



Experiences and needs of parents of young children with active epilepsy: A population-based study

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ABSTRACT

The aim of the study was to gain a comprehensive understanding of the experiences and needs of parents of young children with epilepsy from a total population sample. The parents (mothers (n = 38), fathers (n = 9)) of 40/53 (75% of total population) young children (1–7 years; 23 males, 17 females) with 'active' epilepsy (had a seizure in the last year or taking Anti-epileptic drugs (AEDs)) were interviewed either in person or over the telephone using a semistructured interview schedule. The families were resident in the south of the UK. The interviews were audio-recorded, transcribed, and coded using thematic analysis. Thematic analysis revealed six main themes: diagnostic journey, parental perception of epilepsy management, awareness and impact of associated neurobehavioral difficulties, inconsistent availability of therapeutic and educational supports, impact on family functioning, and need for parental support. Parents reported often having difficulty accessing a professional knowledgeable about epilepsy. While parents were generally satisfied with the initial information they received about seizures and their management, they reported that the association between epilepsy and neurobehavioral issues was often not broached. These developmental/behavioral difficulties often had a bigger impact on child wellbeing and family functioning, but provision of therapeutic and educational supports for the difficulties was often very patchy. Parents noted that early onset epilepsy and associated neurobehavioral difficulties often have a very significant impact on family functioning including increased restrictions on family activities and increased financial burden. Parents would like informational and emotional support to extend beyond the time of epilepsy diagnosis. There is a clear need for comprehensive childhood epilepsy services to include provision for identification and management of child neurobehavioral needs and a focus on family-centered care.

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1. Introduction

The early life epilepsies are often associated with both frequent epileptic seizures [1] and a high frequency of developmental and epileptic encephalopathies [2]. Additional neurobehavioral difficulties include cognitive, behavioral (including autism and Attention-Deficit/Hyperactivity Disorder (ADHD)), motor, sensory processing, and sleep disorders [3,4] that often have a greater impact on child health-related quality of life than the epileptic seizures [4,5] but are often not identified or treated [6,7]. In addition to the impact on the child, epilepsy can impact

the entire family system with parents, particularly mothers, at increased risk of mental health difficulties [8,9], difficulties with sleep, and fatigue [10].

The need for qualitative research in childhood epilepsy has been identified as crucial to deliver a greater depth of understanding to the wide range experiences of children and their parents [11,12]. Such research can provide unique insights into experiences of children with epilepsy, their parents, and siblings [11]. Despite the potentially very significant impact on family functioning, there are limited data on the experiences and needs of parents of young children with epilepsy. One previous interview-based study from a pediatric neurology clinic in southern USA suggested that parents found it difficult to obtain accessible information to understand better their child's diagnosis and treatment [13]. Additionally, parents wanted access to professionals who

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were knowledgeable about the medical, developmental, emotional, and family issues related to coping with epilepsy in young children [13]. However, to our knowledge, there are no previous population-based studies of the needs and experiences of parents of young children with epilepsy.

The Sussex Early Epilepsy and Neurobehavior (SEEN) study is a prospective population-based study focusing on child neurobehavior and parental wellbeing in young children (1–7 years) with epilepsy. The aim of the current paper was to gain a comprehensive understanding of the experiences and needs of parents of young children with 'active' epilepsy (on AEDs and/or experienced at least one seizure in the last year) in a population-based sample via semistructured interviews.

2. Methods

2.1. Study design

The study is an interview study with parents of young children (1–7 years) with 'active' epilepsy (had a seizure in the last year or taking AEDs). Parents were interviewed either in person or over the telephone using a semistructured interview schedule. The data were analyzed using inductive thematic analysis.

2.2. Recruitment

All children born between 2008 and 2014 with epilepsy (a history of two or more unprovoked seizures more than 24 h apart) who were resident in the RH10 to RH14 postal districts of the south of the United Kingdom between September 30th 2014 and February 29th 2016 were eligible for inclusion. Additionally, children needed to be at least one year of age during the study period in order to be included. The prevalence of lifetime epilepsy (a history of 2 or more unprovoked epileptic seizures) in the study area was calculated by using the 2011 UK census population data of 1 to 7-year-olds (19,393) provided by the Office of National Statistics (2011 UK census total population 217,006). With respect to ethnic make-up, the area is similar to the UK average (study area: white 87%, non-white 13%, United Kingdom: white 88% non-white 12%; Office of National Statistics, UK).

