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RESEARCH

The Pediatric Epilepsy Surgery Interest Group (PESIG) under the auspice of the ISPN Research Committee: Availability of relevant technology and geographical distribution

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Abstract

Purpose Epilepsy surgery for pediatric drug-resistant epilepsy has been shown to improve seizure control, enhance patient and family QoL, and reduce mortality. However, diagnostic tools and surgical capacity are less accessible worldwide. The International Society Pediatric Neurosurgery (ISPN) has established a Pediatric Epilepsy Surgery Interest Group (PESIG), aiming to enhance global collaboration in research and educational aspects. The goals of this manuscript are to introduce PESIG and analyze geographical differences of epilepsy surgery and technology availability.

Methods PESIG was established (2022) following an ISPN executive board decision. Using a standardized form, we surveyed the PESIG members, collecting and analyzing data regarding geographical distribution, and availability of various epilepsy treatment-related technologies.

Results Two hundred eighty-two members registered in PESIG from 70 countries, over 6 continents, were included. We categorized the countries by GDP as follows: low, lower-medium, upper-medium, and high income.

The most commonly available technology was vagus nerve stimulation 68%. Stereoelectroencephalography was available for 58%. North America had statistically significant greater availability compared to other continents. Europe had greater availability compared to Africa, Asia, and South (Latin) America. Asia had greater availability compared to Africa. High-income countries had statistically significant greater availability compared to other income groups; there was no significant difference between the other income-level subgroups.

Conclusion There is a clear discrepancy between countries and continents regarding access to epilepsy surgery technologies. This strengthens the need for collaboration between neurologists and neurosurgeons from around the world, to enhance medical education and training, as well as to increase technological availability.

Keywords Education · Global · Collaboration · Research

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Introduction

Epilepsy surgery for pediatric drug-resistant epilepsy (DRE) has been repeatedly shown to improve seizure control, enhance patient and family QOL, and reduce mortality [1]. Traditional resection procedures to remove a lesion associated with seizure (e.g., a tumor, cortical dysplasia, and cavernous malformation) are often performed by general neurosurgeons and pediatric neurosurgeons, not necessarily considering themselves as "epilepsy surgeons."

However, more specific surgical approaches for diagnosis and treatment of refractory epilepsy are less available worldwide, often due to lack of education, traditional referral patterns, and financial and technical limitations.

The International Society of Pediatric Neurosurgery (ISPN) has recently established an epilepsy surgery interest group, aiming to enhance global collaboration in research and educational aspects [2]. The goals of this manuscript are to describe the Pediatric Epilepsy Surgery Interest Group (PESIG), as well as geographical differences in availability of epilepsy surgery and technology.

Methods

Following an ISPN executive board decision (2022), the PESIG group was established with a chair and committee members. The goals of the PESIG are as follows:

- Share knowledge related to epilepsy surgery
- Serve as a research platform for surgeons from around the world
- Collect "real world" data regarding epilepsy surgery
- Enhance epilepsy surgery related education and mentoring
- Serve as a template for other interest groups on rare conditions, while including a wide base of pediatric neurosurgeons

As a primary task, we surveyed the PESIG members regarding their geographic distribution, and availability of various epilepsy-related technologies. Two "reach-out" emails were sent to all ISPN members, with an introduction letter about the goals of PESIG, offering to register the receiver to the PESIG. Basic personal and professional details (such as geographical location), as well as a standard form concerning availability of various technologies, were collected. Data recruitment for the current study included members who were registered between October 10, 2022, and April 18, 2023.

Statistical analysis

Data was tabulated in an Excel spreadsheet. SPSS software was used for all statistical analyses (IBM SPSS Statistics, Version 28, IBM Corp., 2021, Armonk, NY, USA). Categorical variables were reported as number and percentage. Association between categorical variables was assessed using chi-square test or Fisher's exact test. Bonferroni correction was used to adjust the *p* values for multiple comparison.

Results

Overall, 282 ISPN members registered, 4 of whom were students and therefore eliminated from the current analysis. Members were based in 70 countries, distributed over 6 continents (Table 1).

Participants were also classified according to their country's gross domestic product (GDP):

- Low income: 10 participants (7 countries)
- Lower-medium income: 82 participants (19 countries)
- Upper-medium income: 65 participants (18 countries)
- High income: 121 participants (from 26 countries)

Availability of technology

The most common available technology was vagus nerve stimulation (VNS) (68%) (Table 2). Stereoelectroencephalography (SEEG) was also relatively common (58%). Comparing technological availability between continents, North America had statistically significant higher availability compared to other continents. Europe had higher availability compared to Africa, Asia, and South America. Asia had higher availability than Africa (Tables 3 and 4).

