APPENDIX A: Search Strategy

EMBASE (Searched January 1, 1999, to August 19, 2021)

Set	Concept	Search statement
1	Infantile/ Pediatric Epilepsies	'benign childhood epilepsy'/exp OR 'childhood absence epilepsy'/exp OR 'severe myoclonic epilepsy in infancy'/exp OR (dravet* NEXT/1 (disease OR syndrome))
2	0-3 Age Group and Epilepsy	[infant]/lim OR [newborn]/lim OR newborn/exp OR [preschool]/lim OR 'preschool child'/exp OR toddler/exp OR (babies OR baby OR child*:ti OR infan* OR neonat* OR newborn* OR nicu OR paediatric* OR pediatric* OR preschool* OR toddler* OR 'very young'):ab,ti,kw OR ('younger than' OR under OR below) NEAR/3 (3 OR three) OR (3 OR three) NEAR/3 ('or below' OR 'or under' OR 'or younger') AND ('epilepsy'/exp OR 'epileptic patient'/exp OR epilep*:ti)
3	Infantile Spasms/ Neonatal Seizures (not requiring epilepsy)	'infantile spasm'/exp OR (((infan* OR neonat* OR newborn*) NEAR/2 (convuls* OR seizure* OR spasm*)):ab,ti,kw)
4	Other Seizures (not requiring Epilepsy)	([infant]/lim OR [newborn]/lim OR 'newborn'/exp OR babies:ab,ti,kw OR baby:ab,ti,kw OR infan*:ab,ti,kw OR neonat*:ab,ti,kw OR newborn*:ab,ti,kw OR nicu:ab,ti,kw) AND ('febrile convulsion'/exp OR 'seizure'/exp OR convuls*:ab,ti,kw OR spasm*:ab,ti,kw OR seizure*:ab,ti,kw)
5	Pharmacologic/ Vitamin Treatment	acetazolamide OR acth OR 'adrenocorticotropic hormone' OR benzodiazepine* OR brivaracetam OR bromide OR cannabidiol OR carbamazepine OR clobazam OR clonazepam OR clorazepate OR corticotropin OR divalproex OR eslicarbazepine OR ethosuximide OR everolimus OR felbamate OR fenfluramine OR folate OR 'folic acid' OR frisium OR gabapentin OR lacosamide OR lamotrigine OR levetiracetam OR liposteroid OR lorazepam OR mesuximide OR methsuximide OR onfi OR oxcarbazepine OR perampanel OR phenobarbital OR phenytoin OR prednisone OR pregabalin OR primidone OR pyridoxine OR 'pyridoxal 5 phosphate' OR rufinamide OR sabril OR stiripentol OR thiopental OR thiopentone OR tiagabine OR topiramate OR valproate OR 'valproate semisodium' OR 'valproic acid' OR vigabatrin OR zonisamide
6	Diet Therapy	'ketogenic diet'/de OR (keto* OR ketogenic OR 'low glycemic index' OR 'medium chain triglyceride' OR 'modified atkins' OR 'modified keto' OR 'modified ketogenic'):ab,ti,kw
7	Surgical Procedures	craniotomy/de OR hemispherectomy/de OR 'laser surgery'/de OR lobectomy/de OR 'corpus callosotomy' OR craniotom* OR (disconnect* NEAR/3 (hemispher* OR surg* OR procedure*)) OR hemispherecotom* OR hemispherotom* OR lesionectom* OR lobectom* OR (laser* NEAR/3 (ablat* OR operat* OR procedure* OR surg*)) OR (multilobar NEAR/3 disconnect*) OR (palliat* NEAR/3 operat* OR procedure* OR surg*) OR resect* OR resection OR transect* OR transection* OR 'sublobar resection' OR 'subpial transection'
8	Brain Stimulation	'brain depth stimulation'/de OR 'brain responsive neurostimulator'/de OR 'deep brain stimulator'/de OR 'nerve stimulation'/de OR 'nerve stimulator'/de OR 'vagus nerve stimulation'/de OR ('brain stimulat*' OR 'deep brain stimulat*' OR 'electric brain stimulat*' OR 'external trigeminal nerve stimulat*' OR 'responsive brain stimulat*' OR 'responsive neurostimulat*' OR 'vagus nerve stimulat*' OR stimulation OR stimulator*) OR ((brain OR 'deep brain' OR electric* OR responsive OR 'vagus nerve') NEAR/2 (electrostim* OR stimulat*)) OR neurostim*

9	Harms	anhidrosis/de OR 'adverse event'/de OR 'adverse drug reaction'/de OR 'behavior disorder'/de OR 'cognitive defect'/de OR 'developmental delay'/de OR 'developmental disorder'/de OR dystonia/de OR 'liver injury'/de OR 'loss of appetite'/de OR 'motor dysfunction'/de OR 'organ damage'/de OR 'patient harm'/de OR 'sleep disorder'/de OR sweating/de OR (advers* OR harm* OR 'side effect'):ab,ti,kw OR anhidrosis OR (appetite NEAR/3 (lose OR losing OR loss)) OR ((cognitiv* OR behavior* OR develop* OR motor OR movement OR neurodevelop*) NEAR/3 (effect* OR disorder* OR problem* OR symptom*)) OR ((cognitiv* OR develop* OR neurodevelopment*) NEAR/3 (delay* OR disorder* OR regress*)) OR dystonia OR hypohidrosis OR hypohydrosis OR (liver NEAR/3 (damag* OR injur*)) OR (miss* NEAR/3 milestone*) OR ((eat* OR perspir* OR sweat* OR sleep*) NEAR/3 (disorder* OR inability OR unable))
10	Parental Preferences	parent/de OR (parent* OR mother* OR father*):ab,ti,kw
11	Untreated Disease	'treatment refusal'/de OR ('not treated' OR 'no treatment' OR untreat*):ab,ti,kw OR (declin* OR forgo* OR 'not' OR no OR refus* OR withheld OR withhold*) NEXT/3 (treated OR treatment*)
12	Study Designs/ Publication Types	[english]/lim AND [1999-2020]/py NOT ([animals]/lim NOT [humans]/lim OR abstract:nc OR annual:nc OR 'book'/de OR ((case NEXT/1 (report* OR stud*)):ti) OR 'case report'/de OR 'case study'/de OR conference:nc OR 'conference abstract':it OR 'conference paper'/de OR 'conference paper':it OR 'conference proceeding':pt OR 'conference review':it OR congress:nc OR diagnos*:ti OR 'diagnosis'/mj OR 'diagnostic accuracy'/mj OR 'diagnostic procedures'/mj OR 'diagnostic test'/mj OR 'diagnostic test accuracy study'/mj OR 'differential diagnosis'/mj OR 'editorial'/de OR editorial:it OR 'erratum'/de OR guideline*:ti OR letter:it OR 'note'/de OR note:it OR meeting:nc OR 'practice guideline'/de OR 'review'/exp OR sessions:nc OR 'short survey'/de OR symposium:nc OR animal*:ti OR experimental:ti OR (vitro:ti NOT vivo:ti) OR canine:ti OR dog:ti OR dogs:ti OR mouse:ti OR mice:ti OR rabbit*:ti OR rat:ti OR rats:ti OR rodent*:ti OR sheep:ti OR swine:ti)
13	Combine sets	#1 OR #2 OR #3 OR #4
14	Combine sets (KQ1 Pharmacology)	#13 AND #12 AND #5
15	Combine sets (KQ2 Diet, Surgery, Brain Stimulation)	#13 AND #12 AND (#6 OR #7 OR #8)
16	Combine sets (KQ3 Treatment Harms)	#13 AND #12 AND (#5 OR #6 OR #7 OR #8) AND 9
17	Combine sets (CQ1 Parental Preferences)	#13 AND #12 AND (#5 OR #6 OR #7 OR #8) AND #10
18	Combine sets (CQ2 Untreated/ Uncontrolled Epilepsy)	#11 AND #12 AND #13

