Knowledge of and attitudes towards epilepsy among teachers: A systematic review
Chloe Jones¹,²
Patricia Atkinson³
J Helen Cross¹,²,⁴
Colin Reilly¹,²

Affiliations
¹Research Department, Young Epilepsy, Lingfield, Surrey, RH7 6PW, UK.
²UCL Great Ormond Street Institute of Child Health (ICH), 30 Guilford Street London WC1N 1EH UK.
³Child Development Centre, Crawley Hospital, Crawley. West Sussex. RH11 7DH.
⁴Great Ormond Street Hospital for Children NHS Trust, Great Ormond Street, London WC1N 3JH, UK.

Correspondence to: Colin Reilly, Research Department, Young Epilepsy, Lingfield, Surrey, RH7 6PW, UK. creilly@youngepilepsy.org.uk 01342 832243

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Abstract
The objective was to systematically review research which has focussed on knowledge of, and attitudes among teachers towards epilepsy.
EMBASE, PUBMED, PsycINFO, Google scholar and Cochrane library databases were searched from 2000 to 2017. Cross-sectional and intervention studies were included and analysed for quality. Thematic analysis was used to identify common themes in the results. 54 eligible studies (total participants 17,256 in 27 different countries) were identified in the search period, including seven studies which focussed on assessing attitudes and knowledge before and after an educational intervention. It was not possible to systematically analyse levels of knowledge and nature of attitudes due to the wide variety of mostly bespoke study specific instruments used. Few studies employed valid and reliable instruments. Thematic analysis revealed three main themes in the results: 1) deficits in knowledge and negative attitudes were pervasive across all studies 2.) teachers often had a negative attitude towards participation of children with epilepsy in physical activities/sport 3.) teachers often expressed limited knowledge of seizure management/emergency procedures. There was a lower level of knowledge and more negative attitudes amongst teachers towards epilepsy compared to comparison conditions. All studies focussing on interventions showed that at least some aspects of knowledge and attitudes improved as a result of teacher participation in an educational intervention but study quality was universally rated as low. A higher level of education and experience of teaching a child with epilepsy was significantly associated with greater knowledge in a number of studies. Additionally, having experience of teaching a child with epilepsy and greater assessed knowledge of epilepsy were associated with more positive attitudes. The wide range of methods used makes it difficult to generalise regarding level of attitudes and knowledge among teachers towards epilepsy. Nevertheless, all studies indicate that there are some deficits in knowledge of, and negative attitudes towards epilepsy among teachers. It would appear that knowledge and attitudes can be improved by educational interventions. Future research should focus on developing psychometrically sound assessment instruments that can be used globally and on identifying the most effective ways of delivering efficacious educational initiatives employing robust study designs.
1. Introduction
Population-based studies of long-term outcome in childhood epilepsy indicate that the condition is associated with significant adverse outcomes compared with the normal population across a range of domains including education and employment. In addition to seizures, children with epilepsy are at increased risk for learning and behavioural difficulties compared to children without epilepsy and children with other chronic medical conditions. Additionally the condition is often associated with significant stigma which can result in significant impairments in quality of life and mental health difficulties. Stigma and social discrimination are often the most difficult aspects of having epilepsy for individuals with epilepsy especially in resource poor settings.

School-related difficulties, as evidenced by receipt of special educational services, are common in children with epilepsy. Cognitive, behavioral, motor and academic difficulties are often associated with the condition. These additional difficulties often have a greater impact on quality of life than the epileptic seizures and contribute most to the economic cost of the condition. However, the difficulties are often unrecognized despite having a very significant impact on school performance.

A number of studies have highlighted a significant gap in teachers’ knowledge of epilepsy and highlighted the presence negative attitudes. From a list of seven medical conditions, teachers reported lowest familiarity with epilepsy. Teachers including those who were teaching a child with epilepsy at the time, are often not aware of the high risk for learning difficulties in individuals with epilepsy and in many cases, parents are likely to be the main providers of information to teachers of children with epilepsy. Studies have also 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.

