

# Qualitative Analysis of Decision to Pursue Electrical Brain Stimulation by Patients With Drug-Resistant Epilepsy and Their Caregivers

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## Abstract

### Background and Objectives

To understand why patients with drug-resistant epilepsy (DRE) pursue invasive electrical brain stimulation (EBS).

### Methods

We interviewed patients with DRE ( $n = 20$ ) and their caregivers about their experiences in pursuing EBS approximately 1 year post device implant. Inductive analysis was applied to identify key motivating factors.

### Results

The cohort included participants aged from teens to 50s with deep brain stimulation, vagus nerve stimulation, responsive neurostimulation, and chronic subthreshold cortical stimulation. Patients' motivations included (1) improved quality of life (2) intolerability of antiseizure medications, (3) desperation, and (4) patient-family dynamics. Both patients and caregivers described a desire to alleviate burdens of the other. Patient apprehensions about EBS focused on invasiveness and the presence of electrodes in the brain. Previous experiences with invasive monitoring and the ability to see hardware in person during clinical visits influenced patients' comfort in proceeding with EBS. Despite realistic expectations for modest and delayed benefits, patients held out hope for an exceptionally positive outcome.

### Discussion

Our findings describe the motivations and decision-making process for patients with DRE who pursue invasive EBS. Patients balance feelings of desperation, personal goals, frustration with medication side effects, fears about surgery, and potential pressure from concerned caregivers. These factors together with the sense that patients have exhausted therapeutic alternatives may explain the limited decisional ambivalence observed in this cohort. These themes highlight opportunities for epilepsy care teams to support patient decision-making processes.

## Introduction

Although patients with drug-resistant epilepsy (DRE) constitute one of the largest populations to undergo invasive electrical brain stimulation (EBS), primary accounts of their experiences are limited.<sup>1</sup> Uncontrolled seizures profoundly affect quality of life (QOL), psychiatric comorbidity,

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medication burden, and risk of sudden death.<sup>2,3</sup> Pursuing EBS is a decision with psychological, medical, and interpersonal ramifications.<sup>4</sup> What motivates patients with DRE to pursue EBS and what influences that decision-making process?

Invasive EBS for epilepsy includes several approaches. In deep brain stimulation (DBS), electrodes are placed into the brain to stimulate the anterior nucleus of the thalamus and connected to a battery in the chest through wires extending down the neck.<sup>5</sup> In responsive neurostimulation (RNS), electrodes are placed into the brain at the seizure-onset zone where pulses of stimulation are delivered when abnormal activity is detected by the battery implanted in the skull.<sup>6</sup> In vagus nerve stimulation (VNS), a stimulating electrode is wrapped around the vagus nerve in the neck and connected to a battery in the chest.<sup>7</sup> Approaches involving off-label placement of stimulating electrodes are available at some centers as well.<sup>8</sup> Patients with DRE weigh these options when considering EBS.

Published patient experiences of EBS have primarily focused on movement and psychiatric disorders.<sup>9,10</sup> It is unclear whether these observations generalize to epilepsy. Although seizures are infrequent when compared with persistent movement disorder symptoms,<sup>11</sup> seizures can be embarrassing, incapacitating, and result in serious injuries and death.<sup>12,13</sup> The onset of epilepsy is often earlier than that of Parkinson disease,<sup>14</sup> interfering with milestones such as education, employment, and starting a family.<sup>15,16</sup> Improvements in seizure rates with EBS are typically modest and slow,<sup>7,17-20</sup> unlike the rapid improvements seen in movement disorders.<sup>21</sup> Although device-associated risks are likely comparable between epilepsy and movement disorders,<sup>21-25</sup> differences in efficacy highlight important questions regarding motivations to pursue EBS in brain diseases more generally.<sup>26,27</sup>

Our aim was to better understand patients' decisions to pursue invasive EBS for DRE. We interviewed 20 patients and their caregivers approximately 1 year following device implantation. We identified (1) decision drivers including QOL, antiseizure medications (ASMs), and desperation, (2) apprehension regarding electrodes in the brain, (3) tension between expectations and hopes for therapy, and (4) complex caregiver-patient dynamics influencing patients' decisions. We hope that patients and epilepsy care teams use this information to shape their approaches to EBS for DRE.