19	Combine Sets All KQs	#14 OR #15 OR #16
20	Combine Sets All CQs	#17 OR #18

SocINDEX and Web of Science databases (Searched January 1, 1999, to August 19, 2021)

(epilep* OR convuls* OR seizure* OR spasm*)

AND

(acetazolamide OR acth OR 'adrenocorticotropic hormone' OR benzodiazepine* OR brivaracetam OR bromide OR cannabidiol OR carbamazepine OR clobazam OR clonazepam OR clorazepate OR corticotropin OR divalproex OR eslicarbazepine OR ethosuximide OR everolimus OR felbamate OR fenfluramine OR folate OR 'folic acid' OR frisium OR gabapentin OR lacosamide OR lamotrigine OR levetiracetam OR liposteroid OR lorazepam OR mesuximide OR methsuximide OR onfi OR oxcarbazepine OR perampanel OR phenobarbital OR phenytoin OR prednisone OR pregabalin OR primidone OR pyridoxine OR 'pyridoxal 5 phosphate' OR rufinamide OR sabril OR stiripentol OR thiopental OR thiopentone OR tiagabine OR topiramate OR valproate OR 'valproate semisodium' OR 'valproic acid' OR vigabatrin OR zonisamide OR keto* OR ketogenic OR 'low glycemic index' OR 'medium chain triglyceride' OR 'modified atkins' OR 'modified keto' OR 'modified ketogenic' OR 'corpus callosotomy' OR craniotom* OR (disconnect* AND (hemispher* OR surg* OR procedure*)) OR hemispherecotom* OR hemispherotom* OR lesionectom* OR lobectom* OR (laser* AND (ablat* OR operat* OR procedure* OR surg*)) OR (multilobar AND disconnect*) OR (palliat* AND operat* OR procedure* OR surg*) OR resect* OR resection OR transect* OR transection* OR 'sublobar resection' OR 'subpial transection' OR 'brain stimulat*' OR 'deep brain stimulat*' OR 'electric brain stimulat*' OR 'external trigeminal nerve stimulat*' OR 'responsive brain stimulat*' OR 'responsive neurostimulat*' OR 'vagus nerve stimulat*' OR stimulation OR stimulator*) OR ((brain OR 'deep brain' OR electric* OR responsive OR 'vagus nerve') AND (electrostim* OR stimulat*)) OR neurostim*)

AND

(parent* OR mother* OR father*)

AND

(perception OR factor* OR decision)

CINAHL (Searched January 1, 1999, to August 19, 2021)

Set	Concept	Search statement
1	Childhood Epilepsy	"benign childhood epilepsy" OR "childhood absence epilepsy" OR "severe myoclonic epilepsy in infancy" OR dravet*
2	Epilepsy/ 0-3 Age Group	(babies OR baby OR child* OR infan* OR neonat* OR newborn* OR nicu OR paediatric* OR pediatric* OR preschool* OR toddler* OR "very young" OR "younger than three" OR "younger than 3" OR "under three" OR "under 3" OR "below three" OR "below 3" OR "3 or below" OR "3 or younger" OR "three or below" OR "three or younger") AND epilep*
3	Infantile Spasm/ Neonatal Seizure	"infantile spasm*" OR "neonatal seizure*" OR ((babies OR baby OR infan* OR neonat* OR newborn* OR nicu) AND (convuls* OR seizure* OR spasm*))
4	Parental Preferences	father* OR matern* OR mother* OR parent* OR patern*
5	Harms	"adverse drug reaction" OR "adverse effect*" OR "adverse event*" OR anhidrosis OR appetite* OR behavior* OR behaviour* OR cognitiv* OR defect* OR delay* OR development* OR disorder* OR dysfunction* OR dyston* OR harm* OR impair* OR injur* OR liver OR motor OR "organ damage*" OR "sleep disorder*" OR sweat* OR "side effect*"
6	Untreated Disease	"treatment refusal" OR "not treated" OR "no treatment" OR untreat* OR "decline treatment" OR "declined treatment" OR "forgo* treatment" OR "refuse treatment" OR "refused treatment" OR "refusing treatment" OR "withheld treatment" OR "withhold treatment" OR "withholding treatment"
7	Combine Concepts	(S1 OR S2 OR S3) AND S4
8	Apply Limits	S7 AND (Published Date: 19990101-20210831; English Language; Exclude MEDLINE records)
9	Combine concepts	(S1 OR S2 OR S3) AND (S5 AND S6)
10	Apply Limits	S9 AND (Published Date: 19990101-20210831; English Language; Exclude MEDLINE records)

PsycINFO (Searched January 1, 1999, to August 19, 2021)