Eligible children with epilepsy were identified via a link pediatrician on the research team. All pediatricians in the study area were asked to inform the link pediatrician of the current and new diagnoses of epilepsy within the study period. Additionally, neurophysiologists and epilepsy nurses were also asked to identify any cases and report them to the link pediatrician. Hospital letters about these children were reviewed to determine eligibility. The parents/guardians of eligible children were approached by the researchers (sent a letter and/or asked in person) and asked to complete an interest form if they wished to find out about the study. All agreeing parents were met in their home by one of the study psychologists to discuss their child's participation. At this informed consent meeting, the study was described in detail, informing parents that they would be contacted by a member of the research team for an interview regarding their experiences of parenting a young child with epilepsy. Parents were given the option to have the interview in person or via the telephone with either one or both caregivers.

During the study period, 53 children with epilepsy were identified in the study area who met eligibility criteria. The prevalence of lifetime epilepsy during the study period was 2.7 per 1000 (1 in 370, 95% Confidence Interval (CI) 1 in 285–476). Forty-nine parents returned the interest form, and 48 children subsequently underwent psychological assessment. Of those 48 children, two no longer had 'active epilepsy' and were not considered for the interview part of the study. At least one parent (mothers (n = 38), fathers (n = 9)) of 40 of the 46 remaining children (or 40/53 (75%) of eligible children with 'active' epilepsy) agreed to be interviewed (see Fig. 1). In the case of 31 of the children, the mother was the sole respondent, the father was the sole respondent

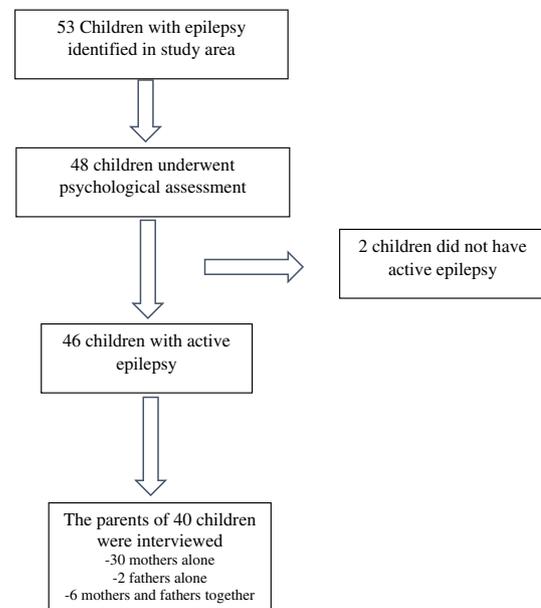


Fig. 1. Recruitment of interview participants with epilepsy in SEEN study.

in two cases, and both mother and father were interviewed together in 7 cases. Of the 40 children, 23 were male and 17 were female. The characteristics of the children whom parents responded about are in Table 1.

2.3. Development of interview protocol

Based on clinical experience and published research, study investigators developed possible topics for the interview protocol (Supplement 1) to elicit parent perspectives on the experiences and needs of

Table 1
Characteristics of children (n = 40) in SEEN study.

Gender (male/female)	23/17
Ethnicity (White/Non-White)	32/8
Age at time of psych. assessment in years (mean/range/SD)	4.60/1.0–7.16/1.49
Educational provision (mainstream/special/home)	25/10/5
On SEN register	23/17
Speech and language provision	27
Occupational therapy provision	21
Physiotherapy provision	22
Psychology provision	6
Psychiatry provision	0
Cerebral palsy	6
EEG	40
MRI	28
Duration of epilepsy in years (mean/range/SD)	2.97/0.28–6.52/1.58
Age of epilepsy onset in years (mean/range/SD)	1.65/0.04–6.00/1.34
Seizure frequency	
-Monthly or more often	29
-Less often	11
Predominant seizure type (generalized/focal)	20/20
Electroclinical syndrome	10
Distinctive constellations	1
Structural/metabolic	11
Unknown causes	10
Unclassifiable	8
Genetic/presumed genetic	13
Structural/metabolic	11
Unknown or undetermined	16
Seizures longer than 30 min	7
Required rescue therapy	24
Developmental level >2SD below mean	30

SEN = Special Educational Needs.

