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Patient, parent and carer perspectives surrounding expedited paediatric epilepsy surgery

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ABSTRACT

Objective: Most paediatric epilepsies with MRI visible lesions do not respond to antiseizure pharmacotherapy. Such medication resistance, which often takes years to become formally defined, is commonly required for surgical candidacy. Expedited surgical referral at lesional epilepsy diagnosis may result in better seizure, cognitive and developmental prognoses. This study explored the views of patients, parents and carers regarding epilepsy surgery, treatment priorities, and participation in a proposed expedited surgery trial.

Methods: 205 patients, parents and carers (61% UK-based, 26% North American) responded to electronic surveys from February to May 2022. Participants were recruited through social media sites, epilepsy charities and societies. Categorical choice and free-text questions were used to investigate participant perspectives, and Pearson's chi-squared test was utilised to detect meaningful differences amongst respondent subgroups.

Results: Almost 90% of respondents who had experienced epilepsy surgery (either themselves or their child) reported seizure cessation or reduction. Postoperative outcome measures prioritised most frequently were seizure freedom (66%), quality of life (47%), seizure severity (30%), seizure frequency (28%) and independence (27%). Most participants support expedited surgery in suitable patients (65%), with just over half (51%) willing to participate in the proposed trial. Many participants (37%) were undecided, often due to fears surrounding neurosurgery. Subgroup perspectives were broadly similar, with more parents and caregivers favouring expedited surgery compared to patients ($p = .016$) and more UK-based participants willing to take part in an expedited surgery trial compared to those from North America ($p = .01$).

Conclusions: Patients, parents and carers are open to considering expedited surgery for lesional epilepsies and would support a trial exploring this approach. Priorities from treatment were largely similar between participant subgroups, with seizure, quality of life and neuropsychological outcomes ranked highly. Accounting for these preferences will facilitate the delivery of a trial that is patient- and caregiver-focused, enhancing feasibility, satisfaction and benefit for prospective participants.

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1. Introduction

Up to 40% of children with epilepsy have drug-resistant epilepsy (DRE) (Kwan et al., 2010; Laxer et al., 2014), commonly regarded as lack of seizure control despite trialling at least two antiseizure medications (ASMs). DRE is associated with significant comorbidities and can have deleterious effects on cognitive development and quality of life (Altwaijri et al., 2020; Berg et al., 2012; Puka and Smith, 2021). DRE is almost inevitable among lesional epilepsies such as focal cortical dysplasias (FCDs) and long-term epilepsy-associated tumours (LEATs), with 81% and 94%of such patients being shown to progress to DRE, respectively (Faramand et al., 2018; Zvi et al., 2022). Current practice regarding referral of children for epilepsy surgery in children with a radiologically detectable lesion necessitates the presence of DRE (Hale et al., 2022). This wait for formal definition of medication refractoriness often contributes to long delays between seizure onset and surgery, with a recent study spanning almost 20 years showing a median wait time of just over five years (Eriksson et al., 2023). Such lengthy intervals prior to surgery have been linked to poorer seizure freedom and cognitive outcomes (Braun and Cross, 2018; Dwivedi et al., 2017; Lamberink et al., 2020; Wiebe and Jetté, 2012; Wiebe et al., 2001), likely due to the damaging impact of prolonged seizures on brain development and functional plasticity (Thomas et al., 2008).

Expedited surgical intervention for children with epilepsy may lead to significant improvements in cognition, development and quality of life. This may be multifactorial in nature, stemming from a shorter duration of epileptic activity whilst the brain is developing (Cossu et al., 2008; Duchowny et al., 1998; Steinbok et al., 2009; Wyllie et al., 1998), a reduction in the possible harmful side effects of ASMs on cognitive function and behaviour (Braun, 2020; Helmstaedter et al., 2020) as well as improved psychosocial wellbeing and reduced impacts on the families of patients (Braun, 2020; Kayyali et al., 2013; Mikati et al., 2010). Undergoing surgery as a child is associated with greater benefits for seizure prognosis compared to those operated on as adults, as demonstrated by Pelliccia et al. (2017). Surgery also results in significantly higher rates of seizure freedom compared to treatment with ASMs alone. A randomised controlled trial (RCT) on paediatric focal epilepsy by Dwivedi et al. (2017) showed that freedom from seizures was achieved in 77% of children undergoing surgery, but only 7% of those treated solely with ASMs. Epilepsy surgery, especially in children, has a good safety profile, and potentially beneficial economic profile relating to long-term pharmacotherapy, regular clinic appointments and hospital admissions (Faramand et al., 2018; Picot et al., 2016; Widjaja et al., 2011; Zvi et al., 2022).

