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Understanding and Improving Epilepsy Care in Primary Healthcare: A Mixed-Methods Study in the West Bank, Palestine

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Dedication

To the soul of my beloved father, whose memory guides me and whose love lives on in my heart...

To my dearest mother, for her prayers, unconditional love, and the strength she gave me….

To my beloved husband, for his patience, faith, and unwavering partnership...

To my children—Rama, Ahmad, Ali, and Talya—my greatest joy and inspiration….

To my brother and sisters, for our unbreakable bond and lifelong support...

To my cherished in-laws, for their kindness and encouragement….

To my dear friend Seema, for her belief in me when I needed it most.

And to all people living with epilepsy, whose courage, resilience, and hope inspire me every day and give this work its true meaning.

With deepest love, this work is dedicated to you all.

Abeer Ali Ghanayem

Declaration

I Certify that this dissertation submitted for the degree of Doctor of Philosophy in Public Health, is the result of my own research, except where otherwise acknowledged, and that this Dissertation (or any part of the same material) has not been submitted for a higher degree to any other university or institution.

Signature: 

Abeer Ali Mohammad Ghanayem

Date: 1/5/2025

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Abstract

Introduction: Epilepsy is a chronic neurological condition affecting over 70 million people worldwide, with the majority residing in low- and middle-income countries. In Palestine, epilepsy care is challenged by fragmented healthcare delivery, limited access to specialized services, inadequate provider training, and pervasive social stigma. Although primary healthcare centers are the main access point for people with epilepsy, care at this level remains underdeveloped, with no standardized treatment protocols or structured self-management support. Addressing these gaps requires a comprehensive understanding of the lived experiences of people with epilepsy, the readiness of the healthcare workforce, and the effectiveness of contextually tailored interventions.

Aim: This study aimed to explore and improve epilepsy management in primary healthcare settings in the West Bank, Palestine, by examining patients' experiences, assessing healthcare providers' knowledge, attitudes, and practices, and evaluating the impact of an educational intervention based on the World Health Organization Mental Health Gap Action Program.

Methods: A sequential exploratory mixed-methods design was employed across three interrelated studies. Study I used Husserlian phenomenology to conduct in-depth interviews with 12 people with epilepsy recruited from governmental primary healthcare centers. Thematic analysis was used to identify essential themes of their lived experience. Study II utilized a cross-sectional survey to assess the knowledge, attitudes, and practices of 300 healthcare professionals working in primary healthcare facilities across the West Bank. Study III implemented a quasi-experimental intervention using mental health-based training, with 68 healthcare providers randomized into intervention and control groups. Pre- and post-training assessments were conducted to evaluate changes in knowledge, attitudes, and self-efficacy after two months.

Results: Study I identified three major themes: emotional and existential disruption, social vulnerability and stigma, and unsatisfactory healthcare experiences. Participants reported living with fear, social exclusion, denial of diagnosis, and a lack of trust in the healthcare system. Stigma was a pervasive theme shaping concealment, low self-esteem, and reduced access to care.

Study II revealed substantial gaps in healthcare providers' knowledge and practices regarding epilepsy care. Pearson's correlation revealed a significant negative relationship between practices and knowledge ($r = -0.170$, $p < 0.01$) and a positive association with attitudes ($r = 0.279$, $p < 0.01$). Nurses and less experienced staff scored significantly lower in all KAP dimensions $p< 0.05$. While attitudes were moderately positive, providers showed poor familiarity with epilepsy self-management, seizure triggers, and psychosocial aspects of care. Multivariate analysis showed that knowledge was negatively correlated with gender and specialty but positively with educational degree (OR = 0.640, 95 % CI: 1.260–0.020, $p = 0.043$; OR = 1.970, 95 % CI: 2.841–0.099, $p < 0.001$). Knowledge scores were lower among certain genders and specialties but increased with higher educational attainment ($p < 0.05$). Attitudes were positively associated with age (OR = 2.552, 95 % CI: 0.974–4.130, $p = 0.002$) and years of experience (OR = 2.387, 95 % CI: 0.546–4.227, $p = 0.011$).

Study III demonstrated that the training significantly improved knowledge ($p < 0.001$) and self-efficacy ($p < 0.001$) in the intervention group. However, attitudinal change was modest

and not statistically significant, suggesting that longer-term or targeted interventions may be required to influence stigma and empathy.

Conclusion: Epilepsy care in Palestinian primary healthcare settings is hindered by systemic fragmentation, insufficient provider training, and sociocultural barriers that limit access to quality care. People with epilepsy experience profound emotional and social burdens, while healthcare providers lack adequate preparation to deliver patient-centered epilepsy management. However, brief, context-sensitive training interventions like World Health Organization Mental Health Gap Action Program can effectively enhance provider knowledge and confidence in the short term.

Keywords: Epilepsy, Primary Healthcare, Palestine, Phenomenology, mhGAP, Mixed Methods, Self-Management, Health Workforce, Stigma, Health Systems Strengthening.

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List of Abbreviations

AEDs	Anti-epileptic Drugs
ANCOVA	Analysis of Covariance
COREQ	Consolidated Criteria for Reporting Qualitative Research
EEG	Electroencephalography
GBD	Global Burden of Disease
HBM	Health Belief Model
ICC	Intra-Class Correlation Coefficient
ILAE	International League Against Epilepsy
IQR	Inter-quartile Range
KAP	Knowledge, Attitudes and Practices
LMICs	Low- and Middle-Income Countries
mhGAP	WHO Mental Health Gap Action Programme
MOH	Palestinian Ministry of Health
MRI	Magnetic Resonance Imaging
OR	Odds Ratio
PHC	Primary Health Care
PWE	People with Epilepsy
R	Pearson's correlation
SD	Standard Deviation
SDG	Sustainable Development Goals
SPSS	IBM Statistical Product and Service Solutions
UNICEF	United Nations Children's Fund
WHO	World Health Organization

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Chapter One

Introduction

1.1 Background

Epilepsy is a prevalent and chronic neurological disorder that is classified as one of the most burdensome non-communicable diseases globally, particularly in low- and middle-income countries (LMICs). Worldwide, the total number of individuals diagnosed with epilepsy, covering all age groups, is approximately 70 million (Trinka et al., 2023; World Health Organization-WHO, 2024a). The incidence of epilepsy in high-income nations is approximately 49 cases per 100,000 people annually, with a higher rate of over 139 cases per 100,000 populations in low-income countries (WHO, 2022, 2024a). Epilepsy has been recognized as a prevalent neurological disorder in Palestine. The incidence rate of epilepsy in the West Bank was reported to be 5.4 per 100,000 citizens in 2023 (Ministry of Health-MOH, 2023).

Epilepsy is defined by the occurrence of repeated seizures, which may be accompanied by periods of unconsciousness, involuntary muscle spasms and loss of control over bowel or bladder function (Beghi, 2020; Riney et al., 2022). People with epilepsy (PWE) face a significantly elevated risk of premature mortality, up to three times higher than that of the general population (Global Burden of Disease-GBD, 2025). This disparity is particularly pronounced in LMICs where healthcare resources and specialized epilepsy care are often limited (WHO, 2024a). In addition to its clinical impact, epilepsy exerts significant mental, economic, and emotional consequences on patients and their families. Stigma, fear, and discrimination continue to be major challenges that negatively influence the quality of life, healthcare-seeking habits, and social integration of PWE (Shi et al., 2017).

Antiepileptic drugs (AEDs) are the first-line therapy for epileptic seizures (Abou-Khalil, 2019; Johannessen Landmark et al., 2020). According to the World Health Organization (WHO), proper diagnosis and adherence to AEDs would provide seizure free living conditions for about 70% of PWE (WHO, 2022). However, some cases of epilepsy remain

resistant to AEDs leading to poor seizure control and contributing to low drug adherence, adverse drug effects, and interactions with other drugs (Jafarpour et al., 2019; Shawahna et al., 2020; Shawahna & Abdelhaq, 2020b). Consequently, these factors significantly impact patients' physical, economic, and psychosocial well-being (Tanywe et al., 2016). The practice of self-management has a vital role in promoting the overall well-being of PWE, as it empowers them to uphold an ideal state of physical, cognitive, and emotional health (Lee et al., 2020; WHO, 2022). A well-structured self-management program helps improve medication adherence, symptom monitoring, lifestyle adjustments, and overall disease control. However, several barriers limit effective self-management, including insufficient communication between patients and healthcare providers, misinformation about epilepsy, and low confidence in the efficacy of AEDs (Chew et al., 2019; Ernawati & Rahmatul Islamiyah, 2018).

Healthcare professionals play a critical role in supporting epilepsy self-management by providing education, guidance, and continuous monitoring. However, gaps in epilepsy management training among healthcare providers remain a significant barrier to optimal care (Chew et al., 2020; Shawahna et al., 2020; Shawahna & Abdelhaq, 2020a). Improving provider-patient communication, patient education, and structured self-management programs are vital for optimal epilepsy care. Healthcare providers often lack formal training in epilepsy management programs and the therapeutic monitoring of AEDs (Chew et al., 2020; Shawahna et al., 2020). Studies highlight that many healthcare practitioners lack formal training in epilepsy self-management programs and therapeutic drug monitoring of AEDs (Assadeck et al., 2020; Singh et al., 2020; Zheng et al., 2019). Moreover, inadequate provider-patient communication often results in misconceptions about epilepsy, poor treatment adherence, and suboptimal patient outcomes (Buddhiraja et al., 2020; Rapport et al., 2015). In Palestine, the lack of standardized epilepsy management guidelines further complicates effective treatment delivery. Understanding patients' perspectives is essential in identifying key factors influencing epilepsy care, while evaluating current healthcare practices can help identify barriers and areas for improvement.

This study is aimed at addressing significant gaps by exploring the lived experiences of PWE, analyzing healthcare provider-patient interactions, assessing healthcare practitioners' knowledge, attitudes, and practices (KAP), and evaluating the effects of an educational intervention utilizing the WHO Mental Health Gap Action Program (mhGAP) training. The findings will provide empirical evidence for supporting the development of structured training programs, patient-centered interventions, and policy recommendations aimed at enhancing epilepsy management in Palestine. In addition to its clinical impact, epilepsy imposes considerable mental, economic, and emotional consequences on patients and their families. Stigma, fear, and discrimination continue to be major challenges that adversely impact on the quality of life, healthcare-seeking behaviors, and social integration of PWE.

1.2 Problem Statement

Epilepsy is a major global public health challenge, affecting approximately 70 million people worldwide and disproportionately impacting LMICs where access to specialized care remains limited (WHO, 2024a). Effective epilepsy management relies not only on proper diagnosis and pharmacological treatment but also on self-management support, patient education, and well-trained healthcare providers (Johannessen Landmark et al., 2020; Niriayo et al., 2018; Trinka et al., 2023). Epilepsy management empowers PWE to control

their condition through focusing on medication adherence, good communication with health professionals, recognizing and avoiding triggers of seizures, and adopting healthy lifestyles (Lee et al., 2020; WHO, 2022). Effective management of epilepsy includes comprehensive care, patient-oriented self-management techniques, and skillful healthcare professionals.

In Palestine, specialized epilepsy care is mainly provided in government hospitals and the private sector, where patients may consult neurologists and access advanced diagnostic services, including electroencephalography (EEG) and MRI. Nevertheless, the follow up and management of chronic diseases such as epilepsy, usually takes place in primary healthcare (PHC) clinics, which lack specialized expertise in epilepsy therapy (Shawahna et al., 2020; Shawahna & Abdelhaq, 2020b). Consequently, PWE lack comprehensive care. Also, the delivery of epilepsy services is fragmented, without formal therapy and management standards within PHC facilities. This has resulted in inconsistent care, gaps in delivering services, and a lack of standard treatment and follow-up protocols for PWE (Jasser & Ahmad, 2023; Morrar et al., 2021).

Poor adherence to AEDs and inadequate medical treatment lead to PWE's experience with societal stigma, limited self-management support, and difficulty connecting with healthcare professionals. Healthcare professionals often lack formal experience in patient education, therapeutic medication monitoring, and self-management strategies (Awan et al., 2022; Getnet et al., 2016).

Prior studies have predominantly focused on examining the impact of various factors associated with epilepsy on the quality of life experienced by people living with epilepsy (PWE). Such as the burden of disease, mental disorders, injury, stigmatization, loss of employment, lifestyle, and discrimination among various age groups. There is a lack of research, whether quantitative or qualitative, on these factors and epilepsy in Palestine (Shawahna et al., 2017; Shawahna & Abdelhaq, 2020b).

This study addresses two key gaps: first, the lack of evidence on the knowledge, attitudes, and practices of PHC providers in epilepsy care; and second, the absence of local studies exploring the effectiveness of training interventions such as the mhGAP in improving epilepsy management. The study explores the lived experiences of individuals with epilepsy in Palestine and examines how they navigate and manage their condition within the existing healthcare system. It also assesses the current level of KAP among PHC providers concerning epilepsy care. Furthermore, the study evaluates the impact of a structured educational intervention on improving healthcare providers' knowledge, attitudes, and self-efficacy in delivering effective epilepsy services.

1.3 Justification/ Rationale

Epileptic seizures are the most-occurring, unpredictable complication of epilepsy. Epileptic seizures are accompanied by increased consequences on the physical, psychological, social, mental and economic living conditions. Increased risk of injury, mortality, depression, discrimination, stigma affects all PWE and extends to affect their families (Shi et al., 2017). The role of health professionals is substantial for achieving effective epilepsy management. Many barriers are recognized to reduce epilepsy management such as poor communication with the healthcare team and low confidence in therapeutic action of AEDs. Investigating individualized dosing effectiveness, adverse effects reduction, patient compliance might

improve the quality of life of PWE (Morrell et al., 2000; Shawahna, 2019; Shawahna et al., 2017; Terman et al., 2020). In Palestine, epilepsy care is particularly underdeveloped, with no standardized management guidelines in PHC settings, limited epilepsy training for healthcare practitioners, and a lack of structured self-management programs for patients. These gaps in epilepsy care contribute to poor treatment adherence, stigma, and inadequate patient-provider communication, ultimately worsening health outcomes for individuals with epilepsy.

Despite these challenges, research on epilepsy management in Palestine remains scarce. There is limited understanding of the lived experiences of PWE, particularly regarding social stigma, self-management barriers, and their interactions with healthcare providers. Previous research on epilepsy has mainly focused on the impact of several factors that are associated with epilepsy on the quality of life of PWE. Such as, burden of disease, mental disorders, injury, stigmatization, loss of employment, lifestyle and discrimination among various age groups, children, adolescents and pregnancy (Jaber et al., 2021; Shawahna et al., 2020; Shawahna & Zaid, 2022).

By addressing the above-mentioned research gaps, this study will generate empirical evidence to support the development of structured training programs, the establishment of national epilepsy management guidelines, and the implementation of patient-centered self-management interventions. Ultimately, the findings will inform policy and practice improvements aimed at enhancing epilepsy care, reducing stigma, and improving health outcomes in Palestine.

While there is no specific Sustainable Development Goal (SDG) solely dedicated to epilepsy, several SDGs address key areas that significantly impact the lives of people living with epilepsy. The SDGs, adopted by all United Nations member states to promote sustainable development by 2030, emphasize health, education, inequality reduction, and inclusive societies. In particular, SDG 3.4 focuses on reducing premature mortality from non-communicable diseases through prevention and treatment, directly supporting better healthcare for epilepsy. SDG 10.2 promotes the inclusion of marginalized groups, including individuals with disabilities and chronic health conditions, while SDG 16.7 advocates for inclusive decision-making processes, ensuring that PWE can participate in shaping health and social policies. Furthermore, SDG 17.7 highlights the importance of global partnerships in advancing research and improving access to care. Although epilepsy is not explicitly mentioned within a single SDG, these interconnected goals collectively contribute to creating a more supportive, equitable and health-promoting environment for individuals with epilepsy, aligning with the broader aims of Universal Health Coverage and sustainable health system strengthening.

The findings of this study are expected to have significant impact across multiple levels of the healthcare system. Primarily, PWE will benefit from improved understanding of their lived experiences, barriers to self-management, and interactions with healthcare providers. This will inform the development of tailored, patient-centered interventions aimed at enhancing adherence, reducing stigma, and improving overall quality of life. Healthcare providers will also gain from evidence-based recommendations that can guide the establishment of national training programs and standardized clinical guidelines for epilepsy management, particularly in primary care settings where specialized care for epilepsy remain limited. Policy makers will be equipped with empirical data to support health system reforms, resource allocation, and the integration of epilepsy into broader non-communicable disease strategies, thus contributing to the goals of Universal Health Coverage and the SDGs,

particularly those related to health equity and inclusion. Moreover, researchers will benefit from the study's contribution to the limited body of literature on epilepsy care in Palestine, offering a foundation for future studies and fostering regional and global academic collaborations focused on neurological health in low-resource settings. Collectively, the study will support improvements in clinical practice, public health policy, and patient empowerment, promoting a more responsive, equitable, and effective epilepsy care system.

1.4 Research Goal

The main goal is to evaluate and improve epilepsy management among healthcare practitioners in PHC settings in the West Bank, Palestine enhance the quality of care, promote patient-centered practices, reduce stigma, and ultimately improve health outcomes for people living with epilepsy.

1.4.1 Study Objectives:

- To explore the lived experiences of PWE, focusing on their personal, social, and healthcare-related challenges and coping mechanisms.
- To investigate the interactions between PWE and their healthcare providers regarding epilepsy treatment and management
- To assess the knowledge, attitudes and practices (KAP) of health professionals who are routinely in contact with PWE in PHC setting.
- To evaluate the impact of an educational intervention (WHO mhGAP training) on healthcare practitioners' knowledge, attitudes, and self-efficacy.

1.5 Research Question

To what extent can a structured educational intervention improve healthcare practitioners' competencies toward epilepsy management in PHC settings in the West Bank, and how do PWE perceive their care and self-management challenges?

1.5.1 Detailed Questions:

1. How do PWE experience care within the Palestinian PHC system?
2. What are the current knowledge levels, attitudes, and practices of healthcare providers regarding epilepsy management?
3. Can a targeted educational intervention improve providers' capacity to deliver quality epilepsy care?

1.6 Context

The Palestinian territories, particularly the West Bank, operate under complex and challenging conditions shaped by prolonged occupation, political instability, economic constraints, and fragmented governance. The population experiences high unemployment, widespread poverty, and limited social protection, contributing to strained living conditions and limited access to essential services (Giacaman et al., 2009; Vitullo et al., 2012).

The healthcare system in Palestine is pluralistic, provided by multiple sectors: the governmental sector (MOH and Military Medical Services), nongovernmental organizations (NGOs), the United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA), and private sector actors (both profit and nonprofit) (El Sharif & Imam, 2019; Imam et al., 2020; Jasser & Ahmad, 2023). These providers deliver primary (mainly), secondary, and tertiary healthcare services across urban and rural areas.

Despite progress in basic health indicators, the healthcare system remains underdeveloped and fragile. It depends heavily on international aid, making it vulnerable to political fluctuations and funding reductions. Import restrictions lead to recurring shortages of medications, medical supplies, and diagnostic equipment (WHO, 2024b). Furthermore, Israeli-imposed mobility restrictions, including checkpoints, the separation wall, and permit systems, impede patient access to timely care, especially for those in remote areas (Barhoush & Amon, 2023).

The quality of care is further compromised by a shortage of trained specialists, including neurologists, oncologists, and mental health professionals, which particularly affects the management of chronic and complex diseases. Geographic fragmentation of the West Bank deepens health disparities, particularly in marginalized communities. Financial barriers also persist, with high out-of-pocket payments, limited insurance coverage, and constrained employment opportunities reducing the population's ability to afford consistent healthcare (Jasser & Ahmad, 2023; MOH, 2023).

There are several challenges associated with epilepsy care in Palestine. Epilepsy is a chronic neurological condition that requires long-term and multidisciplinary management, yet the current system offers limited, inconsistent, and often stigmatized care for PWE (Shawahna & Abdelhaq, 2020).

Specialized services for epilepsy, such as EEG testing and neuroimaging, are mainly available in larger government hospitals, private clinics, or designated referral centers. However, long-term management, including follow-up and AED refills, is typically handled by governmental PHC clinics. These clinics are categorized into four levels, with level 4 centers offering periodic visits by neurologists for neurological and mental health conditions. Despite this stratification, the absence of a unified national protocol or treatment pathway has resulted in fragmented care and inconsistent service delivery (MOH, 2023; Shawahna, 2019).

The situation is exacerbated by several systemic deficiencies: limited availability of AEDs, inadequate therapeutic drug monitoring tools, and a shortage of trained epilepsy care providers. This results in suboptimal treatment outcomes and increases psychosocial burdens on individuals with epilepsy. Additionally, epilepsy remains highly stigmatized in Palestinian society, leading many adults to avoid healthcare facilities for fear of social recognition and discrimination. This often drives PWE into isolation, preventing them from receiving proper care and support (Shawahna, 2020, 2024; Shawahna et al., 2020).

The interaction between healthcare professionals and PWE plays a critical role in shaping treatment outcomes. A lack of provider training, awareness, and communication skills can negatively affect patient trust, adherence, and health-seeking behavior. Addressing these issues requires a systemic shift toward integrated, patient-centered care models. Efforts must be directed toward training healthcare workers, developing national care protocols, strengthening referral systems, and expanding access to essential diagnostics and medicines.

In conclusion, while epilepsy care in Palestine exists within the framework of a broader healthcare system, it is disproportionately impacted by its systemic shortcomings. Comprehensive reform, investment in the healthcare workforce, and the implementation of coordinated, stigma-free services are essential to ensure equitable and effective management of epilepsy across the West Bank.

1.7 Dissertation Structure

This dissertation is organized into six chapters, each serving a distinct purpose to guide the reader through the research process and findings:

- **Chapter 1: Introduction**

  This chapter outlines the background and context of the study, presents the problem statement, and provides justification for the research. It also clearly states the aim, objectives, and main research question that guide the study.

- **Chapter 2: Literature Review**

  This chapter presents a critical review of existing literature on epilepsy management, including international, regional, and Palestinian studies. It identifies knowledge gaps and informs the study design and intervention.

- **Chapter 3: Conceptual Framework**

  This chapter introduces and explains the conceptual framework guiding the study. It integrates relevant models (e.g., the WHO Operational Framework for Primary Health Care) and theoretical underpinnings that shape the research design and interpretation of findings.

- **Chapter 4: Methods**

  This chapter describes the study design and methodology, including the study setting, population, sampling methods, sample size, and data collection tools. It also details the intervention (e.g., mhGAP training), data analysis procedures, and ethical considerations.

- **Chapter 5: Result**

  This chapter presents the results of each component of the study (cross-sectional, interventional, and qualitative), organized according to the research objectives.

- **Chapter 6: Discussion, Conclusions, and Recommendations**

  This final chapter interprets the findings in relation to the research question and existing literature. It discusses the implications for policy and practice, highlights study limitations, and provides recommendations for future research and health system improvements.

Chapter Two

Literature review

2.1 Burden of Epilepsy

Epilepsy is defined by the occurrence of repeated seizures, which may be accompanied by periods of unconsciousness and loss of control over bowel or bladder function (Bankole et al., 2024; Beghi, 2020). The international league against epilepsy (ILAE) defined the epileptic seizure: "a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain." (Falco-Walter, 2020; Riney et al., 2022) An epilepsy condition is characterized by the person with an active, recurrent state of epileptic seizures, defined as at least two unprovoked seizures, and who has experienced at least one epileptic seizure within the five years before the present, despite receiving AED treatment (Falco-Walter et al., 2018; GBD, 2025; Riney et al., 2022). Epileptic seizures have a high negative impact on the physical, psychological, social, mental and economic living conditions of the patients. Increased risk of injury, mortality, depression, discrimination, stigma affects all PWE and extends to affect their families (Ernawati & Rahmatul Islamiyah, 2018).

Epilepsy can be, broadly, classified into two types based on etiology: idiopathic and secondary. Primarily assumed to have a genetic basis, idiopathic epilepsy is the condition in which no apparent structural or metabolic etiology has been determined. Usually presenting in childhood or adolescent, it is linked with normal neurological growth and imaging results. Secondary epilepsy, known as symptomatic epilepsy, results from clearly identified causes such as brain injuries, stroke, central nervous system infections, brain tumors, or congenital defects (Beghi, 2020; Falco-Walter, 2020; Scheffer et al., 2017). Although it may occur to anyone at any age, secondary epilepsy is more common in middle- and low-income countries where head trauma, neuro-infections, and prenatal casualties are more common preventable risk factors (GBD, 2025; Riney et al., 2022; WHO, 2023b).

Epilepsy is a prevalent and chronic neurological disorder that is classified as one of the most burdensome, non-communicable diseases (NCDs) globally, particularly in LMICs. Worldwide, the total number of people diagnosed with epilepsy, covering all age groups, is over 50 million (WHO, 2024a). The WHO and the 75th World Health Assembly declared epilepsy as one of the top priorities in NCD prevention and control in 2022. This resulted in

adoption of a tailored Intersectoral Global Action Plan on Epilepsy and other neurological disorders for 2022–31 (GBD, 2025; WHO, 2023b).

A global study performed in 2021 estimated that 51.7 million PWE (95% UI 44.9–58.9) worldwide. The age-standardized prevalence was 658 per 100,000 people (569–748). Idiopathic epilepsy had an age-standardized prevalence of 307 per 100,000 (235–389) with an overall prevalence of 24.2 million PWE (18.5–30.7). Also, active epilepsy occurred in 0.7% of the population worldwide, with 0.3% attributed to idiopathic epilepsy and 0.4% to secondary epilepsy. Between 1990 and 2021, there was a 10.8% (1.1–21.3) increase in the global age-standardized prevalence, due to changes in secondary epilepsy rates. The burden of active idiopathic epilepsy showed a three- to four-fold variation according to geographical location, with LMICs reporting the highest rates. These countries accounted for 82.1% (81.1–83.4) of the global incidence and 80.4% (79.7–82.7) of the prevalence and for the majority of fatal epilepsy cases (84.7%, 83.7–85.1) and epilepsy-related disability-adjusted life years (DALYs) (87.9%, 86.2–89.2) (GBD, 2025). In Palestine, the age standardized prevalence rate in 2021 was 561.2 per 100,000 citizens (367.2–754.5) accounting for around 30,000 Palestinians with epilepsy (GBD, 2025). However, the MOH stated that the incidence rate of epilepsy in the West Bank in 2023 was 5.4 per 100,000 citizens (MOH, 2023). The exact prevalence has not been accurately measured.

2.2 Psychosocial and Lived Experiences of PWE

A substantial body of literature has documented the multidimensional impact of epilepsy on individuals' lives, extending far beyond the physical manifestations of seizures. Epilepsy has been associated with a wide range of psychological, social, and economic consequences that significantly diminish the quality of life of people living with epilepsy (PWE). Several studies have consistently shown that the unpredictability of seizures can lead to persistent anxiety, depression, low self-esteem, and emotional distress (Chew et al., 2020; Shi et al., 2021; Steiger & Jokeit, 2017; Tanaka et al., 2018). Emotional burden is often exacerbated by internalized stigma and a sense of loss of control, which discourage social interaction and independence.

Stigma remains one of the most widely reported challenges in literature. In many settings, epilepsy continues to be misunderstood and surrounded by cultural misconceptions, resulting in social exclusion, discrimination, and rejection. Henning et al. (2021), in a study involving 1,182 PWE in Norway, found that nearly one-third reported experiencing discrimination, and more than half felt stigmatized (Henning et al., 2021). Stigma was identified as a key predictor of poor quality of life. Similarly, qualitative studies conducted in Ethiopia, India, and South Africa have highlighted the profound impact of stigma on daily life, including reduced access to education, employment, and healthcare services (Demissie et al., 2021; Gosain & Samanta, 2022; Makhado et al., 2024; Tsigebrhan et al., 2024).

Social and interpersonal challenges are also significantly highlighted in the published literature. Many individuals with epilepsy report feelings of social isolation due to fear of having a seizure in public or being misunderstood by peers and colleagues. Mlinar et al. (2021) emphasized that disclosure of the condition often provokes anxiety, fear, and uncertainty, which can undermine interpersonal relationships (Mlinar et al., 2021). Families, too, are affected, experiencing emotional stress, financial burden, and limitations

in social participation due to caregiving responsibilities or fear of stigma by association (Chew et al., 2017; Tanywe et al., 2016).

Academic and occupational outcomes are also negatively influenced by the condition. Recurrent seizures, medication side effects, and social stigma contribute to poor academic performance, school dropout, and reduced employment opportunities (Trinka et al., 2019, 2023). Lee et al. (2022) found significant associations between depression, unemployment, and felt stigma among PWE (Lee et al., 2022). In addition, side effects of AEDs, such as fatigue or cognitive impairment, are reported as key contributors to medication non-adherence and job loss (Getnet et al., 2016; Niriayo et al., 2019; Sweileh et al., 2011).

In recent years, qualitative research has contributed valuable insights into the lived experiences of PWE, highlighting how individuals interpret and cope with their condition in daily life. These studies underscore the importance of capturing patient narratives, which provide a deeper understanding of the social, emotional, and cultural dimensions of epilepsy (Frechette et al., 2020; Maxwell, 2012; Pacheco & Fossa, 2024). Insights are often overlooked in biomedical. For example, Ayele et al. (2023) explored the lived experiences of adolescents with epilepsy in Ethiopia and identified themes related to psychosocial distress, coping strategies, and health system challenges (Ayele et al., 2023). These narratives revealed not only the negative effects of epilepsy but also the resilience and adaptive behaviors of affected individuals.

Integrating lived experience into healthcare planning and delivery has been recognized as essential for improving person-centered care. Patients' perspectives can inform treatment priorities, enhance communication with healthcare providers, and strengthen adherence to therapeutic regimens. Moreover, involving PWE in health policy discussions can help ensure that interventions address their actual needs, including stigma reduction, better communication, and support for social reintegration (Mlinar et al., 2021).

Despite the growing body of international literature on these issues, research in the Palestinian context remains limited. Shawahna et al. (2020) explored clinicians' perspectives on therapeutic drug monitoring for epilepsy in Palestine but did not include patient voices in the study. To date, there has been no comprehensive qualitative research investigating the lived experiences of PWE in Palestine (Shawahna et al., 2020). Given the unique sociopolitical, cultural, and healthcare context of the region, this represents a critical gap. Understanding how Palestinians with epilepsy navigate stigma, treatment barriers, and healthcare interactions is essential for designing effective, culturally sensitive interventions and for informing national epilepsy management strategies.

In summary, global research highlights a wide range of challenges experienced by PWE, including stigma, mental health burdens, limited education and employment, and adverse drug effects. There is a pressing need to explore these issues in the Palestinian setting. Moreover, incorporating the lived experiences of PWE into healthcare policy and practice holds great potential to enhance the quality, responsiveness, and equity of epilepsy care in low-resource and underserved settings.

2.3 Management of Epilepsy

Effective management of epilepsy is focused on the controlling and monitoring of seizures, psychosocial support, education for patients and caregivers, and strategies for reducing stigma and enhancing treatment adherence (Henning et al., 2021; Shi et al., 2021). Comprehensive care typically requires a multidisciplinary team comprising neurologists, primary care physicians, mental health professionals, and social workers to effectively address the medical and psychosocial needs of PWE. Public health initiatives and community-based interventions are essential for improving awareness, reducing treatment gaps, and supporting early diagnosis and access to care, especially in resource-limited environments (Lee et al., 2020; Makhado et al., 2024; Zheng et al., 2019). Optimizing the treatment and management of epilepsy requires clinical expertise and systematic measures to integrate services within PHC, as well as to enhance health systems for sustainable long-term care (Zheng et al., 2019).

The management of epilepsy patients focuses on three primary objectives: seizure control, reduction of treatment-related adverse effects, and maintaining or improving the quality of life (Bradley et al., 2016). Healthcare providers are required to support the autonomy of PWE to adopt lifestyles consistent with their abilities. The optimal treatment plan is derived from an accurate diagnosis of the patient's seizure type(s), an objective measure of the intensity and frequency of the seizures, awareness of medication adverse effects, and an evaluation of disease-related psychosocial problems. Working knowledge of available AEDs, including their mechanisms of action, pharmacokinetics, drug-drug interactions, and adverse effects, is essential (Bacci et al., 2021; Johannessen Landmark et al., 2020). It is usually appropriate to refer the patient to a neurologist when establishing a diagnosis and formulating a course of treatment. Referral to an epilepsy specialist may be necessary if there is doubt about the diagnosis and if the patient continues to have seizures (Johannessen Landmark et al., 2020).

Primary care physicians typically manage epilepsy in LMICs due to a shortage of neurology specialists (O'Dwyer, 2020). The median number of neurologists per 100,000 populations is 0.03 for low-income countries compared with 2.96 for high-income countries, and the recommended number of neurologists in Europe is 1-5 per 100,000 populations (Trinka et al., 2019). Accessibility to imaging technologies, such as EEG, remains limited within MOH facilities, with availability largely restricted to hospitals rather than primary care settings, and often confined to the private sector. This suggests that PHC settings typically diagnose epilepsy based on its symptoms (O'Dwyer, 2020; Trinka et al., 2019). Therefore, incorrect diagnosis of epilepsy may lead to increased morbidity and mortality in Palestine and LMICs. The role of (non-specialized) healthcare professionals working in primary care settings is fundamental in bridging the gap in epilepsy treatment and empowering PWE for optimal management of epilepsy and consequently improving the quality of life (Noe, 2019; O'Dwyer, 2020; Trinka et al., 2019).

2.4 The Role of Health Practitioners in Epilepsy Care

Healthcare professionals play a significant role in the holistic management of epilepsy, including diagnosis, treatment, patient education, and ongoing follow-up. Their role duties include clinical treatment as well as addressing clinical, psychosocial, and educational needs (Jafarpour et al., 2019; Trinka et al., 2019). Optimal epilepsy care and management involve

collaborative efforts among several healthcare professionals, including epileptologists, neurologists, primary care physicians, nurses, psychologists, and pharmacists, to meet both medical and psychosocial needs. Nurses provide critical support in patient education, medication management, and seizure first-aid training, significantly improving self-efficacy and quality of life (Locatelli, 2019). Pharmacists contribute by monitoring antiepileptic drug interactions, mitigating side effects, and promoting adherence—a key factor in reducing breakthrough seizures (Eshiet et al., 2021). Bacci et al. (2021) identified specific community pharmacists providing epilepsy care exceeding medication dispensing. Community pharmacists may educate PWE and their caregivers about epilepsy and AEDs and encourage adherence and self-management (Bacci et al., 2021). Another study examined alternate epilepsy care options such enhancing primary care providers' awareness and treatment adherence. These programs briefly address the treatment gap, epilepsy-related mortality, and comorbidity (Singh et al., 2020).

Research indicates deficiencies in healthcare providers' knowledge and confidence about the management of epilepsy and related comorbidities contributed to the limited implementation of training programs (Ernawati & Rahmatul Islamiyah, 2018; Michaelis et al., 2020). Stigmatizing attitudes among some healthcare professionals reduces the quality of care. Multidisciplinary teams, reinforced by epilepsy clinics and organizations, are essential for addressing these gaps (Alaqeel et al., 2013).

The knowledge of healthcare professionals of epilepsy will influence their communication with people with the disorder, thereby impacting public perception of those with the condition. In developing countries, physicians, nurses, and other healthcare providers are primarily responsible for providing medical care to PWE (Buddhiraja et al., 2020; Trinka et al., 2019). PHC personnel are capable of managing epilepsy and treating neurological complications (Makhado et al., 2024). Several studies have indicated a gap in awareness concerning epilepsy among healthcare professionals (Alaqeel et al., 2013; Giuliano et al., 2018; Vancini et al., 2012). A recent study in India revealed that healthcare providers need improved understanding regarding epilepsy (Buddhiraja et al., 2020).

Researchers have recognized many barriers that reduce self-management, including poor communication with the healthcare team and low confidence in the therapeutic action of AEDs (Chew et al., 2019; Ernawati & Rahmatul Islamiyah, 2018).

In Palestine, healthcare practitioners in PHC centers are tasked with providing routine health services for PWE and other chronic illnesses. Unfortunately, both healthcare practitioners and PWE lack formal training on epilepsy self-management programs or therapeutic monitoring of AEDs (Chew et al., 2019; Shawahna et al., 2020; Shawahna & Abdelhaq, 2020b). It is essential to evaluate the foundational KAP about epilepsy and epilepsy management among the PHC workforce that provides services for PWE.

By improving healthcare providers' knowledge and competencies, they will develop a sense of confidence, consideration, and collaboration by recognizing and appreciating the experiences of their patients. This, in turn, results in enhanced patient satisfaction, increased adherence to treatment plans, and superior health outcomes (Naeem et al., 2023; Rand et al., 2019). The WHO's Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (2022–2031) provides a comprehensive framework aimed at reducing the burden of neurological conditions worldwide (WHO, 2023b). This plan outlines key strategies for improving access to effective care, enhancing the quality of treatment services, and reducing the stigma associated with epilepsy. The WHO (2023) underlines the need of training

healthcare practitioners to better treat these diseases, the integration of epilepsy care into main healthcare systems, and the promotion of evidence-based methods. These will help to enhance health outcomes and well-being of PWE (WHO, 2023b).

Healthcare professionals' attitudes toward epilepsy significantly shape their approach to diagnosis, management, and communication with PWE. Research indicates that stigmatizing beliefs and negative perceptions among some practitioners reduce the quality of care and hinder treatment outcomes (Alaqeel et al., 2013; Michaelis et al., 2020). In many developing countries, including Palestine, cultural misconceptions and limited professional training perpetuate social stigma, leading to reluctance among providers to fully engage with patients or to address epilepsy as a chronic, manageable condition (Buddhiraja et al., 2020; Trinka et al., 2019). This may result in diminished empathy, inadequate counseling, and poor patient–provider relationships, which negatively influence adherence and overall care quality.

Positive attitudes, on the other hand, are associated with improved communication, greater trust, and higher satisfaction among PWE (Naeem et al., 2023). Studies suggest that healthcare providers with greater awareness and confidence in managing epilepsy demonstrate more supportive and inclusive behaviors, which contribute to reducing stigma and encouraging treatment-seeking behaviors (Rand et al., 2019). This highlights the need for structured, culturally sensitive training programs that not only enhance clinical knowledge but also address stigma and attitudinal barriers.

In the Palestinian context, where epilepsy is highly stigmatized, these issues are particularly pressing. Healthcare professionals working in PHC centers often lack the necessary training to address both the clinical and psychosocial dimensions of epilepsy care. This deficiency contributes to fragmented services, limited follow-up, and suboptimal engagement with PWE (Shawahna, 2020; Shawahna & Abdelhaq, 2020a).

Healthcare professionals' practices in managing epilepsy reflect similar limitations. While primary care providers in Palestine are tasked with routine epilepsy care and AED refills, studies show that comprehensive practices, such as seizure first-aid education, therapeutic drug monitoring, and adherence support, are inconsistently applied (Chew et al., 2019; Ernawati & Rahmatul Islamiyah, 2018). Nurses and pharmacists, who could play integral roles in patient education and medication management, are often underutilized in clinical practice (Bacci et al., 2021; Eshiet et al., 2021; Shawahna et al., 2017).

