

Epilepsy in schools: Views on educational and therapeutic provision, understanding of epilepsy and seizure management.

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Abstract

Objective: To gain an understanding of the views of young people with epilepsy, their parents and school staff regarding educational and therapeutic provision, understanding of epilepsy and seizure management in schools.

Methods: School-aged children (n=20) with 'active epilepsy' (taking Anti-Seizure Medications (ASMs) for epilepsy), their parents (n=68) and school staff (n=56) were interviewed or completed bespoke questionnaires. In addition, all participating children underwent psychological assessment including measures of behaviour and cognition.

Results: Only 15% of participating children had received psychological support despite 60% scoring within the at-risk range on a measure of behavioral and emotional difficulties. More than half of the responding children reported that some of their teachers and friends did not know that they had epilepsy. A significant minority of parents (32%) did not feel that the child's transition from preschool to primary, or primary to secondary school was managed well. Knowledge of the child's epilepsy was felt to be significantly better in special schools than mainstream schools according to both parents and school staff. Staff in special schools perceived they were more knowledgeable about the child's ASMs and changes to ASMs than staff in mainstream schools. Staff in special schools were significantly more likely to have received training on general aspects of epilepsy, seizure management and impacts on learning and/or behaviour. Parental interviews indicated difficulties accessing educational and therapeutic supports. Parents often felt that they had to drive the process to gain supports themselves. They also reported limited professional support, and inadequate communication between themselves and the school and school staff and medical/therapeutic professionals regarding their child's needs. Parents would like more school staff to recognise the impacts of epilepsy on learning and behavior and to support their child more holistically. Many parents wanted more resources for assessment and therapeutic provision in relation to their child's learning, behavior and emotions.

Conclusion: Knowledge of epilepsy is felt by parents and staff to be significantly better in special schools compared with mainstream schools. Parents highlighted the need for increased knowledge of the impacts of epilepsy on learning and behaviour and perceived a need for more resources for assessment of these difficulties.

1. Introduction

Difficulties in school as evidenced by provision of additional educational and therapeutic supports - are common in children with epilepsy (CWE)¹. These difficulties arise from the often associated cognitive, emotional-behavioural, motor and academic difficulties^{2,3}. These additional difficulties can have a greater impact on health-related quality of life (HRQoL) than epileptic seizures^{4,5}, and contribute most to the economic cost of the condition⁶. However, the difficulties are often unrecognized⁷ and remain unsupported⁸ despite having a very significant impact on school performance³.

In addition to learning and behavioural difficulties, CWE may also face barriers arising from negative attitudes towards epilepsy and lack of knowledge regarding seizure management. A systematic review of teacher knowledge and attitudes revealed that deficits in knowledge and negative attitudes were pervasive across all studies⁹. From a list of seven medical conditions, teachers reported lowest familiarity with epilepsy¹⁰. Additionally, studies have highlighted teachers' concerns about emergency procedures for students with epilepsy, apprehension in responding to seizures, a lack of resources and knowledge for meeting the needs of a child experiencing a prolonged convulsive seizure, and a fear of liability^{11,12}.

Given the potential wide-ranging impact of epilepsy on a child's education it is important to systematically research educational and therapeutic provision, understanding of epilepsy in schools and aspects of seizure management in schools. Despite the comprehensive impact of epilepsy on school functioning, there is a lack of systematic research on the views of children, their parents and teachers regarding schooling for CWE. The 'What I Need in School' (WINS) - Experiences of children with epilepsy in schools' study focusses on the experiences of CWE, their parents and teachers in schools in a defined geographical area of the United Kingdom (UK). The aims of the current study were to describe educational and therapeutic provision, understanding of epilepsy and seizure management in a population-based sample of school-aged CWE.

2. Methodology

All children born between 2003 and 2014 with 'active' epilepsy (prescribed one or more anti-seizure medication (ASM) for epilepsy) who were resident in the RH10 to RH13 postal districts of the county of West Sussex in the south of the United Kingdom between April 2018 and December 31st, 2019 were eligible for inclusion. Children born before 2003 or after 2014, and/or who did not have 'active' epilepsy were not eligible for inclusion. Children, their parents and teachers participated between 11th September 2018 and 17th March 2020.

The prevalence of 'active' epilepsy in the study area was calculated by using the mid-2010 population estimates of 4 to 15-year-olds (32 212) and 5 to 16-year-olds (32 617) provided by the Office of National Statistics (total mid-2010 population 202 919). The prevalence of 'active' epilepsy in the study area during the study period was 4.20 per 1000 (1 in 238, 95% CI 1 in 200 to 1 in 285) or 0.42%.

2.1 Recruitment of children

Eligible children with 'active epilepsy' were identified at the two paediatric hospitals in the study area and recruited between 21st December 2017 and 31st December 2019. All children had to have had two unprovoked epileptic seizures more than 24 hours

apart and be taking ASMs for their epilepsy. Eligible children were identified and verified by two link paediatricians (community paediatricians with a special interest in epilepsy) and a registrar working at a specialist centre for children with epilepsy.

At one of the participating hospitals the parents of eligible children were approached by their supporting paediatrician, informed about the study and given an interest form. At the other participating hospital some parents of eligible children were approached by the supporting paediatrician, others by an epilepsy support nurse and some via a letter sent to their home address. Additionally, an online portal was created whereby the parents of eligible participants could independently contact the research team and indicate an interest in participating in the study. All parents who were approached were offered a study interest form and asked to complete and return the form if they wished to learn more about the study. All parents who returned a form were contacted by a research psychologist via telephone and subsequently met in their home if they wished to participate. At this informed consent meeting, the study was described in detail and parents were asked for written consent for entry of their child into the study. Participating children, where developmentally appropriate, also gave assent. Anonymized information was obtained on non-participants who met inclusion criteria (n=68), including data on sex, ASM usage, deprivation index, ethnicity, age at median point in study, age of diagnosis/first seizure.

