

Developing a Research Agenda Towards Patient Centered Care for Epilepsy in Nepal

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INTRODUCTION

Epilepsy is one of the most prevalent and stigmatized neurological conditions in the world^{1,2,3}. Stigma often precipitates a cascade of impacts on social and psychological aspects of life for people living with epilepsy (PLWE)⁴. Given the complex interplay of challenges associated with the lived experience of epilepsy, there is a large multisectoral treatment gap for epilepsy which is larger in low and middle income countries (LMICs)⁵. This is partly a consequence of the substantial knowledge and evidence gap in epilepsy in LMICs, which prevents effective advocacy and the development of evidence-based policy and practice. The workshop aimed to identify the landscape of existing support available for people living with epilepsy in Nepal and prioritize related research topics to inform the design of future research.

METHODOLOGY

We brought together a group of diverse stakeholders for

ABSTRACT

Background & Method: There are substantial knowledge, and evidence gaps regarding epilepsy in Nepal which prevent progress towards patient centered care provision. A workshop was conducted in Kathmandu, Nepal where we brought together multidisciplinary stakeholders involved in epilepsy care for a participatory discussion. The workshop aimed to identify the landscape of existing psychosocial and medical support available for people living with epilepsy in Nepal and prioritize research topics related to care service provision, access and delivery to inform the design of future research.

Results: The workshop identified important research topics which were grouped into three major themes: Stigma; Epidemiological studies; and Access to Medicine/ Services/Support. Based on the workshop discussion, we have proposed a priority research agenda to inform development of models of person-centered epilepsy care in Nepal.

Conclusions: Our workshop highlighted the dearth of information regarding all aspects of epilepsy in Nepal, and the urgent need for intersectoral knowledge exchange.

Keywords: Epilepsy; Patient centered care; Research agenda; Stigma; Workshop

a participatory discussion to identify the landscape of existing psychosocial and medical support available for people living with epilepsy in Nepal and prioritize gaps related to care service provision, access and delivery to be addressed in future research studies.

The half-day participatory discussion workshop was conducted on 28th March 2024 in Kathmandu, Nepal. This workshop was a component of the research project “Intersectional psychosocial impacts of epilepsy: a gender lens approach”, that explored the psychosocial impacts of epilepsy on the quality of life of PLWE in Nepal.⁴ The ethical approval for the study was obtained from the Nepal Health Research Council (NHRC) (Protocol Registration number: 564/2022 P). The workshop did not require a separate ethical approval since it was a stakeholder discussion and was a component of the research findings dissemination. The workshop participants voluntarily attended the workshop and shared their ideas. The workshop participants were informed that the discussions

would be reported in a manuscript for academic publication. We conducted a desk review to identify the relevant stakeholders engaged in epilepsy care in Nepal. We also used snowball identification method to identify important stakeholders that the desk review may have missed. The participants in this workshop included relevant stakeholders from multiple sectors including Nepal Epilepsy Association (NEA), Institute of Medicine, Maharajgunj (IOM), Transcultural Psychosocial Organization Nepal (TPO Nepal), Possible health, Annapurna Neurological Institute & Allied Sciences Pvt. Ltd. (ANIAS), Medharma Clinix, Association of Medical Doctors of Asia-Nepal (AMDA Nepal), Center for Mental Health and Counselling Nepal (CMC Nepal) and Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ Nepal), a person living with epilepsy and a caregiver to a person living with epilepsy. The invited experts included a broad range of disciplines: neurologists, general practitioners, psychiatrists, psychologists, PLWE and public health professionals working in the field of mental and neurological health.

Workshop procedure:

The workshop was divided into three complementary sessions.

Session 1 : A person living with epilepsy, Mr. Tek Bahadur Shrestha, resident of Kathmandu, shared his lived experience and the principal investigator presented findings of the research “Intersectional psychosocial impacts of epilepsy: a gender lens approach”.

Session 2 : A group discussion was conducted to identify the existing psychosocial and economic support available for PLWE in Nepal and identify the gaps in the existing support available.

The discussions had three principal aims:

- 1) Identify the existing psychosocial and economic support available for PLWE in Nepal.
- 2) Identify gaps in the existing support available.
- 3) Develop research themes to address these gaps with each professional group reaching consensus on the highest priority evidence gaps which could have significant positive impact to improve the quality of life (QoL) of PLWE.

Session 3 : Participants generated research questions based on the prioritized challenges/gaps that need to be addressed within the identified thematic areas.

