Assessing Quality of Life in People with Epilepsy in the Context of Sleep Disturbances and Neuro-Cognitive Impairment in Zimbabwe.

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DOI: https://doi.org/10.51244/IJRSI.2025.12110161

Received: 30 November 2025; Accepted: 05 December 2025; Published: 22 December 2025

ABSTRACT

Background: Sleep disturbances and neurocognitive impairments are prevalent comorbidities in individuals with epilepsy, significantly affecting their quality of life. Understanding the interplay between these factors is essential for developing effective management strategies. This study aims to explore the subjective experiences of individuals with epilepsy in Zimbabwe, focusing on how sleep disturbances and neurocognitive impairments influence their daily lives.

Objectives: The specific objectives of this research are: To explore individuals' knowledge and understanding of the epilepsy experience and its impact on quality of life. To explore the impact of sleep disturbances on the quality of life in individuals with epilepsy in Zimbabwe. To identify the presence and perceived impact of neurocognitive impairments in people with Epilepsy in Zimbabwe. To understand the health-seeking behaviors of people with epilepsy in Zimbabwe.

Methods: This qualitative study employed semi-structured interviews with 10 participants aged 18 to 25 sampled purposively, from an epilepsy organization in Harare, Zimbabwe. The data was transcribed verbatim and translated into English, and analysed manually. Thematic analysis was performed.

Results: 6 themes emerged from the findings, each with subthemes. Preliminary findings indicate that participants frequently experience significant sleep disturbances and neurocognitive impairments, which adversely affect their daily functioning and Overall well-being. Participants reported a lack of understanding regarding the relationship between their cognitive challenges and sleep issues, highlighting a need for improved education and support.

Conclusion: The findings underscore the importance of addressing sleep disturbances and neurocognitive impairments in individuals with epilepsy to enhance their quality of life. This study contributes valuable insights into the lived experiences of people with epilepsy in Zimbabwe, emphasizing the need for culturally sensitive healthcare practices that consider these interconnected issues. Further research is warranted to develop targeted interventions that address these challenges effectively.

INTRODUCTORY BACKGROUND

Sleep disturbances and neurocognitive impairments have commonly been observed in individuals with various neurological conditions or disorders, with epilepsy being one of them. As presented by the American Academy for Sleep Medicine (2022), comorbid sleep disturbances are common in patients with epilepsy and can affect epilepsy management and quality of life. Epilepsy, on the other hand, is also implicated in neurocognitive impairments and vice versa. A thorough understanding of the relationships between neurocognitive impairments, sleep patterns, and epilepsy is required for targeted therapies and effective management techniques (Roliz & Kothare, 2022; Spruyt, 2021).

Epilepsy is a chronic, noncommunicable disease characterized by sudden bursts of electrical activity in the brain due to abnormal neuronal discharge, causing temporary changes in behaviour or sensation (Sayed et al., 2023). Millions of people worldwide suffer from epilepsy, with an estimated 50 million people diagnosed with the condition. This causes substantial personal and financial hardships (Nicholas, 2023). WHO (2024) noted that nearly 80% of epilepsy cases worldwide are documented in low- and middle-income nations, which suffer the burden. According to studies conducted in several African countries, the prevalence of epilepsy ranges from 0.5% to 10%; however, there are worries that these numbers may be underestimated because of underdiagnosis and underreporting (Bekele et al., 2023). Beyond seizures, neurocognitive impairments (NCIs) and sleep disturbances (SDs) are two uncommon but significant comorbidities associated with epilepsy that have a substantial impact on overall well-being (Staniszewska et al., 2017).

Despite having a threefold higher risk of early death than the general population, people with epilepsy, including those in Africa, experience widespread stigma and prejudice (WHO, 2024). Significant research in Zimbabwe has shed light on the quality of life (QoL) consequences for people with epilepsy (PWEs). Njamnshi et.al (2020) conducted a pilot study in Zimbabwe and discovered that cognitive impairment may not be seen as significantly impeding PWEs' daily functioning. In contrast, a study in Ghana investigated QoL perceptions among people with epilepsy, emphasising the subjective character of global well-being experiences in this population (Deegbe et al., 2022).

As indicated by Roliz and Kothare (2022), individuals with epilepsy face a range of issues, including SDs, which affect up to half of all PWEs. These altered sleep patterns not only increase the risk of seizures but also reduce sleep quality. Nonetheless, PWEs frequently struggle with memory, attention, and emotion regulation issues. Diby (2021) discusses how these NCIs can be caused by factors such as seizure frequency and duration, seizure location in the brain, medications, and sleep quality, all of which have an impact on everyday functioning and independence. Seizures, SDs, and NCIs and QoL in epilepsy, with studies revealing difficulties with social involvement, career attainment, and emotional well-being for many people (Diby et al., 2021). Recognising the linked nature of these disorders is critical for developing comprehensive treatments that extend beyond seizures and improve overall well-being.

According to the International League Against Epilepsy (ILAE) (2018), the epilepsy landscape in Zimbabwe poses a multidimensional issue, with few healthcare resources and specialists affecting the diagnosis, management, and treatment of epilepsy and its comorbidities. Furthermore, Komolafe et al. (2021) state a dearth of studies on how Africans view sleep and cognitive processes in general. Cultural views about epilepsy are likely to affect how PWEs perceive and address their disease, a pattern supported by studies from neighbouring African nations on QoL (Diby et al., 2021; Nicholas, 2023). Understanding these local viewpoints is critical for designing culturally sensitive interventions to improve the quality of life for PWEs in Zimbabwe. While recent research has focused on sleep, cognition, and QoL, there is still a considerable vacuum in understanding the lived experiences of PWEs in Africa, particularly Zimbabwe, in terms of the complex interactions between these characteristics. It seeks to understand the experience of living with epilepsy and its impact on quality of life. (Adem et al., 2020).

LITERATURE REVIEW

Sleep, Cognitive Function, And Quality of Life in Epilepsy.

Research into the science behind sleep, cognitive function, and quality of life in epilepsy reveals a complex interplay that significantly affects patients' overall well-being. Sleep disturbances are prevalent among individuals with epilepsy, often exacerbating cognitive impairments and negatively impacting their quality of life. Studies indicate that poor sleep quality can lead to increased anxiety and depressive symptoms, further complicating the clinical picture for these patients. For instance, findings indicate that sleep disruptions are correlated with cognitive deficits in areas such as executive function and memory, which are essential for daily functioning and overall life satisfaction. Additionally, the bidirectional relationship between sleep disorders and epilepsy highlights how nocturnal seizures and antiepileptic medications can disrupt normal sleep architecture, leading to excessive daytime sleepiness and cognitive challenges. This underscores the need for comprehensive management strategies that address both sleep quality and cognitive health to improve the quality of life for individuals living with epilepsy. By focusing on these interrelated factors, researchers aim to develop targeted interventions that can enhance patient outcomes and inform holistic care practices in epilepsy management.

Sleep And Epilepsy, A Complex Intertwining

According to Schneider (2021), sleep is a complex biological process for essential rest and recharge where brain activity slows down, muscles relax, and various physiological processes occur for repair and restoration. SDs encompass events or conditions that disrupt the quality, timing, and amount of sleep, leading to daytime distress and impaired functioning (Mason et al., 2021). SDs plague up to 80% of PWEs, exceeding rates in the general population (Gutter, 2019). This encompasses a spectrum of challenges, which include insomnia, difficulty falling and staying asleep, occurring twice as often in PWEs compared to the general population (Staniszewska, 2017), somnolence, parasomnias, sleep-related breathing disorders, and sleep movement disorders, such as, in research conducted by Li (2023), refractory epilepsy and nocturnal seizures being strongly correlated with restless leg syndrome (RLS) in patients with epilepsy. In the same research, Li (2023) noted that QoL was significantly impaired in the group with RLS in both the physical and mental domains.

