# Child and parent experiences of childhood epilepsy surgery and adjustment to life following surgery: A qualitative study

Abstract

*Purpose:* Surgical procedures are increasingly used as a treatment option for paediatric patients with refractory epilepsy as seizure relief is often assumed to be associated with positive psychosocial and quality of life outcomes. This study aimed to explore children’s and parents’ experiences of epilepsy surgery and associated psychosocial outcomes.

*Methods:* Semi-structured interviews were conducted with parents and their children aged between 7 and 17 years old, who had undergone epilepsy surgery within the previous six months to three years. Analysis of interview data was interpretive and iterative, using the constant comparison approach, to develop a rich understanding of family experiences throughout the surgery journey.

*Results:* Interviews were conducted with 16 participants, including seven children (aged 8-15 years) and their nine parents. Epilepsy had significant impact on quality of life for children and parents. Concerns about long term wellbeing, risks to safety and hope for a ‘normal’ life contributed to the decision to pursue surgery. All participants described improvements in seizure control, alongside improved psychological wellbeing, quality of life, social relationships and family functioning. However, children and their parents experienced difficulties adjusting to a new post-surgical identity and ‘missing’ aspects of their pre-surgical life with epilepsy.

*Conclusions:* Epilepsy surgery had a positive impact on participants’ lives, but families described difficulties in adjusting to postsurgical changes and leading a ‘normal’ life. Our findings suggest that families would benefit from additional information and clinical support leading up to epilepsy surgery to help them prepare for and adjust to a life without epilepsy.

*Keywords:* childhood epilepsy surgery; adjustment; family perspectives; qualitative research

# Introduction

Individuals with epilepsy report high levels of perceived stigma, which is associated with poorer psychosocial functioning, increased risk of mental health problems and reduced participation in social activities [2]. Surgical treatment may be considered due to the detrimental impact of repeated seizure activity on neurological development. Earlier surgery in children may provide a longer period of neurological plasticity and improved cognitive outcomes [3].

The clinical efficacy of treatments for epilepsy is primarily measured in terms of seizure status or seizure freedom. A typical assumption associated with the surgical approach is that the reduction or alleviation of seizures following epilepsy surgery will improve the psychological development of children. Several studies [4, 5, 6, 7] have challenged the notion that seizure relief or reduction is consistently associated with improved quality of life and psychosocial outcomes in children and adults, yet findings from these studies are heterogeneous and lack insight into patients’ perspectives.

This study aimed to explore children’s and parents’ perspectives on the journey prior to and following surgical treatment, with a focus on the emotional experiences of children and their parents throughout the surgery journey.

# 2. Methods

***2.1 Study design***

We used a qualitative design, involving face to face semi-structured interviews with parents and children following paediatric epilepsy surgery. Both children and parents were interviewed to develop a systemic understanding of the experiences of epilepsy surgery in childhood on the family unit.

The research team, members of the Liverpool Experts by Experience (LExE) group and an adolescent research advisory group developed and reviewed study materials, including an interview topic guide. Topics included: experiences of epilepsy and treatments prior to surgery, impact of epilepsy on daily life, and experiences of post-operative outcomes, including psychological, behavioural, emotional and social outcomes and family dynamics (See full parent and child topic guides Supplementary data Appendix A).

Ethical approval for the study was granted by the West Midlands – Black Country Research Ethics Committee (REC Reference: 17/WM/0159) and NHS Health Research Authority.

*2.2. Recruitment*

Parents and their children who had undergone resective epilepsy surgery were recruited from two hospitals in a joint children’s epilepsy surgery service (CESS). Children and young people (referred to as children in this paper for brevity) met inclusion criteria for the study if they were aged 7 to 17 years old and had undergone epilepsy surgery within the six months to three years prior to recruitment. Families were excluded from the study if they could not speak English.

A member of CESS used hospital records to identify eligible patients. JO and VG approached identified families at outpatient epilepsy clinic appointments and provided information about the study. Participant information packs, including a cover letter, participant information sheet (PIS) for parents and an age-appropriate PIS for children, were posted to identified families who did not attend outpatient epilepsy clinics during the recruitment period. Families contacted JO (female, clinical psychologist, BSc (Hons) and DClinPsy (Doctorate in Clinical Psychology)) to arrange a face-to-face interview at their home address, local health centre or CESS centre. Consent and assent to participate in an interview was sought by JO prior to interview who had no previous relationship with participants but an interest in the topic area.

*2.3 Procedure*

All adult participants were interviewed alone, with the exception of one family in which both parents wished to be interviewed together. Younger participants were provided with the choice of being interviewed alone or in the presence of a parent.

Interviews were semi-structured with open-ended questions and unstructured prompts to facilitate participant led, free-flowing conversation [9]. An ice breaker activity was used to assist children’s engagement and help JO subjectively gauge level of understanding and communication needs to tailor the questioning style. At the end of each interview, participants were reminded of the support networks, local services and national organisations detailed in the PIS.