2.2 Measures

Child-, parent- and school staff-report questionnaires and child and parent interview schedules were developed in partnership with CWE, their parents and staff. Based on clinical experience and published research, study investigators developed possible topics for the questionnaires/interview schedules, to elicit perspectives on seizure management and educational provision. This list of topics was piloted at focus groups and through interviews. The piloting process involved five CWE (four attending a mainstream school, one attending a special school), seven parents (five with children attending mainstream schools, two with children attending special schools), eight teachers (four teaching at mainstream schools, four at special schools) and one school nurse (working at a special school) (see supplement 1). Focus groups and interviews were conducted between May and July 2018. Parents participating in focus groups had already agreed for their child to take part in the WINS study. As a result of the piloting the final interview/questionnaire schedules were developed (see supplement 2).

Participants who completed the written questionnaire measures did so independently or with the assistance of a research psychologist. In addition to the written questionnaires, parents were also asked a series of open-ended questions by way of an audio-recorded interview. The interview questions analysed were 'Please describe the process of securing educational or therapeutic supports for your child in school' and 'What changes, if any, would you make to your child's current educational or therapeutic provision?'. School staff completed their questionnaire measures independently. CWE were given the option of being audio-recorded as a research psychologist asked them questions from the questionnaire booklet, having their answers transcribed without audio-recording or completing the questionnaire independently. Questionnaires included questions with 'yes/no' responses and four-point Likert-type responses ranging from 'strongly agree' to 'strongly disagree'.

In addition to the interview/questionnaire measures, CWE underwent psychological assessment including measures of cognition/development and behavioural/emotional difficulties.

2.3 Analysis

Baseline characteristics of participating CWE, parents and teachers, and data obtained through child-, parent- and staff-reported questionnaire measures were analysed in terms of frequencies and mean averages and are reported as descriptive statistics. For analysis, Likert-type scale variables were condensed as follows – ‘strongly agree’ and ‘agree’ condensed into ‘agree’, and ‘strongly disagree’ and ‘disagree’ into ‘disagree’. Chi-squared tests were used to compare special and mainstream provision on relevant teacher and parent questions. The alpha level for all analyses was $p < 0.05$. All analyses were performed with IBM SPSS version 25.0 (Armonk, NY, USA).

Thematic analysis

The open questions from the parental interview were analysed using Thematic Analysis¹³ by two research psychologists (EJ and CR). All the transcripts were read in their entirety by both researchers. The next stage involved the generating of initial themes that appeared interesting¹³ from the data, and referring to the most basic segment of the raw data or information that can be assessed in a meaningful way regarding the phenomenon¹⁴. The next stage involved sorting out the different initial into potential themes/subthemes and collating all the data within the identified themes/subthemes¹³.

The data from the parental interviews were then blindly rated by the two researchers using the generated codes and themes on three separate occasions. After each occasion, the researchers met to discuss disagreements i.e., lack of consensus regarding where a response should go in terms of themes/subtheme, and agreement was reached before the next coding. The final coding was performed un-blinded by both researchers together in order to facilitate consensus on theme/subthemes, and it is this final rating of themes/subthemes which is reported on. The approach to Thematic Analysis adopted in the current research is ‘inductive’ as opposed to ‘theoretical’ as the data were analyzed without trying to fit it into a pre-existing coding frame or the researchers’ analytic preconceptions¹³. 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 said¹³.

2.4 Ethical Approval

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

3. Results

3.1 Characteristics of the sample

During the study period, 136 children with ‘active’ epilepsy were identified in the study area (see Figure 1). 68 families agreed to participate. There were no significant differences between the participants ($n=68$) and non-participants ($n=68$) with respect to gender ($p=0.441$), current number of ASMs ($p=0.074$) or deprivation ($p=0.872$),

However, participants had a significantly younger age of epilepsy onset (mean=3.81years) than non-participants (mean=7.46) ($p=0.015$). The main characteristics of the children, parents and school staff who participated in the WINS study are shown in Table 1, Supplement 3a and 3b respectively.

Twenty of 68 (29%) child participants were able to complete the study questionnaire/were interviewed. Of these 20, 12 (60%) were interviewed by a research psychologist (EJ) and audio-recorded. Eight children (40%) did not wish to be audio-recorded but completed the questionnaire booklet themselves. Of the 48 children who did not respond, nine (18.7%) were deemed too young to understand the questions and 31 (64.6%) were unable to respond due to their level of cognitive functioning. Two children (4.1%) did not wish to respond because of perceived worry/anxiety, and three (6.3%) declined without providing a reason. Three children (6.3%) did not have the opportunity to respond due to the COVID-19 pandemic restrictions i.e. it was not possible to meet the child. In terms of parental respondents, 61 (90%) were mothers and 7 (10%) were fathers. Fifty-six teachers participated in the study (see supplement 3b).

3.2 Cognition and behaviour

Fifty-four children (80.6%) had an intelligence quotient/developmental quotient (IQ/DQ) score of 85 or less and 40 (59.7%) had an IQ/DQ score corresponding to intellectual disability (IQ/DQ of 70 or less).

Based on parental-report, 25% of children had a previous diagnosis of Autism Spectrum Disorder (ASD), 16% had Attention Deficit Hyperactivity Disorder (ADHD), 9% had Developmental Coordination Disorder (DCD) and 10% had Cerebral Palsy (see table 2). On the parent-reported Strengths and Difficulties Questionnaire (SDQ) 65% of the children scored in the at-risk range for behavioural and/or emotional difficulties. The proportion of children with a parent-reported diagnosis of ASD ($p=0.001$) and DCD ($p=0.007$) was significantly higher in special schools but there was no difference for ADHD or proportion scoring in at-risk range on the SDQ (see table 2).

