Exploring Social Stigma and Body Image Perception Among Women with Epilepsy in India

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ABSTRACT

Background: Epilepsy affects 12 million+ individuals in India, with women experiencing disproportionate psychosocial burdens. In addition to managing seizure activity, they endure stigma, body image disturbances, and social isolation, due to cultural-norms, misconceptions, and side effects of anti-epileptic drugs (AEDs). Objective: To explore the impact of social stigma and body image perception among women with epilepsy, and to identify psychosocial patterns that can inform community-based interventions. Methods: A cross-sectional survey was conducted among 52 women with epilepsy, aged 10-52 years (mean=26.96, SD=10.34). Participants completed a questionnaire assessing demographic details, awareness about seizure type, perceived stigma, AED-related physical changes, and body image perception using a 5-point Likert scale. Results: 94.2% participants were unaware of their seizure type and 59.6% reported visible side effects. Social stigma was prevalent: 73.1% expressed feelings of shame, and 55.8% reported hiding their condition. Body image perception was moderately positive (mean=3.50, SD=1.16), with internal consistency among related domains. Moderate positive correlations were observed between body image satisfaction and self-confidence in public. Marital status did not influence body image or stigma perceptions. Conclusion: This study highlights the burden faced by women with epilepsy: seizure management and psychosocial distress. The high prevalence of stigma, concealment, and body dissatisfaction emphasizes the need for culturally sensitive, community-based rehabilitation programs. Future interventions should incorporate education, peer support, and counseling to promote body positivity and reduce stigma.

KEYWORDS: Epilepsy, Women's Health, Social Stigma, Body Image, India.

INTRODUCTION

Epilepsy is a chronic neurological disorder marked by recurrent, unprovoked seizures due to abnormal cortical neuronal discharges. It affects approximately 50 million people worldwide, making it one of the most prevalent neurological conditions across all ages (1). In India alone, around 12 million individuals live with epilepsy, which constitutes almost one-sixth of the global burden of the disease (2,3). Despite being medically treatable in most cases, epilepsy retains a heavy treatment and social burden, particularly in low- and middle-income countries such as India (2,4). While epilepsy affects both sexes, women with epilepsy (WWE) encounter unique biological, psychological, and sociocultural challenges. Hormonal fluctuations—such as increased estrogen during the luteal phase—can exacerbate seizure activity. Moreover, issues tied to contraception, fertility, pregnancy, and teratogenicity make the clinical management of epilepsy more complex in women, especially those in their

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reproductive years (5). It is estimated that 2.7 million women in India are affected by epilepsy, with over half of them in the prime reproductive age group (15–49 years) (5).

Epilepsy in India

Community-based surveys in regions such as Rajasthan report an active epilepsy prevalence of approximately 1.1 per 1,000 population (6). However, significant treatment gaps are evident, an 18.8% primary treatment gap and 38% noncompliance to antiepileptic therapy were noted, often linked to socioeconomic deprivation (6). Psychological morbidity is highly prevalent: studies report comorbid anxiety or depression in up to 76% of Indian patients with epilepsy (6).

Public knowledge about epilepsy in India remains limited. Many still believe epilepsy is incurable, contagious, or spiritually caused, with a significant minority viewing it as divine punishment or insanity (6,7). Misconceptions persist despite better awareness among healthcare professionals (2). In Kerala, epilepsy has regularly been misclassified as mental illness. In Rajasthan, a study conducted by Sureka et al found nearly 25% of respondents believed the disease results from evil spirits (8).

Social Stigma

Social stigma profoundly affects individuals with epilepsy. In India, it manifests as discrimination in marriage, employment, education, and daily living (2,4). Qualitative studies reveal widespread hesitation among employers, school authorities, and matrimonial decision-makers to accept individuals with epilepsy (9). One mixed-methods study noted that even laws hinder women with epilepsy: driving bans, exclusion from defence jobs, and residual legal references to epilepsy as "insanity," despite being officially removed in 1999 (10). Another pilot study comparing unmarried women with epilepsy versus men showed that 72% of women feared medication adherence problems post-marriage, and 41% of married WWE felt disclosure harmed their marital life (11).

Studies have shown that stigma strongly predicts poor quality of life among Indian women with epilepsy. Greater perceived stigma is significantly related to reduced QOL scores in reproductive-age women, especially those who are uneducated, married, unemployed, or on multiple antiepileptic drugs (12). Furthermore, perceived stigma correlates with disability and higher disease burden (13).

Body Image Perception & Epilepsy

Body image perception refers to one's cognitive and emotional evaluation of their physical appearance, shaped by cultural norms, self-esteem, and bodily functionality (14). Deviations from the socially ideal body (due to illness or physical changes) can lead to dissatisfaction, shame, and psychological distress.

