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Lived experiences that influence the quality of life among patients with epilepsy at Mulago National Referral Hospital

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ABSTRACT

Background: In Uganda, the quality of life (QoL) of patients with epilepsy (PWE) remains poor due to clinical, psychological, and social challenges. While several quantitative studies have documented correlates of poor QoL in Ugandan PWE, the specific mechanisms, contextual meanings, and patient-defined priorities through which epilepsy affects daily life remain poorly understood. This study aimed to explore the lived experiences that influence QoL among PWE at Mulago National Referral Hospital (MNRH) in Uganda.

Methods: We conducted a qualitative study among 12 purposefully selected adult PWE at MNRH. We collected data using in-depth interview guides and analysed the data using inductive thematic analysis with ATLAS.ti software. We used purposive sampling guided by gender and duration of epilepsy care to ensure depth and breadth of perspectives. Data collection continued until thematic saturation was achieved.

Results: Three major themes captured the lived experiences that influence QoL. 1)Psychosocial experiences encompassed social support from friends and religious communities, family relationships that functioned as sources of both support and strain, stigma and discrimination, and psychological, cognitive, and coping processes. 2) Economic and daily living challenges encompassed financial barriers to treatment, employment disruption alongside economic adaptation, and seizure-related physical injury. 3) Healthcare and treatment experiences encompassed access to free antiepileptic drugs (AEDs) and diagnostic services, provider-led counselling and health education, and medication-related effects.

Conclusion: Healthcare services should prioritise a shift to holistic, patient-centred care that integrates psychosocial well-being, economic circumstances, and lived treatment experiences into routine epilepsy management.

1. Introduction

Epilepsy is a common neurological disorder affecting people of all ages, races, social classes, and geographical locations [1]. The global burden of epilepsy resulted in 18.3 million years lived with disability (YLDs) in 2019, accounting for 2.1% of total global YLDs [2]. Multimorbidity in epilepsy creates challenges in management and is associated with functional impairment, disability, and reduced quality of life (QoL) [3,4]. In epilepsy, QoL is predominantly affected by depression, anxiety, psychiatric and somatic comorbidities [5], and is impaired across physical, cognitive, psycho-behavioural, and social dimensions [6,7].

Quality of life (QoL) refers to an individual's perceptions within the context of their culture, goals, expectations, standards, and concerns [8]. The effect of epilepsy on QoL is further compounded by anti-epileptic drug (AED) use, seizure frequency and severity, polytherapy, stigma, depression, anxiety, and mood disorders [6], in addition to a large treatment gap driven by inadequate healthcare systems and

Abbreviations: AED, Anti-epileptic drugs; QoL, quality of life; MakSPH-REC, Makerere University School of Public Health Research Ethics Committee; MNRH, Mulago National Referral Hospital; PWE, People with Epilepsy; IDI, In-depth interview..

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negative community myths about epilepsy [9].

In Uganda, PWE suffer from debilitating seizures alongside associated comorbidities such as depression and neurocognitive delays [10]. Epilepsy is associated with stigma, diminished QoL, morbidity, and economic loss [6], with PWE enduring significant isolation and discrimination that dramatically impairs their functioning [11]. Social rejection and exclusion from marriage and employment increase the community burden of epilepsy [12]. Uganda's health facilities lack specialised epilepsy care across facility levels, with inadequate medication, equipment, and trained specialists [13,14]. Additional barriers include costs, cultural beliefs about seizure causation, use of traditional medicine [15], and economic losses associated with consultations [16]. Socioeconomic factors such as lower educational attainment, unemployment, and poverty are independently associated with diminished QoL [17].

Several quantitative studies have documented correlates of poor QoL among Ugandan PWE, including seizure severity, AED polytherapy, and stigma [16,18]. However, the specific mechanisms, contextual meanings, and patient-defined priorities through which epilepsy affects daily life remain poorly understood. In particular, how patients in low-resource settings experience and navigate the co-occurring burdens of medication side effects, socioeconomic constraints, stigma, and limited psychosocial support has not been qualitatively examined in depth at a Ugandan tertiary referral centre. The quantitative instruments measure the presence and frequency of QoL impairments but cannot capture the subjective meanings, local cultural contexts, or patient-defined priorities that shape how those impairments are experienced and managed. Qualitative inquiry is therefore uniquely positioned to reveal these mechanisms. This study aimed to explore the lived experiences that influence the QoL among PWE at MNRH.

