Original Article

Journal of Child Neurology
2021, Vol. 36(3) 222-229

DOI: 10.1177/0883073820966935
journals.sagepub.com/home/jcn
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Novel Neurotechnological Interventions for Pediatric Drug-Resistant Epilepsy: Physician Perspectives

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Abstract

This qualitative study investigated factors that guide physicians' choices for minimally invasive and neuromodulatory interventions as alternatives to conventional surgery or medical management for pediatric drug-resistant epilepsy. North American physicians were recruited to one of 4 focus groups at national conferences. Discussions were analyzed using qualitative content analysis. A pragmatic neuroethics framework was applied to interpret results. Discussions revealed 2 major thematic branches: (1) clinical decision making and (2) ethical considerations. Under clinical decision making, physicians emphasized scientific evidence and patient candidacy when assessing neurotechnologies for patients. Ongoing seizures without intervention was important for safety and neurodevelopment. Under ethical considerations, resource allocation, among other financial considerations for technology adoption, were considerable sources of pressure on decision making. Access to neurotechnology was a salient theme differentiating Canadian and American contexts. When assessing novel neurotechnological interventions for pediatric drug-resistant epilepsy, physicians balance clinical and ethical factors to guide decision making and best practice.

Keywords

epilepsy, ethics, neurosurgery, pediatric, treatment

Received July 10, 2020. Received revised September 22, 2020. Accepted for publication September 25, 2020.

Background

The risks associated with ongoing seizures are an everyday reality for children with drug resistant epilepsy.[1-3] Resective epilepsy surgery can be an effective treatment in carefully selected individuals, and results in seizure freedom in up to 70% of well-selected cases.[4] However, not all children are candidates for surgery, and the degree of associated invasiveness has prompted the search for alternative neurotechnological solutions (Table 1).

As of July 2019, there were 32 registered neurotechnology clinical trials for epilepsy that included pediatric participants,[5] with vagus nerve stimulation accounting for the majority of neurotechnological interventions. Few trials focus on children. The ethical magnitude of weighing the benefits and risks of emerging neurotechnological treatments for children whose brains and bodies are still developing is further compounded by the limited rigor by which many are first tested in adults, limited randomized controlled trials, and promotion of them by device manufacturers.[6]

For various areas of biomedicine, neuroethics has been used as a lens from which to understand the decision-making values, priorities, needs, and other key factors relevant to diverse stakeholders. For example, in a series of qualitative studies on

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Table 1. Neurotechnologies Used to Treat Drug Resistant Epilepsy (DRE).

Neurotechnology	Mechanism of action/ target	First use in epilepsy	Approval status for epilepsy
Deep brain stimulation (DBS)	Neuromodulatory	1976	Off-label use
Stereotactic radiosurgery (SRS)	Ablative	1982	Off-label use
Vagus nerve stimulation (VNS)	Neuromodulatory	1988	US FDA and Health Canada approved
Responsive neurostimulation (RNS)	Neuromodulatory	2005	FDA approved in adults
Transcranial direct current stimulation (tDCS)	Neuromodulatory	2006	Off label use
Magnetic resonance-guided laser interstitial thermal therapy (MRgLITT)	Ablative	2012	US FDA and Health Canada approved
Magnetic resonance-guided focused ultrasound (MRgFU)	Ablative	2020	Off-label use

stem cells, areas of misalignment were identified between individuals with spinal cord injuries and health care providers in the target timing of clinical trials,[7] definitions of risk,[8] and trust.[9] In the realm of novel neurotechnology, results of a first-in-human brain-computer interface trial on adults with epilepsy revealed a complicated tension between the transformative sense of autonomy afforded by the device and feelings of self-estrangement.[10] The nature of these diverse personal elements is important to consider during the course of treatment, as they have profound implications for defining the necessary factors for patient preparedness and choice.

Very little is known about how clinicians treating children with drug-resistant epilepsy make decisions regarding the adoption of novel interventions and what factors or attributes come into play when deciding whether to recommend a novel neurotechnological intervention that may not have yet been studied rigorously.