## *2.3 Analysis*

Interviews were digitally audio-recorded and transcribed verbatim by a professional transcription company (Voicescript Ltd). Thematic analysis was used as a method of identifying, analysing and reporting themes within and across the data to explore participants’ understanding of their emotional experiences and enable a rich description of the data [9, 13]. Analysis was broadly interpretive, exploring children’s and parents’ views, meanings and accounts of childhood epilepsy surgery, and iterative by referring back and forth between the developing analysis and new data [10, 11, 13, 14]. Themes were inductively derived from the data and the constant comparison approach was utilised with the aim of achieving catalytic validity, whereby findings can help to inform future clinical practice and research [11].

We used QSR NVivo Version 10 software and field notes to help organise interview transcripts and to develop a coding framework. Visual thematic maps were developed to enable JO to conceptualise broader themes and relationships between different levels of themes (see Figure 1) [9]. JO led analysis and KW checked and second coded 30% of the transcripts, alongside discussions of the developing analysis, to ensure a fit between data extracts and the coding framework and to enhance the validity of the analytic process. All participant names are pseudonyms to ensure they are not identifiable.

## 3. Results

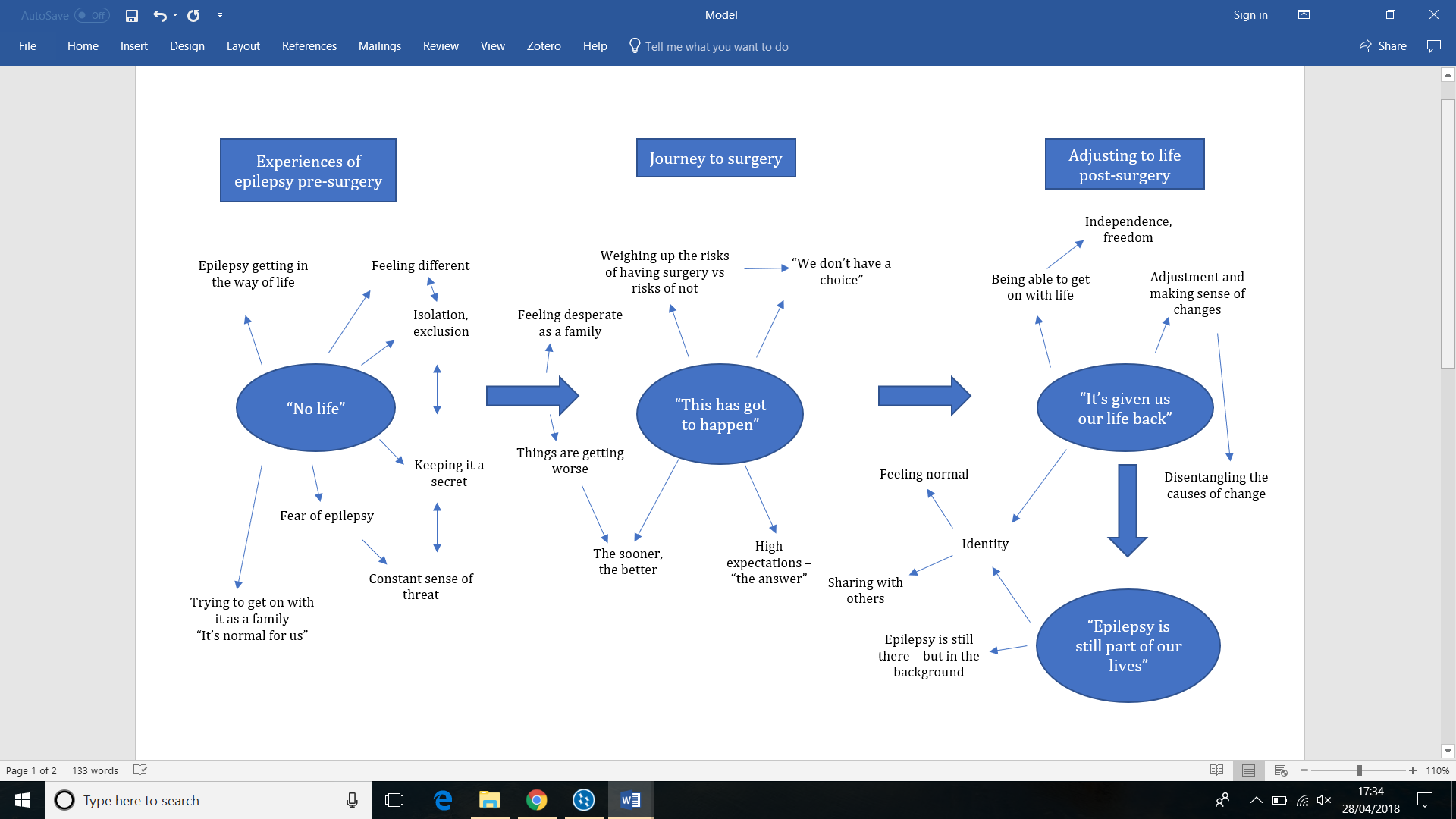
Forty-two families were invited to participate and nine families registered interest. One family withdrew from the study due to deteriorating medical status. Data saturation was reached when sixteen participants had taken part in an interview from eight families (sevenchildren, nine parents). Therefore, no further invitations to participate were sent. Two parents of one family took part in a joint interview and one parent was the only family member interviewed as their child could not communicate verbally. Two children opted to have their parent present during their interview. Interviews ranged between 25 and 75 minutes in length. Demographic information is shown in Table 1.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Participants from family** | **Child’s age** | **Age at epilepsy diagnosis** | **Age at surgery** | **Time since surgery** | **Surgical outcome** | **Interview setting** |
| Lucy and mother | 13 years | 6 years | 11 years | 18 months | Seizure reduction | Home |
| Jack and mother | 13 years | 8 years | 10 years | 28 months | Seizure freedom | Local hospital |
| Charlie, mother and father | 12 years | 8 months | 9 years | 30 months | Seizure freedom | Home |
| Alex and mother | 10 years | 8 years | 8 years | 21 months | Seizure freedom | Health centre |
| Jessica and mother | 10 years | 3 months | 9 years | 14 months | Seizure reduction | CESS centre |
| Matthew - mother only | 17 years | 9 months | 15 years | 20 months | Seizure reduction | Home |
| Andrew and mother | 8 years | 5 years | 5 years | 25 months | Seizure freedom | School and home |
| Kayleigh and mother | 15 years | 9 years | 14 years | 14 months | Seizure freedom | Home |

