

Lived Experiences and Coping Strategies of Primary Caregivers of Children with Epilepsy at Kisii Teaching and Referral Hospital, Kenya

George Monyenye^{1*}, Lister Onsongo², Nickcy Mbuthia³

¹Department of Medical Surgical Nursing and Pre-Clinical Sciences, Kenyatta University, Kenya

²Community Health & Reproductive Health Nursing Department, School of Nursing, Kenyatta University

³Department of Medical Surgical Nursing and Pre-Clinical Sciences, Kenyatta University, Kenya

Corresponding Author Email: georgemonyenye64@gmail.com

Accepted: 08 September 2026 || Published: 21 October 2026

Abstract

Pediatric epilepsy puts high multidimensional pressure on families in Kenya, with the primary caregivers facing either predictable clinical paths or emerging economic issues and societal stigmas. To analyze the lived experiences of primary caregivers of children with epilepsy at the Pediatric Outpatient Clinic at Kisii Teaching and Referral Hospital in Kenya, we conducted a descriptive phenomenological study. Data were collected through semi-structured interviews and analyzed using the seven steps of Colaizzi's descriptive phenomenological method. The analysis revealed the following themes: continuous psychological and physical burden of caregiving, family stress, marital disruptions and social harm; overwhelming financial pressure and loss of income; extensive confidence in biomedicine and aversion to traditional herbs; and empowerment through health literacy and public health advocacy. While traditional beliefs continue to exist in the community, caregivers relied strongly on AEDs and used prayer as another coping mechanism. The clinical education also helped caregivers establish strict household routines and provide immediate assistance. Overall, pediatric epilepsy puts tremendous multidimensional burdens on caregivers that require mental health screening and subsidized distribution of medications.

Keywords: *Pediatric epilepsy, primary caregivers, lived experiences, coping strategies, qualitative phenomenology, Kisii Teaching and Referral Hospital*

How to Cite: Monyenye, G., Onsongo, L., & Mbuthia, N. (2026). Lived Experiences and Coping Strategies of Primary Caregivers of Children with Epilepsy at Kisii Teaching and Referral Hospital, Kenya. *Journal of Medicine, Nursing and Public Health*, 6(8), 71-80.

1. Introduction

Epilepsy is one of the most serious neurological diseases in the world, affecting about 50 million people, including many children, making this population highly vulnerable (World Health Organization, 2019). Due to numerous issues within maternal interventions, increased incidence of obstetric injuries, chronic central nervous system infections, and supply chain challenges, low- and middle-income countries have healthcare challenges exceeding those of high-income countries (Kariuki et al., 2021). In Kenya, access to specialized child neurology services remains limited, creating significant logistical, infrastructural, and financial barriers for families in rural and peri-urban areas (Samia et al., 2019).

At the KTRH Medical Outpatient Clinic, children suffering from different forms of epilepsy receive sufficient neurological care and available anti-epileptic medication. However, due to recurrent stock-outs of critical anti-epileptic drugs by public hospitals across the country, it continues to be challenging for caregivers to obtain the required medication within their localities (Samia et al., 2019). In the case of children, the caregiver plays a key role in ensuring treatment compliance because children do not possess self-care responsibility and thus the treatment processes rely heavily on the caretaker (Yu et al., 2022). In spite of the fact that caregivers are the key component in the treatment success of children, the healthcare system focuses mostly on the clinical aspect of the problem, regardless of the fact that caregivers suffer physically, financially, psychologically, and socially (Chan et al., 2022; Pokharel et al., 2020).

This research study incorporates the Roy Adaptation Model alongside the Theory of Caregiver Stress to assess how environmental factors (such as seizure unpredictability, social stigma, and economic pressures) affect the caregiver context, internal adaptability, and behavior (Chin et al., 2023). This study aims to explore patients' experiences, their understanding of the disease, and their coping mechanisms to inform family-centered clinical nursing practice and public health planning.

