Original article

Epileptic Disord 2018; 20 (4): 239-56

Identifying the educational needs of physicians in pediatric epilepsy in order to improve care: results from a needs assessment in Germany, Spain, and the United States

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Received April 05, 2018; Accepted July 08, 2018

ABSTRACT – *Aims.* The objective of this study was to gather evidence-based data on the educational needs of neuropediatricians. A needs assessment was conducted to identify the clinical challenges of physicians when diagnosing, medically treating, and managing pediatric patients with epilepsy; which could be addressed through educational interventions.
Methods. A two-phase mixed-methods approach was used to conduct the needs assessment in Germany, Spain, and the US. Phase 1 consisted of qualitative data collection through multiple sources: a literature review, semi-structured interviews with clinicians and nurses working in pediatric epilepsy, and interpretation and input from faculty experts. Qualitative data were coded (NVivo) and analyzed using a thematic analysis, and findings were then used to design the second phase. Phase 2 consisted of quantitative data collection through an online survey that aimed to validate the identified challenges and underlying causes using a larger sample than in Phase 1. Data from the survey were analyzed using frequency tabulations and chi-square tests (SPSS).

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doi:10.1684/epd.2018.0989

Results. A total of 267 participants were included in the study. Phase 1 included 88 participants (neurologists, pediatricians, neuropediatricians, and nurses). Phase 2 included 179 participants (neurologists, pediatricians, and neuropediatricians). The main areas of challenge which emerged from the triangulated data included: the integration of guidelines into practice, identification of epilepsy and epilepsy events, integration of genetic testing into practice, integration of non-pharmacological treatments, transition from pediatric to adult care, and involvement and engagement with caregivers. Underlying causes of these challenges are reported, along with supporting qualitative findings.

Conclusions. This study identified the educational needs of physicians working in pediatric epilepsy in Germany, Spain and the USA. Increasingly, educational interventions are required to be evidence-based. The results of this study could be used to design such interventions to support neuropediatricians who wish to specialize in pediatric epileptology, in order to manage the identified challenges.

Key words: pediatric epilepsy, neuropediatricians, needs assessment, medical education

Epilepsy is one of the most common neurological diseases worldwide, and is a condition frequently treated by neuropediatricians or pediatric neurologists in developed countries and by general practitioners or general neurologists in developing countries (World Health Organization, 2005). Recent reports indicate that one in 150 children are diagnosed with epilepsy, with the highest prevalence found in developing countries and rural areas (Aaberg *et al.*, 2017).

Health professionals practicing in the field of epilepsy, and especially pediatric epilepsy, have faced at least three important changes in recent years that have contributed to the increasing complexity of managing this population. First, a lack of clarity around evidence-based recommendations for the treatment of epilepsy in childhood was reported by the International League Against Epilepsy (ILAE). This led, in 2015, to the publication of a summary of the current state of knowledge of pediatric seizures (Wilmshurst *et al.*, 2015). This report aims to support neuropediatricians by providing key drug treatment and management recommendations, which now includes clear indications of the level of supporting evidence for each recommendation. A second key change is the increase in the amount of clinical data available on the indications for early referral for pre-surgical evaluation regarding focal epilepsies (Arzimanoglou *et al.*, 2016; Cross *et al.*, 2016), the use of third-generation anticonvulsant drugs in children, as well as the increased number of newly-approved medications for pediatric patients (Coppola *et al.*, 2017; Moavero *et al.*, 2017). Finally, the diagnosis and classification of epilepsy types has evolved. The ILAE recently published an updated version of the classification of seizure types and epilepsies, which includes modifications to the classification criteria and nomenclature, in addition to providing better detailed etiological categories and consideration of co-morbidities (Fisher *et al.*, 2017; Scheffer *et al.*, 2017).

Despite these recent changes and advancements, there is little evidence indicating which areas pose the greatest challenge to physicians who treat patients with epilepsy, and which of those could be addressed through medical education. Current available data on potential challenge areas is based on extrapolation through literature reviews, rather than using self-reported data gathered through physician needs assessment studies (Wilmshurst *et al.*, 2014). The need and importance of identifying physicians' clinical challenges, including knowledge and skills gaps, was raised in 2012 by the *Institute of Medicine Committee on the Public Health Dimensions of the Epilepsies* (England *et al.*, 2012).

A needs assessment of physicians was conducted to identify their main challenges when treating children with epilepsy. The study objective was to assess the level of knowledge, skills, and confidence of neuropediatricians and physicians treating pediatric patients with epilepsy in developed countries, regarding the multiple clinical and communication dimensions of the patient journey, with the aim of providing information for future educational initiatives. To our knowledge, this is the first needs assessment in pediatric epilepsy conducted among neuropediatricians and physicians working in non-emergency departments within the United States and Western Europe (Germany and Spain).

Materials and methods

Mixed-methods approach and analysis

A mixed-methods approach was used for this needs assessment which consisted of consecutive qualitative and quantitative data collection (Phase 1 and Phase 2, respectively), in Germany, Spain, and the US.

Participants completed the interview or survey in the official language of their country of practice (English, German or Spanish).

Insights were gathered on challenges and barriers to optimal care in pediatric epilepsy in Phase 1, via semi-structured interviews with multiple stakeholders who provide care to pediatric patients with epilepsy in the three targeted developed countries. This qualitative data facilitated the understanding and identification of the causes of these challenges (Maudsley, 2011). Interview transcripts were coded (NVivo, QSR International Pty Ltd, Version 7, 2006) by educational researchers, and the data was processed according to the precepts of thematic analysis (Boyatzis, 1998) and directed content analysis (Hsieh and Shannon, 2005). The themes that emerged from Phase 1 were then used to develop the questions included in the online survey (Phase 2).

The analysis of quantitative data obtained from the online survey allowed for a validation of the presence of specific challenges among a larger sample, and to precisely identify the causalities of these key challenges. Quantitative data were analyzed using frequency tables and cross-tabulations (IBM SPSS 22.0 software, IBM Corporation, Armonk, NY) by country and by self-reported competency. Educational needs for knowledge and skills were identified when participants selected 1, 2, or 3 on a 5-point Likert-type scale (where 1=low and 5=optimal). Similar stratification has been used in previous needs assessments (Lazure *et al*., 2016). Data are presented by countries of practice and by level of competency (*i.e.* participants who reported competency in epilepsy *vs.* those who did not report competency). Pearson chi-squares were calculated to identify sub-group differences (*i.e.* by countries and by competency).

The triangulation of data collection methods (qualitative and quantitative) allowed for an increase in the trustworthiness of the findings (Olsen, 2004). More details about the study design and methodology are available online as *supplementary material*.