Set	Concept	Search statement
1	Childhood Epilepsy	"benign childhood epilepsy" OR "childhood absence epilepsy" OR "severe myoclonic epilepsy in infancy" OR (dravet* adj1 (disease OR syndrome)) OR ((child* OR infan* OR paediatr* OR pediatr*) adj1 epilep*)
2	Epilepsy/ 0-3 Age Group	(baby OR babies OR infan* OR neonat* OR newborn* OR nicu OR paediatric* OR pediatric* OR preschool OR toddler* OR "very young" OR (("younger than" OR under OR below) adj3 ("3" OR three)) OR (("3" OR three) adj3 ("or below" OR "or under" OR "or younger")) AND (epilepsy/ OR epileptic seizures/ OR epileps* OR epileptic*))
3	Infantile Spasm/ Neonatal Seizure	((babies OR baby OR infan* OR neonat* OR newborn* OR nicu) adj3 (convuls* OR seizure* OR spasm*))
4	Parental Preferences	parents/ OR (patern* OR parent* OR matern* OR mother* OR father*)
5	Harms	behavior disorders/ OR cognitive impairment/ OR delayed development/ OR developmental disabilities/ OR liver disorders/ OR motor development/ OR "side effects (drug)"/ OR "side effects (treatment)"/ OR sleep wake disorders/ OR sweating/ OR (advers* OR anhidrosis OR dystoni* OR harm* OR harm* OR hypohidrosis OR hypohydrosis OR "organ damage") OR (appetite adj3 (lose* OR losing OR loss OR

		lost)) OR ((cognitiv* OR behavior* OR develop* OR motor OR movement OR neurodevelop*) adj3 (effect* OR deficit* OR disorder* OR problem* OR symptom*)) OR ((cognitiv* OR develop* OR motor* OR neurodevelopment*) adj3 (delay* OR disorder* OR regress*)) OR ((liver OR organ*) adj3 (damag* OR injur*)) OR (miss* adj3 milestone*) OR ((eat* OR perspir* OR sweat* OR sleep*) adj3 (disorder* OR inability OR unable))
6	Untreated Disease	treatment refusal/ OR ("not treated" OR "no treatment" OR untreat*) OR ((declin* OR forgo* OR "not" OR no OR refus* OR withheld OR withhold*) adj3 (treated OR treatment*))
7	Combine Sets	(1 OR 2 OR 3) AND 4
8	Apply Limits	limit 7 to yr="1999 - 2021"
9	Apply Limits	limit 8 to up=19000101-20210819
10	Apply Limits	9 NOT (1* or 2* or 3* or 4* or 5* or 6* or 7* or 8* or 9*).pm.
11	CQ1	limit 10 to english language
12	Combine Sets	(1 OR 2 OR 3) AND (5 AND 6)
13	Apply Limits Apply Limits	Limit 12 to yr="1999 - 2021"
14	Apply Limits	limit 13 to up=19000101-20210819
15	Apply Limits	14 NOT (1* or 2* or 3* or 4* or 5* or 6* or 7* or 8* or 9*).pm.
16	CQ2	limit 5 to english language

APPENDIX B: The Theoretical Domains Framework*

Domain	Definition	Constructs
Knowledge	An awareness of the existence of something	Knowledge (including knowledge of condition/scientific rationale) Procedural knowledge Knowledge of task environment
Skills	An ability or proficiency acquired through practice	Skills Skills development Competence Ability Interpersonal skills Practice Skill assessment
Social/professional role and identity	A coherent set of behaviors and displayed personal qualities of an individual in a social or work setting	Professional identity Professional role Social identity Identity Professional boundaries Professional confidence Group identity Leadership Organizational commitment
Beliefs about capabilities	Acceptance of the truth, reality or validity about an ability, talent or facility that a person can put to constructive use)	Self-confidence Perceived competence Self-efficacy Perceived behavioral control Beliefs Self-esteem Empowerment Professional confidence
Optimism	The confidence that things will happen for the best or that desired goals will be attained	Optimism Pessimism Unrealistic optimism Identity
Beliefs about Consequences	Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation	Beliefs Outcome expectancies Characteristics of outcome expectancies Anticipated regret Consequents
Reinforcement:	Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus	Rewards (proximal/distal, valued/not valued, probable/improbable) Incentives Punishment Consequents Reinforcement Contingencies Sanctions

Domain	Definition	Constructs
Intention	A conscious decision to perform a behaviour or a resolve to act in a certain way	Stability of intentions Stages of change model Transtheoretical model and stages of change
Goals	Mental representations of outcomes or end states that an individual wants to achieve	Goals (distal/proximal) Goal priority Goal/target setting Goals (autonomous/controlled) Action planning Implementation intention
Memory, attention and decision processes	The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives	Memory Attention Attention control Decision-making Cognitive overload/tiredness
Environmental context and resources	Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence and adaptive behaviour	Environmental stressors Resources/material resources Organizational culture/climate Salient events/critical incidents Person environment interaction Barriers and facilitators
Social influences	Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours	Social pressure Social norms Group conformity Social comparisons Group norms Social support Power Intergroup conflict Alienation Group identity Modelling
Emotion	A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event	Fear Anxiety Affect Stress Depression Positive/negative affect Burn-out
Behavioral regulation	Anything aimed at managing or changing objectively observed or measured actions	Self-monitoring Breaking habit Action planning

*British spelling of definitions is kept from original publication

Atkins L, Francis J, Islam R, O'Connor D, Patey A, Ivers N, Foy R, Duncan EM, Colquhoun H, Grimshaw JM, Lawton R, Michie S. A guide to using the Theoretical Domains Framework of behaviour change to investigate implementation problems. Implement Sci. 2017 Jun 21;12(1):77. doi: 10.1186/s13012-017-0605-9. PMID: 28637486; PMCID: PMC5480145.

APPENDIX C. CERQual assessment components

CERQual Components	**Definition**
Methodological limitations	The extent to which there are problems in the design or conduct of the primary studies supporting a review finding. We used our CASP assessment of each study to guide our assessment of this component.
Coherence	An assessment of how clear and cogent the fit is between the data from the primary studies and the review finding.
Relevance	The extent to which the body of evidence from the primary studies supporting a review finding is applicable to the context specified in the review question.
Adequacy	The degree of richness and quantity of data supporting a review finding.

Noyes J, Booth A, Lewin S, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings-paper 6: how to assess relevance of the data. Implement Sci. 2018 Jan 25;13(Suppl 1):4. doi: 10.1186/s13012-017-0693-6. PMID: 29384080.