Neurocognitive Function in Epilepsy

Neurocognitive deficits are increasingly recognized as common complications of epilepsy (Njamnshi et al., 2020). Neurocognitive decline refers to a decrease in one or more cognitive abilities, such as memory, attention, learning, language, executive functions, processing speed, etc (Spruyt, 2021; Wazema et al., 2023). This decline can be mild or severe, and it can progress slowly or rapidly. Neurocognitive decline becomes a concern when it starts to interfere with daily activities or causes significant distress (Novak et al., 2022). PWEs often struggle with memory impairment, mental slowing, and attention deficits, impacting daily activities and social interactions (Sayed, 2023; Khalife, 2022). Causes include direct neuronal damage, interictal discharges, medications, and psychosocial factors (Papaliagkas, 2023; Sayed, 2023; Schneider, 2020). Some studies conducted in African countries like Kenya, Uganda, and Ghana report 40–60% of PWEs experiencing deficits, particularly in memory and executive functions. Globally, estimates suggest up to 40% face significant cognitive challenges (Novak, 2022). The relationship between cognitive deterioration and seizure frequency has been examined, indicating that high seizure frequency, duration, and area of origin can potentiate the effects of brain damage on memory impairment. Recognizing this burden, the International League Against Epilepsy (ILEA, 2018) stresses the need for comprehensive neuropsychological assessments and interventions to address cognitive challenges and improve well-being.

Sleep and Neurocognitive Function

Rather than a passive state, Mason (2021) asserts that sleep involves a complex ensemble of cognitive functions during its nightly routine. This includes consolidating memories, sharpening attention, and regulating emotion processes, among others, that methodically twirl on the stages of rest (Khalife et al., 2022). However, for individuals with epilepsy, this mechanism falters. Sayed et al. (2023) emphasize that fragmented sleep caused by seizures and other disruptions disrupts critical cognitive processes, impacting memory reinforcement and consolidation, attention, and executive functions. This translates into challenges like memory lapses, attentional drift, and difficulties managing emotions, echoing throughout their daily lives (Khalife et al., 2022). Understanding this intricate interplay between sleep quality and neurocognitive impairment is crucial. By developing interventions that restore harmony between these interconnected aspects, PWEs can get a chance to experience a fully functional quality of life (Mason et al., 2021).

Emotional and Psychological Impact

The emotional and psychological impact of epilepsy on individuals significantly influences their overall quality of life, as evidenced in a growing body of literature. People living with epilepsy often experience heightened levels of anxiety and depression, stemming from the unpredictable nature of seizures and the social stigma associated with the condition (Kanner, 2017). In a systematic review by Baker et al. (2018), research indicates that these emotional challenges can lead to social isolation, reduced self-esteem, and difficulties in interpersonal relationships, which further exacerbate feelings of helplessness and frustration. Moreover, the cognitive impairments frequently associated with epilepsy, such as memory loss and attention deficits, can compound these emotional struggles, creating a cycle that diminishes an individual's ability to engage fully in daily activities and maintain meaningful connections with others (Hermann et al., 2017). The interplay between cognitive challenges and emotional distress highlights the need for integrated care approaches that address both psychological well-being and seizure management, ultimately fostering a more supportive environment that enhances the quality of life for those affected by epilepsy (Kanner et al., 2017). Understanding these emotional and psychological dimensions is crucial for developing effective interventions that not only focus on the medical aspects of epilepsy but also prioritize the mental health and social integration of individuals living with this condition.

Perception and Experiences

Current research in epilepsy focuses on the subjective aspect of QoL, looking beyond seizure frequency to study the diverse views and interpretations of people living with the disorder (Diby et al., 2021). Sayed et al. (2023) shed light on the problems faced by the loss of control inherent in seizures, which elicit feelings of vulnerability that alter self-image and resilience. Navigating cognitive deficits can exacerbate these difficulties, resulting in frustration, social disengagement, and identity crises in people with epilepsy (Novak et al., 2022). Notably, epilepsy may drastically alter self-identity, altering self-worth and social relationships, whereas inadequate sleep combined with emotional dysregulation and decreased productivity has a considerable impact on everyday functionality (Gilkinson et al., 2022; Adem et al., 2020). Cultural beliefs about epilepsy alter people's lives, frequently encouraging feelings of guilt and isolation and lowering their overall quality of life (Nicholas, 2023). Exploring and comprehending these complex cultural dynamics through a phenomenological lens is crucial for developing culturally sensitive therapies to meet the unique obstacles that people with epilepsy experience and improve their overall well-being.

The Unique Challenges of Epilespy in Young Adults

Epilepsy presents a unique set of challenges for young adults transitioning from the structured support systems of childhood to the greater independence of adulthood (Nicholas et al., 2023). While the core aspects of the condition remain the same across age groups, young adults with epilepsy often grapple with specific hurdles that can significantly impact their quality of life. One key difference lies in the social sphere; friendships and romantic relationships become paramount during young adulthood, and the fear of seizures or their unpredictable nature can create social anxiety and isolation. Educational attainment can also be affected. Bai et al.'s 2023 systematic review has shown that many studies share the view that the demands of higher education, coupled with potential cognitive difficulties associated with epilepsy, can make academic success more challenging. Similarly, employment opportunities might be limited by concerns about seizure occurrences in the workplace or discriminatory attitudes towards epilepsy. Batchelor & Taylor, (2021) assert that young adults with epilepsy often face a heightened risk of mental health issues, such as depression and anxiety. The constant struggle with managing their condition, coupled with the social and academic pressures of young adulthood, can take a significant toll on their emotional well-being (Batchelor & Taylor, 2021). This highlights the need for holistic care that addresses not just the physical aspects of epilepsy but also the emotional and social needs of young adults navigating this critical life stage.

Prevalence and Statistics

Epilepsy, a disease of the brain categorized by disorderly discharge of the brain, which manifests as persistent seizures, is the most common neurological disorder in Africa. About 80% of people with epilepsy are found in developing countries (WHO, 2024), where it is a major public health problem, not only because of its health implications alone but also for its social, cultural, psychological, and economic connotations (Bekele et al., 2021). About 25 million people have been reported to have epilepsy in Africa, and about 60% of these patients receive no anti-epileptic treatment. Notably, amongst other African countries, Ghana claims an estimated prevalence of 7.9%, while Tanzania demonstrates a prevalence as high as 10% (Nicholas, 2023). According to the International League Against Epilepsy (ILAE) (2018) in Zimbabwe, estimates suggest a prevalence rate of 1.34%, translating to approximately 134/1000 individuals living with epilepsy, and this is a portentous need for current statistics that give a recent picture. With the above-stated statistics and despite its high burden, epilepsy remains shrouded in stigma and misconceptions, hindering access to proper diagnosis, treatment, and comprehensive care.

Current Healthcare Facilities

Zimbabwe has major treatment gaps in epilepsy care, with only two epilepsy clinics serving a population of 12 million people, a lack of neurologists and neurosurgeons, inadequate imaging facilities, and shockingly high morbidity and fatality rates linked to epilepsy (ZLAE, 2018). In the field of sleep medicine, the sickness affects all age groups, with an increasing prevalence from late infancy to old age due to certain forms of sleep disturbances. A comprehensive analysis of sleep healthcare in Africa by Komolafe et al. (2021) found worrisome limits in facilities, with just Algeria, Egypt, Kenya, Morocco, and Nigeria reporting having sleep laboratories by 2021, and South Africa being the only country having 29 sleep facilities in the southern region. Despite the significant impact of sleep disorders on the community, many instances go undetected or receive poor treatment, compounded by a lack of research data (Adem et al., 2020). A recurrent worry in Africa and Zimbabwe is a lack of academic research in the neuropsychological healthcare arena. Neuropsychological services in Africa, especially Zimbabwe, are still in their early phases of development, resulting in inadequacies in epilepsy care. While the discipline recognises neuropsychology's expanding importance, bridging these gaps requires more investment in training programmes, infrastructural improvements, and joint research activities to meet the requirements of the region's epilepsy patients (Komolafe et al., 2021).

