



Putting children forward for epilepsy surgery: A qualitative study of UK parents' and health professionals' decision-making experiences



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ABSTRACT

Background: Against a backdrop of recommendations for increasing access to and uptake of early surgical intervention for children with medically intractable epilepsy, it is important to understand how parents and professionals decide to put children forward for epilepsy surgery and what their decisional support needs are.

Aim: The aim of this study was to explore how parents and health professionals make decisions regarding putting children forward for pediatric epilepsy surgery.

Methods: Individual interviews were conducted with nine parents of children who had undergone pediatric epilepsy surgery at a specialist children's hospital and ten healthcare professionals who made up the children's epilepsy surgery service multidisciplinary healthcare team (MDT). Three MDT meetings were also observed. Data were analyzed thematically.

Findings: Four themes were generated from analysis of interviews with parents: presentation of surgery as a treatment option, decision-making, looking back, and interventions. Three themes were generated from analysis of interviews/observations with health professionals: triangulating information, team working, and patient and family perspectives.

Discussion: Parents wanted more information and support in deciding to put their child forward for epilepsy surgery. They attempted to balance the potential benefits of surgery against any risks of harm. For health professionals, a multidisciplinary approach was seen as crucial to the decision-making process. Advocating for the family was perceived to be the responsibility of nonmedical professionals.

Conclusion: Decision-making can be supported by incorporating families into discussions regarding epilepsy surgery as a *potential* treatment option earlier in the process and by providing families with additional information and access to other parents with similar experiences.

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1. Background

For children with prolonged, medically intractable epilepsy, surgical intervention can lead to improvements in quality of life by reducing the number and severity of seizures [1–3] and slowing the rate of cognitive decline. Moreover, evidence relating to the negative impact that ongoing seizures have on brain development has led to calls for consideration of surgery as a treatment option at an earlier age (under 5 years) [4]. However, when examining the activity for pediatric epilepsy surgery in England against international benchmarks, less than half the numbers of procedures are performed each year that would be considered beneficial to this population [4]. While it is unclear exactly why UK referral rates for pediatric epilepsy surgery are low in

comparison with those of other countries, possible explanations might include attitudinal differences towards surgical intervention in children, funding differences, or differences in clinical practice [5].

Despite justification of surgical treatment for children with uncontrolled epilepsy in terms of medical and psychosocial burden, there may also be risks attached, for example, impairments to memory or thinking skills [6]. Thus, in cases where surgery is a viable option, families face difficult treatment decisions. The shared decision-making model used in pediatric healthcare proposes that decisions regarding treatment are shared between a team of health professionals, parents, and patients (where appropriate). How these decisions are arrived at is less clear.

From a parent perspective, research identifies several factors influencing treatment decision-making including parents' emotional responses, balancing the child's interests with their own, information from and trust in professionals, uncertainty regarding outcomes, and pressures from people or time [7]. Limited research has specifically

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explored parental decision-making in relation to pediatric epilepsy surgery. A recent systematic review [8] identified nine studies examining patient perceptions of epilepsy surgery, of which, only two related to parents' views [1,2]. A further study has since reported the perspective of parents of children who have undergone epilepsy surgery [9]. These papers suggest that parental decision-making is influenced by the patient's age, parental knowledge of the condition, and their treatment perceptions. Moreover, given the variability in each child's decision-making capabilities, parents can struggle to know when and how to include their child [10].

From a clinical perspective, each designated Children's Epilepsy Surgery Service (CESS) in England has a clinical pathway that encompasses a specialist multidisciplinary healthcare team (MDT). Teams are constituted according to national guidance [4]. Key members include surgeons, neurologists, and neuropsychologists and the therapies. A range of neuroradiological investigations and neurophysiological findings are considered, as well as the clinical presentation of the child/young person. Treatment options are discussed within this context, including the potential risks and benefits of surgery. Multidisciplinary healthcare team decisions are then shared with the family and a plan agreed.

