35 (8.7)	
Yes	22 (88.0)	3 (12.0)	
Duration of care			
5 years or less	200 (93.0)	15 (7.0)	
More than 5 years	189 (89.2)	23 (10.8)	0.160

4.9 Univariate and multivariate logistic regression analysis of factors associated with caregivers' depression

Logistic regression was done to identify factors independently associated with caregiver depression. On univariate analysis, a total of twelve factors were significantly associated with depression in caregivers of CWE. After adjusting for confounders five factors were independently associated with caregivers' depression. Caregivers whose children were younger than five years had eight times higher odds of having depression (aOR=8.65; 95% CI: 1.79-41.82, p=0.007). Likewise, caregivers whose children had epilepsy for more than five years were three times more likely to have depression (aOR= 3.25;95% CI: 1.08 – 9.77). Epilepsy-related injuries (aOR =2.90; 95% CI:1.26 – 6.66, p=0.012) and three or more hospital admissions (aOR=2.70; 95% CI: 1.02 - 7.11, p= 0.044) also increased odds of depression. In contrast, caregivers of children who had not started school (aOR=0.01; 95% CI: 0.001–0.28, p=0.0004) or were in primary school (aOR=0.02; 95% CI: 0.002–0.36, p=0.007) had lower odds of depression compared to caregivers of children in secondary school, indicating a protective effect.

Table 6: Logistic regression of factors associated with depression in caregivers of CWE

	Univariate analysis		Multivariate analysis	
VARIABLE	**cOR (95% CI)**	**P-value**	**aOR**	**P-value**
Residence				
Dar es Salaam	1	Ref	1	Ref
Upcountry	1.72 (0.88 – 3.36)	**0.107**	1.86 (0.84 - 4.11)	0.124
Sex of child				
Male	1	Ref	1	Ref
Female	1.45 (0.88 – 2.40)	**0.142**	1.56 (0.88 -2.75)	0.124
Child age				
Above 10 years	1	Ref	**1**	**Ref**
5 years or less	1.72 (0.73 – 4.09)	0.214	8.65 (1.79 – 41.82)	**0.007**
6 to 10 years	2.62 (1.09 – 6.28)	**0.030**	4.49 (1.44 – 13.98)	**0.010**
Child's education				
Secondary education	1	Ref	1	Ref
Not started school	0.26 (0.04 – 1.67)	**0.158**	0.01 (0.001- 0.28)	**0.004**
Primary education	0.34 (0.05 – 2.13)	0.253	0.02 (0.002 - 0.36)	**0.007**
Duration since epilepsy onset				
5 years or less	1	Ref	1	Ref
More than 5 years	1.46 (0.88 – 2.43)	**0.138**	3.25 (1.08 – 9.77)	**0.035**
Seizure frequency (Past one month)				
No episode	1	**Ref**	1	Ref
1 episode	1.55 (0.85 – 2.84)	**0.151**	0.99 (0.48 – 2.04)	0.995
2 episodes	1.93 (0.59 – 6.29)	0.272	1.39 (0.34 – 5.58)	0.641
3 episodes	3.48 (0.80 – 15.13)	**0.096**	2.93 (0.49 – 17.47)	0.238
4 or more episodes	1.66 (0.63 – 4.35)	0.303	1.65 (0.52 – 5.23)	0.395
Another comorbidity in child				
No comorbidity	1	**Ref**		
Has comorbidity	1.19 (0.72 – 1.98)	0.477		
Epilepsy related injuries				
No injury	1	Ref	1	Ref
History of injury	4.40 (2.24 – 8.64)	**< 0.005**	2.90 (1.26 – 6.66)	**0.012**
Number of admissions				
No admission	1	Ref	1	Ref
One admission	1.83 (0.94 – 3.57)	**0.072**	1.60 (0.76 – 3.37)	0.215
Two admissions	2.90 (1.43 – 5.86)	**0.003**	2.32 (0.99 -5.41)	0.051
Three or more admissions	3.37 (1.50 – 7.54)	**0.003**	2.70 (1.02 – 7.11)	**0.044**
Sex of caregiver				
Male	1	Ref		
Female	1.96 (0.57 – 6.64)	0.280		
Caregiver age (years)				
18-30	1	Ref		
31 – 40	1.13 (0.65 – 1.95)	0.650		
41 – 50	1.09 (0.41 – 2.92)	0.853		
> 50	0.85 (0.18 – 4.04)	0.842		

Marital status				
Married	1	Ref		
Separated	1.75 (0.99 – 3.12)	**0.054**	0.51 (0.17 - 1.52)	0.231
Widow/widower	2.21 (0.41 – 11.71)	0.351	0.53 (0.05 - 5.15)	0.585
Education of caregiver				
College or university	1	Ref	1	Ref
No formal education	3.80 (1.07 – 13.48)	**0.039**	4.19 (0.90 – 19.48)	0.068
Primary education	0.55 (0.26 – 1.16)	**0.117**	0.52 (0.22 – 1.18)	0.118
Secondary	0.82 (0.41 – 1.62)	0.820	0.54 (0.25 - 1.17)	0.123
Caregiver employment				
Employed	1	Ref		
Self-employed	0.80 (0.41 – 1.57)	0.523		
Unemployed	0.89 (0.43 – 1.82)	0.758		
Relationship with the child				
Other	1	Ref		
Mother	2.36 (0.54 – 10.31)	0.253		
Father	1.00 (0.12 – 7.77)	1.000		
Source of support in childcare				
From others	1	Ref	1	Ref
No support	3.59 (1.13 – 11.41)	**0.030**	3.66 (0.96 – 13.91)	0.056
From spouse	1.28 (0.43 – 3.80)	0.655	1.05 (0.26 – 4.23)	0.943
Family size				
3 or less members	1	Ref	1	Ref
4 - 6 members	1.53 (0.82 – 2.84)	**0.176**	1.40 (0.69 – 2.86)	0.346
7 or more members	0.83 (0.22 – 3.12)	0.789	0.49 (0.10 – 2.31)	0.373
Chronic illness of a caregiver				
No chronic illness	1	Ref		
Has a chronic illness	1.25 (0.55 – 2.86)	0.582		
Other family member with epilepsy				
No	1	Ref		
Yes	0.90 (0.30 – 2.71)	0.856		
Duration of care				
5 years or less	1	Ref		
More than 5 years	1.15 (0.70 – 1.91)	0.564		

Factors with p-value < 0.2 in univariate analysis were included in the multivariate analysis model. Statistical significance was defined as p-value <0.05 on multivariate analysis. cOR= crude odds ratio, aOR= adjusted odds ratio.