Health-Seeking Behaviours

Health-seeking behaviours among individuals with epilepsy are profoundly influenced by the complexities of the condition, significantly impacting their quality of life. Research has shown that many individuals with epilepsy exhibit reluctance to seek medical help due to factors such as stigma, fear of discrimination, and previous negative experiences with healthcare providers (Adem et al., 2020). This hesitance can lead to delays in diagnosis and treatment, exacerbating both the frequency of seizures and the associated cognitive and emotional challenges. Furthermore, individuals may resort to alternative therapies or self-management strategies, which can be less effective and potentially harmful (Hermann et al., 2017). The perception of epilepsy within the community also affects health-seeking behaviours; in cultures where epilepsy is heavily stigmatized, individuals may avoid disclosing their condition, further isolating themselves and hindering access to necessary care (Kanner, 2017). Consequently, addressing these barriers through targeted education, community awareness campaigns, and supportive healthcare environments is essential for promoting proactive health-seeking behaviours. By fostering a more supportive atmosphere and enhancing access to appropriate medical care, individuals with epilepsy can improve their health outcomes and overall quality of life, leading to better management of their condition and enhanced social integration.

Theoretical Framework

Biopsychosocial Model

This Model posits that health and illness are the result of the interplay between biological, psychological, and social factors. In the context of epilepsy, this framework allows for a comprehensive understanding of how neurobiological aspects, such as seizure activity and neurocognitive impairments, interact with psychological factors like anxiety and depression, as well as social determinants, including healthcare access and support systems (Elliott & Richardson, 2014). Research indicates that individuals with epilepsy often experience cognitive dysfunction due to the pathological effects of seizures on brain networks, which can lead to diminished quality of life (Gilkinson et al., 2022). Furthermore, sleep disturbances are prevalent among this population and are linked to exacerbated cognitive deficits and emotional distress (Komolafe et al., 2021). The Biopsychosocial Model emphasizes that addressing these interconnected issues, such as improving sleep quality and cognitive function, can lead to better health outcomes for people with epilepsy. By utilizing this model, your study can explore how these various dimensions influence each other and contribute to the overall quality of life for individuals with epilepsy in Zimbabwe. This approach not only facilitates a deeper understanding of the complexities surrounding epilepsy but also informs culturally sensitive interventions aimed at enhancing patient care and support.

Adopting a multi-factorial perspective, the biopsychosocial model acknowledges that health outcomes are not solely determined by biological factors but are significantly influenced by psychological and social elements.

This perspective is critical in epilepsy care, where emotional well-being and social support systems play vital roles in managing the condition (Elliott & Richardson, 2014). Research indicates that psychological factors, including stress and coping mechanisms, can affect seizure control and overall health status. Furthermore, social determinants such as access to healthcare resources and community support can greatly impact the experiences of individuals living with epilepsy (Gilkinson et al., 2022).

The model also highlights the importance of context, asserting that an individual's social environment, including cultural norms, socioeconomic status, and community resources, shapes their health outcomes. In Zimbabwe, where healthcare access may be limited and cultural perceptions of epilepsy can lead to stigma, understanding these contextual factors is essential for developing effective interventions. The biopsychosocial model encourages researchers and practitioners to consider these external influences when assessing quality of life in people with epilepsy (Elliott & Richardson, 2014).

In addition to the holistic perspective of the Biopsychosocial Model, this research will focus on assessing health-seeking behaviours as a critical factor influencing the quality of life in individuals with epilepsy. Health behaviours encompass actions and decisions related to medication adherence, lifestyle choices, and engagement with healthcare services, all of which significantly impact seizure control and overall well-being. Studies have shown that individuals who actively participate in their treatment and maintain healthy lifestyles report better health-related quality of life outcomes (Kobau et al., 2008). The social context, including cultural beliefs about epilepsy and access to healthcare, plays a pivotal role in shaping these behaviours. In Zimbabwe, misconceptions about epilepsy often lead to stigma and a reluctance to seek medical help, with many individuals initially consulting traditional healers due to beliefs linking epilepsy to spiritual causes.

METHODOLOGY

Study Site

The study was conducted at Epilepsy Support Foundation (ESF), a Private Voluntary Organisation registered under the Ministry of Health and Child Care. It provides specialized care services in epilepsy, including the provision of medicines, offering psychosocial support to members and caregivers, as well as training to healthcare workers and the community. ESF serves as a key healthcare provider, receiving patients throughout Zimbabwe. It was selected for this research due to its unique status as one of the organisations actively supporting epilepsy programs nationwide.

RESEARCH DESIGN

This study employed a qualitative research design grounded in the principles of grounded theory methodology. Grounded theory is an inductive approach that allows for the development of theory and conceptual models that are firmly rooted in the lived experiences and perspectives of the research participants (Charmaz, 2014). By utilizing this approach, the researcher aimed to gain a rich, in-depth understanding of the participants' subjective experiences with epilepsy and the multifaceted biopsychosocial factors that shape their lives. Qualitative research is advantageous in this context as it provides flexibility in data collection methods, enabling researchers to adapt questions based on participants' responses and explore emerging themes in depth (Moos & Rydahl-Hansen, 2021a). However, a limitation of qualitative research design is that it may not yield results that are easily generalizable to larger populations due to its focus on specific contexts and individual experiences.

Participant Selection and Sampling

The study's target population consisted of young adults aged between 18 to 25 years with epilepsy registered with the Epilepsy Support Foundation (EFS).

Sampling Method

The participants were recruited using a purposive sampling method to choose individuals who best reflected the target population of people living with epilepsy who experience sleep disturbances and neurocognitive impairment. Participants were specifically obtained from an organisation that offers epilepsy related healthcare services, ESF. This selection strategy guaranteed that participants have relevant insights into the study issues and may contribute useful opinions on the topic under investigation.

Inclusion and Exclusion Criteria

Inclusion: Young adults aged between 18 and 25 years old, diagnosed with epilepsy, registered with the ESF, with a mild neurocognitive deficits score cut off of 25-18 based on Montreal Cognitive Assessment (MoCA), have treatment-managed epilepsy, and can provide informed consent were included.

Exclusion: Current uncontrolled seizures, severe cognitive impairment, and active participation in another epilepsy research study were excluded.

