

STRESS, STIGMA, AND EMOTIONAL ADJUSTMENT IN YOUNG ADULTS WITH EPILEPSY

AYESHA HABIB KHAN*

LECTURER, UNIVERSITY OF AZAD JAMMU & KASHMIR

BISMA SHEIKH

LECTURER, CHANDKA INSTITUTE OF NURSING & ALLIED HEALTH SCIENCES, LARKANA

TASKEEN MANSOOR

PHD SCHOLAR, QUAID. E. AZAM UNIVERSITY, ISLAMABAD

DR. AYESHA KHALID

DEPARTMENT OF PSYCHOLOGY, UNIVERSITY OF HOME ECONOMICS, LAHORE

NOOR.UL.AIN GILLANI

LECTURER, UNIVERSITY OF AZAD JAMMU & KASHMIR

Corresponding Author: Ayesha.habib@ajku.edu.pk

Abstract:

Epilepsy, one of the most prevalent neurological disorders globally, continues to carry profound social and psychological implications, particularly in developing countries where illness is often intertwined with moral, religious, and social interpretations. The study used Interpretative phenomenology analysis (IPA) as its methodological approach to explore how individuals with epilepsy makes sense of their lived experience. By employing Klienman's explanatory model, Goffman's stigma theory and Lazarus & Folkman's coping framework, the study examines how individuals interpret, negotiate, and cope with the illness experience within specific cultural and social contexts. In-depth interviews were conducted with 9 adults (both male and female), diagnosed with epilepsy in Muzaffarabad, Azad Jammu & Kashmir. Participants were recruited using purposive and snowball sampling technique. Findings reveal that participants' emotional responses to epilepsy are deeply embedded within family dynamics, social expectations, and religious frameworks. While some participants experienced feelings of shame, social withdrawal, and internalized stigma, others demonstrated resilience through faith-based acceptance and reframing their identity beyond illness. The study concludes that emotional adjustment among individuals with epilepsy is not merely a personal psychological process but a culturally and relationally mediated experience, influenced by shared beliefs, familial responsibilities, and religious interpretations. The findings also highlight the need for context-sensitive interventions that integrate psychosocial and cultural dimensions of healing, encouraging collaboration between medical, psychological, and faith-based institutions.

Keywords: Epilepsy, Stress and Epilepsy, emotional adjustment in PWE, coping strategy among PWE

INTRODUCTION

Epilepsy is a most common neurological disorder that is affecting over 50 million people worldwide (Trinka & Lee, 2019). Asia which comprises 50% of the world's population, alone estimated to have about million people with epilepsy (Mehndiratta & Wadhai, 2015). The experience of epilepsy is highly contextual (Tanywe et al., 2016). In many cultures due to lack of awareness and certain beliefs associated with epilepsy, patients not only struggle to have basic education, safe housing and a decent job (Boling et al., 2018) but also suffer from stress due the constant fear of going in public place and gathering due to the shame of getting seizure and called out insane or possessed (Khan A & Gillani N, 2024). According to a systematic review by Catalán-Aguilar et al. (2025), previous study has indicated stress as uncontrollable and unpredictable phenomenon that has a tendency of influencing patients' emotional wellbeing more than the seizure perse. One of the contributors to the stress and emotional struggle is the stigma associated with seizures (Cano-López et al., 2019; Jacoby, 2002; Ranjan et al., 2022). According to a 2024 report from Epilepsy Action, 85% of PWE reported experiencing anxiety and 70% reported experiencing depression. 69% of people reported that epilepsy limited their independence, and 50% reported feeling lonely or isolated. Sadly, epilepsy continues to be a



highly stigmatized condition, and the powerful effects of social labelling and the process of internalizing negative stereotypes is undoubtedly detrimental to both the mental health of PWE and their sense of self-empowerment. Psychological disorders are twice as likely to occur in people with epilepsy than the general population (Michaelis et al., 2018) There is a further widespread presence of both depressive and anxious symptoms in PWE which has been correlated with a poor quality of life (Tombini et al., 2024). Many studies indicate stigma being identified as a root cause of the anxiety and depression with patients ranging from 31% to 56%(Qin et al., 2022; Scott et al., 2021). Stigma, often experienced by epilepsy patients is influenced by two factors: personal factors and societal factors. Social factors primarily contribute to patient's experience, whereas patient factors are related to what associated with what patient feels due to the fear of discrimination (Kwon et al., 2022). Stigma also tend to isolate individuals with epilepsy from society and effect their everyday life(Malik et al., 2022). This isolation makes regular life especially managing and adapting to the condition more challenging (Räsänen et al., 1978). International literature indicates that stigma often has gendered consequence(Scott et al., 2021) where both men and women experience the illness differently and have different consequences on their overall life.