2. Methodology

The qualitative phenomenological study design was used to capture primary caregivers' lived experiences and meanings (Okiah et al., 2023). The site of the study is Pediatric Outpatient Clinic of Kisii Teaching and Referral Hospital, which is a Level 5 referral hospital located in Kisii County, Kenya, serving over six million children from surrounding counties. The target population included parents and caregivers of patients diagnosed with pediatric epilepsy and receiving follow-up care at KTRH. The study used purposive sampling to recruit representatives across age, marital status, education, and economic background. Selection criteria included adults aged 18 and older who lived with and cared for their sick child. Caregivers with severe cognitive impairments and serious mental disorders were excluded from the study. After the 14th interview, the study reached saturation and conducted three additional interviews (validation interviews).

Data were collected through one-on-one interviews using a semi-structured interview guide, which was translated into Kiswahili and back into English. The translated guide was tested with five caregivers in sub-county facilities outside the study area to adapt it and ensure caregivers understood it. The audio-recorded interviews were supported by written notes capturing non-verbal cues and the surroundings. Ethical Approval for the study was received

from the Kenyatta University Ethics Review Committee (KU-ERC) [Ref: PKU/3056/I2080], and permission to conduct the research was provided by the National Commission for Science, Technology, and Innovation (NACOSTI). Additionally, the KTRH Research Ethics Committee granted clearance to conduct the study. Written consent before the study was obtained from each participant. To ensure confidentiality, participants' names were not used; instead, codes (i.e., P1 to P17) were assigned to conceal their identities. To validate this study, Lincoln and Guba's trustworthiness framework was used to assess credibility, dependability, confirmability, and transferability through audits, member checking, and systematic coding.

3. Results and Discussion

3.1 Socio-Demographic Profile of Caregivers

Most primary caregivers were female (94.1%), biological parents (82.4%), and of Kisii ethnicity (82.4%). High school (47.1%) and tertiary education (47.1%) were the predominant educational levels. Peasant farming (35.3%) and domestic caregiving (23.5%) were the primary occupations. Most children cared for were female (76.5%), and 82.4% had complied with treatment and experienced clinical improvement. Seizure duration varied, with 41.2% having managed epilepsy for 3–4 years and 35.3% for 5–7 years.

3.2 Theme 1: The Continuous Burden of Caregiving

Caregivers described an overwhelming, multi-faceted burden marked by psychological trauma and continuous physical exhaustion:

Subtheme 1.1 Shock and Fear of Seizures: Initial and recurrent seizure episodes caused acute terror and helplessness.

"When the fits started, I froze completely. Watching his eyes roll back while foam came from his mouth felt like watching my own child slip away into death right in front of me." (Participant 3)

"Nikimfikiria saa zingine ninakuanga na wasiwasi mingi mno." [When I think about him sometimes, I usually worry too much.] (Participant 7)

"Watching your child convulse unexpectedly while at the clinic was emotionally painful and shocking... Hearing this diagnosis broke my heart." (Participant 17)

Subtheme 1.2: Nocturnal Hypervigilance: Caregivers reported severe sleep deprivation resulting from constant monitoring throughout the night to prevent injury or asphyxiation during nocturnal fits.

"Kwa kutolala vizuri nahisi kuumwa na kichwa sana." [Because of not sleeping well, I feel a very bad headache.] (Participant 2)

"Every tiny movement or rustle of the bedsheets wakes me up instantly in a panic. I spend half the night sitting up, staring into the dark, waiting to see if a seizure is starting." (Participant 6)

"You can never close both eyes when you are the mother of a child like this. Sleep is a luxury I had to give up because if I sleep too deeply, a fit might kill him while I am unconscious." (Participant 14)

Subtheme 1.3: Somatic Fatigue and Chronic Distress: Persistent hypervigilance manifested physically through tension headaches, elevated blood pressure, and chronic exhaustion.

