JIMMA UNIVERITY

INSTITUTE OF HEALTH

FACULTY OF MEDICAL SCIENCE

DEPARTMENT OF PEDIATRICS AND CHILD HEALTH

SEIZURE CONTROL STATUS AND ASSOCIATED FACTORS AMONG CHILDREN WITH EPILEPSY AT JIMMA MEDICAL CENTER NEUROLOGY FOLLOW UP CLINIC,SOUTH WEST ETHIOPIA

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POST GRADUATE PROGRAM

SEIZURE CONTROL STATUS AND ASSOCIATED FACTORS AMONG CHILDREN WITH EPILEPSY AT JIMMA MEDICAL CENTER NEUROLOGY FOLLOW UP CLINIC,SOUTH WEST ETHIOPIA

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Study Design	Institutional based cross sectional study
Study Period	July- 08 to October 5 2022
Source Population	Children with epilepsy who have follow up at pediatrics neurology follow up clinic of JMC
Study Population	All children with epilepsy visiting JMC Pediatrics neurology follow up clinic and fulfilling the eligibility criteria during the study period
Budget	24,999 Birr

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DECLARATION

ASSURANCE OF PRINCIPAL INVESTIGATOR

The undersigned agrees to accept responsibility for the scientific ethical and technical conduct of the research project and for provision of required progress reports as per terms and conditions of the faculty of Medical Sciences in effect at the time of grant is forwarded as the result of this application.

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LIST OF ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder
AED	Anti-epileptic Drugs
ASD	Autism Spectrum Disorder
CP	Cerebral Palsy
DC	Data collector
EEG	Electroencephalogram
ETB	Ethiopian Birr
GP	General Practitioner
HMIS	Health Management Information System
JU	Jimma University
JU ERC	Jimma university Ethical Review Committee
JMC	Jimma Medical Center
LMIC	Low and middle-income countries
NR	Non response
PI	Principal Investigator
SE	Status Epilepticus
SPSS	Software Program for Social Science
SSA	Sub-Saharan Africa
SUDEP	Sudden unexplained death in epilepsy
USA	United States of America
WHO	World Health Organization
PHT	Phenytoin
PHB	Phenobarbital
VBP	Valproic Acid

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ABSTRACT

Background: A seizure represents the clinical expression of abnormal, excessive or synchronous discharges of neurons residing primarily in the cerebral cortex. This abnormal paroxysmal activity is intermittent and usually self-limited, lasting seconds to a few minutes.

Childhood epilepsy is a major public health problem worldwide. Even though anti-seizure medications (ASM) have been demonstrated to control seizures, children with epilepsy continue to have frequent seizures. There is a scarcity of data on seizure control status among pediatric epileptic patients in Ethiopia.

Objective: The aim of this study is to assess seizure control status and associated factors among children with epilepsy attending paediatrics neurology follow up clinic of Jimma medical centre, south west Ethiopia..

Methods: A facility based cross-sectional study design was conducted among children with epilepsy attending Pediatrics neurology follow up clinic of Jimma Medical Center from July-08 to October-5, 2022, A total of 150 children with epilepsy was included in the study which was selected Consecutively. Data was collected by using structured pre-tested questionnaire. The data on the questionnaire was entered into Epi data manager version 4.6 and double entry verification was made and then exported to SPSS version 25 for analysis. Logistic regression analysis was done to identify covariates associated with the outcome variable. Statistical significance was considered at a p-value of less than 0.05.

Results: From 150 participants 67.3% have controlled seizure. Durations of AED use more than two years (AOR: 8.9; 95% CI: 1.55–50.9; P = 0.010) ,those children who never miss or stop AEDs use (AOR: 5.3; 95% CI: 1.75–15.9; P = 0.003 Urban residency (AOR: 5.4; 95% CI: 1.75–17.2; P = 0.004), caregiver knowledge (AOR: 8.5; 95% CI: 2.53–28.4; P < 0.001), medication adherence (AOR: 5.3; 95% CI: 1.76–18.0; P = 0. 003) and mono therapy (AOR: 3.5; 95% CI: 1.12–11.5; P =0.031 were significantly associated with seizure control status .

Conclusion: This study indicated that the overall seizure control status of children with epilepsy was found to be high. In addition,seizure control status was influenced by different factors such

as Use of AEDs for more than 2 years, not stopping/missing AEDs doses, urban dwellers, good care giver knowledge , patient adherent to medication and Mode of therapy.

Recommendation: More effort need to raise awareness about seizures in children and adolescents (e.g., educate parents and school personnel).Further study needed to assess the associations between sociodemographic characteristics and seizure control.

Keywords: Seizure, anti-epileptic drugs, children, Treatment outcome, Epilepsy, Jimma University, Ethiopia

1. INTRODUCTION

1.1 Background

Epilepsy is a common chronic non-communicable medical and social disorder or group of disorders with unique characteristics. (1) It is a group of syndromes characterized by unprovoked, recurrent seizures. The word "epilepsy" is derived from Latin and Greek words for "seizure" or "to seize upon".(1)

It has deep physical, psychological and social impacts with a greater impact on a person's quality of life than other chronic disease.(2)

Many children outgrow seizures. There are a number of serious epilepsy syndromes that continue into adulthood. A study suggests that the remission rates for generalized tonic-clonic seizure and partial seizures are approximately 50% and 25% in patients followed into adulthood respectively.(3)

Epilepsy can cause an infinite burden on both the people with epilepsy (PWE) and their family caregivers, decreasing their quality of life and daily efficiency.(3)

Epilepsy, mainly childhood epilepsy, remains a challenge to treat. Even though the increase in the number of antiepileptic drugs (AEDs), over 25% of children with childhood epilepsy continue to have seizures.(4) Usually AEDs are not prescribed until after a second unprovoked seizure occurs. A second seizure typically indicates epilepsy or another neurologic abnormality. Candidates for medication after a first seizure include children who have had a prolonged first seizure (more than 15 minutes), who have multiple risk factors for additional seizures, or who have a significantly abnormal EEG. Each treatment decision must be individualized and based on a child's unique clinical presentation. So treatment with anti-epileptic drug (AED) is selected based on the type of seizure.(3)

Antiepileptic drugs (AEDs) fully control seizures in about 60% of children. Another 10% to 15 % of children will gain good control of their seizures after a trial with a second medication.(3) Children usually continue medications until they are seizure-free for 1-5 years. At that time, a child neurologist will often consider tapering their antiepileptic medication. However, about 90% of epileptic patients in developing countries are not receiving

appropriate treatment due to the cultural attitude, lack of prioritization, poor health care system, economic problems and inadequate supply of AEDs.(5)

Treatment should be aimed at controlling seizures associated with the lowest possible overall cost and occurrence of adverse effects, thus allowing the child to become an active member of the community. Data on the efficacy, potency, safety and tolerability of AEDs are critical in choosing the optimal AED: but monotherapy data specific to children is often not available.(4) Some barriers of adherence include: (1) parental lack of understanding the disease; (2) worries about the effectiveness of medications; (3) fear of medication side effects; (4) extended treatment duration; (5) multiple medications; and (6) periods of seizure free. For example, the parent of a child with a well-controlled seizure disorder may discontinue daily medications to prevent adverse effects.(6)

1.2 Statement of the Problem

The number of people with epilepsy is high in most regions of the world. Thus, epilepsy is a major public health concern. As stated in the WHO report Neurological Disorders: "A clear message emerges that unless immediate action is taken globally, the neurological burden, mainly epilepsy, is anticipated to become more serious and uncontrollable problem in every part of the countries".(7)

Epilepsy affects at least 50 million people in the world. From those 40 million live in developing countries. About 100 million people will have at least one epileptic seizure at some time in their lives.(8) In the United States, about 2.3 million people have epilepsy. Every year, 150,000 new cases are diagnosed as epilepsy.(2) According to WHO, the prevalence (over 80%) of epilepsy is highest in low- and lower middle-income countries of sub-Saharan Africa including Ethiopia.(7)

Epilepsy is the most common neurological disorder in children with an incidence of about 8 per 1000 children below the age of seven years. Around 5-10% of children suffer at least one seizure in the first 16 years of life.(2) The incidence is highest in children below 3 years of age, with a decreasing frequency in older children.(9) Epidemiological studies reveal that almost 150,000 children will sustain a first-time unprovoked seizure every year. From those, 30,000 will develop epilepsy. 65.5 % of children with epilepsy lead to discontinue their education.(10)

Worldwide, the distribution of deaths in children with fewer than five years of age is 33% in south Asia, 50% in sub-Saharan Africa, and less than 1% in high-income countries.(11)

In Africa, the childhood mortality rate is 92 per 1000 live births which are 15 times more than that of the well developed countries.(12)

It was estimated 360 to 400 thousand epileptic Ethiopians are living with poor medication. The prevalence of epilepsy was 5.2/1000 inhabitants at risk, 5.8 for males, and 4.6 for females. The highest age-specific prevalence was found for ages 10-19 years. The annual incidence of epilepsy was 64 in 100,000 inhabitants at risk, 72 for males, and 57 for females.(13)

Poor control of epilepsy is still a major problem with a prevalence of 40%. Inappropriate drug therapy is leading to significant poor epilepsy control.(14) Poorly controlled seizure leads to impairment of quality of life, excessive bodily injury, neuropsychological impairment, reduced marriage rates, poor education, reduced employment levels, reduces the capacity to participate in social activities, and finally shortened life span.(15)

Seizures are common in the pediatrics age group and occur in around 10% of children. However, the current antiepileptic drugs (AEDs) cannot control seizures ill 20-30% of patients. For that reason, new AEDs with better efficacy & fewer side effects are intensely needed.(16)

AED treatment has been demonstrated to control seizure, which decreases morbidity and mortality associated with epilepsy.(17) Therefore, the ultimate treatment outcome of AED therapy is to make patients seizure free throughout the rest of their lives.(18) Outcomes range from no complications to increased risk for behavioral problems, or sudden unexpected death.(19) But the treatment outcome of AED therapy in pediatrics patients depends on numerous factors, including, but not limited to, availability and selections of ADEs, close monitoring of AEDs, identification of underlying cause, type of seizures, pharmacokinetic parameters of AEDs and level of adherence.(20)

Many studies have shown that inappropriate drug therapy and non-adherence were the leading causes of poor seizure control.(9) In both developed and developing countries, non-adherence to medication remains a significant concern for health care providers as well as patients because of its adverse consequences on therapeutic outcomes.(21)

So far, there are not many studies in the Ethiopian literature that examine the factors that influence AED treatment outcome. Identifying the factors associated with AED treatment outcome will allow the development of strategies to improve the treatment gap. Therefore, the present study will be conducted to determine patients' treatment outcome, to evaluate the impact of knowledge of primary care takers on treatment outcome, to evaluate the AED use,

to determine the level of adherence to AEDs, and to identify the factors that influence level of AED adherence in pediatric epileptic patients.

1.3 Significance of study

Assessment of Seizure control status and associated factor in children with epilepsy is crucial to develop treatment optimization strategies and responsible care of patients as clinicians may have difficulty in identifying patients that are less likely to have controlled seizure.

Although different studies have been conducted in different parts of the world, there is no adequate data on seizure control status and associated factors in Ethiopia and Particularly in Jimma University Medical College. ;Hence this study will contribute scientific knowledge for policy makers and health planners in general and it specifically provide necessary information for health care providers to formulate evidence based intervention strategies to improve Seizure control status which increases school performance/productivity, decrease emergency department visit and psychosocial impact of disease, increases seizure free days, decrease morbidity and mortality.

Therefore, this study will try to assess the seizure control status and associated factors among children with epilepsy in Neurology follow up clinic, JMC.