Research from other LMICs demonstrates that when adequately trained, PHC professionals are capable of delivering safe and effective epilepsy care, including initiating treatment, managing comorbidities, and coordinating referrals (Makhado et al., 2024; Shawahna & Abdelhaq, 2020a; Singh et al., 2022; Sweileh et al., 2011). However, in Palestine, the lack of structured protocols and formal self-management programs limits these capabilities. This contributes to poor treatment adherence, inadequate seizure control, and missed opportunities for improving quality of life among PWE (Bankole et al., 2024; Mayor et al., 2022; Shi et al., 2021).

To address these challenges, there is a need for national guidelines on epilepsy management, investment in continuing professional development, and a shift toward integrated, team-based care models that engage physicians, nurses, and pharmacists collaboratively. These reforms, supported by international frameworks such as the WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (2022–2031), aim to improve the

quality of epilepsy care, reduce stigma, and enhance outcomes for individuals living with epilepsy (WHO, 2023b).

2.5 WHO mhGAP

The WHO's Mental Health Gap Action Programme (mhGAP) is a global initiative designed to reduce the treatment gap for mental, neurological, and substance use disorders, particularly in LMICs where access to specialist care remains limited (Keynejad et al., 2021; Sen et al., 2025). Epilepsy has been identified as one of the program's priority conditions due to its high prevalence, substantial burden of disability, and the significant proportion of untreated individuals, especially in resource-constrained settings (Sen et al., 2025).

To operationalize this initiative, the WHO developed the mhGAP Intervention Guide, which provides evidence-based protocols to support non-specialist healthcare workers, such as general practitioners, nurses, and primary care personnel, in the identification, diagnosis, and management of epilepsy and other priority conditions (Keynejad et al., 2021; WHO, 2016). The guide simplifies clinical decision-making and offers practical steps for initiating and monitoring treatment, ensuring continuity of care, and determining when referral to specialized services is necessary (WHO, 2015, 2016).

Empirical studies conducted in diverse LMIC settings have demonstrated the effectiveness of mhGAP training in enhancing the capacity of healthcare providers. Notably, post-training assessments have shown improvements in providers' knowledge, attitudes, and confidence in managing epilepsy, alongside better clinical outcomes among PWE, including reduced seizure frequency and improved engagement with care (Keynejad et al., 2021; Pinchuk et al., 2021; Robles et al., 2019; J. Spagnolo et al., 2020). These findings underscore the utility of mhGAP as a scalable intervention that bridges the treatment gap by enabling task-shifting and integration of epilepsy care into PHC systems.

In the context of the West Bank, Palestine, the potential impact of mhGAP is particularly significant. The region faces persistent challenges such as political instability, limited health infrastructure, and shortages of trained neurologists and mental health professionals (Imam et al., 2020; McNeely et al., 2014; Wazaify et al., 2020). These systemic constraints contribute to delayed diagnosis, poor adherence to antiepileptic medications, and a fragmented continuum of care for PWE (Jaber et al., 2021; Shawahna & Al-Atrash, 2019). Implementing mhGAP in such settings can facilitate earlier detection, promote rational use of AEDs, and empower PHC workers to manage epilepsy more effectively (Sen et al., 2025; WHO, 2016).

Moreover, mhGAP supports contextual adaptation, allowing countries to tailor training content and treatment protocols to local epidemiological profiles, resource availability, and sociocultural factors, including stigma and health-seeking behavior related to epilepsy (Charlson et al., 2019; Keynejad et al., 2021; Kokota et al., 2020; Robles et al., 2019; J. Spagnolo et al., 2018, 2020). This flexibility makes mhGAP particularly suited to fragile health systems such as that of Palestine, where structured, evidence-based guidance can improve both provider competence and patient outcomes.

A study in Fiji implemented the mhGAP training on 66 healthcare providers who deliver mental health services. The identified weaknesses and opportunities for implementation and

targets for change within the mental health system (Charlson et al., 2019). In the Palestinian context, this training could enhance the capabilities of PHC facilities, facilitate task-shifting, and so promote equitable access to neurological treatment. Additionally, it promotes the incorporation of epilepsy management into primary care systems, so enhancing sustainable and patient-centered healthcare delivery in resource-constrained environments in accordance with global health objectives (Sen et al., 2025; Shawahna et al., 2020; WHO, 2023b).

In summary, mhGAP represents a vital tool for strengthening epilepsy care in under-resourced settings. Its integration into PHC systems offers a sustainable approach to addressing the epilepsy treatment gap by decentralizing services, building local capacity, and ultimately improving the quality of life for individuals living with epilepsy.

2.6 Why Primary Healthcare?

Neurologists and epileptologists are the most proficient healthcare providers for epilepsy care and management (Bankole et al., 2024; Falco-Walter, 2020). Unfortunately, there is a worldwide deficiency among these specialists, especially in LMICs. The global neurological workforce is estimated to be 3.1/100,000 population, including neurosurgeons and neurologists for child and adult care (Thakur et al., 2016). This lack of specialist-led care and access has shifted the responsibility for epilepsy management to general practitioners and PHC physicians. Despite the increasing prevalence of multidisciplinary care models, PHC workers remain the principal care providers in numerous regions globally (O'Dwyer, 2020; Sen et al., 2025). A qualitative study was conducted to interview healthcare practitioners to explore the present healthcare provided for women with epilepsy in the Palestinian healthcare system (Shawahna & Zaid, 2022). The study revealed a deficiency in protocols and standards for diagnosis and care of women with epilepsy. Another study identified deficiencies in the evaluation and anesthetic procedures specific to epilepsy, inadequate utilization of neurology referral services, and absence of neuro-monitoring (Jaber et al., 2021). Considering that epilepsy is a persistent disorder necessitating continuous treatment and monitoring, it is imperative that future physicians acquire the requisite knowledge and skills to manage and assist PWE (Keynejad et al., 2021; WHO, 2023b). Studies in several countries as, India, Niger, Ethiopia, Turkey, and Southern China have revealed substantial knowledge deficiencies among healthcare providers about epilepsy management (Assadeck et al., 2020; Buddhiraja et al., 2020; Dayapoğlu et al., 2021; Emiru et al., 2019; Teferi & Shewangizaw, 2015; Yang et al., 2019). Most research in the Palestinian context has quantitatively assessed the knowledge, awareness or attitudes of the general public, health practitioners or even medical students about epilepsy (Shawahna, 2024; Shawahna & Jaber, 2020). These studies revealed the need to implement programs that raise public awareness and address the existing stigma. These studies confirmed the need to improve healthcare providers' competencies in epilepsy care and management (Ghanayem & Hallak, 2025; Jaber et al., 2021; Shawahna et al., 2017, 2020).

2.7 Toward a Patient-Centered Understanding of Epilepsy in Palestine: Addressing a Research Gap

Although epilepsy has been the subject of various research efforts in Palestine, there remains a significant lack of both quantitative and qualitative studies that deeply explore the lived

experiences of PWE, particularly those receiving care through the MOH. Most available studies have either focused on the delivery of care from the healthcare provider's perspective or assessed the knowledge and attitudes of the general public, medical students, or practitioners.

Despite these contributions, the perspectives of PWE themselves, especially in the Palestinian context, remain underexplored. Global qualitative studies on lived experience cannot be directly applied to Palestine due to its unique sociopolitical and healthcare realities. Consequently, the voices of patients, particularly those treated in resource-constrained public healthcare settings, are largely absent from the literature.

This study seeks to fill these critical gaps by exploring the lived experiences, challenges, and needs of PWE in the West Bank. By focusing on patient perspectives within public healthcare services, this research contributes to a more patient-centered and context-specific understanding of epilepsy management in Palestine. The findings aim to inform both policy and practice to promote improved, equitable care and psychosocial support for this marginalized population.

Chapter Three

Conceptual Framework

3.1 Introduction

This chapter presents the conceptual framework guiding the study, integrating WHO Operational Framework for Primary Health Care (PHC) and the Health Belief Model (HBM). The framework systematically examines epilepsy care across three levels: patient behavior, provider readiness, and system support, ultimately leading to patient-centered epilepsy care and improved health outcomes. By combining individual behavioral insights (HBM) with health system strengthening strategies (WHO PHC framework), this study advances a holistic approach to epilepsy management in PHC settings.

3.2 Theoretical Foundations

3.2.1 WHO Operational Framework for Primary Health Care:

This dissertation employed the WHO Operational Framework for PHC as a model for interpreting the findings within a globally acknowledged health systems perspective (Figure 3.1). The WHO Operational Framework for PHC (WHO, 2018; WHO & UNICEF, 2022) provides a structured approach to strengthening health systems through 14 strategic and operational levers, categorized under five pillars:

- Service Delivery: Ensuring integrated, accessible, and quality care.
- Health Workforce: Training and equipping providers for effective service provision.
- Health Information Systems: Data-driven decision-making and monitoring.
- Access to Essential Medicines: Reliable supply chains and affordability.
- Governance & Financing: Policies and funding to sustain PHC services.

This study applies these levers to evaluate epilepsy care integration in PHC, focusing on workforce capacity, community engagement, and systemic barriers.

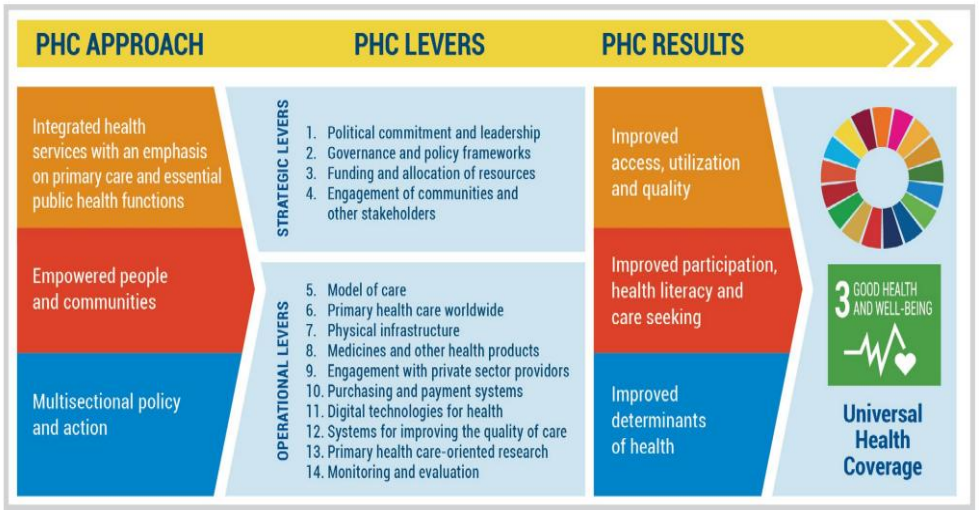

Figure 3.1: WHO Operational Framework for Primary Health Care. Source: (WHO & UNICEF, 2022)

3.2.2 Health Belief Model (HBM):

The HBM (Alyafei & Easton-Carr, 2025; Rosenstock, 1974) explains health-related behaviors based on individual perceptions (Figure 3.2):

- Perceived susceptibility (risk of epilepsy complications).
- Perceived severity (impact of untreated epilepsy).
- Perceived benefits/barriers (motivations vs. obstacles to care-seeking).
- Cues to action (events triggering healthcare utilization).
- Self-efficacy (confidence in managing epilepsy).

The HBM is used to analyze patient adherence, stigma, and care-seeking behavior, as well as provider willingness to adopt epilepsy management guidelines.

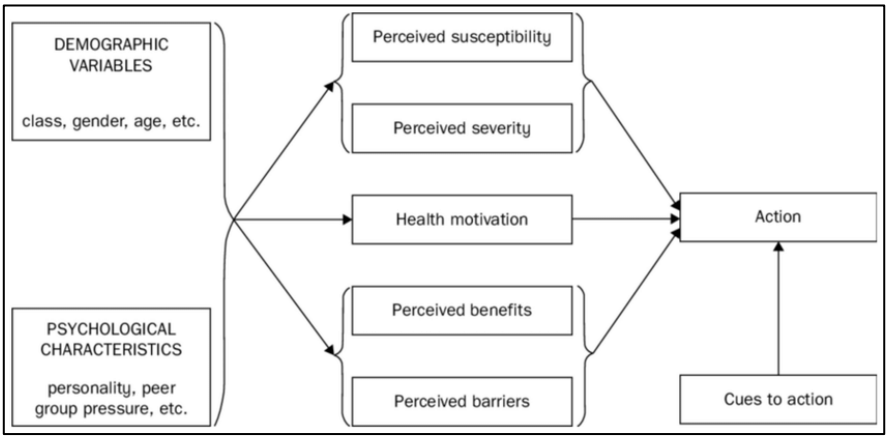

Figure 3.2: Health Behavior Model. Source (Wilderink et al., 2022)

3.3 Integrated Conceptual Framework

This dissertation incorporates the WHO Operational Framework for PHC and the HBM to account for individual-level behavioral determinants influencing both patients and healthcare providers. The integrated conceptual framework enriches the understanding of how patients perceive and respond to epilepsy-related health needs, including stigma, adherence to treatment, and coping strategies. It also offers insight into healthcare providers' readiness to adopt new practices, by evaluating their knowledge, attitudes, and confidence in delivering epilepsy care. The model provides a structured lens to examine behavior change mechanisms before and after targeted interventions, such as mhGAP training. By combining the behavioral focus of HBM with the systems-oriented levers of the WHO framework, this study proposes a holistic approach to improving epilepsy management in primary healthcare; one that addresses both systemic structures and the beliefs and behaviors of those within them. The dissertation situates epilepsy care reform within the broader objectives of improving PHC performance and advancing and SDG 3. The integrated conceptual framework (Figure 3.3) synthesizes the WHO PHC levers and HBM constructs across three dimensions:

1. Patient Behavior (HBM Perspective)
   - Perceived susceptibility & severity – Awareness of epilepsy risks and consequences.
   - Coping mechanisms – Strategies to manage stigma and daily challenges.
   - Perceived benefits/barriers – Weighing treatment advantages against cost, distance, or discrimination.
   - Cues to action – Seizure episodes, family advice, or health campaigns prompting care.
   - Self-efficacy – Confidence in treatment adherence and self-management.

2. Provider Readiness (HBM + WHO Workforce Lever)
   - Knowledge, attitudes, and practices (KAP) – Baseline understanding of epilepsy care.
   - Training interventions (mhGAP) – Structured education to improve competency.
   - Self-efficacy & beliefs – Confidence in diagnosing and managing epilepsy.
   - Guidelines & policy cues – Standardized protocols reinforcing best practices.

3. System Support (WHO PHC Levers)
   - Service delivery models – Integration of epilepsy into routine PHC services.
   - Health workforce distribution – Availability of trained providers.
   - Health information systems – Tracking epilepsy cases and outcomes.
   - Access to medicines & referrals – Availability of anti-seizure drugs and specialist linkages.
   - Community engagement – Reducing stigma and improving health literacy.

4. Convergence: Patient-Centered Epilepsy Care
   The interaction of these dimensions fosters patient-centered care, where:
   - Patient experiences guide tailored interventions.
   - Providers deliver evidence-based care.
   - Health systems ensure proper healthcare delivery.

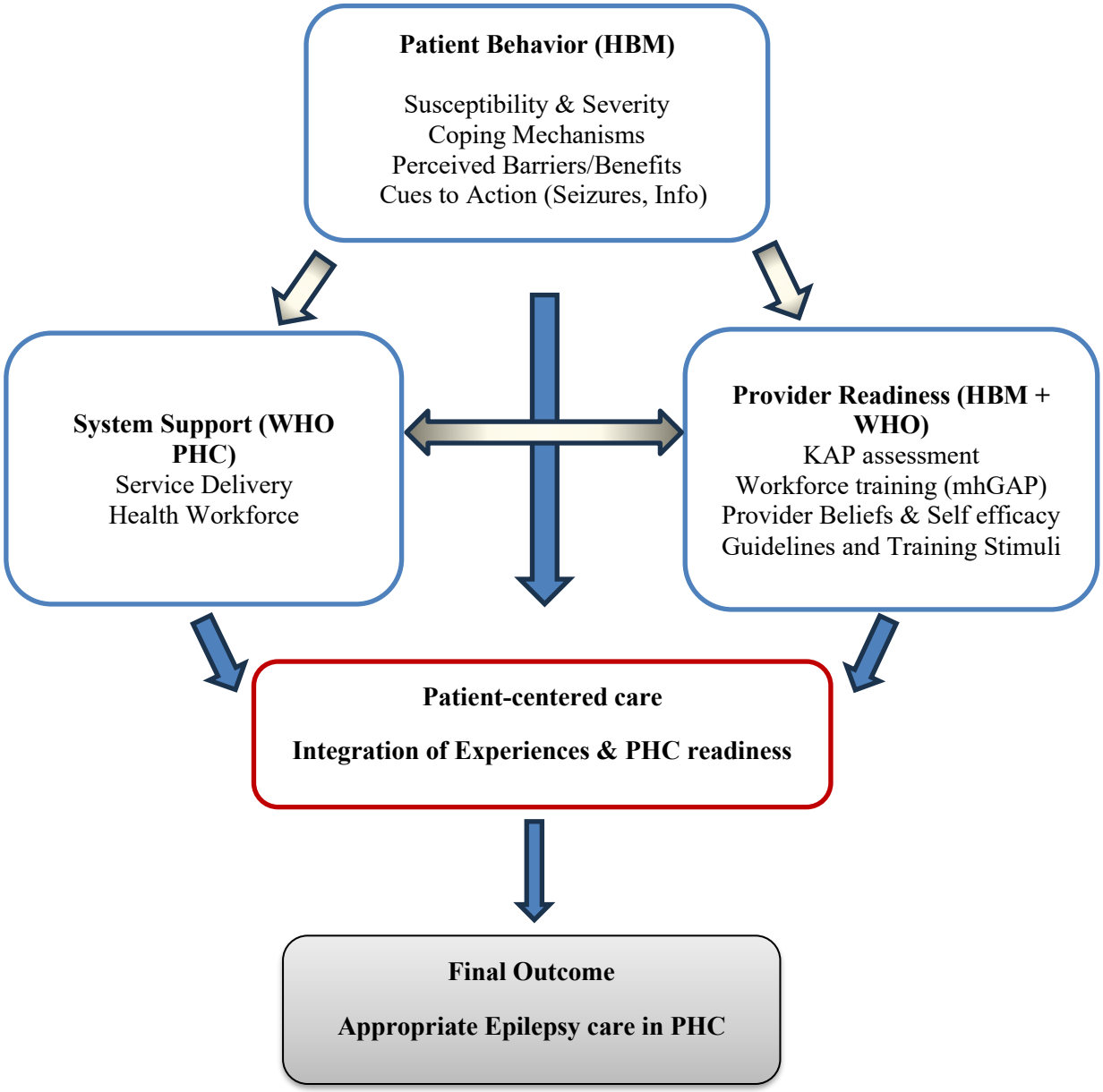

Figure 3.3: Integrated Conceptual Framework for Epilepsy Care in PHC

Chapter Four

Methodology

4.1 Study Design

A sequential exploratory mixed-method approach was used to understand epilepsy patient's perspective then evaluate epilepsy management among healthcare practitioners in PHC settings in the West Bank, Palestine. This design was utilized to comprehensively investigate the complex elements related to epilepsy care. Initially, qualitative in-depth interviews with individuals diagnosed with epilepsy explored their lived experiences and interactions with healthcare, yielding profound contextual insights into unmet needs and systemic deficiencies. The findings guided the development of the subsequent quantitative phase, which evaluated healthcare professionals' KAP via structured surveys, pinpointing areas for improvement. An intervention, training based on the mhGAP guidelines, was carried out, accompanied by pre- and post-test assessments to evaluate differences in healthcare providers' knowledge, attitudes, and self-efficacy. This methodology facilitated a comprehensive understanding by combining qualitative research, quantitative measurement, and interventional evaluation, ensuring the intervention was rooted in the actual experiences of patients and healthcare providers. The mixed- methods approach successfully combined experiential narratives with quantifiable results, providing a comprehensive framework to enhance epilepsy care. This method is suitable to explore a phenomenon that is not well understood, generate new ideas, and develop interventions (McBride et al., 2019). The analysis for each study was performed separately. An overview of the three studies is presented in (Table 4.1).

The first study utilized a qualitative phenomenological design rooted in Husserlian descriptive phenomenology, which seeks to describe the universal "essence" of lived experiences by bracketing (epoché) preconceptions and returning to "the things themselves" (Husserl, 2012). Thematic analysis (Braun & Clarke, 2006) was used as an analytical tool to systematically identify invariant structures of participants' lifeworlds, consistent with phenomenology's focus on intentionality and meaning-making. This method enables the researcher to understand the experiences and awareness of people living with epilepsy and their perceptions of the treatment and management of their condition. Qualitative descriptive design is widely used, particularly to examine healthcare-related phenomena and to gain insight from participants' perceptions and experiences about an insufficiently understood phenomenon (Chew et al., 2019, 2020; Colorafi et al., 2020; Mlinar et al., 2021). The

Husserlian approach would aim to capture the essential qualities of living with epilepsy, such as fear, isolation, or resilience, based purely on participants' accounts, without adding any interpretation or theory about the causes or effects (Husserl, 2012). This methodology is particularly important in studying epilepsy, as it provides insights into how individuals navigate their daily lives, manage their condition, and interact with society.

The second study used a cross-sectional descriptive quantitative design at governmental PHC centers in the West Bank, Palestine. Governmental PHC clinics offer AEDs and follow-up services to all PWE, regardless of age, who fall under the governmental health insurance program. Healthcare practitioners working in these PHC clinics provide health services for chronic diseases, including PWE. This study targeted all healthcare professionals employed in PHC clinics of the MOH who are tasked with delivering health services to PWE, including medical doctors, registered nurses, pharmacists, psychologists, and other paramedical personnel. This study design provided insights on the actual provision of care and gaps that should be addressed to improve the quality of care provided to persons living with epilepsy and their quality of life (Buddhiraja et al., 2020; Ernawati & Rahmatul Islamiyah, 2018; Yang et al., 2019).

A self-administered questionnaire was developed in accordance with the qualitative insights (first study), prior literature and WHO training guidelines (Alaqeel et al., 2013; Buddhiraja et al., 2020; WHO, 2017b, 2022; Yang et al., 2019).

The third study was interventional design. It employed a quasi-experimental approach (pre- and post- measures), with an interrupted time-series design. A piloted educational training was developed based on the WHO mhGAP Action program for mental, neurological and substance use disorders in non-specialized health settings. The mhGAP Intervention Guide version 2.0 (WHO, 2015) is designed to promote task-sharing and capacity-building among PHC professionals, especially in LMICs where access to specialized care is limited. Epilepsy is a prioritized condition within the mhGAP due to its substantial impact, treatability, and the significant global treatment gap. This study aimed to integrate educational training with mhGAP guidelines to equip PHC professionals with the knowledge and skills needed for the effective recognition, diagnosis, and management of epilepsy at the primary care level.

The training module utilized the mhGAP Intervention guide version 2.0 (WHO, 2015) and was adapted to the Palestinian context in reference to prior research and the results of the two studies before implementation (Keynejad et al., 2021; Kokota et al., 2020; Robles et al., 2019; J. Spagnolo et al., 2018). The training module considered general principles of care and epilepsy as priority areas. A self-administered questionnaire was used as the study tool to measure knowledge, attitudes and self-efficacy were measured before, and 2 months after the mhGAP training. Also, on the last day of training, training evaluation data were collected, obtaining feedback about the conduct of the training program.

Table 4.1: Overview of the studies in the thesis

	Study I	**Study II**	**Study III**
Design	Qualitative Descriptive phenomenological	Quantitative Cross sectional	Interventional Quasi experimental
Data Collection	Individual Interviews	Questionnaire (KAP)	Questionnaire, training evaluation
Participants	PWE (n = 12)	Healthcare professionals in primary care settings (n = 300)	Healthcare professionals in primary care settings (n = 68)
Data Analysis	Qualitative thematic analysis	Descriptive and comparative statistics	Descriptive and comparative statistics

4.2 Study setting, participants and recruitment process

4.2.1 Study I:

Purposive sampling was used to identify and recruit PWE who could articulate rich, diverse experiences from the governmental PHC clinics located across all districts in the West Bank. Researchers practiced epoché by documenting and setting aside prior assumptions about epilepsy to minimize bias during recruitment and data collection. Inclusion criteria were adults over 18 years old, diagnosed with epilepsy for at least of one year, without cognitive impairment or significant medical conditions, receiving antiepileptic drug therapy, and capable of providing informed consent. Participants were excluded from the study if they had been diagnosed with epilepsy for less than one year or were under 18 years of age. Additionally, individuals with substantial developmental, intellectual, or cognitive impairments (e.g., cerebral palsy, Down syndrome, attention deficits, and autism spectrum disorders) were not included. Participants with psychological or physiological conditions that might influence the study results, such as cognitive impairment, major depressive disorder, and insomnia, were also excluded.

Age, gender, educational level, employment, marital status, and residency were all taken into consideration to preserve the heterogeneity of the participants. This selection was employed to select participants to explore how epilepsy affects people variably across diverse social and cultural contexts. Purposive sampling is a commonly used technique for qualitative research to select individuals that exhibit an extensive amount of knowledge and experience with a certain phenomenon of interest. Furthermore, it takes into consideration the capacity to convey experiences and viewpoints in a clear, articulate, and analytical manner (Campbell et al., 2020).

Recruitment for the study started in February 2024 and ended in May 2024. Nurses and pharmacists at PHC clinics recruited possible participants based on the researchers' purposive sampling criteria. Potential participants were patients diagnosed with epilepsy, as indicated in their electronic health records from PHC clinics they regularly visit for follow-up and medication refills. They notified potential participants about the study and presented a written information sheet outlining its objectives, procedures, and ethical considerations (Appendix 3). After expressing their willingness to participate, the researcher approached the subjects to explain the study, address questions, and obtain signed consent. A meeting was arranged at a mutually convenient time and location to assure participant privacy and

comfort, also promoting an open and secure environment for collecting data. Twelve individuals were interviewed, following qualitative research procedures that emphasize depth over breadth. Phenomenological research promotes precise, meaningful insights over statistical generalizability, and sample sizes of 6–15 individuals are usually sufficient to reach data saturation (Finlay, 2009; Malterud et al., 2016; Pacheco & Fossa, 2024). This study found saturation after 12 interviews with no significant new themes or differences in the experience. Allowing participants to express their experiences genuinely allowed the researcher to set aside preconceived assumptions and return to "things themselves," as Husserlian philosophy emphasizes. Thus, the sample size was sufficient to describe the basic structures of epilepsy from the perspective of those affected.

4.2.2 Study II:

Convenient sampling was used to identify and recruit healthcare professionals from the PHC clinics located across all districts in the West Bank. Governmental PHC clinics offer AEDs and follow-up services to all PWE, regardless of age, who fall under the governmental health insurance program. Healthcare practitioners working in PHC centers provide health services for chronic diseases, including PWE. Inclusion criteria were healthcare professionals employed in PHC centers who are tasked with delivering health services to PWE, including medical doctors, registered nurses, pharmacists, and psychologists. Healthcare staff not involved in epilepsy care, such as laboratory technicians, administrative personnel, and other non-clinical roles, were excluded from participation.

The cross-sectional study was conducted between April 2024 and June 2024 at governmental PHC centers in the West Bank, Palestine. The sample size of 300 was determined by utilizing the EpiInfo® sample size calculator, predicated on a 95% confidence level, a 5% margin of error, and an anticipated response distribution of 50%.

4.2.3 Study III:

Convenience sampling was used to identify and recruit healthcare professionals employed in PHC centers throughout the Hebron governorate. They were selected for the pilot experiment because it is diverse context, which is indicative of other regions in Palestine. PHC centers provide health services, including counseling, prevention, treatment, and management of chronic illnesses, including epilepsy. Participants recruited are those responsible for providing health services to PWE, including physicians, nurses, and pharmacists. This study aimed to generate insights regarding the intervention (training) its utility and feasibility in our context, serving as a foundation for subsequent experimental studies that may facilitate result generalization.

The sample size was determined to compare two means (pre-test and post-test scores) for the dimensions of knowledge, attitudes, and self-efficacy, with a statistical power of 0.80 and a level of significance of 0.05. A moderate effect size of d = 0.70 was assumed, with equal variances and a two-tailed hypothesis.

To calculate the required sample size for comparing two independent means (e.g., intervention vs. control), the following formula based on Cohen's d was used:

$$n = \frac{2(Z_{1-\frac{\alpha}{2}} + Z_{1-\beta})^2}{d^2}$$

Where:

n = sample size per group

$Z_{1-\alpha/2}$ = 1.96 (two-tailed, α = 0.05)

$Z_{1-\beta}$ = 0.84 (power = 0.80)

d = expected effect size (Cohen's d = 0.70)

$$n = \frac{2(1.96 + 0.84)^2}{0.70^2} = \frac{2(2.8)^2}{0.49} \approx 32$$

The study design, comprising an intervention and control group, required a minimum sample size of 33 individuals per group, resulting in a total of 66 participants to provide sufficient power for identifying significant differences between the groups over time. To verify that a minimum of 66 healthcare professionals completed both the pre-test and post-test assessments, 100 professionals were invited to the training. Out of them, 80 participants supplied written informed consent and were subsequently randomized into either the intervention or control group (40 participants in each group) by a computer-generated randomization technique. The randomization was performed in a blinded design, ensuring that individuals remained blind to their group allocation. The statistical analyst kept blind to the group allocations to reduce bias throughout data analysis. The training course was performed in February 2025 for two consecutive days.

4.3 Data Collection

4.3.1 Study I:

A semi-structured interview guide with open-ended questions was developed and supplemented with follow-up questions derived from the literature review and consultation with experts in qualitative research and epilepsy healthcare (Ayele et al., 2023; Deegbe et al., 2020; Roberts, 2020; Tanywe et al., 2016). The data were gathered using a pretested and approved interview guide. The interview guide aimed to explore three domains: (1) daily life with epilepsy, (2) healthcare interactions, and (3) coping strategies. Probes (e.g., "How did that experience feel?") demonstrated deep descriptions of conscious experiences, aligning with Husserl's emphasis on intentionality. The interview guide is available in Appendix 5. Participants chose to be interviewed at an agreed upon location and were coded, respectively. The participants' consent was obtained for recording audio interviews in order to ensure accurate verbatim transcription. The interviews were conducted by the researcher in the Palestinian dialect of Arabic. The interviewer recorded nonverbal cues, contextual observations to contextualize transcripts and ensure social proximity between interviewer and interviewee (Roberts, 2020). The fieldwork process was reflective and flexible enough to allow for adjustments based on experiences in the field as well as to ensure cultural appropriateness and sensitivity. The duration of the interview was approximately 45-60 minutes. Each interview was carried out until no additional new information was obtained (Guest et al., 2020). Upon ending the interview, the interviewer expressed gratitude to participants.

4.3.2 Study II:

A self-administered questionnaire was used to evaluate health practitioners' KAP about epilepsy management (Appendix 7). The questionnaire was developed in accordance with the WHO training guidelines and prior literature (Alaqeel et al., 2013; Buddhiraja et al., 2020; WHO, 2017b, 2022; Yang et al., 2019). Four public health experts, three governmental healthcare services experts, and one statistician revised the initial draft. A pilot study was done on a small sample size (n = 15), resulting in an overall Cronbach's alpha coefficient of 0.794, demonstrating strong internal consistency. The domain-specific Cronbach's alpha values are illustrated in Table 4.2.

The questionnaire comprised of four sections: health practitioner demographics (6 items); knowledge of monitoring the self-management among PWE (10 items) with 1 point awarded for each correct response and 0 points for incorrect answers, yielding a total score range of 0-10; attitudes towards PWE were evaluated using a five-point Likert scale (10 items) ranging from strongly agree (5 points) to strongly disagree (1 point), resulting in a score range of 10-50; and practices related to the self-management of epilepsy were measured through 12 items, with ratings from very consistent (5 points) to very inconsistent (1 point), allowing for a score range of 12-60.

The questionnaire was written in English and then translated to Arabic. Back translation was employed to ensure grammatical and conceptual equivalence in the translation of the items (Azlan et al., 2020). An independent bilingual translator and the researchers themselves corrected any differences between the two versions and ensured measurement consistency across all items. The data were gathered through an electronic questionnaire disseminated to participants by electronic codes by an independent data collector.

4.3.3 Study III:

A self-administered questionnaire was utilized to gather information from participants (Appendix 9). The questionnaire was developed in accordance with the WHO training guidelines and prior literature (Ghanayem & Hallak, 2025; J. Spagnolo et al., 2018; WHO, 2015, 2017b). The questionnaire consisted of five sections: participants' demographics (6 items); familiarity with epilepsy (4 items) and a knowledge section derived from the WHO mhGAP epilepsy knowledge test to assess knowledge before to and following training. It consisted of ten multiple-choice questions, awarding one point for each correct answer and zero points for incorrect responses, resulting in a total score range of 0 to 10. A higher score indicates greater knowledge of a participant. The attitudes section consisted of 10 items rated using a five-point Likert scale, ranging from strongly agree (5 points) to strongly disagree (1 point), giving a total score range of 10 to 50. A higher score indicates a greater level of the characteristic by a participant. Self-efficacy was assessed before and after training using 12 items, with responses ranging from strongly agree (5 points) to strongly disagree (1 point), resulting in a score range of 12 to 60. The questionnaire was composed in English and subsequently translated into Arabic. Back translation was utilized to guarantee grammatical and conceptual consistency in the translation of the items (Azlan et al., 2020). A bilingual translator and the researchers addressed any discrepancies between the two versions and guaranteed measurement uniformity across all items.

To assess the impact of the pilot training session, self-efficacy was selected as the primary outcome measure rather than changes in clinical practice. Self-efficacy, defined as the

confidence in performing specific tasks, is a proximal outcome that precedes and predicts actual behavior change (Bandura, 2002). The mhGAP intervention guide emphasizes building healthcare providers' competence and confidence as foundational goals of early-stage training. Measuring self-efficacy two months after the training allows for capturing this initial shift in mindset before clinical practices can fully stabilize or be meaningfully assessed. Additionally, self-efficacy can be reliably measured through brief survey instruments, making it practical and feasible for short-term follow-up in resource-limited settings (WHO, 2015). This approach aligns with the WHO's mhGAP monitoring framework, which promotes a staged evaluation process wherein self-efficacy serves as an early indicator of training success, while actual practice change is evaluated over a longer period. Empirical evidence also supports this sequence: studies on short mental health training programs demonstrate that gains in confidence often emerge before changes in practice. For instance, healthcare workers may become knowledgeable about antiepileptic drug protocols during training but delay implementation due to systemic or contextual barriers.(Kokota et al., 2020; J. Spagnolo et al., 2018) Early data on self-efficacy thus provides timely feedback for trainers, helping identify specific areas requiring reinforcement or refresher sessions.

Test–retest reliability examined the temporal stability of a measure over two time points, two months apart (Koo & Li, 2016). In this study, the intra-class correlation coefficient (ICC) was used to evaluate test–retest reliability among 36 participants who were randomly assigned to the control group and completed the same measures twice. A two-way mixed-effects model with absolute agreement was applied for each scale. The knowledge scale demonstrated excellent reliability, ICC = 0.943, 95% CI [0.910, 0.968], $F(35, 35) = 28.403$, $p < 0.001$. The attitudes scale showed moderate reliability, ICC = 0.587, 95% CI [0.210, 0.790], $F(35, 35) = 2.370$, $p = 0.004$. The self-efficacy scale indicated good reliability, ICC = 0.761, 95% CI [0.540, 0.882], $F(35, 35) = 4.072$, $p < 0.001$. These results support the stability of the measures over a two-month period in the absence of intervention. The domain-specific reliability results are illustrated in Table 4.2.

Table 4.2: Domain-Specific Reliability testing results of studies II and III

Study No.	**Internal consistency reliability**	**Test-retest reliability**
Study II	**Cronbach's α results**	
Knowledge	0.799	
Attitudes	0.725	
Practices	0.849	
Study III		**Intra-class correlation coefficient**
Knowledge		0.943, $p < 0.001$
Attitudes		0.587, $p = 0.004$
Self-efficacy		0.761, $p < 0.001$

4.4 Data Analysis

4.4.1 Study I:

Thematic analysis approach was employed due to the study's exploratory nature and the lack of prior studies in the Palestinian context. Verbatim transcriptions of audio records were done in Arabic after each interview session. A bilingual expert translated all interviews from Arabic into English. Confidentiality was ensured during the translation process. All transcripts were reviewed by a bilingual health professional to avoid translation bias.

The data analysis followed Braun & Clarke's (2006) six-phase framework for thematic analysis, interpreted through a phenomenological lens. This framework includes the following steps: becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining themes, and writing up the analysis (Braun & Clarke, 2006; Naeem et al., 2023). Data familiarization was achieved by thoroughly reviewing each Arabic transcript many times, while noting initial impressions (phenomenological reduction). To generate initial codes and themes, the first author and another independent interpreter analyzed the data independently identifying meaning units (noetic-noematic analysis). The data coding process involved thoroughly organizing the information into thematic tables, categorizing it into themes and subthemes (Table 4.3). Codes were clustered into themes reflecting invariant structures of the lifeworld (e.g., "psychosocial burden"). Themes were refined through iterative dialogue, ensuring they captured the essence of participants' experiences (eidetic reduction). Relationships between themes (e.g., stigma and emotional hardship) were mapped (Fig. 4.1). Quotes illustrated each theme while preserving participants' voices. The field notes were additionally examined to enhance the significance of the findings (Appendix 1, Table S 1). The second author checked the interpretations to avoid selective reporting bias and conducted co-coding to complete the themes and subthemes. To maintain anonymity, identifying pseudonym numbers were utilized instead of the actual names of the participants while creating the findings as, P1, P2, …., P12. The data analysis procedure was carried out iteratively, following qualitative research criteria to credibility and rigor of the findings. To ensure phenomenological rigor, researchers kept reflexive journals to bracket biases during analysis; indicated intersubjective validation through co-coding and peer debriefing; confirmed interpretations; and employed thick descriptions where quotes provided "windows" into participants' lifeworlds (Pacheco & Fossa, 2024). Peer debriefing was employed to enhance analytical rigor. A second researcher independently coded a subset of transcripts and compared findings with the primary coder. The process resulted in strong alignment on core themes, with minor variations discussed and reconciled collaboratively. This strengthened the credibility of the analysis and ensured that themes were reflective of participants lived experiences rather than researcher preconceptions.

Credibility was ensured through several strategies. Member checking was conducted by sharing the preliminary thematic summaries with a subset of participants to confirm that the interpretations accurately reflected their lived experiences; their feedback was used to refine and validate the final themes. An audit trail was maintained through the research process, including documentation of coding decisions, reflexive journal entries, and analytic memos, allowing for transparency and traceability of interpretive steps. The study adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong et al., 2007), ensuring methodological transparency in reporting aspects such as researcher reflexivity, sampling, data collection, and analysis procedures. Confirmability was achieved

through verbatim transcripts and co-coding, while dependability was supported by detailed method documentation. Example from the analytical process is presented in Table 4.3.