Building on and complementing work in other areas of biomedicine, the present study investigated factors that guide clinician choices for the adoption of novel neurotechnologies to treat pediatric drug-resistant epilepsy. We consider procedural trade-offs, values, and concerns essential to decision making and communication to patients and families in this effort.

Materials and Methods

Design

This study is based on focus groups with pediatric epileptologists and pediatric neurosurgeons in Canada and the United States who care for children with drug-resistant epilepsy. We recruited physicians attending national conferences using both purposive and convenience sampling methods to a pre-set (time and date) focus group by email. Recruitment began 30 days prior to the date of the meeting, and with announcements and posting at the conferences where the focus groups took place. Physicians who voluntarily disclosed a financial relationship with a neurotechnology company that manufactures a product used for epilepsy surgery were excluded from participation. Consent was obtained via email correspondence. Physicians originated from various provinces and states, but participated in their country-specific focus group. Although demarcation was not perfect, 2 groups were predominantly or exclusively Canadian physicians and 2 groups were predominantly or exclusively American physicians. We used SRQR reporting guidelines.[11]

Setting

Four 60-minute-long focus groups were held at 3 national conferences. Two groups were held at the 2018 meeting of the American Epilepsy Society (AES): one for physicians practicing in Canada and another for physicians practicing in the United States. The other 2 groups were held at the 2019 meetings of the American Society for Pediatric Neurosurgery (ASPN) and the Canadian Pediatric Neurosurgery Study Group (CPNSG). Focus groups were led by the principal investigator or co–principal investigator and supported by a senior researcher and/or research assistant responsible for taking field notes. We collected background information about participants, subspecialty, place of and time since training, estimated number of patients treated with neurotechnologies, and familiarity with various neurotechnologies.

Data Analysis

The discussions were audio-recorded, transcribed verbatim, and made software ready for management in NVivo (QSR 11). We applied qualitative content analysis methods to derive major and minor themes in the discourse.[12,13] Two researchers (V.H. and F.U.) read the transcripts to gain familiarity and open-coded them independently line-by-line to identify salient themes. The unit of analysis for the focus groups was the group, not individuals.[14] Rather than attributing topics to individuals, topic trends were mapped to their dominance in the group discussions and compared across groups. Fifteen percent of the transcripts were co-coded to test for interrater reliability. Discrepancies were discussed until there was consensus. Additional themes were incorporated into the codebook as they emerged through inductive and deductive analysis of the transcripts. Quotes are used here to illustrate salient thematic points. Ellipses have been applied for clarity and readability.

Results were visualized quantitatively into a pedigree structure: major thematic branches (topmost level), major themes, and minor themes. Major themes constituted the top 50% most frequently coded topics in each thematic branch, and were the primary themes of analytic focus. The label of minor is not intended to represent importance, only relative quantitative status. Minor themes were identified as adding qualitative depth or insight.

Results

Features of the Focus Groups

Twenty-seven percent of the 33 focus group participants identified as women (Table 2). Median age was 46 years; range was 35 years.

Table 2. Composition of Focus Groups (N=33).[a]

Gender	
Female	9
Male	18
Unreported	6
Age, y	
Median	46
Range	35
Type of practice	
Academic	1
Private	1
Public	23
Private/public	4
Unreported	4
Years in practice	
Median	8
Range	37

[a] Four participants did not complete the demographic questions.

Physicians self-reported the highest level of familiarity with vagus nerve stimulation and stereoelectroencephalography (sEEG) (Table 3). Across focus groups, Canadian groups (AES, CAD, and CPNSG) reported overall less familiarity with neurotechnology compared with American groups (AES, US, and ASPN) prima facie.

The mean estimated number of patients treated by physicians was self-reported to be highest for vagus nerve stimulation (total mean = 14) (Table 4). Similar to the pattern in Table 3, Canadian focus groups reported fewer patients treated with neurotechnologies compared with American groups.

Table 2 provides a summary of the reported demographics of respondents.

Themes

A Cohen kappa of 80% was achieved in the analysis of transcript coding indicating high intercoder reliability. Focus group analysis revealed 2 major thematic branches: clinical decision making and ethical considerations (Figure 1). Choice and patient candidacy were major themes under clinical decision making; external pressures were under ethical considerations (Figure 2).

