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Epilepsy *(Mirgi)* among adults of Muzaffarabad: An Anthropological Perspective

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Abstract

Epilepsy is a neurological disorder characterised by recurrent seizures. In south Asia, particularly in Pakistan and India, it is commonly referred to as *"Mirgi"* which means *"small death"*, (*Ad Mua*) – often surrounded by cultural beliefs and misconceptions. Therefore, this anthropological study attempts to examine the cultural perceptions, lived experiences, and coping strategies of adults with epilepsy in Muzaffarabad, Azad Kashmir. The research includes nine male and female participants aged 25 to 40, selected through purposive and snowballing sampling. Data was collected through semi-structured interviews. Findings indicate that epilepsy is viewed through both medical and supernatural lenses; however, treatment is predominantly sought through traditional and spiritual healing practices. Gendered experiences play a crucial role in coping mechanisms: women receive more familial support but encounter greater stigma when it comes to marriage, while men rely on internal coping strategies due to societal expectations of resilience. The study emphasizes the need for a holistic approach to epilepsy awareness and management, including reconsideration of terminology to reduce stigma and promote understanding.

Keywords: Epilepsy, Gender and Epilepsy, Epilepsy Among Adults, Stigma Around Epilepsy, Lived Experiences of Epileptic Patients

Introduction

Epilepsy, a largely neurological condition, is an acutely under- researched field in South Asia as a whole(Gosain & Samanta, 2022). Since ancient times, epilepsy has been linked to spiritual or supernatural causes. The word epilepsy comes from the Greek verb epi-lambanein, which means to be seized, to be taken by surprise(Mccagh, 2010). Its relationship to religion is obvious and goes back thousands of years(Oscar Adolfo et al., 2023). Such early portrayals of epilepsy, associated with misfortune and mistrust, likely contribute to the prejudice surrounding the condition today, especially where social-medical awareness is limited. Epilepsy also remains a highly misunderstood condition globally with a cloud of confusion about its symptoms, risks and treatment. It affects about 570 million people worldwide with nearly 80% living in low and middle-income countries (World Health Organisation, 2019). These intersecting factors can further influence the prevalence, experiences, and management of epilepsy among different groups of individuals. For instance, individuals from marginalized communities may face additional barriers in accessing proper healthcare and support for managing their epilepsy (Beghi, 2020). The World Health Organization (WHO) has recognized epilepsy as a public health concern that leads to an increased risk of premature death, increased healthcare needs and expenditure, and loss of work productivity (Spiciarich et al., 2019;