"The constant stress has given me permanent high blood pressure and severe tension headaches that refuse to go away, no matter what painkillers I swallow." (Participant 1)

"Because of the stress of monitoring his breathing every single minute since his early days in the newborn unit, my body is permanently exhausted and my back constantly aches." (Participant 15)

"Akiwa shule hua naogopa anaweza kupoteza fahamu." [When he is at school, I am always afraid that he might lose consciousness.] (Participant 12)

3.3 Theme 2: Family Strain, Disrupted Relationships, and Social Isolation

The impact of pediatric epilepsy extended beyond the individual caregiver to disrupt the domestic ecosystem:

Subtheme 2.1: Marital Strain and Abandonment: Several female caregivers reported spousal alienation or total abandonment, often driven by cultural myths that pathologized epilepsy as an inherited ancestral curse.

"The moment the doctor confirmed it was epilepsy; my husband packed his bags and abandoned us. He claimed that this disease does not exist in his bloodline and that I brought a cursed child into his house." (Participant 9)

"The financial fights over buying these expensive monthly drugs have broken our marriage. We no longer speak as husband and wife; we only argue about medical bills." (Participant 10)

"My husband and I became closer in some ways... However, the stress of caregiving also affected our relationship at times. Worrying about our son's condition... sometimes created tension." (Participant 17)

Subtheme 2.2: Sibling Disparity and Guilt: Caregivers expressed deep maternal guilt over diverting attention, financial resources, and time away from healthy siblings.

"My other children openly ask me why I only love their brother. It breaks my heart because they don't understand that if I take my eyes off him for an hour, he could fall into a fire during a fit." (Participant 5)

"I carry so much guilt as a mother. I am always away at the KTRH clinic with my sick son, meaning my daughters have to cook and raise themselves without my presence." (Participant 12)

"It's a lot to take care of my other child and do the domestic chores at the same time as well... sometimes the prospect leaves me emotionally and physically exhausted." (Participant 16)

Subtheme 2.3: Defensive Social Disengagement: To avoid local gossip, discrimination, and community stigma, caregivers deliberately withdrew socially, avoiding places of worship and community markets.

"Wakati mwingine ninakosa kwenda kuhabundu kanisani kwa sababu ya unyanyapaa na kusengenya na Jamii." [Sometimes I miss going to worship in church because of the humiliation and gossip from the community.] (Participant 8)

"I am very secretive now... I choose who I talk to, and I don't open up to everyone about his sickness because some neighbors will look at you with a bad eye." (Participant 14)

"Naisi kutengwa na majirani kwa sababu mtoto wangu ni mgonjwa. Jirani hukataza watoto wake kucheza na mwanangu!" [I feel isolated by neighbors because my child is sick. The neighbor forbids her children from playing with my child!] (Participant 1)

3.4 Theme 3: Financial Strain and Work Disruptions

Managing pediatric epilepsy imposed severe economic hardships on low-income households:

Subtheme 3.1: Out-of-Pocket Expenditure: High transportation costs to KTRH and out-of-pocket purchases of AEDs from private pharmacies during public stockouts severely strained family microeconomies.

"As an old grandmother relying on casual farm work, every shilling I make goes entirely into paying for transport to KTRH and buying these small white tablets." (Participant 4)

"There are months when I am forced to choose between buying food for the house or buying the anti-seizure syrup. If I don't buy the syrup, the fits return immediately." (Participant 11)

"Wakati mwingine huwa ninakosa pesa za dawa." [Sometimes I lack money for the medicine.] (Participant 3)

Subtheme 3.2: Diversion of Household Resources: Families were forced to deprioritize basic needs, including nutrition and school fees, to ensure uninterrupted access to anti-seizure medications.