These findings indicate that consideration of epilepsy surgery should occur sooner and prior to the establishment of drug resistance. This is particularly applicable to FCDs and LEATs, with their high likelihood of progression to DRE (Faramand et al., 2018; Zvi et al., 2022). However, building a robust evidence base for this is challenging and requires careful thought and incorporation of the opinions of a wide range of stakeholders, including, most importantly, people with epilepsy and their carers (Hale et al., 2022). This will hopefully pave the way for a future national, multi-centre trial referred to as the ExCEL (Expedited Children's Epilepsy Surgery for Lesions) study. Such a potential clinical trial would compare the efficacy of expedited (prior to drug resistance) epilepsy surgery to standard care. In preparation for this, we set out to explore the views of patients, parents and carers regarding epilepsy surgery to gauge their support for such a trial and to ascertain what outcome measures matter most to them from epilepsy treatment. Both the perspectives of those with and without prior experience of epilepsy surgery were investigated. Involving potential study participants in this way helps to design trials which produce meaningful and impactful results for patients and caregivers, and to increase their overall satisfaction with their care (Crocker et al., 2018; Schilling et al., 2019).

2. Methods

2.1. Participants

Between 10th February and 30th May 2022, an anonymous survey was circulated online addressing persons with epilepsy as well as their parents and carers. Inclusion criteria for the study were broad, encompassing individuals with epilepsy, or parents or carers of a person with epilepsy, of all ages. Recruitment was conducted internationally through a number of epilepsy charities and patient/parent/carer support groups including Young Epilepsy (UK), Epilepsy Action (UK), Epilepsy Research UK (UK) and the Pediatric Epilepsy Surgery Alliance (USA). Each charity devised their own strategy to promote the study, including e-mail bulletins and sharing it via social media to their followers (Twitter and Facebook). The size of the mailing lists for each group were unknown, although to provide a sense of reach, the most recent active membership number of Epilepsy Action (UK) was 8288 members (British Epilepsy Association, 2023).

2.2. The survey

The survey consisted of 40 questions split across three main sections. The first part comprised eight categorical questions concerning demographic characteristics, information about the nature of the epilepsy experienced (by the participant, their child or the child they care for) and the impact of any previous surgery on seizure outcomes. The extent of this impact was not quantified.The second section consisted of 26 questions asking about outcome measures following epilepsy surgery. Respondents were given a series of 21 different outcomes (five seizure-related, two neurological, three cognitive, seven longer-term and four other) and asked to assess their importance on a Likert scale from 1–5 (not important-most important). They were then asked to select their top three most important outcomes from a list comprising the same 21 outcomes. Two free text questions enabled respondents to elaborate on the outcome measure list and to identify any domains they felt were not covered. The final section of the survey provided background information to participants about FCD/LEAT drug resistance, the potential benefits of timely surgery and a proposed international randomised controlled trial (ExCEL) on expedited surgery at diagnosis for such patients. This was followed by six questions asking whether participants would consider expedited surgery if they or their child/child they care for were diagnosed with an FCD/LEAT, whether they would consider participation in an expedited surgery trial, and to elaborate further on any reasoning, or provide more information or feedback on the study. A full copy of the survey is available in Supplementary Material 1.

2.3. Statistical analysis

Descriptive statistics were used for summarising and presenting the data. No analytical modifications were required after excluding ineligible participants, as there were no missing responses from survey participants across any of the categorical questions. Views regarding outcome measures and expedited surgery were compared between different subgroups. These comparisons were drawn between patients and parents/carers, and after grouping the cohort by age, geography, preference for expedited surgery, treatment outcome priority and whether or not they have undergone surgery. Pearson's chi-squared tests were used to assess for statistically significant differences ($p < .05$) between the responses of these subgroups. SPSS Statistics version 28 (IBM, Armonk, NY, USA) and Microsoft Excel Version 16 (Microsoft Corp, Redmond, Washington, USA) were used to carry out the statistical analyses.

3. Results

206 responses were obtained. One participant was ineligible and

excluded, since they did not specify whether they were a patient, parent or carer. This made the final study cohort 205 participants.

