Knowledge about, and attitudes towards epilepsy among school staff: A UKbased survey

Emma C Johnson¹ Patricia Atkinson² Amy Muggeridge¹ J Helen Cross^{1,3,4} Colin Reilly^{1,4}

Affiliations

¹Research Department, Young Epilepsy, Lingfield, Surrey, RH7 6PW, UK.

²Child Development Centre, Crawley Hospital, West Green Drive, Crawley, RH11 7DH, West Sussex, UK.

³Great Ormond Street Hospital for Children NHS Trust, Great Ormond Street, London WC1N 3JH, UK.

⁴UCL Great Ormond Street Institute of Child Health (ICH), 30 Guilford Street London WC1N 1EH UK.

Correspondence to: Colin Reilly, Research Department, Young Epilepsy, Lingfield,

Surrey, RH7 6PW, UK. creilly@youngepilepsy.org.uk 01342 832243

Keywords: children, epilepsy, schools, education

Number of words: 3868

Number of figures: 1

Number of tables: 6

Number of references: 23

Short title: Staff Knowledge of Epilepsy in Schools

Abstract

Objective: To survey attitudes towards, and knowledge about, epilepsy among school staff in a defined geographical region in the United Kingdom.

Methods: School staff (n=160) from 18 schools (56% of eligible schools) where children with epilepsy were currently attending were surveyed. Surveys were developed in collaboration with educational professionals. Questions focussed on attitudes towards, and knowledge about, epilepsy. Factors associated with attitudes and knowledge were analyzed using multivariable logistic regression.

Results: The majority of staff expressed positive attitudes towards the inclusion of children with epilepsy in school, although for most questions there was a significant minority who expressed less positive views. Only 30% of staff agreed that they would feel confident managing a child having a seizure whilst 42% of all staff would be concerned if they had to administer emergency medication. Regarding knowledge, half (50%) of respondents correctly indicated that a child who has a seizure should not always leave the classroom, whilst 54% knew that an ambulance should not always be called every time a child has a seizure. Regarding seizure semiology, almost all respondents (96%) answered 'yes' when asked if seizures could involve convulsions/limb jerking or whole-body convulsions. The vast majority (94%) also identified that seizures could involve 'staring blankly into space'. From a list of eight medical/neurodevelopmental conditions, epilepsy was the condition staff ranked of most concern. Factors independently associated with more positive attitudes and better knowledge included working in a special school as opposed to a mainstream school, having previously witnessed a seizure, and having been in receipt of training on epilepsy (all p<0.05). Most respondents expressed a desire for more training on seizure management and on the learning and behavioral aspects of epilepsy.

Conclusion: Whilst attitudes toward children with epilepsy are largely positive, epilepsy was the condition staff were most concerned about. Additionally, attitudes towards seizure management and administration of emergency medication in school are less positive, and knowledge of correct actions in the event of seizures in the classroom is deficient in nearly half of respondents. More positive attitudes and better knowledge were associated with previous experience of witnessing seizures, working in special schools, and having received epilepsy training. School staff in UK schools are likely to benefit from access to training on epilepsy in order to improve attitudes and increase knowledge and confidence towards supporting a child with epilepsy in their classroom.

1. Introduction

Epilepsy is the most common serious neurological condition in the pediatric population, affecting approximately 1 in 150 children in western countries (Boyle et al. 2011). It is a condition associated with significant stigma (Jacoby & Austin, 2007) including negative attitudes among school staff (Bishop & Slevin 2004). Knowledge of the condition is often deficient in school settings (Bishop & Boag, 2006). Previous studies suggest that epilepsy is one of the medical conditions of which teachers have the least knowledge (Bishop & Boag, 2006). Limited knowledge and negative attitudes are likely to contribute to negative experiences of children with epilepsy in schools.

Many staff in schools have concerns about seizure management in the school setting (Dumeier et al 2015). Staff may be apprehensive about responding to seizures (Wait et al 2013) and, in particular, lack knowledge in relation to managing prolonged seizures, showing a reluctance to administer rescue medication and having a fear of liability (Dumeier et al 2015). Fear of administering emergency medication and willingness to administer improves with training (Dumeier et al 2017a). In general, teachers are interested in accessing more training and training has been shown to improve attitudes and knowledge (Jones et al. 2018).

As well as recurrent epileptic seizures, children with epilepsy are at a high risk for a range of learning and behavioral difficulties. The increased risk includes a risk for cognitive impairment including intellectual disability and specific difficulties with memory and processing speed (Reilly et al 2014; Berg et al 2008; Sherman et al 2012) There is also an increased risk for autism, ADHD, motor coordination problems, anxiety and depression (Reilly et al 2014; Davies et al 2003) but difficulties are often not identified (Ott et al 2003) and many children do not access needed assessments and interventions (Welch et al 2014). The risk for learning and behavioral impairments is higher in children with epilepsy than children with other non-neurological chronic medical conditions (Davies et al 2003), and the additional difficulties often contribute more to reduced health related quality of life than the epileptic seizures (Reilly et al 2015; Baca et al 2011).