Given the potential wide ranging impact of epilepsy on a child’s education it is important to understand the levels of knowledge among teachers as well as their attitudes towards epilepsy. The aim of this paper is to systematically review studies which have focused on levels of knowledge and attitudes towards epilepsy among teachers. The review focusses on factors significantly associated with knowledge and attitudes.

2. Methods
The PRISMA (Preferred Reporting Items for Systematic Review and Meta-Analyses) guidelines were followed in order to undertake the systematic review of the literature and to present the results. A literature search was conducted on 15th January 2018. The electronic databases PubMed, Cochrane CENTRAL, EMBASE, ERIC, PsychINFO and Google Scholar were searched using different combinations of the following keywords: teachers, knowledge, attitudes, epilepsy, perception, between the period 1st January 2000 to 31st December 2017. The combinations searched are in supplement 1. Inclusion criteria were: at least some teachers (this included teachers in training) in the sample, a focus on either attitudes towards and knowledge of epilepsy or both, published in English. Studies could be cross sectional or intervention studies.
i.e. studies which assessed attitudes and knowledge before and after an educational intervention. Papers were excluded where there was not a clearly defined measure of attitudes/knowledge or the participants did not include teachers. A data extraction form was developed (see supplement 2) which focussed on extracting the main study characteristics and results. Data was independently extracted by two reviewers (CJ & CR) with any differences being resolved by consensus. The review was registered at https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=91026.

Due to the heterogeneity of methods used it was not possible to systematically review/analyse levels of knowledge or nature of attitudes among teachers. Given this it was decided to conduct a qualitative analysis using thematic analysis\textsuperscript{17} to identify themes in the results regarding levels of knowledge and nature of attitudes among teachers. Thematic analysis is a method for identifying and subsequently analyzing and reporting patterns or themes with data. The process of thematic analysis involved the two raters (CR and CJ) familiarizing themselves with the results in all studies. The results sections in all papers were read through in their entirety by both researchers. At this stage, both researchers took notes to hint at possible themes. The results section of each paper were then blindly rated by both researchers using the generated themes on three separate occasions. After each occasion the raters met to discuss discrepancies i.e., lack of agreement regarding where a response should go in terms of themes and agreement was reached before the next coding. The final coding was performed unblinded by both researchers together in order to facilitate agreement on themes, and it is this final assignment of themes which is reported on in the current paper.

In reporting of results in the intervention studies the term ‘significant’ is use to denote associations between variables that were statistically significant at the $p<0.05$ level.

**Study quality**

All intervention studies were assessed for quality using the Effective Public Health Practice Project (EPHPP) tool quality rating tool (http://www.ephpp.ca/PDF/Quality\%20Assessment\%20Tool_2010_2.pdf accessed May 3\textsuperscript{rd} 2018). This measure includes six questions focusing on selection bias study design, confounders, blinding, data collection methods, and withdrawals and drop-out. Ratings on the six questions are used to derive a global rating which can be ‘Strong’ (no weak ratings), ‘Moderate’ (one weak rating) and ‘Weak’ (two or more weak ratings) and these are reported on in the current study.

Study quality for the cross section studies were based on two questions from the EPHPP focussing on selection bias and data collection methods. On each of these two questions a study was rated as ‘Strong’, ‘Moderate’ or ‘Weak’. Each study was given a rating for both these questions.

Study quality for all studies were rated together by CJ and CR.

3. Results
Figure 1 shows the search process. Fifty-five studies were identified that met eligibility criteria and data was subsequently extracted on these studies. During data extraction it was noted that two studies\textsuperscript{18,19} reported on the same dataset using the same analysis and were identical with respect to study findings. One of these, the study which was published later\textsuperscript{19} was subsequently removed from further analysis. Details on the remaining 54 studies are in Table 1 (cross-sectional studies) and table 2 (intervention studies).