Clinical Decision Making

Choice encompasses the scientific, conceptual, and practical evidence that physicians use to choose between novel neurotechnological and conventional treatments for pediatric drug-resistant epilepsy. A key subtheme was evidence used to scientifically establish the safety and efficacy of neurotechnological treatments. This entailed the instrumental role of evidence to justify technology adoption and use. Physicians across all focus groups expressed concerns over a fundamental need for more evidence and better standard practices for these devices:

> We have no guidelines. I don't know how to use this technology. I don't even know what the true risks are . . . the numbers are so small. You don't really know what's going on at other centres. (ASPN, American)

Given the reported insufficiency of evidence, observing or working alongside adult epilepsy research groups who are testing neurotechnologies was deemed a valuable and much-needed resource for information:

> There is a lot of influence from my adult epilepsy group. . . . They typically acquire the resources sooner than us [pediatric epileptologists] and that gives us the flexibility to start seeing the results in the level of comfort and support, and then we acquire the same techniques and we work together on that. (AES, Canadian)

Evidence of effectiveness was predominantly discussed in the context of seizure reduction, with the goal of seizure freedom. The general consensus was that neuromodulatory interventions, such as responsive neurostimulation or vagus nerve stimulation, are currently partial therapies and are unlikely to provide complete seizure freedom.

Physicians noted that neuromodulatory technologies may offer advantages other than the potential for seizure reduction. These disparate advantages include reducing polypharmacy, improving mood or quality of life, restoring a sense of agency, or simply providing another option for patients unresponsive to other treatments. Individually, each of these advantages were discussed to a much lesser extent compared with seizure reduction, emphasizing the importance clinicians place on seizure reduction as the primary goal of intervention.

Summarizing the uncertainty surrounding the introduction of these new devices alongside conventional surgeries with a strong, evidence-based history of success and standardized practices, one participant stated:

> At what point do I give up the procedure that I know works in my hands, to try something different? How do I convey that uncertainty to the family? And I don't know the answer to that. . . . When should I not do a temporal lobectomy or amygdalohippocampectomy and favour another one of these technologies? How much data do I need? How much experience do I need before I can offer that reliably to families? (ASPN, American)

Criteria for patient candidacy included the appropriateness of a novel neurotechnological intervention based on a patient's personal and familial disposition, and the individual, medically relevant aspects of a patient's epilepsy. Physicians agreed that the foundation of successful patient outcomes was contingent on carefully selecting the right candidate for an intervention. Physicians noted the importance of careful screening and early communication about the options appropriate for them. One participant stated that too few people are properly screened for the surgery they need.

The inherent differences between adults and children were discussed as fundamental to patient candidacy. When transitioning a technology from adult to pediatric populations, safety

Table 3. Mean Self-Reported Familiarity With Neurotechnology in Each Focus Group (Low Rank 1 to High Rank 3).

	Mean Familiarity With Technology				
	AES (CAD)	CPNSG	AES (US)	ASPN	OVERALL
Neuromodulatory					
Vagus nerve stimulation (VNS)	2.1	2.7	2.9	2.8	2.6
Responsive neurostimulation (RNS)	1.1	1.3	2.2	1.8	1.6
Transcranial direct current stimulation (tDCS)	1.1	1.0	1.7	1.2	1.2
Deep brain stimulation (DBS)	1.0	1.9	1.4	1.3	1.4
Ablative					
Magnetic resonance-guided laser interstitial thermal therapy (MRgLITT)	1.1	2.0	1.7	2.2	1.7
Stereotactic radiosurgery (SRS)	1.1	2.1	1.4	1.3	1.5
Magnetic resonance-guided focused ultrasound (MRgFU)	1.1	1.3	1.2	1.0	1.1
Diagnostic					
Stereo-electroencephalography (sEEG)	1.7	2.0	2.5	2.4	2.1

Abbreviations: AES, American Epilepsy Society; ASPN, American Society for Pediatric Neurosurgery; CPNSG, Canadian Pediatric Neurosurgery Study Group.