There have been few surveys of school attitudes and knowledge in the UK despite concerns about seizure management in the school setting and the well-established high level of learning and behavioral needs associated with epilepsy in children. In 1992, Bannon et al reported on a survey of 142 teachers in the North Staffordshire area of the UK and found that most of the respondents did not feel confident when teaching children who had epilepsy and only a minority considered their knowledge of the subject to be adequate. Only four teachers (3%) had received recent specific training on childhood epilepsy and the majority wanted training on epilepsy and other medical conditions. The aim of the current study was to survey knowledge and attitudes and factors associated with knowledge and attitudes among school staff in a defined location of the UK. In particular we wanted to focus on knowledge and attitudes in schools where children with epilepsy had been attending as many previous studies had focused on trainee staff/teachers or staff/teachers in schools where it was not clear that children with epilepsy are currently attending (Jones et al 2013).

2. Methodology

The 'What I Need in School (WINS) - Experiences of children with epilepsy in schools' study focuses on the experiences of children with epilepsy, their parents and school staff in schools in a defined geographical area of the United Kingdom (UK) (Johnson et al 2021). All staff at schools (n=32) with student(s) (n=68) participating in the WINS study were invited to participate in a survey designed to assess their attitudes towards, and knowledge about epilepsy. The WINS study was based in the RH10-RH13 postal districts of West Sussex in the south of the United Kingdom.

The study survey was developed in collaboration with educational professionals. The survey was discussed with eight teachers (four teaching at mainstream schools, four at special schools) and one school nurse (working at a special school) (see supplement 1) via interviews and focus groups conducted between May and July 2018. As a result of the consultation with staff, the final survey was developed (see supplement 2).

Schools who were willing to complete the questionnaire were offered multiple response methods. Initially, surveys and participant information sheets were left in a communal space in the school (often the staff room) with a poster inviting staff to participate in the study by completing the questionnaire and depositing it in the secure box provided. An email script detailing the project and inviting staff to participate was also shared with a member of school staff who was asked to share it with their colleagues. School staff were offered short awareness sessions delivered by members of the research team (EJ and/or CR) providing an overview of epilepsy and possible impacts of epilepsy on learning and behavior. Attending staff were asked to complete the questionnaire at the beginning of the awareness session. Schools who declined the awareness session were offered the opportunity to complete hard copies of the questionnaire as per the original response method or complete the questionnaire online via SurveyMonkey. For schools who favored responding online, a cover letter was shared via email that described the project and contained the link to the online questionnaire. For all response methods school staff were told that their participation was voluntary, and attendance of an awareness session was not dependent on completion of a questionnaire. Surveys were distributed/made available online between October 2018 and February 2020.

2.1 Measure

School staff self-completed a questionnaire composed of a Likert scale, closed questions (yes/no/don't know) and ranking questions. The survey (see supplement 2) contained questions on staff demographics including school type (special vs mainstream), job title, years worked in education, previous experience of teaching children with epilepsy, history of witnessing an epileptic seizure, family history of epilepsy and previous training on epilepsy.

Attitude questions were based on 5-point Likert scale responses. Knowledge questions were based on yes/no/don't know response. A question on familiarity with a range of medical/developmental conditions was based on an 8-point ranking scale.

For a question on concerns if a new child with a named condition was to come into the staff member's class, respondents had to rank eight conditions in order of concern. Questions on perceptions of training needs were based on yes/no responses (see supplement 2).

2.2. Analysis

All analyses were done with IBM SPSS version 27.0 (IBM SPSS Statistics, IBM Corporation, Armonk, NY). Demographic characteristics of participating school staff and data obtained through the staff-report questionnaire measure were analyzed in terms of frequencies and/or means and are reported as descriptive statistics. The responses to the attitude and knowledge questions are reported as descriptive statistics. Strongly agree and agree options are combined into one 'Agree' category. Strongly disagree and disagree are combined into one category 'Disagree'.

Logistic regression analyses were done to identify the factors associated with each individual attitude and knowledge question. The factors included as possible predictors in the univariable analyses were school type (special vs. mainstream), previously witnessed an epileptic seizure (yes/no), number of years working in education (less than or equal to 10 years vs. greater than 10 years), number of children with epilepsy taught (none vs. one or more), family history of epilepsy (yes/no), currently supporting a child with epilepsy (yes/no), and have been in receipt of epilepsy specific training (yes/no).

Multivariable analysis was carried out by backward (conditional) regression, with all predictors significant at the p<0.100 level entered into the model to identify factors independently associated with attitudes and knowledge. For the purposes of regression, all 'neither agree/disagree' responses to the 'attitude' questions were considered to represent more negative attitudes. For the 'knowledge' questions, all 'don't know' responses were considered to represent a lack of knowledge.

2.3 Ethics 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

Staff from 18 (56%) of 32 eligible schools responded (range 1 to 32 staff who responded from each school). The characteristics of the staff who responded are shown in table 1:

3.1 Attitudes towards epilepsy

The responses to the questions focusing on staff attitudes are shown in table 2:

Sixty-four percent of respondents disagreed that children with epilepsy should not be allowed to do certain activities such as attend discos or parties. Eighty-one percent would not feel uncomfortable if a child with epilepsy was in their class and disagreed that there are certain activities that children with epilepsy would not be allowed to do. Sixty-seven percent of respondents disagreed that expectations of children with epilepsy should be no different to others without epilepsy. Ninety-two percent of respondents disagreed that the majority of children with epilepsy should attend special schools. Eighty-seven percent disagreed that children with epilepsy can have an adverse effect on other children in the classroom or playground.

Thirty percent of respondents agreed that they would feel confident managing a child having a seizure. Forty-one percent agreed that they would be concerned if they had to administer emergency medication and another 17% neither agreed nor disagreed. Seventy-eight percent of respondents felt that their school did a good job supporting children with epilepsy. Seventy-six percent of respondents also disagreed with the statement that children with epilepsy are treated differently than other children.

