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Epilepsy and Everyday Life: A Gendered Perspective from Urban Muzaffarabad (AJ&K).

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ABSTRACT

Epilepsy is a chronic neurological disorder that affects beyond seizures, but also affects the social, emotional, and cultural aspects of a person's life. This study was intended to explore the connection between gender roles and epilepsy and how the gender roles defined by culture affect individuals' experiences and capabilities of coping living with epilepsy. The study involved young men and women from urban female and male patients living in District Muzaffarabad of Azad Jammu & Kashmir, looking specifically into how epilepsy affects daily functioning, emotional expression, family roles and social inclusion. A descriptive qualitative method developed for documentary studies was used by interviewing 11 participants (6 males, 5 females) in open-ended, semi-structured interviews. Findings indicated very different gendered responses to living with epilepsy, where women have family-based emotional support, but find difficulties when it comes to marriage and motherhood, as well as stigma. In contrast, men, must maintain an emotional silence due to societal pressures of toughness and ruggedness, so psychological burdens remain unexpressed and unexamined. By recording their experiences, these findings bring attention to the social inequalities that stem from gendered responses to epilepsy that amplify the effects of having a chronic illness. They have implications for designing gender-sensitive health care policy, as well as culturally relevant interventions and support for those living with epilepsy.

Keywords: *Gender and Epilepsy, Epilepsy, Epilepsy and wellbeing, Women with epilepsy, Men with Epilepsy*

INTRODUCTION

Illnesses like epilepsy are influenced by many socio-economic factors, including gender, and its different depth(s) (Mezulis & Harding, 2016). Studies indicate that epilepsy affects men and women differently (Yue, et al., 2011). In light of this, scholars argue for analyzing intersections with other determinants - i.e., race, socioeconomic status, cultural context - to assess the impact of epilepsy (Luef, 2009; Pennell & Thompson, 2009).These intersecting factors often shape individuals' experiences with epilepsy, influencing how the condition is perceived, managed, and treated. Marginalized communities, especially from South Asia in particular encounter additional obstacles in accessing adequate healthcare and support systems (Beghi, 2020). According to the literature, epilepsy remains a widespread condition, and in Pakistan, its prevalence has been estimated at 9.99 per 1,000 individuals (Tanveer, et al., 2022).

Global incidence of the disease shows that about 50 million individuals are impacted by this condition globally with almost 90 % individuals with this condition are residing in developing regions (WHO, 2024). 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 (Guerrant J, 1962). 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 (Volker Rode, 2011) which in turn affects quality of life. Many epidemiological studies have revealed that each of the major determinants of quality of life: employment, social interactions, family relationships, and experiential activities, are at considerable risk in patients with epilepsies (Sherman, 2009).

People with epilepsy are generally found to have fewer social supports compared to those without this condition, are less likely to marry, have fewer children (Merja Jalava, 1997) have lower rates of employment (Tara W. Strine, 2005) and cite lack of social engagement and difficulty in developing satisfying interpersonal relationships as common problems (Bettina K. Steiger, 2016). Moreover, people with epilepsy also face a lot of challenges in daily life including lower levels of education, reduced household income, unemployment, poor health, more disability, and more risky behaviors (Trinka, Kwan, Lee, & Dash, 2018). People with epilepsy are also more likely to perceive limitations in social and emotional support, which along with dissatisfaction with other aspects of life can lead to a decrease in overall life satisfaction (Malvaso & Kang, 2022).

Besides the above-mentioned psychological factors, neurological factors have adverse impacts on the quality of life in people with epilepsy (Hermann & Jacoby, 2009) as well. While commonly used quality-of-life instruments for epilepsy have been applied in clinical settings and formally document patient concerns (Yogarajah & Mula, 2019), much less is known about the relationship of epilepsy and life satisfaction in community-dwelling adults. 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 (Hanneke M.de Boer, 2008). In The Netherlands, children seem to have lower school attendance and performance (Carpio, 2002). 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).

Epilepsy affects individuals of all genders, but women with epilepsy (WE) face distinct challenges, including issues related to sexual and reproductive health such as pregnancy, lactation, menopause, contraception, and mental health concerns (Pallerla Srikanth, 2021). They are also more likely to encounter a range of psychosocial difficulties, including balancing family responsibilities, conception-related concerns, adverse pregnancy outcomes, poor adherence to medication, and unfavorable marital outcomes (Santosh Bangar, 2016). In middle-income countries, the burden is further intensified due to widespread stigma encountered at various stages of life (Fawale MB, 2014). While stigma and negative attitudes affect all individuals living with epilepsy, emerging research indicates that women may be particularly vulnerable to poverty, social exclusion, marital disruption, and inadequate access to medical care (Birbeck, Chomba, Atadzhanov, Mbewe, & Haworth, 2009).