Comparing availability according to income level, high-income countries had statistically significant higher availability compared to other groups. There was no significant difference in availability between the other subgroups (Tables 3 and 4).

Discussion

This is the first study mapping global availability of epilepsy surgery-related technology. As expected, medical centers located in high-income areas, and/or located in North America, have greater availability of various technologies. Our survey did not include questions that provided specific data indicating the reasons for this disparity. However, based on the literature, they are probably multifactorial, related to resource limitations, surgical and neurological education, referral patterns, lack of medical personnel with exposure to the role and efficacy of epilepsy surgery, and patient and family unawareness about the role of surgery, as well as misconceptions about epilepsy and epilepsy surgery.

Table 1 Geographical distribution of participants per continent (number of participants per country)

Continent	Africa (45)	Asia (89)	Australia (4)	Europe (68)	North America (39)	South America (33)
	Nigeria (8)	India (29)	Australia (4)	UK (20)	USA (31)	Brazil (11)
	Malaysia (5)	Japan (7)		Germany, Spain (7 each)	Canada (8)	Mexico (7)
	Egypt, Morocco (4 each)	Israel, Taiwan, Pakistan (6 each)		Turkey, France (5 each)		Paraguay, Colombia (3 each)
	Kenya, Libya, South Africa, Uganda (3)	Armenia, Indonesia (5)		Russia (4)		Argentina, Guatemala, Peru (2)
	Algeria, Zambia (2)	Thailand (4)		Belarus, Ukraine (3)		Chile, Costa Rica, Guyana (1)
	Cameroon, Ethiopia, Guinea, Mali, Mozambique, Niger, Tanzania, Zimbabwe (1)	Bangladesh, Mongolia, Nepal (3)		Croatia, Greece, Italy, Switzerland (2)		
		Iran, Singapore (2)		Austria, Belgium, Norway, Poland, Slovenia, Sweden (1)		
		Hong Kong, Jordan, Cambodia, Lebanon, Philippines, Saudi Arabia, United Arab Emirates, Vietnam (1)				

NA North America, *SA* South America

This study complements other studies which underscore the gap between the need and the availability of diagnostic measures and treatment for children with epilepsy in low- to middle-income countries (L-MIC) [3–5]. This is true for basic tools such as MRI [3], as well as for epilepsy surgery programs [6].

Referral of patients for epilepsy surgery

Epilepsy surgery for treatment of DRE is generally underutilized worldwide. There has been an increase in its availability, especially in high-income countries (HIC) [7, 8]. Reasons for the underuse of surgery as a treatment modality for epilepsy include not only surgical limitations, but also limitations in neurological referral as well as limitations in the willingness of patients and their families to undergo surgical evaluation and treatment [4, 9]. Reasons for these limitations are multifactorial, both educational and cultural, and they are apparent in countries at all different income levels [4–6, 9]. In recent years, several leading epilepsy centers have been established in L-MIC, proving that income level is not the single determining factor. Expanding treatment options is possible even in lower-income locations [6], when the medical centers are able to provide high level surgical abilities, expanded patient and practitioner education, and, most importantly, by providing good treatment results. Menon et al. [10] have shown a threefold increase in epilepsy surgery during 2007–2012 compared to 1995–2000. Nevertheless, rural locations are consistently less likely to have access to epilepsy surgery programs compared to the large cities [11]; thus, even within areas that have increased the treatment options in general, many potential surgical candidates may not have access to adequate treatment [6].

Besides focusing on education for the pediatric neurology community, there is a need to expose general practitioners, family doctors, and pediatricians, to the outcomes of DRE, as well as the role of epilepsy surgery in improving all functional outcomes for these children.

Surgical training in epilepsy surgery

Paralleling the lack of various technologies, there is a lack of epilepsy surgery programs [6, 9]. The high-income countries have more neurosurgical and neurological departments that provide epilepsy surgery programs. Therefore, education and exposure are available to both neurosurgical residents as well as pediatric and adult neurologists [8]. Yet even in HIC, there is a relative lack in epilepsy centers with surgical experience [9]. In low- and medium-income countries, the gap is even larger, and there is a lack in neurological personnel (both in the pediatric and adult populations), with less exposure of trainees to the role of surgery in epilepsy treatment [4, 9, 12]. Despite these limitations, during recent

Table 2 Availability of technology, classified according to income class, and according to continent (%)