Ethical consideration

The study protocol was approved by an independent ethics review board (VERITAS IRB, QC, Canada). Participants received financial compensation for their time in accordance with ethical regulations.

Recruitment and inclusion criteria

Email invitations were sent to potential study participants identified through panels in compliance with the ESOMAR/ICC International Code on Market, Opinion and Social Research and Data Analytics (ESOMAR, 2016), or by using snowball sampling techniques (Palinkas *et al*., 2015).

Neuropediatricians, pediatricians, and general neurologists involved in the treatment and management of pediatric patients with epilepsy were recruited for Phases 1 and 2. To obtain a comprehensive perspective of the current state of pediatric epilepsy care, nurses were included in Phase 1.

Survey participants were asked whether they consider themselves to have competency in epilepsy (*e.g.* certification, fellowship training) and if so, which one. This information was used to distinguish the participants who consider themselves experts in epilepsy, as they may face different challenges relative to the other participants. Hereafter, physicians with this added training or specialization are referred to as "participants with competency in epilepsy". Additional details on the methodology are available online as s*upplementary material*.

Results

Sample characteristics

A total of 267 participants from Germany (*n*=73), Spain (*n*=74) and the US (*n*=120) were included in this needs assessment. The US was included to represent North America, whereas Germany and Spain represented Western Europe. These countries were chosen in anticipation of future comparative research across additional developed countries in North America and Europe. Semi-structured interviews (Phase 1) were conducted with 66 specialists and 22 specialized nurses in pediatric epilepsy, whereas the online survey (Phase 2) was completed by 179 specialists exclusively. Detailed descriptions of the sample by country, study phase, and profession are available in *table 1*. The main findings related to care for pediatric patients with epilepsy were identified and are summarized in *figure 1*; six of these are explored in detail below.

Sub-optimal integration of guidelines into practice

The triangulated data indicated sub-optimal knowledge of guidelines and classifications in epilepsy. Among all participants, 30% reported sub-optimal knowledge of the *ILAE treatment guidelines for epilepsy* (*table 2*). This proportion reached 44% among participants from the US, compared to 16% in Spain and 22% in Germany (*p*=0.001). This knowledge gap was also significant for participants without competency in epilepsy (45%), when compared to participants with competency in epilepsy (21%; *p*=0.001). Knowledge of the *NICE guidelines* and new *2017 ILAE classification of the epilepsies* was also reported as sub-optimal by a larger proportion of participants without competency (60% and 59%,

Table 1. Description of the study sample by country and study phases.

Category of participant		**Germany**		**Spain**		**U.S.**		**Total** *n*=267
		Phase 1: Qualitative	**Phase 2: Quantitative**	**Phase 1: Qualitative**	**Phase 2: Quantitative**	**Phase 1: Qualitative**	**Phase 2: Quantitative**	
Self-reported profession								
Nurses*		6	–	6	–	10	–	**22**
Physicians	Neurologists**	6	18	6	16	10	22	**245**
	Pediatricians***	–	17	–	21	–	24	
	Neuropediatricians	12	14	12	13	20	34	
Self-reported competency in epilepsy (quantitative phase only)								
Yes		35		34		43		**112**
No		14		16		37		**67**
Practice setting								
Community-based		12	16	14	10	21	37	**110**
Academic-based or epilepsy center		12	33	10	38	19	43	**155**
Other / missing		0	0	0	2	0	0	**2**

*Inclusion criteria in Phase 1 (qualitative): a minimum of five pediatric patients with epilepsy.

**Inclusion criteria in Phase 1 (qualitative): two or more new epilepsy patients who have transitioned from pediatric to adult care in the last year. Inclusion criteria in Phase 2 (quantitative): at least 50% of their total caseload was pediatric patients.

***Inclusion criteria in Phase 1 (qualitative): a minimum of five patients with epilepsy. Inclusion criteria in Phase 2 (quantitative): at least 50% of their total caseload was neurology patients.

Table 2. Participants' self-reported knowledge, use, and perception of guidelines in epilepsy care for pediatric patients.

	Sample divided by country			Significant differences by country[c]	Sample divided by competency		Significant differences by competency[c]	Total
	Germany	Spain	U.S.		Without competency	With competency		
ILAE treatment guidelines								
[a]% reporting sub-optimal knowledge	**22%** **(*n*=11)**	**16%** **(*n*=8)**	**44%** **(*n*=35)**	*p*=0.001	**45%** **(*n*=30)**	**21%** **(*n*=24)**	*p*=0.001	**30%** **(*n*=54)**
% using the guidelines most often in practice with pediatric patients	14% (*n*=7)	30% (*n*=15)	24% (*n*=19)	NS	27% (*n*=18)	21% (*n*=23)	NS	23% (*n*=41)
NICE guidelines								
[a]% reporting sub-optimal knowledge	45% (*n*=22)	30% (*n*=15)	51% (*n*=41)	NS	**60%** **(*n*=40)**	**34%** **(*n*=38)**	*p*=0.001	44% (*n*=78)
% using the guidelines most often in practice with pediatric patients	10% (*n*=5)	14% (*n*=7)	19% (*n*=15)	NS	13% (*n*=9)	16% (*n*=18)	NS	15% (*n*=27)
New 2017 ILAE classification of the epilepsies								
[a]% reporting sub-optimal knowledge	42% (*n*=20)	41% (*n*=20)	48% (*n*=38)	NS	**59%** **(*n*=39)**	**35%** **(*n*=39)**	*p*=0.002	44% (*n*=78)

Table 2. Participants' self-reported knowledge, use, and perception of guidelines in epilepsy care for pediatric patients (*Continued*).