The participants were divided into three homogenous groups: group 1- 5 medical practitioners; group 2- 4 psychologists and group 3-5 delegates from the non-governmental sector working in the mental health sphere. The participants were homogeneously grouped by professional expertise to enable a deeper understanding of the shared experiences of participants belonging to similar professional backgrounds due to the time limitations of the workshop. Each group discussion was facilitated by a facilitator and a notetaker from the host organization, Birat Nepal Medical Trust (BNMT). The groups were asked to summarize identified existing support for each thematic area using the supplied grid and to identify and prioritize research gaps to be addressed. They were also asked to select three priority challenges from their group. Thematic areas were based on the review of the existing evidence on recommended support for PLWE which is detailed below.

Review of the existing evidence on recommended support for PLWE

The global evidence on psychosocial and medical support recommended for PLWE includes a broad range of intersectoral support which can improve the quality of life for PLWE. The World Health Organization (WHO) recommends complementing medical support with psychological and social support to improve quality of life in PLWE^{6,7,8}. To inform the workshop structure, we conducted an informal scoping literature review of the globally available and recommended patient centric support for PLWE. The following were the major themes that were identified: Medical support^{9,10,11,12,13}, Non-pharmacological therapies¹⁴, Dietary-interventions¹⁵, Counselling and specialist support^{16,17,18}, Stigma reduction strategies¹⁹, and Financial support^{20,21}. Following the scoping exercise, we prepared a framework categorizing the different types of potential support into medical, non-pharmacological (psychological, dietary, social), financial and holistic support (stigma reduction strategies).

Data capture and synthesis:

A discussion framework was prepared informed by the literature review, which guided participants to discuss specific themes. We emailed the framework to participants a week prior to the workshop and invited them to populate the table for further discussion during the workshop. During the workshop the participants filled in the provided grid and added complementary notes. The data provided along with the notes made by the session

notetakers were then manually analyzed and synthesized by the author SS using coding²².

A deductive method was used to assign codes related to the themes of the discussion framework. An inductive approach was used to group the priority challenges selected by the groups into overarching themes by the facilitators (SS and MC), who were also co-authors of the study. Disagreements among co-authors were resolved through iterative and structured re-examination of the data, facilitating the development of a shared interpretation.

Session outcomes:

Session 1 :The lived experience sharing session included a broad scope of both positive and negative reflections and was followed by a presentation of the findings of the qualitative research on the lived experience of epilepsy in Nepal, which are reported elsewhere⁴.This enabled reflection on the multidimensional impacts of epilepsy, and ensured our discussions were informed by data from lived experiences.

Session 2 : Each group discussed their knowledge of the existing psychosocial and economic support available for PLWE in Nepal. Participants were also tasked with identifying the gaps in the existing support available and selecting the three most important gaps to address with research. The groups discussed the proposed topics for 60 minutes. Since the groups varied in terms of their expertise- multidisciplinary perspectives were generated by the discussions. In the plenary session a volunteer from each group summarized the discussion points and the three prioritized challenges. The floor was open to insights from any of the stakeholders on the shared summary.

Gaps Identified and prioritization of research agenda

All three discussion groups identified important gaps that need to be addressed to improve care for PLWE. The group of doctors stressed the need to evaluate telemedicine to increase access to diagnosis and treatment of epilepsy, especially in rural areas where there is internet availability. The doctors also highlighted the intense stigma in Nepali society associated with mental health issues that creates barriers to the use of psychotropic medicine to treat many of the mental health issues brought about by epilepsy. Another gap identified by the clinicians was limitations in the medical education curriculum. There is a lack of training in

various types of epilepsy, both among clinicians and other professionals providing services to PLWE. Based on the gaps identified, this group suggested the need to evaluate the use of telemedicine to reduce the gap in diagnosis; develop effective training modules for medical staff and non-medical volunteers (such as community health workers) to recognize and diagnose epilepsy; develop support group mechanisms for patients to access information about techniques for the self-management of epilepsy; development of training modules for rural health workers on epilepsy diagnosis and care; advocacy to regulate the price of ASMs; Advocacy and training to increase awareness and reduce stigma related to epilepsy among both medical and non-medical professionals, including, faith healers, community health workers and psychologists; development of epilepsy treatment services, including individualized counselling services, which are scalable to rural areas.