Forty-seven studies were cross-sectional focussing on level of knowledge about or nature of attitudes towards epilepsy whilst seven focused on knowledge and attitudes amongst teachers before and after an educational intervention. Studies took place in 27 different countries. The country where studies were most often undertaken was Nigeria (7) followed by Italy and US (both 5). Study locations are categorised into WHO regions\textsuperscript{71} in Figure 2. The total number of respondents was 17,256 (range 35-1404; mean 319.56). In the 52 studies where gender of the teacher was reported 34\% (5,724) were male and 11,075 (66\%) were female. The response rate to the surveys was reported in 35 of the studies and ranged from 9.3\% to 100\%. Sampling was random in 29 (54\%) cases indicating that either schools and/or teachers were randomly selected for inclusion.

In 83\% (n=45) of the studies the surveys used were bespoke in that they were created specifically for the study or used for the first time in that study. Of the nine studies that employed surveys that were standardised i.e. had previously been used with data available on psychometric properties five studies utilised the Attitudes Towards People with Epilepsy scale (ATPE)\textsuperscript{72}. Forty-eight of the studies considered knowledge and attitudes, four knowledge alone and two attitudes alone. With respect to aspects of attitudes considered, 26 of the studies consider social contacts, 22 marriage, 14 driving, 20 employment, 10 aspects of education (predominantly inclusion of the child with epilepsy in the classroom) and seven participation in sports/physical activities. With respect to aspects of knowledge considered 41 of the studies focussed on management of seizures and 39 on beliefs about causes of epilepsy.

With respect to study quality only three\textsuperscript{44,49,50} of the cross-sectional studies were rated as ‘strong’ with respect to both selection bias and data collection methods.

### 3.1 Level of knowledge and nature of attitudes

It was not possible to conduct any systematic analyses of the studies regarding the levels of knowledge or attitudes towards epilepsy among teachers. The majority of surveys used were bespoke and contained different question types i.e. categorical questions, Likert formats or open questions. Reports of results of levels of knowledge or nature of attitudes were often based on analysis of single questions and/or non-objective criteria i.e. good/poor knowledge/attitudes based on subjective judgement. Even in the studies where a validated measure was used, the same version of the test or reporting of the responses was not uniform across studies.

The qualitative process of thematic analysis study resulted in the following agreed themes: 1.) Deficits in knowledge and negative attitudes were pervasive across all studies. 2.) Teachers had a negative attitude towards participation of individuals with epilepsy in physical activities or sport\textsuperscript{18,21,30,33,47,48,61}. This included a belief that
children/individuals with epilepsy should not participate in certain sports/physical activities or that their participation should be restricted.

3.2 Studies which included comparison conditions
Five studies included questions which focussed on knowledge or attitudes towards other medical or neurodevelopmental conditions in comparison with epilepsy. Aydin & Yildiz\textsuperscript{59} compared knowledge of and attitudes towards epilepsy and asthma in a sample of Turkish teachers. The teachers had significantly more negative attitudes towards children with epilepsy than asthma on all nine attitude questions in the survey which included having a child with epilepsy/asthma in their class, concerns about the child’s aggression, placement a special school, objections from parents if the child with epilepsy was in the class, participation in sports and encouraging their own child to play/sit beside a child with epilepsy. However, significantly more teachers felt that they could manage an epileptic seizure compared with an asthma attack. With respect to knowledge, significantly more teachers felt incorrectly that epilepsy was a psychological disease and was related to poor living conditions compared with asthma. Kampra et al.\textsuperscript{25} reported that with respect to hindering school attendance Greek teachers felt that heart disease was most the important followed by epilepsy, diabetes and asthma. Toli et al\textsuperscript{38} reported that Greek teachers perceived epilepsy as the most difficult condition to manage in school compared to cancer, diabetes and asthma. Bishop and Boag (2006)\textsuperscript{13} considered teacher familiarity with seven conditions. Epilepsy was the condition with lowest familiarity and thus lower than in order of most familiarity ADHD, Diabetes, Asthma, HIV/AIDS, mental retardation and autism. Olson et al.\textsuperscript{57} reported that teachers in the US felt that epilepsy and AIDS were the conditions with the greater overall impact on schooling. The other conditions were asthma, leukaemia, diabetes and congenital heart disease. Epilepsy was most often endorsed as the condition where other children would be disrupted by the presence of a child with epilepsy and teachers believed that children with epilepsy were most likely to more teacher attention and parent contact compared with the other conditions. Additionally, epilepsy was the condition most of with respect to creating a medical emergency in the school.

