PREDICTORS OF QUALITY OF CARE AMONG PEOPLE WITH EPILEPSY RECEIVING TREATMENT AT SELECTED HOSPITALS IN NAIROBI, KIAMBU AND MACHAKOS COUNTIES, KENYA

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2026

Predictors of Quality of Care among People with Epilepsy Receiving Treatment at Selected Hospitals in Nairobi, Kiambu and Machakos counties, Kenya

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A Thesis Submitted in Partial Fulfilment of the Requirements for the Degree of Doctor of Philosophy in Public Health of the Jomo Kenyatta University of Agriculture and Technology

2026

DECLARATION

This is my original work and has not been presented for a degree in any other University.

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DEDICATION

To my family: *Spouse* Margaret; *daughter* Bevalyn; *sons* Eric, Brian, Franklin and Geoffrey; grand-daughter Sarabi Langa, *father* the late Mzee Nyakwana Wangwe and *Mum* the late Mama Siprina Langa, you were the inspiration during this audacious and gratifying journey.

ACKNOWLEDGEMENT

I wish to express my sincere gratitude to the Jomo Kenyatta University of Agriculture and Technology (JKUAT), particularly the School of Public Health, for granting me the opportunity to pursue the Doctor of Philosophy (PhD) degree in Public Health. The University's conducive academic environment, institutional support, and access to essential resources greatly facilitated the successful completion of this study.

I am profoundly indebted to my supervisors, Prof. Simon Karanja and Dr. John Gachohi, for their exemplary mentorship, scholarly guidance, unwavering support, and constructive critique throughout my doctoral training. Their commitment to academic excellence and rigorous scholarship significantly shaped this research and enriched my professional development.

I sincerely appreciate the Institutional Ethics Review Committee (IERC) and the National Commission for Science, Technology and Innovation (NACOSTI) for the timely ethical review and approval of this study. I also thank the management and Research Committees of Kiambu, Gatundu, Thika, Mama Lucy Kibaki, and Machakos Level 5 Hospitals

My heartfelt appreciation goes to Medical Superintendents Dr. Paul Nyamweya of Machakos, Dr. Ann Wairagu of Gatundu, Dr. Emma Mutio Mama Lucy Kibaki, Dr. Jesse Ngugi of Thika and Dr. Cyrus Kamau Mumbura of Kiambu Level 5 Hospitals for granting permission to conduct the research in their respective institutions and their support during data collection exercise. I am equally grateful to Prof. James Jowi, Prof. Simon Kangethe, Prof. Jemimah Simbauni, Dr. Joseph Choge, and the late Prof. Paul Kioy, whose intellectual contributions and scholarly insights strengthened the conceptual and methodological foundations of this study.

I also acknowledge the Dean of the School of Public Health, Prof. Gedion Kikuvi, the Dean of the School of Medicine, Prof. Everisto Opondo, the Principal of the College of Health Sciences, Dr. Reuben Thuo, and the faculty members of both Schools for their mentorship, encouragement, and institutional support throughout this journey. I

extend my appreciation to my colleagues and staff in the School of Medicine and the Department of Clinical Medicine for fostering a supportive academic environment.

I am especially grateful to my fellow doctoral students, Dr. Juliet Gathara, Dr. Andrew Matole, and Mr. Gedion Ogutu Mauti, for their collegiality, intellectual engagement, and constructive feedback. I also thank Sheila Wanjiru Mbugua and Lucy Njeri Gateri for their dedication as research assistants during data collection, management, and cleaning. My sincere gratitude goes to all study participants whose willingness to share their experiences made this research possible. I gratefully acknowledge Mr. Ibrahim Waqo for his generous financial support towards the publication of manuscripts arising from this research.

Finally, I express my profound gratitude to my family, friends, and well-wishers for their unwavering encouragement, moral support, and belief in my abilities throughout this journey. Above all, I give all glory and honour to Almighty God for His abundant grace, wisdom, strength, guidance, and divine protection throughout every stage of this endeavour.

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ACRONYMS AND ABBREVIATIONS

ADR	Adverse Drug Reactions
ASM	Anti-Seizure Medication
CTS	Computerized Tomography Scan
DALYs	Disability Adjusted Life Years
EEG	Electroencephalography
FGD	Focus Group Discussion
fMRI	functional Magnetic Resonant Imaging
KII	Key Informant Interviews
KPHF	Kenya Health Policy Framework
LMIC	Low-Middle Income Countries
MEG	Magneto Encephalography
MOH	Ministry of Health
MRI	Magnetic Resonant Imaging
NACOSTI	National Commission for Science, Technology and Innovation
OR	Odds ratio
PET	Positron Emission Tomography
PWE	People with Epilepsy
PYO	Person Years of Observation

QA	Quality Assurance
QI	Quality Improvement
QoC	Quality of Care
QUIET	Quality Indicators in Epilepsy Treatment
SERVQUAL	Service Quality (Measurement Framework)
SPECT	Single Photon Emission Tomography
SPM	Statistical Parametric Mapping
SUDEP	Sudden Unexpected Death in Epilepsy
WHO	World Health Organization

DEFINITION OF OPERATIONAL TERMS

Healthcare the provision of comprehensive, coordinated, and continuous services to individuals with epilepsy

Quality of care The degree to which care provided increase the likelihood of desired health outcomes

Unemployment individuals who have no independent source of income and depend on relatives for daily livelihood

Knowledge on Epilepsy those who had satisfactory description of epilepsy which included conventional causes, signs and symptoms

Perception thought process about the behaviour of PWE

Practice Behaviour pattern and actions that the community allots to a person with epilepsy

Attitude Mindset about what people with epilepsy are and capable of doing

People with Epilepsy Individuals clinically diagnosed with epilepsy receiving care or follow-up services

Model simplified representation of a concept used for prediction

Burden The Physical, psychological, social, and economic impact experienced by PWE on the health care system

Predictors Variables that influence or are associated with the outcome.

Policies Formal provisions developed by authorities to guide care

Process Measures Indicators assessing activities, interactions, and procedures in delivering healthcare services

Structural Indicators - organizational characteristics of a health facility

Outcome Effect of healthcare service on the health status and quality of care.

Factor weight numerical value representing the relative importance of a specific quality domain

Domain - a specific dimension or component of quality of care measured

Quality measures - Quantifiable indicators used to evaluate the extent to which healthcare providers adhere to recommended standards,

Integrated care services: delivery of medical and social care interventions across levels of the healthcare system

Receive Refers to the healthcare services that people living with epilepsy reported having obtained from Level Five hospitals during their treatment and follow-up

ABSTRACT

Epilepsy is a common neurological disorder affecting over 70 million people globally and accounting for approximately 1% of the global disease burden, with nearly 90% of cases occurring in low- and middle-income countries. In sub-Saharan Africa, an estimated 10 million people live with epilepsy, while Kenya has a prevalence of about 18 per 1,000 population, corresponding to nearly one million people with epilepsy (PWE), of whom approximately 80% do not receive adequate treatment. Beyond its clinical burden, epilepsy is associated with stigma, discrimination, reduced productivity, and increased healthcare utilization. Despite increasing awareness and improved health-seeking behaviour, evidence on the quality of epilepsy care and its determinants in Kenya remains limited. The main objective of this study was to determine predictors of quality of care among PWE receiving treatment at selected Level Five hospitals in Nairobi, Kiambu, and Machakos counties. A cross-sectional mixed-methods study was conducted between May and September 2021. Quantitative data were collected from 373 PWE using semi-structured questionnaires, while qualitative data were obtained through focus group discussions and key informant interviews. The Donabedian Structure–Process–Outcome Framework and the Aday and Andersen Healthcare Utilization Model guided the assessment of quality domains and determinants. Quality of care was measured using a semantic differential scale, and Exploratory Factor Analysis generated normalized factor weights that were used to construct a composite weighted quality index. A median score of 47 was used to categorize quality of care into high and low levels. Although Fisher's finite population correction yielded a minimum sample size of 276 from a sampling frame of 969 patients, the study retained the original Fisher sample size of 385 to enhance statistical power, reduce sampling error, and improve precision. Consecutive sampling recruited 373 participants, representing a 96.9% response rate. Quantitative data were analyzed using descriptive statistics, chi-square tests, logistic regression, and multiple linear regression in SPSS version 26, while qualitative data were analyzed thematically in NVivo and triangulated with quantitative findings. Majority participants were 29–49 years (37.5%), and 52.8% reported receiving high-quality care. Respect, communication, and tolerability of medication side effects were the most important contributors to quality ratings. At bivariate analysis, occupation (χ^2=19.13, p<0.001), duration before treatment initiation (χ^2=6.07, p=0.048), anti-seizure medication use (χ^2=4.024, p=0.045), seizure frequency after treatment initiation (χ^2=7.337, p=0.026), stigma experience (χ^2=5.022, p=0.025), treatment regimen (χ^2=10.464, p=0.015), waiting time (χ^2=6.49, p=0.031), service availability (χ^2=7.137, p=0.029), and affordability of care (χ^2=4.034, p=0.043) were significantly associated with quality of care. Multivariate logistic regression identified stigma as the strongest independent predictor of low-quality care (OR=2.123, 95% CI: 1.119–4.026; p=0.021). Qualitative findings showed that respectful provider interactions, effective communication, and treatment effectiveness enhanced patient experiences, whereas inadequate education regarding seizure management and medication side effects reduced perceived quality. The study concludes that quality of epilepsy care is shaped by a complex interplay of sociodemographic, clinical, psychosocial, and health system factors, with stigma emerging as the most pervasive determinant. Strengthening community sensitization, healthcare worker training, patient education, diagnostic capacity, medication supply systems, and structured counselling and peer-support programmes is essential for

improving quality of care, narrowing the treatment gap, and informing county and national epilepsy policies.

CHAPTER ONE

INTRODUCTION

1.1 Background Information

1.1.1 Global Perspective

Epilepsy is a chronic neurological disorder characterized by recurrent, unprovoked seizures arising from abnormal neuronal activity in the brain. It is among the most prevalent non-communicable neurological disorders globally and contributes substantially to morbidity, mortality, and disability-adjusted life years (DALYs). Current global estimates indicate that approximately 70 million individuals live with epilepsy worldwide, representing nearly 1% of the global disease burden, with almost 90% of affected individuals residing in low- and middle-income countries (LMICs) (de Souza et al., 2018; Kariuki et al., 2021).

Epilepsy is associated with markedly increased mortality, with people living with epilepsy (PWE) experiencing mortality rates approximately three times higher than the general population. Sudden unexpected death in epilepsy (SUDEP) remains a major contributor to epilepsy-related mortality (Trinka et al., 2019). Beyond mortality, epilepsy imposes significant psychosocial and economic burdens, including stigma, social exclusion, reduced educational attainment, diminished productivity, and limited employment opportunities.

The economic burden is substantial, affecting both households and health systems through direct medical costs and indirect productivity losses. Families frequently incur catastrophic expenditures associated with diagnosis, long-term medication, and hospitalization, particularly in resource-limited settings (Fenny et al., 2020). These cumulative impacts establish epilepsy as a condition of major global public health significance.

Quality of care is the degree to which health services increase the likelihood of desired health outcomes and are consistent with current professional knowledge. For people with epilepsy, quality of care is a critical determinant of their health outcomes. High-

quality care characterized by timely diagnosis, availability of antiepileptic medications, patient-centered communication, continuity of care, and regular follow-up has been associated with improved seizure control, better medication adherence, enhanced quality of life, reduced disability, and lower mortality rates (Firat et al., 2023). Conversely, poor-quality care contributes to uncontrolled seizures, preventable injuries, psychosocial distress, increased hospitalizations, treatment discontinuation, and premature mortality (Kruk et al., 2018; WHO, 2023).

In LMICs including Kenya, the quality of care is suboptimal as health systems across the region continue to face challenges related to inadequate infrastructure, inconsistent availability of essential medicines, and inadequate financing. Consequently, many patients receive care that does not fully adhere to evidence-based standards (WHO, 2018). It is influenced by waiting hours, socio-demographic characteristics, education level, and empathy of health care providers (Karume et al., 2025). Gaps in safety, responsiveness to and effectiveness of treatment and continuity of care still persist. Health facility characteristics, provider competence, and access-related factors have also been identified as key determinants especially in maternal and postnatal care quality.

1.1.2 African Context

Sub-Saharan Africa (SSA) bears a disproportionately high burden of epilepsy, with an estimated 10 million people living with the disorder. Regional prevalence estimates range from 5 to 20 per 1,000 population, although variability exists due to differences in study methodologies and population characteristics (WHO, 2020).

Epilepsy represents one of the leading causes of neurological hospital admissions across SSA (Odhiambo, 2021). Despite this high burden, access to quality epilepsy care remains limited. Approximately 70% of individuals with epilepsy do not receive adequate treatment, with treatment gaps ranging from 23% to 100% across countries (Stelzer et al., 2016; Yang et al., 2024).

Several systemic factors contribute to these treatment gaps, including:

- Shortage of trained neurologists and specialized personnel
- Limited diagnostic facilities
- Weak referral systems
- Inconsistent availability of antiseizure medications
- Weak health system infrastructure

Preventable causes of epilepsy—such as birth trauma, perinatal hypoxia, and central nervous system infections—remain highly prevalent in SSA, further compounding disease burden (WHO, 2021; Aderinto, 2023). The high burden of epilepsy and the persistent wide treatment gap underscore the importance of evaluating the quality of care received by people with epilepsy and identifying factors that influence that quality. Epilepsy care outcomes are shaped by the interaction of patient-level factors, hospital-level factors, and broader socio-cultural determinants (WHO, 2024)

Cultural misconceptions associating epilepsy with witchcraft, curses, or supernatural forces exacerbate stigma and discrimination. These beliefs contribute to delayed treatment-seeking behaviors, social isolation, school dropout, reduced marriage prospects, and economic marginalization Stigma associated with epilepsy may discourage patients from openly discussing seizures with healthcare providers. Fear of discrimination can limit disclosure of symptoms, treatment challenges, or medication side effects). This linkage strengthens the theoretical justification for examining socio-demographic, clinical, and hospital-level predictors of quality of care among people with epilepsy in Nairobi and its environs (Braga et al., 2020)

1.1.3 Kenyan Situation

Kenya reflects many of the broader challenges observed across SSA. The estimated national prevalence of epilepsy is approximately 18 per 1,000 population, suggesting that nearly **one** million individuals are affected (Nyakwana et al., 2018).

Epilepsy is the third leading cause of neurological hospital admissions nationally and contributes significantly to disability and productivity losses. Annual productivity

losses associated with epilepsy are estimated at €1,528 per patient, while DALYs associated with epilepsy-related hospital admissions are estimated at 3.1 per 1,000 person-years (Odhiambo, 2021).

Healthcare disparities exist between urban and rural settings. Rural areas report limited access to treatment due to financial constraints and weak healthcare infrastructure, while urban settings such as Nairobi experience challenges related to medication affordability and adherence (Kinyanjui et al., 2013).

Kenya has implemented several policy interventions aimed at strengthening epilepsy care, most notably through the Kenya Mental Health Policy (2015–2030), the Kenya Mental Health Action Plan (2021–2025), and the adoption of the World Health Organization (WHO) Mental Health Gap Action Programme (mhGAP). These policies advocate for the integration of mental, neurological, and substance-use disorders, including epilepsy, into primary healthcare to improve access, equity, and continuity of care (MOH 2021). This policy direction is consistent with the WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (2022–2031), which calls for strengthening governance, improving access to timely diagnosis and treatment, enhancing community-based care, and promoting person-centered services for people with epilepsy. With a treatment gap of 70-90% in epilepsy care in Kenya, WHO technical brief on epilepsy further advocates integration of epilepsy care within universal health coverage and primary healthcare systems, emphasizing patient-centered care, continuity of treatment, and improved health outcomes (WHO, 2024). The policy framework emphasizes decentralization of services from tertiary hospitals to lower-level health facilities, training of non-specialist healthcare workers, strengthening referral systems, improving the availability of essential anti-seizure medications, and reducing stigma associated with epilepsy and other neurological disorders.

Civil society organizations, including KAWE and Shine Epilepsy which have been running epilepsy support programs and specialized clinics, have continued to receive increased number of cases due to increased awareness and service provision. The coverage of these programs is limited and concentrated in selected urban and peri-

urban areas, leaving many rural and underserved populations with inadequate access to specialized epilepsy services. Despite these initiatives, treatment gaps remain wide, and empirical evidence on quality of care remains limited, particularly in peri-urban settings (MOH, 2023).

Despite implementing policy interventions, quality of care for people with epilepsy still varies across healthcare facilities and is influenced by patient-level, clinical, and hospital-level factors. Socio-demographic characteristics such as education, income, and health literacy, clinical factors including duration of illness and comorbidities, and hospital factors such as staffing levels, availability of essential medicines, diagnostic capacity, and adherence to treatment guidelines have been shown to affect quality of care and subsequent patient outcomes (Karume et al., 2025). However, evidence on the quality of care received by people with epilepsy and the predictors of such care remains limited.

1.2 Statement of the Problem

Epilepsy is one of the most common chronic neurological disorders globally, affecting an estimated 70 million people and contributing substantially to disability, premature mortality, and reduced quality of life (Ngugi et al., 2010; WHO, 2022). It is among the most common chronic neurological disorders, affecting an estimated one million Kenyans and contributing substantially to disability, premature mortality, reduced quality of life, and socioeconomic hardship. Although effective and relatively inexpensive treatments exist, nearly 80% of people with epilepsy reside in low- and middle-income countries (LMICs), where health systems are frequently constrained by inadequate infrastructure, shortages of trained personnel, limited diagnostic capacity, and inconsistent access to antiseizure medications (WHO, 2022; IOM 2010).

The burden of epilepsy is particularly high in Sub-Saharan Africa (SSA), where prevalence estimates range from 5 to 20 per 1,000 population and treatment gaps remain among the highest globally, ranging from 69% to 90% (Mbuba et al., 2012; Owolabi et al., 2020). These treatment gaps are driven by multiple factors, including shortages of neurologists and epilepsy-trained healthcare workers, inadequate diagnostic facilities, weak referral systems, financial barriers to care, and persistent

cultural beliefs that attribute epilepsy to supernatural causes. Consequently, many people with epilepsy experience delayed diagnosis, poor treatment adherence, uncontrolled seizures, preventable complications, and diminished psychosocial wellbeing. Seizure control, treatment adherence, patient education, psychosocial support, and continuity of care enhance their quality of life (Owolabi et al., 2020).

Kenya mirrors many of these regional challenges. Epidemiological studies have reported considerable variation in epilepsy prevalence across the country, with some regions documenting lifetime prevalence rates as high as 31.7 per 1,000 population and significantly elevated mortality among people living with epilepsy (Ibinda et al., 2014). In response, the Ministry of Health has developed national epilepsy management guidelines and expanded epilepsy services within referral facilities Additionally, advocacy and support initiatives such as those implemented by the Kenya Association for the Welfare of People with Epilepsy (KAWE) have contributed to increased awareness and improved access to care. (MoH, 2018).

Despite these efforts, adverse patient outcomes continue to be reported among individuals receiving epilepsy care. These adverse outcomes include recurrent uncontrolled seizures, medication-related side effects, poor treatment adherence, epilepsy-related injuries, social stigma, and reduced quality of life. The persistence of these outcomes suggests that improvements in service availability alone may not be sufficient and raises concerns regarding the quality of care received by people living with epilepsy. Quality care encompasses not only access to treatment but also effectiveness, communication, counselling, continuity of care, affordability, accessibility, patient-centredness, and responsiveness of health services (WHO, 2022).

In Kenya there are significant gaps in epilepsy service delivery and a large proportion of people with epilepsy remain undiagnosed, untreated, or inadequately managed, resulting in a treatment gap estimated at 70–90% (MOH, 2021). An estimated 70% of people living with epilepsy either not receiving treatment or receiving inadequate treatment despite the availability of effective and affordable antiseizure medications (WHO, 2022). Treatment gaps are driven by shortages of trained healthcare personnel, limited diagnostic capacity, inconsistent availability of antiseizure medications, weak

referral systems, and financial barriers to accessing care (Owolabi et al., 2020). However, despite national commitments to UHC and implementation of the Kenya Mental Health Policy (2015–2030), people living with epilepsy continue to experience substantial barriers to accessing quality services, including medication stock-outs, inadequate specialist personnel, limited diagnostic capacity, financial constraints, and stigma.

Key evidence gaps identified

- Persistent treatment gap.
- Limited diagnostic services.
- Inconsistent availability of ASM
- High cost of antiseizure medications.
- Weak referral and follow-up systems.
- Shortage of trained personnel and specialists.
- Stigma, cultural misconceptions, and discrimination.
- Poor patient education, counselling, and psychosocial support.
- Limited attention to patient-centred quality-of-care dimensions.
- Insufficient evidence on predictors of quality of epilepsy care in Kenya.
- Limited data to guide policy, resource allocation, and quality improvement initiatives.

Consequently, only about 60% of healthcare providers had received formal epilepsy training, while fewer than half reported receiving ongoing professional development in epilepsy management. Community stigma and cultural misconceptions were also identified as major barriers to effective care delivery. These findings indicate continuing structural, workforce, and socio-cultural barriers that may adversely influence the quality of epilepsy care provided within referral-level health facilities (Wabulya et al., 2024).

Despite the growing recognition of epilepsy as a public health priority, empirical evidence on the quality of care received by people living with epilepsy in Kenya remains scarce. Existing studies have predominantly focused on prevalence, risk

factors, treatment gaps, and clinical outcomes, with limited attention to the quality of care experienced by patients and the factors influencing it. PWE receiving care in the same health system experience different outcomes including variations in Seizure control, Treatment adherence, Continuity of care and patient satisfaction. Potential predictors for the variation include socio-demographic factors, Clinical factors, Cultural beliefs and misconceptions, Stigma and hospital-level factors. Predictors contribute quality outcomes are unknown. It is also not clear whether predictors differ between newly diagnosed and follow-up patients. Therefore, there is need to identify predictors of quality of care, explain variations in quality outcomes, inform targeted interventions and policy improvements and improve epilepsy outcomes and quality of life among PWE (Devinsky et al., 2018).

While national policies advocate for integrated neurological care and reduction of the epilepsy treatment gap, there is limited empirical evidence on the quality of epilepsy care provided in health facilities within Nairobi and its neighboring counties. Specifically, the predictors of high- and low-quality care among people with epilepsy in these counties have not been systematically evaluated. As a result, the extent to which patient characteristics and health system factors influence the quality of epilepsy services and health outcomes remains unclear as little is known about how socio-demographic characteristics, clinical factors, and hospital-level factors interact to influence the quality of epilepsy care peri-urban populations in Nairobi City County and its environs receive. This evidence gap limits the ability of policymakers, healthcare managers, and clinicians to design targeted interventions, implement quality improvement strategies, allocate resources effectively, and strengthen epilepsy services. Consequently, people living with epilepsy continue to experience preventable morbidity, premature mortality, stigma, social exclusion, and economic hardship (Feigin et al., 2024)

In addition to health system constraints, misconceptions linking epilepsy to witchcraft, curses, or supernatural causes continue to contribute to stigma, discrimination, delayed healthcare-seeking behaviour, poor treatment adherence, social exclusion, and reduced quality of life among people living with epilepsy (Braga et al., 2020; Mushi et al.,

2011). Traditional beliefs act as barriers and negatively influence health-seeking decisions.

Newly diagnosed patients often encounter challenges related to delayed diagnosis, inadequate disease knowledge and misconceptions about epilepsy. Although patients on follow-up may experience challenges related to long-term medication adherence, treatment side effects, and rare quality of care as low, those who with continuous care through sustained medication access, effective patient education, regular monitoring, and strong provider-patient relationships with good adherence, seizure control, clinic attendance are expected to report significantly higher quality-of-care scores than those experiencing treatment interruptions, stigma, or poor health-system support. Although quality of epilepsy care outcomes may differ between newly diagnosed patients and those on follow-up**,** the predictors responsible for these differences remain inadequately understood (Fisher et al., 2023).

1.3 Justification for the Study

Epilepsy remains a major public health problem in Kenya, characterized by persistent treatment gaps, inconsistent service delivery, and widespread stigma (Mbuba et al., 2012; WHO, 2019).

i. Quality of Care

- With appropriate medication and follow-up, up to 70% of epilepsy cases can achieve seizure control when comprehensive epilepsy care is consistently delivered (WHO, 2019).
- However, evidence on the effectiveness of national epilepsy management programs remains limited, particularly within Level Five referral hospitals serving Nairobi Metropolitan counties (MoH, 2018).

ii. Socio-demographic relevance:

- Socio-demographic factors influence healthcare access, treatment adherence, and health outcomes (Meyer et al., 2010; WHO, 2019).

- Understanding these factors supports the design of equitable and context-specific interventions.

iii. Clinical relevance:

- Clinical factors such as seizure frequency, treatment delays, and medication adherence are important determinants of quality of care and patient outcomes (Kwan & Brodie, 2000; Newton & Garcia, 2012).
- Identifying these predictors informs clinical decision-making and patient-centered care.

iv. Health systems relevance:

- Hospital-level factors influence service quality and efficiency (WHO, 2022; MoH, 2018).
- Findings will guide health system strengthening initiatives to improve epilepsy care delivery

Beyond Socio-demographic, clinical and hospital level relevance , these has the following benefits

Policy and public health significance:

- The study findings will support integration of epilepsy services into primary healthcare, strengthen referral systems, improve continuity of care, enhance community awareness, reduce stigma, and promote patient-centered care (WHO, 2022; Ba-Diop et al., 2014).

Contribution to Sustainable Development Goals (SDGs):

- Supports SDG 3.4 by improving equitable access to quality epilepsy care and reducing preventable disability and premature mortality (WHO, 2022; Feigin et al., 2020).

- Supports SDG 3.8 through early diagnosis, timely treatment initiation, and improved access to safe and effective medicines (United Nations, 2015; WHO, 2023).

Economic and social relevance:

- Improved quality of epilepsy care can reduce catastrophic healthcare expenditures, productivity losses, unemployment, educational disadvantage, and social exclusion (Meyer et al., 2010; Beghi, 2020; WHO, 2022; United Nations, 2015).

Contribution to sustaining MDG achievements:

- Improving epilepsy care addresses preventable causes such as birth trauma, perinatal complications, neuroinfections, and childhood illnesses, thereby sustaining gains made under MDGs 4, 5, and 6 (Ngugi et al., 2010; WHO, 2022).

National policy relevance:

- The findings support Kenya's Universal Health Coverage agenda and the Kenya Health Policy 2014–2030 by promoting equitable access to quality healthcare, stronger health systems, and improved health outcomes (MoH, 2014).

To the policymakers and health managers, the evidence generated from this study will guide interventions to improve service quality, strengthen health system responsiveness, optimize resource utilization, and reduce the burden of epilepsy and other neurological disorders (MOH, 2020; WHO, 2022).

1.4 Research Questions

i. What is the self-reported quality-of-care among people with epilepsy receiving treatment at selected hospitals in Nairobi, Kiambu and Machakos counties, Kenya?
ii. What are the socio-demographic predictors of quality-of-care among people with epilepsy receiving treatment at the selected hospitals in Nairobi, Kiambu and Machakos counties, Kenya?
iii. What are the clinical predictors of among people with epilepsy receiving treatment at the selected hospitals in Nairobi, Kiambu and Machakos counties, Kenya.
iv. What is the hospital-level predictors of quality-of-care among people with epilepsy receiving treatment at the selected hospitals in Nairobi, Kiambu and Machakos counties, Kenya?

1.5 Objectives

1.5.1 Main Objective

Broad objective

To determine predictors of the quality-of-care among people with epilepsy receiving treatment at the selected hospitals in Nairobi, Kiambu and Machakos counties, Kenya

1.5.2 Specific Objectives

i. To determine self-reported quality of care among people with epilepsy receiving treatment at selected hospitals in Nairobi, Kiambu and Machakos counties, Kenya.
ii. To determine socio-demographic predictors of quality-of-care among people with epilepsy receiving treatment at the selected hospitals in Nairobi, Kiambu and Machakos counties, Kenya.

iii. To determine clinical predictors of quality-of-care among people with epilepsy receiving treatment at the selected hospitals in Nairobi, Kiambu and Machakos counties, Kenya.

iv. To determine hospital-level predictors of quality-of-care among people with epilepsy receiving treatment at the selected hospitals in Nairobi, Kiambu and Machakos counties, Kenya.

1.6 Theoretical Frameworks

The study adopted the theoretical frameworks from the Donabedian (Donabedian, 1988) and Aday & Anderson models (Andersen & Newman, 1973).

1.6.1 The Donabedian Model

The Donabedian model is a conceptual theory that provides a framework for examining health services and evaluating quality of health care (Botma & Labuschagne, 2019). This model was developed by Avedis Donabedia, a physician and health services researcher at the University of Michigan, in 2016 (Berwick & Fox, 2016). It continues to be the dominant paradigm for the determination of quality of healthcare (Endeshaw, 2021). It provides outline for examining health services and evaluating the quality of care given to clients at a service delivery point (Botma & Labuschagne, 2019). In this model, public agents and payers' ultimate concern rests with providers' impact on patient outcomes. Quality of care measure is achieved by observing its structure, its processes and its outcomes (O'Rourke & O'Brien, 2017). Consumers, payers and regulatory agencies demand evidence regarding health care quality as process of care measures grow. Outcome measures of quality represent the desired end results of health care and the validated process of care measures which provide an important additional element to quality improvement efforts. The two items combined illuminate which provider actions could be changed to improve the quality outcomes. The Donabedian Model is therefore designed to provide a clear understanding of the relationship between infrastructure, process and outcome indicators as predictors of quality of a healthcare service.

1.6.1.1 Strength of Donabedian Model

In Donabedian model, access is the level of use of services in relation to the need and not just the presence of facility. In this case clients and healthcare providers evaluate "need" differently (Shackleton et al., 2016). Inherent in this model is the fact that factors may influence "Initiation" and "Continuation" singularly or concurrently. It also acknowledges that barriers to access are not only financial but also psychological, informational, social, organizational, spatial and temporal. They influence whether patients can obtain, utilize, and benefit from healthcare services. In epilepsy care, these barriers affect treatment initiation, adherence, continuity of care, patient satisfaction, and health outcomes, thereby directly influencing the quality of healthcare received. Though many quality factors can influence clinical outcomes, process measures have the potential to identify for clinicians the exact plan processes of care (NICE, 2025)

Empirical standards of measurement are derived from actual practice and used to compare medical care in one setting with that in another with assurance that the clinical material in both settings being compared are similar. On the other hand, statistical averages and ranges are obtained from a larger number of similar settings with normative standards setting knowledge and practice in the dominant medical care system (Ayanian, and Markel, 2016).

1.6.1.2 Application of Donabedian Model

Table 1.1: Application of Donabedian's Structure–Process–Outcome Model to the Study

Donabedian Component	Definition	Study Indicators/Variables	Quality Domain Measured
Structure	Attributes of the healthcare setting that influence service delivery	Availability of epilepsy management guidelines and protocols	Hospital-level predictor
		Availability of antiseizure medications	Hospital-level predictor
		Service availability	Hospital-level predictor
		Referral	Hospital-level predictor
			Hospital-level predictor
Process	Activities occurring during healthcare delivery and provider–patient interactions	Communication between healthcare providers and patients	Communication
		Respectful treatment and dignity during care	Respect
		Counselling on disease management and medication use	Counselling
		Information provided regarding side effects	Tolerability of side effects
		Timeliness of receiving services	Promptness
		Confidentiality during consultation	Privacy
		Ease of reaching health services	Geographical access
		Affordability of treatment and services	Affordability
		Perceived effectiveness of treatment received	Effectiveness
		Follow-up care and continuity of treatment	Continuity of care
Outcome	Effects of healthcare on patients and health status	Composite Quality of Care Score	Overall Quality of Care
		Treatment adherence	Clinical outcome
		Seizure control and reduction in seizure frequency	Clinical outcome
		Improved quality of life and psychosocial well-being	Patient outcome

Relationship within the Donabedian Model:

Donabedian's Structure–Process–Outcome Model was adopted because it provides a recognized framework for evaluating healthcare quality. In this study, structural indicators included Antiseizure medications, Service availability, Recommendation for Referral, Staffing levels, Management guidelines and protocols; Process indicators included Communication, Respect, Counselling, medication use, side effects, Timeliness, Confidentiality Access, Cost affordability, Effectiveness of treatment; and Outcome indicators were Treatment adherence, Seizure frequency, composite quality-of-care score. The framework enabled systematic examination of how health system characteristics influence the quality of epilepsy care delivered within referral hospitals Adequate structural resources such facilitated effective care processes and High-quality care processes subsequently lead to favourable outcomes and higher overall quality-of-care scores among people with epilepsy (Ayanian and Markel, 2016).

1.6.1.3 Weaknesses of Donabedian Model

In Donabedian model, healthcare providers often respond to publicly reported outcomes and discuss practical strategies for using quality measures for continued improvement. They use internally developed report cards which focus on evidence-based process measures. Difficulty therefore arises due to high cost of developing and updating clinical guidelines and process measures. Quite often, there is dearth of clinical information on measures of quality for health care systems that would routinely and easily track the complex clinical processes in individual provider institutions. As a result, considerable debate is still raging with regard to whether quality measures should evaluate processes or outcomes of care (Rubin, 2015).

1.6.2 Aday and Andersen Behavioral Model of Health Services Utilization

The Aday and Andersen Behavioral Model of Health Services Utilization is one of the most widely used frameworks for studying access to healthcare, healthcare utilization, and quality of care. It provides a structured approach for examining how individual characteristics and health system factors influence healthcare access and outcomes. It offers a comprehensive framework for understanding the factors that influence access to healthcare services, utilization of care, and subsequent health outcomes The model

postulates that healthcare utilization is determined by the interaction of predisposing, enabling, and need factors (Aday & Andersen, 1974; Andersen, 1995).

Predisposing factors include individual characteristics such as age, sex, education level, marital status, and health beliefs that influence an individual's propensity to seek healthcare (Andersen, 1995). Enabling factors refer to the resources that facilitate or impede access to healthcare, Income, health insurance, distance to facility, medication availability, diagnostic services (Aday & Andersen, 1974; Andersen, 1995). Need factors encompass Duration of epilepsy, seizure frequency, comorbidities, perceived health status (Andersen, 1995). Together, these factors influence access to care, healthcare utilization, patient satisfaction, quality of care, and health outcomes (Babitsch et al., 2012).

1.6.2.1 Strengths of Aday and Anderson Model

One of the major strengths of the Aday and Andersen model is its comprehensive nature. The model simultaneously incorporates individual, social, and health system determinants of healthcare utilization, making it particularly relevant for studies assessing quality of care among people with epilepsy (Babitsch et al., 2012). In the context of this study, the model provides a useful framework for examining how socio-demographic characteristics, clinical factors, and hospital-level characteristics influence the quality of epilepsy care received by patients. Furthermore, the model acknowledges the role of health system resources, including the availability of trained healthcare workers, diagnostic facilities, referral systems, and essential medicines, which are critical determinants of epilepsy care in low- and middle-income countries (WHO, 2022). Another strength is its recognition of socio-cultural influences on health-seeking behavior. Cultural beliefs, stigma, and perceptions about epilepsy are common in Sub-Saharan Africa and may significantly affect healthcare utilization, treatment adherence, and continuity of care (Mushi et al., 2011; Braga et al., 2020). The model therefore provides an appropriate basis for understanding the complex interactions between patient characteristics and health system factors that influence quality of care.

1.6.2.2 **Limitations of Aday & Anderson**

Despite these strengths, the model has several limitations. First, it was originally developed to explain healthcare access and utilization rather than the quality of care provided (Aday & Andersen, 1974; Andersen, 1995). Consequently, it does not explicitly address important dimensions of healthcare quality such as provider competence, adherence to clinical guidelines, technical quality of care, patient safety, or effectiveness of treatment (Donabedian, 1988). Second, the model assumes that healthcare-seeking decisions are largely rational and influenced by available resources and perceived needs. However, healthcare utilization in many settings is also shaped by social norms, family influences, cultural practices, stigma, and community perceptions, factors that may not be fully captured within the framework (Babitsch et al., 2012; Mushi et al., 2011). Third, although the model includes socioeconomic characteristics, it gives limited attention to broader structural determinants such as poverty, health financing policies, political factors, and health system governance, which may substantially influence access to quality care (Peters et al., 2008). Additionally, the model presents healthcare utilization as a relatively linear process and does not adequately account for the dynamic relationships between previous healthcare experiences, patient satisfaction, treatment outcomes, and future healthcare-seeking behavior (Andersen, 1995).

Notwithstanding these limitations, the Aday and Andersen model remains highly relevant to this study because it provides a robust framework for examining the patient-level and hospital-level factors associated with quality of epilepsy care. To address its limitations regarding healthcare quality, the model was complemented by Donabedian's Structure–Process–Outcome framework, which provides a more explicit assessment of healthcare quality through evaluation of healthcare structures, care processes, and patient outcomes (Donabedian, 2005). The integration of these frameworks enabled a comprehensive examination of how socio-demographic, clinical, and hospital-level factors influence the quality of care received by people with epilepsy in selected referral hospitals in Nairobi, Kiambu and Machakos counties, Kenya.

1.6.2.3 Application to this Study

Table 1.2 Application of Aday and Anderson model:

Aday-Andersen Component	Variables in the Study
Predisposing Factors	Age, sex, education, marital status, cultural beliefs
Enabling Factors	Income, health insurance, distance to facility, medication availability, diagnostic services
Need Factors	Duration of epilepsy, seizure frequency, comorbidities, perceived health status

The model was adopted because it provides a comprehensive framework for understanding how predisposing, enabling, and need factors influence access to healthcare and subsequent health outcomes. It was particularly relevant to this study because it accommodates both patient-level and health-system-level determinants of quality of epilepsy care. However, because the model primarily focuses on healthcare utilization rather than service quality, it was complemented by quality-of-care concepts derived from Donabedian's Structure–Process–Outcome framework to better explain variations in the quality of epilepsy care received by people with epilepsy receiving treatment in the selected hospitals. The two frameworks are integrated because The Donabedian framework provided the structural lens to assess healthcare delivery through structure, process, and outcomes, while the Aday and Andersen model enabled analysis of healthcare utilization determinants, particularly socio-demographic and clinical need factors. Integrating both frameworks allowed a comprehensive multi-level assessment of predictors influencing quality epilepsy care (Ayanian, and Markel, 2016).

1.7 Conceptual Framework

Independent Variables **Moderating Variables** **Dependent Variables**

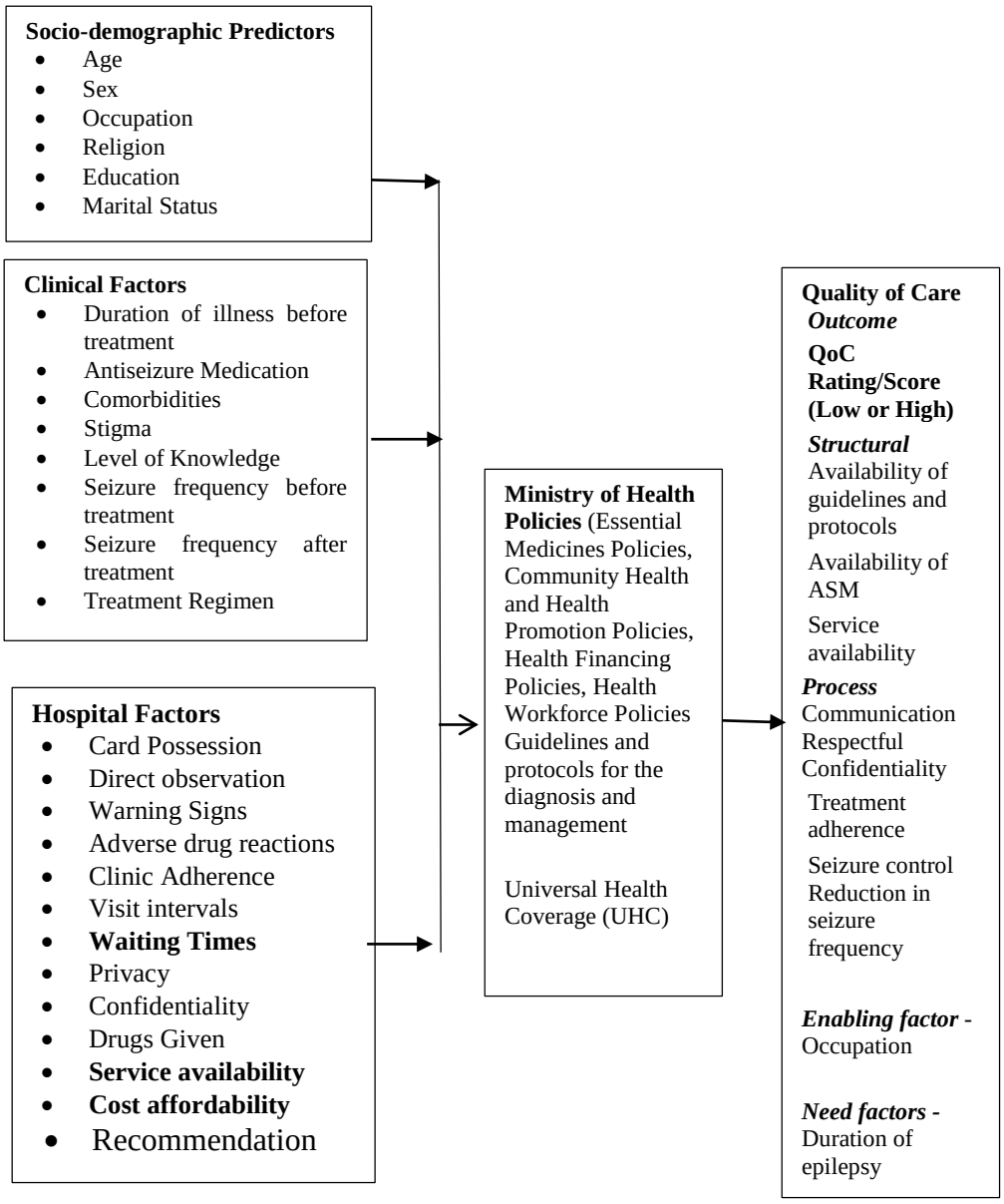

Figure 1.1: Conceptual Framework

1.8 Moderating Variables

Moderating variable is an actor that changes the strength or direction of the relationship between an independent variable and a dependent variable. In this study, the moderating variables included Ministry of Health Policies e.g. Guidelines and protocols for the diagnosis and management of neurological disorders, Universal Health Coverage (UHC) and Health Financing Policies, Health Workforce Policies, Essential medicine supply and Community strategy.

