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Research Paper

Impact of Metacognitive beliefs and Stigma on Quality of Life among Epilepsy Patients

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ABSTRACT

Epilepsy, a chronic neurological disorder, significantly affects various aspects of an individual's life, with psychological factors like metacognitive beliefs and social stigma potentially increasing the challenges faced by patients. This study investigates the impact of metacognitive beliefs and social stigma on the quality of life (QoL) among rural epilepsy patients. Focusing on how negative metacognitive beliefs (e.g., self-efficacy and seizure control) and perceived stigma affect the emotional, social, and physical well-being of individuals with epilepsy, the research involved 50 rural epilepsy patients, selected via purposive sampling. Three standardized tools (Meta-cognition Questionnaire, Kilifi Stigma Scale of Epilepsy, Quality of Life in Epilepsy-31) were used to collect data, which were analysed through correlation and regression techniques. The results revealed that higher levels of negative metacognitive beliefs and perceived stigma were linked to poorer QoL outcomes, especially in emotional and social domains. These findings underscore the importance of psychological interventions, such as metacognitive therapy and stigma reduction, to enhance the Quality of life of rural epilepsy patients. The study also emphasizes the importance to epilepsy care and support to enhance quality of life for this underserved population.

Keywords: *Epilepsy, Metacognitive Belief, Stigma, Quality of life, Well-being and Seizure*

Epilepsy is a neurological disorder affecting approximately 70 million people worldwide, with nearly 90% of those individuals residing in developing regions (Ngugi, Bottomley, Kleinschmidt, Sander, & Newton, 2010). In India, the number of individuals with epilepsy is estimated to be around 10 million, reflecting a prevalence of about 1% of the population (Sridharan & Murthy, 1999). Interestingly, the prevalence is notably higher in rural areas (1.9%) compared to urban ones (0.6%), a trend that has been documented by the Bangalore Urban Rural Neuro-epidemiological Survey (BURNS), which reported a prevalence rate of 8.8 per 1,000 people, with rural communities exhibiting a rate of 11.9, more than double that of urban areas (Gourie-Devi, Gururaj, Satishchandra, & Subbakrishna, 2004).

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A seizure, often associated with epilepsy, is not a disease in itself, but rather a manifestation of abnormal functioning in the central nervous system (CNS). It is estimated that around 1% of the global population experiences epilepsy at any given time (Amudhan et al., 2015). While life expectancy in individuals with epilepsy is typically unaffected, the quality of life (QOL) can be severely compromised if seizures are not adequately controlled. In many instances, the cause of epilepsy remains elusive; however, common contributing factors include cerebrovascular lesions, perinatal or postnatal trauma, CNS infections, brain tumors, and congenital brain malformations. These are often referred to as epileptogenic lesions (Huff & Murr, 2023).

The diagnosis and classification of epilepsy involve several criteria, including the type of seizures experienced. Complex partial seizures, for example, are characterized by impaired consciousness (Johanson, Revonsuo, Chapline, & Wedlund, 2003), while generalized epilepsy, affecting the entire brain, encompasses various seizure types, including absence, myoclonic, tonic-clonic, atonic, tonic, and clonic seizures. Additionally, generalized epilepsy may be classified as partial with "secondary generalization" if there is evidence of preceding symptoms (such as an aura) or if EEG results show relevant changes (Banerjee, Filippi, Allen, & Hauser, 2009).

Beyond the clinical aspects of epilepsy, metacognition plays a crucial role in the cognitive and psychological functioning of individuals with the condition. Metacognition refers to the awareness and regulation of one's cognitive processes, including the evaluation of thoughts and memories (Wells, 1995). It is essential in shaping how individuals manage and cope with psychological challenges, especially when dealing with chronic conditions such as epilepsy. Maladaptive metacognitive patterns, such as the belief that worrying is beneficial or that negative thoughts should be avoided at all costs, can hinder coping abilities and worsen the psychological impact of epilepsy (Wells & Cartwright-Hatton, 2004).

In fact, metacognitive beliefs are now understood to be significant predictors of psychological disorders, including anxiety and depression (Bailey & Wells, 2015; Ruscio & Borkovec, 2004). These beliefs can either support individuals in coping with their condition or become obstacles to their recovery, particularly when facing traumatic experiences.