4.10 Univariate and multivariate logistic regression analysis of factors associated with caregivers' anxiety

On univariate analysis, twelve factors were found with a significant association with caregivers' anxiety. Four factors were independently associated with anxiety after adjusting for confounders. Caregivers whose children had another comorbidity had two times higher odds of having anxiety (aOR=2.01; 95% CI: 1.13 – 3.58, p=0.017). Those whose children had three or more hospital admissions were more than three times as likely to experience anxiety (aOR=3.22; 95% CI: 1.27–8.12, p=0.013). Likewise, caregivers whose children had history of epilepsy-related injuries had two times higher odds of having anxiety (aOR=2.52; 95% CI: 1.10 – 5.78, p=0.028). Additionally, caregivers aged between 41 to 50 years were three times as likely to have anxiety compared to younger caregivers (aOR = 3.30; 95% CI: 1.06 – 10.23, p= 0.039).

Table 7: Logistic regression of factors associated with anxiety in caregivers of CWE

	Univariate analysis		Multivariate analysis	
VARIABLE	**cOR (95% CI)**	**P-value**	**aOR**	**P-value**
Residence				
Dar es Salaam	1	Ref		
Upcountry	1.35 (0.67 – 2.72)	0.386		
Sex of child				
Male	1	Ref		
Female	1.27 (0.77 – 2.11)	0.339		
Child age				
Above 10 years	1	Ref		
5 years or less	0.77 (0.36 – 1.60)	0.486		
6 to 10 years	1.41 (0.67 – 2.93)	0.357		
Child's education				
Secondary education	1	Ref		
Not started school	0.77 (0.08 – 7.12)	0.819		
Primary education	0.89 (0.09 – 8.22)	0.923		
Duration since epilepsy onset				
5 years or less	1	Ref	1	Ref
More than 5 years	1.79 (1.08 – 2.97)	**0.024**	1.97 (0.77 – 5.04)	0.154
Number of ASM				
Not on medication	1	Ref		
One drug	0.21 (0.01 – 3.44)	0.275		
Two or more drugs	0.19 (0.01 – 3.24)	0.253		
Seizure frequency (Past one month)				
No episode	1	**Ref**	1	Ref
1 episode	1.49 (0.80 – 2.75)	0.200	1.27 (0.62 – 2.57)	0.508
2 episodes	2.71 (0.89 – 8.22)	**0.077**	2.03 (0.55 – 7.45)	0.282
3 episodes	5.97 (1.43 – 24.84)	**0.014**	5.32 (0.98 – 28.83)	0.052
4 or more episodes	1.70 (0.65 – 4.48)	0.278	1.29 (0.41 – 4.07)	0.655
Another comorbidity in child				
No comorbidity	1	**Ref**	1	Ref
Has comorbidity	1.78 (1.07 – 2.98)	**0.026**	2.01 (1.13 – 3.58)	**0.017**
Epilepsy related injuries				
No injury	1	Ref	1	Ref
History of injury	3.91 (1.98 – 7.70)	**< 0.001**	2.52 (1.10 – 5.78)	**0.028**
Number of admissions				
No admission	1	Ref	1	Ref
One admission	1.63 (0.85 – 3.12)	**0.138**	1.25 (0.61 – 2.55)	0.532
Two admissions	1.63 (0.77 – 3.43)	**0.193**	1.30 (0.55 – 3.06)	0.536
Three or more admissions	4.45 (2.08 – 9.51)	**< 0.001**	3.22 (1.27 – 8.12)	**0.013**
Sex of caregiver				
Male	1	Ref		
Female	1.39 (0.47 – 4.11)	0.550		

Caregiver age (years)				
18-30	1	Ref	1	Ref
31 – 40	1.32 (0.75 – 2.32)	0.335	1.48 (0.76 – 2.87)	0.245
41 – 50	2.14 (0.88 – 5.19)	**0.092**	3.30 (1.06 – 10.23)	**0.039**
> 50	0.99 (0.20 – 4.74)	0.992	5.10 (0.30 – 84.62)	0.256
Marital status				
Married	1	Ref	1	Ref
Separated	1.80 (1.01 – 3.20)	**0.045**	1.76 (0.86 – 3.60)	0.122
Widow/widower	4.24 (0.92 – 19.54)	**0.063**	3.46 (0.49 – 24.43)	0.212
Education of caregiver				
College or university	1	Ref		
No formal education	2.06 (0.47 – 8.96)	0.332		
Primary education	1.23 (0.55 – 2.71)	0.607		
Secondary	1.43 (0.67 – 3.08)	0.351		
Caregiver employment				
Employed	1	Ref		
Self-employed	0.90 (0.45 – 1.78)	0.774		
Unemployed	0.97 (0.47 – 2.01)	0.941		
Relationship with the child				
Other	1	Ref	**1**	**Ref**
Mother	4.86 (0.64 – 36.71)	**0.125**	13.72 (0.54 – 344.50)	0.111
Father	4.63 (0.47 – 45.08)	**0.187**	9.21 (0.34 – 249.12)	0.187
Source of support in childcare				
From others	1	Ref	1	Ref
No support	1.46 (0.52 – 4.14)	0.467		
From spouse	0.87 (0.34 – 2.22)	0.785		
Family size				
3 or less members	1	Ref	1	Ref
4 - 6 members	2.15 (1.10 – 4.17)	**0.023**	2.02 (0.33 – 12.22)	0.440
7 or more members	0.68 (0.14 – 3.27)	0.638	4.02 (0.75 – 21.43)	0.103
Chronic illness of a caregiver				
No chronic illness	1	Ref	1	Ref
Has a chronic illness	1.74 (0.81 – 3.75)	**0.155**	0.629 (0.20 – 1.90)	0.413
Other family member with epilepsy				
No	1	Ref	1	Ref
Yes	1.94 (0.78 – 4.83)	**0.153**	1.10 (0.37 – 3.32)	0.853
Duration of care				
5 years or less	1	Ref	1	Ref
More than 5 years	1.61 (0.97 – 2.68)	**0.065**	0.95 (0.36 – 2.47)	0.918

Statistical significance was defined as p-value <0.05 on multivariate analysis. cOR= crude odds ratio, aOR= adjusted odds ratio.