SD = Standard Deviation.

MRI = Magnetic Resonance Imaging.

EEG = Electroencephalography.

parents of young children with epilepsy. This list of topics was piloted at focus groups attended by parents of children (five mothers and two fathers) with epilepsy in June 2015. These parents had already agreed to take part in the SEEN study. As a result of the piloting, the final interview schedule (Supplement 2) was developed to elicit parent experiences and needs of having a child with early onset epilepsy. To capture a range of responses, initial topic questions were broad, but then, the interviewer was encouraged to use a variety of prompts to amplify response where necessary. All participants were offered the choice of being interviewed in person or via telephone.

2.4. Collection of interview data

A research psychologist (CJ) conducted the interviews via telephone ($n = 23$) or in the participants' homes ($n = 17$). The mean duration of interviews was 19 min (range: 5–67 min) and a median of 16 min (full details in Supplement 3). The interviews took place between September 2015 and May 2016.

2.5. Analysis

Baseline characteristics and clinical data of the children are described using descriptive statistics. The audiotaped semistructured interviews were transcribed verbatim (in one case, translation was required from Polish to English).

The interviews were then systematically analyzed by two raters (CR and CJ) using thematic analysis.

Thematic analysis is a method for identifying and subsequently analyzing and reporting patterns or themes with data [14]. The process of thematic analysis began with the two raters (CR and CJ) familiarizing themselves with the data generated from the interviews. All the transcripts were read through in their entirety by both researchers. At this stage, both researchers took notes to hint at possible semantic themes/subthemes. The next phase of analysis involved the generating of initial codes [15]. This involves the production of initial codes from the data that appear interesting and refer to the most basic segment of the raw data or information that can be assessed in a meaningful way regarding the phenomenon [14]. Coding was performed manually using numerical codes to identify potential patterns.

The next stage involved sorting out the different codes into potential themes/subthemes and collating all the relevant codes within the identified themes/subthemes [15]. It was agreed to organize the codes into six themes, and each theme had at least two subthemes. The data were then blindly rated by both researchers using the generated codes and themes on three separate occasions. After each occasion, the raters met to discuss discrepancies i.e., lack of agreement regarding where a response should go in terms of themes/subtheme, and agreement was reached before the next coding. The final coding was performed unblinded by both researchers together in order to facilitate agreement on themes and subthemes, and it is this final assignment of themes/subthemes which is reported on here.

The approach adopted in the current research can be considered 'inductive' as opposed to 'theoretical' as the data were analyzed without trying to fit it into a preexisting coding frame or the researcher's analytic preconceptions [15]. Additionally, themes were identified at a semantic or explicit level and not at a latent or interpretative level. With a semantic approach, themes are identified within the explicit or surface meanings of the data and not beyond what a participant has said [15].

2.5.1. Ethical approval

The study was approved by the Westminster Research Ethics Committee and was registered with the collaborating hospital primary care organization: The Sussex Community NHS Trust.

3. Results

Six major themes with associated subthemes were identified: (1) diagnostic journey, (2) parental perception of epilepsy management, (3) awareness and impact of associated neurobehavioral difficulties, (4) inconsistent availability of therapeutic and educational supports, (5) impact on family functioning, and (6) the need for parental support. The six themes, their associated subthemes, and the frequency with which they are mentioned are shown in Table 2. Quotes from participants are used to illustrate the themes.

3.1. Theme 1. Diagnostic journey

Gaining a diagnosis of epilepsy can be challenging and difficult to understand according to the parents who were interviewed. While many parents felt the experience was positive, some felt they needed more information and time with the diagnosing physician. Some parents report that they "migrate" (Mother, Child 14) to the internet, which can be "scary" (Mother, Child 14).

3.1.1. Subtheme: epilepsy could have been identified sooner

At the time of initial seizure onset, some parents reported that it was a challenge to get a diagnosis of epilepsy. They often reported that their child was seen by a number of different doctors before their child accessed a professional knowledgeable about epilepsy who subsequently diagnosed their child. Parents were often frustrated that initial contact with medical professionals had resulted in their concerns regarding the child's possible epilepsy or developmental delays not being taken seriously.