Prior studies in Pakistan have shown that gendered perceptions and cultural taboos significantly shape health awareness and treatment behavior. For instance, Khan, et al (2023) conducted a systematic review on sexually transmitted diseases, revealing how women often face barriers to information due to social stigma, and men exhibit misconceptions rooted in cultural norms. These dynamics are not limited to reproductive health but also affect chronic neurological conditions like epilepsy Allotey’s study on perceptions of people with epilepsy in rural Cameroon also highlights the adverse effects on women’s marital lives, noting that all the female participants in the study were separated and residing with their parents (Pascale & Daniel, 2007). Although several studies have documented the psychosocial challenges faced by people with epilepsy in Nigeria (Imam , Talabi, Sanya, & Ogunniyi, 2003) few have specifically addressed the gendered disparities in these experiences.

While previous studies have extensively examined the quality of life of patients with epilepsy, there remains a notable gap in understanding the subjective wellbeing of male and female patients with epilepsy. Existing research has primarily focused on objective measures of quality of life, such as seizure frequency, medication adherence, and functional limitations. However, there is limited insight into how epilepsy uniquely influences the subjective experiences, emotions, and overall wellbeing of individuals, particularly in relation to gender differences. In an earlier anthropological investigation conducted in Muzaffarabad, Khan, AH & Gillani, N; (2024) examined how epilepsy ("Mirgi") is perceived and experienced by adults in the same region. Building on those findings, the current study aims to explore the intersection of gender roles and epilepsy, examining how culturally defined gender expectations shape the experiences and coping mechanisms of patients living with this condition.

Intersectionality, as conceptualized by Kimberlé Crenshaw, is used in this study to understand how overlapping social identities and structural inequalities shape the lived experiences of individuals with epilepsy. Through this framework we can dig deep to explore the effects of the intersecting factors such as socio-economic status, disability and cultural context on the perception as well as the management of epilepsy. Crenshaw's work emphasizes that individuals do not experience social categories like gender or health status in isolation. Rather, their experiences are shaped by the intersections of multiple identities, which can create complex and compounded forms of marginalization or privilege (Crenshaw, 1991). Within this study, applying an intersectional lens revealed how these intersecting identities influence access to healthcare, availability of social support, stigma, and overall wellbeing for both male and female participants.

MATERIAL AND METHODS

Study Design

This study employed a qualitative descriptive design, grounded in gender theory and intersectionality. The objective was to explore how gender intersects with chronic illness—in this case, epilepsy—to shape the lived experiences, coping strategies, and subjective well-being of male and female participants in Muzaffarabad, Azad Kashmir. Semi-structured, open-ended interviews were conducted with 11 individuals (6 men and 5 women) to allow participants to express their experiences in their own words. This method allowed a contextualized understanding of aspects related to gendered difference in formulation of health self-management supports, stigma, and social support while maintaining some closeness to participants' context and narrative.

Selection of the Participants

Purposive sampling was used to identify participants to obtain a heterogeneity of gender, age, socioeconomic background, and cultural perspectives. The inclusion criteria required that both male and female participants had experienced a diagnosis of epilepsy for greater than 10 years and were between 18 and 45 years of age. The age range of 18 to 45 years was purposely selected because it would focus on persons within their socially and economically productive years, while seeking to better understand the consequences of living with epilepsy on personal, social, and economic/professional lives. The participants were recruited from urban districts of Muzaffarabad which provided the participants a contextually-similar experience based on access to urban healthcare as well as social/cultural settings. Eleven participants were involved in the study, the participants included both patients and family members providing direct care or emotional support to the patients. The registration of participants was hampered by the presence of stigma surrounding epilepsy in the region, making it very difficult to identify willing participants, and therefore the sample size was limited despite several extensive efforts to recruit participants in the field.

Interview Protocol

The interview protocol included a set of open-ended questions and probes designed to elicit rich narrative responses related to gender roles, the experiences of participants, social support they gain and emotional wellbeing. Questions were tailored to each participant's unique experiences and cultural background, ensuring relevance and depth in the data collected. The interviews were conducted from 11 total informants, using snow balling technique. The interviews with the participants were conducted between January 2023 and August 2023 at various locations across Muzaffarabad city. The place and the time of the interviews was chosen by the participants themselves. The prior consent was taken and the purpose of the study was explained to the participants. Each interview took 30 to 50 minutes.