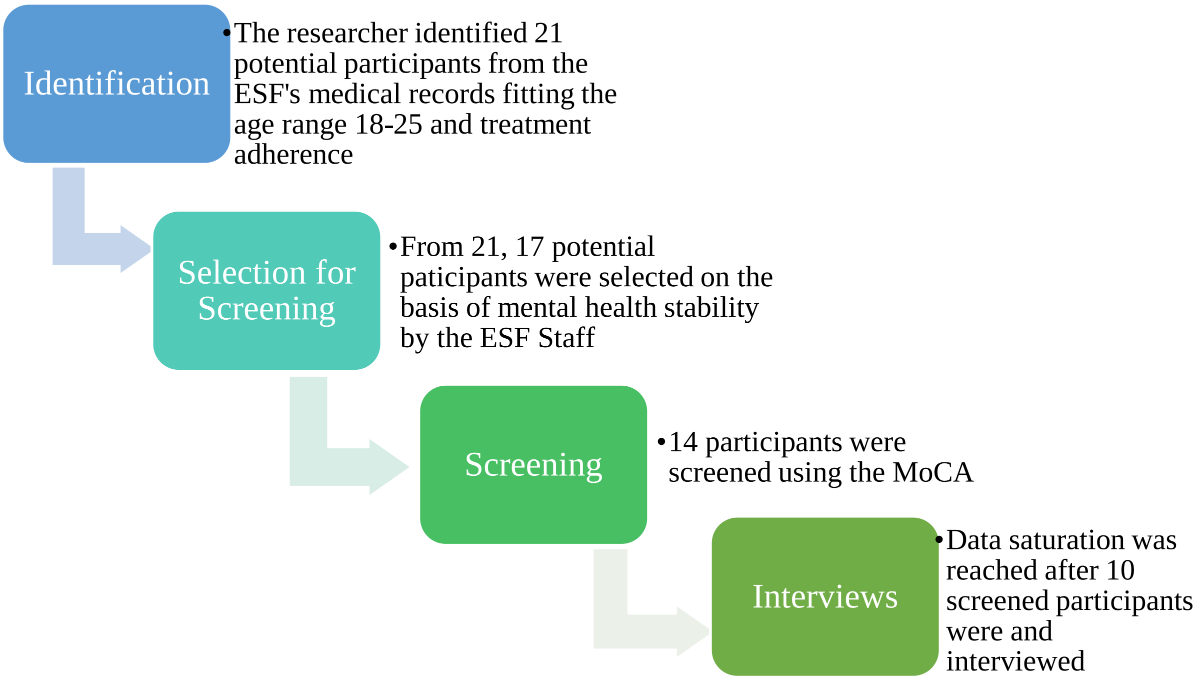
Quantitative Screening Measures

Before the in-depth interviews, potential participants were screened using a standardized, quantitative assessment tool. This two-stage approach allowed for the identification of eligible individuals who met the specific inclusion criteria for the qualitative phase of the study. Participants were first screened using the following validated assessment tool:

The Montreal Cognitive Assessment (MoCA) is a widely used screening tool for mild cognitive impairment, which is a common comorbidity associated with epilepsy. Incorporating the MoCA as a screening measure ensured that the qualitative sample included participants with a range of cognitive abilities, allowing for a more comprehensive understanding of the lived experiences of individuals with epilepsy and their associated challenges. The MoCA has demonstrated high sensitivity (90%) and specificity (87%) for detecting mild cognitive impairment in people with epilepsy (Mason et al., 2021).

Sample Size

Data saturation was reached after 10 screened participants were interviewed; no new ideas were coming, and no new themes were emerging. Below is a diagram illustrating the process for obtaining the study sample.



- The researcher identified 21 potential participants from the ESF's medical records fitting the age range 18-25 and treatment adherence
- From 21, 17 potential paticipants were selected on the basis of mental health stability by the ESF Staff
- 14 participants were screened using the MoCA
- Data saturation was reached after 10 screened participants were and interviewed

Data Collection Procedure

After screening, successful participants were enrolled in the interviews. The researcher further explained the study to the prospective participants and obtained informed consent, and proceeded with interviews.

Interviews

Participants were given room to freely choose between English and the Shona language in assessments, consenting to interviews. Screened and qualifying participants were thus enrolled in the study. Semi-structured interviews were conducted face-to-face in a private, comfortable setting provided by ESF. Interviews were 30minutes long on average and audio-recorded with the participant's consent. After each interview, the researcher debriefed by taking detailed notes on key themes and observations. Each participant was assigned to a code, such as ‘Participant 1 (P1)’. Data collection continued until data saturation was reached, meaning no new significant themes or insights emerged from subsequent interviews. There were no repeat interviews done.

Semi-Structured Interviews

The semi-structured interview guide was developed to cover key topics and areas of inquiry while also allowing for spontaneous follow-up questions and probes. This approach facilitated a rich dialogue and enabled the participants to elaborate on their responses. Interviews attempts to respond to the questions, how do sleep disturbances and neurocognitive impairments impact the quality of life of individuals with epilepsy in Zimbabwe, and what are their health-seeking behaviours?

Data Analysis

The data collected for this study were reported in accordance with the COREQ guidelines to ensure transparency and comprehensive reporting of the qualitative methodology. Each participant was assigned a unique identification code, such as "Participant 1," which was linked to their specific audio recording. The recordings, conducted in Shona, were transcribed verbatim using Microsoft Word. After completing the transcription for each participant, the transcripts were reviewed alongside the corresponding audio files to verify accuracy. The transcribed documents were then translated into English by a professional translator, maintaining the original identification codes. Initially, the English transcripts were printed with their corresponding identification codes. To enhance the study's rigor, two independent analysts were selected to conduct the data analysis, beginning with familiarization with the data.

Thematic Analysis

The data collected from the participants' interviews were analysed using a thematic analysis approach, as outlined by Baker 2018. Thematic analysis is a flexible yet rigorous qualitative method that allows researchers to identify, analyze, and report patterns or themes within a dataset (Braun & Clarke, 2006). This analytical approach was well-suited to the exploratory nature of the study, as it allowed the researcher to gain a deep and nuanced understanding of the participants' experiences and perspectives on epilepsy. By adopting this thematic analysis framework, the researcher was able to systematically organize and interpret the data, leading to the development of a cohesive set of themes that captured the complexities of the biopsychosocial factors influencing the participant's life. This inductive, data-driven analysis ensured that the findings were firmly grounded in the participants' own narratives, providing a solid foundation for the subsequent theory-building and conceptual model development. The analysis was carried out in six stages as follows:

Stage 1, familiarization with the data. The researchers familiarised themselves with the data by reading it multiple times to gain a deep understanding of its content.

Stage 2, coding. Important phrases and concepts were identified and coded based. Labels were attached to different pieces of text to form groups, and the process ended by condensing the labels into data sets.

Stage 3: searching for themes. The coded data were organized into coherent patterns that aligned with the research question, leading to the identification of themes from these groupings.

Stage 4, reviewing themes. The identified themes were revised, refined, and clearly defined to ensure they accurately represented the data and addressed the research objectives.

Stage 5, refining and naming themes. Each theme underwent detailed analysis to capture its essence, resulting in concise names that reflected the overall theme.

Stage 6, write-up. The final stage involved documenting the findings.

The study findings were reported in alignment with the COREQ guidelines, providing thick descriptions of the emergent themes and supporting them with direct quotes from the participants. Quotations were well identified and labelled with participants' codes. Major themes were clearly presented as well, along with the minor themes.

Ethical Considerations

The study was reviewed and approved by the Parirenyatwa Group of Hospitals and the University of Zimbabwe, Faculty of Medicine and Health Sciences Joint Research Ethics Committee (JREC), and the Epilepsy Support Foundation (ESF). Informed consent was obtained from all participants. Participant Identity Code (P1-10) was used instead of the participant's name to anonymize all data and recordings, thus maintaining confidentiality. Interviews were conducted in private. Participants were informed that they had the right to withdraw from the study at any time without consequences. The audios are kept in a password-protected laptop.

RESULTS

This section presents results for a qualitative study conducted among 10 people with epilepsy subscribed as members of the Epilepsy Support. The study aimed at exploring their experiences.

Participants' Characteristics

Ten participants were interviewed. The participants were between the ages of 18 and 25 years, were female (N=6, 60.0%), and of the total participants were married (N=4, 40.0%). Eighty percent (N=8) had attained an ordinary level of education, and sixty percent of them (N=6) were self-employed. More than half were initiated on epilepsy treatment between 11 and 24years (N= 6, 60%). All the participants were Christians.