4.11 Univariate and multivariate logistic regression analysis of factors associated with concurrent depression and anxiety in caregivers of CWE

Logistic regression revealed several factors independently associated with concurrent depression and anxiety among caregivers. Caregivers whose children had a duration of epilepsy more than 5 years were more than four times as likely to have concurrent depression and anxiety compared to those with shorter duration (aOR=4.63; 95% CI: 1.00 – 21.26, p=0.049). A history of epilepsy-related injuries nearly tripled the likelihood of concurrent depression and anxiety (aOR=2.93; 95% CI: 1.12–7.62, p=0.028). Additionally, caregivers whose children had 3 or more hospital admissions were 5 times more likely to have concurrent depression and anxiety (aOR=5.83; 95% CI: 1.73 – 19.63, p=0.004).

Table 8: Logistic regression of factors associated with concurrent depression and anxiety among caregivers of CWE.

	Univariate analysis		Multivariate analysis	
VARIABLE	**cOR (95% CI)**	**P-value**	**aOR**	**P-value**
Residence				
Dar es Salaam	1	Ref		
Upcountry	1.27 (0.50 – 3.19)	0.610		
Sex of child				
Male	1	Ref	1	Ref
Female	1.57 (0.80 – 3.07)	**0.184**	1.75 (0.83 – 3.67)	0.138
Child age				
Above 10 years	1	Ref		
5 years or less	0.92 (0.32 – 2.66)	0.883		
6 to 10 years	1.94 (0.69 – 5.44)	0.205		
Child's education				
Secondary education	1	Ref		
Not started school	0.28 (0.29 – 2.70)	0.272		
Primary education	0.48 (0.05 – 4.47)	0.519		
Duration since epilepsy onset				
5 years or less	1	Ref	1	Ref
More than 5 years	2.27 (1.16 – 4.45)	**0.017**	4.63 (1.00 – 21.26)	**0.049**
Seizure frequency (Past one month)				
No episode	1	**Ref**	1	Ref
1 episode	2.07 (0.94 – 4.57)	**0.071**	2.00 (0.80 – 4.95)	0.133
2 episodes	3.43 (0.89 – 13.16)	**0.072**	2.37 (0.48 – 11.66)	0.287
3 episodes	4.96 (0.93 – 26.36)	**0.060**	2.14 (0.28 – 16.01)	0.457
4 or more episodes	2.58 (0.80 – 8.29)	**0.109**	2.17 (0.56 – 8.31)	0.257
Another comorbidity in child				
No comorbidity	1	**Ref**	1	Ref
Has comorbidity	1.67 (0.84 – 3.30)	**0.138**	1.94 (0.89 – 4.21)	0.091
Epilepsy related injuries				
No injury	1	Ref	1	Ref
History of injury	4.70 (2.13 – 10.38)	**< 0.001**	2.93 (1.12 – 7.62)	**0.028**
Number of admissions				
No admission	1	Ref	1	Ref
One admission	2.61 (1.01 – 6.76)	**0.047**	2.19 (0.81 – 5.91)	0.120
Two admissions	2.29 (0.77 – 6.77)	**0.134**	1.59 (0.48 – 5.22)	0.437
Three or more admissions	7.40 (2.68 – 20.45)	**< 0.001**	5.83 (1.73 – 19.63)	**0.004**
Sex of caregiver				
Male	1	Ref		
Female	2.98 (0.39 – 22.51	0.290		

Caregiver age (years)				
18-30	1	Ref		
31 – 40	0.79 (0.38 – 1.63)	0.534		
41 – 50	1.22 (0.38 – 3.95)	0.732		
> 50	0.70 (0.08 – 5.79)	0.747		
Marital status				
Married	1	Ref	1	Ref
Separated	2.71 (1.32 – 5.55)	**0.006**	1.68 (0.74 – 3.84)	0.212
Widow/widower	5.65 (1.03 – 30.82)	**0.045**	2.19 (0.26 – 18.37)	0.467
Education of caregiver				
College or university	1	Ref		
No formal education	2.66 (0.59 – 11.94)	0.200		
Primary education	0.54 (0.20 – 1.44)	0.221		
Secondary	0.80 (0.33 – 1.95)	0.632		
Caregiver employment				
Employed	1	Ref		
Self-employed	1.02 (0.41 – 2.53)	0.956		
Unemployed	0.88 (0.32 – 2.39)	0.813		
Relationship with the child				
Other	1	Ref		
Mother	2.29 (0.30 – 17.53)	0.423		
Father	1.00 (0.59 – 17.01)	1.000		
Source of support in childcare				
From others	1	Ref		
No support	2.31 (0.61 – 8.74)	0.215		
From spouse	0.758 (0.21 – 2.67)	0.667		
Family size				
3 or less members	1	Ref		
4 - 6 members	1.71 (0.73 – 4.02)	0.216		
7 or more members	0.59 (0.07 -5.05)	0.634		
Chronic illness of a caregiver				
No chronic illness	1	Ref	1	Ref
Has a chronic illness	2.02 (0.78 – 5.18)	**0.143**	0.87 (0.27 – 2.80)	0.823
Other family member with epilepsy				
No	1	Ref		
Yes	1.43 (0.40 – 5.01)	0.577		
Duration of care				
5 years or less	1	Ref	1	Ref
More than 5 years	1.62 (0.82 – 3.20)	**0.163**	0.55 (0.12 – 2.55)	0.451

Statistical significance was defined as p-value <0.05 on multivariate analysis. cOR= crude odds ratio, aOR= adjusted odds ratio.

5.0 DISCUSSION

This study was conducted to establish the prevalence and factors associated with depression and anxiety in the preceding two weeks among caregivers of CWE.

Prevalence of depression among caregivers of children and adolescents with epilepsy

The prevalence of depression among caregivers of children with epilepsy in our study was 17.3%. This is in keeping with other studies conducted in Northern Nigeria and Nepal where 18.7% and 15.1% of caregivers were found to have depression respectively (13,18). However, it is slightly higher than the prevalence of 13.7% found in an Ethiopian study (3) and was lower than the prevalence of 25.0 to 28.0% that was found in studies that were conducted in USA (25) and Turkey (14). The differences may be explained by variation in the study population as demonstrated by a study in Turkey that included mothers of children with epilepsy while the American study focused on mothers of children with intractable epilepsy (14,25). In addition, variations in assessment tools, socioeconomic status, culture, and resilience among study participants across various study settings may account for the differences.