2. LITERATURE REVIEW

Globally epilepsy affects about 70 million people of which 85% live in developing countries. Long-term antiepileptic drug (AED) administration remains the mainstay of epilepsy treatment.(22) In up to 67% of patients with epilepsy, AEDs effectively eliminate or reduce the frequency of seizures.(23)

A Hospital Based Retrospective cohort Study conducted in Gonder.a total of 210 study participants who fulfilled the eligibility criteria was included in the study, the finding revealed that 77% of patients have Good seizure control.(24)

A cross sectional study which was done in Gonder among 261 study participant nearly half (49.0%) of the participants had controlled seizures.(25) A hospital-based cross-sectional study was conducted at the neurologic clinic of Ayder comprehensive specialized hospital 270 patients were included. Of whom, 46.6% had controlled seizures. Epileptic patients with a negative medication belief, comorbidities and low medication adherence were more likely to have uncontrolled seizure. (26)

2.1. Factors associated seizure control status

2.1.1. Socio demographic factor

A cross-sectional study conducted in Gujarat (India) stated that among 100 patients recruited, 40 patients each belonged to 5-10 and 10-15 year age group while 17 patients were from 0-5 year age group and remaining 3 patients were from 15-18 year age group, at the time of admission. 63 were males while 37 were females. Almost half (47%) of sample population had family income <50000 INR annually while 34% had annual family income of 50000-100000 INR. 72 patients were school going and 28 patients had never gone school.(27)

The Study Which was conducted at Uganda Mulago hospital Pediatric Neurology clinic. 122 patients who attended the pediatric neurology clinic during the study period were enrolled into the study Mothers were the majority caregivers (64.8%) and most of the care givers were between 25 - 45 years of age (76.2%). Most caregivers were in unskilled employment such as market vendors, shopkeepers, and peasant farmers (53.7%).(28)

A Mixed Methods Study was conducted in Republic of Guinea of 132 participants (49% children, 44% female, 55% with a university-educated head of household), 79% had seen a traditional healer, and 71% saw a traditional healer before seeing a medical provider for their

epilepsy. Participants were treated by a traditional healer for a mean of 39 months before seeing a medical provider.(29)

A Hospital Based Retrospective cohort Study conducted in Gonder.a total of 210 study participants who fulfilled the eligibility criteria was included in the study Being female child were significantly associated with treatment outcome. The likelihood of developing a successful treatment outcome in females was 2.21 times higher than those with in males. (24)

A Hospital Based prospective cross sectional study was done in Gonder among 261 study participants revealed that the mean age of participants was 10.15 ± 4.6 years. The majority of the patients were males (60.9%), urban dwellers (57.1%).Ninety percent of patients had no family history of epilepsy. Patients from urban area were 2.12 times more likely to have controlled seizure compared to patients from rural residence. Of those patients who live in urban areas, 54.4% of them had contsolled seizure. urban residents' better awareness about the disease, which facilitates a discussion with their health care professionals about the disease and the medications they use. In addition, most rural residents could be inclined to try religious and spiritual healing.(25)

A Hospital Based prospective cross sectional study was done In Gonder among 261 study participants revealed that epileptic seizures were found to be more common in males (60.9%) than in females (39.1%). GTCS was the most common type of epileptic seizure encountered in 98.5% of patients.(25)

2.1.2. Child health related (clinical and treatment profile) factors

A cross-sectional study conducted in Gujarat (India) stated that Out of 100 GTCS was found to be the most common (55%) form of epilepsy among pediatric patients and Carbamazepine was the most commonly prescribed (41%) AED followed by sodium valproate (38%). 71% patients were prescribed monotherapy. Carbamazepine and Clobazam was the most commonly (7%) used combination.(30)

The study conducted in Israel out of 74 participants Fifty-three (72%) children became seizure-free for a mean period of 20 months on antiepileptic drug (AED) therapy and 21 (28%) remained uncontrolled. Sixty out of 74 children (81%) had idiopathic epilepsy and 14 (19%) had symptomatic epilepsy.(31)

The study conducted in Bangladesh number of patients on monotherapy and dual AED therapy were 67% and 24% respectively. Carbamazepine (67%) was the most frequently prescribed AED, followed by valproic acid (43%), Phenobarbitone (17%), and Phenytoin (8%). PHB and PHT were the cheapest of all AEDs. Adverse drug reaction (ADR) were observed among 140 (24.5%) of those with monotherapy. PHT (64%) was the most common drug to cause adverse drug reaction. CBZ was at the bottom of the list to cause adverse effect (11.6%). VPA and PHB caused weight gain commonly.(27)

A cross-sectional study done in UAE investigating seizure control has shown that from different types of seizures, partial (47.6%) and generalized seizures (38.1%) were seizure free, respectively. Mono-therapy 57.1% was superior to polytherapy 42.9% in controlling seizures. Similarly, older AEDs were more effective in producing 85.7% seizure free than new AEDs. Controlling seizures with minimal adverse effects and maintaining the patient's ability to perform daily activities are the critical measures of treatment outcome. In addition to medication adherence, seizure control is concerned with types of seizure and AEDs therapy used.(32)

A cross-sectional observational study was conducted among 253 patients with epilepsy in Bangladesh Monotherapy was commonly (72.7%) used, among which Valproic acid was the most commonly utilized (30.4%) single anticonvulsant drug. (27)

A Cohort Study done in Norway on 606 children with epilepsy, 30% of CWE had DRE, 59% had achieved≥1 year of seizure freedom, and the remaining 12% had intermediate seizure outcomes. Having an identified cause of epilepsy structural, genetic, metabolic, or infectious) was associated with DRE.(33)

A cross sectional study was conducted at Uganda Mulago hospital Pediatric Neurology clinic. 122 patients who attended the pediatric neurology clinic during the study period were enrolled into the study 62.3% (76/122) had generalized seizures. Ninety-eight children (80.3%) were on monotherapy of which 73.5% of the children were taking carbamazepine and the rest taking valproate. Of the 24 children on combination therapy, only one was on three drugs.(28)

A Hospital Based Retrospective cohort Study conducted in Gonder.210 the finding revealed that 73% of participants responded to monotherapy. About one-fourth of the study subjects were commonly used dual therapy in the management of seizure. 71% of the respondents have used phenobarbital and 13.3% of patients were in the escalation phase of treatment.(24)

A Hospital Based prospective cross sectional study was done In Gonder among 261 study participants revealed GTCS was the most common type of epileptic seizure encountered in 98.5% of patients. Patients who used ASMs for 2 to 5 years duration were nearly 6 times more likely to have controlled seizure as compared to patients who took ASMs for 1 to 2 years. Patients who took ASMs for more than 5 years had 4.80 times more control seizure when compared with those patients who took ASMs for 1 to 2 years. Of those patients who used ASMs more than 5 years duration, 52.7% had controlled seizures and only 29.2% of patients who used ASMs for 1 to 2 years had controlled seizures. This shows that a longer duration of ASMs use associated with the seizure control status. (25)

Patients who use combination therapy for their epilepsy had 71.0% less likely to have controlled seizure when compared with patients who were on mono-therapy. Of those patients who were on mono-therapy, 57.1% had controlled seizure and only 24.6% of combination therapy users had controlled seizures. The lower level of adherence because of the prescription of multiple medications could contribute to the lower seizure control in patients on multiple ASMs when compared to those on monotherapy. In support of this justification adherence was shown to positively associate with seizure control status in this study. Phenobarbitone (41.0%) was found to be the most frequently prescribed drug as mono-therapy. In this study, 17.6% of patients reported that they had experienced adverse effects related to their ASMs therapy.(25)

Hundred (33.4%) patients reported that they had experienced adverse effects related to his/her AED therapy. Headache was the commonest adverse effect recorded, 21 (21.6%), followed by epigastric pain, 18 (18.5%) and confusion, 17 (17.5%). The least frequently reported adverse effects, as documented in the record card; include forgetfulness, skin rash, depression and gingival hypertrophy, 2 (2.1%) patients.(4)

Study conducted in ayder hospital revealed that More than half (59.6%) of the participants had lived with epilepsy for five or more years and 37.8% had one or more comorbidities. The most commonly identified comorbidity among epileptic patients was psychiatric disorder (20.4%). Generalized tonic-clonic seizure (GTCS), 84.4% was the most commonly diagnosed type of epilepsy. Nearly half (48.5%) of the study participants were on monotherapy of AEDs. Our finding reported that 43% of the patients complained about adverse drug events (ADEs) related to their medication.(26)

2.2.3. Parent (caregiver) knowledge about seizure and adherence to AEDs factor

A cross-sectional study which was conducted about Knowledge and Attitude toward Epilepsy of Close Family Members of People with Epilepsy in North of Iran stated that 87.1% of respondents answered that epilepsy is a brain disorder, 39 (31.5%) said epilepsy is inherited. As a whole, 62 (50%) had good knowledge about the disease.(22)

A cross-sectional observational study was conducted among 253 patients with epilepsy in Bangladesh indicates 38.8% patients were adherent to their treatment and only 33.6% of the patients had controlled seizure, forgetfulness (35%) was the most reason for non- adherence. Many factors were affecting patient's adherence such as Socio-demographic related actors (age, education, occupation), therapy related factors and cost. Adherence to AED was found to have a significant association with seizure control status.(27)

A cross-sectional study was conducted between among patients attending the Neuro Spinal Hospital in UAE to assess the prevalence of AED adherence and to identify the predictors of non-adherence .70.8% were adherent, the rest were non adherent. The most common factor affecting adherence was forgetfulness. Lower education level and having a seizure within the last 6 months were significant risk of non adherence. 51 patients (16.2% of participants) reported having medication side effects. The most common side effect was nervousness and aggressive behavior (27%).There was a significant association between adherence and history of seizures in the last 6 months. Significantly, higher adherence was found among patients who were treated by Levitracetam and clonazepam, whereas lamotrigine showed borderline adherence. Participants with lower education have 2.6 times higher risk for non adherence. Higher adherence rate among patients receiving monotherapy compared with those receiving polytherapy and adherence rate was higher among participants with lower duration of treatment. results showed that a history of seizure in the last 6 months was a significant predictor of AED adherence, the proportion of poor adherence was significantly higher among patients who reported having seizure within the last 6 months (39.6% vs. 20.5%).(32)

A cross-sectional descriptive study in two local privately owned charity hospitals in Pakistan the study enrolled 130 children. 58% were non adherent and 42% were adherent to the prescribed AEDs for different reasons. 33% were receiving monotherapy and 77% receiving polytherapy. Of the 80 patients receiving polytherapy, 37.5% patients received two AEDs and 62.5% patients received three or more AEDs for seizure control. Polytherapy had strong

association with non-adherence, as 50% of the patients in the adherent group were using monotherapy as compared with 21% monotherapy in non-adherent group. High percentage of adherence had their seizures controlled as compared with non-adherents (40 vs. 7%). No association with partial control and strong association of non-adherence were found with uncontrolled seizures. Lack of funds to purchase AEDs was the reported reason for non adherence 71% of the time.(16)

A cross sectional study was done in Jos, Nigeria to assess the prevalence and factors associated with non-adherence to AEDs among children with epilepsy .A total of 194 subjects were recruited for the study. Out of the 194 patients, 87 (44.8%) had low adherence (non-adherence) to AEDs, 34 (17.5%) had moderate adherence while 73 (37.6%) had high adherence .Factors that were significantly associated with non- adherence were low socioeconomic class, polytherapy and AED therapy for >12 months .The commonest reason for non-adherence was financial constraint followed by forgetfulness, lack of improvement and side effects of medications. non-adherence to AEDs invariably leads to uncontrolled seizures. Being on multiple drugs can lead to non-adherence in many ways. These include increased medication cost, pill burden and more adverse drug reactions (ADRs).(34)

A cross sectional study was conducted at Uganda Mulago hospital Pediatric Neurology clinic revealed that The overall adherence by self-report was 79.5%.There were more children who were non-adherent and lacked knowledge of convulsions compared to the adherent. The proportion of children who had spent less than 2 years on drugs was higher among the non-adherent. There were more non-adherent children with the primary caregiver as a mother compared to the adherent. The proportion of caregivers less than 35 years was higher for the non-adherent compared to the adherent. The commonest reason given for missing drugs was lack of drugs due to their high cost as reported by 36(48.7%) of study participants. This was followed by forgetting, reported by 22(29.7%) of study participants.(28)

A Hospital Based Retrospective cohort Study conducted in Gonder on 210 patients, the study revealed that adherence to anti epilepsy treatment were significantly associated with treatment outcome. Eight percent of the study participants had poor adherence to the treatment regimen. About six percent of the study subjects were suffering from an uncontrolled seizure. The sex of the child and adherence to treatment was significantly associated with treatment outcome. The likelihood of developing a successful treatment

outcome in patients with excellent adherence was about 4.5 times higher than those with poor adherence.(24)

A Hospital Based prospective cross sectional study was done In Gonder among 261 study participants revealed that Adherent patients were almost 4 times more likely to have controlled seizure than non-adherent patients were. the top three barriers for adherence were the child's refusal to take the medicine 17(6.5%), lack of benefit 16(6.1), and forgetfulness to take medication 15(5.7%).(25)

Institutional based cross sectional study design was conducted at Dilla University Referral Hospital 265 individuals was interviewed by using structured questionnaire 8-item Morisky Medication Adherence Scale was used to assess the prevalence of antiepileptic drug non adherence, The prevalence of Antiepileptic's drug none-adherence in this study was 38.1% and getting medication by payment , Patients who did not got health information about (their illness, duration of treatment and drug side effect), poor social support , skip dose, patients who were on treatment for 2-5 years were found to be significantly associated.(35)

2.2. Conceptual frame work

In the conceptualization of this study, different factors like socioeconomic related and other factors can affect the Seizure control status of children with epilepsy. Other factors like, medication side effects and parents'/caregivers' knowledge about epilepsy and health system related factors will have an effect on the adherence status of children/adolescents with epilepsy.

