Epilepsy & Behavior Reports 14 (2020) 100398

Contents lists available at ScienceDirect

Epilepsy & Behavior Reports

journal homepage: www.elsevier.com/locate/ebcr

Addressing the epilepsy surgery gap: Impact of community/tertiary epilepsy center collaboration

Keyan Peterson [a,*], Suzette LaRoche [b], Tiffany Cummings [a], Valerie Woodard [a], Anna-Marieta Moise [b], Heidi Munger Clary [a]

[a] Wake Forest University School of Medicine, Department of Neurology, Winston-Salem, NC, USA
[b] Mission Health, Department of Neurology, Asheville, NC, USA

ARTICLE INFO

Article history:
Available online 29 October 2020

Key Terms:
Epilepsy surgery
Access to care
Health systems
Referrals
Process improvement

ABSTRACT

To assess whether a formal collaboration between a non-surgical, community epilepsy center and a surgical, tertiary-care epilepsy center can improve patient progress throughout the pre-surgical referral process, and to elucidate predictors of referral completion among inter-center referrals.

The inter-center referral process was tracked, and the number of patients completing surgical conference (primary outcome) and epilepsy surgery at the tertiary center were collected and compared in the 45-month immediate pre/post-collaboration periods. Demographic and clinical variables were collected on post-collaboration inter-center patient referrals to explore factors associated with completion of the referral process.

Compared to the pre-collaboration period, the proportion of tertiary center epilepsy surgery conference patients referred from the community epilepsy center increased from 3/88 to 14/113 (263% increase, $p = .01$) during the post-collaboration period. The proportion of patients completing surgery via the community to tertiary referral process increased from 2/63 pre-collaboration to 8/71 post-collaboration (254% increase, $p = .04$). Referral completion was associated with higher seizure frequency, shorter travel distance, private insurance status and positive employment status ($p < 0.05$).

Collaboration agreements between community and tertiary-care epilepsy centers may improve patient completion of the epilepsy surgery referral process. Implementation of similar programs at other centers may be beneficial in reducing the epilepsy surgery gap.

1. Introduction

Epilepsy surgery is effective and early referral is recommended for drug resistant epilepsy, yet despite data showing better outcomes from earlier surgery, a persistent 20-year delay from diagnosis to surgical referral exists [1–5]. Socioeconomic, clinical and systems-level factors contribute to delays in referral for surgical evaluation [6–10]. Further, patients themselves described the epilepsy surgery referral process as arduous and associated with vulnerability and loneliness [11].

The National Association of Epilepsy Centers (NAEC) 2010 guidelines require patients with drug-resistant epilepsy be referred to expert, interdisciplinary, level III or level IV epilepsy centers for evaluation and management recommendations and that community centers (Level III) have a formal referral relationship with a tertiary center (Level IV). The guidelines recommend collaborating centers work together to maintain open communication and establish formal data sharing agreements [12]. Thus, it is important to assess the outcomes of collaborations and disseminate information on processes created during successful collaborations.

The objective of this study was to characterize the surgical referral process developed in a new formal collaboration agreement between a community and tertiary epilepsy center and assess its influence on referral volumes between the centers. Specifically, we examined impact of the collaboration by comparing proportions of community center origin pre-and post-collaboration surgical conference presentations and completed surgeries. Additionally, we explored clinical and sociodemographic variables that were associated with referral completion in the context of the collaboration.

* Corresponding author at: Department of Neurology, Wake Forest Baptist Medical Center, 1 Medical Center Blvd, Winston-Salem, NC 27157, USA.
E-mail addresses: kapeters@wakehealth.edu (K. Peterson), hmungerc@wakehealth.edu (H. Munger Clary).

https://doi.org/10.1016/j.ebr.2020.100398
2589-9864/

2. Methods

A formal collaboration agreement was established between the community-based, non-surgical epilepsy center (Level III) and the tertiary-care, surgical epilepsy center (Level IV) on October 1st, 2015. The collaboration agreement was initiated in order to increase the proportion of referrals completing the referral process from the community to tertiary epilepsy center, as defined by completion of surgical conference and/or the completion of epilepsy surgery. The formal agreement was signed by both centers and was developed in accordance with NAEC guidelines for level III epilepsy center accreditation [12]. The collaboration was a one to one relationship between the two centers with the goal of creating and improving a standardized referral process. Patient flow through the inter-center referral process was mapped and analyzed, and key decision points in the process were elucidated for process improvement and dissemination.