Factors that are significantly associated with each of the attitude questions are shown in table 3. The results of univariable analyses are in supplementary data 3.

School type was significantly associated with staff attitudes for three questions and, in all cases, staff in special schools held more positive attitudes. Having previously witnessed a seizure was also associated with more positive attitudes for three questions. Staff who had previously received training on aspects of epilepsy also held more positive attitudes for three of the questions.

3.2 Knowledge questions

Table 4 shows responses of school staff to the questions about epilepsy knowledge

Sixty-four percent of the school staff correctly identified that the majority of children with epilepsy do not attend special schools. Twelve percent knew that the prevalence of epilepsy in children is typically thought to be about 0.5-1%. Thirty-seven percent of respondents were aware of the fact that not all children with epilepsy have an Education and Health Care Plan (EHCP: An EHCP is a legal document describing the needs and resources to meet those needs for any child or young person in England with significant and complex Special Educational Needs or Disability). Sixty-three percent knew that epilepsy is not a lifelong condition, that anti-seizure medications do not stop seizures in all cases (68%), and that if seizures stop with drugs epilepsy is not cured (91%).

Seventy-seven percent correctly identified that most children with epilepsy do not have a learning (intellectual) disability. Fifty-four percent knew that if a child has a seizure an ambulance must not always be called, whilst sixty-eight percent of respondents indicated correctly that using a spoon or other object to prevent a child from biting their tongue during a seizure is inappropriate. Eighty-four percent of respondents correctly indicated that it is not appropriate to hold a child to stop them shaking if they are having a convulsive seizure. Fifty percent of respondents correctly indicated that a child who has a seizure should not always leave the classroom afterwards, whilst the other half indicated that they should always leave the class, or that they did not know.

Fifty-Two percent of respondents were aware that epilepsy is typically not diagnosed following one confirmed epileptic seizure, although 44% responded 'don't know' to this question. Sixty-Five percent of respondents knew that the majority of behavioral problems in children are not caused by AED treatment, whilst 55% correctly indicated

that effective drug treatment in epilepsy usually does not stops emotional and/or behavioral problems. Fifty-one percent of respondents were aware that children with epilepsy often have memory problems, although many respondents answered 'don't know' to this question.

Regarding seizure semiology, ninety-six percent of respondents answered 'yes' when asked if seizures could involve convulsions/limb jerking or whole-body convulsions. Ninety-four percent also identified that seizures could involve 'staring blankly into space'.

The results of multivariable regression regarding factors associated with knowledge are in Table 5 whilst the results of univariable analyses are in supplementary data 4.

Having previously witnessed an epileptic seizure was significantly associated with better knowledge among school staff in seven of the knowledge questions. School type was significantly associated with staff knowledge for six of the knowledge questions. In all cases, better knowledge was found among staff who worked in special as opposed to mainstream schools. Having previously been in receipt of training on aspects of epilepsy was associated with significantly better knowledge for three of the knowledge questions. Those who had taught one or more child with epilepsy had better knowledge on two questions than those who had never taught a child with epilepsy.

3.3. Familiarity with and Concern about Medical/Neurodevelopmental Conditions Respondents were asked to indicate familiarity with eight medical/neurodevelopmental conditions. There were four possible responses: very familiar, familiar, not familiar and not at all familiar. 'Very familiar' and 'familiar' were combined into one category 'familiar', and 'not familiar' and 'not at all familiar' were combined into one category 'not familiar'. Responses are shown in Table 6:

Staff were most familiar with Autism Spectrum Disorder (ASD), followed closely by asthma, ADHD and dyslexia. Cerebral palsy was the condition staff were least familiar with. Epilepsy was the sixth most familiar condition. Staff in special schools were significantly more familiar with cerebral palsy (p<0.001), Epilepsy (p=0.001) and Down syndrome (p<0.001). Staff in mainstream schools indicated significantly more familiarity with asthma than staff in special schools (p<0.001). There were no other significant differences between staff in mainstream and staff in special schools.

Staff were asked to suppose a new child joined their class with a condition and to rank eight conditions in the order that would cause them the greatest concern. Responses are in Figure 1. Epilepsy was the condition staff were most concerned about, followed by cerebral palsy, whilst dyslexia was the condition staff would be least concerned about.

Concerns were significantly higher in mainstream schools compared with special schools for Down syndrome (p<0.001), epilepsy (p=0.041) and cerebral palsy (p<0.001).

3.4 Staff Training Needs

The responses to questions on staff training needs are in supplement 5:

Seventy-three percent of respondents expressed a desire for more training on epilepsy. Staff in special schools were more likely to indicate a need for training on epilepsy and behavior (p=0.027) compared with mainstream schools. There were no other significant differences between staff in mainstream and special schools regarding training needs.