Data Analysis

Thematic analysis was employed to analyze 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 intersectionality of gender, wellbeing, and epilepsy in the context of Muzaffarabad.

Limitations

Limitations of the study included potential biases in participant selection, reliance on self-reported data, and the contextual specificity of the findings to the Muzaffarabad region. There were some constraints researchers had to face while conducting the research. Some were related to the record of patients with epilepsy, as hospitals had very limited data of the patients diagnosed with epilepsy. Some caregivers of the patients with epilepsy, mostly of female, didn’t allow interviewing them due to the social stigma associated with the disease. However, efforts were made to mitigate these limitations through rigorous data collection and analysis procedures.

Demographic Characteristics of Population

Out of the eleven participants in the study, six were men and five were women. At the time of the interviews, five participants were married, while two were legally divorced—one man and one woman. Additionally, one woman reported being separated from her husband and currently residing with her natal family. Regarding employment status, three men were engaged in low-income jobs primarily for survival, and one man was working abroad. Among the women, two were employed—one as a nurse and the other as a religious teacher in a madrassah (Islamic school). The remaining participants were either unemployed or dependent on family support.

Participants were eligible for inclusion in the study if they had been diagnosed with epilepsy and had experienced at least one seizure in the past two years or were currently seizure-free. In 70% of the cases, epilepsy was diagnosed by a hospital consultant, while the remaining 30% were diagnosed by general practitioners. The average duration since diagnosis was five years for the majority, while five participants had lived with epilepsy for more than ten years, including cases of congenital epilepsy. The interval since the last seizure episode ranged from two days to twelve years; one participant could not recall their most recent seizure.

Socio Demographic details of the participants:

Variable	Value(N=11)	Frequency
Education		
Illiterate	03	27.2%
Literate	08	73%

Marital status		
Single	03	27.2%
Married	05	45.4%
Divorced	03	27.2%
Having children (out of 14)		
Yes	03	27.2%
No	08	73%
Occupation		
Unemployed	05	45.4%
Employed (Men)	04	36.3%
Women	02	18.1%
SES		
Low	03	27.2%
Middle	06	54.5%
High	02	18.1%
Seizure frequency		
Once in less than 2 weeks	04	36.3%
Once in a month	03	27.2%
Once in 2–3 months	04	36.3%

Shame/breaking Taboo:

A university girl who was pursuing masters in social sciences and is a 2nd year student explained that she doesn't feel comfortable in going out or even in university because of the fear that who will be the first person to touch me and weather her head will be covered or not and who will take care of her. Because as a Muslim, no man is supposed to touch a woman and there is a fear of physical exposure which is prohibited in religion as well as in society and if anyone experience it, that can bring shame to them and to their family. Where as in case of man situation is quite normal. Men don't have this concern; all they are concerned is their health and the first aid to be given.

"*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.*"
Another response from 27 years old unmarried woman, who was teaching in a religious centre (Madrassah), told:

"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"

The participants' anxieties surrounding modesty and physical contact during seizures reflect the complex intersection of gender, culture, and health in Muslim societies. While not all women in these communities are required to observe strict veiling or purdah in everyday life, there remains a strong cultural expectation that women should maintain modesty and composure, especially in the presence of non-related men (na-mahram). This expectation becomes a source of distress for women with epilepsy, who fear the loss of bodily control and exposure during a seizure.

The idea of being seen in a disoriented or physically exposed state—such as having one's head uncovered, clothes disarranged, or receiving physical assistance from male bystanders—can evoke shame, not only for the individual but also for her family. These gendered anxieties create practical barriers to receiving immediate and appropriate care, as hesitation or delays in intervention may occur due to cultural discomfort around physical contact between

Living with Epilepsy

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 (Moselhy, 2011).

Participants described about their overall experience with epilepsy and their dealing with it. They were asked about their self-perception related to the disease or how they feel about it. 6 out of 11 participants, among whom 4 were female with age between 23 to 32 told that they are still not aware if it is a disease or they are possessed by some spiritual power, as they were told by relative and other family members. Female participants seemed to be less aware of their disease; they more rely on what family and other people tell them about the seizure attacks. The conversation I had with one of the respondents was transcribed as:

Researcher: Do you remember what actually happened when you had seizure?

Respondent: *“I don’t remember anything, they said I got an attack, some said I am possessed by some evil spirits and some said I am cursed.”*

Researcher: Do you know about the seizure or this thing?