## Methods

### Standard Protocol Approvals, Registrations, and Patient Consents

Participants were consecutively recruited between 2020 and 2021 from the Epilepsy Neuromodulation Clinic at the

Mayo Clinic in Rochester, Minnesota. Inclusion criteria included being fluent in English and having received VNS Therapy (vagus nerve stimulation [VNS]),<sup>7</sup> Neuropace Responsive Neurostimulation RNS,<sup>6,28</sup> anterior nucleus of the thalamus deep brain stimulation (ANT-DBS),<sup>5,19</sup> or chronic subthreshold cortical stimulation (CSCS)<sup>8</sup> within the past year. Before their 1-year postimplant appointment, we contacted patients by phone. Patients had the option to conduct the interview in person, through phone, or over video. Participants could include their caregivers. Although some participants had been seen previously by clinic physicians (G.W. and B.L.), participants had no prior relationship with the data collection team (J.R., I.B., I.L., and R.S.). Researchers' personal rationale for conducting the study were not discussed. Informed consent was obtained in accordance with Mayo Clinic Institutional Review Board protocols. One consented participant did not complete the study because of loss of contact. One patient and caregiver declined consent because of the time commitment.

### Data Collection

Data were collected as part of a larger study evaluating patient experiences of EBS for epilepsy. J.R. (B.S., research assistant; sex: female; experience: 4 years) and I.B. (B.S., MD-PhD candidate; sex: female; experience: 1 year) interviewed 20 patients with DRE and their caregivers approximately 1 year following device implantation using a modified inductive approach. During each interview, participants were asked the same set of open-ended questions from a predefined moderator guide (eFigure 1, [links.lww.com/CPJ/A490](https://links.lww.com/CPJ/A490)). No interviews were repeated. Questions explored patients' paths to neuromodulatory devices, expectations, and factors that contributed to their decision-making process. Follow-up questions by the interviewer then clarified and probed patient responses. Interview duration was approximately 1 hour. Written memos of preliminary findings and themes were documented for each interview. Data collection and review continued until thematic saturation was reached. Audio recordings of the interviews were transcribed verbatim through a transcription service. Each transcription was then reviewed concurrently with the audio recording to check and correct the transcript. Transcripts and final manuscript were not returned to participants for comment. All recordings were deidentified and reviewed for accuracy by the study team.

### Data Analysis

The analysis team included one primary coder, I.L. (B.S., research assistant; sex: female; experience: <1 year) and 2 secondary coders (J.R. and I.B.). A modified inductive approach was used to analyze the transcripts and derive themes from the data. An initial codebook was developed using memos generated during data collection. The analysis team used the initial codebook to code 3 transcripts (one from the beginning, middle, and end of data collection). The codebook was then revised into the final codebook, which was applied to the entire data set.<sup>29</sup> Two coders independently coded each transcript and then met to discuss

any discrepancies and reach a consensus. Coding was conducted using the NVivo 11 Software package (QSR International, Doncaster, Australia). Quotes in the main text have been edited for brevity and clarity. Additional participant quotes to support those in the main text are available in eFigure 2 ([links.lww.com/CPJ/A490](https://links.lww.com/CPJ/A490)). Participants did not provide feedback on the findings.

## Data Availability

Data may be made available on reasonable request and data sharing agreement to protect patient confidentiality.

## Results

The cohort included patients with ages in the teens ( $n = 5$ ), 20s ( $n = 6$ ), 30s ( $n = 2$ ), 40s ( $n = 4$ ), and 50s ( $n = 3$ ). Participant sexes included female ( $n = 13$ ), male ( $n = 5$ ), and those who preferred not to disclose ( $n = 2$ ). Participants' implants were VNS only ( $n = 6$ ), VNS and DBS ( $n = 2$ ), DBS ( $n = 4$ ), RNS ( $n = 6$ ), and CSCS ( $n = 2$ ). Of 20 total interviews, 19 were conducted with a caregiver(s) present. Caregivers included parents ( $n = 19$ ), children ( $n = 2$ ), partners ( $n = 3$ ), and extended family ( $n = 1$ ).

### Motivations to Pursue Electrical Brain Stimulation for Epilepsy Improved Quality of Life

A desire to engage more fully with life emerged throughout the interviews. Patients described how epilepsy interfered with employment, independence, education, family life, hobbies, and social activities.

