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Research Article

Caring Through Challenges: A Narrative Exploration of Epilepsy Caregiving in Rural India

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Abstract

Epilepsy is disproportionately prevalent in low- and middle-income countries such as India. Rural areas in India face unique challenges, including limited access to healthcare, stigma, and cultural misconceptions. This narrative study explores the lived experiences of a 17-year-old female with epilepsy (Y) and her primary caregiver, her brother, in rural India. Using in-depth interviews and thematic analysis, the study uncovers five primary themes: (1) Navigating an Epileptic Episode, (2) The Invisible Struggle of Cognitive Decline, (3) Misconceptions and Knowledge Gaps, (4) Fear-Driven Exclusion by Society, and (5) The Balancing Act of Emotional Resilience and Practical Stress in Epilepsy Caregiving.

The findings reveal that epilepsy's impact extends beyond medical symptoms, significantly influencing cognitive functioning, emotional well-being, and social dynamics. The study highlights the pervasive stigma and discrimination faced by individuals with epilepsy and their families, fueled by misinformation and cultural beliefs. Caregivers, while resilient, endure emotional and practical burdens, balancing caregiving duties with personal aspirations.

The research underscores the urgent need for culturally sensitive education campaigns to dispel myths, strengthen community support, and enhance awareness about epilepsy as a medical condition. Interventions should include accessible healthcare services, counseling for caregivers, and advocacy for disability rights to alleviate stigma and improve quality of life for persons with epilepsy and their families. This study calls for collaborative efforts from healthcare professionals, educators, and policymakers to address epilepsy as a public health priority and foster an inclusive, informed society.

INTRODUCTION

Low- and middle-income countries experience a higher incidence of epilepsy [1], due to factors such as a greater number of road traffic injuries, birth-related complications, underdeveloped medical infrastructure, limited access to healthcare, increased risk of endemic diseases, and insufficient awareness about prevention strategies. India, with over 12 million individuals living with epilepsy (PwE) [2], contributes to more than half of the total Disability Adjusted Life Years (DALYs) attributed to epilepsy in Southeast Asia. The burden of medication, possibility of surgery and required costs contributes to the burden on families, healthcare system, as well as the government.

Epilepsy imposes significant psychological and social stress on both the patient and caregiver, and this burden may often have a greater effect on Quality of Life (QoL) than the seizures themselves [3]. The condition requires significant lifestyle changes for both the patient and caregivers, including limiting certain activities to prevent injuries during seizures. The hidden nature of epilepsy in our community exacerbates discrimination against symptoms that are poorly understood or unfamiliar to society, often leading to misconceptions such as labeling the individuals as "psychotic," "demonic," or "possessed", especially in the rural areas where awareness is even lower.

The Epilepsy-Stigma-Disability (E-S-D) Model [2], illustrates the vicious cycle between epilepsy, stigma, and disability, showing how discrimination is particularly evident in areas like social interactions, marriage, employment, driving, and disability rights, making the pursuit of equal rights challenging [3]. The

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neuropsychological, ecological, social, physical, and emotional effects of this cycle significantly diminish Quality of Life (QoL).

The current narrative explorative study provides an in-depth narrative analysis of a 17 year old female's experiences with epilepsy and her brother's caregiving journey, situated within the context of a rural Indian setting.

METHOD

A patient was referred to Mind Health services for Neuropsychological Psychodiagnostics by a Neurologist with a Reason for Referral as… Neuropsychological Psychodiagnostics followed the following 3 steps: Clinical History, Psychometric testing, and Clinical Observation. An in-depth interview was conducted with the patient and her primary caregiver, following the establishment of rapport. A detailed clinical history was obtained, and neuropsychological psychodiagnostics were administered; however, the results are not included in this paper. The interview was transcribed verbatim using Microsoft Word, and the content was subsequently analyzed. A total of 79 codes were generated during the content analysis process, utilizing Microsoft Excel for organization. The process of coding was structured across three sheets: Sheet 1 contained verbatim transcripts arranged dialogue-wise, with corresponding codes generated for each dialogue; Sheet 2 listed each code individually, grouping similar meaningful codes under a single color to form categories. These categories were defined as "Themes," and appropriate titles were assigned to them; and Sheet 3 presented the codes organized theme-wise.