Factors associated with depression among caregivers of children and adolescents with epilepsy

Regarding factors associated with caregivers' depression, our study found long duration of epilepsy to be independently associated with epilepsy. In line with our results, a Nigerian study showed the duration (> 5 years) since the onset of epilepsy to have a strong association with caregivers' depression (17). This could be explained by several factors; including the chronic nature of epilepsy that may exacerbate caregivers' distress over time. Alternatively, a longer duration of illness may result in a higher financial burden in care from medical consultations and hospital stays which could raise the risk of depression (38). Finally, caregivers' opportunities for social interaction and self-care may be restricted by their continuing caregiving responsibilities.

In our study, we found a positive correlation between the young age of a child and caregivers' depression. O'Dell et al. reported similar findings (4). Taking care of younger children comes with special challenges such as the need for constant supervision and concerns about the impacts of epilepsy on early childhood development, consequently causing depression.

Findings from this study show that depression was more likely to occur in caregivers whose children had a history of epilepsy-related injuries, a finding in keeping with a study by O'Dell et al (4). This highlights the importance of education to prevent epilepsy-related injuries as it is a modifiable risk factor for caregivers' depression. The odds of developing depression were three times higher in caregivers whose children had three or more hospital admissions. This may be explained by medical expenses and disruption of daily routines brought by admissions. Additionally, admitted children may have more severe illness, which could further contribute to the stress experienced by caregivers, increasing their risk for depression.

We also found that in comparison to their peers, caregivers whose children were in secondary school had higher odds of developing depression. This may be explained by several factors; secondary school students with epilepsy may miss school due to seizures increasing the likelihood of poor academic performance and never realizing their full potential, this may have a psychological impact on caregivers. Alternatively, since secondary school students are closer to adolescence which is associated with more social interaction, stigma associated with epilepsy might impede these interactions impacting both the patient and their caregiver. Finally, older children could have a stronger sense of self-reliance and try to fit in with peers and hence exhibit behaviours such as refusal to ASM that can put stress on their caregivers.

Prevalence of anxiety among caregivers of children and adolescents with epilepsy

Our study found a prevalence of anxiety among caregivers of CWE to be 17%. This was slightly higher but comparable to that in Ethiopian study where 10.4% of caregivers had anxiety (3). In contrast to our findings, the prevalence of anxiety was higher in studies done in Saudi Arabia 54.8% (11), and USA 52.8% (6). The observed differences in prevalence may be accounted for by various factors including variations in sample size as seen in a study done in Saudi Arabia which included 31 caregivers compared to 427 participants in our study (11). Additionally, variations in study populations may explain the differences as demonstrated by the USA study

that included caregivers of both children and adults with epilepsy while our study focused on caregivers of children and adolescents (6). Finally, variations in assessment tools for anxiety may account for the differences in prevalence, generalized anxiety disorder tool 7 was used in our study while other tools such as the State-Trait Anxiety Inventory scale have been used in other studies.

Factors associated with anxiety among caregivers of children and adolescents with epilepsy

Regarding factors associated with caregivers' anxiety, our study shows that increasing the age of caregivers had a significant association with caregivers' anxiety, similar findings were observed in Nigeria (17). This may be accounted for by the inability to keep up with challenges related to taking care of children with epilepsy (39). Our study also found that caregiver's anxiety correlated with an increasing number of hospital admissions. This may be rooted in increased financial demands during hospital stays and disruptions of daily routines. Additionally, higher numbers of hospital admissions imply a worsening of a child's condition that could have a psychological impact on the caregiver.

A history of epilepsy-related injuries was found to be independently associated with the caregiver's anxiety. The possible reason behind this might be due to fear of more injuries and death (4). Furthermore, a previous history of injury might be associated with caregivers' heightened level of attention to prevent further injuries eventually leading to anxiety as observed in a review by Kanner et al (40).

Our study highlighted higher odds of anxiety among caregivers whose children had other comorbidities. The presence of comorbidities might be associated with increased complexity of care and medical treatment leading to anxiety among caregivers. In addition, comorbidities might put a greater financial burden on families, which raises anxiety levels among caregivers. Finally, this study showed 4.6 higher odds of concurrent anxiety and depression among caregivers whose children had a duration of epilepsy for more than five years compared to those with children with epilepsy for less than 5 years. In agreement with our findings, a longer duration of epilepsy was associated with anxiety in studies conducted in Nigeria and the USA

(17,41). Over time, caregivers may become more despondent about the possibility of a cure for epilepsy, which increases their risk for anxiety and depression. Alternatively, the longer duration of epilepsy is accompanied by an increased burden of care and financial costs hence affecting the mental health of caregivers.

6.0 STRENGTHS, LIMITATIONS CONCLUSION AND RECOMMENDATION

6.1 Strength of the Study

To the best of our knowledge, this is the first study to assess depression and anxiety among caregivers of children and adolescents with epilepsy in Tanzania. The 17.3% reported prevalence of depression and anxiety provides an important context for understanding the mental health challenges among caregivers of CWE.

The identification of the association of patient-related, disease-related, and caregiver-giver-related factors and the depression, and anxiety experienced by the caregivers offers valuable insight into the complex interplay of various factors affecting caregiver mental health. It will aid in establishing a framework for forming targeted interventions to ensure mental health well-being.

In our study, 427 participants were enrolled. This large sample size provides a good representation and more external validity of our findings on depression, and anxiety among caregivers of CWE.

6.2 Study limitations

This is a cross-sectional study design therefore it has limited ability to establish cause-and-effect relationships. Additionally, the study only included caregivers whose children attended the neurology clinic, which may not represent all caregivers of children with epilepsy. Depression and anxiety were assessed for the past two weeks, not over a longer duration of time.

6.3 Conclusion

- Depression and anxiety are prevalent among caregivers of children and adolescents with epilepsy (Prevalence 17.3% for both).
- Anxiety and depression were observed to coexist in 9% of caregivers.
- Characteristics independently associated with depression of caregiver included; younger age of the child, longer duration since onset of epilepsy, history of epilepsy-related injuries, higher number of hospital admissions, and higher education of the child.
- Caregivers' anxiety was significantly associated with; the presence of other child comorbidities, epilepsy-related injuries, a higher number of hospital admissions, and the older age of the caregiver. Longer duration since epilepsy onset was independently associated with having concurrent depression and anxiety among caregivers.

6.2 Recommendations

- We recommend incorporating mental health services in the regular Paediatric neurology clinic. These should offer a screening of caregivers for depression and anxiety and linkage to counselling and psychoeducation.
- Hospital administrations should offer education programs targeting healthcare workers to raise awareness of the mental health challenges encountered by caregivers of CWE.
- Establishment of peer support groups of caregivers of CWE that will help to support and ensure proper coping mechanisms to their shared challenges.