"We had to cut down on food, change what we eat, and stop buying clothes just to make sure his monthly clinic money and prescription card are always fully paid." (Participant 1)

"Every little money my husband brings home is divided immediately. The drug shop gets their share first before we even look at buying maize flour or paying school fees." (Participant 5)

"We have completely stopped any home improvements or personal spending. If a medical emergency happens tomorrow at KTRH, that is where all our life savings must go." (Participant 10)

Subtheme 3.3: Vocational Loss: The requirement for continuous home supervision led caregivers to close small businesses, reduce working hours, or leave employment entirely.

"I used to run a small vegetable stall at the market, but I had to close it down. You cannot run a business when you are constantly sprinting back home because your child has collapsed." (Participant 3)

"No employer will keep you when you have to pack up and leave in the middle of a shift because your neighbor called to say your child is convulsing on the floor." (Participant 9)

"My small business dissolved because my daily routine is completely chained to this room. I cannot travel to stock goods, nor can I leave him alone for more than ten minutes." (Participant 12)

3.5 Theme 4: Trusting Hospital Treatment While Keeping Faith in Prayer

Caregivers demonstrated complex therapeutic decision-making strategies:

Subtheme 4.1: Reliance on Biomedical Interventions: Caregivers expressed strong confidence in hospital-dispensed pharmaceuticals after witnessing direct clinical reductions in seizure frequency.

"When she takes the clinic tablets exactly as prescribed, the fits drop completely. That proved to me that this is an illness in the body, not a curse from dead ancestors." (Participant 2)

"My neighbors told me my child was possessed by demons, but when I brought her here, and she started these daily medications, the fits completely stopped." (Participant 13)

"Nimejaribu miti shamba lakini dawa za hospitali ni mzuri." [I have tried traditional herbs, but hospital medicines are the good ones.] (Participant 6)

Subtheme 4.2: Rejection of Traditional Herbs: Contrary to traditional assumptions, caregivers explicitly rejected local herbal remedies and folk healers because they feared toxicity and a lack of standardization.

"The village elders brought some bitter herbal roots for the child to drink, but I threw them into the bush. Mixing hospital medicine with local leaves can easily poison a child." (Participant 4)

"People told me to give him local herbs to wash out the evil spirits, but I refused. I will not risk damaging my child's life with leaves when the clinic medicine is working safely." (Participant 8)

"I completely avoid those traditional healers. They give you unmeasured mixtures that can end up destroying the child's liver while the real illness continues to get worse." (Participant 13)

Subtheme 4.3: Complementary Spiritual Coping: Caregivers integrated Christian prayer alongside hospital regimens without competition, using faith for emotional resilience while maintaining strict AED adherence.

"I pray to God constantly for my child's life, but I know very well that prayer alone does not replace the doctor's prescription. God gave the doctors the knowledge to make these drugs work." (Participant 6)

"The church is where I find the emotional comfort and strength to keep going when I am weary, but when it comes to stopping the physical fits, I rely on the hospital clinic." (Participant 11)

"But I don't consider spiritual practices as a treatment for epilepsy. When it comes to seizures, for me, it's the antiepileptic medicine that manages them, not prayer... medical therapy is still the bedrock." (Participant 17)

3.6 Theme 5: Learning to Manage Epilepsy and Educating Others

Structured interaction with healthcare providers facilitated caregiver empowerment:

Subtheme 5.1: Clinical Literacy: Nursing staff provided information that helped caregivers understand the neurological basis of seizures, alleviating superstitious fears.

"The nurses here took their time to teach me what happens inside the brain during an attack. That clinical knowledge changed me from a terrified parent into a capable nurse at home." (Participant 7)

"Learning that her seizures were linked to her difficult birth and early oxygen struggles helped me accept the situation completely. I stopped asking why and started focused care." (Participant 15)

"Education from doctors and nurses helped me understand the condition better, which reduced fear and increased my confidence in caring for him." (Participant 17)

Subtheme 5.2: Emergency Competence: Caregivers acquired practical skills to manage acute fits, such as timing seizure duration, clearing surrounding hazards, and positioning the child on their side to maintain airway patency.