	Sample divided by country			**Significant differences by country**[c]	**Sample divided by competency**		**Significant differences by competency**[c]	**Total**
	Germany	**Spain**	**U.S.**		**Without competency**	**With competency**		
% referring to the different classification guidelines, most often in practice with pediatric patients								
New 2017 ILAE classification of the epilepsies (Published in April 2017 in *Epilepsia*)	33% (*n*=16)	**48%** **(*n*=24)**	34% (*n*=27)	NS	36% (*n*=24)	39% (*n*=43)	NS	38% (*n*=67)
2010 Revised Terminology and Concepts for Organization of Seizures and Epilepsies (published in *Epilepsia*)	**37%** **(*n*=18)**	42% (*n*=21)	**46%** **(*n*=36)**	NS	40% (*n*=27)	43% (*n*=48)	NS	42% (*n*=75)
Semiological seizure classification by Lüders *et al.*, (Published in September 1998 in *Epilepsia*)	4% (*n*=2)	0%	1% (*n*=1)	NS	0%	3% (*n*=3)	NS	2% (*n*=3)
1989 ILAE revised classification of epilepsies and epileptic syndromes	8% (*n*=4)	2% (*n*=1)	9% (*n*=7)	NS	8% (*n*=5)	6% (*n*=7)	NS	7% (*n*=12)
1985 ILAE classification of epilepsies and epileptic syndromes	8% (*n*=4)	6% (*n*=3)	1% (*n*=1)	NS	3% (*n*=2)	5% (*n*=6)	NS	5% (*n*=8)
I do not use any official classifications	10% (*n*=5)	2% (*n*=1)	9% (*n*=7)	NS	13% (*n*=9)	4% (*n*=4)	NS	7% (*n*=13)
Perception that, in most cases, guidelines in pediatric epilepsy are not helpful in treatment decision-making								
[b]% agreeing with the above statement	43% (*n*=21)	50% (*n*=25)	50% (*n*=40)	NS	45% (*n*=30)	50% (*n*=56)	NS	**48%** **(*n*=86)**

[a] Question: for each statement below, please select the number that best describes what you consider your level of knowledge to be, given your professional role; scale: 1 (low) to 5 (optimal). Data are presented as percentages of participants who selected 1, 2 or 3.

[b] Question: based upon your clinical experience with pediatric patients suffering from epilepsy, please indicate your level of agreement with the following statements; scale: 1 (completely disagree), 2 (slightly disagree), 3 (slightly agree), and 4 (completely agree). Data are presented as percentages of participants who selected slightly agree (3) or completely agree (4).

[c] Significant differences calculated using the chi-square test ($p<0.05$).

Data in bold are reported in the text. NS: not statistically significant.

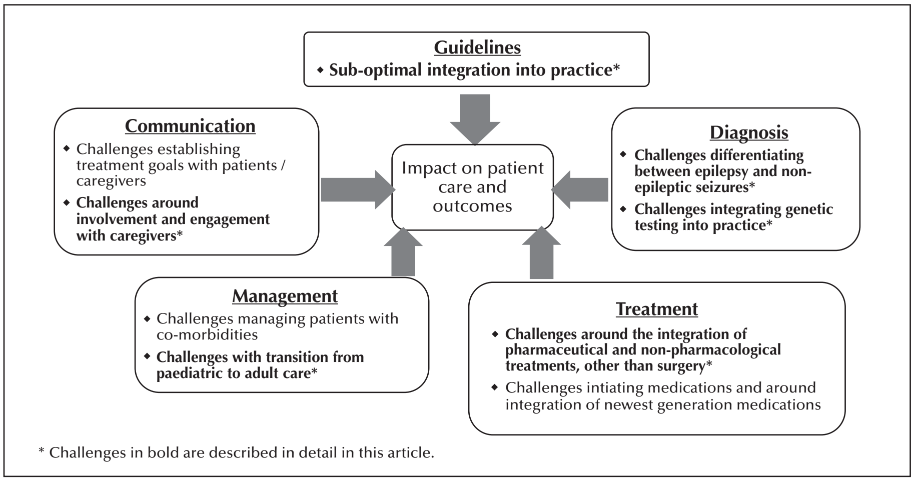


Figure 1. Key findings emerging from the triangulated data of the educational needs assessment.

respectively), compared to participants with competency (34%/*p*=0.001 and 35%/*p*=0.002, respectively).

At the time of this study (early 2017), the *2010 Revised Terminology and Concepts for Organization of Seizures and Epilepsies* was selected as the document used most often and by the highest proportion of German (37%) and US (46%) participants when treating pediatric patients (*table 2*). The new *2017 ILAE classification of the epilepsies* was the reference most often used by Spanish participants (48%).

A recurrent theme that emerged from interviews was the perception that available guidelines lack usefulness, or are incomplete:

"*I don't think there are very good guidelines for that . . . we have guidelines of when to start the treatment, but* ***really not very good guidelines for when to continue therapy***". Epileptologist, US.

In Phase 2, nearly half of the survey participants (48%) agreed that "in most cases, guidelines in pediatric epilepsy are not helpful in my treatment decision-making" (*table 2*).

Challenges with identification of epilepsy and epileptic events

Participants reported challenges distinguishing epilepsy events from non-epileptic events. As shown in *table 3*, a higher proportion of participants without competency in epilepsy, compared to participants with competency in epilepsy, reported sub-optimal skills when differentiating an epileptic event from parasomnia (37% *vs.* 21%; *p*=0.019) and from a movement disorder (49% *vs.* 22%; *p*<0.001). Thirty-seven percent of all participants, regardless of competency status, reported a sub-optimal skill level when diagnosing epilepsy in children with autism spectrum disorders, and when differentiating epilepsy from autonomic failure syndromes.

There was a lack of clarity, especially among participants without competency in epilepsy, when classifying epilepsy by type. Specifically, 35% of participants without competency reported sub-optimal knowledge when classifying epilepsy by type, compared to only 17% of participants with competency (*p*=0.007; *table 3*). Knowledge of different EEG patterns was also reported as sub-optimal by 37% of participants without competency *vs.* 19% with competency (*p*=0.007).

When etiology of epilepsy was identified, sub-optimal skills were reported by 40% of participants without competency, compared to only 25% of those with competency (*p*=0.035). When focal epilepsy was identified, skills were also reported to be at a lower level among those with no competency (35%), compared to those with competency (17%; *p*=0.008). In addition, suboptimal skill in identifying developmental and epileptic encephalopathy was reported by 38% of all participants, regardless of competency status.

Challenges integrating genetic testing into practice

The triangulated data indicated a sub-optimal integration of genetic testing into practice. Ordering genetic testing for refractory patients was reportedly done "most of the time" or "systematically" by 45% of participants (*figure 2*). However, sub-optimal skills regarding interpretation of the results of genetic tests to inform treatment was reported by 36% of participants. This proportion translates to 36% of US participants, 28% in Spain, and 45% in Germany (difference not statistically significant). In addition, 38% of participants reported this task to be "difficult" or "extremely difficult". Among a list of 10 potential barriers, "lack of access to genetic testing due to cost and lack of community resources" was selected by the highest proportion of participants as the principal barrier to providing optimal care to pediatric patients with epilepsy (*figure 3*).

Table 3. Participants' self-reported skills and knowledge related to types of epileptic events and pharmacological and non-pharmacological therapies.