APPENDIX D. Methodological appraisal ratings using the CASP tool

	Study				
CASP question	**O'Brien, 2020**	**Sylven, 2020**	**Heath et al. 2016**	**Ozanne, 2016**	**Pieters, 2016; Baca, 2015**
Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes
Was the qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes
Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Yes
Was the recruitment strategy appropriate to the aims of the research?	No[1]	No[1]	No[1]	No[1]	No[1]
Was data collected in a way that addressed the research issue	Yes	Yes	Yes	Yes	Yes
Was the relationship between researcher and participants adequately considered?	Can't tell	Can't tell	Can't tell	Yes[2]	Can't tell
Were ethical issues taken into consideration?	Yes[3]	Yes[3]	Yes[3]	Yes[3]	Can't tell
Was there sufficient rigor?	Yes	Yes	Yes	Yes	Yes
Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes
How valuable is the research?[4]	Yes	Yes	Yes	Yes	Yes
Overall risk to rigor	Low	Low	Low	Low	Low

Abbreviations: CASP: Critical Appraisal Skills Programme

[1] Participants in these studies were recruited after their child underwent surgery, raising concerns about selection bias due to selecting parents who were a) referred to surgery, b) proceeded with surgery, and c) experience some level of success with surgery. Excludes parents of a child with drug-resistant surgery who were not referred to surgery, who choose not to proceed with surgery, or whose child did not achieve desired outcomes.

[2] Interviewers and researchers not part of care/surgery team

[3] Approved by university ethics committee

[4] "Yes" rating given when study: a) discussed contribution to existing knowledge or understanding, b) identified new areas where research is necessary, and c) discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

APPENDIX E. Coding extracts for treatment decisions for childhood epilepsy into the Theoretical Domains Framework

TDF domain	Author, Year, PMID	Extracted text[A]	Theme
Knowledge	Baca, 2015, 25894906	With the recognition that "something is wrong," parents sought information from multiple sources in an attempt to understand seizures and epilepsy and become better advocates for their child.	Need for information about epilepsy, treatment options, and navigating the healthcare system
Knowledge	Baca, 2015, 25894906	Parents reported difficulties as the they sought information about seizures, epilepsy, medications, and surgery….Parents sought information from a variety of disparate sources including physicians, the Internet, books, and family/friends.	Need for information about epilepsy, treatment options, and navigating the healthcare system
Knowledge	Baca, 2015, 25894906	Through this journey, parents learned to navigate a complicated medical system filled with doctors of different specialties, multiple hospitals, insurance approvals, and numerous treatment options	Need for information about epilepsy, treatment options, and navigating the healthcare system
Knowledge	Pieters, 2016, 27521720	Parents also had to learn about the intricacies of the healthcare system including the types of doctors that were needed to care for their children	Need for information about epilepsy, treatment options, and navigating the healthcare system
Knowledge	Heath, 2016, 27371883	Parents perceived the information they received from professionals as inadequate to make an informed decision. They therefore sought out additional information regarding the surgical procedure and outcomes. Aiming to comprehend what surgery would entail, parents requested information in lay language and searched the internet for information and videos.	Need for information about epilepsy, treatment options, and navigating the healthcare system
Knowledge	Heath, 2016, 27371883	"I googled it until I couldn't google anymore and I think that gave me a better understanding of what was going on."	Need for information about epilepsy, treatment options, and navigating the healthcare system
Knowledge	Heath, 2016, 27371883	Finally, parents emphasized the importance of receiving adequate information regarding epilepsy surgery, including information presented in a variety of formats (e.g., booklets, photographs, videos). They also suggested that a 'frequently asked questions' information sheet would have been beneficial. "I know I got a little booklet about epilepsy surgery services, but it would have been nice for us to have some extra information… just some written up case studies of kids that have gone through, had the same, you know, operation."	Need for information about epilepsy, treatment options, and navigating the healthcare system
Knowledge	Heath, 2016, 27371883	These included …additional information provision	Need for information about epilepsy, treatment options, and navigating the healthcare system
Knowledge	O'Brien, 2020, 33120326	[I]t 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.	Need for information about epilepsy, treatment options, and navigating the healthcare system
Knowledge	Ozanne, 2016, 27176878	Sometimes, parents received more information from other parents, than from the physician. They were disappointed if they felt that information was withheld	Need for information about epilepsy, treatment options, and navigating the healthcare system
Knowledge	Ozanne, 2016, 27176878	Parents thought that it was important to receive the information that surgery was aimed to treat the epilepsy and not other disabilities, such as behavioral problems, in order to have realistic expectations. They emphasized the importance of being informed about both positive and negative outcomes and risks. Even if surgery was a medical success, the family's life situation was	Need for information about epilepsy, treatment options, and navigating the healthcare system

TDF domain	Author, Year, PMID	Extracted text[A]	Theme
		sometimes characterized by sorrow and problems. The deterioration, expected or unexpected, of e.g., motor function, speech, visual field, or attention made life more difficult and burdensome.	
Knowledge	Baca, 2015, 25894906	Parents also reported little initial familiarity with epilepsy and that they felt overwhelmed trying to learn a new language of epilepsy because of the “avalanche of information coming at us.”	Overwhelmed by information
Knowledge	Pieters, 2016, 27521720	She described the hard and time-consuming struggle of trying to synthesize information on her own “because there really wasn't a lot out there and when you're hearing different things from different specialists it's very difficult for parents to make heads or tails of it”. She spent “six months combing through the literature reading everybody's publications from places all over the world … because I wasn't getting a straight answer … my husband was saying to me you know are you going to go and get your degree in neuroscience after this … but you know it's your child, you want to do the best by them and you know you want them to be able to achieve their potential”.	Overwhelmed by information
Knowledge	Baca, 2015, 25894906	As they acquired more epilepsy knowledge, however, many parents felt more empowered and able to ask questions and participate more effectively in the care of their child	Knowledge is empowering
Knowledge	Baca, 2015, 25894906	A mother who stated, “I just think knowledge is power and it also brings some comfort to making a good decision,” exemplified the sense of empowerment associated with gaining fluency in the language of epilepsy	Knowledge is empowering
Knowledge	Heath, 2016, 27371883	Increasing their own knowledge about medically intractable epilepsy and the available treatment options empowered parents to participate more fully in the decision-making process. “I said to him ‘don't tell me in a doctor's term, tell it me in a parent’s term. I want to know the ins and outs; I want to know exactly what the risks are but in terms that I understand’”	Knowledge is empowering
Knowledge	Pieters, 2016, 27521720	[P]arents took on the responsibility for learning as exemplified by the parent who naturally ‘corrected’ her language to imply her understanding of the different terms that clinicians use, “(the seizures) were not controlled … or intractable as you guys call them.”	Knowledge is empowering
Knowledge	Pieters, 2016, 27521720	Being open to learn and learning itself occurred while parents became epilepsy experts in order to be effective advocates for their children	Knowledge is empowering
Knowledge	Pieters, 2016, 27521720	In order to have productive information exchanges with clinicians and engage in shared decision-making, parents realized that they had to learn about a very unfamiliar and unforeseen situation	Knowledge is empowering
Knowledge	Pieters, 2016, 27521720	The lack of understandable information and the experience of information imbalance between the parent and the physician were overwhelming as experienced by a father who described him and his wife as “pretty pragmatic.” He said, “The beginning was terrible, because you’re of course dealing with … specialists in things and that you’ve pretty much never even heard of …. It was tough in the beginning, really tough … (the information that we found) was written by doctors for doctors. It's kinda tough when you don't know what you're talking about to get through that.	Knowledge is empowering
Social role and identity	Heath, 2016, 27371883	However, they also reported a sense of duty to be “strong” (P1) and “brave” (P3, 4) for their children, wishing to protect them from their feelings of anxiety.	Role and responsibility as a parent
Social role and identity	Heath, 2016, 27371883	Parents discussed feeling pressure from a need to ‘do the right thing’ by their child; that is, choosing the treatment option that would give their child the best chance of reaching their full potential	Role and responsibility as a parent