*Table 1. Demographic information*

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As shown in Figure 1, the conceptual model consists of themes which can be characterised by three distinct categories: experiences of epilepsy before surgery, journey to surgery and adjusting to life after surgery.



*Figure 1. Conceptual model of themes*

***3.1 Experiences before surgery***

*3.1.1 Impact of epilepsy on quality of life*

Participant descriptions highlighted the significant impact that epilepsy had upon on the child’s and family’s lives prior to epilepsy surgery. Worries about seizures and the associated risks led to constant fatigue for some: “you’re tired yourself before you even go out the door” (Charlie – mother). In some cases, experiences of epilepsy impacted on their lives to such a degree that parents referred to children as “not having a life” (Charlie - mother).

Before surgery […] She would wake up having a seizure, I would dress her while she had a seizure, every time she seemed to move she had a seizure, any noise she had a seizure. (Lucy - mother)

Children described a range of emotional experiences associated with their pre-surgical experiences of epilepsy, including: “scared” (Jack; Lucy) “nervous” (Andrew) and “angry and fed up” (Charlie). Seizures were described as “dangerous” (Jack - mother) and parents voiced their concerns about the possibility of choking, falling, head injury, dying during sleep and road traffic accidents.

Having epilepsy led children to feel different and excluded from their peers, and correspondingly there was a sense of being treated differently: “I never got to go out and see friends much because I was always having seizures” (Lucy). This sense of exclusion impacted on the family as a whole, with siblings being unable to attend clubs or invite friends to their house, and parents feeling that they “couldn’t join in with what other families were doing” (Lucy – mother). A common theme was parental concern that siblings had less time or attention: as “the focus was on him [child with epilepsy] a lot of the time” (Andrew – mother).

*3.1.2 Child mood and behavioural difficulties- stress, secrecy and shame*

Before surgery children’s mood and behavioural difficulties were a common, causing fear and stress which negatively impacted upon family relationships: *“If there was something there, she would get it, she would want to attack you with it”.* (Jessica – mother) Many described how increased supervision led to a change in their parenting role, negatively impacting on the relationship they or their other children had with their child: “I was just his carer really and didn’t have a relationship with him” (Jack - mother).

Difficulties appeared to be exacerbated by a perceived a lack of understanding from others, which appeared to be tied to a notion of epilepsy being an invisible condition, as seizures commonly occurred behind closed doors: “At the beginning, it was just generally at home, they didn’t understand, they didn’t get it. (Jessica – mother). Most participants described finding it difficult to talk to others about epilepsy, with several reporting that they limited the information they shared, or withholding the diagnosis altogether. “Gosh, we didn’t tell anybody. We were ashamed”. (Jack – mother)

*3.1.3 It’s normal for us*

Despite the considerable impact epilepsy had on the whole family unit, there was a common theme of “carrying on with things” (Jessica - mother) and an aim to “just keep going” (Lucy – mother). This appeared to be related to a sense that the child, and their family, had always had epilepsy in their lives and had not known any different. This was illustrated by both parents and children expressing that epilepsy is “normal to me” (Alex), “it’s the way we have got used to, it’s the only way we know” (Charlie – mother) and “it’s just something you’ve got to do, part of life” (Alex – mother). This was echoed by children, with one participant describing her experiences of epilepsy as “quite scary […] but I’m used to it” (Kayleigh).