Respondent: “*My mother says its effects of some Jinnat, and so she never allows me to get social”*

Researcher: So how they treat you?

Respondent: “*They take me to Peer baba for healing process and I drink the water they give me with some Taweez too”*

The transcription of the interview about self-perception of the disease provides information about the cultural and social understandings of epilepsy in relation to beliefs of possession and supernaturalism. The responses given by the interviewee revealed a layered understanding of their condition, utilized through cultural beliefs and perceptions. Relatedly, the accounts to being "possessed by evil spirits" or "cursed" mirror existing cultural beliefs that see epilepsy as having supernatural origins of evil spirits, or curses alike. Such perceptions can grow towards 'stigma' in society, affect how those with epilepsy are situated within communities as well as how epilepsy is understood. Male participants’ responses on the other hand were converse and were different from these types of hexes. For example one male respondent stated,

“My wife insists me to go to Peer Sahib, but I don’t believe in these things. I am on medication and I believe that I will be fine, Inshallah.”

Gendered Embodiment and Social Fears: Epilepsy in the Lives of Women

Epilepsy, as a chronic neurological disorder, affects not only the physical health of individuals but also profoundly shapes their emotional, social, and gendered realities. In conservative cultural contexts, women with epilepsy face heightened challenges where illness intersects with religious, societal, and gendered expectations. The fear of experiencing a seizure in public is especially intense for women, as such episodes may lead to involuntary physical exposure or misinterpretation—raising concerns about modesty, shame, and their visibility in public spaces.

Two female participants in this study voiced these concerns with striking clarity. A master's student in social sciences shared:
"I'm scared of going to university. What if I get a seizure there—who will make sure my clothes are in place, that my head is covered, who will give me first aid, or even touch me?"

Her fears highlight more than just the physical vulnerability of a seizure—they reflect anxiety about losing control in a space where her modesty and gendered identity might be compromised. Similarly, a 27-year-old student in a madrassah, explained:
"Having a seizure in front of people feels very shameful. That fear, and my parents' concerns, made me leave university and choose religious studies instead."

These anxieties reveal how epilepsy in women is not merely a medical issue but a deeply gendered experience, shaped by structural and symbolic constraints. The informants' fears reflect a form of enacted stigma (Merino, et al., 2024) where the potential social consequences of their illness—rather than the illness itself—become central to life decisions. As Malik, et al. (2022) argue, this intersection of gender and health often leads to internalized social surveillance, where women self-restrict their public engagement to avoid imagined or real dishonour.

One female respondent reflected this concern, saying,

"My seizures usually come before my periods, and I know something is going to happen when I start feeling dizzy or tired—it's like my body gives me a signal."

Such biological vulnerability is further layered with social anxieties, particularly concerning childbearing and maternal responsibilities. A married woman in the study expressed,
"I always fear what if I get a seizure while holding my baby—who will help him if I fall?"

This articulates a fear that is not only about personal safety, but more importantly about inability to fulfill maternal responsibilities. In patriarchal and family-oriented cultures, motherhood is central to a woman's identity and social value. The fear of being perceived as an "incapable mother" can deeply affect a woman's emotional well-being, sense of worth, and autonomy within the household. Her anxiety reflects both internalized expectations and external social pressures to remain the "ideal caregiver"—calm, attentive, physically able. Together, these reflections highlight that for women with epilepsy, the impact of illness is magnified not just by its symptoms but by the social consequences of not being able to meet normative gender roles (such as motherhood and domestic caregiving).

4.4 Emotional support and well-being

An interesting finding is seen in our research that is PWE with epilepsy especially WWE had more empathetic relationships at their home as compared to MWE. When they were asked about their daily life experiences as an epilepsy patient. WWE expressed:

"*When people come to see me, and they get to know about the disease, they refuse the proposal. My mother is very worried about my future but my father is very supportive, he has built a house for me and have rent it out, to secure my finances. He says I don't have to get married and I will always live with him and can rely on his money."*

The experiences narrated by the informants indicate a variety of emotional impacts based on gendered expectations and family support. One female respondent documented the significant emotional pain that the social stigma of epilepsy continued to affect with the rejection of marriage offers after she was diagnosed, the social stigma was acute. The rejection of her marriage offers did not stop any future marriage engagements but rather self-worth and belonging to her community. Another female participant presented a very different environment with her familial support system, especially her father's support. He provided emotional support assuring her that she had a future, and what was more impressive is that he tangibly supported her future by building a house for her and ensuring her financial position. Moreover, familial supports offer strong emotional and financial support, and it reduces the psycho-emotional impact of living with epilepsy.