3.3 Intervention studies
Studies which have focussed on interventions are in Table 2.

The follow up-period after intervention ranged from immediately post intervention\textsuperscript{70} to one year follow up\textsuperscript{65}. The interventions where described mostly consisted of once-off presentation/workshops. In all cases at least some aspects of attitudes or knowledge significantly improved as a result of participation in the intervention. However, global rating of study quality was weak for all interventions studies (see supplement 3 for all ratings). None of the studies involved randomisation or blinding.

3.4 Factors considered as possibly associated with knowledge/attitudes
Table 3 shows the factors considered as possibly associated with levels of knowledge or attitudes towards epilepsy among teachers.

The influence of gender was considered in 13 studies (12 knowledge and 11 attitudes) and results were inconsistent for both knowledge and attitudes. A significant difference was found for knowledge in three studies. Males had significantly higher knowledge in
two studies\textsuperscript{21,45} and females in one study\textsuperscript{29}. A significant difference between males and females in relation to attitudes was found in six studies. Females had significantly better attitudes in four studies\textsuperscript{33,34,13,54} and males in one study\textsuperscript{21} while males had significantly more negative attitudes in one study\textsuperscript{47}.

Age of the teachers was considered in 12 studies for knowledge and eight for attitudes and again results were inconsistent regarding direction of association where a significant difference was found. In two studies younger teachers had significantly better knowledge than older teachers\textsuperscript{18,50}. In two studies younger age was associated with better attitudes\textsuperscript{21,47} whilst in one study better attitudes were found in older teachers\textsuperscript{63}.

Level of education was considered in 16 studies focusing on knowledge and 10 on attitudes and there was a consistent association between higher level of education and knowledge. A higher level of education was associated with significantly better knowledge in eight studies\textsuperscript{27,29,32,34,37,46,13,63} and with better attitudes in two studies\textsuperscript{13,54}. Number of years teaching was considered in 13 studies focusing on knowledge and 11 focussing on attitudes. Three studies showed a significant positive relationship between number of years teaching and knowledge\textsuperscript{24,32,13} and four showed a significant negative relationship\textsuperscript{21,29,18,50}. Four studies showed a significant positive relationship between numbers of years teaching and attitudes\textsuperscript{24,13,58,63}.

Ten studies considered the role of previous experience/contact with a person with epilepsy on knowledge and 12 on attitudes and a consistent association between previous/contact experience and better attitudes was evident. Five studies showed a significant positive association between previous contact/experience and knowledge\textsuperscript{24,37,42,14,13} and ten showed a significant positive association between previous contact/experience and attitudes\textsuperscript{24,27,42,49,50,13,53,54,55,58}. Marital status was considered in six studies on knowledge and six on attitudes. In one study married teachers had significantly better knowledge\textsuperscript{29} and in another study single teachers had significantly better knowledge\textsuperscript{18}. In one study married teachers had significantly better attitudes\textsuperscript{24}. Location was included as a consideration in five studies on knowledge and six studies on attitudes. In two studies urban residence was associated with significantly better knowledge\textsuperscript{25,45}. In two studies urban residence was significantly associated with better attitudes\textsuperscript{13,53}. In the four studies where a possible association between knowledge and attitudes was considered a significant positive association was noted\textsuperscript{27,37,49,50}.

4. Discussion
This systematic review provides a comprehensive overview on studies which have focused on levels of knowledge and attitudes towards epilepsy among teachers. Additionally, the review provides for a consideration of factors associated with knowledge and attitudes as well as the impact of interventions to improve knowledge and attitudes among teachers. This synthesis of the literature can inform directions for policy and future research directions. Despite the heterogeneity in assessment approaches the review suggest that there are sufficient gaps in knowledge and presence of a significant degree of negative attitudes among teachers to warrant concern. The results of the limited number intervention studies suggest however, that
targeted educational initiatives can positively impact knowledge and reported attitudes but study quality was universally low.