***3.2 The journey to epilepsy surgery***

*3.2.1 Decision making – Is there a choice?*

When asked what informed the decision-making process when considering the option of surgery as a treatment for epilepsy, parents discussed how the perceived risks to their child’s safety, as well as the safety of others, were key factors.

Even with all the risks, it wasn’t going to be much worse than having a little girl that was unconscious all the time anyway. (Lucy – mother)

Parents described a process of weighing up the pros and cons based on the information provided by the medical team, which led to the decision to pursue surgery. Many perceived that surgery was the only hope “a simple decision” (Alex – mother), they were “in no doubt” (Lucy – mother) and that they “had no choice” (Jessica mother) as the health and wellbeing of their child would deteriorate or become more serious if surgery was not pursued. There was also a sense of ‘not knowing’ outcomes if surgery was not pursued.

We felt we’ve got to do this because where is she going to end up if we don’t?

(Jessica – mother)

*3.2.2. Child distress during pre-surgical discussions*

In four families, children were involved in discussions about surgery as a treatment option. Children found discussions and the information they were provided frightening, and in some cases “torture” (Jack) to think about. They explained how they “felt really scared” (Charlie) at hospital appointments as “all they ever talked about was the brain and about if they picked the wrong thing up then I would probably die or something could go wrong with me” (Lucy). One child recalled considering how she may be the one of the low percentage of children for whom surgery didn’t work, or who died during surgery:

They were saying it would probably work and there was like low chance, but I was thinking, there is that little chance though, isn’t there? I could be that 2%. (Kayleigh).

Others described mixed feelings about the prospect of surgery: “I wanted the thing in my brain to get out, but I’m like a bit nervous and don’t want to have it” (Andrew). Several expressed a preference for a prompt pathway to surgery once the decision was made “to get it over with, because the wait was “stressful” (Lucy).

***3.3 Experiences following epilepsy surgery***

*3.3.1 Life changing*

Following surgery, all children experienced seizure reduction, or seizure freedom, and all participants described positive changes in psychological wellbeing and functioning, including changes child behaviour, mood or cognitive skills. Children described feeling “more happy”, “more relaxed” (Charlie) and “less tired” (Kayleigh), whilst parents described their children as being “calmer” and “a lot more confident” (Andrew – mother). For some parents, the change was dramatic, as their child had “transformed himself” (Jack – mother), whilst others were described as feeling “more sad-ish and emotional” in the period after surgery but such emotions had “got a bit better” over time (Andrew). All parents stated there child was more independent and had made progress in school. Families had the freedom to pursue activities, which had previously been difficult:

Life is fabulous now, it’s really great. We go on holiday, we don’t have to worry” (Jack – mother).

However, negative behavioural changes were observed by a few parents, including apathy and an unwillingness to engage: “some days he won’t get out of bed, like last weekend, he just stayed in bed all weekend” (Jack - mother).

*3.3.2 Sense of normalcy and adjustment of identity after surgery*

Several children and parents reflected that their pre-surgery expectations had been met, with children reflecting that they felt “normal” after surgery (Lucy; Charlie; Alex). Despite positive changes to overall wellbeing and quality of life, children and parents also spoke of how they struggled to adjust to post-surgical changes and had ongoing worries about the recurrence or deterioration of seizure status. A sense of normalcy was difficult for some children as it had meant a loss of their previous identify: “I just feel different, not me. Like I’ve lost a bit, a part that was me […] that made me a bit more different to everyone else” (Kayleigh).

For both parents and children, there was a sense that epilepsy continued to be a significant part of their lives, even if seizure freedom was achieved from surgery. One child still “feeling scared” of epilepsy pre-operatively in case it “has not gone away completely” after surgery (Charlie). Several children described a sense of ‘missing’ epilepsy following a successful post-surgical outcome, for both children and their parents. Having seizures had been normal, throughout children’s lives, so suddenly losing this aspect of life was unexpectedly difficult. Participant accounts suggested that upon reflection, recovery was not as they had anticipated pre-surgery. It was felt that a greater awareness of potential changes besides seizure control prior to surgery would have been helpful for children and their families in developing realistic expectations and preparing for post-surgical adjustment.

They just tell you medical stuff about it, the recovery, not that it’ll be different…They just tell you about having no seizures […] They don’t tell you what it’s actually going to be like.

(Kayleigh)

*3.3.3 Letting go of the caring role*

The majority of parents could leave their child unsupervised “at home now, whereas [they] couldn’t even leave the room before” (Jack – mother). This led to a sense of the family feeling more able to be “relaxed a lot more” (Jessica – mother). Whilst positive changes were also observed in sibling relationships who no longer had to perform caring roles: “he gets on so much better with his brother” (Jack – mother).

*3.3.4 Support, coping strategies and connecting with others*

The importance of local support from hospital clinicians was emphasised, such as having a named epilepsy nurse to contact after surgery if necessary: “knowing that I could call them at any point in time” (Alex – mother). Some suggested that their family would have liked access to counselling, play/music therapy or similar for their child and siblings after surgery, or to meet other families with similar experiences in a group setting:

I think it would help to meet other children post-surgery and pre-surgery, that she could be part of almost an epilepsy community, but I don’t know any (Lucy – mother).