The group of NGO/INGO stakeholders focused on discussion of the gaps from a program implementation perspective. They discussed the need for increased advocacy to translate policy to practice at local levels, and improved monitoring and evaluation practices. In addition, this group stressed the need for increased deployment of psychiatrists and counsellors to government hospitals; sustainability of provided services; and the need to reduce stigma and discrimination against PLWE. This group also highlighted the need to increase the insurance coverage for PLWE, and to increase the provision of the official government disability cards (known as red and blue disability cards) for PLWE. They suggested this could be achieved by developing simple criteria for eligibility based on sensitivity and level of dependence on PLWE. A further suggestion was research to develop and evaluate eligibility criteria for a monthly allowance for PLWE, set appropriate values and evaluate the impact on QoL of an implemented scheme. The group of psychologists discussed gaps in the provision of counselling services for PLWE and their families. This group also highlighted the lack of basic epidemiological data regarding epilepsy prevalence and types among the Nepali population. This evidence gap plays a critical role in the lack of advocacy, awareness and resource allocation to reduce the impact of epilepsy in LMICs like Nepal. In common with the clinicians, NGO professionals, and people with lived experience of epilepsy, the overarching negative impact of stigma on almost all aspects of life for PLWE was stressed by this group. To address stigma and mental health challenges, this group discussed the urgent need for development and evaluation of helpline services for

PLWE, provision of evidence-based educational initiatives through female community health volunteers (FCHVs) and mothers' groups, and counselling support for PLWE and their family members by trained counsellors. During the workshop, evidence emerged that awareness and networking among professionals providing services to PLWE is limited, highlighting the urgent need for a platform of networking, information sharing and advocacy between professionals providing services to PLWE. To address this need stakeholders working to support PLWE in Nepal other neurological conditions should hold regular conferences and meetings for information sharing, continued professional development training and advocacy⁸.

Table 1. Landscape of existing services and gaps to Epilepsy care in Nepal

Type of support	Paid (out of pocket)	Subsidized	Free	Gaps
Medical	<p>Diagnosis and treatment services are available at private hospitals.</p> <p>AEDs/ASMs available in pharmacies.</p> <p>Medical Investigations like (MRI, Blood work, EEG) available in hospitals</p>	<p>Patients registered in NEA get partial to full subsidy in treatment and medicine.</p>	<p>Free consultation with a neurologist at the NEA.</p> <p>Carbamazepine, Sodium valproate, diazepam, phenytoin, Phenobarbital in the govt list of free medicines as anti-epileptic medications.</p>	<p>Sparse availability of specialist doctors in rural settings to diagnose and treat epilepsy.</p> <p>No subsidized/ free services to diagnose and treat epilepsy in rural settings.</p> <p>Gaps in awareness about availability of some of the ASMs under the government's list of essential drugs amongst PLWE even among healthcare providers.</p> <p>Limited coverage of diagnostic tools such as MRI, ECG in rural areas. Requires referral to tertiary hospitals.</p>
Psychological	<p>Psychological counseling offered at private care centers.</p>	<p>Counselling services of government and Non-Governmental Organization (NGOs).</p>	<p>Helpline number, One stop crisis management center (OCMC) counselling</p>	<p>Need for advocacy to reduce stigma towards psychotropic medication.</p> <p>Limited availability of psychiatrists and counsellors in government hospitals and rural areas.</p> <p>Sparse counselling services for care givers and families of PLWE.</p> <p>Need for advocacy to reduce culturally entrenched stigmatization and discrimination against epilepsy.</p>
Social	<p>Legal social workers provide legal counselling in cases of PLWE with disabilities.</p>	<p>Referral from municipality for subsidy in treatment / surgeries</p> <p>Rural Epilepsy Workshop is conducted by NEA to educate paramedics, faith healers, and volunteers on Epilepsy.</p>	<p>Mental Health Gap Action Program (mhGAP) training, Rural Epilepsy workshop (government health workers, NEA)</p> <p>Community Informant Detection Tool (CIDT) (23) used by some NGOs to pro-actively find people with probable epilepsy in the community and help them seek medical help. Epilepsy advocacy by some NGOs/ International Non-Governmental Organizations (INGOs) working in the mental health sector.</p>	<p>Need for comprehensive recognition of disabilities associated with epilepsy, including invisible disabilities, in eligibility criteria for the Disability card.</p> <p>Need for sustained, comprehensive coverage of training programs for community healthcare workers on epilepsy diagnosis, management and patient-centered care services</p>

Type of support	Paid (out of pocket)	Subsidized	Free	Gaps
			mhGAP training incorporated by Nepal Health Training Center (NHTC)(24). Support groups, community outreach programs from NGOs, INGOs	
Financial	Private financial services provide financial support.	Government insurance policy provides some diagnostic and treatment services for patients for free.		Need for inclusion of epilepsy related health services (including invisible disability) in the government health insurance scheme. Need for financial support to facilitate access to tertiary medical services, especially for PLWE residents in remote and rural areas