"I have trained myself to stay perfectly calm during a fit. I look at the clock to time the episode, turn him onto his side so his airway stays clear, and clear the floor." (Participant 6)

"I live strictly by the clock now. Morning and evening, the phone alarm rings and the medicine is given before any other activity in the household takes place." (Participant 11)

"I established a rigid routine in our house. Even when I am working at the salon, my mind is working on a precise schedule of tracking his doses and checking his behavior." (Participant 14)

Subtheme 5.3: Grassroots Advocacy: Empowered caregivers expressed a strong desire to lead community education initiatives to eradicate local stigma and foster public understanding of epilepsy as a manageable medical condition.

"Schools and local villages need to be openly taught that epilepsy is just a normal medical condition. If teachers understood this, our children wouldn't be chased out of classrooms." (Participant 1)

"The Ministry of Health needs to bring mass awareness to our rural communities. Parents are hiding children in houses because they are afraid of the superstitious blame from neighbors." (Participant 5)

"We need continuous public seminars in our villages to break this ignorance. If people knew epilepsy is just an ordinary brain disease, the heavy stigma on families would disappear." (Participant 8)

4. Conclusion

Primary caregivers of children with epilepsy at Kisii Teaching and Referral Hospital face profound physical, psychological, social, and financial challenges. Caregivers show strong trust in biomedical therapies over traditional folk remedies, using prayer to support emotional resilience while following modern pharmaceutical regimens. Targeted clinical health education from healthcare providers helps caregivers move from initial helplessness to practical competence, enabling them to establish safe home routines and advocate for community awareness.

5. Recommendations

For KTRH Management

- Establish routine psychological and burnout screening protocols for caregivers during pediatric outpatient clinic visits.
- Provide private counseling spaces within the pediatric outpatient clinic to address caregiver mental distress.

For Nurse Practitioners

- Develop bilingual educational literature on seizure management, first aid, and medication adherence in Kiswahili and Ekegusii.
- Conduct practical, nurse-led emergency first-aid demonstrations during outpatient clinic days.

For the Kisii County Department of Health

- Subsidize essential pediatric antiepileptic medications to eliminate out-of-pocket expenses for low-income families.
- Strengthen the pharmaceutical supply chain to prevent stockouts of critical anti-seizure tablets and syrups at public hospital facilities.
- Expand county social health insurance frameworks to cover chronic pediatric neurological diagnostics and long-term care.

For Public and Community Health Officers

- Partner with local administrative leaders to execute anti-stigma campaigns that dismantle cultural myths regarding epilepsy.
- Train community health promoters to identify hidden or isolated children living with epilepsy and connect them to clinical care at KTRH.

References

Alharthi, A. S., Alzahrani, S. A., Alharbi, A. A., Al Thobaiti, L. Y., Alghamdi, Y. S., AlShumrani, K. M., Alghamdi, M. A., Alghamdi, N. K., Alzahrani, S. S., Alharbi, S. A., Alghamdi, A. A., & Alghamdi, K. S. (2023). Parents' knowledge, awareness, and attitude toward children with epilepsy in the Al Baha Region, Saudi Arabia: A cross-sectional study. *Cureus*, 15(11), Article e48057. <https://doi.org/10.7759/cureus.48057>

