

Understanding the lived experiences of people living with epilepsy: Oral history assessment in the Shai Osudoku and Ningo Prampram districts, Ghana

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ABSTRACT

Introduction: Epilepsy is a prevalent neurological condition globally, especially in Sub-Saharan Africa. In Ghana, it is one of the top five causes of premature death and disability, impacting children's neurological development and learning outcomes. Although 25% of epilepsy cases are preventable, many go undiagnosed and untreated. People with epilepsy face social stigma and rejection, hindering their ability to seek healthcare, employment, and social interactions, which worsens their self-esteem and social integration.

Purposes: The study aims to address the critical gaps in understanding and supporting people living with epilepsy (PLWE), through recording and analysing their experiences, and seeks to inform policy and practice, finally contributing to improve healthcare delivery, reduce stigma, and enhance support systems for PLWE.

Methods: A qualitative research design was employed for the study. Oral histories (OHs) were conducted with ten PLWE. These interviews encourage interviewees to focus on the life stories and experiences that mean the most to them and can be shared in their own words. The interview questions were constructed in English and conducted in English, Twi, Ga and Dangme.

Results: The residents of Shai Osudoku and Ningo Prampram hold robust religious convictions and engage in profound spiritual practices as is the case throughout Ghana. When faced with health challenges, the PLWE and their caregivers often seek assistance from faith-based spiritual healers, including pastors or religious leaders, as their initial source of support and healing. These healers provide care by offering prayers, spiritual counselling, and incorporating various religious rituals into their healing practices. It was revealed that many PLWE, caregivers and community members perceived epilepsy differently. Some perceived it as a spiritual or demonic disease. Whilst others attributed to curse and disease of witches, idols, or gods. However, the healthcare practitioners perceived epilepsy as a medical condition. Also, it was found that individuals faced challenges, such as stigma and discrimination.

Conclusion: It is recommended that public education on epilepsy be intensified. Furthermore, there is the need to ensure that PLWE have access to improved healthcare to increase their quality of life.

Abbreviations: ASM, Antiseizure Medication; CHPS, Community-based Health Planning Services; EPInA, Epilepsy Pathway Innovation in Africa; FGD, Focus Group Discussion; IDI, In-depth Interview; IGAP, Intersectoral Global Action Plan; JHS, Junior High School; LI, Legislative Instruments; LMIC, Low- and Middle-Income Countries; MMDAs, Metropolitan Municipal and District Assemblies; OH, Oral History; PLWE, People Living with Epilepsy; SqKM, Square Kilometre; SSA, Sub Saharan Africa; WHO, World Health Organization.

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1. Introduction

Epilepsy is a neurological disorder that is categorised by recurrent seizures, which are the manifestation of abnormal synchronous discharges in the brain. The excessive discharges cause an interference of sensation, convulsive movement, or psychic function with or without loss of consciousness [1].

Globally, epilepsy is the most common neurological disorder, affecting about 70 million people, many of whom (80 %) live in resource-poor countries, where epilepsy continues to be a major public health problem due to its health consequences as well as its social, cultural, psychological, and economic significance [2]. Due to the chronic nature of the disorder, the World Health Organization (WHO) (2014) recognises epilepsy as a major public health concern. Consequently, a global campaign 'Out of the Shadows' was recognised by the WHO, International League Against Epilepsy and International Bureau for Epilepsy to increase public and professional awareness of epilepsy, and to improve acceptability, treatment, services and prevention of epilepsy [3]. This supports the objectives of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP) by providing valuable perception that can drive policy changes, reduce stigma, and improve the quality of care for people with epilepsy [4]. Through community-based research and the empowerment of individuals with epilepsy, the study contributes to a more comprehensive and effectual global health strategy.

The problem of epilepsy is highest in sub Saharan Africa (SSA), with the prevalence and incidence highest in the world, death is more common and stigma more severe than on other continents [2].

In Ghana, it is one of the top five causes of premature death and disability, impacting children's neurological development and learning outcomes [3]. Although 25 % of epilepsy cases are preventable, many go undiagnosed and untreated [5]. People with epilepsy face social stigma and rejection, hindering their ability to seek healthcare, employment, and social interactions, which worsens their self-esteem and social integration [6,7]. We conducted a series of oral histories with PLWE to explore their experiences in various settings, both urban and rural. These life histories provided insight into the lived experiences of epilepsy, highlighting the stigma associated with the condition over a lifetime and its impact on numerous social relationships.

This study aims to address the critical gaps in understanding and supporting PLWE. By recording and analysing their experiences, the study seeks to inform policy and practice, eventually contributing to improve healthcare delivery, reduce stigma, and enhance support systems for PLWE. Through this research, we aim to foster a more comprehensive and supportive environment in the Shai-Osudoku and Ningo-Prampram districts and beyond.

This study is section of a larger study, Epilepsy Pathway Innovation in Africa (EPInA) study which is part of a multi-country project in Ghana, Kenya, and Tanzania aimed at addressing the following issues, improve awareness, diagnosis, care and to reduce stigma of epilepsy. The countries worked closely with local communities, PLWE, carers and nongovernmental organizations (NGOs) to ensure that each country specific project is suitable to the local context.

In Ghana, the study was conducted in the Shai-Osudoku and Ningo-Prampram districts of the Greater Accra Region using a mixed-method approach that combined quantitative and qualitative techniques. This approach enabled us to meet the project's objectives. The qualitative component involved ethnographic research using methods such as oral histories (OHs), In-depth interviews (IDIs), Focus Group Discussions (FGDs), and knowledge-sharing workshops across the two districts. This manuscript specifically focuses on the OH segment of the qualitative research.

We conducted a series of OHs with PLWE to explore their experiences in various settings, both urban and rural. These life histories provided insight into the lived experiences of epilepsy, highlighting the stigma associated with the condition over a lifetime and its impact on numerous

social relationships.