4. Discussion

There is very limited data on the attitudes towards and knowledge about epilepsy among staff in UK schools. As such, the results of this study add to our understanding of attitudes and knowledge towards epilepsy in schools. The majority of staff express positive attitudes towards the inclusion of children in school activities but attitudes towards seizure management and administration of emergency medication in school are less positive. In relation to staff knowledge, whilst most staff have a good knowledge of the common manifestation of seizures, there was more limited knowledge of what to do in the event of a seizure, the potential impact of epilepsy on memory and the possible role of Anti-Seizure Medications (ASMs) in behavioral difficulties displayed by a child with epilepsy. More positive attitudes and better knowledge were found among staff in special schools, among staff who had witnessed a seizure and among staff who had been in receipt of epilepsy training. Whilst epilepsy was in the mid-range with respect to staff familiarity, it was the condition staff would be most concerned about if a new child were to start in their class. The majority of staff would like more training on all aspects of epilepsy. Comparisons between the current study and previous studies focusing on knowledge of and attitudes towards epilepsy among teachers are difficult due to the wide range of methods used in previous studies as acknowledged in a previous systematic review (Jones et al 2018). The main findings of the systematic review and the previous study in the UK (Bannon et al 1992) in comparison with the current study are in supplement 6. The largely positive attitudes expressed by staff towards the inclusion and participation of children with epilepsy in school activities are in line with the positive findings reported by Bannon et al (1992) in their previous study of teachers' perceptions of epilepsy. The two questions where less positive attitudes were expressed, concerned seizure management and administration of emergency medication in school. These less positive attitudes were noted in a previous German study of attitudes of preschool teachers, teachers and student teachers (Dumeier et al 2015). This study found that only 15% of respondents would be willing to administer a prescribed rescue medication under any circumstances. Furthermore, 49% of respondents to the German study were concerned about the legal repercussions of an incorrect response to a seizure. Staff reluctance to administer emergency medication may be due to the fact that existing legal frameworks are vague and open to interpretation according to a review of guidance in six European countries including the UK (Wait et al 2013). Additionally, it has been suggested that the situation regarding the provision of rescue medication in schools varies between schools and depends mainly on the goodwill and resources available locally (Cross et al 2013). Given that it has been shown that training in schools increases self-confidence and reduces fears regarding administration of rescue medication, providing training to all relevant staff should be a priority (Dumeier et al 2017a; Dumeier et al 2017b). In the current study, staff who had previously been in receipt of training expressed more positive attitudes highlighting the value of

training. Additionally, staff at special schools expressed more supportive attitudes highlighting the need to target mainstream schools with training initiatives. It will also be important that staff feel that they are operating within a clear legal framework with respect to the administration of rescue medication to reduce fear of liability (Wait et al 2013; Dumeier et al 2015).

In terms of knowledge, the vast majority of respondents indicated good knowledge of the manifestation of common seizure types. There were, however, a number of questions where the majority or a significant minority of respondents gave incorrect answers or indicated that they did not know the correct answer. Only 37% of respondents correctly indicated that not all children with epilepsy have an Education and Health Care Plan (EHCP). In the English school system, an EHCP is a legal document for children and young people who need more individual support than is available through typical special educational needs support in schools in England. Lack of knowledge that all children with epilepsy do not have an EHCP could lead to the view that their needs are being met whereas, for many children with epilepsy, this will not be the case as they will not have an EHCP. Just under half of respondents indicated 'yes' or 'don't know' regarding whether an ambulance should be called in the event of a seizure. Calling an ambulance should only be necessary in rare cases including where a child's seizure last more than five minutes, in the event of first seizure or the child has sustained an injury (Seizure first aid | What to do when a seizure happens | Epileptic seizures | Guide for schools (youngepilepsy.org.uk)). The incorrect belief that an ambulance should be called on all occasions is likely to lead to significant disruption for both the child and their family. Similarly, the incorrect view expressed by half of respondents that the child should always leave the classroom after a seizure in class is likely to have a negative impact on the child in school. One in three of the respondents incorrectly indicated that the behavioral problems in children with epilepsy are frequently caused by ASM treatment, and over 40% did not indicate that they knew that effective drug treatment in epilepsy does not usually stop Children with epilepsy often have emotional and/or behavioral problems. behavioral/emotional problems before epilepsy debut (Jones et al 2007), whilst ASMs are typically not associated with behavioral and emotional difficulties for the majority of children with epilepsy (Plioplys et al 2007). The erroneous view that ASMs may contribute significantly to emotional and behavioral difficulties in children with epilepsy identification subsequent may prevent and intervention for common neurodevelopmental and mental conditions in the children. Similarly, half of respondents were unaware that memory difficulties are common in children with epilepsy despite evidence that children with epilepsy have a high frequency of memory impairments (Menlove & Reilly, 2015). Failure to recognize memory difficulties may lead to the child with epilepsy not accessing adequate supports in the classroom. Factors associated with better knowledge included having witnessed a seizure, working in a special school environment, and having been in receipt of epilepsy training, suggesting that exposure to children with epilepsy and training are the main contributors to better knowledge.

Familiarity with epilepsy was higher in special than mainstream schools. One reason is likely to be that the proportion of children in a special school with epilepsy is likely to be much higher than in a mainstream school. Despite the fact that epilepsy was in the mid-range of conditions with respect to familiarity, it was the condition respondents expressed the greatest level of concern about. The higher level of concern expressed by staff in relation to epilepsy compared to other conditions is worrying and suggests that there is still significant stigma associated with the condition. Concerns about epilepsy were significantly greater in special than mainstream environments suggesting that staff supporting children in mainstream schooling may be a group that needs targeting regarding training and support. Most respondents would like more training on epilepsy with two in three wanting more training on seizure management, learning and behavior. Previous studies suggest that staff training improves confidence in seizure management (Dumeier et al 2017) and other aspects of epilepsy (Jones et al 2018) highlighting the need to provide training to staff in UK schools.