Thurman et al., 2017) Epilepsy ranks 20th as a cause of years lived with disability (YLDs), globally (Megiddo et al., 2016). Living with epilepsy extends far beyond the medical management of seizures. People with epilepsy (PWE) face a range of challenges, including restricted independence, adverse effects of antiepileptic drugs (AEDs), stigma, and difficulty achieving educational and employment goals. More than the seizures, the illness have noxious effects on the social wellbeing of people with disease. Upon reaching adulthood, those who formerly suffered with epilepsy as children, are often found to have very high rates of social problems, even if they are intellectually within the normal range(Steiger & Jokeit, 2017). Such deficits in social functioning can contribute to difficulties in developing relationships and remaining in employment and thus, participating in life as a member of a family, community and culture (Roder et al., 2011)which in turn affects quality of life. Across the world and throughout history, epilepsy has been a culturally devalued condition. Such devaluing often leads to people with epilepsy being stigmatized and bearing psychosocial burden(de Boer et al., 2008). According to the Epilepsy Program by the US Centers for Disease Control and Prevention, approximately one in five individuals with epilepsy lives alone, while less than a quarter reside in households comprising two adults and children(Divino et al., 2015). Adults with epilepsy who live alone may face an elevated risk of injuries related to uncontrolled seizures, emotional distress caused by social isolation, reduced quality of life, and even premature mortality. Stigma significantly impacts perceptions of epilepsy, influencing personal aspects of life such as cohabitation and marriage. Research has consistently shown that individuals with epilepsy are less likely to marry, and those experiencing enacted stigma are notably more likely to face divorce compared to others(Friedrich et al., 2015; Riasi et al., 2014; Tedrus et al., 2015). In China, difficulty in finding a spouse has been described, with families of people with epilepsy feeling disgrace. In Ecuador, Ethiopia, and Kenya, social exclusion, altered relationships with spouses/parents, housing difficulties, and employment problems have been reported (Carpio, 2002). Beyond these challenges faced by adults, children with epilepsy also encounter significant barriers, including lower school attendance and performance, as observed in The Netherlands (Carpio, 2002). For young adults with epilepsy (YAE), these challenges particularly impact their social and cultural adjustment during important transitional phases, leading to psychological distress and a reduced quality of life. Poor health outcomes for young adults have lifelong impacts, including higher rates of unemployment, unhealthy habits, unplanned pregnancies, and lower high school graduation rates. Educational attainment and socioeconomic factors further compound the challenges faced by people with epilepsy(Otoom et al., 2007). A study conducted in Bahrain found that higher education levels are linked to reduced anxiety, as individuals with lower education levels may lack knowledge about their condition, leading to poorer seizure management and increased distress. In South Kazakhstan, only 22.66% of people with epilepsy (PWE) irrespective of gender, in urban areas and 11.88% in rural areas were employed or they were pursuing education, highlighting significant barriers to social and economic participation(Guekht et al., 2017). In Asian contexts, marriage, education, and employment are positively correlated with better disability status, yet marriages for such people are often forbidden or negated due to epilepsy(Yang et al., 2021). Even in Malaysia, a country with a robust economy, a survey of 250 people with epilepsy (PWE) revealed that 20% were unemployed and 10.4% were employed part-time. Compared to their siblings, people with epilepsy in Malaysia were more likely to remain unmarried, having a lower level of education, and earn lower incomes, that contributed to reduced social security(Trinka et al., 2019). These findings collectively highlight how cultural, social, and economic factors interplay in shaping the experiences and wellbeing of individuals with epilepsy across globe(Jennum et al., 2016, 2017; Moss-Morris, 2013; Wilson et al., 2015). When it comes to the name of epilepsy, every language and culture has different names and meanings of epilepsy that reflect the beliefs associated with it(Patel & Moshé, 2020). For example, meaning of epilepsy in many Asian languages are one variable that affects epileptic stigma. In Japan, it is called "Tankan", it means madness, while in Korea, it is called "Gan-zil," which means "mad sickness". Chinese terms for epilepsy include " diān xián", "madness" and " yáng diān fēng", "goat madness". Due to the influence of Traditional Chinese Medicine, the names of epilepsy in some East and Southeast Asian languages also conjure up images of madness and animals(Kheng Seang Lim; Shi Chuo Li; Casanova-Gutierrez, 2012). The Malay people, mostly Muslims, also believe epilepsy as something spiritually impure (Gila babi, mad pig illness), which adds to the stigma attached to epileptic sufferers. To reduce the stigma associated with epilepsy, the names given to epilepsy have been changed to neutral terminology in Malay in Malaysia. The name of epilepsy in Malay has therefore been changed from from *'gila babi'* to which means pig like which led to stigmatization to 'penyakit sawan' meaning seizure disorder or 'epilepsi' (epilepsy). Penyakit sawan has been well accepted by the professionals as well as the public, and is currently widely used in Malaysia(Lim et al., 2012). The name of epilepsy is also neutralized in Mandarin in China, and Korean in South Korea (Khan, 2015). Epilepsy in Arabic and Turkish languages is called 'Saraa' meaning 'being knocked down'. In Urdu language (India and Pakistan) epilepsy is called 'Mirgi' meaning 'small death'(Wasim Akhtar & Aziz, 2004). Therefore, the experience of epilepsy is culturally mediated and the meanings ascribed to the condition can have great impact on its social course. This cultural variability in the terminology for epilepsy reflects its non-biomedical understanding that reveals the social, emotional, and spiritual dimensions ascribed to the condition within different communities. For instance, in an ethnographic study conducted on women in South India revealed that affected individuals witnessed to link the seizures to black magic or malevolent acts, with suspicions that their condition may result from harmful intentions or supernatural forces(von Gaudecker et al., 2019). Similarly, studies conducted in various parts of India reveals that epilepsy is believed to be caused by evil spirits, supernatural power, or possession along with other causes(Singh et al., 2010). These culturally embedded beliefs create significant barriers to adopting biomedical treatments and profoundly shape the lived experiences of those with epilepsy. In Pakistan, Prevalence of epilepsy in general population is estimated to be 9.99 in 1,000 population. In rural areas the burden of epilepsy is twice of what is observed in urban areas(Khatri et al., 2004). Unfortunately, few studies of epilepsy are available from Pakistan and best of our knowledge, no studies have been conducted to assess the socio-cultural dimensions of epilepsy in Muzaffarabad, Azad Kashmir. Thus, the current study aims to address this gap by examining the cultural meanings ascribed to epilepsy, its impact on the social and educational lives of adults, and the role of family and community support systems. By documenting and analysing these vernacular meanings, this study aims to shed light on the cultural lens through which epilepsy is perceived in Muzaffarabad. Understanding this context is crucial for designing culturally sensitive health interventions that address the social and emotional dimensions of living with epilepsy.