1.1. Standard epilepsy care in Ghana

In Ghana, epilepsy care is mostly delivered through a tiered health-care system that consist of community-based care, district hospitals, and regional hospitals, with some cases requiring referral to specialized tertiary centres. However, access to complete epilepsy care remains inadequate due to numerous systemic challenges. There are PLWE who may not patronise the standard epilepsy care due to several reasons. These reasons are often interconnected and can be broadly categorized into cultural, socio-economic, healthcare system, and individual factors.

1.2. Primary and community-based care

Epilepsy care often commences at the primary healthcare level, where community health workers and nurses offer basic medical services. Nonetheless, these primary care providers characteristically have inadequate training in neurology and epilepsy management, often resulting in unsatisfactory initial treatment and diagnosis.

1.3. District and regional hospitals

For further specialized care, patients are referred to district and regional hospitals. These hospitals usually have more resources and personnel, including general practitioners who might have some training in managing epilepsy. Despite this, the availability of clinicians with specialized training in neurology is inadequate, and access to appropriate diagnostic tools such as electroencephalograms (EEGs) is often limited.

1.4. Tertiary and specialized care

Complicated cases are referred to tertiary hospitals, primarily located in urban centres like Accra and Kumasi. These hospitals have neurologists and access to more advanced diagnostic and treatment options. Though, the number of trained neurologists in Ghana is inadequate to meet the needs of the population, creating major barriers to timely and effective epilepsy care.

1.5. Treatment options

Biological treatments for epilepsy in Ghana primarily include anti-seizure medication (ASM). The most used ASMs are phenobarbital, carbamazepine, and phenytoin, due to their availability and cost-effectiveness. Newer ASMs are often less accessible due to higher costs and limited supply. Moreover, non-pharmacological treatments such as epilepsy surgery and advanced neurostimulation therapies are not often available due to the lack of specialized centres and trained personnel.

1.6. Challenges in epilepsy care

Availability of Medication: There are frequent shortages of essential medications, and the cost can be unaffordable for many patients.

Healthcare Infrastructure: Limited infrastructure and diagnostic facilities hamper effective epilepsy management, especially in rural areas.

Stigma and Cultural Beliefs: Social stigma and cultural misconceptions about epilepsy often prevent individuals from seeking medical care, opting instead for traditional and spiritual healing methods.

1.7. Ongoing efforts

Efforts are ongoing to improve epilepsy care through training programs for healthcare providers, increasing the availability of ASMs, and community education initiatives aimed at reducing stigma. Collaborative projects and partnerships with international organizations similarly

play a crucial role in addressing these challenges and improving the complete care for PLWE in Ghana.

Overall, while there are significant barriers to optimal epilepsy care in Ghana, ongoing initiatives and increasing awareness hold promise for improving the standard of care and quality of life for individuals affected by epilepsy in the Shai Osudoku and Ningo Prampram districts and beyond.

2. Material and methods

2.1. Study setting, design and period

2.1.1. Approach and setting

A qualitative study using oral history, was conducted from 12th August 2022 to 8th September 2022. Oral history interviews are a valuable way to gather information about personal experiences and perspectives that may not be captured in written records or more structured survey or interviews. These interviews in particular encourage interviewees to focus on the life stories and experiences that mean the most to them and can be shared in their own words [8].

The study was conducted in the homes of PLWE in selected communities within the districts and government health facilities in the Shai Osudoku and Ningo Prampram districts in Ghana. These facilities are a district hospital and a polyclinic respectively with psychiatric clinics where epilepsy care is given on specific clinic days for PLWE. The Shai-Osudoku District is one of the 260 Metropolitan, Municipal and District Assemblies in Ghana and forms part of the twenty-nine (29) Metropolitan, Municipal and District Assemblies (MMDAs) in the Greater Accra Region. The district has a hospital, three health centres, eight Community-based Health Planning Services (CHPS) compounds, seventeen CHPS zones, and four private facilities [9]. The area is rural with majority of the people depending on farming and fishing as their main source of livelihood [10].

There are eight (8) Government owned and 6 private health facilities in the district. The district is sub-divided into six sub-districts namely: Afienuya/Mataheko, Dawhenya, Ningo, Lekpongunor, Nyigbenya/Dawa sub-district, Prampram sub-districts.

2.2. Population and sample

We recruited a total of 10 participants from Shai-Osudoku and Ningo-Prampram districts. As this was the first attempt to use OH as a methodology in the districts and considering the sensitivity of the topic, a sample size of five participants from each district was used as a pilot study to test the feasibility of conducting larger-scale research on the experiences of PLWE in these districts. The participants were eligible for the study if they were diagnosed with epilepsy for more than a year and could express themselves by sharing their experience of living with epilepsy. Seriously ill patients who were unable to communicate at the time of the data collection period were excluded from the study. All participants were people who could communicate without assistance. A heterogeneous type of purposive sampling approach was used to recruit the participants. Purposeful sampling is a method extensively used in qualitative research for the selection of information-rich cases, persons that are experienced with a phenomenon of interest. In addition, it considers the capacity to communicate experiences and opinions in an expressive, sensitive, and reflective manner [11]. A heterogeneous type of purposive sampling specifically critical case sampling and snowball sampling technique was used to recruit the participants. The heterogeneous characteristics of participants were maintained by considering age, marital status, educational status, health facilities, and residence, including the most susceptible young people in the context of their community priorities and culture. This was done to be able to see the different forms of the lived experience of PLWE from their various viewpoints.

2.3. Data collection

The Interviewer was the key instrument for data collection and the interpreter of the findings in this study. Literature was reviewed to develop an interview guide for data collection [12]. To explore the lived experiences of PLWE in the Shai Osudoku and Ningo Prampram districts of Ghana, a comprehensive and culturally sensitive interview guide was developed taking into consideration the main objective of the study. Though OHs allow participants to narrate their own stories, developing a structured yet flexible interview guide assisted the moderator to probe along the objectives of the study. The interview guide contains socio-demographic questions which was critical for gaining in-depth insights into the lived experiences of people with epilepsy.