Parents highlighted a desire to have contact with the surgical team in the post-surgical adjustment period, yet this had not occurred: “Maybe, even if someone had just rung to say, is he doing alright, we’re just checking up… as a reassurance” (Andrew – mother). Several participants reflected on the benefits of being able to speak with other children and parents who had already been through the process of surgery, through face to face meetings instigated by parents, or through online social media groups: “I’ve spoken to someone who had the same operation, same thing done […] that was helpful” (Kayleigh); “From the support point of view, I think [support via social media] has been invaluable” (Andrew – mother).

# 4. Discussion

This study provides unique insight into families’ experiences throughout their epilepsy surgery journey and includes children’s perspectives, which are often neglected in the literature. Our findings highlight the many difficulties families experienced in coping with intractable epilepsy before surgery. Epilepsy had a negative effect impact on children’s health, psychological and social functioning, as well as on the whole family unit, impacting on parental stress, parenting styles, sibling relationships and quality of life. Families found it difficult to talk to others about epilepsy due to feeling judged or misunderstood, reinforced by the fact that epilepsy is an ‘invisible’ condition, with the effects often being unseen to others outside the immediate family. Due to seizures and associated risks deteriorating, the decision to pursue neurosurgery was seen as ‘an easy decision’, but had to reconcile this decision with worries and concerns they had about the surgical procedure and potential outcomes.

Participant accounts suggested that children’s psychological wellbeing and quality of life had generally improved after surgery and their pre-surgical expectations were met. However, difficulties in adjusting to postoperative changes were described, even when the child achieved seizure freedom. Social support, shared experiences with others in similar circumstances and ‘carrying on as normal’ helped to support a positive journey throughout the process.

Child and parent reflections on the pre and post-surgical lives highlight the complexity and range of experiences and challenges families can encounter in the journey before and even after epilepsy surgery. Although all participants spoke of positive surgery outcomes, there were also continuing and emergent difficult experiences associated with adjustment to post-operative change. This finding is in line with previous quantitative studies that have reported how [6, 8] patients’ satisfaction with surgery and quality of life ratings can be both positive and negative across a range of domains. Mihara and colleagues [6] noted that improvements or deterioration in satisfaction and self-reported or family-reported quality of life does not appear to be dependent on seizure reduction or freedom, but instead was associated with post-operative psychosocial difficulties.

Our study illustrates how children struggled to establish a different identity after surgery, compared to their pre-surgery sense of self. This led to a period of adjustment for families post-surgery. The implicit association of starting to ‘lead a normal life’ after successful surgery appeared to lead to a sense of apathy for some. Missing epilepsy reflected a sense of wanting to return to a life that the child and family had always known. In the adult epilepsy surgery literature, ‘the burden of normality’ [15] is frequently referenced to refer to the potential challenges patients face in the transition from refractory epilepsy to seizure freedom. This conceptual framework proposes that adults can struggle to cope with a successful seizure outcome after surgery because living with epilepsy hinders the development of daily living skills and functioning. Our findings can suggest ‘the burden of normality’ is experienced by children and their families following epilepsy surgery and are aligned with Wilson and colleagues’ position that postoperative psychosocial outcomes can be difficult to predict and that adaptation to psychological changes after surgery may be difficult for children and adolescents, in a similar way to adults [16, 17, 18, 19, 20].

Our findings suggest that paediatric epilepsy services should consider the wider psychosocial impact of epilepsy and epilepsy surgery throughout the clinical pathway. For most families, difficulties in adjusting to post-surgical changes, regardless of seizure outcome, had not been anticipated and resulted in a significant period of adjustment for the whole family. To help increase awareness it is recommended that in the early stages of the surgery pathway medical teams provide parents with information about the potential impact of surgery on a range of aspects of the child’s and parents’ lives. This information may be helpful in exploring and managing expectations and hopes for surgery, as well as for life after surgery. Pre-surgical discussions may also benefit from emphasising that positive seizure outcomes may not automatically equate to positive overall outcomes for children and their families, and similarly, ongoing seizures may not represent ‘unsuccessful’ surgery as quality of life may be significantly improved. This information may help prepare families for adjustment to post-operative changes and subsequent potential shift in family roles and relationships, activity, mood, behaviour and aspects of self-identity.

Finally, most parents and children reflected on the importance of shared experiences, both in seeking support from other families who have experienced the pathway to surgery, and also in fulfilling the desire to give their time to support other families. In addition to specialist information and post-surgery support, epilepsy surgery services should consider providing families with information of third sector agencies or online parent support groups to facilitate access to wider support networks.

***4.2 Strengths and limitations***

To our knowledge, there has been only one previous published study which has qualitatively explored family perspectives on epilepsy surgery [8], however, the study focused on identifying adolescents’ post-surgical outcomes within quality of life domains. The present study extends previous research by providing insight into family perspectives across the surgery journey, from pre-surgical experiences of epilepsy for the child and the family unit, decision-making processes and experiences of preparing for surgery, and post-surgical adjustment and support for the child, their parents and siblings.