Through National Clinical Guidelines, the Kenyan Ministry of Health has developed national guidelines and protocols for the diagnosis and management of neurological disorders, including epilepsy. If these guidelines are implemented effective, they would standardize treatment protocols reduce variations in care between facilities, promote early diagnosis and timely treatment initiation and consequently improve seizure control through evidence-based management. The overriding impact is reduced negative effects of delayed treatment initiation and inconsistent clinical management on quality of care (WHO, 2022).

Universal Health Coverage (UHC) and Health Financing Policies. The Ministry of policies support the implementation of the Kenyan UHC as part of the Big 4 agenda. The transition from NHIF to the Social Health Authority aim to improve financial access to healthcare services. This policy aims to reduces out-of-pocket expenditure, improve affordability of consultations including anti-seizure medications and enhances continuity of care among low-income and unemployed patients. The overall impact is positive influence of unemployment and poverty on quality of care (MOH, 2023).

Through Essential Medicines Policies, The Ministry of Health maintains an Essential Medicines List that includes anti-seizure medications. This policy aims to promote continuous availability of anti-seizure drugs, reduce treatment interruptions and improves medication adherence and seizure control. Consequently, there effect of service availability and affordability challenges will be mitigated (WHO, 2022).

Through Health Workforce Policies, the Ministry of Health aims to support training of healthcare workers and promote continuous professional development. The impact will be improved provider competency in epilepsy management, enhanced communication and respectful care; and reduced diagnostic delays. The overall result will be improved quality domains such as communication, respect, effectiveness, and counselling (MOH 2023).

Through Community Health and Health Promotion Policies, the Kenya's community health strategy promotes health education, community awareness programmes and community health volunteer engagement. This policy aims to reduce stigma and misconceptions surrounding epilepsy, encourages early healthcare seeking and Improves treatment adherence. This will directly address stigma (WHO, 2022).

The conceptual framework posits that the quality of epilepsy care is determined by the interaction between individual patient characteristics and hospital-level factors. Adequate structural resources, effective care processes, good treatment adherence, and improved access to services increase the likelihood of achieving high-quality care, whereas deficiencies in these factors contribute to low-quality care. Consequently, both patient-level and facility-level predictors collectively determine whether people with epilepsy receive high- or low-quality care and ultimately influence treatment outcomes and disease management (MOH, 2023).

Ministry of Health policies act as moderating factors by shaping the healthcare environment within which epilepsy services are delivered. Effective implementation of policies on universal health coverage, essential medicines, workforce development, community health, and quality assurance can mitigate the adverse effects of socioeconomic, clinical, and hospital-level barriers, thereby improving the quality of care and outcomes for people living with epilepsy in Kenya (WHO, 2022).

Socio-demographic factors (age, sex, education, occupation, marital status, religion) influence quality of care, but their effects are moderated by UHC, health financing, and community health strategies, which improve equitable access and reduce socioeconomic disparities.

Clinical factors (stigma, seizure frequency, duration before treatment, treatment regimen, medication use, comorbidities, knowledge) are moderated by clinical guidelines, medicine supply policies, and community strategies, which improve standardized management, treatment continuity, adherence, and patient support.

Hospital-level factors (waiting time, service availability, affordability, counseling, privacy, confidentiality, provider communication, drug availability) are moderated by health workforce policies, treatment guidelines, UHC, and medicine supply policies, which determine how effectively health facilities can deliver services.

CHAPTER TWO

LITERATURE REVIEW

2.1 Quality of care for People with Epilepsy

Quality of care is a subjective, complex and multi-dimensional concept. It incorporates maximising patients' welfare by improving or maintaining the high calibre for the duration of life of the affected individual (Singh & Boyle, 2020). It is the degree to which health services increase the likelihood of desired health outcomes of individuals and populations in the context of prevailing professional knowledge (Almomani et al., 2020). This includes proper performance (according to standards) of interventions that are known to be safe, affordable, and that can produce an impact on mortality, morbidity and disability (Reynolds, 2000). It is therefore the provision of care that exceeds patient expectations and achieves the highest possible clinical outcomes with the resources available (Dixon-Woods, 2019).

Quality healthcare for people with epilepsy maximizes patients' welfare, maintains standards and increase the likelihood of favourable health outcomes of individuals, households, families and communities. Aspects attributed to quality health care for people with epilepsy encompass effectiveness, efficiency, accessibility, evidence-based, timeliness and limited wastage. Effective health care delivery should therefore adhere to the evidence base that results in improved outcomes for them based on their expressed needs. Efficiency in health care for people with epilepsy should limit waste and maximize resource utilization within the context of healthcare provision (Yip *et al.*, 2015).

2.1.1 Self- Reported Quality of Care for People with Epilepsy

Self-reported quality of care reflects patients' perceptions and experiences regarding the care they receive, including communication with healthcare providers, respect and dignity, access to services, involvement in decision-making, timeliness, continuity of care, affordability, and satisfaction with treatment. Increasingly, patient-reported experience measures (PREMs) are recognized as essential indicators of healthcare

quality because they complement traditional clinical outcomes and provide insight into the responsiveness and person-centeredness of he

In Sub-Saharan Africa, self-reported quality of epilepsy care studies have indicated low rating. This is attributes to long waiting times, poor communication, limited access to trained healthcare professionals and diagnostic equipment and regular stockout of anti-seizure medications, The epilepsy treatment gap remains high, resulting in poor patient experiences and reduced confidence in healthcare services (WHO, 2024).

In Kenya, studies evaluating self-reported quality of epilepsy care in Kenya remains limited, particularly using validated patient-reported quality-of-care measures. Most Kenyan studies have focused on prevalence, treatment gaps, seizure control, stigma, and medication adherence rather than patients' experiences of healthcare quality. This evidence gap highlights the need for studies that comprehensively assess patient-reported quality of care and identify patient- and facility-level predictors, particularly among newly diagnosed and follow-up patients attending public hospitals. However , efforts to improve epilepsy care have been strengthened through the Kenya Health Policy 2023–2030, the Kenya Community Health Policy 2020–2030, the Kenya Mental Health Policy 2015–2030, and implementation of Universal Health Coverage. These barriers negatively affect patients' perceptions of care quality, treatment adherence, continuity of care, and overall satisfaction with health services (MOH, 2023).

2.1.2 Domains of Quality Care

Domains of quality in health care in this study relates to safety, courtesy, communication, tolerability, effectiveness, access, affordability, privacy, promptness, equity and affordability

Efficiency: Avoiding waste, including waste of equipment, supplies, ideas, and energy. It can be measured by utilization of hospital services, procedures, discharge rates and length of stay. It relates to maximizing the quality of a comparable unit of health care delivered or unit of health benefit achieved for a given unit of health care resources used.

Safety: Avoiding harm to patients from the care that is intended to help them relating to actual or potential bodily harm

Courtesy: Providing care that is respectful of and responsive to individual patient preferences, needs, values and ensuring that patient values guide all clinical decisions. They can report on the care they receive from the hospital or care instructions upon hospital discharge

Communication: in healthcare it helps develop a sense of trust between the patient and provider, which might make it easier for patients to adhere to a provider's recommendations.

Tolerability: the degree to which overt adverse effects of a drug can be tolerated by a patient.

Effectiveness: Providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding under-use and misuse, respectively). These include percentage of patients receiving recommended hospital care for specific conditions

Accessibility: the ease with which health services are reached in terms of physical access (geographical distribution), costs, time, and availability of qualified personnel.

Affordability: whether a person or organization has sufficient income to pay for or provide for health care costs.

Privacy: This encompasses personal space (physical privacy), personal data (informational privacy), personal choices including cultural and religious affiliations (decisional privacy), and personal relationships with family members and other intimates (associational privacy).

Promptness: obtaining needed care while minimizing delays. Reducing waits and sometimes harmful delays for both those who receive and those who give care.

Equity: relates to providing health care of equal quality to those who may differ in personal characteristics other than their clinical condition or preferences for care.

The domains also make it easier for consumers to grasp the meaning and relevance of quality measures. They were chosen to address aspects of patient care that research evidence and practical experience consider appropriate for reporting to consumers (WHO, 2024).

2.1.3 Perspectives of Quality Services for PWE

Perspectives of quality services for people with epilepsy are that services should be accessible, acceptable, equitable and patient-centred, thus considering aspirations and preferences, including community cultural heritage. It should be as appropriate for clinical care as for management services that support service delivery. Skills used by healthcare providers to promptly respond to the healthcare needs of the population and keep the facilities within a reasonable geographical distance enhance accessibility and amount to equity. These aspects should be kept safe with minimal risk and harm to service users and should not vary with personal characteristics. Therefore, the dimensions of quality include efficiency, continuity, safety, availability of amenities, technical competence, access to services, effectiveness and interpersonal relations, each considered in the light of specific programs and the local context (Manatos et al., 2017).

2.1.4 Principles of Quality Care for PWE

Quality health services for people with epilepsy emphasise early diagnosis of epilepsy and comorbid conditions. Development of national quality framework and implementation of practice management guidelines, improving treatments, developing, implementing, and assessing performance metrics are core to the provision of quality care. Improving communications between the care team and patients; and evaluation and accreditation of epilepsy care centres are equally central in this arrangement (England *et al.,* 2012).

2.1.5 Perspectives of the Quality of Care

Perspective of quality of health care refers to the meaning of quality for the communities and clients that depend on it, the clinicians who provide it, and the managers and administrators who oversee it. For the clients and communities served by health care facilities, it is the care that meets their perceived needs, delivered courteously, on time and effectively relieves their symptoms and prevents illness. Thus, the dimensions of quality that relate to client satisfaction affect the health and well-being of the community at large (Yip et al., 2015).

From the provider's perspective, quality care implies skills and conditions necessary to improve the health status of the patient and the community, based on the prevailing technical standards and available resources. The provider's commitment and motivation depend on the ability to carry out his or her duties in an ideal or optimal way with a focus on technical competence, effectiveness and safety. Health care providers are the healthcare system's internal clients. They need and expect effective and efficient technical, administrative, and support services in providing high-quality care (Mosadeghrad, 2013).

For Healthcare managers, quality care requires that managers are rarely involved in delivering patient care, although the quality of patient care is central to everything they do. They focus on the various dimensions of quality that can help to set administrative priorities e.g., supervision, financial and logistics management. They must therefore provide for the needs and demands of both providers and patients as they are expected to be responsible stewards of the resources entrusted to them by the government, private entities, and the community (Handfield et al., 2020). These dimensions present many unexpected challenges and crises to them. This can leave a manager without a clear sense of priorities or purpose.

2.1.6 Dimensions of Quality Care

The dimension of interpersonal relations refers to the interaction between providers and patients, managers and health care providers, health institution and the community. Good interpersonal relations establish trust and credibility through demonstration of

respect, confidentiality, courtesy, responsiveness and empathy. Effective listening and communication are also important in this regard. Inadequate interpersonal relations can reduce the effectiveness of a technically competent health service (Upadhyai et al., 2019).

2.1.7 Quality Measurement of Quality of Care

Quality measure is the mechanism to assign a quantity to a quality of care by comparison to a criterion. It is the process of using a scientifically sound tool to assess the extent to which clients receive health care in any of the quality domains. It is a rigorous, systematic and quantifiable exercise that focuses on structures or processes of care that demonstrate a relationship to positive health outcomes under the control of the health care system. Quality measures can therefore be used to evaluate health facility, Managed Care Organization (MCO), Health Program or Health Care Practitioner (Franco Montoya et al., 2020). According to the Agency for Healthcare Research and Quality, to use quality measurement, a responsible entity with a reasonable degree of control over the aspect of care being evaluated needs to be identified and held accountable for its observed behaviour. It is, therefore, a type of evaluation that is usable in many industries. In healthcare quality measurement today, expert consensus is often used to reach agreement on precise definitions and measurement specifications. In developing a quality measure, it must be tested to ensure that it is: Reliable, indicating that use of the tool results in the same reading regardless of who does the measuring or when the location of measurement. Secondly, the tool should be valid, meaning the tool measures what is intended. Lastly, the tool should be standardised in terms of data elements definitions, data collection and data analyses that are sufficiently precise and comprehensible and that can be understood and applied in the same way regardless of who refers to or applies them (Health & Services, 2011). It is important to note that, the further a measure is from these ideal technical conditions, the greater the difficulty in using the measurement information to compare health plan or program results or in answering specific questions about the health care being provided (Donabedian,1988).

2.1.8 Significance of Quality of Care

Concerns about patients occasionally receiving poor‑quality health care demands for greater transparency and accountability. Uncertainty still remains over which policies work best in delivering safe, effective health care that provides a good patient experience, and on which quality-improvement strategies can help deliver the best care at the least cost (WHO, 2006).

Knowledge of challenges and good practices helps to support improvements in health care quality and help ensure that the substantial resources devoted to health are used effectively in supporting clients with epilepsy to live healthier and more satisfying lives. Outcomes reported by patients themselves underpin standards, guidelines, incentives and innovations in service delivery. Greater transparency that leads to optimization of quality can be supported by; making changes in where and how care is delivered, modifying the roles of patients and professionals, and by employing appropriate tools (Black, 2013; Buccheri & Sharifi, 2017).

Patient views on quality of care are of paramount importance with respect to the implementation of quality assurance (QA) and improvement (QI) programmes. Therefore, patient satisfaction plays an important role in maintaining relationships between patients and health care providers, compliance with medical regimens and continued use of medical services. Patient satisfaction is felt to be of paramount importance with respect to quality assurance (QA) and the expected outcome of care (Sofaer & Firminger, 2005).

Approaches to delivering quality are variable. The first is a quality culture among both clinicians and service managers, to encourage continuously better and safer care. Ways to encourage a culture of continuous quality improvement include educational measures, feedback on performance, and learning and sharing from good practices. This is essential to change behaviour and to seek opportunities for quality improvement (Wolfe, 2001). The second ingredient is a clear accountability framework. This entails a role for central authorities to: set system-wide priorities; provide consistent approach to measure them; identify excellence; and support poor

performers. Ambitious quality-improvement programmes can fail to deliver expected results in a system characterized by a weak accountability framework with fragmented leadership. Therefore, sufficient space for local innovations to improve care quality is encouraged Institute of Medicine, United States of America (Wolfe, 2001).

Care continuity and care co-ordination are important for people with higher health care needs, such as those with epilepsy, who often need both medical and social care over time. Without consistently good co-ordination, there is a real risk that complex health needs will go unmet. Poorly coordinated and fragmented care is often caused by services operating independently of each other, and can lead to poor patient outcomes, inefficient services and wasted resources. Co-ordination difficulties occur at the interfaces between various parts of the health care system and between health care, social care and long-term care. Most often, new models of shared care are required to promote co-ordination across health and social care systems.

Transformation towards more integrated and coordinated care requires the courage to challenge the ways in which patients have traditionally been treated. It effectively requires developing new models of care such as multidisciplinary health centres, which offer the potential to encourage health and social care to work more closely together. Centres that offer a range of services, including clinical pathways, disease management and case management are key instruments to promote communication and collaboration (WHO, 2016). Factors that have been identified as the key to satisfaction are preference of patients, coordination of care, the physical comfort of patients, emotional support from family and friends, continuity, transition, information, education and access (Batbaatar et al., 2017).

2.2 Socio-Demographic Predictors of Quality of Care

Sociodemographic factors influence risk attitudes, risk perceptions and socioeconomic status (SEP), which are widely associated to disease incidence and mortality (Lo Presti *et al.,* 2022). Additionally, the majority of recognised risk factors for a disease are more likely to have an impact on individuals with lower SEP. Although SEP has previously been recognized as a potential risk factor for the majority of diseases in general, it also has a significant impact on the outcomes of PWE, either directly or

indirectly, through occupation, living situation, health-related behaviours, the presence of comorbidities, and immunological function. However, epilepsy is linked to psychological, social, physical and behavioural health (Jehi *et al.,* 2022).

Health-seeking behaviour can be directly influenced by marital status, education level and gender. Marriage offers an opportunity for social and psychological support with a reduction of the negative impact of the disease as family members share in bearing the social burden (Xiao *et al.,* 2020). Education affords a chance for an individual to adjust emotionally and possibly handle stigma better. It positively correlates with quality of care as lower education level predicts lower quality of care total score (Tinsae *et al.,* 2024).

Biological differences between the sexes can influence risks and vulnerability to diseases as well as their outcomes (WHO, 2022). The demographic characteristics that are substantially linked with low quality of care ratings are advanced age, female sex, and a low level of education. However, marital status and occupation do not significantly affect the quality of care for patients with epilepsy as reported previously (Mesraoua et al., 2021).

Knowledge of socio-demographic characteristics of respondents helps to categorise them into different sub-groups so as to have a better understanding of the target audience for public health interventions. These factors not only influence an individual's ability to acquire knowledge but also to obtain effective social support around their diagnosis and to communicate effectively with their health care providers (Singh et al., 2024).

2.3 Clinical Predictors of Quality of Care for PWE

Stigma, psychiatric co-morbidities, social or physical limitations and the possibility of unexpected death are key clinical attributes to quality care for PWE (Pace *et al.,* 2024). The fact that a sizable fraction of PWE still suffer from recurrent seizures is concerning, especially in light of the wide range of cutting-edge therapies that are currently accessible. Some of this treatment disparity may be caused by social factors. Moreover, mental functioning, emotional well-being and self-esteem are also

significant predictors of the care they receive as they have a direct impact on all dimensions of the life of PWE. Physical activities are restricted for fear of seizure occurrence, and internal stigma explains poor emotional well-being (Mendes et al., 2017).

For patients on treatment, medication side effects, nature of therapy and seizure frequency are critical predictors as seizure control alone cannot necessarily improve the social limitations, such as chances of marriage and employment. Consequently, victims of stigma may not adhere to AEDs therapy and hence achieve limited seizure control. Therefore, low social functioning and low emotional well-being from stigma, which arises from a lack of knowledge on epilepsy on the part of the public and family members, can cause a significant barrier to seeking treatment (Ibinda et al., 2017).

Patients on poly-therapy due to complex dosing regimens have a higher number of drug side effects (Welton et al., 2020). Continuous administration of some AEDs is associated with memory lapse, motor disorientation and aggressive behaviour. A study by Chen et al. (2016) showed that clinical variables that significantly impacted HRQL were high seizure frequency and prolonged epilepsy (Chen et al., 2016). Additionally, a cross-sectional study in Korea looking at predictors of quality of care for PWE found an association between seizure drugs and QOC as well as a complicated interaction between adverse effects of ASMs and QOC for PWE. Duration of epilepsy affects the quality of care for PWE, and it is among the variables that are a potential predictor of low quality of care (Mesraoua et al., 2021).

Level of knowledge has often been a factor that affects the quality of care for patients, as persistent educational initiatives might result in a sizable shift in societal attitudes towards epilepsy (Giuliano et al., 2019). Anti-epileptic drugs (AEDs) are the primary therapeutic modalities for epilepsy management. However, one-third of patients continue to experience seizures even after starting on an appropriate drug and remain at an increased risk for seizure-related injury at home, streets and in places of work. Seizure-free clients have high levels of quality of care as compared to those of the general population. Increased seizure frequency is associated with impaired outcome

regardless of time since last seizure, gender, and comorbid status (Medel-Matus et al., 2022).

The clinical stage of illness influences healthcare providers' job stress, which in turn affects the overall quality of medical services. Knowledge about the clinical sickness and its severity helps to evaluate the hospital's resources and establish patient care guidelines. It is also useful for the quick understanding of the patient's needs in order to set priorities for the response teams. The more well-defined the illness factor, the more likely the team will be on the same page and be able to react appropriately to the demand level for the service that needs to be put in place (Abu-Rish Blakeney, 2025).

2.4 Hospital-Level Predictors of Quality of Care for PWE

Hospital-level factors that predict the quality of care for a client are factors that affect the setting in which care is delivered. These factors include physical facilities, human resources, equipment and the organisational characteristics, policies, financing, health coverage and facility infrastructure. They create demand for services on the part of patients and meet the needs on the part of the providers. As a result, stewardship for the resources provided, equitable allocation of resources for the service delivery, management practices, staffing norms and technical competencies are critical entities. They dictate how providers and patients act in a healthcare system and are a measure of the average quality of care within a facility or system. These factors not only have an influence on the access but also on the effectiveness and efficiency of the services they receive (Ward et al., 2024).

Other factors that can predict the quality of care that occur in the course of service delivery include diagnosis, treatment, preventive care, and patient education, including actions taken by the patients or their families. Technical processes refer to how care is delivered, and interpersonal processes refer to how care is delivered (Upadhyai et al., 2019). Its measurement is nearly equivalent to the measurement of quality of care because it contains all acts of healthcare delivery (Ibn El Haj et al., 2013). Information about it can be obtained by interviews with patients and practitioners, direct observations of healthcare visits or from medical records. Some of the factors include; the time patients wait to receive services. Longer wait times not only have a negative

influence on satisfaction but also have an impact on how patients perceive the information, directions, and overall care offered by carers (Batbaatar et al., 2017). Also, there is a financial burden on people and health care systems around the world due to the direct costs of caring for someone with epilepsy and the indirect costs brought on by reduced productivity.

Internal and external factors, such as availability of resources and collaboration among healthcare providers, directly affect treatment outcomes and patient level of satisfaction. Supportive leadership, education and training and effective management of resources and processes improve the quality of medical services (Bhaladhare & Rishipathak, 2025). A physician's character and personality affect the quality of medical services (Mosadeghrad, 2014).

Health care providers develop a good rapport with their patients using some personality characteristics such as respect, helpfulness, reliability, intelligence, and confidence. The quality of healthcare does not only depend on practitioners' knowledge and technical skills but also attitude, communication with patients and the income they receive. In a public hospital, the demand for medical services is very high, yet physicians are not motivated to improve their communication skills (Kim et al., 2024).

Medical insurance companies have always made it even more affordable for patients to see a medical specialist and increase access. Lack of patient trust in healthcare workers and lack of familiarity with medical practices increases uncertainty and leads to repeated medical visits Healthcare workers who take part in a study often complain that they are overworked and as public healthcare system suffers from staff shortage and have to spend less time on each patient They have to limit their flexibility and adaptability to the patients' individual needs due to staff shortages and time constraints (Gu et al., 2022).

Leadership capital is the leader's ability to direct an organisation forward in a positive direction. Healthcare managers must develop their leadership skills and demonstrate their commitment to quality by establishing a shared vision and setting a clear direction for the hospital. Healthcare managers should transform their organisational value

system and ultimately the organisational culture, policies and structure to meet the needs of their employees and customers (Elamir, 2021).

Clinical guidelines are standardized documents with treatment and management protocols. If implemented effective, they would reduce variations in care between facilities, promote early diagnosis and timely treatment initiation and consequently improve seizure control through evidence-based management. The overriding impact is reduced negative effects of delayed treatment initiation and inconsistent clinical management on quality of care.

The study has direct implications for healthcare providers. Healthcare managers are encouraged to regularly monitor healthcare quality and, accordingly, initiate continuous quality improvement programmes to maintain high levels of patient satisfaction Knowledge of hospital-level factors helps in developing a conceptual framework for understanding factors that influence the quality of care. The findings will have important implications for policymakers, including provisions for necessary resources and the establishment of supportive rules and regulations to maintain high levels of patient satisfaction (Tibeihaho et al., 2021).

2.5 History of Epilepsy

The term ‘epilepsy’ is derived from a Greek word “epilambanein” which means ‘attack’, ‘grab’, ‘capture or ‘seize’ or to be overwhelmed by surprise. Its first mention in history dates back to 930-1037 by an Arabian physician and philosopher, Ibn Sina (Francomano, 2008). Being the most common serious brain disorder, it is probably the most universal of all medical disorders (Thijs et al., 2019). However, it is often surrounded by prejudice and myths and attached social stigma is its most debilitating accompaniment with negative impact on self-image, self-esteem and self-respect leading to anxiety, depression and decreased life satisfaction. Stigma and low self-esteem among people with epilepsy arise from persistent misconceptions, discriminatory attitudes, fear of unpredictable seizures, inadequate public awareness, and poor seizure control.

The myths that surround epilepsy contribute to social exclusion, psychological distress, reduced healthcare utilization, poor treatment adherence, and ultimately poorer quality-of-care and health outcomes for PWE (WHO, 2024). It is also associated with neurological, cognitive, psychological consequences, social isolation, increased risk of unexpected death and reduced life expectancy (Beghi, 2020). Without proper treatment, they have significant morbidity and mortality than the general population (Thurman et al., 2017).

The many implications of a stigmatized identity for the individual with epilepsy is to open oneself to the full force of past and contemporary social prejudice and misunderstanding (Nyakwana *et al*., 2018). Epilepsy is a condition characterized by enduring predisposition to generate two or more unprovoked seizures occurring more than 24 hours apart (Johnson, 2019). Its management has substantial disparities in outcomes as its care has propensity to be fragmented and poorly co-ordinated in countries where it exists. Health care system factors associated with its improved outcomes are modifiable. Therefore, changes in its preventive care, monitoring and effective self-care are part of its process improvement.

2.6 Burden of Epilepsy

Epilepsy is a significant public health problem. About 70 million people have epilepsy worldwide, with another additional 500 million people affected as family members and caregivers of patients. It is increasingly recognized as a neglected chronic neurological disorder (Beghi et al., 2019).

In Kenya, it is estimated that about 800,000 to 1 million people are living with epilepsy (Kariuki et al., 2021). In 2010, the WHO's Global Burden of Disease ranked epilepsy as the second most burdensome neurologic disorder worldwide in terms of disability-adjusted life years. It is a serious neurologic condition associated with stigma, psychiatric comorbidity and high economic costs ("Global, regional, and national burden of epilepsy, 1990-2021: a systematic analysis for the Global Burden of Disease Study 2021," 2025).

Though numerous studies have been carried out in different parts of the world in an attempt to compare the burden across different regions, comparisons across studies have been challenging to make due to differing study methodologies, case ascertainment and diagnosis (Abramovici & Bagić, 2016). Studies suggest a higher burden of epilepsy in LMICs when compared to high-income countries. This higher burden is attributed to higher levels of known risk factors, including infections and poor antenatal and perinatal care in these contexts (Ba-Diop et al., 2014).

In Kenya, there are six different levels of public health care facilities. At the lowest level are Community facilities run by certified medical clinical officers, followed by Health dispensaries also run by clinical officers. The third level is Health centres, which are small hospitals with minimal facilities. Level four hospitals are the County hospitals, which provide holistic services. The highest levels of hospitals in the country are Country referral hospitals (Level five) and the National referral hospitals (Level six) (Kairu et al., 2021). The first five are managed at the county level, and the sixth level by the national government. In this system, the patients may move from one level to the next by using a referral letter.

Special conditions like epilepsy are usually attended to at the level 5 facilities, where the resources and infrastructure are favourable. The health-seeking behaviour among people with epilepsy is culturally driven, and data on epilepsy management are limited (Kiwanuka and Olyet, 2018). Therefore, not many people seek epilepsy care services, as it is mainly associated with supernatural forces. As a consequence, there is a wide treatment gap due to low rates of epilepsy and poor access to treatment (Samia et al., 2023). However, many of them do not seek biomedical treatment, and many of those who are on prescribed treatment do not adhere to it, thus contributing to the wide treatment gap (Ibinda et al., 2017).

Beliefs that epilepsy is caused by spiritual forces such as witchcraft, curses, evil spirits, ancestral displeasure, or demonic possession can significantly influence treatment-seeking behavior and health outcomes. In many African settings, including Kenya, epilepsy is often interpreted through cultural and spiritual frameworks rather than as a neurological disorder, resulting in delayed access to biomedical care and reduced

adherence to antiepileptic medications Individuals and families who attribute seizures to supernatural causes frequently seek help from traditional healers, spiritual leaders, or faith-based interventions before consulting health facilities. This may delay diagnosis and initiation of appropriate treatment, thereby worsen seizure control and increase the risk of disability and premature mortality (WHO, 2024).

Evidence from Sub Saharan Africa and rural Kenya indicates that traditional animistic religious beliefs were significantly associated with failure to seek biomedical treatment among people with epilepsy. Such beliefs contribute to the epilepsy treatment gap by reducing utilization of formal health services and adherence to prescribed antiepileptic drugs (Chabangu, 2012)

Spiritual explanations of epilepsy also reinforce stigma and discrimination. Misconceptions that epilepsy results from curses, possession, or moral wrongdoing may lead to social exclusion, reduced educational and employment opportunities, delayed marriage, and psychological distress. Consequently, many people with epilepsy conceal their condition or avoid seeking treatment because of fear of discrimination (Thijs et al., 2019).

Reliance on spiritual healing alone may result in discontinuation of medication when individuals believe they have been cured through prayer, rituals, or traditional remedies. Poor adherence contributes to recurrent seizures, preventable injuries, and poorer quality-of-life outcomes. Conversely, when religious leaders encourage both spiritual support and adherence to medical treatment, spirituality can play a positive role by improving coping, emotional well-being, and social support (Mbewe et al., 2023)

2.7 Prevalence of Epilepsy

Globally, active epilepsy has a pooled point prevalence of 6.38 per 1,000 persons. The pooled lifetime prevalence of epilepsy is 7.60 per 1,000 persons and a median lifetime prevalence of 7.06 per 1,000 persons in high-income countries, but in middle- and low-income countries, it is 49.00 per 1,000 persons (Fiest et al., 2017; WHO, 2024). The high-income countries and a median point prevalence of 5.40 per 1,000 persons. In the

Low- and Medium-income countries the median annual period prevalence is 13.56 per 1,000 persons (Arom et al., 2023) .

In Africa, though very few extensive population-based studies have been conducted, the prevalence rate of epilepsy has been seen to vary with individual reviews and country by country ranging from 0.7 to 1.5% with bimodal distribution peaks at 20-29 and 40-49 years (Odhiambo, 2021). In Tanzania, random cluster sample survey in Ulunga District reported a prevalence of 10.2 per 1000 (Kariuki et al., 2021). A door-to-door survey in Zambia found an unadjusted incidence of 14.5 per 1000 (Pi et al., 2014). A meta-analysis found a prevalence rate of 9.39 per 1000 individuals with a median of 14.2 (interquartile range of 8.0-33.2 per 1000) in Sub Saharan Africa (Ba-Diop et al., 2014; Bistet et al., 2024). Generally, in Africa, the prevalence rate of epilepsy is 11.29 per 1000 population (WHO, 2008, 2024).

In rural Kenya and other African countries, about 69% of the seizures began in childhood. Its prevalence in these countries is about 20 cases in every 1,000 people and about 77 in every 100,000 new cases are diagnosed every year. These estimates are 2-3 times higher than in developed countries. In a cross-sectional survey carried out in Kilifi, a prevalence of 3.5 per 1000 inhabitants at risk with 3.8 for males and 3.3 for females (Elger & Schmidt, 2008). An earlier survey carried out in Nakuru District found a prevalence rate of 18 per 1000 of the population (Fiest et al., 2017; Ngugi et al., 2021). However, it is a well-known condition among the top 12 common diseases usually identified by families, often using local names (Nyakwana et al, 2018)

2.8 Incidence of Epilepsy

The pooled annual cumulative incidence of epilepsy is 67.77 per 100,000 persons and a median cumulative incidence of 65.61 per 100,000 persons in high income countries and 189.96 per 100,000 persons in medium and low-income countries (Fiest et al., 2017). The pooled incidence rate of epilepsy is 61.44 per 100,000 person-years and the median incidence rate of epilepsy is 56.79 per 100,000 person-years. The incidence rate of epilepsy is higher in low–middle income countries compared to high–middle-income countries (Kariuki et al., 2021).

2.9 Risk of Epilepsy

Epilepsy occurs in any person irrespective of age, sex, economic or geographic location. Though the actual cause is not fully understood, it is attributed to abnormal and excessive electrical discharges in the brain, which may result from birth trauma, infections of the brain and head injuries. Other risk factors include a family history of seizures (Sveinsson *et al*., 2020).

2.10 Diagnosis and Care for People with Epilepsy

Epilepsy management requires a multidisciplinary and multisectoral approach involving patients, families, healthcare providers, health facilities, policymakers, professional bodies, and community stakeholders. Each plays a complementary role in improving diagnosis, treatment, adherence, seizure control and quality of life. (Fisher et al., 2023). The diagnosis of epilepsy is made based on a history of having had two or more unprovoked seizures in one year, 24 hours apart. In most instances, physical examinations do not yield enough data apart from those with other co-morbid conditions. Laboratory and other tests can also be done to rule out any underlying cause of severe seizures (NICE, 2025).

The tests to confirm abnormalities in the structure and functions of the brain include:

i. **Electro-encephalogram (EEG)** can use conventional or high-density waves to determine areas affected by seizures. It can be used to measure electrical activity in different parts of the brain and to diagnose some forms of epilepsy, particularly in people without physical signs of the condition.

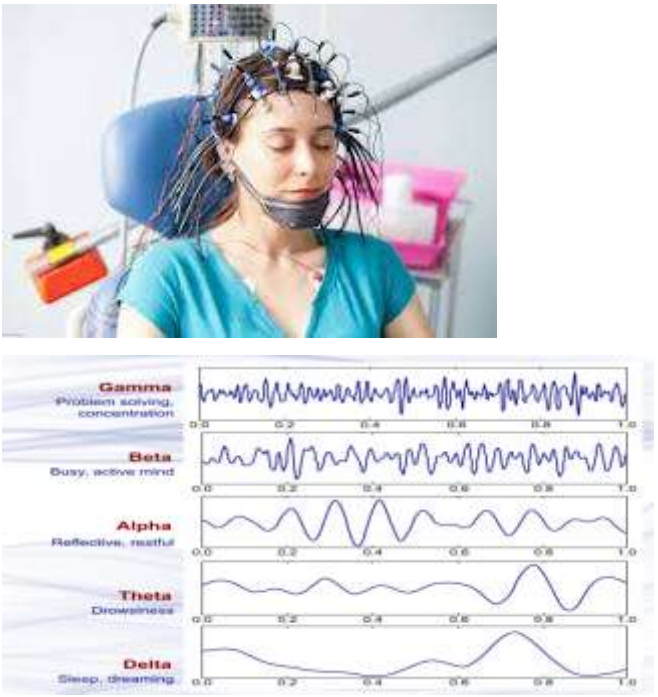

Figure 2.1: Electroencephalography

Source https://shardaneuropsychiatryhospital.com/eeg-electroencephalogram/

ii. **Computerised Tomography scan**-uses x-rays to obtain cross-sectional images of the brain to rule out abnormalities that may be causing seizures, e.g. tumours, bleeding and cysts.

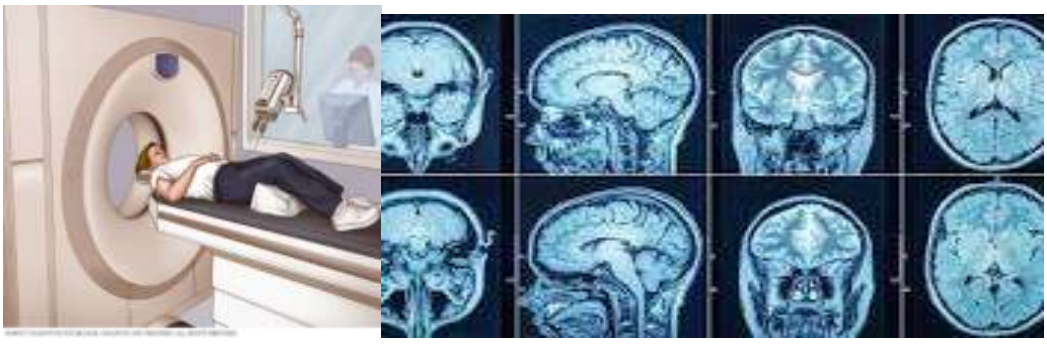

Figure 2.2: Computerised Tomography

Source: (https://www.altru.org/health-library/conditions/epilepsy)

iii. **Magnetic Resonance Imaging -** uses radio waves and powerful magnets to view the brain in details and detect abnormalities or lesions that could be causing seizures.

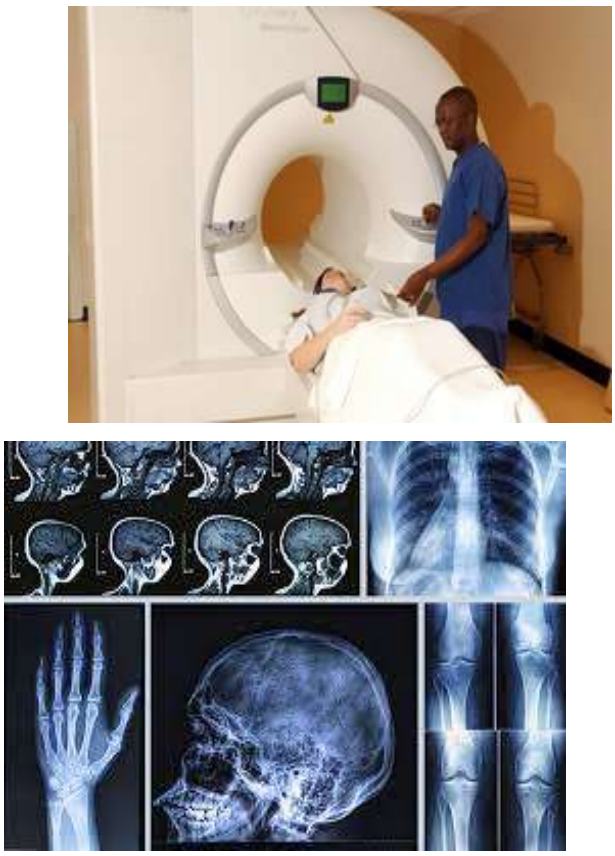

Figure 2.3: Magnetic Resonance Imaging

Source: (ttps://www.nhs.uk/tests-and-treatments/mri-scan/)

iv. **Functional MRI (fMRI)-**measures changes in blood flow in specific parts when brain is working. fMRI may be used before surgery to identify the exact location of critical functions such as speech and movement to avoid surgeons injuring those places while operating.

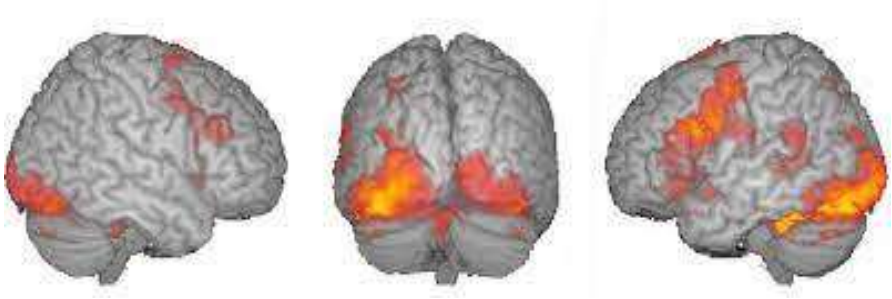

Figure 2.4: Functional MRI (fMRI)

Source https://med.nyu.edu/thesenlab/research-0/research-functional-magnetic-resonance-imaging-fmri/

v. **Positron emission tomography (PET)** - scans that use a small amount of low-dose radioactive material that's injected into a vein to help visualize active areas of the brain and detect abnormalities.

Figure 2.5: Positron Emission Tomography (PET)

Source https://quizlet.com/au/882970761/son1101-lecture-2-flash-cards/

vi. Single-photon emission computerised tomography (SPECT) - uses a small amount of low-dose radioactive material that's injected into a vein to create a detailed, 3-D map of the blood flow activity in the brain during seizures.

Figure 2.6: Single-Photon Emission Computerized Tomography (SPECT)

Source https://icloudhospital.com/specialties/cardiac-spect-imaging

vii. **Subtraction ictal SPECT** co-registered to MRI (SISCOM) - provide more-detailed results.

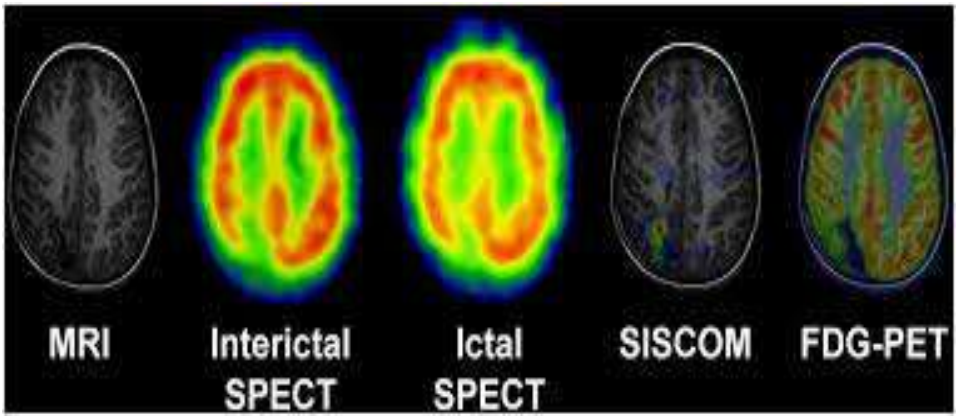

Figure 2.7: Subtraction ictal SPECT Co-Registered to MRI (*SISCOM)*

Source https://jnm.snmjournals.org/content/55/7/1099

viii. **Neuropsychological tests** used to assess thinking, memory and speech skills and determine which areas of the brain affected. Along with test results, a combination of analysis techniques helps to pin-point where in the brain seizures start:

a. **Statistical parametric mapping (SPM)** -compares areas of the brain that have increased metabolism during seizures to normal brains and give idea of where seizures begin.