The Case

Y is a 17-year-old female diagnosed with epilepsy. The onset of her condition dates back to 2017 when she was 10 years old. Her first seizure occurred at school, lasting approximately ten minutes and accompanied by convulsions. Over the next six months, seizures persisted until she was eventually taken to a local doctor in her village. According to her brother, who serves as her primary caregiver, the prescribed medication helped alleviate the "major seizures," though "smaller" seizures subsequently emerged. At present, Y experiences 1–2 seizures per day, occurring both during sleep and while awake, with episodes lasting between 30 seconds and 2 minutes.

Emerging Themes

Five primary themes emerged [Table 1]: (1) Navigating an Epileptic Episode, (2) The Invisible Struggle of Cognitive Decline, (3) Misconceptions and Knowledge Gaps, (4) Fear-Driven Exclusion by Society, and (5) The Balancing Act of Emotional Resilience and Practical Stress in Epilepsy Caregiving.

Navigating an Epileptic Episode

According to Y's brother, during seizures, Y screams loudly, bites, and holds onto those nearby with considerable force. Y described her experience, stating, *"In that moment, I am not in anyone's control. No matter who is around, I bite them unknowingly. I get a very bad headache".* She also reported that her hands and brain begin to feel numb before a seizure occurs. Her brother shared that her current condition is concerning, as she often experiences anxiety and requires constant supervision, with someone always needing to be present to care for her.

Y's sister, referred to here as X, also experiences seizures, though hers are currently under control, with the last seizure occurring six months ago. X's seizures differed in presentation; she would fall backward, lose consciousness, and lose bladder and bowel control, often lying motionless as if unconscious. Despite these episodes, X maintained a more outgoing and carefree temperament, frequently engaging with others and expressing herself openly. In contrast, Y is described as reserved and fearful, often keeping her thoughts and emotions to herself. The family was advised by the doctor to maintain a stress-free and light environment for Y to help manage her condition. Research suggests management of psychiatric aspects of epilepsy such as depression can aid in better seizure control, indicating a link between mood disturbances and seizure occurrence [2].

The Invisible Struggle of Cognitive Decline

A decline in comprehension, executive functioning, response time, and memory was reported by Y's caregiver. He noted a reduction in her ability to comprehend tasks, exemplified by her difficulty in boiling milk when instructed, indicating impaired executive functioning. Y herself described fluctuations in attention and cognitive processing, stating, *"Sometimes my mind works too fast, and sometimes it is too low."* When asked questions, she experiences significant cognitive strain and often requires 10–15 minutes to formulate a response. Regarding memory, her brother observed a noticeable decline. He shared that while she previously remembered Apps she had used on his phone even after six months, but her ability to retain such information has significantly deteriorated over time.

Misconceptions and Knowledge Gaps

In rural areas of India, home births remain common.

Table 1: Emerging themes and respective codes.

Navigating an Epileptic Episode	***The Invisible Struggle of Cognitive Decline***	***Misconceptions and Knowledge Gaps***	***Fear Driven Exclusion by the Society***	***The Balancing Act of Emotional Resilience and Practical Stress in Epilepsy Caregiving***
Screaming loudly	Declines in Executive functioning, problem solving	Birth at home	Discrimination in the classroom	Abusing
Holding tightly	Impacted comprehension	Precautions for caregivers	Social stress triggered seizure onset for sister	Aggressive
Biting	Varying levels of attention and processing	Carelessness during infancy or developing years	Unconsciousness	Deteriorating condition
Headache	Cognitive load/strain	Lack of childrearing knowledge	Falling	Unresponsive to medicines
Out of control	Delayed response time	Lack of awareness about epilepsy	Isolated in class	Dependence
Bite unknowingly	Declined memory	Misconception that epilepsy is transmittable	Drooling	Caregiver burden
Hands go numb	Declining memory		Classmates getting scared	Caregiver's own responsibilities and education.
Brain goes numb			Stressed younger sister	Help required with house chores/burden of home chores.
Unconsciousness			Screaming began post isolation in class	Burden of educating other caregivers how to help
Anxiety			Screaming during seizures	Inability to contribute at home
Fall backwards			Misunderstanding in social setting,	Increased and uneven burden of responsibilities
Loss of bladder and bowel control			Possessed by evil spirit	Self-induced or familial Pressure and Expectation to get educated and find success
Difference in temperament			Discrimination in the neighborhood	Speaking politely irrespective of what patient is saying
Doctor recommended a stress free environment.			Feeling of being perceived as stupid for taking care of patient	Abusing
			Misinterpretation and polarized effect in society, Solution to "keep her at home" by neighbors	Getting upset
			Patient being perceived as evil spirit	Holding old grudges
			Prejudice	Short temper
			Overt discrimination	Mood disturbances
			Isolation by society,	Disturbed, Stress on family
			Shouting	Abusing in response to polite requests
			Isolated by relatives due to fear of transmission	Fear of impact on family
			Isolation by close relatives due to unintentional social commotion	Possible worry, stress or guilt
			Resistance in society against attempts to spread awareness	Burden on patient due to expenditure on treatment
			Defiance from society	Financial stress on family
			Unrealistic expectations from "Treatment"	
			Helplessness	