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APPENDICES

Appendix 1: Consent form (English version)

CONSENT TO PARTICIPATE IN A STUDY TITLED "DEPRESSION, ANXIETY AND ASSOCIATED FACTORS AMONG CAREGIVERS OF CHILDREN AND ADOLESCENTS WITH EPILEPSY ATTENDING PAEDIATRICS NEUROLOGY CLINIC AT MNH"

Introduction: My name is DR ERNEUS ERNEST, a second-year postgraduate student in Paediatrics and Child Health at Muhimbili University of Health and Allied Sciences. I am conducting research titled "Depression, anxiety and associated factors among Caregivers of Children and Adolescents with Epilepsy attending paediatrics neurology clinic at MNH"

Purpose of the study: To determine the number of caregivers of children with epilepsy that have depression, anxiety and the factors that increase the risk of depression and anxiety.

Participation in the study: I respectfully request your participation in this study and you will be free to decline participation. Once you accept, I will interview you but also request you to fill in other information on the questionnaire by yourself.

Confidentiality: All information gathered will be confidential and only used for research purposes, during data entry, a code number will be used to identify you instead of your name.

Risk: There are no foreseen risks linked to participation in this study.

Benefits: This study will help us identify the magnitude of depression and anxiety among caregivers of children and adolescents with epilepsy. This will help us in setting future strategies for tackling this problem to ensure that caregivers have good mental health to take care of their children.

Withdraw rights: Your participation in this study is voluntary. You are free to decline or withdraw anytime during your participation in the study.

Whom to contact: Please feel free to contact the principal researcher or other relevant authorities using the following contacts for any concerns regarding this study.

DR ERNEUS ERNEST, Muhimbili University of Health and Allied Science,
P.O BOX 65001, Dar es Salaam.

Email: erneusernest255@gmail.com

Phone number: 0765-849095

DR OBREY URIO, Muhimbili University of Health and Allied Science,

P.O BOX 65001,

Dar es Salaam.

Email: obreyharold@rocketmail.com

Phone number: 0712-961792

Dr. Nahya Salim

Chairperson, Institutional Review Board,

Muhimbili University of Health and Allied Science,

P.O.BOX 65001, Dar es Salaam.

Phone number: 0713 250074

Email: nahya.salim@gmail.com

Agreement to participate

I have read and understood the purpose of this study. I voluntarily agree to participate in this study.

Name of participant: ……

Signature of participant: ……..……

Date: ……..……

Appendix 2: Consent Form (Swahili Version)

Fomu ya makubaliano ya ushiriki

KUSHIRIKI KWENYE UTAFITI UNAOHUSU "SONONA, WASIWASI MIONGONI MWA WALEZI WA WATOTO NA VIJANA WENYE KIFAFA WANAOHUDHURIA KLINIKI YA MISHIPA YA FAHAMU YA WATOTO KATIKA HOSPITALI YA TAIFA YA MUHIMBILI"

Utangulizi: Kwa majina naitwa Dr Erneus Ernest, ni mwanafunzi wa shahada ya uzamili ya udaktari wa binadamu idara ya watoto katika Chuo Kikuu cha Afya na Sayansi Shirikishi Muhimbili.

Ninafanya utafiti unaohusu "Sonona,wasiwasi miongoni mwa walezi wenye watoto wenye kifafa wanaohudhuria kliniki ya mishipa ya fahamu ya watoto katika hospitali ya taifa Muhimbili".

Dhumuni la utafiti: Utafiti huu utasaidia kujua ukubwa wa tatizo la sonona na wasiwasi miongoni mwa wazazi na walezi wa watoto wenye ugonjwa wa kifafa.

Jinsi ya kushiriki: Ninaomba ushiriki wako katika utafiti huu. Unayo haki ya kuamua iwapo utashiriki au hutoshiriki kwenye utafiti huu na uamuzi wako hautoathiri upataji wako wa huduma katika hospitali hii. Iwapo utakubali kushiriki,nitafanya mahojiano na wewe na nitakupa dodoso usome na kujibu vipengele vingine vilivyo ainishwa.

Usiri: Taarifa zote utakazozitoa ni siri na zitatumika kwa ajili ya madhumuni ya utafiti tu. Jina halitoandikwa katika karatasi hizi na badala yake tutatumia namba katika hatua zote za utafiti.

Madhara: Hatutegemei madhara yoyote yale kutokea kwa ushiriki wako katika utafiti huu.

Faida: Kushiriki kwako kutatusaidia kujua ni kwa kiasi gani walezi wa watoto wenye kifafa wanapata changamoto ya sonona na wasiwasi na visabishi vyake. Hii itasaidia hapo baadae, katika kutengeneza mikakati ya kutatua tatizo hili, ili kuhakikisha walezi wa watoto wana afya nzuri ya akili ili waweze kutoa malezi bora na huduma stahiki kwa watoto wao.

Haki ya kujitoa katika utafiti: Ushiriki wako katika utafiti huu ni hiari. Upo huru kushiriki au kutokushiriki au kujiondoa muda wowote utafiti unapoendelea.

Mawasiliano: Iwapo utakua na swali lolote linalohusu utafiti huu, unaweza kuwasiliana na mtafiti au mamlaka husika kwa anuani zifuatazo;

DR ERNEUS ERNEST
Chuo cha Afya na Sayansi Shirikishi Muhimbili
S.L.P 65001, Dar es Salaam.
Barua pepe: erneusernest255@gmail.com
Namba ya simu: 0765-849095

DR OBREY URIO,
Chuo cha Afya na Sayansi Shirikishi Muhimbili
S.L.P 65001, Dar es Salaam.
Barua pepe: obreyharold@rocketmail.com
Namba ya simu: 0712-961792

Dr. Nahya Salim
Mwenyekiti, bodi ya ukaguzi wa kitaasisi,
S.L.P 65001, Dar es Salaam.
Namba ya simu: 0713 250074
Barua pepe: nahya.salim@gmail.com

Makubaliano ya ushiriki: Nimesoma na kuelewa dhumuni la utafiti huu. Nipo tayari kushiriki katika huu utafiti kwa hiari yangu.
Jina la mshiriki: ……..
Sahihi ya mshiriki: …….
Tarehe: …….