To assess the effect of this collaboration on inter-center surgical referral volume, institutional review board approval was obtained and the population of individuals undergoing presurgical evaluation at the surgical, tertiary care epilepsy center from January 2012 to May 2019 was retrospectively identified from the institutional epilepsy database. Data collection and analysis for this study took place from June 2019 to December 2019. The patients were separated into pre- and post-collaboration groups based on date of surgical workup initiation within two equivalent consecutive 45-month timeframes before and following the center collaboration agreement (pre-collaboration: January 2012–September 2015; post-collaboration October 2015–June 2019). Clinical and sociodemographic variables were collected on post-collaboration patients from the community, non-surgical center to explore factors associated with referral completion (primary and secondary outcomes defined below) in the post-collaboration period. Sociodemographic variables collected included race/ethnicity, marital status, insurance status, driving status, employment status, and zip code of primary residence. Clinical variables included epilepsy duration, seizure frequency, number of lifetime antiseizure medications, history of prior epilepsy surgery, and history of psychiatric disease. For all patients, the primary outcome was defined as the final decision rendered following epilepsy surgical conference presentation at the tertiary care/surgical center. The secondary outcome measure was defined as completion of epilepsy surgery, including those patients who received neuromodulation. For both the pre- and post-collaboration timeframes, final outcome collection was locked from data analysis 6 months after the end of the period.

2.1. Data analysis

The two-proportion *z*-test was used to compare proportions of total inter-center referrals completing epilepsy surgical conference (primary outcome) or surgery (secondary outcome) in the pre-collaboration and post-collaboration timeframes. To explore factors associated with completion of surgical conference or surgery among those referred by the community center in the post-collaboration period, Fisher's exact test was used to compare categorical variables, and continuous variables were analyzed using Student's *t*-test. A *p* value less than 0.05 was considered significant. Analysis was not adjusted for multiple comparisons, as the analysis of factors associated with completion of surgery or surgical conference was hypothesis-generating.

3. Results

3.1. Process analysis

Patient flow through the referral process is shown in Fig. 1. Medical records, scalp video EEG monitoring data and neuroimaging (3T MRI) were sent from the community center to the tertiary center's epilepsy coordinator, who ensured raw data from prior testing was uploaded to the tertiary center imaging and EEG systems. The epilepsy coordinator also discussed the patient with the community and tertiary center epileptologists to decide whether an early formal tertiary consultation was needed. If early consultation was not required, the patient proceeded through the streamlined workup pathway (Fig. 1). This expedited workup was facilitated by the epilepsy coordinator, who streamlined appointments for referred patients, allowing them to see multiple providers and have multiple tests performed in one day to reduce travel burden. For example, during initial workup at the tertiary center, patients may have had a PET scan, an epileptologist consult and a neuropsychological visit on the same day. Closer to surgery, packaging of visits with the epileptologist, neurosurgeon and anesthesia teams on the same day further reduced travel burden. Finally, when a community/non-surgical center patient reached surgical conference presentation at the tertiary center, the referring epileptologist was present via video conferencing to maintain ongoing care collaboration. At the tertiary care center, surgical conference occurred weekly with 1–3 patients discussed.

3.2. Pre/post-collaboration referral volume analysis

A total of 201 patients were presented at surgical conference from all referral sources at the tertiary center during the study period: 88 pre-collaboration and 113 post-collaboration. The proportion of patients presented at surgical conference referred from the community epilepsy center increased from 3 out of 88 (3.4%) pre-collaboration to 14 out of 113 (12.4%) post-collaboration – representing a 263% increase (p = .01, Z = 2.27). Post-collaboration, there was an increase in the geographical distribution of patients completing the referral process from the 17-county catchment served by the community epilepsy center (Fig. 2). The proportion of community/nonsurgical epilepsy center patients that completed surgery at the tertiary center increased from 2 out of 63 (3.2%) pre-collaboration to 8 out of 71 (11.3%) post-collaboration – a 254% increase, (p = .04, Z = 1.78).