3.1. Demographics

Table 1 reports the demographics of the participant cohort. Parents/carers of a person that had not undergone epilepsy surgery comprised the largest subgroup at 42%, followed by parents/carers of a person who has had surgery (24%), persons with epilepsy who have not had surgery (20%) and finally those who have had epilepsy surgery themselves (14%). The largest age group of patients represented was the 0–20 years old age category (61%), with the vast majority of responses for this young age group coming from parents/carers (93%). The majority of respondents were from the UK (61%) and North America (26%).

Of the 77 (38%) responses from those who have undergone surgery or are parents/carers of children that underwent surgery, the most common procedures were resections and disconnections (each comprising 39%), with far fewer having undergone procedures such as vagus nerve stimulation (8%) or laser therapy (5%). The majority of responses were very favourable regarding the impact of such surgeries, with just under half of respondents (49%) reporting complete cessation of seizures following surgery, and an additional 40% saying that seizure frequency and/or severity had reduced postoperatively. Only 6% said that there had been no effect on seizures, with fewer still reporting seizure worsening following surgery (4%).

3.2. Outcomes following surgery

When asked to rate the 21 different postoperative outcomes on a scale from 1–5 (not important-most important), quality of life, seizure freedom and language/communication showed the highest median scores, with overall, a favouring of seizure-related outcomes (Fig. 1).

The outcomes with the highest proportion of 'most important' ratings were quality of life (77%), being seizure free (75%), language and communication (66%), frequency of seizures (64%) and mood and mental health (62%). Similar findings were noted when participants ranked their top three most important outcomes. As shown in Fig. 2, being seizure free was selected most often (n = 136, 66%), followed by quality of life (n = 96, 47%), severity of seizures (n = 62, 30%), frequency of seizures (n = 57, 28%) and independence (n = 56, 27%).

A variety of free text comments were made by participants regarding the outcome measures listed. Several participants emphasised their highly correlated nature, with one participant commenting: "without seizure control there is no independence, no quality of life, etc.". Another emphasised that "mood and mental health are inextricably linked to epilepsy and medication". Respondents frequently reiterated the importance of improving their quality of life and having fewer limitations, one parent stating their wish for their child "being able to be an active and contributing member of society in whichever field they choose". Seizure freedom was regarded as paramount by many, one comment noting: "I think almost any 'side effect' from surgery is worth it in exchange for seizure freedom. Quality of life without seizures despite new disabilities caused by surgery is still so much better than life with daily seizures". Some participants described additional outcome measures of importance not covered by the survey, including self-esteem and self-confidence, vision and its impact on reading and driving, associated neurological symptoms (e.g. headaches) and behavioural difficulties.

When drawing comparisons by most important outcome following surgery, there were no statistically significant differences between the views of patients and parents/carers and those who have and have not undergone surgery (both $p > .05$). More younger respondents (aged ≤20 years old, or parents/carers of patients in this age group) rated being seizure free (93% vs 84%, $p = .041$), seizure severity (88% vs 78%, $p = .046$), language and communication (83% vs 66%, $p = .005$), mobility (81% vs 68%, $p = .031$) and quality of life (95% vs 86%, $p = .023$) more or most important compared to older participants (>20 years old). No outcomes displaying greater preference by the older participant cohort reached statistical significance (all $p > .05$). Notably, there were no statistically significant differences in outcome preferences by age group noted when comparing patients and parents/carers separately (all $p > .05$).

Responses of participants were compared by most important

Table 1
Respondent demographic information. Demographic variable 1 relates to the survey respondent. Demographic variables 2–8 relate to the person with epilepsy. N = 205.