Appendix 3: Questionnaire (English version)

A STUDY ON DEPRESSION, ANXIETY, AND ASSOCIATED FACTORS AMONG CAREGIVERS OF CHILDREN AND ADOLESCENTS WITH EPILEPSY ATTENDING THE PAEDIATRIC NEUROLOGY CLINIC AT MNH

STUDY PARTICIPANT ID		
		CODE
1. Date of interview		
2. Telephone contact (Caregiver)		
3. Residence		
PART A: INFORMATION ABOUT THE CHILD OR ADOLESCENT		**CODE**
4. Date of birth of the child		
5. Age (in months)		
6. Sex of the child	1. Male 2. Female	
7. Education level of the child	1. Not started school 2. Primary school education 3. Secondary school education	
8. What is the duration since the child started having seizures for the first time? (In months)		

9. What is the duration of time since the child was diagnosed with epilepsy? (In months)		
10. Type of epilepsy (as diagnosed by a paediatric neurologist or paediatrician)	1. Focal 2. Generalized 3. Combined generalized and focal 4. Unknown	
11. For how long has the child been on Anti Seizures Medications? (In months)		
		CODE
12. How many Anti Seizures Medications does the child use?	1. One 2. Two 3. Three 4. Four or more	
13. What Anti Seizures Medications Does the child use? (Circle all that apply)	1. Sodium valproate 2. Carbamazepine 3. Phenobarbitone 4. Levetiracetam 5. Clonazepam 6. Others (mention)……..	
14. What other comorbidities have been diagnosed in this patient	1. None 2. Cerebral palsy 3. Autism 4. Attention deficit hyperactivity disorder 5. Intellectual disability	

(As documented by a Paediatric neurologist or Paediatrician)	6. Others (mention)……	
15. In the past month, how many seizure episodes has the child had?	1. Did not have seizures 2. One seizure episode 3. Two seizure episodes 4. Three seizure episodes 5. Four or more seizure episodes	
16. Does the child have a history of injury due to epilepsy that required medical consultation?	1. No 2. Yes	
17. Throughout the course of illness, how many times has a child ever been admitted due to seizures?		
PART B: INFORMATION ABOUT THE CAREGIVER OF THE CHILD OR ADOLESCENT		**CODE**
18. Age of the caregiver (in years)		
19. Sex of the caregiver	1. Male 2. Female	

20. Marital status of the caregiver	1. Single 2. Married 3. Cohabiting 4. Divorced 5. Widowed or widower	
21. Level of education attained by the caregiver	1. No formal education 2. Primary education 3. Secondary education 4. College or university education	
22. Occupation of the caregiver	1. Student 2. Employed 3. Self-employed 4. Unemployed	
23. What is your relationship with this child?	1. Mother 2. Father 3. Grandmother 4. Others (mention)……	
24. To whom do you get support in taking care of this child?	1. I don't get any support 2. I get support from my partner 3. I get support from other people (mention)……	
25. For how long have you been taking care of this child? (in Months)		
26. How many people make up your family?		

27. Do you have any chronic medical illnesses?	1. No 2. Yes (Mention)……	
28. Are there any other family members with epilepsy?	1. No 2. Yes	

PART C: INFORMATION REGARDING THE DEPRESSION OF THE CAREGIVER

Over the last 2 weeks, how often have you been bothered by any of the following problems? (Use "✔" to indicate your answer)	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3

9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3
TOTAL COLUMN SCORE				
If you checked off any problems how difficult have these made it for you to do your work, take care of things at home or get along with people?	Not difficult at all…… Somewhat difficult…….. Very difficult……... Extremely difficult……..			

PART D: INFORMATION REGARDING ANXIETY IN THE CAREGIVER

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all	Several days	Over half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it's hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3
Total column Scores =	+	+	+	+

If you checked any problems, how difficult have they made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
☐	☐	☐	☐

THANK YOU

Appendix 4: Questionnaire (Swahili version)

UTAFITI UNAOHUSU SONONA, WASIWASI MIONGONI MWA WALEZI WA WATOTO NA VIJANA WENYE KIFAFA WANAOHUDHURIA KLINIKI YA MISHIPA YA FAHAMU YA WATOTO KATIKA HOSPITALI YA TAIFA MUHIMBILI

UTAMBULISHO WA MGONJWA		
		ALAMA
1. Tarehe ya mahojiano		……....
2. Nambari ya simu (Ya mlezi)		
3. Mahali anapoishi		
SEHEMU A: TAARIFA ZINAZOMUHUSU MTOTO AU KIJANA		**ALAMA**
4. Tarehe ya kuzaliwa mtoto		
5. Umri (Miezi)		
6. Jinsia ya mtoto	1. Me 2. Ke	
7. Kiwango cha elimu cha mtoto	1. Hajaanza shule 2. Elimu ya msingi 3. Elimu ya sekondari	
8. Je, ni muda gani umepita tokea mtoto aanze kupata kifafa kwa mara ya kwanza? (Miezi)		

9. Je, ni muda gani umepita tokea mtoto agundulike na ugonjwa wa kifafa? (onesha kwa miaka au miezi)		
10. Aina ya kifafa (kama ilivyochunguzwa na daktari bingwa wa mishipa ya fahamu ya watoto au daktari wa watoto)	1. Focal 2. Generalized 3. Combined generalized and focal 4. Unknown	
11. Je, mtoto ana muda gani tokea aanze kutumia dawa za kuzuia kifafa?(Miezi)		
		ALAMA
12. Je mtoto anatumia aina ngapi za dawa za kuzuia kifafa?	1. Moja 2. Mbili 3. Tatu 4. Nne au Zaidi	
13. Ni dawa gani za kuzuia kifafa anazotumia mtoto? (Zungushia zote anazotumia)	1. Sodium valproate 2. Carbamazepine 3. Phenobarbitone 4. Levetiracetam 5. Clonazepam 6. Nyingine (Taja)……..	

14. Ni magonjwa gani mengine yamegunduliwa kwa mtoto? (Kama ilivyoainishwa na daktari bingwa wa mishipa ya fahamu ya watoto au daktari bingwa wa watoto)	1. Hakuna 2. Cerebral palsy 3. Autism 4. Attention deficit hyperactivity disorder 5. Intellectual disability 6. Mengine (Taja)……	
15. Katika mwezi mmoja uliopita, mtoto amepatwa na kifafa mara ngapi?	1. Hakupata kifafa 2. Alipata kifafa mara moja 3. Alipata kifafa mara mbili 4. Alipata kifafa mara tatu 5. Alipata kifafa mara nne au zaidi	
16. Mtoto ana historia ya kuumia kutokana na kifafa na kuhitaji kupelekwa hospitali kwa matibabu?	1. Hapana 2. Ndio	
17. Je, katika kipindi chote cha kuumwa mtoto amewahi kulazwa hopsitali mara ngapi kwasababu ya kifafa?		