Material and Method

Study Design

The study recruited 9 adults as participants, both men and women, aged 25 to 40 years, selected through purposive and snowball sampling techniques. The age group was considerably selected as epilepsy during adulthood can profoundly disrupt crucial responsibilities, including career development, family life, and social obligations (Kirabira et al., 2018; Rani & Thomas, 2019a; Yeni, 2023). And studying such factors provide valuable insight into how cultural perceptions of epilepsy influence social roles, employment, and relationships (Wood et al., 2017). The lead author, who is a faculty member at the University of Azad Jammu & Kashmir, initially connected with two students living with epilepsy during academic interactions. These students played a crucial role as key informants, helping to identify additional participants through their personal networks. Their involvement was particularly valuable in reaching individuals who might have been difficult to access due to societal stigma and reluctance to disclose their condition. The co-author actively ensured adherence to ethical guidelines during the recruitment process and supported efforts to build trust and rapport with participants. This collaborative approach facilitated a thorough understanding of the participants' experiences while upholding confidentiality and respecting their privacy. Sample inclusion criteria included adults who were: (1) over the age of 25 to focus on adult experiences with epilepsy, (2) self-identified as residents of Muzaffarabad city, (3) diagnosed with epilepsy and living with the condition for at least one year prior to the study, (4) capable of effective communication and willing to share their experiences through interviews, and (5) willing to provide informed consent for participation. The exclusion criteria included (1) individuals who are less than 25 and more than 40. (2) individuals who were unable to communicate effectively due to severe physical or cognitive impairments, (3) those unwilling to discuss their condition due to stigma. The socio-demographic profile of the sample is summarized in Table 1.

Interview Protocol

The interview protocol consisted of open-ended questions and follow-up probes designed to elicit detailed narratives on cultural perceptions of epilepsy (mirgi), healthcare-seeking behaviors, stigma, social support networks, and the lived experiences of individuals managing epilepsy in Muzaffarabad. Questions were tailored to each participant's specific context and experiences, ensuring cultural sensitivity and depth in the data collected. Interviews were conducted between January 2023 and August 2023 at various locations across Muzaffarabad city, with the time and place chosen by the participants for their convenience. For some participants, multiple interviews (two to three sessions) were conducted to deepen understanding and clarify key aspects of their narratives. Prior to each interview, informed consent was obtained, and the purpose of the study was clearly explained. Each session lasted between 30 to 50 minutes, depending on the depth and breadth of the discussion.

Research Setting

The study is conducted in the capital city of Azad Kashmir, that is Muzaffarabad. Muzaffarabad is one of the largest districts occupying 2496 sq/km of Azad Kashmir and is also the capital of Azad Kashmir. It consists of around 1lac 50 thousand inhabitants. Since Azad Kashmir is a state hence majority is Muslims while there is percentage of Christians as a minority group(Sultan, 2022). Literacy rate of Azad Kashmir as a whole is 75%. Majority of women are independent and working in various professions. The area has one government hospital (CMH) and other small clinics. Most of the inhabitants of the area utilize the government health facilities with the rich ones preferring private hospitals. Some of them utilize traditional healers and believes in faith healing too.

Demographic characteristics of Respondents:

Variable	**Frequency (%)**
Total Respondents	9 (100)
Age (years)	
25–30	4 (44.44%)
30–35	3 (33.33%)
35–40	2 (22.22%)
Sex	
Male	4 (44.44%)
Female	5 (55.56%)
Marital Status	
Single	3 (33.33%)
Married	4 (44.44%)
Divorced	2 (22.22%)
Education	
Primary	2 (22.22%)

Secondary	4 (44.44%)
Higher	3(33.33)
Current Occupation	
Student	3 (33.33%)
Formal Job	1 (11.11%)
Informal Job	3 (33.33%)
Homemaker	2 (22.22%)
Duration of Illness	
1–5 years	4 (44.44%)
5–10 years	2 (22.22%)
>10 years	3 (33.33%)

Table 1 Demographic details of the participants

Data Analysis

The audio-recorded data from the individual interviews were transcribed from local Urdu language to English language. Each completed transcript was checked by the first author for accuracy by reading the transcript while listening to the audio-recorded interview. Thematic analysis was employed to analyse the interview data, following a systematic process of coding, categorization, and interpretation. The themes identified were then organized into a comprehensive framework that captured the cultural perceptions, lived experiences, and challenges of adults with epilepsy *(Mirgi)* in the context of Muzaffarabad. This approach allowed for an in-depth exploration of the interplay between health, stigma, and social dynamics within the specified age group.

Limitations

The study's focus on adults aged 25 to 40 years may limit its relevance to younger or older individuals with epilepsy, whose experiences could vary significantly. Moreover, the stigma associated with epilepsy in Muzaffarabad presented challenges in participant identification and recruitment, which may have constrained the diversity of perspectives included in the research.

Cultural Meanings and Perception of Epilepsy

Mirgi as *"Ad Muha"*

In India and Pakistan, epilepsy is commonly referred to as *Mirgi* in both Hindi and Urdu. The term carries deep cultural and linguistic connotations, shaping how the condition is understood within communities. According to the (*Feroz Ul Lughat (Urdu to Urdu Dictionary) (New Edition),* 1993) *Mirgi* is defined as "a disease in which a person loses control, falls to the ground, and becomes unconscious," meaning a state of being neither fully alive nor entirely lifeless. Akhtar and Aziz (2004) further interpret *Mirgi* as "small death" or "half death," emphasizing the cultural metaphor of temporary loss of vitality and consciousness during seizures. In their response to the question, "What understanding you have about the word "*Mirg*i?". Most of the participants in interpreted *Mirgi* as *ad mua* ("half dead"), associating epilepsy with an incapacitating condition marked by a loss of control and vitality. Some described it as *to mara hua* ("as if dead"), reinforcing its metaphorical link to death.