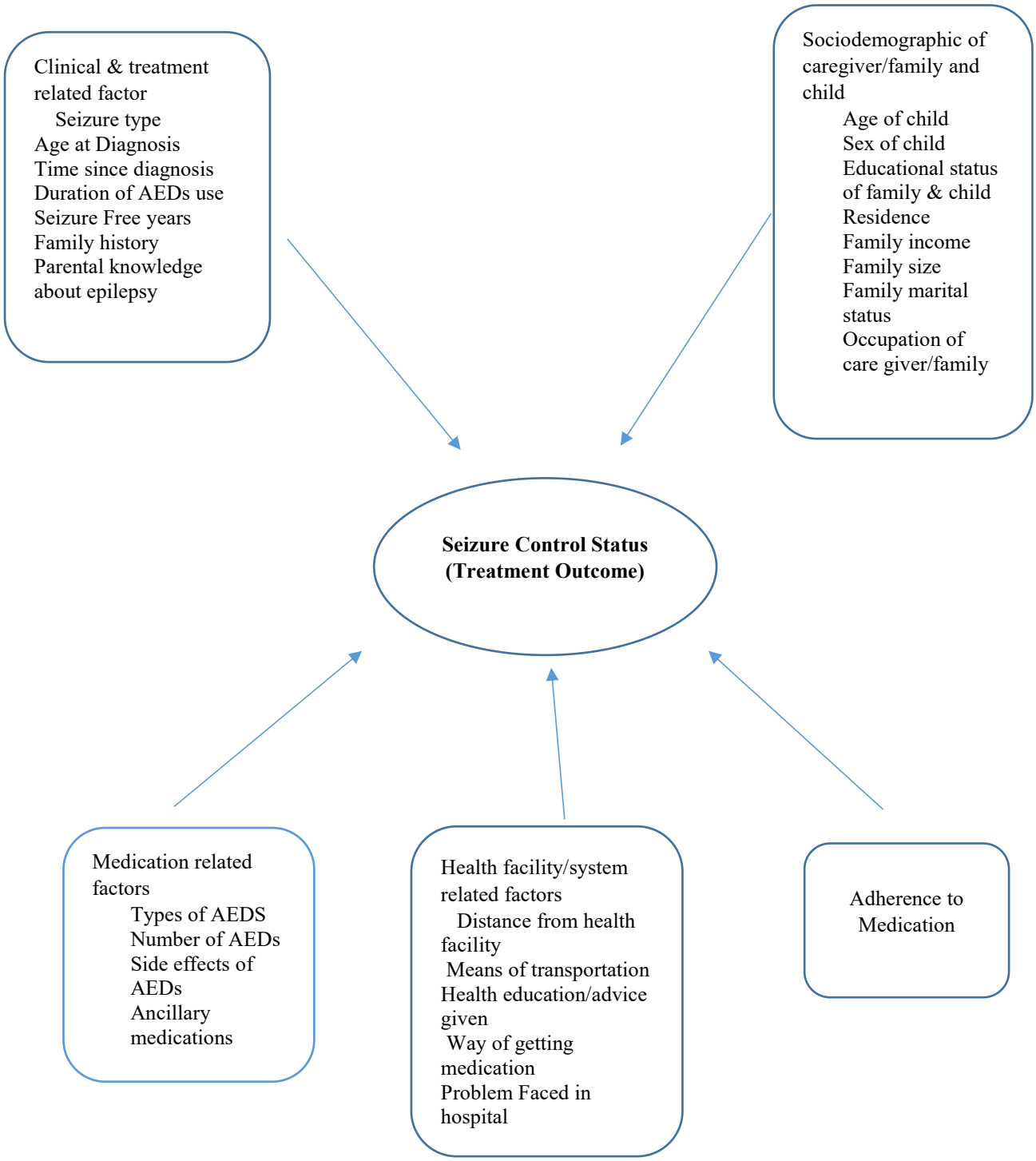

Figure 1: Conceptual framework for Seizure control status and associated factors among children with epilepsy at JMC neurology outpatient clinic, 2022

3. OBJECTIVES OF THE STUDY

3.1. General objective

To assess seizure control status and associated factors among children with epilepsy at Jimma Medical Center Pediatrics neurology outpatient clinic, Jimma, southwest Ethiopia, 2022

3.2. Specific objectives

- To determine Seizure control status of children with epilepsy at JMC pediatrics neurology clinic
- To identify factors associated with poor seizure control status of children with epilepsy at JMC pediatrics neurology clinic.
- To determine the level of adherence of children with epilepsy to AEDs at JMC pediatrics neurology clinic.

4. METHODS AND MATERIALS

4.1 Study area and Period

This study was conducted from July-08 to october 5, 2022 in Jimma Medical Center (JMC), Jimma, Oromia, South West Ethiopia. The center is one of the oldest public hospitals in the country located in Jimma town of Oromia Regional State, Ethiopia. Jimma town is located around 352 km far away from Addis Ababa.

JMC is used as a referral and specialized medical center; located in the out skirt of the Jimma town, it gives services for an estimated 20 million people from Jimma zone and the catchment population, particularly the south western Oromia and as referral centre for regions of South Western part of Ethiopia including Gambella and Southern Nations Nationalities and People (SNNP) Regional states.

With a bed size of 800, JMC provides services for approximately 15,000 inpatient, 160,000 outpatient attendants, 11,000 emergency cases and 4,500 deliveries per year coming to the hospital. It also serves as teaching hospital for several undergraduate and postgraduate programs in the field of basic sciences as well as clinical medicine for health science students of Jimma University. The hospital has many follow-up clinics for both children and adult patients (Cardiac, ART, Nephrology, Endocrinology, etc.). Pediatrics neurology clinic is one of such chronic follow-up clinics run in once weekly base.

4.2 Study design

A facility based cross- sectional study design was Conducted.

4.3 Populations

4.3.1 Source population

Children with epilepsy who have follow up at pediatrics neurology follow up clinic of JMC.

4.3.2 Study population

The study population was all children with epilepsy visiting JMC Pediatrics neurology follow up clinic and fulfilling the eligibility criteria during the study period

4.4 Inclusion and exclusion criteria

Inclusion criteria.

• Patients of age ≤ 18 years and diagnosed to have epilepsy,

• Patients who were on ASMs for at least 3 month, and

• Patients whose caregivers were willing to give informed consent.

Exclusion criteria.

•Children with epilepsy who are taking their AEDs for < 3 month**.**

•Those parents having hearing problems who are unable to respond/speak.

•Those who refuse to participate in the study will be excluded.

4.5 Sample size determination and sampling techniques

The required sample size for this study is determined by using single population proportion estimation formula and considering the following assumptions ; Study done in Gonder revealed that 77% of Participants have Controlled Seizures with 95% of confidence interval and 5% of margin of error was taken. Accordingly, the calculated sample size is 272

$$No = \frac{[(Z_{1-\alpha/2})^2 pq]}{d^2}$$ Where

- No = Initial/Desired sample size.
- d = Precision of measurement (acceptable marginal error) = 0.05
- $(Z_{1-\alpha/2})$= the critical value at 95% level of significance (1.96)
- P = Prevalence of Good Seizure Control in Gonder was 77 %.(24)
- q = 100-p =23%.
- NR = Non response Rate

Hence; $No = \frac{(1.96)^2 0.77 (0.23)}{(0.05)^2}$ $No = \underline{\underline{272}}$

Since the source population is < 10,000; final sample size is determined by applying the finite population correction formula and adding 5% non-response rate. Accordingly, the calculated final sample size became 143 children/adolescents with epilepsy.

$$Nf = \frac{No}{1+ \{(No-1)/N\}}$$ Where

- No = Initial sample size (272)
- Nf = final sample size
- N = Children with epilepsy who are registered and on follow up at pediatric neurology follow up clinic of JMC, which is estimated to be 300.

- NR = Non response rate

Hence, Nf $= \dfrac{272}{1+ \{(272-1)/300\}} = 143$

By taking 5% NR; the final sample size becomes **150** Children with epilepsy.

4.5.1 Sampling techniques and Procedure

According to the three consecutive months Health Management Information System (HMIS) report/activity report of JMC; the average monthly visit load at pediatrics neurology follow up clinic is around 300 children in the past 3 months, so by using this data and calculated sample size which is 150 children with epilepsy; all children with epilepsy who fulfill the inclusion criteria and consented to participate in the study was interviewed by Consecutive sampling technique.

4.6 Study variables

4.6.1 Dependent variables

- Seizure Control Status(Treatment Outcome)

4.6.2 Independent variables

A. **Child's and Parent's Socio-demographic and economic related factors:** Sex, Age, Place of residence, Family history of seizure, educational status, primary care giver(parents),Age, Marital status, Educational status, Occupation status, , Family size, Family's Monthly income.
B. **Clinical and treatment profiles** Age at Diagnosis of Epilepsy(Years), type of seizure, ,presence of other medical illness/Comorbid illness/, Number of AEDs prescribed, Type of AED used, duration on treatment, Seizure free years, Reported side effects, Diagnosis other than epilepsy, Concomitantly used drugs.
C. **Health facility/service related factors:** Distance from home to the hospital, Means of transportation to the hospital, way of getting medication (Cash/payment, CBHI, Free), getting health information and advice about epilepsy & AEDs during collection, Problems faced in the hospital during health care delivery like shortage of AEDs, poor communication & poor governance issues that hindered them from taking the AEDs.
D. **Parental Knowledge about Epilepsy:** Knowledge about epilepsy, its causes, the sign and symptoms, consequences, prevention and treatment of epilepsy.

E. Adherence to AED Medication

- Non-adherence:- Patients scores < 6 of 8 item MMAS-8.
- Adherence: - Patients scores 6-8 of 8 item MMAS-8.

4.7 Data collection tools and procedures

Data collectors through an interviewer-administered pre-tested questionnaires and chart revision collected data. Data was collected by two registered BSC Nurse Professionals and supervised by General Practionner (GP) who has previous experience in data collection by using Pre- tested interview administered Structured questionnaire which are developed by compiling a number of questions adapted from similar study materials and review of relevant literatures that could address the objective of the study.

The eligible participants was approached and interviewed at their exit from neurologic follow up clinic. The diagnosis of each child/adolescent including comorbidities, types of anti-epileptic drug(s) he/she is taking and some of the AED side effects was retrieved from charts at time of interview.

4.8 Data management and quality control

The questionnaire is prepared in the English language and then translated to the local languages; Amharic & Afaan Oromoo by language expert (who is fluent in English, Amharic and Afaan Oromoo languages) and then re translated back to English by experts who have similar experiences for checking consistency.