2. Methods

2.1. Study design and setting

This qualitative study was conducted at Mulago National Referral Hospital (MNRH), located in the Kawempe division of Kampala City. MNRH is the largest hospital in Uganda, with a bed capacity of 1790 and a busy outpatient department of approximately 50 0 patients per day. The medical neurology outpatient clinic is open Monday to Friday and receives 8–12 PWE per day. MNRH was selected because it provides care to the most complex and critically ill patients in Uganda and serves as the national final referral point.

2.2. Study population and selection procedures

The study population comprised adult PWE enrolled in care at MNRH. Eligible participants required a documented diagnosis of epilepsy in medical records, enrolment in care for at least one year, and clinical stability (not critically ill at the time of enrolment). The criterion “critically ill” was defined as participants who were acutely unwell at the time of enrolment, including those with status epilepticus, recent major seizure-related injury requiring hospitalisation, or inability to provide informed consent due to acute illness. This exclusion means the findings do not represent PWE with very high seizure burden, severe cognitive impairment, or acute medical complications, who may have qualitatively distinct experiences.

Adult PWE were selected purposively, guided by gender (equal numbers of males and females) and duration of epilepsy care, to ensure depth and breadth of perspectives. A sample of 12 was deemed adequate; empirical research has demonstrated that thematic saturation can be achieved within 12 purposively selected in-depth interviews in studies with relatively homogeneous populations and narrowly defined objectives [19]. Data collection continued iteratively until no new themes emerged across successive interviews, confirming thematic saturation.

2.3. Data collection tools

In-depth interview (IDI) guides were used because they capture individual, lived experiences in depth without the social pressures inherent in group settings. IDIs enable thorough, candid exploration of complex, sensitive topics and allow researchers to probe the experiences and motivations underlying particular needs and behaviours.

2.4. Data collection procedure

In-depth interviews were conducted in quiet, safe rooms to encourage freedom of expression. Trained, experienced qualitative researchers conducted all interviews and noted non-verbal cues. Participants were explicitly invited to describe their lived experiences with epilepsy and reflect on how epilepsy affected their QoL across physical, social, emotional, and daily functioning dimensions. Interviews lasted 45–60 min and were conducted in Luganda. All interviews were audio-recorded. The IDI guide was pre-tested with four PWE attending the same clinic, and necessary adjustments were made.

2.5. Rigour and trustworthiness

Ensuring rigour and trustworthiness involved strategies to enhance credibility, dependability, transferability, and confirmability [20]. Credibility was ensured through prolonged engagement with participants. Dependability was enhanced by adhering to stated research methods. Transferability was ensured by clearly describing the purposive sampling approach. Confirmability was ensured by tracking the research process and verifying that findings fit the raw data. Coding was conducted by the lead researcher (H.A); emerging codes and themes were reviewed and discussed with co-investigators (J.N & D.L) to achieve consensus. Disagreements were resolved through discussion. The research team acknowledged that their clinical and public health backgrounds may have shaped sensitivity to biomedical themes; reflexive journaling and regular debriefing sessions were used to surface and manage these assumptions. Written summaries of emerging findings were shared with all 12 participants for member checking. Minor clarifications were incorporated; no major themes were disputed.

2.6. Data management and analysis

Audio-recorded interviews were transcribed verbatim, cleaned, and translated into English by a trained bilingual research assistant. Translation accuracy was verified by an independent bilingual reviewer through back-translation, with discrepancies resolved by consensus. Data were analysed using inductive thematic analysis using ATLAS.ti software, following steps: (1) familiarisation with data, (2) initial coding; (3) clustering codes into sub-themes, (4) integrating sub-themes into themes, (5) member checking, and (6) reporting per the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines [21].