Demographic Variable	Response	N (%)
1. Which of these best describes you?	I am a person with epilepsy and I have had epilepsy surgery	28 (14%)
	I am a person with epilepsy and I have not had epilepsy surgery	41 (20%)
	I am a parent/carer of a person with epilepsy and they have had epilepsy surgery	49 (24%)
	I am a parent/carer of a person with epilepsy and they have not had epilepsy surgery	87 (42%)
2. How old are they?	0-20 years old	125 (61%)
	20-40 years old	55 (27%)
	40-60 years old	19 (9%)
	60-80 years old	6 (3%)
3. Where do they live?	North America	54 (26%)
	UK	125 (61%)
	Europe (except UK)	14 (7%)
	Asia	3 (2%)
	Africa	1 (1%)
	South America	2 (1%)
	Australia	6 (3%)
4. Do they have an intellectual disability?	Yes	90 (44%)
	No	115 (56%)
5. What type of seizures do they have?	Focal-onset	84 (41%)
	Generalised-onset	23 (11%)
	Both	65 (32%)
	Not sure	33 (16%)
6. At the moment, how often do they have seizures?	Every day	47 (23%)
	Every week	38 (19%)
	Every month	24 (12%)
	Less than once a month	26 (13%)
	They haven't had a seizure in the last 6 months	70 (34%)
7. If they have had surgery, what type of surgery have they had?	Resection	30 (39%)
	Disconnection	30 (39%)
	Laser therapy	4 (5%)
	Vagus nerve stimulation	6 (8%)
	Multiple (e.g. both resection and disconnection)	6 (8%)
	Other	1 (1%)
8. If they have had surgery, what impact has it had on their seizures?	Stopped seizures completely	38 (49%)
	Reduced seizure frequency and/or severity	31 (40%)
	Not affected seizures	5 (6%)
	Worsened seizures	3 (4%)

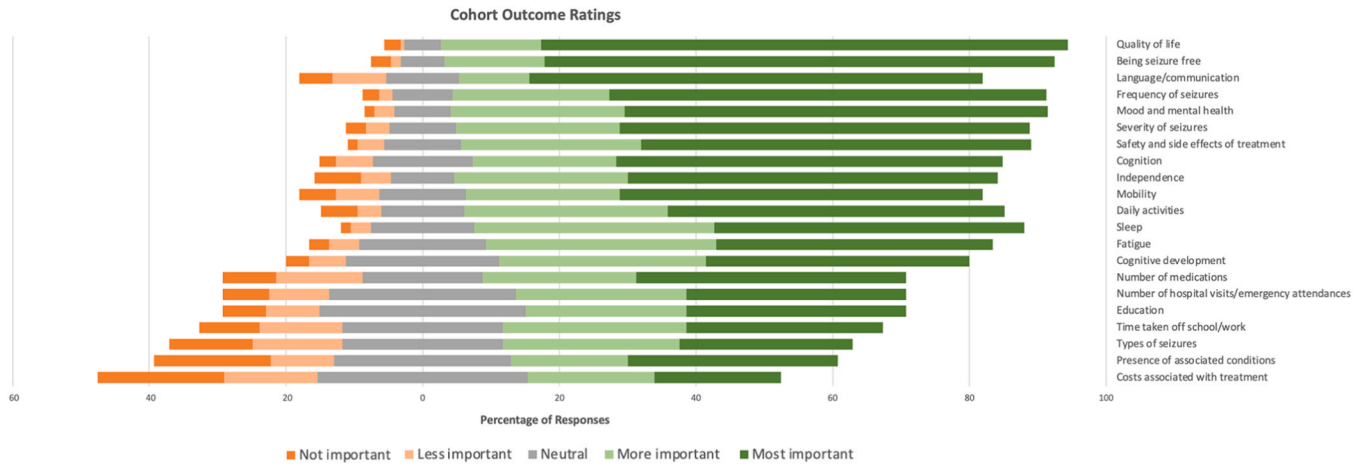

Fig. 1. Outcome ratings following epilepsy surgery, ordered by median rating. Respondents ranked the various outcome domains on a scale from 1–5 (not important-most important). Neutral ratings are centred around zero along the x-axis. N = 205.