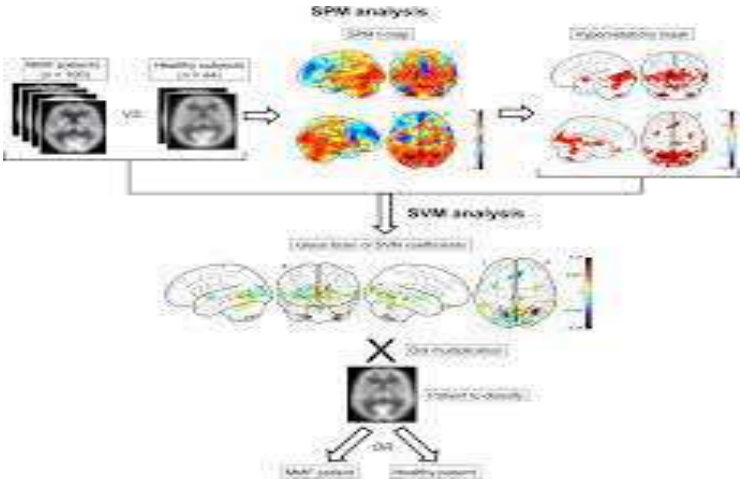

Figure 2.8: Statistical parametric mapping (SPM)

Source https://www.researchgate.net/figure/Statistical-parametric-mapping-SPM-and-support-vector-machine-SVM-procedures-MMF_fig1_318405163

b. **Curry analysis -** a technique that takes EEG data and projects it onto an MRI of the brain to show where seizures are occurring.

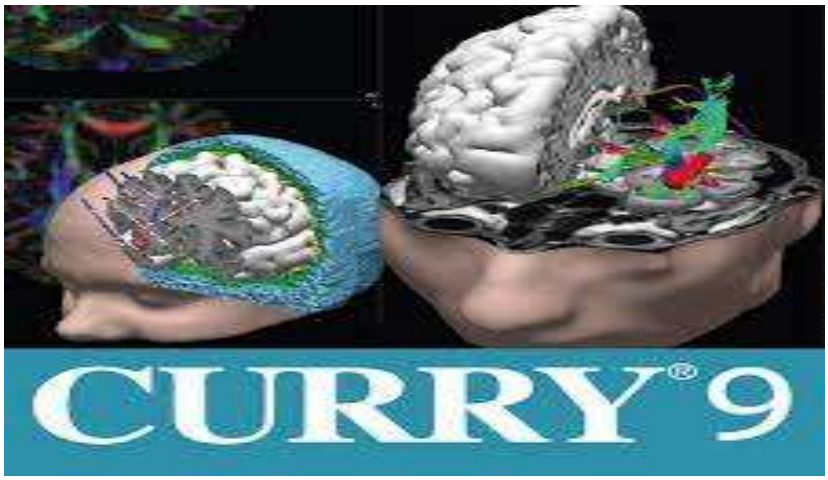

Figure 2.9: Curry Analysis

Source https://compumedicsneuroscan.com/product/curry-9-s-signal-processing/

c. Magnetoencephalography (MEG) - measures the magnetic fields produced by brain activity to identify potential areas of seizure onset.

d.

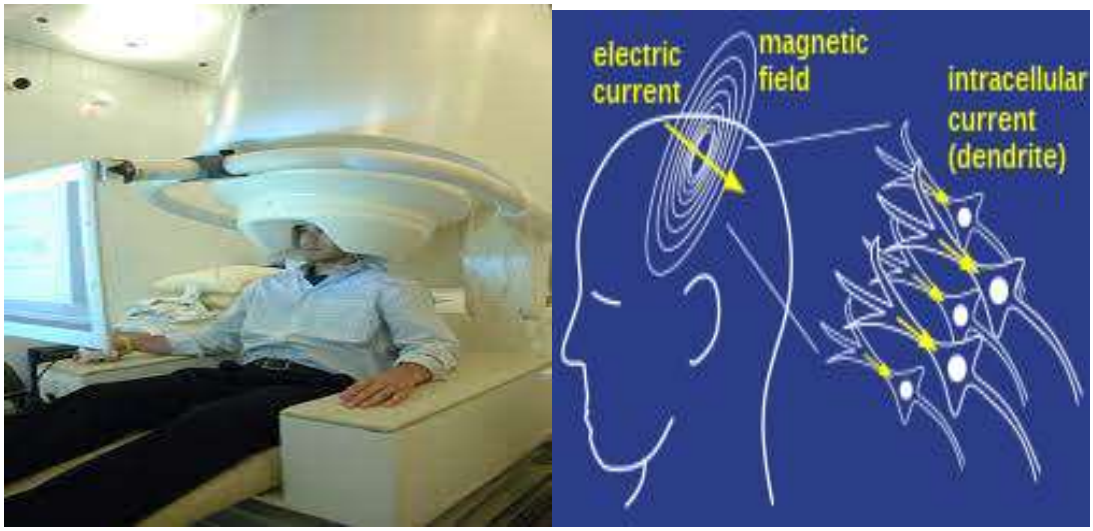

Figure 2.10: Magnetoencephalography (MEG)

Source https://www.topdoctors.co.uk/medical-dictionary/magnetoencephalography/

NB: Accurate diagnosis of seizure type and where seizures begin gives the best chance for finding an effective treatment.

N/B Computerised Tomography (CT) scan and Magnetic Resonance Imaging (MRI) can be used on people with a history of birth problems or head injuries to rule out lesions.

Anti-epileptic drug therapy should be given immediately after the diagnosis is confirmed to control seizures and improve the quality of life (Rehman et al., 2019).

2.11 Gaps in Epilepsy Care

Access to diagnostic technologies is a critical determinant of quality of care in epilepsy**.** It influences the accuracy of diagnosis, appropriateness of treatment, continuity of care, and ultimately patient health outcomes. Such technologies enable healthcare providers to correctly identify seizure types, determine underlying causes, and develop appropriate management plans. Accurate diagnosis is fundamental to quality epilepsy care. Inadequate access to diagnostic technologies may result in misdiagnosis, delayed treatment initiation, inappropriate medication use, and poor seizure control. Studies indicate that a substantial proportion of patients referred with

suspected epilepsy are later found to have non-epileptic conditions, highlighting the importance of diagnostic confirmation through EEG and neuroimaging where appropriate (NICE, 2022).

In Kenya, there is limited access to diagnostic tools such as electroencephalography (EEG), magnetic resonance imaging (MRI), computed tomography (CT), and laboratory investigations enable clinicians to accurately classify seizure types, identify epilepsy syndromes, and detect underlying causes of seizures. Poor access to such tools together with shortage of trained personnel remain a significant barrier to quality epilepsy care. The World Health Organization has identified strengthening diagnostic capacity as a priority intervention for reducing the epilepsy treatment gap and improving outcomes among people with epilepsy (WHO, 2022). Therefor care of epilepsy in a clinical setting begins with a detailed medical history from the patient, family members and eyewitness's account. The health worker conducts systemic enquiry of the central nervous system, possible triggers, specific circumstances and any other related past medical history. Birth history is also taken to ascertain the perinatal risk factors. Any video recordings are vital for assessment (Tatum et al., 2020).

Often PWE delay or fail to seek medical treatment due to traditional belief that epilepsy is caused by supernatural forces or powers. The stigma and discrimination they face in the society and lack of accessible and affordable health care help to widen the treatment gap. There is also lack of awareness about the disease which reinforces delay. However, upto 70% of people with epilepsy can be successfully treated with anti-epileptic drugs. There are few epilepsy specialists and they are mostly based in urban centres. Many of PWE do not seek biomedical treatment and many of those who are on prescribed treatment do not adhere to it thus contributing to the wide treatment gap (Ibinda et al., 2017). The quality of care and its predictors have not been determined and documented. The risk of premature death is 6.5 times greater among people with convulsive epilepsy versus those without (Thurman et al., 2011; Han et al., 2025).

Disparities in access to epilepsy healthcare are reflected in treatment gaps (TG) across various regions of the globe. It exists in access to specialised epilepsy care, especially in populations of low socio-economic status (SES). This definition includes diagnostic and therapeutic deficits. Low-income people with epilepsy are 50 per cent less likely to report taking seizure medications (Bensken et al., 2021). People using emergency rooms for treatment of seizures were more likely to be uninsured (Schiltz et al., 2013). Other studies found a lower rate of neurologists' visits for uninsured individuals and considerable difficulties for children enrolled in Medicaid to obtain neurologist appointments (Bailey et al., 2021; Elkhider et al., 2022). Physicians serving patients covered by public insurance (Medicaid and the Child Health Insurance Program) reported difficulty finding a neurologist to whom to refer patients (Marrie et al., 2022). Access to AEDs is both a cause and an obstacle to bridging the treatment gap (Marshall et al., 2021). Apart from phenobarbitone, other AEDs, i.e. phenytoin, carbamazepine and valproate are significantly more costly (Abou-Khalil, 2019).

In sub-Saharan Africa, disparities vary widely, ranging from 23% in Senegal to 100% in Uganda, Tanzania and Gambia (Spaull & Jansen, 2019). In Togo, the Treatment Gap in six primary care centres, determined by treatment interruption, ranged from 94% to 98% (Baptiste et al., 2020). Limitations to access quality epilepsy health care may result from the location of services in multiple health care and community facilities with limited transportation options, as well as from limits in health insurance plans for the coverage.

2.12 Health care Delivery in Kenya

2.12.1 Organization of Healthcare System in Kenya

The Organization of Healthcare Service Delivery System in Kenya's health care system is structured in a hierarchical manner that begins with primary healthcare, with the lowest unit being the community, and then graduates, with complicated cases being referred to higher levels of healthcare. Primary care units consist of dispensaries and health centres. The current structure consists of: Level 1: Community, Level 2: Dispensaries, Level 3: Health centres, Level 4: Primary referral facilities, Level 5:

Secondary referral facilities and Level 6: Tertiary referral facilities (Nyawira et al., 2022).

The Kenya government in collaboration with other stakeholders in the health sector has made strides to improve the health of the population and overall socio-economic status of her citizens. Some of the initiatives include the development and implementation of the policies. The country has striven to overcome development obstacles and improve the socio-economic status of her citizens, including health. Some of the initiatives include the development and implementation of the Kenya Health Policy Framework (KHPF 1994−2010), Vision 2030, the promulgation of the Kenya Constitution 2010, and fast-tracking actions to achieve the Millennium Development Goals. The government also upholds the fundamental right to health access for every Kenyan as envisaged in Vision 2030 (MOH, 2023).

2.12.2 The Kenya Health Policy (2014–2030)

The Kenya Health Policy, 2014–2030 gives directions to ensure significant improvement in overall status of health in Kenya in line with the Constitution of Kenya 2010, the country's long-term development agenda, Vision 2030 and global commitments. It demonstrates the health sector's commitment, under the government's stewardship, to ensure that the country attains the highest possible standards of health, in a manner responsive to the needs of the population (Kibui et al., 2015, MOH, 2023). It focuses on ensuring equity, people centeredness and a participatory approach, efficiency, a multi-sectoral approach and social accountability in the delivery of healthcare services. It proposes a comprehensive and innovative approach to harness and synergize health services delivery at all levels and engage all actors. In addition, policy principles and orientations have been formulated to facilitate the development of comprehensive health investments, health plans, and service provision within the devolved healthcare system (Mauti et al., 2020).

2.12.3 Universal Health Coverage

The UHC concept as envisioned by WHO reflects three dimensions; population covered, services coverage and extent to which services are funded from pooled

resources. The three dimensions of the WHO "UHC cube" are reproduced below (Ochalek et al., 2020).

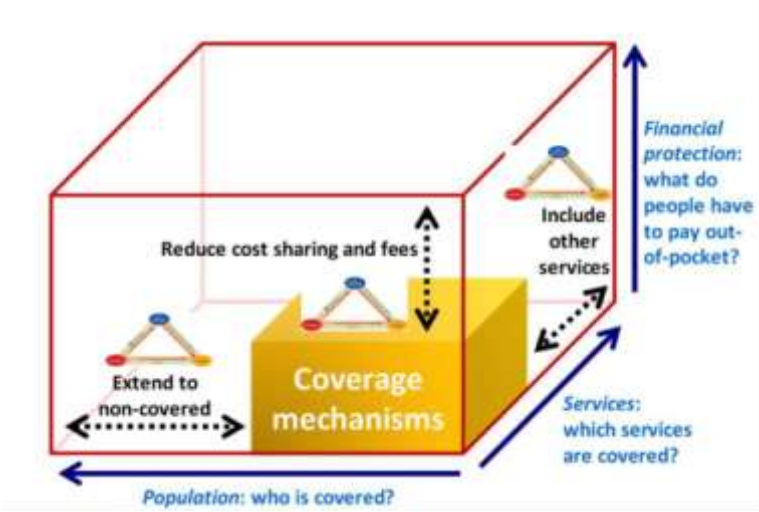

Figure 2.11: Universal Health Coverage (UHC) cube

Source https://www.intechopen.com/chapters/69420

The Universal Health Coverage (UHC) exists when all people receive the quality health services they need without suffering financial hardship (Darrudi et al., 2022). In Kenya, it aims to close the service provision and financing gap for all people and to protect the poor and vulnerable from financial catastrophe in seeking health care. The Constitution of Kenya recognises diversity across demographics and health needs. The health policies and strategies, including the Kenya Vision 2030 and Medium-Term Plan 2017 – 2022, are major considerations in outlining the formulation of strategies within which the UHC agenda is outlined (Kibui et al., 2015).

Despite the indictment of out-of-pocket payments, most of the healthcare finance in Kenya comes from households; 32% in 2013, up from 30% in 2010, as the donor funding took a downturn. The government budgetary allocation to health, though has increased in nominal terms, has declined as a ratio of the overall government spending. Therefore, the financing gap and threat to health care access remain a major drawback to a large proportion of the population (Okech & Lelegwe, 2015).

In 2013, only about one in every five Kenyans (17.1%) had some form of health insurance coverage. The population in the richest wealth quintile and urban dwelling reported higher coverage (41.5%) and (26.6%) respectively compared to those in the poorest quintile (2.9%) and rural dwelling (12.1%). Evidence is rife that Insurance enrollment positively correlates with improved utilization of services. Lack of insurance cover deters access to health care and out-of-pocket payment still subjects an estimated 6.2% of the population to catastrophic expenditure for health care and plunges thousands to impoverishment (Njeru et al., 2021).

2.13 Epilepsy Care as a Fundamental Human Right

People with epilepsy can experience reduced access to educational opportunities, a withholding of the opportunity to obtain a driving license, barriers to entering particular occupations, and reduced access to health and life insurance. In many countries, legislation reflects centuries of misunderstanding about epilepsy, for example, there are still laws which permit the annulment of a marriage on the grounds of epilepsy and laws that deny people with seizures access to restaurants, theatres, recreational centres and other public buildings. Legislation based on internationally accepted human rights standards can prevent discrimination and rights violations, improve access to health-care services, and raise the quality of life for people with epilepsy. Although there is no legislation specific to epilepsy in Kenya per se, the Kenya National Guidelines for the Management of Epilepsy are important policy instruments (MOH 2015, 2023: WHO, 2022).

2.14 Cultural Beliefs in Epilepsy Care

Sub-Saharan Africa (SSA) bears a disproportionately high burden of epilepsy, with approximately 10 million people living with the disorder and prevalence estimates ranging from 5–20 per 1,000 population (WHO, 2020). Despite the availability of effective treatments, the epilepsy treatment gap remains substantial, with approximately 70% of people with epilepsy not receiving adequate care (Stelzle et al., 2022; Yang et al., 2024). The persistence of this treatment gap is attributable not only to health system weaknesses but also to socio-cultural factors, particularly cultural beliefs and stigma surrounding epilepsy.

Within the study's conceptual framework, cultural beliefs function as distal determinants that influence both patient-level and health-system-level predictors of quality of care. In many SSA communities, epilepsy is often attributed to witchcraft, curses, possession by evil spirits, ancestral punishment, or contagion rather than recognized as a neurological disorder (Mushi et al., 2011; Braga et al., 2020). Such beliefs significantly affect healthcare utilization and quality of care outcomes.

2.14.1 Cultural Beliefs and Patient-Level Predictors

Cultural misconceptions contribute to delayed healthcare-seeking behavior, as individuals frequently consult traditional healers and faith-based practitioners before seeking biomedical care. Delayed diagnosis and treatment initiation have been associated with poorer seizure control and lower quality of care (Mushi et al., 2011; Aderinto et al., 2023).

Furthermore, beliefs in supernatural causation negatively affect adherence to antiseizure medications. Patients who perceive epilepsy as a spiritual condition may discontinue treatment in favor of traditional remedies, resulting in poor treatment outcomes and recurrent seizures (Mbuba et al., 2012; Meyer et al., 2010).

Stigma arising from these cultural beliefs also influences communication between patients and healthcare providers. Fear of discrimination and social exclusion may discourage patients from discussing symptoms, medication side effects, or treatment challenges, thereby limiting effective counselling and shared decision-making (Braga et al., 2020; Mushi et al., 2011).

Additionally, stigma contributes to missed clinic appointments and poor continuity of care. Studies in Kenya and other SSA countries have shown that people with epilepsy often conceal their condition due to fear of discrimination in schools, workplaces, and social settings, resulting in irregular follow-up and reduced treatment adherence (Mbuba et al., 2012; Newton & Garcia, 2012).

2.14.2 Cultural Beliefs and Socioeconomic Predictors

Cultural stigma may lead to unemployment, educational disadvantage, marital instability, and social isolation among people with epilepsy. These socioeconomic consequences reduce patients' ability to afford transport, investigations, and medications, thereby affecting affordability and access domains of quality care (WHO, 2021; Braga et al., 2020).

2.14.3 Cultural Beliefs and Hospital-Level Predictors

The influence of cultural beliefs extends beyond patients to healthcare systems. In settings where epilepsy-specific training is limited, healthcare providers may themselves hold misconceptions regarding epilepsy or lack confidence in managing the condition. This can affect counselling quality, communication, referral practices, and overall responsiveness to patient needs (World Health Organization, 2022; Aderinto et al., 2023).

Consequently, cultural beliefs interact with hospital-level factors such as availability of trained personnel, diagnostic capacity, referral systems, and medication availability to influence process measures of quality care (Kwon et al., 2022).

CHAPTER THREE

MATERIALS AND METHODS

3.1 Study Design

The study design was a cross-sectional utilizing both quantitative and qualitative approaches which allowed simultaneous assessment of quality and determinants across multiple hospitals efficiently. It is suitable for describing associations between predictors and quality at a specific time point thus providing critical baseline data for intervention and policy planning (STROBE Initiative, 2024).

The study was implemented through a six-phase process. First, selected health facilities were approached and informed about the study. Administrative approval was subsequently sought from facility management, with only facilities granting permission proceeding to the next stage. Following authorization, facility infrastructure and service delivery processes were assessed through structured observation. Key study information and secondary data were then identified and validated to ensure data quality and reliability. Data collection was subsequently undertaken across the four objectives encompassing assessment of quality of care, socio-demographic, clinical, and hospital-level predictors, as well as stakeholder perspectives on epilepsy care. Quantitative data was collected by using questionnaires while the qualitative data was collected using, Key informant Interview guide and Focus Group discussion guide.

The final phase involved data cleaning, analysis, interpretation, integration of findings, and dissemination through reports and thesis documentation.

The study proceeded as follow:

3.1.1 Phase I Facility Approach

Initial contact with selected hospitals and health facilities to introduce the study and seek collaboration.

3.1.2 Phase II: Administrative Authorization

Obtain permission to conduct the study from facility management. Outcomes included either permission granted or permission denied. Facilities denying permission were excluded from subsequent phases

3.1.3 Phase III Facility Assessment and Observation

Conduct infrastructure observation and assessment of facility readiness, service organization, and availability of resources relevant to epilepsy care.

3.1.4 Phase IV Information Verification and Validation

Identify key information required for the study and validate secondary data sources to ensure completeness, consistency, and relevance

3.1.5 Phase V Data Collection

Implement data collection procedures across all study objectives using the approved data collection tools and protocols.

3.1.5 Phase VI Data Analysis

The final phase involved data cleaning, analysis, interpretation, report writing, submission for examination, defence, correction and final submission.

3.2 Study Sites

This study was conducted in five selected level V hospitals in the three counties of Nairobi, Kiambu and Machakos that form the Nairobi Metropolis where epilepsy services are provided. It was carried out in Mama Lucy Lev 5 Hospital, Kiambu Level 5 Hospital, Gatundu Level 5 Hospital, Thika Level 5 Hospital and Machakos Lev 5 Hospital. These level five hospitals provide integrated epilepsy care services. Level 5 hospitals are key referral facilities in Kenya’s devolved health system, serving both urban and peri-urban populations. They provide specialized services, including neurological care, yet often face resource constraints, high patient volumes, and

organizational challenges. By focusing on Level 5 hospitals, the study evaluates the quality of care at a critical level of service delivery where both systemic factors and patient experiences converge, providing insights that are strategically relevant for policy, resource allocation, and capacity strengthening within the public referral system. There is also an ongoing epilepsy community sensitization and mobilization campaigns in the region by non-governmental organizations which has already gained traction in the catchment areas served by these hospitals (NECC, 2023).

The selection of Nairobi metropolitan region aimed to capture variability in population density, health system capacity and urbanization. Nairobi represents an urban referral hub with high patient throughput; Machakos represents a semi-rural context and Kiambu combines peri-urban and rural catchment areas. As a Level 5 county referral hospital, Machakos Level 5 Hospital receives referrals from Level 4 sub-county hospitals within Machakos County and functions as the principal referral facility for the county, manages a larger epilepsy caseload, and provided a broader range of epilepsy-related services. Its selection ensures diverse socio-demographic representation and enables the analysis of the influence of geographic and contextual factors on the quality of care, while remaining feasible logistically for a cross-sectional study.

Table 3.1: Characteristics of the Selected Hospitals

Hospital	County	Level	Bed Capacity	Daily Outpatient Attendance / Population Served	Workforce Capacity	Registered Epilepsy Patients	Active Follow-up Epilepsy Patients
Mama Lucy Kibaki Hospital	Nairobi	Level 5	**112 beds**	Handles approximately **250 patients/day**	468 staff (21 consultants, 10 medical officers, 67 clinical officers, 193 nurses, 15 pharmacists, 50 laboratory technologists, among others)	342	206
Kiambu Level 5 Hospital	Kiambu	Level 5	**411 beds**	**700–1,000 outpatients/day**	Specialized referral hospital with modern theatres and specialized treatment services	316	190
Gatundu Level 5 Hospital	Kiambu	Level 5	**200 maternity beds** plus a modern 5-floor inpatient wing	Serves a catchment population of approximately **500,000 people**	Over 200 health workers including specialists, 10 medical officers, 12 clinical officers, and 120 nurses	287	172
Thika Level 5 Hospital	Kiambu	Level 5	**265 beds**	Serves mixed urban and rural populations from Thika and surrounding areas	Comprehensive secondary-care facility with ICU and multiple specialized services	293	175
Machakos Level 5 Hospital	Machakos	Level 5	**507 beds**	Major referral facility serving Machakos County and surrounding regions	Provides inpatient, outpatient and specialized services including a cancer centre	376	226

3.3 Study Population

The study focused on at the respective facilities from whom appropriate number was selected using consecutive sampling technique for the primary respondents. Table 3.2 below shows the distribution of patients across all the five facilities. The study population was 1614 registered who were the total number registered patients with epilepsy with 969 patients on active follow-up. This formed the target population. A total of 373 respondents were accessed out of the expected sample size of 385

calculated by formula as used by Fisher et al., 1988. The accessed respondents were using consecutive sampling method and were distributed as follows: Gatundu Level 5 Hospital 69 (8.5%), Kiambu Level 5 Hospital 73(19.6%), Thika Level 5 Hospital 79 (21.2%), Machakos Level 5 Hospital 74 (19.8%) and Mama Lucy Kibaki Level 5 Hospital 69 (18.5%). This sample size of 373 represent 96.9% response rate of the estimated sample size of 385.

Table 3.2: Distribution of Respondents sampled from the health facilities

Health Facility	Registered Patients	Active patients	Expected	Finite corrected population	Actual numbers accessed
Gatundu	287	172	68	49	78
Kiambu	316	190	75	54	73
Thika	293	175	70	49	79
Mama Lucy	342	206	82	59	69
Machakos	376	226	90	65	74
Total	**1614**	**969**	**385**	**276**	**373**

For each selected respondent, an interviewer-dependent semi-structured questionnaire was used. Additional qualitative information was obtained through; key informant interviews with the consultant physicians, hospital administrators, medical superintendents, pharmacist and radiologist in each of the study sites (25KIIs); two focus group discussions were conducted with selected clients in each of the facilities (10 FGDs) with each session comprising of 6-9 people. The deliberations were recorded in verbatim.

3.3.1 Selection Criteria

People with epilepsy (PWE) were identified from the epilepsy clinics and outpatient departments of the participating health facilities. The sampling frame consisted of 969 patients diagnosed with epilepsy and registered for follow-up care in the selected facilities during the study period. Patient identification was based on diagnosis of epilepsy, hospital epilepsy registers, clinic appointment books, and medical records maintained in the respective facilities. The criteria ensured that participants were selected from the sample frame to enhance the validity, reliability, and generalizability of findings regarding predictors of quality of epilepsy care. Newly diagnosed and

follow-up patients are part of the same care continuum as people with epilepsy and experience the same health system factors and the inclusion of both groups provided a more comprehensive assessment of quality of care.

3.3.1.1 Inclusion Criteria

Participants were enrolled based on a confirmed clinical diagnosis of epilepsy documented in medical records: those with reviewed diagnostic investigations those who were on seizure remission and on follow-up, newly diagnosed patients who had completed the initial diagnostic and treatment assessment and had been put on treatment, aged 18 years and above and able to provide informed consent, had sufficient cognitive and communication ability to respond to questions, children and adolescents (<18 years), whose consent was obtained from parents or guardians and assent was sought from eligible minors according to ethical requirements. Follow-up threshold was defined by confirmed diagnosis, appointment adherence, clinical review and duration after onset of treatment. This threshold is consistent with quality assessment approaches commonly applied in chronic disease management. However, completion of all investigations was not a prerequisite for inclusion because access to advanced diagnostic modalities varies across healthcare facilities in Kenya.

3.3.1.2 Exclusion Criteria

Patients whose diagnosis had not been confirmed, had acute medical emergencies requiring immediate intervention at the time of data collection, severe cognitive impairment, altered mental status, or active seizures that prevented meaningful participation in interviews, declined or withdrew consent to participate, too ill to complete the interview. The objective was to determine predictors of quality of care among all people living with epilepsy attending the selected facilities.

3.3.2 Sample Size Determination

The sample size was calculated by formula as used by Fisher *et al*., 1995 based on the assumption that the three counties are one system and that prevalence of epilepsy varies with the population (Fisher et al., 1991).

$$n = \frac{Z^2 p(1-p)D}{d^2}$$

Where;

Z = standard deviation usually 1.96 at 95% confidence interval

n = is the desired sample size

p = proportion of population estimated to have epilepsy = 0.5

q = 1 – p (1 – 0.5) = 0.5

d = degree of accuracy = 0.05

Substituting:

$$n = \frac{(1.96)^2(0.5)(0.5)}{(0.05)^2}$$
$$n = \frac{3.8416 \times 0.25}{0.0025}$$
$$n = \frac{0.9604}{0.0025}$$
$$n = 384.16$$
$$n \approx 385$$

Finite Population Correction

Since the population of active patients 969 **patients (<10,000)**, the Fisher correction formula was applied:

$$n_f = \frac{n}{1 + \frac{n}{N}}$$

Where:

- n_f = adjusted sample size, *n*= 385, *N*= 969

$$n_f = \frac{385}{1 + \frac{385}{969}}$$
$$n_f = \frac{385}{1 + 0.3973}$$
$$n_f = \frac{385}{1.3973}$$
$$n_f = 275.5$$

$$n_f \approx 276$$

Applying Fisher's finite population correction on 969 as the sampling frame, the adjusted minimum sample size of approximately 276. Due to its multicenter nature, this study retained Fisher sample size of 385 despite a finite population. In order to enhance the precision of estimates, a larger sample size was necessary. Therefore, using consecutive sampling, all eligible patients attending clinics were recruited up to a total of 373 participants. Compared to the finite correction sample of 276, this high sample size increased statistical power, minimize sampling error, and compensated for the potential negative impact of non-response and incomplete data. It represented a response rate of 96.9% of the target sample size which was considered adequate and unlikely to compromise the validity of the findings.

3.3.3 Sampling Techniques

Consecutive sampling was employed in this study because it was the most feasible and appropriate sampling approach within the prevailing clinical and operational context. Data collection was conducted during the COVID-19 pandemic when patient attendance at epilepsy clinics was considerably reduced, although infection rates were beginning to decline. Consequently, patient flow was low and variable across the study facilities, making it difficult to implement probability-based sampling methods.

Although simple random and systematic sampling offer stronger theoretical protection against selection bias, their application requires a complete and up-to-date sampling frame of all eligible patients. Such a sampling frame was unavailable due to the dynamic nature of clinic attendance and the unpredictability of patient visits during the pandemic period. Consecutive sampling therefore enabled the recruitment of every eligible patient who attended the epilepsy clinics and consented to participate until the required sample size was attained.

To minimize potential selection bias associated with this non-probability sampling method, data collection was conducted across multiple facilities and clinic days, and all eligible patients presenting during the study period were included consecutively without investigator discretion. This approach maximized participant recruitment,

enhanced representation of routine clinic attendees, and ensured adequate sample size despite the reduced patient flow. In addition, qualitative data were obtained through five Key Informant Interviews and two Focus Group Discussions comprising 6–9 participants per facility, providing complementary perspectives that strengthened the validity and comprehensiveness of the study findings.

Therefore, consecutive sampling was considered the most practical and methodologically appropriate strategy for recruiting participants in a multicenter facility-based study conducted under the constraints imposed by the COVID-19 pandemic.

3.4 Study Variables

The study variables were Independent, Moderating and Dependent variables. The independent variables were Sociodemographic factors, Clinical factors and Hospital-level factors and Dependent Variable was Quality of Care The independent variables in this study were socio-demographic, clinical and hospital-level factors. They include Structural indicators (Availability of guidelines and protocols, Availability of ASM, Service availability); Process indicators (Respect, Counselling, Timeliness, Confidentiality, Communication); Moderating Variables were Ministry of Health Policies (Essential Medicines Policies, Community Health and Health Promotion Policies, Health Financing Policies, Health Workforce Policies, Guidelines and protocols for the diagnosis and management of neurological disorders, Universal Health Coverage (UHC)

Dependent variables were Outcome indicators ((QoC Rating/Score (Low or High), Treatment adherence, Seizure control, Reduction in seizure frequency and Predisposing (age, sex, education, marital status, cultural beliefs). Enabling (income, health insurance, distance to facility, medication availability, diagnostic services) and Need factors - duration of epilepsy, seizure frequency, comorbidities)

3.5 Research Instruments

3.5.1 Questionnaire

Quantitative data was collected from 373 respondents using semi-structured questionnaires administered to the clients who came for treatment at the facility in order to obtain quantitative data. For purposes of clarity, the questionnaires were administered by trained research assistants and where necessary, additional assistance was sought from translators who were competent in Kiswahili and local dialects.

3.5.2 Interview Guides

3.5.2.1 Focus Group Discussion Guides

Focus Group Discussions Guides were used as a qualitative research instrument to obtain in-depth perspectives from clients living with epilepsy attending selected hospitals in Nairobi, Kiambu, and Machakos counties. Participants for the FGDs were identified from those who had participated in the quantitative surveys and had indicated willingness to take part in further discussions. Their contact details were recorded for follow-up.

A total of ten FGDs were conducted across the selected facilities, with each group consisting of 6–9 participants. In each facility, two FGDs were held: one comprising clients aged 18–35 years and the other consisting of clients aged above 35 years.

Each FGD was moderated by experienced qualitative research assistant fluent in English, Kiswahili, and the local dialects of the study area. A note-taker assisted in capturing both verbal and non-verbal responses. The discussions were conducted in appropriate, private venues within the health facilities, selected to ensure confidentiality and minimal disruption. Informed consent was obtained from all participants prior to the discussions.

3.5.2.2 Key Informant Interview Guides

Key Informant Interview (KII) guides were used as a qualitative data collection instrument to obtain expert perspectives on hospital-level factors influencing the quality of healthcare services provided to people living with epilepsy.

A total of 25 key informant interviews were conducted across the five selected Level 5 hospitals, with five interviews undertaken in each facility. Participants were purposively selected based on their roles in the delivery, management, or oversight of epilepsy care. They included medical superintendents, consultant physicians or consultant paediatricians, pharmacists, radiologists, and hospital administrators from the selected hospitals in Nairobi, Kiambu, and Machakos counties.

Data were collected using a semi-structured interview guide developed in accordance with the study objectives. The guide comprised open-ended questions designed to elicit in-depth information on hospital-level factors affecting the quality of epilepsy care, including service delivery, availability of resources, referral systems, adherence to clinical guidelines, and institutional challenges. All interviews were conducted in English at a time and location convenient to the participants to minimize disruption of routine hospital operations. Written informed consent was obtained from all participants before the interviews commenced.

3.6 Validity and Reliability

Data collection tools used were questionnaires, Key Informant Interview (KII) guides, and Focus Group Discussion (FGD) guides. They were developed following review of literature on epilepsy care, the Donabedian Structure–Process–Outcome framework and Aday & Anderson Utilization model.

To ascertain their validity and reliability, the draft instruments were discussed with my supervisors, subject matter expert in public health, neurology, epidemiology, health systems and biostatistics. The experts assessed the relevance, clarity, comprehensiveness, appropriateness, and consistency of the items in measuring the study constructs. Their recommendations were incorporated to improve content

validity and ensure that all dimensions of quality of care and its predictors were adequately represented.

Reliability of data collection tools was ensured through standardization of data collection procedures comprehensive training research assistants on study objectives, interviewing techniques, ethical considerations, administration of questionnaires, and recording of responses. A detailed data collection protocol was used to ensure uniform application of procedures across all study sites. For qualitative tools, trustworthiness was strengthened through use of standardized interview guides, peer review of coding, verbatim transcription, audio recording and triangulation of data source

Reliability was achieved by using Test-retest method. To ensure external validity, the findings and results were generalized to the Kenyan settings, and to other developing country contexts as regards quality of epilepsy care. The indulgence of experts, including my supervisors, was sought to align the research instruments to cover all the constructs being studied. The study tools developed were compared with other similar validated service quality instruments developed by Parasuraman et al and Gronroos, and have been used in several studies (Ahmed *et al*., 2024).

3.7 Data Management and Analysis

3.7.1 Quantitative Data

The study sample size of 373 respondents was calculated using the Fisher et al. formula for estimating a single population proportion and adjusted for the finite population of 969 eligible patients. The sample was powered to provide statistically reliable estimates of quality of care and its predictors among people with epilepsy across the overall study population at a 95% confidence level and 5% margin of error. It was therefore sufficient for assessing associations between predictor variables and quality-of-care outcomes but was not specifically powered to detect statistically significant differences between counties, as no stratified sample size calculation was undertaken for county-level comparisons.

Quantitative data were coded, double-entered to ensure accuracy, cleaned, and analyzed using Statistical Package for the Social Sciences (SPSS) version 26. Descriptive statistics were used to summarize the study variables. Bivariate analyses were conducted to examine associations between quality of care and socio-demographic, clinical, and hospital-level factors using the Chi-square test, with statistical significance set at $p < 0.05$. Variables found to be statistically significant at the bivariate level were subsequently entered into a multivariable logistic regression model to identify independent predictors of quality of care while controlling for potential confounders.

3.7.1.1 Determination of Quality of Care

Quality of care for people with epilepsy was determined using the composite for the standard domains of respect, communication, tolerability of side effects, effectiveness, affordability, counselling, geographical access, privacy rating, and promptness measure. These domains were selected based on established patient-centred quality of care frameworks by Donabedian and Aday and Anderson utilization models and their relevance to epilepsy management in resource-constrained settings. It was a self-reported scale with a score of 1 for lowest and 10 for the highest. Using a nine-point rating scale, it yielded a lowest possible total score of 9 and the highest possible score of 90.

A Semantic Differential Scale (SDS) was employed to measure patients' perceptions of each quality domain enabled respondents to express varying degrees of satisfaction and perception regarding healthcare services received. Respondents were asked to rate their experiences on a ten-point continuum, where a score of 1 represented the poorest possible quality and a score of 10 represented the highest possible quality for each of the 9 domains selected. Since nine domains were assessed, the minimum possible composite quality score was 9 (1×9 domains), while the maximum possible score was 90 (10×9 domains). Higher scores indicated better perceived quality of care.

Prior to generating the composite quality index, Exploratory Factor Analysis (EFA) was conducted to examine the underlying factor structure of the quality domains and to determine the relative contribution of each domain to the overall quality construct

since quality of care is a multidimensional latent construct that cannot be measured directly by a single indicator. The factor loadings generated from the EFA represented the strength of association between each quality domain and the underlying quality construct.

To account for the varying contribution of each quality domain to overall quality of care, factor loadings obtained from the EFA were transformed into factor weights and converted into normalized factor weights. This weighting approach ensured that domains contributing more strongly to the latent construct received proportionately greater influence in the composite score.

The normalized factor weight for each domain was computed as:

$$W_i = \frac{L_i}{\sum_{i=1}^{n} L_i}$$

Where:

- W_i= normalized factor weight for domain *i*;
- L_i= factor loading for domain *i* obtained from EFA;
- $\sum L_i$= sum of all retained factor loadings;
- n= number of quality domains.

The weighted composite quality score for each respondent was then calculated as:

$$Q = \sum_{i=1}^{n} (W_i \times S_i)$$

Where:

- Q= overall quality of care score;
- W_i= normalized factor weight;
- S_i= respondent's score on domain *i*.

This procedure produced a weighted quality index that reflected both respondents' ratings and the empirically derived importance of each domain. For comparative importance analysis, we applied a normalized factor weight to the different domains of quality under study. This allowed for a more accurate assessment of the relative contribution to the overall quality score

Quality totals were obtained by aggregating scores from predefined indicators representing structure, process, and outcome dimensions of care. Each indicator was scored according to Semantic differential scale of 1-10 These totals provided a composite measure of quality of care and were subsequently categorized into high or low quality based a median of 47 as a cut-off point.

Due to the skewness of the data, median was used. The composite score had a median of 47, with the minimum score of 15 and a maximum of 71 and a range 56. Out of 373 respondents, 197 (52.8%7) rated quality of care as high and 176 (47.2%) rating it as low. Quality was measured as the cumulative performance across multiple indicators rather than by any single variable

A combination of a Semantic Differential Scale, Exploratory Factor Analysis-derived weights, and median-based categorization enhances both the construct validity and measurement precision of the quality-of-care index, while accommodating the non-normal distribution commonly observed in patient-reported outcome measures.

3.7.1.2 Bivariate Analysis

3.7.1.2.1 Determination of Socio-Demographic Predictors

Information on respondents' socio-demographic characteristics was collected through a semi-structured questionnaire. It captured the following variables: age, sex, occupation, religion, education level, and marital status. Respondents were asked to rate the quality of care they received, which was coded into two categories: high quality and low quality.

To ensure analysis against quality ratings, each variable was organized into clear categories. A contingency table was generated to compare distribution of respondents

who reported high quality versus low quality of care. This produced the raw frequency counts for each category of each variable in relation to the outcome (Quality of Care). Finally, the findings were consolidated into a single summary table showing percentages of respondents, ratings of quality of care as high or low, Chi-square statistics, associated p-values and degrees of freedom.

3.7.1.2.2 Determination of Clinical Predictors

Data on clinical factors was collected using semi-structured questionnaire. Based on clinical experience, literature search and specific objectives under this study, key clinical and demographic information were consolidated into accessible format to allow easy interpretation and facilitation of analysis. Information on Duration of illness before treatment initiation, Anti-seizure Medication, Co-morbidities, Stigma experience, Level of knowledge on Epilepsy, Seizure frequency before the onset of Treatment, Seizure frequency after the onset of Treatment and Treatment regimen were selected to provide insight into the clinical profile of the respondents for a more nuanced interpretation of the results and understanding of the population. Differences in treatment approaches also ensured that the analysis considered both patient characteristics and the impact of medical interventions.

For clarity, conciseness, and comparability across study groups, the results were presented in tabular form to display a summarized large dataset for readers to identify relationships, trends and contrasts trends within the study population. The consolidated diverse clinical variables into a single organized presentation supports transparency, improves the interpretability and strengthens the discussion of results in relation to established clinical knowledge.

3.7.1.2.3 Determination of Hospital Level Predictors

Information on hospital-level factors was collected using both quantitative and qualitative methods. Quantitative data were obtained through structured and semi-structured questionnaires, while qualitative data were collected through twenty Key Informant Interviews (KIIs) and ten Focus Group Discussions (FGDs). Based on the study objectives and conceptual framework, key hospital-level factors assessed

included card possession, use of Directly Observed Therapy Support (DOTS), patient education on warning signs, adverse drug reaction management, waiting time, privacy during consultations, staffing adequacy, availability of clinical guidelines, diagnostic technologies, antiseizure medications, referral systems, and integrated care services.

For quantitative analysis, hospital-level variables were coded into categorical forms and linked to individual patient records according to the facility where each participant received care. The quality-of-care outcome was similarly categorized into two groups: high quality and low quality. Constructs under Hospital-level factors were coded then cross-tabulated against the binary quality-of-care outcome (high versus low quality), with associations tested using Chi-square. Frequencies and percentages were computed to describe the proportion of respondents reporting high or low quality of care within each category.

Pearson's Chi-square test of independence was used to assess the statistical association between hospital-level factors and quality-of-care outcomes. Variables demonstrating statistically significant associations were considered for inclusion in subsequent multivariable analyses to determine their independent contribution to quality-of-care outcomes.