These contrasting accounts reveal the vital role that family support—or its absence—plays in shaping the emotional well-being of individuals with epilepsy. While stigma and societal judgment can fuel isolation and anxiety, nurturing familial relationships can foster acceptance, resilience, and hope. These insights point toward the urgent need for broader public awareness campaigns that challenge negative perceptions of epilepsy and promote supportive, inclusive environments.

While for men the situation is quite different, it is equally complex. One male respondent articulated the emotional neglect that men are sometimes subjected to, quite powerfully as follows:

“In any kind of disease, a human being has a need for emotional support and I expect that too, but nobody considers that. They think I am a man; I'm supposed to be strong. I'm an emotional Godzilla and, no matter the after effects of the seizures, I can handle it.”

This statement captures the deeply rooted gender norms in patriarchal societies: men should be tough and resilient and cannot show difficulty. The construction of masculinity as emotionally invulnerable denies men a needed source of empathy and emotional care. Instead of being provided with support, they will often publicly cope with their struggles in silence—internalizing their struggles and minimizing their feelings, which may exacerbate their mental health and reduce their quality of life.

This lack of articulation does not mean they do not have emotional needs; it rather shows they are adapting to restrictive gendered norms. This unusual silence also signals an important gap concerning the emotional well-being of male patients suffering from chronic health conditions such as epilepsy: a shortfall of safe spaces to share their struggles with no space to be acknowledged. Otherwise, it is likely they may never be articulated and instead suffer in silence/ invisibly.

Examining men and women’s experiences of emotional support indicated many of the same issues—stigma and societal judgement being the legacy shared by all—while revealing expertly perceived differences. Admittedly, women face significant stigma in the context of marriage; however, familial and social support tends to be comparatively stronger. Men, on the other hand, struggle more with emotional isolation due to the constraints masculinity places on showing vulnerability.

Research indicates that emotional support is crucial for managing chronic conditions. In recent studies, Aguilar et al. (2023) found that strong socially connected and empathetic networks greatly improved life satisfaction in people living with epilepsy. The emotional validation and support we receive from our loved ones contribute to feelings of being seen, accepted, and capable of dealing with the complexities of the chronic illness.

As such, this analysis calls into question the need to police gender norms in favour of modes of emotional support that are responsive to the unmentionable needs of men. We can think about ways to develop more inclusive models of compassionate care that attend to visible and invisible challenges to well-being in order to improve the lives of people living with epilepsy and the spectrum of experiences across gender identities.

Social Stigma

Historically, the stigma and misconceptions associated with epilepsy may lead to discrimination or social isolation. Stigma associated with epilepsy may impact individuals differently and while social stigmatization affects both genders, there may be different consequences that affect their self-esteem, relationships, and work opportunities. Individuals with epilepsy may suffer difficulties in terms of education, work and relationships as a result of the stigma and misconceptions about epilepsy.

Men in this study didn't express any kind of fear of stigma related to job or overall professional life except when it comes to their personal relationship and marriage. A male participant expressed that how his marriage had a rough patch and ended up on a divorce as his wife thought that his disease was the reason, they couldn't have a baby besides five years of marriage.

A male respondent: "*my wife never expressed verbally but she used to make me realized that she faces social stigma because of my disease and that put her in a mental pressure, so I let her go"*

A female respondent: "*I am having issues with marriage proposal. No body accepts me with these seizures"*.

Another female respondent had different story; she expressed:

"*Due to societal pressure of getting married, my father got me married with his nephew as he will accept me with the disease and will take care of me. Our marriage lasted for less than a year because whenever I had a seizure my in laws and my husband would pick me up and would drop me at my father's home and used to tell them that when she gets over this, drop her back. And finally, one day my husband asked my father not to send me back. They said they can't handle her nor they can answer to relatives about this."*.

Comparison and Analysis

Effects on Marital Relationships: Both male and female participants reported the strain caused by stigma on their marital relationships. The stress of dealing with social stigma, rejection, and lack of understanding can lead to emotional distress and strain within close partnerships.

Social Stigma and Rejection**:** Each gender demonstrated challenges related to social acceptance when marrying them, and stigma related to epilepsy was a hurdle for both genders and their marriage proposals. This is representative of broader societal perceptions of stigma and discrimination based on a medical condition.