	Sample divided by country			**Significant differences by country**[d]	**Sample divided by competency**		**Significant differences by competency**[d]	**Total**
	Germany	**Spain**	**U.S.**		**Without competency**	**With competency**		
[a]% reporting sub-optimal skills when identifying the epilepsy type, etiology and syndrome								
Differentiating epileptic event from parasomnia	31% (*n*=15)	18% (*n*=9)	30% (*n*=24)	NS	**37%** **(*n*=25)**	**21%** **(*n*=23)**	*p*=0.019	27% (*n*=48)
Differentiating epilepsy from a movement disorder (paroxysmal dyskinesia)	31% (*n*=15)	24% (*n*=12)	37% (*n*=29)	NS	**49%** **(*n*=32)**	**22%** **(*n*=24)**	*p*<0.001	32% (*n*=56)
Diagnosing epilepsy in children with an autism spectrum disorder	42% (*n*=20)	36% (*n*=18)	34% (*n*=27)	NS	42% (*n*=28)	34% (*n*=37)	NS	**37%** **(*n*=65)**
Differentiating epilepsy from pseudo-seizures or psychogenic seizures	27% (*n*=13)	19% (*n*=9)	28% (*n*=22)	NS	28% (*n*=19)	23% (*n*=25)	NS	25% (*n*=44)
Differentiating epilepsy from autonomic failure syndromes	33% (*n*=16)	34% (*n*=17)	41% (*n*=32)	NS	42% (*n*=28)	33% (*n*=37)	NS	**37%** **(*n*=65)**
Detecting focal epilepsy	18% (*n*=9)	18% (*n*=9)	31% (*n*=24)	NS	**35%** **(*n*=23)**	**17%** **(*n*=19)**	*p*=0.008	24% (*n*=42)
Identifying epilepsy etiology (*i.e.* structural, genetic, infectious, metabolic, or immune)	29% (*n*=14)	28% (*n*=14)	34% (*n*=27)	NS	**40%** **(*n*=27)**	**25%** **(*n*=28)**	*p*=0.035	31% (*n*=55)
Identifying "developmental and epileptic encephalopathy"	38% (*n*=18)	38% (*n*=18)	39% (*n*=30)	NS	41% (*n*=27)	36% (*n*=39)	NS	**38%** **(*n*=66)**
Identifying juvenile myoclonic epilepsy	29% (*n*=14)	22% (*n*=11)	27% (*n*=21)	NS	28% (*n*=19)	24% (*n*=27)	NS	26% (*n*=46)
Identifying Lennox-Gastaut syndrome	39% (*n*=19)	26% (*n*=13)	30% (*n*=23)	NS	36% (*n*=24)	28% (*n*=31)	NS	31% (*n*=55)
[b]% reporting sub-optimal knowledge regarding diagnosis and classification of epilepsy								
Classifying type of epilepsy	20% (*n*=10)	16% (*n*=8)	30% (*n*=24)	NS	**35%** **(*n*=23)**	**17%** **(*n*=19)**	*p*=0.007	24% (*n*=42)
Different EEG patterns	20% (*n*=10)	26% (*n*=13)	29% (*n*=23)	NS	**37%** **(*n*=25)**	**19%** **(*n*=21)**	*p*=0.007	26% (*n*=46)
[b]% reporting sub-optimal knowledge regarding non-pharmacological therapies								
Low glycemic index treatment (LGIT)	52% (*n*=25)	44% (*n*=22)	51% (*n*=41)	NS	57% (*n*=38)	45% (*n*=50)	NS	**49%** **(*n*=88)**
Modified Atkins diet	49% (*n*=24)	46% (*n*=23)	49% (*n*=39)	NS	53% (*n*=35)	46% (*n*=51)	NS	**48%** **(*n*=86)**

Table 3. Participants' self-reported skills and knowledge related to types of epileptic events and pharmacological and non-pharmacological therapies (*Continued*).

	Sample divided by country			**Significant differences by country**^{d}	**Sample divided by competency**		**Significant differences by competency**^{d}	**Total**
	Germany	**Spain**	**U.S.**		**Without competency**	**With competency**		
[b]% reporting sub-optimal knowledge regarding non-pharmacological therapies								
Ketogenic treatment	43% (*n*=21)	44% (*n*=22)	41% (*n*=32)	NS	51% (*n*=34)	37% (*n*=41)	NS	**42%** **(*n*=75)**
Vagus nerve stimulation therapy (VNS)	42% (*n*=20)	46% (*n*=23)	41% (*n*=33)	NS	46% (*n*=30)	41% (*n*=46)	NS	**43%** **(*n*=76)**
[a]% reporting sub-optimal skills regarding the use of pharmacological treatments								
Deciding when to change from monotherapy to polytherapy	27% (*n*=13)	22% (*n*=11)	30% (*n*=24)	NS	34% (*n*=23)	23% (*n*=25)	NS	**27%** **(*n*=48)**
Deciding if treatment should be initiated in the case of benign rolandic epilepsy	25% (*n*=12)	20% (*n*=10)	31% (*n*=25)	NS	32% (*n*=21)	23% (*n*=26)	NS	26% (*n*=47)
Combining different medications to find balance between side effects and efficacy	38% (*n*=18)	20% (*n*=10)	25% (*n*=20)	NS	32% (*n*=21)	24% (*n*=27)	NS	27% (*n*=48)
Mitigating the risk of over-treating patients with epilepsy (*i.e.* too much sedation leading to a reduced quality of life)	31% (*n*=15)	30% (*n*=15)	30% (*n*=23)	NS	32% (*n*=21)	29% (*n*=32)	NS	30% (*n*=53)
Mitigating the risk of over-treating (*i.e.* polypharmacy) patients with refractory epilepsy	35% (*n*=17)	26% (*n*=13)	31% (*n*=25)	NS	37% (*n*=25)	27% (*n*=30)	NS	**31%** **(*n*=55)**
[c]% reporting the following as difficult or extremely difficult to consider in clinical decision-making								
The interactions between different antiepileptic drugs	29% (*n*=14)	39% (*n*=19)	28% (*n*=22)	NS	29% (*n*=19)	32% (*n*=36)	NS	**31%** **(*n*=55)**
The interactions between antiepileptic drugs and drugs used in psychiatry	27% (*n*=13)	48% (*n*=24)	35% (*n*=28)	NS	40% (*n*=27)	34% (*n*=38)	NS	**37%** **(*n*=65)**