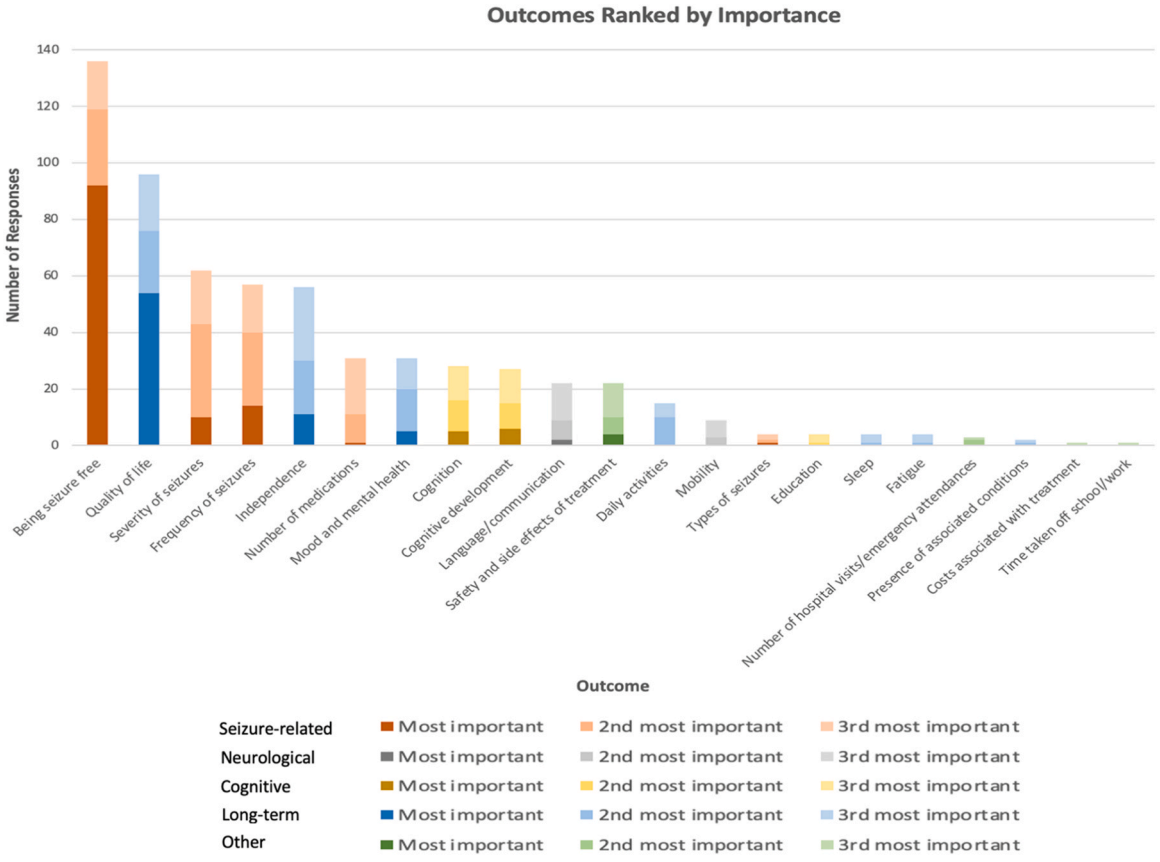

Fig. 2. Outcomes ranked by how often they were chosen by participants as part of their three most important measures following epilepsy surgery. Outcomes are colour-coded by group. Of the 21 outcome domains presented to participants, five were seizure-related, two neurological, three cognitive, seven longer-term and four grouped as other. N = 205.

postoperative outcome, by dividing the cohort into two groups – those that selected being seizure free, and all other top choices. There were no statistically significant differences when comparing the views of these two groups regarding expedited surgery ($p = .429$) or willingness to consider taking part in an expedited surgery trial ($p = .481$).

3.3. Expedited surgery trial support

When asked about whether they would support a trial of expedited presurgical evaluation and surgery, 65% of respondents would consider early surgery at the time of an FCD or LEAT diagnosis, with 35% wishing to try pharmacological treatment first. Slightly more than half (51%) say that they would consider participation in an expedited surgery trial, with a large proportion (37%) being undecided. The views of those who would and would not consider expedited surgery did not differ significantly regarding top outcomes post-surgery ($p > .05$).

Free text explanations given for wishing to participate in an expedited surgery trial included parents wishing to benefit their child and

improve their quality of life in any way possible, to share personal experiences to help others, "spread awareness" and improve medical knowledge and current clinical practice. Several responses described general feelings of frustration and lack of support as an incentive to take part. Reasons for uncertainty regarding participation included a desire for more information regarding risks, and whether the respondent or their child would be ineligible (due to factors such as age, geographical location, previous surgery and lack of structural abnormality on imaging). Further information requested by participants included more details surrounding surgery such as benefits and risks, success rates, long-term effectiveness and duration of recovery from procedures.

A greater proportion of parents/carers would consider expedited surgery at FCD/LEAT diagnosis compared to patients (71% versus 54%, $p = .016$), although no statistically significant difference was found between the groups regarding participation in a surgical trial ($p = .472$). Similarly, more participants who have undergone surgery (or care for a child who has) are in favour of considering expedited surgery compared to those who have not (74% versus 59%, $p = .033$). They were also more willing to participate in the proposed trial (56% compared to 48%), although this difference was not statistically significant ($p = .059$).