3.1.2. Subtheme: epilepsy identified quickly

Parents who gained a diagnosis quickly were often those who had children who were already in hospital or seen regularly by their pediatrician because of a related neurological or neurodevelopmental condition. Parents found that once they had access to a knowledgeable professional, things became clearer, and they could understand their child's difficulties better.

3.1.3. Subtheme: epilepsy diagnosis was overwhelming

A small number of parents reported feeling overwhelmed by the diagnosis and found it difficult to process. Some of these parents received a diagnosis of an epilepsy syndrome associated with significant developmental impairment and found it difficult to process both the epilepsy and likely developmental impairment.

3.1.4. Subtheme: need for more information as the initial information was not comprehensive

Parents reported information to be limited with one mother saying "No I have never really been told anything comprehensive to be honest. We need more than books on epilepsy, we need time with a professional who can explain everything". (Mother, Child 6). Parents often sought further information via the internet after diagnosis. However, the search results often came up with worst-case scenarios that scared parents.

3.2. Theme 2. Parental perception of epilepsy management

Having gained a diagnosis of epilepsy, parents then want to understand treatment options and in particular, possible side effects of AEDs. They also want, where possible, one physician to manage both their child's epilepsy and associated comorbidities.

3.2.1. Subtheme: lack of explanation and understanding of treatment and possible side effects

Parents understood the importance of treatment and why their child needed to take AEDs but felt there was a lack of explanation of certain

Table 2
Themes and subthemes identified in parental interviews in the Sussex Early Epilepsy and Neurobehavior (SEEN) study.

