

Supplementary material

Additional information on methodology

Phase 1: semi-structured interviews

A review of the literature was conducted to identify topics and potential areas of improvement in the domain of pediatric epilepsy. Key words, including “pediatric epilepsy”, “challenges”, and “needs”, were entered in the search engine, MEDLINE, and articles restricted to Europe and the U.S. were reviewed. The main areas identified were presented to, and discussed with, a group of clinical experts in pediatric epilepsy (co-authors SK, IM, GK, PO, AA). The final selected improvement areas were used to develop each section of the interview guide. Open-ended, non-directive questions were designed to obtain unbiased insights into the clinical challenges and barriers faced by the participant when diagnosing, treating, managing or communicating with pediatric patients with epilepsy or their caregivers. Interviews lasted 45 minutes and were conducted in either English, German, or Spanish by interviewers trained in educational research (including co-authors PL and SM). Informed consent to participate and be audio-recorded was obtained prior to each interview.

Qualitative thematic analysis

A four-step approach to the qualitative analysis consisted of: (1) developing a coding tree based on areas of investigation and study objectives; (2) executing the coding according to the coding tree themes and codes; (3) adding additional codes for data that were not initially included in the coding tree (and stopping once data saturation was reached); and (4) identifying the most significant themes mentioned during the interviews.

Phase 2: online survey

The main themes identified in the qualitative analysis were used to design the 15 to 20-minute online survey. The survey was divided into nine sections, in which participants were asked to: assess their own level of knowledge and skills in different areas of clinical care for pediatric patients with epilepsy (Sections 1 and 2); rate their level of agreement with multiple statements related to care for pediatric patients with epilepsy (Section 3); select the most difficult comorbidities/side-effects to manage (Section 4); indicate the average age at which they initiate a discussion on the transition of care (Section 5); select the most important contextual/systemic barriers to optimal care in epilepsy with pediatric patients (Section 6); assess their own level of difficulty with various elements of the treatment decision-making process (Section 7); assess the frequency at which they themselves currently engage in different clinical activities (Section 8); and indicate which guidelines they use most often (Section 9). Response formats consisted of Likert-type scales or multiple nominal choices.

Triangulated analysis

The main themes emerging from Phase 1 (qualitative) were triangulated with data from Phase 2 (quantitative) to identify the key gaps, barriers, and clinical challenges faced by

neuropsychiatrists in epilepsy. Triangulation of sources (neuropsychiatrists, general neurologists, and nurses [Phase 1]) and methodologies (qualitative and quantitative) was used to increase the trustworthiness of findings. Final findings were interpreted by a working group of clinical experts (co-authors SK, IM, GK, PO, AA) and educational experts (including co-authors SM, SL and PL).

Recruitment and inclusion criteria

Invitations included a secure link to access eligibility screening questions. Eligible participants were then re-directed to the informed consent agreement, and then either to the availability form for the interview (Phase 1), or to the online survey (Phase 2).

Eligible professions for Phase 1 were: neuropsychiatrists, general neurologists or epileptologists with two or more new epilepsy patients who have transitioned from pediatric to adult care in the last year, and nurses with five or more pediatric patients with epilepsy in their total patient caseload.

Given the focus of this needs assessment on neuropsychiatrists and specialists with a majority caseload of pediatric patients, eligible participants in the online survey (Phase 2) were required to be either a neuropsychiatrist, a general neurologist (with pediatric patients corresponding to at least 50% of their total caseload), or a pediatrician (with neurology patients corresponding to at least 50% of their total caseload).

To qualify, all participants were required to be actively practicing (*i.e.* more than 50% of their time spent with patients) in one of the three targeted countries (Germany, Spain, or the US), have at least two years of practical experience, and have a minimum of five pediatric patients with epilepsy among their total patient caseload.