People with epilepsy frequently experience body image concerns. Certain antiepileptic medications cause weight gain, hair loss, acne, or hirsutism (15). Seizure-related injuries, such as bruises or scars, and physical limitations in social situations further impact body image (15). A recent clinical study involving 63 adults with epilepsy observed significantly elevated trait body-image dissatisfaction compared to controls (16). Among these participants, poorer body image was the strongest independent predictor of low quality of life, exceeding even depressive symptoms (16).

While global literature highlights body image issues in epilepsy, there is limited empirical research focused on Indian women with epilepsy, a group vulnerable to compounded stigma due to gendered expectations and marital norms. Appearance ideals and social "normalcy" hold strong cultural importance in India, further exacerbating dissatisfaction (17).

Intersection: Stigma × Body Image in Indian WWE

The convergence of epilepsy-related stigma and body image concerns can severely impact Indian WWE's mental health and self-worth. Maternal expectations, arranged marriage systems, and cultural beauty norms intensify fears of "defectedness." Yet, despite this critical intersection, few studies directly examine the lived experience of body image among Indian WWE or how stigma shapes those perceptions.

This research aims to:

1. **Explore** body image perceptions in Indian WWE, focusing on self-esteem, satisfaction, and social-comparison dimensions.
2. **Examine** how external stigma—from family, peers, and institutions—affects these perceptions.
3. **Assess** relationships between stigma intensity, body image distress, and quality of life outcomes.

By illuminating the psychosocial contours of epilepsy in Indian women, this study seeks to inform more culturally sensitive mental-health and social interventions that attend not just to seizure control but to dignity, appearance, and psychosocial well-being

METHODOLOGY

Study Design

This study adopted a **mixed-methods, cross-sectional design** to explore the experiences of Indian women with epilepsy regarding social stigma and body image perception. The integration of quantitative and qualitative data allowed for a comprehensive understanding of both the prevalence and lived experiences associated with stigma and body image concerns.

Study Setting and Participants

Participants were contacted through Epilepsy Foundation, Mumbai, a non-profit organization providing neurological care and support for individuals living with epilepsy. All participants were female patients aged between 10 and 55 years with a clinical diagnosis of epilepsy. Only individuals who provided informed consent were included.

The inclusion criteria were:

- Female gender
- Age 10 to 55 years
- Confirmed clinical diagnosis of epilepsy
- Ability and willingness to provide informed consent

A purposive sampling approach was employed. For the quantitative phase, 52 women were selected based on eligibility during routine visits to the Foundation's outreach programs

Data Collection

Participants completed a **researcher-administered structured survey** distributed via **Google Forms**.

The survey consisted of four sections:

1. **Demographic and Clinical Profile** – Including age, marital status, education, seizure type, and medication side effects.
2. **Stigma Scale** – A culturally adapted yes/no scale assessing perceived and internalized stigma (e.g., shame, concealment, and discrimination).
3. **Body Image Scale** – A five-item Likert scale (1–5) assessing satisfaction, avoidance, and confidence related to physical appearance and epilepsy-related changes.
4. **Open Feedback** – Optional space for participants to provide short written comments.

Once all relevant data was collected it was then transferred onto an excel file to be analysed.

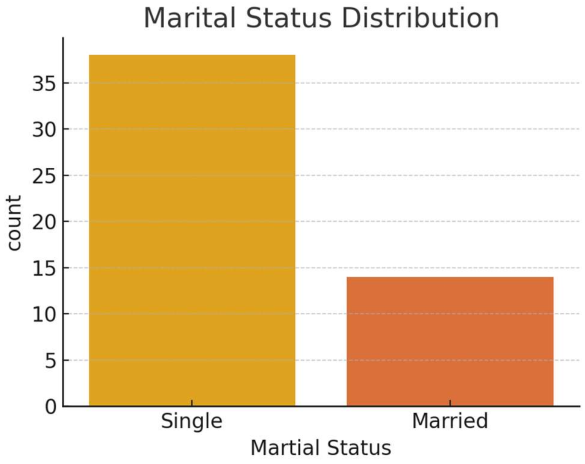
RESULTS

Descriptive statistics were computed for key numeric variables. The average age of respondents was 26.96 years (SD=10.34), with ages ranging from 10 to 52 years.(Graphs1,2,3,4)
Body image perception scores showed moderate averages, with 'I feel good about my body' averaging 3.50 (SD=1.16).