Although a guide was used, the interviewees were allowed to speak at length and to avoid interrupting or guiding their responses, as this could limit the richness of the information they provided. The data was collected by means of pretested interview guide.

Interviews were conducted in two local languages, Dangme which is the main local language spoken by the people in the study area and Twi which is a common language spoken in many communities in Ghana. A comprehensive cultural immersion, engaging in a thorough cultural preassessment to deeply understand and appreciate the nuances of the selected communities was conducted before initiating the study. We made a list of the characteristics that our participants should have, which included age, duration of condition, willingness to be interviewed and healthy and active individuals. Then we identified and sampled every person who meets the sample criteria. The nurses working at the psychiatric units of the selected health facilities helped in identifying patients that satisfy the inclusion criteria of the study. The participants were communicated with before or after their review sessions at the health facilities and during home visits. When the participant agreed to participate in the study, a meeting was scheduled at a time that is convenient for the participant. Seven (7) of the interviews were conducted at their homes to ensure the participant's privacy. Two (2) interviews were conducted in a separate room in the hospital and one who was on admission at the hospital was interviewed on the ward with a screen around her bed to ensure privacy which she consented. The interview consisted of open-ended questions that encourage the interviewees to share their thoughts and memories in their own words, face-to-face with the interviewer in a quiet location. The interviewer requested permission to start the interview and audio recording to ensure verbatim transcription. The probing technique was applied by using how and why, to get satisfactory data on the point of interest. Participants were coded as P1, P2, and P3..... respectively according to their order of interviewing and labelled the audio according to participants' codes. The interview took from 30 to 45 min.

Through OHs, participants provided insights into their journeys in managing epilepsy, revealing the complex interplay of social, cultural, and healthcare factors.

Conducting OHs with PLWE, participants recounted their personal experiences with the condition, detailing the challenges they faced in accessing care and managing their symptoms. Interviewer probed participants with questions aimed at understanding their treatment-seeking behaviours, perceptions of epilepsy, and interactions with healthcare providers. Participants endeavoured to provide comprehensive responses, often delving into their emotional and practical struggles with epilepsy.

2.4. Data management and analysis

After data collection, the audio recordings were downloaded onto a laptop and transcribed verbatim by professional transcribers who are fluent in the local languages (Dangme and Twi) as well as English, transcribed the audio recorded data in the participants' local languages into written form in English. The research team reviewed the transcripts to ensure that there were no gaps or errors.

The analysis adopted the framework approach that embraces deductive and thematic methods [13]. This method is extensively used amongst health researchers and scientists and working in groups to describe and interpret participants' opinions. It is an iterative data analysis procedure involving familiarisation with the data, generation of preliminary codes, persistent searching for patterns and codes across interview transcripts, amendment of codes, definition and naming of codes, production, and interpretation of findings.

Before coding, the research team used the questions in the interview guide to develop a preliminary codebook that guided coding and analysis of data. The preliminary codebook included broad codes (sub-topics in the guide), sub-codes (questions) and code definitions. The initial codebook was shared with other research team members for their input and review. As coding advanced, emerging codes were inductively included. The codebook was concluded after the last transcript was coded. The transcripts were coded by the team of researchers to reach inter-coder agreement.

The consistency of procedures and the impartiality of the investigator about findings or decisions was guaranteed. Data collection sessions included only those who are sincerely willing to take part and prepared to offer data freely. Data collection tools were pretested before the actual study in a similar location and populace to confirm that the length of the interview and clarity of guide were suitable for the actual participants. Additionally, the interview guide was tested for consistency and correctness by an expert in dealing with issues in connection with epilepsy. The audio data, transcriptions, and findings were given to a peer (who had qualitative research skill) to validate the processes, evaluate the findings for comments (peer debriefing) [14]. Appropriate probes had been used to attain detailed information on responses. This was achieved by describing the study setting, sample, and data collection procedure clearly and using qualitative expert for peer debriefing [15].

Accuracy of documentation was ensured by reducing spelling errors through frequent check, including all documents in the final report such as including the notes that were written during the interview and certify that the details of the procedures were defined to allow the readers to see the basis upon which conclusions were made [16]. To certify that the study's findings are supported by the data collected and reveals the objectivity of the data, every activity of the participants during the time of the interview was recorded [17]. In addition, the audio-taped interviews were not destroyed which can enable others to track the process. Moreover, data analysis, interpretations and conclusions of findings were shared with experienced qualitative researchers for peer debriefing before synthesizing the final outputs. It was also completed by using quotes which meanings relate the words of the participants with the findings [12].

3. Ethical consideration

Ethical approval for this study was obtained from the Institutional Review Board of the Dodowa Health Research Centre as well as Ghana Health Service Ethics Review Committee with the following approval numbers respectively (Approval numbers: DHRCIRB/95/08/20 and GHS-ERC 022/08/20). An informed consent was obtained from all study participants. During the consenting process, the privacy of the respondents was continued by making sure that study activities are carried out in a limited area with little or no attention of other people. The aim, justification, and study methods as well as the possible risks and potential benefits of the study was explained to all participants, and they were granted the opportunity to ask questions. Participation in this study was entirely voluntary. Though participants did not get immediate or direct benefits in taking part in the study it was clarified to them that the information they provide will help advance our understanding and perhaps the management of epilepsy. Respondents were given the opportunity to pull out from the study at any time without suffering any penalties. The study team requested for permission from respondents

before interviews are digitally recorded. Audio and transcribed data were stored on password protected computers and backups kept by only the study team members. All hard and soft data were stored in locked file cabinets, and accessed is limited to the study team.

4. Results

4.1. Socio-demographic characteristics of respondents

See Table 1.