Themes	Subthemes	Quotes
Diagnostic journey	Epilepsy should have been identified sooner	“Its good when you get it but you know you have to wait so long for it, to get to the right person and get to the top of the right list, that’s the frustrating part, when you actually get to the top of the list I think medically its good but we had so many false starts as we were referred to professionals who were not epilepsy experts” (Mother, Child 16). “I am afraid that the doctor did not listen to us. They must listen to us. We went back about 4 times and then I demanded to see a paediatrician and then they did an EEG and discovered that she had epilepsy but it was me who pushed. They need to listen to us properly and we can help the doctors and work together but only if they listen” (Mother, Child 31).
	Epilepsy identified quickly	“We were lucky that we for referred to the right person. The doctor explained it in its clearest sense and was magnificent and her information was brilliant, we couldn’t have asked for a better source of information really” (Father, Child 23).
	Epilepsy diagnosis was overwhelming	“It all happened with the diagnosis so quickly so it was hard to process it and it would have been better if it had happened a bit slower” (Father, Child 4).
	Need for more information as initial explanation was not comprehensive	“I don’t think they had enough knowledge about epilepsy and I still feel I am kind of in the dark about epilepsy” (Mother, Child 21). “Of course you go home after the diagnosis and look on the internet and see what is involved and it frightened the hell out of me” (Mother, Child 2).
Parental perception of epilepsy management	Lack of explanation and understanding of treatment and possible side effects	“No it was just like have this medication and then when I said about her behaviour and it was like oh yes that can happen, because I mean every medication has such long lists of side-effects doesn’t mean it’s for everyone so I don’t really like to read them but teasing out what is real behaviour and what are the meds is hard” (Mother, Child 17).
	Need for integrated healthcare	“We got told from the beginning we could either have a behavioural paediatrician or an epilepsy paediatrician and because his behaviour was a big concern where as his seizures weren’t as frequent... we went for behavioural doctor rather than the epilepsy and it felt like you could have either or you can’t have both you know and he should have had both” (Mother, Child 13).
Awareness and impact of associated neurobehavioral difficulties	Lack of information/awareness of associated neurobehavioral difficulties	“They did mention a possible link with learning but they didn’t really explain it they said it can possibly cause the children problems, but they didn’t really go into detail about what it could cause and they need to explain better what causes what and what problems to look out for” (Mother, Child 5).
Inconsistent availability of therapeutic and educational supports	Neurobehavioral difficulties often have more impact on child wellbeing	“His seizures are under control now so I don’t think they are affecting him anymore. His behaviour however, is hard to manage and affects him greatly” (Mother, Child 29).
	Inadequate educational or therapeutic provision	“Yes now that I have fought for what I believe he needs, I love the school they are really attentive but the support they now are implementing is as a result of me hassling the educational department for a year” (Father, Child 23).
Impact on family functioning	Long waits for assessment and intervention	“There are a lot of steps in the education system to get the right support. You know what your child needs and the professionals often know as well but there are lots of visits and assessments before the help comes it is just really like a waiting game really” (Mother, Child 9).
	Impact on parental and sibling sleep	“When we are having a bad period like now, its about everybodys’ sleep being affected, you know my 7 year old being woken up with her brother erm.. crying at 3 and 4 in the morning” (Mother, Child 37).
	Impact of child’s ‘challenging’ behavior and developmental delay	“The family is kind of at breaking point. We can’t get out or do anything you know. And it was just there is nothing until there is a label, its (the supports) not based on the child’s needs” (Mother, Child 21).
	Restrictions on family activities due to seizures or associated difficulties	“It’s how her behaviour is now, you can’t have a normal family day out, you can’t do anything normal because of these meltdowns. We don’t do certain things or go certain places” (Mother, Child 7). “When she had really bad seizures we would stay with her in shifts you know so I would go for 2 days while my wife stayed here with the other two children and then we would have to swap you know, we had to do it at Christmas once and stay in on Christmas day, and everyone else went home apart from us which was, well it was necessary because at that time they couldn’t get her seizures under control but it’s heart breaking for the family when that happens” (Mother, Child 36).
Need for parental support	Negative financial/employment impact	“I only work 3 days because I always keep the two days open for hospital appointments because they (the appointments with health professionals) could happen anytime or they could land all together so trying to work it where I have those two spaces to play with so to speak so I don’t have to cut into my working hours” (Mother, Child 19).
	Future concerns for the child	“I’ve clung onto her (the doctor) saying they can grow out of epilepsy and I know they don’t know but that’s what I really hope for because she’s got so much going on but then you know it could get worse the epilepsy and the behaviour. What will we do if it gets worse? I don’t know how we will cope”
	Need for continued emotional/informational support	“We need regular contact, you know if there is someone to talk to, to ask questions and you know at first obviously its starts off every 6 weeks (doctor appointments) and then you kind of see them every 6 months and then it kind of there is a long time in between but in the beginning you feel like you need more help and support but you’re not directed to any support groups so you use the net for support” (Mother, Child 24).
	Support for managing behavior	“I feel with the behavior as a family we really need support and its only now that he has had the diagnosis (autism) that we are having someone come next week to discuss his behaviour, and I think there should be support before the diagnosis. It should be based on needs not on the label” (Mother, Child 18).

aspects. One mother said “We had obviously looked it up and researched what it was but no one has ever gone into any detail with us. Even to this day, he’s just started school and we had to give them his emergency medication. They have had a nurse to come in and give

full training and I am like I have never had training even though I am responsible when he is not at school” (Mother, Child 11). Parents often expressed concerns about possible impact of AEDs on their child’s behavior and learning and felt that they had not been adequately informed

about the possible impact of side effects. In particular, they struggled with differentiating the impact of AED side effects on behavior from behavior that was more enduring and likely to be neurodevelopmental in nature.

3.2.2. Subtheme: need for integrated healthcare

Parents reported that their child was often seen by a variety of doctors who focused on different aspects of their child's care and would have to see one pediatrician for one thing and another for something else. In particular, parents noted the need to see one specialist for their child's epilepsy and another specialist for neurodevelopmental concerns. They felt that because of this, care was often "not joined up", (Mother, Child 13), and there was a lack of understanding of the relationship between the child's epilepsy and child's behavior/development which they felt were often closely related.

3.3. Theme 3. Awareness and impact of associated neurobehavioral difficulties

Parents reported that despite frequent presence of additional neurobehavioral needs in the early onset epilepsies, the possible association between epilepsy and neurobehavior was often not considered or discussed with respect to their child's care. This was despite the neurobehavioral needs often having a greater impact on the child's everyday functioning.