TDF domain	**Author, Year, PMID**	**Extracted text^A**	**Theme**
Emotion	Baca, 2015, 25894906	Parents reported personal and family stress throughout the journey. Caring for children with a chronic, severe, and paroxysmal neurologic condition meant being "on call" all the time; they had to be prepared to respond to an emergency at all times	Drained from managing epilepsy
Emotion	O'Brien, 2020, 33120326	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)	Drained from managing epilepsy
Emotion	O'Brien, 2020, 33120326	Child mood and behavioural difficulties-stress, secrecy and shame. Before surgery children's mood and behavioura 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)	Drained from managing epilepsy
Emotion	Baca, 2015, 25894906	Parents frequently described that medication trials continued often with little to no mention of surgery. One mother told of her frustrations with multiple medications, "It was, 'Let's work on all the different medical aspects or medicines before going to surgery or even talking about surgery."	Desperate to help their child
Emotion	Pieters, 2016, 27521720	Parents felt desperate not only to find a treatment option that would work, but also to persevere and actively do something that was productive and necessary to help their child	Desperate to help their child
Emotion	Pieters, 2016, 27521720	Wanted to play an active role	Desperate to help their child
Emotion	Pieters, 2016, 27521720	[W]anted to use time constructively	Desperate to help their child
Emotion	Pieters, 2016, 27521720	Another mother remembered that she felt "desperate" to take her adolescent son to another doctor, but she needed to wait for referrals because of insurance	Desperate to help their child
Emotion	Pieters, 2016, 27521720	[P]arents felt frustrated and desperate to get help for their child.	Desperate to help their child
Emotion	Heath, 2016, 27371883	Following indication of surgery as a potential treatment, parents and families faced what they described as a "difficult decision" (P5) which was experienced as "daunting", "frightening", "scary", and "stressful"	Difficult and stressful decision
Emotion	Pieters, 2016, 27521720	"It was not only in terms of time, it was mentally draining as well. It took a lot of time and it took a lot of concentrated thought to figure this out."	Difficult and stressful decision
Emotion	Ozanne, 2016, 27176878	Parents were afraid and worried	Fear (unspecified)

TDF domain	Author, Year, PMID	Extracted text^A	Theme
Emotion	Heath, 2016, 27371883	Last treatment of choice. For most parents, surgery was a last-resort treatment option that would only be considered following the exhaustion of all other options. This perception was influenced by parental fear regarding the irreversibility of surgery, as well as by professionals who had informed them that surgery was the only remaining treatment for controlling their child's seizures	Fear of surgery
Emotion	Pieters, 2016, 27521720	For the majority of parents, brain surgery was a frightening possibility as described by the mother who said, “At first I was horrified at the thought of this innocent – having her brain opened and operated on. It just seemed so barbaric.” Another mother's statement reflected upon her initial feelings of fear and avoidance when she said that she and her husband, “just couldn’t deal with (having our daughter go through brain surgery)	Fear of surgery
Emotion	Sylven, 2020, 32480305	Parents mentioned the possibility that their child would experience “a change in personality” as a result of the surgery. They did not mention particular personality characteristics but feared that the child's personality would change for the worst	Fear of surgery
Emotion	Sylven, 2020, 32480305	Some parents reported that they were concerned that surgery would lead to a loss of function including that language/speech would be negatively affected. This concern included a worry that the child would develop speech difficulties or that they would lose the ability to talk completely as a result of the surgery. Parents also mentioned concerns that their child would acquire motor difficulties or even be paralyzed as a result of the surgery. Parents were also worried that any loss of function would be irreversible after the surgery	Fear of surgery
Emotion	Sylven, 2020, 32480305	Many parents were worried that their child's epilepsy would be “worse” after the surgery, and as a result, the operation would have been “in vain”. This included a risk that seizure frequency might increase, that seizures might be longer or be of a different character, or that seizure frequency might not improve.	Fear of surgery
Emotion	Ozanne, 2016, 27176878	It was demanding not to know if surgery would be possible, and the parents were thankful when the decision was finally made	Relief after decision was made
Emotion	Sylven, 2020, 32480305	Many parents described a general hope for improved behavior and emotional functioning for their child. Behavior encompassed a wide variety of outcomes including that the child would be “calmer” with fewer behavioral outbursts, have better attention and concentration, and “feel better”	Hope for better health and quality of life
Emotion	Sylven, 2020, 32480305	Parents hoped that the surgery would lead to better health and quality of life for their child	Hope for better health and quality of life
Emotion	Sylven, 2020, 32480305	Parents often expressed a desire that surgery would result in their child being “more alert”, less “tired”, and “have more energy”. They also mentioned that they hoped that surgery would result in better sleep quality	Hope for better health and quality of life
Emotion	Sylven, 2020, 32480305	Some parents mentioned complete freedom from medicine while others mentioned a reduction in AEDs. Parents believed a reduction in AEDs and associated adverse side effects of AEDs including “tiredness” would lead to a “normal life” for their child	Hope for better health and quality of life
Emotion	Baca, 2015, 25894906	As parents learned that surgery was a potential viable option for their child, they “hoped” for candidacy	Hope for surgical candidacy
Emotion	Heath, 2016, 27371883	When a decision to accept surgery had been made, parents hoped for the procedure to be carried out as soon as possible. Waiting for a date for surgery was described as an anxious time for parents, who experienced relief when a date was set.	Hope for surgical candidacy