Facilitating a semi-structured participant-led interview ensured that the most salient and meaningful aspects of the journey for each participant were explored [21]. To help ensure the quality of research conduct, guidelines for conducting and reporting qualitative research were used as a framework of reference throughout the study [22]. Multiple perspectives also provided a systemic understanding of the impact of childhood epilepsy and treatment on the family unit, culminating in a proposed contextual understanding of this process for families. However, parents tended to provide more detailed accounts and descriptions of their experiences. Children’s accounts were less verbose and experiences were often summarised by a word or a phrase. The different levels of descriptions are reflected in the data extracts used to illustrate the findings. Accounts of pre-surgery life and decisions about surgery were reflective and reliant on recall. Such retrospective accounts may therefore have affected their recall of pre-surgery expectations, particularly given post-surgery outcomes were generally positive for most participating families. Future studies would benefit from taking a prospective approach by conducting research with children and their families before surgery and at a specified time point after surgery, to explore pre- and post-expectations, quality of life and factors which mediate perceived ‘success’.

Although 42 families were approached to participate, only 8 families (16 participants) responded to the study invitation and the reason for low response was unknown. However, additional families were not approached as data saturation point was reached (no new information was being identified in the analysis). A strength of the study lies in both children and parents taking part in interviews. The present sample was varied with representation from male and female child participants, with ages ranging from eight to 15 years old. Of nine parents who participated, only one father opted to take part in an interview. Participants were recruited from one joint CESS service in the North West of England. It is therefore not known whether their views and experiences are similar to families accessing different epilepsy surgery services in the United Kingdom. Further research may benefit from involving families who have accessed other epilepsy surgery services across England.

**5. Conclusion**

Epilepsy surgery can have a positive impact on children’s psychological, social and behavioural functioning. However, both children and parents experienced unanticipated difficulties in making sense of changes following epilepsy surgery and described a period of adjustment in becoming accustomed to changes in behaviour, family roles and self-identity.

Our findings suggest the need for epilepsy services and healthcare professionals to recognise the importance of working together with families to discuss and consider the impact of epilepsy and surgery issues, at all stages of the surgery pathway. There is also a need for increased support for families, particularly in relation to sharing their experiences with others to help facilitate adjustment and help children to consolidate altered aspects of their self-identity in life after surgery.

**Ethical approval:** Ethical approval for the study was granted by the West Midlands – Black Country Research Ethics Committee (REC Reference: 17/WM/0159) and NHS Health Research Authority.

**Declaration of Competing Interest.** The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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**Supplementary data:** Appendix A

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## References

[1] Suris JC, Michaud PA, Viner R. The adolescent with a chronic condition. Part I: developmental issues. Arch Dis Child 2004;89(10):938-42.

[2] Taylor J, Baker GA, Jacoby A. Levels of epilepsy stigma in an incident population and associated factors. Epilepsy Behav 2011;21(3):255-60.

[3] Ravindra VM, Sweney MT, Bollo RJ. Recent developments in the surgical management of paediatric epilepsy. Arch Dis Child 2017; 102(8):760-6.

[4] [13] Jobst BC, Cascino GD. Resective epilepsy surgery for drug-resistant focal epilepsy: A review. JAMA. 2015;313(3):285–93.

[5] Meyer FB, Marsh WR, Laws ER, Sharbrough FW. Temporal lobectomy in children with epilepsy. J Neurosurg. 1986;64(3):371-6.

[6] Mihara T, Inoue Y, Watanabe Y, Matsuda K, Tottori T, Hiyoshi T, et al. Improvement of quality‐of-life following resective surgery for temporal lobe epilepsy: Results of patient and family assessments. Psychiatry Clin Neurosci 1994;48(2):221-9.

[7] Vickrey BG, Rausch R, Engel Jr J, Ary CM, Visscher BR, Hays RD, et al. Outcomes in 248 patients who had diagnostic evaluations for epilepsy surgery. The Lancet. 1995;346(8988):1445-9.

[8] Elliott IM, Lach L, Smith ML. Adolescent and maternal perspectives of quality of life and neuropsychological status following epilepsy surgery. Epilepsy Behav 2000;1:406-17.

[9] Braun V, Clarke V. Successful qualitative research: A practical guide for beginners. 2013. London: Sage.

[10] Glaser BG. The constant comparative method of qualitative analysis. Soc probl 1965;12(4):436-45.

[11] Stiles WB. Evaluating qualitative research. Evid Based Ment Health. 1999;2(4):99-101.

[12] Terry G, Hayfield N, Clarke V, Braun V. Thematic analysis. In: Willig C, Rogers WS, editors. The SAGE handbook of qualitative research in psychology. London: Sage; 2017, p. 17-37.

[13] Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3(2):77-101.

[14] Tebes JK. Community science, philosophy of science, and the practice of research. Am J Community Psychol 2005;35(3-4):213-30.

