

# Assessing Challenges for people living with Epilepsy in Nepal



## PROBLEM STATEMENT

Epilepsy is a neurological disease which has long been associated with stigma and discrimination. The prevalence of epilepsy in lower- and middle-income countries is higher than in the rest of the world. However, there is very little research exploring the broad and often severe psychosocial aspects of the impact of epilepsy in low- and middle-income countries like Nepal.

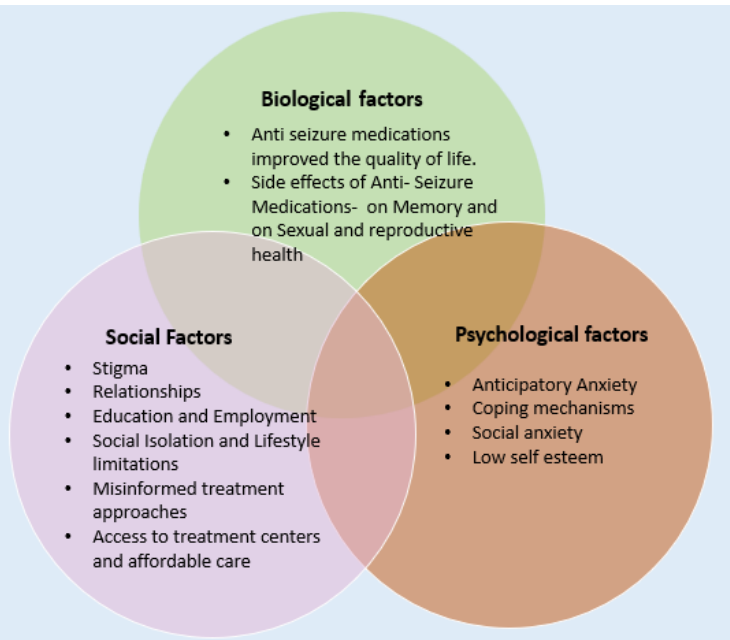
The effects of epilepsy on the lives of people living with the disease are profound and intersectional. The disease impacts multiple aspects of the lives of people living with Epilepsy.

Understanding the impact of Epilepsy on quality of life can inform design and prioritization of interventions to improve the quality of life of people living with Epilepsy.

## METHODOLOGY

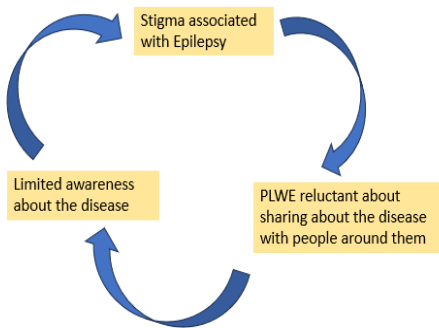
We explored the lived experiences and psychosocial impact on the Quality of Life for people living with Epilepsy in Nepal through semi-structured interviews. Interviews were designed to also explore the intersectionality of gender with the impacts of epilepsy.

We interviewed twenty participants (10 male and 10 female) receiving treatment for epilepsy at two centers providing epilepsy care in Kathmandu, Nepal- The Nepal Epilepsy Association (NEA) and Kathmandu Medical College (KMC). The participants were aged between 18 - 40 years, had been diagnosed with epilepsy for more than 6 months and had no other serious comorbidity which would prevent informed consent or participation, and were attending the outpatient clinic at the participating care centers. Participants gave written informed consent to participate in the study and were free to decline to answer any questions or withdraw from the study at any time.



*Impact of Epilepsy on the lives of PLWE presented in Biopsychosocial Model*

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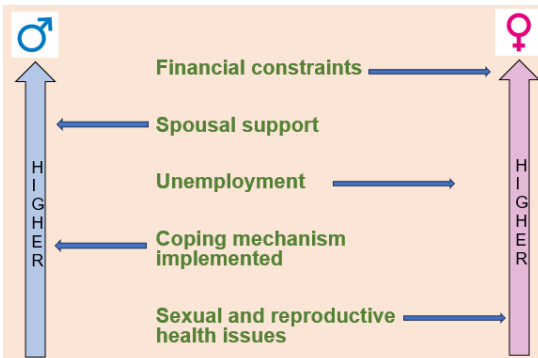


*Vicious cycle of stigma in Epilepsy*

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## TEN KEY FINDINGS

1. Stigma associated with the disease was highly prevalent and the most common factor affecting the quality of life of people living with Epilepsy.
2. Stigma and misconceptions surrounding the disease caused the majority of the participants to approach traditional healers for remedies in the first instance, which was a major cause of delays to receiving effective treatment.
3. Lack of access to treatment facilities in rural areas was also a major cause of treatment delay.
4. Participants who achieved control of seizures with effective Anti-Seizure Medications had a more positive outlook towards life than those whose seizures were not under control.
5. Epilepsy affected interpersonal relationships of people living with Epilepsy, especially spousal relationships and friendships.
6. The negative impact on spousal relationships was more severe for women living with epilepsy than for men living with epilepsy.
7. The psychosocial impacts of epilepsy were broad, complex, often severe, and highly gendered. Impacts included limited employment and educational opportunities, limited socializing, unable to drive or ride vehicles, unable to engage in sports and activities such as swimming . Access to effective anti seizure medications mitigated many of the most severe impacts for both men and women living with epilepsy.
8. Unemployment because of the disease was more frequently reported by the female participants than males. Two women mentioned discontinuing their employment or never starting a career whereas none of the men mentioned so.
9. Epilepsy and anti seizure medications had marked effect on the sexual and reproductive health of the participants. Women living with Epilepsy faced more sexual and reproductive health problems than men.
10. Participants adopted various coping mechanisms to deal with the disease. More male participants mentioned actively adopting coping mechanisms to improve their quality of live with epilepsy.



*Gender differences in the impact of Epilepsy on the lives of People living with epilepsy*

## THREE KEY RECOMMENDATIONS

1. The research highlighted the urgent need for and potentially broad ranging impact of a culturally contextual intervention to reduce stigma against Epilepsy. Research should identify, challenge and change the root causes and complex manifestations of stigma against people living with epilepsy within Nepali culture.
2. There is also a need for treatment centers and access to affordable medications, particularly outside the Kathmandu valley. Specialist care and treatment centres with subsidised medications should be accessible to all people living with epilepsy in Nepal.
3. Individualized counselling for people living with epilepsy and their families can dramatically improve quality of life and holistic wellbeing. Treatment centers should include skilled psychological counselling.

## CONTACT INFO

**Dr Swastika Shrestha**  
Principal Investigator  
Project ACE (Assessing Challenges in Epilepsy)  
Email: swastika@bnmt.org.np

**Dr Maxine Caws**  
Senior Researcher  
Liverpool School of Tropical Medicine (LSTM)  
/ Birat Nepal Medical Trust (BNMT)  
Email: maxine.caws@bnmt.org.np

**Mr Raghu Dhital**  
Executive Director  
BNMT  
Email: raghu.dhital@bnmt.org.np