3.3 Educational and Therapeutic Provision

Thirty-six participating children (52.9%) attended mainstream schools, and 32 (47.1%) attended special schools. Parent-report indicated that 44 children (67.7%) had Individual Healthcare Plans (IHPs) and 38 (56.7%) had Education and Healthcare Plans (EHCPs) (see table 2). An EHCP is for children and young people who need more individual support than is available through special educational needs support in schools in England.

The majority of children were, or had been previously, in receipt of speech and language therapy (79%) whilst approximately half were or had been in receipt of occupational and/or physiotherapy. Fifty-three percent had undergone a psychological assessment but only 15% were, or had been, in receipt of psychological therapy and none had psychiatric assessment or treatment. Only 9% had assessed or treated by Child and Adolescent Mental Health Services (CAMHS).

Children attending special schools were significantly more likely to have an EHCP ($p<0.001$), have received physiotherapy ($p=0.001$), occupational therapy ($p<0.001$) or

speech and language therapy ($p < 0.001$) and have had a psychological assessment ($p = 0.003$). There were no significant differences between children attending mainstream and special schools with respect to provision of IHPs, receipt of psychological treatment and/or assessment or treatment by CAMHS.

3.4 Understanding of epilepsy

3.4.1 Communication of information regarding child's epilepsy diagnosis (see table 3)

Ten children (50%) reported that their epilepsy was explained to them by their parents. Eight (40%) learned of their diagnosis from a doctor (see table 3).

Thirty-four parents (51%) reported that they informed their child of their epilepsy diagnosis. Twenty-one parents (31%) stated that a doctor explained epilepsy to their child and six (9%) stated the diagnosis was explained by a nurse. Twenty-four parents (36%) reported that it was not applicable for their child to have their epilepsy diagnosis explained to them due to their level of cognitive functioning (see table 3)

Forty-five parents (68%) whose children had transitioned to new schools after being diagnosed with epilepsy agreed that the transition was managed well, whilst 32% felt that it was not. Thirty-six (62%) parents agreed that the transfer of knowledge between schools was effective whilst the remaining 38% felt that knowledge transfer was not effective. There was no significant differences between parents of children attending special and mainstream schools.

Twenty-eight teachers (52%) were informed of their student's epilepsy diagnosis by the child's parents. Thirty-one (57%) learned of the child's diagnosis via a colleague, 10 (19%) via the child's previous school and 11 (20%) were informed by a nurse. Forty-seven teachers (92%) agreed that communication regarding the child's epilepsy diagnosis was effective and there was not a significant difference between teachers in special and mainstream schools.

3.4.2 Perceived Epilepsy knowledge among school staff and students (see table 3)

Five children (26%) believed that all their teachers were aware of their epilepsy diagnosis, and 13 children (68%) believed that only some of their teachers knew they had epilepsy. Eight children (42%) stated that all their friends were aware of their epilepsy diagnosis (see table 3).

Forty-six parents (74%) agreed that their child's class teacher had a good understanding of epilepsy, and 53 parents (80%) agreed that the wider body of staff at their child's school had a good understanding of epilepsy. Parents of children in mainstream schools were significantly more likely to agree that the child's teachers ($p < 0.001$) and school staff were knowledgeable about epilepsy ($p = 0.002$).

Forty-three staff (92%) agreed they were knowledgeable about epilepsy in general, and 45 teachers (83%) agreed they were knowledgeable about their participating student's epilepsy. Forty-four staff (81%) agreed that knowledge of epilepsy across the wider body of staff at their school was good. Thirty-seven staff (67%) reported being aware of the ASMs the child was taking, and 41 staff (73%) said they were informed of any changes. Staff in special schools were significantly more likely to report that they

were knowledgeable about the CWE in their class ($p=0.020$), knowledgeable about the child's ASMs ($p=0.009$) and that they were informed of changes in ASMs ($p=0.003$).

3.5 Management of epilepsy in school

3.5.1 Management of epilepsy and seizures in the school environment (see supplement 4)

Responses regarding management of seizures in school are in supplement 4. Eight children (40%) reported having had a seizure at school. Regarding the person who helped them most with their epilepsy in school the children mentioned a range of different individuals (see supplement 4).

Fifty-five parents (82%) reported that, if their child had a seizure at school, there was a management plan that staff would follow. Seventeen parents (25%) stated their child's teacher would call an ambulance and 37 parents (55%) reported the teacher would call the parent. Fifty-four parents (89%) agreed that school staff were competent at helping their child if/when they were having a seizure. A greater proportion of parents of children in special schools agreed that staff were competent at helping their child but this did not reach statistical significance.

Forty-six teachers (87%) reported knowing how to manage their student's seizures and 49 teachers (94%) stated that their school had a seizure management plan in place. There were no significant differences difference between mainstream and special school teachers.

Forty-four teachers (79%) reported that they would follow the management plan if the child were to have a seizure at school, 21 teachers (38%) would call an ambulance and 31 (56%) would call a parent. In 32 instances (63%) the class teacher was identified as the key member of staff responsible for managing the child's epilepsy. In 24 cases (47%) the school nurse was responsible, and in 14 cases (28%) the Special Educational Needs Coordinator (SENCO) was responsible. Thirteen teachers (25%) reported using seizure diaries to document seizures during the school day.

3.5.2 Epilepsy and seizure management training in schools (see table 4)

Responses regarding training in epilepsy and seizure management are in Table 4. Thirty-seven parents (90%) whose children were prescribed emergency medicine reported that a member of school staff had received training regarding the administration of the medicine.

Thirty-seven teachers (66%) reported having received general training about epilepsy, and 34 (61%) had received training in seizure management. Twenty-five teachers (45%) reported having received training regarding the impact of epilepsy on learning and behavior. Significantly more teachers in special schools reported receiving training than teachers in mainstream schools for all three types of training.