"Having seizures, you can't drive. I can't be in football. I can't do this. I can't do that. I could name a couple more. Having seizures is stressful. You don't get a lot of free will on like flashing lights, with big—sometimes even with movies, and these seizures they really do cause trouble with fun with tons of stuff, stayin' up all night, eating foods." Patient, VNS, teens

The risks and unpredictability of seizures necessitate constant supervision for many patients, creating a burden for patients and caregivers. For one participant, desires for independence manifested in the simple goal of being left alone.

"Just to live on my own and not have my parents hovering over me all the time, or when I do live on my own, they're not calling me every other day making sure I'm doing everything okay." Patient, VNS, 20s

Devices were seen as an opportunity to improve QOL for patients and caregivers, benefitting the entire family.

"I was excited because [the device] could help him, and I was thinking, 'Well, it would get rid of these seizures, maybe he's gonna live a normal life, which in turn makes everyone else's life easier.'" Parent

### Driving

Gaining the ability to drive was a key motivation for many participants. With that goal in mind, one participant felt they had no choice but to pursue EBS.

"I knew that I wanted it figured out because I wanted to drive eventually, and if I didn't get it done, then I wasn't going anywhere. I told myself that it wasn't really a choice." Patient, DBS, teens

Driving was associated with priorities such as supporting families financially and emotionally.

Patient: "My only hope was that eventually I'd get to be able to drive. With the seizures and the medication, with the implant and the medication, I'm hoping that on the good days that I have, which I know when the good days are that I hope that I'm able to drive." Interviewer: "Is there a specific reason why driving's really important to you?" Patient: "Well, just because on those days, I hope—'cause we live in a very small town—that I can drive to go see my parents or something like that. That's all." Patient, RNS, 50s

### Limited Options and Desperation

Exasperation with current circumstances pushed many patients to consider EBS despite fears about surgery and the possibility that the device may not reduce their seizures. The decision to pursue EBS followed an arduous process of trial and error, disappointment, and risk.

"Well, I think it almost felt like the next step of my whole—I had been on how many medications at that point? At least 10, and after 5 I think the chance of another medication working was almost 0. It was almost like, 'Well, they're giving me an option that feels like it might work. I need to try something so I might as well do it and be brave.' It was really scary, and to come all the way to Minnesota and to not even be anywhere near your home was so nerve wracking. That SEEG wasn't even a potential solution. It was just a step towards a solution so it wasn't like I was gonna walk outta the hospital and be potentially seizure free. It was just sitting there in pain for a week and then maybe me stepping towards a solution in the future." Patient, RNS, 50s

Although many patients did refer to pursuing EBS as a "choice," it was in the context of disruptive seizures, poor QOL, medication side effects, limited alternatives, and desperation. One patient's frustration manifested in their attitudes toward procedural risk and mortality.

"... I'm like, just get in there, do it, take care of it, and we'll be done. I'll either wake up, or I won't wake up. Either way, it's a win-win for me 'cause I don't wanna live like I've been living. When it's done, it's done. That's all. I wanted to get it done. I don't wanna take any more of the other crappy medicine, and that's all I gotta say about it..." Patient, RNS, 50s

### Burdens of Current Treatment Antiseizure Medications

Side effects from ASMs affected patients' QOL and contributed to the desperation with which they pursued EBS. By and large, patients were motivated to pursue neuromodulatory therapy in hopes they could reduce or stop their ASMs. Fatigue, cognitive slowing, irritability, and personality changes associated with medication regimens emerged frequently.

Patient: "I think our goal wasn't to get rid of the seizures, it was to get rid of some of the medicines because it made me so tired." Parent: "He was basically drugged. Most of the time, he felt just drugged." Parent and patient, RNS, 40s

Patients trialed numerous medications for years and decades. Patients and their families reflected on the positive and negative impacts of different medications. The fact that EBS delivered therapy with fewer side effects was seen as a major advantage to EBS.

“The VNS really comes with very few side effects. I certainly think that if there’s data to show that it can help, I would certainly recommend it because we’ve only learned it three or four years ago, [patient]’s anticonvulsants were changed, and she is a completely different person on these different—in a very good way. We have a different person here than we thought we had for many, many of those years, and the difference was the change in medication, so in that the VNS comes without all of those side effects, should I say, constant dampening side effects.” Parent

In reflecting on their experiences with medications, many patients wished EBS had been offered to them earlier.

“I wish we would have come here sooner and bypassed the year and a half of the ton of medications.” Patient, DBS, teens

## Apprehensions Implantation Procedure

Surgery and potential complications constituted serious fears for patients and caregivers. The complexity of the procedure together with the risk of stroke and other deficits were major concerns.