Table 4.3: Examples from the analytical process in Study I

Theme	Subtheme	Code	Data Extract	Quote
Disruption of the Emotional and Social Lifeworld	Emotional Disturbance as Lived Anxiety and Powerlessness	Depression	Crying and depression from having epilepsy	*"When I sit alone and start thinking about my condition, I feel depressed and afraid that someone outside my family might find out and my secret will be exposed. Who would want to marry my daughters after that?"*
Healthcare Encounters as Structures of Meaning-Making	The Lived Meaning of Professional Care—Between Empathy and Neglect	Bad counseling and treatment experiences	Not knowing the treatment plan and side effects of the drugs	*"The neurologist was not a nice part of my life, it always bothered me because he didn't explain to me and didn't tell me what the nature of my seizures was… and I don't understand what the side effects of my medications are."*

4.4.2 Study II:

Data was analyzed using IBM Statistical Product and Service Solutions (SPSS) version 25. Descriptive statistics were employed to summarize the overall knowledge levels, attitudes, and practices of health practitioners in percentage. Continuous data were reported by means and standard deviations (SD), and categorical data were provided as n (%). The non-parametric Mann-Whitney and Kruskal-Wallis tests were conducted to analyze KAP scores according to demographic variables. Pearson's correlation (r) and multivariate regression analysis were carried out to analyze relationships between the KAP outcomes and participants' demographics. The p value ≤ 0.05 was chosen as the level of statistical significance for all analyses.

4.4.3 Study III:

Descriptive statistics were utilized to describe the overall knowledge levels, attitudes, and self-efficacy of health practitioners in (%). Data were examined for normal distribution using Shapiro-wilk normality testing and normality values of skewness and kurtosis indicated that data were not normally distributed. This might be attributed to the relatively small sample size of the study (n=68). For continuous variables, summary statistics were obtained and presented as median (inter quartile range [IQR]). Mann-Whitney U and Wilcoxon signed-rank tests were conducted to analyze between-group and within-group changes, respectively. Statistical analyses were conducted utilizing SPSS version 25.0 was used to perform these tests (IBM Corp., 2017). Quade's ANCOVA was performed using R-4.5.0 version to detect group differences in post-intervention scores while controlling for baseline scores, using

ranked data to account for the non-normal distribution. P value ≤ 0.05 was chosen as the level of statistical significance. Effect sizes (e.g., partial eta squared) were also reported to assess the practical significance of the intervention.

4.5 Ethical considerations

Approvals for the study was ethically approved by the Research Ethics committee at Al-Quds University (ref. 12/24), and the MOH (ref. 162/550/2024) for study I and II while study III was approved by the Research Ethics committee at Al-Quds University (ref. 5/25) (Appendix 2). Ethical guidelines and principles were considered through all stages of the research process as addressed by Declaration of Helsinki (World Medical Association, 2013). All participants were provided with both oral and written information regarding the study, emphasizing its voluntary nature and the possibility to withdraw without justification. All participants provided verified oral or written consent, as gathered by the researcher. No incentives were provided to PHC professionals for disseminating information about the research, and participants did not receive reimbursement for their involvement. The participants were reassured of the confidentiality and anonymity of their participation.

Chapter Five

Results

This section presents the findings from the three consecutive studies that comprise this research. The results of each study are reported separately to demonstrate their specific objectives, methodologies, and data sources.

5.1 Results of Study I

Overall, 12 in-depth interviews were conducted out of 43 participants with a 27.9% response rate. This is moderate response rate for qualitative research, especially in sensitive topics like epilepsy, where stigma and discomfort discussing personal experiences might discourage participation. The participants' ages ranged from 20 to 67 years. Seven participants were males. Participants were classified as single, married, or divorced in terms of marital status. The socio-demographic characteristics of the participants are detailed and summarized in Table 5.1. The demographic variability provided diverse perspectives, consistent with the study's phenomenological approach to exploring the lived experiences of epilepsy.

Table 5.1: Summary of demographic characteristics of study participants (n = 12)

Major characteristic	**Sub-category**	**Frequency (%)**
Sex	Male	7 (58.3%)
	Females	5 (41.7%)
Age	20–29	5 (41.7%)
	30–39	3 (25.0%)
	40–49	3 (25.0%)
	50+	1 (8.3%)
Marital status	Married	5 (41.7%)
	Divorced	1 (8.3%)
	Single (Never married)	6 (50.0%)
Region	Southern West Bank	5 (41.7%)
	Middle West Bank	3 (25.0%)
	Northern West Bank	4 (33.3%)
Employment	Student	2 (16.7%)
	Employed	6 (50.0%)
	Unemployed	4 (33.3%)
Number of drugs taken	One drug	6 (50.0%)
	More than one drug	5 (41.7%)
	Unrevealed	1 (8.3%)

After implying the phenomenological reduction and eidetic analysis, three essential structures of the lifeworld emerged, reflecting the invariant features of the lived experience of epilepsy among Palestinian adults: (1) Disruption of the Emotional and Social Lifeworld, (2) Healthcare Encounters as Structures of Meaning-Making and (3) Intentional Coping and Sources of Support in the Lived Body. These themes were not predetermined but emerged inductively through an eidetic examination of participants' descriptions of their lived realities. These themes and subthemes were developed inductively from the narratives of participants following Braun & Clarke's six-step framework rather than being predefined. Table 5.2 summarizes the emergent themes and subthemes. Table 5.3 provides a sample of the quotes that were used in generating the themes and subthemes.

Table 5.2: All emerged themes and subthemes

Theme	Subthemes	Key Findings
Disruption of the Emotional and Social Lifeworld	Emotional Disturbance as Lived Anxiety and Powerlessness	Depression, fear of seizures, denial of diagnosis, family stress.
	Social Alienation and the Gaze of the Other	Stigma (exclusion), misconceptions ("craziness"), hiding epilepsy.
	Cognitive Disruption and Academic Vulnerability	Academic struggle, AED-related cognitive side effects (e.g., alertness issues).
Healthcare Encounters as Structures of Meaning-Making	The Lived Meaning of Professional Care—Between Empathy and Neglect	Poor counseling, mistrust in providers, unmet needs, and non-adherence to treatment.
		Empathetic care, effective counseling, patient motivation.
	The Body as Site of Conflict—Adverse Effects of AEDs	Physical (fatigue, kidney injury), psychological (mental deterioration).
Intentional Coping and Sources of Support in the Lived Body	Familial Support as Embodied Belonging	Spouses, parents, siblings, and friends provide emotional/practical help.
	Faith and Complementary Practices as Acts of Meaning-Making	Avoid triggers, multivitamins, therapy, religious practices.

Table 5.3: Illustrative quotes for different subthemes

Theme / Subtheme	Illustrative quote
Theme 1: Disruption of the Emotional and Social Lifeworld	
1.1 Emotional Disturbance as Lived Anxiety and Powerlessness	*"This condition (epilepsy) is not like other diseases. Sometimes I wish I had a heart problem instead, and then I will not feel this amount of helplessness."* Male, 25 years old.
1.2 Social Alienation and the Gaze of the Other	*"I don't have close friends with whom I can talk about my condition (epilepsy). But honestly, I don't trust friends. I swear that stigma surrounds us."* Female, 41 years old.
1.3 Cognitive Disruption and Academic Vulnerability	"*There is a lot of stuttering in my speech, and I need time until the word comes out, as you see."* Male, 23 years old.
Theme 2: Healthcare Encounters as Structures of Meaning-Making	
2.1 The Lived Meaning of Professional Care—Between Empathy and Neglect	*"I should have had psychological care because I needed it. But the doctor was not interested in psychological aspects.* Female, 35 years old.
	"The doctor always asks me about my medicine and if there is anything wrong and adjusts my dose." Male, 40 years old.
2.2 The Body as Site of Conflict—Adverse Effects of AEDs	*"The doctor prescribed it (drug) to me, which I had not seen before. My mental state deteriorated, and I started having seizures."* Female, 23 years old.
Theme 3: Intentional Coping and Sources of Support in the Lived Body	
3.1 Familial Support as Embodied Belonging	*"My mother is my main supporter and caregiver"* Female, 36 years old.
3.2 Faith and Complementary Practices as Acts of Meaning-Making	*"Al-fajr prayer (prayer at dawn) helps me relax and takes the negative energy out of me. And seizures happen less to me."* Male, 67 years old.

Theme 1: Disruption of the Emotional and Social Lifeworld

All participants experienced at least one unfavorable psychosocial experience as a result of their epilepsy. This theme highlights the impact of epilepsy on participants' consciousness as a source of emotional burden, social marginalization, and existential insecurity. The intentional acts of perceiving, feeling, and interpreting epilepsy as part of the self were often exaggerated by fear, shame, and a diminished sense of agency. Participants confirmed that the unpredictable seizures and the gaze of others reshaped their sense of identity and affected their lifeworlds. The participants characterized these distressing encounters under three subthemes.

Subtheme 1: Emotional Disturbance as Lived Anxiety and Powerlessness

The uncertainty and unpredictable nature of seizures in epilepsy creates substantial emotional challenges for people living in this condition. This impaired their sense of temporal stability and bodily autonomy. The seizure exceeded just a medical incident, functioning as a noema—an object of consciousness—that defined their lived experience with anticipation, fear, and helplessness. Eight participants expressed passing through phases of sadness and feelings of helplessness and frustration for being diagnosed with epilepsy. All participants experienced feeling burdened by one or more negative emotions or physical distress due to the possibility of having unpredicted seizures:

> *"Sometimes, when I'm sitting alone, I start crying…"* Female, 36 years old.

> *"I'm not sure when it (the seizure) will happen. It appears unexpectedly every four or five days" Male, 20 years old.*

Many participants exhibited noetic denial of their illness as a defensive mechanism, indicating a disconnection between their embodied self and diagnostic label. This fostered a situation where patients were likely to deny their epilepsy diagnosis (6 participants).

> *"I have only increased electrical activity in the brain; my brain can't handle the existing energy."* Male, 21 years old.

> *"Honestly, I am convinced that I have nerve issues, not epilepsy."* Male, 20 years old.

Also, four participants expressed feeling that they are a burden on their families and a constant source of fear and anxiety for their loved ones. This sensation of burden influences the embodied vulnerability of the participants. Feeling that their families are always worried and nervous reduces their self-esteem and promotes fear and isolation.

> *"When the seizure happens, it causes a state of panic at home."* Male, 67 years old.

> *"My mother is always concerned that others will learn about my condition and that I won't get married."* Female, 23 years old.

Subtheme 1.2: Social Alienation and the Gaze of the Other

Living with epilepsy can be extremely challenging due to the societal conceptions of epilepsy that individuals face. These lead to self-stigma, concealment, reduced quality of life, and social seclusion. Each participant experienced one or more of these features. These experiences were not passive; rather, they were actively shaped through multiple experiences with judgment and rejection. The social lifeworld, previously regarded as shared, emerged as a source of risk and exclusion. Suffering from stigmatization was reported by the majority of participants. Most participants described how society uses derogatory terms to characterize PWE, such as treating them like they are mentally retarded or dangerous.

> *"Many people use the term epilepsy to describe mentally retarded people."* Female, 41 years old.

> *"The name of the disease scares people and makes people think that the patient with epilepsy is crazy, and you become afraid that it will affect your life in terms of work or study."* Female, 35 years old.

Almost half of the participants also faced different forms of social exclusion. For instance, they encountered rejection from others, which prevented them from forming friendships, romantic relationships, or marriages.

> *"People don't want to marry a girl with epilepsy; they are afraid that their children will be born insane."* Female, 23 years old.

> *"Some people got scared and close friends and family started pulling away because they thought they might not be safe."* Male, 20 years old.

> *"Many girls refused to marry me because I might harm them, and their parents are concerned about their daughter's safety with me."* Male, 33 years old.

The fear of the public gaze and its impact on social roles (e.g., marriage, work) led participants to engage in intentional acts of hiding their diagnosis:

> *"I don't have close friends with whom I can talk about my condition (epilepsy). But honestly, I don't trust friends. I swear that stigma surrounds us."* Female, 41 years old.

Subtheme 1.3: Cognitive Disruption and Academic Vulnerability

The majority of the participants reported experiencing difficulties or challenges related to cognitive embodiment, learning, and intellectual tasks both from seizures and AED side effects. These problems were integral to the noematic content of their epilepsy experiences. The seizure-related symptoms were related to their self-esteem and academic identity. Half of the participants reported passing through negative experiences because of the recurrence of uncontrolled seizures or related circumstances. Others describe experiencing learning or intellectual difficulties because of taking AEDs. The following narratives illustrate the challenges faced in academic settings:

"I struggled with assembling words into sentences... I find it hard to organize words into sentences... I barely succeeded in the languages in high school." Male, 23 years old.

"I always stop taking the medicine before the exams because I fall asleep and forget all that I studied." Female, 23 years old.

One participant lost his undergraduate scholarship to study courses of his interest and suffered from psychological setbacks. This loss reflected deep existential disruptions that transcended simple memory lapses, instead affecting their projected futures and life plans.

"Unfortunately, as a result, I lost my scholarship in the exchange program. They changed my medication, and I had to return to Palestine. I was traveling to take physics courses that are not available in my country…" Male, 21 years old.

Theme 2: Healthcare Encounters as Structures of Meaning-Making

Healthcare interactions were not experienced neutrally but were influenced by intentional awareness, shaped by support, empathy, and anticipations of recognition. These experiences either improved or disrupted the feeling of coherence and agency of the participants throughout their journey of epilepsy.

Subtheme 2.1: The Lived Meaning of Professional Care—Between Empathy and Neglect

Participants reported experiences that varied from highly rewarding to intensely discouraging. In situations where providers exhibited empathy and effective communication, participants underwent intersubjective healing, resulting in a restoration of trust in both themselves and the healthcare system. These positive relationships were noetically constituted as secure spaces fostering self-acceptance and optimism. Only four participants emphasized good relationships and belief in the healthcare staff, highlighting the positive role of trust and rapport in shaping their healthcare experiences. For PWE, sympathetic, responsive, and encouraging healthcare staff offered psychological comfort and stability during periods of social stigma and dread. Those whom doctors listened to and valued felt more in charge of their health and more willing to adhere to treatments. Usually, good experiences resulted in reduced clinical anxiety, higher confidence in the healthcare system, and an improved perspective on long-term medical management.

"The doctor told me that I will get special skills and true, I am excellent in Mathematics." Male, 23 years old.

"My doctor told me it's normal, there's nothing wrong. He told me that Napoleon had the same thing but still conquered the world. I always remember these words." Male, 21 years old.

"The doctor always asks me about my medicine and if there is anything wrong and adjusts my dose." Male, 25 years old.

The lack of psychological responsiveness or clinical engagement resulted in existential discomfort, reducing participants' confidence in the healthcare system. The lack of adequate knowledge, negative attitudes, and diagnostic delays manifested as noematic contents of frustration and neglect. The majority of the participants expressed negative experiences with healthcare professionals. Some participants encountered difficulties during diagnosis, while others indicated a preference for seeking medical advice or counseling outside the country, reflecting concerns about the quality and reliability of local services.

> *"...my father preferred to follow up with a doctor in Jordan, not here."* Male, 23 years old.

> *"The neurologist was not a nice part of my life, it always bothered me because he didn't explain to me and didn't tell me what the nature of my seizures was... and I don't understand what the side effects of my medications are."* Female, 41 years old.

> *"I feel that in our hospitals, the nurses and medical staff don't have enough information. I changed many doctors even though my condition is very clear, but it took them more than two months to figure it out"* Male, 21 years old.

> *"Not everyone in the health staff knows how to deal, sometimes they accept my illness"* Male, 20 years old.

Subtheme 2.2: The Body as Site of Conflict—Adverse Effects of AEDs

The majority of patients underwent intervals of discontinuing and resuming their treatment. The problems were mostly related to the adverse effects of AEDS, particularly constant drowsiness, which restricted their daily functioning. Some participants reported more serious medical effects, including the development of kidney-related complications, which they attributed to prolonged use of drugs. These incidents affected not only adherence but also shaped a complex relationship with treatment characterized by anxiety and dissatisfaction.

> *"I always stop taking the medicine before the exams because I fall asleep and forget all that I studied."* Female, 41 years old.

> *"My mental state deteriorated, and I started having seizures. I went to the hospital and stayed for 6 days. Then the doctors decided to switch my drug."* Female, 23 years old.

> *"I stopped the drugs because they make my kidneys injured, but the seizures came back. I then was forced to continue the drug"* Male, 20 years old.

Theme 3: Intentional Coping and Sources of Support in the Lived Body

PWE often face unique challenges in their daily lives and may require a range of coping strategies to manage the condition effectively. This theme focuses on the structures of resilience that participants developed for the purpose to keep their emotional grounding, meaning, and stability. When people felt isolated and that their bodies were unpredictable

and uncontrollable, they turned to familial support, faith-based practices, and alternative therapies as lifeworld anchors that made them regain the sense of wholeness.

Subtheme 3.1: Familial Support as Embodied Belonging

The participants' narratives intimately link the daily struggles with life in the extended family. Parents play a major role in helping the participants accept the illness, reduce difficulties from the time of diagnosis, throughout the treatment journey, and continue to support them throughout their lives, acting as their advocates and believers in them. Participants described those family members as their existential companions for their role in helping them to overcome uncertainty and anxiety. Familial interactions stood for intersubjective places where PWE may comfortably live with their vulnerabilities. Some participants mentioned receiving social and emotional support from their friends. They confirmed that they needed their friends around them all the time to help them handle sudden seizures and protect them. Married participants emphasized the importance of receiving support and confidence from spouses, whether husbands or wives, in addition to maintaining the condition's confidentiality from others. Married participants stated that they accept, understand, and work to cover the family's financial needs.

> "*I am proud of them and thankful to my family for this support, they always wanted to listen to me even if I was weaker than others*." Female, 23 years old.

> *"I told him (husband) that I have this problem and that it might stay with me forever. His reaction was normal and understanding; he was positive, and he accepted it.*" Female, 35 years old.

> *"My father was my biggest supporter; he always came with me to the doctor and for the brain scans."* Female, 43 years old.

Subtheme 3.2: Faith and Complementary Practices as Acts of Meaning-Making

Religious coping can take many forms, such as prayer, meditation, and seeking guidance from religious leaders. This type of coping can be particularly important for adults with epilepsy, who may find that their faith provides a sense of stability and purpose as they face the challenges of their condition. Most participants declared having faith, accepting their condition as a gift from God, and practicing religious acts to help them cope with epilepsy and live their daily lives. The following participant recounted the positive outcomes of strengthening his relationship with God and engaging in religious activities:

> *"Prostration became a habit for me……and I have improved a lot with prostration."* Male, 25 years old.

Some participants reported attempting various therapies, including psychological support, energy therapy, and using food supplements to improve their health status as detailed in the following narratives.

"Yes, I went to a therapist for two years. I would sit and talk, even bring up topics like why my hair was curly and why I didn't like it. Currently, I am very stable and have psychological support from my friends and from where I live." Female, 23 years old.

"I wear a silver bracelet and tried having energy sessions." Male, 33 years old.

These practices illustrate how participants intentionally constituted meaning through diverse modalities of care that extended beyond biomedical frameworks.

5.2 Results from Study II

A total of 351 responses were obtained from the survey. The responses of 51 questionnaires were excluded because of logical discrepancies. The study effectively collected 300 valid questionnaires, resulting in a response rate of 85.5%.

The majority of participants were female (74.3%) and (42.0%) in the age range of 40 to 49 years old. Nearly half of the participants were nurses (56.0%) and have bachelor's degrees in their field (57.0%). A substantial percentage worked in Southern governorates (41.7%) and possessed clinical experience in PHCs for less than 10 years (43.3%) (Table 5.4).

The average scores for KAP were 6.34 ± 2.57 (range: 0–10), 36.87 ± 4.55 (range: 10–50), and 46.73 ± 6.92 (range: 12–60), respectively. Male participants exhibited significantly higher knowledge scores ($p = 0.002$), as did those with higher educational degree ($p < 0.001$). Doctors had significantly higher knowledge scores ($p < 0.001$). Participants in the 30- to 39-year-old age group had higher attitude scores ($p = 0.045$), as did those with over 20 years of experience ($p = 0.017$). Psychologists demonstrated the highest practice scores among other health practitioners in PHCs ($p = 0.036$) (Table 5.4). All scores are displayed in Appendix 1, Table S 2.

Table 5.4: Participants' demographic characteristics (n = 300)

	N	(%)	Knowledge score		Attitude score		Practice score	
			Mean ± SD	*P*	Mean ± SD	*P*	Mean ± SD	*P*
Overall	300	100	6.34 ± 2.57		36.87 ± 4.55		46.73 ± 6.92	
Gender				0.002*		0.590		0.580
Male	77	25.7	7.06 ± 2.61		36.47 ± 5.51		46.55 ± 6.48	
Female	223	74.3	6.10 ± 2.52		37.01 ± 4.17		46.80 ±7.08	
Age groups				0.116		0.045*		0.258
20 – 29 years	56	18.7	5.96 ± 2.50		35.14 ± 5.59		46.14 ± 5.51	
30 – 39 years	71	23.7	6.79 ± 2.56		38.11 ± 4.25		46.69 ± 6.10	
40 – 49 years	126	42.0	6.44 ± 2.55		36.71 ± 4.61		45.15 ± 7.99	
≥ 50 years	47	15.7	5.87 ± 2.67		37.51 ± 2.32		47.98 ± 6.55	
Clinical experience				0.574		0.017*		0.077
≤ 10 years	130	43.3	6.31 ± 2.60		36.15 ± 4.77		46.07 ± 6.40	
11 – 20 years	106	35.3	6.47 ± 2.69		37.06 ± 4.63		46.73 ± 7.73	
≥ 21 years	64	21.3	6.20 ± 2.32		38.03 ± 3.65		48.09 ± 6.39	
Education /Qualification				0.000*		0.536		0.709
Diploma	74	24.7	5.45 ± 2.38		36.68 ± 4.09		46.62 ± 6.88	
Bachelors	171	57.0	6.20 ± 2.51		36.73 ± 4.82		46.92 ± 7.10	
Higher education	55	18.3	7.98 ± 2.28		37.58 ± 4.28		46.29 ± 6.48	
Profession				0.000*		0.324		0.036*
Doctor	38	12.7	8.37 ± 1.95		36.08 ± 5.27		46.71 ± 5.51	
Pharmacist	87	29.0	7.06 ± 2.27		36.89 ± 3.63		45.19 ± 7.23	
Nurse	168	56.0	5.55 ± 2.51		36.95 ± 4.85		47.41 ± 7.04	
Psychologist	7	2.3	5.57 ± 2.23		39.29 ± 2.63		49.71 ± 3.30	
District				0.792		0.555		0.204
North	100	33.3	6.41 ± 2.60		37.00 ± 3.80		47.14 ± 7.99	
Middle	75	25.0	6.45 ± 2.58		37.35 ± 4.10		45.65 ± 6.91	
South	125	41.7	6.22 ± 2.56		36.49 ± 5.30		47.06 ± 5.92	
* Significant differences in respondent scores within each category (p-value ≤ 0.05)								

The statement with the highest scores for the knowledge items was "Body convulsions are a sign of epilepsy" at 96.00%. Conversely, the two items with the lowest scores were: "Involuntary urination is a sign of epilepsy" at 25.67% and "Dizziness and vertigo are common side effects of AEDs" at 26.00% (Figure 5.1).

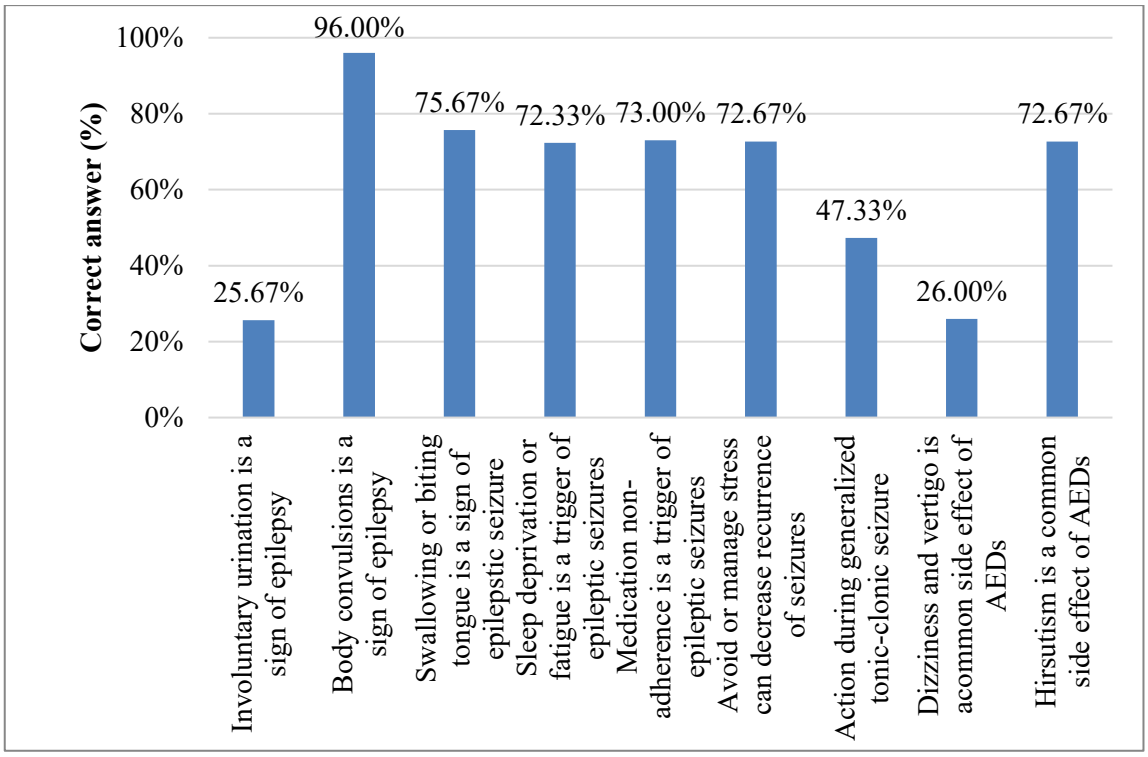

Figure 5.1: Knowledge scores in percentages of participants (n = 300)

A substantial majority (94.7%) indicated a favorable attitude, highlighting the significance for adherence to AEDs (Figure 5.2). The favorable attitudes were considered as the sum of the percentages of both totally agree and agree responses. Almost all participants (94.7%) expressed that PWE can live a normal life if they adhere to treatment Conversely, the lowest percentage (14.7%) expressed disapproval of social seclusion of PWE (more details in Appendix 1, Table S 3).

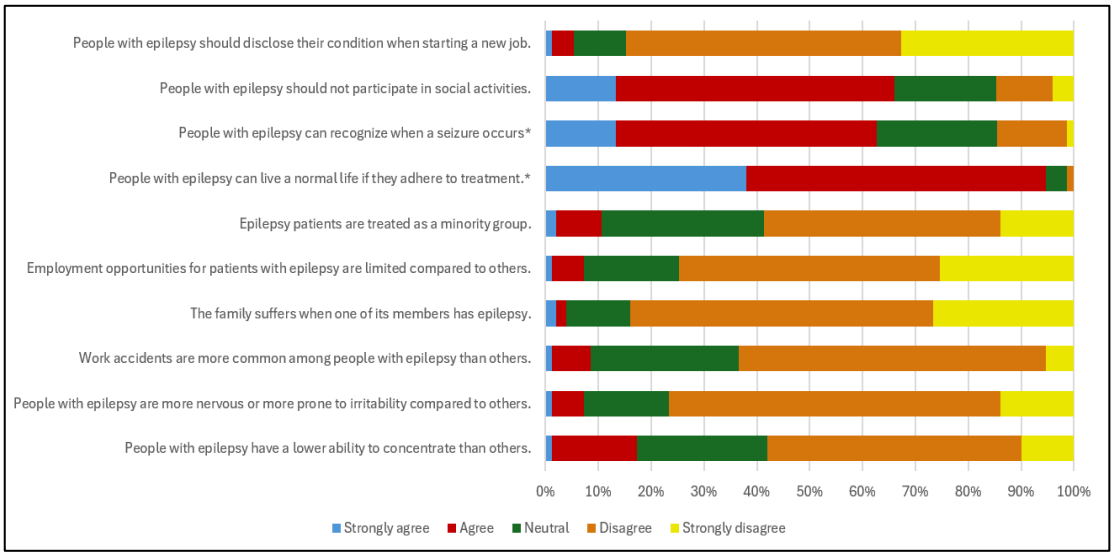

Figure 5.2: Attitudes in percentages of participants (n = 300)

Regarding practice, the highest proportion of participants (88.6%) helped the patient in setting goals for improving epilepsy management (Figure 5.3). In contrast, only 8.70% adjust AEDs without referring the patient to a specialist, and 58% tend to adjust the AED regimen without checking its blood serum level (more details in Appendix 1, Table S 4).

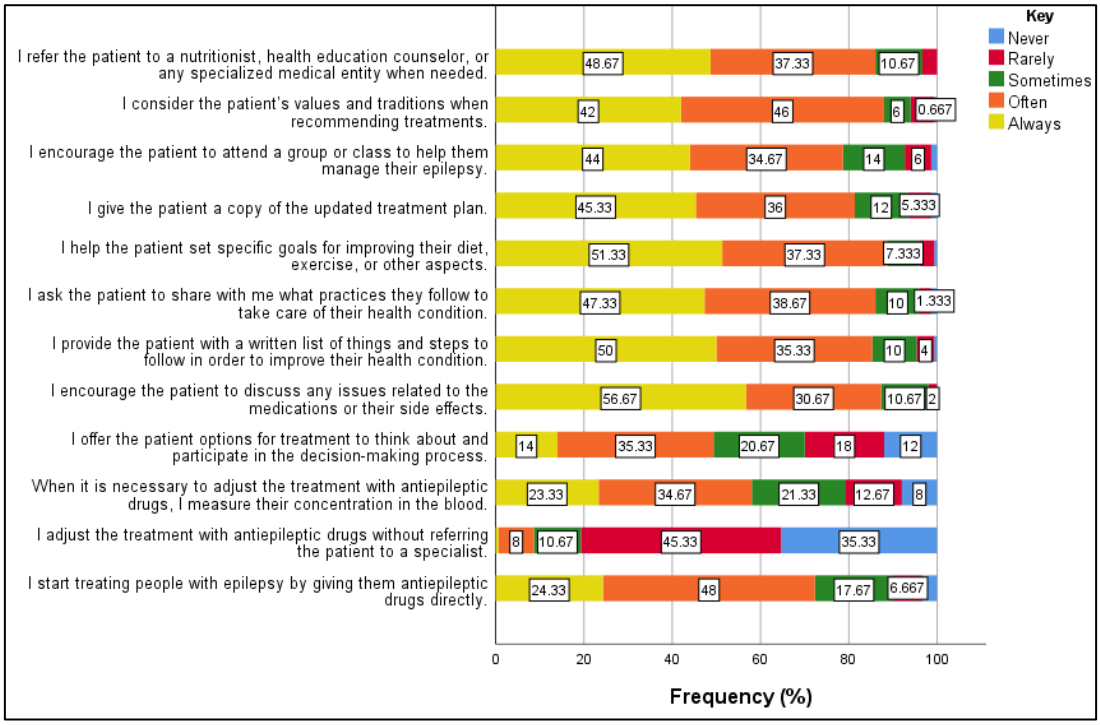

Figure 5.3: Participant's practice scores in percentages (%) (n = 300)

The Pearson correlational analysis was conducted to evaluate the relationship between KAP. The analysis indicated a negative correlation between knowledge and practices ($r = -0.170$, $p < 0.01$). A positive correlation was observed between attitude and practice scores ($r = 0.279$, $p < 0.01$) (Table 5.5).

Table 5.5: Pearson's correlation matrix of KAP of participants

Variable	**Knowledge**	**Attitude**	**Practice**
Knowledge	1		
Attitude	-0.046	1	
Practice	-0.170*	0.279*	1

*Correlations between all variables (%) are significantly different at $P < 0.01$

Multivariate analysis showed that being female was negatively associated with knowledge score (OR = 0.640, 95% CI: 0.020–1.260, p = 0.043), indicating lower odds of higher knowledge compared to males. Similarly, nurses (OR = 0.497, 95% CI: 0.099–0.841, p < 0.001) and psychologists (OR = 0.501, 95% CI: 0.149–0.853, p = 0.034) had significantly

lower knowledge scores compared to physicians. Practitioners with a bachelor's degree or higher had lower odds of achieving higher knowledge scores compared to those with lower educational attainment (OR = 0.822, 95% CI: 0.182–1.462, p = 0.012). However, the confidence interval crosses 1.0, suggesting this result should be interpreted with caution despite the significant p-value. On the other hand, participants aged 30-39 years old (OR = 2.552, 95% CI: 0.974 - 4.130, p = 0.002), and those with more than 21 years of experience (OR = 2.387, 95% CI: 0.546 - 4.227, p = 0.011) all showed positive associations with attitudes score (Table 5.6) (univariate analysis in Appendix 1, Table S 5).

Table 5.6: Multivariate analysis of knowledge and attitudes of participants (n = 300):

Domain	**Knowledge**		**Attitude**	
	OR (95%CI)	**P**	**OR (95%CI)**	**P**
Gender				
Male	ref.			
Female	-0.640 (-1.260, -0.020)	0.043*		
Age groups				
20 – 29 years			ref.	
30 – 39 years			2.552 (0.974, 4.130)	0.002*
40 – 49 years			0.212 (-1.606, 2.031)	0.818
≥ 50 years			0.242 (-1.999, 2.483)	0.832
Clinical experience				
≤ 10 years			ref.	
11 – 20 years			1.152 (-0.318, 2.621)	0.124
≥ 21 years			2.387 (0.546, 4.227)	0.011*
Education /Qualification				
Diploma	ref.			
Bachelors	0.822 (0.182, 1.462)	0.012*		
Higher education	2.128 (1.294, 2.963)	0.000*		
Profession				
Doctor	ref.			
Pharmacist	-0.650 (-1.569, 0.269)	0.165		
Nurse	-1.970 (-2.841, -1.099)	0.000*		
Psychologist	-2.001 (-3.853, -0.149)	0.034*		

5.3 Results of Study III

One hundred healthcare professionals were invited conveniently to participate in the training. Of these, 80 provided written informed consent and were subsequently randomized as intervention group (n = 40) and control group (n = 40) using a computer-generated randomization process. Of the 80 randomized participants, 32 in the intervention group completed the training and both pre- and post-test assessments. In the control group, 36 participants completed both assessments, yielding an overall response rate of 68%.

The majority of participants were female (61.8%) and (36.8%) in the age range of 40 to 49 years old. Almost half of the participants were nurses (45.6%) and have bachelor's degrees in their field (58.8%). Table 5.7 summarizes the demographic characteristics, previous epilepsy training, and clinical experience with epilepsy management for both the intervention and control groups.

Table 5.7: Characteristics of participants (both intervention and control groups

Descriptive	**Intervention group (n=32)**		**Control group (n = 36)**	
	N	**(%)**	**N**	**(%)**
Gender				
Male	11	(34.4)	15	(41.7)
Female	21	(65.6)	21	(58.3)
Age (in years)				
20 – 29	7	(21.9)	10	(27.8)
30 – 39	9	(28.1)	6	(16.7)
40 – 49	12	(37.5)	13	(36.1)
more than 50	4	(12.5)	7	(19.4)
Experience (in years)				
1 – 9	12	(37.5)	19	(52.8)
10 – 19	9	(28.1)	8	(22.2)
more than 20	11	(34.4)	9	(25.0)
Educational degree				
Diploma	5	(15.6)	7	(19.4)
Bachelor’s degree	18	(56.3)	22	(61.1)
Higher education	9	(28.1)	7	(19.4)
Profession				
Doctor	9	(28.1)	10	(27.8)
Pharmacist	9	(28.1)	9	(25.0)
Nurse	14	(43.8)	17	(47.2)
Previous training on epilepsy				
Yes	3	(9.4)	6	(16.7)
No	29	(90.6)	30	(83.3)
Previous experience in treating PWE				
Yes	32	(100)	36	(100)
No	0	(0)	0	(0)

The baseline (pre-training) data collection was conducted in February 2025 before the training course, and the post-training data collection was conducted in April 2025. Table 5.8 presents the median scores and interquartile ranges for knowledge, attitudes, and self-efficacy before and after 2 months post training, along with the results of Wilcoxon signed-rank tests within each group. In the intervention group, knowledge scores significantly increased from pre- to post-intervention (median = 7.0, IQR = 5.25 to median = 8.5, IQR = 1.75; Z = -2.97, p = 0.003). No significant change was observed in the control group (Z = -1.22, p = 0.222). No significant differences in attitudes were found between pre- and post-intervention assessments in either group (p > 0.05). The Wilcoxon signed-rank test showed a significant increase in self-efficacy scores from baseline (median=49.50 [IQR 12.0]) to

post-intervention (median =51.50 [IQR 10.00]), Z = -4.93, p <0.001. In contrast, no significant change in self-efficacy was found in the control group (Z = -0.22, p = 0.823).

Table 5.8: Knowledge, attitudes and self-efficacy before and after training (within-group change) (pre vs. post)

Variable	Intervention group						Control Group					
	Pre		Post		Z	*P*	Pre		Post		Z	*P*
	Median	IQR	Median	IQR			Median	IQR	Median	IQR		
Knowledge	7.00	5.25	8.50	1.75	-2.97	0.003*	7.50	5.75	8.00	3.00	-1.22	0.222
Attitudes	37.50	7.75	37.50	7.00	-0.09	0.926	37.00	5.00	38.00	5.00	-0.09	0.925
Self-efficacy	49.50	12.0	51.50	10.0	-4.93	<0.001*	47.00	7.50	47.00	7.00	-0.22	0.823

*Significant value at p < 0.01

Post-intervention differences between intervention and control groups

Mann-Whitney U test was performed to compare the post-intervention scores between the intervention and control groups on knowledge, attitudes, and self-efficacy (Table 5.9). The difference in knowledge between the two groups was not statistically significant (Z = -0.608, p = 0.543), with a very small effect size (0.07), indicating minimal practical difference in knowledge scores. Similarly, no significant difference was found in attitude scores (Z = -0.296, p = 0.768), with a very small effect size (0.04), suggesting negligible impact on attitudes between groups. On the other hand, a statistically significant difference was observed in self-efficacy scores (Z = -2.806, p = 0.005), with a medium effect size (0.34). This suggests that the intervention had a moderate and meaningful impact on improving self-efficacy among participants in the intervention group compared to the control group. These results were similar to Quade's ANCOVA test when comparing the post-intervention scores after adjusting the baseline data as a covariate (Table 5.10).

Table 5.9 displays the results of the Mann-Whitney U test comparing post-intervention scores between groups. Only self-efficacy showed a statistically significant difference, favoring the intervention group.

Table 5.9: Mann-Whitney U test between intervention and controls

Item	Z	P value	Effect[a]
Knowledge	-0.608	0.543	0.07 → very small effect
Attitudes	-0.296	0.768	0.04 → very small effect
Self-efficacy	-2.806	0.005*	0.34 → medium effect

*Significant value at p < 0.01
[a]Eta partial squared η^2 is the effect size reported

Post-intervention comparisons revealed a statistically significant improvement in self-efficacy in the intervention group compared to the control group ($Z = -2.806$, $p = 0.005$, effect size = 0.34). No significant differences were observed in knowledge or attitudes.

To account for baseline differences, Quade's ANCOVA was conducted using pre-intervention scores as covariates (Table 5.10). The analysis confirmed a significant effect of the intervention on self-efficacy ($F(1,65) = 7.67$, $p = 0.007$), with no significant effects observed for knowledge or attitudes.

