

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

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Abstract

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; 23male, 17 female) with 'active' epilepsy (had a seizure in the last year or taking AEDs) were interviewed either in person or over the telephone using a semi-structured 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 centred care.

1. Introduction

The early life epilepsies are often associated with both frequent epileptic seizures¹ and a high frequency of developmental and epileptic encephalopathies². Additional neurobehavioral difficulties include cognitive, behavioral (including autism and 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 for mental health difficulties^{8,9} and difficulties with sleep and fatigue¹⁰.

The need for qualitative research in childhood epilepsy has been identified as crucial to deliver a greater depth of understanding of 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 siblings¹¹. Despite the potentially very significant impact on family functioning there is limited data on the experiences and needs of parents of young children with epilepsy. One previous interview based study from a paediatric neurology clinic in southern USA suggested that parents found it difficult to obtain accessible information to understand better their child's diagnosis and treatment¹³. Additionally, parents wanted access to professionals who were knowledgeable about the medical, developmental, emotional and family issues related to coping with epilepsy in young children¹³. 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 focussing 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 semi-structured 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 semi-structured interview schedule. The data was analysed 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 hours 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 paediatrician on the research team. All paediatricians in the study area were asked to inform the link paediatrician of 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 paediatrician. 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% CI 1 in 285-476). 49 parents returned an 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 figure 1). In the case of 31 of the children the mother was the sole respondent, the father was the sole respondent 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 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 minutes (range 5-67 minutes) and a median of 16 minutes (full details in supplement 3). The interviews took place between September 2015 and May 2016.

2.4 Analysis

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

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

Thematic analysis is a method for identifying and subsequently analysing and reporting patterns or themes with data¹⁴. 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 codes¹⁵. 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 phenomenon¹⁴. 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/subthemes¹⁵. It was agreed to organise 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 was analyzed without trying to fit it into a pre-existing coding frame, or the researcher's analytic preconceptions¹⁵. 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 said¹⁵.

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 3. Quotes from participants are used to illustrate the themes.

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).

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.

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 paediatrician 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.

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.

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 which scared parents.

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.

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 lack of explanation of certain 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.

Subtheme: Need for integrated health care

Parents reported that their child was often seen by a variety of doctors who focussed on different aspects of their child’s care and would have to see one paediatrician 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.

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.

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).

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).

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).

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.

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).

Theme 5: Impact on family functioning

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

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 due to concerns that he going to sleep later would disturb the child with epilepsy's sleep.

Subtheme: Impact of child's 'challenging' behavior and development 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.

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 due to 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 that there was an increased need to monitor the child and care for the child after they had a seizure.

Subtheme: Negative financial/employment impact

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

Theme 6: Need for parental support

Parents wanted support 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 that professionals listened to their concerns.

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.

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.

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 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 emphasising 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 indicates 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 recognise seizures and make appropriate referrals. At the end of the diagnostic journey, some parents were satisfied with initial explanations whilst others felt that they required more time with the supporting medical professionals. This highlights the need for individualised 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 problems¹⁶. There exists reliable measures of AED side-effects in children¹⁷ and discussing side-effects with families may lead to dosing or medication changes which can optimise treatment effects while minimising 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 improved¹⁸.

The need for integrated care in childhood epilepsy expressed by parents echoes a proposed model of integrated epilepsy care¹⁹ which 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 seizures²⁰ 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 co-expression of developmental brain disorders leading to effective multidisciplinary care and anticipatory guidance and counseling of parents²¹.

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 difficulties²³. 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 epilepsy⁷. Thus, having epilepsy may result in diagnostic overshadowing⁷ with the need to treat seizures overshadowing possible recognition of

the often present neurobehavioral difficulties. The responsibility to recognise the full range of needs in childhood epilepsy has led to calls for a paradigm shift in childhood epilepsy care¹⁹ so that the full spectrum of potential difficulties might be recognised. 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 epilepsy²⁵. 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 finances²⁶. 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 effects²⁷.

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 reported²⁵. Parents want to feel listened to, highlighting the need to include parents in decisions making in epilepsy¹⁹. 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 epilepsy²⁸ 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 focussed 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 focussing 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 affected 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 health care system our findings may not generalise to other parts of the UK or further afield.

5. Conclusion

Parents of children with young epilepsy report a wide range of experiences and needs which emphasise 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, emphasises that child neurobehavior should always be considered in epilepsy. The comprehensive psychosocial impact reported by parents highlights the needs for family-centre holistic integrated care and the need for ongoing informational and emotional support.

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