Numerous studies have examined and explored the socio and psychological consequences of the epilepsy. In some part of the world patients with epilepsy still don't have acceptance in social circles, they are often stigmatized and pushed to isolation, whereas the consequences or the effects can be universal as people are discriminated and face hurdle in getting equal opportunities(de Souza et al., 2018; Khan et al., 2025). As the consequences vary so are the strategies to the patients adopt to cope with the emotions and stress that comes along. Mlinar et al. (2021) conducted a qualitative phenomenological study of 22 individuals with epilepsy and found that beyond seizure symptoms, participants experienced major lifestyle changes, altered relationships, and significant limitations in daily life — which they termed "secondary factors" of burden. This highlights the importance of examining not only clinical factors but the broader psychosocial meaning of epilepsy, a focus that our study expands by exploring stress, stigma, and emotional adjustment within a specific cultural context. Fouad (2011)examined psychosocial and cultural dimensions of epilepsy, highlighted how social beliefs, stigma and non-medical impacts (such as on reproductive health and daily functioning) becomes a broader burden of epilepsy. A cross-sectional study conducted in Ethiopia found that stress was more prevalent among the patients who had to face more stigma in everyday life(Seid et al., 2023).

Fitri et al. (2024) found that among adults in Indonesia, 8 in 10 reported moderate stigma score. It further concludes that men are prone to experiencing stigma than women in their specific cultural and clinical context. In response to the persistent stress being found in patients with epilepsy, studies also explored how such patients employ strategies to cope with the stress and emotional imbalances. The literature shows that the coping strategies vary on the basis of culture, religion, gender and social background of the patients. For instance, a quantitative study conducted by Şenadım et al. (2021) found that gender, marital status, treatment type, and medical history shape coping behaviors among patients with epilepsy where women with epilepsy has higher acceptance of illness, they talk about emotional instability and hence try to cope with it as compares to men who rely on internal coping and avoid showing vulnerability due to societal expectations. However, while all these studies provide important quantitative data on stigma, it lacks identifying how patients understand epilepsy, and makes meaning surrounding it and try to cope with it. Hence, based on the objectives, the study employed Kleinman's explanatory model integrating it with Goffman's stigma theory and Lazarus & Folkman's Stress & Coping Model to understand how participants interpret their illness within culture, how people see their illness and it amplifies the experience of stress and how participants cope with that stress.

MATERIAL AND METHODS

We employed qualitative research design using interpretative phenomenological method because the study aimed not only to understand stress and stigma but also how the young adults make sense of this experience and do emotional adjustment within their cultural worldview. The study was conducted in Urban Muzaffarabad, Azad Kashmir. We recruited 9 participants, 5 females and 4 males. Purposive sampling was used to recruit potential participants as it helped us identity and reach the young adults diagnosed with epilepsy and snowball sampling was used as due to stigma and shame surrounding epilepsy, individuals are often hesitant in disclosing their information and so this helped us approach them through connections. The inclusion criteria comprised of: (1) young adults aged 18 to 35, as in this age adults usually experience major transition in education, employment and social identity(Arnett, 2000);(2) the duration of epilepsy was 2 to 5 years; (3) willing to participate in the interviews. The exclusion criteria were; (1) Patients or adults who had serious cognitive impairment due to epilepsy or had critical medical condition in which they were unable to speak or participate. The interviews were conducted from March, 2022 to October 2022. Before conducting the interviews with the adults, the verbal consent of the participants and their family was taken. All the interviews were conducted by one researcher. The place and time were chosen by participants. All of the participants chose their homes as per their comfort. Data were collected through in-depth semi structure interviews. Researchers visited participants for more than one time as per the availability of the participants.



interviews when more elaboration and clarification was needed to understand in depth the experience of the participants.

Table 1: Demographic characteristics of participants

	Gender	Age	Marital	Education	Duration of	Occupation
			Status	Level	Epilepsy (years)	
P1	Female	23	Divorced	BA student	7	University student
P2	Male	28	Married	Intermediate	8	Shopkeeper
P3	Female	30	Married	Secondary	3	Housewife
P4	Male	21	Single	Undergraduate	3	Student
P5	Female	32	Married	Primary	8	Housewife
P6	Male	26	Single	Bachelors	7	Private employee
P7	Female	27	Engaged	College	4	Private Madrassah
P8	Male	34	Married	Secondary	5	School teacher
P9	Female	25	Single	Intermediate	6	Tailor

Analysis:

Systematic steps of Interpretative phenomenological analysis as proposed by Smith, Flowers and Larkin(Tindall, 2009) were used to analyze the data, followed by idiographic approach that first focused on individual cases and then identified shared pattern across participants. The audio-recorded data inform of interviews were then transcribed and were read several times to gain deep familiarity with participants narrative, their emotions and to understand their context. Detailed observation was made during initial noting phase and emphasized on three types of comments, on what participants said (the descriptive), how it was said (including the tone, pauses and metaphors used) and the interpretative reflection of underlying meanings (the conceptual). To capture the essence of each participants lived experience, emerging themes were made from these detailed notes. These themes developed from each participants' notes were then compared and clustered into broader superordinate themes by identifying shared meaning and conceptual connection within each transcript. Throughout the interpretative phase, three theoretical lenses were integrated to deepen analysis: Kleinman's explanatory model guided the exploration of how participants culturally framed and made sense of their illness within local belief systems; Goffman's stigma theory informed the interpretation of how participants experienced, internalized, or resisted stigma in social interactions; and Lazarus and Folkman's stress and coping framework provided insight into how individuals appraised, managed, or redefined emotional stress associated with their condition. The combined use of these frameworks allowed a culturally grounded, psychologicalanthropological interpretation of illness narratives.

Researchers maintained reflexivity throughout the process through the use of a reflexive journal to acknowledge positionality, biases, and evolving interpretations, ensuring that participants lived realities remained central to the analysis.

RESULTS

1. Living Under the Shadow of Stigma

Findings reveal that participant in this study feel that living with epilepsy is like constant negotiating a sense of being different. Many participants expressed that they have the feeling of being watched and judged in a social circle. P 9, A 25 years old female participant said:

"hum chotay sy sheher me rehte hain, yahan sub ak doosre ko jantay han, agr me ksi ko nahi b janti tw ho skta ha wo mje jantay hon k mje ye bimari ha."

"This is a small city, and everyone is connected to each other by one or other way. Even if I don't know someone, they might know I am suffering from this disorder"

A 35 years old man said:

"Logo me jana prta ha.... Na chahte hue bhi, wrna baten bn jati han, k isy doray parte han."

"I have to socialize even if I don't want to, otherwise people gossip that I get fits"

The statement not only shows the challenge patients with epilepsy face in a social setting but also a constant struggle of proving themselves and others which can be overwhelming for patients and leads to stress and anxiety.

A28 years old married woman, a mother of two children told:

"mere bacho ko kaha jata ha k is sy door rehna, isy jinn atay han, ye nuqsan kr de gi"

My kids are told that they should avoid me as I am being possessed by evil spirit and can harm them.



The statement carries the embodied pain of a mother whose children are asked to avoid her. She carries the weight of not only social rejection but also rejection from her own children, and the stigma whose effect goes beyond her. The seizures are seen and projected on the patients as possession by evil spirits result to isolation and fear.

Living in a close-knit society like Muzaffarabad, where people are closely related with each other, shape identity and affect people everyday life.

1.1 Feeling "Different" and Socially Watched

Participants described a heightened self-awareness and discomfort in public spaces due to fear of judgment or pity. "Jb me family gathering me hoti hu, logo ki nazren chubhti han, kcuh bechargi se dekjhte hain..... tars wali nazro sy, yaa shayd mje esa lagta ha aur wo esa Nahin sochte ho"

"When I attend family gatherings, peoples' eyes pierce me, some pity me... or may be its me who think this way and they don't think like that."

The excerpt reflects the weight of perceived stigma. Her words, eyes pierce through reveals the embodied nature of stigma where she actually experience is almost physical like a pain. And even when the participant accepts that "maybe they don't think that way" reflect how years of social judgment effects, how an individual internalizes when he made to feel and start seeing him/her in a same way.

1.2 Concealment as Survival

Many participants said that they deliberately hid their condition from peers or employers to avoid discrimination and labeling, but still found it hard to keep it hidden because of unpredictable seizures. P7, an unmarried female who work in a private school said:

"Me regular medicine leti hu, takay seizures control rhen lekkin phr b har waqt dar lga rehta hai k kabi workplace pay attack na ajaye"

"I take regular medicine to control the seizures... since its unpredictable and so all the time at work place, I am afraid I don't get it here".

Another participant, P8, 34 years old married man working as a labor in a construction company told that,

"ye bimari ksi sy chupai nai ja skti... kiun k phr log sochte hain Jinn hain is k sath aur avoid krte hain...is lye btana prta ha k Mirgi hai, koi jinn wagera nai"

"This disease cannot be kept hidden from peer group, because then people think he is possessed by spirits and they avoid you... so one has to tell that its epilepsy and not any spirit possession".

This illustrates how the epilepsy keeps the person in a state of uncertainty and a constant vigilance that leads to anxiety and restlessness hence affecting not only emotional and mental wellbeing but also govern his everyday life. The second statement shows the intertwines of social stigma and supernatural explanation of the disease, that force an individual to disclose their condition as a medical reason so people don't misinterpret it and avoid them.