Table 5.10: Quade's ANCOVA test between intervention and controls

Outcome	**F (df=1,65)**	**p-value**	**Effect[a]**
Knowledge	2.97	0.090	0.04
Attitudes	0.05	0.822	0.001
Self-Efficacy	7.67	0.007*	0.15

*Significant value at $p < 0.01$
[a]Eta partial squared η^2 is the effect size reported

Chapter Six

Discussion

This study includes discussion of all parts of the dissertation, conclusion, limitations and recommendations.

6.1 Discussion

This dissertation investigated epilepsy care in the West Bank, Palestine, employing a sequential mixed-methods approach. The three interrelated studies explored were (1) the lived experiences of PWE, (2) the KAP of healthcare providers in managing epilepsy, and (3) the efficacy of mhGAP-based educational interventions in improving providers' knowledge, attitudes, and self-efficacy. The findings undertaken together provide robust, contextually based knowledge of the multi-layered challenges facing epilepsy care and highlight strategic points regarding priorities for strengthening health systems and patient-centered reforms.

6.1.1 Integration of Patient Narratives and Provider Realities:

The qualitative findings of Study I present a compelling illustration of the psychosocial, existential, and healthcare-related burden PWE experience. Participants indicated that their social relationships, emotional well-being, and interactions with the healthcare system were significantly influenced by their stigmatized identity as much as by their medical condition, epilepsy. These findings suggest that participants' interactions with the healthcare system were shaped not only by the clinical manifestations of epilepsy but also by the social stigma attached to the condition (Mayor et al., 2022; Shi et al., 2021). Stigmatized identity influenced how individuals were perceived and treated by healthcare professionals, often leading to feelings of being dismissed, misunderstood, or inadequately supported. Rather than encountering empathy and patient-centered care, several participants described interactions characterized by distance, lack of engagement, or assumptions about their

mental stability. This reflects how stigma can become embedded in clinical encounters, undermining trust, communication, and continuity of care. Such dynamics may discourage PWE from seeking regular follow-up or disclosing important aspects of their condition, ultimately compromising health outcomes. These insights are consistent with studies from other low- and middle-income settings, where stigma has been shown to affect not only social relationships but also the accessibility and quality of healthcare services for PWE (Andersson et al., 2019; Demissie et al., 2021; Shawahna & Zaid, 2022; Yewnetu et al., 2024). Fear of unpredictable seizures, anxiety about being viewed as "insane," and experiences of rejection and marginalization dominated their narratives. These findings are consistent with the broader literature, which has consistently emphasized the psychosocial dimensions of epilepsy, especially in LMICs (Ayele et al., 2023; Fazekas et al., 2021; Shi et al., 2021).

Healthcare interactions identified by a deficient sense of empathy, poor communication, and a lack of targeted education added to participants' vulnerability. Many declared dissatisfaction with the healthcare and psychological support they received in primary care centers. These experiences reflect systematic weaknesses in the main healthcare infrastructure, including resource limits, labor shortages, and insufficient training in neurological and psychological care (El Sharif & Imam, 2019; Morrar et al., 2021).

Study II reinforced the patient-reported concerns by highlighting significant inconsistencies and gaps in healthcare professionals' preparedness to effectively manage epilepsy. Although most of the providers demonstrated a baseline level of knowledge and generally favorable attitudes, there were still some significant gaps, especially with relation to seizure recognition and long-term care strategies. Lower KAP scores among nurses and less experienced healthcare professionals highlight significant deficiencies in pre-service education and access to structured continuing professional development. This disparity underscores significant deficiencies in pre-service education and limited access to structured continuing professional development for certain provider groups. These findings are consistent with previous research in similar settings, which has shown that provider performance tends to correlate with level of education, professional role, and clinical experience, with physicians and senior staff typically outperforming their counterparts in epilepsy-related competencies. (Buddhiraja et al., 2020; Sen et al., 2025; Tanywe et al., 2016; Yang et al., 2019).

Participation in epilepsy-specific education initiatives and conferences is mostly limited to specialized physicians and highly experienced staff in the PHC facilities of the West Bank; other personnel, such as nurses, pharmacists, and early-career practitioners, aren't greatly involved. This disparity suggests broader systemic neglect of epilepsy as the major issue within health services at the PHC level. Compared to other non-communicable diseases (NCDs), such as diabetes or cardiovascular disease, epilepsy management receives limited attention, resulting in minimal allocation of resources, insufficient development of tailored training programs, and a lack of institutional emphasis on capacity building for epilepsy care. The situation is further compounded by chronic shortages of funding, fragmented service delivery models, and an overarching absence of national protocols for epilepsy management in PHC facilities. These systemic restrictions manifest in the limited availability of specialized human resources, such as neurologists and epileptologists, the uneven distribution of specialized services, and the prioritization of other public health challenges in the West Bank, thereby marginalizing epilepsy within the PHC agenda (Asi et al., 2021; Giacaman et al., 2009; McNeely et al., 2014; Morrar et al., 2021). Addressing these gaps

implies including epilepsy training in national continuing education programs and supporting broader health system reforms aimed at achieving equitable management of chronic neurological conditions within primary care.

Persistent misconceptions regarding epilepsy, including its links to mental and psychiatric disorders, continue to be prevalent among particular groups of the healthcare workforce. The misconceptions demonstrate dominant community attitudes in Palestine, where epilepsy is significantly stigmatized, contributing to social exclusion, unemployment, and marginalization of people with the condition. As mentioned previously, epilepsy care within the healthcare system is not properly defined in primary care settings, often resulting in fragmentation between PHC clinics and community mental health centers, which leads to a lack of cohesive, specialized services. This fragmentation drives people to seek epilepsy care in the private sector, resulting in increased financial burdens (Barhoush & Amon, 2023; McNeely et al., 2014; Morrar et al., 2021). Consequently, a substantial gap exists between patient needs, specifically regarding accurate medical management, psychological support, stigma-sensitive care, and the capabilities and attitudes of healthcare providers. The systemic and societal barriers collectively limit the provision of effective and equitable epilepsy care.

6.1.2 The Promise and Limits of Educational Interventions:

Study III evaluated the impact of a piloted mhGAP-based training program on the knowledge, attitudes, and self-efficacy of healthcare providers. The results indicated significant improvements in self-efficacy and slight advancements in knowledge among participants in the intervention group relative to the control group, whereas attitudes toward epilepsy did not exhibit a statistically significant alteration. The results underscore the significant role of self-efficacy as an essential, however often neglected, component of clinical competence. Confidence in the ability to recognize, treat, and refer epilepsy cases is particularly important in primary care settings, where non-specialist providers often work without the presence of neurologists or epileptologists (J. Spagnolo et al., 2018; WHO, 2017a).

The research indicated a statistically significant improvement in knowledge scores among PHC providers after the mhGAP-based epilepsy training, with median scores rising from 7.0 to 8.5 ($p = 0.003$). This is consistent with findings from comparable interventions in low-resource contexts, including Malawi and Tunisia, where mhGAP training improved healthcare workers' comprehension of epilepsy diagnosis and management (Keynejad et al., 2021; Kokota et al., 2020). The observed improvement highlights the training's efficacy in addressing significant knowledge deficiencies, especially in non-specialist environments where epilepsy care tends to be fragmented. The absence of significant differences between the intervention and control groups after training ($p = 0.543$) may be attributed to similar baseline knowledge levels, given that participants from both groups were part of the same healthcare system and may have had comparable exposure to epilepsy-related cases. Additionally, it is plausible that the control group benefited from informal learning opportunities in the workplace, such as peer interactions or observational learning. In this context, the lack of a clear post-intervention difference is not entirely unexpected. These findings highlight the complexity of evaluating educational interventions in real-world clinical environments, where external learning influences and shared institutional practices can affect both study arms. The modest effect size of 0.07 suggests that, although the training

was advantageous, its influence on knowledge may necessitate reinforcement via continuous education or additional interventions. The findings underscore the utility of mhGAP as a fundamental resource for epilepsy education while also stressing the necessity for ongoing training and contextual modifications to maintain and enhance knowledge retention over time.

The lack of attitude change aligns with research conducted in Malawi and Tunisia, underscoring the greater challenge in transforming persistent attitudes regarding epilepsy and other mental and neurological disorders (Kokota et al., 2020; J. Spagnolo et al., 2020).

Prior studies indicate that mental health outcomes improve when training is accompanied by organizational support, including supervision, collaboration with mental health specialists, and access to necessary medications (Keynejad et al., 2021).

This study conducted the post-training assessment two months post-intervention, consistent with WHO recommendations for evaluating capacity-building program effects (DeCorby-Watson et al., 2018; J. Spagnolo et al., 2020). During this period, changes in actual practice are frequently not fully apparent, especially in settings with limited resources where structural and systemic challenges hinder the immediate application of newly acquired knowledge and skills. Consequently, self-efficacy was chosen as the primary outcome rather than direct practice measures. Self-efficacy serves as a valid alternative to competence assessment in the short term, providing insight into providers' perceived readiness to manage epilepsy cases despite contextual barriers. Using self-efficacy aligns with recent research showing that it is important for predicting changes in practice and the sustainable impact of long-term interventions. Confidence in clinical competence affects non-specialist physicians' readiness to manage cases or make appropriate referrals (J. Spagnolo et al., 2018). Despite its significance, self-efficacy is inadequately represented in the mhGAP literature and the WHO evaluation tool (WHO, 2015, 2017a, 2019). Our findings underscore the importance of incorporating self-efficacy as a fundamental outcome in future evaluations.

The training outcomes align with findings from other mhGAP evaluations in LMICs, indicating improvements in knowledge and self-efficacy, while attitudinal changes remain more challenging to achieve. These findings correspond with similar research conducted in Tunisia, Mexico, South Africa, and Malawi, wherein mhGAP-based training has resulted in measurable improvements in knowledge and self-efficacy among primary care (Kokota et al., 2020; Robles et al., 2019; Sibeko et al., 2018; J. Spagnolo et al., 2020). In our setting, the training seems to be a feasible and efficient method for building capacity in epilepsy care within PHC. However, as reported in other LMICs, changes in attitudes are more resistant to short-term interventions, indicating that attitude improvement might require prolonged, multifaceted strategies (Kokota et al., 2020; Robles et al., 2019; Sibeko et al., 2018; J. Spagnolo et al., 2020). This pattern indicates that, although short-term educational interventions can enhance factual comprehension and increase confidence, attitudes rooted in cultural, social, and institutional norms require more sustained, multi-faceted strategies for change. While the training intervention demonstrated positive effects on participants' knowledge and self-reported practices, the most persistent challenges were observed in the domain of attitudes. Similar to findings from other LMICs, our results suggest that attitudinal change is more resistant to short-term interventions. Although factual understanding and clinical confidence improved, deeply rooted beliefs and perceptions related to epilepsy—often shaped by cultural, social, and institutional norms—require more sustained and multifaceted strategies to shift meaningfully. This highlights the importance of integrating

long-term educational reinforcement, reflective learning, and value-based engagement when aiming to transform healthcare providers' attitudes toward epilepsy care. Potential strategies consist of peer-led mentoring, reflective supervision, longitudinal follow-up, and community engagement initiatives aimed at addressing stigma both within as well as outside the healthcare system (Keynejad et al., 2021; Patel et al., 2018).

The study substantially contributes to the limited experimental research on mhGAP within the Middle East and North Africa (MENA) region. The use of a control group in the research provides stronger evidence for the effectiveness of the intervention and supports the argument for incorporating experimental methods in global mental health implementation science (Keynejad et al., 2021).. The study identifies self-efficacy as an essential evaluative metric, emphasizing its relevance for inclusion in future training assessments and WHO guidance documents.

6.1.3 Toward a Contextualized and Integrated Model of Epilepsy Care:

The three studies collectively illustrate a fragmented system wherein PWE contend with an emotionally challenging and socially isolating condition, all within a healthcare framework characterized by inconsistency, inequity, and inadequate responsiveness. The findings demand a shift to an integrated, person-centered model of epilepsy care that prioritizes clinical competence, psychosocial support, and community awareness equally.

A comprehensive model should consider systemic constraints within the Palestinian health sector, such as funding limitations, shortages of human resources, and disparities in access to care between rural and urban areas (Asi et al., 2021; Giacaman et al., 2009). Geopolitical instability, restricted mobility, and occupation-related barriers complicate access to continuity of care, especially for marginalized groups. Empowering PHC through task-shifting, decentralization, and culturally grounded training is an ethical and practical need.

The findings indicate potential opportunities that remain unexplored. Family support is a crucial protective factor for PWE, reducing psychological distress and promoting resilience. This study indicates that interventions focused on empowering families, strengthening social networks, and fostering collective caregiving may be utilized within a comprehensive public health strategy. The high baseline attitudes noted among healthcare providers indicate willingness to change, which can be fostered through continuous education and policy alignment. Based on the study findings and contextual challenges in epilepsy care in Palestine, we propose an Integrated Epilepsy Care Model tailored to PHC settings. As illustrated in the Figure 6.1, this model consists of four interlinked components:

- Provider Training: Continuous, structured training programs to build healthcare professionals' knowledge, attitudes, and self-efficacy in managing epilepsy.
- Community Engagement: Awareness campaigns and collaboration with community leaders to address stigma, promote understanding, and mobilize support for PWE.
- Patient Support: Empowering patients and families through self-management education, peer support networks, and psychosocial care.
- Coordinated Care: Strengthening referral pathways, multidisciplinary collaboration, and integration of epilepsy services within the PHC system.

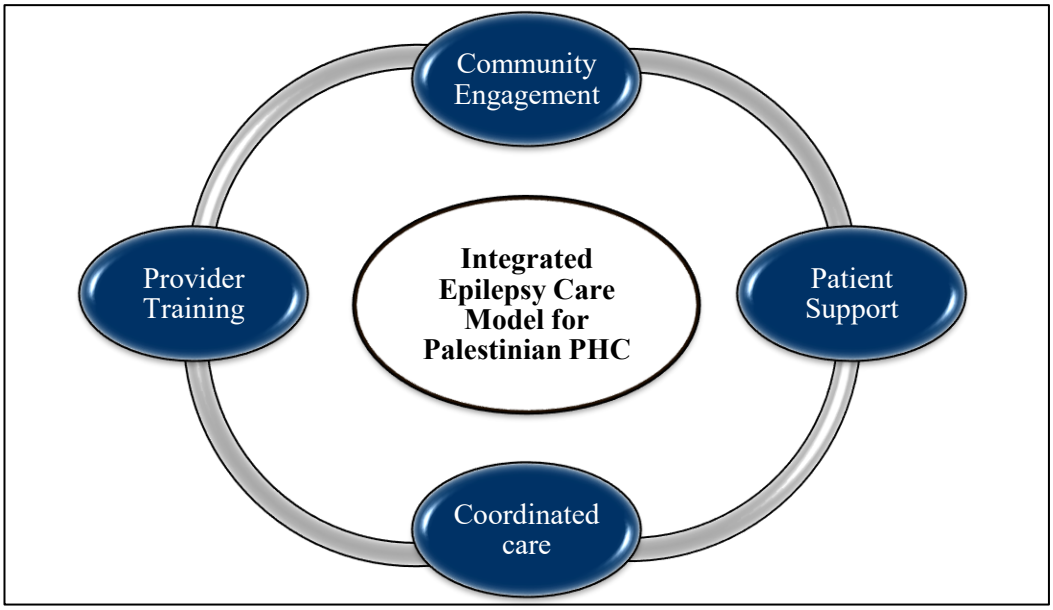

Figure 6.1: Integrated Epilepsy care Model in PHC settings

This model reflects a holistic, person-centered approach that addresses the clinical, social, and structural dimensions of epilepsy care. It aims to close the gap between knowledge and practice, reduce stigma, and enhance the long-term well-being of people living with epilepsy in resource-limited settings.

6.1.4 Conformity with the WHO Operational Framework for Primary Health Care:

The WHO Operational Framework for Primary Health Care offered a useful structure for analyzing the findings of this dissertation across its three studies. The study identified significant gaps in community engagement, health literacy, and quality of care. Participants' narratives revealed ongoing stigma, poor healthcare interactions, and a lack of emotional support, challenges closely associated with operational levers including care models, PHC workforce development, and quality improvement systems. Despite the clinical management of epilepsy, the lack of supportive, stigma-sensitive community-based services persisted in undermining patient well-being.

Study II identified differences in KAP related to epilepsy among healthcare professionals, especially among nurses and less experienced providers. The findings underscore the need for improved capacity-building systems, refined monitoring and evaluation mechanisms, and improved integration of epilepsy care competencies into PHC services, key operational levers within the WHO framework.

Study III indicated that mhGAP-based training had a positive impact on self-efficacy and knowledge acquisition among healthcare providers, though changes in attitudes were less significant. The findings support the lever concerning the role of digital and educational tools in health, while highlighting the difficulties of changing deeply held beliefs through short-term interventions (Keynejad et al., 2021; Kokota et al., 2020; Robles et al., 2019; J.

Spagnolo et al., 2018). The application of the WHO PHC framework facilitated the comprehensive investigation of systemic barriers to epilepsy care in Palestine. The significance of strategic policy levers, such as governance, financing, and leadership, was emphasized, paired with operational improvements in workforce development, service organization, and quality advancement. This dissertation highlights the need to incorporate epilepsy services into standard PHC delivery by situating epilepsy care within the context of broader PHC reform, thereby contributing to the achievement of SDG 3.

6.2 Conclusions

This dissertation presents a comprehensive examination of epilepsy care within PHC settings in the West Bank, Palestine, through a sequential mixed-methods approach integrating qualitative and quantitative research. The findings from the three interrelated studies underscore the complex and multidimensional challenges faced by PWE and healthcare providers alike.

Study I revealed profound emotional, social, and healthcare-related burdens experienced by PWE, highlighting stigma, inadequate psychosocial support, and fragmented services. Study II identified significant gaps in healthcare professionals' KAP, especially among nurses and less experienced staff. Study III demonstrated that mhGAP-based educational interventions significantly improved self-efficacy and knowledge among primary care providers, although attitudinal change remained limited.

Collectively, the dissertation emphasizes the need for a paradigm shift toward a more integrated, person-centered model of epilepsy care that addresses not only clinical competence but also the psychosocial dimensions of the disorder. The findings align with the WHO Operational Framework for PHC and underscore the importance of workforce development, community engagement, and stigma-sensitive care models. Based on the evidence generated, this study contributes a context-specific, evidence-informed model for strengthening epilepsy care in Palestine, which includes four key pillars: (1) ongoing provider training tailored to epilepsy care, (2) structured patient and family support programs, (3) community engagement to reduce stigma, and (4) coordinated care pathways within the PHC system.

By promoting these interventions, epilepsy care can be more effectively integrated into routine primary care, ensuring continuity, cultural sensitivity, and responsiveness to patients' lived experiences. These strategies offer a practical roadmap for health planners and policymakers in Palestine and similar low-resource settings to enhance the quality, accessibility, and equity of epilepsy services. Strengthening epilepsy care in primary health services is both a public health necessity and a moral imperative for promoting equity and dignity for people living with epilepsy in Palestine.

6.3 Limitations

Despite the significant contributions of this dissertation, several limitations must be acknowledged:

- The qualitative study employed a small, purposively selected sample, potentially limiting the transferability of the findings to larger populations of PWE.
- The qualitative phase involved participants recruited from assigned healthcare settings, which may introduce selection bias and restrict the diversity of perspectives.
- The cross-sectional survey of healthcare professionals employed self-reported data, which is susceptible to social desirability bias and may not accurately represent actual clinical practices.
- The interventional study consisted of a limited sample size and a brief follow-up period, potentially lacking to reflect for the long-term effects of the mhGAP training.
- The intervention was conducted only in Hebron Governorate, which may limit the generalizability of the findings to other regions with different healthcare contexts and provider experiences.
- The study included only adults with epilepsy and excluded children and individuals with cognitive or developmental disabilities, reducing the applicability of findings to the broader epilepsy population.
- Contextual and systemic factors, including resource limitations, variability within health systems, and cultural stigma, may have impacted the implementation and outcomes of the intervention, thereby reducing its external validity.

6.4 Recommendations

1. **Health System Reform and Policy**

- Develop Contextualized Guidelines: The MOH should develop locally relevant, evidence-based epilepsy management protocols with specialists and primary care teams, aligning with WHO standards while accounting for Palestinian-specific resource and cultural realities.
- Expand and Support the Workforce: Introduce targeted training and retention incentives for rural areas and promote task-sharing between general practitioners and specialists to improve access to epilepsy care.

2. **Capacity Building and Clinical Training**

- Integrate WHO mhGAP into CPD: Embed the mhGAP epilepsy module into continuing education for PHC workers focusing not only on clinical knowledge but also on communication and stigma reduction.
- Reform Health Education Curricula: Ensure medical, nursing, and pharmacy schools include epilepsy care within broader psychosocial, ethical, and stigma-related modules using scenario-based simulations.

3. **Community and Patient Engagement**

- Empower Through Self-Management: Train community health workers to deliver culturally appropriate epilepsy self-management education, focusing on seizure monitoring, trigger control, and crisis response.
- Combat Stigma Through Campaigns: Launch public education initiatives using stories of PWE, faith leaders, and public figures to challenge harmful beliefs and foster social inclusion, especially in schools and workplaces.

4. **Research and Monitoring for Action**

- Evaluate Program Impact: Conduct studies to assess whether epilepsy training improves clinical practices and patient outcomes.
- Use Data for Real-Time Decisions: Integrate epilepsy indicators (e.g., seizure-free rates) into primary care monitoring systems and incorporate community feedback to guide service adjustments.

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Appendices:

Appendix 1: Supplementary tables

Table S 1: Demonstration of Husserlian Epoché and Reflexivity in Data Collection & Analysis (Bracketing Notes)

Stage	Participant/Context	Preconceptions/Biases Identified	Bracketing Actions	Outcome/Lessons Learned
Pre-Interview	Whole-team reflexivity	1. "Epilepsy patients feel isolated due to stigma." 2. "West Bank healthcare providers are unsupportive."	- Documented assumptions in team notes. - Committed to open-ended questions (e.g., *"Describe your relationships with others."*).	*Recognized literature-driven biases. Interviews prioritized participant-led narratives over researcher assumptions.*
Post-Interview	Participant #3 (P3) *Fear of stigma*	- Researcher: Over-empathized with P3's isolation. - Researcher: Focused only on negative experiences.	- Added balance probe: *"Can you share a time you felt supported?"* - Re-coded for agency/resilience.	*Uncovered coping strategies (e.g., familial support) that countered initial 'victimhood' framing.*
Data Collection	Participant #8 (P8) *Abandoned by friends*	- Emotional reaction to stigma narrative risked neutrality.	- Paused interview to reset. - Used neutral probes: *"How do you wish people would respond?"*	*Epoché practice ensured P8's experience was described, not interpreted. Revealed nuanced societal attitudes beyond stigma.*
Analysis	Theme: Healthcare Experiences	- Expected negative interactions to dominate. - Initially dismissed positive accounts as outliers.	- Re-examined raw data frequencies. - Renamed subthemes (e.g., "Varied counseling experiences").	*Identified invariant structures (e.g., empathy mattered even in resource-limited settings), aligning with phenomenology's focus on essences of experience.*

Table S 2: Knowledge of health practitioners about epilepsy management (n = 300)

	Knowledge Question	**Correct N**	**%**
K1	Involuntary urination is a sign of epilepsy	77	25.7%
K2	Body convulsions are sign of epilepsy	288	96.0%
K3	Swallowing or biting tongue is a sign of epileptic seizure	227	75.7%
K4	Sleep deprivation or fatigue is a trigger of epileptic seizures	217	72.3%
K5	Medication non-adherence is a trigger of epileptic seizures	219	73.0%
K6	Avoiding or managing stress can decrease recurrence of seizures	218	72.7%
K7	Action during seizure attack is to put object in the patient's mouth to prevent their jaws from locking	142	47.3%
K8	Dizziness and vertigo are a common side effect of AEDs	78	26.0%
K9	Hirsutism is a common side effect of AEDs	218	72.7%
K10	Increased seizures are a common side effect of AEDs	218	72.7%

Table S 3: Attitudes of health practitioners (n = 300)

No.	Attitude	Strongly agree		Agree		Neutral		Disagree		Strongly disagree		Positive attitudes	
		N	%	N	%	N	%	N	%	N	%	N	%
A1	People with epilepsy have a lower ability to concentrate than others.	4	1.3%	48	16.0%	74	24.7%	144	48.0%	30	10.0%	174	58.0%
A2	People with epilepsy are more nervous or more prone to irritability compared to others.	4	1.3%	18	6.0%	48	16.0%	188	62.7%	42	14.0%	230	76.7%
A3	Work accidents are more common among people with epilepsy than others.	4	1.3%	22	7.3%	84	28.0%	174	58.0%	16	5.3%	190	63.3%
A4	The family suffers when one of its members has epilepsy.	6	2.0%	6	2.0%	36	12.0%	172	57.3%	80	26.7%	252	84.0%
A5	Employment opportunities for patients with epilepsy are limited compared to others.	4	1.3%	18	6.0%	54	18.0%	148	49.3%	76	25.3%	224	74.7%
A6	Epilepsy patients are treated as a minority group.	6	2.0%	26	8.7%	92	30.7%	134	44.7%	42	14.0%	176	58.7%
A7	People with epilepsy can live a normal life if they adhere to treatment.*	114	38.0%	170	56.7%	12	4.0%	4	1.3%	0	0.0%	284	94.7%
A8	People with epilepsy can recognize when a seizure occurs*	40	13.3%	148	49.3%	68	22.7%	40	13.3%	4	1.3%	188	62.7%
A9	People with epilepsy should not participate in social activities.	40	13.3%	158	52.7%	58	19.3%	32	10.7%	12	4.0%	44	14.7%
A10	People with epilepsy should disclose their condition when starting a new job.	4	1.3%	12	4.0%	30	10.0%	156	52.0%	98	32.7%	254	84.7%

*Inversely coded

Table S 4: Practices of health practitioners (n = 300)

No.	Practice	Never		Rarely		Sometimes		Often		Always		Positive practices	
		N	%	N	%	N	%	N	%	N	%	N	%
P1	I start treating people with epilepsy by giving them antiepileptic drugs directly.	10	3.3%	20	6.7%	53	17.7%	144	48.0%	73	24.3%	217	72.3%
P2	I adjust the treatment with antiepileptic drugs without referring the patient to a specialist.	106	35.3%	136	45.3%	32	10.7%	24	8.0%	2	0.7%	26	8.7%
P3	When it is necessary to adjust the treatment with antiepileptic drugs, I measure their concentration in the blood.	24	8.0%	38	12.7%	64	21.3%	104	34.7%	70	23.3%	174	58.0%
P4	I offer the patient options for treatment to think about and participate in the decision-making process.	36	12.0%	54	18.0%	62	20.7%	106	35.3%	42	14.0%	148	49.3%
P5	I encourage the patient to discuss any issues related to the medications or their side effects.	0	0.0%	6	2.0%	32	10.7%	92	30.7%	170	56.7%	262	87.3%
P6	I provide the patient with a written list of things and steps to follow in order to improve their health condition.	2	0.7%	12	4.0%	30	10.0%	106	35.3%	150	50.0%	256	85.3%
P7	I ask the patient to share with me what practices they follow to take care of their health condition.	4	1.3%	8	2.7%	30	10.0%	116	38.7%	142	47.3%	258	86.0%
P8	I help the patient set specific goals for improving their diet, exercise, or other aspects.	2	0.7%	10	3.3%	22	7.3%	112	37.3%	154	51.3%	266	88.7%
P9	I give the patient a copy of the updated treatment plan.	4	1.3%	16	5.3%	36	12.0%	108	36.0%	136	45.3%	244	81.3%
P10	I encourage the patient to attend a group or class to help them manage their epilepsy.	4	1.3%	18	6.0%	42	14.0%	104	34.7%	132	44.0%	236	78.7%

P11	I consider the patient's values and traditions when recommending treatments.	2	0.7%	16	5.3%	18	6.0%	138	46.0%	126	42.0%	264	88.0%
P12	I refer the patient to a nutritionist, health education counselor, or any specialized medical entity when needed.	0	0.0%	10	3.3%	32	10.7%	112	37.3%	146	48.7%	258	86.0%

Table S 5: Univariate analysis of knowledge, attitudes and practice of participants (n = 300):

	Knowledge		Attitude		Practice	
	OR (95%CI)	**P**	**OR (95%CI)**	**P**	**OR (95%CI)**	**P**
Gender						
Male	ref.		ref.		ref.	
Female	**-0.971 (-1.631, -0.310)**	**0.004***	0.546 (-0.638, 1.730)	0.365	0.253 (-1.550, 2.056)	0.783
Age groups						
20 – 29 years	ref.		ref.		ref.	
30 – 39 years	0.824 (-0.076, 1.725)	0.073	**2.970 (1.400, 4.539)**	**0.000***	0.547 (-1.891, 2.985)	0.659
40 – 49 years	0.472 (-0.337, 1.282)	0.252	**1.563 (0.153, 2.974)**	**0.030***	0.413 (-1.778, 2.603)	0.711
≥ 50 years	-0.092 (-1.089, 0.905)	0.856	**2.368 (0.631, 4.105)**	**0.008***	1.836 (-0.863, 4.534)	0.182
Clinical experience						
≤ 10 years	ref.		ref.		ref.	
11 – 20 years	0.164 (-0.500, 0.828)	0.627	0.903 (-0.258, 2.064)	0.127	0.657 (-1.120, 2.434)	0.467
≥ 21 years	-0.105 (-0.879, 0.670)	0.791	**1.877 (0.523, 3.232)**	**0.007***	2.025 (-0.049, 4.098)	0.056
Education /Qualification						
Diploma	ref.		ref.		ref.	
Bachelors	**0.759 (0.091, 1.426)**	**0.026***	0.055 (-1.192,1.302)	0.930	0.302 (-1.598, 2.202)	0.754
Higher education	**2.536 (1.682, 3.390)**	**0.000***	0.906 (-0.689, 2.502)	0.265	-0.331 (-2.762, 2.100)	0.789
Profession						
Doctor	ref.		ref.		ref.	
Pharmacist	**-1.311 (-2.219, -0.403)**	**0.005***	0.806 (-0.935, 2.547)	0.363	-1.515 (-4.144, 1.114)	0.258
Nurse	**-2.821 (-3.659, -1.982)**	**0.000***	0.867 (-0.741, 2.476)	0.289	0.700 (-1.729, 3.129)	0.571
Psychologist	**-2.797 (-4.717, -0.877)**	**0.004***	3.207 (-0.476, 6.890)	.088	3.004 (-2.557, 8.565)	0.289
District						
North	ref.		ref.		ref.	
Middle	0.043 (-0.731, 0.818)	0.912	0.347 (-1.022, 1.715)	0.619	-1.487 (-3.565, 0.592)	0.160
South	-0.186 (-0.866, 0.494)	0.591	-0.512 (-1.714, 0.690)	0.403	-0.084 (-1.910, 1.742)	0.928

Appendix 2: Ethical Approvals

Al-Quds University
Jerusalem
School of Public Health

جـامـعـة الـقـدس
القدس
كلية الصحة العامة

التاريخ: 2024/2/17
الرقم: REF. 12/24

عزيزتي الطالبة عبير عنايم المحترمة
برنامج الدكتوراة في الصحة العامة

الموضوع: موافقة لجنة اخلاقيات البحث العلمي

قامت اللجنة الفرعية لأخلاقيات البحث التابعة لكلية الصحة العامة بمراجعة مشروع الرسالة بعنوان:

"Understanding Epilepsy Self-Management Practices in Primary Healthcare settings in the West Bank - Palestine: A Mixed Methods Study"

المقدم من (مشرف البحث/د. حسين حلاق).

يعتبر مشروعك مستوفيًا لمتطلبات أخلاقيات البحث في جامعة القدس.

نتمنى لكم كل التوفيق في تسيير المشروع.

ملاحظة: في حالة الحاجة الى موافقة من اللجنة المركزية في الجامعة، تستطيع التقدم باستخدام هذه الموافقة على الرابط. https://research.alquds.edu/en/ethics/48-how-to-apply.html

رئيسة اللجنة الفرعية لاخلاقيات البحث
كلية الصحة العامة
د. نهى الشريف

نسخة/ أعضاء لجنة البحث
نسخة/ الملف

Jerusalem Branch/Telefax 02-2799234
Gaza Branch/Telefax 08-2644220 -2644210
P.O. box 51000 Jerusalem

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فرع غزة / تلفاكس 08-264420-2644210
ص.ب. 51000 القدس

Al-Quds University
Jerusalem
School of Public Health

جـامـعـة الـقـدس
القدس
كلية الصحة العامة

التاريخ: 4/2/2025
الرقم: REF. 5/25

عزيزتي الطالبة عبير عنايم المحترمة
برنامج الدكتوراة في الصحة العامة

الموضوع: موافقة لجنة اخلاقيات البحث العلمي

قامت اللجنة الفرعية لأخلاقيات البحث التابعة لكلية الصحة العامة بمراجعة مشروع الرسالة بعنوان:

"Exploring Epilepsy Management Among Healthcare Practitioners in Primary Care Settings: A Mixed Methods Study in the West Bank, Palestine"

المقدم من (مشرف البحث/د. حسين حلاق).

يعتبر مشروعك مستوفيًا لمتطلبات أخلاقيات البحث في جامعة القدس.

نتمنى لكم كل التوفيق في تسيير المشروع.

ملاحظة: في حالة الحاجة الى موافقة من اللجنة المركزية في الجامعة، تستطيع التقدم باستخدام هذه الموافقة على الرابط. https://research.alquds.edu/en/ethics/48-how-to-apply.html

رئيسة اللجنة الفرعية لاخلاقيات البحث
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فرع القدس / تلفاكس 02-2799234
فرع غزة / تلفاكس 08-264420-2644210
ص.ب. 51000 القدس

State of Palestine
Ministry of Health
Education in Health and Scientific Research Unit

دولة فلسطين
وزارة الصحة
وحدة التعليم الصحي والبحث العلمي

Ref.: ....
Date:..................

الرقم: ١٦٢/٥٥٠/٢٠٢٤
التاريخ: ٢٤/٣/٢٠٢٤

عطوفة الوكيل المساعد لشؤون الصحة العامة وصحة الاسرة المحترم،،،

تحية واحترام،،،

الموضـوع: تسهيل مهمة بحث

يرجى تسهيل مهمة **الطالبة:عبير غنايم -دكتوراه الصحة العامة / جامعة القدس**، وباشراف د. حسين الحلاق ، في عمل بحث بعنوان:

" Understanding Epilepsy Self-Management Practice in primary Health setting in the west bank - Palestine :a Mixed methods study "

من خلال السماح للطالبة بجمع معلومات عن طريق تعبئة استبانة الدراسة على جميع الكوادر الطبية، وذلك في:

- مراكز الرعاية الصحية الاولية في جميع انحاء الضفة

على ان يتم الالتزام باساليب واخلاقيات البحث العلمي، وعد التعرض للمعلومات التعريفية للمشاركات.
على ان يتم تزويد الوزارة بنسخة PDF من نتائج البحث، التعهد بعدم النشر لحين الحصول على موافقة الوزارة على نتائج البحث.

مع الاحترام،،،

د. عبد الله القواسمي
رئيس وحدة التعليم الصحي والبحث العلمي

نسخة: منسق / عميد كلية الصحة العامة المحترم/ جامعة القدس

Telfax.:09-2333901 scientificresearch.dep@gmail.com تلفاكس: 09-2333901

Appendix 3: Participant Information Sheet and consent form – English version

School of Public Health

Participant Information Sheet & Consent Form

Study Title**: "Exploring the Lived Experiences of People with Epilepsy in Palestine"**

Dear Sir / Madam,
You are invited to participate in a research study titled: "Exploring the Lived Experiences of People with Epilepsy in Palestine." This study is being conducted by Abeer Ghanayem, a PhD student in Public Health at Al-Quds University. Before deciding whether or not to participate, it is important that you understand the purpose of the research and what your participation will involve.

The purpose of this research is to explore and understand how adults with epilepsy experience and manage their condition in the West Bank, Palestine. This study uses a qualitative, phenomenological approach to capture your thoughts, feelings, and lived experiences in your own words.

You are invited to take part in this study because you are an adult (18 years or older) living with epilepsy and are willing to share your personal experiences. Your perspectives and experiences are valuable in learning about epilepsy in depth.

It is your own decision whether to participate in the research or not. You are free to withdraw from the interview at any time and without giving a reason. It is your complete choice to accept involvement in the interview. Also, it is your choice to withdraw at any time and to refuse to answer any question without giving any reason.

The interview will last approximately 60 minutes and will be voice recorded with your permission. The purpose of the recording is to help accurately capture your responses for later analysis. No one will be identified by name in any report or publication. Each recording will be labeled using a code number to maintain anonymity.

All data will be securely stored and handled confidentially. Transcripts will be anonymized, and recordings will be deleted after they are transcribed and verified. Only the research team will have access to the data.

This study has been reviewed and approved by the Research Ethics Committee at Al-Quds University. There is no compensation for participation in this study. You have received this information sheet and a verbal explanation of the study. By agreeing and signing the consent form, you confirm your voluntary consent to participate.

If you have any questions or need further information, you may contact the researcher: Abeer Ghanayem

Email: abeerghanayem@gmail.com

Thank you for your time and willingness to contribute to this important research.

School of Public Health

Participant Consent Form

By signing this form, I agree to the following:

☐ I have been informed about the study's objective by the researcher.

☐ I understand that my personal data and the information collected will remain confidential and used only for research purposes.

☐ I am aware that I have the right to withdraw from the study at any time.

☐ I understand that I may skip any question I do not wish to answer.

Participant Name: _____Signature:_____ Date: _____

Researcher Name: Abeer Ghanayem Signature:_____ Date: _____

Appendix 4: Participant information sheet and consent form – Arabic version

كلية الصحة العامة- جامعة القدس

نموذج التعريف بالدراسة للمشاركين

دراسة: **" استكشاف التجارب المعيشة للأشخاص المصابين بالصرع في فلسطين"**

عزيزي المشارك الفاضل/ عزيزتي المشاركة الفاضلة،

ندعوك للمشاركة في دراسة بحثية بعنوان: "استكشاف التجارب المعيشة للأشخاص المصابين بالصرع في فلسطين". تجرى هذه الدراسة بواسطة عبير غنايم، طالبة دكتوراه في الصحة العامة في جامعة القدس .قبل اتخاذ قرارك بشأن المشاركة، من المهم أن تفهم هدف الدراسة وما ستتضمنه مشاركتك.

تهدف هذه الدراسة إلى استكشاف وفهم كيفية تجربة البالغين المصابين بالصرع لحالتهم الصحية وإدارتها في الضفة الغربية، فلسطين .تعتمد هذه الدراسة على منهج نوعي(كيفي) وظاهراتي يركز على التعبير عن مشاعرك وتجاربك الذاتية كما تعيشها.

تمت دعوتك للمشاركة لأنك شخص بالغ (أكبر من 18 سنة) مصاب بالصرع، ويمكنك مشاركة تجاربك الشخصية .تعد رؤيتك وتجاربك ذات أهمية كبيرة لفهم احتياجات مرضى الصرع وتحسين جودة الرعاية الصحية المقدمة لهم.

مشاركتك في هذه الدراسة اختيارية تمامًا .يمكنك الانسحاب في أي وقت دون الحاجة إلى تقديم أي مبرر، ودون أن يترتب على ذلك أي تبعات .كما يمكنك رفض الإجابة على أي سؤال لا تشعر بالراحة تجاهه.