MoCA Screening Scores

The MoCA scores for the 14 participants were as follows: 25, 20, 18, 21, 23, 16, 26, 25, 19, 28, 22, 18, 10, 17. The MoCA is scored out of a maximum of 30 points, with higher scores indicating better cognitive function. Generally, the interpretation of MoCA scores is as follows:

- **26-30**: Normal cognitive function; **18-25**: Mild cognitive impairment (MCI); **10-17**: Moderate cognitive impairment; **0-9**: Severe cognitive impairment

Descriptive Analysis

- The Mean score: 20.5
- Median score: 19.5
- Normal Scores (≥26): 2 participants (14.3% of the sample)
- Mild Cognitive Impairment (25-18): 9 participants (64.3%)
- Moderate Cognitive Impairment (17-10): 3 participants (21.4%)
- Severe Cognitive Impairment (<10): 0 participants (0.00%)

Participants' individual MoCA scores

Participant	**Score**
P1	17
P2	19
P3	23
P4	20
P5	25
P6	21
P7	18
P8	22
P9	18
P10	25

Table 4.2: Participants' Individual MoCA Scores

Emerging Themes

There were six themes (as shown in Table 4.2 below). Each theme had subthemes, then the main theme.

Table 4.2 Summary of emerging themes

Theme	**Subthemes**
Understanding and Managing epilepsy	Awareness and diagnosis Unobserved Episodes during Sleep Reliance on Witness Accounts Challenges in Current Predictability Caregiver Role in Seizure Identification
Impact of epilepsy on life	Stigma and Societal Perceptions
	Missed opportunities Resilience and adaptation Family perspectives and limitations
Sleep disturbances	Difficulties falling asleep
	Bedtime routine

	Night-time sleep interruptions Daytime sleepiness
Perceived cognitive challenges	Memory challenges
	Memory retention and learning Methods Variability in cognitive function
Overall quality of life	Perceived physical well-being
	Mental health awareness and resilience
	Social Isolation and Relationships
	Stigma and emotional growth Occupational Aspirations and Purpose Parenting as a Source of Joy and Motivation
Health-seeking behaviours	Reliance on General Healthcare Providers
	Low Frequency of Specialized Epilepsy Care
	Effective Medication Use and Monitoring
	Value of Peer Support Networks
	Desire for Tailored Resources and Opportunities

Understanding and Managing Epilepsy

Awareness and diagnosis: Participant PM005 indicated that he became aware of their epilepsy in grade three, with the first symptoms occurring during sleep. Parents played a critical role in identifying the issue and seeking medical help. Diagnostic tools like EEG confirmed the condition, leading to the initiation of treatment. The initial medications, carbamazepine and phenobarbitone, had significant side effects, hinting at challenges with drug tolerance. The following quote suggests when and how PM, not his real name, got to know that he had epilepsy:

“I started to know about it when I was in grade three. It started when I was sleeping. My parents were the first to notice that there was something that was happening to me. The first time they took me to the clinic, and later on, there were tests done on me, including the EEG, and that is when they established that I had epilepsy and immediately initiated treatment. I was started on carbamazepine and phenobarbitone. For me, the level of the drugs was too high. Later on in life, we met one of the workers at the Epilepsy Support Foundation, who then told my parents that I am supposed to join the support groups.” **P5Q1.**

Unobserved Episodes during Sleep: Potential nocturnal seizures are unmonitored, with jerking possibly occurring during sleep but lacking documentation or witness accounts. This emphasizes the difficulty in identifying and managing nocturnal seizures, which can remain unnoticed without external observation or diagnostic tools like an overnight EEG. 7 Participants who experienced episodes during sleep would only be able to tell after seeing blood on the pillow due to tongue biting or severe headaches, according to the following quotes

“If mom and dad are there, probably, they can tell that I had a seizure, but if I'm alone, I can tell maybe say I might have sores in my mouth after biting my tongue or I just wake up with a bit of a severe headache and yeah that's how I can tell that I had a seizure while sleeping.” **P5Q1**

“These seizures when they happen in the evening, I can only tell when I wake up and I am seeing blood on my pillow that shows that I did bite myself and if it is during the day and I will wake up feeling tired and having body aches and a sore body and that can indicate that yeah I really did hit myself when I had a fall.” **P2Q2**

Reliance on witness accounts: Participants noted that they depend on others to describe seizure events; therefore, in this case, no witnesses provide details about nighttime occurrences. The absence of observations during sleep highlights the importance of caregivers and technology in comprehensively capturing seizure activity to enhance understanding and treatment.

“As I said, they happen at any time, even whilst I'm asleep, and with the medication that I take, I get to urinate a lot. Sometimes I just wake up to go and use the restroom, and I will be in confusion and have no idea that I woke up and went to pee. Then it would be explained to me that this is what you did, and in cases of having messed up, I will have to take a mop and clean up.” **P9Q1**

Challenges in current predictability**:** While some participants have auras and can be able to predict the next seizure, some expressed concern over the challenge. The ability to tell or pick tell-tale signs places one in a safer position where they can prepare and be in a harmless space.

“In my body, sometimes I experience euphoria; I just feel happy, like overly happy.” **P3Q1**

“There's a distant smell that I cannot put a name on, which just comes disappear, comes disappears, and sometimes I have controlled saliva from my mouth. Then the next thing that happens, I don't remember anything.” **P8Q1**

For some, it emerged that over time, the ability to identify warning signs has diminished, leaving seizures largely unpredictable. The unpredictability increases the individual's vulnerability and dependence on preventive measures and external support. It also highlights potential changes in seizure patterns or the individual’s perception of preictal cues.

“Nowadays it's hard to tell, but back then, probably I would experience sort of something like heaviness in the chest that I could probably say maybe I need to look for a safe space where I can sit. But most of the time I would just black out, and I can't tell where I'm going or what's happening.” **P5Q1**

Caregiver role in seizure identification: All participants agreed that the family plays a vital role in noticing seizures when they are present. This illustrates the supportive role of family in identifying and addressing seizures, highlighting the value of having caregivers who can recognize and assist during and after an episode.

“Yes, she does if I'm looking at it, my wife is supportive because to notice most of the time, if she gets to know that if she hears that this is what would have happened, well, she would do the very best that she can. Of course, she can't manage to lift me, but she should do the very best she can.” **P2Q5.**

Impact of Experiencing Epilepsy on Life

4.3.2.1 Stigma and Societal Perceptions**:** Negative societal attitudes toward epilepsy limit opportunities for employment and social participation, and more than half of the participants attested to that. The perception of epilepsy as a condition that makes individuals unreliable or unfit for certain tasks, such as driving or working, reinforces discrimination. This stigma creates significant barriers, restricting the individual's potential and self-determination.

“Looking at this condition of epilepsy, sometimes you really can't work for big companies or even companies with young people, especially when it comes to this type of work that I do, of technical skills like the mechanics or building. Because it's very dangerous, you can actually fall whilst you're on top of a car or you're on top of a house. And these are some of the challenges. There was even one company that I actually left because I was seeing it directly. I was experiencing seizures, and the way they were happening wasn't safe for me. Some big companies will probably approach you and tell you, the way we are working with you, we cannot manage, we cannot proceed with you." **P7Q1**

One of the participants expressed that in as much as life can be challenging, life with epilepsy has empowered them to do more positively than society has benchmarked.