“Just, I don’t know, anytime you go into surgery, and then you start talking about going into the skull and into the brain and all that kind of stuff, that just—I guess [laughter] I’m not smart enough to see how that could be done. [laughter]” Interviewee 2: “Yeah, just if there’s anything, the worse that could happen, things that could happen. They talked about the brain bleeds and all that kind of stuff, so that was scary.” Patients, VNS and DBS, 30s

Notably, reflections on the fear, pain, discomfort, and stress of prior evaluations with intracranial EEG featured prominently in discussions of surgery and invasive electrodes. Multiple patients compared the device implant with their previous surgeries.

“... I already basically, had brain surgery once. At that point, I didn’t see any reason not to pursue it and see what options might be there to try to make my quality of life better.” Patient, RNS, 40s

## Hardware and the Brain

Apprehensions about the device focused heavily on the placement of the device in the brain and body and included pain, scarring, battery appearance, and risk of hitting the device. The invasiveness of different devices was a common theme, with the presence of electrodes in the brain constituting a major fear.

“The fact that they were putting leads in my brain is what scared me.” Patient, DBS, 40s

Patients saw devices on a spectrum of risk. For VNS, the placement of electrodes outside the brain was considered favorably. Some felt most comfortable with a staged approach: beginning with VNS and progressing to RNS or DBS if the outcome from VNS was inadequate.

“Then [physician] suggested the VNS and really pretty quickly, I said, ‘Yes, let’s do that.’ A whole lot easier, more livable than doing brain surgery.” Patient, VNS, 50s

The clinical team including epileptologists, neurosurgeons, nurses, and technicians affected patient attitudes toward devices. The confidence of the clinical team was a helpful counterpoint to the fear and uncertainty surrounding the invasive procedures.

“Just the fact of them removing a piece of my skull and replacing it with another—a battery. It’s simply just crazy, and that staying in there for the rest of my life or—it’s just absolutely crazy to me. At the same time, the way the doctors reassured us was—it was just, again, a no-brainer.” Patient, RNS, teens

Patients benefitted from seeing and touching devices (batteries, electrodes, telemetry, wands, chargers, etc.) in office visits. Appreciating the physical scale of the hardware aided visualization and comprehension.

Patient: “When he brought the little battery pack in and let me feel it and see it, and look at it and see how big it actually was, it was like, ‘Oh, well, there’s not much to that at all,’ and then to see the—’cause he showed me what the little leads looked like. That was probably one of the best things that they could have done for me to help me go into it very—I guess carefree was not the—” Patient: “Informed.” Parent and patient, RNS, 40s

## Caregiver and Family Influences on Patient Choices Epilepsy Affects the Family Unit

Epilepsy affects patients and caregivers. Caregivers described feelings of pain and powerlessness watching patients suffer through seizures and surgeries.

“...Yeah. It’s been a battle for her, which makes it a battle for us. Epilepsy has gotta be one of the worst things—well, I’m sure there’s other things, but it’s like there’s nothing you can do. You’re so helpless and hopeless at everything. There’s nothing I can do.” Parent

Reciprocal emotional connections were evident between patients and their families. Some patients wanted to ease the burden epilepsy placed on their loved ones.

“It was really hard watchin’ my family watch me ’cause you could see them hurt see me goin’ through all this stuff, and that’s when I was like, ‘Well, I need to do somethin’’. So that’s the main reason I did it is my mom. My twin brother..., my dad, my wife everyone was just, ‘Please do something.’ That’s the other reason why I did it.” Patient, VNS, 20s

Once devices became a possibility, the extent to which caregiver preferences influenced patient choices varied. In some families, it was caregivers and not patients who felt uneasy about devices and exhibited skepticism.

Patient: “Some of my family were kinda skeptical about having it done—” Interviewer: “Having the RNS?” Patient: “The RNS placed. Well, they weren’t in my shoes. I thought for a while, and while I lived with it, epilepsy, for so many years, some people knew I had it. Some people didn’t. My husband, [husband], next to me, he was a little leery, but he was by my side. We went for it. I did it, and I did it for

myself first. But then because I just got married, I did it for himself. I wanted my life better. I wanted to do everything I've always wanted to do." Patient, RNS, 50s

### Individual Choice and Family Pressure

Caregivers were often referenced as the ones who sought out additional epilepsy treatments and facilitated the patients' pursuit of EBS. This was especially evident for adolescent patients.