3.3. Post-collaboration factors associated with referral completion

Demographic and clinical data for post-collaboration inter-center referral patients is presented in Table 1. In the period post-collaboration, a total of 21 patients were referred from the community epilepsy center to the tertiary center for pre-surgical evaluation, with 14 presented in surgical conference and 8 of those completing surgical intervention by the time of final outcome collection. Of the 14 patients presented in surgical conference only 5 required repeat video-EEG monitoring at the tertiary center. Of the 6 surgical conference patients that had not completed surgery by the post-collaboration data collection cutoff of December 31, 2019, only 2 rejected surgeries outright, with the remaining 4 still engaged at various stages of the pre-surgical evaluation process. Only 1 patient required intracranial stereo-EEG placement of electrodes. Of the 8 surgeries completed, there were 4 vagal nerve stimulator implants, 3 laser ablations (1 after a stereo-EEG evaluation) and 1 temporal lobectomy. All surgical patients returned to

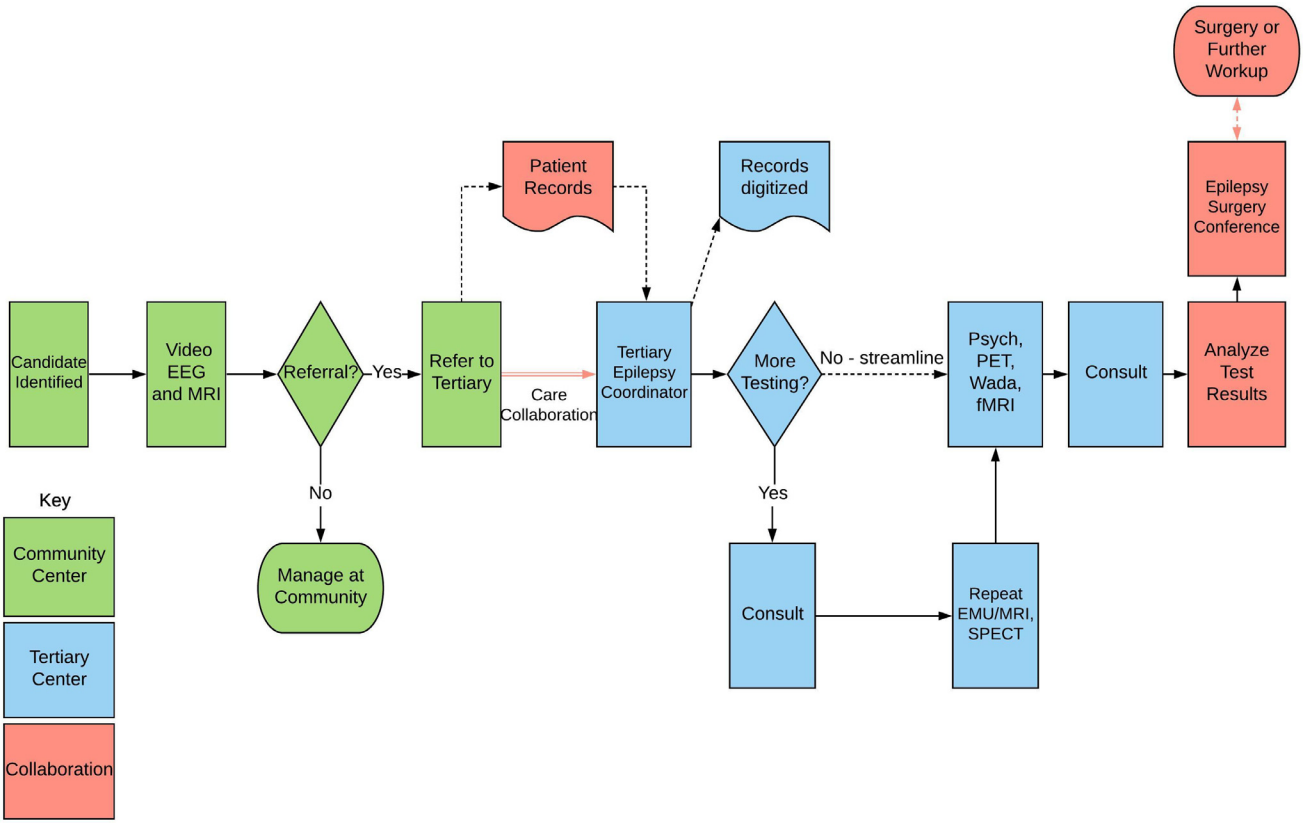

Fig. 1. Referral process flowchart (Interactive Process Diagram). Community to tertiary center referral process for epilepsy surgery evaluation. (Figure 1 is available in online interactive format. Please click hyperlink above, and use the 'present' feature to view the process diagram interactively)

Fig. 2. Geographical distribution of patients referred from the community center completing surgical conference pre/post-collaboration. Geographical distribution of patients completing surgical conference at the tertiary center from the 17-county catchment served by the community center.

their primary epilepsy care service at the community center after post-operative follow-up at the tertiary center. Surgical conference completion among post-collaboration referrals was associated with higher seizure frequency, shorter travel distance, private insurance rather than government (Medicare/Medicaid insurance) and active employment (Table 2). The other variables collected were not associated with completion of surgical conference or surgery.

4. Discussion