One participant enlightened,

"As far as I've heard from elders, *Mirgi* means dead, as if a person is unconscious and constantly falling."

Similarly, two other participants translated it as *mara hua* ("being dead").

Unlike the term "epilepsy," derived from the Greek word *epilambanein* (meaning "to seize or attack"), no documented evidence traces the linguistic roots of *Mirgi*. While there is speculation about Arabic or Persian origins, this remains inconclusive. The divergence between dictionary meanings and local interpretations reflects the deeply embedded cultural beliefs surrounding epilepsy, influencing societal attitudes and the self-perception of individuals with the condition. This lack of clarity about the term's etymology highlights a gap in linguistic scholarship that warrants further exploration.

Perception of Epilepsy and The Role of Language in shaping perception

In light of this finding, 85% of informants, when asked about the disease, referred to it as *migri ka dora*. A significant percentage of informants used this term in their interviews while discussing the condition, underscoring its prevalent usage within the community. This linguistic and cultural framing highlights the community's understanding of the episodic nature of the condition, where the person experiencing a seizure is symbolically caught between life and death.

As one informant stated: *"we call it Mirgi ka Dora"*

26 years old girl who was pursuing Masters from University, said,

"When I have an episode of seizure, people say I had a "Dora" (Doray parna). They often don't understand that it's a medical condition and hence avoid me. Knowing that I lose control of myself during the attack, which get revealed to me later, I feel different of myself, as I am not a normal human being".

The statement of the respondent reflects the common perception that epilepsy is something beyond medical understanding, leading to the association of "*Doray parna"* (having fits) with loss of control or mental instability. In many cases, this cultural understanding minimizes the medical aspects of the condition and reduces it to a mere physical event, which is often surrounded by stigma and social exclusion. that people in the community would only understand epilepsy once it was framed as a condition marked by "fits," or "dauray parna" reflecting the limited medical understanding of the condition and hence does not only serve as a medical label but also carries social connotations, often linked to deviant behavior. This aligns with the findings of Gosain and Samanta in India, where terms like "pagal pan ke daure" (acting like a lunatic) were used to describe epilepsy, reinforcing its association with insanity and social marginalization.

One more male participant shared,

"*They said, 'He gets dauray anytime,' which comes across as ridiculing."*

The societal understanding of epilepsy in current study discourages individuals from seeking appropriate medical help due to the fear of being labelled socially deviant or insane. This perception of epilepsy, often viewed through spiritual or supernatural lenses, results in individuals seeking traditional or spiritual remedies rather than biomedical treatment(Antimov et al., n.d.; Keikelame & Swartz, 2015). Both terms—*migri ka dora* and *mirgi ke jhatkay*—reveal cultural interpretations of epilepsy that shape how the condition is socially constructed and understood. The reference to *dora* (attack) suggests an external force acting upon the individual, often linked to supernatural or fatalistic beliefs in many South Asian cultures. Similarly, the term *jhatkay* may evoke fear or aversion due to its association with uncontrollable physical episodes, further reinforcing the stigmatization of individuals with epilepsy. This cultural framing has significant implications for the affected individuals. The use of terms like "*Migri ka dora"* and "*Mirgi ke jhatkay"* not only highlights the episodic and physical characteristics of epilepsy but also perpetuates a sense of "otherness" by linking the condition with concepts of death, violence, and unpredictability. As a result, these linguistic choices may contribute to social stigmas, including fear, shame, and discrimination(Ahad et al., 2023), which often isolate individuals with epilepsy from their communities.

Traditional and Community based responses to Epilepsy

During fieldwork, it was observed that people rely on various traditional first aid measures when witnessing a seizure. These responses are shaped by cultural beliefs and local understandings of the epilepsy, often influenced by supernatural or folk explanation. One widely practiced method is *Joota Sungwana, (smelling a shoe),* which is an attempt to bring the patient back to consciousness. One of the informants explained:

"Some people believe that making a patient smell a shoe during a seizure brings them back to their senses."

The researcher further verified the statement and assessed that this practice is widely accepted as an immediate response, reflects the cultural misunderstanding of epilepsy. The strong odor of a shoe is basically thought to "shock" the patient out of a seizure, implying that the condition is caused by an external or temporary disturbance rather than being a neurological disorder. This act of making someone smell a shoe-an object considered dirty and degrading in many South Asian cultures- carries an element of ridicule. It suggests that the individual needs to be "shamed" or "forced" back to consciousness, rather than treated with medical care and dignity. Such cultural practices have been observed in many native American's and South African's communities where epilepsy is being treated according to their cultural, magical and natural knowledge. This reinforces societal attitudes that view epilepsy not just as an illness but as a condition that diminishes a person's social standing. Overall the rate of treatment epilepsy in Asia has been hindered by several issues, including insufficient healthcare, lack of specialist care, limited pharmacological treatment options, lack of affordable options, distance from medical facilities, lack of awareness, stigma, beliefs, and traditional medicine.