1.3 Internalized Shame and Self-Stigma

The negative societal attitudes gradually shaped self-perception, leading to a feeling of inferiority or a guilt. P1, A 23 years old divorced female told her story of a divorce that how her own fraternal cousin divorced her just within few months of marriage, she said:

"mujhe shadi nai krni chiayeh thee, me normal life nai guzar skti, is baat ka andaza hona chaiyeh tha. Ab me kabi shadi nai kru gi, sirf prhu gi, job kru gi aur independent ho jaun gi"

The expression of a young female student and a divorcee reflect a deep internalized guilt that led to self-stigmatization resulting from her bad experience in marriage. Her words, "mujhe shadi nai krni chiayeh thee" (I shouldn't have gotten married) reveals how she sees herself through the lens of how people made her feel throughout her condition especially how she was being stigmatized in her marriage. At the same time her resolve to be independent reflect her adaptive response to her condition that had her redefining her identity and womanhood through embodying strength in the response of her hardships.

Another respondent, P8 male, 34 years old expressed:

"main khandan ki shadiun wagera me nahi jata... naa he ghar walay mje force krte hain, unhen b pta ha aur me b janta hu k ese insan k lye situation ka kuch pta nahi hota, me sharmindagi ka baais nahi banna chahta un k lye, is lye avoid krta hu..... hala k mje mirgi ka dora itna shadeed nai hota, lekin phr bhi, me nahi chahta log mj pay tars khayen"

"I don't attend family weddings etc, nor my family forces me to attend, they also understand as me that my situation is unpredictable, I don't want to be cause embarrassment for them, so I avoid it.... although my situation doesn't get that much worse, but still, I don't want people to pity me"

The narrative from participant illustrates the internalization of the societal attitudes toward epilepsy in which patient self-attributes himself as harmful that can damage family's reputation by bringing shame to them, hence isolate themselves from social gatherings. Moreover, the participant explicitly rejects sympathy from others "I still don't want people to pity me", that demonstrates an active negotiation of social identity. This shows a psychological strategy to preserve dignity and maintain autonomy, even within the constraints of a stigmatized condition.



2. The Cultural Context of Epilepsy

2.1 Traditional Beliefs and Misattributions

Participants narratives found similar to the long existing beliefs surrounding epilepsy that is embedded in cultural and spiritual understanding of the disease especially in countries of Asia and Africa(Cavanna et al., 2010; DeToledo & Lowe, 2003; Kaculini et al., 2021). Though many participants believed it's a disease, many also acknowledged spiritual (divine will) and supernatural (evil eye, magic, possession of spirits/Jinn) influence in its onset or persistence. As, told by a respondent:

"logo ne kaha mere andr Jinn hain.... Aur mere parents ko btaya k usy Peer k pas le kr jayen... Kuch mera Mazak b urate hain family me, k mje Jin atay han... Meri waalidah mje Peer k pas le kr gyin, un ne mje taweez dia galay me pehnne k lve"

'They said, I am possessed... and told my parents to take me to a Peer.... Some would make fun of me by saying, 'She gets Jin'". My mother used to take me to Peer, he gace me an amulet to wear"

Through Goffman's stigma theory (1963), this experience reflects the social labeling process in which the individual becomes "discredited" because the visible symptoms of epilepsy are reinterpreted as moral or spiritual weakness. The mocking tone ("She gets Jin") as narrated by respondent, reflects the public stigma that reinforces exclusion and emotional distress. Such labeling not only affects social relationships but also contributes to internalized stigma and self-consciousness, impacting psychological wellbeing. At the same time, Lazarus and Folkman's stress—coping framework (1984) helps explain the participant's adaptation. Despite being subjected to ridicule and alternative healing practices, the act of wearing an amulet or visiting a *Peer* can be seen as a cultural coping mechanism, which helped participant's family to regain a sense of control during unpredictable illness.

3. Emotional Turbulence and Psychological Stress

Participants shared how stigma, judgment of others, and the challenges that come along with managing a chronic condition contribute to psychological stress, affecting their daily life, social interactions, and overall emotional well-being. The following excerpts illustrate how these stressors reflect in participants lived experiences.