2.7. Ethical considerations

Ethical review and approval were obtained from the Makerere University School of Public Health Research Ethics Committee (MakSPH-REC). Site clearance was sought from the hospital director, head of research, and the mental health unit in charge at MNRH. All participants provided written informed consent.

3. Results

3.1. Demographic summary of participants

Table 1 presents the demographic characteristics of the 12 participants.

Table 1
Demographic characteristics of the in-depth interview participants.

Characteristic	Frequency
Age in years (mean)	35
Duration on AEDs in years (mean)	13
Gender	
Male	6
Female	6
Marital status	
Single	5
Cohabiting	3
Married	1
Divorced	3
Employment	
Self-employed	3
Employed	3
Unemployed	6
Education	
Primary	4
Secondary	4
More than secondary	4
Total	**12**

An equal number of males and females participated. The mean age was 35 years (ranging from 22 to 62 years). Five participants had never been married, and six were unemployed. Mean duration on AEDs was 13 years (ranging from 5 to 22 years).

3.2. Thematic framework

Inductive thematic analysis identified three major themes, comprising nine sub-themes, that describe the lived experiences influencing QoL among PWE, and they include (1) psychosocial experiences, (2) economic and daily living challenges, and (3) healthcare and treatment experiences. Table 2 presents the thematic framework.

Table 2
Thematic framework of lived experiences that influence QoL of PWE.

Theme	Sub-theme	Representative codes
Psychosocial experiences	Social support	Daily companionship and practical help from friends, pastoral counselling, congregational acceptance, prayer support
	Family relationships	Medication reminders, seizure-time care, financial assistance, family-based exclusion, stepfamily discrimination, partner abandonment and divorce
	Stigma and discrimination	Witchcraft attribution; public gossip, peer avoidance, concealment of condition, shame, fear of business/career exposure
	Psychological, cognitive, and coping experiences	Self-acceptance, seizure-trigger avoidance, depression and anxiety, anticipatory fear, memory impairment, academic difficulty
Economic and daily living challenges	Financial challenges	Cost of medication; inability to maintain consistent treatment
	Employment and economic adaptation	Job loss, work absenteeism, reduced productivity, starting own business, achieving financial independence
	Physical injury and activity limitation	Burns, tongue injury, falls, restriction on outdoor mobility
Healthcare and treatment experiences	Access to care	Free AEDs, free consultations, reduced financial burden
	Provider support and health education	Counselling on seizure management, lifestyle advice, treatment information
	Medication-related effects	Sedation and physical weakness, non-adherence, seizure recurrence due to missed doses.

3.3. Theme 1: Psychosocial experiences

3.3.1. Social support

Friends and religious communities were frequently described as sources of social and psychological support. Friends provided companionship, emotional reassurance, and practical assistance during seizure episodes; some participants reported that friends also offered critical financial support, enabling economic recovery after seizure-related setbacks such as divorce or job loss.

> "I got this job with the help of my friend. When I separated from my husband, I told my friend to help me get a job because I left my husband's home with no money." (Female, 33 years).

Religious communities offered another source of support. Participants reported that religious leaders provided spiritual counsel, congregations offered prayer and emotional reassurance, and church ushers provided practical assistance during public seizures. Participants described religious engagement as complementary to medical care and reinforcing treatment adherence. Religious engagement fostered a supportive environment that helped PWE manage epilepsy and improved acceptance and QoL.

> "I am born again, and people at church, especially our pastor, know my condition and always advise me to continue taking my drugs while I pray; then when I get a seizure at church, the ushers are usually there to help me out." (Female, 23 years).

3.4. Family relationships

Family emerged as a major influence on the quality of life of PWE, though its influence was not uniformly positive. For most participants, family members assisted with daily activities, provided emotional encouragement, helped with medication acquisition, and responded during seizure episodes. Family was the main pillar of support, providing daily companionship and care for managing epilepsy.

> "My family supports me in everything. When my drugs are finished, they help me get other medications, provide me with food and also encourage me to take drugs." (Male, 32 years).

> "People at home have supported me because whenever they realise that I am in danger, they take charge to look after me. We are always together." (Male, 38 years).