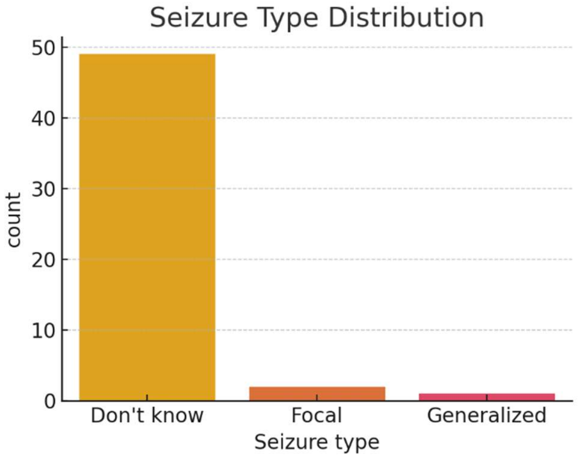
Frequency distributions for categorical variables showed the following key results:
- Majority were single (38 out of 52), with 14 married participants.
- Most participants (49 out of 52) were unaware of their seizure type.
- A majority (31 out of 52) reported visible side effects like weight gain or hair loss.
- Feelings of shame and hidden condition were common, with 38 participants feeling ashamed and

29 having hidden their condition.

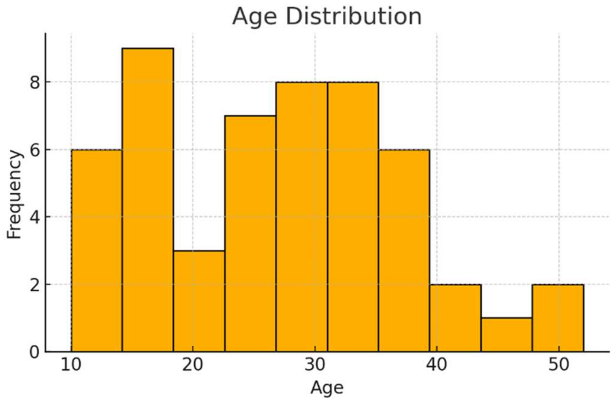
Correlation analysis revealed weak associations between age and body image variables, with moderate positive correlations among body image perception scores themselves. For example, feeling good about one's body correlated moderately with confidence in public spaces.



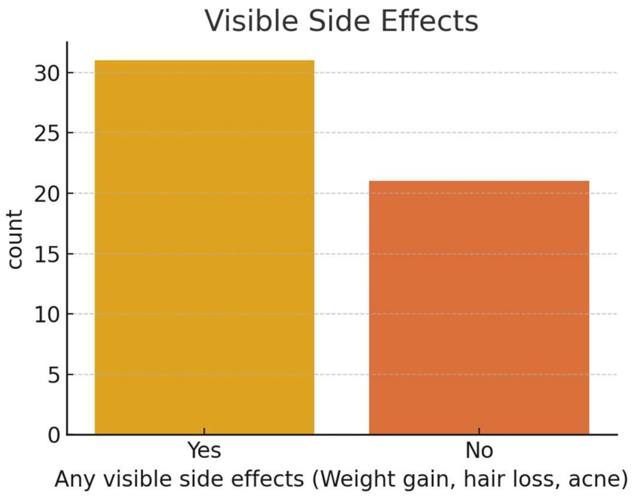
Graph 1: Showing the Martial Status of the study poulation.



Graph 2: Showing the Seziure Type Distribution of the study population.



Graph 3: Showing the age wise distribution.



Graph 4: Showing the Visible side effects of AED.

DISCUSSION

This study provides important insights into the lived experiences of Indian women with epilepsy (WWE), emphasizing how social stigma and body image dissatisfaction intersect to influence psychosocial well-being. Our findings are consistent with prior literature that underscores the disproportionate stigma and emotional burden WWE face due to both their gender and neurological condition (2,5,12).

One of the most significant findings was the **lack of awareness regarding seizure type**, with nearly 94% of participants unable to identify their condition. This reflects existing data showing poor epilepsy literacy and widespread treatment gaps in India (6). Low health literacy has been associated with increased stigma and poorer health outcomes (3), making it imperative to incorporate structured education and awareness campaigns into community-based epilepsy care.

The **prevalence of perceived stigma** was also high—73% reported feelings of shame, and more than half concealed their condition. This aligns with earlier studies reporting that WWE in India are more likely to internalize stigma due to social pressures, fear of rejection in marriage, and cultural misconceptions surrounding epilepsy (4,9,11). In many regions, epilepsy is still perceived as a divine punishment or spiritual affliction (7,8), contributing to social isolation and limited access to opportunities in education and employment (2,10). These experiences reflect not just interpersonal stigma but also structural discrimination, where laws and policies have historically marginalized individuals with epilepsy, particularly women (10).

Body image dissatisfaction among participants was moderate, with visible antiepileptic drug (AED)-related side effects such as weight gain and hair loss being commonly reported. This corroborates findings from prior studies indicating that AED-induced physical changes can negatively affect body image and psychosocial adjustment (15). Moreover, recent evidence suggests that body image dissatisfaction may be a stronger predictor of reduced quality of life in WWE than even depressive symptoms (16), highlighting the need to address appearance-related concerns in epilepsy care.