Two registered BSC Nurse Professionals and one General practitioner was recruited as data collectors and supervisor respectively. In order to keep uniformity of the data collection process; data collectors and supervisors was trained and adequately oriented for two days on the objective of the study, method of data collection, interview technique and on context of data collection tool.

Data was checked for completeness, accuracy and consistency by principal investigator on daily base. Double entry of data for checking errors was performed to assure quality of data before analysis. In order to evaluate the clarity of the questionnaire and the reaction of the respondent, pilot test on 10 children with epilepsy (5% of the total sample) was done 1 week before the beginning of the actual data collection in JMC and excluded from the study. After the pretest, the findings and observations obtained was used to correct unclear idea, modify the questionnaire and the data collection process accordingly. The principal investigator closely supervises the entire data collection processes on a daily basis.

4.9 Data processing & analysis

Data was coded and entered into Epi-data manager version 4.6 Software and exported to the Statistical Package for the Social Sciences (SPSS) version 25 for statistical analysis. Descriptive statistics (frequencies, percentages,) was calculated for demographic and economic, self-care behavior status of the participants. Results was reported as percentages (frequency), cross tabulation for categorical variables. Binary logistic regression analysis was used to identify factors influencing Seizure Control Status. The crude odd ratio was done and All variables that have p-value ≤ 0.25 was entered into multivariable logistic regression model to assess the association between dependent and independent variables. The final model was fitted using enter methods. P-values of ≤ 0.05 was considered for statistical significance. Findings was presented by using tables, graph, charts and narration.

4.10 Ethical consideration

Ethical clearance was obtained from Institutional Review Board (IRB) of Institute of Health of Jimma University. The study participants was informed about the objective's/aims of the study and specific details concerning participation in the study and written consent was obtained from each eligible study participants. Verbal informed consent/assent was obtained from parents/caregivers after clearly informing them the purpose and procedure of the study. Confidentiality of information collected from each study participant was maintained at all levels. All steps in data collection and compilation was conducted and supervised by the principal investigator. Strict confidentiality was assured through anonymous recording and coding of questionnaires and placed in a safe place. Participation in this study is completely voluntary. If the family or guardians choose to participation of his/her children in this study, they have full right to withdraw the consent and leave the study at any time without any prejudice or effect on the clinical management of their children.

4.11 Operational definitions and Variable measurements

- Epilepsy-Two or more unprovoked seizure occur in a time frame of > 24 hour
- Seizure is a transient occurrence of signs and/or symptoms resulting from abnormal excessive or synchronous neuronal activity in the brain

SEIZURE CONTROL STATUS

- **Uncontrolled Seizure**-More than one seizure a month and/or less than 3 consecutive months of seizure freedom.
- **Controlled Seizure**- ≤ 1 Seizure a month and/or more than 3 consecutive months of seizure freedom.

Medication Adherence: - Refers to the extent to which a patient's behavior corresponds with the recommendations of a health professional with respect to timing, dosage, and frequency of medication persistence as the duration of time from initiation to discontinuation of therapy.(36)

Adherence to AEDs: Measured by eight-item Morisky Medication Adherence Scale (MMAS)(37)that is widely used to measure self-reported adherence adopted from previous study. . Total score ranges from 0 to 8. The MMAS-8 has widespread acceptance in clinical settings and has been found to be internationally consistent and validated in Nigeria(34) and Ethiopia.(35)

- Non-adherence:- Patients scores < 6 of 8 item MMAS.
- Adherence: - Patients scores 6- 8 of 8 item MMAS. (26)

Knowledge about epilepsy: Caregiver knowledge of epilepsy was computed by summing up 13 multiple-choice items having yes, no and I do not know A correct answer for each item was scored as "1" and incorrect/not sure answer will be scored as "0." In this study, participants who score equal to or above the mean was classified as having good knowledge of Epilepsy and those who score below the mean was considered as having poor knowledge.

4.12 Dissemination and Utilization of Results

The Finding of the study would be presented to the department of pediatrics and child health, Jimma University. The final result from the study would be submitted to the Research and Postgraduate Office, Jimma University in a form of written report. Subsequently, the study result would be published on peer reviewed journal.

5.RESULT

5.1. Socio-demographic and economic characteristics of participant and participant caregiver

One hundred fifty epileptic patients were interviewed and their medical record data was revised. The demographic data revealed that the number of male and female patients were 87(58.7%) and 63(42.0%) respectively, among these 5.1-10 and 10.1-15 years of age groups are more prevalent that accounted 52(34.7%) and 47 (31.3%) respectively, rural dwellers (54.7%).86% of patients had no family history of epilepsy. 48(32.0%), of the study participants were pre-school at the time of data collection. Near to half of caregivers of children having epilepsy were father 70 (46.7%) and mother 62 (41.3%).Most caregiver's age was between 18-35 years accounted 59(39.3%). About 119(79.3%) of parents/caregivers were married and 51(34.0%) of caregivers attended Primary school, 61 (40.7%) of parents/caregivers were farmers, 53 (35.3%) of their monthly income was 1,001-2000 ETB and 78 (52.0%) had family size of > 5. (Table 1).

Table 1 : Socio-demographic characteristics pediatric epileptic patients and parents (caregiver)

Variable	**Frequency**	**Percentage (%)**
Patient gender		
Male	87	58.0
Female	63	42.0
Age		
0 – 5	37	2 4.7
5.1-10	52	34.7
10.1-15	47	31.3
51.1-18	14	9.3
Residency		
Urban	68	45.3
Rural	82	54.7
Educational status of patient		
Pre-school	48	32.0
Elementary	39	26.0
Junior school	22	14.7
High school	6	4.0
not attendee school	35	23.3
Family history of seizure		

Yes	21	14.0
No	129	86.0
Primary care giver		
Father	70	46.7
Mother	62	41.3
Brother	4	2.7
Sister	9	6.0
Grandparents	2	1.3
uncle\aunt	3	2.0
Care giver age		
18 – 35	59	39.3
35 – 45	50	33.3
≥45	41	27.3
Marital status of care giver		
Single	12	8.0
Married	119	79.3
Separated	1	0.7
Divorced	11	7.3
Widowed	7	4.7
Educational status of care giver		
Cannot read & write	44	29.3
Can read & write	18	12.0
primary school	51	34.0
Secondary school	27	18.0
College/university	10	6.7
Occupational status of care giver		
House wife	34	22.7
Farmer	61	40.7
Marchant	14	9.3
Gov't employee	14	9.3
Daily laborer	5	3.3
Student	10	6.7
Pensioner	2	1.3
private job	10	6.7
Annual average monthly income of the family		
<1000 ETB*	27	18.0
1001 - 2000 ETB	53	35.3
2001 - 3000 ETB	32	21.3
>3000	38	25.3

Family size		
≤5	72	48.0
> 5	78	52.0

*ETB-Ethiopian Birr

5.2 Child health related factors (clinical and treatment profiles)

Generalized seizure was the most common 139 (92.7%) type of seizure. Mono-therapy was commonly used in the management of seizure which accounted 98(65.3%), followed by poly-therapy 52(34.7%). 107(71.3%) of study participant were diagnosed for more than 2 year and 83(55.3%) of study participants were on treatment for more than two years.126 (84%) of them were not having EEG. Mostly prescribed AED was phenytoin only ,89(59.3%). 57(38.0%) of the children were stopped/missed their AED doses since starting of therapy, among main reasons of stopped/missed AEDs were run out of drug25(43.1%) and forgetfulness 25(43.1%). About 46(30.7%) of the study participants reported some adverse effects with AEDs, 19(41.3%) of them were reporting deceased concentration. With regard to co-morbidity, 33(22.0%) of the study participants have additional diagnosis, from which 12(36.3%) accounted for cerebral palsy. (Table 2)

Table 2 : Clinical characteristics of pediatric epileptic patients on follow up at JUMC

Variables	Frequency	Percentage (%)
Age at seizure onset(Yr.)		
<2	34	22.7
2-5	62	41.3
>5	54	36.0
Type of seizure		
Focal seizure	8	5.3
Generalized seizure	139	92.7
Unclassified	2	1.3
Absence seizure	1	0.7
Mode of therapy		
Mono-therapy	98	65.3
Poly- therapy	52	34.7
Type of antiepileptic drug		
PHT	89	59.3
PHB	8	5.3
VPA	1	0.7
PHB + PHT	43	28.7
PHT + VPA	7	4.7
PHB + carbamazepine	1	0.7

PHB + PHT + VPA	1	0.7
Duration since seizure onset (Yr.)		
≤2	43	28.7
> 2	107	71.3
Duration of AEDs used(Yr.)		
<1	17	11.3
1-2	50	33.3
>2	83	55.3
Does EEG done		
Yes	24	16.0
No	126	84.0
Miss or stop AEDs since starting therapy		
Yes	57	38.0
No	93	62.0
Reason to miss or stop AEDs (n=57)		
Run out of drug/Did not get adequate tablets from the hospital	25	43.8
Forgetfulness	25	43.8
Feeling better	3	5.2
I did not know its importance well	2	3.5
Financial constraints	1	1.7
Fear of side effects	1	1.7
When was the last Seizure		
<3 month	50	33.3
3-12 month	57	38.0
1-2 year	34	22.7
>2 years	9	6.0
Does the child develop Adverse effects		
Yes	46	30.7
No	54	36.0
I do not know	50	33.3
Type of adverse effects(n=46)		
Decreased concentration	19	41.3
Behavioral abnormality	20	43.4
Gum hyperplasia/swelling	13	28.2
Drowsiness	17	36.9
Skin rash	2	4.3
Constipation	2	4.3
Fatigue	1	2.1
Additional diagnosis		
Yes	33	22.0
No	117	78.0
Type of co-morbid illness(n=33)		
Cerebral palsy	12	36.4
ADHD	2	6.0

Type 1 DM	4	12.1
ASD	4	12.1
Developmental delay	4	12.1
Hydrocephalus	2	6.0
HIV	1	3.0
MDD	2	6.0
Down syndrome	1	6.0
Asthma	1	3.0

PHT, Phenytoin; PHB, Phenobarbitone; VPA, Valproic acid

5.3 Access to antiepileptic drugs (service related factor)

Among the study participants 67(44.7%) have to travel more than 20 Km to get health care service 121(80.7%) of them were using public transport. 80% of study participants received counseling about epilepsy & AEDs during follow up visit. 121(97.5%) of them were counseled about importance of AEDs tablet, 79(52.7%) of them get AEDs through CBHI and 113(75.3) of the study participant faced problems in hospital during follow up time; 111(98.2%) of the reported problems were shortage of AEDs. (**Table 3**)

Table 3 : Access to antiepileptic drugs (service related factor) among study participant

Variables	**Frequency**	**Percentage (%)**
Distance from hospital		
<10 km	43	28.7
10-20 km	40	26.7
>20 km	67	44.7
Means of transportation		
On foot	11	7.3
public transport	121	80.7
on foot then transport	18	12.0
Advice get from hospital		
Yes	124	82.7
No	26	17.3
What type of advice do you get(n=124)		
Importance of AEDs tablets	122	98.3
method of use	121	97.5
side effects	110	88.7
not to miss doses & appointment	111	89.5
Source of AEDs		
Cash/payment	59	39.3
CBHI	79	52.7
Free of charge	12	8.0

Do you face problem in hospital		
Yes	113	75.3
No	37	24.2
What are the problems(n=113)		
shortage of AEDs	111	98.2
long waiting time	16	14.15
Poor communication to health care staff	4	3.57

5.4 Parents (caregiver) knowledge about epilepsy and medication adherence status to AEDs of study participant.

Among the study participants 110(73.3%) of them were found to have good knowledge and 99(66.0%) of them were having good adherence to AEDs.

Table 4 : Parents (caregiver) knowledge about epilepsy and medication adherence status of

Variables	**Frequency**	**Percentage (%)**
Care giver knowledge about seizure		
good knowledge	110	73.3
poor knowledge	40	26.7
Medication adherence to AEDS		
Adherent	99	66.0
None adherent	51	34.0

AEDs

5.5 Seizure control status among study participant

Among the study participants, more than half 101(67.3%) of patients had controlled seizure and 49(32.7%) had uncontrolled seizure.