3.6. Parental open questions

3.6.1 Describe the process of securing educational or therapeutic supports for your child in school

Five major themes with associated subthemes were identified with respect to parental views on the process of securing educational or therapeutic supports for their child in school. The themes, their associated subthemes, and illustrative quotes are shown in table 5.

3.6.1.1 Education and Health Care Plan (EHCP) process

Most parents found the EHCP process onerous and bureaucratic. They often felt that they were unsupported, being the sole advocates for their child throughout the process. For a small number of parents of children with severe or profound intellectual disability, EHCP applications were started early and often instigated by medical personnel or pre-school/primary school; in these instances the process appeared much smoother and parents felt supported.

3.6.1.2 Process of securing supports in school

Parents of children in mainstream schools reported that it often took a long time for the school to recognize their child's learning and behavioral needs and subsequently put support in place. In some cases this resulted in the child not attending school for a period of time.

3.6.1.3 Therapeutic provision process

The majority of parents reported difficulties in accessing needed therapeutic provision, including long waiting lists and inconsistent access. Some parents resorted to private providers due to perceived problems in accessing services in the National Health Service (NHS). For children attending special schools access was often much smoother.

3.6.1.4 Inadequate communication /supports

Parents often felt that they were not informed of progress regarding the acquisition of supports for their child in school and also regarding the child's learning progress and daily activities in school. They also reported a lack of communication between health and educational sectors and also a lack of communication with respect to the annual change of teachers.

3.6.1.5. Negative impact of processes on families

Most parents reported that the process of securing educational and therapeutic supports had a negative impact on the family. They often felt "helpless" and some felt that had to resort to legal recourse of private assessment and therapy for their children.

3.6.2 Desired changes to child's educational and therapeutic provision

Nine themes were identified based on parental views regarding desired changes parents would make to their child's current educational or therapeutic provision. The themes, their associated subthemes, and illustrative quotes shown are shown in table 6.

3.6.2.1 Better understanding of epilepsy at school

Many parents expressed a desire that school staff would have a better understanding of the link between epilepsy and learning and behavioural difficulties. They would also like both staff and peers to have a better awareness of possible triggers for the child's seizures and how child's seizures would likely present. Additionally, parents wanted all staff who work with child and not just the core team to be aware of the child's needs. Parents also felt that epilepsy is associated with stigma and would welcome efforts directed towards reducing this stigma among both staff and peers.

3.6.2.2 Better home-school communication regarding child's progress

Parents reported a need for better communication regarding their child's academic progress, what support they get and how they can help the child's learning and behaviour at home.

3.6.2.3 Increased adult support at school

Many parents identified their child's need for increased adult support in school including one-to-one and small group support, consistency of adult support and the need for adult support to extend beyond the classroom.

3.6.2.4 Assessment and therapeutic provision

In some cases parents felt that further assessment with the possibility of diagnosis would be very beneficial for their child. They also wanted therapeutic interventions to be delivered consistently as provision was often "patchy" with unexpected breaks between blocks of therapy.

3.6.2.5 Support for child's behavioural or emotional development

Some parents identified the need for increased support for the child's behaviour at home and at school. Additionally, a number of parents identified the need for the child to talk to someone regarding their experiences of living with epilepsy and also wanted some strategies to improve the child's confidence.

3.6.2.6 Child's schoolwork needs to be appropriate

Parents felt that expectations in school regarding the child's performance needed to reflect both the child's cognitive and behavioral profile but also how epilepsy can impact on their daily performance. They also emphasized the need for support strategies thought to be useful for CWE with additional learning needs to be incorporated into the child's programme to enhance their potential.

3.6.2.7 Non-academic learning

Parents, the majority of whom had children attending special schools, wanted their child to have more opportunities to develop life skills in school but also more integration with the community and mainstream peers.

3.6.2.8 Need for family-focused supports

Parents identified the need to consider the whole family with respect to supporting the child including increased access to respite, support in creating a safe home environment and need for suitable leisure activities for the child.

3.6.2.9 No changes needed

A small number of parents did not feel any changes to their child's current educational or therapeutic provision were needed.

4. Discussion

This study provides data of the experiences of children with epilepsy, their parents and staff in school and thus adds to our understanding of the impact of epilepsy on schooling. Despite a high level of parental-reported mental health difficulties many children are not accessing support for these difficulties. Whilst the vast majority of teachers agreed that communication of the child's diagnosis was effective, a significant minority of parents believed that transition and knowledge transfer was not optimal. Additionally many of the young people who replied did not believe that all teachers are aware of their epilepsy diagnosis. Perceived knowledge of epilepsy in general, the specific child's epilepsy and ASMs were significantly better in special than in mainstream schools according to both parents and teachers. Additionally, significantly more teachers in special schools reported receiving training on aspects of epilepsy. Parental interviews indicated that parents often face challenges in accessing needed therapeutic supports for their child. They also report inadequate communication regarding their child's progress in school and between health and educational professionals. Parents would like a better understanding of epilepsy at their child's school, better communication between home and school and increased adult support for the child at school. They would also like more support for assessment and therapeutic interventions for the child's learning and behavioral-emotional needs, and would like supports to be family-focussed.

One third of parents reported that that their child did not have an Individual Healthcare Plan (IHP). This is despite the fact that Department of Education in England mandates that all children with epilepsy attending school should have an individual IHP documenting the child's medical needs¹⁷. Lack of provision of IHPs is likely to lead to an inadequate understanding of the child's medical and educational needs and inadequate provision of support for those needs.