For the qualitative component, thematic analysis of KIIs and FGDs was undertaken to provide deeper insights into facility-level influences on quality of epilepsy care. Nine major themes and several sub-themes emerged, complementing the quantitative findings and providing contextual explanations for the observed associations. Qualitative findings from KIIs and FGDs were used to explain and contextualize the quantitative results. Cross-tabulations (contingency tables) were then generated to examine the distribution of quality-of-care outcomes across categories of each hospital-level factor. The integration of quantitative and qualitative findings strengthened the interpretation of hospital-level predictors of quality healthcare among people living with epilepsy

3.7.1.3 Multivariate Analysis

Cross-tabulations describing the data was undertaken to identify statistically appropriate predictors for inclusion in the multivariate model. A logistic regression was then fitted which generated adjusted odds ratios that quantified the relative likelihood of respondents rating quality of care as high or low for the candidate predictors. To show the precision of the odds ratio, 95% confidence intervals were calculated and p-values were derived to test the statistical significance of each predictor. while adjusting for the influence of others.

At multivariate analysis, systematic analytical process was designed to account for the simultaneous influence of multiple factors on dichotomous outcome. Logistical regression was considered appropriate tool because it allows the estimation of relationships between several predictor variables and the dichotomous outcome while controlling for potential confounding effects. The predictor variables which were drawn from socio-demographic, clinical, and hospital-level characteristics of the study population included occupation, onset of illness, type of medication, experience of stigma, seizure frequency after initiation of treatment, treatment regimen, waiting time, service availability, and affordability and one category in each and fixed with an odds ratio of 1.000 to serve as the baseline against which the relative effects of the other categories could be compared. The adjusted odds ratios, corresponding confidence intervals, and the p-values for each dichotomous outcome were included. This dual presentation provided a comprehensive view of how each predictor variable contributed to both outcomes as a rigorous statistical framework for understanding the independent contribution of multiple predictors to quality of care experienced.

3.7.2 Qualitative Data

3.7.2.1 Data from FGD and KII

Qualitative data from FGDs and KIIs were analyzed using Braun and Clarke's thematic analysis framework. Transcripts were audio-recorded, transcribed verbatim, and reviewed for accuracy prior to analysis. The codes were grouped into categories, and categories synthesized into themes. To ensure consistency and maintain participant

confidentiality, transcripts were assigned unique identifiers according to the sequence of data collection (FGD001–FGD010 and KII001–KII025) and imported into NVivo Version 20 as separate source documents. The data were then coded line-by-line based on the study objectives and emerging concepts. Similar codes were systematically grouped into categories, which were subsequently refined into broader themes and sub-themes through thematic analysis. The resulting themes were reviewed and interpreted to capture participants' experiences, perceptions, and insights regarding the quality of epilepsy care, while ensuring coherence, relevance, and alignment with the study objectives. The findings were presented narratively and supported with verbatim quotations to illustrate key themes and preserve the authenticity of the respondents' perspectives.

3.7.2.1 Triangulation of Qualitative and Quantitative Findings

The qualitative findings were then triangulated with quantitative results during interpretation to enhance the validity and comprehensiveness of the findings. Triangulation of quantitative and qualitative findings was undertaken using a convergent mixed-methods design in which both datasets were analyzed independently and merged during interpretation. Quantitative analysis identified the magnitude of quality of care and its predictors, while qualitative findings from focus group discussions (FGDs) and key informant interviews (KIIs) provided contextual explanations and deeper understanding of the observed relationships. Triangulation of findings was employed to identify areas of convergence, complementarity, and divergence between the two data strands.

The integration process was guided by both the Donabedian framework and the Aday and Andersen model of healthcare access and utilization. The Donabedian framework provided the basis for evaluating quality of care through the domains of structure, process, and outcomes, whereas the Aday and Andersen model facilitated interpretation of factors influencing healthcare utilization and access through predisposing, enabling, and need-related characteristics.

Findings from the quantitative and qualitative strands were compared and synthesized to provide a comprehensive understanding of quality of epilepsy care. Areas where

both datasets produced similar results were considered convergent and strengthened interpretation. Qualitative findings were used to explain statistically significant associations observed in quantitative analyses, while discrepancies between the two datasets were explored to identify contextual and system-level influences.

3.8 Application of Conceptual Frameworks

3.8.1 Application of Donabedian Framework

The Donabedian framework was used to organize findings into three interrelated domains:

Structural quality factors comprised health system characteristics that support care delivery, including availability of anti-seizure medications, diagnostic equipment, infrastructure, staffing levels, clinical guidelines, and organizational support. Information on these factors was obtained from facility assessments, KIIs, and quantitative questionnaires.

Process quality factors encompassed activities involved in delivering care and interactions between healthcare providers and patients. These included timeliness of diagnosis, continuity of care, patient education, counseling, provider-patient relationships, privacy, communication, and adherence to clinical practices. Process-related findings were derived from both quantitative responses and qualitative narratives.

Outcome quality factors reflected the effects of healthcare services on patients and included treatment adherence, seizure control, adverse effects, patient satisfaction, and the overall quality-of-care outcome categorized as high or low quality. These outcomes were measured quantitatively and enriched through participants' lived experiences obtained during FGDs.

3.8.2 Application of the Aday and Andersen Model

The Aday and Andersen model was used to explain factors affecting access to and utilization of epilepsy services and to interpret predictors of quality of care.

Predisposing characteristics included socio-demographic variables such as age, sex, marital status, educational level, religion and occupation. Qualitative findings provided insights into stigma, misconceptions, and social attitudes influencing healthcare-seeking behavior.

Enabling factors referred to resources that facilitate or hinder access to healthcare and included health insurance status, distance to health facilities, availability of medications, staffing, and support systems. These factors emerged from both quantitative analyses and narratives from key informant interviews and focus group discussions.

Need factors comprised clinical characteristics that determine the necessity for healthcare services, including duration of epilepsy, seizure frequency, comorbidities, treatment history and medication use. These factors were evaluated quantitatively and further explained through patient experiences shared during FGDs.

Thus, the Donabedian framework enabled assessment of the quality dimensions of epilepsy care, whereas the Aday and Andersen model explained how predisposing, enabling, and need-related factors influenced access to care and ultimately affected quality outcomes. The combined application of the two frameworks provided a comprehensive conceptual basis for understanding quality of care and its predictors among people with epilepsy.

3.9 Ethical Considerations

Ethical approval was obtained from the Jomo Kenyatta University of Agriculture and Technology Institutional Ethics Review Committee (JKUAT-IERC) (Approval Number: JKU/IERC/02316/0039) and the Board of Postgraduate Studies. Research authorization was subsequently granted by the National Commission for Science, Technology and Innovation (NACOSTI) (Ref. No. 691998).

Following approval, further administrative clearance was obtained from the respective County Research Coordinators through the offices of the County Executive Committee Members responsible for health. Letters requesting permission to conduct the study

were submitted to the County Chief Officers, County Directors of Health, and Medical Superintendents of the five selected hospitals. Upon review and approval by the respective hospital management teams, authorization was granted to undertake the study within the participating institutions. Courtesy visits were then made to the relevant offices for formal introduction and coordination of the research activities.

Participation in the study was entirely voluntary. All eligible participants were adequately informed about the purpose, procedures and potential benefits and minimal risks associated with the study before being recruited to participate. Written informed consent was obtained from all respondents prior to data collection. Participants were assured of their right to decline participation or withdraw from the study at any stage without any consequences to their routine care.

Confidentiality and privacy of participants were strictly maintained throughout the study. Personal identifiers were excluded from study records, and all data were securely stored and used solely for the purposes of the research. Given the social stigma associated with epilepsy, particular attention was paid to protecting sensitive information related to participants' diagnosis, treatment practices, and adherence behaviors.

Ethical principles were rigorously upheld throughout the study in accordance with institutional research committee standards and national and international guidelines. The study posed minimal risk to participants and did not interfere with routine healthcare services. Throughout the research process, the principles of autonomy, beneficence, non-maleficence, justice, and respect for persons were upheld, thereby ensuring the protection of participants' rights, dignity, and welfare.

CHAPTER FOUR

RESULTS

The findings are presented using a contiguous approach, where quantitative results are presented first for each objective and immediately followed by qualitative findings and finally triangulation. The purpose of qualitative data is to explain, support, or contextualize the results to facilitates triangulation and enables the development of robust conclusions

4.1 Characteristics of the Study Respondents

Table 4. below shows the characteristics of the study respondents. The mean age of participants was 29.51 ± 11.79 years with a range of 2–71 years. The age category compositions, as used by (Ngugi et al., 2013), were as follows; 0-5yrs constituted 10 (2.7%), 6-12 years were 13 (3.5%), 13-28 years were 58 (15.5%), 19-28 years were 132 (35.5%), 29-49 were 140 (37.5%) and those aged 50+ comprised of 20 (5.4%). More than half of the respondents (51.2%) were males, three quarters (67.6%) were married, more than a half (53.6%) had attained primary school level of education and below. Most of the participants 288 (77.2%) were Christians and 75 (20.1%) were Muslims and 10 were Hindus (2.7%) and 225 (60.3%) are in informal employment.

Table 4.1: Socio-Demographic Characteristics of the study respondents

Characteristics	Categories	Frequency	Percentage
Age groups	*2-5*	10	2.7
	6-12	13	3.5
	13-18	58	15.5
	19-28	132	35.4
	29-49	140	37.5
	50+	20	5.4
Sex	*Male*	191	51.2
	Female	182	48.8
Occupation	*Formal Employment*	76	20.4
	Informal Employment	225	60.3
	Not employed	72	19.3
Religion	*Christian*	288	77.2
	Muslim	75	20.1

	Hindus	10	2.7
Education	*No formal Education*	20	5.4
	Primary	180	48.3
	Secondary	114	30.6
	Tertiary	59	15.8
Marital status	*Single*	104	27.9
	Married	224	60
	Under-age	45	12.1

4.2 Quantitative findings

4.2.1 Self-Reported Quality of Care

Self-reported quality of care rating based on a median split of 47 computed from quality totals of individual respondents' cores. The mean value was 46.61 (±0.49 standard error) and median was 47**, S**tandard Deviation of was 9.2 and variance of 88.75**,** range of 56 **(**from a minimum of 15 to a maximum of 71), negative skewness (-0.788) and a kurtosis value of 1.539. Median split was used to categorize the score into Low and High Quality of care. Out of 373 respondents, 142 (47.2%) rated quality of care as low and 197 rated Quality of care as high

Table 4.2: Overall Self-Reported Quality of Epilepsy

Quality Rating	Frequency	Percentage
Low	176	47.2
High	197	52.8
Total	373	100

4.2.1.1 Comparative Load of Quality Domains Based on Normalized Factor Weight

Table 4.2 below shows the normalized factor weighting for the 9 domains for measuring weight. A factor weight was used to assign the comparative load to the various quality domains under study. Based on normalized factor weight, respect had the most positive weight/loading of 0.153 followed by communication (0.139), tolerability (0.123), effectiveness (0.122), affordability (0.107), counselling (0.096), geographical access (0.095), privacy (0.095) and promptness (0.069).

Table 4.3: Normalized Factor Weights for Quality Domains

Quality Domains	Frequency	Normalized Factor Weight
Respect	373	0.153
Communication	373	0.139
Tolerability of side effects	373	0.123
Effectiveness	373	0.122
Affordability	373	0.107
Counselling on side effects	373	0.096
Geographical Access	373	0.095
Privacy Ratings	373	0.095
Promptness Measure	373	0.069

4.2.1.2 Quality of Care rating by hospitals

Across five healthcare institutions show the following result: Gatundu, Kiambu, Thika, Mama Lucy, and Machakos. At Gatundu, ratings are relatively balanced at low quality 38 (48.7%) and high-quality 40 (51.3%), Kiambu there is lower satisfaction profile with low quality 39 (53.4%), compared to high quality 34 (46.8%), at Thika there was modest satisfaction with low quality rating 38 (48.1%) and high-quality ratings 41 (51.9%), at Mama Lucy with pronounced satisfaction with low quality 24 (34.2%) and high quality 46 (65.8%) and Machakos there was identically divided distribution with low quality were 37 (50%) and high quality were also 37 (50%).

Table 4.4: Self-Reported Quality of Care Rating By Hospitals

Hospital	Low	Percentage	High	Percentage	Total
Gatundu	38	48.7	40	52.3	78
Kiambu	39	53.4	34	46.6	73
Thika	38	48.1	41	51.9	79
Mama Lucy	24	34.8	45	65.2	69
Machakos	37	50	37	50	74
Total	**176**		**197**		373

4.2.2 Bivariate Analysis

4.2.2.1 Socio-Demographic Factors as Predictors of Quality of Care for PWE

Socio Demographic factors used in the Study were age, sex, occupation, education, religion and marital status. The results indicate that 7(70%) of respondents whose

children were 2-5 years rated the quality of care as high while 3(30%) rated it as low. Age groups 19 to 28 and 50+ differed from other age groups in that they had lower percentages of individuals who rated quality of care as high compared to those who rated it as low-quality care. This contrasts with other age groups, which had higher percentages of individuals who rated quality of care as high compared to those who rated it as low-quality care. With a p-value of 0.109 > 0.05, χ^2 =9.005, df= 5, the age group variable had no significant association with the quality-of-care result.

While 101 (52.9%) of males rated quality of care as high, the remaining males rated it as low, while 96 (52.7%) of females rated it as high-quality care and 90 (47.3%) rated it as low-quality care. Using a χ^2 test, it was determined that the sex variable had no significant association with the outcome of the perceived quality of care given to epilepsy patients (χ^2 = 0.001, p-value = 0.980, df=1). Apart from occupation (χ^2=19.127, p=0.000) all other socio-economic demographic characteristics in the table had p>0.05.

Table 4.5 below presents percentages of participants who rated quality of care as high or low across the various socio-demographic categories, along with the Chi-square statistics, associated p-values and degrees of freedom. The integration of both descriptive and inferential statistics, providing a comprehensive overview of the relationship between socio-demographic characteristics and quality of care experienced.

Table.4.5: Bivariate Analysis between socio-demographic characteristics and Quality of Care.

	Categories	High quality		Low quality		χ^2	p-value	df
		(%)	CI	(%)	CI			
Age group	*2-5*	7(70)	38.4-90.0	3(30)	10.0-61.5	9.005	0.109	5
	6-12	9(69.2)	40.0-91.7	4(30.8)	8.3-60.0			
	13-18	32(55.2)	41.8-67.5	26(44.8)	32.5-58.2			
	19-28	61(46.2)	37.0-54.0	71(53.8)	46.1-63.0			
	29-49	81(57.9)	49.6-65.9	59(42.1)	34.1-50.4			
	50+	7(35.0)	13.3-56.3	13(65.0)	43.8-86.7			
Sex	*Male*	101(52.9)	45.7-59.9	90(47.1)	40.1-54.3	0.001	0.980	1
	Female	96(52.7)	45.0-59.7	86(47.3)	40.3-55.1			
Occupation	***FormalEmployment***	**57(75.0)**	**31.6-66.7**	**19(25.0)**	**33.3-68.4**	**19.127**	**0.000**	**2**
	Informal	**108(48.0)**	**47.8-74.0**	**117(52.0)**	**26.0-52.2**			
	Not employed	**32(44.4)**	**52.2-77.2**	**40(55.6)**	**22.8-47.8**			
Religion	*Christian*	151(52.4)	46.3-58.5	137(47.6)	41.5-53.7	0.152		
	Muslim	41(54.7)	43.3-66.7	34(45.3)	33.3-56.8			
	Hindus	5(50.0)	18.2-80.0	5(50.0)	20.0-81.8		0.927	2
Education	*No formal Education*	10(50.0)	26.3-71.4	10(50.0)	28.6-73.7	0.777		
	Primary	99(55.0)	47.7-61.8	81(45.0)	38.2-52.5			
	Secondary	59(51.8)	42.5-61.5	55(48.2)	38.5-57.5			
	Tertiary	29(49.2)	36.23-62.5	30(50.8)	37.5-63.7		0.855	3
Marital status	*Single*	54(51.9)	42.5-62.1	50(48.1)	37.9-57.5	1.061		
	Married	116(51.8)	45.2-58.2	108(48.2)	41.8-54.8			
	Under-age	27(60)	45.7-74.1	18(40)	25.9-54.8		0.588	2

4.2.2.2 Clinical Factors as Predictors of Quality of Care

Clinical Predictors used for the Study were; Duration of illness before treatment initiation, Anti-seizure Medication, Co-morbidities, Stigma experience, Level of knowledge on Epilepsy, Seizure frequency before the onset of Treatment, Seizure frequency after the onset of Treatment and Treatment regimen

Table 4.6 below shows bivariate analysis between clinical predictors and Quality of care. Out of eight parameters used, five showed a significant statistical relationship with quality of care. Duration from seizure onset to treatment initiation (χ^2=6.072, p=0.048, df=2), Ant seizure medication (χ^2 = 4.024, p=0.045, df=1), stigma (χ^2 =5.022, p=0.025, df=1), Seizure (χ^2 =7.337, p=0.026, df=2) and treatment regimen (χ^2 =10.464, p=0.015, df=3).

Table 4.6: Bivariate Analysis between Clinical Predictor and Quality of Care

Factor	Categories	Non response	High quality		Low quality		χ^2	p-value	
			(%)	CI	(%)	CI			df
Duration of illness before treatment initiation	***< 1 year***		**41 (58.6)**	**46.3-70.0**	**29 (41.4)**	**30.0-53.8**	6.072		
	1 – 3 years		**77 (58.8)**	**50.3-66.7**	**54 (41.2)**	**33.3-49.7**			
	> 3years	**0**	**79 (45.9)**	**8.3-3.1**	**93 (54.1)**	**46.9-61.7**		**0.048**	2
Anti-seizure Medication	***Yes***		**180 (54.7)**	**49.0-60.0**	**149 (45.3)**	**40.1-51.1**	**4.024**		
	No	**0**	**17 (38.6)**	**23.8-53.8**	**27 (61.4)**	**46.2-76.2**		**0.045**	**1**
Co-morbidities	*Yes*		86 (49.7)	42.2-56.6	87 (50.3)	43.45-57.8	0.137		
	No	63	71(51.8)	43.3-60.1	66 (48.2)	38.9-56.7		0.712	1
Stigma experience	***Yes***		**106 (48.4)**	**41.5-54.6**	**113 (51.6)**	**45.4-58.5**	**5.022**	**0.025**	**1**
	No	**17**	**83 (60.6)**	**52.8-68.8**	**54 (39.4)**	**31.2-47.2**			
Level of knowledge on Epilepsy	*Low (1-2)*		98 (58.7)	51.4-65.8	69 (41.3)	34.2-48.64	3.803		
	Mod (3-4)	16	78 (48.8)	40.8-56.5	82 (51.3)	43.5-59.2		0.149	2
	High (5-6)		14 (46.7)	28.6-64.0	16 (53.3)	36.0-71.4			
Seizure frequency before the onset of Rx	*< 1 /week*		55 (57.3)	47.6-66.7	41(42.7)	33.3-52.4	1.289		
	1 – 4 /weeks		79 (51.0)	42.7-59.1	76 (49.0)	40.9-57.2		0.525	2
	>/ 4 weeks	18	41 (39))	40.1-60.2	63 (61)	39.8-59.5			
Seizure frequency after the onset of Rx	***< 1 /week***		**122 (56.5)**	**49.8-63.8**	**94 (43.5)**	**36.2-50.2**	**7.337**	**0.026**	**2**
	1 – 4 /weeks	**21**	**52 (52.5)**	**42.9-62.6**	**47 (47.5)**	**37.4-57.1**			
	> 4 /weeks		**12 (32.4)**	**17.3-48.0**	**25 (67.6)**	**52.2-86.4**			
Treatment regimen	***CBZ***		**107 (52.5)**	**45.6-59.3**	**97 (47.5)**	**40.7-54.5**	**10.464**		
	Val		**39 (65.0)**	**52.8-77.9**	**21 (35.0)**	**22.1-47.2**		**0.015**	**3**
	Others	**62**	**0(0.0)**	*	**3 (100.0)**	*			
	No regime		**17 (38.6)**	**24.5-54.8**	**27 (61.4)**	**45.3-75.5**			

Results shown in the table 4.6 above indicate that the level of knowledge about epilepsy, the presence of co-morbidities and seizure frequency before onset of treatment had p-value > 0.05 and therefore had no significant relationship with the quality of care.

4.2.2.3 Hospital-level Predictors of Quality of Care for PWE

The hospital level factors selected for the determination of quality of care were card possession, direct observed treatment, information on warning signs, caution on adverse drug reactions, adherence to medication, intervals of clinic visits, advise,

waiting time, privacy, confidentiality, drugs given, service availability, cost affordability and recommendation of the family to another contact.

Descriptive analysis of hospital-level factors showed variations in the perceived quality of care among people with epilepsy. Table 4.7 below shows bivariate analysis between hospital level factors and quality of care. Waiting time, service availability and cost affordability had a p-value <0.05 and therefore had as significant relationship with the rating of quality of care. Out of the 97 patients who waited for less than 30 minutes, 54 (55.7%) minutes rated quality of care as high and while 43 (44.3% of them rated it as low. For those who waited between 30 and 1 hour to be attended to, 76 (50.3%) of them rated quality as high and 75 (49.7%) of them rated it as low. For those who waited more than an hour to receive care, 58 (46.4%) rated quality of care as low and 67 (53.6%) rated quality of care as high (χ^2 = 6.490, p = 0.031, df = 2). For patients who received services whenever they needed it, 160 (52.6%) of them rated quality of care as high, whereas 144 (47.4%) rated quality of care as low. Also, of the 69 patients who did not have access to services when they needed them, 37(53.6%) rated quality of care as low, while 32 (46.4%) rated it as high. The results indicate that 262 (52.3%) of epilepsy patients with the financial means to pay for medication rated quality of care as high quality, compared to 125 (47.7%) who rated it as low. For those who were unable to pay for their medications, 59 (54.1%) rated quality as low, while 5 (45.9%) rated it as high. Of those 76 patients who brought cards or books to the hospital, 32 (42.1%) of people who carried it frequently received low-quality care, compared to 44 (57.9%) of those who did not. Of those 292 patients who always carried their identification cards on the appointment day, 150 (51.4%) of them received high-quality, compared to 142 (48.6%) of those who did not (p = 0.310 > 0.05). Of the 292 patients who received education on the symptoms of attacks, 126 (52.7%) of those who knew about warnings for the assaults rated quality as high compared to 113 (47.3%) who rated quality of care as low (p = 0.961 > 0.05).

Table 4.7: Bivariate Analysis between Hospital-level Factors and Quality of Care

Variables	**Categories**	**High quality**		**Low quality**		χ^2	**p-value**	**df**
		(%)	CI	n (%)	CI			
Card possession	*Most times*	44 (57.9)	46.08-68.42	32(42.1)	31.58-53.92	1.030	0.310	
Non-response (5)	*Always*	150(51.4)	44.99-57.38	142(48.6)	42.62-55.01			1
Dots	*Yes*	49(55.1)	44.16-65.55	40(44.9)	34.45-55.84	0.236	0.627	1
	No	148(52.1)	46.26-57.50	136(47.9)	42.50-53.74			
Warning signs	*Yes*	126(52.7)	45.85-58.92	113(47.3)	41.08-54.15	0.002	0.961	1
	No	71(53.0)	44.53-61.48	63(47.0)	38.52-55.47			
ADR	*Yes*	156(52.0)	46.23-57.57	144(48.0)	42.43-53.77	0.409	0.523	1
	No	41(56.2)	45.59-67.06	32(43.8)	32.94-54.41			
Clinical adherence	*Yes*	158(53.0)	47.27-58.94	140(47.0)	41.06-52.73	0.066		
	No	38(51.4)	39.13-62.86	36(48.6)	37.14-60.87		0.797	1
Non-response (1)								
Visit interval	*< 1 month*	67(57.3)	48.31-65.79	50(42.7)	34.21-51.69	1.385		
	2 – 3 months	88(51.2)	43.89-58.82	84(48.8)	41.18-56.11		0.500	2
	> 3 months	42(50.0)	39.73-61.11	42(50.0)	38.89-60.27			
Waiting time	***< 30 min***	**54(55.7)**	**45.22-65.69**	**43(44.3)**	**34.31-54.78**	6.490		
	1/2 – 1hr	**76(50.3)**	**41.42-59.26**	**75(49.7)**	**41.67-57.72**		**0.031**	2
	> 1hr	**67(53.6)**	**44.45-62.32**	**58(46.4)**	**37.68-55.55**			
Privacy	*Yes*	161(52.8)	47.18-58.17	144(47.2)	41.83-52.82	0.001	0.982	1
	No	36(52.9)	41.67-65.33	32(47.1)	34.67-58.33			
Confidentiality	*Yes*	35(59.3)	46.94-71.74	24(40.7)	28.26-53.06			
	No	123(49.8)	43.37-56.08	124(50.2)	43.92-56.63	2.687	0.261	2
	Don't know	39(58.2)	*45.31-69.35*	*28(41.8)*	*30.65-54.69*			
Drugs given	*PB*	78(57.4)	48.95-65.54	58(42.6)	34.46-51.05	3.161	0.367	3
	PHT	35(46.7)	35.14-57.31	40(53.3)	42.69-64.86			
	CBZ	78(51.0)	42.95-58.96	75(49.0)	41.04-57.05			
	OTHERS	6(66.7)	33.33-90.00	3(33.3)	10.00-66.67			

Variables	Categories	High quality		Low quality		χ^2	p-value	df
		(%)	CI	n (%)	CI			
Service availability	***Yes***	**160(52.6)**	**47.02-58.08**	**144(47.4)**	**41.92-52.98**	**7.137**	**0.029**	**1**
	No	**37(53.6)**	**42.11-65.71**	**32(46.4)**	**34.29-57.89**			
Affordability	***Yes***	**137(52.3)**	**46.10-58.59**	**125(47.7)**	**41.41-53.90**	**4.034**	**0.043**	**1**
Non-response (2)	***No***	**50(45.9)**	**44.36-63.56**	**59(54.1)**	**36.44-55.64**			
Recommendation	*Yes*	155(51.5)	45.82-57.10	146(48.5)	42.90-54.18	1.090	0.296	1
	No	42(58.3)	46.84-69.14	30(41.7)	30.86-53.16			

From the table, only three hospital-level factors were statistically significant: Waiting time (χ^2 =6.490; p = 0.031, df = 2), Service availability (χ^2 =7.137 p = 0.029, df=1) and Affordability (χ^2 = 4.304; p = 0.043, df= 1).

4.2.3 Multivariate Analysis

The multivariate analysis was performed to quantify the relative contribution of each predictor. Quality of care is a multifactorial phenomenon resulting from the interaction of structural, process, and outcome components, while healthcare utilization and access are influenced simultaneously by predisposing, enabling, and need-related characteristics as explicated in the both the Donabedian framework and the Aday and Andersen model. Examining variables in isolation would fail to capture the complex pathways through which individual, clinical, and facility-level factors affect quality outcomes.

Table 4.8 below shows multivariate logistic regression of all the predictors that had a significant relationship with quality of care at bivariate level. In the analysis only stigma retained statistical significance in the adjusted model thus representing independent determinants of quality of care for both high (OR=0.471, p=0.021) and low quality of care (OR=2.123, p=0.021) for people with epilepsy (PWE). Stigma exert direct influence on quality outcomes and does not merely reflecting associations attributable to other covariates.

Though occupation, onset of epilepsy, medication, seizure frequency, care regimen, waiting time, service availability, and cost affordability are not statistically significant predictors (p>0.05) in this model, still remain contributory predictors to quality of care

Table 4.8: Multivariate Analysis of Quality of Care for PWE

Variable	Category	H QoC Odds Ratio	95% CI	p-value	L QoC Odds Ratio	95% CI	p-value
Occupation	Formally employed	0.455	0.149–1.388	0.166	2.198	0.721–6.705	0.166
	Informally employed	0.535	0.246–1.165	0.115	1.868	0.859–4.064	0.115
	Unemployed – REF	1	–	–	1	–	–
Onset	<1 year	1.246	0.530–2.926	0.614	0.803	0.342–1.886	0.614
	1–3 years	1.193	0.605–2.355	0.61	0.838	0.425–1.654	0.61
	>3 years (REF)	1	–	–	1	–	–
Medication	Yes	1.367	0.664–2.818	0.396	0.731	0.355–1.507	0.396
	No – REF	1	–	–	1	–	–
Stigma	**Yes**	**0.471**	**0.248–0.893**	**0.021**	**2.123**	**1.119–4.026**	**0.021**
	No – REF	**1**	**–**	**–**	**1**	**–**	**–**
Seizure Frequency after onset of Rx	<1 week	2.085	0.775–5.609	0.146	0.48	0.178–1.290	0.146
	1–4 weeks	1.909	0.666–5.474	0.229	0.524	0.183–1.502	0.229
	>4 weeks (REF)	1	–	–	1	–	–
Regimen	Val	1.422	0.569–3.558	0.451	0.703	0.281–1.759	0.451
	Other	2.117	0.742–6.035	0.161	0.472	0.166–1.347	0.161
	CBZ (REF)	1	–	–	1	–	–
Waiting Time	<30 min	0.718	0.321–1.606	0.42	1.393	0.623–3.116	0.42
	30 min–1 hr	0.803	0.392–1.647	0.55	1.245	0.607–2.553	0.55
	>1 hr (REF)	1	–	–	1	–	–
Service Availability	Yes	0.981	0.449–2.146	0.963	1.019	0.466–2.228	0.963
	No – REF	1	–	–	1	–	–
Cost Affordability	Yes	0.761	0.361–1.604	0.473	1.314	0.623–2.772	0.473
	No – REF	1	–	–	1	–	–

4.3 Qualitative Findings

To explore the clinical predictors and hospital level factors for quality of healthcare provided to clients with epilepsy attending selected hospitals in Nairobi, Kiambu and Machakos counties, Kenya, Key Informant Interviews and Focus Group Discussions were conducted. Twenty-five KII (01-025) and ten FGDs (01-010) were carried out. Eight key thematic areas were identified with several emerging themes. The thematic analysis sought to provide deeper understanding of the research question and draw conclusions based on the data collected.

Table 4.9: Themes and Subthemes

Parent theme	Child theme	Emerging themes
1.0 Client Experience		
	1.1 Service	
		1.1.1 Privacy
		1.1.2 Satisfaction
	1.2Stigma	
2.0 Quality of care		
	2.1 High quality of care	
	2.2 Inadequate care	
3.0 Service Access		
4.0 Healthcare provider interaction		
	4.1 Regularity	
	4.2 Condition and treatment education	
		4.2.1 Treatment education
		4.2.2 Communication clarity
		4.2.3 Self-management readiness
	4.3 Client provider relationship	
5.0 Provider clinical practices		
6.0 Service Availability		
	6.1 Psychosocial support gaps	
7.0 Support and infrastructure		
	7.1 Diagnostic equipment	
	7.2 Support systems	

	7.3 Limited resources 7.4 Specialist collaboration 7.5 Referral system effectiveness 7.6 Treatment guidelines
8.0 Feedback and improvement	
	8.1 Client feedback methods 8.2 Areas of improvement

4.3.1 Client Experience

4.3.1.1 Service

Participants reported a varied range of experiences with healthcare services for epilepsy. Many found their overall experience positive, appreciating the knowledge, compassion, and involvement in decision-making provided by doctors and nurses whenever they sought services. Initial anxieties reported by some of the participants were often mitigated by supportive care and thorough instructions; though frustrations sometimes arose from long wait times. Some participants experienced a mixed quality of care, noting inconsistencies in the attentiveness and thoroughness of consultations, and a perceived lack of specialized support services such as counselling. While the effectiveness of diagnostic equipment and the coordination between departments were valued, there were suggestions for integrating alternative therapies to clients.

"My experience has been quite positive. The doctors and nurses at the hospital are very knowledgeable and compassionate. They take the time to explain my condition and treatment options in detail, which makes me, feel more confident in managing my epilepsy. I appreciate that they listen to my concerns and involve me in the decision-making process." [FGD-001]

"At first, I was quite anxious about seeking treatment for my epilepsy, but the healthcare providers made me feel comfortable and supported. They conducted thorough assessments and provided clear instructions on how to take my medication and what to do in case of a seizure, they should be applauded for that. The follow-up appointments are regular and help in monitoring my progress. However, sometimes the wait times can be long, which can be frustrating."[FGD-009]

Financial challenges and the need for persistent advocacy to ensure their symptoms are taken seriously were significant concerns among some respondents, despite the dedication of healthcare providers. Participants also described variability in the quality of consultations, where some visits were detailed and supportive while others felt rushed, alongside limited access to specialized services such as counselling or structured support systems for epilepsy management.

"Mine has been mixed, I would say. While the medical staff are generally helpful and skilled, mmh I sometimes feel that the services are inconsistent. For example, during some visits, I receive detailed information and personalized care, but on other occasions, the consultations feel rushed I do not know why. Also, the availability of specialized services like counselling or support groups for epilepsy patients seems limited."[FGD-003]

Some clients reported high levels of satisfaction, appreciating the attentive and good care, detailed explanations, and supportive follow-ups provided by their healthcare teams. They reported feeling well supported and secure in managing their condition. Others expressed moderate to low satisfaction raising concerns such as rushed appointments, a lack of additional support resources, long wait times, and issues with coordination between departments.

"According to me, my satisfaction level is low due to the inconsistency in the quality of care. However, some doctors are very attentive and thorough, while others seem less engaged and don't take the time to listen to my concerns. Additionally, there are frequent changes in my care team, which disrupts continuity and makes it harder to build a trusting relationship with my providers."[FGD-002]

"I am generally satisfied with the care I receive. The hospital has good facilities, and the staff are well trained in managing epilepsy. However, there is always room for improvement, especially in providing more holistic care options and reducing the financial burden of treatment. Despite these challenges, I appreciate the dedication and effort of the healthcare professionals."[FGD-001]

4.3.1.2 Stigma

Clients experienced stigma related to epilepsy in various settings, which significantly impacted their well-being and interactions. In healthcare settings, clients felt dismissed or judged during follow-up appointments and routine check-ups, especially when the staff showed impatience or a lack of empathy. They also experienced stigma in waiting areas, consultation rooms, and even the hospital cafeteria, where negative attitudes from staff and other patients were prevalent. This led to feelings of distrust and reluctance to seek further care, adversely affecting the quality of their healthcare. In societal perspective like school, participants said they encountered teasing and exclusion from peers, lack of support from teachers and counsellors, and inappropriate comments during physical education classes. Some felt stigmatized by their spouse's family and friends, who expressed doubts about their ability to contribute meaningfully, and by their spouse's downplaying of their condition in social settings.

"There were occasions when my spouse would express frustration or concern about how my epilepsy might affect our future together, which made me feel like a source of stress rather than a partner. He once told me that I was lucky he married me" [FGD-002]

"I experienced stigma during my follow-up appointments, especially when the doctors seemed impatient or dismissive about my concerns. It usually happened in the late morning when the clinic was busy." [FGD-006]

These experiences of stigma extended beyond isolated incidents and often resulted in feelings of shame, social withdrawal, low self-esteem, and reluctance to disclose their condition to others. Consequently, stigma negatively affected social relationships, educational participation, healthcare-seeking behaviour, and overall quality of life among persons living with epilepsy.

"Sometimes I prefer not to tell people that I have epilepsy because once they know, they start treating me differently. Some avoid me, others think I cannot do certain things, and it makes me feel isolated. Even at the hospital, there are times when you feel judged rather than supported." [FGD 010]

Healthcare providers also reported observing stigma among clients living with epilepsy, particularly in how patients interact with health services and disclose their condition. Respondents noted that some clients appeared reluctant to openly discuss their diagnosis or symptoms due to fear of negative judgment, which in some cases affected the continuity of care and patient engagement during consultations. It was further observed that stigma sometimes influenced how patients presented for care, with some delaying visits or minimizing symptoms, thereby indirectly affecting treatment outcomes and follow-up adherence.

"Some patients do not openly talk about their condition or even miss appointments because they fear being judged or labeled. You can tell that stigma affects how they engage with care, especially when it comes to discussing seizures or mental wellbeing." [KII-007]

"In some cases, patients are hesitant to fully disclose their condition or history of seizures during consultations. You can sense that they are worried about how they will be perceived, and this sometimes makes it difficult to get complete information for proper management." [KII-020]

4.3.2 Quality of Care

4.3.2.1 High Quality Care

According to the respondents, high-quality care for epilepsy encompasses several key elements but most important is having a knowledgeable and attentive healthcare team that stays current with treatment options, listens to patient concerns, and involves them in decision-making. Participants also noted personalized treatment plans tailored to individual needs, along with a range of treatment options and support services, as crucial. Based on the responses given, comprehensive and coordinated care, with effective communication among all healthcare providers and a dedicated care coordinator, is highly valued. Clients also consider respect and empathy essential, appreciating providers who understand the impact of epilepsy on their daily lives and collaborate on management strategies.

"To me it is having healthcare team that is knowledgeable and up-to-date with the latest treatment options. It is important that they listen to my concerns, provide clear and thorough explanations, and involve me in decision-making about my treatment plan. Then also…consistency in care, with regular follow-ups and easy access to emergency support when needed."[FGD-001]

"I consider high-quality care to be comprehensive and coordinated. This means having all my healthcare providers, including neurologists, primary care physicians, and specialists, working together to manage my epilepsy effectively. [FGD-002]

Access to advanced diagnostic tools, proactive monitoring, and timely interventions were said to be vital, along with thorough education about the condition and supportive healthcare teams. Moreover, a well-organized system where medical records are easily accessible and reliable emergency care available enhances the overall quality of care said a participant.

"I think high-quality care for epilepsy includes having access to state-of-the-art diagnostic tools and treatments. It also means having healthcare providers who are proactive in monitoring my condition and adjusting my treatment as needed. Easy access to specialists and timely interventions when I experience issues with my epilepsy are also key components of high-quality care."[FGD-004]

"For me, high-quality care involves comprehensive education about epilepsy and its management. This includes understanding my medication, potential side effects, and lifestyle changes that can help manage my condition. It's also important that my healthcare team is supportive and approachable, so I feel comfortable discussing any concerns or symptoms I experience."[FGD-007]

Participants further associated high-quality care with continuity and stability in service provision, emphasizing the importance of receiving care within a predictable and dependable healthcare system. They valued healthcare environments that fostered confidence, reassurance, and a sense of security throughout their treatment journey. Respondents indicated that quality care extends beyond clinical management to include systems that enable patients to maintain independence, cope effectively with

their condition, and achieve improved overall well-being and quality of life. The analysis demonstrated substantial consistency in the experiences reported across all hospitals, with common themes relating to provider-patient communication, medication availability, waiting time, counselling, stigma, continuity of care, and healthcare worker attitudes. Although the intensity of some experiences varied between facilities, no entirely new themes were unique to any single hospital.

"When I know that I can come to the hospital and get the help I need without challenges; it gives me confidence. Good care makes it easier for me to live my life, plan for the future, and not constantly worry about my condition." [FGD-009]

"For me high quality care is when I feel understood by my doctor, and I don't have to keep repeating my story every visit. It also means the treatment works well and I can see improvement in how I manage my seizures over time." [FGD-003]

Ther difference between perceived quality and objective quality indicators is expected and reflects the complexity of healthcare quality rather than a contradiction. The mixed-methods approach allowed for the integration of quality of care and the predictors in order to draw conclusions based on convergent evidence rather than patient perception alone.

4.3.2.2 Inadequate Care

Participants reported experiencing inadequate care in various ways. Some felt their care was inadequate due to delays in receiving timely medical advice, such as long waits for appointments during periods of increased seizure frequency. Other respondents encountered problems with clear communication, such as not being informed about potential side effects of new medications, which led to unnecessary frustration and self-research. Additionally, respondents reported lack of continuity of care especially when substitute doctors made uninformed medication changes, leading to severe seizures. Other participants experienced inadequacy due to rushed appointments, which made them feel their concerns were not fully addressed. Some also reported difficulties accessing advertised support services, leaving them feeling isolated.

"Yes, I experienced inadequate care when I tried to access support services for epilepsy. At one time, the hospital advertised counselling and support groups, but when I tried to join, I found out that these services were either full or not available. This left me feeling isolated and without the additional support I needed to manage my condition."[FGD-008]

"I felt the care was inadequate during a period when my regular doctor was on leave. The substitute doctor didn't have access to my full medical history and made changes to my medication without understanding my previous reactions and treatment plan. This resulted in a severe seizure episode that could have been prevented with better continuity of care."[FGD-002]

Participants further associated inadequate care with systemic gaps within health service delivery, particularly where fragmented care pathways and limited coordination between providers undermined effective epilepsy management. In some instances, they expressed that insufficient patient engagement in clinical encounters contributed to uncertainty in treatment decisions and reduced confidence in the care received. This was compounded by perceived weaknesses in follow-up systems, where patients felt left on their own to manage emerging complications without adequate clinical guidance or timely review.

"Sometimes after my visit, I am not sure what exactly I am supposed to do next if something changes. There is no clear follow-up plan and no one to consult about my needs, and I end up trying to figure things out on my own until the next appointment." [FGD-005]

4.3.3 Service Access

According to participants, some had relatively easy experience when accessing services, benefiting from specialized neurology departments and urban resources, while others encountered moderate challenges, such as long travel distances or reliance on general practitioners.

"Accessing epilepsy care in my area is relatively easy… [Child crying] The local hospital has a specialized neurology department, and I can usually get an appointment within a week or two at most. They also have a dedicated epilepsy clinic with knowledgeable staff who provide comprehensive and good care." [FGD-002]

"I find it moderately easy to access epilepsy care. The main issue is the distance to the nearest hospital with a neurology department, which is about an hour's drive and you know how many people can afford that... However, once I get there, the care is excellent, and the staff are very supportive." [FGD-009]

A few faced significant difficulties due to limited local resources, financial constraints, or the need to travel to different cities in order to seek services. Additionally, disparities in access were noted, with some good services being located in more affluent areas, creating barriers for those in lower-income neighborhoods. Overall, the accessibility of epilepsy care varied widely, influenced by location, financial factors, and the availability of specialized services.