4.2. Themes and subthemes

The findings from the analysis of OHs are presented as themes and sub-themes. The data analysis revealed three main themes expressing the lived experiences of people with epilepsy: The themes are:

1. **Diagnosis:** This major theme includes nine sub-themes: Onset of disease, Seizure Experiences, Treatment received, Emotional Responses, Stigma and Social Challenges, Impact on Daily Activities, Support Systems, Future Aspiration and Coping Mechanisms.
2. **Knowledge:** This theme encompasses three sub-themes: Understanding of Epilepsy, Awareness of Seizure Types, and Misconceptions and Myths.
3. **Cultural Belief:** This theme includes two sub-themes: Cultural Perceptions of Epilepsy and Stigma and Taboos (Fig. 1).

4.2.1. Theme 1: Diagnosis

4.2.1.1. Subtheme 1: Onset of disease. The subtheme of the onset of the disease explores the participants' accounts of their initial experiences and the early stages of living with epilepsy. By focusing on this sub-theme, we aim to gain insights into the participants' recollections, emotions, and challenges surrounding the onset of their epilepsy. Participants shared their experiences of recognizing and understanding the symptoms that led to the diagnosis of epilepsy. They discussed the initial confusion, fear, and uncertainty they faced when experiencing their first seizure and the subsequent medical consultations and diagnostic processes. This subtheme provides valuable insights into the emotional, social, and practical implications of the diagnosis and sets the stage for further exploration of the participants' lived experiences throughout their epilepsy journey.

Table 1
Socio-demographic characteristics of study participants within Shai Osudoku and Ningo Prampram districts, Ghana 2022.

Sex	Male	6
	Female	4
Age	19–26 years	4
	30–38 years	5
	60 years	1
Residence	Rural	2
	Urban	8
Marital status	Underage/single	8
	Divorced	2
Educational status	Not attended	1
	Primary	6
	Junior High School	2
	Secondary	1
Occupational status	Self-employed	3
	Trader/private employee	2
	Apprentice	1
	Unemployed	4
Religion	Christian	10

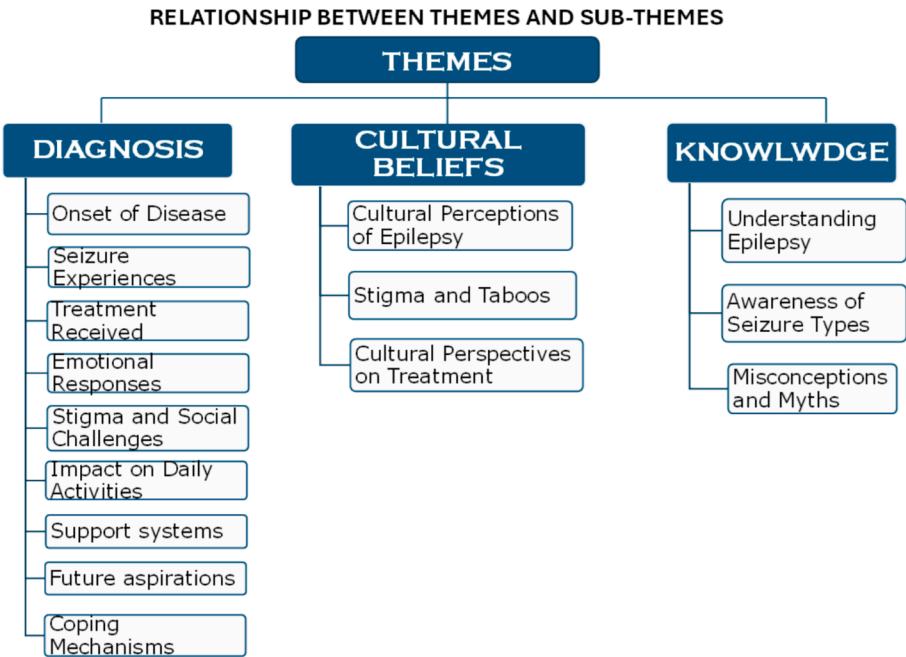


Fig. 1. Relationship between themes and sub themes.

“So, when I was sitting down, I realize that something entered my body and when it entered ...by the time I realize, I was laying down behind our building” 24 years old male participant.

4.2.1.2. Subtheme 2: Seizure experiences

“Whenever it comes, I scream “Jesus” several times and lose consciousness. By the time I gain consciousness, I find myself standing before my gate or somewhere I shouldn’t be, usually holding something. When it happens, I end up taking anything I can find in my room, sometimes an electrical extension board. When I do gain consciousness, I end up asking myself what I am doing. After this, I always tell my mother to have patience with me”. 36 years old male participant.

“I felt dizzy and fell, like someone who had fallen, and all my hands and legs were shaking and when that happened, I bit my tongue and my mouth, so they(family) also decided to take me somewhere to see if I could be cured... So, they took me to see a traditionalist and he also said he could cure me”. 38 years old male participant.

“I had set fire in a coal pot and then I slept. I was sleeping on a bench, and I had the attack I fell down into the fire; it was the sickness that made me fall down” 26 years old female participant.

“And when it happens, I start foaming”. 21-year-old female participant.

“I get frightened that the disease will cause me to fall down”. 26-year-old female participant.

Seizure experiences delve into the participants’ descriptions and reflections on their actual seizure episodes. By focusing on this sub-theme, we aimed to gain insights into the participants’ experiences of seizures, including the physical sensations, emotional impact, and aftermath. Participants discussed the support they received during and after seizures. They shared stories of family members, friends, or caregivers who provided immediate assistance and comfort during seizure episodes. Participants also highlighted the importance of safety measures, such as informing others about their condition, and creating seizure response plans. By examining the subtheme of seizure experiences, we gained a deeper understanding of the participants’ first-hand encounters with epilepsy’s hallmark symptom. This subtheme provided valuable insights into the physical, emotional, and social impact of

seizures on the participants’ lives and helped us comprehend their unique perspectives and challenges. It sets the stage for further exploration of the participants’ coping strategies, management techniques, and overall wellbeing in relation to their seizure experiences.