Studies focusing on teacher attitudes and knowledge on all continents in the study area with the exception of Oceania have been published in the period considered in this review. This highlights that teacher attitudes towards and knowledge of epilepsy is a global issue. The wide variation in survey instruments used makes it impossible to compare results between studies or across countries but the qualitative analysis suggest that attitudes and knowledge are a concern in all countries where they have been assessed. Limited knowledge and negative attitudes among teachers are likely to add to the challenges faced by children with epilepsy who already are a group at increased risk for cognitive, behavioral and academic difficulties. The results of this review suggest that attitudes towards participation in physical activities are particularly negative. People with epilepsy have often been advised against participating in sports and exercise because of fear, overprotection and ignorance. However, The International League Against Epilepsy (ILAE) Task Force Report on Sports and Epilepsy emphasizes the importance of sport and exercise in epilepsy due to the positive medical and psychosocial effects that there are a few sports that should be off limits provided appropriate individualized risk assessment has been carried out. Given this, a particular focus on improving attitudes towards physical activity among teachers children with epilepsy will be useful. Another theme that emerged from the analysis was that teachers often felt ill equipped to deal with management of seizures and administration of emergency medication. A previous review focusing on emergency medication practices in six European countries identified that existing legal frameworks are vague and open to interpretation. Additionally, it was suggested that whether a child receives rescue medication at school depends primarily on the availability of a willing teacher. A study focussing on the training of preschool teachers in the administration of rescue medication showed that such training improved both self-confidence but also reduces errors in administration of medication. Thus training as well as comprehensive guidelines may be needed to ensure that teachers feel comfortable administering emergency medication.

The studies which have compared epilepsy to other chronic medical conditions indicate that not only have teachers limited knowledge of epilepsy but have more negative attitudes towards it. This highlights that even though school professionals may have positive attitudes about children with chronic health conditions concern about specific diseases such as epilepsy persist. In the case of epilepsy, parents are often the sole providers of disease information but school professionals often only feel confident dealing with the situation when someone perceived to be an expert in epilepsy visits that school. This increases the risk that educational professionals’ concerns may not be addressed and the need for epilepsy professionals to support parents in informing educational professional about the condition.

This review included seven intervention studies to improve knowledge and attitudes and in all cases improvements were noted indicating that educational interventions are likely to be useful. The areas where improvements were noted varied significantly across studies probably reflecting the differing focus of the interventions. Therefore, identifying what aspects of the interventions are mostly successful with respect to which aspects of knowledge and attitudes is difficult. Additionally, none of the studies
included control group or randomization highlighting the need for more robust study design in this area.

Regarding factors associated with increased knowledge, previous/current contact/experience with a child with epilepsy was associated with improved knowledge in most studies where it was considered suggesting that teachers may learn on the job when they come into contact with a child with epilepsy. Better attitudes were also associated with contact with a child with epilepsy perhaps decreasing fear of the unknown. Better attitudes were associated with better knowledge emphasizing the positive role of knowledge based interventions to increase not only knowledge but also attitudes. Future intervention studies should include more robust study design including randomized controlled studies. Educational interventions in epilepsy employing RCT designs have been successfully used to improve student knowledge of and attitudes towards epilepsy and individuals’ knowledge of epilepsy. Online training to reduce stigma in young adults has been successful and the use of online training for teachers should also be evaluated to maximize participation. Multisite studies across countries using agreed up on assessment methods to assess attitudes and knowledge but also interventions should be considered. The development of education programs should be done collaboratively with teachers, parents and young people so as they address the areas important stakeholders. Follow up over a long period of time is needed to assess whether knowledge gains and attitude changes are sustained.

5. Summary and conclusion

Deficient knowledge and negative attitudes towards epilepsy among teachers are found in all parts of the world where they have been studied. Educational interventions appear to be useful in improving knowledge and attitudes. However, better quality research is needed employing more robust study design and to develop a better understanding of what negative attitudes exits and what are the most effective methods of improving both attitudes and knowledge.

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