"It has impacted, what I can say in other ways negatively and to a greater extent positively. When I was still young, it was very negative because of stigma and discrimination. But as I was growing up, I became an inspiration to many, because they would really want to know how I am managing it, how I am conquering it. And it had actually given me the opportunity, even to interact with many doctors and many psychologists who have assisted me greatly, and who actually wanted to learnt through me how, so that they can actually help others, so to a certain extent, I think I have made more friends than enemies because of my conditions." **P8Q1**

Missed Opportunities: Epilepsy has led to the loss of significant life opportunities, particularly in employment and personal development. **P3** reflects on how the condition has impeded access to jobs and other milestones, such as driving or securing long-term stability, such as owning property. These missed chances highlight the broader socioeconomic impact of living with a chronic condition compounded by societal bias.

"I just feel it's on a lot of things, especially when it comes to employment. Most of the jobs that I know and that I can do are general manual labor. I know a lot of things, and I'm good at a number of things. Sometimes people might leave me out when it comes to taking me out for jobs, not because they don't want to, but because they refer to the things that they would have seen or witnessed me experiencing. And the question would be like, what if he gets to experience this again? I get it because people really don't understand." **P3Q1**

"So now I can see it's a chance that I missed if I were like others, I could have gotten the job, and some are now doing stuff with their life, they now have their own stands and are building houses. As someone who will be having a disease and wishes that this is what I would want to achieve in life." **P5Q1**

Resilience and Adaptation: In response to exclusion, it emerged that individuals with epilepsy explore self-reliance and independent avenues for progress. All participants expressed that, despite systemic barriers, there is a determined effort to find alternative paths for success and self-sufficiency. This resilience underscores the individual's adaptability and drive to overcome the challenges posed by epilepsy and its social implications. Of the 10 participants, 6 were self-employed, and 2 were formally employed. Below are how others would manage life financially.

"I do part-time general handywork. I do cleaning, house chores, laundry, and stuff." **P6Q4**

"I am working on my own stuff, I sell overnight 'Maheu' (brewed non-alcoholic beverage). I go and sell in the home industry, and you see, I will not have a lot of things to stress me." **P4Q4**

Family Perspectives and Limitations: P5 stated that family members, such as the father, hold protective yet limiting views about the individual's capabilities. The father's hesitation to support driving or workplace engagement stems from concerns about safety and the unpredictability of seizures. While rooted in care, this perspective inadvertently contributes to the perpetuation of restrictions and missed opportunities.

"You get to a point where you try to see how best I can work for myself, try to do stuff on my own. Even my father actually says I am not supposed to drive maybe because he hasn't gotten anyone who can be able to explain better to him that a person with epilepsy can drive and now you see that I missed a lot of opportunities and chances at his workplace and some workers there with that would take their kids to get employed but my father couldn't accept that I could work and drive in my condition." **P5Q1**

The experience of epilepsy has profoundly shaped the individual's life, affecting opportunities, relationships, and self-perception. While the societal and familial constraints highlight persistent stigma and misunderstanding, the individual's drive to seek independence and redefine their path reflects resilience and hope amidst these challenges. Addressing stigma and educating families and communities could significantly alleviate these burdens, fostering more inclusive opportunities for individuals with epilepsy.

Sleep and sleep disturbances

Difficulty falling asleep: On average, participants reported that they have individual struggles with initiating sleep despite going to bed early. This difficulty may be indicative of insomnia or heightened mental activity at bedtime, possibly exacerbated by lifestyle factors or underlying stress. The behaviour of engaging in activities like reading, watching movies, or playing games to induce sleep suggests a coping mechanism but may also disrupt the natural sleep-wake cycle.

“I really don't think I have a sleep schedule that I am consistent with. Sometimes, you know, you might have a lot of stress, and you are trying to think whilst you are also trying to sleep. At times, if I take my medication early, they make me sleepy as well, and they sometimes make me feel dizzy.” **P6Q2**

“It's not like I'll be thinking as such, but sometimes I just can't find sleep, and I wouldn't be able to tell what could really be happening.” **P2Q2**

Bedtime Routine: It emerged that routines that include family prayer time and setting boundaries, such as removing children from the TV, followed by personal attempts to fall asleep, are frequent behaviours among three participants. A structured bedtime routine indicates an effort to promote good sleep hygiene. However, the individual's description of “just seeing colours” instead of falling asleep suggests underlying challenges with relaxation or transitioning into a sleep state.

“Sometimes I might get to sleep around 11 pm or 12 am because possibly what I can say is we normally get to remove the kids from the TV around 8 pm, and we do our prayers, and at 8:30 get in bed, but once in bed, you just see the colours, and there is no sleep. So now what I do is maybe I will read my bible, watch a movie, or I play games, then maybe around 11 pm or 12 am, that's when I will get sleep.” **P5Q2**

Night-time Interruptions: Some participants reported that they rarely wake up during sleep or visit the restroom at night. Once sleep is achieved, it appears to be relatively uninterrupted, suggesting that the primary sleep challenge lies in initiation rather than maintenance. This might imply that the issue is rooted in pre-sleep factors rather than conditions like nocturia or frequent arousals. On the same aspect, P2 and P7 complained of waking up more than twice to use the restroom ever since they were diagnosed with epilepsy.

“I often wake up to use the restroom, maybe three times in one night. I never used to do this much. I think the change, um, happened when I started epilepsy medication.” **P7Q2”**

“I wake about three- or four-times during sleep to use the restroom, depending on the temperature is like or maybe depending on what I have spent my whole day doing, it's cold or it's hot, or probably I would have taken a lot of water. Sometimes I can just wake up once.” **P2Q2**

Coping Strategies for Sleeplessness: It emerged that in three participants, activities such as reading the Bible, watching movies, or playing games are used to pass the time until sleep comes. These strategies reflect an attempt to self-soothe or distract from frustration over sleeplessness. However, engaging in screen time or stimulating activities late at night could further delay sleep onset, creating a cycle of sleeplessness.

“It depends on what I'm doing, and then sometimes I kind of like my phone, although I know I should not get my phone too much, but around 10 – 11 pm, that's my bedtime.” **P10Q2**

Daytime sleepiness: P2 and P9 expressed worry over severe challenges with daytime sleepiness, attributing it to seizures during sleep and sleep disturbances. Some participants, only after being asked, noted at times after a bad night, narrated experiencing fatigue, and at times avoided work that is really mentally demanding on a disturbed day.

"I have seen that it happens quite a lot. When I get in a 'combi' (public transport in the form of a minibus), if I sit, then the next thing I will wake up when the next person is shaking me, asking what's going on." **P2Q2**

"This happens a lot. Sometimes I just wake up when the 'combi' is almost getting home. I kind of like lightly sleeping, and I listen to tunes so I can say maybe it's body relaxing and not fully sleeping." **P9Q2**

Perceived Cognitive Challenges

The responses provided illustrate a nuanced interplay between self-awareness of memory and cognitive performance within the context of epilepsy. Below are themes that are drawn from these narratives, especially considering the impact of neurocognitive impairments such as memory challenges.