4.2.1.3. Subtheme 3: Treatment received. We explored the theme of treatment received as a subtheme within the broader context of their lived experiences. Caregivers play a crucial role in the lives of PLWE. The study found that the caregivers have significant responsibility and decision-making power in seeking appropriate care for their loved ones. Caregivers navigate various healthcare options, including both traditional and modern services, to find the best care for individuals with epilepsy.

Inhabitants of Shai Osudoku and Ningo Prampram have strong religious beliefs and practices. The individuals and their caregivers turn to faith-based spiritual healers, such as pastors or religious leaders as their first point of contact, for support and healing. These healers offer prayers, spiritual counselling, or other religious rituals as part of their care. The study area just as in many parts of Ghana has a rich cultural heritage that includes traditional healing practices. Most of the PLWE and their caregivers seek care from traditional healers who use herbal remedies, rituals, or spiritual interventions as part of their treatment approach.

“We’ve been to many churches including one in Kumasi. However, there have been no impacts”. 36-year-old male participant.

“There is a Traditional healer who said he can do it; he gave me marks on my body, but it did not cure the disease”. 38-year-old male participant.

“The medicine that was given to me to drink by the Pastor, it looked like it was prepared from herbs, and it was green in colour, it was poured into gallons”. 21-year-old female participant.

Despite the presence of modern healthcare facilities in Ghana, the study found that some PLWE and their caregivers within the study area face challenges in accessing these services. Factors such as distance, cost, or lack of awareness about available medical resources contributed to limited utilization of modern healthcare options which mostly turns to be their last option for care after the spiritual and traditional healers have failed in their management.

4.2.1.4. Subtheme 4: Emotional responses. The emotional subtheme revealed a range of emotions experienced by individuals with epilepsy, including fear, frustration, anxiety, sadness, hope, resilience, and empowerment. These emotions were intertwined with various aspects of their lives and influenced their overall well-being and quality of life. Fear emerged as a prominent emotion among the participants. Many expressed fears of seizures occurring in public, leading to embarrassment, stigma, and social exclusion. They also feared the potential consequences of seizures, such as injuries and limitations on their daily activities. The fear of unpredictability and loss of control over their bodies was a recurring theme among the participants. Frustration was another common emotional response reported by these individuals. They expressed frustration with the limitations imposed by epilepsy, such as restricted employment opportunities, difficulties in pursuing education, and challenges in maintaining relationships. The unpredictability of seizures and the impact on their daily lives contributed to their frustration.

4.2.1.5. Subtheme 5: Stigma and social challenges. We identified stigma and social challenges as a prominent subtheme. The findings shed light on the various ways in which PLWE face discrimination, prejudice, and exclusion within their communities. One key finding was the prevalence of negative attitudes towards them, leading to social stigma. Participants reported being subjected to derogatory labels and stereotypes, which affected their self-esteem and overall well-being. Stigma often resulted in social isolation, with individuals being excluded from social gatherings, educational opportunities, and employment prospects.

"In all one thing that hurt me most is that; my father hasn't been taking care of me. When I ask him of money, he refuses to give me. As we speak there is an ongoing festival at Ningo, and he has left with his wife and my other siblings with his car and he has left me behind at my mother's end". 21-year-old female participant.

Another significant aspect of the social challenges they faced, was the impact on interpersonal relationships. Participants described strained relationships with family members, friends, and romantic partners due to misunderstandings, fear, and misconceptions surrounding epilepsy.

"We do stuff such as playing football together. However, they do not eat with me". 36-year-old male participant.

"People don't really want to get close to me because of my situation" 19-year-old male participant.

"I was divorced the second time because my sister-in-law and other family members of my ex-husband refused to accept me into their family because of my condition". 60-year-old female participant.

"Even here that I stay a lot of the people isolate themselves from me whenever I experience the sickness". 21-year-old female participant.

4.2.1.6. Subtheme 6: Impact on daily activities. We recognised the impact on daily activities as an important subtheme. The results established the challenges faced by PLWE in carrying out their day-to-day tasks and participating fully in various aspects of life. One key finding was the disruption of work and employment opportunities. Participants reported difficulties in securing and maintaining employment due to the unpredictable nature of seizures. Many shared experiences of discrimination and job loss, which not only affected their financial stability but also contributed to feelings of low self-worth and dependency.

"Now that I am sick, I overheard him (employer) telling the madam (nurse) that they have to lay me off because of this epilepsy". 36-year-old male participant.

Education was another area significantly affected by epilepsy. Participants highlighted the challenges they faced in attending school regularly and keeping up with academic demands. Seizures often led to

missed classes, limited participation, and academic underachievement. The lack of understanding and support from teachers and peers further compounded these difficulties.

"When my neighbour who's also my teacher saw us fighting, instead of punishing the twos of us she punished only me, she also slapped me and sacked me from school". 21 year old female participant.

Participants also reported limitations in their ability to engage in social and recreational activities. Fear of having a seizure in public or being judged by others often resulted in social withdrawal and isolation. Individuals expressed feelings of frustration and a sense of missing out on important social experiences, such as attending gatherings, parties, or cultural events. Furthermore, the impact on daily activities extended to personal care and independent living. Participants described the need for constant supervision and assistance with tasks such as cooking, bathing, and transportation. This dependence on others not only affected their sense of autonomy but also placed a burden on their caregivers and family members.

We identified financial burden as a significant area. This explores the economic challenges and financial implications faced by individuals with epilepsy in communities. Our research revealed that PLWE often face limited financial resources, which can be attributed to various factors such as unemployment, low wages, and limited educational opportunities. The lack of adequate income exacerbates the financial burden associated with managing epilepsy, including the costs of medication, medical consultations, and diagnostic tests. Participants in our study reported that the cost of medication for epilepsy management posed a significant financial burden. Anti-epileptic drugs, which are essential for controlling seizures and maintaining quality of life, can be expensive and often require long-term use. The high cost of medication contributes to the financial strain they and their families experienced.