Just over half of the children in the current study had been assessed by a psychologist previously although children in mainstream schools were significantly less likely to have been assessed by a psychologist. The International League Against Epilepsy (ILAE) recommend that all children with new-onset epilepsy should be screened for difficulties with cognition and behaviour¹⁸. Lack of assessment by a psychologist is likely to lead to under-identification of learning and behavioral needs and subsequent lack of understanding, and is line with previous studies of children with epilepsy which have shown that many children are not assessed^{7,8,19}. Only 15% of the children had received psychological treatment and only 9% had been seen for treatment at a Child and Adolescent Mental Health Clinic (CAMHS) despite 65% scoring in the at-risk range on the SDQ²⁰, a well-validated measure of behavioural-emotional functioning. The lack of support for behavioral and emotional needs has previously been reported in children with epilepsy⁸ and is particularly concerning given that these difficulties often lead to the greatest reduction in health related quality of life. Additionally, there is evidence

that psychological therapies can reduce symptoms of behavioural and mental disorders in children with epilepsy^{21,22}.

Regarding communication of the child's epilepsy diagnosis, most teachers and parents felt that it was effective which is positive. However, a significant minority of parents felt that when the child was transitioning between schools communication and transfer of knowledge were not optimal. These concerns highlight the need to for effective communication at times of transition. Half of teachers reported that they learned of the child's diagnosis from the child's parents. However, a previous study noted that staff may only feel confident dealing with epilepsy when someone perceived to be an expert in epilepsy visits that school²³. Responding children indicated that they believed that not all of their teachers or friends knew they had epilepsy. Teachers not being aware of the child's epilepsy diagnosis could have significant implications with respect to seizure management and also regarding their understanding of the child's learning and behavioral needs. Another possibility with regard to teacher and peer awareness is that children may have not disclosed their diagnosis. Children with epilepsy may be reluctant to disclose a diagnosis because of felt and enacted stigma which is perceived to lead to social exclusion and teasing/bullying²⁴. Although the majority of parents believed that their child's teachers and staff in general were knowledgeable about the child's epilepsy, there was a higher level of perceived knowledge in special schools. This was echoed in teacher responses. Lack of knowledge in mainstream schools could lead to poorer experiences for children with epilepsy and lack of awareness of appropriate support among staff. Knowledge of the child's current ASMs and changes to ASMs among teachers was also perceived to be higher in special schools. Side-effects of ASMs can include tiredness, memory difficulties, stomach complaints and mood²⁵, all of which can affect a child's performance and wellbeing in school and therefore knowledge of ASMs and related changes would be important for school staff.

The majority of parents felt that teachers would know what to do in the event of a seizure and the majority of school staff reported the same. Despite this, approximately one in five parents and one in five teachers indicated that the child's seizure management plan would not be followed in the event of a seizure, suggesting that teachers may lack confidence in the child's plan. Additionally, one in four parents and nearly 40% of teachers would call an ambulance in the event of the child having a seizure despite this usually only being necessary when the seizure cannot be stopped by the use of emergency medication. Previous research suggested that one in three epilepsy professionals believed that lack of confidence and fear of liability were barriers to administering emergency medication in schools²⁶, whilst teachers who had received training reported feeling confident in administering emergency medication²⁷. Teachers in special schools were significantly more likely to have received training in all aspects of epilepsy, underscoring the need for a focus on the needs of teachers in mainstream schools.

Parents view the process of securing educational and therapeutic supports for their children as arduous for both themselves and the wider family. A previous study of young children with epilepsy also found that parents perceive that the provision of therapeutic and educational supports is often inconsistent and inadequate²⁸. Parents perceived that communication between themselves and their child's school was often

deficient, and they also reported a lack of communication between health and educational sectors involved in their child's care. This lack of integration of health and educational services has been flagged previously and leads to fragmentation of services and poor outcomes for children²⁹. With regard to desired changes, parents would like a better understanding of the impact of epilepsy on learning and behavior among all school staff, not just those working directly with the child, highlighting the need for whole-school approaches to reduce stigma and increase knowledge. Parents would like increased supports for assessment and intervention of the child's learning and behavioral needs, highlighting the findings of the current study and others which have shown that difficulties are often not identified or supported^{7,8}. Parents also identified the need for a better awareness of their child's learning profile among school staff so that supports can be better adapted. There is evidence of a specific cognitive profile in epilepsy including specific deficits in memory and processing speed^{30,31} which may, as parents suggest, have implications for supports and interventions in schools. Although this study focussed on schooling, some parents mentioned a desire family-focussed supports highlighting that epilepsy can affect whole family and not just the diagnosed child.

4.1 Implications for Practice and Future research directions

The reported lack of provision of IHPs for one in three children highlights that despite legislation many children with epilepsy still lack this basic support in school and, therefore, there is a need for continued advocacy. Parents often feel unsupported when seeking educational and therapeutic supports and thus there is a need for a keyworker/caseworker to support them in school-related matters and also at the interface between health and education services. The lack of identification of learning and emotional-behavioral difficulties highlights the need for further resources for assessment and subsequent support/treatment. The need for training of staff personnel in all aspects of epilepsy is particularly great in mainstream schools.

It would appear that knowledge and attitudes of epilepsy in schools can be improved by educational interventions⁹ but there is a need for more robust studies including trialling remote training which may facilitate a larger number of staff accessing training. When designing teacher training, it is important to include the views of children with epilepsy and their parents as well as educational staff. With respect to supporting parents it will be useful to evaluate a keyworker model who can support parents with in the process of securing supports, but also with respect to facilitating integrating of support from health and education sectors for the child and transition between schools.

4.2 Strengths and Limitations

This is one of the first studies to include the views of school staff as well as young people with epilepsy and parents regarding the impact of epilepsy in the school setting. All the staff were currently teaching or supporting a child with 'active' epilepsy, unlike many previous studies where many teachers surveyed were not currently supporting a child with epilepsy. The inclusion of open questions and subsequent qualitative analysis allows for the generation of a more nuanced picture of parental experiences and goes beyond reporting results of closed questions.