[15] Wilson S, Bladin P, Saling M. The “burden of normality”: Concepts of adjustment after surgery for seizures. J Neurol Neurosurg Psychiatry 2001;70(5):649-56.

[16] Kemp S, Garlovsky J, Reynders H, Caswell H, Baker G, Shah E. Predicting the psychosocial outcome of epilepsy surgery: A longitudinal perspective on the ‘burden of normality’. Epilepsy Behav 2016;60:149-52.

[17] Derry PA, Wiebe S. Psychological adjustment to success and to failure following epilepsy surgery. Can J Neurol Sci 2000;27(S1):116-20.

[18] Dupont S, Tanguy ML, Clemenceau S, Adam C, Hazemann P, Baulac M. Long‐term prognosis and psychosocial outcomes after surgery for MTLE. Epilepsia 2006;47(12):2115-24.

[19] Schachter SC. Paradoxical phenomena in epilepsy. In: Kapur N, editor. The paradoxical brain. Cambridge: Cambridge University Press; 2011, p. 204-20.

[20] Wilson SJ, Bladin PF, Saling MM. Paradoxical results in the cure of chronic illness: The “burden of normality” as exemplified following seizure surgery. Epilepsy Behav 2004;5(1):13-21.

[21] Achenbach TM, McConaughy SH, Howell CT. Child/adolescent behavioral and emotional problems: Implications of cross-informant correlations for situational specificity. Psychol Bull 1987;101(2):213.

[22] Walsh D, Downe S. Appraising the quality of qualitative research. Midwifery 2006;22(2):108-9.

## Supplementary file Appendix A

**Interview topic guides**

*Interview topic guide for parents*

*1. DEMOGRAPHICS*

* 1. **At what age did {*your child*} receive a diagnosis of epilepsy?**
  2. **What type of epilepsy was diagnosed?**
  3. **Did {*your child*} receive other treatments prior to epilepsy surgery?** Prompt: explore other treatments and side effects.
  4. **When did {*your child*} undergo epilepsy surgery? At what age, and time period since operation?**
  5. **Approximately, how often was {*your child*} experiencing seizures prior to the operation?**
  6. **Approximately, how often does {*your child*} experience seizures after the operation?**
  7. **Does {*your child*} continue to receive treatment for epilepsy?** Prompt: explore current treatments and side effects.
  8. **What type of schooling does/did {*your child*} receive?** Prompt: mainstream or special needs schooling, learning support in classroom.

*2:* ***BEFORE SURGERY:*** *PARENTS’ EXPERIENCES OF THEIR CHILD’S EPILEPSY*

* 1. **Could you describe in what way you feel your child’s life was affected by epilepsy before surgery?**
  2. **Could you describe how your child’s diagnosis of epilepsy impacted on their behaviour and activities?**
  3. **Did {*your child*}’s epilepsy have an impact on school before their operation?** Prompt: explore whether child had to take time off school - how often, how long and perceived impact - impact of epilepsy on schoolwork, such as concentration, energy levels.
  4. **Could you tell me about your child’s social activities and friendship groups prior to their operation?**
  5. **Could you tell me whether you felt that epilepsy impacted on your child’s emotions and mood and, if so, in what way?**
  6. **Could you describe your child’s relationship with epilepsy before their surgery?** Prompt: explore impact on how they think about themselves, sense of identity, expectations from self and others.
  7. **Could you describe in what way *your* life has been affected by your child’s experiences of epilepsy?**
  8. **In what way did {*your child*}’s epilepsy affect your family situation?** Prompt: explore effects on family dynamics.

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*3: PARENTS’ EXPERIENCES OF EPILEPSY SURGERY*

* 1. **Could you tell me about when surgery was first discussed as an option for treatment for your child?**
  2. **What information did you receive about epilepsy surgery?**
  3. **How did you feel about your child undergoing this procedure?**
  4. **Was anyone outside of the immediate family aware of {*your child*}’s diagnosis of epilepsy and referral for surgery?** Prompt: explore whether parent shared with wider family, friends, teachers, and why/why not.
  5. **Could you tell me what helped you in making the decision about epilepsy surgery?** Prompt: social support, professional support.
  6. **What did you hope the surgery would do for your child?** Prompt: explore factors related to health, social, behavioural and psychological outcomes.
  7. **Is there anything that you think would have been helpful in supporting you and your family before the operation?**

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*4: PARENTS’ EXPERIENCES OF POST-OPERATIVE ADJUSTMENT*

**4.1 Following surgery, how long did it take {*your child*} to recover?** Prompt: explore what the parent/family was looking for as a sign that the child was recovering from surgery.

**4.2 When did {*your child*} start to go back to their normal activities?** Prompt: return to school, hobbies/activities.

**4.3 Thinking about the time since your child started to return to their normal activities following the operation to the present day, can you describe whether you feel the surgery met your expectations?** Prompt: explore factors which the parent feels influence the success or failure of surgery.