"Accessing care can be challenging at times. There are only a few specialists in the area, and getting an appointment often means waiting for several weeks. This can be problematic if I have urgent concerns or need to adjust my medication quickly."[FGD 004]

"Accessing epilepsy care in my area is quite difficult. There are limited resources and specialists available, [coughing]. What was I saying? …and the local clinics are often overbooked. I sometimes have to travel to a different city to see a specialist, which is inconvenient and costly."[FGD 001]

Beyond differences in ease of access, participants also highlighted structural and system-level constraints that shaped their overall experience of service access. These included variability in referral efficiency between facilities, limited availability of specialist services at lower-level health facilities, and dependence on overburdened public hospitals, which sometimes affected timely entry into care pathways. Some respondents also pointed to inconsistent appointment scheduling systems and

occasional disruptions in service delivery, which influenced continuity and predictability of care access.

"Even when you know where to go, sometimes the system itself makes it hard. You are referred from one place to another, and by the time you get the appointment, the problem has already changed or worsened." [FGD-003]

The findings suggest that access to epilepsy services was an important determinant of perceived quality of care. Participants who reported timely access to specialist services, shorter waiting times, and well-coordinated care pathways generally described more positive care experiences. Conversely, barriers such as long travel distances, limited specialist availability, delayed appointments, and inefficient referral processes were perceived to compromise continuity, timeliness, and effectiveness of care, thereby negatively influencing the overall quality of care received.

4.3.4 Healthcare provider Interaction

4.3.4.1 Regularity

Having a regular healthcare provider for epilepsy is highly valued and important for effective care. Many respondents emphasized the benefits of continuity, noting that seeing the same provider helps in building trust, understanding medical history, and ensuring cohesive and personalized treatment. Those who had a consistent provider appreciated the familiarity and rapport that developed, which facilitated better management of their condition. In contrast, participants without a regular provider found the lack of consistency challenging, often having to repeatedly explain their medical history and experiencing less coordinated care. While some managed with occasional provider changes, most recognized the significant advantages of having a stable, familiar healthcare professional overseeing their care.

"Yes, I have a regular provider, he is so good and it makes a big difference. Seeing the same doctor means, they know all the details about my condition and treatment preferences. It also makes me feel more comfortable discussing sensitive issues because we have built a rapport over time." [FGD-004]

"Unfortunately, I don't have a regular healthcare provider due to the high turnover rate at the clinic I attend and by the way that needs to be addressed. It's frustrating because I feel like I'm starting from scratch at each visit. Having a consistent provider would definitely improve my overall care experience." [FGD-001]

"I see the same healthcare provider most of the time, but there are occasional changes. While I prefer seeing the same person for consistency, I have also found that different perspectives from other doctors can sometimes be helpful. It's important, but I've learned to be flexible." [FGD-007]

Participants further associated continuity with healthcare providers not only with improved communication but also with enhanced clinical safety and efficiency in care delivery. They indicated that consistent follow-up by the same provider reduced the likelihood of medication errors, unnecessary changes in treatment plans, and duplication of clinical assessments. In addition, regular provider-patient relationships were described as facilitating more proactive management of epilepsy, where subtle changes in symptoms could be identified earlier and addressed promptly. Some respondents also noted that continuity contributed to emotional reassurance, as familiarity with a provider reduced anxiety associated with clinical encounters and improved overall engagement with care services.

"For me, when I keep seeing the same doctor, they notice even small changes in my condition. It becomes easier to adjust treatment early instead of waiting until things get worse, and I don't have to start explaining everything from the beginning every time." [FGD-003]

4.3.4.2 Condition and Treatment Education

4.3.4.2.1 Treatment Education

Participants generally valued healthcare providers who offered comprehensive education regarding epilepsy, treatment options, medication use, and long-term disease management. Many respondents described receiving detailed explanations that enhanced their understanding of both immediate treatment plans and the broader

aspects of living with epilepsy. The provision of educational materials and opportunities to discuss treatment-related concerns further strengthened participants' knowledge and confidence in their care. Participants particularly appreciated explanations that clarified the purpose of medications and the rationale behind treatment decisions, enabling them to better understand and engage with their care.

However, participants reported variations in the depth and comprehensiveness of information provided by healthcare providers. While some providers delivered detailed and informative explanations, others were perceived as offering only brief discussions that left patients with unanswered questions regarding their condition and available treatment options. Respondents expressed a desire for more detailed consultations that explored treatment alternatives, expected outcomes, and long-term management strategies. These inconsistencies sometimes limited patients' understanding of epilepsy and their ability to fully participate in treatment decision-making.

"The explanations are very clear and thorough. My doctors make sure I understand not just the immediate treatment plan, but also the long-term management of my condition and I appreciate them for that. They provide a lot of educational materials, which I find very helpful." [FGD-010]

"According to me, they are usually brief and to the point, which can be frustrating. I often leave appointments with unanswered questions. I would prefer more detailed discussions about my condition and the rationale behind different treatment options." [FGD-002]

4.3.4.2.2 Communication Clarity

Clear and effective communication emerged as a critical aspect of treatment education. Participants appreciated healthcare providers who used understandable language and took sufficient time to explain medical information in a manner that was easy to comprehend. Such communication practices helped participants feel informed, reassured, and actively involved in their care. Respondents valued providers who

encouraged dialogue and created opportunities for patients to ask questions and seek clarification regarding their condition and treatment.

"The explanations are very clear and thorough. My doctors make sure I understand not just the immediate treatment plan, but also the long-term management of my condition." [FGD-010]

Despite these positive experiences, participants reported inconsistencies in communication practices across providers. Some consultations were described as rushed, limiting opportunities for discussion and clarification. Others noted that the use of medical terminology without adequate explanation sometimes hindered understanding. Participants also highlighted the need for improved follow-up mechanisms, noting that additional questions often arose after appointments. Suggestions included written summaries, more detailed consultations, and accessible channels for post-consultation communication. Overall, respondents emphasized the importance of consistent, patient-centered communication that supports understanding and informed decision-making.

"My healthcare providers do a good job of explaining things, but they could improve on follow-up. Sometimes, after I leave the appointment, I think of more questions and it's hard to get the additional information I need." [FGD-005]

"According to me, they are usually brief and to the point, which can be frustrating. I often leave appointments with unanswered questions." [FGD-002]

4.3.4.2.3 Self-Management Measures

Participants emphasized that effective education and clear communication significantly enhanced their ability to actively manage epilepsy. Adequate information enabled them to better understand their condition, adhere to prescribed medications, monitor symptoms, and recognize changes that required medical attention. Respondents described feeling more confident and capable of participating in their care when healthcare providers took time to explain treatment plans and address their concerns comprehensively.

"The explanations are very clear and thorough. My doctors make sure I understand not just the immediate treatment plan, but also the long-term management of my condition..." [FGD-010]

Many participants indicated that education reduced uncertainty regarding epilepsy management and empowered them to make informed decisions about their health. Understanding the reasons for medication use, recognizing potential warning signs, and knowing how to respond to changes in their condition were viewed as important outcomes of effective patient education especially among the newly diagnosed. They emphasize challenges of accepting the diagnosis inadequate understanding of epilepsy, anxiety about lifelong treatment, and the need for comprehensive counseling. Those on follow up were more concerned with continuity of care, medication availability, waiting times, appointment scheduling, and long-term psychosocial support.

Participants also valued receiving information tailored to their individual circumstances, as this strengthened their confidence in managing their condition independently. Conversely, limited explanations and inadequate opportunities for clarification sometimes reduced confidence and hindered effective self-management.

"When my healthcare provider takes time to explain things properly, I feel more confident about managing my epilepsy you know. It helps me understand why I am taking certain medications and what I should look out for, which makes it easier to follow the treatment plan." [FGD-004]

"Participants indicated that adequate education helped reduce uncertainty regarding treatment, improved confidence in medication use, and enabled them to recognize and respond appropriately to changes in their condition." [FGD 001]

4.3.4.3 Client Provider Relationship

Client provider relationship is built on mutual respect, trust and open communication. Participants reported a range of experiences regarding their relationship with healthcare providers with majority feeling comfortable and valued, noting that their providers encouraged open communication and actively listened to their concerns.

Some participants acknowledged providers who created a supportive and respectful environment, making them feel like active participants in their care. However, some participants reported inconsistencies, feeling comfortable with certain providers but not others.

"I feel very comfortable… [Car hooting]. My healthcare team has created a trusting and respectful relationship with me and they always take my concerns seriously, provide detailed answers to my questions and …" [FGD-009]

"Sometimes I feel comfortable, but other times I don't. It can be hard to bring up concerns, especially if I feel like the provider is in a hurry. I think more encouragement and reassurance from the providers would help." [FGD-002]

Issues such as providers seeming rushed, using intimidating communication styles, or not being receptive to questions affected client comfort levels. A few participants mentioned feeling hesitant to ask questions due to brief appointment times or concerns about taking up too much time. There was a desire for more consistent and supportive interactions across the board as many valued a positive, open relationship with their providers.

"Let me tell you my experience. I am usually hesitant to ask questions. I feel like the appointments are often too short, and I don't want to take up too much time. It would be great if there was more time allocated for patient questions and discussions." [FGD-007]

"No, I don't always feel comfortable. Sometimes I feel intimidated or worry that my questions might be seen as silly or unimportant. I think it would help if the providers made more of an effort to create an open and welcoming environment." [FGD-003]

Participants further indicated that strong client-provider relationships fostered confidence in treatment and encouraged continued engagement with healthcare services. Respondents described feeling more motivated to adhere to treatment recommendations when they perceived their providers as approachable, empathetic, and genuinely interested in their well-being. They also highlighted the importance of

being treated as partners in care, where their experiences, preferences, and concerns were acknowledged and incorporated into treatment decisions. Such interactions were perceived to strengthen trust in the healthcare system and contribute to a more positive care experience.

"Wait, I think what makes the biggest difference for me is when the healthcare provider treats me as someone who understands my own condition. When they listen to my experiences and include me in decisions, I feel respected and more confident about following the treatment plan." [FGD-005]

4.3.5 Provider Clinical Practices

To ensure high-quality care for patients with epilepsy, healthcare providers implement several key practices. They follow evidence-based guidelines and protocols adjusting treatment plans for individual based on thorough assessments and regular monitoring. The respondents emphasized on effective communication ensuring that patients and their families understand their condition and treatment options.

"I prioritize a comprehensive and personalized approach to care. This means conducting thorough initial assessments to understand each patient's specific type of epilepsy, triggers, and overall health before I make any decisions. I then develop a tailored treatment plan that may include medication, lifestyle modifications, and education on seizure management."[KII-003]

Moreover, regular follow-ups are conducted to adjust treatments and review progress. Providers also engage in interdisciplinary collaboration, working with a range of professionals to address all aspects of care, and prioritize patient education to empower active management of the condition.

"Interdisciplinary collaboration is crucial in providing high-quality care. You know teamwork works wonders. So I work closely with other healthcare professionals, such as neurologists, psychologists, and social workers, to address all aspects of a patient's health. This team-based approach helps in providing care that meets the diverse needs of epilepsy patients or rather clients." [KII-014]

Respondents reported using advanced diagnostic tools for accurate diagnosis, and integration of mental health support to address associated psychological issues. A few highlighted continuous professional developments through training and detailed medical record-keeping further supporting coordinated and up-to-date care.

"I use advanced diagnostic tools and technology to accurately diagnose and monitor epilepsy, the good thing is that they are available. This includes using EEGs, MRIs, and other imaging techniques to get a detailed understanding of each patient's condition, which helps in formulating effective treatment plans." [KII-020]

"To ensure continuous improvement in care quality, I engage in regular training and professional development. Attending workshops, seminars, and conferences helps me stay abreast of the latest trends and treatments in epilepsy care, ensuring that my patients benefit from the most current knowledge and practices." [KII-017]

4.3.6 Services Availability

This theme examines services available in the named health facilities. Participants unanimously acknowledged having most of the services at the patients' disposal. Majority of the facilities had inpatient, outpatient, outreach, dialysis, dermatology, referral, imaging, cancer care and gender-based violence services as indicated below.

"You know this is a level 5 hospital…and we have services like dermatology, facial surgery, mmh.. . Impatient and such like." [KII-013]

"Services...outreach, referral, impatient, outpatient, dialysis…yes there are so many on the checklist" [KII-002]

Extensive array of services offered included emergency care for trauma, advanced imaging like MRI, neurological services, cardiac care and specialized treatment conditions like cancer.

"First of all this is a tertiary care hospital. There are so many services available like we have emergency care for people with trauma, advanced medical imaging like medical resonance imaging, outpatient and cancer treatment. Maybe yeah," [KII-020]

"I will start by saying referral cases, minimal outpatient, emergency care like heart attacks, cardiac care, neurological services, paediatric services, dermatology they are so many..." [KII-015]

Participants also reported the importance of proactive and preventive approaches in the clinical management of epilepsy. Healthcare providers described the need for continuous assessment of treatment outcomes, early identification of emerging complications, and timely interventions to prevent deterioration of patients' conditions. They emphasized the value of maintaining flexibility in treatment planning, recognizing that epilepsy management often requires adjustments over time in response to changes in seizure patterns, treatment response, and individual patient circumstances. Such practices were viewed as essential in optimizing clinical outcomes and enhancing patients' quality of life as reported below:

"Managing epilepsy is not a one-time intervention, it requires ongoing evaluation. We continuously assess how patients are responding to treatment and make necessary adjustments to ensure optimal seizure control while minimizing adverse effects. This helps us provide care that remains responsive to the patient's changing needs." [KII-011]

4.3.6.1 Psychosocial Support Services

Participants reported that psychosocial support services for persons living with epilepsy were available only to a limited extent across the facilities. While some respondents indicated the existence of counselling services, support groups, and mental health support mechanisms, access to these services was often inconsistent or inadequate to meet patient needs. Several participants noted that specialized psychosocial support services were either unavailable, oversubscribed, or difficult to access when required. Healthcare providers similarly acknowledged gaps in counselling and emotional support services, particularly for patients experiencing stigma, social challenges, and psychological distress associated with epilepsy. The findings suggest that although psychosocial support was recognized as an important component of comprehensive epilepsy care, its availability remained insufficient in many facilities.

"Also, the availability of specialized services like counselling or support groups for epilepsy patients seems limited." [FGD-003]

"Yes, I experienced inadequate care when I tried to access support services for epilepsy. At one time, the hospital advertised counselling and support groups, but when I tried to join, I found out that these services were either full or not available. This left me feeling isolated and without the additional support I needed to manage my condition." [FGD-008]

"I would suggest that we get more supplies or stocks especially the drugs, better quality equipment, more staff, transport and emotional counselling especially to the youths and married." [KII-004]

4.3.7 Support and Infrastructure

4.3.7.1 Diagnostic Equipment

Level 5 hospitals are expected to have a number of diagnostic equipment. This theme examines the available diagnostic equipment in the facilities and their condition. Majority of the facilities did not have enough diagnostic equipment despite being expected to.

"Unfortunately there is nothing much in our facility. We have lab imaging and no EEG" [KII-004]

"Is there any?...uum there is Medical Resonance Imaging(MRI)..yes"[KII-013]

Respondents indicated that the availability of diagnostic equipment varied across facilities, with some hospitals relying on a limited range of diagnostic services to support epilepsy care. Participants noted that while basic laboratory and imaging services were generally available, specialized equipment essential for comprehensive epilepsy assessment was often lacking. This constrained the capacity of some facilities to conduct complete diagnostic evaluations within the hospital, necessitating referrals or alternative arrangements for specialized investigations. The adequacy and

functionality of diagnostic infrastructure were therefore perceived as important determinants of timely diagnosis and effective clinical management of epilepsy.

"We can do some of the routine investigations, but for certain specialized tests we have to refer patients elsewhere because the equipment is not available within the facility. This can sometimes delay the diagnostic process." [KII-025]

"At this level hospital, we do not have advanced diagnostic tools like EEG. We rely mostly on basic tests and clinical assessment, so whenever a patient needs detailed epilepsy investigations, we have to refer them to higher-level facilities for further evaluation." [KII-007]

4.3.7.2 Support Systems

This theme assesses whether the staff receive any support from the government and other organizations. This is evidenced from the results as most reported to have been trained on epilepsy, funded by the government and received technical and pharmaceutical support though not sufficient.

"Yes…On training we do receive trainings both general training and based on people living with epilepsy. At times we receive finances from the county at times not...technical and pharmaceutical support I am not sure…" [KII-001]

"We are supposed to be receiving support but unfortunately that is not the case…but trainings we do, there is a time we were supposed to do a collaboration from NGO, s in clinical trials and sponsorship I don't know what happened." [KII-005]

Generally, participants indicated that support systems for epilepsy care existed in different forms, mainly through periodic training opportunities, institutional collaborations, and occasional government or partner-funded initiatives. However, the support was described as inconsistent and not systematically sustained across all facilities. While training was the most commonly reported form of support, respondents highlighted gaps in financial assistance, structured technical backing, and consistent pharmaceutical support. This variability in support systems was perceived

to influence the extent to which facilities could effectively strengthen epilepsy service delivery.

"We do get some form of support, especially through training sessions and occasional collaborations with partner institutions, but it is not something that is consistent. Other areas like funding and steady supply of support services are not always guaranteed." [KII-012]

"Maybe yes, maybe no…Trainings have been done before though not regularly. Financial support I can't attest to any, then what was the one…? Pharmaceutical support on some drugs" [KII-004]

Yes…Mostly trainings, we've partnered with institutions in exchange for services like students from Kenya Medical Training College." [KII-020]

4.3.7.3 Limited Resources

Resource limitations significantly affect the quality of epilepsy care. Some respondents reported that their facility struggles with outdated and insufficient diagnostic tools, such as malfunctioning MRI equipment, which delays accurate diagnosis and treatment. Some reported a shortage of specialized personnel, leading to long wait times for appointments. Budget constraints also limit access to newer antiepileptic drugs, forcing reliance on less effective medications. Additionally, inadequate facility infrastructure, such as the absence of rooms for continuous video EEG monitoring, affects diagnostic capabilities. Moreover, resource allocation imbalances, where other departments receive more attention, further straining the epilepsy care unit was reported. Limited patient education programs and geographic barriers for patients in rural areas worsen these issues, affecting treatment adherence and quality of care.

"Since I came to this facility we often encounter challenges due to the limited availability of advanced diagnostic tools. Out MRI equipment is not in good condition and this can result in delays in identifying the right treatment strategies for patients." [KII-015]

"Resource allocation has been a challenge, I have a feeling other departments receive more attention and funding compared to epilepsy care unit. This imbalance can impact the quality of care we provide. We also lack robust patient education programs due to limited resources. Effective management of epilepsy requires thorough patient education about lifestyle modifications and medication adherence, but without these programs, patients might not receive the support they need to manage their condition effectively. That's all I can say" [KII-012]

Participants further reported that resource constraints not only affected the availability of equipment and infrastructure but also influenced the efficiency and responsiveness of service delivery. In some cases, limited staffing levels and competing clinical demands were reported to overburden available healthcare workers, reducing the time available for comprehensive patient assessment and follow-up. These constraints were perceived to contribute to delays in service provision and reduced capacity for individualized care, particularly in managing complex epilepsy cases that require close monitoring and multidisciplinary input.

"At times the number of patients is high compared to the available staff, so consultations become rushed and it becomes difficult to give each patient enough time, especially those with complicated epilepsy cases that need closer follow-up." [KII-025]

4.3.7.4 Specialist Collaboration

Respondents emphasized the importance of regular multidisciplinary team meetings, which bring together specialists such as neurologists and psychologists to ensure good and coordinated treatment plans. The well-established referral systems and integrated care plans further enhance this collaboration by allowing flawless patient transitions between different care providers. Participants highlighted the use of shared electronic health records which facilitate effective communication across the team. Moreover, participants reported joint educational sessions and case conferences that contribute to staying updated and making well-informed treatment decisions as highlighted below:

"We often collaborate with surgeons and radiologists for cases that may require surgical intervention or advanced imaging. We have also had joint educational sessions and workshops with other specialists especially in the county to stay updated on the latest developments in epilepsy care."[KII-009]

"Our facility has a well-established referral system for all patients who need additional care. Like if a patient requires specialized cognitive therapy or psychiatric support, we refer them to our network of specialists, which helps them receive comprehensive care." [KII-013]

Additionally, the healthcare providers further noted that effective specialist collaboration enhanced continuity of care and improved clinical decision-making through shared expertise. This collaborative approach was described as particularly important in complex epilepsy cases that required input from multiple disciplines to address both neurological and psychosocial needs. Respondents indicated that structured communication channels among specialists helped reduce delays in decision-making and minimized fragmentation of care, thereby improving the overall coordination of patient management across different levels of service delivery.

"When we manage complicated epilepsy cases, having input from different specialists helps us agree on the best treatment approach quickly. It ensures that decisions are not made in isolation but are informed by multiple perspectives, which improves patient outcomes." [KII-023]

4.3.7.5 Referral System Effectiveness

According to the respondents, the referral system is generally effective, showcasing strengths in coordination between departments, ease of access to specialists, and integration with electronic health records. The streamlined process ensures patients connection with the appropriate specialists and seamless sharing of patient information, which helps in reducing duplication and coordinating care. However, participants reported occasional challenges, including delays in processing referrals to specialized epilepsy clinics and challenges in maintaining consistent follow-up tracking. Patients had mixed feedback, with some expressing frustration over waiting

times and communication gaps. Participants reported resource availability affecting effectiveness since delays may occur if specialists are overbooked or unavailable.

"Our referral system works well in terms of coordination between departments. When a patient is referred from the neurology department to a specialist, the transition is usually smooth, and communication between teams is effective." [KII-020]

"The patient feedback we have received on the referral system is mixed. While some patients appreciate the efficiency and clarity of the process, others experience frustration with the waiting times and the lack of communication about the referral status. So I'd suggest we try and work like a team and be able to get where the gap is" [KII-011]

Participants also mentioned that the effectiveness of the referral system was also influenced by the clarity of referral pathways and patient navigation within the healthcare system. In some instances, respondents noted that patients experienced uncertainty regarding where to go next after being referred, particularly when multiple service points were involved. This highlighted the importance of clear communication at each stage of referral to ensure patients understand the process, reduce missed appointments, and improve continuity of care across different levels of the health system.

"Sometimes patients are referred correctly, but they are not always clear about where to go next or what to expect, so they end up missing appointments or delaying follow-up because the instructions were not well understood." [KII-024]

4.3.7.6 Treatment Guidelines

Participants reported following a variety of guidelines to ensure high-quality care for epilepsy across most facilities. They adhere to standardized protocols from several key organizations, including the Ministry of Health (MOH). These guidelines provide evidence-based recommendations for diagnosing, managing, and treating epilepsy, covering aspects from initial assessment to long-term management and treatment options for different clients. Additionally, some participants mentioned using a

combination of national guidelines and hospital-specific protocols to stay updated with the latest advancements and maintain consistent care for the clients.

"We follow a combination of guidelines, including those from the World Health Organization (WHO) and from MOH. The guidelines help us maintain a high standard of care and to even stay updated with the latest advancements in epilepsy treatment."[KII-019]

"We adhere to treatment guidelines developed by our hospital's neurology department, which are based on national and international guidelines, yes. I think this ensures that all patients receive consistent and high-quality care."[KII-005]

Furthermore, it was reported that treatment guidelines also serve as a framework for standardizing clinical decision-making across different levels of care, thereby reducing variability in epilepsy management practices. Respondents noted that adherence to these guidelines supports rational prescribing, promotes patient safety, and ensures alignment with current evidence-based practices. However, they also highlighted the need for periodic review and adaptation of guidelines to reflect emerging evidence and local clinical realities, as well as continuous sensitization of healthcare providers to enhance consistent implementation across facilities.

"The guidelines are very helpful in standardizing how we manage epilepsy, especially in terms of drug selection and follow-up schedules. However, it is also important that they are regularly updated and that all staff are continuously reminded and trained on how to apply them in daily practice." [KII-022]

4.3.8 Feedback and Improvement

4.3.8.1 Client Feedback Methods

Different facilities use different methods to gather patient feedback on their care services. Majority commonly employ patient surveys to collect quantitative data on satisfaction levels and identify areas for improvement. Feedback forms are available in some facilities during visits for patients to share their thoughts. Moreover, some

reported having dedicated complaint and suggestion channels that allow patients to voice concerns, which are reviewed by quality improvement teams.

"For us, we have dedicated channels for patients to voice their complaints or suggestions. And…these are reviewed by our quality improvement team, who then work on addressing the concerns and making necessary improvements yes." [KII-005]

"We regularly distribute patient satisfaction surveys to gather feedback on their experience with our epilepsy care services. The results help us identify areas for improvement and adjust our practices accordingly." [KII-017]

Participants further noted that feedback collection was increasingly being integrated into routine service delivery processes to promote continuous quality improvement. In some facilities, feedback was obtained informally through direct patient-provider interactions during clinic visits, allowing healthcare providers to capture immediate concerns and respond in real time. Respondents indicated that combining structured feedback tools with informal communication channels enhanced the responsiveness of services and helped identify emerging issues that may not always be captured through formal surveys or complaint systems.

"Apart from formal surveys, we also get feedback directly from patients during clinic visits. Sometimes patients are more open when speaking face-to-face, and this helps us pick up issues early and address them immediately." [KII-020]

"In addition to suggestion boxes and surveys, patients often share their experiences during follow-up visits. These informal conversations are very useful because they give us immediate insight into what is working and what needs improvement in our epilepsy services." [KII-001]

4.3.8.2 Areas of Improvement

This theme highlights key areas within epilepsy care services that require strengthening to enhance overall service delivery and patient outcomes. Respondents pointed to persistent gaps in the availability and consistency of essential supplies, including antiepileptic drugs and other critical commodities required for effective

management of epilepsy. In addition, limitations in diagnostic capacity, particularly the availability and functionality of advanced imaging and EEG services, were identified as major constraints affecting accurate diagnosis and clinical decision-making. These resource-related challenges were seen as central barriers to delivering comprehensive and timely epilepsy care.

"Patient education, community education, CMEs for staff, No need for special clinic (to be integrated or psychiatric clinic), Supply of IEC materials and also …alot should be done, but my greatest concern is recruitment of neurologist, EEG" [KII-013]

"All I can say is maybe there is a need for better diagnostic equipment and also improvement in other departments, including probably the department of surgery." [KII-017]

Additionally, the participants further emphasized the need to strengthen service integration and expand supportive care within outpatient and specialized services. Gaps were noted in the integration of psychiatric services within epilepsy care pathways, as well as limited counselling services for patients requiring psychosocial support. Improvements in outpatient service organization, availability of essential supplies, and expansion of maternal and adolescent-focused care were also highlighted as important areas requiring attention. These gaps were viewed as limiting the ability of facilities to provide holistic, patient-centered epilepsy care.

"I would suggest that we get more supplies or stocks especially the drugs,and.. better quality equipment, more staff, transport and emotional counselling especially to the youths and married." [KII-004]

I think improve on outpatient services, more supplies, enough equipment, more counselling to psychiatric patients and proper maternal care. [KII-023]

Respondents also expressed broader concerns regarding overall system capacity and long-term improvement of epilepsy services. These included the need for increased human resources, particularly specialists such as neurologists, improved infrastructure, and strengthened training opportunities for healthcare workers. There was also an

expressed aspiration for continuous improvement and transformation of service quality to ensure that facilities can meet the growing needs of patients with epilepsy more effectively.

"One day I would like to see Machakos hospital become the best health facility. There is a lot to be improved" [KII-009]

"There is still a gap in terms of specialists and infrastructure, and this affects how we deliver services. With more staff, better training opportunities, and improved facilities, epilepsy care would be much more effective and responsive to patient needs." [KII-015]

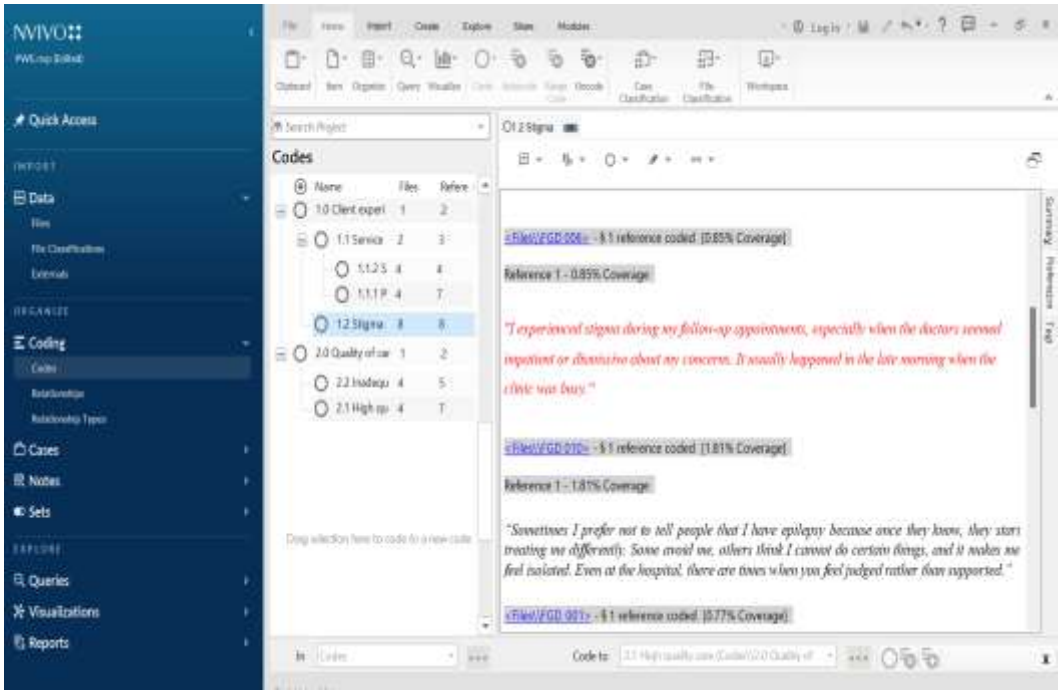

Figure 4.1: NVivo Screenshot

4.4 Triangulation of Quantitative and Qualitative Findings

Table 4.10: Triangulation of Quantitative and Qualitative Findings on Quality of Care

Quantitative Finding	Qualitative Finding	Meta-Inference
Respect had the highest factor weight (0.153)	Participants emphasized empathy, being listened to, involvement in decision-making, and feeling understood by providers	Respect is a dominant determinant of quality of epilepsy care, suggesting that interpersonal interactions strongly influence patient evaluations of services.
Communication ranked second (0.139)	Respondents valued clear explanations about epilepsy, medications, side effects, and treatment options	Effective communication enhances patient understanding, trust, and engagement in care.
Tolerability and effectiveness were highly weighted domains	Participants highlighted symptom control, treatment effectiveness, proactive monitoring, and management of side effects	Patients assess quality not only through clinical outcomes but also through their treatment experience.
Affordability had moderate importance	Participants discussed access to services and continuity of care	Financial accessibility contributes to quality perceptions but may be secondary to relational and clinical dimensions.
Promptness received the lowest factor weight (0.069)	Waiting times were rarely mentioned by participants	Operational efficiency appears less influential than provider competence, respect, and treatment outcomes in shaping quality perceptions.
52.8% reported high quality care	Participants generally described positive experiences characterized by coordinated and comprehensive care	Qualitative findings provide contextual explanations for the relatively high-quality ratings observed quantitatively.

The integration of quantitative and qualitative findings demonstrates strong convergence on the key dimensions shaping patients' perceptions of quality epilepsy care. Quantitatively, respect emerged as the most influential domain, followed by communication, treatment effectiveness, tolerability of side effects, affordability, counselling, geographical access, privacy, and promptness. Qualitative findings broadly reinforced this hierarchy, with participants consistently emphasizing

respectful interactions, empathy, active listening, and shared decision-making as central markers of high-quality care. Together, these findings position respect as a foundational determinant of perceived quality, reflecting the importance of interpersonal care relationships.

Communication ranked second in the quantitative weighting and was similarly prominent in qualitative accounts. Participants associated quality care with clear explanations of epilepsy, treatment options, medication use, and side effects, as well as opportunities to ask questions and participate in decisions. This alignment suggests that effective communication strengthens understanding, trust, and sustained engagement in care.

Effectiveness and tolerability of treatment also showed convergence across both strands. Quantitative results highlighted their importance, while qualitative narratives described quality care in terms of seizure control, minimal side effects, and ongoing treatment adjustments. This indicates that patients assess quality not only through service processes but also through clinical outcomes and treatment burden.

Qualitative findings further elaborated the quantitative framework by contextualizing counselling, geographical access, and continuity of care. Participants valued comprehensive education on epilepsy management, accessible specialist services, coordinated care pathways, reliable follow-up, and timely emergency support. These elements clarified how broader system features shape experiences captured within the quantitative domains.

Promptness showed relative divergence. Although included in the quantitative model, it had the lowest weighting and was seldom highlighted in qualitative accounts as a defining feature of quality care. Instead, participants prioritized relational and outcome-oriented aspects such as provider competence, continuity, respect, and treatment effectiveness, suggesting these are more central to quality perceptions than service speed.

Overall, just over half of respondents (52.8%) rated care as high quality, a finding supported by qualitative descriptions of positive experiences characterized by

respectful providers, effective communication, coordinated care, and clinical improvement. These experiences were linked to increased confidence, reassurance, and improved self-management. The integrated evidence indicates that strengthening respectful provider–patient relationships, communication, counselling, clinical effectiveness, and continuity of care is likely to yield the greatest improvements in perceived quality of epilepsy services.

Table 4.11: Triangulation of Quantitative and Qualitative Findings on Clinical Predictors on Quality of Care

Clinical Predictor	Quantitative Finding	Qualitative Finding	Integration
Duration before treatment initiation	Significant (p=0.048)	Most participants reported long illness duration before treatment	Convergence
Anti-seizure medication	Significant (p=0.045)	Participants emphasized importance of medication	Convergence
Stigma experience	Significant (p=0.025)	Extensive stigma reported in social and healthcare settings	Strong convergence
Seizure frequency after treatment	Significant (p=0.026)	Participants linked seizure control to positive care experiences	Convergence
Treatment regimen	Significant (p=0.015)	Medication effectiveness frequently discussed	Convergence
Knowledge on epilepsy	Not significant (p=0.149)	Knowledge gaps on warning signs and side effects identified	Discordance
Co-morbidities	Not significant (p=0.712)	Broader psychosocial challenges described	Partial complementarity

The integration of quantitative and qualitative findings indicates that clinical experiences play a central role in shaping perceived quality of care among people living with epilepsy. Overall, both strands demonstrate substantial convergence on the importance of treatment-related factors and stigma, while also highlighting contextual influences on patient experience.

Quantitative analysis identified duration before treatment initiation as a significant predictor of quality of care, with earlier initiation associated with higher ratings. Qualitative accounts reinforced this finding, with participants describing prolonged

periods before diagnosis and treatment that contributed to uncertainty, prolonged symptom burden, and psychosocial difficulties. These narratives suggest that timely initiation of care is linked to more positive healthcare experiences.

A similar convergence was observed for anti-seizure medication and treatment regimens. Quantitatively, receipt of medication and established treatment schedules were significantly associated with higher perceived quality of care. Qualitative findings echoed this, as participants consistently associated medication access with seizure control, improved functioning, and confidence in the health system. Continuity of treatment and perceived effectiveness of therapy therefore emerged as central to quality evaluations.

The most pronounced convergence was observed in relation to stigma. Quantitatively, stigma experience was significantly associated with lower quality ratings. Qualitative narratives elaborated this relationship, describing discrimination, social exclusion, employment and relationship challenges, and negative healthcare interactions. Stigma also affected disclosure, care-seeking behaviour, and psychological wellbeing, while providers confirmed its impact on engagement and continuity of care. This positions stigma as a key cross-cutting determinant of quality of care beyond clinical dimensions.

Seizure frequency after treatment initiation also showed convergence. Quantitative findings indicated that persistent seizures were associated with lower quality ratings, while qualitative accounts linked improved care experiences to effective seizure control, functional improvement, and return to daily activities. Patients therefore evaluated quality not only through service delivery processes but also through treatment outcomes.

An area of divergence emerged regarding knowledge of epilepsy. Quantitative results showed no significant association between knowledge level and quality of care, yet qualitative findings revealed persistent gaps in understanding of seizure warning signs, medication use, and self-management. While knowledge did not influence overall quality ratings statistically, it remained an important aspect of patient experience and highlighted unmet educational needs not captured in quantitative measures.

A similar pattern was observed for co-morbidities, which were not significantly associated with quality of care in the quantitative strand. However, qualitative narratives emphasized the broader psychosocial burden of epilepsy, including emotional distress and social limitations, indicating that co-occurring conditions and lived burden shape overall wellbeing even when not reflected in statistical associations.

Overall, triangulation shows consistent convergence on treatment initiation, medication access, treatment effectiveness, seizure control, and stigma as key determinants of quality of care. Qualitative findings further deepen this understanding by illustrating how these factors shape lived experiences, engagement with care, and perceptions of health services. The integrated evidence underscores the need for interventions that strengthen timely treatment and clinical management while also addressing stigma, educational gaps, and psychosocial consequences of epilepsy.

Table 4.12: Triangulation of Quantitative and Qualitative Findings on Hospital-Level Predictors of Quality of Care

Hospital-level factor	Quantitative findings (bivariate results)	Qualitative findings (FGDs & KIIs)	Triangulated interpretation
Waiting time	Significant association with QoC ($\chi^2 = 6.490$, $p = 0.031$). Longer waiting time (>1 hr) associated with more low QoC ratings.	Patients reported long queues, delayed consultations, and rushed care during peak workloads. Providers confirmed staff shortages and high patient volumes causing delays.	Strong convergence: both datasets show that longer waiting time reduces perceived quality of care due to inefficiency and reduced consultation time.
Service availability	Significant association with QoC ($\chi^2 = 7.137$, $p = 0.029$). Availability of services linked to higher QoC ratings.	Wide variation in availability of neurology services, diagnostics (EEG/MRI), specialists, and medicines. Frequent referrals and travel to other facilities reported.	Strong convergence: limited service availability reduces access and continuity of care, negatively affecting QoC.
Cost affordability	Significant association with QoC ($\chi^2 = 4.034$, $p = 0.043$). Inability to pay associated with lower QoC ratings.	Patients reported financial barriers to medication, transport, and specialist care; providers noted limited access to newer antiepileptic drugs due to funding constraints.	Strong convergence: financial constraints reduce access, adherence, and continuity of care, lowering QoC.

Hospital-level factor	Quantitative findings (bivariate results)	Qualitative findings (FGDs & KIIs)	Triangulated interpretation
Card possession	Not significant (p = 0.310). No clear association with QoC.	Patients inconsistently carried clinic cards; continuity issues persisted due to provider changes and repeated history-taking.	Partial convergence: documentation alone does not ensure continuity or perceived QoC without integrated records and consistent care teams.
Direct observed treatment (DOT/adherence support)	Not significant (p = 0.627).	Mixed experiences in adherence support; some received structured guidance while others had limited follow-up reinforcement.	Partial convergence: adherence support is inconsistently implemented and may influence QoC indirectly rather than statistically.
Information on warning signs	Not significant (p = 0.961).	Education provided inconsistently; some patients received clear guidance while others reported gaps or lack of reinforcement.	Convergence (non-significant): patient education exists but is uneven, limiting measurable impact in quantitative analysis.
Adverse drug reaction (ADR) counselling	Not significant (p = 0.523).	Some patients not adequately informed about side effects or medication changes, leading to confusion and self-management challenges.	Partial convergence: inconsistent ADR counselling likely weakens measurable association with QoC despite qualitative relevance.
Visit interval (follow-up scheduling)	Not significant (p = 0.500).	Irregular follow-up systems, missed appointments, and inconsistent scheduling due to workload and system inefficiencies.	Convergence (non-significant): follow-up inconsistency affects continuity of care but not strongly captured quantitatively.
Privacy	Not significant (p = 0.982).	Mixed experiences; some patients reported respectful care while others experienced crowded and rushed consultations.	Partial convergence: privacy is context-dependent and influences comfort but not strongly reflected in QoC scoring.
Confidentiality	Not significant (p = 0.261).	Stigma influenced disclosure; some patients hesitant to fully share diagnosis due to fear of judgment. Providers confirmed disclosure challenges.	Partial convergence: confidentiality affects engagement and trust more than measurable QoC outcomes.
Drug availability/type	Not significant (p = 0.367).	Limited access to newer antiepileptic drugs; reliance on older medications due to funding and supply constraints.	Partial convergence: drug constraints exist but are likely masked in aggregated quantitative categories.
General hospital service availability	Significant association (same as	Facilities reported broad but uneven service	Strong convergence: broader service availability improves

Hospital-level factor	Quantitative findings (bivariate results)	Qualitative findings (FGDs & KIIs)	Triangulated interpretation
	above framework variable).	packages including imaging, neurology, emergency, and referral services.	perceived QoC through improved access and comprehensiveness.
Recommendation of facility	Not significant (p = 0.296).	Patients' willingness to recommend linked to satisfaction with waiting time, provider attitude, and service reliability.	Partial convergence: recommendation reflects overall experience shaped by efficiency and accessibility rather than standalone predictor.

The integration of quantitative and qualitative findings shows that hospital-level factors significantly shape perceived quality of care among people living with epilepsy. Quantitative results identified waiting time, service availability, and affordability as the only variables significantly associated with quality of care, while qualitative findings explained and expanded these relationships through lived experiences and health system perspectives.

Service availability demonstrated strong convergence across both strands. Quantitatively, access to needed services was significantly associated with higher quality ratings. Qualitative accounts confirmed that better experiences were reported in facilities with available neurology services, emergency care, diagnostics, and trained personnel. In contrast, shortages of specialists, limited diagnostic capacity (including EEG and MRI), drug stock limitations, and reliance on referrals constrained care and reduced perceived quality.

Affordability showed a similar pattern. Patients who could meet treatment costs reported higher quality of care, while those facing financial constraints reported poorer experiences. Qualitative narratives extended this finding by showing that costs included not only medication but also transport, referrals, and travel to higher-level facilities, making access to epilepsy care economically burdensome.

Waiting time also demonstrated clear convergence. Longer waiting times were significantly associated with lower perceived quality of care. Qualitative findings attributed delays to high patient volumes, staffing shortages, and limited-service

capacity. Both patients and providers noted that these system constraints reduced timeliness and efficiency of care delivery.