Table 4. Mean Estimated Numbers of Patients Treated With Neurotechnologies in Each Focus Group.[a]

	Mean Estimated Patients Treated With Technology				
	AES (CAD)	CPNSG	AES (US)	ASPN	Overall
Neuromodulatory					
Vagus nerve stimulation (VNS)	6	4	20	26	14
Responsive neurostimulation (RNS)	1	0	2	6	2
Transcranial direct current stimulation (tDCS)	0	0	1	3	1
Deep brain stimulation (DBS)	0	3	1	0	1
Ablative					
Stereotactic radiosurgery (SRS)	0	43	1	0	11
Magnetic resonance-guided laser interstitial thermal therapy (MRgLITT)	1	1	3	5	2
Magnetic resonance-guided focused ultrasound (MRgFU)	0	0	3	0	1
Diagnostic					
Stereo-electroencephalography (sEEG)	4	6	10	8	7

Abbreviations: AES, American Epilepsy Society; ASPN, American Society for Pediatric Neurosurgery; CPNSG, Canadian Pediatric Neurosurgery Study Group.
[a]The inflated disproportionately high mean for stereotactic radiosurgery is attributable to a single individual in the CPNSG focus group.

and tolerability of the device and the procedure were important considerations:

> We always have to think about developmental trajectories, not just whether somebody's here and then they have a deficit. (AES, American)

Disposition—the preferences, values, adherence, and willingness of parents and the patient—was a key sub-theme of patient candidacy. On parent disposition, expectation management and the manner of information presentation were reportedly essential to the decision-making process, as the authority ultimately rests with them:

> It's different for every family too because you really have to be good at gauging what their level of understanding is . . . you do a lot of sort of real time adjustment to how you say things. I think that's part of the art of being a child neurologist in general . . . to clearly and simply explain the different technologies and then very simply say, "This is what I recommend because x, y, z." (AES, American)

Some physicians noted that parents tend to prefer less invasive procedures such as laser interstitial thermal therapy (LITT), even if the intervention of interest was not necessarily suitable for their child. However, the existence of the technology created opportunities for discussion by getting individuals "in the door" both in general and in conversation about specific technologies. This condition was sometimes challenged by families with preconceptions toward new devices and who had had prior encounters with medical device representatives.[15] Although parents are the final decision makers, physicians also prioritized the disposition of patients and confirmation of their assent.

Another important factor was the compatibility of a neurotechnology for the family lifestyle or dynamic. High maintenance responsive neurostimulation, requiring daily and weekly upkeep, was not perceived as suitable for all families.

The type of intervention was a minor theme under clinical decision making. Physicians identified different interventions based on type (ie, neuromodulatory versus ablative) and their perceived medical benefits and risks. A key risk considered by

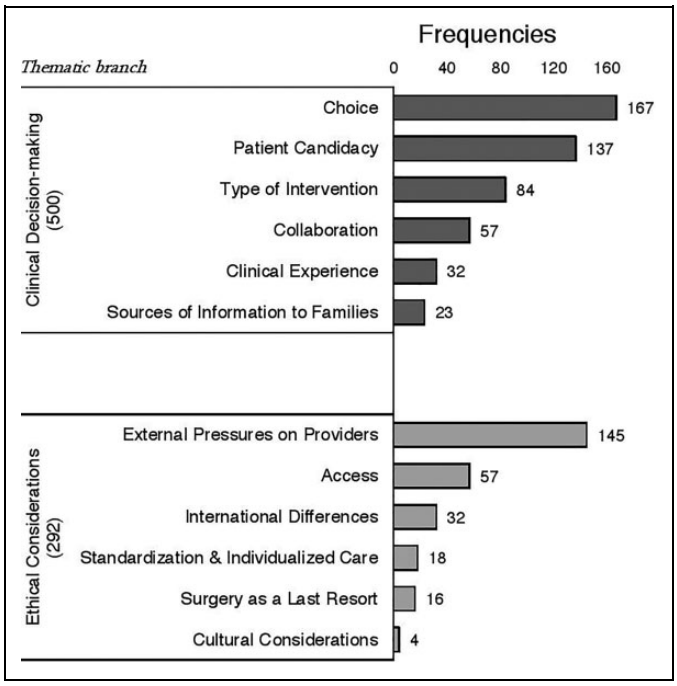

Figure 1. Frequency of themes under each major thematic branch.

physicians was the risk of ongoing seizures without surgery, particularly sudden unexpected death in epilepsy (SUDEP), irrespective of novel or conventional approaches. Participants perceived that parents sometimes do not fully appreciate this risk. Nonetheless, opting to do nothing or to maintain an ineffective treatment regime is a decision unto itself.