However, family relationships were not always supportive. Some participants described family-based exclusion, including being denied access to household items, told not to play with other children, or experiencing neglect. One participant's grandmother refused her access to household items and food and, on one occasion, beat her without cause; another described stepfamily discrimination, being excluded from household utensils, with food refused because she might spread the disease.

> "Sometimes they could tell me don't touch my thing, don't play with my child, so in that whole situation, I would find myself very heavily laden." (Female, 29 years).

Family and intimate relationships were also disrupted directly by epilepsy. Accounts highlighted partner abandonment, divorce, and difficulty forming or sustaining romantic partnerships, driven by stigma, emotional withdrawal, behavioural changes, or partners' fear of the condition. Several participants noted that disclosure of epilepsy to potential partners was itself a major barrier.

> "I was divorced because of this condition; my wife decided to leave me alone, and it affected me a lot." (Male, 43 years).

Others experienced emotional rejection or isolation, leading to divorce, despite initial support. In some cases, denial and non-acceptance of the condition contributed to misunderstandings and separations among the partners. These disruptions not only affected the participants' mental and emotional well-being but also reflected broader psychosocial burdens that epilepsy imposes on daily functioning, self-worth and overall QoL.

"I'm not married, but also when you tell a person about your sickness, they start changing..." (Male, 35 years).

3.5. Stigma and discrimination

Beyond the family unit, stigma was socially enacted in multiple forms within the wider community. Community members, and in some cases family members, attributed epilepsy to witchcraft, bewitchment, or traditional spirits, producing misunderstanding and social marginalisation. Participants reported exclusion from the use of household items, prohibition from playing with others' children, gossip, and public labelling. Some accounts recounted being shunned by friends following public seizures, with peers withdrawing due to fear of contagion.

"As you know, people will say, you are bewitched... sometimes they could tell me don't touch my thing, don't play with my child, so in that whole situation, I would find myself very heavily laden." (Female, 29 years).

Internalised stigma was characterised by feelings of shame, perceived devaluation, identity concealment, and self-imposed social withdrawal, driven by anticipated negative reactions from others rather than by the psychological distress of seizures themselves. Accounts conveyed patterns of concealing the condition, withdrawing from public spaces, and relinquishing social roles.

"I am frustrated with myself as a person. I am home and protect myself just like the way someone hides from a thief. I spend all the time in the house alone." (Male, 32 years).

Fear of business and career consequences, driven by epilepsy-related stigma, also emerged. Accounts highlighted avoidance of business ventures, employment opportunities, and public participation, out of fear that others would discover the condition and respond negatively.

"Yeah, of course it has affected me because I wanted to do some business, but I can't because of the fear of getting attacks and sometimes I wake up in the morning when I have forgotten everything..." (Female, 45 years).

3.6. Psychological, cognitive, and coping experiences

Participants described a range of cognitive and behavioural strategies for managing epilepsy alongside significant psychological and cognitive burden. Self-acceptance was a key coping strategy; several participants narrated a shift in perception over time, moving from distress at diagnosis to a normalised and positive view, facilitated by comparative perspective-taking, recognising others with more severe conditions and reframing one's own situation accordingly.

"But as time went on, I got used to it, and I just saw it as normal. I'm not the only one. That's how I could just comfort myself. And it's not the end of life; I love myself the way I am." (Male, 26 years).

Participants recounted deliberate lifestyle modifications aimed at reducing seizure triggers, including avoiding stressful or noisy environments, refraining from alcohol consumption and nightlife, avoiding fireplaces and long-distance travel alone, and careful attention to rest.

"From the time I was told about this disease, I stopped being near fireplaces, noisy places, walking long distances, and moving alone even in cars... what if the seizure comes, yet I am alone." (Male, 38 years).

"I attribute all this to maintaining myself, being in a quiet environment and finding the best situations for myself. There are many things I try to avoid because they may stimulate the attacks." (Male, 32 years).

Alongside these coping strategies, participants described substantial psychological and cognitive difficulties. Several described anticipatory fear of seizure recurrence as a persistent source of anxiety, even during seizure-free periods, together with depression, reduced motivation, and reduced self-efficacy.

