ABSTRACT

Background:

Epilepsy remains a significant public health concern in Ghana, with sociocultural beliefs, healthcare access, and support systems playing critical roles in shaping the experiences of people living with the condition. Misconceptions about epilepsy often lead to stigma, delayed treatment, and reliance on alternative care pathways. Understanding these contextual experiences is crucial for informing more responsive and inclusive health interventions.

Methods:

This qualitative study employed a combination of phenomenological and narrative designs. The phenomenological approach guided oral histories (OH) with 50 persons living with epilepsy (PLWE), while the narrative approach informed in-depth interviews (IDIs) with 10 caregivers, 10 healthcare providers, 6 spiritualists, 5 religious leaders (Christians and Muslims), and 10 traditional healers. Additionally, 12 focus group discussions (FGDs) were conducted with community members. Participants were selected through snowball sampling (for PLWE and caregivers) and maximum variation purposive sampling (for the other groups). Data were analysed thematically using NVivo 20 software.

The study was guided by a conceptual framework grounded in Social Support Theory, which emphasises emotional, informational, and instrumental support as critical in managing chronic illnesses. The framework integrated key components, including demographic characteristics, lived experiences, sociocultural perceptions of epilepsy, barriers to care, and available forms of support. It mapped how these factors interact to influence the epilepsy care pathways taken by PLWE and their caregivers, whether through biomedical, traditional, faith-based, or home-based approaches.

Results:

The study found that epilepsy in the Shai-Osudoku and Ningo-Prampram districts is deeply embedded in sociocultural interpretations, often linked to spiritual or supernatural causes, which intensifies stigma, discrimination, and silence. PLWE and their caregivers navigate significant emotional, social, and economic burdens, with limited formal healthcare support and a heavy reliance on traditional, spiritual, and informal systems. Fragmentation across care pathways, poor service coordination, and entrenched stigma were evident, despite the presence of some community-driven facilitators. Challenges such as inadequate health infrastructure, misinformation, and systemic neglect limit access to continuous, holistic care. These dynamics have resulted in considerable unmet emotional and psychosocial needs, with urgent calls for culturally relevant advocacy, service reform, and integrated support structures.

Conclusion:

The study underscores the need for culturally sensitive, community-based interventions and integrated support systems to improve the quality of life for PLWE. It offers critical insights for policymakers, healthcare professionals, and community stakeholders to guide the development of inclusive epilepsy care strategies in Ghana. Anchored in its general objective to explore the lived experiences along the pathways to care and support systems for people living with epilepsy in the Shai-Osudoku and Ningo-Prampram districts, this study highlights the complex interplay of sociocultural, health system, and individual-level factors that shape epilepsy care and support in these communities.