Another important facet of epilepsy is the stigma often associated with the condition. Epilepsy-related stigma is a well-documented issue, frequently identified as a significant source of psychosocial distress for those affected. Stigma, as defined by sociologist Erving Goffman (1963), is a characteristic or attribute that sets a person apart from others, tarnishing their identity and transforming them from "a whole and normal person to a tainted, devalued one." The impact of stigma on individuals with epilepsy has been widely explored, with numerous studies examining how the condition is perceived across different cultures (Baker, Jacoby, Boer, Doughty, Myon, & Taïeb, 1999; Baker, Jacoby, Gorry, Doughty, & Ellina, 2005). Epilepsy is considered stigmatizing in virtually all cultures, although the specific nature of the stigma may vary depending on cultural contexts (Jacoby, 2002).

One factor contributing to the stigma experienced by individuals with epilepsy is the concealment of the condition. Many people with epilepsy (PWE) choose to hide their condition due to the fear of discrimination or exclusion. In some cases, this concealment extends even within the family unit (Scambler & Hopkins, 1996). According to Major and O'Brien (2005), the impact of stigma on an individual's well-being is multifaceted, with both direct and indirect consequences. Stigmatized individuals may experience limited access to quality healthcare and may find themselves in unhealthy environments, which exacerbates their physical and psychological challenges. Moreover, stigma often leads to negative physiological and psychological responses, further contributing to poor health outcomes.

Epilepsy is not just a medical condition; it is also a chronic disorder with profound social, physical, and psychological consequences (Lee, Yoo, & Lee, 2005). Many individuals with epilepsy experience diminished quality of life due to high rates of psychological distress, including anxiety, depression, and feelings of helplessness. They often face lower self-esteem, poor educational outcomes, and higher unemployment or underemployment rates (Jacoby & Baker, 2000). Additionally, the effects of epilepsy extend beyond the individual and can place a significant burden on family members and close relationships (Panayiotopoulos, 2007).

The challenges of living with epilepsy go beyond the direct effects of seizures and can lead to disability and a further decline in quality of life (QOL). Particularly for those with refractory epilepsy, individuals who struggle with seizures that are not well-controlled by medication, the consequences are more pronounced. They often encounter a lack of family support, cognitive difficulties, medical and psychiatric comorbidities, and stigmatization. Research has shown that people with epilepsy also report higher numbers of disability days, greater physical limitations in their daily activities, and lower annual income compared to individuals with other chronic illnesses (Wiebe, Bellhouse, Fallahay, & Eliasziw, 1999).

Rationale of the present study:

This study aims to assess the impact of meta-cognitive beliefs and stigma on quality of life in epilepsy patients in eastern India. Cultural and religious practices in India perpetuate epilepsy misconceptions, exacerbating global stigma. This leads to low awareness, social exclusion, psychological burden, and inadequate treatment. Research on epilepsy stigma and meta-cognitive beliefs in India is limited.

Objectives:

- To determine the relationship between metacognitive belief, stigma, and quality of life in epileptic patients.
- To find out the impact of meta-cognitive belief and stigma as predictors of quality of life in epileptic patients.

Hypotheses:

- There would be significant relationship between meta-cognitive belief, stigma and quality of life in epileptic patients.
- Metacognitive belief and stigma would predict the quality of life in epileptic patients.

METHODOLOGY

Participants

The study was conducted with 50 rural patients diagnosed with epilepsy aged between 18 and 60 years (mean age = 29.06, SD = 7.80), using purposive sampling. The epileptic patients were selected from the Department of Neurology at S.S. Hospital, B.H.U. Varanasi, Care Hospital DLW Bhikharipur, Galaxy Hospital Mahmoorgunj, and Tripathi Neurocare Tulsipur, Varanasi. All participants were interviewed regarding their demographic (age, sex, marital status) and clinical (disease duration) history. Patients who did not meet the inclusion criteria were excluded from the study.

Psychometric Measures:

The following tools were used in this study to assess the participants.

- **Meta-cognition Questionnaire (MCQ-30):** To assess the metacognitive beliefs of rural epileptic patients, the MCQ-30 (Wells & Cartwright-Hatton, 2004) was used in the present study. This questionnaire evaluates various metacognitive domains through 30 items across five subscales. The Cronbach's alpha for the study sample was as follows: cognitive confidence (α = 0.80), positive beliefs (α = 0.75), cognitive self-consciousness (α = 0.78), negative beliefs (α = 0.81), need to control thoughts (α = 0.81), and the overall MCQ score (α = 0.79).
- **Kilifi Stigma Scale of Epilepsy (Mbuba et al., 2012):** o assess stigma in the current study, the Kilifi Stigma Scale of Epilepsy (KSSE) was used. This scale, developed and validated in Kilifi, Kenya, is known for its strong psychometric properties and effectiveness in measuring stigma. It employs a 3-point Likert scale (scored 0, 1, and 2) and consists of 15 items. The total score is calculated by summing the individual item scores. In the present study, the reliability coefficient of the scale was 0.77.
- **Quality of Life in Epilepsy-31 (QOLIE-31, Cramer, Perrine, Devinsky, Bryant-Comstock, Meador, & Hermann, 1998)**: This tool was used to assess the quality of life (QOL) of rural epileptic patients. A self-administered questionnaire and a shortened version of the QOLIE-89, it comprises 31 items across seven subscales: Seizure Worry (5 items), Emotional Well-Being (5 items), Energy/Fatigue (4 items), Social Functioning (5 items), Cognitive Functioning (6 items), Medication Effects (3 items), and Overall QOL (2 items), along with a single item on overall health status. Reliability analyses revealed the following alpha coefficients for the domains: Emotional Well-Being = 0.84, Energy/Fatigue = 0.82, Seizure Worry = 0.79, Overall QOL = 0.81, Cognitive Functioning = 0.75, and the total score = 0.79.