SEHEMU B: TAARIFA ZINAZOMUHUSU MLEZI WA MTOTO AU KIJANA		**ALAMA**
18. Umri wa mlezi (miaka)		
19. Jinsia ya mlezi	1. Me 2. Ke	
20. Hali ya ndoa ya mlezi	1. Sijaoa / Sijaolewa 2. Nimeoa / Nimeolewa 3. Naishi kinyumba 4. Nimeacha / Nimeachika 5. Mjane / Mgane	
21. Kiwango cha elimu cha mlezi	1. Sijasoma 2. Elimu ya msingi 3. Elimu ya sekondari 4. Elimu ya chuo	
22. Hali ya ajira ya mlezi	1. Mwanafunzi 2. Nimeajiriwa 3. Nimejiajiri 4. Sijaajiriwa	
23. Una uhusiano gani na huyu mtoto?	1. Mama 2. Baba 3. Bibi 4. Mwingine (taja)…….	

24. Unapata msaada kutoka kwa nani katika kumtunza mtoto huyu?	1. Sipati msaada wowote 2. Napata msaada kutoka kwa mzazi mwenzangu 3. Napata msaada kutoka watu wengine (taja)…… ……	
25. Je una mda gani tokea uanze kumlea mtoto huyu? (miezi)		
26. Ni watu wangapi wanaunda familia yako?		
27. Je, una ugonjwa wowote sugu?	1. Hapana 2. Ndio (Taja)…….	
28. Kuna mwanafamilia mwingine aliye na kifafa?	1. Hapana 2. Ndio	

SEHEMU C

TAARIFA KUHUSIANA NA DALILI ZA SONONA KWA MLEZI WA MTOTO (PHQ-9)

Katika kipindi cha wiki mbili zilizopita ni mara ngapi umesumbuliwa na matatizo haya yafuatayo? (Weka vema kuonyesha jibu sahihi)	**Hakuna Kabisa**	**Siku kadhaa**	**Zaidi ya nusu ya siku zote**	**Karibu kila siku**
1. Kuwa na mwelekeo mdogo na kukosa raha ya kufanya vitu	0	1	2	3
2. Kujisikia huwezi kuchangamka, kuwa na huzuni au kukosa tumaini	0	1	2	3
3. Tatizo la kupata usingizi, au kuendelea kulala baada ya kuupata au kulala kupita Kiasi	0	1	2	3
4. Kujisikia kuchoka na kuwa na nguvu kidogo	0	1	2	3
5. Kupungua hamu ya kula chakula au kula kupita kiasi	0	1	2	3
6. Kujisikia vibaya au kujisikia kama umeshindwa au umejishusha au kuishushia (thamani) familia yako	0	1	2	3
7. Tatizo la kutuliza akili kwenye vitu kama kusoma magazeti au kuangalia luninga	0	1	2	3
8. Kusogea au kuzungumza polepole sana hata ingeweza kuonekana kwa watu wengine ama kuwa na mashaka/	0	1	2	3

wasiwasi au kufadhaika Kiasi hata ukitembea, unatembea kuliko kawaida				
9. Fikira kwamba heri kufa au kuwaza kujiumiza	0	1	2	3
JUMUISHO LA KILA SAFU ZA JEDWALI				
Kama kumekuwa na tatizo lolote hapo juu, je ni kwa kiasi gani hili tatizo limeacha usiweze kufanya kazi, kushughulikia maswala ya nyumbani au katika mahusiano yako na watu wengine?	Sio vigumu hata kidogo…… Vigumu kidogo……. Vigumu sana……..... Vigumu kupita kiasi……			

SEHEMU D: TAARIFA KUHUSIANA NA DALILI ZA WASIWASI KWA MLEZI WA MTOTO (GAD 7)

Katika wiki mbili zilizopita, je umesumbuliwa na matatizo yapi katika yafuatayo? (Weka vema "✔" kuonyesha jibu lako)	**Haijajitokeza Kabisa**	**Siku kadhaa**	**Zaidi ya nusu ya siku hizo**	**Karibu kila siku**
1. Kujisikia kuwa na hofu au wasiwasi	0	1	2	3
2. Kushindwa kukaa bila kuwa na au kuudhibiti wasiwasi	0	1	2	3
3. Kuwa na wasiwasi sana kwa vitu vingi (kadha wa kadha)	0	1	2	3
4. Shida kutulia	0	1	2	3
5. Shida ya kuweza kupumzika hadi kushindwa kukaa tuli	0	1	2	3
6. Kuwa na hasira na kukasirika kwa kirahisi	0	1	2	3
7. Kuwa na woga kwamba jambo baya linaweza kutokea	0	1	2	3

JUMUISHO LA KILA SAFU ZA JEDWALI =				

Kama kumekuwa na tatizo lolote hapo juu, je ni kwa kiasi gani hili tatizo limeacha usiweze kufanya kazi, kushughulikia maswala ya nyumbani au katika mahusiano yako na watu wengine?

Sio vigumu hata kidogo ☐ Vigumu kidogo ☐ Vigumu sana ☐ Vigumu kupita kiasi ☐

ASANTE

Appendix 5: Patient Health Questionnaire 9 (PHQ-9)

(Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues)

Over the last 2 weeks, how often have you been bothered by any of the following problems? (Use "✔" to indicate your answer)	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3
FOR OFFICE CODING	0 + _____ + _____ + _____ =Total Score: _____			

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home or get along with people?	Not difficult at all…… Somewhat difficult…… Very difficult…… Extremely difficult……

Total Score Depression Severity

1-4 Minimal depression

5-9 Mild depression

10-14 Moderate depression

15-19 Moderately severe depression

20-27 Severe depression

Appendix 6: Generalized Anxiety Disorder- 7 (GAD-7)

(Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues)

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all	Several days	Over half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it's hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3
Total column Scores =	+	+	+	+

If you checked any problems, how difficult have they made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all ☐ Somewhat difficult ☐ Very difficult ☐ Extremely difficult ☐

Scoring GAD-7 Anxiety Severity This is calculated by assigning scores of 0, 1, 2, and 3 to the response categories, respectively, of "not at all," "several days," "more than half the days," and "nearly every day." GAD-7 total score for the seven items ranges from 0 to 21.