3.3.1. Subtheme: lack of information or awareness of associated difficulties

Parents reported that they were not initially aware of the association between epilepsy and neurobehavioral difficulties but were surprised that their child's physicians had not commented on the potential association. Some became aware of the association only after concerns were expressed about behavior at school/preschool but not when their child was diagnosed with epilepsy. One mother explained "To say your child has got epilepsy is one thing but to pretend it's usually just about seizures is wrong. My child is now getting assessed for autism - there has to be a link" (Mother, Child 3).

3.3.2. Subtheme: neurobehavioral difficulties have more of an impact on child's wellbeing

Parents often reported that seizures were well-controlled and that the child's developmental or behavioral problems were having a bigger impact on their wellbeing. One mother said "His seizures are under control now. His behavior is what's frustrating, like when he goes outside he screams and we just want him to be more comfortable when he goes outside" (Mother, Child 13).

3.4. Theme 4. Inconsistent availability of therapeutic and educational supports

Parents reported that getting the necessary therapeutic or educational supports for their child was often challenging. They expressed the view that the supports are not always available when the child needs them, and there typically are "lots of processes you need to go through to ensure you child gets the support they need" (Mother, Child 8).

3.4.1. Subtheme: inadequate educational or therapeutic provision

Parents reported having to move their child from one school/preschool to another and fight to get the appropriate educational provision for their child. This was due to a lack of recognition of the child's neurobehavioral needs or a failure to manage the child's epilepsy in school/preschool. Some parents also felt that getting professionals to acknowledge their child's needs was difficult, and they had to "battle" (Mother, Child 28) to get assessments so that the child's developmental needs were adequately supported.

3.4.2. Subtheme: long waits for assessment and intervention

There was often a long wait for therapeutic assessments and subsequent interventions which parents found frustrating as they often felt "that the professionals know what is needed but the waiting lists are long and valuable time is lost" (Mother, Child 39).

3.5. Theme 5. Impact on family functioning

Almost all parents acknowledged the impact that epilepsy and associated difficulties had on family functioning.

3.5.1. Subtheme: impact on parental and sibling sleep

Parents indicated that their own sleep was affected by the child's sleep difficulties. Issues included that the child often slept in the parents' bed, the child frequently woke during the night, or the child had difficulty falling sleep. Parents also reported that sibling sleep was also affected with one parent reporting that an older brother had to be moved from a shared bedroom because of concerns that he going to sleep late would disturb the child with epilepsy's sleep.

3.5.2. Subtheme: impact of child's 'challenging' behavior and developmental delay

Parents report that the child's "challenging behavior" often led to "tension within the family" (Father, Child 11) regarding how best to respond to the behavior. Additionally, parents indicated that delays in child development led to a feeling of loss in that the child may not achieve the same milestones as children without such problems or had the life they had anticipated.

3.5.3. Subtheme: restrictions on family activities due to seizures or associated difficulties

Family holidays, going shopping together, and other family activities were often cancelled or rescheduled because of concerns about the possible impact of the child's epilepsy or associated difficulties on the activity. Parents indicated that for some children with frequent seizures, there was an increased need to monitor the child and care for the child after they had a seizure.

3.5.4. Subtheme: negative financial/employment impact

Mothers reported that they often had to restrict their employment because of increased care responsibilities accruing from the child's epilepsy or developmental needs.

3.6. Theme 6. Need for parental support

Parents wanted support not only in relation to managing the child's behavioral needs and future independence needs but also in relation to their own needs regarding informational and emotional support. They also wanted to feel that professionals listened to their concerns.

3.6.1. Subtheme: future concerns for the child

Some parents reported that they would like support regarding planning for their child's future particularly in the case of children who had significant developmental delay and were likely to have difficulty living independent lives.

3.6.2. Subtheme: need for continued emotional/informational support

The need for ongoing informational and emotional support was identified as key by many parents. Parents mentioned both parent support groups and internet forums as possible sources of support. Some parents reported that while they were satisfied with support at diagnosis, their need for ongoing support was not acknowledged, and they felt that they needed "someone at the end of a phone line to listen to their concerns about their child" (Mother, Child 12). A small number of children had access to epilepsy nurse support, and all parents

spontaneously mentioned this support as valuable with respect to parental support.

3.6.3. Subthemes: support for managing behavior

Many parents felt that a key support would be help for managing “challenging” behavior displayed by their child, “I just want someone to come to our home and see what we have to experience and then give us tips and strategies. It would help so much but this does not seem to be available” (Mother, Child 40).