Y was delivered at home through a normal childbirth, although her birth weight remains unknown. When Y was three years old, her mother left her with a close relative while she attended to some errands outside. Upon returning, her mother found Y sleeping outside in the sun for over an hour, and she was found to be very hot and red. At 8 months of age, very hot boiling water was dropped on her body. This incident could suggest Hot Water Epilepsy (HWE), a form of reflex epilepsy triggered by exposure to hot water. While three-quarters of HWE cases are benign with a good prognosis, the remaining cases may progress to chronic epilepsy [2]. This highlights the urgent need for educational and awareness programs focused on prevention in epilepsy care.

The caregiver also mentioned a neighbor with epilepsy, who speculated that Y may have contracted the condition after visiting their home and sharing food. This led to the misconception within the neighborhood that epilepsy is contagious, resulting in the isolation of Y and her family. This reflects the persistent misconceptions about epilepsy and the limited dissemination of scientific knowledge in rural communities.

Fear Driven Exclusion by the Society

When asked about Y's developmental milestones, the informant reported that Y's early development was normal, and she was a top performer in school until the 5th grade. However, her academic performance began to decline shortly after the onset of her seizures. Initially, the family did not recognize the cause of her academic struggles. Y's sister, X, was also a high achiever, but it was later discovered that both Y and X were seated separately from the rest of the class due to Y's seizures. These separations deeply affected X, and soon after, she began experiencing seizures as well. During Y's seizures, she would lose consciousness, fall, and drool for about ten minutes before returning to normal. This frightened her classmates, which led the teacher to place them apart from the others. This further highlights the importance of awareness programs in the country. Six months later, Y started screaming during her seizures.

The relationship between Y and her parents was also discussed. Initially, her parents believed that something was wrong with her and suspected she was possessed by an evil spirit. This belief was influenced by the negative attitudes of the village community, who did not treat the family well. The caregiver shared an incident highlighting the urgent need for intervention in rural areas: *"One time, we were walking, and Y had a seizure. She began screaming, which caused an elderly man nearby to get frightened and fall. He was injured. A crowd gathered and started hitting us, thinking she had caused it on purpose. When I explained her condition, they told me to keep her at home."* The brother also shared that the villagers viewed his family as ignorant for seeking medical treatment for Y, as they believed she was under the influence of an evil spirit. Neighbors rarely visit their home, and when they do, they avoid drinking water from their glasses, further emphasizing the social isolation the family faces.

The caregiver expressed his desire to start a support group and raise awareness about epilepsy. However, this initiative was met with resistance from the villagers, who responded by saying, "*First, treat your sister; once she is cured, you can spread awareness about treatment.*" This response reflects unrealistic and misguided expectations regarding the treatment and management of epilepsy.