"Sometimes I feel depressed. Because you want to do some things... you want to take care of your life, and it's not so easy. Because of this disease. I am frustrated with myself as a person..." (Female, 22 years).

"So, you can be there, and you feel scared because something is going to happen, because I don't know at any time it can happen." (Male, 62 years).

Cognitive difficulties memory impairment, reduced concentration, and difficulty comprehending academic content were reported as having interrupted educational trajectories in ways participants attributed specifically to epilepsy. Several participants recounted leaving school before completing their studies due to cognitive challenges attributable to epilepsy. Emotional difficulties included feelings of frustration, reduced confidence, and occasional isolation, driven by emotional exhaustion rather than by stigma from others.

"Epilepsy made my days in school very difficult because my brain was weak; even when I was given the simplest words, they still gave me a hard time, and even writing was an issue. I lost my memory; you ask me this, and I respond off topic." (Male, 32 years).

3.7. Theme 2: Economic and daily living challenges

3.7.1. Financial challenges

Financial barriers directly limited access to AEDs. Some medications were not routinely available free of charge at MNRH, requiring participants to purchase them privately, sometimes creating cycles of missed doses and breakthrough seizures. They emphasised that financial barriers to accessing AEDs affected seizure control, exacerbating the effects of seizure unpredictability and medication side effects.

"In general, some medications, they've never given it to me for free, and they are very expensive. So sometimes, you do not have the money to buy the medication." (Female, 45 years).

3.8. Employment and economic adaptation

Seizure-related employment disruption was described across multiple participants. Unpredictable seizures were associated with repeated absenteeism, episodes of public incapacitation, and, in some cases, job loss. One participant described losing a formal-sector job at an airport due to the frequency and visibility of her morning-after symptoms; another described being unable to hold employment and being forced into a dependent role at home. The physical pain following night-time seizures severely impairs the participant's ability to work the following day, limiting their capacity to maintain routine work activities.

"But at first, I had many challenges because somebody who was working then came back and sat at home. Somebody who could provide for myself, now I depend on others." (Male, 43 years).

When I get attacks, I experience fatigue, headache, and I feel the only thing I need is rest till the next day to be fine. Even at work workplace… I can get so tired. (Male, 26 years with good HRQOL).

Some participants responded to these disruptions through economic adaptation, transitioning to employment or small business ownership as a means of achieving financial independence while accommodating the unpredictability of epilepsy.

"When I got some capital from my family members, I started my own business and improved myself. I no longer beg for money, and it keeps me busy. I don't think about other challenges." (Female, 45 years).

3.9. Physical injury and activity limitation

Participants described physical injury and activity limitation as extending harm across multiple functional domains. Accounts included burns from falling near open fires, tongue lacerations from biting during seizures, fall-related fractures, and restricted outdoor mobility arising from fear of seizures in public places. These physical consequences were experienced as limitations to participants' independence and daily functioning.

"I got the seizure, and fell in a burning charcoal stove, so I got burnt up. Also, sometimes I bit my tongue; it's always full of wounds and scars." (Male, 32 years).

The participants verbalised limitations in their mobility and outdoor activities due to fear of having seizure attacks in public; the confined living space severely limits the individual's freedom to move around and access fresh air, which is essential for physical and mental well-being. This confinement restricts routine outdoor activities and physical movement, contributing to difficulties in managing daily routines. The inability to move freely outdoors exacerbates feelings of isolation and reduced opportunities for social interaction and physical exercise.

"Usually, most of my time I am home, and so I try very hard to avoid situations that may bring me a seizure; I try to avoid being near fireplaces, walking long distances, moving alone, even in cars." (Female, 23 years).

3.10. Theme 3: Healthcare and treatment experiences

3.10.1. Access to health care

Access to healthcare services, particularly free AEDs and diagnostic services, was consistently identified as central to participants' QoL. Participants linked treatment initiation with marked reductions in seizure frequency, describing healthcare access as enabling them to regain control over daily life. Access to free medication at MNRH was specifically contrasted with unaffordable medications at private facilities, highlighting the material significance of public provision.