There are a number of limitations that need to be considered when interpreting the results of the current study. The majority of children and young people were unable to participate in the interviews/survey questions despite support being available to aid understanding. The participants had an average age of epilepsy onset significantly younger than non-participants, and given that age of onset is associated with greater neurodevelopmental impairment¹⁹ it is likely that participants had more significant learning and behavioral difficulties than non-participants. The majority of parental respondents were mothers, and the views of fathers may differ. We did not have responses from a representative staff member for all participating children and we do not have details on non-participating children or non-participating staff. The study is based in a defined geographical region of the UK, and although the UK has a national healthcare system and England a national education system, findings may not generalize to other parts of the UK or other jurisdictions. We had a much higher participation rate in our study at site 1 compared with site 2. One reason for this may be that whilst all parents were informed in person about the study at Site 1, an unknown number were informed and invited to participate at site 2 by varying methods. This difference in participation rates may have affected the representativeness of our study population. We were not able to compare responses between matching parents and children as questions differed or when addressing similar areas had to be adapted to ensure understanding. Future studies should explore whether experiences and views regarding provision in school differ between parents and their children

5. Conclusion

Although the majority of parents report positive aspects of their child with epilepsy's experiences at school, there were also a number of concerning aspects. Inadequate communication between home and school and between health and education services was a commonly reported concern. Additionally, more than half of the responding children reported that some of their teachers and friends did not know that they had epilepsy. Knowledge of epilepsy is felt by parents and teachers to be significantly higher in special schools. Parents highlight the need for increased knowledge of the impact of epilepsy on learning and behaviour, and want more resources for assessment of these difficulties.

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Table 1: Characteristics of children (n=68) in WINS study

Child Characteristics	n (%)
Gender - male/female	39/29 (57.4/42.6)
Ethnicity - White British/Non-White British	49/19 (72.1/27.9)
Age at time of assessment in years – Median (Q25/Q75)	10.46 (3.17, 7.85-12.77)
Educational provision - mainstream/special	36/32 (52.9/47.1)
School type - primary/secondary	40/28 (58.8/41.2)
Duration of epilepsy in years at time of assessment – Median (Q25/Q75)	6.00 (3.75,9.42) ^a
Age at seizure onset – Median (Q25/Q75)	2.50 (0.96, 6.00) ^a
Age at seizure onset – Under 2years/2years or older	22/42 (34.4/65.6) ^a
Seizure Frequency - Monthly or more frequently/less than monthly	34/32 (51.5/48.5) ^b
No. of seizure types - One type/two types/three+ types	22/29/13 (34.4/45.3/20.3) ^a
Child had Electroencephalogram (EEG)	67 (100) ^c
Child had Magnetic Resonance Imaging (MRI)	40 (85.1) ^d
Vineland Adaptive Behavior Composite (ABC) – Median (Q25/Q75)	78.00 (60.00, 90.50) ^e
Developmental level (IQ/DQ/ABC) – Median (Q25/Q75)	60.00 (44.00, 82.00) ^c
Developmental level (IQ/DQ/ABC) – ≤85	54 (80.6) ^c
Developmental level (IQ/DQ/ABC) – ≤70	40 (59.7) ^c
Wide Range Achievement Test – any domain score ≤85	33 (73.3) ^f
Seizure type	
-Generalised	31 (46)
-Focal	35 (52)
-Unknown	2 (3)
Epilepsy type	
-Focal	34 (50)
-Generalised	26 (38)
-Combined generalised and focal	7 (10)
-Not enough data to classify	1(2)
Etiology	
-Structural,	23 (34)

-Genetic,	30 (44)
-Infectious,	1 (2)
-Metabolic,	0 (0)
-Immune	1 (2)
-Unknown	10 (15)
-Not enough data to classify	3 (4)
ASM burden – mono/polytherapy	44/23 (65.7/42.6) ^c
ASM burden – Mean (SD, range)	1.46 (0.7, 1-3) ^c
Required rescue therapy	34 (51.5) ^b

^an=64, ^bn=66, ^cn=67, ^dn=47, ^en=65, ^fn=45, IQ=Intelligence Quotient, DQ Developmental Quotient, ASM= Anti-Seizure Medication, SD= Standard Deviation, Q25/Q75 = Quartile 25/Quartile 75

Table 2: Educational and therapeutic provision for children with epilepsy in WINS study

Aspect of provision	n (%)	Special	Mainstream	p
EHCP/Statement of SEN ^a	38 (56.7) ^b	29(94%)	9 (25%)	<0.001
Individual Healthcare Plan (IHP)	44 (67.7) ^c	19(63%)	25 (71%)	0.487
Speech and language therapy (SLT)	44 (69.7) ^d	28(93%)	18 (50%)	<0.001
Occupational therapy (OT)	36 (54.5) ^d	24(80%)	12 (33%)	<0.001
Physiotherapy	33 (50) ^d	22 (73%)	11 (31%)	0.001
Psychological assessment	35 (53) ^d	22 (73%)	13 (36%)	0.003
Psychological treatment	10 (15.2) ^d	4 (13%)	6 (17%)	0.707
Psychiatric assessment and treatment	0 (0) ^d	0 (0%)	0 (0%)	NA
Referral to Child and Adolescent Mental Health Services (CAMHS)	13 (19.4) ^e	9 (29%)	4 (11%)	0.064
Been seen for assessment or treatment at CAMHS	6 (9%) ^e	4 (13%)	2 (6%)	0.294
Been professionally diagnosed with:				
ADHD ^b	11 (16%)	8 (26%)	3 (8%)	0.054
ASD ^b	17 (25%)	14 (45%)	3 (8%)	0.001
DCD ^b	6 (9%)	6 (19%)	0 (0%)	0.007
Scored above cut-off on SDQ ^d	43	22 (73%)	21 (58%)	0.023
ASSQ ^f – At risk for ASD	32(51%)	19 (70%)	13 (36%)	0.027
ADHD Rating Scale-IV – At risk for ADHD ^f	39(62%)	16(59%)	23(64%)	0.708
DCD-Q- At-risk for DCD ^g	48(75%)	26 (93%)	22(61%)	0.004