Interestingly, despite these challenges, the mean body image score was moderately positive, and correlated with increased public confidence. This suggests the presence of **psychological resilience** or mitigating factors such as family support, social adaptation, or involvement in community support networks like the Epilepsy Foundation (12,17). Such resilience highlights the value of psychosocial support services in promoting positive self-perception among WWE.

Contrary to assumptions, **marital status was not significantly associated with body image or stigma perception**. This contradicts earlier assertions that marriage might buffer social stigma (11) and suggests that internalized societal beliefs and normative pressures may outweigh the protective effects of personal relationships. It reinforces the argument that interventions must target community attitudes rather than placing the onus of change on individuals.

The **moderate positive correlation between body satisfaction and self-confidence in public** settings supports findings from global literature that improved body image perception can enhance social participation and self-esteem (14,16). Therefore, mental health services should include body image counseling, peer group support, and interventions that build confidence in social functioning.

This study has several limitations. The small sample size (n=52), single-center setting, and reliance on self-reported data may limit generalizability. Furthermore, the lack of a control group and qualitative interviews constrains the depth of insight into lived experiences. Nonetheless, this study fills a critical gap in the Indian context, providing a foundation for larger, longitudinal studies to further explore the psychosocial dimensions of epilepsy in women.

Implications for Practice and Policy

1. **Integrate Psychosocial Support in Care Pathways**: Multidisciplinary epilepsy care should include counseling that addresses stigma, self-image, and emotional well-being (13,16).
2. **Culturally Tailored Health Education**: Public awareness campaigns must confront traditional myths and improve understanding of epilepsy as a medical, not moral, issue (2,7).
3. **Strengthen Peer Support Networks**: Community-based programs that promote peer interaction and shared experience can mitigate isolation and improve self-perception (12,17).
4. **Train Health Workers on Gendered Stigma**: Frontline providers should be sensitized to the unique challenges faced by WWE, particularly those involving appearance, fertility, and marriage (5,9).
5. **Promote Legal and Policy Reforms**: Efforts should continue to dismantle residual legal discrimination and promote inclusion in education, employment, and family life (10).

CONCLUSION

This analysis provides an overview of the demographic and psychosocial characteristics of the epilepsy patient sample. The data highlights prevalent issues such as lack of awareness about seizure type, frequent visible side effects, and social stigma reflected in feelings of shame and concealment of condition. Body image perceptions varied but were moderately interrelated, indicating potential targets for psychosocial support. Future research could focus on tailored interventions addressing stigma and improving self-confidence among people living with epilepsy.

REFERENCES

1. Fisher RS, et al. Epileptic seizures and epilepsy: definitions proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). Epilepsia. 2005;46(4):470–2.
2. Amudhan S, Gururaj G, Satishchandra P. Epilepsy in India II: Impact, burden, and need for a multisectoral public health response. Ann Indian Acad Neurol. 2015;18(3):370–78.
3. Dahiya L, Bagga R. Digital Epidemiology: Leveraging Social Media for Insight into Epilepsy and Mental Health. arXiv. 2024. Dec 2.
4. Das K, et al. Complementary and Alternative Medicine use among Indian epilepsy patients. [PubMed ID].
5. Biospectrum India. The epilepsy burden in India. 2023.
6. Sinha S, et al. Community-based prevalence and psychological issues of epilepsy in Rajasthan. J Neurosci Rural Pract. 2019;10(2):155–62.
7. Radhakrishnan K, et al. Kerala population-based survey of epilepsy prevalence and misconceptions. Neurology. 2000;55(4):754–8.
8. Sureka PK, Sureka RK. Rural beliefs about epilepsy as evil spirits. Epilepsy Res. 2000;39(1):45–52.
9. Santosh P, et al. Understanding stigma via mixed methods in India. Frontiers Soc. 2022;7:790145.
10. Santosh et al. Hipp. Significance of legal references to epilepsy in marriage/defense jobs. 2022.
11. Gupta AK, et al. Gender-based stigma prior to arranged marriages among Indian WWE. Int J Epilepsy. 2018;5:1–7.
12. Sharma V, et al. Quality of life and stigma among women with epilepsy during reproductive years. Seizure. 2021;85:260–6.
13. Verma M, et al. Inverse relationship between stigma and QOL among PWE in India. Epilepsy Res. 2014;108(3):325–30.
14. Cash TF. The body-image experience. In: Cash TF, Pruzinsky T, editors. Body Image. 2nd ed. Guilford; 2004.
15. Leaffer EB, et al. Physical side effects of AEDs and their impact. Epilepsy Behav. 2014;30:149–54.
16. Nieuwkerk PT, et al. Body image dissatisfaction: predictor of poor QOL in epilepsy. Epilepsy Behav. 2023;149:108881.
17. Women's health in India – cultural impact on treatment and self-perception. Public Health Rev. 2022.

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