Spiritual Healing Practices

When it comes to the choice of treatments for epilepsy, traditional views significantly influence perceptions among respondents and their families. Most participants regarded epilepsy as a spiritually inflicted disease, with a majority, particularly WWE and their mothers, associating it with spiritual possession. While some had a vague awareness of possible biological explanations, spiritual interpretations overwhelmingly shaped their understanding and guided their approach to treatment. A mother of PWE expressed,

"I have been taking my daughter to a Peer Baba, a spiritual healer. She has been drinking the water he blessed, and since then, she hasn't experienced any seizures. This has strengthened our belief in his healing powers."

These findings further underline the significance of local cultural narratives in shaping health-seeking behaviors and social support systems, suggesting the need for health interventions that integrate cultural sensitivity. Another, 32-year-old man with epilepsy shared that he had never visited a hospital or received a formal diagnosis. Instead, based on his symptoms, family members identified his condition as *"mirgi k jhatkay*" (seizure attacks) and encouraged him to seek help from their spiritual healer. He further explained, "Since then, we have been seeing our family spiritual healer." When asked whether he personally believed in the healer's approach, he stated,

"My wife strongly believes in these things, so that's why we follow it."

In contrast, in contexts where terms like *mirgi* remain prevalent, the stigmatization persists. This highlights the need for similar linguistic reforms in South Asia, where epilepsy continues to be perceived through the lens of spiritual possession and social deviance. By promoting the use of neutral, medically accurate terminology, healthcare systems and advocacy groups can foster a more inclusive understanding of epilepsy, reducing the psychological and social burden on individuals living with the condition.

Gender Dimension to living with epilepsy:

Epilepsy, as a chronic neurological condition, significantly impacts not only the physical health of individuals but also their emotional and social lives. In some societies, the challenges faced by individuals, particularly women, are compounded by cultural and religious norms. The fear of public episodes, potential physical exposure, and societal judgment creates unique struggles for women, who often navigate a delicate balance between managing their condition and adhering to societal expectations. Two female informants expressed similar concerns with fear of going out in a public. A university girl who was pursuing masters in social sciences and is a 2nd year student said,

"*I am scared of going to university that if I get seizure there, who will take care of my clothes and who will care if my head is covered or not, who will give me first aid, who will touch me."*

And another response from 27years old Rabia, who is pursuing religious studies from Madrassah said,

"It can be very shameful, having seizure in front of people, this scares me, and was one of the biggest concerns of my parents. This is the reason I didn't continue formal education from university but getting religious education from Madrassah".

Almost all female adults with epilepsy expressed a fear of being exposed in public, along with the shame they associate with such exposure. The first respondent, expressed fear about having a seizure at university, emphasizes her concerns about how her personal space, like her clothes, would be managed in such a scenario, alongside worries about who would provide first aid or ensure her modesty (i.e., keeping her head covered). This concern reflects a broader cultural emphasis on women's modesty and the fear of losing control in a public space. These issues highlight the intersection of health and gender, where women with epilepsy are not only worried about the physiological aspects of their condition but also about societal expectations regarding their appearance, behavior, and the potential shame they may cause their families(Malik et al., 2022). This connects with the idea of enacted stigma, as Rabia's worry about public humiliation reflects how epilepsy, in her context, is linked to shame, especially when it comes to gendered expectations of behavior (Merino et al., 2024). Rabia's perspective of "It can be very shameful, having seizure in front of people, this scares me, and was one of the biggest concerns of my parents," further deepens the exploration of societal norms and pressures. For Rabia, the fear of a seizure in front of others isn't only about physical vulnerability but is tied to her identity as a woman in a cultural context where being "publicly exposed" in a vulnerable state is perceived as dishonourable. It is interesting to note that Rabia's decision to pursue her education in a religious setting, such as a madrassah, is a reflection of the desire to mitigate these risks. Rabia sought an environment where she felt more control over the potential risks of her epilepsy, influenced by cultural and familial pressures to protect her reputation and maintain her modesty.

Emotional Vulnerability and Masculine Expectations

30 years old, Muhammad Riyaz is married and has 2 kids. Riyaz was working as a labour, on construction projects under the supervision of a contractor. According to his wife,

"One year ago, while sleeping, Riyaz got a seizure attack for the first time while everyone else was sleeping. It was something new and strange for me, I ran to the next-door neighbour house and called them for help. The old man who is our neighbour told me that he got Mirgi (Epilepsy) attack. Since then, whatever is suggested by family and elders, I am doing every possible thing, making visits to doctors in different cities and also seeking spiritual healers too. He doesn't like it to be dependent on me, he often expresses that I was supposed to take care of you all and sometimes he doesn't cooperate going with me for checkups."