ستستغرق المقابلة حوالي 60 دقيقة، وسيتم تسجيلها صوتيًا بعد أخذ موافقتك .والغرض من التسجيل هو ضمان توثيق إجاباتك بدقة لتحليلها لاحقًا .لن يتم الكشف عن اسمك في أي تقارير أو منشورات، حيث سيتم ترميز كل تسجيل برقم لضمان عدم التعرف على هوية المشاركين.

سيتم تخزين جميع البيانات بشكل آمن وسري .وسيتم حذف التسجيلات الصوتية بعد تحويلها إلى نصوص ومراجعتها .ولن يتمكن من الاطلاع على البيانات سوى فريق البحث فقط.

تمت مراجعة هذه الدراسة والموافقة عليها من قبل لجنة أخلاقيات البحث العلمي في جامعة القدس .

لا توجد مكافأة مالية للمشاركة في هذه الدراسة .لقد حصلت على هذه الورقة بالإضافة إلى شرح شفهي حول الدراسة . ومن خلال موافقتك الشفوية ومشاركتك، فإنك تؤكد موافقتك الطوعية على المشاركة في هذا البحث.

إذا كانت لديك أي أسئلة أو تحتاج إلى معلومات إضافية، يمكنك التواصل مع الباحثة :عبير غنايم

البريد الإلكترونيabeerghanayem@gmail.com :

شكرًا لك على وقتك واستعدادك للمساهمة في هذا البحث المهم.

كلية الصحة العامة- جامعة القدس

نموذج الموافقة للمشاركين

التوقيع على هذا النموذج يعني أنني أوافق على ما يلي			
1	لقد تم إبلاغي عن هدف الدراسة من قبل الباحث	نعم	لا
2	تم ابلاغي بأن معلوماتي الشخصية والمعلومات التي سيتم جمعها من هذه الدراسة البحثية ستبقى سرية وسوف تستخدم من اجل البحث العلمي فقط	نعم	لا
3	أدرك أن لدي الحق في الانسحاب من الدراسة في أي وقت	نعم	لا
4	لدي خيار عدم الإجابة عن أي سؤال أحدده	نعم	لا

اسم المشارك/ة_____التوقيع:_____التاريخ_____

اسم الباحث: _____التوقيع:_____التاريخ_____

Appendix 5: Interview guide – English version

School of Public Health

Interview guide

Study Title**: "Exploring the Lived Experiences of People with Epilepsy in Palestine"**

Hello. My name is Abeer Ghanayem, and I am a PhD student in Public Health from Al-Quds University. Thank you for taking the time to participate in this research study and talking with me today. Today's interview is part of a research project that aims to understand the experiences of people living with epilepsy in Palestine, especially in relation to their emotional, social, and healthcare journeys. Please note that there are no correct or wrong answers. I want you to feel comfortable during this interview, and I hope you will feel free to share your thoughts and feelings openly. With your permission, I would like to record this interview to ensure all details are documented because it is difficult to write everything down while maintaining good conversation and being attentive to you and your experiences. Everything you say will remain confidential. Your participation is entirely voluntary. You may choose not to participate, or you can choose to change your mind at any time. If you choose to quit at a later date, you may do so by contacting me directly. Please note that there is no compensation for participating in this study. You have been given a copy of the participant information sheet and the informed consent document. By verbally agreeing and participating in this interview, you are giving your consent, again, to participate in this research study.

Do you have any questions or concerns before we begin?

Part 1: Background and Consent Check

- What do you understand about this study?
- What made you agree to take part?
- Can you briefly introduce yourself (age, work, family situation, etc.)?

Part 2: Lived Emotional and Existential Experience

- Can you tell me about your condition, "epilepsy"?
- Who knows about your condition?
- How would you describe your experience of living with epilepsy?
  - Probe: emotional, social, economic, physical situations. Can you give me an example of when that happened and how it happened? Can you explain how you feel about it?
- What situations have you encountered in your life because of your epilepsy?
  - Probe: social contribution, social acceptance, social support, personal relationship, self-esteem, autonomy, satisfaction with life roles.
- How has this condition impacted your family's life? Friends' lives?
- From your point of view, how do others look at the patient with epilepsy?

- What do you hear from others about people with epilepsy?
- What do you do if a seizure occurs?

Part 3: Healthcare-Related Experiences

- How often do you visit healthcare providers for epilepsy care?
  - What kind of care or advice do you receive?
- How do you feel about your healthcare provider's understanding of epilepsy?
- What changes would you like to see in the way healthcare providers support people with epilepsy?

Part 4: Coping and Self-Management

- What strategies do you use to cope with challenges related to epilepsy?
- Who supports you most in your journey with epilepsy?
  - How do they support you—emotionally, practically, or medically?

Closing Questions

- Is there anything else you would like to share about your experience that we haven't discussed?

Thank you for volunteering and for taking the time to participate in this interview. Please feel free to reach out to me if you have questions or additional comments at a later date.
Before we end this interview, do you have any questions for me?
Thank you again for your time and participation.

Appendix 6: Interview guide – Arabic version

دليل المقابلة:

مرحبًا، اسمي عبير غنايم، وأنا طالبة دكتوراه في الصحة العامة في جامعة القدس .شكرًا لك على تخصيص الوقت للمشاركة في هذه الدراسة البحثية والتحدث معي اليوم .تأتي هذه المقابلة ضمن مشروع بحثي يهدف إلى فهم تجارب الأشخاص الذين يعيشون مع مرض الصرع في فلسطين، لا سيما من حيث الجوانب العاطفية والاجتماعية وتجاربهم مع النظام الصحي .أود أن أوضح أنه لا توجد إجابات صحيحة أو خاطئة .أرجو أن تشعر بالراحة أثناء المقابلة، وآمل أن تشارك أفكارك ومشاعرك بحرية وصدق.

بموافقتك، سأقوم بتسجيل هذه المقابلة لضمان توثيق جميع التفاصيل، لأن من الصعب تدوين كل شيء يدويًا أثناء الحفاظ على الحوار والانتباه لتجربتك .جميع ما تقوله سيبقى سريًا .مشاركتك في هذه الدراسة اختيارية تمامًا، ويمكنك أن تختار عدم المشاركة أو التراجع عن قرارك في أي وقت .وإذا قررت الانسحاب لاحقًا، يمكنك التواصل معي مباشرة .علمًا أنه لا توجد مكافأة مادية للمشاركة في هذه الدراسة .لقد تم تزويدك بنسخة من ورقة معلومات المشاركة ونموذج الموافقة المستنيرة .من خلال موافقتك الشفوية ومشاركتك في هذه المقابلة، فإنك تؤكد موافقتك مرة أخرى على المشاركة في هذه الدراسة البحثية.

هل لديك أي أسئلة أو استفسارات قبل أن نبدأ؟

الجزء الأول :الخلفية والتحقق من الموافقة

- ما الذي تفهمه عن هذه الدراسة؟
- ما الذي دفعك للموافقة على المشاركة؟
- هل يمكنك أن تعرّفني على نفسك بإيجاز(العمر، العمل، الوضع العائلي، إلخ)؟

الجزء الثاني :التجربة العاطفية والوجودية للصرع

- هل يمكنك أن تخبرني عن حالتك، "الصرع"؟
- من يعرف عن حالتك؟
- كيف تصف تجربتك في العيش مع الصرع؟
  - استفسار: الجوانب العاطفية، الاجتماعية، الاقتصادية، والجسدية. هل يمكنك أن تعطيني مثالًا على موقف حدث وكيف حدث؟ هل يمكنك أن تشرح لي شعورك حيال ذلك؟
- ما هي المواقف التي واجهتها في حياتك بسبب إصابتك بالصرع؟
  - استفسار: المساهمة الاجتماعية، القبول الاجتماعي، الدعم الاجتماعي، العلاقات الشخصية، تقدير الذات، الاستقلالية، الرضا عن أدوار الحياة.
- كيف أثرت هذه الحالة على حياة عائلتك؟ وحياة أصدقائك؟
- من وجهة نظرك، كيف ينظر الآخرون إلى مريض الصرع؟
- ماذا تسمع من الآخرين عن الأشخاص المصابين بالصرع؟
- ماذا تفعل إذا حدثت نوبة صرع؟

الجزء الثالث :التجارب المتعلقة بالرعاية الصحية

- كم مرة تراجع مقدمي الرعاية الصحية لمتابعة حالتك؟
  - ما نوع الرعاية أو النصائح التي تتلقاها؟
- هل أنت راضٍ عن العلاج والمتابعة التي تحصل عليها في مركز الرعاية الصحية الأولية؟
- كيف ترى مدى فهم مقدمي الرعاية الصحية لحالة الصرع؟
- ما التغييرات التي تتمنى رؤيتها في طريقة تعامل مقدمي الرعاية الصحية مع مرضى الصرع؟

الجزء الرابع: التكيّف والإدارة الذاتية

- ما الاستراتيجيات التي تستخدمها للتكيّف مع التحديات المرتبطة بالصرع؟
- من هو الشخص أو الجهة التي تدعمك أكثر خلال رحلتك مع المرض؟
  - كيف يتم تقديم هذا الدعم – نفسيًا، عمليًا، أو طبيًا؟

الأسئلة الختامية

- هل هناك شيء آخر تود مشاركته عن تجربتك ولم نناقشه اليوم؟
- شكرًا لك على تطوعك للمشاركة في هذه الدراسة وعلى وقتك الثمين .لا تتردد في التواصل معي لاحقًا إذا كانت لديك أي أسئلة أو تعليقات إضافية.
- قبل أن ننهي هذه المقابلة، هل لديك أي سؤال لي؟
- شكرًا مجددًا على وقتك ومساهمتك.

Appendix 7: KAP Questionnaire - English version

School of Public Health

Participant Information Sheet & Consent Form

Study Title: **"Assessment of Knowledge, Attitudes, and Practices of Healthcare Providers in Primary Health Centers Regarding Epilepsy Care and Management in the West Bank – Palestine: A Cross sectional Study"**

Dear Participant,

I am Abeer Ali Ghanayem, a PhD student conducting research titled as above. This study aims to explore and evaluate the Knowledge, Attitudes, and Practices of Healthcare Providers in Primary Health Centers Regarding Epilepsy Care and as a requirement for my PhD dissertation at Al-Quds University, School of Public Health, under the supervision of Dr. Hussein Hallak.

The study involves completing the attached questionnaire (Knowledge, Attitudes, and Practices of Healthcare Providers Regarding Epilepsy Care and Management in Primary Health Centers). The collected data will be used strictly for academic and scientific research purposes to support evidence-based decision-making and improvements.

Please be assured that all data collected will be treated with strict confidentiality. Participation is voluntary, and you may withdraw from the study at any time without any consequences. Your participation includes the following:

Knowledge, Attitudes, and Practices Questionnaire on Epilepsy Management in Primary Health Centers.

School of Public Health

Participant Consent Form

Study Title**: "Assessment of Knowledge, Attitudes, and Practices of Healthcare Providers in Primary Health Centers Regarding Epilepsy Care and Management in the West Bank – Palestine: A Cross-sectional Study"**

By signing this form, I agree to the following:

☐ I have been informed about the study's objective by the researcher.

☐ I understand that my personal data and the information collected will remain confidential and used only for research purposes.

☐ I am aware that I have the right to withdraw from the study at any time.

☐ I understand that I may skip any question I do not wish to answer.

Participant Name: _____ Signature: _____ Date: _____

Researcher Name: Abeer Ali Ghanayem___ Signature: _____ Date: _____

For inquiries, contact: abeerghanayem@gmail.com

Section 1: Demographic Information

This section collects demographic information for research purposes only. Responses will remain anonymous and untraceable. Please mark (x) in the appropriate box.

Gender: ☐ Male ☐ Female

Age (in years): _____

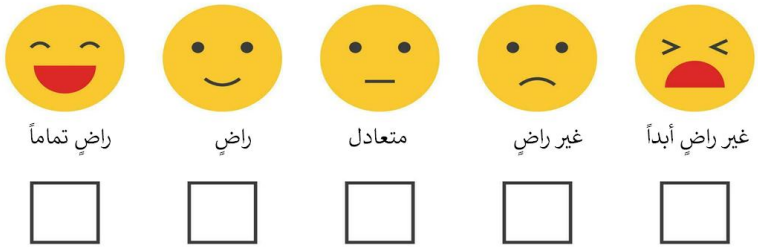
Years of experience in PHC: _____

Educational level: ☐ Diploma ☐ Bachelor's ☐ Higher education or Specialty

Profession: ☐ Physician ☐ Nurse ☐ Pharmacist
☐ Other (please specify): _____

Work location: ☐ Hebron ☐ Bethlehem ☐ Jericho ☐ Ramallah
☐ Jerusalem ☐ Nablus ☐ Jenin ☐ Tulkarem
☐ Qalqilya ☐ Tubas ☐ Salfit

How satisfied are you with your knowledge about epilepsy?



Section 2: Knowledge about Epilepsy

Please answer the following according to your knowledge and beliefs.

No.	Knowledge Question	Yes	No	I don't know
K1	Involuntary urination is a sign of epilepsy			
K2	Body convulsions are a sign of epilepsy			
K3	Swallowing or biting the tongue is a sign of an epileptic seizure			
K4	Sleep deprivation or fatigue can trigger epileptic seizures			
K5	Medication non-adherence can trigger epileptic seizures			
K6	Avoiding or managing stress can decrease the recurrence of seizures			
K7	The appropriate action during a seizure is to put an object in the patient's mouth to prevent jaw locking			
K8	Dizziness and vertigo are common side effects of antiepileptic drugs (AEDs)			
K9	Hirsutism is a common side effect of AEDs			
K10	Increased seizures are a common side effect of AEDs			

Section 3: Attitudes toward Epilepsy

Please mark the answer that most reflects your opinion.

No.	Attitude Statement	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
A1	People with epilepsy have a lower ability to concentrate than others.					
A2	People with epilepsy are more nervous or more prone to irritability compared to others.					
A3	Work accidents are more common among people with epilepsy than others.					
A4	The family suffers when one of its members has epilepsy.					
A5	Employment opportunities for patients with epilepsy are limited compared to others.					
A6	Epilepsy patients are treated as a minority group.					
A7	People with epilepsy can live a normal life if they adhere to treatment.					
A8	People with epilepsy can recognize when a seizure is about to occur.					
A9	People with epilepsy should not participate in social activities.					

A10	People with epilepsy should disclose their condition when starting a new job.					

Section 4: Practices in Epilepsy Care

Please mark the frequency that best describes your practice.

No.	Practice Statement	Always	Often	Sometimes	Rarely	Never
1	I initiate antiepileptic drug (AED) therapy immediately for epilepsy patients.					
2	I adjust AED treatment without referring the patient to a specialist.					
3	I determine AED blood levels when needed to adjust treatment.					
4	I provide patients with treatment options and involve them in decision-making.					
5	I encourage patients to discuss problems related to their medications or side effects.					
6	I give patients a written plan or checklist to improve their health status.					
7	I ask patients to share their current self-care practices.					
8	I help patients set specific goals for improving diet, exercise, or other health behaviors.					
9	I provide patients with an updated copy of their treatment plan.					
10	I encourage patients to attend support groups or classes to manage epilepsy.					
11	I consider patients' values and traditions when recommending treatments.					
12	I refer patients to dietitians, health educators, or specialized services when needed.					

THANK YOU

Appendix 8: KAP Questionnaire – Arabic version

كلية الصحة العامة- جامعة القدس

نموذج الموافقة للمشاركين

دراسة: " تقييم المعرفة والمواقف والممارسات للكادر الصحي في مراكز الرعاية الأولية حول رعاية وادارة مرض الصرع في مراكز الرعاية الأولية في الضفة الغربية – فلسطين: دراسة منهجية"

عزيزي المشارك الكريم / عزيزتي المشاركة الكريمة:

أنا الطالبة عبير علي غنايم أقوم بإجراء بحث بعنوان **"تقييم المعرفة والمواقف والممارسات للكادر الصحي في مراكز الرعاية الأولية حول رعاية وادارة مرض الصرع في مراكز الرعاية الأولية في الضفة الغربية – فلسطين: دراسة منهجية "** حيث يهدف هذا البحث إلى استكشاف وفهم محددات رعاية وإدارة مرض الصرع في القطاع الصحي كمتطلب لرسالة الدكتوراه في الصحة العامة في جامعة القدس كلية الصحة العامة تحت اشراف الدكتور حسين حلاق.

تتضمن الدراسة تعبئة الاستبيان المرفق (استبيان المعرفة والمواقف والممارسات للكادر الصحي في مراكز الرعاية الأولية حول رعاية وادارة مرض الصرع). وسيتم استخدام المعلومات لأغراض البحث العلمي فقط وذلك بهدف التحسين والتطوير وأخذ القرارات المبنية على الحقائق.

نؤكد بأنه سيتم التعامل مع جميع المعلومات التي سيتم جمعها خلال هذه الدراسة بسرية تامة. لذا نرجو من حضرتكم التعاون بالإجابة على أسئلة الاستبانات، علما بأن المشاركة طوعية ويمكنك اختيار الانسحاب في أي وقت دون مواجهة أي عواقب. تتضمن مشاركتك في الدراسة على التالي:

- استبانة المعرفة والمواقف والممارسات للكادر الصحي في مراكز الرعاية الأولية حول رعاية وادارة مرض الصرع

كلية الصحة العامة- جامعة القدس

نموذج الموافقة للمشاركين

دراسة: "تقييم المعرفة والمواقف والممارسات للكادر الصحي في مراكز الرعاية الأولية حول رعاية وادارة مرض الصرع في مراكز الرعاية الأولية في الضفة الغربية – فلسطين: دراسة منهجية "

التوقيع على هذا النموذج يعني أنني أوافق على ما يلي			
1	لقد تم إبلاغي عن هدف الدراسة من قبل الباحث	نعم	لا
2	تم ابلاغي بأن معلوماتي الشخصية والمعلومات التي سيتم جمعها من هذه الدراسة البحثية ستبقى سرية وسوف تستخدم من اجل البحث العلمي فقط	نعم	لا
3	أدرك أن لدي الحق في الانسحاب من الدراسة في أي وقت	نعم	لا
4	لدي خيار عدم الإجابة عن أي سؤال أحدده	نعم	لا

اسم المشارك/ة---------- التوقيع ----------التاريخ----------

اسم الباحثة ---------- التوقيع----------التاريخ----------

إذا كان لديك أي سؤال أو كنت بحاجة إلى أي معلومات، فيرجى الاتصال بـ

عبير علي غنايم

abeerghanayem@gmail.com

القسم الأول: السمات الديموغرافية:

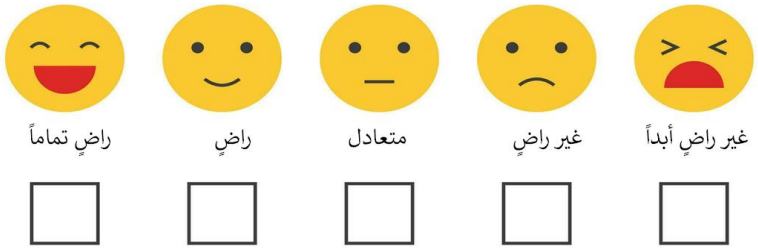
يهتم هذا القسم بجمع السمات الديموغرافية للمشاركين لأغراض البحث العلمي فقط. الردود ستكون مجهولة ولا يمكن تتبعها أو ربطها بك أو بأحد المشاركين. يرجى وضع (x) على الخيار المناسب:

1) الجنس: 1. ذكر 2. أنثى
2) العمر (بالسنوات) _____
3) عدد سنوات الخبرة في مراكز الرعاية الأولية _____
4) المستوى التعليمي: 1. دبلوم 2. بكالوريوس 3. اختصاص أو دراسات عليا
5) المهنة: 1. طبيب 2. ممرض 3. صيدلاني
4.غير ذلك (الرجاء التحديد) _____

6) مكان العمل:

1 الخليل	2 بيت لحم	3 أريحا
4 رام الله	5 القدس	6 نابلس
7 جنين	8 طولكرم	9 قلقيلية
10 طوباس	11 سلفيت	

7) ما مدى رضاك عن معلوماتك حول مرض الصّرع؟



القسم الثاني: المعرفة بمرض الصرع وكيفية رعايته

يبحث هذا القسم في المعرفة الفعلية للمشاركين حول مرض الصّرع. يرجى الإجابة على الأسئلة وفقًا لمعرفتكم ومعتقداتكم.

الرقم	سؤال المعرفة	نعم	لا	لا أعلم
K1	التبول اللاإرادي هو أحد علامات الصرع			
K2	التشنجات الجسدية هي علامة على الصرع			
K3	بلع أو عضّ اللسان هو علامة على نوبة صرعية			
K4	الحرمان من النوم أو الإرهاق من محفزات النوبات الصرعية			
K5	عدم الالتزام بتناول الدواء من محفزات النوبات الصرعية			
K6	تجنب أو إدارة التوتر يمكن أن يقلل من تكرار النوبات			
K7	الإجراء أثناء النوبة هو وضع جسم في فم المريض لمنع انغلاق الفك			
K8	الدوخة والدوار من الآثار الجانبية الشائعة للأدوية المضادة للصرع			
K9	فرط نمو الشعر من الآثار الجانبية الشائعة للأدوية المضادة للصرع			
K10	زيادة النوبات من الآثار الجانبية الشائعة للأدوية المضادة للصرع			

القسم الثالث: المواقف تجاه مرض الصرع

يناقش هذا القسم موقفك وآرائك وانطباعاتك حول مرض الصّرع. يرجى وضع (x) على الإجابة الأكثر ملائمة:

الرقم	البند	موافق بشدة	موافق	محايد	لا أوافق	لا أوافق بشدة
A1	الأشخاص المصابون بالصرع لديهم قدرة أقل على التركيز مقارنةً بالآخرين.					
A2	الأشخاص المصابون بالصرع أكثر عصبية أو عرضة للانفعال مقارنةً بغيرهم.					
A3	حوادث العمل أكثر شيوعًا بين المصابين بالصرع مقارنةً بغيرهم.					
A4	تعاني الأسرة عندما يكون أحد أفرادها مصابًا بالصرع.					
A5	فرص العمل المتاحة لمرضى الصرع محدودة مقارنةً بغيرهم.					
A6	يُعامل مرضى الصرع كمجموعة أقلية.					
A7	يمكن للأشخاص المصابين بالصرع أن يعيشوا حياة طبيعية إذا التزموا بالعلاج.					
A8	يمكن للأشخاص المصابين بالصرع التعرف على توقيت حدوث النوبة.					
A9	لا ينبغي للأشخاص المصابين بالصرع المشاركة في الأنشطة الاجتماعية.					
A10	ينبغي على الأشخاص المصابين بالصرع الإفصاح عن حالتهم الصحية عند بدء وظيفة جديدة.					

القسم الرابع: الممارسات في أساليب الرعاية الصحية للصرع

يناقش هذا القسم الممارسات التي تقوم لمساعدة المريض في إدارة مرض الصرع. يرجى وضع (x) على الإجابة الأكثر ملائمة:

الرقم	البند	دائمًا	غالبًا	أحيانًا	نادرًا	أبدًا
1	أبدأ علاج مرضى الصّرع بإعطائهم الأدوية المضادة للصرع مباشرة.					
2	أقوم بتعديل العلاج بالأدوية المضادة للصرع دون إحالة المريض إلى الطبيب المختص.					
3	عندما يقتضي الأمر تعديل العلاج بالأدوية المضادة للصرع أقوم بتحديد تركيزها في الدم					
4	أعطي المريض خيارات عن العلاج ليفكر فيها ويشارك في القرار					
5	أشجع المريض على التحدث عن أي مشاكل تتعلق بالأدوية أو آثارها					
6	أعطي المريض قائمة مكتوبة بالأمور والخطوات التي يجب القيام بها لتحسين وضعه الصحي					
7	أطلب من المريض أن يشاركني ما يفعله من ممارسات للعناية بحالته الصحية					
8	أساعد المريض على وضع أهداف محددة لتحسين الأكل أو ممارسة الرياضة أو غيرها					
9	أعطي المريض نسخة من الخطة العلاجية المحدثة					
10	أشجع المريض على الذهاب إلى مجموعة أو صف معين لمساعدته في التعامل مع مرض الصرع					
11	أراعي قيم المريض وتقاليده عندما أوصيه بالعلاجات					
12	أقوم بتحويل المريض إلى اختصاصي تغذية أو مرشد تثقيف صحي أو أي جهة طبية متخصصة عند الحاجة					

شكرًا لتعاونكم

Appendix 9: mhGAP Questionnaire - English version

School of Public Health

Participant Information Sheet & Consent Form

Study Title: **"Impact of mhGAP-Based Epilepsy Training Program on Primary Healthcare Providers in Palestine: A Quasi-Experimental Study"**

Dear Participant,

I am Abeer Ali Ghanayem, a PhD student conducting research titled as above. This study aims to explore the impact of an mhGAP-Based Epilepsy Training Program on Primary Healthcare Providers in Palestine: A Quasi-Experimental Study as a requirement for my PhD dissertation at Al-Quds University, School of Public Health, under the supervision of Dr. Hussein Hallak.

The study involves completing the attached questionnaire (Knowledge, Attitudes, and Self-efficacy of Healthcare Providers Regarding Epilepsy Care and Management in Primary Health Centers). The collected data will be used strictly for academic and scientific research purposes to support evidence-based decision-making and improvements.

Please be assured that all data collected will be treated with strict confidentiality. Participation is voluntary, and you may withdraw from the study at any time without any consequences. Your participation includes the following:

Knowledge, Attitudes, and Self-efficacy of Healthcare Providers Regarding Epilepsy Care and Management in Primary Health Centers.

School of Public Health

Participant Consent Form

Study Title: **"Impact of mhGAP-Based Epilepsy Training Program on Primary Healthcare Providers in Palestine: A Quasi-Experimental Study"**

By signing this form, I agree to the following:

☐ I have been informed about the study's objective by the researcher.

☐ I understand that my personal data and the information collected will remain confidential and used only for research purposes.

☐ I am aware that I have the right to withdraw from the study at any time.

☐ I understand that I may skip any question I do not wish to answer.

Participant Name: _____ Signature: _____ Date: _____

Researcher Name: Abeer Ali Ghanayem Signature: _____ Date: _____

For inquiries, contact: abeerghanayem@gmail.com

Section 1: Demographic Information

This section collects demographic information for research purposes only. Responses will remain anonymous and untraceable. Please mark (x) in the appropriate box.

Gender: ☐ Male ☐ Female

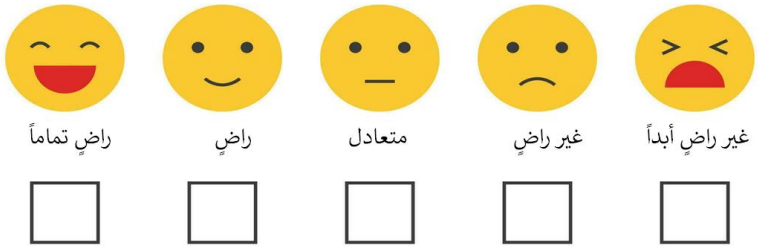
Age (in years): _____

Years of experience in PHC: _____

Educational level: ☐ Diploma ☐ Bachelor's ☐ Higher education or Specialty

Profession: ☐ Physician ☐ Nurse ☐ Pharmacist
☐ Other (please specify): _____

How satisfied are you with your knowledge about epilepsy?



Section Two: Sources of Knowledge and Management of Epilepsy

This section aims to determine the extent of participants' interaction with epilepsy patients during their work. Please mark (x) next to the appropriate option:

1. **Do you deal with epilepsy patients as part of your work?**
   ☐ Yes ☐ No
2. **Number of epilepsy patients you deal with weekly in your work:**
   ☐ (1 – 4) ☐ (5 – 9) ☐ More than 10 patients
3. **Do you follow up with the same patients regularly (e.g., weekly or monthly)?**
   ☐ Yes ☐ No
4. **Did you receive previous training for epilepsy?**
   ☐ Yes ☐ No

Section 3: Knowledge about Epilepsy

Please choose the best answer according to your knowledge and beliefs.

1. Which of the following is a common presentation of epilepsy?
a) Delayed developmental milestones.
b) Slow respiratory rate and pinpoint pupils.
c) Tremor in hands, sweating and vomiting.
d) Convulsive movements or fits.

2. Which of the following is a common presentation of epilepsy?
a) Loss of consciousness, stiffness/rigidity, tongue-biting and urinary incontinence.
b) Marked behavioral changes and neglecting usual responsibilities
c) Bleeding from a self-inflicted wound.
d) Smell of alcohol on breath, slurred speech and uninhibited behavior.

3. Which of the following statements concerning epilepsy is correct?
a) Epilepsy is a communicable disorder of the brain.
b) Epilepsy is a sign of spirit possession.
c) Epilepsy is always genetic in cause.
d) Epilepsy is one of the most common neurological disorders.

4. Which of the following statements concerning epilepsy is correct?
a) Epilepsy can often cause people to be dangerous to others.
b) Epilepsy does not occur in children or adolescents.
c) Epilepsy can be well-controlled in the majority of people with proper treatment.
d) Epilepsy is not present as an emergency situation and does not always require medication.

5. Which of the following is a common cluster of symptoms in epilepsy?
a) Eclampsia and fever, followed by head injury.
b) Signs of poisoning and self-harm, followed by loss of consciousness.
c) Loss of consciousness and tongue-biting, followed by confusion.
d) Nausea and headache, followed by increased pulse.

6. Which of the following is a common cluster of symptoms in epilepsy after a seizure?
a) Drowsiness, confusion, abnormal behavior.
b) Extreme hopelessness and despair, thoughts of self-harm or suicide.
c) Excessive crying, clinging to a carer, sleeping and eating difficulties.
d) Dilated pupils, abdominal cramps, diarrhea.

7. Which of the following is an important step in the emergency treatment of someone with epilepsy having a convulsion?
a) Use a calm voice when talking with the patient and listen carefully.
b) Check airway, breathing and circulation.
c) Give intramuscular or subcutaneous naloxone.
d) Give thiamine injection.
8. Which of the following is the best combination treatment for epilepsy?
a) Seeing a traditional healer and taking herbal products as advised by them.
b) Pharmacological interventions and herbal products.
c) Psychosocial interventions and antiepileptic medication.
d) Psychosocial interventions and magnesium sulphate.

9. Which of the following might you say to a carer of someone with epilepsy?
a) Epilepsy is contagious – they should be careful of touching the person when they are having a seizure.
b) When the person is having a seizure, they should try and restrain them.
c) The person only needs medication if they feel that a seizure is imminent.
d) Epilepsy is the recurrent tendency for convulsions.

10. Which of the following requires emergency medical treatment?
a) When someone starts to feel that a seizure is imminent.
b) If the seizure lasts for more than one minute.
c) If the seizure lasts for more than five minutes.
d) If the person is drowsy once the seizure is over

Section 4: Attitudes toward Epilepsy

Please mark the answer that most reflects your opinion.

No.	Attitude Statement	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
A1	People with epilepsy have a lower ability to concentrate than others.					
A2	People with epilepsy are more nervous or more prone to irritability compared to others.					
A3	Work accidents are more common among people with epilepsy than others.					
A4	The family suffers when one of its members has epilepsy.					
A5	Employment opportunities for patients with epilepsy are limited compared to others.					
A6	Epilepsy patients are treated as a minority group.					
A7	People with epilepsy can live a normal life if they adhere to treatment.					
A8	People with epilepsy can recognize when a seizure is about to occur.					
A9	People with epilepsy should not participate in social activities.					
A10	People with epilepsy should disclose their condition when starting a new job.					

Section 5: Self-efficacy in Epilepsy Care

Please mark the frequency that best describes you.

No.	I feel confident in my capability to:	Always	Often	Sometimes	Rarely	Never
1	Provide pharmacological treatment for patients presenting with epilepsy					
2	Provide support (ex: active listening) for patients presenting with epilepsy					
3	Provide psychoeducation for patients presenting with epilepsy					
4	Treat patients having issues relating to epilepsy					
5	Develop a clinical plan for patients presenting with epilepsy					
6	Refer my patient to a specialized physician					
7	Involve family members/ friends in the management plan					
8	Involve other professionals in the management plan					
9	Collect information to detect an epilepsy case					
10	Explain the diagnosis to patients					
11	Diagnose a mental health problem					
12	Use tools and techniques to detect mental health problem					

THANK YOU

Appendix 10: mhGAP Questionnaire – Arabic version

كلية الصحة العامة- جامعة القدس

نموذج تعريف بالدراسة وموافقة للمشاركين

دراسة: " تأثير تدريب mhGAP حول الصرع على مقدمي الرعاية الأولية في فلسطين: دراسة شبه تجريبية "

عزيزي المشارك الكريم / عزيزتي المشاركة الكريمة:

أنا الطالبة عبير علي غنايم أقوم بإجراء بحث بعنوان **" تأثير تدريب mhGAP حول الصرع على مقدمي الرعاية الأولية في فلسطين: دراسة شبه تجريبية "** حيث يهدف هذا البحث إلى استكشاف وفهم مدى التغيير في المعرفة والممارسات والكفاءة برعاية وإدارة مرض الصرع لدى الكادر الصحي العاملين في مراكز الرعاية الأولية في منطقة الخليل بعد اجراء دورة تدريبية. كمتطلب لرسالة الدكتوراه في الصحة العامة في جامعة القدس كلية الصحة العامة تحت اشراف الدكتور حسين حلاق.

تتضمن الدراسة تعبئة الاستبيان المرفق (استبيان المعرفة والممارسات والكفاءة للكادر الصحي في مراكز الرعاية الأولية حول رعاية وإدارة مرض الصرع). وسيتم استخدام المعلومات لأغراض البحث العلمي فقط وذلك بهدف التحسين والتطوير وأخذ القرارات المبنية على الحقائق.

نؤكد بأنه سيتم التعامل مع جميع المعلومات التي سيتم جمعها خلال هذه الدراسة بسرية تامة. لذا نرجو من حضرتكم التعاون بالإجابة على أسئلة الاستبانات، علما بأن المشاركة طوعية ويمكنك اختيار الانسحاب في أي وقت دون مواجهة أي عواقب.

كلية الصحة العامة- جامعة القدس

نموذج الموافقة للمشاركين

دراسة: " تأثير تدريب mhGAP حول الصرع على مقدمي الرعاية الأولية في فلسطين: دراسة شبه تجريبية "

التوقيع على هذا النموذج يعني أنني أوافق على ما يلي			
1	لقد تم إبلاغي عن هدف الدراسة من قبل الباحث	نعم	لا
2	تم ابلاغي بأن معلوماتي الشخصية والمعلومات التي سيتم جمعها من هذه الدراسة البحثية ستبقى سرية وسوف تستخدم من اجل البحث العلمي فقط	نعم	لا
3	أدرك أن لدي الحق في الانسحاب من الدراسة في أي وقت	نعم	لا
4	لدي خيار عدم الإجابة عن أي سؤال أحدده	نعم	لا

اسم المشارك/ة ---------- التوقيع ---------- التاريخ----------

اسم الباحثة ---------- التوقيع---------- التاريخ----------

إذا كان لديك أي سؤال أو كنت بحاجة إلى أي معلومات، فيرجى الاتصال بـ

عبير علي غنايم

abeerghanayem@gmail.com

القسم الأول: السمات الديموغرافية:

يهتم هذا القسم بجمع السمات الديموغرافية للمشاركين لأغراض البحث العلمي فقط. الردود ستكون مجهولة ولا يمكن تتبعها أو ربطها بك أو بأحد المشاركين. يرجى وضع (x) على الخيار المناسب:

الجنس: 1. ذكر 2. أنثى

العمر (بالسنوات) _____

عدد سنوات الخبرة في مراكز الرعاية الأولية _____

المستوى التعليمي: 1. دبلوم 2. بكالوريوس 3. اختصاص أو دراسات عليا

المهنة: 1. طبيب 2. ممرض 3. صيدلاني

4. غير ذلك (الرجاء التحديد) _____

القسم الثاني: مصادر المعرفة والتعامل مع مرض الصرع

يهتم هذا القسم بتحديد مدى تعامل المشاركين مع مرضى الصرع خلال العمل. يرجى وضع (x) على الخيار المناسب:

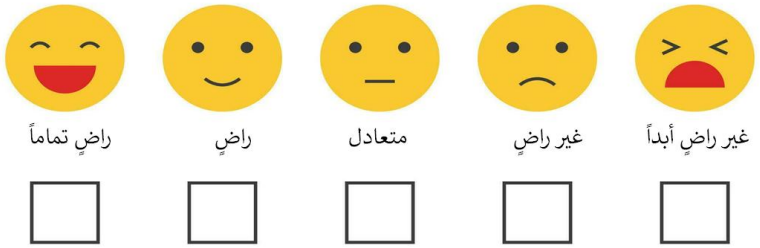
1. هل تتعامل مع مرضى الصرع من خلال عملك؟
   1) نعم 2) لا

2. عدد مرضى الصرع الذين تقوم بالتعامل معهم في عملك أسبوعيا
   1) (1 – 4) 2) (5 – 9) 3) أكثر من 10 مرضى

3. هل تتعامل مع نفس المرضى بشكل دوري (مثلا أسبوعيا أو شهريا):
   1) نعم 2) لا

4. هل تلقيت تدريبا مسبقا عن الصرع؟
   1) نعم 2) لا

5. ما مدى رضاك عن معلوماتك حول مرض الصّرع؟



القسم الثالث: المعرفة بمرض الصرع وكيفية رعايته

يبحث هذا القسم في المعرفة الفعلية للمشاركين حول مرض الصّرع. يرجى اختيار الاجابة المناسبة لكل سؤال.

1. **أي مما يلي يُعتبر عرضًا شائعًا للصرع؟ اختر الإجابة الصحيحة:**
   A) تأخر في معالم النمو.
   B) معدل تنفس بطيء وحدقة ضيقة.
   C) رعشة في اليدين، تعرق وقيء.
   D) حركات تشنجية أو نوبات صرعية.

2. **أي مما يلي يُعتبر عرضًا شائعًا للصرع؟ اختر الإجابة الصحيحة:**
   A) فقدان الوعي، تصلب/تيبس، عض اللسان وسلس البول.
   B) تغيّرات سلوكية ملحوظة وإهمال المسؤوليات المعتادة.
   C) نزيف من جرح ذاتي.
   D) رائحة الكحول في النفس، كلام متداخل وسلوك غير منضبط.

3. **أي من العبارات التالية حول الصرع صحيحة؟ اختر الإجابة الصحيحة:**
   A) الصرع هو اضطراب معدٍ في الدماغ.
   B) الصرع علامة على المسّ الروحي.
   C) الصرع سببه وراثي دائمًا.
   D) الصرع هو أحد أكثر الاضطرابات العصبية شيوعًا.

4. **أي من العبارات التالية حول الصرع صحيحة؟ اختر الإجابة الصحيحة:**
   A) الصرع غالبًا ما يجعل الشخص يشكل خطرًا على الآخرين.
   B) الصرع لا يحدث عند الأطفال أو المراهقين.
   C) يمكن السيطرة على الصرع بشكل جيد لدى معظم المرضى من خلال العلاج المناسب.
   D) الصرع لا يُعتبر حالة طارئة ولا يتطلب دائمًا علاجًا دوائيًا.