Beyond the significant factors, qualitative findings highlighted additional dimensions not statistically significant but important to patient experience. Patient education and counselling were valued, although inconsistently delivered, affecting understanding and self-management. Continuity of care was also emphasized, with participants noting that frequent provider changes, weak follow-up systems, and fragmented care pathways undermined care experience despite non-significant quantitative results.

Qualitative evidence further revealed broader system constraints, including workforce shortages, inadequate funding, limited diagnostic infrastructure, uneven resource allocation, and inconsistent institutional support. These factors contextualized the observed challenges in access, affordability, and service delivery.

Other variables such as card possession, adherence support, privacy, confidentiality, medication type, and recommendation of services showed no significant quantitative association and were minimally reflected in qualitative accounts, suggesting a limited role in shaping overall quality perceptions compared to structural system factors.

Overall, the findings show strong convergence on three key determinants of quality of care: service availability, affordability, and waiting time. Qualitative evidence further explains these relationships through underlying health system constraints affecting capacity, efficiency, and access to epilepsy care.

CHAPTER FIVE

DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 Discussion

This study sought to evaluate the quality of care provided to people with epilepsy (PWE) attending selected hospitals in Nairobi, Kiambu, and Machakos counties, Kenya, while identifying the socio-demographic, clinical, and hospital-level predictors influencing patient's quality of care experienced. The findings highlight multifaceted determinants of epilepsy care quality, demonstrating that both individual patient characteristics and health system factors significantly shape experiences and outcomes of care.

5.1.1 Quality of Care

Quality of care for people with epilepsy (PWE) in this study which was determined using a composite score based on standard domains of healthcare delivery. In this study, domains included respect, communication, tolerability of side effects, effectiveness, affordability, counselling, geographical access, privacy, and promptness of care. Each of the 373 respondents was evaluated on patient-rated domains with median score and a factor weights. The overall dichotomous classification of care was high were 197 (52.8%) and low at 176 (47.2%).

A total of 52.8% of respondents rated the quality of epilepsy care as high. This proportion is comparable to findings from other low- and middle-income settings but substantially lower than reports from specialized epilepsy services in high-income countries.

In Ethiopia, a facility-based study conducted in public hospitals in Arba Minch Town reported that 54.3% of patients received good quality epilepsy care, a finding closely comparable to the present study (BMC Neurology, 2024). Similarly, an evaluation using the Quality Indicators in Epilepsy Treatment (QUIET) measure in the United States demonstrated an overall quality score of 55.6%**,** suggesting that only about half of recommended epilepsy care processes were performed, even within a high-resource

setting. These similarities indicate that gaps in epilepsy care quality are not unique to resource-constrained environments and may reflect broader challenges in the continuity and comprehensiveness of epilepsy services (Fekadu, et al., 2024)

However, the proportion observed in this study is considerably lower than patient satisfaction levels reported in studies conducted in specialized epilepsy clinics. A systematic review involving 6,336 patients found that the median overall satisfaction with epilepsy care was 86%**,** while approximately 85% were satisfied with providers' interpersonal skills and 78% with access to care. Likewise, a study from a specialized epilepsy assessment unit in the United Kingdom reported that nearly 90% **of** patients perceived improvements in their medical and social conditions following specialized care (Wiebe et al.. 2014)

The lower proportion of respondents reporting high quality of care in the present study may be attributable to differences in healthcare infrastructure, availability of specialized personnel, diagnostic capacity, continuity of follow-up, and psychosocial challenges, particularly stigma. Furthermore, whereas studies from high-income countries often assess satisfaction within specialized epilepsy centers, the present findings reflect routine care in general health facilities where resource limitations and social barriers may adversely affect patient experiences. Consequently, the observed prevalence of high-quality care (52.8%) suggests that although more than half of patients perceived care positively, substantial opportunities remain to improve service delivery, communication, patient education, and psychosocial support.

The narrow margin between the two cluster groups reflecting mixed experiences thus highlighting the importance of examining both domain performance and their relative weights. Using a normalized factor weigh to provide a convenient metric for the relative contribution of each domain to the composite quality construct, the most influential domains were respect (0.153) and communication (0.139), followed by tolerability (0.123) and effectiveness (0.122). These domains, carry the greatest impact on the overall quality composite, making them high-leverage improvement areas. This is contrary to Shepherd et al., 2019 who reported safety, effectiveness, timeliness and caring are the top metrices that influence care quality

Respect creates a dutiful environment and a reliable relationship that enhance care rating. A respectful interaction between the patient and the healthcare provider fosters trust, and this augments the patient experience and may play a key role in patients keeping their appointment schedules regardless of the disease and the indirect outcome of keeping scheduled appointments will be improved care quality (Cubaka et al., 2018).

Effective communication emerged as an important key for both the health practitioner and patient. This encompasses eliciting information, for instance, the description of specific symptoms, and giving information such as recommendations for disease management (Gao et al., 2024). From the qualitative perspective, we noted that patients appreciated effective communication, similarly reported in Malawi (Madula et al., 2018). Clear communication is key in promoting adherence to care, in that when instructions are clearly articulated, patients are likely to follow care instructions and adhere to the prescribed management plan (NICE, 2025).

Tolerability to the anti-seizure medication was another key domain for measuring the quality of care. Anti-seizure drugs are the only proven seizure-reducing modalities. However, adverse drug effects may hinder adherence, leading to treatment failure and a poor quality of life. Some authors have suggested titration; that is, beginning with small doses to improve tolerance (Seiden & Connor, 2022). It is noteworthy that patients would benefit from information about the adverse effects, as expressed by a patient who mentioned drowsiness and irritability. This domain highlights the importance of a discourse between the health provider and the patient about what patients should expect in the course of prolonged epilepsy management. Generally, poor tolerability to anti-seizure medication remain burdened by adverse effects in essence reduces their adherence to medication and overall satisfaction with the treatment.

Effective treatment is another key domain that entails seizure control and improved clinical outcome due to drug adherence and sustained treatment. It encompasses early initiation to treatment, and the choice of treatment based on the locally available resources and availability of facilities for monitoring epilepsy with consideration for

age, seizure type and gender. It determines actual improvement and stabilizes the patient and facilitates recovery pathway. Measuring effectiveness ensures that care delivered achieves the desired clinical results, by minimizing disability and prevents, reduces disability and prevents premature death (WHO, 2021).

Affordability as a measure of quality, counselling on side effects, geographical access, privacy and promptness though had little contribution to the overall rating. Financial barriers can interfere with the ability to seek treatment, threaten continuity of healthcare and adherence to treatment with the negative effect of worsening health outcomes. Inadequate counselling has enormous clinical consequences. It has direct link to medication adherence, recognition of adverse drug reactions and patients' capacity to make informed choices and may conversely contribute to unexpected discontinuation of treatment. Geographical access is used as a measure of quality. It measures the effect of physical or structural barriers (distance, transport, distribution of facilities). Physical accessibility materially affects by care influencing service utilization and continuity thus aggravating inequities. Access problems may also increase indirect costs of healthcare e.g. transport and time away from work. Good privacy practices are necessary especially for conditions that carry stigma like epilepsy. Among other benefits, privacy in healthcare fosters candid disclosure (Mula and Kanner, 2021).

Promptness had both the lowest score and the lowest weight (0.069), indicating that although patients rated it poorly, its contribution to overall quality rating is relatively limited. Promptness is the lowest-weighted domain signaling dissatisfaction with waiting times, slow or delayed services and irregular timelines. Operational inefficiencies (triage, flow of clinic schedules, staffing, triage) that produce delays can negatively influence quality of care and satisfaction, technical competency and clinical efficiency notwithstanding (Patil, 2024).

As per the institutions, there was heterogeneous distribution of quality of care across the five institutions. Gatundu and Machakos exhibit near-equal proportions of low- and high-quality ratings, reflecting institutional ambivalence where neither positive nor negative perceptions dominate. Such balance may indicate inconsistent service

standards or variability in patient-provider interactions. Kiambu showed predominance of low-quality ratings suggesting systemic service delivery shortcomings, potentially linked to resource constraints, patient overload, or organizational inefficiencies. Thika demonstrated a slight leaning toward high-quality perceptions a comparatively stronger service provision. Mama Lucy had high-quality ratings substantially exceeding low-quality perceptions pointing to a consistently positive patient experience, positioning it as a benchmark for service delivery excellence among peer institutions. The overall picture illustrates marked institutional disparities that may be driven by contextual factors such as facility-level governance, staff competence, infrastructure, and patient volume as observed by Spencer et al 2023. These findings highlight the necessity of tailored interventions rather than uniform system-wide reforms to address quality-of-care gaps

5.1.2 Socio-Demographic Predictors of Quality of Care

The analysis of socio-demographic factors explored the influence of age, sex, occupation, religion, education, and marital status had on the quality of care on the 373 respondents. Bivariate analysis revealed that occupation was the only variable significantly associated with quality of care among people with epilepsy($p<0.05$).

5.1.2.1 Occupation

Respondents in formal employment were more likely to report high QoC (62.5%) compared to those informally employed (38.7%) or unemployed (33.1%). The significant association between occupation and QoC suggests that socioeconomic position plays a critical role in shaping health care experiences as those in formal employment rated quality of care as high. We speculate that individuals in formal employment are likely to enjoy better care, as they often have, higher income, job security, access to medical insurance, and it is easier for them to communicate with healthcare providers due to their higher literacy levels. (Bakibinga et al., 2022). This finding concurs with Ngugi et al., 2012 and Kariuki et al., 2015 whose studies linked economic stability to improved access, treatment continuity, and satisfaction with care provided. Formal employment confers higher and more predictable income which can facilitate access to health insurance and enhances health literacy, all of which

positively influence patient experiences. Those who were formally employed were three times more likely to rate the quality of care as high compared to those who were unemployed because, in Kenya, most people without formal employment fund healthcare out of pocket further impeding access and adherence to treatment and management of those chronic conditions (Wilmshurst et al., 2014).

In contrast, the low quality-of-care rating among the patients who worked in the informal sector was almost similar and we observed similar findings for the unemployed. Conversely, informal employment and unemployment are associated with financial vulnerability and fragmented care resulting from limited financial capacity to access consistent, comprehensive care, thereby influencing lower ratings of Quality of care (Arisa, 2025). Additionally, the disruptive nature of epilepsy in social situations strongly interferes with PWE employability as the attacks are highly unpredictable and do not remain hidden in the social environment (St Louis, 2009); (Bainbridge & Oh, 2014) This finding also resonates with the wider social determinants of health literature, which emphasizes employment and income security as critical enablers of access, continuity, and satisfaction in chronic disease care (WHO, 2010). Occupation is therefore a key socio-demographic determinant of Quality of care. PWE suffer higher rates of unemployment and underemployment as they often have greater difficulty keeping their jobs (de Souza et al., 2018). Many employers reject them because they believe they are more susceptible to accidents and absenteeism from work. This observation calls for the timely implementation of comprehensive healthcare to curb the risk of disability or death due to untreated epilepsy.

Quality of care is largely dependent on the availability and quality of health services and on psychosocial influences rather than on inherent demographic characteristics (Donabedian, 1988). Consequently, factors such as stigma, economic productivity, social support, and healthcare accessibility may exert a stronger influence on quality of care than age, sex, or educational attainment (Jacoby et al., 2005; World Health Organization, 2022). The significance of occupation in this study therefore highlights the importance of socioeconomic empowerment and financial capacity in facilitating equitable access to high-quality epilepsy services. This finding is consistent with the

Aday and Andersen behavioural model, which recognizes enabling resources, including economic capacity, as important determinants of access to healthcare and subsequent health outcomes (Aday & Andersen, 1974).

5.1.2.2 Age:

Most respondents were in the 29-49 age bracket, with mixed feelings about the quality of care. The 2-5 range were satisfied with the quality of services, but the 19-29 and 50+ rate the quality-of-care low, indicating that the current practice of one-fits-all may not be optimal across all ages. The higher rating in the 2-5 category was likely due to the common practice of prioritizing younger children in our hospitals due to their vulnerability. Although age was not statistically significant, notable distributional trends were observed. Children aged 2–12 years had the highest proportion of high QoC ratings (56.4%), possibly reflecting strong parental involvement and advocacy in care-seeking as observed by Nazareth, 2025.

In contrast, older adults (≥50 years) recorded the lowest QoC perceptions (29.7%), which may reflect cumulative comorbidities, system-level deficiencies in geriatric epilepsy care, and reduced caregiver advocacy (Mugambi-Nyaboga, 2025). A higher burden of comorbidity may complicate their treatment in terms of polypharmacy and balancing the epilepsy medication along with other medicines which may ultimately affect their overall experience and satisfaction with the care (Hesdorffer et al., 2011). Additionally, older patients are likely to have cognitive decline which further complicates their care by affecting the older patients' ability to understand the epilepsy care plan and adhere to medication. The lack of or limited understanding or breakdown in communication will likely elicit negative feelings such as frustrations among these patients affecting their quality-of-care rating (Helmstaedter et al., 2020).

Although age group differences were not statistically significant, the distribution patterns are notable

These findings echo patterns reported in sub-Saharan studies, where older adults consistently face greater barriers to quality chronic disease management (Ba-Diop et al., 2014; Ibinda et al., 2014).

5.1.2.3 Sex

Sex was not significantly associated with Quality of care. Out of 191 males and 182 females who participated in the study, 101 (52.9%) and 96 (52.7%) rated quality as high. This broadly comparable gender experiences aligns with studies in Kenya showing that gender differences are more pronounced in care-seeking and treatment adherence than in service quality once patients are engaged in the healthcare system (Kariuki et al., 2015). The male and female patients had similar feelings about the quality of care and we did not observe a statistical significance indicating that gender did not play a role in influencing perceptions of care quality in this study. This finding is consistent with the idea that the quality of healthcare services provided to individuals with epilepsy is perceived equally across gender lines, suggesting that gender biases in healthcare delivery were minimal or absent in this particular context observed from various regions (Comfere et al., 2020; Makhado et al., 2024). This aligns with studies showing that gender disparities in healthcare access may be more evident in the utilization patterns rather than perceptions of quality once care is received (Wangari, 2021).

However, epilepsy affects males and females differently specifically in the effects the anti-epileptic drugs have on the reproductive hormones and it is crucial to counsel women of reproductive age on contraception (Voitiuk, 2019; Fitzsimons et al., 2013). Therefore, the similarity in satisfaction rating may reflect that the current treatment is appropriate for the general needs of males and females but it is crucial to tailor treatment across gender lines to address the different needs and adverse reactions of the anti-epileptic drugs.

5.1.2.4 Religion

Though not significantly associated with Quality of care in this study, lack of variation across religious groups suggests equitable service provision irrespective of faith. Similar observation was made by Allen, 2024

5.1.2.5 Education:

Though not statistically significantly associated with Quality of care , the absence of education effects in this study points to experiential factors during clinic visit rather than cognitive ability and formal education in rating Quality of care as observed by Muthuri et al., 2020

5.1.2.6 Marital Status

Though not significantly associated with Quality of care, social support from marital status influences treatment adherence, it may not strongly alter quality of care as reported by clients. This finding concurs with Magrin et al., 2015 who found out that marital status also did not confer advantages among hypertensive clients. The similarity across marital status groups further indicates that family or social support structures may not strongly alter individual perceptions of service quality in this population (Okoth et al., 2023)

Based on these results, it is imperative to conclude that though socio-demographic variables remain key factors in quality-of-care rating, they do not independently determine quality of care. This aligns with broader literature on social determinants of health, which consistently highlights the role of employment and economic security in shaping healthcare access, utilization, and satisfaction (Bakibinga et al., 2022).

5.1.3 Clinical Predictors of Quality of Health Care

The bivariate analysis of clinical factors demonstrated that several clinical characteristics, including duration of epilepsy, antiseizure medication, seizure frequency, stigma experience and treatment regimen were significantly associated with quality of care among people with epilepsy. These findings provide empirical evidence supporting the high health burden of epilepsy in Kenya and other LMICs. The findings on clinical predictors of quality of care highlight the central role of clinical management and patient experiences in shaping quality of care rating among people with epilepsy seeking treatment.

Frequent seizures and prolonged duration of illness reflect the chronic and recurrent nature of epilepsy, which places substantial physical, psychological, social, and economic demands on affected individuals and their families. Patients experiencing recurrent seizures often require more frequent healthcare visits, effective antiseizure medication, and increased support, thereby increasing healthcare utilization and contributing to the overall disease burden.

These findings indicate that the burden of epilepsy is not merely a function of prevalence but also of the chronic and complex clinical challenges faced by patients. Thus, the bivariate clinical results provide empirical support for the assertion that epilepsy constitutes a substantial public health burden requiring sustained and quality healthcare interventions

5.1.3.1 Duration since Onset of the Illness

The majority of the patients had delayed for more than 3 years before seeking treatment, as previously reported by other authors who reported a mean delay of seven years and 50 ± SD 77 months (0 and 362 months) in their respective studies (Gasparini *et al.*, 2013; Parviainen *et al.*, 2020).The delay in seeking treatment could be attributed to a lack of awareness of the signs and symptoms of a seizure and patients failing to recognize subtle events as being of concern (Berg et al., 2014).According to a study by Aydemir and colleagues, the long delay in diagnosis alone might not affect the long-term outcome, but an increasing number of seizures before diagnosis indicated a worse seizure outcome (Aydemir, 2020). Closer home, similar to our study, observed delay in treatment due to the cultural and supernatural associations to the disease which resulted in cumulative negative effects on mental health and integration into society (Mushi et al., 2011). Delayed treatment affects the quality of life and quality of care as patients with a shorter duration were likely to report better quality of care, highlighting the need for treatment at the onset of the epilepsy.

5.1.3.2 Anti-Seizure Medication

Anti-seizure medication is the most effective method for seizure control in about 7 out of 10 people who experience the seizures and this positively affects not only the quality

of life but also the quality of health care for the people living with epilepsy. In a recent study, the majority of those on treatment 54.7% of respondents rated the quality of care as high (Han et al., 2017). Adherence to the prescribed ASM is influenced by several factors. In Ethiopia for instance, patients who did not regularly use medicine were likely to have recurrent seizures and the lack of adherence in this context was attributed to the adverse side effects (Andualem et al., 2024). It is imperative therefore to counsel patients on the expected side effects, how to handle them and the importance of adherence thus empowering them to manage their conditions well. Additionally, the prohibitive costs of treatment for patients in lower socioeconomic cadres further hinder access to adherence to medication, especially for patients managing epilepsy out of pocket. The high costs deter patients from regularly accessing the medication, ultimately negatively impacting their quality of care. This issue underscores the importance of affordable medication to improve adherence to medication and epilepsy management (Wilmshurst et al., 2014). At bivariate level, the use of anti-seizure medication had a statistically significantly relationship with perceived quality of care. Pharmacological management in epilepsy care is central in achieving favourable outcomes and access to treatment coupled with good adherence improve clinical outcomes and enhance patient satisfaction as observed by Murphy et al., 2025.

5.1.3.3 Co-morbidities

Data indicates 173 of the respondents had co-morbid conditions, accounting for 46.3%. Comorbid conditions are common in people with epilepsy, and their presence has important implications for diagnosis, treatment, medical costs and quality of life (Aydemir, 2020). These conditions in epilepsy are found across the lifespan, and include medical, psychiatric, physical, psychological and cognitive conditions alone or in combination. According to Rudzinski and Meador, 2013, nearly every patient with epilepsy will experience a comorbid medical condition at some point during the course of treatment. Proposed explanations for this association include the possibility that first, epilepsy (including its treatment) has a strong association with the comorbid condition; second, the comorbid condition (including its treatment) has a strong association with epilepsy; or third, a common pathogenic mechanism mediates the co-occurrence of epilepsy and the comorbid condition as a shared underlying mechanism

also mediates the occurrence of both (Rudzinski & Meador, 2013). This finding concurs with Dekker, 2008 who found that 44.1 % of epilepsy clients attending KAWE clinics had either physical or mental handicap. Sometimes the insult to the brain can be so severe that other impairments may occur in people with epilepsy. These impairments may result in physical, social, psychological or behavioural deficits. These include mental retardation, cerebral palsy, learning disorders, attention deficits, hyperactivity, maladjustment, and early-onset dementia. The majority of those who reported comorbidity rated quality of care as low (50.3%) and the majority of those who reported no comorbidity rated quality of care as high (51.8%). Though the association between comorbidities and outcome was not significant, comorbidities of epilepsy are associated with poorer treatment outcomes hence the low rating of the quality of care (Kanner, 2016).

The absence of statistically significant associations between comorbidities and quality of epilepsy care may suggest that the presence of additional illnesses did not substantially influence patients' perceptions and experiences of care within the study settings. This finding could be attributed to the integration of management for common comorbid conditions into routine clinical practice, thereby minimizing their impact on the quality of epilepsy services received. It is also possible that the effect of comorbidities on quality of care was mediated through other factors such as disease severity, treatment adherence, stigma, and healthcare accessibility, resulting in attenuation of their independent contribution after adjustment for confounding variables (Hosmer et al., 2013). Similar inconsistencies regarding the influence of comorbidities on quality of care have been reported in previous studies, indicating that the mere presence of additional medical conditions does not necessarily translate into poorer patient experiences or outcomes (Pugh et al., 2007; Institute of Medicine, 2001).

5.1.3.4 Stigma Experiences

Stigma is a label assigned to an individual or a feeling of being designated as different from the normal population due to a life condition, invoking feelings of dread or fear among others. Out of the sampled population, 373 patients, 229 (61.5%) experienced

stigma. Epilepsy carries with it a certain stigma in society or at least a perceived stigma among persons with epilepsy. The majority of those who reported stigma experience also rated quality of care as low (51.6%) (P. Braga et al., 2020). The association between stigma and quality of care was statistically significant. This finding concurs with Kanner, 2016 who found that perceived stigma is significantly associated with higher levels of psychological distress symptoms and lower quality of life. Stigmatization has been widely documented to impede treatment-seeking behavior, erode trust and confidence in healthcare providers and reduce adherence to prescribed treatment. It stems from misconceptions such as witchcraft and possession by spirits associated with epilepsy in Kenya (Samia et al., 2023). Therefore, the significant statistical association between stigma and care quality in the results underscores the psychosocial dimension of epilepsy management and fosters the idea that addressing stigma at individual, family, community and healthcare settings is critically essential to improving patient experiences and quality of care rating (WHO, 2022).

5.1.3.5 Level of Knowledge on Epilepsy

The results indicate that 46.8 % of respondents had low level of knowledge about the causes of the condition with 44.8% and 8.4% exhibiting moderate and high level of knowledge respectively. However, many of them rated the quality of care as high. This finding concurs with a study that revealed a significant lack of knowledge about epilepsy among PWE and an overall poor understanding of the aetiology of epilepsy (Mameniskiene et al., 2015) . Lack of knowledge about epilepsy among PWE leads to a low QoL, inadequate management, barriers to opportunities, social isolation, feeling of stigmatization, poor compliance to medications as well as an increase in the frequency of seizure attacks. Similarly, the empirical studies by Ibinda and colleagues, concluded that low social functioning and low emotional well-being from stigma, which arise from a lack of knowledge on epilepsy on the part of the public and family members, can cause barriers to seeking treatment (Ibinda et al., 2017). Among those who had high level of knowledge about epilepsy, only 46.7% rated quality of care as high and the association between level of knowledge about the causes of epilepsy and quality rating was not statistically significant. This finding concurs with another study that reported no significant correlation between the level of knowledge and age,

gender, marital status, occupational status, type of seizure, duration of epilepsy, source of information, number of antiepileptic drugs (AEDs), and family history of epilepsy (Yu et al., 2023).

Although level of knowledge was not significantly associated with quality of care, respondents with higher levels of knowledge were more likely to rate the quality of care highly. Greater understanding of epilepsy has been linked to improved patient empowerment, self-efficacy, and more realistic expectations regarding treatment outcomes, all of which may positively influence perceptions of care (Holmes, 2024). Consequently, educational interventions remain an important component of comprehensive epilepsy management and should be integrated into routine care to enhance patient understanding and satisfaction.

The lack of a statistically significant association suggests that knowledge alone may be insufficient to translate into improved quality of care when structural and psychosocial barriers persist. According to the Aday and Andersen behavioural model, health outcomes are shaped by the interaction of predisposing, enabling, and need factors rather than by knowledge in isolation (Aday & Andersen, 1974). Thus, patients with adequate knowledge may still experience challenges related to stigma, financial constraints, transportation difficulties, medication stock-outs, and inadequate provider–patient communication, which can limit the extent to which knowledge is transformed into positive healthcare experiences (World Health Organization, 2022).

Furthermore, the absence of statistical significance may reflect relatively limited variation in knowledge levels among participants or the provision of standardized health education during clinic visits, thereby reducing differences in perceived quality of care. Previous studies have similarly shown that knowledge often exerts its effects indirectly through mediating factors such as treatment adherence, self-efficacy, and social support rather than acting as an independent determinant of quality of care (Bandura, 1997; Jacoby et al., 2005). These findings suggest that while patient education remains essential, improvements in quality of epilepsy care require complementary interventions that address broader psychosocial and health system barriers.

5.1.3.6 Seizure Frequency before Treatment Initiation

Seizure frequency is an important aspect with a direct influence on the quality of life for people with epilepsy, informing the need for anti-seizure medication. Most of the patients in this study reported experiencing between one and four seizures in a week, similarly observed in a study conducted in coastal Kenya (Mbuba et al., 2012). Interestingly, the frequency of seizures did not significantly affect the quality-of-care rating, and we can speculate that this indirectly indicates that for people living with epilepsy, living without experiencing seizures is more important than the number of seizures. After the patients were initiated on epilepsy treatment, the majority reported less than one seizure within a week, showing that biomedical management of epilepsy is effective in seizure reduction. This was a significant factor for the quality-of-care rating, which lost significance in at multivariate analysis, possibly due to the sample size used in the present study. It is worth noting that in a recent study, withdrawal of patients from anti-seizure medication resulted in recurrence of seizures in a quarter of the study population within the first 24 months, signifying the importance of treatment adherence (Odero et al., 2023). Similarly, a linear decrease in seizure frequency was observed after initiation of anti-epileptic drugs; however, the resurgence of seizures after a long duration might indicate lack of adherence due to apathy towards the adverse drug reactions (Raru et al., 2021).

5.1.3.7 Seizure Frequency after Treatment Initiation

Respondents who were already on medication continued to experience seizures, though 61% were getting fewer than one attack per week. This finding concurs with previous findings indicating that, though anti-epileptic drugs (AEDs) are the primary therapeutic modalities for epilepsy management, one-third of patients continued to experience seizures even after initiation of appropriate drugs. The majority of those who experienced more than four attacks per week after the onset of treatment rated the quality of care as low (67.6%) (Nasir et al., 2020). Following the start of treatment, people who had less than one seizure per week had a 2.405 times likelihood of rating their care as high compared to those who had more than four seizures per week. Patients who experienced more than four seizures per week following the start of the

treatment had a lower chance of receiving better care than patients who only experienced one seizure per week, concurring also with the study by Haag and colleagues (Haag et al., 2010). This could be attributed to the fact that they remained at an increased risk for seizure-related injuries not just at home but also in the streets and places of work. Additionally, the frequency of seizures led to negative feelings, such as embarrassment if they occurred in social gatherings or public places. Similarly, frequent seizures were a hindrance to driving, and this aspect was associated with poor perceptions of living with epilepsy (Yesuf et al., 2024) ;(Kasradze et al., 2025). The significant statistical relationship between seizure frequency after treatment initiation and quality of care indicates that clinically effective treatment with resultant reduced seizure burden and tangible outcome directly influences patient perception and quality rating (Kariuki and Newton, 2025). Therefore, post diagnosis antiseizure treatment needs to be optimized with judicious prescription of appropriate medication and comprehensive follow ups.

5.1.3.8 Treatment Regimen

The decision for treatment regimen is determined by the varied patient needs per the WHO recommendations (Organization, 2016). The recommended practice is the use of monotherapy, which is titrated to the highest tolerable dose, followed by double monotherapies, and then a combination therapy is prescribed if the seizures persist. Generally, a combination is discouraged (National Institute for Health and Care Excellence, 2012, UK, 2012). Although the drug choice was not a significant predictor of the quality-of-care rating, from the literature, the key aspect of the treatment regimen is the drug burden. Polytherapy comes with potential for more adverse reactions due to drug-drug interaction, coupled with the high cost of medication, may deter adherence. Additionally, drug combination may require frequent monitoring, which translates to frequent scheduled clinics (Raru et al., 2021). A discourse between the health provider and the patient is key for the patient to understand the epilepsy management schedule. Monotherapy is associated with a better quality of life, indirectly indicating higher quality of care (Thomas et al., 2005).

The type of regimen used for epilepsy management was not significantly associated with quality of care though the medication prescribed has implications for both seizure control and patient satisfaction. Carbamazepine and valproate, being commonly used and clinically effective antiseizure drugs, were associated with higher quality rating relative to other regimes or absence of a defined treatment. This finding suggests that factors such as adherence to prescribed treatments, the side effect profiles of medications, and effective communication between patients and healthcare providers about treatment plans are critical to patients' perceptions of care quality as opposed to the type of drugs prescribed (Religioni et al., 2025). On the other hand, adherence to clinical visits and visit intervals did not show a significant association with quality of care, highlighting the context-specific nature of these variables. This notwithstanding, findings indicated the importance of follow-up visits in that, patients who received appropriate care through proper and friendly communication were more adherent to ant-seizure medication (Price et al., 2020). We, however, believe that, in economically disadvantaged populations, as represented in this study, the affordability of medications may play a more pivotal role in determining quality of care than visit adherence alone (Samia et al., 2023).

These findings suggest that improving quality of epilepsy care requires more than addressing clinical comorbidities or increasing patients' knowledge alone. Greater attention should be directed towards psychosocial and contextual factors, particularly stigma and socioeconomic barriers, which may exert stronger influences on patients' experiences and perceptions of care. This interpretation is supported by the multivariate analysis, which identified stigma as the only independent predictor of quality of care after controlling for other variables.

5.1.4 Hospital-Level Predictors of Quality Of Care

This study investigated several hospital-level factors that may influence the quality of care for PWE. These factors included card possession, directly observed treatment, provision of information on warning signs, caution on adverse drug reactions, adherence to medication, recommended intervals between clinic visits, advice given, waiting time, privacy and confidentiality, availability of drugs, overall service

availability, cost affordability, and recommendations made by family members to other potential clients. These variables represent structural and process-level factors within healthcare facilities that potentially shape patients experience with care quality at service delivery points. In Donabedian's model of quality (structure–process–outcome), these variables fall into structural inputs (e.g., service availability, affordability, card possession) and process indicators (e.g., waiting time, privacy, confidentiality, clinical adherence). Each of these factors has theoretical and practical significance in the evaluation of care and continuous quality improvement. Among these variables, waiting time, service availability, and cost affordability demonstrated statistically significant associations with the quality of care experienced (p-value < 0.05).

5.1.4.1 Waiting Time

Waiting time had a significant statistical relationship with quality of care rating. In comparison to patients who waited more than an hour for care, those who waited less than 30 minutes or between 30 and 60 minutes were more likely to rate the quality of care as high. These results underscore the profound impact that waiting time has on patient perceptions of the quality of care they receive. This aligns with findings, which emphasised that long waiting times not only negatively influence key healthcare metrics but also diminish overall satisfaction with the healthcare experience (Bleustein et al., 2014). Prolonged waiting times can adversely affect how patients interpret the information provided, the directions given, and their overall perception of the care they receive. Other authors also observed a negative correlation between long waiting times and clinical provider scores for patient satisfaction, patient confidence, and perceived quality of care. In this study's context, the low ratings observed in cases of extended wait times may be tied to the emotional and logistical burdens these delays impose (Maina et al., 2025). For instance, patients who travel long distances to access care or those who miss work, especially considering that a significant portion of our study population works in the informal sector are more likely to feel frustration and dissatisfaction. These challenges could also lead to poor adherence, as patients might be discouraged from attending follow-up appointments due to the anticipation of prolonged wait times. Therefore, reducing waiting times is not only crucial for

enhancing the perceived quality of care but also for improving patient adherence to treatment regimens (Bleustein et al., 2014). Patients who experienced shorter waiting periods were more likely to rate quality of care as high in consonance with global evidence that places timeliness as one of the strongest predictors of patient satisfaction (Bikorimana,2023). This highlights the process efficiency dimension in Donabedian Model as a quality measurement and reinforces perceived respect for patients' time as central to service experience.

5.1.4.2 Service Availability

Service availability and affordability were critical factors associated with the quality of care in this study. In our study, among patients who accessed services when they needed them, 160 (52.6%) rated the quality of care as high, while 144 (47.4%) rated it as low. These findings align with previous findings that showed the importance of reliable and timely access to healthcare services in enhancing patient satisfaction (Olkiewicz & Bober, 2015). However, significant barriers to care persist, especially in sub-Saharan Africa, where health system challenges are prevalent. According to the World Health Organisation, the region has an average of only 1.3 health workers per 1,000 people, well below the recommended threshold of 4.5 needed to meet essential healthcare demands among the vulnerable population. This shortage exacerbates delays in care delivery, especially for conditions requiring specialised diagnostics and treatment. For instance, a lack of neuroimaging machines and trained professionals contributes to misdiagnoses or delayed diagnoses of epilepsy, disproportionately affecting rural and underserved populations (Samia et al., 2023).

Evidently, efforts to mitigate these challenges are seen in the integration of mobile health (mHealth) technologies and the development of point-of-care diagnostic tools tailored for diseases prevalent in the region. These tools aim to address the severe gaps in service availability, more so for rural communities, thus enhancing early detection and management of health conditions (Osei et al., 2021). Although this study focused on HIV and TB, we can extrapolate these findings to epilepsy, as the systemic challenges cut across all health conditions in sub-Saharan Africa. Addressing them is

essential to improving access to care and subsequently enhancing the perceived quality of care among patients in sub-Saharan Africa.

The lack of anti-seizure medications (ASMs) in some healthcare facilities exacerbates this issue, as noted in studies from Zambia (Mambo et al., 2024). Patients who cannot access these essential medications are more likely to experience non-adherence, resulting in poorer health outcomes. These findings highlight the urgent need for innovative approaches to improving service availability, such as telemedicine, mobile clinics, or task-sharing strategies, particularly in rural and underserved areas. Affordability also played a critical role in determining the perceived quality of care. The significant statistical relationship between service availability and quality of care at bivariate level demonstrates that patients are highly sensitive to consistent services accessibility (Mugumbate, 2025). As a structural determinant of quality, availability captures the reliability of systems to deliver services when needed. Patients who reported service availability underscored accessibility as a major driver of satisfaction, trust and confidence.

5.1.4.3 Cost Affordability

Patients who could afford their medications were 1.790 times more likely to rate the quality of care as high (CI: 2.427–3.642) compared to those who could not. These results align with findings elsewhere that demonstrated that the cost of treatment directly influences the quality of care that patients perceive and receive (Ostendorf & Gedela, 2017). Access to ASMs significantly reduces seizure frequency, thereby improving the quality of life for individuals with epilepsy. However, the inability to afford these medications creates a barrier to treatment, leading to poor adherence and suboptimal health outcomes (Mambo et al., 2024). Addressing affordability concerns is essential to ensuring equitable access to care and improve patient outcomes, particularly in economically disadvantaged populations. In this study, the fact that affordability emerged as statistically significant variable with quality of care highlights the role of financial accessibility in shaping quality of care rating. Patients who considered services affordable rated them more positively, while those facing financial barriers perceived care as lower quality. This finding concurs with those of Sarkar,

2020 who observed the equity dimension of care, affirming that cost is not merely an economic barrier but a determinant of quality itself in patients' assessments.

While waiting time, service availability, and affordability were significantly associated with quality of care, other variables did not demonstrate significant associations. Provider communication and condition-specific education also emerged prominently. Respondents valued explanations regarding the nature of epilepsy, medication use, and expected treatment outcomes. Effective communication fostered better understanding and strengthened patient-provider relationships, which participants perceived as integral components of high-quality care (Institute of Medicine, 2001).

5.1.4.4 Card Possession

For instance, card possession, which may signify previous hospital visits and registration in the local context, did not show a significant relationship with perceived quality of care. In other contexts, possession of a hospital card may indicate health insurance coverage, which could influence access to and continuity of care. Proper documentation of seizure frequency, treatment regimens, and comprehensive patient histories are essential components of quality care, as reported by LaFrance Jr et al., 2013.

While not statistically significant, card possession represents the administrative backbone of continuity of care, prevention of duplication, and enhancement of coordination. Its presence guarantees continuous flow of health information with limited disruption to medication, drug regimens and follows ups. By providing written evidence of care provided, it serves as both legal and ethical purposes in disputes or adverse outcomes and also as documentation of medical advice and treatment given. It also enhances accountability and transparency in patient–provider interactions. Its limited influence in this study is a strong pointer that patients view it as a bureaucratic requirement rather than an experiential determinant (Dibie, 2025).

5.1.4.5 Direct Observation Treatment (DOT)

“Direct observed treatment (DOT) is one strategy to ensure that patients with a disease take all their medication. It reflects a structured system of monitoring and accountability in chronic disease management where an 'observer' acceptable to the patient and the health system observes the patient taking every dose of their medication, and records this for the health system to monitor” (Karumbi & Garner, 2015). In the current study, the majority of the patients did not receive DOTs; however, this did not significantly affect quality of care rating. This notwithstanding, this model of treatment may not offer a solution for non-adherence (Karumbi & Garner, 2015). Other aspects of treatment such as affordability and effective treatment may take precedence for patients as opposed to this model of treatment more so, when there is a cordial relationship and clear communication between the health provider and the patient. Although it was not statistically significant in this study, its system-wide importance lies in demonstrating adherence support mechanisms and contributes to sustainable health outcomes and quality of care rating (Mugambate, 2025).

5.1.4.6 Warning Signs

Warning signs, also referred to as pre-ictal events in epilepsy include but not limited to unusual sensations, behavioral changes, psychological or physiological disturbances that precede seizure onset. Educating patients and caregivers to recognize and appropriately respond is integral to patient empowerment, early detection, and prevention of complications. Though this variable did not have a statistically significant relationship with quality of care at bivariate analysis, conceptually it reflects the information domain of quality of care. Knowledge on these signs holds significant clinical, psychosocial, and safety implications and supports health literacy which enjoys global recognition as pillar to sustainable healthcare care systems (WHO, 2022).

5.1.4.7 Adverse Drug Reactions

Adverse drug reactions (ADRs) are unwarranted and unintended responses to medications that can range from mild to severe and occasionally pose life-threatening

risks (Kommu et al., 2024). Studies have shown that adverse drug reactions are key indicators for PWE quality of life and care by extension (Thomas et al., 2005). In the current study, this domain was not a significant predictor for the quality of care, but that notwithstanding, adverse reactions significantly increase with Polytherapy (George et al., 2015). Adverse drug reactions include changes in sleep quality, which may include spontaneous awakening and daytime sleepiness. Consequently, these can affect productivity, such as school performance; social interactions are also influenced (Becker et al., 2004). Other common adverse reactions reported previously include epigastric pain and headaches, which seem to be more common among PWE than the public (Keezer et al., 2016). It is worth noting that adverse reactions are often reported among patients with co-morbidities likely attributed to drug interactions from management of all the existing conditions (Bayane et al., 2024). We can therefore infer that adverse reactions to anti-seizure medication not only impacts care due to non-adherence, but also the quality of life due to resurgence of seizures when medication is stopped as well as due to the adverse reactions.

5.1.4.8 Clinical Adherence

Adherence to clinical guidelines ensures that patients receive evidence-based care. However, clinical guidelines are essential for operation standards and capturing technical quality (Nchindila,2021). Lack of statistical association between this variable and quality of care can be attributed to the fact that study participants may not have observed adherence to clinical guideline. This finding demonstrates that quality of care experienced at the service delivery point does not necessarily align with the clinicals rigors that underpins the services provided but also with other subjective and objective quality measures (WHO,2022).

5.1.4.9 Clinic Visit Intervals

Clinic Visit intervals are critical for continuity of in epilepsy care. Although the association with quality was not statistically significant, the trend toward higher quality perceptions with shorter visit intervals (<1 month) suggests that patients value continuity and proactive follow-up. Regular and appropriately timed follow-up visits remain indispensable on clinical grounds as they allow for review of seizure diaries

and clinical progress; monitor therapeutic drug levels where applicable, identify and ascertain the management of adverse drug reactions (ADRs), and permit alteration of medication dosages and drug regimens as deemed necessary. Without timely follow-up, patients may remain on suboptimal therapy, risking uncontrolled seizures or drug toxicity (Yardi et al., 2025). Too short intervals increased patient cost, travel fatigue, and health system congestion and too long intervals escalates the risk of poor monitoring, loss to follow-up and uncontrolled seizure exacerbation

Therefore, clinic visit intervals in chronic conditions such as epilepsy are important for maintaining treatment effectiveness, adherence to medication, prevention of complications, patience and continuity of care. For long term quality outcomes, optimal schedule should be observed and should balance patient convenience, clinical necessity and system capacity and preparedness.

5.1.4.10 Privacy

Privacy in healthcare refers to the protection of personal space reflecting dignity, respect and confidentiality during clinical encounters at service delivery points. It ensures that patients are examined, treated, or counseled in a manner that prevents unnecessary exposure to others, whether physically or through the sharing of sensitive information. Although it did not influence quality ratings statistically, it remains an essential and a fundamental human right and a domain for measuring quality of care. Though not statistically significant in this study, it ensures that ethical obligations and operational efficiencies are considered in the evaluation of hospital-level factors in quality measurement (Sarkar, 2020).

5.1.4.11 Confidentiality

Confidentiality is considered a key domain of quality care. As a hospital level factor, it is known to safeguard patient trust, promote openness in disclosure and enhances long-term adherence to prescribed medication. It reflects courtesy and respect domain which underpins robust relationship between the provider and the patient (Nyungu and Wainaina, 2024). Although not statistically significant, the trend observed suggests

that patients who felt confidentiality was upheld were more likely to rate services as high quality.