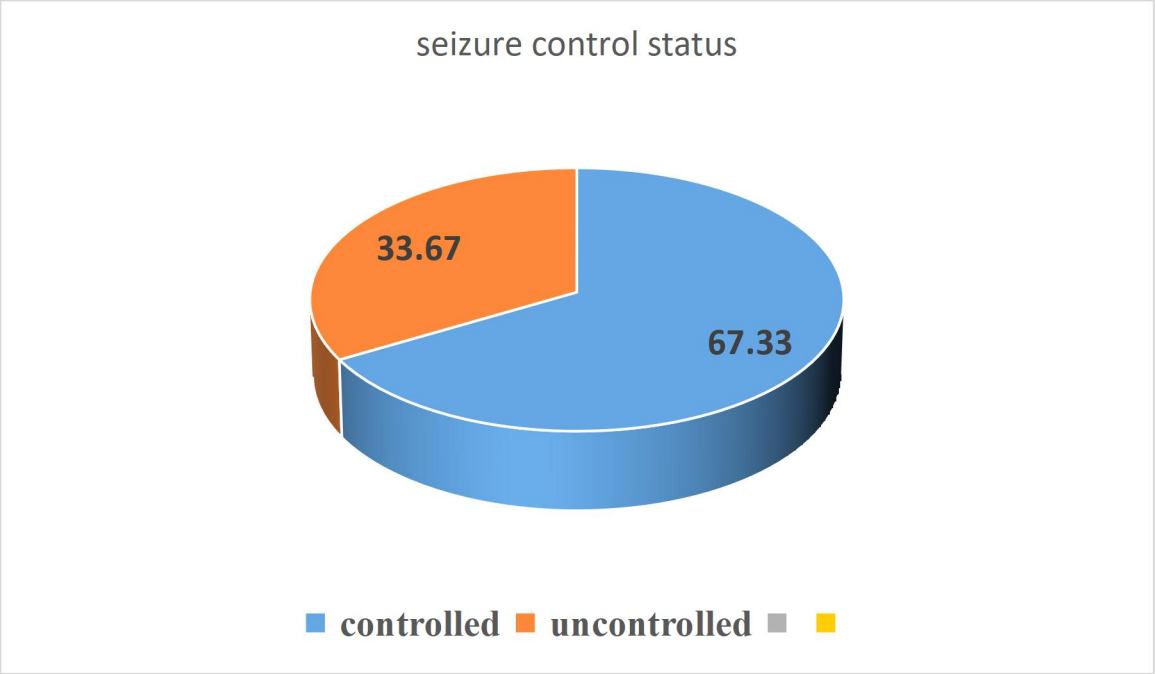

Figure 2 : seizure control status among participant

5.6 Candidate variables factor associated to Seizure control status

Bivariate logistic regression analysis was made to identify candidate variables for multivariate analysis factors socio-demographic, clinical and treatment related characteristics. Accordingly, Total family size(<=5), Duration of AEDs use for more than 2 years, do not miss or stop AEDs dose, urban dweller, Good caregiver knowledge about seizure, Adherent to epileptic medication and mode of therapy (monotherapy) were candidate variables for the outcome variable (Table 5).

Table 5 : Bivariate analyses for factors associated with seizure control status among study participants

Variable	Seizure control status		COR (95%)	p value
	uncontrolled	Controlled		
Total family size				
≤ 5	17	55	2.25(1.11,4.5)	0.024*
>5	32	46	1	1
Duration of AEDs used(years)				
<1	6	11	1	1
1-2	29	21	0.39(0.126,1.1.23)	0.11
>2	14	69	2.688(1.65,18.17)	0.009*
Stopped or miss AED s dose				
Yes	35	22	1	1
No	14	79	8.9(4.11,19.6)	0.000*
Place of residence				
Urban	11	57	4.5(2.05,9.74)	0.000*
Rural	38	44	1	1
Care giver knowledge about epilepsy				
Good knowledge	22	88	8.3(3.69,18.67)	0.001*
Poor knowledge	27	13	1	1
Medication adherence				
Adherent	19	80	6.01(2.84,12.72	0.000*
Non-adherent	30	21	1	1
Mode of therapy				
Mono-therapy	21	77	4.3(2.06,8.86)	0.001*
poly therapy	28	24	1	1

5.7 Predictor variables of seizure control status

Multivariable logistic regression analysis was used to calculate odds ratios and corresponding 95% confidence intervals for the predictors of seizure control status. Seven variables were selected by bivariate analysis and then analyzed with multivariate logistic regression those children use AEDs for more than two year [AOR= 8.9 (95% CI= 1.55,50.9)], those children who never stopped/missed AEDs doses [AOR= 5.3 (95% CI= 1.75, 15.9)], those children live urban area [AOR= 5.4(95% CI =1.35,14.2)], children of those caregivers

who had good knowledge [AOR= 8.5 (95% CI =2.53,28.4)] ,children adherence to their medication[AOR= 5.3 (95% CI =1.76, 18.0)]and those children on monotherapy[AOR= 3.5 (95% CI =1.12, 11.5)] were significantly associated with seizure control (Table 6).

Table 6: Multiple logistic regression model predicting factors associated with seizure control status among study participants

Variable	Seizure control status		AOR (95%)	P-value
	uncontrolled	Controlled		
Duration of AEDs used(years)				
<1	6	11	1	1
1-2	29	21	0.757(0.15,3.75)	0.764
>2	14	69	8.9(1.55,50.9)	0.010*
Stopped or miss AED s dose				
Yes	35	22	1	1
No	14	79	5.3(1.75,15.9)	0.003*
Place of residence				
Urban	11	57	5.4(1.75,17.2)	0.004*
Rural	38	44	1	1
Care giver knowledge about epilepsy				
Good knowledge	22	88	8.5(2.53,28.4)	0.001*
Poor knowledge	27	13	1	1
Medication adherence				
Adherent	19	80	5.3(1.76,18.0)	0.003*
Non-adherent	30	21	1	
Mode of therapy				
Mono-therapy	21	77	3.5(1.12,11.5)	0.031*
poly therapy	28	24	1	1

6.DISCUSSIONS

The total seizure control rate showed that more than half of the respondents (67.3%) had seizures controlled. This is greater than studies done in Norway (59.0%).(33) and Gonder (49%) (25).This may be justified by due to the difference in definition of a controlled seizure in the study conducted in Norway and Gonder (≥1 year seizure free considered as controlled seizure). This finding was consistent with a study in Nigeria (64%).(38) Possibly due to nearly comparable socio-economic status. On the other hand our finding is lower than a study done in Israel (72%),(31) and Gonder.(24), the possible justification for the disparities between these studies might be difference Sociodemographic status & lower study population in Israel and relatively large sample size in Gonder(n = 210).

Multivariate binary logistic regression analysis revealed factors associated with seizure control status Patients who used AEDs for >2 years duration were 8.9 times more likely to have controlled seizure as compared to patients who took AEDs for 1 to 2 and <1 years. Of those patients, AEDs used more than two years 68.3% had control seizure. This study higher than study done in Gonder Patients who used AEDs for 2 to 5 years duration were nearly 6 times more likely to have controlled seizure as compared to patients who took AEDs for 1 to 2 years This indicates the relation between the usage of AEDs for a longer period of time and seizure control(25).

Children/adolescents who never missed/stopped AEDs 5.3 times more likely to have controlled seizure as compare miss or stop AEDs.

Patients from urban area were 5.4 times more likely to have controlled seizure compared to patients from rural residence. Of those patients who live in urban areas, 56.4% of them had controlled seizure this finding line with study done in Gonder.(25), this could be related to urban inhabitants having a greater understanding of the illness, which makes it easier for them to talk to their doctors about it and the treatments they take. This finding line with study done in Republic of Guinea the majority of rural dwellers could be prone to seek out spiritual and religious healing before seeing a medical provider and lack of awareness about the illness.(29)

Adherent patients were almost 5.3 times more likely to have controlled seizure than non-adherent patients this finding higher than the study done in Bangladesh which shows 38.8% patients were adherent to their treatment and only 33.6% of the patients had controlled seizure, Adherence to AED was found to have a significant association with seizure control

status.(27) And supported by study done Pakistan Polytherapy had strong association with non adherence, as 50% of the patients in the adherent group were using monotherapy as compared with 21% monotherapy in non-adherent group. High percentage of adherence had their seizures controlled as compared with non-adherents.(16)

The top three barriers for adherence were the child's refusal to take the medicine 17(6.5%), lack of benefit 16(6.1), and forgetfulness to take medication 15(5.7%).(25)The commonest reason given for missing drugs was run out of drug from hospital 23(46.9%) and forgetfulness 18(36.7%) This finding is in line with the study conducted in Uganda.(28)

Those parents/caregivers whose knowledge about epilepsy was good 8.5 times more likely to have controlled seizure compared to caregiver who have poor knowledge about epilepsy. Of those caregivers who have good knowledge, 110 (73.3%), this result higher than study conducted in North of Iran, 62 (50%) had good knowledge about the disease and the potential contributions of similar cultural, economic, and sociodemographic characteristics. Our findings showed a significant association with seizure control status.(22)

Those patient on monotherapy 3.5 times more likely to have control seizure than Patients who use combination therapy for their epilepsy .Of those patients who were on mono-therapy, 76.2% had controlled seizure and only 23.7% of combination therapy users had controlled seizures this finding similar to study done UAE, higher adherence rate among patients receiving monotherapy compared with those receiving polytherapy and adherence rate was higher among participants with lower duration of treatment.(32)and supported by study done Nigeria.(34) Only 27.9% of those on polytherapy achieved remission compared to 85.8% of those on monotherapy. The goal of AED therapy is to achieve full seizure control with one drug at the lowest possible dose. This due to multiple medications can cause non-adherence in a variety of ways. These include rising medicine costs, pill load, and an increase in adverse drug reactions (ADRs).(34)

In this study, phenytoin (59.3%) was found to be the most frequently prescribed drug as mono-therapy. The finding of the present study is different from studies done in different places, where valproic(30.4%) were the most commonly prescribed AEDs in Bangladesh(27) ,carbamazepine 73.5% in Uganda (28) and phenobarbitone 41.0% in Ethiopia (25). This could be due to long-term use history, safety profile, availability, and affordability. Differences in country specific treatment guidelines could be the reason for differences in prescribing practices across different countries.(25) Phenytoin with

phenobarbitone was the most frequent 2-drug combination in our study. Even though combination of phenytoin and phenobarbitone is important in maximum control of seizure occurrence, the risk of combined toxicity is high.(4)

In present study, 27.3% of patients reported, that they had experienced adverse effects related to their AEDs therapy and decreased concentration was the majority patient reported adverse effect. This result is lower than the finding from a study carried out in Ethiopia which the adverse effects of AEDs were reported by (33.4%) of participants. Headache was the commonest adverse effect recorded.(4)

6.1 Strength

Being facility-based has a benefit over a community-based house-to-house survey in that it better represents the study district on the results variable. This was due to the fact that it included the respondents' most recent service usage. Recall bias was thus significantly reduced. It was also helpful the data collectors (Registered BSC clinical Nurses) and supervisors (Medical Doctors) to have knowledge and experience in data collection because it can be challenging for non-health professionals to collect clinical and treatment profiles related to children's health from respondents.

6.2 Limitation

The results of this study have some restrictions. Parent reports provided some information about children who had seizures, but these reports were not verified by other sources and could have been misclassified or subject to response bias. It is difficult to draw a cause and effect relationship because a cross sectional study design was used. Lack of imaging modalities like EEG and other neuro-imaging to reach to a specific type of seizure and etiology and we were only able to investigate short-term seizure control status.

7. CONCLUSION AND RECOMMENDATION

7.1 Conclusion

This study indicated the overall seizure control status of children with epilepsy was found to be high. In addition, seizure control status influenced by use of AEDs for more than two years, never stopping or missing AEDs dosage, urban residence, good caregiver knowledge, patient adherence to medication, and patients on monotherapy treatment. Patients from rural areas, non-adherent to their AEDs, and those who had been using AEDs for less than two years were found to have a substantial correlation with uncontrolled seizures and required specialized care to keep those seizures under control.