The few studies that have explored professionals' views regarding epilepsy surgery [3,11,12] report variable attitudes, indicating an underlying uncertainty or ambivalence towards this treatment [11]. Barriers to epilepsy surgery referral include insufficient knowledge about the procedure and outcomes and the lack of clarity regarding the concept of refractory epilepsy and drug resistance. Such shortfalls have led to delays in referring patients for surgical intervention and overextension of suboptimal pharmacological treatments [11]. While contributing valuable insights, these studies do not consider *how* MDTs agree to propose a child for epilepsy surgery. Research-examining influences on MDT decision-making within the context of other health services reveal that professional expertise, government health policy, and familiarity with the patient are key factors in shaping treatment decision-making [13,14].

Against a backdrop of recommendations for increasing access to and uptake of epilepsy surgery in those children for whom surgical intervention is an option and would be of benefit [4], it is imperative that we improve understanding on how parents and professionals make decisions regarding pediatric epilepsy surgery, in order to be able to address their decisional support needs.

2. Aim

The aim of this study was to explore how parents and health professionals make decisions regarding pediatric epilepsy surgery.

2.1. Objectives

The objectives of this study were the following:

- to identify factors that influence the process of decision-making regarding pediatric epilepsy surgery from the perspective of parents and professionals and
- to identify the support needs of those considering surgery as a treatment option for a child with medically intractable epilepsy.

3. Method

3.1. Design

As the aim was to explore, in depth, the processes of decision-making from the perspectives of those making the decisions, the study employed a qualitative methodology using semi-structured interviews and nonparticipant observations. A favorable review was obtained

from an NHS Research Ethics Committee prior to commencement of the study (REC Ref: 15/WM/0123).

3.2. Setting

The study was undertaken at a UK specialist children's hospital which hosts one of four national centers in England, commissioned to provide a Children's Epilepsy Surgery Service (CESS).

3.3. Sample

Purposive sampling was used to generate a diverse sample of parents who had put their child forward for epilepsy surgery and healthcare professionals who made up the CESS multidisciplinary healthcare team.

3.4. Recruitment

Parents were identified and recruited through a nurse specialist, who introduced them to the study by providing an invitation letter and information leaflet. Interested parents were then invited to contact the research team to discuss their participation and schedule a time for interview. Access to MDT meetings and identification of health professionals were facilitated by one of the study investigators (SK) who was also a member of the pediatric epilepsy surgery MDT. Potential participants were recruited for interview via email invitation and information sheet.

3.5. Data collection

3.5.1. Observations

A member of the research team (RB) attended three MDT meetings over a two-month period to observe how the process of decision-making was carried out. Detailed field notes were made using a data collection tool developed in accordance with best practice guidelines [15]. This focused on the process of team decision-making, including how MDT members interacted and arrived at a consensus agreement, what function or role each MDT member played, and what their contributions were. Informed consent was obtained prior to data collection.

3.5.2. Interviews

Parents and health professionals participated in individual interviews which were digitally audio-recorded. To promote inclusivity, a choice of interview methods was offered (e.g., face-to-face, telephone, Skype) at times/locations of the participant's choice (e.g., home, hospital). Interviews were guided by a semi-structured schedule of open questions based on concepts identified from the literature and, for professionals, on observations of the MDT meetings. Parent interviews explored how they experienced decision-making regarding their child's epilepsy surgery, motivations and beliefs that influenced their decisions, and resources they found helpful or would be helpful for others. Health professional interviews explored their experience of deciding that a child was eligible for surgery, their role in this process, and views on how decision-making could be improved. Interviews were facilitated by a member of the research team (SA, RB) and lasted approximately 1 h.

3.6. Data analysis

Data were transcribed verbatim, anonymized and analyzed using an inductive thematic approach. Thematic analysis is a flexible, systematic, and transparent method that serves to highlight similarities and differences across the data set and facilitates the production of rich and interpretive yet data-driven themes [16]. Analysis involved identifying and reporting patterns within the data through a process of familiarization and coding before generating, defining, and naming themes. Data were

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