	Total	SEEG	Robot	LITT	DBS	VNS	RNS	SEEG + Robot	SEEG + LITT + DBS	SEEG + LITT + DBS + RNS	SEEG + Robot + LITT + DBS + RNS
Total	278	161 (58%)	94 (34%)	59 (21%)	92 (33%)	188 (68%)	38 (14%)	90 (32%)	35 (13%)	19 (7%)	16 (6%)
Classified by GDP (low, low-med, upper-med, high)											
LIC	10	2 (20)	2 (20)	1 (10)	1 (10)	2 (20)	1 (10)	1 (10)	1 (10)	1 (10)	1 (10)
LMIC	82	37 (45)	17 (21)	8 (10)	24 (29)	34 (41)	8 (10)	16 (20)	7 (9)	6 (7)	5 (6)
UMIC	65	28 (43)	4 (6)	5 (8)	21 (32)	42 (65)	3 (5)	4 (6)	4 (6)	1 (2)	0 (0)
HIC	121	94 (78)	71 (59)	45 (37)	46 (38)	110 (91)	26 (21)	69 (57)	23 (19)	11 (9)	10 (8)
Classified by continent											
NA	39	38 (97)	31 (79)	26 (67)	15 (38)	37 (95)	20 (51)	31 (79)	11 (28)	8 (21)	8 (21)
SA	33	14 (42)	2 (6)	3 (9)	10 (30)	19 (57)	2 (6)	2 (6)	2 (6)	0 (0)	0 (0)
Asia	89	54 (61)	25 (28)	9 (10)	28 (31)	52 (58)	10 (11)	24 (27)	8 (9)	8 (9)	6 (7)
Africa	45	12 (27)	4 (9)	3 (7)	8 (18)	16 (36)	2 (4)	3 (7)	2 (4)	1 (2)	1 (2)
Europe	68	41 (60)	30 (44)	17 (25)	29 (43)	60 (88)	4 (6)	28 (41)	10 (15)	2 (3)	1 (1)
Australia	4	2 (50)	2 (50)	1 (25)	2 (50)	4 (100)	0 (0)	2 (50)	1 (25)	0 (0)	0 (0)

LIC low income, *LMIC* low medium income, *UMIC* upper medium income, *HIC* high income, *NA* North America, *SA* South America

years, especially since the COVID-19 pandemic, there has been an increase in web-based seminars, conferences, and workshops spreading high-level meetings and educational knowledge globally. However, these web-based platforms do not replace the need for actual clinical programs, with physical hands-on training in epilepsy surgery. Kuzniecky et al. [13] have reported their experience with a collaborative program between a US-based epilepsy center and a public hospital in Panama, creating an epilepsy surgery service for children with DRE. Other studies have shown that with adequate mentoring and collaboration, surgeons in L-MIC have the potential to provide excellent surgical treatment, with similar epilepsy control outcomes and similar complication rates to HIC [6, 14].

Cost and availability of technology

The cost of epilepsy surgery is multifactorial. Noninvasive EEG and VEEG, high-quality MRI, PET, SPECT, MEG, fMRI, and fMRI-EEG are not readily available, and are important for presurgical evaluation and defining the goals of surgery in many cases. Even MRIs are not always readily available [3, 9]. SEEG, stereotaxy (using a frame or with robotic assistance) is not widely available either, limiting invasive recording abilities. Beyond diagnostics, treatment using various stimulators (DBS, RNS) is also not widely accepted, even in some of the HIC, thus limiting treatment options.

Over the years, various technologies have penetrated the market. SEEG, originally developed in Europe during the 1960s and 1970s, has gained popularity in North America only during the last 2 decades. Other technologies, such as RNS, are not yet distributed outside of the USA. DBS has only recently been approved by the FDA and EU for pediatric use. One of the driving forces for technological distribution is the manufacturing companies, which focus on large and concentrated markets. Thus, technologies are not equally marketed or distributed around the world; availability is thus limited globally, especially in L-MIC. Compare these limitations to use of VNS, which is widely distributed globally; we anticipate a similar trend for other newer technologies.

Nevertheless, epilepsy surgery is often an option, even with these limitations. In many cases, evaluation may be straightforward using EEG and MRI, for example, hemispheric epilepsy, temporal lobe epilepsy, and even for Lennox-Gastaut diagnosis and treatment [12–15]. Lesional epilepsy is also straightforward, and often there is no need for sophisticated workup and treatment [12].