3.1 Fear of Seizures and Loss of Control

Anxiety stemmed from unpredictability and embarrassment associated with seizures especially in women. "mujhe har time ye tension rehti ha k agr me Kahin bahir hue aur mje attack aya tw meri chadar na utar jye sir sy, ya mje koi mard na, Naa Mehram, hath lga de smbhalne k gharz sy... is dar ki wja sy me koshish krti hu k bahir akeli na jaun"

The excerpt highlights how when epilepsy intersect with gender norms and stigma amplifies deep psychological burden where her fear is both physical and social. She is not worried about her health as much as she is worried about the violation of cultural and religious norms that can lead to misinterpretation and shaming by public. In result to this she limits her exposure to outside world and restrict her movement to public places. For her epilepsy is no remain a medical condition but it has become a lens through which social vulnerability, shame, and fear of judgment constantly mediate her daily action.

I have this fear that if I am outside in a public place and I get seizure, God forbidden, anyone would see me bare-head or I don't get touched by any man. Due to all this fears, I try not to step out of home alone.

3.2 Struggling Between Dependence and Autonomy

Participants described tension of becoming burden emotionally, socially and financially on family members and in some cases on friends. Some participants expressed a strong desire to become independent and make decisions for themselves, yet found that social structures, family control, and cultural expectations limited their ability to exercise autonomy. Despite their aspirations, they experienced frustration and emotional tension because they were not empowered to act independently in daily life.

Conversely, in some cases, particularly of women, they did not articulate a sense of dependency, even when their circumstances placed them in dependent roles. For these women being cared for or controlled by family members was normalized and accepted, suggesting that the internalization of cultural expectations can sometimes mask feelings of restriction, making dependency invisible to the individual.

4. Coping, Meaning-Making, and Emotional Adjustment

This theme explores how participants attempted to rebuild psychological stability and self-worth.

4.1 Spiritual and Religious Coping

Many participants turned to faith, prayer, or belief in destiny as emotional anchors. P9, A 27 years old female participant who is an Aalima Fazilah and also teach in religious center (Madrassah) said:

"Ap yakeen Nahin kren gy, lekin jb sy mene ye maan lia ha k is me Allah ki raza hai, mje depression nahin hota, mje ye soch nhi aati k log kya sochte hain aur un ka kya rawaiya hai meri tarf. Me khush rehti hu is bimari k sath bhi. Madrassah me parhati hu bacho ko. Isi me Ilaaj dhund lia ha".



"You won't believe but since I have accepted that its Allah's will. I don't feel depress anymore, nor I even think what people think about me and their behavior towards me. I stay happy even with this illness. I teach in Madrassah and have found healing in this."

The participant's narrative reflects acceptance through faith as a transformative coping strategy. By interpreting her illness as Allah's will, she reconstructs her relationship with epilepsy — from one of helplessness and social vulnerability to one of spiritual empowerment and emotional peace. Her reliance on divine purpose not only reduces psychological distress (depression, social anxiety) but also allows her to detach from the weight of societal judgment. Her statement, "I've found my healing in teaching children at the madrassah," reveals how religious engagement provides both emotional regulation and a sense of agency. The act of teaching in a religious institution becomes a form of active coping, merging spirituality with social contribution. The common practices found among humans from different religions, where people when find no hope or in a state of helplessness, devote themselves to the supernatural or divine power, in order to seek guidance and light(Balamir & Yılmaz, 2025). Previous study has also indicated that religious practices and spirituality have positive effects on the life of patients with epilepsy(Fu et al., 2025; Sarpdağı et al., 2025). A study conducted by Başak and colleagues(2025) showed that internal spirituality in individuals with epilepsy has a positive relationship with psychological resilience and a negative relationship with hopelessness. These results indicate that spirituality or religious elements contribute to individuals' emotional empowerment and thus mitigate the negative emotional consequences that the stigma may cause.

4.2 Reframing Identity Beyond Illness

Some participants began to accept epilepsy as part of their identity rather than its definition. P4, 21 years old student, pursing degree from university said:

"mujeh pichle 5 saal sy mirgi ha, jb mje smjh b nai the k mje kya hota ha, kiun hota ha. lekin ab kaafi awareness agyi ha is k baray me. Me dawai leta hu regular aur hr tra ki care krta hu, Peer, faqeer k pas b jata hu aur doctors ko b consult krta hu....Me ghar ka bara hu, mere sir pay zimmedari hai, is lye me ab is k baray me nai sochta. Agr ye kabi theek na hua tw Zindagi ka hissa rhe ga."

"I have epilepsy for past 5 years now when I wasn't even aware, what was happening to me and why? But now I know a lot about it. I do take medicine and take all the necessary care I can, visit Peer, Faquer and also consult medical specialists......I am elder one in my home and being an elder one I have many responsibilities, that's why I don't think much about it. If it's not going to cure, it will be a part of my life.