4.2.1.7. Subtheme 7: Support systems. Findings from the study highlighted the various sources of support that they rely on to cope with the challenges they face. One significant finding was the importance of family support. Participants emphasized the crucial role of family members in providing emotional support, understanding, and the encouragement they receive from them. Families often helped with daily activities and advocating for their needs. They often played a central role in accompanying individuals with epilepsy to the various treatment choices they decide on including medical appointments and transportation to healthcare facilities. They also ensure medication adherence and offering a safe and understanding environment.

Community support from certain community members in providing emotional support was highlighted by the PLWE. Community members offer empathy, understanding, and encouragement to individuals with epilepsy, helping them feel accepted and valued. Simple acts of kindness, such as listening without judgment or offering a comforting presence, made a significant difference to the participants.

"So, now, my mother is the one who looks after me. From time to time, she would give me GHc 5.00 in the morning to buy food". 36-year-old male participant.

"It's my mother who sometimes assist me when I experience the convulsion, and I start foaming and sometimes my brother assists me as well". 21-year-old female participant.

Healthcare professionals were identified as another important source of support. Participants expressed the joy for healthcare providers who demonstrated empathy, understanding, and knowledge about epilepsy. Access to quality healthcare services, including regular check-ups, medication management, and counselling, was crucial in managing the condition and addressing related challenges. Religious and spiritual support was also mentioned by participants. Many reported seeking solace, guidance, and strength from their faith communities. Religious leaders were seen as sources of comfort and provided prayers,

encouragement, and a sense of hope.

4.2.1.8. Subtheme 8: Future aspiration and coping mechanisms. Future aspirations and coping mechanisms emerged as significant subthemes during the analysis of the data.

4.2.1.9. Future aspiration. Participants expressed a strong desire to pursue their aspirations despite the challenges posed by epilepsy. Most of the participants demonstrated resilience and determination to achieve their goals. They expressed aspirations in various domains, including education, career, relationships, and personal growth. Participants highlighted the importance of having a positive outlook on life and maintaining hope for a better future. They acknowledged the impact of epilepsy on their aspirations but emphasized the need to adapt and find alternative paths to success.

“So, I told my mother if God helps me to complete the apprenticeship, I will want to go back to school. She said I should wait if I complete my apprenticeship successfully, she will enrol me in school”. 21-year-old female participant.

“I want to assist people in their shops as an attendant and I also want to be a driver (drive a bus or taxi)” 19-year-old male participant.

4.2.1.10. Coping mechanisms. Similarly, participants demonstrated a range of coping mechanisms to manage the challenges associated with epilepsy. These coping strategies were identified as essential for maintaining a sense of control and well-being. Participants reported utilizing both individual and social coping mechanisms. Individual coping mechanisms included self-education about epilepsy, adhering to medication regimens, practicing relaxation techniques, engaging in physical exercise, and adopting a healthy lifestyle. Social coping mechanisms involved seeking emotional support from family, friends, and support groups, as well as educating others about epilepsy to reduce stigma and discrimination.

4.2.2. Theme 2: Knowledge

In our study on the lived experience of PLWE, one prominent theme that emerged from our analysis is the concept of knowledge. Knowledge plays a vital role in shaping the experiences, perceptions, and actions of individuals dealing with epilepsy daily. In this section of our results, we will delve into the multifaceted aspects of knowledge that were highlighted by the participants, providing a comprehensive understanding of how knowledge influences the lived experience of PLWE.

“Physically if you don’t have spiritual eyes, you won’t know it’s epilepsy, you might assume the person is just sick”. 32-year-old male participant.

“I would say that epilepsy is as a result of head injury or infection or anything that affects the brain”. 38-year-old male participant.

“With epilepsy we have various types. For others it’s from their families. Others too for instance it is due to witchcraft”. 26-year-old female participant.

“I also think personally that a child convulsed almost all the time, it can lead to head injury, which can also result in epilepsy”. 60-year-old female participant.

4.2.2.1. Subtheme 1: Understanding of epilepsy. One of the subthemes that emerged from our analysis was the understanding of epilepsy. We found that there were varying levels of understanding and knowledge about epilepsy among PLWE and their community members. Some participants demonstrated a limited understanding of epilepsy, often associating it with supernatural or spiritual causes. They believed that epilepsy was a result of curses, witchcraft, or divine punishment. This understanding led to stigmatization and discrimination, with individuals being ostracized from their communities and facing challenges in social relationships.

“When it happened, they told me somebody did that to me” 26-year-old female participant,

“They said witches also cause it, and idols or gods” 38-year-old participant.

On the other hand, we also identified participants who understood epilepsy as a neurological condition. They recognized it as a medical condition that could be managed with appropriate treatment and support. These individuals had sought information from healthcare professionals, support groups, or other reliable sources, enabling them to better navigate their epilepsy journey.

“We’ve sought treatment from many places including the 37 Military Hospital. The Military hospital was where I felt better after visiting. I was given a medicine that made me feel better”. 36-year-old male participant

Furthermore, we found that misconceptions and myths surrounding epilepsy were prevalent in the community. These misconceptions often hindered early recognition of epilepsy symptoms, delayed help-seeking behaviours, and led to ineffective traditional remedies being sought instead of evidence-based medical interventions.

4.2.2.2. Subtheme 2: Awareness of seizure types. Our findings revealed uncertain levels of knowledge and understanding regarding different types of seizures. Some participants demonstrated a limited awareness of seizure types, often only recognizing generalized tonic-clonic seizures, which are characterized by convulsions and loss of consciousness. They were unaware of other seizure types, such as absence seizures, focal seizures, or myoclonic seizures. This lack of awareness led to challenges in recognizing and describing their own seizures accurately, which in turn affected their ability to communicate their condition to healthcare professionals and seek appropriate treatment.