7.2. Recommendation

- It is recommended to Jimma Medical Center to avail medications; the majority of respondent complain about shortage of medication; most rural residents need medication available freely in our study period we observed small amount of respondent could get medication freely.
- The caregivers have crucial roles to play in monitoring and addressing the possible barriers for non-adherence and adverse drug events. Caregivers should be continuously counseled on proper treatment adherence to improve seizure control status.
- Avail imaging modalities like EEG and other neuro-imaging to reach to a specific type of seizure to get specific treatment.

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9.LIST OF ANNEXES

9.1 GUCA RAGAAFI EYYAMUMMAA GAAFACHUU

GUCA RAGAA

Akkam jirtu, akkam bultan/oltan. Ani maqaan koo _____jedhama. Har'aa kanan asitti argame qorannoo dr. Anwar Hussain (kan Yuunivasiitii jimmaa giddu-gala, kutaa dhukkuba ijjoollee kan deddebi'anii yaaluu, '**Haala to'annoo gaggabdoo da'immanii fi sababoota walitti dhufeenya qaban' irratti dha.**

Ani, isinis ta'ee, namoonni biroo qorannoo kana irratti fedha(fedhi) keessaniin akka hirmaattanidha. Kan isinirraa eeggamu, wantoota isin gaafannuuf deebii akka nuuf kennitanidha. Kunis yeroo daqiiqaa 25 ol kan hin caalle kan fudhatudha. Ragaa isinirraa fudhannu kan sassabnu koodii fayyadamna. Enyuummaa keessanis ta'ee kan mucaa keessanii, akkasumas iddoon jireenya keessanii guca kana irratti hin guutaamu. Eyyamamaa yoo ta'uu baattanis tajaajiila mucaa keessaniif kennamu irratti hooma rakkoo hin uumu. Hirmaannaia keessanif isin galateeffanna.

GUCA EYYAMUMMAA

Qorannoo irratti hirmaanchuuf eyyamamaadhaa?

Eeyyeen eyyamamaadha ☐ Lakkii hin barbaadu ☐

Nama ragaa sassaabuun kan mallatteffamu, guca armaan olii kana dubbisee, hirmaataa hubachiisuu koo mallattoo kootiin nan mirkaneessa.

Koodii gaaffichaa: _____

Guyyaa : _____

Maqaa fi mallattoo sassaabaa: _____

Maqaa fi mallattoo to'ataa:

_____

9.2 Gaaffii

koodii qorannoo _____ Lakk.kardii _____

Kutaa I

Gaaffilee Daa'imman irratti xiyyefattan(hawwasummaa,dhukkuba fi yaala isaa)

Lakk.	Gaaffilee	Ramaddii koodii	Koodi	
101	Umurii	Waggaa_____		
102	Saala	1.Dhiira 2.Dhalaa		
103	Sadarkaa barnoota	1.olmaa daa'imaa 2.kutaa 1-4 3.kutaa 5-8 4.kutaa 9-12		
104	Gosa dhibee gaggabdoo	1.gaggabdoo murta'aa(focal) 2.gaggabdoo waliigalaa(generalized) 3.kan hin qoodamiin 4.gaggabdoo gosa garaa garaa	Galmee sakkata'i	
105	Qorannoo EEG qabaa?	1.eyyee_____ 2.miti	Galmee sakkata'i	
106	Yeroo hangamiif dhukkubsatte?	Baatidhan _____		
107	Yeroo hangamiif dawaa fudhatte?	Baatidhan_____		
108	Maati keessa namni gaggabdoo qabu jiraa?	1.eyyee 2.miti 3.hin beeku sirritti		
109	Daa'imni qoricha adda kutee ykn irra dabarsee bekaa?	1.eyyee 2.miti	Yoo miti ta'e 110 irra tari	
110	Yoo debiin gaaffi 109 eye ta'e;sababni qoricha dhabuu ykn yeroo isaa irra dabarsuu	1.dagachuudhan 2.faayidaa isaa akka gaaritti		

	maalidha?	waanan hin beeknef 3.rakkoo dawaan fidu waanan sodaadhef 4.waan naat fooya'eef 5.qoricha waanan fixeef ykn qoricha ga'aa waanan dhabeef 6.daa'imni dawaa fudhachuu waan dideef 7.hanqina maallaqaa 8.kan biraa_____		

111.	Daa'imni dhukkuba biraa nii qabaa? Yoo qabaate dhibee isaa barreessi	1.eyyee(_____) 2.miti	Galmee ilaalli
112.	Daa'imni qoricha biroo dawaa gaggabdoo waliin nii fudhataa?	1.eyyee 2.miti	
113.	Qoricha aadaa dhibee gaggabdoo kanaf fudhatee tureraa?	1.eyyee 2.miti	

Kutaa II.gaaffilee hawaassummaa fi galiiwwan kunuunsitootaa irratti xiyyeffattan

Lakk.	Gaaffilee	Ramaddii koodii	koodii
201	Kunuunsitootaa	1.Abbaa 2.haadha 3.Akkayoo/Akkakayuu 4.fira 5.eessuma/adaadaa 6.kan biro_____	
202.	Umurii	Waggaadhan_____	

203.	Iddoo jireenyaa?	1.magalaa 2.badiyyaa	
204.	Sadarkaa gaa'ela kunuunsitoota	1.qophaa 2.kan gaa'ela qaban 3.kan wal hiikan	
205.	Sadarkaa barnootaa kunuunsitootaa	1.barressuu fi dubbisuu kan hin dandeenye 2.barressuu fi dubbisuu kan danda'an 3.barnoota sadarkaa 1ffaa 4.barnoota sadarkaa 2ffaa 5.yuniversitii/kollejjii	
207	Hojjii kunuunsitootaa	1.haadha warraa 2. qonnaan bulaaa 3.daldalaa 4.hojjetaa mottumaa 5.hojjii guya guyaa 6. kan biroo_____	
207	Baay'inni maatii meeqa?	_____	
208	Galiin ji'aan meeqa ta'a?	_____birr.	

Kutaa III ;Gaaffile dhaabbata fayyaa kennan irratti xiyyefattan

Lakk.	Gaaffilee	Ramaddii koodii	Koodii
301	Faggenya mana fi hospitaala gidduu	_____km(s)	
302	Geejjiba yommuu hospitaala deeman fayadamaan	1.miillan 2.geejjiba hawaasan	
303	mana fi hospitallii gidduun yeroo hangam fudhata?(sa'attin)	Sa'attii_____	
304	Yommuu hordoffiitti barnootni hubannoo uumu dhibee gaggabdoo fi	1.eyyee 2.miti	Yoo miti ta'e 305 irra

	qorichaa isaa kennameraa?		darbi
305	Yoo gaaffiin 304 eyyee ta'e;qoricha gaggabdoo ilaallichisee gorsa maaltu kenname?	1.faayidaa qoricha gaggabdoo 2.akkataa itti fayyadama isaa 3.midhaa isaa 4.yeroo fayyadama qorichaa 5.kannen biro_____	
306	Qoricha akkamitti argatta?	1.qarshiidhan 2.inshuransii hawaasan 3.tolaan	
307	Yeroo yaalamaa turtetti rakkoon hospitaala keessatti sii mudatteraa?	1.eyyee 2.miti	Yoo miti ta'e 308 irra darbi
308.	Yoo 307 eyyee ta'e,rakkoo akkamiifattu sii mudatte(deebii baay'ee ta'uu danda'a)	1.hanqina qoricha gaggabdoo 2.yeroo n turtii dheerachuu 3.hanqina sab-qunnamtii fi bulchinsa gaarii(qoricha argachuu irratti danqaa kan uumu) 4.kan biro_____	

Kutaa IV ;dhibee gaggabdoo irraatti hubannoo maatii

Lakk.	Gaaffilee	Ramaddii koodii	Koodii
401.	Gaggabdoo dhaggessee bektaa?	1.eyyee 2.miti	
402.	Ijji hamaa gaggabdoof nama saaxila jettee amantaa?	1.eyyee 2.miti Hin beeku	
403.	Rukkunnaan mataa gaggabdoof nama saaxila jettee amantaa?	1.eyyee 2.miti	

		3.Hin beeku	
404.	Gaggabdoon dhibee daddarbaa miti jettee amantaa	1.eyyee 2.miti 3.hin beeku	
405.	Ijjolleen dhibee gaggabdoo qaban yeroo dhibeen kun itti ka'u gargaarsa nii barbaaduu(lafaa ol qabuu,naannoo isaani qulleessuu,morma isaanitti jabaate kan jiru laafisu)?	1.eyyee 2.miti 3.hin beeku	
406	Gaggabdoon yaala qabaa?	1.eyyee 2.miti 3.hin beeku	
407	Yaalla arifachisaa gaggabdoof godhamu beekta?	1.eyyee 2.miti 3.hin beeku	
408	Kibiritii qabsiisuun funyaanitti qabuun gaggabdoo nii dhabaa?	1.eyyee 2.miti 3.hin beeku	
409	Yeroo gaggabdoon itti ka'utti daa'ima qabuun miidhaa qabaa?	1.eyyee 2.miti 3.hin beeku	
410	Gaggabdoon miidhaa lubbuu nii geessisaa?	1.eyyee 2.miti 3.hin beeku	
411	Miidhaan qorichoota gaggabdoo yaaddessoodhaa?	1.eyyee 2.miti	
412	Dhibeen gaggabdoo jireenya fulduraaf yaaddessadhaa?	1.eyyee 2.miti	
413	Qorichootni gaggabdoo iddoo ijjolleen hin geenye ta'uu qaba jettee	1.eyyee 2.miti	

	amantaa?	3.hin beeku	

Kutaa v ;itti fayyadama qorichaa

Lakk .	Gaaffilee	Ramaddii koodii		Koodii
		eyyee=0	Miti=1	
501	Yeroo tokko tokko qoricha kee fudhachuu nii dagattaa?			
502	Namootni al tokko tokko sababa dagachuun malee qoricha isaanii osoo hin fudhattiin hafu .torbaan 2 n darbe yeroo ati qoricha kee itti hin fudhattiin nii jiraa?			
503	Qoricha kee yommuu fudhattu naa yaaddesse jettee oggeessa kee osoo hin mari'achisiin qoriicha kee adda kuttettaa?			
504	Yommuu manaa baatu qoricha kee fudhachuu dagattee beektaa?			
505*	**Kalleessa qoricha kee hundaa fudhattee?** **(yes=1) (no= 0)**			
506	Mallattoon dhibee gaggabdoo yommuu sii dhiisu qoricha kee addaan kuttee beektaa?			
507	Nama tokko tokkoof guyya guyyaan qoricha fudhachuun rakkisaadha.kanaf sagantaa qoricha fudhachuu kee jijjirtettaa			
508	Qoricha kee yaadattee fudhachuu			

	dadhabdee beektaa? Lakkii____ Al tokko tokko_____ Yeroo tokko_____ Yeroo hunda_____ Darbee darbee_____			

Q505*,yoo deebiin isaa **eyyee** ta'e =**1**,yoo **miti** ta'e=**0**

Kutaa VI;Qabxillee yaala waliin wal qabataan

Lakk	Gaaffilee	Ramaddii koodii	Koodii
601	Akkattaa itti fayyadamaa	1.gosa tokko 2.gosa lama 3.gosa sadii	Galmee ilaalli
602	Gosa qoricha gaggabdoo	1.phenobarbitone 2.phenytoin 3. valporic acid 4.carbamazepime 5.kan biro_____	Galmee ilaalli
603	Gaggabdoon amma dhaabbateraa?	1.eyyee 2.miti 3.sirritti hin beeku	
604	Yoo gaaffiin 603 eyyee ta'e,yeroo dhumaaf yoom siit ka'e gaggabdoon?	Baatii_____	