4. Discussion

This study provides population-based data of the experiences and needs of parents of young children with epilepsy and as such, adds to our understanding of the wide-ranging impact of the early onset epilepsies. The six identified themes cut across the comprehensive psychosocial impact of early onset epilepsy on both the individual child and the family. The theme diagnostic journey highlights that for some children, diagnosis comes quickly after initial concerns, but for others, the journey to diagnosis is more challenging and may involve a frustrating wait before the child has contact with a medical professional knowledgeable about epilepsy. For some parents, the initial explanation of epilepsy is comprehensive, but others are left with a feeling that initial information given was not sufficient. This can lead to parents using online resources to search for further information about the child's epilepsy, and the online experience can be ‘scary’ for parents. Some parents felt that the explanation of the proposed treatment is not sufficient and that in particular, they would like to know more of the potential side effects of AEDs. Parents would also like information about the associated neurobehavioral comorbidities at diagnosis as these difficulties often have more of an impact on child wellbeing than the epileptic seizures. Parents bemoaned the often long wait for therapeutic inputs for their child's neurobehavioral difficulties and found securing appropriate educational provision a ‘battle’. The potential wide-ranging impact of childhood epilepsy on family functioning was highlighted by parents including the negative impact on parental and sibling sleep, restrictions on family activities, and negative impact on finances and employment. Parents would like continued emotional and informational support emphasizing that access to supports should extend beyond diagnosis and also encompass the wide range of neurobehavioral issues the child may have.

The diagnostic journeys reported by parents in the current study indicate that the pathway from parental-observed epileptic seizure to diagnosis is not always smooth. The National Institute for Clinical Excellence (NICE) in the UK recommends that children presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation (<https://www.nice.org.uk/guidance/qs27/chapter/Quality-statement-1-Referral-to-a-specialist>, accessed 27 November 2017). It appears that referral to a specialist may not be happening due to lack of recognition of seizures despite parental concerns, highlighting the importance for professionals based in the community to be able to recognize seizures and make appropriate referrals. At the end of the diagnostic journey, some parents were satisfied with the initial explanations while others felt that they required more time with the supporting medical professionals. This highlights the need for individualized approaches and the necessity to be able to refer parents to reliable sources of information. Parents should have access to epilepsy specialist nurses and also be directed towards suitable online resources.

Regarding understanding of epilepsy treatment, parents had a number of concerns regarding the use of AEDs and their potential side effects. Common side effects of AEDs include cognitive problems, fatigue/tiredness, motor problem, gastrointestinal complaints, and mood behavior problems [16]. There exists reliable measures of AED side effects in children [17], and discussing side effects with families may lead to dosing or medication changes which can optimize

treatment effects while minimizing side effects. An additional benefit to discussing potential side effects and monitoring side effects on an ongoing basis in a systematic way is that adherence to AED treatment could be improved [18].

The need for integrated care in childhood epilepsy expressed by parents echoes a proposed model of integrated epilepsy care [19] that highlights the need to consider seizure freedom not as the end goal but rather as one important outcome alongside others such as improved school attendance, educational attainment, and gainful employment. Given that neurobehavioral difficulties are often present prior to onset of seizures [20], asking about such difficulties in epilepsy clinics may help enhance parental understanding of the potential association and lead to efficacious assessment and treatment for the neurobehavioral difficulties. For epilepsy professionals, asking about neurobehavioral and other medical difficulties may help frame the child's needs as a coexpression of developmental brain disorders leading to effective multidisciplinary care and anticipatory guidance and counseling of parents [21].

Parents wanted to know about the association between epilepsy and neurobehavioral difficulties, but this was often not discussed. There is a substantial amount of evidence highlighting that children with epilepsy are a high-risk group [7,22], and it has been recommended that all children with epilepsy be screened for such difficulties [23]. Parental views that these additional difficulties often have a greater impact on quality of life echoes quantitative research studies which has shown that mental health difficulties and/or cognitive difficulties have often the greatest impact on Health Related Quality of life (HRQOL) [4,5]. Parental reports of difficulties accessing educational and therapeutic supports is backed up by research which shows that mental health and neurodevelopmental conditions are often not diagnosed in the context of childhood epilepsy [7]. Thus, having epilepsy may result in diagnostic overshadowing [7] with the need to treat seizures overshadowing possible recognition of the often present neurobehavioral difficulties. The responsibility to recognize the full range of needs in childhood epilepsy has led to calls for a paradigm shift in childhood epilepsy care [19] so that the full spectrum of potential difficulties might be recognized. Even though parents highlighted difficulties in educational provision, there remains a lack of guidelines regarding the management of children with epilepsy in schools.