No difference in preferences for expedited surgery was shown between those living in the UK and North America ($p = .704$), although a greater proportion of UK participants would consider participation in an expedited surgery trial (60% vs 37%, $p = .01$). Views regarding outcomes following surgery were largely similar between UK and North American respondents, although a greater proportion of UK-based patients and parents/carers rated fatigue (80% vs 63%, $p = .016$) and time taken off school or work (60% vs 43%, $p = .032$) more or most important compared to North American respondents.

With regards to considering expedited surgery at FCD/LEAT diagnosis, many free text comments from those in favour of this option cited the importance of timely management to limit the deleterious effects of seizures and ineffective medications during development. One response noted: "we have seen the damages caused by frequent seizures on a developing brain up close", another commenting: "because I have witnessed DRE first hand and would do anything to avoid it if possible". Another participant stated: "I feel that surgery at this stage, provided it is safe, would save the often-traumatic effects of continuing to have the seizures while the right combination of medication is found. This would allow for an improved quality of life and less long-term impact on mental health". Another emphasised their support, stating: "I've already had brain surgery and [I'm] living seizure free". Among those who were unsure or against expedited surgery, many explanations cited general fear of surgery on the brain and its associated risks. Several responses described uncertainty due to the invasive nature of neurosurgery, that procedures are "not always successful" and that they would prefer to "try all other options first" before opting for surgery as a "last resort". One parent emphasised the difficulty weighing up the risks and benefits of surgery in particular cases: "It depends on the surgery. My child's proposed surgery would leave her visually impaired (TPO disconnection or hemispherectomy). It's a huge price for seizure freedom and a difficult decision to make when seizures are controlled [by ASMs]."

4. Discussion

There seems to be a scientific rationale to explore whether selected children with lesional epilepsies such as FCDs and LEATs may benefit from surgery before the establishment of formal DRE. The majority of such epilepsies (81–94%) progress to drug resistance, and thus surgical candidacy (Aronica et al., 2001; Faramand et al., 2018; Zvi et al., 2022). Fewer than 10% of surgically managed FCD patients have been shown to respond to a trial of a third ASM, in comparison to the 50–75% who exhibit seizure freedom postoperatively (Chang et al., 2011; Choi and Kim, 2019; Hader et al., 2004; Rowland et al., 2012; Zvi et al., 2022). This is corroborated by data from Garcia-Fernandez et al. (2011), showing improved seizure and cognitive outcomes among those operated on prior to their seizures becoming drug-resistant. These findings are potentially accounted for by a reduction in the number of seizures the developing brain experiences, and provision of a greater window of opportunity to regain cognitive function whilst neural plasticity is high (Vendrame et al., 2009). Gains in intelligence quotient (IQ) measures following resective surgery have also been observed secondary to ASM weaning in seizure-free individuals, relieving the associated cognitive and behavioural side effects (Boshuisen et al., 2015; Skirrow et al., 2011).

Resective surgery has low complication rates (Faramand et al., 2018; Hale et al., 2022; Zvi et al., 2022) and can be cost-effective when compared to prolonged pharmacotherapy (Picot et al., 2016; Widjaja et al., 2011). In instances where the risk of developing DRE is high, delaying surgery to enable the standard trial of two ASMs may result in suboptimal seizure and cognitive outcomes for patients and increased healthcare resource utilisation. Whilst in many instances, testing two or more ASMs can be feasibly conducted across a 12–18 month period post epilepsy diagnosis, the argument proposed is that outcomes may be improved further by avoiding this delay. As outlined in the recent review by Hale and colleagues (2022), it is hypothesised that performing surgical resection in suitable candidates soon after seizure onset, when plasticity is high in the young, developing brain, may safeguard against the detrimental cognitive impacts of prolonged epileptic activity and ASM exposure, improve seizure outcomes and have potential health-economic benefits. This has beneficial implications across multiple domains spanning seizure control, cognitive development and overall quality of life (Hatoum et al., 2022). This study explored the views of people with epilepsy, their parents and carers with respect to surgery, the outcomes that matter most to them and their stances surrounding an expedited surgery trial.

Among the respondents who had undergone surgery previously (or had/cared for a child who underwent surgery), a majority (89%) reported favourable outcomes postoperatively (89%) – 49% becoming completely seizure free and 40% reporting a reduction in seizure frequency and/or severity. This proportion is similar to the 50–75% seizure freedom rates following epilepsy surgery reported in the literature (Chang et al., 2011; Choi and Kim, 2019; Hader et al., 2004; Radhakrishnan et al., 2016; Rowland et al., 2012; Zvi et al., 2022). Only a very small proportion (4%) stated that their seizures had gotten worse following surgery.