Procedure:

The participants were approached after obtaining permission from the respective hospitals and consent from the individuals. Data collection took place in the neurology departments of the Institute of Medical Sciences, B.H.U., Varanasi, Galaxy Hospital Mahmoorganj, and Tripathi Neurocare Tulsipur. Participants were given detailed information about the scales and questionnaires, as well as the procedure for completing them. Any questions or concerns were addressed. Patients were reassured that their confidentiality would be upheld and informed that the data collected would only be used for research purposes.

RESULTS

The collected data were analysed using means, standard deviation, Pearson’s correlation coefficient (r), and hierarchical multiple regression analysis.

To examine the relationship between Metacognitive beliefs, Stigma and Quality of Life among Epilepsy Patients the correlation was performed, and the obtained result are reported in the following table.

Table 1: Summary of the correlation analysis between meta-cognitive beliefs and quality of life in rural epileptic patient (N=50).

Variables	**M**	**SD**	**SW**	**OQ**	**EW**	**E/F**	**CF**	**ME**	**SF**	**TQ**
Cognitive-confidence	15.74	1.17	.80*	-.56**	-.45**	-.47**	-.42**	.75**	-.49**	-.22**
Positive belief	15.44	1.18	.82**	-.55**	-.40**	-.40**	-.50**	.77**	-.39**	-.20*
Cognitive self – consciousness	15.86	1.61	.78**	-.51**	-.41**	-.44**	-.43**	.68**	-.43**	-.18*
Uncontrollability and danger	15.74	1.17	.85**	-.50**	-.39**	-.39**	-.40**	.78**	-.40**	-.17*
Need to control thoughts	15.78	1.55	.81**	-.51**	-.48**	-.41**	-.49**	.79**	-.39**	-.17*
Total MCQ	86.12	5.08	.85**	-.55**	-.42**	-.44**	-.43**	.79**	-.44**	-.20**

**p<.05, **p<.01*

The correlation analysis presented in Table 1 reveals significant relationships between meta-cognitive beliefs and various dimensions of quality of life in rural epileptic patients. Cognitive confidence, positive belief, cognitive self-consciousness, uncontrollability and danger, and the need to control thoughts were all significantly correlated with multiple quality of life factors, including seizure worry, overall quality of life, energy/fatigue, cognitive functioning, and emotional wellbeing. Most correlations were moderate to strong (ranging from -.20 to .85), indicating that higher levels of certain meta-cognitive beliefs, such as confidence and positive beliefs, were associated with better quality of life outcomes, whereas beliefs like uncontrollability and the need to control thoughts tended to correlate negatively with quality-of-life factors. These findings underscore the relevance of meta-cognitive beliefs in influencing the psychosocial and functional well-being of epileptic patients in rural settings.

Table 2: Summary of the correlation analysis between stigma and quality of life in rural epileptic patients (N=50)

Variable	**M**	**SD**	**SW**	**OQ**	**EW**	**E/F**	**CF**	**ME**	**SF**	**TQ**
Stigma	14.00	1.71	.83**	-.52**	-.45**	-.46**	-.42**	.71**	-.42**	-.22**

**p<.05, **p<.01*

Table 2 shows significant correlations between stigma and quality of life in rural epileptic patients (N=50). Stigma was positively correlated with seizure worry (r = .83, p < .01) and negatively correlated with overall quality of life, emotional wellbeing, energy/fatigue, cognitive functioning, and medication effects (ranging from r = -.42 to -.52, p < .01). A weaker, non-significant correlation was found with social function (r = -.22). These findings suggest that higher stigma is associated with poorer quality of life in various dimensions for these patients.