Session 3

The priority challenges that came from the three stakeholder groups were grouped into three overarching themes namely: Stigma, Epidemiological studies, and access to medicine/services/support. The participants then generated research questions based on the prioritized challenges/gaps that need to be addressed for an additional 30 minutes. Important research questions based on the themes were generated across all three professional groups which is shown in Table 2. Our workshop highlighted the critical information gaps, amounting to a data vacuum, regarding epilepsy in Nepal, which reflects the broader lack of research on epilepsy across LMIC settings. Research evidence is a critical driver of evidence informed policy, and without data, no effective action will be taken to address the complex needs of PLWE. Based on the workshop discussion, we propose a priority research agenda towards developing evidence informed models of patient centered epilepsy care in Nepal.

Table 2: Priority research agenda to develop evidence informed models of patient centered epilepsy care

Theme 1: Epidemiology of epilepsy	
Knowledge gap	Actions
<ul style="list-style-type: none"> Understand the prevalence, etiology, clinical phenotypes and geographic variation of epilepsy in Nepal 	<ul style="list-style-type: none"> Conduct a national prevalence survey. Establish a national patient registry for epilepsy to track trends in prevalence and clinical phenotypes and to optimize treatment procurement, distribution and access.
<ul style="list-style-type: none"> Understand the prevalence, distribution, causes and consequences, including long term impact on QoL of seizure induced injuries among PLWE in Nepal 	<ul style="list-style-type: none"> Conduct integrated multidisciplinary qualitative and clinical research to explore the prevalence, root causes and types of seizure induced injuries to improve holistic support service provision and strengthen preventative strategies for common injuries.
<ul style="list-style-type: none"> Understand the frequency, type and long-term consequences of side effects to ASM medications 	<ul style="list-style-type: none"> Conduct a cross-sectional survey among PLWE and establish a robust reporting and monitoring system for ASM medication side effects.
<ul style="list-style-type: none"> Understanding the psychosocial impacts of epilepsy on PLWE, caregivers and families 	<ul style="list-style-type: none"> Conduct in depth qualitative research exploring the broad scope of impacts on the lived experience of people affected by epilepsy.
<ul style="list-style-type: none"> Understand the prevalence and intensity of co-morbidities among PLWE 	<ul style="list-style-type: none"> Conduct cross sectional research among PLWE and establishment of a national clinical registry which captures data on co-morbidity prevalence and incidence for periodic trend analysis.

Theme 2: Understanding and addressing epilepsy-related stigma

Knowledge gap	Actions
<ul style="list-style-type: none"> Understanding the role of faith healers and spiritual leaders in the health seeking behavior of PLWE. 	<ul style="list-style-type: none"> Understand the knowledge, attitude and practice in Nepali communities in consulting faith healers and spiritual leaders for PLWE. Understand the knowledge attitude and practice among faith healers and spiritual leaders in treating PLWE.
<ul style="list-style-type: none"> Understanding and eliminating epilepsy-related stigma among diverse Nepali cultures 	<ul style="list-style-type: none"> Develop and validate standardized tools to describe and measure the causes, manifestations and consequences of epilepsy-related stigma among the different ethnic communities of Nepal.
<ul style="list-style-type: none"> Evidence-based culturally and contextually appropriate effective stigma reduction intervention strategies 	<ul style="list-style-type: none"> Development and robust evaluation of evidence-based stigma reduction interventions for epilepsy which are co-developed with people with lived experience of epilepsy across diverse cultural contexts of Nepal. Evaluate the effectiveness of photovoice as a tool for addressing epilepsy-related stigma and empowering PLWE. Co-development and efficacy evaluation of epilepsy-related stigma behavioral change communication media for different target audiences (children, healthcare professionals, faith healers, teachers etc.)
<ul style="list-style-type: none"> Understanding interventions to improve the Quality of life, self-esteem and self-management throughout the life course for children living with epilepsy 	<ul style="list-style-type: none"> Development and evaluation of counselling materials, support programs and allied interventions throughout the life course for parents and families of children living with epilepsy.
<ul style="list-style-type: none"> Intersectionality of gender, disability, socioeconomic status, and ethnic identity with stigma for PLWE 	<ul style="list-style-type: none"> Conduct in depth, richly exploratory qualitative research to understand and improve the diverse lived experiences of PLWE throughout the life course in Nepal.