**4.4 Can you tell me if there have been any changes in your child’s health since the surgery?**

**4.5 Could you describe whether there have been any changes in your child’s behaviour and activities since they have recovered from the operation?**

**4.6 Could you tell me about your child’s social activities and friendship groups following their operation?**

**4.7 Could you tell me if you feel there have been any changes in your child’s emotions and mood since the operation and, if so, in what way?**

**4.8 Could you describe your child’s relationship with epilepsy following surgery?** Prompt: impact on how they think about themselves, sense of identity, expectations from self and others.

**4.9 Can you describe the support you and/or your child have received in adjusting after surgery?**

Prompt: explore what the parent thinks would have beenhelpful in supporting the family after the operation.

**4.10 Do you feel that your family situation has changed in any way since the operation?** Prompt: explore effects on family dynamics

**4.11 Could you tell me if any changes following surgery have affected your relationship with your child? If yes, in what way?**

**4.11 Have any changes since the surgery affected your own life in any way? If yes, could you tell me a bit more about that?**

**4.12 What are your hopes for your child for the future?** Prompt: explore hopes for family.

*Thank for time.*

*Interview topic guide for children*

*1. DEMOGRAPHICS AND ICE BREAKER QUESTIONS*

**1.1 How old are you?**

**1.2 What school year are you in?**

**1.3 Do you have any brothers or sisters?**

**1.4 What is your favourite thing to do? *(Prompt: hobbies, sports, favourite film)***

**1.5 What would you like to be when you grow up?**

*Additional ice breaker exercise here, if necessary.*

*2: CHILDREN’S EXPERIENCES OF EPILEPSY*

**Is it ok if I ask you a few questions about your experience of having epilepsy?**

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**2.1 Could you tell me what it feels like to have epilepsy?**

**2.2 Has epilepsy ever affected school?** Prompt: explore taking time off school - how often, how long and child’s thoughts about this – impact on schoolwork, concentration, energy levels*.*

**2.3 What types of treatments for epilepsy did you have before surgery?** Prompt: Did they help, any side effects?

**2.4 Have you ever had any worries related to having epilepsy?**

**2.5 Have you ever felt different to other children/young people who don’t have epilepsy?** Prompt: in what way, perception/treatment.

**2.6 Have you ever felt that epilepsy gets in the way of activities, such as going out with friends, school trips and hobbies?**

**2.7 Did you ever feel that epilepsy affected your social life before your operation, such as meeting new people and making friends?**

**2.8 How did epilepsy affect your emotions and mood before your operation, such as feeling happy, sad, grumpy, confused?**

**2.9 Can you tell me what you think about having epilepsy and how it makes you think about yourself?** Prompt: explore self-perception, sense of identity, expectations from self and others.

**2.10 Do you feel that, before your operation, epilepsy affected your family situation or your relationships with your family members?** Prompt: explore effects on family dynamics.

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*3: CHILDREN’S EXPERIENCES OF EPILEPSY SURGERY*

* 1. **How did you feel about having an (operation/epilepsy surgery)?** *Use term child uses throughout.*
  2. **Could you tell me what information you got about your (operation/epilepsy surgery)?**
  3. **Other than your (parents/caregivers), did you tell anyone about your (operation/surgery)? How do you think other people felt about the (operation/surgery)?** Prompt: parents, other family members.
  4. **What were your hopes for the surgery?**
  5. **Could you tell me what it was like going into hospital for the (operation/surgery)?**
  6. **Could you tell me how it felt when you woke up after the operation?**

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*4: CHILDREN’S EXPERIENCES OF POST-OPERATIVE ADJUSTMENT*

**4.1 How long did it take you to recover from the operation?** Prompt: explore what the child was looking for as a sign of recovery from surgery.

**4.2 When did you start going back to your normal activities?** Prompt: school, going out with friends, hobbies.

**4.3 Could you tell me any good things about having the operation?**

**4.4 Could you tell me any bad things about having the operation?**

**4.5 Did your hopes about the operation come true?**

**4.6 Could you tell me about the support you got after your operation?**

**4.7 Would it have been helpful to have any more support or information?**

**4.8 Has your experience of epilepsy changed since the operation?** Prompt: seizure frequency, ongoing treatments.

**4.9 Have there been any changes in your day-to-day life and activities since you have recovered from the operation?** Prompt: hobbies, going out with friends.

**4.10 Can you tell me whether there have been any changes in your social life since your operation?** Prompt: how child feels about making friends, meeting new people and spending time with friendship groups.

**4.11 Could you tell me what you think about epilepsy now you have had the surgery?** Prompt: impact on how they think about themselves, sense of identity, expectations from self and others.

**4.12 Have you noticed any changes in your relationships with your parents and family?**

**4.13 Have you noticed any changes in your mood since the operation?** Prompt: feeling happy, sad, grumpy, confused?

**4.14 Have you noticed any changes in how relaxed you feel since the operation?**

**4.15 What has been most helpful for you in coping before and after your operation?**

**4.16 Now you have had the operation, what are your hopes for the future?**

*Thank for time.*

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