"She told me about the RNS after they told me the surgery—the resection wouldn't work. I was just over it all. I wanted to test and to be done, and the four seizures to be done. I was just like, 'I'm just gonna live with medication.' I wasn't eager to go anywhere else. I just was gonna put up with every—with the minor seizures and just live with it like that. I wasn't interested in moving any further. Then, obviously, with my parents taking me to Mayo Clinic and hearing from the doctors, how great of a plan they did have, that's when I was very—became very open-minded." Patient, RNS, teens

By and large, caregivers said that EBS was ultimately the patient's personal decision and that they played a supporting role in that decision. Though, caregivers' drive to help might create pressure for patients. One parent wondered if they pushed too much.

"She was scared. She told me that it's her life. I feel maybe bad about that 'cause maybe she didn't want it a hundred percent, but that's for an—that's where I had to make a tough call." Parent

### Dissonance Between Goals, Hopes, and Expectations

When asked about expectations for EBS, patients responded with seizure reduction rates as counseled by their physicians. They primarily anticipated modest and gradual reductions in seizures and months of stimulation parameter adjustments.

"The doctors up at the Mayo made us feel very—they were very informative. They explained everything. They handed out stuff explaining and told us to expect maybe a 50 percent improvement, but even that, we were willing to accept the 50 percent." Patient, RNS, 40s

But, when asked about their goals and motivations in pursuing EBS, patients responded with previously described themes of improved QOL, such as driving and medication reductions. There was tension between knowing the most probable outcomes and hoping to be a rare exception that achieves seizure freedom with the device.

"You always just have that in the back in your mind that they're just gonna go away, though." Patient, VNS and DBS, 30s

One family's reflection captured how the hope for something better is driven by personal goals yet limited by the need for realistic expectations.

"I think we were realistic about it. I don't think we expected it to be this silver bullet that would all the sudden sweep everything away, and life goes on happily ever after. I think we were realistic about the—I think the big hope was that you would go through this, you would have this thing in your head, you would have this daily maintenance and the check-ins and all that stuff, but that it would at least dramatically reduce the amount of medication you would have and therefore the kinda side effects. Whether it's because you wanna have a baby someday, or you wanted to go to school and get a job or

normal life stuff that seizures can make challenging sometimes. The hope was to dial the impact of all that back in a way that would give you a shot at not havin' this experience which was like havin' a leg tied—you can't tie your leg behind your back. That was always the—or just carrying around something super extra that made everything more difficult. I think that was our hope was that the device would—it would be like a—it would just improve her quality of life, and it would also, I think, eliminate not the number of variables, at least the feeling of just randomness." Parent

## Discussion

We identified motivating factors for, apprehensions about, and influences on patient decisions to pursue EBS for DRE (Table). Motivating factors, such as improved QOL and decreasing medications, stemmed from side effects and a lack of adequate seizure control, which have been directly connected to QOL in epilepsy.<sup>30</sup> After years of medication trials, despite fears about surgery and intracranial electrodes, patients were determined to pursue what was seen as the last remaining therapeutic option. Caregiver-patient dynamics factored strongly into the decision, with both describing a desire to unburden the other. The confidence and expertise of the clinical team increased patients' overall comfort with EBS.

This study was limited by the absence of perspectives from patients who considered then did not pursue EBS. Patients with DRE have heterogeneous attitudes toward procedural risk and anticipated efficacy, with some favoring continuing medications over surgical interventions.<sup>31</sup> In movement disorders, reasons patients chose not to participate in adaptive DBS research are largely practical but also include discomfort with being among the first to try a new therapy.<sup>32</sup> Because we interviewed participants 1 year post implant, it is possible that outcome bias involving seizure control and complications influenced participant valuations of their motivations. We were also unable to control for the initial presentation of information regarding EBS to participants, which likely influences attitudes toward EBS. Given disparities in access to specialized epilepsy centers such as ours,<sup>33</sup> economically disadvantaged voices may be underrepresented in our cohort. Further work is necessary to describe attitudes among patients who have not chosen or lack access to EBS.

The cohort's comments reflected the literature on QOL in epilepsy, especially regarding driving privileges.<sup>12</sup> Driving restrictions constitute a major impediment to QOL.<sup>34</sup> Although many participants named regaining the ability to drive as a motivator, modest and gradual response rates to EBS<sup>19,20</sup> indicate that regaining driving privileges may not be a realistic goal. Patient expectations surrounding driving and EBS warrant additional attention because it remains unclear how much driving privileges are an expectation of EBS therapy and ultimately related to patient satisfaction.