Self-Perception of Memory Challenges: Six out of ten participants indicate that they were unaware of memory difficulties until prompted. This suggests that memory issues might not always be immediately apparent to individuals but may surface through reflection or detailed questioning. For instance, P5 mentioned that;

"Not that I can say um, maybe that now you have mentioned it, but I have noticed if I read something and get to understand it, I rarely forget stuff." **P5Q3**

"Sure, I have, there are several things that I've noticed, but I try to look at it like it's something that everyone else might go through, but my memory is really affected on the part that if I'm introduced to someone, and probably I don't get to talk to them the next time I meet them, I won't be able to recognize them until they talk. That is when I will be able to pick, so probably my memory is poor, especially on facial recognition." **P8Q3**

"For instance, with this forgetfulness issue, I can't even hide my money because if I hide it, the next thing I no longer know where I hid it." **P9Q3**

"Maybe just being forgetful. I think I used to be smarter, or maybe I'm just overthinking things I don't know. Let's say drugs with similar endpoints like as just don't find the right prefix for it. I can understand I have difficulty finding words, well, I don't know, and it's so annoying and sometimes almost frustrating." **P10Q3**

P8 noted the memory challenge to be quite disturbing, seeing that she was struggling to recall faces, which is known as prosopagnosia, and she inquired with the healthcare providers. This not only shows the existence of challenges but highlights a good health-seeking behaviour as stated below,

"I shared with them in our last session, we concluded with the psychologist that, after all, why do I need faces for because they were now thinking of changing my medication, thinking they might be interfering with my memory, then my issue was that the medication is working for me and it's helping me, and also that it is affordable. The ones that they were considering were expensive for me, and won't I even get worse?" **P8Q5**

Memory Retention and Learning Methods: A strong reliance on understanding and context aids in memory retention. While epilepsy may introduce general forgetfulness, understanding material deeply may mitigate its impact on memory for specific tasks or information. Deep engagement with material could serve as a compensatory mechanism for memory impairments. Here is what P5, P8 and P10 stated,

"I was average in many subjects. I passed 5 subjects because the teachers were good, patient with me, and also books were available" **P5Q3**

"Like I said earlier, my support system is that powerful. People around me, normally support me, just like waking up at 6 am is the time that I want to wake up, but I might fail to wake up at that time and the people I stay with, they will definitely wake me up because they know that at 6 am I'm supposed to be up, so I would tell them that tomorrow I would want to do this, or probably in a week, I want to do A, B, C, D. they would remind me." **P8Q3**

"I take notes, I'm sticking out my room is all these notes on the wall, and then mind mapping, no, these weird techniques they teach us on TikTok. And then, yeah, I like colour too. Sometimes I even want to wear a colour a day. It's on Monday, and I'm going to wear it. And then when I remember things, it was that I was wearing a certain colour. So, it kind of helps. And I will stick to that for detail. If I remember something to play out eventually, and I remember it, I'm just I'm just try.” **P10Q3**

Variability in Cognitive Functioning: Three of the ten participants interviewed indicated that they forget things easily. Experiences with memory can vary significantly, even within the same condition. While some participants experience significant memory problems, others retain strong memory capabilities in specific areas like education or learned tasks. Individual differences play a crucial role in the manifestation and impact of memory impairments. The following quotes support the effects of individual differences on cognitive functioning for people with epilepsy:

“I've gone to school up to tertiary level. I've got my first degree, and I also have a diploma” **P8Q1**

“I wrote five subjects and passed five” **P5Q1**

“I did my Form 4, and after finishing, I went to mechanics’ school.” **P7Q1**

Overall quality of life

Perceived physical well-being: Most participants expressed satisfaction with their physical health, suggesting it is not a limiting factor in their quality of life. However, they suggested that the absence of a job or meaningful work creates a significant gap in overall well-being. For example, P6 said,

“I think, besides the issue of epilepsy, my physical health is okay.” **P6Q4**

“I think it's all good. My mental health is okay.” **P8Q4**

‘All I can say is my physical health is all right; it's just that I don't have a job and work to do, but otherwise I'm good.” **P5Q4**

Mental health awareness and resilience: Participants understood differently. There were as many views as there were participants on what mental health is, ranging from the realisation of potential,

“In my opinion, it is being able to understand and utilise one’s abilities to cope with challenges of life” **P8Q4.**

It is about being able to build and maintain relationships, foster healthy interactions with others in both personal and professional contexts (P1, P5, P8 & PM10), and some perceived it as contributing to the community, for example, participating productively in social, work, or community activities.

“I don't think much, but I'm kind of positive about my life. I don't want to be negative. I'm doing all good in school so far.” **P10Q4**

Participant 4 initially sought clarification on the concept of mental health and then identified it as a state of rational thinking and the absence of mental disorders. He affirmed that he does not experience mental health challenges, signalling a sense of stability and resilience. He stated that,

‘I think it's the way of thinking well...but now what I'm thinking if someone might have a mental disorder...but well, myself I don't have that mental challenge, I'm okay." **P4Q4**

Social isolation and relationships: The absence of intimate relationships and indirect references to past stigmatization linked to epilepsy was noted in one. This suggests lingering impacts on social integration, despite progress in personal acceptance of the condition.

“For now, I am not in any relationship.” **(P9Q4)**

“Well, on that note, I really don't have someone I can call my friend. Wherever I go in that specific time, I just socialize with people, and when I leave, that's the end of it.” **P2Q4**

Occupational aspirations and purpose: Unemployment emerged as a dominant challenge, significantly influencing the participant's sense of purpose and self-worth. Most participants expressed a strong desire for meaningful work, tied to traditional roles of provision and contribution within the family and society. According to P6

“The challenge I have is to find something to do like an occupation. I know myself, I can do a lot of things”. **P6Q4**

“One of the challenges, say you might have a client. The moment that they get to know that you've got epilepsy, they no longer trust you. Probably I can't give someone my car, especially if they are sick, or let me look for another mechanic. It's hard for me to give you the task of working on my car. What if you fall or have a seizure in my car?” **P7Q4**

Parenting as a source of joy and motivation: Parenting stood out as a central source of satisfaction and pride. Some participants expressed determination to provide for their child, drawing strength from their role as a parent despite financial difficulties. Participant P5 said,

‘I am looking at my baby, and if I am there, I am supposed to be able to provide, and I am happy about that.’

“One thing that makes me happy is that I can be able to take care of my family. I even managed to get my garage set up and my company registered, so that I can work well, be happy, and take care of my family, and I can manage to take care of myself. One good thing, I don't even take alcohol, and it makes me happy. That if I can at least be able to take care of my family, take care of myself, and I can have a happy life and work for myself.” **P7Q4**

The participants’ overall quality of life is marked by a balance between resilience and persistent challenges. Physical and mental health were seen as stable, but financial insecurity and social isolation weighed heavily. The journey from past trauma and stigma to current acceptance of epilepsy reflects significant emotional growth. Despite difficulties, most participants found joy and motivation in their role as a parent, underscoring the interplay between personal agency, external challenges, and sources of intrinsic fulfilment.

HEALTH SEEKING BEHAVIOURS

Reliance on General Healthcare Providers: All participants suggested that they rely on private general practitioners for routine health concerns and epilepsy medication management. Their disclosure of epilepsy to these professionals ensures continuity of care but highlights a lack of engagement with epilepsy-specific specialists. Taking a look at P6, the report was that

“The doctor that I get to see, I can just tell them I have got epilepsy, and they will just look at the medication that I am already taking.” **P6Q5**

“I have a GP Doctor that I see for general health, and whenever I need my medicines, I call Epilepsy Support Foundation, this is where I get my medication.” **P7Q5.**

“That's a long time ago. I used to see a doctor when I used to have Cimas. I now get my medicines here at Epilepsy Support Foundation, if I'm flexible at work, and if not, and I have money, I will simply buy at local pharmacies, and for my medicines I need about US30 per month.” **P3Q5**

Furthermore, the participant's preference for general practitioners over epilepsy specialists suggests a pragmatic approach to managing their condition. However, the lack of specialized consultations may lead to missed opportunities for advanced care and tailored advice.

Low frequency of specialized epilepsy care: Some participants reported that they have not consulted a healthcare provider specialising in epilepsy for an extended period. This could suggest barriers such as accessibility, cost, or perceived adequacy of current care. Below P2 noted that, “Well, it's been long after I visited the doctor; I can't tell how long it has been. You see what would happen when my mother was still around, she's the one who would say Let's go see the doctor. So, if I'm to say I will go, that would be a lie because I don't even know where to start from and where to go.” **P2Q5**

Effective medication use and monitoring: About 4 participants indicated regularly using carbamazepine, as presented by demographics, and they have not reported any noticeable side effects, as described by P6 and P2. This suggests routine monitoring, but may also reflect limited awareness of possible subtle or long-term effects.