People with epilepsy, due to the disease unique presentation, other factors, such as the stigma associated with seizures, may have a more significant impact on their perceptions of care quality. Stigma can negatively influence patients' self-esteem, confidence in their healthcare providers, and ultimately their overall satisfaction with care (Yeni et al., 2023). Therefore, addressing stigma through community education, counselling, and support groups could play an essential role in improving the perceived quality of care for patients with epilepsy.

5.1.4.12 Drugs Given

The type of drug administered represents pharmacotherapeutic intervention in epilepsy treatment. It reflects therapeutic dimension of quality. Its inclusion in quality measurement highlights its importance in the essential drug supply chain as a structural enabler of quality care. Though there was no statistically significant relationship with quality of care rating in this study, differences across regimens reflect patient perceptions of medicine effectiveness and availability, an indication that patients evaluate quality of care more on system performance than on specific pharmacotherapy (Massawe, 2024). However, the availability of essential drugs remains a core measure of structural quality with implications for favourable clinical outcomes.

5.1.4.13 Recommendations to Other to Seek Services from the Same Facility

The willingness of a client to recommend services to a fellow colleague captures an overall holistic judgement of care experience at service deliver point in the health facility. It allows the study to account for the broader relational and reputational aspects of healthcare quality, beyond immediate service encounters at the respective facilities. While statistically non-significant, it remains an important proxy for the overall loyalty, trust and confidence the patient bestowed in the health facility. Those who were patients willing to recommend tended to rate quality higher. This suggests that the recommendation made may have acted as a proxy indicator of overall

satisfaction shaped by core experiential hospital level drivers of affordability and availability of desired services as observed by Mugamate, 2025.

Hospital-level factors like waiting time, service availability and cost affordability had a significant influence on the quality of healthcare received by people living with epilepsy. This could imply that facilities with favorable organizational capacity and service availability were associated with higher quality-of-care outcomes, while deficiencies in these factors were associated with lower quality ratings

5.1.5 Discussion of Multivariate Analysis

The use of multivariate analysis was essential in this study because it enabled the identification of factors that independently influenced quality of epilepsy care after controlling for the effects of potential confounding variables. Although several socio-demographic, clinical, and hospital-level factors demonstrated significant associations with quality of care at the bivariate level, these associations did not persist after adjustment for the influence of other covariates. Multivariate logistic regression revealed that stigma was the only variable that remained significantly associated with quality of care, thereby distinguishing a true independent predictor from apparent associations resulting from interrelationships among explanatory variables. This analytical approach strengthened the validity of the findings by providing a more accurate understanding of the determinants of quality of care and highlighting the predominant role of psychosocial factors in shaping the experiences and outcomes of people living with epilepsy (Hosmer et al., 2013).

The analysis highlights stigma as the most influential predictor of perceived quality of care. Individuals experiencing stigma were markedly less satisfied with their care, irrespective of structural or clinical aspects of service delivery. This finding reflects the pervasive impact of cultural misconceptions and social prejudice surrounding epilepsy. As observed by Makado, 2023, stigma can erode trust, hinder provider–patient relationships, and diminish the overall care quality even when technical standards are met. It underscores the central role of psychosocial dynamics in shaping patient experiences at the service delivery points.

Other variables, though not statistically significant at multivariate level, revealed interesting patterns. Occupation which had shown statistically significant relationship with quality of care at bivariate level, showed that formally employed individuals tended to rate quality of care high as opposed to the informally employed and unemployed individuals, possibly due to higher expectations or competing work-related demands. In consistence with the bivariate analysis, patients with shorter disease duration exhibited slightly higher odds of rating quality as opposed to the other counterparts thus reflecting optimism when treatment is initiated. Medication use was associated with increase in the likelihood of reporting high QoC. This finding therefore suggests that patients have higher expectations and hopefulness when treatment is initiated (Sarkar, 2020).

Seizure frequency after treatment initiation also showed a non-significant trend toward higher perceived quality when control was achieved earlier, pointing to the importance of treatment effectiveness in shaping satisfaction. However, the type of treatment regimen, whether valproate, carbamazepine, or other drugs, did not appear to influence patient perceptions of quality, indicating that patients may evaluate quality based on broader service and relational factors rather than specific medications.

Seizure frequency, treatment regimen, waiting time, service availability, and cost affordability, though lacked statistical significance in this study, are regarded as pillars in healthcare quality measurement. However, they do not fully capture what patients value most as absence of stigma as a prime predictor of quality of care in this study. Instead, relational and psychosocial factors, particularly the absence of stigma. Stigma is the prime driver and dominant predictor of Quality of Care for people with epilepsy. Therefore, epilepsy care requires going beyond structural efficiency and affordability of medication but must include stigma reduction strategies through education, awareness campaigns, and provider training to strengthen quality of care for PWE,

5.1.6 Stigma as the Independent Predictor

The finding that stigma emerged as the only independent predictor of quality of care underscores the central role of psychosocial determinants in epilepsy management and suggests that stigma reduction should constitute a strategic priority for improving

health outcomes and reducing the overall burden of epilepsy. This finding extends beyond the traditional biomedical paradigm and highlights the need for a holistic and multisectoral approach encompassing clinical practice, health systems strengthening, family and community engagement, workplace inclusion, public health interventions, and policy reforms. It further contributes to the growing body of evidence emphasizing the importance of addressing social determinants of health in the management of chronic neurological disorders (Beghi et al., 2019).

From a clinical perspective, the findings suggest that optimal epilepsy management requires addressing psychosocial factors alongside pharmacological treatment. Stigma negatively affects treatment adherence, continuity of care, health-seeking behavior, and patient-provider interactions, thereby compromising quality outcomes (Jacoby, 2002; Baker et al., 2005). Healthcare providers should therefore integrate psychosocial assessment, stigma screening, counseling, and patient-centered communication into routine epilepsy care. Strengthening provider competencies in mental health and epilepsy counseling may enhance trust, improve adherence, and promote continuity of care. Consequently, comprehensive epilepsy management should extend beyond seizure control to encompass psychological and social well-being (WHO, 2022).

At the health system level, stigma reduction necessitates the integration of epilepsy services within primary healthcare and mental health programs. Healthcare workers require continuous professional development to address misconceptions and discriminatory attitudes that may exist within healthcare settings. Establishing multidisciplinary care teams and support mechanisms can improve continuity and coordination of care. In addition, strengthening referral systems, ensuring uninterrupted medication supply, and integrating psychosocial support services within epilepsy clinics are likely to enhance patient experiences and quality outcomes. Such approaches are consistent with Donabedian's proposition that healthcare structures influence care processes and ultimately determine outcomes (Donabedian, 1988).

At the individual level, interventions should focus on empowering people with epilepsy through health education, self-management support, and psychosocial counseling. Improved knowledge of epilepsy has been shown to reduce self-stigma,

enhance self-esteem, and improve treatment adherence (Jacoby et al., 2005). Support groups and peer networks may further promote coping mechanisms and social integration, thereby improving quality of life and reducing the psychosocial burden associated with epilepsy (De Boer et al., 2008).

Families constitute an important source of emotional, social, and financial support for people with epilepsy. However, misconceptions and stigma within families may contribute to isolation, poor adherence, and diminished quality of life (Mushi et al., 2011). Family-centered interventions aimed at improving knowledge and dispelling myths surrounding epilepsy can foster supportive environments and enhance adherence to treatment. Active involvement of family members in patient education and counseling is therefore essential for improving quality outcomes (WHO, 2022).

Community misconceptions and cultural beliefs remain major contributors to epilepsy-related stigma (Mushi et al., 2011; Baskind & Birbeck, 2005). Community-based awareness programs involving religious leaders, community health promoters, teachers, and local administrators are essential for addressing myths and discriminatory practices. Public sensitization campaigns can improve societal understanding of epilepsy as a neurological disorder rather than a spiritual or contagious condition, thereby facilitating social inclusion and increasing healthcare utilization (ILAE, 2022).

5.1.7 The Importance of Stigma in Epilepsy care

At multivariate level, stigma was the only statistically significant predictor of quality of care among people living with epilepsy as other indicators lost significance after adjustment for confounding variables. This finding suggests that it has a strong psychosocial influence on perceived quality of care beyond clinical and system factors. Within the Kenyan context, the stigma exerts a stronger influence on patients' experiences and outcomes than disease severity itself. Such an observation highlights the need to conceptualize epilepsy not merely as a neurological disorder but also as a socially mediated condition whose consequences are shaped by cultural beliefs, health systems, and societal attitudes (Mula and Kanner, 2021).

This finding converges with broader literature, which consistently identifies stigma as one of the most debilitating dimensions of epilepsy. According to the World Health Organization (WHO, 2022), stigma and discrimination remain among the principal barriers to effective epilepsy management worldwide, particularly in low- and middle-income countries where misconceptions regarding supernatural causation and contagion persist. The burden of epilepsy extends beyond seizure occurrence and encompasses social exclusion, impaired identity, and reduced quality of life (Jacoby et al., 2005). Thus, the current finding reinforces the notion that the psychosocial burden of epilepsy often outweighs the direct effects of recurrent seizures and those with controlled seizures may continue to experience social discrimination because stigma persists independently of clinical status. Similar from sub-Saharan Africa include Mushi et al. (2011) who reported that epilepsy was widely associated with witchcraft, evil spirits, and hereditary curses, resulting in delayed treatment-seeking and social isolation. Similar observations have been documented in Kenya, where Mbuba et al. (2012) found that cultural misconceptions and stigma significantly contributed to the epilepsy treatment gap through poor adherence and preference for traditional healing practices. This evidence supports the proposition that stigma functions as an upstream determinant influencing multiple pathways including delayed diagnosis, medication non-adherence, and discontinuity of care.

Social model of disability posits that impairments alone do not produce disability; rather, disability arises from environmental and societal barriers (Shakespeare, 2018). From this perspective, seizure frequency may represent the biological manifestation of epilepsy, whereas stigma constitutes the social mechanism that transforms the condition into a disabling experience. Consequently, patients with relatively infrequent seizures may nevertheless experience profound reductions in quality of life because of discrimination, unemployment, educational exclusion, and marital difficulties. Such observations lend support to the Donabedian framework, which recognizes interpersonal relationships and patient experiences as integral components of healthcare quality (Ayanian and Markel, 2016)**,**

Conversely, Baker et al. (1997) and Kwan and Brodie (2000) demonstrated that seizure frequency and seizure control are among the strongest determinants of quality of life

and biomedical indicators tended to exert greater influence than stigma. In environments where epilepsy is relatively well understood and discrimination is less pronounced, clinical severity naturally becomes a more dominant determinant of outcomes. Therefore, clinical frequency and stigma are interacting phenomena where seizure recurrence may itself precipitate stigmatization by increasing public visibility of the condition. Stigma may worsen seizure control through poor medication adherence, delayed care-seeking, stress, and social withdrawal. Hence, the relationship between seizure frequency and stigma is bidirectional rather than mutually exclusive ((Mula and Kanner, 2021)).

Seizure frequency represents an objective clinical parameter measured by healthcare providers, whereas stigma reflects subjective experiences embedded within personal, familial, and community contexts. WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031 emphasizes social inclusion, human rights, and stigma reduction as essential components of comprehensive epilepsy care (WHO, 2022). Within the Kenyan context, stigma intersects with poverty, educational attainment, unemployment, and gender inequalities, thereby amplifying vulnerability among people living with epilepsy. Consequently, stigma transcends the individual level and becomes a community and health-system issue. Fear of discrimination may discourage disclosure, weaken patient-provider communication, reduce attendance at clinics, and undermine adherence to antiepileptic medications. Thus, stigma affects structure, process, and outcomes indicators (Thijs et al., 2019)

The present findings contribute to the growing body of evidence advocating a paradigm shift from a purely biomedical approach to a biopsychosocial model of epilepsy care. While seizure control remains indispensable, interventions focusing exclusively on clinical management may yield suboptimal outcomes if stigma remains unaddressed as epilepsy-related stigma represents one of the greatest barriers to achieving optimal care and social participation (de Boer et al., 2008). Stigma reduction therefore remains a strategic priority intervention for improving quality of care for people with epilepsy.

At the clinical level, stigma-sensitive counselling and psychosocial support should accompany pharmacological management. At the family and community levels, educational interventions should challenge myths relating to contagion, witchcraft, and spiritual causation. At the health-system level, healthcare providers require training to foster respectful and person-centred interactions. From a public health perspective, anti-stigma campaigns should be integrated into community health programmes and primary healthcare services. At the policy level, the Ministry of Health should incorporate stigma indicators within epilepsy monitoring frameworks and align epilepsy interventions with Universal Health Coverage and the Kenya Mental Health Policy (MOH, 2021).

While other clinical variables remain clinically important, stigma as an independent predictor assumes greater significance within the Kenyan setting because it permeates multiple dimensions of health and healthcare. Unlike pure clinical predictors, stigma influences health-seeking behaviour, medication adherence, psychosocial wellbeing, economic productivity, family relationships, and social participation. Consequently, stigma reduction emerges as a strategic and modifiable priority whose impact extends beyond seizure control to encompass the broader goals of quality, equity, and social inclusion (Mula and Kanner, 2021).

5.1.8 Stigma at the Workplace

Stigma frequently manifests through discrimination in employment, reduced economic opportunities, and social exclusion. Employment-related discrimination contributes substantially to the socioeconomic burden of epilepsy and adversely affects quality of life (De Boer et al., 2008). Workplace policies promoting non-discrimination, occupational inclusion, and awareness of epilepsy can enhance productivity and social participation among people with epilepsy. These measures are consistent with the rights-based approach advocated by the United Nations Convention on the Rights of Persons with Disabilities (WHO, 2022).

5.1.9 Public Health Implications of Stigma

From a public health perspective, stigma reduction represents a critical strategy for reducing the epilepsy treatment gap and improving access to quality healthcare services . Community awareness initiatives, school-based health education, and integration of epilepsy into broader non-communicable disease and mental health programs may contribute to earlier diagnosis, improved treatment adherence, and reduced disability (Feigin, 2024). Addressing stigma may therefore contribute to achieving Universal Health Coverage and the Sustainable Development Goals by promoting equitable access to healthcare and improving health-related quality of life (WHO, 2022).

5.1.10 Implications for Ministry of Health Policy

The finding that stigma independently predicts quality of care has important implications for health policy. Ministries of Health should incorporate stigma reduction strategies into national epilepsy and mental health policies through development of national awareness campaigns, integration of psychosocial services within epilepsy clinics, capacity building of healthcare workers on stigma-sensitive care, and strengthening community health systems. Such interventions are aligned with the WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031, which recognizes stigma reduction as a fundamental component of improving epilepsy outcomes and promoting social inclusion (WHO, 2022).

In the Kenyan context, these findings support the objectives outlined in the Kenya Mental Health Policy 2015–2030 and the Kenya National Strategy for Prevention and Control of Non-Communicable Diseases, which emphasize equitable access to mental and neurological healthcare services and community participation in health promotion (MoH, 2015).

5.1.11 Contribution of the Study to Body of Knowledge

The study contributes to the existing body of knowledge by demonstrating that psychosocial factors, particularly stigma, may exert a stronger influence on quality of

epilepsy care than many socio-demographic, clinical, and structural variables traditionally emphasized in healthcare research. While previous studies have predominantly focused on seizure control, medication adherence, and healthcare access (Baker et al., 2005; Beghi et al., 2019), the present findings provide empirical evidence that stigma constitutes a central determinant of quality outcomes. This observation reinforces the biopsychosocial model of epilepsy and supports calls for a more integrated approach to epilepsy management (Engel, 2012).

Furthermore, by employing a mixed-methods approach guided by the Donabedian framework (Donabedian, 1988) and the Aday and Andersen model (Aday & Andersen, 1974; Andersen, 1995), the study advances theoretical understanding of the pathways through which psychosocial factors influence healthcare utilization and quality outcomes. The findings suggest that stigma may mediate or modify the effects of structural and process-related factors on patient outcomes, thereby extending existing conceptual models of healthcare quality. Consequently, the study provides evidence supporting the integration of psychosocial dimensions into quality-of-care frameworks and offers a foundation for future research aimed at elucidating the mechanisms through which stigma affects epilepsy outcomes.

Overall, the emergence of stigma as the sole independent predictor of quality of care highlights the need to reorient epilepsy care from a predominantly biomedical approach toward a comprehensive, patient-centered, and socially responsive model. Addressing stigma across clinical, family, community, workplace, and policy domains has the potential to improve quality of care, reduce the treatment gap, enhance social participation, and ultimately mitigate the burden of epilepsy (ILAE, 2022).

5.2 Conclusions

This study evaluated the quality of care provided to people with epilepsy attending selected hospitals in Nairobi and its environs and demonstrated that, although overall care was generally perceived as high, important disparities in access, experience, and outcomes persist across patient groups. Quality of care was shaped by the interaction of socio-demographic, clinical, and health system factors.

Socio-demographic characteristics significantly influenced care experiences. Individuals in formal employment reported better quality of care, likely reflecting greater financial capacity and insurance coverage, whereas unemployed and socioeconomically disadvantaged patients experienced poorer care, highlighting persistent inequities and the need for strengthened financial protection mechanisms. Age-related differences were also evident, with younger patients reporting more favourable experiences than older adults, whose lower ratings may reflect multimorbidity, complex care needs, and communication challenges.

Clinical factors similarly affected perceptions of care. Delayed health-seeking behaviour, persistent seizures after treatment initiation, and experiences of stigma were associated with poorer quality ratings. Delayed diagnosis and treatment may increase disease severity and reduce perceived effectiveness of care, while uncontrolled seizures undermine trust, satisfaction, and treatment adherence. Stigma emerged as a particularly important determinant, negatively affecting disclosure, social functioning, adherence, and continued engagement with healthcare services, underscoring the need to integrate psychosocial support, patient education, and community-based stigma reduction strategies into routine epilepsy care.

Health system factors also substantially influenced patient experiences. Long waiting times, inconsistent availability of anti-seizure medications, and high costs of diagnosis and treatment were associated with lower quality ratings, particularly among economically disadvantaged patients. These findings point to the need for strengthened pharmaceutical supply chains, improved resource allocation, and expanded financing mechanisms to ensure equitable and uninterrupted access to care.

This study found that the majority of people with epilepsy attending selected Level 5 hospitals in Nairobi, Kiambu, and Machakos counties reported high overall quality of care (52.8%). After adjustment for potential confounders, perceived stigma remained a significant independent predictor of quality of care, with participants experiencing high stigma being significantly twice as less likely to report high quality care (AOR = 2.123, 95% CI: 1.119-4.026, p= 0.21). These findings suggest that, although epilepsy

services are generally well-rated, psychosocial factors continue to influence patients' care experiences and should be addressed alongside clinical management.

5.2 Contribution of the Study

5.2.1 Contribution of this Study to Body of Knowledge

This study quantitatively determined the socio-demographic, clinical, and hospital-related predictors of quality of care among people with epilepsy receiving treatment in selected Level 5 hospitals in Nairobi, Kiambu, and Machakos counties, Kenya. After controlling for potential confounders, stigma emerged as the strongest independent predictor of quality of care, highlighting the central role of psychosocial factors in shaping patient experiences and perceptions of care.

Structural and process-related factors, particularly drug availability and accessibility, also significantly influenced quality-of-care ratings, demonstrating that quality of epilepsy care is determined largely by modifiable health system factors rather than patient demographic characteristics. In addition, the study provided context-specific evidence on the interplay between geographical accessibility, hospital readiness, and patient experiences, while quantifying critical health system bottlenecks, including workforce shortages and inconsistent availability of anti-seizure medications. These findings are consistent with the World Health Organization Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders, which identifies stigma, inadequate access to essential medicines, and limited human resources as major barriers to quality epilepsy care globally (WHO, 2022).

This study makes an important original contribution to the body of knowledge on epilepsy care and health systems research in Kenya. It is among the first studies to systematically evaluate quality of epilepsy care in Level 5 hospitals using a multidimensional composite quality-of-care index grounded in the Donabedian framework (Donabedian, 1988). Unlike previous studies that have predominantly focused on seizure control and clinical outcomes, it provides novel, context-specific evidence on the determinants of epilepsy care quality in Kenya's Level 5 hospitals by integrated structural, process, and patient-level dimensions to provide a holistic

assessment of quality of care. This approach is consistent with contemporary quality paradigms that emphasize effectiveness, accessibility, continuity, people-centeredness, and equity as essential characteristics of high-performing health systems (WHO and UNICEF, 2020; WHO, 2022).

Methodologically, the study introduces a validated, multidimensional quality-of-care tool which is a contextually appropriate and validated multidimensional framework for measuring quality of epilepsy care. By operationalizing the interrelationships among structure, process, and outcomes, the study demonstrates the practical application of the Donabedian model in evaluating chronic disease care within resource-constrained settings (Donabedian, 1988). It suitable for adaptation to other NCDs.

By identifying modifiable socio-demographic, clinical and hospital level predictors, the study bridges the gap between patient experience and health system performance thus advancing health systems research in Kenya and other LMIC.

The framework provides a robust analytical approach that can be adapted for assessing quality of care for other non-communicable diseases in Kenya and similar low- and middle-income countries. Consequently, the study contributes to the growing body of implementation and health systems research aimed at strengthening quality measurement and performance improvement (Kruk et al., 2018).

Beyond epilepsy research, the study advances health systems research by demonstrating that improving quality of care requires integrated interventions that simultaneously address structural, process, psychosocial, and socio-cultural determinants. By identifying empirically validated targets for quality improvement, resource allocation, workforce planning, service organization, and community engagement, the study bridges the gap between health system performance and patient experiences. These findings reinforce the principles of Primary Health Care articulated in the Declaration of Astana, which advocates for integrated, people-centered, comprehensive, and equitable health services delivered across the continuum of care (WHO and UNICEF, 2018). They further support the World Health Organization's conceptualization of Primary Health Care as the foundation for achieving Universal

Health Coverage and the health-related Sustainable Development Goals (United Nations, 2015; WHO and UNICEF, 2020).

Importantly, the findings provide empirical evidence capable of informing Ministry of Health policies, county health planning, clinical practice guidelines, quality improvement initiatives, and community-based interventions. The study demonstrates that quality epilepsy care cannot be achieved through biomedical interventions alone but requires system-wide and multilevel approaches that address health system functionality, psychosocial determinants, and social influences such as stigma. Such an approach aligns with the Kenya Health Policy 2014–2030 and the Kenya Primary Health Care Strategic Framework, which emphasize integrated service delivery, continuity of care, community participation, and equitable access to quality healthcare as critical pillars for achieving Universal Health Coverage (Ministry of Health, 2014; Ministry of Health, 2020).

Overall, the principal contribution of this study lies in its comprehensive assessment of epilepsy care quality and its generation of context-specific evidence on modifiable structural, process, psychosocial, and socio-cultural determinants of care. By integrating patient experiences with health system performance, the study provides a replicable and evidence-based framework for evaluating and improving chronic disease care in low- and middle-income countries. In doing so, it advances both the science and practice of health systems strengthening and contributes to ongoing local, national, and global efforts aimed at achieving equitable, accessible, and people-centered healthcare under the Primary Health Care, Universal Health Coverage (WHO and UNICEF, 2020; WHO, 2022) and Bottom-Up Economic Transformation Agenda.

5.2.2 Contribution to Community and Public Health

Beyond academic contribution, the study has considerable implications for community health and social well-being. By documenting patient experiences and identifying determinants of quality care, the findings provide evidence that can guide interventions aimed at improving treatment adherence, patient satisfaction, and clinical outcomes. Better quality care is likely to reduce seizure frequency, disability, preventable hospitalizations, and epilepsy-related mortality.

Importantly, the study highlights the central role of stigma and socio-cultural perceptions in shaping care experiences in epilepsy management. Consequently, community-based awareness programs, health education campaigns, and psychosocial support interventions should be prioritized to reduce discrimination and promote social inclusion. Engagement of community health promoters, schools, workplaces, religious institutions, and patient support groups can foster greater acceptance and improve health-seeking behaviors.

The findings also provide evidence for advocacy aimed at elevating epilepsy as a public health priority within Kenya's non-communicable disease agenda. Enhanced recognition of epilepsy by policymakers, development partners, and civil society organizations would facilitate mobilization of resources and expansion of specialized services.

Ultimately, this study bridges the gap between research and practice by generating contextually relevant evidence that can inform policy formulation, strengthen health systems, improve service delivery, and enhance the quality of life of people living with epilepsy in Kenya. Though its focus on patient-centered care, equity, and health system responsiveness, the study contributes to the realization of Universal Health Coverage and Sustainable Development Goal 3, which seeks to ensure healthy lives and promote well-being for all at all ages.

5.2.3 Limitations and Delimitations of the study

5.2.3.1 Limitations of the Study

The study provided important insights into the quality of care among people with epilepsy receiving treatment at the five selected Level 5 hospitals. However, the study acknowledges the following limitations

Cross-sectional design provided only a snapshot of quality of care and patient experiences at a single point in time. This limited the ability to establish causal or temporal relationships between the identified predictors and quality outcomes. Self-reported measures could introduce recall, reporting or social desirability bias; Focus

on Level 5 hospitals may limit generalizability to lower or higher-level facilities. With this design, changes in service quality and patient experiences over time could not be assessed.

Study was conducted in selected Level 5 hospitals in Nairobi, Kiambu, and Machakos counties, which may limit the generalizability of the findings to lower-level health facilities or other regions of Kenya with different health system characteristics. In addition, patients with cognitive impairments and those seeking emergency care only were excluded from the study, potentially resulting in underrepresentation of vulnerable populations and limiting the comprehensiveness of the findings.

Furthermore, quality of care was measured using a composite index based primarily on patient-reported experiences. Although validated instruments were employed, the subjective nature of self-reported responses may have introduced recall and social desirability biases. Similarly, some structural and process-related variables were obtained through self-report and facility records, which may have been subject to reporting inaccuracies.

Constraints related to time, resources and scope limited inclusion of additional variables, particularly long-term patient outcomes. Consequently, the study was unable to examine longitudinal effects, explore the influence of provider-specific factors on quality of care and develop a predictor model for quality of Care for PWE. Nevertheless, despite these limitations, the study employed rigorous methodological and statistical approaches that enhanced the validity and reliability of the findings, thereby providing valuable evidence to inform policy and practice aimed at improving epilepsy care in Kenya.

5.2.3.2 Delimitations of the Study

Though it was a cross-sectional study with reliance on patient-reported measures, the study provided robust and representative evidence on predictors of quality of care. Any potential bias was delimited by use of standardized tools adopted from Donabedian and Aday & Anderson framework and confounders controlled through multivariate adjustment. The methodological rigor involving mixed-methods approach and

triangulation of quantitative findings with qualitative insights further delimited the study and strengthened the credibility and contextual interpretation of the results and enhanced the contribution of the study to the evidence base on epilepsy care which provides a sound basis for policy formulation and health system interventions.

5.3 Recommendations

Based on the foregoing findings, discussions and conclusions, the following recommendations are made in order to improve epilepsy outcomes through a comprehensive framework that aims to address quality, socio-demographic, clinical, and hospital-level predictors.

5.3.1 Recommendations on Quality of Care for PWE

- The study recommends strengthening of early recognition and prompt management of seizure disorders by the Division of Non-Communicable Diseases and in collaboration with county governments, through integration of epilepsy screening into primary healthcare and community health programmes coupled with continuous capacity building of frontline healthcare workers

- Ministry of Health to institutionalize standardized epilepsy treatment protocols and clinical practice guidelines across all levels of care to optimize seizure control, improve medication adherence, monitor adverse drug effects, and promote continuity and quality of care for persons living with epilepsy.
- Embedment of stigma-reduction interventions by the Ministry of Health through public health education, culturally sensitive communication, psychosocial support services, peer support groups, and patient-centred approaches to address misconceptions, reduce discrimination, and empower persons living with epilepsy and their families.
- Mainstreaming of human rights-based approach in the existing health policies and service delivery frameworks by the Kenya National Commission on Human Rights, and patient advocacy groups for equitable, person-centred, and dignified care.

- Review and strengthening of legal and policy frameworks to provide explicit protection against stigma, discrimination, and social exclusion of persons living with by the Attorney General's Office, the Kenya National Commission on Human Rights.

- The ministry of Health in collaboration with other partners to safeguard the rights to healthcare, education, employment, and social participation of PWE in accordance with the Constitution of Kenya (2010), the Persons with Disabilities Act (2025), the United Nations Convention on the Rights of Persons with Disabilities, and the WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (2022–2031).

- Quality assurance for epilepsy care by Ministry of Health and county governments to institutionalize routine supportive supervision, patient feedback systems, and periodic facility-based assessments using standardized quality-of-care tools to continuously monitor epilepsy management, identify gaps in service delivery, and guide evidence-based quality improvement initiatives.
- Establishment of a national epilepsy registry to strengthen operational research and surveillance systems through collaboration between the government and research and academic institutions to generate reliable data for monitoring patient outcomes, informing policy decisions, and guiding equitable allocation of resources.
- Promotion of comprehensive epilepsy care by strengthening social protection mechanisms, and improve the overall quality of life of persons living with epilepsy by enhancing multi-sectoral collaboration among the Ministry of Health, county governments, the Social Health Authority, professional associations, civil society organizations and patient advocacy groups
- Ministry of Health to align epilepsy care programmes with the Kenya Health Policy (2014–2030), the Kenya National Strategy for Prevention and Control of Non-Communicable Diseases (2022–2027) and the Universal Health Coverage

5.3.2 Recommendations on Socio-Demographic Predictors of QoC for PWE

- Expansion of access to subsidized epilepsy care, essential anti-seizure medicines, and transport support by both The Ministry of Health, county governments, and the Social Health Authority (SHA) to strengthen financial risk protection for people living with epilepsy in line with the Universal Health Coverage agenda and the Kenya Essential Package for Health.
- Development and implementation of age- and vulnerability-sensitive epilepsy care models by the Ministry of Health, through the Division of Mental Health and County Health Services prioritizing children, the elderly adults, persons with disabilities, and patients with comorbid conditions aligned with Kenya National Policy on Prevention and Control of Non-Communicable Diseases and the Kenya Mental Health Action Plan
- Socio-economic empowerment of persons living with epilepsy by the Ministry of Labour and Social Protection, and county governments by providing vocational training, educational support and linkage to existing social protection programmes aligned with the Kenya Vision 2030 agenda, the Persons with Disabilities Act, and the principles of Universal Health Coverage.

5.3.3 Recommendations on Clinical Predictors of QoC for PWE

- The Ministry of Health, through the Division of Non-Communicable Diseases, in collaboration with County Departments of Health, to enhance capacity building initiatives and strengthen and enhance patient referral pathways and reduce delays in diagnosis
- Increased access to essential diagnostic services (by investing in and equitably distributing electroencephalography (EEG) machines, neuroimaging services, and other diagnostic infrastructure) by the Ministry of Health, through the Directorate of Health Products and Technologies, in collaboration with county governments, referral hospitals, and development partners.
- Institutionalization of standardized longitudinal follow-up across all levels of care by Ministry of Health together with County Departments of Health in order to promote continuity of care, medication adherence, treatment response

and adverse drug reactions, and enable timely optimization of therapeutic regimens.

- The Ministry of Health and county governments should establish multidisciplinary epilepsy care teams comprising neurologists, psychiatrists, physicians, nurses, pharmacists, psychologists, social workers, rehabilitation specialists, and Community Health Promoters as part of support and collaboration to ensure holistic management of epilepsy that addresses biomedical, psychological, psychosocial, and socio-cultural dimensions of care.
- The Ministry of Health, through the Mental Health Unit and Division of Non-Communicable Diseases, in collaboration with county governments and referral hospitals, should integrate psychosocial support and routine stigma assessment into epilepsy services. Healthcare providers should screen for self-stigma and enacted stigma, provide counselling services, and establish referral pathways for specialized mental health care, recognizing stigma as the strongest predictor of poor quality of care.
- Strengthening of patient and caregiver education programmes through facility- and community-based platforms by the County Departments of Health to improve understanding of epilepsy with culturally sensitive information tailored to patients' literacy levels in order to encourage early health-seeking behaviour.
- The Ministry of Health, county governments, teaching and referral hospitals, academic institutions, and development partners should strengthen specialized epilepsy services through continuous professional development, clinical mentorship, supportive supervision, and capacity building to enhance the quality and comprehensiveness of epilepsy care in line with the Kenya Health Policy (2014–2030), the Kenya National Strategy for Prevention and Control of Non-Communicable Diseases (2022–2027), and the Universal Health Coverage agenda.

5.3.4 Recommendations on Hospital-Level Predictors of QoC for PWE

- County governments, academic institutions, and professional bodies to scale up continuous professional development programmes, in-service training, and supportive supervision for healthcare workers involved in epilepsy care to address emerging service demands and maintain quality standards.
- Enhancement of clinical competencies for technical staff through technical support and mentorship programmes by partners, county governments, universities and professional associations in order to improve the quality of epilepsy services.
- Health, through the Directorate of Health Products and Technologies, in collaboration with the Kenya Medical Supplies Authority (KEMSA), the Social Health Authority (SHA), county governments, and development partners, to strengthen pharmaceutical and non-pharmaceutical support systems to ensure uninterrupted availability of anti-seizure medications and essential diagnostic commodities across all levels of care.
- Strengthening financial and organizational support at county level would facilitate sustained implementation of quality improvement measures and reduce inequities in epilepsy care across the three counties.
- County Departments of Health in the three counties to institutionalize an Epilepsy Quality of Care Scorecard based on the respect, communication, tolerability of side effects, effectiveness, affordability, counselling, access, privacy and promptness which should be incorporated into routine quality assurance and supportive supervision systems and reviewed regularly to monitor performance and guide corrective actions.

5.3.5 Recommendations on Further Research on QoC for PWE

Despite being novel study with scientific rigor and multilevel scope and intelligible findings, further research would be necessary into the following areas:

- *Expanded scope:* Inclusion of more counties across diverse regions of Kenya and incorporation of Level 4 and Level 6 facilities would be necessary in order

to increase statistical power, capture variability in health system contexts, and allow more nuanced comparisons between different tiers of care, ultimately improving external validity.

- *Longitudinal Study Design:* A longitudinal study would be able to track changes in quality of care, adherence, and clinical outcomes over time and provide stronger evidence of causal relationships and intervention effectiveness in the care of people with epilepsy.
- *Deeper Qualitative assessments* with more measurable quality indicators to enrich greater understanding of patient experiences, provider perspectives, and systemic barriers. More in-depth interviews, focus group discussions, and ethnographic observations would uncover subtle sociocultural and organizational factors influencing quality of care for PWE.
- *Cost-Effectiveness Analysis:* Analysis of health economics and quantification of the cost-effectiveness of different quality improvement strategies, including counselling, medication adherence programs, and community outreach would provide policymakers with actionable evidence for resource allocation.
- *Assessment of Clinical Outcomes* incorporating clinical measures such as seizure frequency logs, medication plasma levels, and hospital readmission rates would strengthen the linkage between quality-of-care rating and clinical effectiveness.
- A comprehensive, longitudinal, multi-level study with clinical, economic, and sociocultural perspectives would enhance and strengthen the validity, policy relevance, and practical impact of the findings, ultimately contributing to improved quality of care for people with epilepsy in Kenya.

5.3.6 Proposed Implementation Matrix for The Recommendations

A major strength of the study is that its recommendations are largely implementable within existing health system structures and are aligned with current health sector reforms in Kenya, including the Universal Health Coverage (UHC) agenda, the Community Health Strategy (2020–2025), and the Kenya Digital Health Strategy (2024–2028). A feasible implementation framework is outlined below.

5.3.7 Proposed Implementation Framework for Improving Quality of Epilepsy Care in Kenya

Table 5.1: Proposed Implementation Framework

Recommendation/Intervention	Key Activities	Responsible Agencies/Stakeholders	Time Frame	Resource Requirement	Monitoring Indicators
Strengthen counseling and health education services	Train healthcare workers on structured counseling, adherence support, stigma reduction, and patient-centered communication	Ministry of Health (MoH), Division of Non-Communicable Diseases (DNCD), County Departments of Health, Level 5 Hospitals, Nursing Council of Kenya, Kenya Medical Training College (KMTC)	Short-term (1–2 years)	Low	Number of staff trained; proportion of patients receiving counseling; patient satisfaction scores
Integrate psychosocial and stigma screening into routine epilepsy care	Develop screening tools and referral pathways; incorporate stigma assessment into epilepsy follow-up clinics	MoH-DNCD, County Health Departments, Kenya Psychiatric Association, Neurological Society of Kenya, Hospital Management Teams	Short-term (1–2 years)	Low	Percentage of patients screened for stigma; referral rates; stigma scores
Standardize follow-up protocols and continuity of care	Develop appointment systems, follow-up guidelines, multidisciplinary review clinics, referral pathways	MoH, County Health Departments, Hospital Management Teams, Kenya Association of Neurological Sciences	Medium-term (2–3 years)	Low–Moderate	Follow-up adherence rates; missed appointment rates; continuity of care indicators
Strengthen referral systems and clinic workflow	Harmonize referral pathways between primary, secondary and tertiary facilities; establish feedback mechanisms	MoH, County Referral Hospitals, Kenya Health Referral Strategy Unit, County Health Management Teams	Medium-term (2–3 years)	Moderate	Referral completion rates; waiting times; turnaround time
Leverage digital health technologies	Implement SMS reminders, telemedicine consultations,	Ministry of Health Digital Health Directorate, Safaricom	Medium-term (2–4 years)	Moderate	Missed clinic rates; treatment adherence

Recommendation/Intervention	Key Activities	Responsible Agencies/Stakeholders	Time Frame	Resource Requirement	Monitoring Indicators
	electronic appointment systems and electronic medical records integration	Foundation, County Governments, ICT Authority, Digital Health Agencies, Referral Hospitals			rates; teleconsultation uptake
Integrate epilepsy services into Community Health Promoter (CHP) programs	Train CHPs on epilepsy awareness, treatment adherence, stigma reduction and early complication identification	MoH, County Health Departments, Community Health Units, CHPs, AMREF, Red Cross Kenya, NGOs	Medium-term (2–3 years)	Low	Number of CHPs trained; community referrals; adherence rates
Establish multidisciplinary epilepsy clinics	Incorporate neurologists, psychiatrists, psychologists, nurses, pharmacists, social workers and rehabilitation personnel	MoH, County Governments, Level 5 Hospitals, Professional Associations, Universities	Long-term (3–5 years)	Moderate	Number of multidisciplinary clinics established; patient outcomes; quality-of-care scores
Promote public awareness and stigma reduction campaigns	Community sensitization, media campaigns, school-based programs and workplace awareness	MoH, Ministry of Education, County Governments, Media Houses, Faith-Based Organizations, Epilepsy Support Groups	Long-term (3–5 years)	Moderate	Community knowledge scores; stigma prevalence; health-seeking behavior
Strengthen policy and financing for epilepsy care	Incorporate epilepsy into county health plans, UHC benefit packages, and NCD strategic frameworks	Ministry of Health, County Governments, Social Health Authority (SHA), National Treasury, Parliament	Long-term (3–5 years)	Moderate–High	Budget allocations; medicine availability; service coverage

5.3.8 Proposed Governance Structure

National Level

Lead Agency: Ministry of Health (Division of Non-Communicable Diseases)

Supporting Agencies

- Digital Health Directorate
- Social Health Authority (SHA)
- Kenya Medical Supplies Authority (KEMSA)
- Kenya Medical Training College (KMTC)
- Regulatory and professional bodies

County Level

Lead Agencies

- County Departments of Health
- County Health Management Teams (CHMTs)

Supporting Institutions

- Level 5 Referral Hospitals
- Community Health Units
- Community Health Promoters (CHPs)
- County Referral Networks

Facility Level

Lead Agencies

- Hospital Management Teams
- Multidisciplinary Epilepsy Clinics

Supporting Personnel

- Neurologists
- Psychiatrists

- Clinical officers
- Nurses
- Pharmacists
- Psychologists
- Social workers

Community Level

Lead Actors

- Community Health Promoters (CHPs)
- Faith-based organizations
- Schools
- Community leaders
- Epilepsy support groups
- Non-governmental organizations

Majority of these interventions require organizational strengthening, capacity building, and better coordination rather than substantial infrastructural investments, making them highly feasible within Kenya's devolved health system. Existing structures such as the Community Health Strategy, Community Health Promoter program, digital health platforms, county referral systems, and UHC reforms provide an enabling environment for implementation. Consequently, these recommendations represent practical, scalable, and sustainable approaches for improving epilepsy care and may serve as a model for strengthening chronic disease management more broadly within Kenya and similar low- and middle-income countries.

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Ibinda, F., Odermatt, P., Kariuki, S. M., Kakooza-Mwesige, A., Wagner, R. G., Owusu-Agyei, S., Masanja, H., Ngugi, A. K., Mbuba, C. K., & Doku, V. C. (2017). Magnitude and factors associated with nonadherence to antiepileptic drug treatment in Africa: a cross-sectional multisite study. *Epilepsia Open*, *2*(2), 226-235.

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APPENDICES

Appendix I: Tool 1: Questionnaire

My name is Tiberry Nyakwana, a PhD student at Jomo Kenyatta University of Agriculture and Technology, School of Public Health. I am conducting a study on Predictors of Quality of Care for Epilepsy ClientsAppendix A in Level Selected Hospitals in Nairobi, Machakos and Kiambu Counties. Information from this interview is confidential and will only be used for the purposes of this study.

PART A: Characteristics of study population

Health Facilities

1. Gatundu ☐ 2. Kiambu ☐ 3 Thika ☐ 4. Mama Lucy ☐ 5. ☐ Machakos

Medical Service

1. Inpatient…… 2 Outpatient……

Age

2 – 5 ☐ 6 – 12 ☐ 13 – 18 ☐ 19 – 28 ☐ 29 – 49 50+ ☐

Sex

1. Male ☐ 2. Female ☐

Level of Education

1. No formal Education ☐ 2. Primary ☐ 3. Secondary ☐ Tertiary ☐

Occupation

1. Formal employment ☐ 2. Informally Employed ☐ 3. Not Employed ☐

Religion

1. Christian ☐ 2. Muslim ☐ 3. ☐ dus

Marital status

☐ ☐

1. Single 2. Married ☐ 3. Underage

PART B: DATA ON STUDY OBJECTIVES

1. Objective 1: Quality of care provided to people with epilepsy

I. EVALUATION OF FIRST VISIT

a) Have you been requested to do EEG?