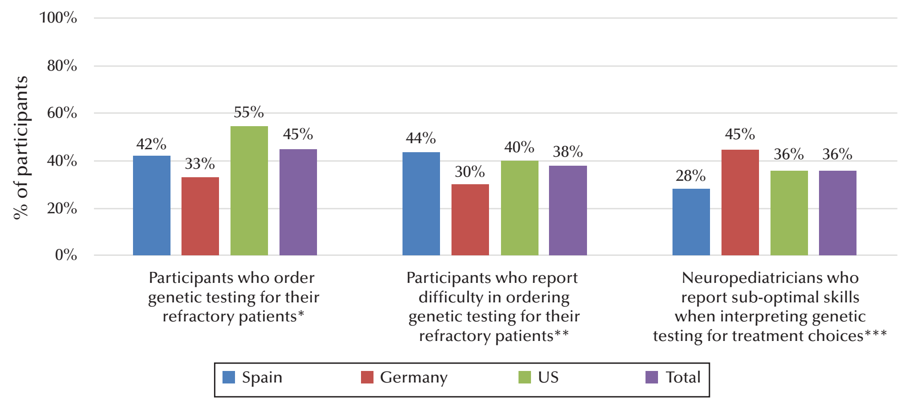
[a] Question: for each statement below, please rate your current level of skills in relation to what they should be, given your professional role; scale: 1 (low) to 5 (optimal). Data are presented as percent of participants who selected 1, 2 or 3.

[b] Question: for each statement below, please select the number that best describes what you consider your level of knowledge to be, given your professional role; scale: 1 (low) to 5 (optimal). Data are presented as percentage of participants who selected 1, 2 or 3.

[c] Question: how challenging is it to consider each of these factors in your clinical decisions? Scale: 1 (extremely difficult), 2 (difficult), 3 (neutral), 4 (easy), and 5 (extremely easy). Data are presented as percent of participants who selected 1 or 2.

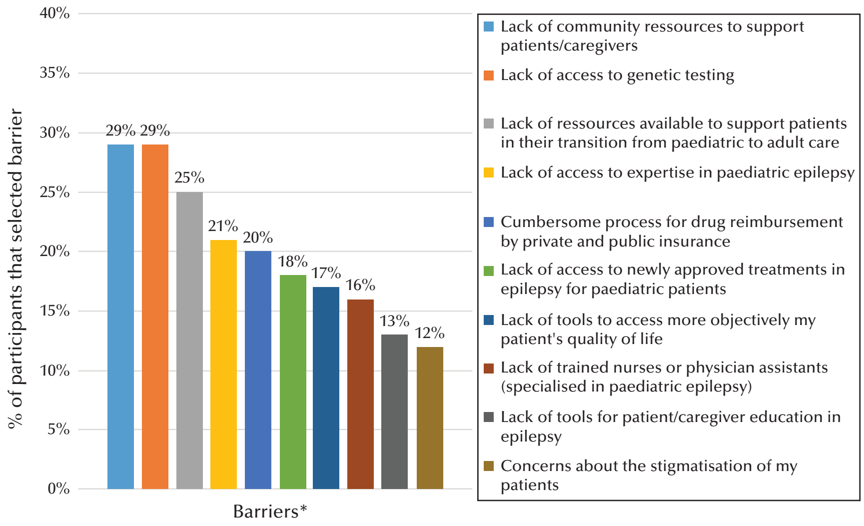
[d] Significant differences calculated using the chi-square test ($p<0.05$).

Data in bold are reported in the text. NS: not statistically significant.



*Percent of participants that reported doing the task in most of the time (4) or systematically (5) (scale: 1. Never, I don't think it's important, 2. Never, why (Open field), 3. Only with few of my patients, 4. Most of the time, 5. Systematically).
**Percent of participants that selected difficult (2) or extremely difficult (1) (scale: 1. Extremely difficult, 2. Difficult, 3. Neutral, 4. Easy, 5. Extremely easy).
***Percent of participants selected 1, 2 or 3 (scale: 1. Low, given my professional role to 5. Optimal, given my professional role).

Figure 2. Perception and use of genetic testing.



*Question: Among the following, please select the two barriers that have the most impact on your ability to provide optimal care to pediatric patients with epilepsy. Data is the percent of respondents that selected the barrier as having the most impact on their ability to provide optimal care.

Figure 3. Perceived barriers that have the most impact on ability of neuropediatricians to provide optimal care.

Systemic barriers to genetic testing due to lack of local reimbursement policies also emerged as a key theme from semi-structured interviews:

"It is very difficult to achieve this [genetic] test in Spain because ***it is very expensive and the National Health System does not fund it****. Not all the families are able to afford it.* ***All the neuropediatricians know that this test is essential, but it is not as available as in other country****"*. Neuropediatrician, Spain.

Challenges around pharmacological and non-pharmacological treatments, other than surgery

Participants reported an overall lack of knowledge of non-pharmacological treatment options, other than surgery, for management of epilepsy in pediatric patients. As shown in *table 3*, sub-optimal knowledge of low glycemic index treatment (LGIT) and the modified Atkins diet were reported by half of neuropediatricians (49% and 48%, respectively). In addition, 42% and 43% of neuropediatricians reported sub-optimal knowledge of the ketogenic diet and vagus nerve stimulation (VNS) therapy, respectively.

A lack of knowledge of non-pharmacological treatments, combined with challenges when discussing these options with parents or caregivers, was mentioned by neuropediatricians as a contributor to the use of these therapies as a last-resort treatment only:

"*The international definition* [for using a non-pharmacological therapy] *is two antiepileptics without achieving seizure freedom. And I do not see it like that.* ***I see it after 3, 4, 5 or 6 medications.*** *It depends a bit on the family too*". Neuropediatrician, Germany.

"*I guess another challenge* ***is trying to encourage the use of other modalities such as vagal nerve stimulation for patients****...* ***There's some hesitancy to look at the diet, or give it a try and see whether it could be effective. It's certainly easier to take a pill than it is to do the diet.*** *That's for sure*". Neuropediatrician, US.

A third of patients reported "decision-making regarding the use of pharmacological treatment" as a challenge. Specifically, 31% reported sub-optimal skills "mitigating the risk of over-treating patients with refractory epilepsy" and 27% when "deciding when to change from monotherapy to polytherapy" (*table 3*). Managing patients with multiple medications was also perceived as challenging. The interactions between different antiepileptic drugs, and between antiepileptic drugs and drugs used in psychiatry, were reported as factors that are difficult to consider when making clinical decisions by 31% and 37% of participants, respectively (*table 3*).

Challenges with transition from pediatric to adult care

Preparing patients and caregivers for the transition from pediatric to adult care emerged as an important challenge for participants. Participants reported an average age of between 17 and 18 years old corresponding to when they first initiated discussion for this transition. As reported in *table 4*, a large majority of participants agreed they "should begin discussing the transition to adult care earlier with their patients with cognitive comorbidities" (81%) as well as those without cognitive comorbidities (76%). Nearly three quarters (72%) of participants also agreed they "could do better to prepare their patients for their transition to adult care". A majority of participants (64%) agreed "there is a lack of communication between themselves and the adult neurologist during the transition from pediatric to adult care".