0–4: minimal anxiety

5–9: mild anxiety

10–14: moderate anxiety

15–21: severe anxiety

Appendix 7: Ethical Clearance

UNITED REPUBLIC OF TANZANIA

MINISTRY OF EDUCATION, SCIENCE AND TECHNOLOGY

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

OFFICE OF THE DIRECTOR – RESEARCH, PUBLICATIONS AND INNOVATION

In reply quote;
Ref. No.DA.282/298/01.C/1679

Date: 16/05/2023

MUHAS-REC-05-2023-1679
ERNEUS ERNEST
School of Medicine
MUHAS.

RE: APPROVAL FOR ETHICAL CLEARANCE FOR A STUDY TITLED: "DEPRESSION, ANXIETY AND ASSOCIATED FACTORS AMONG CAREGIVERS OF CHILDREN AND ADOLESCENTS WITH EPILEPSY ATTENDING MUHIMBILI PEDIATRIC NEUROLOGY CLINIC"

Reference is made to the above heading.

I am pleased to inform you that the Chairman has on behalf of the University Senate approved ethical clearance of the above-mentioned study, on recommendations of the Senate Research and Publications Committee meeting accordance with MUHAS research policy and Tanzania regulations governing human and animal subjects research.

APPROVAL DATE: 16/05/2023
EXPIRATION DATE OF APPROVAL: 15/05/2024

STUDY DESCRIPTION:
Purpose:
The purpose of this hospital-based descriptive cross-sectional study is to to determine the prevalence of depression, anxiety and their associated factors among caregivers of children and adolescents with epilepsy attending pediatric neurology clinic at Muhimbili National Hospital (MNH)

The approved protocol and procedures for this study is attached and stamped with this letter, and can be found in the link provided:
https://irb.muhas.ac.tz/storage/Certificates/Certificate%20-%201098.pdf and in the MUHAS archives.

The PI is required to:

1. Submit bi-annual progress reports and final report upon completion of the study.
2. Report to the IRB any unanticipated problem involving risks to subjects or others including adverse events where applicable.
3. Apply for renewal of approval of ethical clearance one (1) month prior its expiration if the study is not completed at the end of this ethical approval. You may not continue with any research activity beyond the expiration date without the approval of the IRB. Failure to receive approval for continuation before the expiration date will result in automatic termination of the approval for this study on the expiration date.
4. Obtain IRB amendment (s) approval for any changes to any aspect of this study before they can be implemented.
5. Data security is ultimately the responsibility of the investigator.
6. Apply for and obtain data transfer agreement (DTA) from NIMR if data will be transferred to a foreign country.
7. Apply for and obtain material transfer agreement (MTA) from NIMR, if research materials (samples) will be shipped to a foreign country,
8. Any researcher, who contravenes or fail to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine as per NIMR Act No. 23 of 1979, PART III section 10 (2)
9. The PI is required to ensure that the findings of the study are disseminated to relevant stake holders.
10. PI is required to be versed with necessary laws and regulatory policies that govern research in Tanzania. Some guidance is available on our website https://drp.muhas.ac.tz/

Dr. Nahya Salim Masoud,
Chairman, MUHAS Research and Ethics Committee

Muhimbili University of Health and Allied Sciences
DIRECTOR
Research & Publications
Box 65001

Appendix 8: Introduction Letter

UNITED REPUBLIC OF TANZANIA
MINISTRY OF EDUCATION, SCIENCE AND TECHNOLOGY
MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES
OFFICE OF THE DIRECTOR – POSTGRADUATE STUDIES

In reply quote;
Ref. No. HD/MUH/T.199/2021

01st June, 2023

MUHIMBILI NATIONAL HOSPITAL
RECEIVED
02 JUN 2023
REGISTRY
File No:

The Executive Director,
Muhimbili National Hospital,
P.O. Box 65000,
DAR ES SALAAM

Re: INTRODUCTION LETTER

We would like to inform you that the bearer of this letter is Erneus Ernest with Reg. No. HD/MUH/T.199/2021 is a student at Muhimbili University of Health and Allied Sciences (MUHAS) "pursuing MMed. Paediatrics/Child Health.

As part of his studies, he will be doing an elective research titled: "***Depression, Anxiety and Associated Factors Among Caregivers of Children and Adolescents with Epilepsy Attending Muhimbili Pediatric Neurology Clinic."*** he is being supervised by Rodrick Kisenge from MUHAS and Zameer Fakih from MNH.

The research has been approved by the Chairman of University Senate.

Kindly provide him the necessary assistance to facilitate the conduct of his research.

We thank you for your cooperation.

Ms. Victoria Mwanilwa
For: DIRECTOR, POSTGRADUATE STUDIES

c.c Erneus Ernest

9 United Nations Road; Upanga West; P.O. Box 65001, Dar Es Salaam: Tel. G/Line: +255-22-2150302/6; Ext. 1015; Direct Line:+255-22-2151378;Telefax:+255-22-2150465;E-mail:dpgs@muhas.ac.tz;Web:https://www.muhas.ac.tz

Appendix 9: Permission Letter

THE UNITED REPUBLIC OF TANZANIA

MINISTRY OF HEALTH

MUHIMBILI NATIONAL HOSPITAL

In reply please quote:

Ref. No.: MNH/CRTCU/Perm/2023/397 Date: 12th June, 2023

Head of Department,
Paediatrics and Child Health
Muhimbili National Hospital

RE: PERMISSION TO COLLECT DATA AT MNH.

Name of student	**Erneus Ernest**
Title	**"Depression, Anxiety and Associated Factors Among Caregivers of Children and Adolescents with Epilepsy Attending Muhimbili Pediatrics Neurology Clinic".**
Institution	Muhimbili University of Health and Allied Sciences
Supervisor	Rodrick Kisenge (MUHAS)
Co - supervisor	Zameer Fakih (MNH)
Period	12th June, 2023 to 30th October, 2023

Approval has been granted to the above mentioned student to collect data at MNH. Dissemination of study findings at MNH shall be overseen by **Zameer Fakih** (MNH) Co - supervisor.

Kindly ensure the named principal investigator abide to the ethical principles and other conditions of the research approval.

Sincerely,

Dr. Jessie Mbwambo
Head of Clinical Research, Training and Consultancy Unit

c.c DMS
c.c Erneus Ernest

Upanga West, Kalenga Street, Plot No. 10480/3, P.O. BOX 65000, Dar es Salaam, Tanzania.
Telephone: +255-22-2151367-9, Telephone: +255-22-2151351-2