Ethical Considerations

Ethical considerations impact the decision-making process when choosing to acquire and utilize novel neurotechnologies, and are assessed by physicians through an evaluative and moral lens. One ethical consideration dominant in the discussion was external pressure on providers, and the major subtheme of financial considerations. This included the costs to acquire and maintain the technologies, which were noted many times in every group to be very expensive, sometimes to the point of being unmanageable. One physician weighed cost with effectiveness:

> They're expensive technologies and they don't cure, they're not curing patients and half the patients don't even benefit . . . so it's the cost-benefit, it's not great. (CPNSG, Canadian)

Even with the earlier reported need for testing and standardization of novel treatments for pediatric drug-resistant epilepsy, physicians described how other factors are still required to justify need and offset the financial burden of these technologies. These factors include a number of the themes already discussed (eg, evidence) and additional themes: the receptiveness of the hospital administration toward innovation, pressure from parents (ie, public demand), competition for funding and patients, and pressure from medical device representatives,[15] or the physicians themselves to bring in and keep the technology. Such pressures shape the standard of care:

> The reason that we got VNS in [Canadian city] was because of parental pressure on the government to pay for it. (AES, Canadian)

This statement introduces the divergence in the nature of the reported financial considerations between Canadian and American physicians, demonstrably based on single-payer and multipayer health care systems. Physicians in the USA discussed insurance approval; in Canada, physicians mentioned allocation of government funding and the utility of curating evidence for technology acquisition:

> We'll always [be] behind the US in having the access to the technology and so it gives us time to let the evidence accumulate, let our neurosurgeons speak to their buddies and understand the practical experiences and then have that influence our decision, because we only get to choose one toy instead of three toys. (AES, Canadian)

Access was an important minor theme under ethical considerations, often intimately linked to, but distinct from, discussions of financial considerations. Although not mentioned as frequently, accessibility of a technology was noted as a fundamental consideration because it creates the opportunity for decision making. Wait times were a subtheme of access. Canadian physicians reported that when the number of government or hospital-funded devices run out for the year or when an institution cannot afford to acquire or maintain a technology, there is a profound impact on wait times and a patient's course of treatment. One physician detailed a treatment strategy for navigating wait times in Canada:

> There's only a number of devices, there's a long waiting list for patients and so often that will influence your decision whether to refer to ketogenic diet, or to start another medication because families are waiting in the interim and that's a long time to wait for a child who's having lots and lots of seizures. . . . [I]t has influenced what I do. I'll make the referral, but do other things in the interim. (AES, Canadian)

The ability of the patient to pay for a neurotechnology itself, and indirect costs such as missing work for checkups and even Internet for responsive neurostimulation was another key barrier to access. This was primarily discussed by American physicians in the context of health insurance. However, when asked if type of insurance affects the initial treatment options presented to parents, the answer was a resounding no.

For some physicians, the latest technologies were not readily available (ie, responsive neurostimulation in Canada) or were only available at select institutions and required a referral. Complications to access and treatment recommendations were described as challenging:

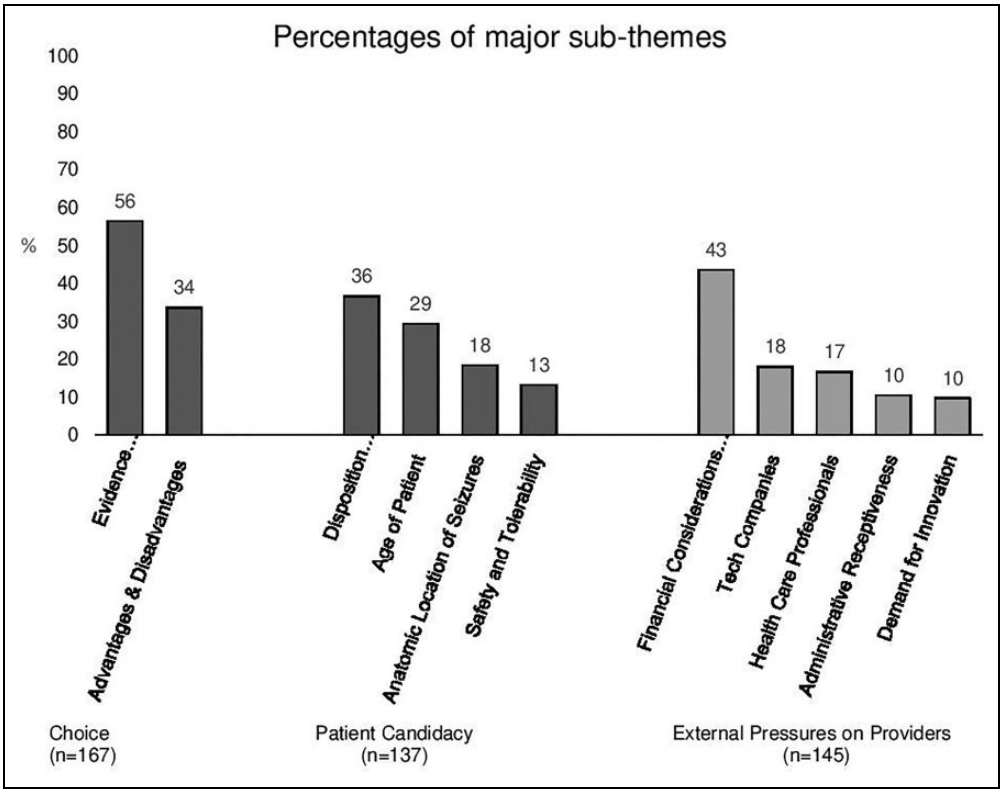

Figure 2. Percentage breakdown of major themes into subthemes.

> It's difficult as a surgeon in an institution that does not have any of this technology. . . . It's very difficult to know how to recommend treatment plans to patients. [Sometimes] the patient comes in and says, "Have you heard about this new technology, this interstitial laser?" And I say, "Well, yes, I've heard about it but I don't have any experience of it." (CPNSG, Canadian)

Discussion

Ethical issues in the adoption of novel neurotechnologies abound.[16] Novel surgical interventions are infrequently held to the same rigor as novel pharmaceuticals before adoption into practice. There is a learning curve for neurosurgeons to use a new device or technique, and safeguards for both initial and ongoing competence are lacking.

Here we explored the values, trade-offs, and concerns of pediatric neurosurgeons and neurologists in decision making for novel neurotechnological treatments for pediatric drug-resistant epilepsy. The results indicate that physicians are ready to recommend and are generally optimistic about the future of novel neurotechnology where conventional surgery is not a feasible or first option for parents. However, physicians asserted that more scientific evidence is needed to understand effectiveness and suitability of the diverse and unfolding range of neurotechnology for children. This priority permeated every level of decision making: upstream decision processes in the deliberation and acquisition of technology and downstream decision making for implementation and patient care. To this we add the importance of understanding the influence of a rapidly evolving relevant literature and pressures by industry.

Matching the right patient with the right treatment was another key decision feature for physicians. The unique developmental needs of children are essential for gauging the safety and tolerability of novel neurotechnologies. Physicians also consider the preferences and capacity and assent of the patient, and the overall family dynamics, especially for high maintenance neurotechnologies. Physicians expressed that parents do not always appreciate the risks associated with drug-resistant epilepsy, and that ongoing seizures are more dangerous than the risks involved with conventional neurosurgery or novel neurointerventions. Concerns around SUDEP, and the impact of seizures on neurodevelopment and psychiatric comorbidity, are embedded in these concerns.

Financial considerations are a major source of external pressure on upstream treatment decision-making processes. The expense of acquiring and maintaining novel neurotechnologies is a barrier to acquisition and availability. To overcome this issue, physicians need to justify the cost-benefit of the technology with evidence for its utility and need in their patient population. If the technology is not readily available, it is difficult for physicians to gain practical familiarity with these options to support referrals.