- Chan, S. L., Matsah, N. S. B., Yusuf, A. A. B., Khaidir, A. S. B. M., Hamdan, N. H. B., & Kamizi, Z. N. B. (2022). A review on family caregiving challenges in Malaysia. *ProGCouns: Journal of Professionals in Guidance and Counselling*, 3(1), 1–12. <https://doi.org/10.24036/00534pro2022>
- Chin, W.C., Chang, H. L., & Chao, K.-Y. (2023). Exploring coping strategies of parents of children with autism spectrum disorder in Taiwan: A qualitative study. *Journal of Nursing Research*, 31(3), Article e278. <https://doi.org/10.1097/jnr.0000000000000556>
- ELsayed, E., Hossein, Y., Aly, S., & Abd Elwahab, A. (2022). Parents' awareness regarding their epileptic children in Minia University Maternal and Children Hospital. *Minia Scientific Nursing Journal*, 12(1), 38–46. <https://doi.org/10.21608/msnj.2022.257211>
- Hussain, S. A., Ortendahl, J. D., Bentley, T. G. K., Harmon, A. L., Gupta, S., Begley, C. E., Khilfeh, I., & Knoth, R. L. (2020). The economic burden of caregiving in epilepsy: An estimate based on a survey of US caregivers. *Epilepsia*, 61(2), 319–329. <https://doi.org/10.1111/epi.16424>
- Kariuki, S. M., Ngugi, A. K., Kombe, M. Z., Kazungu, M., Chengo, E., Odhiambo, R., Nyaguara, A., Neville, B. G., & Newton, C. R. (2021). Prevalence and mortality of epilepsies with convulsive and non-convulsive seizures in Kilifi, Kenya. *Seizure*, 89, 51–55. <https://doi.org/10.1016/j.seizure.2021.04.018>
- Okiah, L., Olowo, S., Iramiot, S. J., Nekaka, R., & Ssenyonga, L. V. N. (2023). Lived experiences of caregivers of persons with epilepsy attending an epilepsy clinic at a tertiary hospital, eastern Uganda: A phenomenological approach. *PLOS ONE*, 18(7), Article e0274373. <https://doi.org/10.1371/journal.pone.0274373>
- Pokharel, R., Poudel, P., & Lama, S. (2021). Quality of life among caregivers of children with epilepsy: A cross-sectional study at Eastern Nepal. *Epilepsia Open*, 6(1), 120–126. <https://doi.org/10.1002/epi4.12453>
- Pokharel, R., Poudel, P., Lama, S., Thapa, K., Sigdel, R., & Shrestha, E. (2020). Burden and its predictors among caregivers of patients with epilepsy. *Journal of Epilepsy Research*, 10(1), 24–30. <https://doi.org/10.14581/jer.20004>
- Sabo, U. A., Buttner, P., & Scher, G. (2020). Impact of caregiver burden on health-related quality of life and family functioning of carers of children with epilepsy at the Charlotte Maxeke Johannesburg Academic Hospital, South Africa. *South African Journal of Child Health*, 14(2), 66–72. <https://doi.org/10.7196/SAJCH.2020.v14i2.1641>
- Samia, P., Hassell, J., Hudson, J.-A., Kanana, M., Kariuki, S. M., Newton, C. R., & Wilmshurst, J. M. (2019). Epilepsy diagnosis and management of children in Kenya: Review of current literature. *Research and Reports in Tropical Medicine*, 10, 91–102. <https://doi.org/10.2147/RRTM.S193809>
- Shahin, M. A. H., & Hussien, R. M. (2021). Knowledge, attitude, practice, and self-efficacy of caregivers of children with epilepsy: Impact of a structured educational intervention program. *Epilepsy & Behavior*, 125, Article 108381. <https://doi.org/10.1016/j.yebeh.2021.108381>

- World Health Organization. (2019). *Epilepsy: A public health imperative*. World Health Organization. <https://www.who.int/publications/i/item/9789241515795>
- Yang, C., Yao, T., Huang, Y., Zhao, L., & Zhang, L. (2021). Prevalence and influencing factors of depression of caregivers in children with epilepsy in southwestern China: A cross-sectional study. *Medicine*, 100(10), Article e23571. <https://doi.org/10.1097/MD.00000000000023571>
- Yu, Z., Shao, Q., Hou, K., Wang, Y., & Sun, X. (2022). The experiences of caregivers of children with epilepsy: A meta-synthesis of qualitative research studies. *Frontiers in Psychiatry*, 13, Article 987892. <https://doi.org/10.3389/fpsy.2022.987892>