

# INPLASY

## What are the unmet needs of people with epilepsy and their family caregivers? A Scoping Review Protocol

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### ADMINISTRATIVE INFORMATION

**Support** - Organisational funding.

**Review Stage at time of this submission** - Formal screening of search results against eligibility criteria.

**Conflicts of interest** - None declared.

**INPLASY registration number:** INPLASY202510047

**Amendments** - This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 14 January 2025 and was last updated on 14 January 2025.

### INTRODUCTION

**Review question / Objective** What are the unmet needs of people with epilepsy and their family caregivers? A Scoping Review Protocol.

**Rationale** To provide a broad map of the unmet needs of adults with epilepsy, extracted from the literature, that ultimately serves as a guide for future studies and potential interventions.

**Condition being studied** Epilepsy.

### METHODS

**Search strategy** Searches were developed for the concepts: Epilepsy, epilepsy populations (patients, family, caregivers, bereaved), unmet needs and healthcare access issues (broader indicators of unmet needs). Subject headings and free text words were identified for use in the search

concepts by the Information Specialist and project team members.

Limits for language and publication date were not used. Animal studies were removed. The search was peer-reviewed by a second Information Specialist using the PRESS checklist.

The search strategies were reviewed before running the final update searches and MeSHh headings were checked for updates. No changes or additions were made before the searches were run.

The database searches identified 10,790 records. Search results were managed in an EndNote library where duplicates were removed automatically and manually using University of Leeds AUHE guidance. Covidence is our selected database for citation and data management, and once the final search results were uploaded into Covidence, a further 27 duplicate references were identified and removed. Once all duplicates were removed there were 5,453 records.

**Participant or population** Studies involving adults with epilepsy, current or bereaved family caregivers, and proxy-reporting paid caregivers.

**Intervention** Not applicable.

**Comparator** Not applicable.

**Study designs to be included** Any observational study design where original data from populations covering outcomes as described above is included.

**Eligibility criteria** Inclusion criteria;

- Studies involving adults with epilepsy, with or without family caregivers
- Studies involving current or bereaved family caregivers of human patients with epilepsy (i.e., spouses, family members, or friends providing unpaid practical or emotional support), with or without patients
- Studies involving paid caregivers (e.g., healthcare professionals), if proxy-reporting on patient needs as detailed below
- Studies reporting self- or proxy reported data on any needs, or unmet needs of epilepsy patients and/or their caregivers, including e.g., information-, education-, health-, healthcare-, accessibility-, wellbeing-, support-, physical-, social-, emotional-, mental-, psychological-, spiritual-, vocational-, financial-, IADL-needs
- Any observational study design where original data from populations covering outcomes as described above is included
- Studies conducted in the European Union, Norway, Switzerland, Iceland, UK, USA, Canada, Australia, New Zealand, Japan, Israël, and South-Korea
- Published in English, Dutch, or German

**Exclusion criteria**

- Studies involving patients with psychogenic non-epileptic seizures (PNES; may be referred to as pseudo-seizures, non-epileptic attack disorder (NEAD), functional seizures, or dissociative seizures)
- Studies reporting on mixed participant samples (e.g., only a proportion of the sample suffers from epilepsy)
- Studies involving animals with epilepsy
- Studies reporting on data extracted from medical records only
- Case studies, reviews (not original research), non-peer reviewed studies, conference abstracts, grey literature, intervention studies including (randomized) clinical trials.

**Information sources** CINAHL (EBSCOhost)

Embase Classic+Embase (Ovid)  
 Google Scholar <https://scholar.google.co.uk/>  
 Ovid MEDLINE(R) ALL  
 APA PsycInfo (Ovid)  
 Scopus <https://www.scopus.com/>  
 Core Collection (Web of Science) SCI-EXPANDED  
 1900+, SSCI 1900+, A&HCI 1975+ and ESCI  
 2015+ searched simultaneously.

**Main outcome(s)** In this scoping review, we aim to (1) identify and narratively synthesize evidence on the unmet needs that adult patients with epilepsy and their caregivers report, (2) map these onto health-related quality of life domains, and, (3) define any knowledge gaps to explore through further study.

**Additional outcome(s)** Not applicable.

**Data management** Full text screening will be performed by one reviewer with reasons for exclusion noted in the web-based application 'Covidence'. A standardized data extraction template will be developed based on the 'JBI scoping review template' for data extraction adapted to suit the present review. In our data extraction form, we will use pre-specified categories for consistency to avoid the need for extensive data cleaning. For any free text fields, spelling mistakes will be filtered out through visual inspection before exporting the data to Microsoft Excel or SPSS. A PRISMA flow diagram will be developed to display our study selection process.

**Quality assessment / Risk of bias analysis** We will use the pre-specified in- and exclusion criteria during title/abstract screening. Initially, we conducted a pilot of the the title/abstract screening process. Two reviewers applied the criteria to the first 25 hits and met to discuss any discrepancies or uncertainties. Clarifications to the existing criteria were noted before one reviewer continued with title/abstract screening. Full text screening was performed by one reviewer with reasons for exclusion noted in 'Covidence'. Ambiguous information was discussed in team meetings. We do not anticipate to contact study authors directly.

**Strategy of data synthesis** In our data extraction form, we will use pre-specified categories for consistency to avoid the need for extensive data cleaning. For any free text fields, spelling mistakes will be filtered out through visual inspection before exporting the data to our chosen software package. A PRISMA flow diagram will be developed to display our study selection process. Basic details on publications and study participants will be analyzed descriptively. We will

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divide papers into those covering the unmet needs of adult patients, and those focusing on caregiver unmet needs. Using a quality of life framework, we will categorize the unmet needs reported in the literature into the domains of physical, cognitive, mental, social, and spiritual functioning. The information, education, healthcare, support, and accessibility needs data extracted will be incorporated as cross-cutting themes.

**Subgroup analysis** Not applicable.

**Sensitivity analysis** Not applicable.

**Language restriction** We only include studies published in English, Dutch, or German.

**Country(ies) involved** The Netherlands.

**Keywords** Epilepsy; Adult; Caregiver; quality of life; Unmet needs.

**Dissemination plans** We envision this scoping review will yield a publication covering the unmet needs of adult patients with epilepsy and their caregivers.

#### **Contributions of each author**

Author 1 - Jacob Reijneveld - Conceptual framework; Secondary review; Study conflict resolution; Data extraction and analysis; Manuscript preparation.

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