The Balancing Act of Emotional Resilience and Practical Stress in Epilepsy Caregiving

The caregiver reported that Y experiences significant anxiety and requires constant accompaniment by a family member. This dependency has impacted the caregiver's ability to focus on his studies, a source of personal and familial pressure as the only male child in the family. He expressed a strong sense of obligation, both self-imposed and indirectly influenced by family expectations, to succeed academically and secure the family's future. Reflecting on these challenges, he stated, *"I have a lot of pressure as I need to study and become successful, but I'm not able to give it my all due to all this."*

When asked about the distribution of caregiving responsibilities within the family, the caregiver explained that his mother, although uneducated, is cooperative but requires guidance to care for Y effectively. Their father goes out for work and is able to contribute less to caregiving. He also mentioned that X's seizures are now controlled, enabling her to assist with household chores, which has eased some of the caregiver's burden. Y shared, *"I used to do all the chores at home very well before this happened. Now I'm not able to,"* and her brother emphasized her past proficiency in managing domestic tasks.

Regarding mood disturbances, the caregiver noted that Y becomes irritable and abusive, often overreacting to minor or even positive remarks. The family has tried to maintain a calm and polite demeanor, following the doctor's advice to keep interactions light, but Y's aggressive tendencies persist. He shared an example of Y holding grudges, stating, *"She still remembers and gets upset about an incident where I slapped her six years ago."* A 2015 study found a connection between Expressed Emotions (EE) from family, relatives, or society and experiences of stigma or co-morbid depression in individuals with epilepsy. The study concluded that EE from relatives often goes unnoticed but can profoundly affect patients, contributing to depression and feelings of stigma [2].

The caregiver also described an instance of social isolation stemming from misconceptions about epilepsy. He shared that their married sister, who has a six-month-old baby, avoids visiting due to fear of disease transmission and prior disruptive episodes during visits. He recounted one such incident, stating, *"One time our elder sister came home with her baby, and Y started shouting during a seizure, causing the baby to cry. No one comes to visit us because of these disturbances."* This isolation has further strained the family dynamic.

Additionally, the caregiver expressed concern about Y overhearing discussions about her treatment and its associated financial burden, which causes her visible distress. He observed that these conversations lead to Y experiencing emotional and physical symptoms, described as going *"completely pale and yellow."* The mention of the amount of expenditure done on treatment and a seemingly lack of progress in prognosis leads to possible guilt or worry for Y, and has left the family struggling to balance emotional support with the practical challenges of caregiving.

CONCLUSION

This narrative analysis highlights the multifaceted challenges faced by individuals with epilepsy and their caregivers in rural Indian settings. Through the experiences of Y and her brother, the study underscores the complex interplay of medical, cognitive, psychological, social, and economic factors that influence the quality of life for persons with epilepsy and their families. Key findings reveal how epilepsy is not only a medical condition but also a deeply stigmatized issue, exacerbating social isolation, cognitive decline, and emotional stress. Misconceptions and knowledge gaps perpetuate a cycle of discrimination and inadequate support in the society, while the caregiving experience is marked by significant personal sacrifices.

Despite these challenges, the caregivers demonstrate resilience in their advocacy for better awareness, and their attempts to create supportive environments. It is evident that the stigma surrounding epilepsy in rural areas is driven by fear, misinformation, and cultural beliefs, necessitating targeted efforts to increase community-level education and acceptance.

FUTURE DIRECTIONS

To address the multifaceted challenges of epilepsy in rural areas, future efforts should prioritize culturally sensitive education campaigns to dispel myths, emphasize the medical nature of epilepsy, and promote community inclusivity through the involvement of local leaders and healthcare workers. Caregiver support must include the establishment of counseling services, support groups, and skill-based training to balance caregiving responsibilities with personal aspirations. Improving access to affordable medical treatment, diagnostic facilities, and telemedicine, alongside development of financial assistance programs, is critical for reducing the economic burden of epilepsy management. Most importantly, awareness about disability rights for persons with epilepsy should be spread to reduce the burden on the caregivers.

By addressing these dimensions, this study provides an overview of the unique struggles faced by persons with epilepsy and their caregivers, In an effort to inspire the pursuit of solutions for building a more inclusive and supportive community in rural India. The findings also serve as a call to action for stakeholders in healthcare, education, and policymaking to prioritize epilepsy as a public health concern and respond with evidence-based, equitable solutions.

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