605	Yoo gaaffiin 603 miti ta’e,ji’a 3n darbanitti mucaan kee gaggabdoo al meeqa godhate?	_____	
606	Mucaan kee miidhaa qoricha gaggabdoo godhatteraa?	1.eyyee 2.miti 3.hin beeku	
607	Yoo gaaffin 606 eyyee ta’e,miidhama akkamii faa godhate? **Deebii baay’ee ta’uu danda’a**	1.rakkoo amalaa 2.hidhii dhiittessuu 3.dhibee gogaa 4.dadhabbii 5.bususa 6.hanqinna xiyyeffannoo 7.bolii guddaan dhibuu 8.kan biro_____	

gaaffileen keenya kanuuma dha.deebii nuu kennuuf yeroo keessan waan nuu laattaniif galattomaa.gaaffilee xummmuruu keessan al tokko irra deebi’aa ilaalla

maqaa nama **data** fuunaanu____

mallattoo_____

guyyaa _____

9.3 የመረጃ እና የፈቃደኝነት መጠየቅያ ቅጽ

የመረጃ ቅጽ

ሰላም! ደህና አደሩ/ዋሉ! እኔ ስሜ _____ ይባላል። ዛሬ እዚህ የተገኘሁት በዶ/ር አንዋር ሁሴን ለሚሰራ ጥናት(በጅማ ሜዲካል ሴንተር የህፃናት ተመላላሽ ህክምና ክሊኒክ፤ የሚጥል በሽታ መድሃኒት ቁጥጥር ና ተያያዥ ነገሮች) መረጃ ለመሰብሰብ ነው። የዚህ ጥናት ዋና አላማው የሚጥል በሽታ ያለባቸው ህፃናት ለመድሃኒቱ ያላቸውን ቁጥጥር ለማጥናት ነው።

እኔ እርሶንም ሆነ ልሎችን የምጠይቀው በሙሉ ፈቃደኝነታችሁ በዚህ ጥናት እንድትሳተፉ ነው። ከርሶ የሚጠበቀው ለምንጠይቆት ጥያቅ ምላሽ መስጠት ነው። ይህም ከ25 ደቂቃ የማይበልጥ ግዜ ነው የሚወስድብን። ከርሶ የምንወስደውን መረጃ ምስጥራዊነቱን ለመጠበቅ በመረጃ ሰብሳቢው የሚሞላ ኮድ እንጠቀማለን። የርሶም ሆነ የልጅዎ ማንነት ወይም አድራሻ በመጠይቁ ላይ አይሞላም። ፍቃደኛ አለመሆንዎ ልጅዎ በሚያገኘው ማነኛውም የጤና እርዳታ ላይ ምንም አይነት ተጽእኖ አይኖረውም። ስለተሳትፎዎ እናመሰግናለን።

የፈቃደኝነት ቅጽ

በጥናቱ ለመሳተፍ ተስማምተዋል?

ኣዎ ተስማምቻለሁ ☐ ኣይ አልተስማማሁም ☐

በመርጃ ሰብሳቢው የሚፈረም፡ ከላይ በመረጃ ቅጽ ላይ ያለውን ለጥናቱ ተሳታፊ በተገቢው ሁኔታ በንባብ ማስረዳቴን በፊርማዬ አረጋግጣለሁ።

የ መጠይቅ ኮድ፡ _____

ቀን፡ _____

የጠያቂው ስምና ፊርማ፡ _____

የተቆጣጣሪው ስምና ፊርማ፡

_____

9.4 መጠይቅ

የጥናት ኮድ : _____ **ካርድ ቁጥር :** _____

ክፍል 1: ማህበረሰባዊ እና ግላዊ ጥያቄዎች

ተ.ቁ.	ጥያቄ	አማራጭ መልስ	ኮድ
101	እድሜ	_____ አመት	
102	ፆታ	1. ወንድ 2. ሴት	
103	የትምህርት ሁኔታ	1. ቅድመ መደበኛ 2.ኣንደኛ ደረጃ (1-4) 3. ሁለተኛ ደረጃ (5-8) 4. መሰናዶ(9-12)	
104	ዋና የሚጥል በሽታ አይነት	1. Focal የሚጥል በሽታ 2. Generalized የሚጥል በሽታ 3. Unclassified የሚጥል በሽታ	በጥያቄ ወይም ከካርድ
105	EEG ተደርጓል?	1.አዎ (.....)	ከካርድ

		2አይ	
106	ህመሙ ከጀመረ ምን ያህል ጊዜ ነው ?	_____ ወራት	
107	ህክምና ከጀመረ ምን ያህል ጊዜ ነው?	_____ ወራት	
108	ከቤተሰብ አባላት የሚጥል በሽታ ያለበት አለ?	1. አዎ 2. አይ 3. አርግጠኛ አደለሁም	
109	ልጅት የሚጥል በሽታ መድሃኒት አቋርጦ ወይም አሳልፎ ያውቃል ?	1. አዎ 2. አይ	አይ ከሆነ መልሱ 110 ላይ ያለውን ጥያቄ ዝለሉ
110	108 ላይ ያለውን ጥያቄ አዎ ካሉ መድሓኒቶቹን ያቋረጠበት ወይም ያቆመበት ዋነኛ ምክኛት ምንድን ነው	1. መርሳት 2. ጥቅሙን በደንብ አላወኩም 3. የጎንዮሽ ጉዳት በመፍራት 4. ስለተሻለው 5. መድሓኒት አልቆ ወይም በቂ መድሐኒት ከ ጤና ተቋም አላገኘሁም 6. ህጻኑ መድሐኒት አልወስድም ማለት 7. የ ገንዘብ አጥረት 8. ሌላ ካለ _____	
111	ህጻኑ ሌላ ህመም አለው ? አዎ ካላቹ የ ህመሙን አይነት ግለጹ	1. አዎ (_____) 2. አይ	ከካርድ
112	ህጻኑ ከሚጥል በሽታ መድሃኒት በተጨማሪ የሚወስደው ምድሓኒት አለ ?	1. አዎ 2. አይ	
113	ለሚጥል በሽታ ከመድሃኒቱ በተጨማሪ የሚጠቀሙት ባህላዊ መድሃኒት አለ?	1. አዎ 2. አይ	

ክፍል ሁለት:የ ተንከባካቢው ማህበረሰባዊ እና ግላዊ ጥያቄዎች

ተ ቁ	ጥያቄዎች	አማራጭ መልስ	ኮድ
201	ተንከባካቢው ከልጁ ጋር ያለው ግንኙነት ምንድን ነው?	1.አባት 2. እናት 3. አህት/ወንድም 4. አያት 5. አጎት/አክስት 6.ሌላ ግለጽ_____	
202	አድሜ	_____ አመት	
203	መኖሪያ ቦታ ?	1. ከተማ 2. ገጠር	
204	የተንከባካቢው የጋብቻ ሁኔታ	1. ያላገባ/ች 2. ያገባ/ች 3.የተለያዩ 4. የተፋታ/ች 5. ባል/ሚስት የሞተበት	

205	ተንከባካቢ የትምህርት ደረጃ	1. ያልተማሩ (ማንበብና መፃፍ የማይችሉ) 2.መጻፍ ና ማንበብ የሚችሉ 3. አንደኛ ደረጃ (1-8) 4. ሁለተኛ ደረጃ 5. ኮሌጅ/ዩኒቨርስቲ	
206	የተንከባካቢው ሥራ ምንድን ነው?	1. የቤት እመቤት 2. ገበሬ 3. ነጋዴ 4. የመንግስት ሰራተኛ 5. የቀን ሰራተኛ 6. ሌላ ግለጽ _____	,
207	ላጠቃላይ የቤተሰብ ቁጥር ስንት ነው ?	_____	
208	የቤተሰቡ አማካይ ወርሃዊ ገቢ ስንት ነው?	_____(ETB)	

ክፍል ሶስት : የ ጤና ትቋም አገልግሎቶች ተያያዥ ምክንያት

ተ ቁ	ጥያቄዎች	አማራጭ መልስ	ኮድ
301	ከ ቤት አስከ ሆስፒታል ያለው ርቀት ምን ያህል ነው ?	_____ኪሜ	
302	የመጓጓዣ አማራጭ	1. በአግር 2. በሕዝብ ትራንስፖርት 3 በ አግር ከዛ በ ትራንስፖርት	
303	በህፃናት ተመላላሽ ህክምና ክሊኒክ ውስጥ ያገኙት ትምህርት / ምክር ላለ	1. ላዎ 2. ላይ	ላይ ካሉ ጥያቄ 306 ዝለሉ
304	ላዎን ካሉ ምን ላይነት ምክር አግኝተዋል	1 የሚጥል በሽታ መድሃኒት ጥቅም 2. የመድሓኒቱ ላወሳሰድ 3. የጎንዮሽ ጉዳቱ 4. መድሓኒቱን በላግባቡ መውሰድ እና በቀጠሮ ቀን መገኘት 5. ሌላ ግለጽ : _____	
305	መድሓኒቱን እንዴት ነው የሚያገኙት ?	1. በብር በመግዛት 2. በ ጤና መድህን 3. በ ነጻ	
306	ሆስፒታል ውስጥ የገጠሞት ችግር አለ ከትትል በሚያረጉበት ወቅት ?	1. ላዎ 2. ላይ	If No, skip to Section IV
307	ላዎ ካሉ ያጋጠሞት ችግሮች ምንድናቸው ?	1. የሚጥል በሽታ መድሃኒት እጥረት 2. ወረፋ መጠበቅ 3. ጥሩ መስተንግዶ ላለማግኘት	

		4. ሌላ ግለጽ : _____	

ክፍል አራት : ስለ የሚጥል በሽታ የወላጆች እውቀት

ተ ቁ	ጥያቄዎች	አማራጭ መልስ	ኮድ
401	ስለ የሚጥል በሽታ ሰምተው ያውቃሉ?	1. አዎ 2. አይ	
402	evil-eye' ለ የሚጥል በሽታ አያጋልጥም ብለው ያምናሉ?	1. አዎ 2. አይ 3. አላውቅም	
403	ጭንቅላት ላይ የሚደርስ ጉዳት ለሚጥል በሽታ ያጋልጣል ብለው ያምናሉ ?	1. አዎ 2. አይ 3. አላውቅም	
404	የሚጥል በሽታ አይተላለፍም ብለው ያምናሉ ?	1. አዎ 2. አይ 3. አላውቅም	
405	የሚጥል በሽታ ያለባቸው ልጆች እርዳታን ይፈልጋሉ (ለምሳሌ መሬት ላይ ማስተኛት, አካባቢው ላይ ሊጎዳቸው የሚችሉ ነገሮችን ማስወገድ ,አንገታቸው ላይ ያለ ልብስ ማላላት) በ ሚጥላቸው ወቅት?	1. አዎ 2. አይ 3. አላውቅም	
406	የሚጥል በሽታ ይታከማል?	1. አዎ 2. አይ 3. አላውቅም	
407	ለሚጥል በሽታ የሚደረገውን የመጀመሪያ እርዳታ ያውቃሉ?	1. አዎ 2. አይ 3. አላውቅም	
408	ክብሪት ለኩሶ ወደ አፍንጫ ማስጠጋት ማንቀጥቀጡን አያቆመውም?	1. አዎ 2. አይ 3. አላውቅም	
409	በሚያንቀጠቅጠው ሰአት ልጁን መያዝ	1. አዎ 2. አይ 3. አላውቅም	

	ይጎዳል?		
410	የሚጥል በሽታ ገዳይ በሽታ ነው?	1. ኣዎ 2. ኣይ 3. ኣላውቅም	
411	ስለ ምድሓኒቱ የጎንዮሽ ጉዳት ይጨነቃሉ?	1. ኣዎ 2. ኣይ	
412	ስለ ወደፊት ጉዳት ወይም የሚጥል በሽታ ስለሚያመጣው ተያያዥ ችግር ይጨነቃሉ?	1. ኣዎ 2. ኣይ	
413	መድሓኒቱ ህጻናት ከማይደርሱበት ቦታ መቀመጥ ኣለበት ብለው ያምናሉ?	1. ኣዎ 2. ኣይ 3. ኣላውቅም	