Sub-optimal skills to manage patients' and caregivers' emotional insecurity during these transitions were reported by 31% of participants. Treating patients during transition from pediatric care was also an important theme that emerged from interviews with neurologists who treat adult patients:

"***Not only do you have to deal with the kids, you are dealing with parents,****...* ***with somebody who may have been coddled in the pediatric world****... You know, you call me every day with little stuff, I am going to tell you, you got to be crazy. So, you are treating the patient, but you are also treating the parent...*". General Neurologist, US.

A "lack of resources available to support patients in their transition from pediatric to adult care" was ranked as the third barrier (selected by 25% of participants) among a list of 10 barriers that have the most impact on their ability to provide optimal care (*figure 3*).

Challenges around involvement and engagement with caregivers

Two specific aspects of caregiver communication emerged as areas in need of improvement: the inconsistent level of involvement with caretakers and discussion of sudden unexpected death in epilepsy (SUDEP).

In the online survey, 73% of physicians agreed that "the level of effort I put in supporting caregivers depends on how active and involved they are in the care of their child" (*table 4*). Neuropediatricians reported that their level of engagement with caregivers varied according to caregiver characteristics:

"*The well-educated [who] can advocate better for their children get the quality care [and] are socially better off ...* ***We may not be offering the same care to all the patients which is really not the child's fault*** *... Maybe we don't put in our best effort and ultimately [it is] the child that suffers*". Neuropediatrician, US.

The lack of clarity regarding when and how to discuss the risk of SUDEP also emerged as an important theme:

"*A topic that's kind of like the elephant in the room is, we call it SUDEP ... We don't have a good handle on why this occurs ... I'm not really good at trying to go over that with families because it's just a worrisome thing ...* ***I don't know the right way to do that.*** *So I guess that's my biggest issue*". Neuropediatrician, US.

"Sub-optimal knowledge of cases in which SUDEP needs to be discussed with caregivers" was reported by 41% of physicians, though almost all of them (91%) agreed that "it is important to systematically discuss risk of SUDEP with caregivers" (*table 4*). Meanwhile, 75% agreed with the statement: "I always discuss the risk of SUDEP with caregivers", and roughly half (52%) agreed that these conversations are "almost always" initiated by the caregivers.

Discussion

This needs assessment provides indicators of the most important challenges faced by neuropediatricians

Table 4. Participants' perception, self-reported knowledge, and communicating skills with caregivers regarding the transition of care and SUDEP.

	Sample divided by country			**Significant differences by country**[d]	**Sample divided by competency**		**Significant differences by competency**[d]	**Total**
	Germany	**Spain**	**U.S.**		**Without competency**	**With competency**		
[a]% of participants who agreed with the following statement related to transition of care								
I feel that I should begin discussing the transition to adult care earlier with my patients who have cognitive comorbidities	79% (*n*=37)	78% (*n*=39)	85% (*n*=66)	NS	86% (*n*=56)	78% (*n*=86)	NS	**81% (*n*=142)**
I feel that I should begin discussing the transition to adult care earlier with my patients who do not have cognitive comorbidities	84% (*n*=41)	64% (*n*=32)	79% (*n*=63)	*p*=0.05	82% (*n*=55)	72% (*n*=81)	NS	**76% (*n*=136)**
I feel I could do better to prepare my patients for their transition to adult care	78% (*n*=38)	69% (*n*=33)	71% (*n*=57)	NS	74% (*n*=49)	71% (*n*=79)	NS	**72% (*n*=128)**
There is a lack of communication between myself and the adult neurologist during the transition from pediatric to adult care	58% (*n*=28)	61% (*n*=30)	70% (*n*=56)	NS	66% (*n*=44)	64% (*n*=70)	NS	**64% (*n*=114)**
[b]% reporting sub-optimal skills								
Managing patients'/caregivers' emotional insecurity during the transition to adult care	31% (*n*=15)	28% (*n*=14)	34% (*n*=27)	NS	31% (*n*=21)	31% (*n*=35)	NS	**31% (*n*=56)**

Table 4. Participants' perception, self-reported knowledge, and communicating skills with caregivers regarding the transition of care and SUDEP (*Continued*).

	Sample divided by country			**Significant differences by country**[d]	**Sample divided by competency**		**Significant differences by competency**[d]	Total
	Germany	**Spain**	**U.S.**		**Without competency**	**With competency**		
[a]% of participants who agreed with the following statement related to level of involvement with caretakers and communication around SUDEP								
The level of effort I put in, supporting caregivers, depends on how active and involved they are in the care of their child	72% (*n*=34)	82% (*n*=41)	69% (*n*=55)	NS	70% (*n*=46)	76% (*n*=84)	NS	**73%** **(*n*=130)**
It is important to systematically discuss the risk of SUDEP with caregivers	90% (*n*=44)	96% (*n*=48)	89% (*n*=71)	NS	93% (*n*=62)	90% (*n*=101)	NS	**91%** **(*n*=163)**
I always discuss the risk of SUDEP with caregivers	71% (*n*=34)	86% (*n*=42)	71% (*n*=55)	NS	68% (*n*=45)	79% (*n*=86)	NS	**75%** **(*n*=131)**
Discussions about the risk of SUDEP are almost always initiated by caregivers	47% (*n*=23)	44% (*n*=22)	60% (*n*=47)	NS	60% (*n*=39)	47% (*n*=53)	NS	**52%** **(*n*=92)**
[c]% reporting sub-optimal knowledge regarding communication around SUDEP								
Cases in which SUDEP needs to be mentioned and discussed with caregivers	40% (*n*=19)	44% (*n*=22)	40% (*n*=32)	NS	49% (*n*=33)	36% (*n*=40)	NS	**41%** **(*n*=73)**

[a] Question: based upon your clinical experience with pediatric patients suffering from epilepsy, please indicate your level of agreement with the following statements; scale: 1 (completely disagree), 2 (slightly disagree), 3 (slightly agree), and 4 (completely agree).
Data are presented as percent of participants who selected slightly agree (3) or completely agree (4).

[b] Question: for each statement below, please rate your current level of skills in relation to what they should be, given your professional role; scale: 1 (low) to 5 (optimal).
Data are presented as percent of participants who selected 1, 2 or 3.

[c] Question: for each statement below, please select the number that best describes what you consider your level of knowledge to be, given your professional role; scale: 1 (low) to 5 (optimal). Data are presented as percentage of participants who selected 1, 2 or 3.