5. **أي مما يلي يُعتبر مجموعة أعراض شائعة في الصرع؟ اختر الإجابة الصحيحة:**
   A) تسمم الحمل والحمى، يتبعها إصابة في الرأس.
   B) علامات التسمم وإيذاء النفس، يتبعها فقدان الوعي.
   C) فقدان الوعي وعض اللسان، يتبعها ارتباك.
   D) غثيان وصداع، يتبعهما زيادة في النبض.

6. **أي مما يلي يُعتبر مجموعة أعراض شائعة في الصرع بعد حدوث نوبة صرعية؟ اختر الإجابة الصحيحة:**
   A) نعاس، ارتباك، سلوك غير طبيعي.
   B) يأس شديد وشعور بالاكتئاب، أفكار إيذاء النفس أو الانتحار.
   C) بكاء مفرط، التشبث بالمُعتني، صعوبات في النوم والتغذية.
   D) توسع حدقة العين، تقلصات في البطن، إسهال.

7. **أي من الخطوات التالية يُعتبر مهمًا في العلاج الطارئ لشخص يعاني من نوبة صرعية؟ اختر الإجابة الصحيحة:**
   A) استخدام صوت هادئ عند التحدث مع المريض والاستماع بعناية.
   B) فحص مجرى الهواء، التنفس، والدورة الدموية.
   C) إعطاء نالوكسون عن طريق الحقن العضلي أو تحت الجلد.
   D) إعطاء حقنة ثيامين.

8. **أي من العلاجات التالية هو الأفضل لعلاج الصرع؟ اختر الإجابة الصحيحة:**
   A) زيارة معالج تقليدي وأخذ المنتجات العشبية كما ينصح بها.
   B) العلاجات الدوائية والمنتجات العشبية.
   C) التدخلات النفسية الاجتماعية والأدوية المضادة للصرع.
   D) التدخلات النفسية الاجتماعية وكبريتات المغنيسيوم.

9. **أي مما يلي يمكنك قوله لمُقدم الرعاية لشخص مصاب بالصرع؟ اختر الإجابة الصحيحة:**
   A) الصرع معدٍ – يجب أن يكون حذرًا عند لمس الشخص أثناء النوبة.
   B) عندما يكون الشخص في نوبة، يجب محاولة تقييده.
   C) الشخص يحتاج إلى الدواء فقط إذا شعر بأن النوبة وشيكة.
   D) الصرع هو الميل المتكرر للنوبات التشنجية.

10. **أي من الحالات التالية تتطلب علاجًا طبيًا طارئًا؟ اختر الإجابة الصحيحة:**
   A) عندما يبدأ الشخص بالشعور بأن النوبة وشيكة.
   B) إذا استمرت النوبة لأكثر من دقيقة واحدة.
   C) إذا استمرت النوبة لأكثر من خمس دقائق.
   D) إذا كان الشخص يشعر بالنعاس بعد انتهاء النوبة.

القسم الرابع: المواقف تجاه مرض الصرع

يناقش هذا القسم موقفك وآرائك وانطباعاتك حول مرض الصّرع. يرجى وضع (x) على الإجابة الأكثر ملائمة:

الرقم	البند	موافق بشدة	موافق	محايد	لا أوافق	لا أوافق بشدة
A1	الأشخاص المصابون بالصرع لديهم قدرة أقل على التركيز مقارنةً بالآخرين.					
A2	الأشخاص المصابون بالصرع أكثر عصبية أو عرضة للانفعال مقارنةً بغيرهم.					
A3	حوادث العمل أكثر شيوعًا بين المصابين بالصرع مقارنةً بغيرهم.					
A4	تعاني الأسرة عندما يكون أحد أفرادها مصابًا بالصرع.					
A5	فرص العمل المتاحة لمرضى الصرع محدودة مقارنةً بغيرهم.					
A6	يُعامل مرضى الصرع كمجموعة أقلية.					
A7	يمكن للأشخاص المصابين بالصرع أن يعيشوا حياة طبيعية إذا التزموا بالعلاج.					
A8	يمكن للأشخاص المصابين بالصرع التعرف على توقيت حدوث النوبة.					
A9	لا ينبغي للأشخاص المصابين بالصرع المشاركة في الأنشطة الاجتماعية.					
A10	ينبغي على الأشخاص المصابين بالصرع الإفصاح عن حالتهم الصحية عند بدء وظيفة جديدة.					

القسم الخامس: الفعالية الذاتية في الرعاية الصحية للصرع

يناقش هذا القسم الثقة في القدرة على رعاية مريض الصرع. يرجى وضع (x) على الإجابة الأكثر ملائمة:

الرقم	أشعر بالثقة في قدرتي على:	دائمًا	غالبًا	أحيانًا	نادرًا	أبدًا
1	تقديم العلاج الدوائي للمرضى المصابين بالصرع					
2	تقديم الدعم (مثل: الإصغاء الفعال) للمرضى المصابين بالصرع					
3	تقديم التثقيف الصحي النفسي للمرضى المصابين بالصرع					
4	علاج المرضى الذين يعانون من مشاكل متعلقة بالصرع					
5	وضع خطة علاجية للمرضى المصابين بالصرع					
6	تحويل المريض إلى طبيب مختص					
7	إشراك أفراد العائلة/الأصدقاء في خطة العلاج					
8	إشراك متخصصين آخرين في خطة العلاج					
9	جمع المعلومات للكشف عن حالة صرع					
10	شرح التشخيص للمرضى					
11	تشخيص مشكلة صحية نفسية					
12	استخدام الأدوات والتقنيات للكشف عن مشكلة صحية نفسية					

شكرًا لتعاونكم

Appendix 11: Published Article

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Research Paper

Epilepsy management in primary healthcare: Knowledge, attitudes, and practices among health professionals in Palestine

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ABSTRACT

Background: Primary healthcare practitioners play a key role in the comprehensive care of epilepsy. People with epilepsy require suitable guidance for self-management to enhance their health and well-being. The aim was to evaluate knowledge, attitudes, and practices about epilepsy management among the primary healthcare professionals.

Methods: Cross-sectional quantitative research was employed. Healthcare professionals working in primary healthcare clinics completed an online, self-administered questionnaire between April and June 2024.

Results: Three hundred valid questionnaires were analyzed. Healthcare professionals demonstrated moderate knowledge, favorable attitudes, and proactive practices in epilepsy management. Pearson's correlation revealed a significant negative relationship between practices and knowledge ($r = -0.170$, $p < 0.01$) and a positive association with attitudes ($r = 0.279$, $p < 0.01$). Multivariate analysis showed that knowledge were negatively correlated with gender and specialty but positively with educational degree (OR = 0.640, 95 % CI: 1.260–0.020, $p = 0.043$; OR = 1.970, 95 % CI: 2.841–0.099, $p < 0.001$). Attitudes were positively associated with age (OR = 2.552, 95 % CI: 0.974–4.130, $p = 0.002$) and years of experience (OR = 2.387, 95 % CI: 0.546–4.227, $p = 0.011$).

Conclusions: Findings indicate gaps in epilepsy knowledge, attitudes, and practices. The study underscores the need for comprehensive training initiatives in Palestine to enhance epilepsy management in primary healthcare settings.

1. Introduction

Epilepsy is a prevalent, chronic neurological condition that is signified by recurring seizures [1]. Epilepsy diagnoses approximately 50 million people worldwide, leading to 13 million disability-adjusted life years [2,3]. Epilepsy patients are at a threefold increased risk of sudden mortality compared to the general population in low- and middle-income countries [3]. Epilepsy imposes several effects on patients and their families that involve economic, physical, emotional, and social factors. These represent experiences of discrimination, stigma, and social isolation [1,2]. Epilepsy is a common neurological disorder in Palestine, however statistics are rare. The West Bank had 6.5 new cases per 100,000 in 2022 [4].

The role of health professionals is substantial for achieving effective epilepsy self-management. Researchers have recognized many barriers that reduce self-management, including poor communication with the healthcare team and low confidence in the therapeutic action of ASMs [5,6]. Primary healthcare personnel are capable of managing epilepsy and treating neurological complications [2]. The practice of self-management has a vital role in promoting the overall well-being of people with epilepsy, as it empowers them to uphold an ideal state of physical, cognitive, and emotional health [7].

Bacci et al. (2021) identified specific community pharmacists providing epilepsy care exceeding medication dispensing. Community pharmacists may educate PWE and their caregivers about epilepsy and ASMs and encourage adherence and self-management [8]. Another study examined alternate epilepsy care options such enhancing primary care providers' awareness and treatment adherence. These programs briefly address the treatment gap, epilepsy-related mortality, and co-morbidity [9].

In Palestine, healthcare practitioners in primary healthcare centers (PHCs) are tasked with providing routine health services for PWE and other chronic illnesses. Unfortunately, both healthcare practitioners and PWE lack formal training on epilepsy self-management programs or

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therapeutic monitoring of ASMs [5,10,11]. It is essential to evaluate the foundational knowledge, attitudes, and practices about epilepsy and epilepsy management among the primary healthcare workforce that provides services for PWE. The study aimed to identify existing gaps in knowledge, attitudes, and practices to guide future interventions and training programs about epilepsy self-management with the purpose of improving the quality of care for people with epilepsy.

2. Methods

2.1. Study design

A cross-sectional study was conducted between April 2024 and June 2024 at governmental primary healthcare centers (PHCs) in the West Bank, Palestine. Palestine is divided into the West Bank and Gaza Strip. Due to political and security constraints, we had difficulties accessing any healthcare center in the Gaza Strip. PHCs are designated to deliver health services, covering counseling, prevention, treatment, rehabilitation, and palliative care.[4] Governmental PHCs offer anti-seizure medications (ASM) and follow-up services to all people with epilepsy, regardless of age, who fall under the governmental health insurance program. Healthcare practitioners working in these PHCs provide health services for chronic diseases, including people with epilepsy. This study targeted all healthcare professionals employed in PHCs of the Ministry of Health who are tasked with delivering health services to people with epilepsy, including physicians, registered nurses, pharmacists, psychologists, and other paramedical personnel.

A sample size of 300 was determined utilizing the EpiInfo® sample size calculator, predicated on a 95 % confidence level, a 5 % margin of error, and an anticipated response distribution of 50 %.

2.2. Ethical approval

The study was ethically approved by the ethical committee at Al-Quds University (ref. 12/24) and the Ministry of Health (ref. 162/550/2024) to collect data. The participants were informed of the study's context and aims. Participants were informed that they were allowed to withdraw at any time without clarification, and that all submitted data would be kept anonymous and confidential. The participants signed a written consent form before enrolling in the study.

2.3. Study tool

A self-administered questionnaire was used to evaluate health practitioners' knowledge, attitudes, and practices about epilepsy management. The questionnaire was developed in accordance with the WHO training guidelines and prior literature.[7,12–15] Four public health experts, three governmental healthcare services experts, and one statistician revised the initial draft. A pilot study was done on a small sample size ($n = 15$), resulting in a Cronbach's alpha coefficient of 0.794, demonstrating strong internal consistency.

The questionnaire comprised of four sections: health practitioner demographics (6 items); familiarity with epilepsy (5 items); knowledge of monitoring the self-management among people with epilepsy (10 items) with 1 point awarded for each correct response and 0 points for incorrect answers, yielding a total score range of 0–10; attitudes towards people with epilepsy were evaluated using a five-point Likert scale (10 items) ranging from strongly agree (5 points) to strongly disagree (1 point), resulting in a score range of 10–50; and practices related to the self-management of epilepsy were measured through 12 items, with ratings from very consistent (5 points) to very inconsistent (1 point), allowing for a score range of 12–60.

The questionnaire was written in English and then translated to Arabic. Back translation was employed to ensure grammatical and conceptual equivalence in the translation of the items [16]. An independent bilingual translator and the researchers themselves corrected any differences between the two versions and ensured measurement consistency across all items. The data were gathered through an electronic questionnaire disseminated to participants by QR codes by an independent data collector.

2.4. Statistical analysis

Data were analyzed using IBM Statistical Product and Service Solutions (SPSS) version 25. Descriptive statistics were employed to summarize the overall knowledge levels, attitudes, and practices of health practitioners in percent. Continuous data were reported by means and standard deviations (SD), and categorical data were provided as n (%). The non-parametric Mann-Whitney and Kruskal-Wallis tests were conducted to analyze knowledge, attitude, and practice scores according to demographic variables. Pearson's correlation (r) and multivariate regression analysis were carried out to analyze relationships between the KAP outcomes and participants' demographics. The p value < 0.05 was chosen as the level of statistical significance.

3. Results

A total of 351 responses were obtained from the survey. The responses of 51 questionnaires were excluded because of logical discrepancies. The study effectively collected 300 valid questionnaires, resulting in a response rate of 85.5 %.

The majority of participants were female (74.3 %) and (42.0 %) in the age range of 40 to 49 years old. Nearly half of the participants were nurses (56.0 %) and have bachelor's degrees in their field (57.0 %). A substantial percentage worked in Southern governorates (41.7 %) and possessed clinical experience in PHCs for less than 10 years (43.3 %) (Table 1).

The average scores for knowledge, attitudes, and practices were 6.34 ± 2.57 (range: 0–10), 36.87 ± 4.55 (range: 10–50), and 46.73 ± 6.92 (range: 12–60), respectively. Male participants exhibited significantly higher knowledge scores ($p = 0.002$), as did those with higher educational degree ($p < 0.001$). Physicians had significantly higher knowledge scores ($p < 0.001$). Participants in the 30- to 39-year-old age group had higher attitude scores ($p = 0.045$), as did those with over 20 years of experience ($p = 0.017$). Psychologists demonstrated the highest practice scores among other health practitioners in PHCs ($p = 0.036$) (Table 1).

The statement with best scores for the knowledge items was "Body convulsions are a sign of epilepsy" at 96.00 %. Conversely, the two items with the lowest scores were: "Involuntary urination is a sign of epilepsy" at 25.67 % and "Dizziness and vertigo are common side effects of ASMs" at 26.00 %. About half of the participants (52.67 %) didn't answer the proper action when encountering a patient experiencing a generalized tonic-clonic seizure and chose to restrain the patient or put solid object in their mouth (Fig. 1), (Supplementary Table, S1).

A substantial majority (94.7 %) indicated a favorable attitude, highlighting the significance for adherence to anti-seizure medications (ASM) (Fig. 2). Conversely, the lowest percentage (14.7 %) expressed disapproval of social seclusion of people with epilepsy. Also, 58.0 % indicated recognition of people with epilepsy as a minority in the community (Table S2, Supplementary material).

Regarding practice, the highest proportion of participants (88.6 %) helped the patient in setting goals for improving epilepsy management (Fig. 3). In contrast, only 8.70 % adjust anti-seizure medications (ASM) without referring the patient to a specialist, and 58 % tend to adjust the ASM regimen without checking its blood serum level (Table S3, Supplementary material).

The Pearson correlational analysis was conducted to evaluate the relationship among knowledge, attitudes, and practices. The analysis indicated a negative correlation between knowledge and practices ($r = -0.170$, $p < 0.01$). A positive correlation was observed between attitude and practice scores ($r = 0.279$, $p < 0.01$). (Table S4, Supplementary material).

Table 1
Participants' demographic characteristics (n = 300).

	N	(%)	Knowledge score Mean ± SD	P	Attitude score Mean ± SD	P	Practice score Mean ± SD	P
Overall	**300**	**100**	**6.34 ± 2.57**		**36.87 ± 4.55**		**46.73 ± 6.92**	
Gender				0.002*		0.590		0.580
Male	77	25.7	7.06 ± 2.61		36.47 ± 5.51		46.55 ± 6.48	
Female	223	74.3	6.10 ± 2.52		37.01 ± 4.17		46.80 ± 7.08	
Age groups				0.116		0.045*		0.258
20 – 29 years	56	18.7	5.96 ± 2.50		35.14 ± 5.59		46.14 ± 5.51	
30 – 39 years	71	23.7	6.79 ± 2.56		38.11 ± 4.25		46.69 ± 6.10	
40 – 49 years	126	42.0	6.44 ± 2.55		36.71 ± 4.61		45.15 ± 7.99	
≥ 50 years	47	15.7	5.87 ± 2.67		37.51 ± 2.32		47.98 ± 6.55	
Clinical experience				0.574		0.017*		0.077
≤ 10 years	130	43.3	6.31 ± 2.60		36.15 ± 4.77		46.07 ± 6.40	
11 – 20 years	106	35.3	6.47 ± 2.69		37.06 ± 4.63		46.73 ± 7.73	
≥ 21 years	64	21.3	6.20 ± 2.32		38.03 ± 3.65		48.09 ± 6.39	
Education /Qualification				0.000*		0.536		0.709
Diploma	74	24.7	5.45 ± 2.38		36.68 ± 4.09		46.62 ± 6.88	
Bachelors	171	57.0	6.20 ± 2.51		36.73 ± 4.82		46.92 ± 7.10	
Higher education	55	18.3	7.98 ± 2.28		37.58 ± 4.28		46.29 ± 6.48	
Profession				0.000*		0.324		0.036*
Physician	38	12.7	8.37 ± 1.95		36.08 ± 5.27		46.71 ± 5.51	
Pharmacist	87	29.0	7.06 ± 2.27		36.89 ± 3.63		45.19 ± 7.23	
Nurse	168	56.0	5.55 ± 2.51		36.95 ± 4.85		47.41 ± 7.04	
Psychologist	7	2.3	5.57 ± 2.23		39.29 ± 2.63		49.71 ± 3.30	
District				0.792		0.555		0.204
North	100	33.3	6.41 ± 2.60		37.00 ± 3.80		47.14 ± 7.99	
Middle	75	25.0	6.45 ± 2.58		37.35 ± 4.10		45.65 ± 6.91	
South	125	41.7	6.22 ± 2.56		36.49 ± 5.30		47.06 ± 5.92	

* Significant differences in respondent scores within each category (p-value < 0.05)

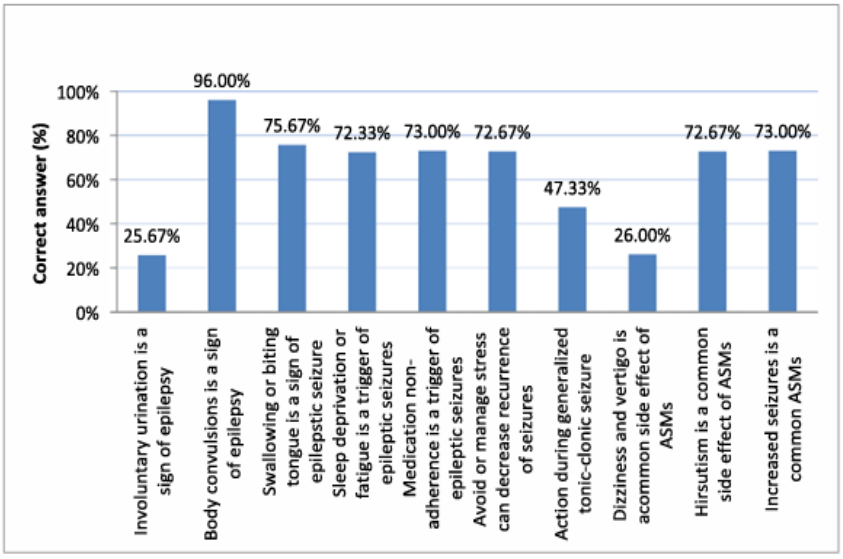

Fig. 1. Knowledge scores in percentages of participants (n = 300).

Multivariate analysis indicated that females (OR = 0.640, 95 % CI: 1.260–0.020, p = 0.043) exhibit a negative association with knowledge. Nurses (OR = 1.970, 95 % CI: 2.841–0.099, p < 0.001) and psychologists (OR = 2.001, 95 % CI: 3.853–0.149, p = 0.034) exhibited negative correlations with knowledge score. There are positive associations between knowledge and practitioners with a bachelor's degree or higher (OR = 0.822, 95 % CI: 0.182, 1.462, p = 0.012). On the other hand, participants aged 30–39 years old (OR = 2.552, 95 % CI: 0.974–––4.130, p = 0.002), and those with more than 21 years of experience (OR = 2.387, 95 %CI: 0.546–4.227, p = 0.011) all showed positive associations

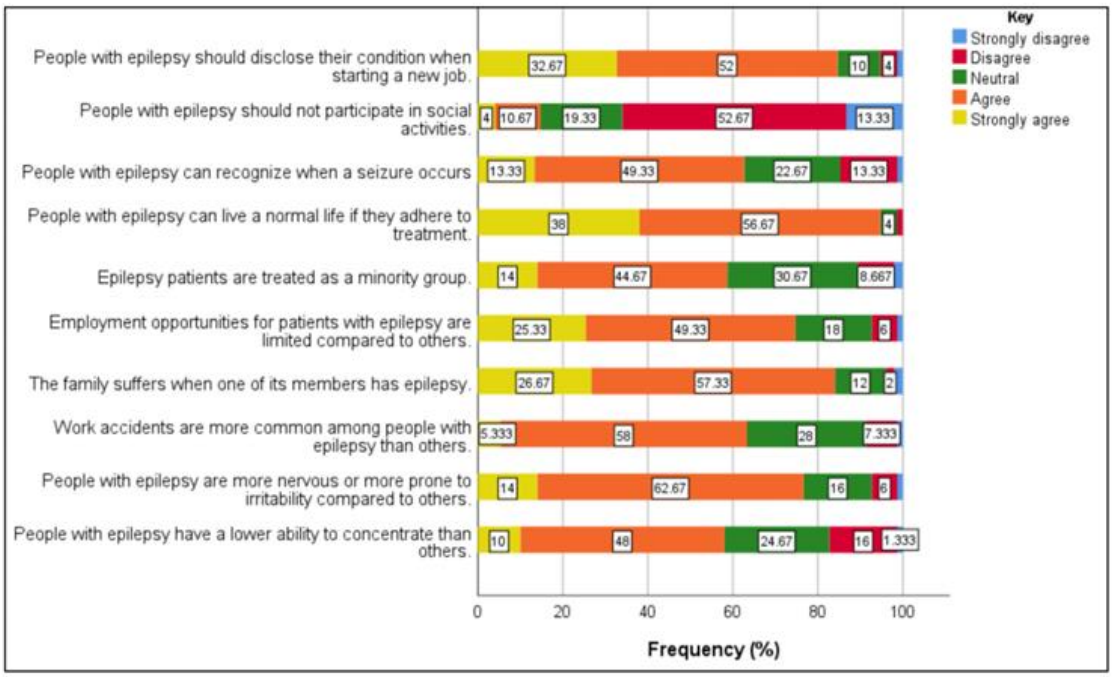

Fig. 2. Attitude scores in percentages of participants (n = 300).

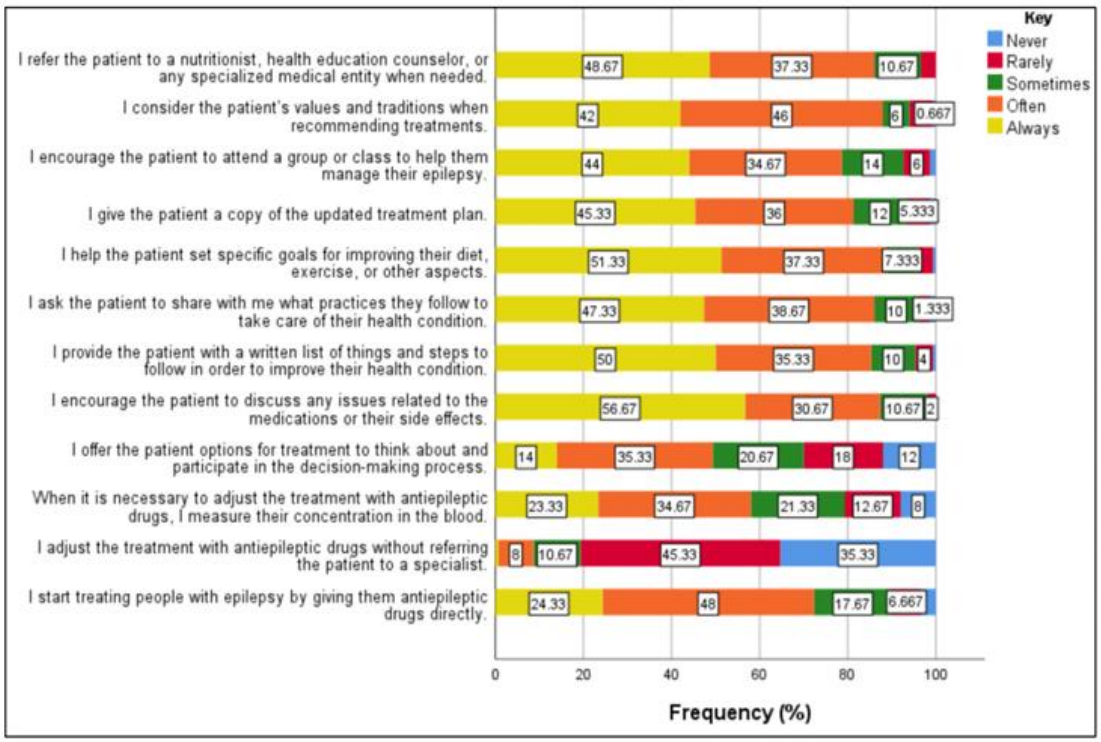

Fig. 3. Participant's practice scores in percentages (%) (n = 300).

with attitudes score (Tables S5 and S6, supplementary material).

4. Discussion

Primary healthcare workers' participation in KAP assessments is rare in the field of epilepsy, with only a few reports emerging from low- and middle-income countries. KAP assessment was performed on the management of epilepsy treatment and management knowledge, attitude, and practice among different primary healthcare workforce in a resource-constrained environment [13,14,17]. Several studies have demonstrated the significance of primary health care in the management of epilepsy and the improvement of health outcomes [14,18,19]. It is fundamental to prioritize the practical and tailored training of primary care workers in epilepsy treatment and management in these settings, taking into account the personnel's varying degrees of professional competence and their specific tasks. Formal programs that offer these types of training in Palestine are lacking [20–22]. The results indicate that healthcare professionals possess a good level of knowledge, maintain favorable attitudes, and engage in proactive practices about epilepsy management. The scores exceed those reported in a study conducted in North India [13]. Physicians achieved significantly the highest scores, which were markedly distinct from those of other different professions. The same result was reported in Niger [23]. Physicians are the most accessible health workforce to knowledge while nurses, who constitute the essential workforce in PHCs, lack adequate training in the management of epilepsy in Palestine. The observed positive relationships between knowledge, educational background, and the professions of the participants reinforces our claim.

Widespread misconceptions persist about epilepsy signs and symptoms. The prevalence of misidentifying signs and symptoms of epilepsy, along with the practice of deficient first-aid measures for seizures, were significant. This aligns with findings from studies conducted in China and Saudi Arabia [14,18]. These findings underscore the need of implementing first aid and educational initiatives to improve healthcare professionals' knowledge and expertise of epilepsy, thereby enhancing their involvement in management strategies for individuals with epilepsy.

Key predictors of participant knowledge in this study were gender, educational level, and profession. Other publications support this finding, indicating that males, more educated participants, and physicians exhibit greater knowledge of epilepsy along with its treatment and management procedures [13,14]. Education and professional specialty in healthcare services are significantly associated with knowledge [2,6,24]. The findings suggest the need for tailored training programs and campaigns aimed at the low-educated primary healthcare workforce, nurses, and females to enhance knowledge of epilepsy management and treatment.

Better attitudes were associated with sustained expertise. Primary healthcare practitioners and PWE may have developed a familiarity through routine visits for ASMs refills and follow-ups, resulting in this outcome. Extended engagement in PHCs and consistent interaction with PWE may enhance understanding, commitment, and feeling for PWE, thereby fostering the observed favorable attitudes. Comparable findings were documented in Italy [17]. Medication adherence is crucial for sustaining normal life conditions, facilitating the social inclusion of PWE, and reflecting the community's perception of PWE as a minority group. These favorable attitudes highlight the need to actively engage PWE in the community and address discrimination. This indicates healthcare professionals' preparedness to interact with patients with epilepsy), similar to their approach towards other chronic disease patients. Interventional programs to improve epilepsy management knowledge and practices are needed. The results align with those reported in Italy [17]. This study identified age and years of experience as significant predictors of participant attitudes. Additional studies corroborate this finding [13,14,17]. Empowering the primary healthcare workforce is crucial for enhancing the acceptance of PWE's illness and fostering social acceptance. Psychological programs targeting early-career healthcare professionals with limited experience may achieve it.

Psychologists significantly outperformed other healthcare professionals working in PHCs in terms of best practices. In Palestine, community and mental healthcare centers assign psychologists to work without specifically targeting epilepsy in their healthcare delivery. The study result underscores the actual need to increase and empower psychologists in PHCs to enhance epilepsy management and other chronic conditions. Several studies confirmed the role of psychological therapy as a main component of epilepsy well-being [25,26].

Training programs for healthcare professionals in PHCs are lacking in Palestine, even though the WHO's mhGAP functions as a universally effective framework for improving the professional competencies to align with the expected level of care for PWE [13,27]. It is essential to adopt training programs to meet the customized needs of the community, along with the knowledge and understanding of epilepsy among primary healthcare personnel and the community. The study findings can guide policymakers and healthcare professionals in developing policies, public health initiatives, health awareness and education programs Targeted and decisive actions addressing epilepsy as a chronic neurological condition are essential to enhancing the quality of life for people living with epilepsy.

5. Study limitations

The research identified several limitations. The cross-sectional design posed challenges in determining the relationships among variables in our findings. Additionally, using self-reported data presents the possibility of social desirability bias, potentially resulting in overestimated scores.

6. Conclusion

The overall knowledge, attitudes and practices regarding epilepsy and its management among healthcare professionals in primary healthcare centers has been observed to be favorable. The results revealed an existing gap in epilepsy management that indicates the urgent need for robust training programs in Palestine aimed at enhancing the management of epilepsy within PHCs. Such initiatives can empower individuals with epilepsy and improve health outcomes. Qualitative studies, such as in-depth interviews, can illuminate patient and healthcare provider experiences. To improve epilepsy care in Palestine, a multifaceted strategy is needed.

Author contributions

Abeer Ghanayem conceptualized and designed the study, conducted the data collection and analysis, and drafted the manuscript. Prof. Hussein Hallak provided guidance on the study design, supervised the research process, and critically reviewed and edited the manuscript. Both authors approved the final version of the manuscript for publication.

Ethical considerations

Our study was ethically approved by the ethical committee at Al-Quds University (ref. 12/24) and Palestinian Ministry of Health (ref. 162/550/2024).

Consent to participate

All participants were informed about the study's background and objectives. Participants were notified that they could withdraw anytime without justification and that all provided data would remain anonymous and confidential. The participants signed a written consent form prior to enrollment in the study.

Consent for publication

Not applicable.

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CRediT authorship contribution statement

Abeer Ghanayem: Writing – review & editing, Writing – original draft, Validation, Methodology, Investigation, Formal analysis. **Hussein Hallak:** Writing – review & editing, Supervision, Methodology, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.yebeh.2025.110345.

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Appendix 12: Article 1 in Peer review process:

Journal: BMC Health Services Research

Collection: Amplifying Marginalized Voices: conducting health services research by or with marginalized communities

Submission ID: 63d6408f-31c7-4403-bb01-79946dd20fa0

Title:

Understanding the psychosocial impact and healthcare navigation of people living with epilepsy on the West Bank, Palestine: Insights from a qualitative study

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Abstract

Background: Epilepsy has several effects on patients and their families, including experiences of fear, stigma, and discrimination. Insights into their well-being are lacking in several under resourced and politically constrained contexts, such as Palestine. This study aimed to explore the lived experiences of people with epilepsy, focusing on their personal, social, and healthcare-related challenges and coping mechanisms.

Methods: A qualitative study employing a Husserlian phenomenological approach was conducted through semi structured in-depth interviews from February to April 2024 from primary healthcare clinics throughout the West Bank. The inclusion criteria consisted of adults aged 18 years and older who had been diagnosed with epilepsy for at least one year, who did not have cognitive impairment or significant medical conditions, who had been prescribed antiepileptic drug therapy, and who were able to provide informed consent. Thematic analysis was utilized, focusing on phenomenological reduction and eidetic analysis to identify recurring patterns of experience.

Results: We purposively interviewed twelve participants, aged 20–65 years, of both genders, residing across all districts of the West Bank. Three major themes emerged regarding the lived experiences of people with epilepsy: disruption of the emotional and social lifeworld; healthcare encounters as structures of meaning-making; and intentional coping and sources of support in the lived body. The participants' narratives illustrate how epilepsy intersects with stigma, systemic inadequacies, and sociopolitical constraints, shaping their daily experiences and identities.

Conclusions: The perceptions and lived experiences of people with epilepsy affect the psychosocial well-being of people with epilepsy, such as stigma, loss of autonomy, and dependence on others and medication. Narratives emphasized the importance of accepting people with epilepsy from society, regaining control strategies, and cultivating resilience through supportive relationships. The lived experience of epilepsy in Palestine is shaped not only by seizures but also by deep psychosocial distress, societal exclusion, and inadequate healthcare support. Despite these challenges, participants demonstrated resilience through familial bonds, faith, and self-developed strategies. These findings call for context-sensitive interventions that integrate psychosocial care into epilepsy management and address structural barriers to equitable healthcare. Amplifying patient voices is essential for informing policy and enhancing support for marginalized populations living with neurological conditions in conflict-affected settings.

Keywords: Epilepsy, Lived Experience, Qualitative Research, Phenomenology, Psychosocial Burden, Healthcare Navigation, Coping Strategies, Stigma, Palestine

Background

Epilepsy is a prevalent and chronic neurological disorder that is classified as one of the most burdensome noncommunicable diseases globally, particularly in low- and middle-income nations. Worldwide, the total number of individuals diagnosed with epilepsy, covering all age groups, is over 50 million (WHO, 2024a). The incidence of epilepsy in high-income nations is approximately 49 cases per 100,000 people annually, with a higher rate of over 139 cases per 100,000 people in low-income countries (WHO, 2022, 2024a). Epilepsy has been recognized as a prevalent neurological disorder in Palestine; however, its exact prevalence has not been accurately measured. In 2023, the incidence rate of epilepsy in the West Bank was reported to be 5.4 per 100,000 citizens (MOH, 2023).

Epilepsy is defined by the occurrence of repeated seizures, which may be accompanied by periods of unconsciousness and loss of control over bowel or bladder function (Bankole et al., 2024; Beghi, 2020). Epileptic seizures have a significant negative impact on the physical, psychological, social, mental, and economic conditions of patients. The increased risk of injury, mortality, depression, discrimination, and stigma affects all people with epilepsy (PWE) and extends to their families (Ernawati & Rahmatul Islamiyah, 2018). Previous qualitative research on epilepsy has focused on the impact of several factors that are associated with epilepsy on the quality of life of people with epilepsy (PWE), such as burden of disease, mental disorders, injury, stigmatization, and loss of employment among various age groups, genders, and health statuses (Ayele et al., 2023; Deegbe et al., 2020; Demissie et al., 2021). People with epilepsy face difficulties in accepting and adapting to their condition within the limited framework of the medical plan, which is primarily within the limits of the medical plan that focuses on the administration of antiepileptic drugs (AEDs) for treatment and seizure control. The medical model adjusts responsibility for seizure occurrence, creating a sense of detachment for PWE, yet it may hinder holistic adaptation (Bankole et al., 2024; Getnet et al., 2016).

The healthcare system in the West Bank, Palestine, is complicated. The health infrastructure in Palestine has encountered significant challenges because of the Israeli occupation, restricted access to medical care, and inherent issues within the developing healthcare system. Despite significant progress in basic healthcare, there are still limitations in the treatment and management of chronic disorders such as epilepsy (Giacaman et al., 2009; Imam et al., 2020; Shawawra & Khleif, 2011; Vitullo et al., 2012). For people living with epilepsy, adjusting to the medical model that focuses mainly on medication and controlling seizures can be isolated, as it often overlooks the emotional and social challenges they face every day (Beghi, 2020; Ernawati & Rahmatul Islamiyah, 2018). Healthcare services are provided by the Ministry of Health and Military Medical Services, nongovernmental organizations (NGOs), the United Nations Relief and Work Agency (UNRWA), and the private sector (both profit and nonprofit). These multiple, fragmented sectors provide primary (mainly), secondary, and tertiary care to the entire population (Giacaman et al., 2009; Imam et al., 2020; Jasser & Ahmad, 2023). Political instability, economic constraints, and fragmented governance impose numerous challenges on the Palestinian healthcare system (WHO, 2023a). The system mostly depends on international aid, making it vulnerable to political fluctuations and funding reductions. Limited quality and access to care are due to many complex factors, such as import restrictions that cause regular shortages of essential medical supplies, medications, and diagnostic tools, resulting in an underdeveloped healthcare infrastructure. The lack of specialist healthcare workers, such as neurologists, oncologists, and mental health providers, and Israeli restrictions, such as checkpoints, the separation wall, and movement

permits, are also contributing factors to limited health access (Vitullo et al., 2012). Palestinians encounter challenges in accessing healthcare because of high out-of-pocket expenses, limited insurance coverage, and considerable unemployment rates (Jasser & Ahmad, 2023; MOH, 2022).

The incorporation of insights obtained from lived experiences into healthcare practice holds significant importance. This enhances communication between patients and healthcare providers, fostering trust, empathy, and teamwork as practitioners acknowledge and value patient experiences. This may result in increased patient adherence to treatment protocols, increased satisfaction levels, and improved health results (Naeem et al., 2023; Rand et al., 2019). The World Health Organization's Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (2022–2031) provides a comprehensive framework aimed at reducing the burden of neurological conditions worldwide, especially in resource-limited or conflict-affected settings. This plan outlines key strategies for improving access to effective care, enhancing the quality of treatment services, and reducing the stigma associated with epilepsy. It underlines the need for training healthcare practitioners to better treat these diseases, the integration of epilepsy care into primary healthcare systems, and the promotion of evidence-based methods to enhance health outcomes and the well-being of PWE (WHO, 2023b).

The Husserlian phenomenological approach was utilized in this study to explore the lived experiences of PWE in the West Bank, Palestine. Husserlian phenomenology describes the subjective reality of individuals by focusing on their experiences directly, without external interpretations or theoretical frameworks. Edmund Husserl suggested that to fully understand human experience, we must return "to the things themselves" to examine how experiences appear in consciousness, free from presumptions or conceptualization (Gutland, 2018; Husserl, 2012; Pacheco & Fossa, 2024). This philosophy emphasizes intentionality, the concept that consciousness is directed toward objects, events, or states of being in the world (Cudjoe, 2023; Husserl, 2012). It highlights epoché (bracketing), in which researchers must suspend personal biases to objectively examine events as they manifest (Gutland, 2018). In this study, we employed reflexive journaling and iterative dialog during data collection and analysis to remain aware of our own positions and intentionally set aside interpretations shaped by biomedical or sociocultural assumptions about epilepsy (Cudjoe, 2023; Finlay, 2009; Pacheco & Fossa, 2024). The use of eidetic reduction to identify common themes across narratives aided in revealing the core of experiences (Cudjoe, 2023; Husserl, 2012). In this study, we identified recurring themes in narratives, including stigma, psychological uncertainty, and interaction with healthcare services, which are essential aspects of the lived experience of epilepsy in this sociopolitical context. This approach emphasizes the lived experiences of participants and identifies themes that reflect their reality, such as challenges with stigma, emotional distress, and the effects of epilepsy on social and healthcare interactions. Combining psychosocial well-being, that is, emotional, mental, and social aspects, helps us understand broader backgrounds, including emotional difficulties, coping strategies, and social support (Mlinar et al., 2021). This phenomenological study offers rich insights into the embodied, existential elements of living with epilepsy; therefore, it supports long-term conversations aimed at enhancing healthcare support systems for this population.