Riyaz's reluctance to accept help from his wife and his desire to maintain his role as the family caretaker showcases how gender norms (especially in traditional societies) shape the experience of illness. Men, particularly those with epilepsy, may feel emasculated by their dependence on others, particularly in cultures where men are expected to be the primary providers and protectors. This participant's experience highlights the tension between his perceived role as a husband and father and the reality of living with a condition that disrupts his ability to fulfil these roles. This experience is in line with broader findings in the literature, where studies have indicated that men with epilepsy often face stigmatization related to their perceived loss of control, both over their condition and their social roles. As the literature suggests, men are more likely to internalize feelings of inadequacy, leading to resistance in accepting help and avoiding situations that might highlight their vulnerability(McKenzie et al., 2018). This fear of perceived weakness is compounded by societal expectations around masculinity and autonomy.

One more male participant Muhammad Din told,

"I feel helpless, I can't express how weak I feel, not because of my disease but the helplessness of being dependent on my wife as a man"

Men in the study expressed concerns about being perceived as incapable of performing their social roles, especially in terms of employment or relationships. These concerns are more practical, revolving around the fear of not being able to manage their condition in a work setting, but also reflect broader gender norms about independence, control, and authority. Studies have shown that men with epilepsy are less likely to be employed or married, largely due to the stigma attached to the condition and the fear of being seen as unreliable or fragile(Gosain & Samanta, 2022b; Henning et al., 2021). Thus, both male and female respondents, though expressing different specific concerns, share a common experience of fear and isolation related to their condition. However, the differences lie in the way these concerns are framed: women's fears often centre around their appearance, modesty, and public judgment, whereas men tend to be more concerned about their social and economic roles and the stigma of being seen as dependent or weak.

Stigma and Emotional Challenges:

A 39 years old male participant Rizwan, expressed:

"*Sometimes, my family avoids inviting me to social gatherings, afraid I might have a seizure in front of others. They think people will laugh at me or judge me. It makes me feel isolated, like I am not allowed to be a part of the community."*

The participant expresses that their family, out of concern for how epilepsy might be perceived by others, excludes them from social gatherings. This exclusion is rooted in the fear that witnessing a seizure could lead to ridicule or judgment from others. The idea that others might laugh at or judge the participant points to a common misconception in many cultures that epilepsy is either a sign of mental instability or some form of moral or spiritual weakness, often leading to mockery rather than sympathy. Furthermore, the participant's feeling of being isolated highlights the emotional and social toll that this stigma can take. They describe being excluded from community life, which not only affects their sense of belonging but also reflects how epilepsy can severely limit participation in social and communal activities. The exclusion experienced by this individual is not merely physical (i.e., not being invited) but emotional as well, as they are made to feel that they are "not allowed" to be part of the community, reinforcing their social isolation. This aligns with broader research that shows how stigma around epilepsy can lead to significant emotional distress, mental health issues, and a sense of alienation from family and community networks(Guo et al., 2012; Rani & Thomas, 2019b). It also illustrates that misconceptions about epilepsy can lead to actions that further isolate and marginalize individuals with the condition, preventing them from leading a fulfilling social life.

Rabia (the female participant) also expressed,

"I don't have friends; my mother is my friend and she is my big supporter too."

This reveals the deep sense of social isolation she feels due to her epilepsy. Her reliance on her mother as both a friend and supporter underscore the emotional toll epilepsy can have, particularly on women, as they often experience heightened societal pressures regarding their roles in family and community. This suggests that Rabia has internalized her condition's impact on her social life, limiting her interactions with others and relying on the close support system of her mother. When further probed about whether her isolation was due to her condition or other factors, Rabia explained, "You know, I didn't attend my brother's wedding, it's not that I feel bad about it, but now I am happy being alone and not attending gatherings." This response illustrates how epilepsy has not only restricted her social participation but also shaped her emotional response to these limitations. While she does not express regret for missing her brother's wedding, she highlights a sense of contentment in withdrawing from social gatherings, possibly as a way to shield herself from the stigma associated with her condition. Rabia's statement, "Although now I am fine and due to medication, I didn't have seizures for a long time, but my life is like this now and I am happy about it," reflects a form of resignation and adjustment to her new reality. Despite being medically stable, she has adapted to a life of social withdrawal, which points to the emotional and psychological challenges women with epilepsy often face. Rather than actively seeking out social engagement, Rabia has chosen to embrace solitude, possibly to avoid the judgment or discomfort she associates with her condition in social contexts.

One of a married participants Maryam, who has one child told us that:

"*Sometimes, I am not able to take care of my child properly because of my condition. On such days, my mother-in-law taunts me, saying, 'What kind of a mother are you if you can't even handle your own child?' She compares me to other women who manage everything effortlessly and says I am a burden on the family. These comments make me feel useless, as if my illness defines my worth as a mother and wife."*

This reflects the societal expectations placed on married women, particularly mothers, to fulfil caregiving roles flawlessly, regardless of their health conditions. Such negative remarks from close family members, especially in-laws, can exacerbate feelings of inadequacy and emotional distress for women with epilepsy. Research indicates that stigma within familial structures often stems from cultural norms that idealize women's roles in caregiving, leading to criticism when they are unable to meet these expectations. These experiences underscore the need for a supportive family environment to mitigate the emotional burden faced by women living with chronic condition

While a male participants expressed that:

"I used to work as a labour, but due to seizures I can't continue with that job. Now I am jobless, I do nothing, earn nothing, we survive on my father's pension. Whatever he brings me and my children eat.