On the other hand, we also identified participants who had a broader understanding of seizure types. They were able to recognize and describe different seizure manifestations, including focal seizures with or without impaired awareness, absence seizures characterized by brief lapses in consciousness, and myoclonic seizures characterized by sudden muscle jerks. These individuals had sought information from healthcare providers, support groups, or other educational resources, enabling them to better understand and articulate their seizure experiences. Additionally, we found that misconceptions and myths surrounding seizure types were prevalent in the community. Some participants believed that certain seizure types were more severe or dangerous than others, leading to fear, stigma, and discrimination. This lack of awareness and accurate understanding of seizure types contributed to delays in seeking appropriate medical care and hindered effective management of epilepsy.

“This disease makes my mouth shake uncontrollably which gets me scared that, even when I am outside, it can happen to me at any time”. 32-year-old male participant.

“I feel like a demon has entered my body, then I begin to suffer from the disease”. 24-year-old male participant.

“It frequently happens unaware”. 26-year-old female participant.

4.2.2.3. Subtheme 3: Misconceptions and myths. Our analysis revealed widespread misconceptions and myths about epilepsy among individuals with the condition, the community, and society at large. Many participants mistakenly believed that epilepsy was caused by supernatural or spiritual influences, such as curses, witchcraft, or divine punishment. These beliefs often resulted in stigmatization and discrimination, leading to individuals being turned out from their communities and facing difficulties in their social relationships.

“People get it through spiritual means at birth. That is when the person comes to look at the baby’s face”. 24-year-old male participant.

“People also believe that it is a spiritual sickness which was inherited as a result of a grandparent’s sin that he committed, and the affected person is paying for the grandparent’s deeds”. 26-year-old female participant.

Additionally, we identified various myths associated with epilepsy. For example, some participants believed that epilepsy was contagious, leading to fears of close contact with individual living with epilepsy. Others believed that epilepsy was a sign of mental illness or intellectual disability, perpetuating negative stereotypes and misconceptions about the condition. These myths further contributed to the social isolation and marginalization experienced by PLWE. Furthermore, we found that these misconceptions and myths hindered early recognition of epilepsy symptoms and delayed help-seeking behaviours. Instead of seeking evidence-based medical interventions, some participants turned to traditional remedies or spiritual healers, influenced by the belief that epilepsy had supernatural origins.

“There is a saying that if you get burnt through this sickness, nothing can be done, you can never be cured” 60-year-old female participant.

4.2.3. Theme 3: Cultural belief

Another prominent theme that emerged from our analysis is the influence of cultural beliefs. Cultural beliefs play a significant role in shaping the experiences, perceptions, and behaviours of individuals dealing with epilepsy within their respective cultural contexts. In this section of our results, we will delve into the multifaceted aspects of cultural beliefs that were highlighted by the participants, providing a comprehensive understanding of how these beliefs influence the lived experience of individuals. First, it is important to acknowledge that cultural beliefs surrounding epilepsy can vary widely across different societies and communities. These beliefs may stem from religious, spiritual, or traditional cultural practices and can shape the way epilepsy is understood, interpreted, and managed. By exploring the cultural beliefs held by PLWE, we gained insight into the unique challenges they face and the coping mechanisms they employ within their cultural context.

4.2.3.1. Subtheme 1: Cultural perceptions of epilepsy. In our analysis another subtheme that emerged from our findings is the cultural perceptions of epilepsy. The study area, like many other communities in Ghana, has a rich cultural heritage and beliefs that influence how epilepsy is perceived and understood within the society. In this section of our results, we will explore the cultural perceptions of epilepsy that were highlighted by the participants, shedding light on the impact of cultural beliefs on their lived experiences. One significant finding is that epilepsy is often stigmatized and misunderstood within Ghanaian culture. Participants shared experiences of discrimination, social exclusion, and negative stereotypes associated with epilepsy. Many attributed this stigma to cultural beliefs that view epilepsy because of spiritual possession and witchcraft. These cultural perceptions contribute to the marginalization of individuals, hindering their social integration, educational opportunities, and employment prospects.

“When the demons enter my body, then I begin to suffer from the disease”. 24-year-old male participant.

4.2.3.2. Subtheme 2: Stigma and taboos. In our study examining the lived experience of PLWE, we identified stigma and taboos as a prominent subtheme. This subtheme sheds light on the societal attitudes, beliefs, and practices that contribute to the marginalization and discrimination faced by individuals with epilepsy in the study area.

Our research revealed that these individuals often encounter stigma, which manifests in various ways. Firstly, there is a prevailing perception that epilepsy is a contagious condition, leading to the fear of close contact with those affected. This fear can result in social isolation and exclusion from community activities. Additionally, individuals with

epilepsy are often subjected to insulting and offensive language, further intensifying the stigma they face. Our findings also highlighted the existence of cultural taboos surrounding epilepsy. These taboos are deeply rooted in traditional beliefs and superstitions. For example, some communities associate epilepsy with spiritual possession or witchcraft, leading to the belief that affected individuals are cursed or have evil spirits within them. Consequently, individuals may face discrimination, mistreatment, and even violence due to these deeply ingrained cultural beliefs.

“My father said I am a fool, he also said when I am walking, I walk like a mad person”. 24 years old male participant.

4.2.3.3. Subtheme 3: Cultural perspectives on treatment. Participants in our study shared various cultural perspectives on epilepsy treatment, revealing a rich tapestry of traditional beliefs and practices interlinked with modern medical approaches. Participants highlighted the enduring role of traditional healing practices in the management of epilepsy. Herbal remedies, rituals, and spiritual healings were commonly mentioned as alternative treatment options sought by individuals with epilepsy or their families. They belief in the power of traditional healers and their ability to connect with the spiritual realm to cure or manage epilepsy was evident in the narratives.

Participants shared that traditional healing practices are often perceived as culturally acceptable within the study area. Seeking help from traditional healers was seen as a natural course of action for many, given the longstanding cultural beliefs surrounding epilepsy and the belief that supernatural forces might be responsible for the condition. While traditional healing practices hold cultural significance, many participants also acknowledged the importance of biomedical treatments, such as antiepileptic medications and medical interventions. Some participants mentioned combining traditional remedies with modern treatments, indicating the coexistence of both approaches in managing epilepsy.