“Yes, my medication is working for me, and also what I then discovered is the doctor suggested that the dosage I was started on was too high, and I was having about four to five seizures in a day, and it was that severe. So, they started reducing my dosage bit by bit.” **P6Q1**

“I can say for now, I do not have any problems; the medicine is working for me.” **P2Q1**

Value of peer support networks: The Interviews revealed that the Epilepsy Support Foundation plays a vital role in fostering a sense of community and providing emotional reassurance. Shared experiences with peers offer motivation and combat feelings of isolation.

‘The feeling of being around someone that you perceive is more or less like you are helping relieve pain. It would be nice to have someone who understands your situation.’ **P5Q5.**

Friends and support networks like the Epilepsy Support Foundation contribute significantly to the participant's emotional and practical well-being. These relationships help mitigate stigma and foster a sense of normalcy.

Desire for tailored resources and opportunities: Participant P3 expressed a strong need for employment and structured opportunities that accommodate epilepsy. Safe and inclusive work environments are perceived as essential for improving their quality of life. The assertion was that,

‘If there could be opportunities...for people to have something safe for people with epilepsy to do, the world would be a better place for them.’ **P3Q5**

The participant’s health-seeking behaviours underscore the importance of integrating specialized care, enhancing peer support systems, and addressing socioeconomic barriers. Fostering awareness, providing accessible epilepsy-specific healthcare, and creating inclusive work opportunities can significantly improve the overall quality of life for individuals living with epilepsy.

DISCUSSION OF RESULTS

The interviews revealed several key themes that align closely with the biopsychosocial framework, emphasizing the interplay between biological, psychological, and social factors in the lives of individuals with epilepsy. Participants articulated their experiences with seizures, medication adherence, and the psychological impacts of living with a chronic condition. For instance, the occurrence of nocturnal seizures and the subsequent cognitive challenges, such as memory lapses and difficulties in concentration. These findings support existing literature that highlights cognitive impairment as a common consequence of epilepsy (Adem et al., 2020; Hermann et al., 2017).

The characteristics of the participants in the study showed that more than half the participants were female, which is often supported by literature that confirmations positive health-seeking behaviours in females than males, though there is a higher incidence of epilepsy in males than in females (Hermann et al., 2017). Some of the participants did not manage to get to an ordinary educational level due to poor health, as reported by some of the participants, which supports some literature that shows neglect and misconceptions of the condition.

Moreover, the emotional toll of epilepsy surfaced in the narratives, with participants expressing feelings of anxiety and frustration stemming from societal stigma and personal challenges. Such experiences resonate with previous studies indicating that individuals with epilepsy often encounter social isolation and mental health issues (Baker et al., 2018). The participants' descriptions of their support systems, including family and friends, underscore the importance of a strong social network in mitigating these negative effects, aligning with the biopsychosocial model's emphasis on social support as a critical component of health outcomes (Berkman et al., 2000).

Furthermore, sleep disturbances emerged as a significant theme in the participants' narratives. Many reported experiencing difficulties falling asleep or maintaining sleep, often exacerbated by anxiety about life in general and potential seizures. This aligns with findings from previous studies that suggest a bidirectional relationship between epilepsy and sleep disorders (Mason et al., 2021). The participants noted that poor sleep quality not only increased their susceptibility to seizures but also contributed to heightened fatigue and irritability during the day. This cyclical nature of sleep disruption and seizure activity emphasizes the need for integrated treatment approaches that address both sleep hygiene and seizure management.

Cognitive challenges were reported in depth, with participants expressing difficulties in memory recall, failure to recognise faces, and concentration. These cognitive impairments were often described as frustrating and led to decreased academic performance and difficulties in professional as well as social settings. The participants' accounts align with research indicating that individuals with epilepsy frequently face challenges in executive function, which can impact their daily lives (Hermann et al., 2017; Smith et al., 2019). The cognitive challenges reported also highlight the importance of tailored educational interventions that can help individuals develop strategies to cope with memory difficulties and improve their overall cognitive function.

The cognitive challenges experienced by participants were not isolated issues; they were intertwined with emotional and psychological well-being. Many participants reported feelings of anxiety and depression linked to their cognitive impairments. For instance, the fear of forgetting important information or the embarrassment of not recognizing someone could trigger anxiety, which in turn exacerbates cognitive difficulties.

Health-seeking behaviours also surfaced as a critical issue among participants. Some expressed hesitance in seeking medical attention, primarily due to previous negative experiences with healthcare providers or fears of stigma. This reluctance can lead to delays in treatment and inadequate management of their condition. In contrast, others reported proactive engagement with healthcare services, often seeking out specialists and support groups to better understand their condition and treatment options (Elliott & Richardson, 2014). This variance in health-seeking behaviour underscores the necessity for healthcare systems to create more supportive environments that encourage individuals with epilepsy to seek care without fear of judgment or misunderstanding.

Overall, the impact of epilepsy on quality of life was a central theme throughout the interviews. Participants articulated how their condition influenced various aspects of their lives, including social interactions, employment opportunities, and family dynamics. While some reported feeling empowered by their experiences and actively engaging in self-management strategies, others described feelings of isolation and frustration due to the stigma associated with epilepsy. The findings resonate with existing literature that highlights the multifaceted nature of quality of life among individuals with epilepsy, underscoring the importance of addressing both medical and psychosocial needs in clinical practice (Baker et al., 2018).

RECOMMENDATIONS

Routine neurocognitive assessments should be integrated into the standard care protocols for individuals with epilepsy. These assessments can help identify specific cognitive impairments, such as memory and attention deficits, allowing for early intervention and personalized management plans, thereby improving patients' overall functioning and quality of life.

Further research is needed to explore the specific mechanisms linking sleep disturbances and cognitive impairments in individuals with epilepsy. Longitudinal studies could provide insights into how these factors evolve and their cumulative impact on quality of life.

Healthcare providers should adopt a holistic approach to epilepsy management that integrates medical treatment with psychological and social support, especially in a setting where sleep hygiene and cognitive health are not prioritised.

Advocating for policies that prioritize comprehensive epilepsy care, including mental health support and sleep management, is crucial.

CONCLUSION

In conclusion, this research provides a comprehensive exploration of the interrelated effects of sleep disturbances and neurocognitive impairments on the quality of life of individuals with epilepsy in Harare, Zimbabwe. The findings illuminate the profound impact that cognitive challenges, such as memory deficits and attention difficulties coupled with sleep issues, have on the daily functioning and emotional well-being of those living with this condition. By integrating the biopsychosocial framework, the study emphasizes the necessity of adopting holistic management strategies that encompass medical, psychological, and social dimensions of care. As such, the insights gained from this research not only highlight the urgent need for targeted interventions and community support but also advocate for a broader societal understanding of epilepsy that empowers individuals to navigate their challenges with resilience and dignity. Ultimately, addressing these interconnected factors is essential for enhancing the overall quality of life for individuals with epilepsy and fostering a more supportive environment within the community.

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LIST OF ACRONYMS/ ABBREVIATIONS

ASSM	American Academy for Sleep Medicine
COREQ	Consolidated Criteria for Reporting Qualitative Research
ESF	Epilepsy Support Foundation
ILAE	International League Against Epilepsy
NCI	Neurocognitive Impairment
MoCA	Montreal Cognitive Assessment
PWE	People with Epilepsy
QoL	Quality of Life
SD	Sleep Disturbances
WHO	World Health Organisation
ZLAE	Zimbabwe League Against Epilepsy