Unpredictability of Seizures:

For many individuals with epilepsy, the unpredictability of seizures significantly limits their capacity to perform physically demanding or consistent work, as in the case of this participant who worked as a labourer. Without the ability to earn a living, the individual's reliance on others, particularly family members, for financial support becomes crucial. In this case, the participant's economic stability is dependent on his father's pension, underscoring the financial strain on families when individuals with epilepsy cannot participate fully in the workforce. The lack of income and job opportunities exacerbates feelings of dependence and helplessness, contributing to both the personal and familial burden of the condition. The impact of this participant's experience aligns with broader findings in existing literature, which demonstrate that the medical and social burdens of epilepsy, including restricted employment opportunities, contribute to significant financial challenges for those affected(Allers et al., 2015; Jennum et al., 2011; Willems et al., 2023). In societies where formal employment opportunities are limited and labour-intensive jobs are often the only available option, the inability to work due to seizures can lead to economic vulnerability, deepening the social isolation and stigma often faced by individuals with epilepsy. Both men and women living with epilepsy experience fear, stigma, and isolation, but these challenges manifest differently based on societal expectations and gendered roles. Women often face stigma tied to their caregiving and social responsibilities(Zwar et al., 2021). For instance, Rabia shared how her fear of having a seizure in public led to her withdrawal from social gatherings. This self-imposed isolation reflects the social stigma and fear of judgment associated with her condition. Similarly, Maryam, a mother with epilepsy, described the criticism she faced within her family, saying, "Sometimes, I am not able to take care of my child properly... My mother-in-law taunts me, saying, 'What kind of a mother are you if you can't even handle your own child?" Such remarks amplify the emotional toll for women, who are often judged harshly for not fulfilling traditional caregiving roles. On the other hand, men with epilepsy experience fear and stigma rooted in their societal roles as providers and protectors. Male participants expressed anxiety over being perceived as incapable of maintaining employment or fulfilling family obligations. Their concerns often centred around fears of being seen as unreliable or weak. While men grapple with the pressure to sustain independence and authority, their stigma is linked to their ability to meet societal expectations of masculinity (Kleinman, 1980). Studies have consistently found that the fear of epilepsy, its unpredictability, and its social consequences lead to heightened emotional distress and a desire to avoid public situations (Rauh et al., 2022; Yin et al., 2024), mirroring the experiences of the participants in present study.

Coping strategies

Coping strategies refer to the ways individuals manage stress, challenges, and the emotional burden associated with living with a chronic condition like epilepsy (Şenadım et al., 2021; Westerhuis et al., 2011). These strategies can be psychological, behavioural, or social, and vary depending on cultural, social, and individual factors. Similarly in case of current study, coping strategies for individuals with epilepsy are multifaceted and deeply influenced by cultural, familial, and social factors. Spiritual and religious coping provided emotional solace and resilience in the face of uncertainty, while social and familial support networks played a crucial role in managing both the physical and emotional challenges(Aggarwal et al., 2023) of living with epilepsy.

Psychological and Familial Coping

In addition to spiritual and psychological coping strategies, familial support played a significant role in shaping how participants managed their condition. One participant, Muneera, shared her experience of navigating familial relationships and support structures. She explained that she got married to her cousin, the son of her father's sister. However, every time she experienced a seizure, her mother-in-law, who is also her paternal aunt, would send her back to her parental home to avoid the responsibility of caring for her.

Muneera recounted:

"Every time I had a seizure, my mother-in-law would send me back to my parents' home so she wouldn't have to take care of me. My parents, especially my father, would look after me. He even told me I shouldn't go back to my in-laws because my husband and his family were least caring and concerned about my condition. My father has been my strongest support—he built a house for me so I can live independently after getting divorced. He wants me to secure a good government job as a teacher because he's concerned about my future and stability."

Muneera's story highlights the important role of parental support, particularly that of fathers, in providing emotional, financial, and social stability for women with epilepsy. Her father's proactive measures, such as building a home and encouraging her to pursue a teaching career, reflect his dedication to ensuring her long-term well-being and independence. His decision to discourage her from continuing a relationship with an unsupportive spouse further emphasizes his protective role, prioritizing her health and happiness over societal expectations or family pressures. This highlights a broader theme within the study: the pivotal role of close family members in mitigating the challenges posed by epilepsy. Research indicates that individuals with chronic illnesses often experience dissatisfaction and perceive limited family support. A deeper understanding of how family support is perceived in the context of epilepsy can enhance insights into health-related quality of life (QoL) for those living with the condition. This understanding informs strategies aimed at reducing stigma and addressing the social limitations faced by adults with epilepsy(Siarava et al., 2019; Wang et al., 2015). Although Muneera's marital relationship lacked care and concern, leading to emotional distress, her father emerged as a pillar of strength and unwavering support. Contrary to the familial dysfunction commonly reported in such cases(Ong et al., 2021; Onyango et al., 2022; Yu Cheng et al., 2023). Raising awareness about epilepsy and its impacts on individuals and their families can encourage more inclusive and supportive caregiving practices, enabling individuals to better cope with the stress and anxiety linked to the condition.