Family Dynamics: Participants illuminated family dynamics and the decisions they were required to make based on societal pressure; these decisions involved forced marriages, separation, and decision-making which could further impact the emotional and social stigmas people with epilepsy experience.

To summarize, the crisis narratives provided a calling for a greater awareness and education, and advocacy to confront stigma and discrimination associated with epilepsy. Narratives delimit the rich and helpful support of family and social networks which create acceptance, understanding, and inclusion for people with epilepsy. It has been observed that people with epilepsy refer to educational, employment, and relationships impacted by the misunderstandings constructed about the illness.

Effect on Quality of Life

Epilepsy causes unique problems for women. Seizure frequency and severity can affect them biologically as it exacerbated by menstrual hormonal changes as well as socially. Women with epilepsy often experience anxieties concerning children. Whereas it can have more adverse impact equally an adolescent or an unmarried woman with ambition. Men also face the same challenges. As Banerjee, Filippi, & Hauser, 2009 concluded in their study on Gender and Socioeconomic Disparities in Global Burden of Epilepsy that Males have a higher lifetime risk of suffering from epilepsy, and this might be owing to men's occupation and their exposure to risk factors, such as head trauma and alcohol use. When asked from both men and women if they think they are enjoying their life or if they feel their quality of life is affected by the seizures. Their response was the same. One woman said,

"I can't enjoy like others. Even when I laugh too much, I get scared something will happen." A man similarly noted,

"I stay away from gatherings now. It's better than embarrassing myself in front of everyone." These statements reveal that although the types of struggles differ, the emotional toll is shared. There is a common thread of anxiety, social avoidance, and lowered self-esteem across genders.

These findings underscore the need for gender-sensitive, individualized interventions. Health programs need to account for the way men and women interact with traditional vs. biomedical systems. For example, a woman with low income may suffer barriers beyond veteran's stigma, including economic dependency, limited mobility, or caregiving control. A man with epilepsy has expectations placed on him to be stoic or a breadwinner, which may prompt him to hide his illness or eschew traditional healing that looks feminine or irrational.

CONCLUSION

The aim of this study was to investigate the ways in which gender intersects with the experiences of individuals living with epilepsy in Muzaffarabad, Azad Kashmir, specifically in relation to emotional wellbeing, social relationships, and social roles. Amidst an intersectional approach grounded in Crenshaw's theory of intersectionality, the study examined how the intersections of multiple identities such as gender, health status, and sociocultural positioning, result in unique challenges for male and female individuals living with epilepsy. The results indicate that epilepsy is a gendered experience that extends beyond the physical experience. Women are disproportionately impacted by stigma associated with social (dis)respectability, particularly in the contexts of marriage and public exposure (Birbeck, Chomba, Atadzhanov, Mbewe, & Haworth, 2009). The traditional expectations of female respectability relate directly to concerns about modesty, shame and acceptability in public spaces. and are barriers to women's educational and social mobility. The anxiety of being viewed in a vulnerable moment such as a seizure, by unknown men, also limits women when trying to engage in society. Women depend heavily on social support groups for coping and healing, which, while often emotionally uplifting, fosters a reliance on familial or communally based acceptance.

Men with epilepsy, while faced with a different set of factors, still experience socially constructed limitations. Prevailing gender norms, which associate masculinity with physical strength, emotional strength, and financial support, set expectations that male patients simply endure the illness. In the study, male participants discussed a significant lack of emotional support, and described the expectation of never speaking of it at all as a significant barrier to accessing psychological support. The expectation of silence increased their suffering and isolation. Additionally, when epilepsy hinders their ability to meet traditional expectations as breadwinners, they often experience societal stigmatization, which lowers their self-worth, and compromises their family life.

Health campaigns must recognize how men and women relate differently with traditional and biomedical therapies. A woman from an economically disadvantaged group may be disadvantaged through stigma around epilepsy; however, additional constraints include economic dependency, lack of mobility, and response to caregiver decisions. A man with epilepsy may be obligated to remain stoical or to be the breadwinner and thus hide his illness, or avoid traditional healing as a feminine or irrational behavior.

In summary, although epilepsy negatively impacts the lives of both men and women, the impacts on their lives are heavily gendered. While society places stigma on women regarding modesty, marriage, and public participation, they have to assume a role that incorporates emotional repression, suppression of feelings, and social expectations of maintaining a provider role. We must appreciate these gendered dynamics in the design of gender-inclusive, culturally-competent health facilities and programs that respond to the needs of male and female persons living with epilepsy.

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.

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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