

ACE 2: Experiences of pregnancy and early motherhood in young women living with epilepsy in Nepal



PROBLEM STATEMENT

Women living with epilepsy (WLWE) face a unique set of challenges during pregnancy and postpartum. Physiological changes during pregnancy alter the absorption, distribution, metabolism and elimination of Anti-Seizure Medication (ASM). This can escalate seizure frequency, which also increases the risk of miscarriage and preterm labor.

Anxiety surrounding the safety of the unborn child causes significant mental stress for pregnant WLWE. Postpartum depression is also common amongst WLWE.

Failure to address the problems faced by WLWE during pregnancy and post-partum can have adverse effects on the health of both the WLWE and their children.

This study aimed to explore and understand the lived experiences of WLWE during pregnancy and in the post-partum phase in Nepal to facilitate the design of people-centered solutions.

METHODOLOGY

We interviewed seventeen WLWE (aged 18 years and above) receiving treatment for epilepsy at four centers providing epilepsy care in Kathmandu, Nepal- The Nepal Epilepsy Association (NEA), Kathmandu Medical College (KMC), Annapurna neurological institute and allied sciences (ANIAS) and Institute of medicine (IOM). The participants were interviewed after giving written informed consent. Interviews were transcribed. Thematic analysis and coding were done manually using the biopsychosocial framework (BPS) (shown right).



Impact of Epilepsy on the lives of WWE during pregnancy and postpartum presented in Biopsychosocial Model

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KEY FINDINGS

1. Preconception counselling and appropriate treatment was a strong facilitator of positive pregnancy and postpartum experience for WLWE.
2. Women reported additional costs incurred for tests related to their use of ASMs during pregnancy.
3. Support from the family, especially the spouse, was essential to navigate the pregnancy and postpartum journey.
4. Stigma often created a significant barrier preventing WLWE disclosing their disease status to their husband's family, who are a major source of support during pregnancy and post-partum.
5. Fear of children inheriting epilepsy or being born with disability was common and a major driver of mental stress amongst pregnant WLWE.
6. Participants who understood their seizure triggers and mitigators used effective coping strategies, helping reduce risks to both mother and baby during pregnancy and the postpartum period.
7. Many women were uncertain about future pregnancies, influenced by their first pregnancy experience, seizure frequency, and the effectiveness of their ASMs.

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



KEY RECOMMENDATIONS

1. A multidisciplinary, integrated, person-centered approach for the treatment and counselling of WLWE and their families prior, during and post pregnancy is needed to improve wellbeing of mother and child and mitigate the challenges faced by WLWE.
2. Stigma reduction interventions are necessary to transform attitudes and facilitate supported disclosure of epilepsy.