Comparison With Other Studies

To our knowledge, this is the first qualitative study to analyze physician choice of novel treatments against conventional

surgery for pediatric drug-resistant epilepsy through a neuroethical lens. Physicians expressed concern toward the underselection of conventional surgical candidates. This finding is consistent with the literature on lower-than-expected numbers for epilepsy surgery in children and adults.[17,18] As well, this study incorporated the perspectives of physicians practicing at different sites across North America. Previous decision-making studies were typically held at a single site and did not compare emerging neurotechnologies against established conventional epilepsy surgery (eg, Heath et al, 2016).[19] Our findings complement other neuroethics studies and results about the importance of ethical guidelines and public engagement around neurotechnologies.[20]

Implications of This Study

First, the need for evidence poses challenges for understanding the effectiveness of these neurotechnologies, but also highlights the need for alignment between physician and parental definitions of success. Physicians identified neuromodulatory technologies to be effective as partial therapies primarily for seizure reduction; they also discussed other potential benefits on cognition and quality of life.[21,22] The focus on the goal of seizure freedom could improve by incorporating the values of parents, who emphasize the importance of quality of life and a holistic risk-benefit trade-off on treatment, as supported in other decision-making and outcome literature.[8,19,23,24] In addition, as parents may have early preferences for the latest neurotechnologies, physicians identified the role of careful communication and guidance toward the most appropriate treatment. Communication style—for example, timing and responsiveness—is important to decision making for resective epilepsy surgery[19] and other pediatric chronic disease[25] and is critical for informed consent. Overcoming scientific gaps will support physicians and facilitate communication channels throughout the decision-making process.

Second, the reported trend across Canadian focus groups was lower familiarity and fewer patients treated with neurotechnology compared with the US groups. This difference may be related to availability, as Canadian physicians push for technology implementation within the resource limitations of a public system. For example, vagus nerve stimulation is readily available and relatively standard, which is reflected in its higher numbers of self-reported familiarity across all focus groups. In the literature, this growth of vagus nerve stimulation as a treatment for pediatric epilepsy is supported by its focus in media articles.[26] For families located far from specialized epilepsy centers, barriers to availability pose a risk for access not only to neurotechnology but all types of health care.

Limitations

We recognize the limitations of a sample of only 33 English-speaking health care professionals. The focus groups also did not benefit from the perspectives of allied health professionals such as nurses. Gender and cultural diversity were challenging to balance given the demographics of pediatric neurosurgeons in North America. The voices of youth have been captured recently[27] and shed light on their priorities for neurotechnology for drug-resistant epilepsy. Future studies that capture the voices of parents and other caregivers will further inform best strategies for shared decision making on this ethically complex landscape.

Conclusion

When assessing novel neurotechnological interventions for pediatric drug-resistant epilepsy, physicians seek to balance clinical and ethical factors to guide decision making and best practice. Ongoing seizures without surgery is a major risk for the safety of children with drug-resistant epilepsy, yet much remains to be learned about emerging neurotechnologies, and the benefits and risks they present for these young patients whose brains and bodies are still developing. Clinical trials with adults provide some, but limited, transferable information. The perspectives of the full range of stakeholders—physicians, parents and caregivers, and the youth themselves—are vital to understanding and translating bench innovation into clinical care.

Author Contributions

PJM and VH are co–first authors. The study was conceptualized by JI and PJM and the methodology designed by FU, VH, and JI. The investigation was performed by JI, PJM, MBC, MJH, GMI, RPN, and WC, and the manuscript was drafted by all authors. The funding was by JI and PJM. And JI was the supervision and guarantor.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the National Institutes of Health (NIH) BRAIN Initiative on Neuroethics [RF1 MH117805 01]. JI is Canada Research Chair in Neuroethics. PJM is UBC Alcan Chair in Neurosciences at UBC.

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Ethics Approval

The research was approved by the University of British Columbia Research Ethics Board #H18-02783. Consent was obtained from study participants prior to all focus groups.

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