1.Yes ☐ 2.NO ☐ 3.Don't Know ☐ (If NO, proceed to no.4)

b) Do you have the results of the EEG?

1.Yes ☐ 2.NO ☐ 3.Don't Know ☐

c) Has it been reviewed?

1.Yes ☐ 2.NO ☐ 3.Don't Know ☐

d) Have you been done MRI (Preferred)

1.Yes ☐ 2.NO ☐ 3.Don't Know ☐

e) Have you been done CT Scan

1.Yes ☐ 2.NO ☐ 3. Don't Know ☐

f) Have you been given information on safety precautions

1.Yes ☐ 2.NO ☐ 3.Don't Know ☐

If yes, specify …… Driving ……. Cooking…….. Others…….

II. INITIAL DIAGNOSIS & TREATMENT

a. Has diagnosis of epilepsy included seizure types? (Refer to patient recor ☐ Yes ☐ NO Don't ☐ w

a. Has the seizure medication (SM) been discussed with you or caregivers?

1.Yes ☐ 2. N ☐

No of drugs given 1.One (Preferred) ☐ 2.Two ☐ 3. >two ☐

b. For a woman of childbearing potential (12-44 years old): Have you been referred to a neurologist or an epilepsy specialist?

1.Yes ☐ 2.No ☐ 3. Don't Know ☐

b. For a woman of childbearing potential (12-44 years old): have you been given information about the risk (teratogenicity) associated with treatment

1.Yes ☐ 2.No ☐ 3. Don't Know ☐

c. Did you understand those risks prior to starting treatment?

1.Yes ☐ 2.No ☐ 3. Don't Know ☐

d. Have you been given on diagnosis?

1.Yes ☐ 2.No ☐ 3. Don't Know ☐

III. <u>CHRONIC EPILEPSY CARE</u>

1. Has the number of attacks since last visit been estimated? (from records)

1.Yes……. 2.No …… 3. Don't Know ……

2. Has assessment of drug side-effects been documented

1.Yes……. 2.No …… 3. Don't Know ……

3. Have you continued to have seizures after initiating treatment

1.Yes……. 2.No …… 3. Don't Know ……

4. Which of the following interventions has been performed?

i. Compliance assessment/enhancement

1.Yes……. 2.No …… 3. Don't Know ……

ii. SM blood levels monitored

1.Yes……. 2.No …… 3. Don't Know ……

iii. SM dose changed

1.Yes……. 2.No …… 3. Don't Know ……

iv. Patient education regarding lifestyle

1.Yes……. 2.No …… 3. Don't Know ……

v. Referred to higher level of epilepsy care

1.Yes……. 2.No …… 3. Don't Know ……

5. Have you continued to have seizures after 12 months

1.Yes……. 2.No …… 3. Don't Know ……

i. Have you been receiving annual review of information on:
i. Drug side-effects

1.Yes……. 2.No …… 3. Don't Know ……

ii. Contraception

1.Yes……. 2.No …… 3. Don't Know ……

iii. Pregnancy effects on seizures

1.Yes……. 2.No …… 3. Don't Know ……

iv. menopause effects on seizures

1.Yes……. 2.No …… 3. Don't Know ……

v. Screening for mood disorders

1.Yes……. 2.No …… 3. Don't Know ……

vi. Triggers and lifestyle issues that may affect seizures

1.Yes……. 2.No …… 3. Don't Know ……

vii. Lifestyle issues

1.Yes……. 2.No …… 3. Don't Know ……

viii. Impact of epilepsy on other chronic and acute diseases

1.Yes……. 2.No …… 3. Don't Know ……

ix. Safety issues

1.Yes……. 2.No …… 3. Don't Know ……

x. Patient self-management issues

1.Yes……. 2.No …… 3. Don't Know ……

6. For those on SM for 2 or more years, has your bone health been assessed?

1.Yes……. 2.No …… 3. Don't Know ……

7. Have you been screened for depression/suicide related behaviors

1.Yes……. 2.No …… 3. Don't Know ……

8. For those found to have evidence of a mood disorder: have you received treatment or a referral for mental health care.

1.Yes……. 2.No …… 3. Don't Know ……

IV. CHRONIC EPILEPSY CARE FOR WOMEN

A. For a woman with epilepsy is of childbearing potential (12-44 years old), have you received daily 400 mcg supplemental folate?

1.Yes……. 2.No …… 3. Don't Know ……

B. For a woman with epilepsy of childbearing potential (12-44 years old) and receives oral contraceptives in conjunction with an enzyme inducing SM: has the decreased effectiveness of oral contraception been addressed?

1.Yes……. 2.No …… 3. Don't Know ……

C. For antenatal woman with epilepsy, are you co-managed by a neurologist and an obstetrician

1.Yes……. 2.No …… 3. Don't Know ……

V. PATIENT GENERATED QUALITY INDICATOR STATEMENTS

Have you been referred to local support groups or other resources to obtain psychosocial support?

1.Yes……. 2.No …… 3. Don't Know ……

Have you been encouraged to become educated about epilepsy and to advocate for yourself in the health care system and with providers(- provide patients with written material about epilepsy, references to epilepsy foundation or epilepsy web sites).

1.Yes……. 2.No …… 3. Don't Know ……

Have you been communicated to about potential medication side effects, including cognitive, emotional, physical and sexual side effects.

1.Yes……. 2.No …… 3. Don't Know ……

Have you been referred to social services to assist with employment, negotiating through the Social Security Disability Insurance, insurance and alternative transportation for patients who cannot drive.

1.Yes……. 2.No …… 3. Don't Know ……

Have you been discussed with the complexity of epilepsy treatment and explained to that each patient responds to medications differently and that they may need to try several different medications before they find out what works best for that individual?

1.Yes……. 2.No …… 3. Don't Know ……

VI: QUALITY OF RATING

In a scale of 1-10 (1-lowest; 10-highest), rate the following quality indicators

1) To what extent do you think you were handled with privacy (Privacy)
2) How prompt was the duration of service (Promptness)

3) To what extent was treatment explained to you (Communication)
4) To what extent were you counselled on side effects of medication (Counselling)
5) How convenient is the distance from the facility to your residence (Geographical Access)
6) To what extent is the care affordable (Financial Access)
7) To what extent do you feel you were handled by the healthcare workers (Courtesy)
8) To what extent do you think the drugs are helpful? (Effectiveness)
9) To what extent are the drug side effects tolerable (Tolerability)

Objective 2: Socio-demographic factors for quality of health care provided to people with epilepsy

Tool : Semi-structured Questionnaire

Socio-demographics (Refer to part A)

1. Age

1. 0-5 2. 6-12 3. 13-18 4. 19-28 5. 29—49 6. 50+

2. Sex

1. Male ……. 2. Female ……..

3. Occupation

1. Formal Employment…….. 2. Informal Employment …… 3. Not employed ….

4. Religion

1. Christian ……. 2. Muslim …….. 3. Hindus ……

5. Level of Education

1. None …… 2. Primary……. 3. Secondary…… 4. Tertiary…….

6. Marital Status

1. Single 2. Married 3. Underage

Objective 3 Clinical Factors for Quality of Care for PWE

i. Illness factors

Onset……1. <1year 2. 1-3years 3. >3years

Treatment……1. Yes 2. No

Co-morbidities

-psychological (low esteem, withdrawal),

-social (withdrawal, stigma, discrimination),

-physical (cerebral palsy, HHE, Flaccidity,

-behavioural (attention deficit, hyperactivity) well-being 1. Yes 2. No

iii. Have you experienced stigma 1. Yes……. 2. No …….

iv. Knowledge on causes 1. Low (1-2) ……. 2. Mod (3-4) ……. 3. High (5-6)

Risk factors

a) heads injury b) genetics c) hunger d) birth injuries e) Electrical shock f) Alcohol/drugs

vi. Seizure frequency 1. <1 per week 2. 1-4 per week 3. >4 per week

vii. Seizure frequency before onset of Rx 1. <1 per week 2. 1-4 per week 3. >4 per week.

viii Seizure frequency after onset of Rx…1. <1 per week 2.1-4 per week 3. >4 per week.

xi. Drug regimen 1. CBZ…2. Val/Lamotrigine 3. Others 4. None

Objective 4. Hospital-level factors for quality of healthcare given to people with epilepsy

1. How often have you had a card/book with you during the visits 1-5 1. Never 2. Rarely 3. Few times 4. Most times 5. Always

2. Were you asked to swallow the pills while still in the facility and in the presence of a provider DOTs) 1.YES…… 2.NO…….

3. How often did healthcare worker talk to you about any signs that should warn you of the attacks (Warning signs) 1.YES…… 2.NO……..

4. Were you advised by the provider to come to hospital if you experienced any side effects (Action on Side effects).. 1.YES…… 2.NO…….

5. During this visit (or previous visits) did a provider talk to tell you that you need to come to the clinic regularly for medication and follow-up (Clinic adherence)? 1.Yes 2.NO.

6. For how many months did the provider recommend that you come back for another refill of medicine (Clinic interval)? 1. <=1mo 2. 2-3mo 3. >3mo

7. If woman in child – bearing age, how often do you did healthcare worker talk with you about using contraceptives (FP advise) ? 1.YES…… 2.NO…….

8. How long do you take to be attended to (Waiting time) 1. <30mns 2. 30mn-1hr 3. >1 hr

9. Were you attended to in privacy away from others (Privacy)1. YES……2. NO…….

10. Were the other people able to hear your conversation during consultation (Confidentiality)?

1. YES. 2. NO 3. Don't Know…….

11. What medicines were you given today? (Drugs given) 1. PB 2. PHT 3. CBZ 4. Others

12. Are services available to you whenever you need them? (Service availability) 1.YES…. 2.NO…

13. Was the cost of drugs affordable? (affordability) 1. YES…… 2.NO…….

14. Will you recommend this health facility to a friend or family member? (Recommendation) 1. YES…2.NO

CLIENT SATISFACTION

How would you rate the satisfaction with the services provided to you using the following scale?

1. Very satisfied 2. Somewhat satisfied 3. A bit satisfied 4. Dissatisfied 5. Very dissatisfied

	1	2	3	4	5
How satisfied were you with services given?					
How satisfied are you with physical infrastructure?					
How satisfied are you with the cleanliness?					
How satisfied are you with the process you go through during clinic visits?					

THANK YOU FOR YOUR TIME

Appendix II: Interview Guide (To the C.E.O. of the Facility)

Hello. I am Tiberry Nyakwana, a PhD student from Jomo Kenyatta University of Agriculture and Technology, School of Public Health. I am currently conducting a study on predictors of Quality of Care for People with Epilepsy in Level 5 Hospitals in Nairobi, Machakos and Kiambu Counties. The information obtained is confidential and will only be used for the purposes of this study.

Do I have your permission to proceed with the interview? YES……..NO……

1. Incharge Information

a. i. Doctor i. Medical Officer……. ii. Specialist…….

ii. Clinical officer i. Specialist….. ii. General……

iii. Nurse i. BsN….. ii. Registered…….. iii. Enrolled…….

b. Sex of the Incharge i. Male……..ii. Female……..

2. Information about the interview i. date……ii. time started …..……

- Services available: Outpatient (1), Inpatient(2), Referral(3), Outreach(4)
- Outpatient visits related to epilepsy per month Present (1) Absent(2)
- Referred patients per month
- Reason for referrals
- Basic diagnostic equipment for Seizures/ Epilepsy
- Supplies and reports - .

• Bin cards. 1, 2

• Minutes 1, 2

- Inventory 1, 2

- Drug supply

- First-line drugs for Epilepsy PB,PHT

- Stock outs

- Training,

- Supervision

- Reporting systems

- Staffing

- Basic laboratory services – Bs for mps, RBS

- Outreach activities for health promotion

- Epilepsy-screening outreach 1, 2

- Basic essential knowledge related to Epilepsy

- Feeling “comfortable” managing epilepsy

- Policy framework

1. Staff 2. Finances 3. Information flow 3. Commodity supplies 4. Transport, 5. Communications 6. Patients flow

- Staff Workload /per day 1.[<5] 2.[6-9] 3.[10-15] 4. [>16]

- Training

1.[CME<3m] 2. [CME 4-6m] 3.[CME7-12mo] 4. [CME >12m] 5.[Nil]

 Clinical Standards for epilepsy care 1. Displayed 2. Not Displayed 3. Absent 4. Don’t know

Appendix III: Interview Guide for the Consultant

WHO adopted WHO SF-36v2™ Health Survey form for Process Indicators

(Adopted for Key Informant Guide for the Personnel – Consultant)

1. Identification

i. Facility Number: *MACHAKOS LVH*

ii. Interviewer Code: *010*

iii. Provider SERIAL Number: ***10***

iv. Provider Sex: (1=MALE; 2=FEMALE)

2. Education/Professional Background

2a. What is you highest attained education Diploma [01] HND [02] Degree [03] Masters [04] Fellowship [05] PhD [06]

2b. How long ago was it attained [<1 yr] [1-5] [> 5yrs]

2c. What is your current occupational category or qualification?

i. GENERALIST MEDICAL OFFICER. 01

ii. SPECIALIST MEDICAL DOCTOR 02

iii. GENERAL CLINICAL OFFICER 03

iv. SPECIALIST CLINICAL OFFICER……..04

v. DEGREE NURSE. 05

vi. REGISTERED NURSE……..06

vii. ENROLLED NURSE / ENROLLED MIDWIFE 07

viii. OTHER_____ 96

2c. For how long have you been in this position [<1 yr] [1-5] [> 5yrs]

2d. In which year did you start working in this facility …….

3. In your **current** position, and as a part of your work for this facility, do you personally provide any epilepsy services? YES. .1 NO... 2

3a. How many epilepsy patients do you attend to per week/month?

3b. What diagnostic equipment do you have within your facility?

3c. What do you do for those not properly diagnosed?

3d. Do you provide follow-up services

4. a. Have you received any updates on epilepsy? Training [1] , CME[2] Nil[3]

4b. if yes, how long ago? Within 12 months (1), 12- 24 months ago (2), > 24 months (3)

5. Have you received update on:

a. Health Management Information Systems (HMIS) YES .1 NO.2 DK 3

b. reporting requirements for any service? 1,2, 3

c. rights to non-discrimination practices for people living with epilepsy1,2, 3

Support and collaboration

6. Do you receive technical support from other stakeholders e.g. pharmaceuticals. .YES .1 NO.2

6a. If yes, specify the nature of support

7. Are you also involved in the capacity building for the staff you work with? Yes [1] No[2]

7a. If yes, does the training contain aspects of epilepsy management?

7b. Who are the target audience

7c. Do you evaluate their work thereafter

Personnel/ Work related

8. In your **current** position, do you have a written job description of your current job? YES, OBSERVED (1). YES, REPORTED (2) NOT SEEN (3). NO (4)
9. Which are the major components of written job description 1… Clinical 2…Managerial

10. Apart from clinical work, what other work do you do in this facility

11. Do you receive management support on either/one of the above from your supervisors?

12. How long ago were you last supervised

13.The last time you were supervised, did your supervisor do any of the following: YES….1 NO……2

i. Observe your work? 1 2
ii. Provide any feedback (either positive or negative) on your performance? 1 2
iii. Give you verbal or written feedback that you were doing your work well? 1 2
iv. Provide updates on administrative or technical issues related to your work? 1 2
v. Discuss problems you have encountered? 1 2

14. Are there any opportunities for promotion in your current job?

Yes…… No …… Donk Know…….

15. Which type(s) of salary supplement do you receive, if any? SUPPLEMENT. .(1) . . . . . PERDIEM WHEN ATTENDING TRAINING (2) DUTY ALLOWANCE (3) PROBE: Anything else? PAYMENT FOR EXTRA ACTIVITIES (NOT ROUTINELY PROVIDED).(4) OTHER(specify)____(5)NONE.(6).

16.In your current position, what non-monetary incentives do you receive for the work you do, if any?

i. TIME OFF / VACATIONS . . . . . A
ii. UNIFORMS, BACKPACKS, CAPS, etc.. . . . . B
iii. DISCOUNT MEDICINES, FREE TICKETS FOR CARE, VOUCHERS, etc. .. C
iv. TRAINING. . . . . D
v. FOOD RATION / MEALS. . . . . E
vi. SUBSIDIZED HOUSING . . . . . F
vii. NONE . . . . . Y

17. a. Out of a score of 1-10, how do you rate your capacity to provide quality care for PWE?

b. What are reasons for the score

18. In relation to your working situation, in order of priority, what would you like to see improved to provide good quality of care for people with epilepsy?

i. MORE SUPPORT FROM SUPERVISOR. . . . . A
ii. MORE KNOWLEDGE / UPDATES TRAINING. . . . . B
iii. MORE SUPPLIES/STOCK. C
iv. BETTER QUALITY EQUIPMENT/SUPPLIES. . . . . D
v. MORE STAFF. . . . . E

vi. BETTER WORKING HOURS / FLEXIBLE TIMES. . . . . F

vii. HOLIDAYS. . . . . G

viii. TRANSPORTATION FOR REFERRAL PATIENTS. . . . . H

ix. INCREASED SECURITY. . . . . .I .

x. BETTER FACILITY INFRASTRUCTURE. . . . . J

xi. MORE AUTONOMY / INDEPENDENCE. . . . . M

viii. EMOTIONAL SUPPORT FOR STAFF (COUNSELING / SOCIAL ACTIVITIES). N

ix. OTHER. X

19. Do you have personal experience with epilepsy apart from work environment that you can report Yes No

20. If yes kindly share the experience

THANK YOU FOR YOUR TIME AND HONEST RESPONSES

Appendix IV: Focus Group Discussion Guide

Study Title: Predictors of Quality of Healthcare for People iith Epilepsy attending Level Five Hospitals in Nairobi, Kiambu and Machakos Counties, Kenya

Principal Investigator: Tiberry Nyakwana

Facility name:

Let us have a discussion about some issues have had at this health facility.

1. Date and time the interview begins

2. Do you have any card/book with you today?

3. During this visit (or previous visits) did a provider give you medicine, or give you a prescription for them

4. During this visit has a provider explained to you how to take the medicine?

5. For how many months did the provider recommend that you come back for another consignment of medicine?

6. If woman in child – bearing age, during this visit (or previous visits) did a provider talk with you about using family planning?

7. How long have you waited to see a provider?

8. Were you attended to in privacy away others?

9. During this visit (or previous visits) has a provider discussed with you the side effects of the drugs?

10. Please tell me any side effects of the pill that you know of.

11. Please tell me any signs of complications that you know of.

12. Were you asked to swallow the pills while still in the facility and in the presence of a provider

13. During this visit or previous visits, has a provider talked with you about any signs that should warn you of the attacks or complications of the epileptic seizure?

14. What did the provider advise you to do if you experienced any of the signs of complications?

15. Do you have any medical cover

16. Is this the nearest health facility to your home?

17. During this visit did a provider talk to tell you that you need to come to the clinic regularly for medication and follow-up?

18. What medicines were you able to obtain at this facility?

19. What can you say about cleanliness of the facility

20. How do the staff treated you when you visit

21. What was the main reason you did not go to the facility nearest to your home?

22. In general, give a statement that best describes your opinion of the services you either received or were provided at this facility today

23. Will you recommend this health facility to a friend or family member?

24. Satisfaction Item: In the last 3 months how satisfied were you with how well doctors, clinical officers, nurses, or other health care providers explained things in a way you could understand?

Appendix V: Consent Form for the C. E. O. of the Hosptal

Name of the Hospital ……..

Postal address……...

Details of Research/Investigation

Title of the study: Predictors of quality of healthcare for people with epilepsy attending Level 5 hospitals in Nairobi, Kiambu and Machakos counties, Kenya.

Principal Investigator: Tiberry D.O. Nyakwana

Name of Institution: Jomo Kenyatta University of Agriculture and Technology

Contact of PI: 0722965008

Ethics Committee reference number: JKU/IERC/02316/0039

Name of Sponsor (if any)……

You are hereby authorized to proceed with the research in the hospital

Name…….Signature …….Date……..

Appendix VI: Consent form for PWE

I volunteer to participate in research conducted by Tiberry D.O. Nyakwana

1. My participation is voluntary and I understand that I will not be paid for it. I am aware that I have the right to withdraw and discontinue participating at any time
2. I understand that participation involves being interviewed by researchers and during interview, the required data will be recorded.
3. I have been assured that my identity and information obtained from this interview will not be disclosed and that my confidentiality as a participant in this study will remain secure. Subsequent use of records and data will be subject to standard data use policies which protect the anonymity of individuals and institutions
4. However, the access to the above-mentioned information is strictly open to only the researcher involved
5. I understand that this research study has been reviewed and approved by Institutional Ethics committee and for further enquiries, I am allowed to contact the committee
6. I have read and understood the explanation provided to me. I have had all my questions answered to my satisfaction and I voluntarily agree to participate in this study.
7. I have been given a copy of this consent form

Participant sign and date	Witness sign and date	PI sign and date

For further information, please contact:

Principal Investigator: Tiberry D.O. Nyakwana

Contact: 0722965008

e-mail: Nyakwana.tiberry@jkuat.ac.ke

Part I Information Sheet

The information on this sheet is to help you to decide whether to participate in the study. Please read this form carefully and in case of any questions about the study, please fill free to ask. I will be available to answer them both during the study and thereafter.

Invitation to participants

- What is the purpose of the proposed research?
- Why have I been asked to participate?
- What is the duration of the proposed research?
- What are my responsibilities as a participant?
- Are there any benefits for participating in the proposed research?
- Will I be at a risk during and after the completion of the proposed research?
- Are there any chances of me getting injured during of after the completion of the proposed research?
- Is it in compulsory for all the invitees to accept and participate?
- Will I be penalized for declining , withdrawing from participation?
- If I agree to participate, do I have any alternative or options?
- Who will have the access to my clinical records or data?
- Will I get to know my results or will I be able to have a copy of my data?
- Will I be paid for participating in the proposed research?
- Should I bear the expenses?
- Is there any additional information that I should know?

Research title: Predictors of quality of healthcare for people with epilepsy attending Level 5 hospitals in Nairobi, Kiambu and Machakos counties, Kenya.

Date…….

Part II Certificate Consent

Statement/Declaration by the participant

	YES	NO
I have read or have had been read to me in my native language and I understand the participant information sheet		
I have been given sufficient time to consider whether or not to participate in this research		
I have had the opportunity to use a translator, legal representative, family support or friend to help me ask questions and understand the proposed research		
I am satisfied with the answers that have been given regarding the research and I have a copy of this consent form and information sheet		
I understand that taking part in the study is voluntary (my choice)		
I understand my responsibilities as a participant		
I give consent to the research staff, for collecting and processing of my information including those about my general health		
I am assured that confidentiality of the data will be maintained		
I understand I will be given a copy of my results		
I understand that I will neither have to bear any expenses nor receive any financial gain for participating		
I understand that I may withdraw from the study at any time		
If I decide to withdraw from participating, I agree that the information or data collected about me up to the time of withdrawal may be utilized		
I know who contact if I have any questions		
I hereby give the consent to participate		
Name/Code of the participant …… Signature of participant…….. Date……..		

Adopted from Helsinki Declaration format – the participant information sheet

Statement/Declaration by the parent/guardian

	YES	NO
I have read or have had been read to me in my native language and I understand the participant information sheet		
I have been given sufficient time to consider whether or not to participate in this research		
I have had the opportunity to use a translator, legal representative, family support or friend to help me ask questions and understand the proposed research		
I am satisfied with the answers that have been given regarding the research and I have a copy of this consent form and information sheet		
I understand that taking part in the study is voluntary (my choice)		
I understand my responsibilities as a participant		
I give consent to the research staff, for collecting and processing of my information including those about my general health		
I am assured that confidentiality of the data will be maintained		
I understand I will be given a copy of my results		
I understand that I will neither have to bear any expenses nor receive any financial gain for participating		
I understand that I may withdraw from the study at any time		
If I decide to withdraw from participating, I agree that the information or data collected about me upto the time of withdrawal may be utilized		
I know who contact if I have any questions		
I hereby give the consent to participate		
Name of participant ……		

Signature of participant……. Date……..		

Adopted from Helsinki Declaration format – Parent/Guardian information sheet

Statement/Declaration by the translator

I…… …. declare that:

I am proficient in a participant's native language and I have agreed to be a translator. I have assisted the Principal Investigator in explaining the document having the information about the proposed research in a participant's native language. The participant was encouraged to ask questions and answers to all the queries were addressed patiently. I have assisted in the factual translation of the information provided to me. After the discussion, I am satisfied that the participant has adequately understood about the information provided.

Translator…….

Signature…….

Date……

Statement/Declaration by the Investigator

I, Tiberry D.O. Nyakwana, declare that

I have provided the document having the information about the proposed research and I have explained the same. I have encouraged the participant to ask questions and answered to all the queries of the participant patiently. After the discussion, I am satisfied that the participant has adequately understood about the information provided. I have / have not used a translator in the process.

Principal Investigator: Tiberry D.O. Nyakwana,

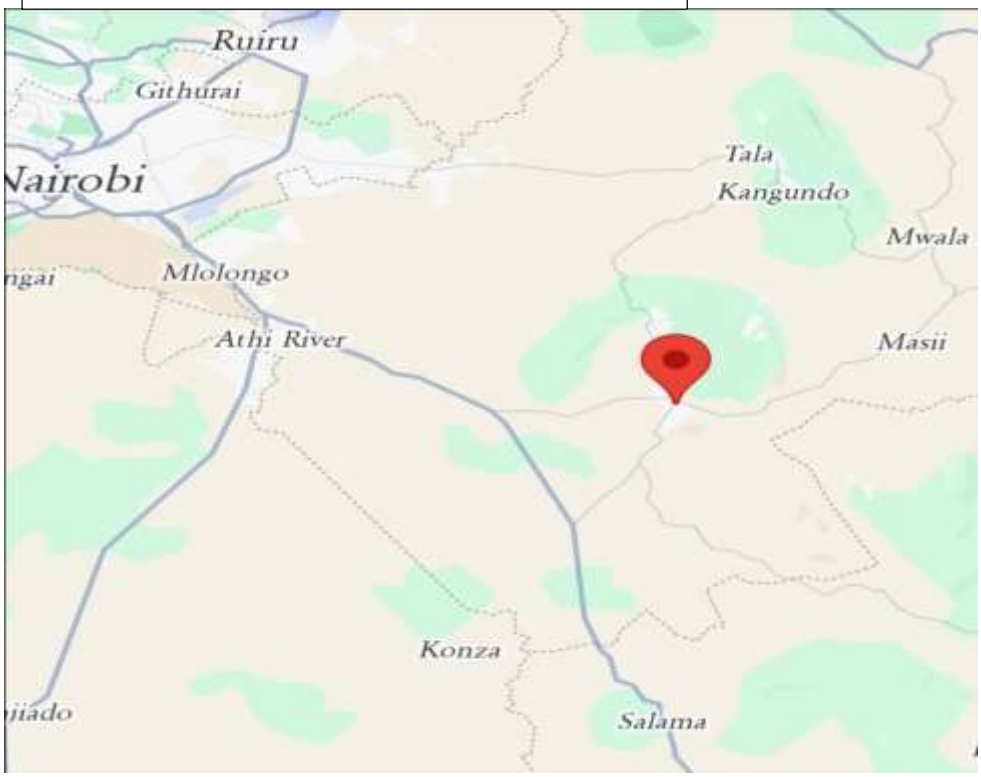
Signature……..…….

Date……

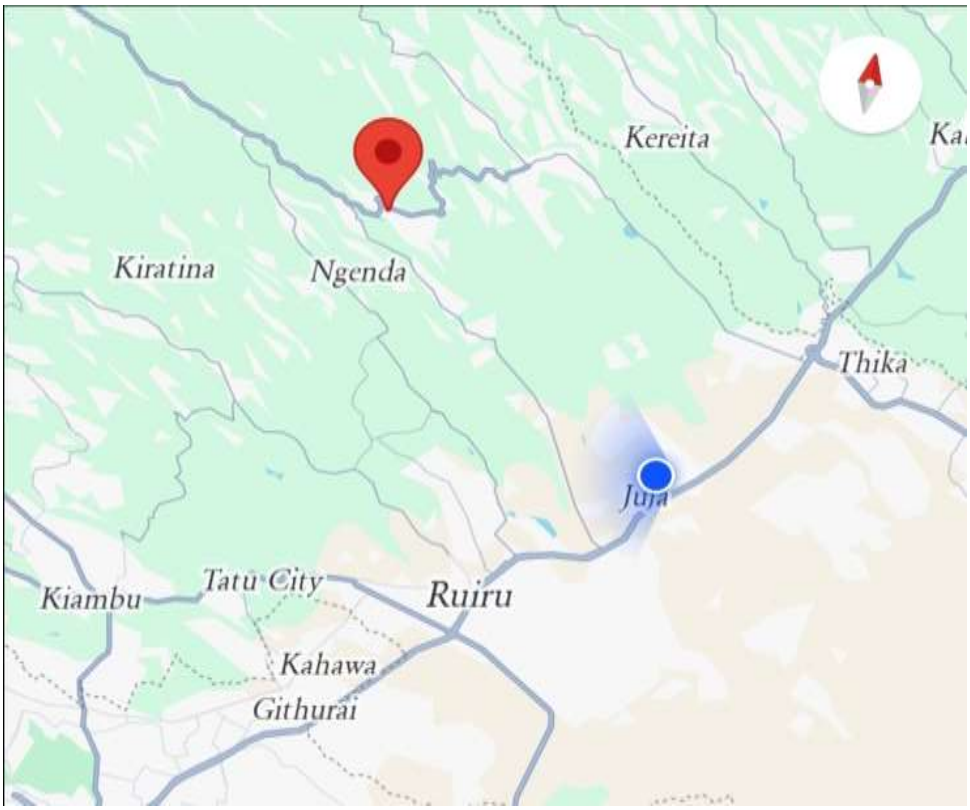
Appendix VII: Maps of Study Sites in three counties respectively

Mama Lucy Kibaki Hospital – Nairobi County

Machakos Level 5 Hospital – Machakos County



Gatundu Level 5 Hospital – Kiambu County



Thika Level 5 Hospital – Kiambu County

Kiambu Level 5 Hospital – Kiambu County

Appendix VIII: Authority Letter from Ethics Review Committee (IERC)

JOMO KENYATTA UNIVERSITY OF AGRICULTURE AND TECHNOLOGY
P.O BOX 62000(00200) NAIROBI, Tel:(067) 58700001-4
(Office of the Deputy Vice Chancellor, Research Production and Extension Division)

JKUAT INSTITUTIONAL ETHICS REVIEW COMMITTEE

REF: JKU/2/4/896B **Date: 10th December 2020**

To: Tiberry Nyakwana
School of Public Health, JKUAT

Dear Mr. Nyakwana,

RE: PREDICTORS OF QUALITY OF HEALTHCARE FOR PEOPLE WITH EPILEPSY ATTENDING LEVEL FIVE HOSPITALS IN NAIROBI, KIAMBU AND MACHAKOS COUNTIES, KENYA

This is to inform you that JKUAT Institutional Ethics Review Committee has reviewed and approved your above research proposal. Your application approval number is **JKU/IERC/02316/0039**. The approval period is **10th December 2020** to **9th December 2021**.

This approval is subject to compliance with the following requirements;

i. Only approved documents including (informed consents, study instruments, MTA) will be used
ii. All changes including (amendments, deviations, and violations) are submitted for review and approval by JKUAT IERC.
iii. Death and life threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to JKUAT IERC within 72 hours of notification
iv. Any changes, anticipated or otherwise that may increase the risks or affected safety or welfare of study participants and others or affect the integrity of the research must be reported to JKUAT IERC within 72 hours
v. Clearance for export of biological specimens must be obtained from relevant institutions.
vi. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. Attach a comprehensive progress report to support the renewal.
vii. Submission of an executive summary report within 90 days upon completion of the study to JKUAT IERC.

Prior to commencing your study, you will be expected to obtain a research license from National Commission for Science, Technology and Innovation (NACOSTI) https://oris.nacosti.go.ke and also obtain other clearances needed.

Yours sincerely

Dr Patrick Mburugu
Chair, JKUAT IERC

INSTITUTIONAL ETHICS REVIEW COMMITTEE
10 DEC 2020
APPROVED
P.O. Box 62000-00200 NAIROBI

JKUAT is ISO 9001:2015 and ISO 14001:2015 certified
Setting Trends in Higher Education, Research, Innovation and Entrepreneurship

Appendix IX: NACOSTI Approval

REPUBLIC OF KENYA

NATIONAL COMMISSION FOR SCIENCE,TECHNOLOGY & INNOVATION

Ref No: **691998**

Date of Issue: **09/February/2021**

RESEARCH LICENSE

This is to Certify that Mr., TIBERRY DICKENS ODHUL NYAKWANA of Jomo Kenyatta University of Agriculture and Technology, has been licensed to conduct research in Kiambu, Machakos, Nairobi on the topic: PREDICTORS FOR QUALITY OF HEALTHCARE PROVIDED TO PEOPLE WITH EPILEPSY AT LEVEL FIVE HOSPITALS IN NAIROBI, KIAMBU AND MACHAKOS COUNTIES, KENYA for the period ending : 09/February/2022.

License No: **NACOSTI/P/21/8768**

691998

Applicant Identification Number

Director General
NATIONAL COMMISSION FOR SCIENCE,TECHNOLOGY & INNOVATION

Verification QR Code

NOTE: This is a computer generated License. To verify the authenticity of this document, Scan the QR Code using QR scanner application.

Appendix X: Approval Letter from Medical Superintendent – Thika Level 5 Hospital, Kiambu County

COUNTY GOVERNMENT OF KIAMBU
DEPARTMENT OF HEALTH SERVICES

P.O BOX 227-01000 THIKA, KIAMBU
TEL:+254722106797 EMAIL: thikahospital@yahoo.com
REF: MOH/TKA/GEN/VOL. V(213) DATE: 4th April, 2021

APPROVAL TO CARRY OUT RESEARCH

Principle Investigator: Tiberry Nyakwana

RE: PREDICTORS OF QUALITY HEALTHCARE WORKER FOR PEOPLE WITH EPILEPSY ATTENDING THIKA LEVEL 5 HOSPTIAL

Following deliberations by Thika Level 5 Hospital Research Committee, your proposal to carry out the above research at this facility has been approved. However, you will need to provide us with license from NACOSTI or Ethical Clearance from KEMRI before you can commence the data collection.

Take note that you are required to submit a copy of your research findings upon completion of the study to the hospital. It is also expected that ethical consideration and the research subjects' confidentiality will be maintained as you have outlined in your proposal.

Any patient confidential information that you may access during your research should not be used without consent. This letter is valid up to September, 2021.

For any queries fell free to contact the committee chair through the Medical Superintendent's office or training, research and ethics committee office. Thank you and all the best.

ESTON MBUTHIA
FOR: MEDICAL SUPERINTENDENT
THIKA LEVEL 5 HOSPITAL

Appendix XI: Authority Letter from Hospital Superintendent – Kiambu county Referral Hospital

COUNTY GOVERNMENT OF KIAMBU

DEPARTMENT OF HEALTH SERVICES

Telephone: (066) 2022191
Email address:
kiambudistricthospital@yahoo.com

When replying please quote:

KIAMBU COUNTY REFERRAL LEVEL 5 HOSPITAL
P. O. BOX 39 – 00900,
KIAMBU

Ref No: KBU/STAFF.17A/VOL IV/57 **Date: 9th April 2021**

Tiberry D.O Nyakwana
P O Box 62000-00200
NAIROBI

RE: REQUEST TO CONDUCT RESEARCH AT KIAMBU LEVEL 5 HOSPITAL

Your letter dated 30th March 2021 refers.

Kiambu Hospital has no objection to you carrying out the research.

DR CYRUS MUMBURA
MEDICAL SUPERINTENDENT
KIAMBU COUNTY REFERRAL HOSPITAL

MEDICAL SUPERINTENDENT
KIAMBU SUB COUNTY LEVEL 4
HOSPITAL
P.o. Box 39-00900
KIAMBU
TEL: 0662022191

Appendix XII: Letter of Clearance from County Clinical Research Officer – Kiambu County

COUNTY GOVERNMENT OF KIAMBU
DEPARTMENT OF HEALTH SERVICES

All correspondence should be addressed to HEAD
HRDU – HEALTH DEPARTMENT
Email address: [redacted]
Tel. Nos: 0721641516
0721974833

HEALTH RESEARCH AND DEVELOPMENT
UNIT
P. O. BOX 2344 – 00900
KIAMBU

Ref. No.: KIAMBU/HRDU/21/03/29/RA_NYAKWANA Date: 29th Mar 2021

TO WHOM IT MAY CONCERN

RE: CLEARANCE TO CONDUCT RESEARCH IN KIAMBU COUNTY

Kindly note that we have received a request by Mr. Tiberry Dickens Odhui Nyakwana of Jomo Kenyatta University of Agriculture and Technology to carry out research in Kiambu County, the research topic being on **"Predictors For Quality Of Healthcare Provided To People With Epilepsy At Level 5 Hospitals In Nairobi, Kiambu And Machakos Counties, Kenya"**

We have duly inspected his documents and found that he has been cleared by NACOSTI to carry out the research for a period ending **09th February 2022.** He thus does not need any further clearance with another regulatory body in order to conduct research within the county of Kiambu.

However, it is incumbent upon the institution where he is carrying out research to ensure that he receives adequate supervision during the process of conducting the research. This note also accords him the duty to provide a feedback on his research to the county at the conclusion of his research.

DR. MWANCHA KWASA
COUNTY CLINICAL RESEARCH OFFICER
KIAMBU COUNTY

Appendix XIII: Permission Letter from Hospital Superintendent –Mama Lucy Kibaki Hospital

THE PRESIDENCY
EXECUTIVE OFFICE OF THE PRESIDENT
NAIROBI METROPOLITAN SERVICES

Telephone:
020 - 2297000
E-mail: medsupnedh@yahoo.com
When replying please quote

MAMA LUCY KIBAKI HOSPITAL-EMBAKASI
P.O. Box 1278-00515
NAIROBI

Ref: No.- MLKH/ADM/RES/1

Date: 5th May, 2021

Mr. Tiberry D.O. Nyakwana,
Jomo Kenyatta University of Science & Technology
Departmental of Environmental Health & Disease Control
NAIROBI

RE: PERMISSION TO COLLECT DATA

TITLE: "PREDICTORS OF QUALITY OF HEALTHCARE FOR PEOPLE WITH EPILEPSY ATTENDING LEVEL FIVE HOSPITALS IN NAIROBI, KIAMBU, MACHAKOS COUNTIES, KENYA"

Refer to your application to collect data on the above research in this institution.

This is to inform you that hospital has given you permission to allow you collect data subject to the following.

1. You are expected to adhere to the rules and regulations pertaining to the data collection.

2. You are expected to submit a copy of the final findings collected after completion to the research committee.

05 MAY 2021

DR. EMMA MUTIO
MEDICAL SUPERINTENDENT.

Appendix XIV: Authority Letter from Hospital Superintendent – Machakos County Referral Hospital

REPUBLIC OF KENYA

GOVERNMENT OF MACHAKOS COUNTY
DEPARTMENT OF HEALTH AND EMERGENCY SERVICES
Office of the County Director of Medical Services

Machakos Highway
P.O. Box 2574-90100
Machakos, Kenya
REF: MKS/DHES/RSCH/VOL 1/26

Telephone: +254 -44-20575
Fax: 254-44-20655
15th April 2021

Principal Investigator - ATTN: Tiberry Nyakwana

Dear Nyakwana,

RE: LETTER OF AUTHORIZATION FOR CONDUCTING PROPOSED RESEARCH

Reference is made to your request to conduct a study titled "Predictors of quality of care for people with Epilepsy in Level 5 hospitals in Nairobi, Machakos and Kiambu Counties."

Thank you for selecting Machakos Level 5 Hospital as your study site. Kindly adhere to research ethics during your study.

You are hereby authorized to proceed with the research and urged to share the findings with the Department of Health and Emergency Services; Machakos County, through this office. We can organize an opportunity for you to disseminate your findings to the relevant department to inform them on the state of the services provided for Epilepsy patients.

Sincerely,

DIRECTOR
15 APR 2021

Dr. Clarice Ambale

Research Co-ordinator

Machakos Level 5 Hospital

Cc -Medical Superintendent – Machakos Level 5 Hospital

Appendix XV: Authority Letter from Director Health Services Nairobi County

NAIROBI METROPOLITAN SERVICES

REPUBLIC OF KENYA

Directorate of Health Services

REF: EOP/NMS/HS/130 DATE: 30TH MARCH 2021

TIBERRY D.O. NYAKWANA
JOMO KENYATTA UNIVERSITY OF AGRICULTURE & TECHNOLOGY
NAIROBI

Dear Sir,

RE: RESEARCH AUTHORIZATION

This is to inform you that the Nairobi Metropolitan Services - Health Directorate's Research Technical Working Group (RTWG) reviewed the documents on the study titled "Predictors of Quality of HealthCare for People with Epilepsy attending Level 5 Hospitals in Nairobi, Kiambu and Machakos Counties, Kenya".

I am pleased to inform you that you have been authorized to undertake the study at Mama Lucy Kibaki Hospital. The researcher will be required to adhere to the ethical code of conduct for health research in accordance to the Science Technology and Innovation Act, 2013 and the approval procedure and protocol for research for Nairobi.

On completion of the study, you will submit one hard copy and one copy in PDF of the research findings to the RTWG. By copy of this letter, the Medical Superintendent - Mama Lucy Kibaki Hospital is to accord you the necessary assistance to carry out this research study.

Yours sincerely,

DR. OUMA OLUGA
FOR: DIRECTOR HEALTH SERVICES

Cc: Medical Superintendent - Mama Lucy Kibaki Hospital,

Authority Letter from Hospital Superintendent

Authority Letter for data collection from Mama

Authority Letter from Director Health Services Nairobi county

Authority Letter from Medical Superintendent – Machakos County