Variety was noted in the treatment outcomes prioritised most highly by participants, with seizure symptoms, quality of life, and cognitive domains ranking highly. Seizure freedom and quality of life were selected most frequently, with many participants elaborating on their crucial nature and their willingness to accept some trade-offs (for example, additional medication side effects) in exchange for gains in these domains. Additionally, many survey respondents believe that the outcomes listed are highly interlinked, explaining that good seizure control facilitates improvements in many other avenues (such as quality of life, independence, mood, cognition etc.). This crucial interplay aligns with the findings of Smith et al. (2023), who showed that improvements in health-related quality of life for patients treated surgically compared to those managed with medical therapy alone were mainly due to gaining better seizure control postoperatively. Accounting for these preferences when designing the future ExCEL trial will aid with recruitment and feasibility as well as ensure that the study is patient- and carer-centred. For example, the primary outcome measure of the trial could be seizure freedom after a specified period following randomisation into expedited surgery and standard care arms. Secondary outcome measures can be guided by the study findings and include factors such as number of ASMs, quality of life, neuropsychological and developmental outcomes.

Views were largely similar when comparing cohort subgroups. No meaningful differences in outcome preferences were noted when comparing patients and parents/carers, those who have undergone surgery and those who have not, those for and against expedited surgery,

younger and older age groups, and UK and North American respondents.

There was majority support for considering expedited surgery at FCD/LEAT diagnosis (65%). Over half (51%) would consider participating in an expedited surgery trial, although a large proportion of respondents were undecided (37%). Many of those who were against or unsure about expedited surgery elaborated that they were fearful of brain surgery and its risks. This is in keeping with the findings of Steinbrenner et al. (2023), who reported that 59% of their DRE patient cohort opted not to undergo surgery due to fears about operating on the brain, and a further 18% due to worries concerning potential complications. Other studies have similarly found that fear regarding neurosurgical procedures is a widely held barrier among patients (Anderson et al., 2013; Choi et al., 2008; Hrazdil et al., 2013; Steinbrenner et al., 2019). Despite the favourable data on postoperative seizure outcomes, many participants still regard surgical intervention as a last resort which should only be trialled after all other management options. Conducting the ExCEL trial should help to challenge these oppositional views and provide much needed data on the efficacy of expedited surgery in appropriate patients. Recruitment for the trial may require some modification to increase feasibility and account for the substantial proportion of survey respondents voicing uncertainty or unwillingness to take part. For example, all those eligible may be offered expedited surgery, in the form of a single-arm trial, with those who decline being recruited to the control arm of the study. The survey findings also emphasise the importance of providing all available information on treatment outcomes and potential risks to patients and their caregivers, to enable prospective study participants to make informed decisions with regards to their treatment.

When comparing stances of cohort subgroups regarding expedited surgery specifically, more parents/carers were in favour of this management option compared to patients (71% vs 54%, $p = .016$). Additionally, more UK-based participants would consider participating in an expedited surgery trial compared to their North American counterparts (60% vs 37%, $p = .01$), which warrants consideration of a clinical trial specific to the UK. These differing perspectives may reflect variable exposure to treatment options among patients and their caregivers, and between those undergoing treatment in publicly funded and private healthcare systems.

It is important to acknowledge the ethical, psychological and clinical challenges which face clinicians, patients, parents and carers when making decisions surrounding paediatric epilepsy surgery. As with all invasive surgical trials, patients, parents and carers considering enrolment into a study investigating the timing of epilepsy surgery would need to be carefully informed of the benefits and risks of surgery as well as prolonged treatment with ASMs, with reference to the best available research data. This would facilitate the conducting of a rigorous clinical trial which offers children with epilepsy the opportunity to become seizure free sooner than current standard practice, lowering the number of seizures their brains are exposed to and facilitating the weaning of ASMs. This has the potential for cognitive, behavioural and quality of life benefits to be realised.

Importantly, study design and informed consent discussions need to be influenced by the patient/carer perspective, which is why data such as these are vital in shaping research studies. The current data make a case that about half of patients/carers may not choose to participate in a randomised study and therefore, warrant a reconsideration of study design. The content of the informed consent discussions of any study in this space would need to be refined with further patient/carer input in the form of focus groups.