4.1 Implications and future research

The current study emphasizes that whilst positive attitudes towards epilepsy and children with epilepsy are common in UK schools, there are a number of areas where there are more negative attitudes and insufficient knowledge highlighting the need for staff training. Although a number of studies have highlighted that staff training can lead to better knowledge and attitudes, there is a lack of studies employing robust designs. There is also a need for training to be rolled out on a large scale in an accessible way. Online training may be particularly useful in terms of reaching a large number of educational professionals. Training should focus not only on seizure management but also on learning and behavioral aspects of pediatric epilepsy. The difference in attitudes and knowledge between mainstream and special schools means that training may need to be tailored to school type. Given that witnessing a seizure was an important independent factor associated with more positive attitudes and better knowledge, including videos of seizures may be useful in reducing concerns around epilepsy among staff. The current study was based in a defined geographical area of the UK. Garnering attitudes and knowledge in other areas of the UK will also be helpful in understanding the picture at a national level. It would be useful in future studies to explore why response rates to surveys might vary between schools and explore strategies to try to increase response rate in schools with a low response rate. Given the unpredictable nature of seizures it is important that epilepsy is not seen as the responsibility of one staff member or a small group of staff but that all staff have knowledge about the condition.

4.2 Limitations

A number of limitations need to be borne in mind when interpreting the results of the current study. The response rate at the school level was 56% indicating that a significant percentage of eligible schools did not take part and we have no indication of staff views in these schools. Additionally, there was wide range in terms of number of staff from each school who responded, and we have no data on those who did not respond. We also have no data on why the response rate varied between schools. It may be that in schools with a low response rate one staff member took responsibility for answering the survey. The study is based in the south of the UK and findings may not be generalizable to other parts of the UK or internationally. The majority of respondents were staff in primary as opposed to secondary school settings. The survey was bespoke, developed specifically for the current study and thus has not previously been validated. For the purposes of regression modelling, all 'neither agree/disagree' responses to the 'attitude' questions and 'don't know' responses were considered to represent more negative attitudes and lack of knowledge. This was a

pragmatic choice but may have affected the nature of relationships between factors and attitudes/knowledge.

4.3 Conclusions

Attitudes towards epilepsy among school staff were largely positive but more negative attitudes towards seizure management in schools and administration of emergency medication were also evident. Limited knowledge of the correct actions in the event of seizures and knowledge of the relationship between epilepsy, ASMs and learning and behavior were also concerning. Additionally, epilepsy is the condition staff expressed most concern about. Knowledge and attitudes were better among staff in special schools, staff who had previously witnessed a seizure and in those who had been in receipt of training. Staff expressed a desire for more training particularly in the areas of seizure management and impact of epilepsy on learning and behavior.

Acknowledgements

We would like to thank all participating schools.

Funding

The WINS study was funded by Ronald and Barbara Abbott, the George E. Neville Foundation, UCB Pharma (through an educational grant with no editorial involvement), Young Epilepsy, the Sobell Foundation, the Childwick Trust and two anonymous donors. JHC is supported by the National Institute of Health & Care Research (NIHR) Biomedical Research Centre at Great Ormond Street Hospital.

References

Baca, C. B., Vickrey, B. G., Caplan, R., Vassar, S. D., & Berg, A. T. (2011). Psychiatric and medical comorbidity and quality of life outcomes in childhood-onset epilepsy. *Pediatrics*, *128*(6), e1532-e1543.

Bannon, M. J., Wildig, C., & Jones, P. W. (1992). Teachers' perceptions of epilepsy. *Archives of Disease in Childhood*, *67*(12), 1467-1471.

Berg, A. T., Langfitt, J. T., Testa, F. M., Levy, S. R., DiMario, F., Westerveld, M., & Kulas, J. (2008). Global cognitive function in children with epilepsy: a community-based study. *Epilepsia*, *49*(4), 608-614.

Bishop, M., & Boag, E. M. (2006). Teachers' knowledge about epilepsy and attitudes toward students with epilepsy: results of a national survey. *Epilepsy & Behavior*, 8(2), 397-405.

Bishop, M., & Slevin, B. (2004). Teachers' attitudes toward students with epilepsy: results of a survey of elementary and middle school teachers. *Epilepsy & Behavior*, *5*(3), 308-315.

Boyle CA, Boulet S, Schieve LA, Trends in the prevalence of developmental disabilities in US Children, 1997-2008. *Pediatrics* 2011; 127: 1034-42.

Cross, J. H., Wait, S., Arzimanoglou, A., Beghi, E., Bennett, C., Lagae, L., ... & Harvey, G. (2013). Are we failing to provide adequate rescue medication to children at risk of

prolonged convulsive seizures in schools?. *Archives of disease in childhood*, *98*(10), 777-780.

Davies, S., Heyman, I., & Goodman, R. (2003). A population survey of mental health problems in children with epilepsy. *Developmental Medicine & Child Neurology*, *45*(5), 292-295.

Dumeier, H. K., Neininger, M. P., Bernhard, M. K., Merkenschlager, A., Kiess, W., Bertsche, T., & Bertsche, A. (2017a). Providing teachers with education on epilepsy increased their willingness to handle acute seizures in children from one to 10 years of age. *Acta Paediatrica*, *106*(11), 1811-1816.

Dumeier, H. K., Neininger, M. P., Kaune, A., Schumacher, P. M., Merkenschlager, A., Kiess, W., ... & Bertsche, A. (2017b). Seizure management by preschool teachers: a training concept focussing on practical skills. *Seizure*, *50*, 38-42.