Table 3: Summary of the correlation analysis between Metacognitive belief and Stigma in rural epileptic patients (N=50) **p<.05, **p<.01*

Variables	**M**	**SD**	**Stigma**
Cognitive- confidence	15.74	1.17	-.272**
Positive belief	15.44	1.18	-.476**
Cognitive self –consciousness	15.86	1.61	.076
Uncontrollability and danger	15.74	1.17	.153
Need to control thoughts	15.78	1.55	-198*
Total MCQ	86.12	5.08	.115

Note: ***SW*** *(Seizure Worry),* ***EF*** *(Energy/Fatigue),* ***SF*** *(Social Function),* ***OQ*** *(Overall Quality of Life),* ***CF*** *(Cognitive Functioning),* ***TQ*** *(Total Quality of Life),* ***EW*** *(Emotional Wellbeing), and* ***ME*** *(Medication Effect)*

Table 3 presents the correlation analysis between meta-cognitive beliefs and stigma in rural epileptic patients (N=50). Cognitive confidence and positive belief were both significantly negatively correlated with stigma (r = -.27, p < .01; r = -.48, p < .01, respectively), suggesting that higher levels of these beliefs are associated with lower stigma perceptions. The need to control thoughts also showed a negative correlation with stigma (r = -.20, p < .05). In contrast, cognitive self-consciousness, uncontrollability and danger, and the total meta-cognitive belief score did not show significant correlations with stigma. These results indicate that certain meta-cognitive beliefs, particularly cognitive confidence and positive belief, may play a role in reducing stigma in rural epileptic patients.

To understand how these factors influence each other, a multiple regression analysis (simultaneous) was done. In this analysis, Metacognitive beliefs(dimensions) and Stigma and were used to predict Quality of Life. The results of this analysis are shown in Table 4.4

Table 4: Results of Multiple regression (simultaneous) analysis

Predictor	**Criterion**
	Quality of Life
Cognitive- confidence	-.560**
Positive belief	.013
Cognitive self –consciousness	.034
Uncontrollability and danger	.069
Need to control thoughts	.141*
Stigma	-.227**
R	.565
R Square	.319
F	15.065***

**p< .05, **p< .01, ***p < .001 Note- Standardized Beta (ß) is reported in the table*

Table 4 presents the results of a multiple regression analysis that examined how meta-cognitive beliefs and stigma predict quality of life in rural epileptic patients. The analysis shows that cognitive confidence (ß = -.560, p < .01) and stigma (ß = -.227, p < .01) were significant negative predictors of quality of life, indicating that higher levels of these factors were associated with poorer quality of life. The need to control thoughts (ß = .141, p < .05) was a positive predictor, suggesting that this belief was associated with better quality of life. However, positive belief (ß = .013), cognitive self-consciousness (ß = .034), and uncontrollability and danger (ß = .069) were not significant predictors. The model explained 31.9% of the variance in quality of life, and the overall model was highly significant (F = 15.065, p < .001). These findings highlight the significant role of cognitive confidence and stigma in shaping the quality of life for rural epileptic patients.

DISCUSSION

The present study aimed to explore the relationship between meta-cognitive beliefs, stigma, and quality of life in rural epileptic patients. Results from the correlation and multiple regression analyses provide valuable insights into how these factors interact and influence the quality of life in this population.

The correlation analysis revealed that certain meta-cognitive beliefs, such as cognitive confidence and positive belief, were significantly associated with better quality of life outcomes, while beliefs like uncontrollability and the need to control thoughts were correlated with poorer outcomes. These findings are consistent with previous research indicating that individuals with higher cognitive confidence and positive beliefs tend to report better emotional and functional wellbeing (Wells, 2009). The negative associations between uncontrollability and the need to control thoughts with quality of life are in line with the cognitive-behavioral model, which suggests that dysfunctional thinking patterns, such as perceiving thoughts as uncontrollable, can negatively impact psychological wellbeing (Wells & Matthews, 1994).

Stigma was found to have a significant negative relationship with quality of life, as higher levels of perceived stigma were associated with greater seizure worry and poorer overall wellbeing. This result underscores the detrimental effects of stigma on individuals with epilepsy, particularly in rural settings, where stigma may be exacerbated by social isolation and lack of understanding about the condition (Hami et al., 2014). The findings support the growing body of literature highlighting the importance of addressing stigma in the treatment and care of individuals with epilepsy to improve their quality of life (Reeve et al., 2019).