The role of the ISPN and PESIG

In parallel to official national epilepsy surgery programs [16, 17], we as surgeons have a role to play in expanding access

Table 3 Comparison of technology availability between continents and between income groups

Continent comparison	SEEG	Robot	LITT	DBS	VNS	RNS
NA-SA	0.0000	0.0000	0.0000		0.0013	0.0004
NA-Asia	0.0004	0.0000	0.0000		0.0007	0.0000
NA-Africa	0.0000	0.0000	0.0000		0.0000	0.0000
NA-Europe	0.0004	0.0056	0.0003			0.0000
SA- Europe		0.0013			0.0034	
Asia-Africa	0.0023					
Asia-Europe					0.0009	
Africa-Europe	0.0068	0.0010			0.0000	
Income group						
LIC-HIC	0.0024				0.0000	
LMIC-UMIC					0.0316	
LMIC-HIC	0.0000	0.0000	0.0001		0.0000	
UMIC-HIC	0.0000	0.0000	0.0001		0.0001	0.0150

Only significant differences are presented. Numbers represent p value. Empty grayed cells represent comparisons which were statistically insignificant

to epilepsy surgery, through education and collaboration. For example, collaborative studies on epilepsy surgical topics, gathering data from multiple centers, allow us to complete studies focusing on rare conditions and outcomes [18–21]. Despite their retrospective nature and associated limitations, these studies shed light on rare conditions and outcomes, for which a prospective study may not be practical. The ISPN has encouraged similar studies on various projects over the years, serving as a platform for both educational and research activities [22, 23]. The PESIG, focusing on epilepsy surgery, is the first of other focused research groups. These groups are intended to promote research and educational activity on rare conditions, for which individual surgeons have smaller numbers of cases. Collaboration makes it possible to study these conditions meaningfully rather than anecdotally. However, the goal is beyond research. Increased collaboration must lead to awareness, education, and providing better care globally. We must all work together to reduce the gap between the need and availability of surgical treatment for pediatric epilepsy [9].

Limitations

The study represents a select group of surgeons, all members of the ISPN. Many neurosurgeons that treat children worldwide, and many surgeons that treat epilepsy, are not part of the ISPN.

Some mistakes in reported technologies may have occurred (such as surgeons outside of the USA reporting the use of RNS). Not all technologies currently in use were included (such as RF ablation). Similarly, we did not evaluate the availability of a neurologist trained in pediatric epilepsy surgery evaluations, nor did we evaluate availability of presurgical phase 1 technologies (high-quality MRI, VEEG, PET, MEG, fMRI, SPECT), and newer technologies (e.g., rsMRI, fMRI-EEG). The availability of the presurgical evaluation options (MRI, VEEG, PET, fMRI) should be prioritized over high-end surgical technologies (such as Robots, LITT, DBS, and RNS), as the cost-effectiveness, and ability to control seizures is significantly better once a focus is defined and neutralized.

Table 4 Comparison of technology availability between continents and between income groups

Continent comparison	SEEG	Robot	LITT	DBS	VNS	RNS
NA-SA	97 vs 41	79 vs 6	67 vs 9		95 vs 57	51 vs 6
NA-Asia	97 vs 61	79 vs 28	67 vs 10		95 vs 58	51 vs 11
NA-Africa	97 vs 27	79 vs 9	67 vs 7		95 vs 36	51 vs 4
NA-Europe	97 vs 60	79 vs 44	67 vs 25			51 vs 6
SA-Europe		6 vs 44			57 vs 88	
Asia-Africa	61 vs 27					
Asia-Europe					58 vs 88	
Africa-Europe	27 vs 60	9 vs 44			36 vs 88	
Income Group						
LIC-HIC	20 vs 78				20 vs 91	
LMIC-UMIC					41 vs 65	
LMIC-HIC	45 vs 78	21 vs 59	10 vs 37		41 vs 91	
UMIC-HIC	43 vs 78	6 vs 59	8 vs 37		65 vs 91	5 vs 21

Only significant differences are presented. Numbers represent the percentage of responders that had a specific technology. Empty grayed cells represent comparisons which were statistically insignificant

Conclusion

There is a clear discrepancy between countries and continents regarding availability of epilepsy surgery technologies. This strengthens the argument for more collaboration between neurologists and neurosurgeons around the world, to enhance medical education and training, and increase treatment options, as well as awareness amongst patients and their families on the role of epilepsy surgery. The ISPN has a role and commitment to lead and pursue this goal.

Abbreviations DBS: Deep brain stimulation; EEG: Electroencephalography; fMRI: Functional MRI; fMRI-EEG: FMRI coupled with EEG; LITT: Laser interstitial thermal therapy; MEG: Magnetoencephalography; MRI: Magnetic resonance imaging; PET: Positron emission tomography; RNS: Responsive neurostimulation; SEEG: Stereo-EEG; SPECT: Single photon emission computed tomography; VEEG: Video EEG; VNS: Vagus nerve stimulation

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Author contributions JR collected the data and wrote the manuscript. JR and SC conceptualized the study. All authors reviewed the manuscript and approved it.

Declarations

Conflict of interest The authors declare they have no financial interests.

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