Dumeier, H. K., Neininger, M. P., Bernhard, M. K., Syrbe, S., Merkenschlager, A., Zabel, J., ... & Bertsche, A. (2015). Knowledge and attitudes of school teachers, preschool teachers and students in teacher training about epilepsy and emergency management of seizures. *Archives of disease in childhood*, *100*(9), 851-855.

Jacoby, A., & Austin, J. K. (2007). Social stigma for adults and children with epilepsy. *Epilepsia*, 48, 6-9

Johnson, E. C., Atkinson, P., Muggeridge, A., Cross, J. H., & Reilly, C. (2021). Epilepsy in schools: Views on educational and therapeutic provision, understanding of epilepsy and seizure management. *Epilepsy & Behavior, 122, 108179.*

Jones, C., Atkinson, P., Cross, J. H., & Reilly, C. (2018). Knowledge of and attitudes towards epilepsy among teachers: a systematic review. *Epilepsy & Behavior*, *87*, 59-68.

Jones, J. E., Watson, R., Sheth, R., Caplan, R., Koehn, M., Seidenberg, M., & Hermann, B. (2007). Psychiatric comorbidity in children with new onset epilepsy. *Developmental Medicine & Child Neurology*, *49*(7), 493-497.

Menlove, L., & Reilly, C. (2015). Memory in children with epilepsy: A systematic review. *Seizure*, *25*, 126-135.

Ott, D., Siddarth, P., Gurbani, S., Koh, S., Tournay, A., Shields, W. D., & Caplan, R. (2003). Behavioral disorders in pediatric epilepsy: unmet psychiatric need. *Epilepsia*, *44*(4), 591-597.

Plioplys, S., Dunn, D. W., & Caplan, R. (2007). 10-year research update review: psychiatric problems in children with epilepsy. *Journal of the American Academy of Child & Adolescent Psychiatry*, *46*(11), 1389-1402.

Reilly, C., Atkinson, P., Das, K. B., Chin, R. F., Aylett, S. E., Burch, V., ... & Neville, B. G. (2014). Neurobehavioral comorbidities in children with active epilepsy: a population-based study. *Pediatrics*, *133*(6), e1586-e1593.

Reilly, C., Atkinson, P., Das, K. B., Chin, R. F., Aylett, S. E., Burch, V., ... & Neville, B. G. (2015). Factors associated with quality of life in active childhood epilepsy: a population-based study. *European Journal of Paediatric Neurology*, *19*(3), 308-313.

Sherman, E. M., Brooks, B. L., Fay-McClymont, T. B., & MacAllister, W. S. (2012). Detecting epilepsy-related cognitive problems in clinically referred children with epilepsy: Is the WISC-IV a useful tool?. *Epilepsia*, *53*(6), 1060-1066

Wait, S., Lagae, L., Arzimanoglou, A., Beghi, E., Bennett, C., Cross, J. H., ... & Harvey, G. (2013). The administration of rescue medication to children with prolonged acute convulsive seizures in the community: what happens in practice?. *European Journal of Paediatric Neurology*, *17*(1), 14-23.

Welch, A., Shafran, R., Heyman, I., Coughtrey, A., & Bennett, S. (2018). Usual care for mental health problems in children with epilepsy: a cohort study. *F1000Research*, 7

.

	n (%)	
School type		
Mainstream Primary	96 (60)	
Mainstream Secondary	16 (10)	
Special School (covers primary and	48 (30)	
secondary)		
Staff Role		
Class Teacher	70 (44)	
Subject Teacher	9 (6)	
Teaching Assistant	29 (18)	
Learning Support Assistant	11 (7)	
SENCO	7 (4)	
Head Teacher	2 (1)	
Pastoral Care	3 (2)	
Other	29 (19	
Age in years – mean/ median/	40.49/ 41.00/ 30.00,	
quartiles (SD, range)	50.00 (11.6, 21-64)	
Gender – M/F/Prefer not to say	16/143/1 (10/89/1)	
Years worked in education - mean	12.72/ <mark>10.00/ 6.00,17.50</mark>	
<mark>/median/ quartile</mark> (SD, range)	(8.99, 0-42)	
Family history of epilepsy – Y/N	29/131 (18/82)	
-Who in family has epilepsy	-Respondent (2)	
	-Parent (5)	
	-Sibling (2)	
	-Child (9)	
	Other Family member	
	(14)	
Currently teach/support a child with	73/85 (46/54)	
epilepsy – Y/N*		
Number of children with epilepsy	0 <mark>children</mark> : 27 (17)	
taught/supported during career**	1-2 children : 67 (43)	
	3-5 <mark>children</mark> : 29 (18)	
	6-10 children : 9 (6)	
	10+ <mark>children</mark> : 25 (16)	
Witnessed a seizure – Y/N***	94/65 (59/41)	
Received epilepsy-specific training in	79/79 (50/50)	
current role – Y/N*		
- number of respondents V/N- Ver	No SENCO- Special E	

Table 1: Characteristics of staff (n=160) who responded to epilepsy in schools survey

n= number of respondents, Y/N= Yes/No, SENCO= Special Educational Needs Coordinator, M=mean, SD= Standard Deviation, * n=158, **n=157, ***n=159