The statement of the participant reflects a shift from the phase of confusion during early stage of illness when patient experience biographical disruption and feel helplessness and no control over his body, to the stage when he realizes that it's beyond his control and so he cannot do anything about it. With the passage of time as participant got enough knowledge and awareness about his disease ("now I know a lot about it") he adhered to biomedical treatment. "I do take medicine and take all the necessary care I can, visit Peer, Faquer and also consult medical specialists"), and also adopts a pluralistic help-seeking strategy that combines traditional as well as religious and biomedical resources. The plural help-seeking is integrative as it reflects a culturally embedded explanatory model in which spiritual and medical routes coexist as complementary ways to manage illness. His words, "I am elder one in my home and so have responsibilities" represents a person's strength and a coping strategy of positioning himself more than a patient, a family member whose role and obligations transcend his condition.

CONCLUSION:

Findings revealed that stigma and misunderstanding continue to shape the psychosocial realities of individuals living with epilepsy. Participants described facing discrimination, labeling, pity, and social exclusion, particularly in social and marital contexts that led to self-exclusion as a coping management in some cases. The internalization of stigma often resulted in self-doubt, reduced self-esteem, and emotional withdrawal, reflecting concept of "spoiled identity" (Goffman, 2022). However, unlike earlier literature that portrays stigma as solely disempowering, this study found that participants navigated stigma with diverse coping strategies—spanning religious acceptance, cognitive reframing, and role redefinition—demonstrating an active, agentive engagement with their condition. A second key finding was the central role of religious coping in fostering acceptance and emotional stability. Many participants framed epilepsy as part of Allah's will, reinterpreting their suffering through faith. This meaning-making process significantly reduced psychological distress and transformed illness from a source of despair to one of spiritual growth and resilience. For instance, female participants often described engaging in prayer, Our'anic teaching, or service at the madrassah as forms of "healing through purpose." Such coping aligns with Lazarus and Folkman's (2017) stress and coping model, which emphasizes the significance of cognitive appraisal and meaning-making in emotional adjustment. In contrast, men often internalized stress silently, relying on self-control, responsibility, and emotional suppression due to societal expectations of masculine strength. This reinforces prior evidence that gender norms significantly shape stigma, emotional adjustment, and coping pathways in this region (Khan & Gillani, 2025).



A third dimension that emerged was identity reconstruction and role continuity. Participants, particularly male respondents, often emphasized their familial duties and responsibilities as central to their self-concept. By identifying as caretakers, providers, or educators rather than patients, they reframed their identities beyond illness. This shift reflects a redefinition of self that integrates epilepsy as one aspect of life rather than its defining feature—an insight consistent with theories of narrative identity and chronic illness adaptation (Charmaz, 2010).

Overall, the findings underscore that emotional adjustment among young adults with epilepsy is a culturally embedded process, mediated by family structure, religious worldview, and community norms. Whereas previous research has largely centered on clinical symptoms or the psychological impact of stigma, this study highlights the interpretative and cultural dimensions of coping and adjustment—how people with epilepsy actively construct meaning and reclaim agency in the face of social marginalization.

From a methodological standpoint, the use of Interpretative Phenomenological Analysis proved particularly suited to this inquiry, as it enabled the nuanced exploration of inner meanings and lived realities often overlooked in quantitative paradigms. The idiographic focus allowed themes such as "reframing identity beyond illness" and "faith as emotional healing" to emerge organically from participants' own language and interpretations.

In conclusion, this study contributes to psychological and anthropological understandings of chronic illness by illustrating how young adults with epilepsy negotiate between social stigma and self-acceptance through culturally grounded coping strategies. It suggests that psychological interventions and community health programs must consider spiritual beliefs, family support, and cultural meanings to foster holistic adjustment. Future research may expand this work by integrating longitudinal qualitative approaches or participatory frameworks to further explore how meaning-making evolves across the illness trajectory. Ultimately, the study affirms that for many individuals, living with epilepsy is not a narrative of limitation but one of resilience, reinterpretation, and identity transformation—where faith, responsibility, and understanding replace fear, stigma, and isolation.

Declarations

Ethical Approval

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.

Consent for publication

Verbal consent was obtained from all participants for their involvement in the study. Confidentiality was maintained by not disclosing the names of the participants in the paper.