The present study also explored the relationship between meta-cognitive beliefs and stigma in rural epileptic patients. The results indicated that Cognitive Confidence and Positive Belief were significantly negatively correlated with stigma, suggesting that individuals who exhibit greater cognitive control and more optimistic beliefs about their thoughts are less likely to experience stigma. This aligns with previous research by Wells and Matthews (1994), which demonstrated that higher levels of cognitive confidence act as a protective factor against the social and psychological effects of stigma, as individuals with stronger cognitive control are better able to manage the emotional consequences of stigma. Moreover, Positive Belief, which involves a more positive outlook on one's cognitive processes, has been shown to reduce the impact of perceived stigma, further supporting the idea that positive meta-cognitive beliefs can buffer against stigma (Piek et al., 2012). Conversely, other dimensions such as Cognitive Self-Consciousness and Uncontrollability and Danger displayed weaker or non-significant correlations with stigma, suggesting that not all meta-cognitive beliefs are equally influential in shaping stigma experiences. These findings suggest that interventions aimed at enhancing Cognitive Confidence and Positive Belief could be particularly beneficial in reducing stigma and improving the quality of life for individuals with epilepsy, especially in rural areas where stigma may be more pervasive (Hami et al., 2014).

In the multiple regression analysis, Cognitive Confidence and Stigma emerged as significant predictors of quality of life, highlighting their critical roles in shaping wellbeing. Specifically, higher levels of cognitive confidence were associated with lower levels of stigma and better quality of life outcomes, while greater stigma was linked to poorer quality of life. This finding aligns with previous research, which suggests that individuals with higher cognitive confidence are better able to cope with the psychological and social impacts of stigma, leading to improved emotional wellbeing and overall quality of life (Wells & Matthews, 1994; Piek et al., 2012). The significant relationship between stigma and quality of life is also consistent with studies demonstrating that stigma can significantly detract from the life satisfaction and emotional wellbeing of individuals with chronic conditions like epilepsy (Link & Phelan, 2001). Additionally, the Need to Control Thoughts emerged as a significant predictor of quality of life, with individuals who felt a greater need to control their thoughts reporting better quality of life. This suggests that meta-cognitive beliefs related to thought control may help individuals manage their condition and cope more effectively, leading to improved psychological outcomes (Wells, 2009). Interestingly, other dimensions of meta-cognitive beliefs, such as Positive Belief, Cognitive Self-Consciousness, and Uncontrollability and Danger, were not significant predictors of quality of life in this analysis. These findings suggest that the influence of these beliefs on quality of life may be more indirect or context-dependent, warranting further exploration to understand their role in different settings or among different patient populations.

Limitations

While this study provides valuable insights into the relationship between meta-cognitive beliefs, stigma, and quality of life in rural epileptic patients, several limitations should be acknowledged. First, the sample size was relatively small (N=50), which may limit the generalizability of the findings to broader populations. Second, the cross-sectional design of the study restricts the ability to make causal inferences. While significant associations were found between meta-cognitive beliefs, stigma, and quality of life, the direction of these relationships remains unclear. Longitudinal studies are needed to examine how changes in meta-cognitive beliefs and stigma over time impact quality of life. Third, the use of self-reported data could introduce response biases, such as social desirability or recall bias, especially in sensitive areas like stigma and quality of life. Future research could incorporate multiple data sources, such as interviews or reports from caregivers or healthcare providers, to enhance the reliability of the findings. Lastly, the study did not assess other potential confounding variables, such as socioeconomic status, comorbid mental health conditions, or the severity of epilepsy, which may also influence quality of life. Accounting for these factors could provide a more comprehensive understanding of the factors influencing quality of life in epileptic patients.

Future Suggestions

Future research should focus on expanding the sample size and using a longitudinal design to explore causal relationships between meta-cognitive beliefs, stigma, and quality of life. This would help to better understand how changes in these factors over time affect patients' wellbeing. Additionally, research could explore the impact of specific interventions, such as cognitive-behavioural therapy or stigma reduction programs, on improving quality of life in individuals with epilepsy. It would also be valuable to investigate the role of other psychological factors, such as emotional regulation and coping strategies, in mediating the relationships between meta-cognitive beliefs, stigma, and quality of life. Future studies could also include more diverse populations, such as individuals from different cultural or socioeconomic backgrounds, to explore whether the findings are consistent across various groups. Lastly, it would be beneficial to examine the role of healthcare providers and caregivers in supporting patients' mental health and quality of life, as their perceptions and interactions may influence patients' experiences of stigma and their meta-cognitive beliefs.

The present study contributes to our understanding of how meta-cognitive beliefs and stigma interact to influence quality of life in rural epileptic patients. These findings emphasize the need for comprehensive approaches that address both cognitive beliefs and stigma to enhance the psychological and functional wellbeing of this population.

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Conflict of Interest

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