Table 2: Staff responses to attitudes towards epilepsy questions				
Attitude Statement	Number of	<mark>% of</mark>		
	Respondents	respondents		
	(n)			
There are certain social activities (e.g. parties, discos)	26 /100/30	17/ 64 /19		
that children with epilepsy should not be allowed to do –				
Agree/Disagree/Neither agree or disagree*				
I would feel uncomfortable if there was a child with	12/ 126 /18	8/ 81 /11		
epilepsy in my class – Agree/Disagree/Neither agree or				
disagree*				
There are certain physical activities (e.g., swimming,	8 /127/22	5/ 81/14		
cycling) that children with epilepsy should not be				
allowed to do – Agree/Disagree/Neither agree or				
disagree**				
Expectations of children with epilepsy should be no	26/104/26	17/ 67/17		
different to others without epilepsy –				
Agree/Disagree/Neither agree or disagree*				
The majority of children with epilepsy should go to	3 /143/10	2/92/6		
special schools – Agree/Disagree/Neither agree or				
disagree*				
Children with epilepsy can have an adverse effect on	4/140/14	3/89/9		
other children in the classroom or playground –				
Agree/Disagree/Neither agree or disagree***				
Would feel confident managing a child experiencing an	41/92 /25	26/58/16		
epileptic seizure – Agree/Disagree/Neither agree or				
disagree***				
Would be concerned if I had to administer emergency	64/ 67/ 27	41/42/17.		
medication to a child with epilepsy –				
Agree/Disagree/Neither agree or disagree***				
School does a good job supporting children with	2/122/33	1/78 /21		
epilepsy – Agree/Disagree/Neither agree or disagree****				
Children with epilepsy are treated differently than other	13/120 / 25	8/76 /16		
children – Agree/Disagree/Neither agree or disagree***				
*~ 450 **~ 457 ***~ 450 **** ~ 457				

Table 2: Staff responses to attitudes towards epilepsy questions

*n=156,**n=157,***n=158,****, n=157

Table 3: Factors significantly associated with staff attitudes towards epilepsy on multivariable regression

Attitude	Predictor	Adjusted OR 95% Cl	p value
There are certain social activities (e.g. parties, discos) that children with epilepsy should not be allowed to do	School Type	1.157-5.713	0.020
Would feel uncomfortable if there was a child with epilepsy in my class	Had previously witnessed a seizure	0.117-0.631	0.002
There are certain physical activities that children with epilepsy should not be allowed to do	School Type	0.062-0.747	0.016
Children with epilepsy can have an adverse effect on other children in the classroom or playground	No significant predictors	NA	NA
Would feel confident managing a child experiencing an epileptic seizure	Had previously witnessed a seizure	0.105-0.498	<0.001
	School Type	0.127-0.933	0.036
	Received training	0.158-0.735	0.006
Would be concerned if I had to administer	Had previously witnessed a seizure	0.203-0.863	0.018
emergency medication to a child with epilepsy	Received training	0.223-0.892	0.022
School does a good job supporting children with epilepsy	Received training	0.158-0.930	0.034

OR= Odds Ratio

Knowledge guestion		
response category response (<mark>% for each</mark>	
	category	
Majority of children with epilepsy		
attend special schools – 10/101/48 6/ 64	/30	
Yes/No/Don't know		
Proportion of children with epilepsy		
is 0.5-1% of population- 19/13/125 12/8/	/80	
Yes/No/Don't know		
All children with epilepsy have an 57/59/42 36/37	7/07	
EHCP – Yes/No/Don't know	/21	
Epilepsy is a life-long condition in 24/100/34 15/ 63	2/22	
all cases – Yes/No/Don't know 24/100/34 15/ 63	5/22	
Anti-epileptic drugs stop seizures	/20	
in all cases – <u>Yes/No/Don't know</u> 2/108/48 1/ 69	/30	
If seizures stop with drugs epilepsy	10	
is cured – Yes/No/Don't know 1/144/14 1/91	/9	
The majority of children with		
epilepsy are learning		
(intellectually) disabled – 6/121/30 4/77/	/19	
Yes/No/Don't know		
If a child has a seizure an		
ambulance must always be called- 46/84/27 29/54	/17	
Yes/No/Don't know	7 1 7	
It is important to use a spoon or		
other object to prevent a child from		
biting their tongue during a seizure 8/108/43 5/68/	/27	
- Yes/No/Don't know		
If a child is having a convulsive		
seizure it is important to hold them		
	/15	
to stop them shaking -		
A child who has a seizure should		
always leave the classroom 30/78/47 19/50	//30	
afterwards - Yes/No/Don't know		
Epilepsy is diagnosed following	1 1 1	
one confirmed epileptic seizure - 7/82 /70 4/ 5	44	
Yes/No/Don't know		
The majority of behavioural		
problems in children are caused by 3/102/52 2/65/	/33	
AED treatment- Yes/No/Don't		
know		
Effective drug treatment in		
epilepsy usually stops emotional 5/85/65 3/55/	/42	
and/or benavioural problems -	· ~	
Yes/No/Don't know		
Memory difficulties are very		
common in children with epilepsy - 80/11/67 51/7/	/42	
Yes/No/Don't know		

Table 4: Staff Responses to Knowledge about epilepsy questions

Seizures can involve		
Convulsions/limb jerking - Yes/No/Don't know	153/0/6	96 /0/4
Whole body convulsions/jerking - Yes/No/Don't know	153/0/6	96/0/4
Staring blankly into space - Yes/No/Don't know	149/0/10	94/0/6