Current epilepsy surgery referral processes have been described as slow, arduous, and lacking continuity due to disrupted care transitions between centers [11,13]. Pre-surgical evaluations are underutilized by patients and some epileptologists [14]. The results of this study demonstrate that an organized collaboration between community/tertiary epilepsy centers can increase referrals and completion of pre-surgical evaluation among patients with drug-resistant epilepsy, and ultimately increase surgical treatments. The results also suggest that, within the context of this collaboration, increased severity of disease at time of referral, travel distance and socioeconomic status may influence patient decisions to pursue further pre-surgical workup and complete the referral process.

Epilepsy centers may use both internal and external methods to enhance the pre-surgical referral process. Internal improvements such as increasing surgical conference frequency, adding a dedicated epilepsy surgery nurse navigator, and scheduling diagnostic

Table 1
Demographic and clinical data for post-collaboration inter-center referral patients (n = 21).

Variable	Mean (SD) or % (n)
Age (years)	35.5 (±15.2)
Gender	67% male
Insurance Status	
– Private	38% (8)
– Medicare	9% (2)
– Medicaid	48% (10)
– Self-Pay	5% (1)
Marital Status	
– Single	62% (13)
– Married	28% (6)
– Divorced	10% (2)
Employment Status	
– Employed	52% (11)
– Unemployed*	48% (10)
Epilepsy Duration (years)	12.3 (±8.7)
Seizure Frequency (months)	19.6 (±23.2)
Travel Distance (miles)	150.8 (±24.8)
Lifetime AEDs	5.5 (±3.0)

* Includes disabled.

Table 2
Factors significantly associated with completed surgical conference in post-collaboration referral cohort (n = 21).

	Surgical Conference Complete (n = 14)	Surgical Conference Incomplete (n = 7)	p-value
Mean Seizure Frequency (months)	26.9 (±25.1)	2.4 (±2.8)	p = .001^
Mean Travel Distance (miles)	123.5 (±10.8)	157.1 (±22.5)	p = .003^
Employment Status			
– Employed	91% (10/11)	9% (1/11)	p = .02#
– Unemployed*	40% (4/10)	60% (6/10)	
Insurance Status			
– Private	100% (8/8)	0% (0/8)	p = .02#
– Other (Medicaid, Medicare, Self)	46% (6/13)	54% (7/13)	

^ Student's t-test, two-tailed.
# Fisher's exact test.
* Includes disabled patients.

tests more quickly, have been shown to reduce time to surgery and improve patient throughput [15,16]. External process improvements could address issues of continuity of care when transitioning patients from community to surgical epilepsy centers. Examples of external process improvements, such as collaboration agreements between independent surgical centers, are surprisingly absent in the literature.