TDF domain	**Author, Year, PMID**	**Extracted text^A**	**Theme**
Social influence	O'Brien, 2020, 33120326	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).	Social exclusion
Social influence	O'Brien, 2020, 33120326	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)	Social exclusion
Social influence	Heath, 2016, 27371883	In addition, parents emphasized the importance of accessing the experience and expertise of other parents who had followed a similar treatment pathway. Such peer support was suggested to facilitate understanding of the surgical procedure from a 'parental perspective', as well as provide emotional support. "If people could freely put their experiences on either a forum or even if you get a group, you know, parents talking to other parents who have gone through the experience to get a real idea of what's happening."	External support from peers and healthcare professionals
Social influences	Heath, 2016, 27371883	These included … peer support	External support from peers and healthcare professionals
Social influence	Pieters, 2016, 27521720	Those parents who were able to connect with other parents and families of children with epilepsy found it to be very helpful to be able to communicate with peers with seizures unresponsive to medication who were on the same journey.	External support from peers and healthcare professionals
Social influence	Pieters, 2016, 27521720	[E]xchanging shared experiences with peers gave direction to decision-making because it helped with processing complex factual and emotional information	External support from peers and healthcare professionals
Social influence	Pieters, 2016, 27521720	Three key facilitators were identified as follows: (a) having a champion, (b) finding a good team of epilepsy providers, and (c) connecting with others who shared the experience of epilepsy. (Fig. 1; Table 2). Such facilitators played a key role during the times when parents especially needed support to act purposefully and move out of vulnerable periods.	External support from peers and healthcare professionals
Social influence	Pieters, 2016, 27521720	However, using time constructively happened after the parents described finding a champion that advocated for them and helped them navigate their journey. It was a champion, whether a doctor, nurse, or social worker, that facilitated steady and purposeful progress over more manageable portions of the journey	External support from peers and healthcare professionals
Social influence	Pieters, 2016, 27521720	One mother favorably described one such champion, a nurse coordinator, "she's like wonderful for us. She's been our lifesaver." These champions helped parents get referrals and seek different treatment options or were the persons that believed them and pushed them to seek better or additional care. For one mother, her daughter's pediatrician acted as her champion. She said, "He encouraged me and gave me the confidence that if I wasn't happy with what five other pediatric neurologists were saying that it was okay to go and you know continue to seek out other opinions."	External support from peers and healthcare professionals

TDF domain	**Author, Year, PMID**	**Extracted text[A]**	**Theme**
Social influence	Heath, 2016, 27371883	Family decisions. Parents described decision-making as a family choice involving partners, siblings, grandparents, and the child (where developmentally appropriate). Discussing treatment options with family members was generally considered to be helpful. “I remember my mother-in-law was in Pakistan and I called her up and I was very teary…I felt like I had been punched in the stomach to be honest ‘cause, you know, brain surgery is not something you take lightly and she said ‘well if it's for his betterment and to improve his life then we will do whatever it takes’.”	Family decision
Social influence	Heath, 2016, 27371883	For some families, decision-making regarding surgery gave rise to conflicts. For example, one mother described herself as more agreeable to surgery than the child's father because, as the primary carer, she ‘witnessed’ the true extent of their child's seizures. In cases where the child's epilepsy was considered to impact on the whole family (e.g., where a parent could not return to work because of a need to look after the child), then, the decision was understood as a responsibility of the whole family	Family decision
Belief about consequences	Baca, 2015, 25894906	On their journey, many parents transformed their view of surgery from a scary, last resort treatment to a necessary and hopeful option. One mother explained, “By the time she got it—it got so serious I was looking toward that as being an answer to our prayers rather than just something that I couldn’t even think about.” This transformation occurred as parents became increasingly aware of the severity of their child’s epilepsy and its impact on their child’s and their future life. Although surgery remained scary, epilepsy was or became scarier than surgery. As some parents feared that their child would die from epilepsy, surgery was no longer perceived as an elective treatment.	Transformation towards surgery as the treatment choice informed by experiences, emotions, and knowledge
Beliefs about consequences	Baca, 2015, 25894906	Many parents initially perceived epilepsy brain surgery to be “pretty horrific” and a treatment of “last resort.”	Transformation towards surgery as the treatment choice informed by experiences, emotions, and knowledge
Beliefs about consequences	Baca, 2015, 25894906	After an arduous journey, parents reached the right doctor and center; epilepsy surgery, although previously seen as a last ditch option, became a viable option and a source of hope.	Transformation towards surgery as the treatment choice informed by experiences, emotions, and knowledge
Beliefs about consequences	Pieters, 2016, 27521720	After persevering through hard times with unsuccessful medications and interventions, they eventually decided to proceed with surgery, the option that they perceived to be the best treatment for the epilepsy.	Transformation towards surgery as the treatment choice informed by experiences, emotions, and knowledge
Beliefs about consequences	Pieters, 2016, 27521720	Because surgery was viewed as a treatment of last resort for many parents, time was required to process the initial fear, make sense of the emotional information, and consider the factual risks and benefits in order to decide on surgery as the best option for their child. Reflecting on why it took longer than six years to get to surgery for her 9-year-old daughter, a mother said, “Of course you need to take a lot of time to think about it. It's very invasive…. I did as much research as I could about it, and talked to the doctor a lot about it, and I decided that that was her best chance of having a normal life in the future.”	Transformation towards surgery as the treatment choice informed by experiences, emotions, and knowledge