ክፍል ኣምስት : መድሃኒት ክትትልን ተዛማጅ ጥያቄዎች

ተ ቁ	ጥያቄዎች	ኮድ ኣሰጣጥ		ኮድ
		ኣዎ =0	ኣይ =1	
501	ኣንዳንድ ጊዜ መድሃኒትዎን ሳይወስዱ ረስቶ ያዉቃሉ?			
502	ባለፉት ሁለት ሳምንታት ዉስጥ መድሃኒትዎን ያልወሰዱባቸው ቀናት ነበሩ?			
503	ለሐኪምዎ ሳይገለጹ መድሃኒቱን መውሰድ ያቆሙበት ጊዜ ኣለ?			
504	በጉዞ ሰዓት ወይም ከቤት ስትወጡ, ኣንዳንድ ጊዜ መድሃኒትዎ ይረሳሉ?			
505*	ትናንትና መድሃኒትዎን ወስደዋል?			
506	መድሃኒቱን እየወሰዱባሉበት ሰዓት ህመሙን ተቆጣጥሮልኛል በማለት ለማቆም ሞክሮ ያቃሉ?			
507	በየቀኑ ምድሓኒት መውሰድ ለ ኣንዳንድ ሰዎች ከባድ ነው መድሃኒቶችዎን በሚውስዱበት ጊዜ መሰላችት ኣጋጥሞት ያውቃል			
508	ሁሉንም ምድሃኒቶችዎን ለመውሰድ ምን ያህል ጊዜ ለማስታወስ ይቸገራሉ ? በፍጹም ☐ ኣንድ ☐ ኣ ☐ ጊዜ ኣብዛኛው ጊዜ ☐ ሀ ☐			

ጥያቄ505*, መልሱ ኣዎ ከሆነ ውጤት =1 እና መልሱ ኣይ ከሆነ ውጤት =0

ክፍል ስድስት : ሕክምና ተዛማጅ ጥያቄዎች

ተ ቁ	ጥያቄዎች	ኮድ ኣሰጣጥ ምድን	ኮድ
601	ጥቅም ላይ የዋለው የሕክምና ዘዴ (የመድሃኒት ብዛ)	1. ኣንድ መድሃኒት 2. ሁለት መድሃኒት 3. ሶስት መድሃኒት	ክካርድ
602	የታዘዘው የመድሃኒት ኣይነት	1. Phenobarbitone 2. Phenytoin 3. Valproic acid 4. Carbamazepine	ክካርድ

		5. Others(specify) _____	
603	ማንቀጥቀጡ አሁን አቁሟል ?	1. ኣዎ 2. ኣይ 3. እርግጠኛ አደለሁም	
604	ለ 603 ጥያቄ አዎ ካሉ መቼ ነበር ለመጨረሻ ጊዜ ያንቀጠቀጠው?	_____ወራት	
605	ለ ጥያቄ ቁጥር 603 አይ ካሉ ' ምን ያህል ጊዜ ነው ባለፈው ሶስት ወራት ማንቀጥቀጡ የነበረው	_____	
606	ልጁ የ መድሃኒቱ አሉታዊ ተጽኖ አድሮበታል?	1. ኣዎ 2. ኣይ 3. እርግጠኛ አደለሁም	
607	ለ ጥያቄ 606 አዎ ካሉ ምን አይነት አሉታዊ ተጽኖ አድሮበታል? (**ከ አንድ በላይ መልሶች ይቻላል**)	1. የ ባህሪ መዛባት 2. የ ድድ ማበጥ 3. የ ቆዳ ሽፍታ 4. ድብታ 5. ድካም 6. ትኩረት ማጣት 7. ድርቀት 8. ሌላ ግለጽ _____	

® ይህ የጥያቄአችን መጨረሻ ነው ። ጊዜ ወስደህ ጥያቄዎቹን ስለመለስክ በጣም አመሰግናለሁ ለ እርዳታዎ እናመሰግናለን . እባክዎ ሁሉም ጥያቄዎች መሞላታቸውን ያረጋግጡ።

የመረጃ ሰብሳቢው ስም

_____

ፊርማ _____

ቀን _____

9.5 Information sheet and informed consent form (English version)

Dear Sir, madam

Good morning / afternoon; My name is _____. I am here today to collect data for a study entitled "Seizure Control status and associated factors among children with epilepsy attending pediatrics neurology follow up clinic of JMC, 2021" which is being conducted by Anwar Hussen (MD, Pediatrics Resident) from department of Pediatrics and Child health, Jimma Medical Center. The main purpose of this study is to assess Seizure Control Status and associated factors among children with epilepsy attending pediatrics follow up clinic of JMC.

I am asking you and others to voluntarily participate in this study. What is expected from you is to respond questions which take about 25 minutes. The data you provided will be kept in a highly confidential manner by using only code number which is filled by the principal investigator and locking the data and none of your personal and child's identifiers will be on the questionnaire. If you do not like to participate in this study, it will never affect your child's treatment. If you feel discomfort with the study, it is your right to drop it any time you want. Thank you.

Are you willing to participate?

☐ Yes ☐ No

Signature of the interviewer certifying that informed consent has been given verbally by respondent!

Questionnaire Code_____

Date_____

Sign of DC _____

Sign of PI _____

9.6 Questionary

Study code: _____ Card/chart Number: _____

Part I:

Section I: Child related factors [Socio-demographic, clinical and treatment profiles].

S. №	Questions	Coding Categories	Code
101	Age	_____ Years	
102	Sex	1. Male 2. Female	
103	Educational status	1. Pre-school 2.Elementary (1-4) 3. Junior school (5-8) 4. High school(9-12)	
104	Main seizure type	1. Focal seizure 2. Generalized seizure 3. Unclassified seizures	Ask or review chart
105	Is there EEG done?	1.yes(.....) 2.No	review chart
106	Duration since Diagnosis?	_____ in Months	
107	Duration on treatment?	_____ in Months	
108	Is there any family member who has seizure/epilepsy?	1. Yes 2. No 3. I am not sure	
109	Have the child ever stopped or missed AEDs dose?	1. Yes 2. No	If No, skip to 210
110	If Yes to Q 208; What were your main reasons for stopping or for not taking the tablets regularly? (multiple answers are possible)	1. Forgetfulness 2. I did not know its importance well 3. Fear of side effects 4. Feeling better 5. Run out of drug/Did not get adequate tablets from the hospital 6. Child refuses to take drugs 7. Financial constraints 8. If other (specify): _____	
111	Does the child has other diagnosis? If yes write the diagnosis.	1. Yes (_____) 2. No	See chart
112	Does the child take other drug(s) concomitantly with AEDs?	1. Yes 2. No	

	[Medication other than AEDs]		
113	Use of herbal/traditional medicine as additional treatment for epilepsy?	1. Yes 2. No	

Section II: Parent's/caregiver's Socio-demographic and economic Characteristics.

S. №	Questions	Coding Categories	Code
201	Primary caregiver (Caregiver's identity)	1. Father 2. Mother 3. Sibling 4. Grandparents 5. Uncle/Aunt 6. Other(specify)_____	
202	Age	_____ years	
203	Place of Residence?	1. Urban 2. Rural	
204	Current Marital status of the caregiver	1. Single 2. Married 3. Separated 4. Divorced 5. Widowed	
205	Educational status of the caregiver	1. Cannot read & write 2. Can read & write 3. primary school 4. Secondary school 5. College/university	
206	Occupational status of the Caregiver	1. House wife 2. Farmer 3. Marchant 4. Gov't employee 5. Daily laborer 6. Other (Specify) _____	,
207	What is the total family size?	_____	
208	What is the average **monthly** income of the family?	_____(ETB)	

Section III: Health facility/service related factors.

S. №	Questions	Coding Categories	Code
301	Distance from home to the hospital	_____Km(s)	

302	Means of transportation to the hospital	2. On foot 2. Public transport	
303	How much time it takes from your home to the hospital? (in hours)	_____hr	
304	During any of your neurology clinic visit did you get health education &/or advice about epilepsy and AEDs during collection of tablets?	1. Yes 2. No	If No, skip to 306
305	If Yes to Q 304, What type of advice did you get about AEDs?	1. Importance of AEDs tablets 2. Method of use 3. Side effects 4. Not to miss doses & appointments 5. If other specify: _____	
306	How do you get the medication(s)?	1. Cash/payment 2. CBHI 3. Free of charge	
307	Have you ever faced problems in the hospital during health care delivery?	1. Yes 2. No	If No, skip to Section IV
308	If Yes to Q 307, what are these problems? (multiple answers are possible)	1. Shortage of AEDs 2. Long waiting time 3. Poor communication & good governance issue (that hindered you from taking AEDs) 4. If other specify: _____	

Section I V: Parental Knowledge about Epilepsy

S. №	Questions	Coding Categories	Code
401	Do you heard about epilepsy?	1. Yes 2. No	
402	Do you believe that **'evil-eye' not** predispose to seizure/epilepsy?	1. Yes 2. No 3. I do not know	
403	Do you believe that **head injury** predisposes to seizure/epilepsy?	1. Yes 2. No 3. I do not know	
404	Do you believe that epilepsy is **non-contagious** disease?	1. Yes 2. No 3. I do not know	
405	Do children with epilepsy need help (like ease them to the floor, clear the area around them, loosening ties or anything around the neck) during seizure episodes?	1. Yes 2. No 3. I do not know	
406	Do seizures are treatable?	1. Yes 2. No 3. I do not know	
407	Do you know how to perform first aid for seizures?	1. Yes 2. No 3. I do not know	
408	Does placing 'matches' around nose not stop seizure?	1. Yes 2. No 3. I do not know	
409	Does restraining the child during seizures episodes harm the child?	1. Yes 2. No 3. I do not know	
410	Do seizures are being fatal or life threatening?	1. Yes 2. No 3. I do not know	
411	Do you worried about side-effects of medications?	1. Yes 2. No	
412	Do you worry about future risks and potential consequences of seizures?	1. Yes 2. No	
413	Do you believe that Medicines have to be kept out of reach of children?	1. Yes 2. No 3. I do not know	

Part V: Medication adherence status: Drug adherence status will be assessed by using 8 item version of self reporting questionnaire of Morisky medication adherence scale (MMAS-8)(37)

S. №	Questions	Coding Categories		Code
		Yes=0	No=1	
501	Do you sometimes forget to take your medication?			
502	People sometimes miss taking their medications for reasons other than forgeting. Over the past 2 weeks, were there any days when you did not take your medications?			
503	Have you ever cut back or stopped taking your medication without telling your doctor because you felt worse when you took it?			
504	When you travel or leave home, do you sometmes forget to bring your medication?			
505*	**Did you take all your medications yesterday? (Yes= 1) (No= 0)**			
506	When you feel like your symptoms are under control, do you sometimes stop taking your medication?			
507	Taking medication every day is a real inconvenience for some people. Do you ever feel hassled about sticking to your treatment plan?			
508	How often do you have difficulty remembering to take all your medication? Never/Rarely ☐ Once in a while ☐ Sometimes ☐ Usually ☐ All the time ☐			

Q505*, if the answer is **'YES'** it will score=**1** & if the answer is **'NO'** it will score=**0**

Section VI: Treatment related factors.

S. №	Questions	Coding Categories	Code
601	Mode of therapy used	1. Mono-therapy 2. Dual therapy 3. Triple therapy	Review chart
602	Type of anti-epileptic drugs prescribed	1. Phenobarbitone 2. Phenytoin 3. Valproic acid 4. Carbamazepine 5. Others(specify) _____	Review chart
603	Is the seizure stopped now?	1. Yes 2. No 3. Iam not sure.	
604	If the answer to Q603 is'Yes', when was the last seizure episode?	_____month(s)	
605	If the answer to Q603 is'No', how many seizure episodes do your child have in each month for the past 3 month?	_____	
606	Does your child develop adverse effects to antiepileptic drugs?	1. Yes 2. No 3. I do not know	
607	If the answer to Q606 is 'Yes', which adverse effects does your child develop? (**Multiple answers are possible**)	1. Behavioral abnormality 2. Gum hyperplasia/swelling 3. Skin rash 4. Drowsiness 5. Fatigue 6. Decreased concentration 7. Constipation 8. If others (Specify) _____	

® This is the end of our questionnaire. Thank you very much for taking time to answer my questions. We appreciate your help. Please re-check that you have filled all the questions.

Name of data Collector _____

Signature _____

Date _____