Previous research has highlighted that parents of children with epilepsy – and mothers in particular – are at increased risk of reduced quality of life and increased mental health difficulties [8,9,24]. The current study builds on this and shows that having a child with epilepsy can have a wide-ranging impact on family functioning. Seizures and/or associated neurobehavioral difficulties can place restrictions on family activities. Parents talked about the importance of monitoring the child closely, echoing the need for ‘constant vigilance’ which has previously been reported in an interview-based study of caregivers with epilepsy [25]. The potential negative impact on family finances and employment was also mentioned and is in line with research showing that the onset of a chronic long-term condition adversely affects family finances [26]. Low household resources impair parental capacity for supportive, stimulating, and consistent parenting leading to poorer mental health, intellectual development, and behavioral problems. Thus, it is important that parents of children with epilepsy can access all available supports to mitigate the potential for these effects [27].

In the current study, parents expressed a desire for continued informational and emotional support beyond the child's epilepsy diagnosis. Parents reported often using online support groups and liked that they could direct their searching as opposed to “just reading a book”. Given that parents use online resources to access information and support it is important that they have access to quality resources. Parents also mentioned concerns regarding their child's future and talked about the uncertainty surrounding the prognosis in epilepsy, an uncertainty which has previously been reported [25]. Parents want to feel listened to, highlighting the need to include parents in decision-making in

epilepsy [19]. The desire for support with managing the child's behavior indicates the importance of developing evidence-based interventions for emotional and behavioral needs in young children with epilepsy.

4.1. Future research directions

The responses of parents lead to a number of possible research directions. Research initiatives must now focus on how best to inform parents of the nature of both epilepsy and associated conditions as well as how best to support parents informational and emotional needs after diagnosis. While there are some good examples of psychoeducational interventions in childhood epilepsy [28], these should also be adapted for digital use and subsequently evaluated. There is also a need to investigate the best ways to support parents to navigate the health and education system so as to access effective educational and therapeutic provision. Research on epilepsy and associated conditions must take a wider focus with measures of parent and family functioning being included. While there are some studies focusing on management of neurobehavioral difficulties in children with epilepsy [29,30], these have not focused on younger children, and thus, there is a need for research in this area. The frustrations parents reported regarding their child's current or previous educational provision highlights the importance of better understanding the experiences of children with epilepsy in the school system. Research focusing on the identification of potential barriers to inclusion and participation may lead to suggestions that can improve the experience of the children in educational settings.

4.2. Limitations

There are a number of limitations that need to be considered when interpreting the results of the current study. The majority of respondents were mothers, and the views of fathers may differ. Some of the interviews were conducted in person and some via the telephone, and this may affect participants' responses in terms of content and length.

The children in the study were aged between one and seven years, and our findings may not be of relevance for younger children or children over seven years of age. The study is based in a defined geographical region of the UK, and although the UK has a national healthcare system, our findings may not generalize to other parts of the UK or further afield.

5. Conclusion

Parents of young children with epilepsy report a wide range of experiences and needs that emphasize the wide-ranging impact of early onset epilepsy on both child and family functioning. The diagnosis of epilepsy is often delayed, and at diagnosis, some parents feel that explanations are insufficient highlighting the need to improve access to knowledgeable medical professionals. They often reported lack of information about associated developmental and behavioral difficulties, which often have a greater impact on child and family wellbeing, emphasizing that child neurobehavior should always be considered in epilepsy. The comprehensive psychosocial impact reported by parents highlights the needs for family-centered holistic integrated care and the need for ongoing informational and emotional support.

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Conflict of interest

Professor Brian Neville was a Trustee of the George E Neville Foundation. None of the remaining authors have any conflict of interest to declare. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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