Examining the lived experiences of people with epilepsy is vital for effectively addressing the global burden of epilepsy. In Palestine, there is a lack of research, both quantitative and qualitative, focusing on these experiences within the local context. Existing qualitative studies have focused primarily on exploring the delivery of healthcare services from the

providers' perspective rather than the patients' perspective. A qualitative study conducted interviews with healthcare practitioners, revealing deficiencies in the protocols for diagnosing and managing care for women with epilepsy (Shawahna & Zaid, 2022). Another study revealed weaknesses in the assessment and anesthetic protocols tailored for epilepsy, insufficient use of neurology referral services, and a lack of neuromonitoring for people with epilepsy (Jaber et al., 2021). The focus of quantitative research has been on evaluating knowledge and attitudes within the public and among health practitioners, highlighting the importance of public awareness campaigns to address stigma and the need for improved training for practitioners (Shawahna, 2024; Shawahna & Jaber, 2020). The results highlight the importance of working to address gaps in knowledge to improve overall care strategies for people with epilepsy (Shawahna, 2024; Shawahna et al., 2020). While qualitative research that investigates the lived experiences of people with epilepsy has been conducted globally, such findings cannot be applied to the special societal, political, and healthcare setting of Palestine. Current research in Palestine has neglected the perspectives of people with epilepsy, especially those treated in governmental Ministry of Health (MoH) facilities, resulting in a significant deficiency in comprehending the direct experiences, challenges, and needs of this patient population. The findings underscore the importance of addressing these gaps to enhance a patient-centered and context-specific approach to epilepsy management. This study aims to address the existing gap by examining the lived experiences of PWE on the West Bank. It emphasizes their personal, social, and healthcare-related challenges and coping strategies, employing a phenomenological approach that produces insights useful to policy and practice in resource-limited or conflict-affected settings.

Methods

Study Design

The study utilized a qualitative Husserlian descriptive phenomenology methodology. This approach aims to understand and demonstrate the core nature of a lived experience "essence" as recognized by individuals, highlighting an emphasis on the "things themselves" by employing the practice of bracketing or suspending prior assumptions (epoché) (Cudjoe, 2023; Husserl, 2012; Pacheco & Fossa, 2024). Thematic analysis, as described by Braun and Clarke (Braun & Clarke, 2006), was utilized as a systematic method for identifying, analyzing, and reporting patterns (themes) within qualitative data, aligning with the phenomenological objective of uncovering the meaning structures present in participants' experiences. This descriptive qualitative approach effectively facilitates the exploration of healthcare-related phenomena, allowing for a deeper understanding of participants' perspectives on issues that are not yet fully comprehended (Chew et al., 2019; Colorafi et al., 2020; Mlinar et al., 2021). By concentrating on participants' personal narratives without imposing external interpretations, the Husserlian approach sought to disclose the essential elements of living with epilepsy, including experiences of fear, isolation, or resilience (Husserl, 2012). This method offers significant insights into how individuals cope with their daily lives, manage their condition, and engage with society in the Palestinian context.

Study setting, participants, and recruitment process

The study was conducted in governmental primary healthcare clinics across various districts of the West Bank, Palestine. It focuses primarily on the experiences of PWE dependent on governmental health services rather than those receiving care from the

private sector or nongovernmental organizations, which may not necessarily be represented, underscoring the need for a more comprehensive investigation across various healthcare sectors. Purposive sampling was used to identify and recruit people with epilepsy who could articulate rich, diverse experiences. Researchers practiced epoché by documenting and setting aside prior assumptions about epilepsy to minimize bias during recruitment and data collection. To ensure heterogeneity and explore how epilepsy affects individuals across diverse social contexts, participants were selected considering variations in age, gender, educational level, employment status, marital status, and residency (0Table 2). The inclusion criteria were adults (over 18 years old), who were diagnosed with epilepsy for at least one year, who were receiving antiepileptic drug therapy (AEDs), who were capable of providing informed consent and without significant cognitive impairment or other major medical conditions that could confound their experiences related to epilepsy. Participants who were diagnosed with epilepsy for less than one year; who were under 18 years of age; or who had substantial developmental, intellectual, or cognitive impairments (e.g., cerebral palsy, Down syndrome, attention deficits, and autism spectrum disorders) were not included. Participants with psychological or physiological conditions that might influence the study results, such as cognitive impairment, major depressive disorder, and insomnia, or those unwilling to participate were also excluded from the study.

Purposive sampling is a commonly used technique for qualitative research to select individuals who exhibit an extensive amount of knowledge and experience with a certain phenomenon of interest. Furthermore, it takes into consideration the capacity to convey experiences and viewpoints in a clear, articulate, and analytical manner (Campbell et al., 2020). The study recruitment phase started in February 2024 and ended in May 2024. Healthcare professionals, including nurses and pharmacists, at primary healthcare clinics initially identified potential participants by applying the inclusion criteria, utilizing electronic health records of patients who regularly attended for follow-up and medication refills. They notified potential participants about the study via a written information sheet outlining its objectives, procedures, and ethical considerations. Upon expressing their willingness to participate, the primary researcher (AG) approached the subjects for further explanation, addressed questions, and obtained written informed consent. The interviews were scheduled at a mutually convenient time and location to assure participant privacy and comfort, also promoting an open and secure environment for collecting data.

Data saturation, defined as the stage where additional interviews yield no significant new themes or insights, was achieved after interviews were conducted with twelve individuals. The sample size aligns with phenomenological research methodologies that emphasize the depth and richness of data rather than large numbers, typically achieving saturation with 6–15 participants (Guest et al., 2020; Malterud et al., 2016). The final sample size was considered adequate to characterize the basic components of the lived experience of epilepsy in this population.

Data collection

A semi structured interview guide with open-ended questions was developed from the previous literature and was counseled by two experts in neurology and public health (Ayele et al., 2023; Deegbe et al., 2020; Roberts, 2020; Tanywe et al., 2016). We designed an interview guide to explore the participants' experiences with epilepsy, its impact on daily life, their interactions with healthcare professionals, and their coping strategies. Pilot testing

of the guide was performed on two individuals with epilepsy meeting the inclusion criteria (results not included in the final analysis) to improve the flow and clarity of the questions. Probes (e.g., "How did that experience feel?") demonstrated descriptions of conscious experiences, aligning with Husserl's emphasis on intentionality (Appendix 1). The interviews were conducted by the first author (AG) in the Palestinian dialect of Arabic. Each interview lasted approximately 45–60 minutes and was audio-recorded with the participants' permission to ensure accurate verbatim transcription. The interviewer recorded nonverbal cues and contextual observations to contextualize transcripts and ensure social proximity between the interviewer and the interviewee (Roberts, 2020). The fieldwork process was reflective and flexible enough to allow for adjustments on the basis of experiences in the field as well as to ensure cultural appropriateness and sensitivity. Each interview was carried out until no additional new information was obtained (Guest et al., 2020). Upon ending the interview, the interviewer expressed gratitude to the participants.

Data Analysis

Audio recordings were transcribed verbatim in Arabic and subsequently translated into English by a professional translator. The accuracy of the translation was confirmed by a bilingual primary researcher (AG). Thematic analysis was performed in accordance with the six phases established by Braun and Clarke (2006) (Braun & Clarke, 2006; Naeem et al., 2023). Each Arabic transcript was reviewed several times, and initial impressions (phenomenological reduction) familiarized with the data were documented. The original author and another independent interpreter independently identified meaning units to construct first codes and themes. The data were organized into thematic tables and subthemes (Table 1) during the data coding phase. Code themes reflected lifeworld invariants (e.g., "psychosocial burden"). Iterative discourse improved themes to capture participants' experiences (eidetic reduction). Quotes highlighted themes while preserving participants' voices. To strengthen the findings, the field notes were evaluated (Appendix 2). To eliminate selective reporting bias, the second author verified interpretations and co-coded themes and subthemes. P1, P2, …., P12 were used to create the findings to maintain anonymity. The data were analyzed iteratively via qualitative research criteria to ensure credibility and rigor. Researchers kept reflexive journals to bracket biases during analysis, indicated intersubjective validation through co-coding and peer debriefing, confirmed interpretations, and used thick descriptions with quotes as "windows" into participants' lives to ensure phenomenological rigor (Pacheco & Fossa, 2024).

Table 1: Examples from the analytical process

Theme	Subtheme	Code	Data Extract	Quote
Disruption of the Emotional and Social Lifeworld	Emotional Disturbance as Lived Anxiety and Powerlessness	Depression	Crying and depression from having epilepsy	*"When I sit alone and start thinking about my condition, I feel depressed and afraid that someone outside my family might find out and my secret will be exposed. Who would want to marry my daughters after that?"*
Healthcare Encounters as Structures of Meaning-Making	The Lived Meaning of Professional Care—Between	Bad counseling and treatment experiences	Not knowing the treatment plan and side effects of the drugs	*"The neurologist was not a nice part of my life; it always bothered me because he did not explain to me and did not tell me what the nature of my seizures was… and I do not*

	Empathy and Neglect			*understand what the side effects of my medications are."*

Ethical considerations

Ethical approval for this study was obtained from the Research Ethics Committee at Al-Quds University (ref. 12/24). All the methods were performed in accordance with the Declaration of Helsinki (World Medical Association, 2013). All participants provided written informed consent before the interviews started. Confidentiality and anonymity were guaranteed for the participants; identifying information was removed from the transcripts, and pseudonyms were employed. The participants were notified of their right to withdraw from the study at any time without consequence. The data were stored in an undisclosed location.

Results

Among the 43 potential participants identified, 12 consented and completed the in-depth interviews, resulting in a response rate of 27.9%. The participants' ages ranged from 20 to 67 years. Seven participants were males. The participants were classified as single, married, or divorced in terms of marital status. The sociodemographic characteristics of the participants are detailed and summarized in 0Table 2. The demographic variability provided diverse perspectives, which is consistent with the study's phenomenological approach to exploring the lived experiences of PWE.

0Table 2: Summary of the demographic characteristics of the study participants (n = 12)

Major characteristic	Subcategory	Frequency (%)
Sex	Male	7 (58.3%)
	Females	5 (41.7%)
Age (in years)	20–29	5 (41.7%)
	30–39	3 (25.0%)
	40–49	3 (25.0%)
	50+	1 (8.3%)
Marital status	Married	5 (41.7%)
	Divorced	1 (8.3%)
	Single (Never married)	6 (50.0%)
Region	Southern West Bank	5 (41.7%)
	Middle West Bank	3 (25.0%)
	Northern West Bank	4 (33.3%)
Employment	Student	2 (16.7%)
	Employed	6 (50.0%)
	Non employed	4 (33.3%)
Number of AEDs taken	One drug	6 (50.0%)
	More than one drug	5 (41.7%)
	Unrevealed	1 (8.3%)

After implying phenomenological reduction and eidetic analysis, three essential structures of the lifeworld emerged, reflecting the invariant features of the lived experience of epilepsy among Palestinian adults. These themes, developed inductively via Braun & Clarke's

framework, were (1) Disruption of the Emotional and Social Lifeworld, (2) Healthcare Encounters as Structures of Meaning-Making and (3) Intentional Coping and Sources of Support in the Lived Body. summarizes the emergent themes and subthemes.

Table 3 summarizes the emergent themes and subthemes.

Table 3: All emerged themes and subthemes

Theme	Subthemes	Key Findings
Disruption of the Emotional and Social Lifeworld	Emotional Disturbance as Lived Anxiety and Powerlessness	Depression, fear of seizures, denial of diagnosis, family stress.
	Social Alienation and the Gaze of the Other	Stigma (exclusion, unemployment), misconceptions ("craziness"), hiding epilepsy.
	Cognitive Disruption and Academic Vulnerability	Academic struggles, AED-related cognitive side effects (e.g., alertness issues).
Healthcare Encounters as Structures of Meaning-Making	The Lived Meaning of Professional Care—Between Empathy and Neglect	Poor counseling, mistrust in providers, unmet needs, and non-adherence to treatment.
		Empathetic care, effective counseling, patient motivation.
	The Body as Site of Conflict—Adverse Effects of AEDs	Physical (fatigue, kidney injury), psychological (mental deterioration).
Intentional Coping and Sources of Support in the Lived Body	Familial Support as Embodied Belonging	Spouses, parents, siblings, and friends provide emotional/practical help.
	Faith and Complementary Practices as Acts of Meaning-Making	Avoid triggers, multivitamins, therapy, religious practices.

Theme 1: Disruption of the Emotional and Social Lifeworld

All the participants experienced at least one unfavorable psychosocial experience because of their epilepsy. This theme highlights the impact of epilepsy on participants' consciousness as a source of emotional burden, social marginalization, and existential insecurity. The intentional acts of perceiving, feeling, and interpreting epilepsy as part of the self were often exaggerated by fear, shame, and a diminished sense of agency. The participants confirmed that the unpredictable seizures and the gaze of others reshaped their sense of identity and affected their lifeworld. The participants characterized these distressing encounters under three subthemes.

Subtheme 1: Emotional Disturbance as Lived Anxiety and Powerlessness

The participants often reported significant emotional distress, encompassing depression, pervasive fear associated with seizure occurrence, and a sense of helplessness. This explained the lived experience of seizures not only as a medical condition but also as a noema—an object of consciousness. The unpredictability of seizures creates a sense of

powerlessness regarding bodily autonomy and temporal stability. Eight participants expressed passing through phases of sadness and feelings of helplessness and frustration related to being diagnosed with epilepsy. All the participants experienced feelings burdened by one or more negative emotions or physical distress due to the possibility of having unpredicted seizures:

> **P5:** *"Sometimes, when I'm sitting alone, I start crying…"*
>
> **P8:** *"I am not sure when it (the seizure) will happen. It appears unexpectedly every four or five days."*

Many participants exhibited noetic denial of their illness as a defensive mechanism, indicating a disconnection between their embodied self and diagnostic label. This fostered a situation where patients were likely to deny their epilepsy diagnosis (6 participants).

> **P6:** *"I have only increased electrical activity in the brain; my brain cannot handle the existing energy."*
>
> **P8:** *"Honestly, I am convinced that I have nerve issues, not epilepsy."*

Additionally, four participants expressed the feeling that they are a burden on their families and a constant source of fear and anxiety for their loved ones. This sensation of burden influences the embodied vulnerability of the participants. The feeling that their families are always worried and nervous reduces their self-esteem and promotes fear and isolation.

> **P2:** *"When a seizure happens, it causes a state of panic at home."*
>
> **P4:** *"My mother is always concerned that others will learn about my condition and that I will not get married."*

Subtheme 1.2: Social alienation and the gaze of the other

The social dimension of living with epilepsy was heavily marked by stigma and misconceptions. The participants reported experiencing social exclusion, difficulties finding or maintaining employment, and encountering widespread misunderstandings about epilepsy, sometimes equating it with mental illness or "craziness." This led many to conceal their condition from friends, colleagues, and the wider community for fear of negative judgment or discrimination. The perceived "gaze of the other" created a significant barrier to open social engagement.

Living with epilepsy can be extremely challenging because of the societal conceptions of epilepsy that individuals face. These factors lead to self-stigma, concealment, reduced quality of life, and social seclusion. Each participant experienced one or more of these features. These experiences were not passive; rather, they were actively shaped through multiple experiences with judgment and rejection. The social lifeworld, previously regarded as shared, emerged as a source of risk and exclusion. Most participants reported suffering from stigmatization. Most participants described how society uses derogatory terms to characterize people with epilepsy, such as treating them such as being mentally retarded or dangerous.

> **P3:** *"Many people use the term epilepsy to describe mentally retarded people."*
>
> **P7:** *"The name of the disease scares people and makes people think that the patient with epilepsy is crazy, and you become afraid that it will affect your life in terms of work or study."*

Almost half of the participants also faced different forms of social exclusion. For example, they encountered rejection from others, which prevented them from forming friendships, romantic relationships, or marriages.

> **P4:** *"People don't want to marry a girl with epilepsy; they are afraid that their children will be born insane."*
>
> **P8:** *"Some people got scared and close friends and family started pulling away because they thought they might not be safe."*
>
> **P9:** *"Many girls refused to marry me because I might harm them, and their parents are concerned about their daughter's safety with me."*

The fear of the public gaze and its impact on social roles (e.g., marriage, work) led participants to engage in intentional acts of hiding their diagnosis:

> **P3:** *"I do not have close friends with whom I can talk about my condition (epilepsy). However, honestly, I don't trust friends. I swear that stigma surrounds us."*

Subtheme 1.3: Cognitive Disruption and Academic Vulnerability

Most of the participants reported experiencing difficulties or challenges related to cognitive embodiment, learning, and intellectual tasks, both from seizures and AED side effects. These problems were integral to the noematic content of their epilepsy experiences. Seizure-related symptoms are related to self-esteem and academic identity. Half of the participants reported passing through negative experiences because of the recurrence of uncontrolled seizures or related circumstances. Others described experiencing learning or intellectual difficulties because they were taking AEDs. The following narratives illustrate the challenges faced in academic settings:

> **P1:** *"I struggled with assembling words into sentences... I find it hard to organize words into sentences... I barely succeeded in the languages in high school."*
>
> **P4:** *"I always stop taking the medicine before the exams because I fall asleep and forget all that I studied."*

One participant lost his undergraduate scholarship to study courses of interest and suffered from psychological setbacks. This loss reflected deep existential disruptions that transcended simple memory lapses, instead affecting their projected future and life plans.

P6: *"Unfortunately, as a result, I lost my scholarship in the exchange program. They changed my medication, and I had to return to Palestine. I was traveling to take physics courses that are not available in my country…"*

Theme 2: Healthcare Encounters as Structures of Meaning-Making

Healthcare interactions are not experienced neutrally but are influenced by intentional awareness, which is shaped by support, empathy, and anticipations of recognition. These experiences either improved or disrupted the feeling of coherence and agency of the participants throughout their journey to epilepsy.

Subtheme 2.1: The Lived Meaning of Professional Care—Between Empathy and Neglect

The participants reported experiences that varied from highly rewarding to intensely discouraging. In situations where providers exhibited empathy and effective communication, participants underwent intersubjective healing, resulting in a restoration of trust in both themselves and the healthcare system. These positive relationships were noetically constituted as secure spaces fostering self-acceptance and optimism. Only four participants emphasized good relationships and beliefs among healthcare staff, highlighting the positive role of trust and rapport in shaping their healthcare experiences. For PWE, sympathetic, responsive, and encouraging healthcare staff offered psychological comfort and stability during periods of social stigma and dread. Those whom doctors listened to and valued felt more in charge of their health and more willing to adhere to treatments. Typically, good experiences result in reduced clinical anxiety, increased confidence in the healthcare system, and an improved perspective on long-term medical management.

P1: *"The doctor told me that I will get special skills and true, I am excellent in mathematics."*

P6: *"My doctor told me it is normal; there's nothing wrong. He told me that Napoleon had the same thing but still conquered the world. I always remember these words."*

P11: *"The doctor always asks me about my medicine and if there is anything wrong and adjusts my dose."*

The lack of psychological responsiveness or clinical engagement resulted in existential discomfort, reducing participants' confidence in the healthcare system. The lack of adequate knowledge, negative attitudes, and diagnostic delays manifested as noematic content of frustration and neglect. Most of the participants expressed negative experiences with healthcare professionals. Some participants encountered difficulties during diagnosis, whereas others tended to seek counseling in another country.

P1: *"…my father preferred to follow up with a doctor in Jordan, not here."*

P3: *"The neurologist was not a nice part of my life; it always bothered me because he did not explain to me and did not tell me what the nature of my seizures was… and I do not understand what the side effects of my medications are."*

P6: *"I feel that in our hospitals, the nurses and medical staff do not have enough information. I changed many doctors even though my condition is truly clear, but it took them more than two months to figure it out."*

P8: *"Not everyone in the health staff knows how to deal; sometimes, they accept my illness."*

Subtheme 2.2: The Body as Site of Conflict—Adverse Effects of AEDs

Most patients underwent intervals between discontinuation and resumption of treatment. The problems were mostly related to the adverse effects of antiepileptic drugs, particularly constant drowsiness, which restricted their daily functioning. Some participants reported more serious medical effects, including the development of kidney-related complications, which they attributed to prolonged use of drugs. These incidents not only affected adherence but also shaped a complex relationship with treatment characterized by anxiety and dissatisfaction.

P3: *"I always stop taking the medicine before the exams because I fall asleep and forget all that I studied."*

P4: *"My mental state deteriorated, and I started having seizures. I went to the hospital and stayed there for 6 days. Then, the doctors decided to switch my drug."*

P8: *"I stopped the drugs because they made my kidneys injured, but the seizures came back. I then was forced to continue the drug."*

Theme 3: Intentional Coping and Sources of Support in the Lived Body

People with epilepsy often face unique challenges in their daily lives and may require a range of coping strategies to manage their condition effectively. This theme focuses on the structures of resilience that participants developed for the purpose of maintaining their emotional grounding, meaning, and stability. When people feel isolated and that their bodies are unpredictable and uncontrollable, they turn to familial support, faith-based practices, and alternative therapies as lifeworld anchors that make them regain the sense of wholeness.

Subtheme 3.1: Familial Support as Embodied Belonging

The participants' narratives intimately linked the daily struggles with life in the extended family. Parents play a significant role in helping the participants accept the illness, reduce difficulties from the time of diagnosis throughout the treatment journey, and continue to support them throughout their lives, acting as advocates and believers in them. The participants described those family members as their existential companions for their role in helping them overcome uncertainty and anxiety. Familial interactions stand for intersubjective places where people with epilepsy may comfortably live with their vulnerabilities. Some participants mentioned receiving social and emotional support from their friends. They confirmed that they needed their friends around them all the time to help

them manage sudden seizures and protect them. The married participants emphasized the importance of receiving support and confidence from spouses, whether husbands or wives, in addition to maintaining the condition's confidentiality from others. Married participants stated that they accept, understand, and work to cover the family's financial needs.

> **P4:** "*I am proud of them and thankful to my family for this support; they always want to listen to me even if I am weaker than others*."

> **P7:** *"I told him (husband) that I have this problem and that it might stay with me forever. His reaction was normal and understood; he was positive, and he accepted it.*"

> **P12:** *"My father was my biggest supporter; he always came with me to the doctor and for the brain scans."*

Subtheme 3.2: Faith and Complementary Practices as Acts of Meaning-Making

Religious coping can take many forms, such as prayer, meditation, and seeking guidance from religious leaders. This type of coping can be particularly important for adults with epilepsy, who may find that their faith provides a sense of stability and purpose as they face the challenges of their condition. Most participants reported having faith, accepting their condition as a gift from God, and practicing religious acts to help them cope with epilepsy and live their daily lives. The following participant recounted the positive outcomes of strengthening his relationship with God and engaging in religious activities:

> **P11:** *"Prostration became a habit for me……and I have improved a lot with prostration."*

Some participants reported attempting various therapies, including psychological support, energy therapy, and the use of food supplements, to improve their health status, as detailed in the following narratives.

> **P4:** *"Yes, I went to a therapist for two years. I would sit and talk, even bring up topics such as why my hair was curly and why I did not like it. Currently, I am very stable and have psychological support from my friends and from where I live."*

> **P9:** *"I wear a silver bracelet and tried having energy sessions."*

These practices illustrate how participants intentionally constituted meaning through diverse modalities of care that extended beyond biomedical frameworks.

Discussion

This qualitative study employed a Husserlian phenomenological approach to investigate the lived experiences of Palestinian adults with epilepsy who are receiving care in governmental primary healthcare clinics. By bracketing preconceptions and concentrating

on participants' direct accounts, we identified three fundamental themes that represent the essential structures of their lived experiences: disruption of the emotional and social lifeworld, healthcare encounters as structures of meaning-making, and the intentional coping and sources of support in the lived body. This study provides context-specific insights into the challenges and resilience of PWE as a marginalized group within the distinct sociopolitical and healthcare setting of the West Bank, Palestine, thereby addressing a significant gap in regional studies.

The psychosocial burden emerged as an essential component of the lived experience, frequently regarded as more debilitating than the seizures themselves. The participants reported significant emotional turmoil that involved anxiety, depression, and an ultimate sense of fear associated with the unpredictability of seizures, which is consistent with observations from research conducted in various international settings (Fazekas et al., 2021). This fear was frequently intensified in public contexts, leading to a sense of social seclusion. The sense of helplessness and its effect on self-esteem were evident in the stories shared by the participants. These findings are consistent with studies emphasizing the considerable mental health comorbidities linked to chronic conditions such as epilepsy (Bankole et al., 2024; Fazekas et al., 2021; Mlinar et al., 2021; Tanywe et al., 2016).

The presence of stigma was a prevalent component of the social experiences of the participants. The fear related to negative societal perspectives, frequently based on misunderstandings that associated epilepsy with craziness, resulted in the concealment of the diagnosis and withdrawal from social interactions. This is consistent with an extensive body of literature that documents the stigma associated with epilepsy on a global level (S.-A. Lee et al., 2022; Shi et al., 2021) and aligns with prior research conducted in Palestine, which highlights a lack of public awareness and the existence of negative attitudes (Shawahna, 2024). The impacts reached into several aspects of life, such as challenges in building relationships, obtaining employment opportunities, and academic achievement, aligning with issues noted by people with epilepsy in similar low- and middle-income contexts (Ayele et al., 2023; Tanywe et al., 2016). The participants indicated experiencing cognitive difficulties that affected their academic performance and daily functioning. They attributed these challenges to both the condition and the side effects of AEDs, which further exacerbated their psychosocial issues. These challenges are not exclusive to Palestine. Comparable structural and psychosocial barriers have been recorded in various low- and middle-income countries. Studies conducted in Ethiopia and Ghana indicate that widespread stigma, cognitive side effects from antiepileptic drugs (AEDs), and inadequate provider training are significant concerns for individuals with epilepsy (Ayele et al., 2023; Deegbe et al., 2020; Demissie et al., 2021). Primary care providers in India reported insufficient confidence and preparedness in managing epilepsy, which was attributed to inadequate continuing education and systemic deficiencies (Gosain & Samanta, 2022). The identified parallels highlight the necessity for strategies that are both context sensitive and globally informed to enhance epilepsy care in fragile and under-resourced settings.

Healthcare encounters serve as essential frameworks for meaning making, significantly impacting the experiences and coping mechanisms of participants. The narratives revealed a clear contrast: empathetic and communicative care developed trust, self-acceptance, and motivation, whereas experiences considered neglectful or deficient in psychosocial understanding resulted in frustration, mistrust, and the potential for nonadherence. A substantial number of participants expressed their dissatisfaction with the information available concerning their condition and treatment, especially in relation to the side effects

of AEDs and the lack of psychological support in primary care settings. This underscores an essential requirement for enhanced communication, patient education, and the incorporation of psychosocial support within epilepsy care pathways in Palestine, reflecting the demands of international health initiatives (WHO, 2023b). The challenges identified, including diagnostic delays and a perceived deficiency in provider knowledge, highlight more extensive systemic issues within the fragmented and resource-limited Palestinian healthcare system (Jaber et al., 2021; Shawahna & Zaid, 2022; Vitullo et al., 2012; WHO, 2024b).

The Palestinian healthcare system is controversial because of debilitating conditions related to the region's complicated political and socioeconomic situation. One major issue is the unequal distribution of healthcare resources, inadequate numbers, and uneven distribution of healthcare workers, with urban areas receiving more healthcare resources than rural areas. Hospital infrastructure, equipment, and specialist care exhibit these differences (El Sharif & Imam, 2019). Insufficient healthcare funding hinders the provision of vital drugs and technology, infrastructure improvements, and access (Asi et al., 2021; Morrar et al., 2021). To create sustainable healthcare systems in Palestine, we must address resource and workforce issues, as well as financial and public–private collaboration (El Sharif & Imam, 2019; Morrar et al., 2021). More recently, the expansion of primary healthcare services has, to an extent, improved access to basic medical care, especially in rural and underserved areas that are still suffering from the aforementioned obstacles. However, these factors exert a substantial influence on the quality and provision of primary healthcare services. This made healthcare for PWE dependent on personal healthcare initiatives and advocacy, which in turn led to discrepancies in the care plan, as clearly declared by our participants. Similar controversies have been reported in studies addressing low- and middle-income countries (Bankole et al., 2024; Buddhiraja et al., 2020).

Despite these challenges, participants demonstrated resilience by using deliberate coping mechanisms and relying on support systems. Familial support, especially parental and marital support, was identified as an essential foundation, offering emotional support, practical assistance, and a sense of connection that mitigated feelings of isolation. This study highlights the fundamental role of the family in collectivist cultures such as Palestine. Religious and faith-based practices have emerged as the most prevalent and vital components of resilience and affirmation for many people, providing a structure for interpreting and managing their circumstances (Almuhtaseb et al., 2021; Ayele et al., 2023; Hammoudeh et al., 2017). The less common complementary practices also demonstrated participants' initiative-taking efforts to reclaim control and improve their well-being beyond conventional medical interventions. The findings illustrate the importance of utilizing existing social and cultural resources, such as family and faith-based support, in the development of holistic healthcare models.

The findings align closely with global guidelines, especially the WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (2022–2031). This confirms the need to integrate epilepsy care within primary health systems and address the psychosocial needs of PWE, including the reduction of stigma. The study contributes to the comprehension of Sustainable Development Goal 3 (Good Health and Well-being) by highlighting the ongoing disparities in access to quality healthcare services for PWE in resource-limited, conflict-affected regions. Addressing the challenges faced by this group, such as inconsistent communication from healthcare providers and antiepileptic drugs (AEDs) and a lack of psychological support, can guide the development of more inclusive

health system strategies that promote equity, resilience, and dignity in accordance with global health goals.

The strength of this study is its application of a phenomenological approach, which offers deep, contextual insights into the lived experiences of underrepresented populations within a complex setting. Concentrating on the perspectives of participants provides essential insights for adapting interventions. Nonetheless, limitations arise from the relatively small sample size characteristic of qualitative studies, which restricts generalizability. Recruitment from governmental clinics may not fully represent the experiences of individuals who exclusively seek care in the private sector or through different healthcare providers. Despite the measures taken to guarantee translation precision, certain nuances may not have been fully captured. Future investigations might explore experiences across various healthcare sectors and utilize longitudinal designs to better understand the trajectory of living with epilepsy over time in Palestine.

Conclusion

This study focused on exploring the lived experiences of Palestinian adults with epilepsy, specifically in relation to the psychological, emotional, social, and healthcare dimensions of living with the condition. Additionally, this study aimed to understand the various coping mechanisms employed by these individuals. The psychosocial impact identified emotions related to living with epilepsy, social isolation, and academic challenges. The study examined healthcare experiences within the context of epilepsy care and the connection between health professionals and patients, which often led patients to experience dissatisfaction with the quality of service. Furthermore, this study revealed that people with epilepsy utilize coping mechanisms such as asking their family for assistance, seeking societal support, and resorting to religious practices and other traditional forms of support.

People with epilepsy suffer from negative societal prospects such as discrimination and stigma. However, family support and cultural solidarity, which are major values in the Palestinian community, decreased the negative effect and contributed strongly to their feelings and resiliency.

One major concern is identifying the protocols and guidelines followed by Palestinian healthcare professionals in treating and managing epilepsy. Future studies should focus on investigating the facets of medical, psychological, or educational professional care that enhance the quality of life for individuals with epilepsy. By amplifying marginalized voices, especially in under-resourced and politically constrained settings, we hope that these areas of weakness receive attention, care, and support to empower the implementation of global equity commitments, including SDG 3 and the WHO's Intersectoral Action Plan for Neurological Disorders not only in Palestine but also in other low- and middle-income countries.

Declarations

Ethics approval and consent to participate

Ethical approval for this study was obtained from the Al-Quds University Research Ethics Committee (Reference number: 14/21). All methods were performed in accordance with the relevant guidelines and regulations, including the Declaration of Helsinki. Written informed consent was obtained from all participants prior to their inclusion in the study.

The participants were informed about the study's purpose, procedures, voluntary nature, confidentiality, and right to withdraw at any time.

Consent for publication
Not applicable. This manuscript does not contain any individual person's data in any form (including individual details, images, or videos) that require specific consent for publication beyond the initial consent to participate in the research.

Availability of data and materials
The datasets generated and/or analyzed during the current study are not publicly available because of the sensitive nature of the qualitative data and the potential for participant identification within the specific context of Palestine. However, anonymized data are available from the corresponding author upon reasonable request, subject to ethical considerations and participant confidentiality.

Competing interests
The authors declare that they have no competing interests.

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Authors' contributions
AG conceived and designed the study, collected the data, performed the primary data analysis, and drafted the manuscript. HH contributed to the study design, supervised the data analysis process, critically reviewed the manuscript, and contributed to the interpretation of the findings. Both authors read and approved the final manuscript.

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Authors' information (optional)
A.G. conceptualized the study, conducted data collection and analysis, interpreted the findings, and drafted the manuscript. H.H. supervised the research process, provided critical guidance on study design and methodology, contributed to data interpretation, and reviewed and revised the manuscript for intellectual content. Both authors read and approved the final manuscript and are accountable for all aspects of the work.

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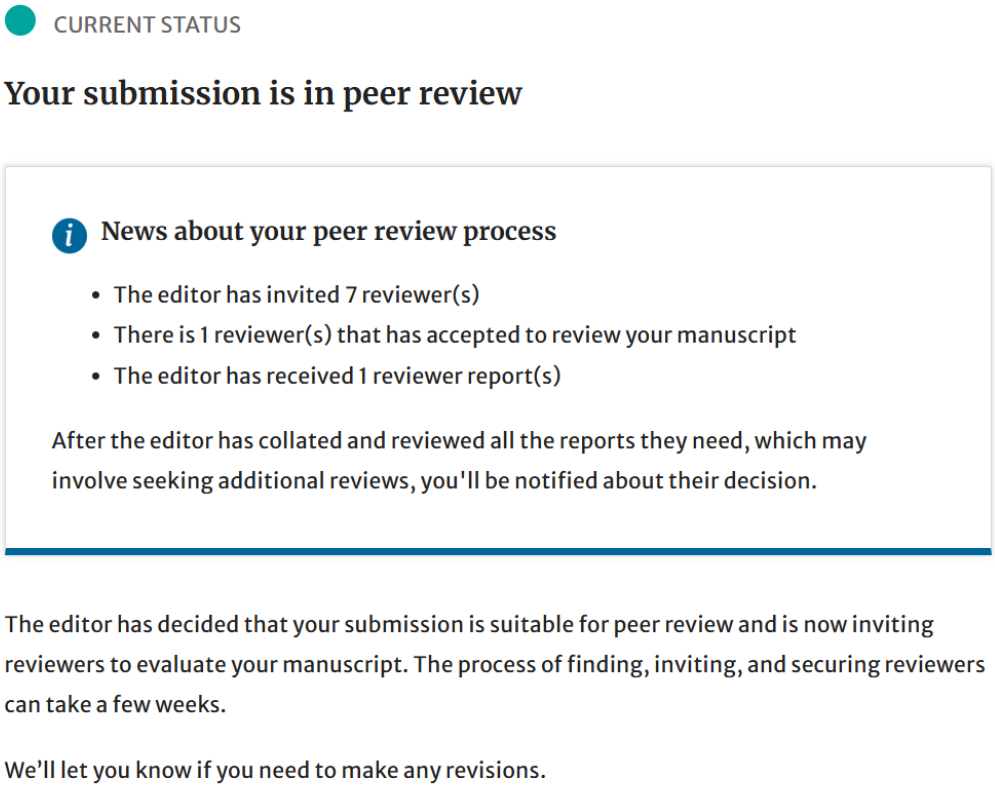
Supporting information

S 1 File. Interview guide. This file contains the semi-structured interview protocol and questions used in this study.



Appendix 13: Article 2 in Peer review process:

Journal: BMC Primary Care

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Title

Impact of an mhGAP-Based Epilepsy Training Program on Primary Healthcare Providers in Palestine: A Quasi-Experimental Study in an Under-resourced Setting

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Title

Impact of an mhGAP-Based Epilepsy Training Program on Primary Healthcare Providers in Palestine: A Quasi-Experimental Study in an Under-resourced Setting

Abstract

Background

In low- and middle-income countries (LMICs) such as Palestine, where healthcare systems are under-resourced and politically constrained, epilepsy is a prevalent neurological illness characterized by significant treatment gaps. Marginalized populations experience these gaps disproportionately. The WHO Mental Health Gap Action Program Intervention Guide (mhGAP-IG) seeks to rectify these disparities by training non-specialist primary healthcare practitioners in the management of priority diseases. This article evaluates the impact of a culturally adapted mhGAP-based epilepsy training on the knowledge, attitudes, and self-efficacy of primary healthcare providers (PHCPs) in the West Bank, Palestine.

Methods

Sixty-eight primary healthcare providers in the Hebron governorate engaged in a quasi-experimental pre-post design that included a control group. Participants were randomly

assigned to an intervention group (n = 32), which received a 3-day mhGAP epilepsy training, or a control group (n = 36), which received no training. Validated assessments were employed to collect data at baseline and three months post-intervention. Outcomes were assessed using non-parametric tests and Quade's ANCOVA.

Results
Following the adjustment for baseline scores, the intervention significantly enhanced knowledge ($p < 0.001$, $\eta^2 = 0.320$) and self-efficacy ($p < 0.001$, $\eta^2 = 0.106$). Attitudes exhibited minimal change, probably due to ceiling effects and the brief follow-up duration. Despite requests for further psychosocial and stigma-reducing resources, participant feedback emphasized enhanced confidence in patient communication and seizure management.

Conclusions

In a politically complex, resource-limited context, the mhGAP-based training significantly enhanced provider competence. This intervention promotes equitable treatment of individuals with epilepsy in poor and rural settings by equipping non-specialist primary healthcare providers with essential skills. Utilizing task-sharing in primary care, the widespread implementation of culturally tailored training in comparable under-resourced settings can significantly reduce global health disparities and promote health equity.

Trial registration: Not applicable.

Keywords

Epilepsy, mhGAP, self-efficacy, knowledge, attitudes, primary healthcare, Palestine, non-specialist training, capacity building, task-sharing, health equity, health disparities, under-resourced setting, cultural adaptation

Background

Epilepsy is a chronic, prevalent, non-communicable neurological condition defined by recurring, unpredictable seizures (Falco-Walter, 2020). The worldwide prevalence of epilepsy surpasses 50 million individuals across all age groups (WHO, 2024a). Low- and middle-income countries (LMICs) represent the majority of global incidence (82.1%), prevalence (80.4%), fatal cases (84.7%), and disability-adjusted life years (DALYs) (87.9%) associated with epilepsy (GBD, 2025), underscoring substantial health inequities in epilepsy management and outcomes compared to more high-income regions. The WHO and the 75th World Health Assembly recognized this global disparity by prioritizing epilepsy in the Intersectoral Global Action Plan on Epilepsy and other neurological illnesses for 2022–31 (GBD, 2025; WHO, 2023b).