"… life changed completely because now I only need to get transport to come to the hospital, and get free medication. The drugs from private clinics were expensive, but here the medication is available and free." (Male, 62 years).

"I remember those days, I would experience over five episodes of seizures a week, but when I began treatment, seizures started coming after a month, then after two months, then after a year, because I take my drugs regularly." (Male, 43 years).

3.11. Provider support and health education

Healthcare providers were also described as offering health education and counselling that empowered participants to make informed decisions. Participants valued provider explanations about epilepsy, lifestyle advice, and ongoing reassurance that the condition was manageable.

"After treating us, they also educate us on how we should handle ourselves to avoid those attacks, and they also provide counselling to us, because you see, this disease you have to live with it until you die, so they advise us on how to live with it." (Female, 22 years).

3.12. Medication-related effects

Participants described two conceptually distinct medication-related experiences. The first was the pharmacodynamic effects of AEDs, physical weakness, excessive sedation, and dizziness described as direct effects of drug use, particularly when medication was taken on an empty stomach. These effects disrupted daily functioning and were experienced as an ongoing burden.

"I get a lot of sleep, and am always weak, so they told me it's because of these drugs, because they are strong." (Male, 62 years).

"Waking up is quite hard for me, and sometimes I wake up with no energy and the whole body is aching, so I can't work; I can't go to work because I have to stay and rest most of the time." (Female, 33 years).

Non-adherence as a result of missed doses, due to forgetting when away from home or financial inability to purchase medication, was reported to result in seizure recurrence and emotional distress. This subtheme reflects adherence behaviour and its consequences rather than the pharmacological properties of the drugs themselves.

"When I don't take my medication, that's when I get issues, and I don't usually forget to take medicine. Maybe if I had gone to visit far and I forgot to carry my drugs, that's when I get seizures." (Female, 29 years).

"If I take my medication, I usually am fine; I don't find any difficulties, but if not, I surely get disturbed and become uncomfortable." (Male, 32 years).

4. Discussion

This study explored the lived experiences that influence QoL among PWE at MNRH, Uganda. Using inductive thematic analysis of in-depth interviews, we identified three major themes, comprising nine subthemes, that provide a nuanced, mechanism-level account of how epilepsy affects daily life in a low-resource, tertiary-care context: psychosocial experiences, economic and daily living challenges, and healthcare and treatment experiences.

The centrality of social support in shaping QoL was a consistent finding across participants. Peer relationships provided social capital, including financial support and access to employment, echoing findings on the role of social networks in protecting against isolation and reduced confidence [23]. Religious engagement served a distinct psychosocial function: pastoral counselling reinforced medication adherence, congregational acceptance reduced internalised stigma, and practical assistance during public seizures helped participants maintain social participation, complementing evidence from Ethiopia and Ghana that religious communities foster acceptance, reduce stigmatisation, and strengthen personal coping [23,24].

Family involvement, particularly daily companionship, medication reminders, and seizure-time assistance, emerged across accounts as integral to stronger treatment adherence and emotional resilience, aligning with evidence from West Africa and Ethiopia showing that family involvement buffers against the effects of social stigma and isolation [22]. However, family relationships were not uniformly protective. Several participants experienced family-based exclusion, including denial of access to household items, prohibition from food preparation,

and, in one case, physical punishment, while marriage and intimate partnerships were disrupted by disclosure fears, emotional withdrawal, and partners' fear of the condition. These findings are consistent with prior Ugandan evidence showing family neglect and misunderstanding, particularly in early stages of diagnosis [26], and with qualitative evidence from Uganda and Pakistan showing that friends and family members sometimes withdraw from PWE due to fear or misinformation [26,27]. Family relationships can be transformative, but they cannot be assumed to be uniformly supportive. Clinicians should routinely assess the quality of patients' family and social environments rather than treating family presence as synonymous with beneficial support.