Studies from other disciplines reveal that specialized centers with well-developed relationships and connections to community-level referring centers are able to maintain high referral rates of service completion with minimal patient attrition [17]. Conversely, failures of inter-communication between specialty and community centers can directly lead to missed patient appointments and delays in needed assessment and treatment [18]. Further, smooth inter-center referral practices can influence patient satisfaction [19], a known obstacle in epilepsy surgical referral pathways [11]. NAEC guidelines exist regarding when to refer patients to level III (community) or level IV (tertiary) epilepsy centers, based on the specialized resources available at these facilities and the patient's clinical course [12]. However, little instruction exists on when or how to facilitate a coordinated referral between the specialized centers, nor the benefits a coordinated referral process may yield.

The referral process implemented in our collaboration offered several points of synergism between the two centers, some that parallel single-center process improvements and others unique to this inter-center collaboration. The value of a community epilepsy center as the origin for these patients may relate to both the experience provided by an epileptologist as the referring provider, as well as the ability to begin the surgical evaluation process closer to home. Patients receiving information about their epilepsy from specialized epilepsy centers were demonstrated to feel more connected to their personal disease state and have more positive perceptions about epilepsy surgery [6,13]. Further, beginning the surgical evaluation close to home at a regional, community-based facility may encourage patient engagement from those who would not otherwise travel to a distant tertiary epilepsy center for evaluation. Finally, the presence of the referring community center epileptologist at the tertiary center surgical conference provides improved continuity of patient care by providing expertise and clarity on the patient's clinical course that is not always effectively captured in standard clinical documentation.

The epilepsy coordinator acts as a referral hub in our model, allowing for centralized care coordination between referring centers, patients, and receiving epileptologists. This single point of contact helps to streamline the referral process for patients by providing scheduling of multiple appointments across disciplines in a single day. Patients referred to a tertiary center from a community epilepsy center may come with more substantive epilepsy records, including high-resolution brain MRI and completed video-EEG monitoring sessions, compared to other referral sources. In our model, the community center's epilepsy coordinator collects records and ensures transfer to the tertiary center epilepsy coordinator. These records are then processed by the receiving epilepsy coordinator, uploaded to the tertiary care center data systems for primary review prior to epileptologist consultation, and coalesced into a single document in preparation for surgical conference presentation.

In our study, the collaboration agreement appears to increase the reach of the tertiary center in the broader geographical catchment of the community center. Such collaboration agreements may allow for increased patient recruitment through the previously mentioned benefits of increasing patient knowledge of their condition through community-center provided patient-education and streamlined scheduling between centers which may ultimately decrease travel burden for patients from more rural communities.

Despite the improvements in patient retention that collaboration networks may offer, there remain significant barriers to completion of the surgical referral process. In our population, patients with lower seizure frequency, a longer travel distance to the receiving center, and those of lower socioeconomic status (suggested by findings on insurance/employment as proxies of socioeconomic status), were less likely to complete the referral process. This may suggest that the completion of patient referrals is influenced by clinical, geographic and socioeconomic level factors. Previous research supports the notion that lower socioeconomic status and lower disease severity may prevent patients from completing the pre-surgical evaluation [6,8,20]. Whether the collaboration networks have the potential to reduce the influence of these factors remains to be elucidated and is an important area for future research. Longer travel distance has been documented as a reason for delayed referral completion [21], and the results of this study further support that longer distance to the receiving center may deter patients from pursuing pre-surgical workup. This could suggest a geographical limit, in a radius around the receiving center, where the majority of patients would not be willing to travel outside to pursue pre-surgical evaluation. The implications of defining this boundary would mean that centers should focus on developing

collaboration networks within their geographical catchment area to maximize patient referrals.

A comprehensive pre-surgical evaluation is both beneficial for patients and helpful in promoting patient care and clinical research [22,23]. One benefit of inter-center collaboration agreements that may not be immediately evident is the potential role for standardized data collection. The heterogeneous pathways that patients take prior to epilepsy surgery makes collecting data on these patients an arduous task fraught with confounding variables and inconsistent reporting of key outcome variables [5]. Collaboration agreements help to standardize the patient pathway to surgery, from initial contact at the community center through the surgical evaluation process at the tertiary receiving center. This allows for a more homogenous pre-surgical process that lends itself to analysis by eliminating barriers related to different referral pathways and allow for greater confidence when analyzing and reporting factors associated with referral.