Competing interests

It is declared that the authors have no competing interests

REFERENCES:

- 1. Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. American Psychologist, 55(5), 469–480. https://doi.org/10.1037/0003-066X.55.5.469
- 2. Balamir, F., & Yılmaz, S. (2025). Religious Healing in the Modern World: Faith, Culture, and Social Dynamics. Religions, 16(7), 883. https://doi.org/10.3390/rel16070883
- 3. Başak, S., Turan, G. B., Özer, Z., & Tan, M. (2025). The relationship between intrinsic spirituality, resilience and hopelessness in patients with epilepsy: A PATH analysis. Epilepsy & Behavior, 163, 110230. https://doi.org/10.1016/j.yebeh.2024.110230
- 4. Biggs, A., Brough, P., & Drummond, S. (2017). Lazarus and Folkman's Psychological Stress and Coping Theory. In The Handbook of Stress and Health (pp. 349–364). Wiley. https://doi.org/10.1002/9781118993811.ch21
- 5. Boling, W., Means, M., & Fletcher, A. (2018). Quality of Life and Stigma in Epilepsy, Perspectives from Selected Regions of Asia and Sub-Saharan Africa. Brain Sciences, 8(4), 59. https://doi.org/10.3390/brainsci8040059
- 6. Cano-López, I., Hidalgo, V., Hampel, K. G., Garcés, M., Salvador, A., González-Bono, E., & Villanueva, V. (2019). Cortisol and trait anxiety as relevant factors involved in memory performance in people with drug-resistant epilepsy. Epilepsy & Behavior, 92, 125–134. https://doi.org/10.1016/j.yebeh.2018.12.022
- 7. Catalán-Aguilar, J., González-Bono, E., & Cano-López, I. (2025). Perceived stress in adults with epilepsy: A systematic review. Neuroscience & Biobehavioral Reviews, 170, 106065. https://doi.org/10.1016/j.neubiorev.2025.106065
- 8. Cavanna, A. E., Cavanna, S., & Cavanna, A. (2010). Epileptic seizures and spirit possession in Haitian culture: Report of four cases and review of the literature. Epilepsy & Behavior, 19(1), 89–91. https://doi.org/10.1016/j.yebeh.2010.07.002
- 9. Charmaz, K. (2010). Studying the Experience of Chronic Illness through Grounded Theory. In New Directions in the Sociology of Chronic and Disabling Conditions (pp. 8–36). Palgrave Macmillan UK. https://doi.org/10.1057/9780230297432 2