TDF domain	**Author, Year, PMID**	**Extracted text^{A}**	**Theme**
Beliefs about consequences	Pieters, 2016, 27521720	Through internal processing, parents worked through the diverse emotions and large amount of information that they were receiving and gathering to move forward and thereby develop a greater understanding of their child's illness and prognosis in order to ultimately reach the point where surgery became the treatment of choice	Transformation towards surgery as the treatment choice informed by experiences, emotions, and knowledge
Beliefs about consequences	Heath, 2016, 27371883	Parents were clear that putting their child forward for epilepsy surgery was the best and right decision for their child, demonstrating a high level of satisfaction with the treatment outcome. However, initial perceptions of surgery were often negative, particularly if it was not a treatment option that had previously been considered or that professionals had indicated. Many parents described attending their child's clinic appointment expecting to talk about more conventional treatments (e.g., medication or diet), leading to them feeling surprised when surgery was raised for discussion. "We went originally to talk about the ketogenic diet and then the doctor said 'oh I think surgery's your best option' which came as a bit of a shock really because no one had ever mentioned the surgery before." (P5) "It actually came as a bit of a surprise to us that option, in that it was mentioned in a review visit, that maybe the time had come to look at the option of surgery but we weren't really aware of that option at that point so it came as quite a shock to us." (P6) While some parents took comfort from the possibility of an additional treatment pathway, others felt excluded from the decision to assess their child for surgical candidacy, leading to their feeling unable to participate in an informed discussion	Transformation towards surgery as the treatment choice informed by experiences, emotions, and knowledge
Beliefs about consequences	Heath, 2016, 27371883	Some parents were unconvinced about the efficacy of surgery for reducing their child's seizures. Skepticism stemmed from their experience of other pharmacological and dietary treatments which had resulted in little improvement in seizure control. In weighing up treatment options, parents also discussed the side effects of alternative treatments. For example, medications were perceived to have a range of adverse side effects, whereas ketogenic diets were viewed as negatively affecting the child's ability to live a 'normal' life. "We thought about the effects of the medication if we chose to continue on the path of finding a different medication… but then how long would that have taken us? Like how long would it work for? Then it would develop, then how long 'til we have to find something else, with all the side-effects that can happen? I didn't want to put her through that as well." (P9)	Balancing potential benefits of surgery with concerns of adverse effects
Beliefs about consequences	Heath, 2016, 27371883	Balancing potential costs and benefits. When deliberating surgery, parents balanced their perceived necessity of the treatment in terms of how epilepsy currently affected and would, in the future, affect their child's quality of life, against concerns regarding the possibility of negative outcomes. In other words, parents weighed up the potential benefits of surgery such as freedom from seizures against what they understood as the risks, including cognitive impairments. "There was no quality of life for him; we had to do what was best. We were told of the risks of the surgery and we were told that actually this would be the best thing for him… we don't regret it, but it was, it's not an easy decision to take because you're worried about the risks of things."	Balancing potential benefits of surgery with concerns of adverse effects
Beliefs about consequences	Sylven, 2020, 32480305	Some parents mentioned that while they would like seizure freedom, any reduction in seizures would be "welcome" and a clear improvement for their child and for the family in general.	Balancing potential benefits of surgery with concerns of adverse effects
Beliefs about consequences	Sylven, 2020, 32480305	Some parents mentioned complete freedom from medicine while others mentioned a reduction in AEDs. Parents believed a reduction in AEDs and associated adverse side effects of AEDs including "tiredness" would lead to a "normal life" for their child.	Balancing potential benefits of surgery with concerns of adverse effects

TDF domain	**Author, Year, PMID**	**Extracted text^A**	**Theme**
Beliefs about consequences	Sylven, 2020, 32480305	Many parents mentioned a desire for seizure freedom for their child after surgery. They wanted their child to be free from the “trouble” of seizures and everything that follows from seizures	Balancing potential benefits of surgery with concerns of adverse effects
Beliefs about consequences	Sylven, 2020, 32480305	They wanted that their child could do everything their friends could do like “play football, cycle, and swim independently”. Some parents mentioned that they wanted their child to be able to go back to school and have a “proper social life” while some parents referenced the future hoping that the child would be better placed to get a job and driving license as a result of surgery.	Balancing potential benefits of surgery with concerns of adverse effects
Beliefs about consequences	Sylven, 2020, 32480305	Parents mentioned the possibility that their child would experience “a change in personality” as a result of the surgery. They did not mention particular personality characteristics but feared that the child's personality would change for the worst	Balancing potential benefits of surgery with concerns of adverse effects
Beliefs about consequences	Sylven, 2020, 32480305	Some parents reported that they were concerned that surgery would lead to a loss of function including that language/speech would be negatively affected. This concern included a worry that the child would develop speech difficulties or that they would lose the ability to talk completely as a result of the surgery. Parents also mentioned concerns that their child would acquire motor difficulties or even be paralyzed as a result of the surgery. Parents were also worried that any loss of function would be irreversible after the surgery	Balancing potential benefits of surgery with concerns of adverse effects
Beliefs about consequences	Sylven, 2020, 32480305	The majority of parents mentioned concerns about possible complications that could occur during or soon after the surgical procedure	Balancing potential benefits of surgery with concerns of adverse effects
Beliefs about consequences	Sylven, 2020, 32480305	A small number of parents said that they had no concerns before the surgery. One parent said that they were not worried as “no concerns arose in the discussions with professionals” before the surgery	Balancing potential benefits of surgery with concerns of adverse effects
Beliefs about consequences	Sylven, 2020, 32480305	The results of the current study suggest that parents frequently worry about that the child would lose skills or function, or complications would arise during surgery that could result in injury.	Balancing potential benefits of surgery with concerns of adverse effects
Beliefs about consequences	Heath, 2016, 27371883	For all parents in this study, the perceived need of surgery outweighed the possible risks and side effects. “We thought this is going to be no life for him… He was on this diet which meant he couldn't go out with friends; he couldn't stay at friends' houses, all the things that other kids do, he couldn't do… and then he got these fits virtually every night and we thought… you know what, there is no decision to make, we gotta do it… We knew there were risks, we talked about them with [child] and he was frightened but he said no, we gotta do it.” (P3)	Only choice left
Beliefs about consequences	Heath, 2016, 27371883	Last treatment of choice. For most parents, surgery was a last-resort treatment option that would only be considered following the exhaustion of all other options…Some parents felt that they had little alternative but to accept surgical intervention in order to provide their child with the best possible chance of improving their quality of life. “We felt it was our only option really in her having a more independent future.”	Only choice left
Beliefs about consequences	Heath, 2016, 27371883	“My husband and I walked out of the appointment saying we feel like we don't have a choice… we felt like it was the only choice we could make.”	Only choice left