^aEducation and Health Care Plan/Statement of Special Educational Needs ^bn=67
^cn=65 ^dn=66 ^en=67 ^fn=63 ^gn=64

ASSQ¹⁴ - Autism Spectrum Screening Questionnaire

DCD-Q¹⁵ – Developmental Coordination Disorder -Questionnaire

ADHD Rating Scale-IV¹⁶

SDQ= Strengths and Difficulties Questionnaire

ADHD=Attention Deficit Hyperactivity Disorder

ASD= Autism Spectrum Disorder

DCD= Developmental Coordination Disorder

Table 3: Communication of information regarding child's epilepsy diagnosis and perceived epilepsy knowledge among school staff and students

Respondent	Item	n (%)	p
Child	Epilepsy explained to you by... (Y/N) ^a	Parents 11/8 (57.9/42.1) Doctor 9/10 (47.4/52.6)	N/A
	In school, who knows that you have epilepsy? ^A	Some teachers 13 (68.4) All teachers 5 (26.3) Some friends 8 (42.1) All friends 8 (42.1) Office staff 14 (73.7) Nurse/Medical staff 14 (73.7) Head of Year 1 (5.3)	N/A
Parent	Epilepsy explained to your child by... (Y/N)	Parents 34/33 (50.7/49.3) Doctor 21/46 (31.3/68.7) Nurse 6/61 (9/91) Other 1/66 (1.5/98.5) ^b N/A due to level of cognitive functioning 24/43 (35.6/64.2)	N/A
	Child's transition from preschool to primary or primary to secondary was managed well (agree/disagree) ^{cd}	45/21 (68.2/31.8)	0.772
	Transfer of knowledge regarding my child's epilepsy was effective (agree/disagree) ^{ce}	36/22 (62.1/37.9)	0.223
	Child's class teacher has good understanding of epilepsy (agree/disagree) ^{fc}	46/16 (74.2/25.8)	<0.001
	School staff have a good understanding of epilepsy (agree/disagree) ^{bd}	53/13 (80.3/19.7)	0.002
	Child's epilepsy explained to you by... (Y/N) ^g	Parent 28 (51.9) Teaching colleague 31 (57.4) Nurse 11 (20.4) Previous school/preschool 10 (18.5) Other 6 (11.1)	N/A
Staff	Communication regarding child's epilepsy diagnosis was	47/4 (92.2/7.8)	0.357

	effective (agree/disagree) ^{ch}		
	Knowledgeable about epilepsy in general (agree/disagree) ^{cl}	43/9 (92.2/7.8)	0.113
	Knowledgeable about the child's epilepsy (agree/disagree) ^{c,e}	45/9 (83.3/16.7)	0.020
	Know what medication (AEDs) child takes for their epilepsy (Y/N) ^j	37/18 (67.3/32.7)	0.009
	Informed about changes to child's epilepsy medication (AEDs) (Y/N) ^k	41/15 (73.2/26.8)	0.003

^an=19 ^bChild overheard mother talking about epilepsy diagnosis ^cFor analysis scale variables were condensed as follows – 'strongly agree' and 'agree' condensed into 'agree', and 'strongly disagree' and 'disagree' into 'disagree' ^dn=66 ^en=58 excluded parents of children who did not have epilepsy whilst at previous school, ^fn=62, ^gn=54, ^hn=51, ⁱn=52, ^jn=55, ^kn=56, N/A

Table 4: Epilepsy and seizure management training in schools

Respondent	Item	n (%)	p [#]
Parent (N=68)	Staff at child's school have had training in administration of emergency medication (Y/N/Don't know) ^a	37/1/3 (90.2/2.4/7.3)	0.343
	Who is trained in administration of emergency medication ^a	Class teacher 4 (9.8) TA 2 (4.9) SENCO 1 (2.4) Nurse/First aider 6 (14.6) Office/reception staff 1 (2.5) ^b Multiple staff 10 (24.4) Unknown 3 (7.3)	N/A
Teacher (N=56)	Received training about epilepsy in general (Y/N)	37/19 (66.1/33.9)	0.001
	Received training about seizure management (Y/N)	34/22 (60.7/39.3)	<0.001
	Received training about learning and behavioural aspects of epilepsy (Y/N)	25/31 (44.6/55.4)	0.004

Y/N = Yes/No

^a n=41, excluding parents of children who don't require emergency medication ^bn=40, ^cno and Don't know combined for the purpose of statistical analysis. p[#] -p-values refer to comparison between special and mainstream schools

Table 5: Themes regarding the process of securing educational and therapeutic supports