[d] Significant differences calculated using the chi-square test ($p<0.05$).

Data in bold are reported in the text. NS: not statistically significant.

when diagnosing, treating, and managing pediatric patients with epilepsy, as well as when communicating with caregivers. Gaps in knowledge and skills were identified as causalities of the identified challenges and indicate areas of educational need among neuropediatricians.

The results from this study indicate that neuropediatricians are not optimally familiar with current guidelines in epilepsy, and that they are not perceived as useful in practice. A low level of knowledge of the new *2017 ILAE classification* guide, as reported by a majority of neuropediatrician participants, could be explained by its relatively recent publication (Fisher *et al.*, 2017). It is possible that changes to criteria and nomenclature had not yet been disseminated among the community at the time of data collection for this study (June-July 2017 for Phase 2).

The new ILAE classifications have underscored the need to move towards a comprehensive patient care approach that consists of establishing the correct diagnosis of seizure types, epilepsy categories, and syndromes, as well as identifying correct etiologies. Alongside these changes is a need for greater consideration of co-morbidities when adapting care to a patient's needs. The new ILAE classification's renewed emphasis in this area provides an opportunity to support neuropediatricians through knowledge-based educational interventions that are needed, in particular around the diagnosis and classification of epilepsy, as indicated throughout this study.

A trend towards the use of genetic testing in identifying the etiology of certain epilepsy types has also emerged in the literature in recent years. There is an increase in scientific knowledge of the genes associated with epilepsy, as well as an increase in recommendations that physicians should perform genetic screening for all drug-resistant forms of epilepsy (Ream and Patel, 2015; Wilmshurst *et al.*, 2015; Bevilacqua *et al.*, 2017). In fact, the hope that genetic testing would help achieve better treatment (*i.e.* personalized treatment) has declined within recent years, as only rarely will genetic diagnosis influence the decision-making process of choosing between "antiseizure" drugs. Understanding EEG patterns are important when making clinical decisions regarding when to offer genetic testing, which type of testing is the most appropriate to conduct, and how to interpret the results of those genetic tests (Pal *et al.*, 2010; Noh *et al.*, 2012).

Indeed, a lack of knowledge of EEG patterns was observed among neuropediatricians who participated in the needs assessment, especially those without competency in epilepsy. The ILAE indeed recognizes the challenges that emerge when interpreting genetic tests, and thus recommends the systematic involvement of genetic providers (*e.g.* geneticists, genetic counselors) as part of the healthcare team (Ream and Patel, 2015). Despite this recommendation, increasing specialized resources, or the presence of tertiary specialized centers for referrals, might not be realistic in many community settings, even in developed countries. This presents an opportunity, as well as a need, for neuropediatricians to be provided with knowledge and skill-based educational interventions on when genetic testing should be ordered, which includes in-depth knowledge and understanding of EEG patterns, as well as the interpretation of genetic test results and how to incorporate them into treatment decision-making.

The triangulated data revealed that neuropediatricians have a low level of knowledge of non-pharmacological therapies (other than epilepsy-surgery indications; not assessed in the present study), and tend to use them only as a last resort. Indications for a pre-surgical evaluation and knowledge on epilepsy surgery results according to etiology were not assessed in the present survey. This gap could be explained by the lack of evidence of efficacy for a number of these therapies in non-refractory patients, in particular VNS (Connor *et al.*, 2012). Studies on VNS treatment are often retrospective with rather loose criteria of inclusion and follow-up, rarely providing evidence-based indications for specific epilepsy syndromes. The ketogenic diet, which is among the most well-known non-pharmacological therapies, was however found to be effective, and its utilization is recommended in children with intractable epilepsy (Kossoff *et al.*, 2009; Freeman *et al.*, 2007; Hartman and Vining, 2007; Auvin, 2016). Despite this, there remain several challenges that discourage neuropediatricians from recommending a ketogenic diet. In particular, the complexity of initiating the diet, the insufficient resources available to support patients and caregivers when making difficult lifestyle changes, and, importantly, the unknown anticonvulsant mechanisms of the diet (Misiewicz Runyon and So, 2012). Just as the findings on *non-pharmacological therapies* suggest gaps in knowledge, the findings on *pharmacological treatment* gaps are reported by a smaller proportion of participants and suggest that these gaps relate to skill level and decision-making processes. This would indicate a greater need for developing education on non-pharmacological therapies.

Preparing the transition of patients from pediatric to adult care was found to be a challenge for neuropediatricians as well as adult neurologists. Challenges in treating young adults with epilepsy may be compounded by multiple stressors that patients often face during this age period. Changes to one's environment are understood to be a significant source of anxiety and stress, resulting in emotional states that are known risk factors for triggering seizures. For example, patients in this age group are often in the process of transitioning from one school environment to another, and these disruptions may place the patient at a greater risk of seizure events (Neugebauer *et al*., 1994; Nakken *et al*., 2005). A change from a neuropediatrician (often known by the patient and their caregivers from early childhood) to a general neurologist may be an additional stressor, especially given the differences in the way patients are managed in pediatric *versus* adult care. For example, neuropediatricians often play a coordinating role and engage with other comorbidities the patients may have, whereas adult neurologists will generally limit their interventions to main neurological symptoms and refer the patient to other specialists for comorbidities. Similarly, neuropediatricians also participate in discussions with both the patients and their caregivers, whereas adult neurologists often deal only with the patient. Previous studies report that during this transition, parents of children with significant intellectual impairments often perceive a lack of coordination between pediatric and adult healthcare settings, which contributes to a feeling of fear and sense of loss (Davies *et al*., 2011). This suggests that the challenges faced during transition would be exacerbated in patients who have mental deficits or severe behavioral disorders.

Along with increasing the resources offered to the family, a skill-based educational intervention that addresses communication between the patient, caregiver, and their health care provider should be offered to both neuropediatricians and adult neurologists. This activity would enable health care providers to better manage patient and caregiver stress and anxiety during this transition. Nurses specialized in epilepsy might also be the target of these educational interventions, as educating patients and caregivers falls within their professional roles. A lack of patient or caregiver education may also have direct consequences on the health care system. It has been reported that a patient or caregiver's lack of education regarding seizure management, including education on the importance of compliance with antiepileptic drugs, and reliably attending outpatient neurology clinic appointments contribute to the burden on emergency departments to provide epilepsy care (Carvalho *et al*., 2018).