Both socially enacted and internalised stigma substantially shaped QoL in this sample. Attributions of epilepsy to witchcraft, bewitchment, and traditional spirits produced community misunderstanding and exclusion [24]. Physical avoidance by community members and family-based restrictions on household participation reflected enacted stigma, while self-isolation, concealment, and perceived devaluation reflected internalised stigma. These patterns are consistent with evidence from Uganda and Ghana. [18,25] and contrast with findings from high-income countries where anti-discrimination legislation and advocacy have reduced stigma-related effects [34].

Coping patterns among participants were varied, and the distinction between adaptive and maladaptive responses carries direct clinical implications. Adaptive strategies were described as improving self-perception and sustaining functional daily living, aligning with Ugandan and Ethiopian studies showing that adaptive coping and lifestyle modification are associated with improved seizure control [11,25]. However, some coping responses shaded into maladaptive withdrawal: several accounts narrated sustained social withdrawal remaining exclusively at home, avoiding all social venues, and disengaging from friendships as the primary response to epilepsy. While targeted trigger avoidance has an adaptive rationale, sustained global withdrawal is a well-established negative determinant of QoL, linked with reduced mental health, physical deconditioning, and progressive social exclusion [18,28]. Clinicians and counsellors should actively distinguish between targeted trigger avoidance and global social withdrawal, and address the latter through structured psychosocial intervention.

Significant psychological burden, including depression, anxiety, anticipatory fear, and low self-efficacy, was reported across participants, consistent with the broader literature showing high rates of depression and anxiety among PWE globally [5]. Cognitive difficulties, particularly memory impairment and reduced academic capacity, interrupted educational participation and were reported independently of medication effects, suggesting that epilepsy-related cognitive burden is a distinct QoL determinant [32], consistent with evidence from Ethiopia showing that PWE often experience cognitive deficits that reduce academic attainment [33]. Emotional difficulties, frustration, self-blame, and reduced motivation were described as being driven primarily by the lived experience of epilepsy itself rather than by the social reactions of others. This distinguishes them from stigma-driven psychological distress and points to different intervention pathways: stigma requires social and educational interventions, whereas intrinsic psychological burden may respond to structured psychosocial support, cognitive-behavioural approaches, or mental health referral.

The economic and functional burden of epilepsy was evident across participants. Financial barriers to AED access undermined treatment continuity and seizure control, consistent with previous findings from Uganda [16]. Employment was substantially affected by unpredictable seizures through absenteeism, episodes of public incapacitation, and job loss, reflecting the broader restriction of social participation and life opportunities that epilepsy imposes, including in the domains of employment, education, and marriage [16]. Some participants responded with economic adaptation, including transitioning to small business ownership, illustrating agency within constrained economic circumstances.

Physical consequences of seizures burn, tongue lacerations, fall injuries, and restricted mobility were described as substantially limiting independence and daily functioning. Fear of public seizures restricted outdoor activity and social participation, contributing to a sedentary lifestyle with measurable negative implications for QoL [28,30]. It remains important to distinguish fear of physical recurrence (a psychological construct, discussed above) from the direct physical and functional consequences of injury described here.

Access to free AEDs and provider counselling at MNRH was described as central to QoL, with participants reporting marked reductions in seizure frequency relative to their pre-treatment baseline and describing healthcare access as enabling them to regain control over daily life. This reinforces the fundamental role of healthcare infrastructure in epilepsy outcomes, consistent with studies from Ethiopia and Uganda [7,11]. It should be noted that the data do not allow claims about the effects of early versus delayed treatment initiation; rather, participants described improvement after beginning consistent AED therapy, the timing of which varied considerably across individuals. The contrast between unaffordable private-sector medications and free MNRH provision highlighted a critical access differential that shapes QoL directly. Accessing MNRH meant that transport cost became the only remaining expense, with medication provision secured free of charge. This finding should not be generalised to settings where medication provision is not free, where transportation costs may compound medication unaffordability.