Theme	Subtheme	Quotes
<ul style="list-style-type: none"> Education and Health Care Plan (EHCP) Process 	<ul style="list-style-type: none"> The EHCP process was a struggle/difficult Parents often the main advocates Gathering evidence takes time and paperwork makes process bureaucratic Inflexibility in review process, no recognition or adaptations as child develops For children with severe or profound intellectual disability, EHCP applications were started early and often instigated by medical personnel or pre-school/primary school 	<p><i>'It was really long, it was a really long difficult process... you had to explain yourself over and over again to lots of different people'</i></p> <p><i>"A lot of hard working! Busting doors down!"</i></p>
<ul style="list-style-type: none"> Process of Securing Supports in School 	<ul style="list-style-type: none"> Difficulties in process resulted in child staying at home or having reduced time at school Mainstream schools inability to meet or understand child's needs but worked much better after move to special school For children in mainstream schools with mild/moderate intellectual disability or behavioral difficulties, it took longer for schools to recognize needs and for supports to be put in place One person helped greatly (e.g. doctor, nurse, school staff or social worker) 	<p><i>"[child] was going to [mainstream school] at the time and they weren't able to meet his needs there. He wasn't learning much in the classroom, they weren't able to offer the one-to-one support... and I looked in to [special school] and it looked like an amazing place so obviously I jumped at the chance... and it all just fell in to place"</i></p> <p><i>"[It was] down to the community nurse... if it had not been for her honestly I wouldn't have known what to do... I wouldn't even have known where to start. She did everything"</i></p>
<ul style="list-style-type: none"> Therapeutic provision process 	<ul style="list-style-type: none"> Often long waiting lists/times Parents accessing private provision due to lack of provision in National Health Service (NHS) Works much better at special school for the majority Inconsistent access due to varying availability of provision Lack of agreement between health and educational professionals regarding extent of child's needs affects access to support 	<p><i>"There's a massive waiting list, still it would be months before she would be seen"</i></p> <p><i>"At [special school] it seems to be quite seamless and it's just sort of the facilities are there, everyone knows her... they can automatically just schedule stuff in, they know when they've got that resource to call upon so they can just say '[child] needs to be slotted in for some more sessions"</i></p>
<ul style="list-style-type: none"> Inadequate Communication /Supports 	<ul style="list-style-type: none"> Parents uninformed of options or progress of applications for support Inadequate dissemination within and between health and therapeutic services Lack of communication/planning at transition time resulting in new school/teachers not addressing child's learning/behavior needs and epilepsy Parents don't know what child is doing (what activities) at school 	<p><i>"Obviously they hadn't read the report... it wasn't relayed to his year one teacher and we had I had the battle of going in again"</i></p>
<ul style="list-style-type: none"> Negative impact of processes on families 	<ul style="list-style-type: none"> Feeling of helplessness - parents don't know how best to help child Family forced to finance assessments/supports privately Family having to take legal action to secure supports 	<p><i>"We had to use a solicitor (Lawyer), we had to go to tribunal, we had to get an [educational psychologist] to do an independent report for [child] – which costs a significant amount of money"</i></p>

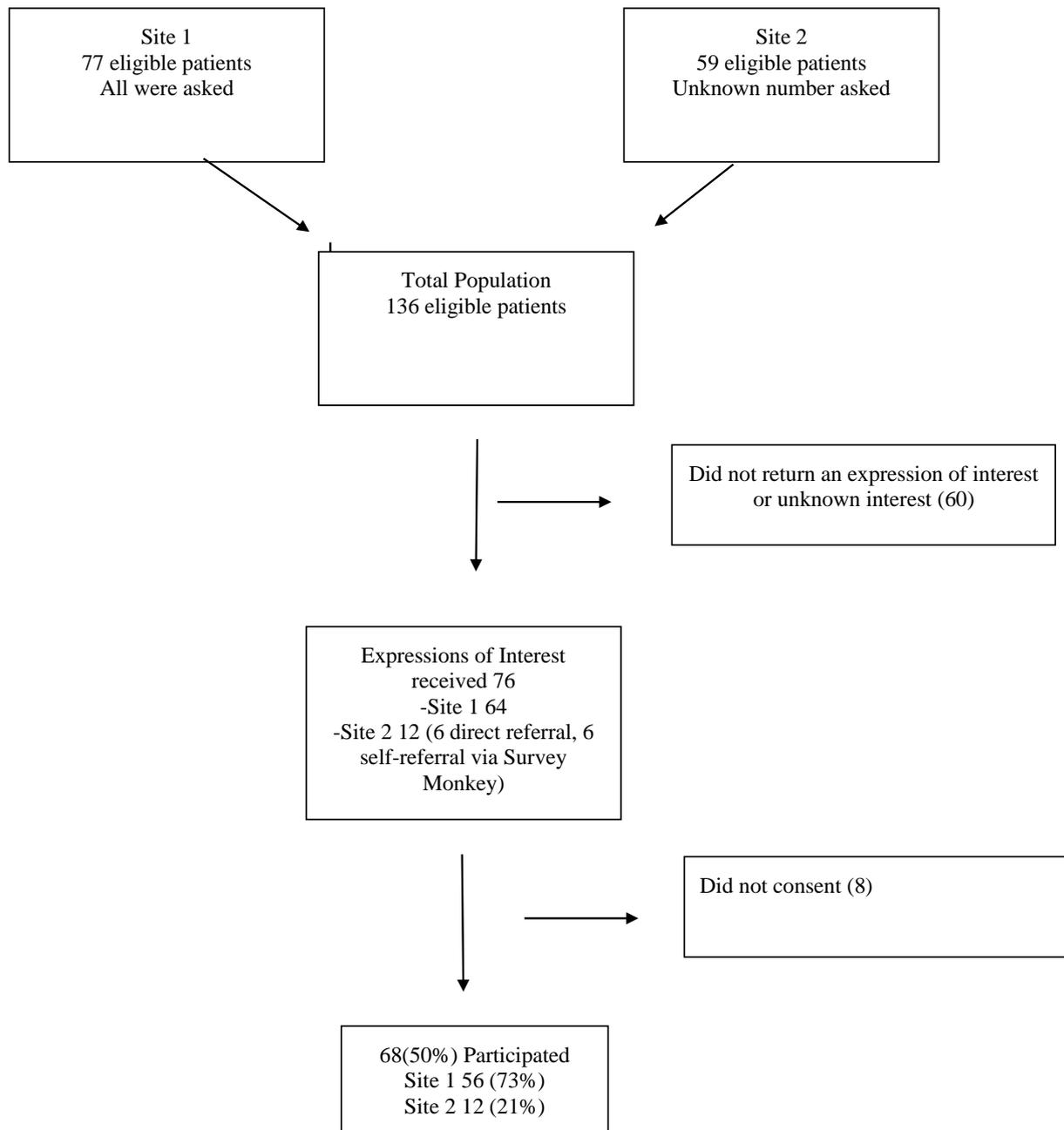


Figure 1: Recruitment in WINS study