EHCP=Education and Health Care Plan

 Table 5: Factors significantly associated with staff knowledge on multivariable regression

Knowledge Question	Predictor	Adjusted OR 95% CI	p value
Majority of children with epilepsy attend special schools	School Type	1.189-4.818	0.014
Proportion of children with epilepsy is 0.5-1% of population	Working in Education longer than 10 years	0.250-0.940	0.016
All children with epilepsy have an EHCP	No significant predictors	NA	NA
Epilepsy is a life-long condition in all cases	Witnessed a seizure	0.177-0676	0.002
	Witnessed a seizure	0.155-0.679	0.003
Anti-seizure medicines stop seizures in all case	Number of children with epilepsy taught	0.312-0.781	0.003
If seizures stop with drugs epilepsy is cured	Witnessed a seizure	0.073-0.808	0.021
The majority of children with epilepsy are learning disabled	Family History of Epilepsy	0.075-0.991	0.048
	Witnessed a seizure	0.155-0.726	0.006
Call an ambulance	School Type	0.028-0.268	<0.001
It is important to use a spoon or other object to	Witnessed a Seizure	0.116- 0.615	0.002
prevent a child from biting their tongue during a	School Type	0.072-0.817	0.022
seizure	Received Epilepsy training	0.092-0.513	<0.001
If a child is having a convulsive seizure, it is important to hold them to stop them shaking	Received Epilepsy training	0.109-0.967	0.043
A shild who has a saizura should always lasve the	School Type	0.037-0.319	<0.001
A child who has a seizure should always leave the classroom afterwards	Number of children with epilepsy taught	0.446-0.930	0.019
	Witnessed a seizure	0.221-0.892	0.023
Epilepsy is diagnosed following one seizure	Received Epilepsy training	0.213-0.832	0.013
The majority of behavioural problems in children are caused by AED treatment	Working in Education longer than 10 years	0.193-0.858	0.018
	School Type	0.094-0.667	0.006
	Witnessed a seizure	0.218-0.970	0.041
Effective drug treatment in epilepsy usually stops	School Type	0.145-0.783	0.011
emotional and/or behavioural problems	Witnessed a seizure	0.199-0.823	0.012

OR= Odds Ratio

Familiarity with	n	%	Mainstream	Special	P value
			School	School	
ASD – Familiar/Not familiar	152 / 6	96.2 / 3.8	105 / 6	47 / 0	0.104
Asthma – Familiar/Not familiar	149 / 7	95.6 / 4.4	111 / 0	38 / 7	<0.001
ADHD – Familiar/Not familiar	144 / 14	91.1 / 8.9	100 / 11	44 / 3	0.476
Diabetes – Familiar/Not	122 / 36	77.2 / 22.8	90 / 21	32 / 15	0.075
familiar					
Cerebral Palsy – Familiar/Not	79 / 77	50.6 / 49.4	32 / 78	41 / 5	<0.001
familiar					
Epilepsy – <i>Familiar/Not</i>	121 / 37	76.6 / 23.4	77 / 34	44 / 3	0.001
familiar					
Dyslexia – <i>Familiar/Not</i>	140 / 18	88.6 / 11.4	100 / 11	40 / 7	0.367
familiar					
Down Syndrome –	95 / 63	60.1 / 39.9	58 / 53	42 / 5	<0.001
Familiar/Not familiar					
ASD= Autism Spectrum Disorder					

 Table 6: Staff Familiarity with different medical conditions

ADHD= Attention Deficit Hyperacidity Disorder

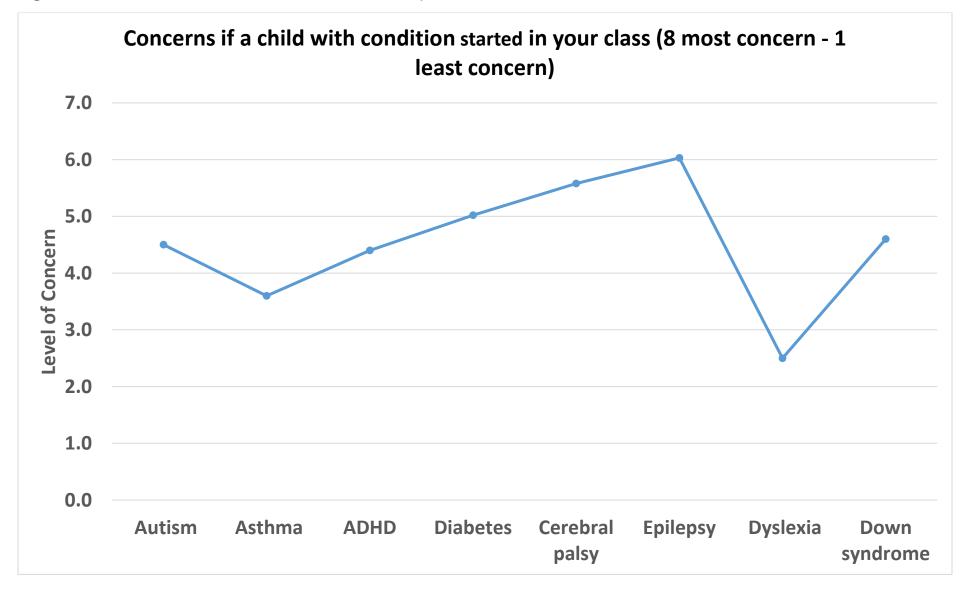


Figure 1: Staff concerns about medical and neurodevelopmental conditions