Findings related to a low level of knowledge and uncertainty among neuropediatricians regarding the discussion of SUDEP is of key importance, considering recommendations that there should be full disclosure of SUDEP risk (NICE, 2012; Ramachandran Nair *et al*., 2016). There is still debate on the universal value of a discussion of SUDEP with caregivers, as some neuropediatricians report that they do not want to increase the family's anxiety by discussing it. In a survey conducted among UK neurologists, participants reported that the most common reason to discuss SUDEP is because the patient is explicitly seeking that information (Morton *et al*., 2006). Similar findings were revealed in our needs assessment, in which a majority of neuropediatricians reported that the discussion around SUDEP is almost always initiated by the caregivers. A previous study reported that caregivers have a desire to be informed of the risk of SUDEP (Prinjha *et al*., 2005), while another study found that 91% of surveyed caregivers expect to be informed by physicians of the risk of SUDEP (Gayatri *et al*., 2010). Despite multiple associated factors, there is still little evidence as to the exact causalities of SUDEP (Opeskin and Berkovic, 2003; Tomson *et al*., 2008). Previous studies report that the risk of SUDEP may depend on epilepsy type and the brain regions involved in the seizure event (Tomson *et al*., 2005; DeGiorgio *et al*., 2017). A lack of conclusive evidence-based information might cause confusion for neuropediatricians regarding when and how to correctly discuss this topic with caregivers.

The dimensions of this issue may transform, as caregivers and patients increasingly access and gather information from the internet, which is not always a reliable source. In order to reduce unnecessary anxiety that could provoke patients to seek unreliable information online, it has become increasingly important for healthcare teams to personally address this topic with caregivers. This can be done by providing caregivers with clear patient-level educational materials on the risk of SUDEP, even in cases in which the exact degree of risk posed to the individual patient is not necessarily clear.

Study limitations

Given the objective of informing future educational programs, solely the areas where challenges were identified are reported in this manuscript. Although acceptable for this type of methodology, caution should be exercised when generalizing the findings to a national or global scale. In addition, local needs assessments should be conducted prior to the development of educational interventions. There is a possibility of erroneous self-assessment bias, though it is ameliorated by the mixed-methods triangulated design. To mitigate potential selection bias, purposive sampling (including participants with different years of practice and practice settings) was employed. The present study was not designed to identify the educational needs of neuropediatricians regarding indications for early pre-surgical evaluation and the eventual gaps of the results, per etiology, following epilepsy surgery.

Conclusion

This study identifies challenges faced by neuropediatricians practicing in three developed countries, related to diagnosing, treating, and managing pediatric patients with epilepsy. Specific gaps in knowledge and skills were identified, and should be addressed by medical educational interventions.

Epileptic seizures are one of the most frequent, and often the first, symptoms of a large number of neurological diseases in children. All child neurologists need to be trained to recognize if a first paroxysmal event is epileptic in nature or not, to identify the seizure type, and to prescribe the most appropriate diagnostic investigations to identify the syndrome and etiology. They also need to know the indications and pharmacological characteristics well in order to choose a first or second drug treatment. According to the ILAE definition, when the first two treatment choices fail to fully control the patient's seizures, the patient is to be considered as drug-resistant (Kwan *et al.*, 2010), and therefore should rapidly seek specialized advice. The child should then be referred to a child neurologist who is specialized in epilepsy.

As demonstrated by our study, child neurologists specialized in epilepsy need to master not only the clinical characteristics of each of the epilepsy syndromes and the semiological expression of all types of focal seizures, but also video-EEG interpretation, interpretation and comprehensive analysis of neuroimaging findings, interpretation of genetic results, and the indications for early referral for a pre-surgical evaluation and appropriate interpretation of the results of that evaluation. In summary, child neurologists expected to treat children with complex and/or drug-resistant epilepsies need to benefit from high-level educational interventions that comprehensively cover all the above-mentioned aspects of clinical epileptology and treatment.

In the context of new classification guidelines and an increased need to provide comprehensive care, providing support to neuropediatricians in these areas will become a priority to improve the quality of care offered to pediatric patients with epilepsy.

As clinical challenges may vary according to the context of practice, studies should also be conducted that aim to identify the educational needs of physicians practicing in developing countries. □

Supplementary data.

Supplementary material and summary didactic slides are available on the www.epilepticdisorders.com website.

Acknowledgements and disclosures.

This study was conducted by the AXDEV Group. The authors would also like to acknowledge the support provided by Morgan Peniuta (Researcher, AXDEV Group, Canada) and Sophie Péloquin (Director Performance Strategy, AXDEV Group, Canada), who supported the analysis and interpretation of the data, as well as Marie-Aimée Fournier (Project Manager, AXDEV Group, Canada) and Marc Distexhe (Project Coordinator, AXDEV Group, Canada), who supported data collection, communications and other coordination aspects of the research. The authors would like to thank Marc De Backer (Stakeholder Learning Lead Neurology, UCB Pharma) and Thomas Kellner (Head of Stakeholder Learning Solutions, UCB, UCB Pharma) without whom this study would not have been possible, as well as all of the healthcare providers who participated in this study.

SM, SL, SK, and PL declare that they have no competing interests. GK received advisory boards honoraria from GW Pharma, UCB, EISAI, and Desitin Arzneimittel. IM received funding for participation in advisory boards for UCB, Rubio, Shire and Rubió, and Research Grants from the Spanish Ministry of Health (Instituto de Salud Carlos III) and Juste. PO received funding as a member of the advisory board for Novartis and education consultant for Cyberonics (liva nova). AA received funding for participation in advisory boards for UCB, Zogenix, GW, Eisai, Shire and Biomarin, and Research Grants from the European Union, UCB and the Caixa Foundation.

Funding. This study was financially supported by an educational grant from UCB. The funding body had no role in the design of the study or the collection, analysis, or interpretation of data. UCB reviewed the manuscript, but final decisions regarding the manuscript's content was the responsibility of the authors.

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TEST YOURSELF

(1) For which of the following tasks did neuropediatricians report the greatest proportion of sub-optimal skills?
A. Differentiating epilepsy from pseudo-seizures or psychogenic seizures
B. Differentiating epileptic events from parasomnia
C. Differentiating epilepsy from autonomic failure syndromes

(2) In which of the following areas did nearly half of neuropediatricians report sub-optimal knowledge?
A. Cases in which SUDEP needs to be mentioned and discussed with caregivers
B. Different EEG patterns
C. Classifying types of epilepsy

(3) Which of the following was reported as one of the two principal barriers to a neuropediatrician's ability to provide optimal patient care?
A. Lack of access to newly approved treatments in epilepsy for pediatric patients
B. Lack of access to expertise in pediatric epilepsy
C. Lack of community resources to support patients and caregivers

Note: Reading the manuscript provides an answer to all questions. Correct answers may be accessed on the website, www.epilepticdisorders.com, under the section "The EpiCentre".