This survey explored the views of a large, heterogeneous cohort of patients, parents, and caregivers. Participants exhibited diversity with regards to demographics, epilepsy characteristics and treatment exposure, with a range of ages and geographical regions sampled as well as a variety of epilepsy illness courses and management approaches accounted for. Despite this, several study limitations must be acknowledged. Information concerning those who opted not to take part in the survey was not collated. The significant respondent heterogeneity is reflected by only 34% of participants having undergone epilepsy surgery or having cared for someone who has. It can be argued that their responses may be more informed compared to the larger majority with no direct exposure to epilepsy surgery – although interestingly, views between those who have and have not had surgery were similar in this study, with those who have undergone surgery being more supportive of early surgery compared to those who have not (74% versus 59%, $p = .033$). Although the anonymous participants were provided with some background information on DRE and expedited surgery (Supplementary Material 1), it is not known whether they had exposure before the survey to information regarding the merits and risks of surgery, as well as the potential detrimental effects of prolonged seizure activity on the brain and development. Age ranges were collected (for example, 0–20 years old) as opposed to specific ages. It is not known, therefore, whether parents or carers are responsible for children, youths or young adults with epilepsy. The impact of caring for these age subcategories on early epilepsy perspectives was thus not ascertained. Four large epilepsy charities and support groups were approached – three based in the UK and one in the USA – to facilitate collation of patient/parent/carer views internationally. The mailing list sizes of these organisations disseminating the survey were not known, however, and thus response rates could not be calculated. The majority of responses (87%) were obtained from the UK and North America, which may not be entirely reflective of the views of participants from developing countries across the globe. These North American perspectives were gathered primarily from one US site, the breadth of which could have been expanded by dissemination via other large nationwide chapters in the US and Canada. Additionally, survey participants were recruited largely via social media, epilepsy charities and societies. This may introduce respondent bias, as those individuals affiliated with such organisations may be more willing to complete such a survey. It is difficult to ascertain whether such views are entirely representative of those of the wider paediatric epilepsy population. An additional limitation to acknowledge concerns the greater support for expedited surgery among those with prior experience of surgery compared to those without. Their favourable views may have been biased by their own exposure to successful surgical outcomes.

5. Conclusions

This study highlights that a majority of people with epilepsy, their parents and caregivers are generally in favour of expedited epilepsy surgery for suitable candidates, and many would support a trial assessing the benefits of such an intervention. Concordance was displayed with regards to the treatment outcomes that these respondent subgroups value most highly. Seizure symptoms, quality of life and cognitive domains ranked highly, with many participants emphasising their highly correlated nature. Understanding these shared priorities will facilitate future trial design which values the preferences of those undergoing epilepsy surgery, their relatives and carers, with the ultimate goal of delivering beneficial and worthwhile findings for such individuals.

Ethics approval statement

The procedures performed in this study involving human participant data were in accordance with the ethical standards of the institution and national research committee and with the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Compliance with ethical standards

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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Contributions

AC, IBZ, RB and MJ conceived of the study idea and contributed to study design. Data was collected by AC and IBZ. OS interpreted the data and drafted the original manuscript. TB, JHC and MT supervised the study. All authors reviewed and revised the manuscript draft.

Conflicts of interest disclosure

None of the authors has any conflict of interest to disclose.

Patient consent statement

Consent was implied through completion of the questionnaire.

Conference presentations

Data partly presented as poster presentation at ILAE International Epilepsy Congress, Dublin, Ireland, September 2023.

CRediT authorship contribution statement

Tisdall Martin: Conceptualization, Supervision, Writing – original draft, Writing – review & editing. **Batchelor Rachel:** Conceptualization, Methodology, Writing – review & editing. **Jones Monika:** Conceptualization, Investigation, Methodology, Writing – review & editing. **Baldeweg Torsten:** Conceptualization, Resources, Writing – review & editing. **Cross J Helen:** Conceptualization, Writing – review & editing. **Zvi Ido Ben:** Conceptualization, Writing – review & editing. **Salim Omar:** Formal analysis, Methodology, Writing – original draft, Writing – review & editing. **Chari Aswin:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Supervision, Writing – original draft, Writing – review & editing.

Data Availability

The dataset is available from the corresponding author(s) on reasonable request.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.eplepsyres.2024.107309.

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