Medication side effects profoundly affect QOL in epilepsy.<sup>35</sup> Frustration with side effects and a desire to decrease medications

**Table** Main Findings

Decisional considerations		Clinical relevance
<b>Improved QOL</b>	Improved QOL means different things to different patients	Evaluate patient-specific goals and how realistic they are in relation to expected therapeutic outcomes. For example, driving is a common patient goal related to QOL, but this may not be a realistic outcome for most patients with DRE
<b>Antiseizure medications</b>	Patients are extremely motivated to decrease or stop medications	The comparatively lower side effect profile of EBS is very appealing for patients. EBS is worth considering as soon as a patient's seizures are deemed drug resistant
<b>Invasiveness</b>	The presence of electrodes in the brain is a major fear	Seeing and touching device electrodes and hardware at office visits improves patients' visualization and comfort
<b>Caregiver dynamics</b>	Epilepsy affects the entire family unit	Reciprocal desires to reduce burdens between patients and caregivers may create pressure for patients. Creating ample time and space for patients to come to their own decision is warranted
<b>Expectations</b>	Despite realistic expectations, patients often maintain hope for an exceptional outcome	Although patient expectations are typically grounded in the medical literature, exploring patients' deeper hopes may aid counseling before and after implant

Abbreviations: DRE = drug-resistant epilepsy; EBS = electrical brain stimulation; QOL = quality of life. Key factors and findings regarding patient decision-making processes to pursue EBS for DRE are described here. The potential impact of these findings on clinical counseling approaches are discussed.

were key motivators for patients pursuing EBS. ASM side effects together with depression symptoms mediate the negative association between ASM polytherapy and health-related QOL.<sup>36</sup> Given patients' desperation to reduce medications, prompt consideration of EBS, after patients are determined not to be candidates for resective surgery, is warranted.<sup>37</sup>

Although EBS for epilepsy is considered palliative, class I evidence supports seizure reduction, decreased medications, and periods of seizure freedom with EBS. At 9-year follow-up after RNS implant, there is a 75% median reduction in seizure frequency with a responder rate of 73%.<sup>20</sup> At 5-year follow-up after DBS implant, there is a 69% median reduction in seizures frequency with a responder rate of 68%.<sup>17</sup> At least 1 year of seizure freedom is seen in 16% of DBS<sup>17</sup> and in 18% of RNS patients.<sup>20</sup> Participant understandings of EBS efficacy based on the medical literature held space with hopes for becoming one of the exceptions who achieves rapid seizure freedom. An opportunity to alleviate some of this tension may exist in directly juxtaposing anticipated efficacy rates with QOL goals while counseling patients.

Reciprocal burdens between patients with epilepsy and their caregivers have been previously described, with both attempting to protect the other from the demands of caregiving.<sup>38</sup> Caregiver burden has a negative impact on caregiver QOL.<sup>39</sup> Caregivers in our study described pain at watching the patients suffer and strongly encouraged the patients to consider EBS. Patient comfort may be of immediate concern to caregivers over long-term goals. Caregivers tend to give lower priority to patients' driving and professional goals than patients but give higher priority to the tolerability of side effects.<sup>30</sup> Because caregiver-patient dynamics may exert pressure on patients, ensuring patients and caregivers discuss their preferences and concerns, both together and individually, may be advised.

Desperation and choice are nuanced subjects in palliative treatments for chronic illnesses such as DRE.<sup>40,41</sup> Although patients reported feeling free to pursue or not to pursue EBS, this sense of choice was muddled in their descriptions of their ongoing frustrations and lack of alternatives. For patients who are desperate to change the status quo and who have exhausted available therapies, the decision to pursue EBS becomes obvious. Patients may express less decisional ambivalence because they feel to continue ASMs as before is unacceptable. Although these patients may eagerly consent to EBS, taking additional time to describe uncertainties, explore expectations, and visualize life after surgery remains essential. In comparing EBS devices, unless patients had strong preferences for electrodes outside or inside the brain, patients typically deferred to their physicians. There is often little to no data to support one device over another, and physicians and patients must work together on a what they suspect will be best. Patients may be best served not by making the perfect choice but by improving how informed they are along the path they follow, uncertainty included.

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