Spiritual and Religious Coping

Religion has also been considered as a potential source of existential meaning that has a significant impact on psychological well-being(Aflakseir, 1999). In the last decades, there is an increasing number of publications with interesting results on the relationship between religiosity and mental health, both on a theoretical and a clinical level(Kioulos et al., 2015; Othman et al., 2023). In current study, almost all participants believed in the significance of prayer and religious recitation in coping with their condition. Specifically, 75% of both male and female participants mentioned the recitation of Masnoon Duas, such as *"Hasbunallahu wa ni'mal wakeel"* (Allah is sufficient for us, and He is the best disposer of affairs), during moments of distress. Some of them shared that they regularly recited Ayat-ul-Kursi, Surah Al-Falaq, and Surah An-Nas, the Surah's of Holy Quran, as a source of emotional strength and a spiritual shield. They regarded their illness as a test of faith and found solace in the belief that their struggles were a means of spiritual purification, allowing them to strengthen their connection with Allah. This strong reliance on religious practices highlights the deep integration of faith in their coping mechanisms. 4 out of 5 female participants, and 2 male participants with epilepsy were wearing an amulet with Quranic verses, which they believed provided protection against seizures.

One of the female participants expressed that:

"*My mother brought this amulet from our family religious peer two years ago, which was an year after I was medically diagnosed with the epilepsy. Since then, I am wearing it and I had felt significant difference in my condition. The seizures gap is prolonged."*

The participant's reliance on an amulet provided by a family religious peer reflects the integration of spiritual and cultural beliefs into their health practices, which aligns with the folk sector in Kleinman's health model. This finding highlights how the participant perceives their illness not solely through the biomedical lens but also as a condition that requires spiritual intervention. The reported prolonged gap between seizures after wearing the amulet suggests a psychosomatic benefit, potentially stemming from the participant's belief in the amulet's efficacy and the emotional reassurance it provides. This aligns with Kleinman's notion that healing is not only about the physical symptoms but also about addressing the cultural and emotional dimensions of illness(Kleinman et al., 2006). The act of wearing the amulet could symbolize hope, spiritual protection, and a sense of control over an otherwise unpredictable condition. As concluded by Moselhy in his study on Psychosocial and Cultural Aspects of Epilepsy, epilepsy in Asia as compare to other region is not controlled by genetic differences or environmental factors but more than that socio-economic factors along with political and organizational factors influence epilepsy management (Fouad, 2011).

Conclusion

The research reveals how epilepsy—referred to *"Mirgi*" in Urdu language," which translates to "small death"—is deeply stigmatized. Local interpretations such as "Ad Mua" (half dead) or "Mara Hua" (dead) further exacerbate this stigma, fostering isolation and social exclusion for those affected. While both male and female respondents share the overarching experiences of fear and isolation, their specific concerns diverge. Women predominantly worry about societal judgment concerning their appearance, modesty, and public perception, while men are more focused on their roles as providers, fearing dependence and a loss of respect. These gendered differences highlight the profound impact of societal expectations on the lived experiences of individuals with epilepsy. The study also highlights the common practice of "*Joota Sungwana",* where individuals attempt to revive a person experiencing a seizure by making them smell a shoe. This not only reflects cultural misconceptions surrounding epilepsy but also reinforces stigma, emphasizing the need for awareness and medically appropriate first aid interventions. Familial support and psychological acceptance further emerge as critical sources of resilience and adaptation. Furthermore, as evidenced by successful interventions in other countries, renaming the condition in culturally sensitive terms could help dismantle entrenched stereotypes and reduce stigma. By addressing these challenges, it is possible to create a more supportive environment, enabling individuals with epilepsy to navigate their condition with dignity and confidence.

Abbreviations

PWE: Patients with Epilepsy, WWE: Women with Epilepsy, MWE: Men with Epilepsy

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Declarations

Ethical Approval and Participant Consent:

This study was approved by the Ethics Board of the Office of Research, Innovation, and Commercialization (ORIC) at the University of Azad Jammu and Kashmir. The ethical approval was granted on November 13th, 2024, with the reference number NO/602/ORIC/2024. In addition, informed consent was obtained from all participants prior to their involvement in the study. All participants were informed about the study's objectives, the voluntary nature of their participation, and their right to withdraw at any time without consequence.

Consent for publication

Verbal consent was obtained from all participants for their involvement in the study. The names of only those participants who provided explicit consent for publication are revealed in the written report and associated publications. Confidentiality was maintained for those who opted not to have their names disclosed.

Competing interests

It is declared that the authors have no competing interests.

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