- de Souza, J. L., Faiola, A. S., Miziara, C. S. M. G., & de Manreza, M. L. G. (2018). The Perceived Social Stigma of People with Epilepsy with regard to the Question of Employability. Neurology Research International, 2018, 4140508. https://doi.org/10.1155/2018/4140508
- 11. DeToledo, J. C., & Lowe, M. R. (2003). Epilepsy, demonic possessions, and fasting: another look at translations of Mark 9:16. Epilepsy & Behavior, 4(3), 338–339. https://doi.org/10.1016/S1525-5050(03)00038-6
- 12. Fitri, F. I., Fitri, A., Nasution, A. N. Z., Kadri, A., & Dachi, O. A. (2024). Factors Associated with Internalized Stigma in People with Epilepsy: A Hospital-based Study in Medan, Indonesia. Archives Of Epilepsy. https://doi.org/10.4274/ArchEpilepsy.2024.24136
- 13. Fouad, H. (2011). Psychosocial and Cultural Aspects of Epilepsy. In Novel Aspects on Epilepsy. InTech. https://doi.org/10.5772/17530
- 14. Fu, Q., Huang, Y., & Liu, D.-F. (2025). Assessment of psychological resilience in adult patients with epilepsy: a cross-sectional study. Acta Neurologica Belgica, 125(5), 1309–1317. https://doi.org/10.1007/s13760-025-02856-2
- 15. Goffman, Erving. (2022). Stigma: notes on the management of spoiled identity. Penguin Classics.
- 16. Jacoby, A. (2002). Stigma, epilepsy, and quality of life. Epilepsy & Behavior, 3(6), 10–20. https://doi.org/10.1016/S1525-5050(02)00545-0
- 17. Kaculini, C. M., Tate-Looney, A. J., & Seifi, A. (2021). The History of Epilepsy: From Ancient Mystery to Modern Misconception. Cureus, 13(3), e13953. https://doi.org/10.7759/cureus.13953
- 18. Khan A, & Gillani N. (2024). Epilepsy (Mirgi) Among Adults of Muzaffarabad: An Anthropological Perspective. Social Science Review Archives, 2(2), 2217–2233. https://doi.org/10.70670/sra.v2i2.392
- 19. Kwon, C., Jacoby, A., Ali, A., Austin, J., Birbeck, G. L., Braga, P., Cross, J. H., de Boer, H., Dua, T., Fernandes, P. T., Fiest, K. M., Goldstein, J., Haut, S., Lorenzetti, D., Mifsud, J., Moshe, S., Parko, K. L., Tripathi, M., Wiebe, S., & Jette, N. (2022). Systematic review of frequency of felt and enacted stigma in epilepsy and determining factors and attitudes toward persons living with epilepsy—Report from the International League Against Epilepsy Task Force on Stigma in Epilepsy. Epilepsia, 63(3), 573–597. https://doi.org/10.1111/epi.17135
- 20. Malik, N. I., Fatima, R., Ullah, I., Atta, M., Awan, A., Nashwan, A. J., & Ahmed, S. (2022). Perceived stigma, discrimination and psychological problems among patients with epilepsy. Frontiers in Psychiatry, 13. https://doi.org/10.3389/fpsyt.2022.1000870
- 21. Mehndiratta, M., & Wadhai, S. (2015). International Epilepsy Day A day notified for global public education & warp; awareness. Indian Journal of Medical Research, 141(2), 143. https://doi.org/10.4103/0971-5916.155531
- 22. Michaelis, R., Tang, V., Goldstein, L. H., Reuber, M., LaFrance, W. C., Lundgren, T., Modi, A. C., & Wagner, J. L. (2018). Psychological treatments for adults and children with epilepsy: Evidence-based recommendations by the International League Against Epilepsy Psychology Task Force. Epilepsia, 59(7), 1282–1302. https://doi.org/10.1111/epi.14444
- 23. Mlinar, S., Rener Primec, Z., & Petek, D. (2021). Psychosocial Factors in the Experience of Epilepsy: A Qualitative Analysis of Narratives. Behavioural Neurology, 2021, 1–9. https://doi.org/10.1155/2021/9976110
- 24. Qin, S., Yang, Z., Guan, Z., Zhang, J., Ping, X., Lu, Y., & Pei, L. (2022). Exploring the association between epilepsy and depression: A systematic review and meta-analysis. PLOS ONE, 17(12), e0278907. https://doi.org/10.1371/journal.pone.0278907
- 25. Ranjan, L. K., Gupta, P. R., & Srivastava, M. (2022). Perceived Stigma and Its Association With Stress, Anxiety, and Depression Among Patients With Epilepsy. Journal of Nervous & Mental Disease, 210(3), 219–222. https://doi.org/10.1097/NMD.000000000001431
- 26. Räsänen, O., Järvinen, M., & Rinne, A. (1978). Localization of the human SH-protease inhibitor in the epidermis. Immunofluorescent studies. Acta Histochemica, 63(2), 193–196. https://doi.org/10.1016/S0065-1281(78)80025-7
- 27. Sarpdağı, Y., Kiraz, M., Örün, M. O., Sir, Ö., Kaplan, E., Atan, K., Çiftci, N., & Yıldız, M. (2025). The role of psychological well-being in the effect of spirituality on stigma in individuals with epilepsy. Seizure: European Journal of Epilepsy, 133, 128–136. https://doi.org/10.1016/j.seizure.2025.10.005
- 28. Scott, A. J., Sharpe, L., Thayer, Z., Miller, L. A., Nikpour, A., Parratt, K., Wong, T., & Gandy, M. (2021). How frequently is anxiety and depression identified and treated in hospital and community samples of adults with epilepsy? Epilepsy & Behavior, 115, 107703. https://doi.org/10.1016/j.yebeh.2020.107703
- 29. Seid, J., Gebrehiwot, B., Andualem, F., Kassaye, A., Mohammed, J., & Akele, M. (2023). Factors associated with stress-related symptoms among people with epilepsy in Ethiopia, a cross-sectional study. Frontiers in Neurology, 14. https://doi.org/10.3389/fneur.2023.1218448
- 30. Şenadım, S., Alpaydın Baslo, S., Uygun, E., Erdoğan, M., Balçik, Z. E., Tekin, B., & Ataklı, D. (2021). The strategies for coping with stress of epilepsy patients. Neurological Sciences, 42(10), 4265–4270. https://doi.org/10.1007/s10072-021-05372-2





- 31. Tanywe, A., Matchawe, C., & Fernandez, R. (2016). The experiences of people living with epilepsy in developing countries. JBI Database of Systematic Reviews and Implementation Reports, 14(5), 136–192. https://doi.org/10.11124/JBISRIR-2016-002182
- 32. Tindall, L. (2009). J.A. Smith, P. Flower and M. Larkin (2009), Interpretative Phenomenological Analysis: Theory, Method and Research . Qualitative Research in Psychology, 6(4), 346–347. https://doi.org/10.1080/14780880903340091
- 33. Tombini, M., Narducci, F., Ricci, L., Sancetta, B., Boscarino, M., Quintiliani, L., Lanzone, J., Straffi, M., Di Lazzaro, V., & Assenza, G. (2024). Resilience and psychosocial factors in adult with epilepsy: A longitudinal study. Epilepsy & Behavior: E&B, 154, 109746. https://doi.org/10.1016/j.yebeh.2024.109746
- 34. Trinka, E., & Lee, B. (2019). Epilepsy in Asia. Epilepsia, 60(S1), 5–6. https://doi.org/10.1111/epi.14507