TDF domain	**Author, Year, PMID**	**Extracted text^A**	**Theme**
Beliefs about consequences	Heath, 2016, 27371883	For one family with an adolescent child, it was considered necessary to accept surgery while the child received care from the children's hospital as they believed that the treatment would become unavailable once transitioned to adult services.	Only choice left
Beliefs about consequences	O'Brien, 2020, 33120326	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?	Only choice left
Beliefs about consequences	O'Brien, 2020, 33120326	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.	Only choice left
Beliefs about consequences	Ozanne, 2016, 27176878	Parents felt that epilepsy surgery was a question of life or death, of chaos or control. It was terrifying to see the child so ill. The epilepsy was uncontrolled, and drugs gave side effects. Parents felt that there was no alternative to surgery. However, it was a difficult decision since they did not know the outcome.	Only choice left
Beliefs about consequences	Ozanne, 2016, 27176878	Information about possible complications related to surgery did not prevent the parents from wishing to proceed with the operation. They preferred to take a risk rather than live in constant fear	Only choice left
Environmental context and resources	Baca, 2015, 25894906	The journey to finding the right doctor was further complicated by parental perceptions that doctors sometimes lacked knowledge of or familiarity with epilepsy. Many parents went to numerous doctors searching for the "right" doctor, or one who had a strong epilepsy knowledge base, could effectively identify the problem, and then make a clear plan of action	Challenges with navigating the healthcare system
Environmental context and resources	Baca, 2015, 25894906	Parents expressed that their children were seen, evaluated, and cared for by a variety of doctors of different specialties throughout their journey. Parents frequently described difficulty finding the "right" doctor(s). Difficulty was associated with a lack of pediatric neurologists in their local area and with different doctors having different recommendations.	Challenges with navigating the healthcare system
Environmental context and resources	Baca, 2015, 25894906	Parents depicted a pathway filled with multiple doctors and treatments, insurance battles, and work and life obstacles as they sought a cure for their child's seizures, becoming ever more knowledgeable about epilepsy	Challenges with navigating the healthcare system
Environmental context and resources	Pieters, 2016, 27521720	Further, finding the best clinicians for the needs of their child required an understanding of the relationship between different medical (sub)-specialties and thereby represented dual and concurrent use of processing and navigating mechanisms	Challenges with navigating the healthcare system
Environmental context and resources	Pieters, 2016, 27521720	The second mechanism, navigating, was when the parents kept and directed their way along their journey often through uncharted territory as they steered through various aspects of the health-care system and learned about epilepsy itself and its various treatments.	Challenges with navigating the healthcare system

TDF domain	**Author, Year, PMID**	**Extracted text^A**	**Theme**
Environmental context and resources	Pieters, 2016, 27521720	A mother described her disappointment with being denied by insurance despite doing all the work that was required	Challenges with navigating the healthcare system
Environmental context and resources	Pieters, 2016, 27521720	"We'd already been fighting her seizures for two and a half, approaching three years, and because we were new there and per protocol, they wanted to try these other treatments for another year."	Challenges with navigating the healthcare system
Environmental context and resources	Ozanne, 2016, 27176878	The Swedish Social Insurance Agency, technical aids center, school, and municipality were criticized by the parents. Based on their experience, they felt that the bureaucracy had been problematic and had taken a great deal of time. They had to fight for their rights, despite physicians' certificates. Without specific diagnoses of comorbidities, it was even more difficult to get adequate support. They thought that it would be helpful if the authorities understood that parents only asked for help when they had reached their limit, and then, urgent help was necessary	Challenges with navigating the healthcare system
Environmental context and resources	Ozanne, 2016, 27176878	Parents were disappointed if it took a long time to get a correct diagnosis	Challenges with navigating the healthcare system
Environmental context and resources	Baca, 2015, 25894906	Several parents experienced feeling doubted by a doctor; some were told that nothing was wrong with their child initially	Interactions with providers (barriers)
Environmental context and resources	Baca, 2015, 25894906	As parents learned that surgery was a potential viable option for their child, they "hoped" for candidacy. This hoping required persistence and sometimes disregarding doctors who initially felt surgery was not an option. Looking back, one father voiced happiness that he listened to his parental instincts rather than the opinion of one doctor. He (doctor) said, "'I don't believe that she is a surgical candidate.' As a parent, I listened and I wanted to think otherwise.... In hindsight, I'm glad I didn't listen to him."	Interactions with providers (barriers)
Environmental context and resources	Baca, 2015, 25894906	Parents also reported notable physician-based barriers including variability in perceived knowledge of epilepsy, criteria for presurgical referral and appropriateness of epilepsy surgery	Interactions with providers (barriers)
Environmental context and resources	Pieters, 2016, 27521720	[C]rossing such an information divide was an uphill battle as stated by a mother who described feeling dismissed by doctors until she found someone who was approachable and was "gracious enough to talk to a mere mortal mother on the phone … because a lot of docs won't, they've got lots of protective armor around them shielding off potential patients or worse yet parents."	Interactions with providers (barriers)
Environmental context and resources	Heath, 2016, 27371883	Parents perceived a lack of control over the decision-making process through their limited involvement in initial discussions regarding surgical candidacy	Interactions with providers (barriers)
Environmental context and resources	Heath, 2016, 27371883	These included earlier and softer introduction of surgery as a possible treatment option	Interactions with providers (barriers)
Environmental context and resources	Ozanne, 2016, 27176878	During the long hospitalizations, some parents felt that nobody had time for them. Arrogance of some professionals made them very disappointed	Interactions with providers (barriers)

TDF domain	**Author, Year, PMID**	**Extracted text**[A]	**Theme**
Environmental context and resources	Ozanne, 2016, 27176878	If the pediatric neurologists revealed their own worries and insecurities regarding epilepsy surgery, this could have negative effects	Interactions with providers (barriers)
Environmental context and resources	Ozanne, 2016, 27176878	Parents described that support and information were inadequate before the epilepsy was recognized to be drug-resistant, especially from the local hospital. Their concerns were not taken seriously	Interactions with providers (barriers)
Environmental context and resources	Ozanne, 2016, 27176878	The support and information went from poor to strong when specialists at the university hospitals were involved	Interactions with providers (facilitators)
Environmental context and resources	Ozanne, 2016, 27176878	The pediatric neurologist's worry and sympathy for the family could also strengthen them since they felt invited and could be insecure together	Interactions with providers (facilitators)
Environmental context and resources	Ozanne, 2016, 27176878	Trust and safety characterized the relations to the pediatric neurologists and specialist nurses. It strengthened parents' trust to see that the pediatric neurologist fought for the child and that the parents' opinions counted in the decision process. Parents appreciated continuous contact.	Interactions with providers (facilitators)
Environmental context and resources	Pieters, 2016, 27521720	Trust in the information that they received was greater when their child was in the hands of a team with different expertise, as exemplified by the mother who said, “They get all the doctors together to look at all the information … that felt a lot more helpful because if we were at a different hospital and you only had the one doctor, then they would have misdiagnosed him.”	Interactions with providers (facilitators)
Environmental context and resources	Pieters, 2016, 27521720	When parents finally reached a comprehensive center to seek evaluation for potential pediatric epilepsy surgery, they recognized the importance of having a medical team of experts	Interactions with providers (facilitators)

[A] Study participant (first order statement) or study author (second order statement). We kept original spelling from primary study.