Anti-epileptic drug side effects, particularly sedation, physical weakness, and morning dizziness, are direct pharmacological consequences of the drugs themselves and were experienced even by participants who adhered consistently [30], sometimes more severe when medication was taken on an empty stomach, a modifiable factor that can be addressed through patient counselling. This is consistent with evidence from Ethiopia and globally showing that AED side effects significantly influence daily functioning and treatment adherence [8,29]. Consequences of non-adherence, by contrast, are primarily seizure recurrence and associated emotional distress, driven by interrupted drug levels rather than by drug pharmacology [31]. This distinction carries direct clinical implications: side-effect burden warrants medication review, dose timing adjustments, or drug switching, whereas adherence failures warrant assessment of barriers and targeted adherence support.

4.1. Study strengths and limitations

This study used a qualitative design enabling in-depth exploration of lived experiences and mechanisms through which epilepsy affects QoL, a dimension that standardised quantitative instruments cannot fully capture.

In-depth interviews relied on participants' verbal accounts and were shaped by the interviewer's probing, the degree of trust established in the interview context, and participants' willingness to disclose sensitive experiences.

The study was conducted at a single tertiary referral facility, limiting generalisability to PWE in rural, community-based, or lower-facility-level settings, where access to free AEDs, trained providers, and psychosocial services may be substantially more limited.

The sample purposively excluded PWE who were critically ill at the time of enrolment, defined as those with acute medical instability, recent seizure-related injury requiring hospitalisation, status epilepticus, or inability to provide informed consent.

5. Conclusions

Psychosocial experiences, encompassing social support, family relationships, and stigma; economic and daily living challenges; and healthcare and treatment experiences jointly shaped the well-being and QoL of PWE in this study. Family, community, and healthcare environments were influential but not uniformly protective, and medication-related effects, socioeconomic pressures, and psychological and

cognitive difficulties influenced QoL requiring clinical attention. Epilepsy management in Uganda requires holistic, context-sensitive, and patient-centred care that addresses both the clinical and social determinants of health, integrates psychosocial support, distinguishes between conceptually distinct QoL determinants, and responds to the specific modifiable barriers identified in this and other Ugandan studies.

Author Contribution

H.A: Conceptualisation, methodology, investigation, data curation, formal analysis, software, visualisation, writing original draft, project administration. J.N: Conceptualisation, methodology, validation, review & editing. D.L: Methodology, supervision, validation, review & editing. M.K: Conceptualisation, resources, supervision, funding acquisition, review & editing. M.S.: Conceptualisation, supervision, funding acquisition, resources, review & editing.

Contribution to knowledge

This study explores how psychosocial experiences, economic and daily living challenges, and healthcare and treatment experiences shape QoL among PWE in Uganda. By distinguishing family support from family-based stigma, medication pharmacodynamic effects from consequences of non-adherence, and seizure-related functional impairment as conceptually distinct mechanisms, the study offers a more precise account of the determinants of QoL than prior Ugandan studies. The findings provide actionable evidence to improve epilepsy care by identifying modifiable determinants and highlighting priority areas for intervention, particularly stigma reduction, integration of psychosocial support, and anti-epileptic drug access.

Ethical publication statement

We confirm that we have read the Journal's position on ethical publication issues and affirm that this report is consistent with those guidelines.

Declaration of generative AI use

Generative artificial intelligence tools were used solely for language editing and grammar checks (specifically Grammarly). No AI tools were used for content generation, data analysis, interpretation, or decision-making. The authors take full responsibility for the content of this manuscript.

CRediT authorship contribution statement

Humphrey Atwijukiire: Writing – review & editing, Writing – original draft, Visualization, Software, Resources, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Juliana Namutundu:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Formal analysis, Conceptualization. **David Lubogo:** Validation, Supervision, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Mark Kaddumukasa:** Writing – original draft, Visualization, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Conceptualization. **Martha Sajatovic:** Writing – original draft, Visualization, Validation, Supervision, Project administration, Methodology, Investigation, Funding acquisition.

Ethical Statement

Ethical review and approval were obtained from the Makerere University School of Public Health Research Ethics Committee (MakSPH-REC), while site clearance was sought from the hospital director, head of research, and the mental health unit in charge at MNRH. The principal investigator and research assistants explained the purpose of the study to all the participants before enrolling on the study, and all those who agreed to take part in the study were required to sign the informed.

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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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