This report may help to guide the implementation of similar formal collaboration agreements between epilepsy centers. Collaborating centers can address continuity of care by centralizing the referral process through a facilitator, and including referring clinicians in surgical conference discussions [15,16]. Bundling appointments may improve referral attrition by reducing patient travel burden, as has been demonstrated in cross-discipline process improvement initiatives [24]. If possible, the referring center should have experienced epileptologists able to funnel appropriate surgical candidates, to improve patient education and increase confidence in the potential for surgical intervention. Finally, consideration of the referral patient population's geographical distance, clinical severity and socioeconomic stratification should be monitored when designing collaboration networks.

This study is limited by a retrospective design, small sample size, and a two-center perspective, which limits generalization to other care networks. Our study analyzing factors associated with a referral network was exploratory in nature. Further studies are needed to clarify important features of successful collaborations.

5. Conclusion

This report outlines one successful model of how formal collaboration between community and tertiary epilepsy centers may be implemented to improve patient care and extend the geographical network involved in the referral process. Future studies may demonstrate alternative models of successful inter-center collaboration. These models should address whether formal collaborations can reduce delay in epilepsy surgery and improve the patient experience in the referral process.

6. Declarations of interest

None.

Ethics and Conflict of Interest Declaration

We confirm that any aspect of the work covered in this manuscript that has involved either experimental animals or human patients has been conducted with the ethical approval of all relevant bodies and that such approvals are acknowledged within the manuscript.

Acknowledgements

This work was supported by the National Center for Advancing Translational Sciences. Grant numbers: UL1TR001420 and 2KL2TR001421-05.

Appendix A. Author Contributions

Name	Location	Contribution
Keyan Peterson, MS, MBA	Wake Forest University, Winston-Salem, NC	Study design, Data collection and analysis, Drafted the manuscript for intellectual content.
Suzette LaRoche, MD	Mission Health, Asheville NC	Study design, Revised the manuscript for intellectual content.
Tiffany Cummings, Psy.D	Wake Forest University, Winston-Salem, NC	Study design, Revised the manuscript for intellectual content.
Valerie Woodard, RN	Wake Forest University, Winston-Salem, NC	Data acquisition, Inter-center collaboration and communication.
Anna-Marieta Moise, MD	Mission Health, Asheville NC	Revised the manuscript for intellectual content.
Heidi Munger Clary, MD, MPH	Wake Forest University, Winston-Salem, NC	Study design, conceptualization and oversight. Data interpretation, Revised the manuscript for intellectual content.