A global shortage of neurologists and epileptologists—the experts best suited to treat epilepsy—makes it difficult to address these health disparities, especially in LMICs where the neurological workforce density is extremely low (estimated at 3.1/100,000 population) (Bankole et al., 2024; Sen et al., 2025; Thakur et al., 2016). The lack of expert access shifts the major responsibility for epilepsy management to primary healthcare providers (PHCPs). Despite the advancement of multidisciplinary approaches, PHCPs still serve as the primary point of contact for patients in various settings (O'Dwyer, 2020; Sen et al., 2025). Empowering these non-specialists with essential knowledge and skills is vital for the efficient management of this chronic condition and the advancement of health equity

(Keynejad et al., 2021; WHO, 2023b). Nonetheless, global studies, encompassing India, Niger, Ethiopia, Turkey, and Southern China, indicate considerable knowledge deficiencies among PHCPs concerning epilepsy management (Assadeck et al., 2020; Buddhiraja et al., 2020; Dayapoğlu et al., 2021; Emiru et al., 2019; Teferi & Shewangizaw, 2015; Yang et al., 2019). Research conducted in Palestine confirms this need, highlighting deficiencies in provider competences (Ghanayem & Hallak, 2025; Jaber et al., 2021; Shawahna & Jaber, 2020).

Palestine's resource-limited environment and distinct political limitations exacerbate these challenges. The healthcare system is fragmented, with specialized epilepsy services predominantly located in hospitals and private clinics, mainly lacking primary healthcare settings (Jasser & Ahmad, 2023; MOH, 2023). As a result, the management of epilepsy is often dependent on PHCPs who lack specialized training or guidelines (Ghanayem & Hallak, 2025; MOH, 2023). The ambiguity in care tracks, resulting from overlapping roles between mental health and primary care, complicates the situation. Patient access to care, including neurologists and essential anti-seizure medications, is critically constrained by systemic issues prevalent in this marginalized community: limited insurance coverage, limited resources, and substantial geographical and political constraints imposed by the ongoing Israeli occupation, such as military checkpoints and permit requirements, particularly impacting rural and underserved populations (Barhoush & Amon, 2023; WHO, 2024b).

The WHO designed the Mental Health Gap Action Program Intervention Guide (mhGAP-IG) to address the worldwide deficiency in mental health and neurological services in primary care. It provides evidence-based guidelines for non-specialists to manage priority conditions such as epilepsy, thereby promoting task-sharing along with improving service accessibility and quality (WHO, 2015, 2016, 2023b). The WHO advises tailoring the mhGAP-IG to align with specific national contexts, resources, and cultural settings, acknowledging that successful implementation requires understanding the local context. Cultural adaptation, including the utilization of the local language (Arabic) and the integration of discussions regarding local beliefs about disease etiology, is essential for enhancing training acceptance and effectiveness, as well as for mitigating potential barriers such as stigma and improving patient-provider communication within the Palestinian primary care framework. The effect of implementing a culturally tailored epilepsy training module, grounded in the WHO mhGAP-IG, for primary care workers in the complex Palestinian context has yet to be investigated. This study aimed to evaluate the impact of an adapted mhGAP epilepsy training program on the knowledge, attitudes, and self-efficacy of PHCPs in the West Bank, Palestine, to understand its potential for improving care capacity in this resource-limited setting.

Methods

Study design

The study employed a quasi-experimental approach (cohort with pre- and post-measures) conducted within primary healthcare settings in Palestine. The implementation of the culturally adapted mhGAP training served as the intervention. Knowledge, attitudes, and self-efficacy were measured at baseline, before, and 3 months post-intervention. Training evaluation data were also collected on the final day. Anonymity was maintained using unique identifiers on questionnaires to allow for matching of pre- and post-training data. Any document containing the information linking trainees to their unique identifier,

corresponding names, codes, and contact details was kept confidentially in a password-protected spreadsheet to avoid loss of follow-up.

Sample and setting

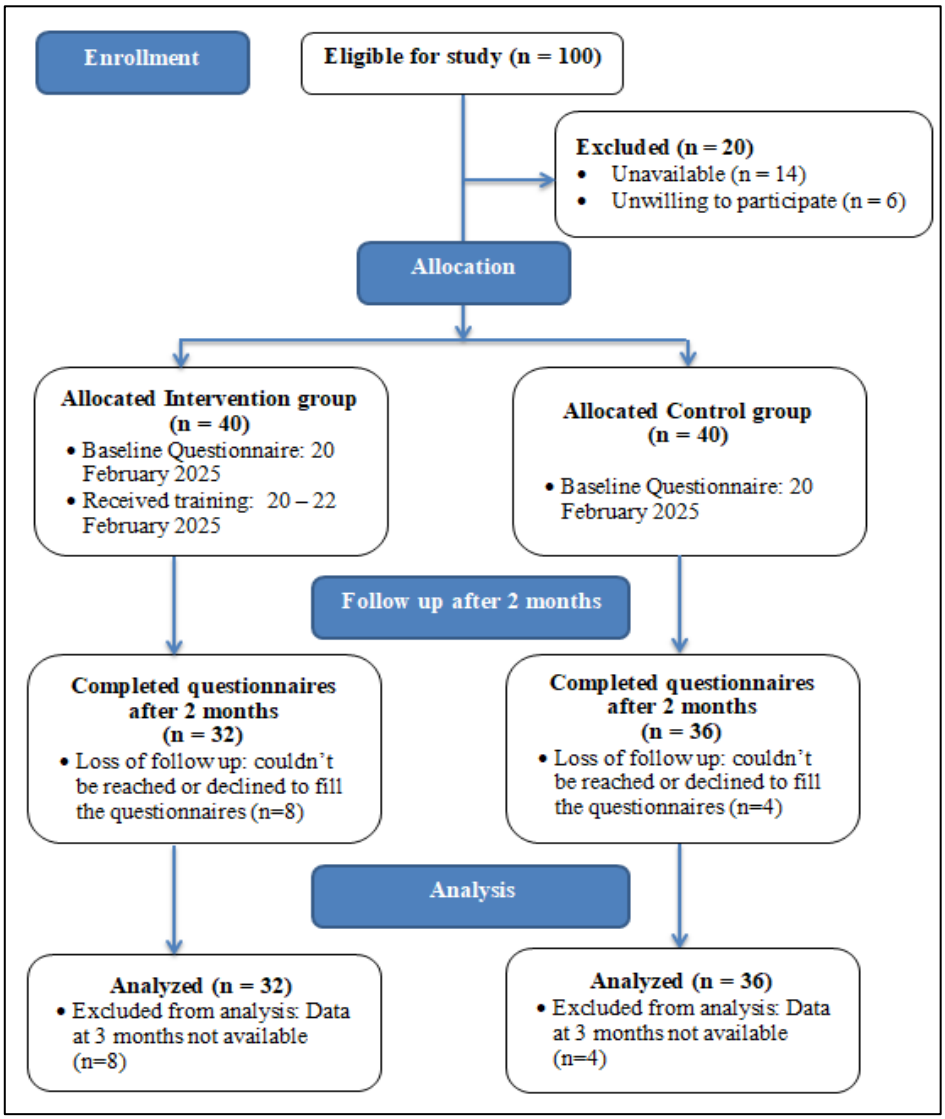
The study was conducted in the Hebron Governorate, a large and diverse region representative of the broader West Bank in terms of its mix of state, private, and NGO services and previously documented healthcare provider KAP regarding epilepsy (Ghanayem & Hallak, 2025). Hebron, the most densely populated governorate in the West Bank with approximately 1.2 million people (PCBS, 2023), faces significant healthcare requirements, especially for non-communicable diseases (NCDs) such as diabetes and hypertension. Targeted capacity-building initiatives are especially important in the area given its high density as well as systematic challenges, including staff shortages, inconsistent medicine supply, and low diagnostic capacity (MOH, 2023). Hebron's geographical and political complexity, including remote rural areas, movement restrictions, and regular service delays resulting from military closures, also makes it a suitable setting to evaluate training efficacy in resource-constrained and conflict-affected contexts. Its socio-demographic variety, e.g., urban areas, refugee camps, and marginalized areas, helps to further generalize results to other West Bank governorates. Hebron serves as a critical case study for evaluating interventions aimed at improving healthcare resilience and scalability in similar conflict-affected regions.

The study targeted primary healthcare centers that are the primary point of community-based care for chronic conditions, including epilepsy, within this under-resourced population. Participants were primary healthcare providers (physicians, nurses, and pharmacists) directly involved in providing epilepsy care within primary healthcare clinics. The challenging geopolitical context, characterized by mobility restrictions (checkpoints, roadblocks) due to the Israeli occupation, significantly impacts healthcare delivery and patient access, particularly for marginalized communities, and was a key factor considered in the study's feasibility and implementation within this under-resourced setting (Vitullo et al., 2012; WHO, 2024b).

Inclusion criteria were licensed primary healthcare providers, including general practitioners, family medicine doctors, or other non-specialist physicians, nurses, and pharmacists. They are directly involved in the care and follow-up of people with epilepsy, working in primary healthcare centers and willing to participate in the training program and complete pre- and post-training assessments. Other PHCPs not involved in epilepsy care, such as specialists in neurology, psychiatry, or other fields directly related to epilepsy management, who were unwilling or unavailable to complete the training or assessments or had previously completed formal mhGAP epilepsy training were excluded from the study.

We used convenience sampling to recruit participants. This sampling approach aimed at serving the effectiveness of the training in the local context and at establishing a basis for future experimental research that could facilitate broader generalization. The sample size was calculated for a two-arm, pre-post design comparing intervention (mhGAP training) and control (no training) groups. Using a moderate effect size (Cohen's $d = 0.7$) for knowledge improvement based on related studies and accounting for potential attrition (20%) and clustering effects (ICC = 0.05) in this challenging setting, the target sample size was set at 40 participants per group (80 total) to ensure adequate power (90%, alpha = 0.05, pre-post correlation = 0.6).

A total of 100 PHCPs were invited to participate in the training. Of these, 80 provided written informed consent and were subsequently randomized into either the intervention (n=40 initially) or control group (n=40) using a computer-generated randomization process. Randomization was conducted by an independent researcher not involved in recruitment or data collection. The outcome analyst was blinded to group allocation to reduce potential bias. The intervention group received the 3-day training course, while the control group adhered to their usual working routine. Due to dropouts (detailed below), the final analysis included 32 in the intervention and 36 in the control group.



Error! Reference source not found.: Participants' recruitment flow diagram.

Development of Training program

The education and intervention guidelines were drawn from the World Health Organization Mental Health Gap Action Program (WHO mhGAP) Intervention Guide. The mhGAP-IG (version 2.0) is a standardized training tool requiring adaptation to the local context before implementation (WHO, 2016). The training module considered general principles of care and epilepsy as priority areas based on previous research and WHO recommendations (Bankole et al., 2024; Ghanayem & Hallak, 2025; Jaber et al., 2021; Shawahna et al., 2020; Trinka et al., 2019; WHO, 2024b). The training course took into account locally accepted

theories of disease etiology as well as existing cultural beliefs. It highlights their influence on stigma, health-seeking behavior, and clinical decision-making (Gopalkrishnan, 2018; Kleinman, 2023). To ensure contextual relevance, the training modules were adapted to the Palestinian setting and validated by two experts in training and research, two neurologists, and two healthcare providers experienced in mental and neurological healthcare delivery. The training materials, which consisted of presentations, videos, and case studies, were presented in Arabic. A 'train the trainer' model was implemented, with a neurologist and a mental health nurse specialist delivering the adapted mhGAP training (WHO, 2017a, 2019). The training employed presentations, tutorials, videos, case studies, and role-plays, encouraging reflection and discussion.

Test–retest reliability examined the temporal stability of a measure over two time points, 3 months (Koo & Li, 2016; Martin Bland & Altman, 1986). In this study, the intra-class correlation coefficient (ICC) was used to evaluate test–retest reliability among 36 participants who were randomly assigned to the control group and completed the same measures twice. A two-way mixed-effects model with absolute agreement was applied for each scale. Excellent reliability resulted for the knowledge scale, ICC = 0.979, 95% CI [0.958, 0.989], $F(35, 35) = 45.839$, $p < 0.001$. The attitudes scale showed moderate reliability, ICC = 0.629, 95% CI [0.268, 0.812], $F(35, 35) = 2.659$, $p = 0.002$. The self-efficacy scale indicated good reliability, ICC = 0.771, 95% CI [0.550, 0.884], $F(35, 35) = 4.295$, $p < 0.001$. These results support the stability of the measures over time in the absence of intervention.

The face-to-face training was developed, divided into two modules, and delivered separately, on three subsequent days. Module 1 focused on essential care and practice (communication, respect, dignity, and assessment skills), and Module 2 focused on epilepsy detection and management (assessment, acute convulsions, underlying causes, psychosocial interventions, rational use of anti-seizure medications, and special populations). Details are presented in Table 4.

Table 4: Details of training program:

Training topic	Details	Time
Module 1: Essential care and practice	General principles: 1. Use effective communication skills 2. Promote Respect and Dignity	6 hours
	Essentials of mental health clinical practice: 1. Assess Physical Health 2. Conduct a MNS[a]	
	Assessment for MNS[a] conditions	
	Management steps for MNS[a] conditions	
Module 2: Detection and management of Epilepsy	Recognition and assessment of epilepsy: 1. Emergency Assessment 2. Assessment & management of acute convulsions 3. Assess if person has convulsive seizures 4. Assess for an acute cause (e.g., neuro-infection, trauma, etc.) 5. Assess if the person has epilepsy and for any underlying causes (by history or examination) 6. Assess for concurrent priority MNS conditions	6 hours
	Management of epilepsy: 1. Identify special populations: (woman of childbearing age, children and adolescents)	

	2. Psychosocial interventions: psychoeducation to the person and carers, promote functioning in daily activities and community life 3. Pharmacological interventions: antiepileptic medications, oral dosing for children and adults, side effects, contraindications and cautions	
	Follow up: 1. Review the current condition 2. Monitor treatment 3. Consider medication discontinuation when appropriate	3 hours
Open discussion and lessons learnt		2 hours
Evaluation of the program		

[a]MNS; Mental, Neurological and Substance use disorders

Data Collection

A validated self-administered questionnaire was used to collect information from participants. The questionnaire comprised four sections: participants' demographics (6 items); a knowledge section, which was developed from the WHO mhGAP epilepsy knowledge test to evaluate knowledge before and after training. The questions were multiple-choice questions (10 items) with 1 point awarded for each correct response and 0 points for incorrect answers, yielding a total score range of 0-10. The higher the score, the more knowledgeable a participant was. The attitudes section was composed of 10 items, which were evaluated using a five-point Likert scale ranging from strongly agree (5 points) to strongly disagree (1 point), resulting in a score range of 10-50. The higher the score, the more of that attribute a participant has. The self-efficacy section was composed of 12 items that were evaluated using a five-point Likert scale, ranging from strongly agree (5 points) to strongly disagree (1 point), allowing for a score range of 12-60 (Ghanayem & Hallak, 2025; A. Spagnolo et al., 2018; J. Spagnolo et al., 2018; WHO, 2016).

The questionnaire was written in English and then back-translated to Arabic by an independent bilingual translator. The researchers themselves corrected any differences between the two versions and ensured measurement consistency across all items. We conducted pilot testing with 10 primary healthcare providers (not included in the main study) to assess clarity and refine wording.

Prior to the start of their training, participants completed a pre-training questionnaire assessing attitudes, knowledge, and self-efficacy. Each participant was allocated a participant code, which they wrote on the questionnaires to allow the pre- and post-intervention questionnaires to be paired for analysis. After two months, participants completed the same questionnaire.

Ethical considerations

Ethical approval for this study was obtained from the Research Ethics Committee at Al-Quds University (ref. 5/25). All the methods were performed in accordance with the Declaration of Helsinki (World Medical Association, 2013). Participants were provided with verbal and written information on the study. Informed written consent was obtained from all participants. Participants were free to withdraw from the study at any time, not from the training itself. Participants were also encouraged to discuss the study with the trainers and ask any questions.

Statistical analysis

Descriptive statistics (frequencies, medians, and interquartile ranges [IQR]) were used to obtain participants' characteristics and outcome scores. Shapiro-Wilk normality testing and

values of skewness and kurtosis indicated non-normal distribution of data. This might be attributed to the relatively small sample size of the study (n=68). Mann-Whitney U and Wilcoxon signed-rank tests were conducted to analyze between-group and within-group changes, respectively. SPSS version 25.0 was used to perform these tests (IBM Corp., 2017). Quade's ANCOVA was used to compare post-intervention scores between groups while controlling for baseline scores. Effect sizes (eta-squared, η^2) were calculated for significant findings (small: 0.01, medium: 0.06, large: 0.14). The p-value < 0.05 was chosen as the level of statistical significance.

Results

Participant characteristics

Eighty PHCPs provided written informed consent and were subsequently randomized as an intervention group (n = 40) and a control group (n = 40) using a computer-generated randomization process. Only 32 participants completed the training course and completed all pre-test and post-test measures. The final control group consisted of 36 participants with an overall 85% response rate (**Error! Reference source not found.**). The primary reasons f or dropout were logistical challenges and inability to attend follow-up assessments due to work constraints exacerbated by the political situation. Baseline socio-demographic characteristics were comparable between the intervention and control groups. The majority of participants were female (61.8%) and one-third (36.8%) were in the age range of 40 to 49 years old. Almost half of the participants were nurses (45.6%) and have bachelor's degrees in their field (58.8%). Both intervention and control participants' socio-demographics, epilepsy training, and previous experience treating people with epilepsy are detailed in Table 5.

Table 5. Characteristics of participants (both intervention and control groups)

Descriptive	Intervention group (n=32)		Control group (n = 36)	
	N	(%)	N	(%)
Gender				
Male	11	(34.4)	15	(41.7)
Female	21	(65.6)	21	(58.3)
Age (in years)				
20 – 29	7	(21.9)	10	(27.8)
30 – 39	9	(28.1)	6	(16.7)
40 – 49	12	(37.5)	13	(36.1)
more than 50	4	(12.5)	7	(19.4)
Experience (in years)				
1 – 9	12	(37.5)	19	(52.8)
10 – 19	9	(28.1)	8	(22.2)
more than 20	11	(34.4)	9	(25.0)
Educational degree				
Diploma	5	(15.6)	7	(19.4)
Bachelor's degree	18	(56.3)	22	(61.1)
Higher education	9	(28.1)	7	(19.4)
Profession				
Doctor	9	(28.1)	10	(27.8)
Pharmacist	9	(28.1)	9	(25.0)
Nurse	14	(43.8)	17	(47.2)

Previous training on epilepsy				
Yes	3	(9.4)	6	(16.7)
No	29	(90.6)	30	(83.3)
Previous experience in treating people with epilepsy				
Yes	32	(100)	36	(100)
No	0	(0)	0	(0)

Knowledge, attitudes, and self-efficacy

The baseline (pre-training) data collection was conducted in February 2025 before the training course, and the post-training data collection was conducted in May 2025. Table 6 shows the collected data median scores before and 3 months post-training.

Wilcoxon signed-rank tests revealed statistically significant within-group improvements in the intervention group for both knowledge (pre: 7.0 [IQR = 5.25] vs. post: 8.5 [IQR = 1.75], $Z = –2.968$, $p = 0.003$) and self-efficacy (49.5 [IQR = 12.0] vs. 51.5 [IQR = 10.0], $Z = –4.932$, $p < 0.001$), while attitude scores remained unchanged ($p = 0.926$). In the control group, no significant pre–post changes were observed in knowledge, attitudes, or self-efficacy ($p > 0.05$ for all) (Table 6).

Table 6. Knowledge, attitudes, and self-efficacy before and after training (within-group change) (pre vs. post)

Variable	Group	N	Pre-Median (IQR)	Post-Median (IQR)	Z	P-value
Knowledge	Intervention	32	7.0 (5.25)	8.5 (1.75)	-2.968	0.003*
	Control	36	7.5 (5.75)	6.5 (1.75)	-0.258	0.796
Attitudes	Intervention	32	37.5 (7.75)	37.5 (7.0)	-0.093	0.926
	Control	36	37.0 (5.0)	38.0 (4.75)	-0.245	0.806
Self-efficacy	Intervention	32	49.5 (12.0)	51.5 (10.0)	-4.932	<0.001*
	Control	36	47.0 (7.5)	47.0 (6.0)	-0.479	0.632

*Significant value at $p < 0.01$

Mann–Whitney U tests were used for comparisons between groups; the change in scores indicated a statistically significant difference only for self-efficacy ($Z = –2.402$, $p = 0.016$, $\eta^2 = 0.086$), favoring the intervention group. Although a large effect size was observed for knowledge ($Z = –4.377$, $p < 0.001$, $\eta^2 = 0.286$), this was not supported after adjusting for baseline scores using ANCOVA (Table 7).

Table 7. Mann-Whitney U test between intervention and controls

Variable	Z	P-value	η^2	Interpretation
Knowledge	-4.377	<0.001*	0.286	Large effect
Attitudes	-0.031	0.975	0.000	Negligible effect
Self-efficacy	-2.402	0.016*	0.086	Medium effect

*Significant value at $p < 0.01$

η^2 is the effect size reported.

Quade's ANCOVA was conducted to examine post-intervention differences between the intervention and control groups across knowledge, attitudes, and self-efficacy, while controlling for respective baseline scores. The analysis revealed a statistically significant group effect for knowledge, $F(1, 65) = 30.55$, $p < 0.001$, with a large effect size (partial $\eta^2 = 0.320$), indicating that participants in the intervention group demonstrated greater knowledge gains after adjusting for baseline levels. In contrast, there was no significant group effect for attitudes, $F(1, 65) = 0.000$, $p = 0.987$, with a negligible effect size (partial $\eta^2 = 0.000$), and baseline attitudes were also not a significant covariate. For self-efficacy, a statistically significant group effect was observed, $F(1, 65) = 7.68$, $p = 0.007$, with a moderate effect size (partial $\eta^2 = 0.106$). Baseline self-efficacy was also a strong predictor of post-test scores (Table 8). These results indicate that the mhGAP-based training intervention led to significant improvements in self-efficacy and knowledge among PHCPs, with self-efficacy effects persisting after controlling for baseline variation. In contrast, attitudes remained unchanged, suggesting greater resistance to short-term modification.

Table 8. Quade's ANCOVA results for post-intervention scores controlling for baseline levels

Variable	F (df = 1,65)	p-value	η^2	Interpretation
Knowledge	30.55	< .001*	0.320	Large effect
Attitudes	0.00	0.987	0.000	No effect
Self-efficacy	7.68	0.007*	0.106	Moderate effect

*Significant value at $p < 0.01$
η^2 is the effect size reported

Evaluation of Training

On the third day, participants responded to the assessment form for the mhGAP training and engaged in an open discussion. The feedback revealed that the training components were readily accessible, informative, and quite relevant to their clinical practice. Many participants declared a shift in perception, from the biomedical model of care about epilepsy toward a more holistic, patient-centered approach. One participant stated, "*I see epilepsy differently now. It is not only about medicine management.*" P12.

Facilitators were described as highly skilled, culturally sensitive, and supportive. Practical examples, dialects, and interactive education methods greatly improved knowledge and engagement. Although some participants acknowledged initial challenges managing seizures or communicating with families, they pointed out the importance of peer support and shared information. Group conversations created a supportive setting and emotional connection. One participant said, "*Listening to others helped me feel I'm not alone in facing these challenges.*" P14, while another one admitted, "*I realized I have been avoiding discussions with families about seizure types because I didn't feel confident in my explanations*." P2.

Participants identified the sessions' clarity and practicality. Participants also appreciated interactive approaches, locally relevant case studies, and simple, instructed guidelines. Key areas of benefit were psychoeducation, communication strategies, and emergency seizure management. Many appreciated the facilitators, pointing out their respectful delivery of information and commitment to local clinical challenges. "*This was the first time I felt I could actually explain epilepsy clearly to my patients.*" P8.

Participants' recommendations for future training

Participants suggested including additional psychosocial intervention training, visual aids for patient education, and printed handouts. Future workshops covering caregiver support and epilepsy-related stigma were also recommended. Several participants requested additional knowledge on drug-resistant epilepsy care as well as on comorbid conditions (such as anxiety and depression). Others suggested extending the duration of sessions or offering refresher training. One participant suggested, *"The training is good but too short. We need more time, especially to discuss epilepsy and mental illness together."* P17.

Discussion

This quasi-experimental study assessed the effects of a culturally tailored mhGAP-based epilepsy training program on the knowledge, attitudes, and self-efficacy of PHCPs in the Hebron governorate of the West Bank, Palestine (WHO, 2017a). The results indicate that the intervention resulted in statistically significant improvements in self-reported knowledge and self-efficacy among participants in the intervention group compared to the control group, even after adjusting for baseline scores. However, the training didn't provide significant changes in attitudes toward epilepsy among the two groups. The findings are consistent with Sustainable Development Goal 3 (SDG 3), which advocates for universal health coverage and access to quality essential healthcare services, especially for neurological conditions such as epilepsy. Using integrated, people-centered training in non-specialized settings, the intervention enhances the capacity of PHCPs therefore supporting the WHO's Primary Health Care Operational Framework. These findings provide significant insights into the feasibility and efficacy of task-sharing strategies such as mhGAP to strengthen epilepsy care capacity in a politically restricted and resource-limited primary care environment, especially meaningful for reducing health disparities in marginalized populations.

The significant improvement in self-efficacy observed among the trained PHCPs is a major result. Self-efficacy, defined as confidence in one's capacity for completing particular activities, is a validated predictor of clinical behavior and performance. The medium effect size for self-efficacy improvement indicates that the training successfully empowered PHCPs, likely increasing their confidence in diagnosing, managing, and delivering psychoeducation for epilepsy in primary care settings. This corresponds with prior studies illustrating the beneficial effect of mhGAP training on healthcare providers' confidence in addressing mental and neurological problems in diverse low- and middle-income country contexts (Kokota et al., 2020; Robles et al., 2019; Sibeko et al., 2018; J. Spagnolo et al., 2020). Improved self-efficacy is important in settings like Palestine, where restricted access to specialists drives PHCPs to face increased responsibility for chronic healthcare. A higher sense of capability can lead to more proactive and efficient patient care, thereby reducing the epilepsy treatment gap.

The substantial improvement in knowledge scores within the intervention group, exhibiting a large effect size after accounting for baseline disparities, highlights the training's efficacy in addressing identified knowledge gaps among Palestinian PHCPs about epilepsy. Although the initial non-parametric comparison revealed no significant difference in the change of scores for knowledge between groups, the ANCOVA results, adjusted for baseline knowledge, clearly favored the intervention group. This indicates that the training effectively presented essential information on epilepsy assessment, management (including the rational use of anti-seizure drugs and the management of acute convulsions), and psychosocial considerations, in alignment with the mhGAP-IG framework. Enhancing

provider expertise is essential for improving care quality and reducing diagnostic delays and mismanagement, which significantly contribute to health disparities in epilepsy.

The study revealed no significant changes in attitudes about epilepsy, in contrast to knowledge and self-efficacy, after the training. This absence of effect may be attributable to various variables. Initially, baseline attitude scores were elevated in both groups, suggesting a ceiling effect wherein the assessment scale was insufficiently sensitive to identify more positive changes (Keynejad et al., 2021). The participating PHCPs may have previously possessed predominantly positive or neutral attitudes, limiting the potential for demonstrable change via the employed Likert scale. Future research should employ different tools (e.g., implicit association tests, qualitative methods) to probe attitudes more deeply. Secondly, attitudes are frequently firmly established, shaped by overarching societal and cultural actions, and may exhibit considerable resistance to alteration through short-term educational initiatives. The stigma associated with epilepsy constitutes a substantial obstacle for several communities, including Palestine. Addressing this issue necessitates comprehensive, multifaceted, and long-term strategies that extend beyond mere knowledge transfer, potentially involving direct patient interaction, community involvement, and structural reforms. Participant response requesting additional training on stigma and psychosocial therapies reinforces this concept. Thirdly, the difficult implementation setting, characterized by political instability and logistical obstacles, may have diminished the potential impact on more subtle factors such as attitudes.

The study's strengths comprise its quasi-experimental design, including a control group, which facilitates temporal comparisons, and the cultural adaptation of the mhGAP module to the distinctive Palestinian setting, thereby enhancing its relevance and possible acceptability. The use of validated assessment instruments and suitable statistical methods, such as ANCOVA to account for baseline disparities, enhances rigor. Moreover, incorporating qualitative feedback from participants offers essential context and insights into the training experience and potential areas for enhancement.

However, certain limitations must be acknowledged. The quasi-experimental design, although pragmatic in this context, is vulnerable to selection bias and confounding variables in contrast to a randomized controlled trial (RCT). Convenience sampling restricts the generalizability of the results outside the clinics in Hebron; however, the characteristics of the governorate provide some representativeness for the West Bank. Also, participants were recruited depending on availability and willingness to participate. Participants may have expressed greater motivation or interest in epilepsy care, thus contributing to selection bias. Emphasis on self-reported measures for knowledge, attitudes, and self-efficacy may be susceptible to social desirability bias. The brief follow-up duration of three months may be inadequate to assess the long-term sustainability of the reported improvements or any potential delayed impacts on attitudes or behavioral practices. Attrition, despite being considered in the sample size calculation, resulted in a final sample size less than originally intended, thereby diminishing statistical power for identifying smaller effects, especially regarding attitudes. The study ultimately failed to assess the influence of the training on real-world clinical practice or patient outcomes, indicating an essential further step for research.

Despite these constraints, the study offers critical evidence endorsing the viability and effectiveness of mhGAP-based training to enhance epilepsy care capacity among non-specialist providers in Palestine, a context marked by considerable resource deficiencies and political challenges affecting healthcare accessibility for marginalized populations. The results indicate that this training can significantly enhance provider knowledge and

confidence, essential requirements for enhancing service delivery. The lack of change of attitudes highlights the necessity for more rigorous or alternatively structured approaches to tackle this intricate aspect, possibly incorporating qualitative methodologies to enhance understanding of attitudinal obstacles and enablers. Subsequent research ought to implement more rigorous methodologies such as randomized controlled trials (RCTs), extend follow-up durations, employ objective assessments of clinical practice (e.g., chart reviews, simulated patients), and evaluate patient-level outcomes to fully evaluate the influence of mhGAP training on the quality of epilepsy care and health equity in the present and analogous challenging environments. Moreover, examining the incorporation of mhGAP training into comprehensive efforts to improve the health system and tackling systemic challenges, such as pharmaceutical availability and referral processes, would be essential for sustainable advancements in epilepsy management for underserved populations.

This study concludes that a culturally tailored mhGAP epilepsy training program can markedly improve the knowledge and self-efficacy of primary healthcare workers in a resource-limited and politically intricate environment such as Palestine. These enhancements offer possibilities for bolstering primary care capacity and may enhance access to and quality of epilepsy care, fostering more health equity for individuals with epilepsy in marginalized communities. Addressing provider attitudes, however, requires further investigation and potentially more comprehensive, sustained interventions.

Conclusions

This study demonstrates that a culturally adapted, mhGAP-based epilepsy training program is a feasible approach to significantly enhancing the knowledge and self-efficacy of primary healthcare providers within the under-resourced primary care setting of Palestine. These improvements in provider capacity represent a vital step toward addressing health disparities in epilepsy care. By empowering non-specialists, such interventions hold the potential to improve health equity and enhance the quality and accessibility of care for people with epilepsy in marginalized communities facing limited specialist access. While attitudes proved more resistant to change, highlighting the need for comprehensive, culturally sensitive strategies, the findings strongly support the value of adapting and scaling up mhGAP training as a key component of health system strengthening in similar resource-limited contexts globally.

List of abbreviations

mhGAP-IG	Mental Health Gap Action Programme Intervention Guide
WHO	World Health Organization
LMICs	Low- and Middle-Income Countries
PHCPs	Primary Healthcare Providers
DALYs	Disability-Adjusted Life Years
MOH	Ministry of Health
MNS	Mental, Neurological, and Substance Use (disorders)
NCDs	Non-Communicable Diseases
ICC	Intra-class Correlation Coefficient
RCT	Randomized Controlled Trial
IQR	Interquartile Range
SPSS	Statistical Package for the Social Sciences
ANCOVA	Analysis of Covariance
η^2 (eta squared)	Effect Size (measure of variance explained)
PCBS	Palestinian Central Bureau of Statistics

Ethics approval and consent to participate

Ethical approval for this study was obtained from the Research Ethics Committee at Al-Quds University (Reference No. 5/25). All participants received verbal and written information about the study and provided written informed consent before participating. Participation was voluntary, and participants were assured of confidentiality and the right to withdraw at any time. The study was conducted in accordance with the Declaration of Helsinki.

Consent for publication

Not applicable. This manuscript does not contain any individual person's data in any form (including individual details, images, or videos).

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

AG was responsible for the work's design, data collection, data analysis and interpretation, and article drafting. Professor HH also participated in the methodology and design of the data analysis, contributing significant intellectual revisions and editing to the draft. All authors have read and agreed to the published version of the manuscript.

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العنوان

دراسة متعددة المنهج لفهم وتحسين رعاية مرضى الصرع في مراكز الرعاية الصحية الأولية في الضفة الغربية، فلسطين

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ملخص:

المقدمة:

الصرع هو اضطراب عصبي مزمن يؤثر على أكثر من 70 مليون شخص حول العالم، وتتركز النسبة الأكبر من المصابين في البلدان ذات الدخل المنخفض والمتوسط. في فلسطين، تعاني رعاية مرضى الصرع من تحديات عديدة تشمل تجزئة تقديم الخدمات الصحية، وصعوبة الوصول إلى الرعاية المتخصصة، ونقص تدريب مقدمي الرعاية الصحية، وانتشار وصمة العار الاجتماعية. على الرغم من أن مراكز الرعاية الصحية الأولية تُعد نقطة الوصول الأساسية لمرضى الصرع، إلا أن الرعاية على هذا المستوى لا تزال غير مطورة بشكل كافٍ، وتفتقر إلى بروتوكولات علاجية موحدة أو برامج منظمة لدعم الإدارة الذاتية. سد هذه الفجوات يتطلب فهماً شاملاً لتجارب المصابين بالصرع، وجاهزية الكوادر الصحية، وفعالية التدخلات المصممة حسب السياق المحلي.

الهدف:

هدفت هذه الدراسة إلى استكشاف وتحسين إدارة الصرع في مراكز الرعاية الصحية الأولية في الضفة الغربية، فلسطين، من خلال دراسة تجارب المرضى، وتقييم معارف ومواقف وممارسات مقدمي الرعاية الصحية، وتحليل أثر تدريب تعليمي مستند إلى برنامج منظمة الصحة العالمية لسد الفجوة في الصحة النفسية.

المنهجية:

تم اعتماد تصميم بحثي مختلط استكشافي متسلسل شمل ثلاث دراسات مترابطة. استخدمت الدراسة الأولى المنهج الفينومينولوجي (الظاهراتي) الهوسيرلي لإجراء مقابلات معمقة مع 12 شخصاً يعانون من الصرع، تم تجنيدهم من مراكز الرعاية الصحية الأولية الحكومية، وتم تحليل البيانات باستخدام التحليل الموضوعي لاستخلاص السمات الجوهرية لتجاربهم المعيشة. أما الدراسة الثانية، فقد استخدمت مسحاً مقطعياً لتقييم معارف ومواقف وممارسات 300 من مقدمي الرعاية الصحية في مراكز الرعاية الأولية في الضفة الغربية. في الدراسة الثالثة، تم تنفيذ تدخل شبه تجريبي باستخدام تدريب يستند إلى دليل برنامج منظمة الصحة العالمية لسد الفجوة في الصحة النفسية، شمل 68 مشاركاً تم توزيعهم عشوائياً إلى مجموعتين: تدخل وشاهد. وقد تم تقييم المعرفة والمواقف والكفاءة الذاتية قبل وبعد شهرين من التدريب.

النتائج:

كشفت الدراسة الأولى عن ثلاثة محاور رئيسية: الاضطراب العاطفي والوجودي، الهشاشة الاجتماعية والوصمة، وتجارب صحية مجزأة. أبلغ المشاركون عن شعور بالخوف، والإقصاء الاجتماعي، وإنكار التشخيص، وفقدان الثقة بالنظام الصحي. كانت وصمة العار عاملاً مركزياً أثّر في إخفاء المرض، وتدني احترام الذات، وصعوبة الوصول إلى الرعاية. بينما كشفت الدراسة الثانية عن تغيرات ملحوظة في معارف وممارسات مقدمي الرعاية الصحية المتعلقة بالصرع. أظهر تحليل الارتباط علاقة سلبية بين الممارسات والمعرفة ($r = -0.170,\ p < 0.01$) وعلاقة إيجابية بين الممارسات والمواقف ($r = 0.279,\ p < 0.01$)، سجّل الممرضون وذوو الخبرة المحدودة درجات أدنى في جميع أبعاد ($p < 0.05$). المعرفة والاتجاهات و الممارسات كانت المواقف إيجابية إلى حد ما، لكن المعرفة بالإدارة الذاتية، ومثيرات النوبات، والجوانب النفسية والاجتماعية للرعاية كانت ضعيفة. أظهر التحليل المتعدد أن المعرفة كانت مرتبطة سلبًا بالجنس والتخصص كما أن الممارسات كانت مرتبطة بشكل سلبي مع المستوى التعليمي ($OR = 0.640,\ 95\ \%\ CI: 1.260–0.020,\ p = 0.043;\ OR = 1.970,\ 95\ \%\ CI: 2.841–0.099,\ p < 0.001$). أما المواقف فكانت مرتبطة إيجابيًا بالعمر ($OR = 2.552,\ 95\ \%\ CI: 0.974–4.130,\ p = 0.002$)، وسنوات الخبرة 95%: CI 0.974–4.130، ($OR = 2.387,\ 95\ \%\ CI: 0.546–4.227,\ p = 0.011$). وأخيرا، أظهرت الدراسة الثالثة أن تدريب برنامج منظمة الصحة العالمية لسد الفجوة في الصحة النفسية حسّن بشكل ملحوظ المعرفة ($p < 0.001$) والكفاءة الذاتية ($p < 0.001$) لدى مجموعة التدخل. إلا أن التغير في المواقف كان

محدودًا وغير ذي دلالة إحصائية، مما يشير إلى الحاجة إلى تدخلات طويلة المدى أو أكثر تركيزًا لتغيير الوصمة وتعزيز التعاطف.

الاستنتاج:

تعاني رعاية الصرع في مراكز الرعاية الصحية الأولية الفلسطينية من تجزئة النظام، ونقص تدريب الكوادر، وحواجز اجتماعية وثقافية تعيق الوصول إلى الرعاية الجيدة. يعاني المرضى من أعباء نفسية واجتماعية عميقة، بينما يفتقر مقدمو الرعاية إلى التأهيل الكافي لتقديم رعاية شاملة تتمحور حول المريض. ومع ذلك، فإن التدخلات التدريبية القصيرة والمصممة وفق السياق المحلي، مثل تدريب برنامج منظمة الصحة العالمية لسد الفجوة في الصحة النفسية، يمكن أن تعزز بشكل فعال المعرفة والثقة في المدى القصير.

الكلمات المفتاحية: الصرع، الرعاية الصحية الأولية، فلسطين، الظاهراتية، mhGAP، المنهجية المختلطة، الإدارة الذاتية، القوى العاملة الصحية، الوصمة، تعزيز النظم الصحية.