5. Discussion

The analysis of OHs from PLWE has brought forth a complex picture of their experiences, surrounding various emotional, social, and cultural dimensions. The following discussion will provide a broad analogy and context for the themes and sub-themes identified in the study.

5.1. Diagnosis

The theme of diagnosis discloses the intricate journey individuals face from the onset of symptoms to receiving a formal diagnosis. The subthemes under diagnosis, Onset of Disease, Seizure Experiences, Treatment Received, Emotional Responses, Stigma and Social Challenges, Impact on Daily Activities, Support Systems, Future Aspirations, and Coping Mechanisms illustrate the multifaceted nature of this journey. For instance, participants shared their initial confusion and fear when experiencing their first seizure, as well as the emotional and social disturbance that followed. This aligns with existing literature that explains the significant psychological and social impact of an epilepsy diagnosis [18]. The accounts of traditional and spiritual treatments before seeking modern medical care highlight the influence of cultural beliefs on healthcare decisions, a pattern detected in many low-resource settings [19].

5.2. Knowledge

The knowledge theme emphasises the importance of understanding epilepsy to manage the condition efficiently. Participants’ unpredictable stages of understanding, from relating epilepsy with supernatural causes to identifying it as a medical condition, replicate the broader societal

misconceptions and myths about epilepsy. This difference in knowledge can affect how individuals seek treatment and manage their condition, as noted by Baker et al. (1999) [20]. The awareness of seizure types was also inconsistent, with some participants only recognizing generalized tonic-clonic seizures. This partial understanding can hinder effective communication with healthcare providers and delay the precise treatment. The endurance of misconceptions and myths about epilepsy further complicates these challenges, reinforcing stigma and affecting help-seeking behaviour.

5.3. Cultural beliefs

Cultural beliefs knowingly shape the experiences and perceptions of individuals with epilepsy. The theme of cultural belief, with subthemes such as Cultural Perceptions of Epilepsy and Stigma and Taboos, highlights how deeply rooted cultural attitudes contribute to the stigma and discrimination faced by individuals with epilepsy. The belief in spiritual possession or witchcraft as causes of epilepsy is common in many parts of Africa [21], and these cultural perceptions can lead to social exclusion and marginalization. The stigma related with epilepsy is not just a result of ignorance but also of deeply rooted cultural taboos, which can intensely affect the quality of life and social integration of individuals with epilepsy.

5.4. Emotional responses

The emotional responses theme describes the wide range of emotions experienced by individuals with epilepsy, including fear, frustration, anxiety, and hope. These emotions are affected by various factors, including the unpredictability of seizures, social stigma, and the challenges of daily living. Fear of seizures happening in public, and the associated stigma was a common concern among participants, constant with results from previous studies [22]. Frustration with the restrictions imposed by epilepsy, such as problems in employment and education, further intensifies the emotional burden. However, participants also expressed hope and strength, revealing their determination to overcome these challenges and carry out their aspirations.

5.5. Support systems

Support systems play a critical role in the lives of individuals with epilepsy. The theme of support systems highlights the reputation of family, community, and healthcare professionals in providing both emotional and practical support. Participants highlighted the crucial role of family members in daily activities and navigating healthcare options. Community support, though inadequate, was also valued for providing empathy and understanding. The role of healthcare professionals in providing quality care and emotional support was crucial, as noted in previous research [23]. Religious and spiritual support also appeared as significant, revealing the cultural context of the study population.

5.6. Impact on daily activities

The impact of epilepsy on regular activities was a persistent theme, with participants reporting major challenges in work, education, social interactions, and personal care. The irregularity of seizures and the related stigma often led to job loss, academic difficulties, and social isolation. These findings are consistent with studies that emphasise the socioeconomic impact of epilepsy on individuals [24]. The financial burden of managing epilepsy, as well as the cost of medication and healthcare, further intensified these challenges, affecting participants' overall quality of life.

5.7. Future aspirations and coping mechanisms

Notwithstanding the challenges, participants stated their aspirations and demonstrated various coping mechanisms. The theme of future aspirations and coping mechanisms highlights the resilience and purpose of individuals with epilepsy to pursue their goals. Participants engaged both individual and social coping strategies, such as self-education about epilepsy, adherence to medication, and seeking emotional support from family and friends. These coping mechanisms are necessary for maintaining a sense of control and well-being, as highlighted in the literature [25].

6. Conclusion

The lived experiences of individuals with epilepsy are formed by a complex interplay of medical, emotional, social, and cultural factors. The themes and sub-themes categorised in this study offer a comprehensive understanding of these experiences, emphasising the need for an all-inclusive approach to epilepsy care. Addressing the cultural beliefs and misconceptions about epilepsy, improving awareness and education, and increasing support systems are essential for improving the quality of life for individuals with epilepsy. Future research should continue to explore these themes in diverse cultural contexts to develop effective interventions and support mechanisms for PLWE.

6.1. Limitation

The use of a small sample size in this study limits generalization of the findings to PLWE in Shai Osudoku and Ningo Prampram districts, however, it provided deep insight into the phenomenon under study, a hallmark of qualitative studies.

CRediT authorship contribution statement

Sabina Asiamah: Writing – review & editing, Writing – original draft, Supervision, Formal analysis, Conceptualization. **Phyllis Dako Gyeke:** Writing – review & editing, Formal analysis. **Emmanuel Kwame Darkwa:** Writing – review & editing. **Sloan Mahone:** Writing – review & editing, Conceptualization. **John Williams:** Writing – review & editing. **Albert Akpalu:** Writing – review & editing. **Charles R. Newton:** Writing – review & editing. **Cynthia Sottie:** Writing – review & editing. **Patrick Adjei:** Writing – review & editing.

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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

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