References

[1] Meguins LC, Adry RAR da C, Silva-Junior SC da, Araújo Filho GM de, Marques LHN. Shorter epilepsy duration is associated with better seizure outcome in temporal lobe epilepsy surgery. Arq Neuropsiquiatr. 2015;73(3):212–217.
[2] Radhakrishnan A, Menon R, Thomas SV, Abraham M, Vilanilam G, Kesavadas C, et al. "Time is Brain"-How early should surgery be done in drug-resistant TLE?. Acta Neurol Scand 2018;138(6):531–40.
[3] Bjellvi J, Olsson I, Malmgren K, Wilbe Ramsay K. Epilepsy duration and seizure outcome in epilepsy surgery: A systematic review and meta-analysis. Neurology 2019;93(2):e159–66.
[4] Haneef Z, Stern J, Dewar S, Engel J. Referral pattern for epilepsy surgery after evidence-based recommendations. Neurology 2010;75(8):699–704.
[5] Mumford V, Rapport F, Shih P, Mitchell R, Bleasel A, Nikpour A, et al. Promoting faster pathways to surgery: a clinical audit of patients with refractory epilepsy. BMC Neurol 2019;19(1):29.
[6] Baca CB, Vickrey BG, Vassar S, Hauptman JS, Dadour A, Oh T, et al. Time to pediatric epilepsy surgery is related to disease severity and nonclinical factors. Neurology. 2013;80(13):1231–9.
[7] Hauptman JS, Dadour A, Oh T, Baca CB, Vickrey BG, Vassar S, et al. Time to pediatric epilepsy surgery is longer and developmental outcomes lower for government compared with private insurance. Neurosurgery. 2013;73(1):152–7.
[8] Rubinger L, Chan C, Andrade D, Go C, Smith ML, Snead OC, et al. Socioeconomic status influences time to surgery and surgical outcome in pediatric epilepsy surgery. Epilepsy Behav 2016;55:133–8.
[9] Fois C, Kovac S, Khalil A, Uzuner GT, Diehl B, Wehner T, et al. Predictors for being offered epilepsy surgery: 5-year experience of a tertiary referral centre. J Neurol Neurosurg Psychiatry 2016;87(2):209–11.
[10] Prideaux L, Barton S, Maixner W, Harvey AS. Potential delays in referral and assessment for epilepsy surgery in children with drug-resistant, early-onset epilepsy. Epilepsy Res 2018;143:20–6.
[11] Pieters HC, Iwaki T, Vickrey BG, Mathern GW, Baca CB. "It was five years of hell": Parental experiences of navigating and processing the slow and arduous time to pediatric resective epilepsy surgery. Epilepsy Behav 2016;62:276–84.
[12] Labiner DM, Bagic AI, Herman ST, Fountain NB, Walczak TS, Gumnit RJ, et al. Essential services, personnel, and facilities in specialized epilepsy centers–revised 2010 guidelines. Epilepsia 2010;51(11):2322–33.
[13] Shih P, Nikpour A, Bleasel A, Herkes G, Mitchell R, Seah R, et al. Leading up to saying "yes": A qualitative study on the experience of patients with refractory epilepsy regarding presurgical investigation for resective surgery. Epilepsy Behav 2018;83:36–43.
[14] Steinbrenner M, Kowski AB, Holtkamp M. Referral to evaluation for epilepsy surgery: Reluctance by epileptologists and patients. Epilepsia 2019;60(2):211–9.

[15] Drees C, Sillau S, Brown M-G, Abosch A. Preoperative evaluation for epilepsy surgery: Process improvement. Neurol Clin Pract 2017;7(3):205–13.
[16] Hill CE, Raab J, Roberts D, Lucas T, Pollard J, Kheder A, et al. Addressing barriers to surgical evaluation for patients with epilepsy. Epilepsy Behav 2018;86:1–5.
[17] Frechette KM, Conley SM, Tang A, Welch TD. Cardiac rehabilitation in a rural setting: optimization of referral and participation rates. J Cardiopulm Rehabil Prev 2019;39(1):E4–7.
[18] Porras-Javier L, Bromley E, Lopez M, Coker TR. Challenges to effective primary care-specialty communication and coordination in the mental health referral and care process for publicly insured children. J Behav Health Serv Res 2018;45(4):668–77.
[19] Zhang X, Wang T, Yu Y, Zhao S. Key nodes affecting patient satisfaction in a cross-regional referral service process: an empirical analysis study in Sichuan. BMC Health Serv Res 2018;18(1):840.
[20] Lim ME, Bowen JM, Snead OC, Elliott I, Donner E, Weiss SK, et al. Access to surgery for paediatric patients with medically refractory epilepsy: a systems analysis. Epilepsy Res 2013;107(3):286–96.
[21] Jackson HN, Gadgil N, Pan I-W, Clarke DF, Wagner KM, Cronkite CA, et al. Sociodemographic factors in pediatric epilepsy surgery. Pediatr Neurol 2019.
[22] Boon P, Vandekerckhove T, Calliauw L, Achten E, De Reuck J, Thiery E, et al. Epilepsy surgery in Belgium, the Flemish experience. Acta Neurol Belg 1996;96(1):6–18.
[23] Boon P, Vandekerckhove T, Achten E, Thiery E, Goossens L, Vonck K, et al. Epilepsy surgery in Belgium, the experience in Gent. Acta Neurol Belg 1999;99(4):256–65.
[24] Thomas NJ, Mertens P, Danaila T, Polo G, Klinger H, Broussolle E, et al. Optimizing the deep brain stimulation care pathway in patients with Parkinson's disease. J Neurol 2017;264(7):1454–64.