Theme 3: Improving the equity of access to clinical care and support for PLWE

Knowledge gap	Actions
<ul style="list-style-type: none"> Facilitators and barriers to accessing effective patient-centered care for people living with epilepsy in Nepal 	<ul style="list-style-type: none"> Conduct qualitative research with people with lived experience of epilepsy and key informants to comprehensively map available services and explore facilitators and barriers to care.
<ul style="list-style-type: none"> Effective strategies for the Integration of faith healer’s role into care pathways 	<ul style="list-style-type: none"> Multidisciplinary consultation and co-development of integration strategies for development and effective implementation of effective evidence-based strategies to engage diverse actors across the spectrum of patient centered care for epilepsy.
<ul style="list-style-type: none"> Improving medical education on epilepsy for doctors and other healthcare providers 	<ul style="list-style-type: none"> Development and ongoing evaluation of improved training modules for epilepsy into medical curricula, including differentiating psychogenic nonepileptic seizure Development and ongoing and evaluation of training modules for community health workers on recognizing and supporting PLWE to access care services
<ul style="list-style-type: none"> Understanding the treatment gap and access to ASM 	<ul style="list-style-type: none"> Representative surveys to quantify treatment gaps in accessing ASM and obtaining optimal ASM regimens, particularly in remote and underserved populations. Evaluation of the effectiveness of currently available ASM regimens for PLWE
<ul style="list-style-type: none"> Quantifying Health Economics of epilepsy 	<ul style="list-style-type: none"> Studies on the intensity and distribution of financial burden associated with epilepsy for PLWE Studies on health service costs of providing the current standard of care and resource optimization for improved patient centered care models for PLWE

- Optimal role of telemedicine for access to diagnosis and treatment in remote and rural areas.
- Optimal approaches to Improve psychosocial support for PLWE, carers and families.
- Optimal mechanisms for facilitating access to essential economic support to PLWE.
- Facilitators and barriers to effective use of telemedicine for consultation and referral for PLWE in remote areas.
- Development and evaluation of interventions to establish peer support networks, online information resources and professional support services leveraging existing networks like mother's groups, female community health volunteer network etc.
- Resource mapping and development of advocacy strategies to facilitate provision and access to financial support mechanisms for PLWE. Development and evaluation of interventions to address critical gaps in financial support mechanisms for PLWE, especially for remote and underserved population groups.

CONCLUSION & RECOMMENDATION

The workshop showed there is an urgent need for a systematic multidisciplinary research program to address chronic gaps in knowledge, awareness and care provision for people living with epilepsy in Nepal. The existing medical and psychological support system for PLWE is mostly limited to the urban areas of the country and are only accessible to patients with adequate financial resources. The most vulnerable people affected by epilepsy are therefore left behind, without access to basic care or support, which could significantly improve their QoL and livelihoods. The government of Nepal (GoN) has included five ASMs in the list of essential drugs provided free of cost which potentially provides critical support to the most vulnerable PLWE.²⁵

However, awareness of this provision is not universal, even among professionals involved in epilepsy care, and this is an example of a critical gap which could be addressed relatively easily. No dedicated financial support through the government was identified for PLWE. Although some support is available through mechanisms such as disability support, the bureaucracy to access such support is complex. Accessing such services requires specialist knowledge and support to navigate, particularly for individuals who have limited literacy or education and are also living with epilepsy. The discussion highlighted the lack of information and knowledge exchange among professionals providing services to people affected by epilepsy. Establishing a professional networking forum and regular discussion or seminar/conference series would facilitate multidisciplinary collaboration to address this issue. The workshop mapped critical topics of research which could guide efforts to address the research and evidence gaps towards implementing improved patient centered care for epilepsy. The workshop also provided a forum for knowledge exchange among stakeholders from diverse fields relevant to Epilepsy care, a critical ingredient to foster the development of multidisciplinary holistic support.

Based on the discussions, we propose the following 3-point **"Call to Action"** agenda to address the most important gaps in knowledge to improve access to patient-centered support for PLWE in Nepal:

1. Conduct national epidemiological research to understand the prevalence and patterns of different forms of epilepsy in the Nepali population.
2. Increase epilepsy advocacy and awareness to generate action for subsidized epilepsy care and medication; and to reduce the stigma surrounding epilepsy.
3. Establish an effective platform for professional networking and knowledge exchange among multidisciplinary professionals involved in epilepsy care, and to disseminate accurate information to PLWE.

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